'One Gives You Roots, the Other...Wings':
Understanding the experiences of children on the autism spectrum and their parents as they co-navigate the Irish early years education system together

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Abstract

This study explores the experiences of parents and their young children before, during and after accessing preschool and primary school education, placing particular emphasis on the factors that enabled or hindered their inclusion. The conceptual framework employed throughout the study is informed by relevant research and policy and incorporates five fundamental areas: (1) The Narrative of Autism (2) Families' Experiences (3) Inclusion in Education (4) Reconceptualising Quality and (5) Conflict in Practice. The importance of Bronfenbrenner's (1979) Ecological Theory of Human Development in understanding and evaluating the lived experiences of these young children on the autism spectrum and their parents cannot be overstated. This ecological stance facilitated the exploration and interpretation of the action inherent within the interconnected social systems of these young children's homes, educational settings, communities and wider society. The research throughout was underpinned by critical narrative inquiry, whereby, the importance of narrative (families' experiences) and grand narratives (wider social issues) permeate the methodology and associated methodological tools. Six parents shared stories of navigating the Irish early years education system with their young child on the autism spectrum. Their children's voices were incorporated into these narratives using visual storytelling methods. Through an analysis of narratives, parents' experiences revealed the presence of conflicting and contradictory perspectives and action at macro-level that, in some instances, resulted in the exclusion of their children from education and support settings. A child-centred narrative analysis offered further insight into these young children's experiences of inclusion, and indeed exclusion, and highlighted how their voices and self-identity are co-constructed ecologically. This premise constitutes the central theme of the reconstructed narratives (folktales) and informs the conclusions and recommendations, where empowering partnerships among all stakeholders in inclusive education are urged.

Declaration

I hereby declare that this thesis represents my own work and has not been submitted in whole or in part, by me or another for the purpose of obtaining any other qualification.

Signed:

Sarah O'Leary

Date:

4th June 2020

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List of Abbreviations

AAC-Augmentative and Alternative Communication
AIM-Access and Inclusion Model
ASD-Autism Spectrum Disorder
CAMHS-Child and Adolescent Mental Health Services
CECDE- Centre for Early Childhood Development and Education
CoE-Council of Europe
CRA-Children’s Rights Alliance
DCYA-Department of Children and Youth Affairs
DJELR-Department of Justice, Equality and Law Reform
DES-Department of Education and Skills
DF-Department of Finance
DH-Department of Health
ECCE-Early Childhood Care and Education
ECCN-European Commission Childcare Network
EP-European Parliament
GI-Government of Ireland
HSE- Health Service Executive
ID-Intellectual Disability
LINC-Leadership for Inclusion in the Early Years programme
OECD-Organisation for Economic Co-operation and Development
NCC-National Competitive Council
NCCA-National Council for Curriculum and Assessment
NCSE-National Council for Special Education
NDA-National Disability Authority
NEPS-National Educational Psychological Service
PECS-Picture Exchange Communication System
SENO-Special Educational Needs Co-ordinator
SEN-Special Educational Needs
SERC-Special Education Review Committee
SNA-Special Needs Assistant
UNESCO-United Nations Educational Scientific and Cultural Organisation
WHO-World Health Organisation

Contents

Chapter One

Introduction

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1.1: Introduction and Conceptual Framework

The importance of locating the experiences of children on the autism spectrum, and their families, within the wider social realm of narrative and action was fundamental to this research throughout. This study is premised upon the belief that the narratives, and indeed voices, of children on the autism spectrum are co-constructed with and between the significant others present within their homes, educational settings and beyond. The dominant narratives and actions within education and wider society therefore influence their narratives and voice. Exploring these children's and parents' experiences of co-navigating the Irish early years education system (pre-school and primary school) centred upon enabling a deeper understanding of the multi-dimensional aspects of these experiences and associated narratives. The conceptual framework employed throughout the study is informed by relevant research and policy. As illustrated in Figure 1, it incorporates five fundamental areas (1) The Narrative of Autism (2) Families' Experiences (3) Inclusion in Education (4) Reconceptualising Quality and (5) Conflict in Practice.

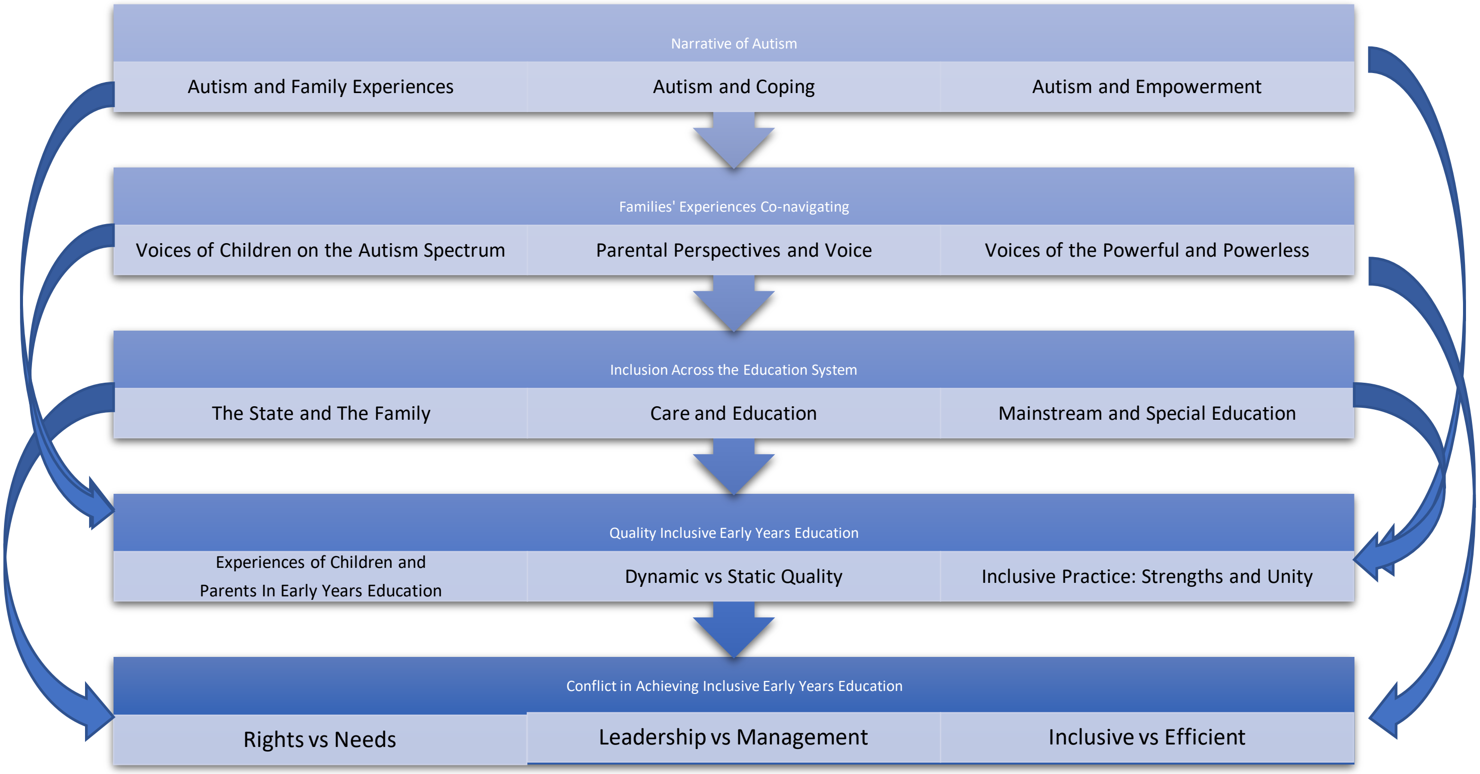

Figure 1: A Relational Conceptual Framework

As shown, the primary components comprising each of the five areas: *The Narrative of Autism*, *Families' Experiences*, *Inclusion in Education*, *Reconceptualising Quality* and *Conflict in Practice*, point to the relational nature of this research. In essence, the framework incorporates the action and narratives that influence and affect the experiences and voices of children on the autism spectrum, and their parents, as they co-navigate the educational and social landscape together.

1.1.2: Research Rationale

Recognition of the human rights of individuals with additional needs in Ireland has been a recurring topic within the narrative of social justice for the past number of years. Consequently, there has been an emerging shift towards integrating children with additional needs into mainstream education settings. The rationale informing this research encompasses three main components: policy changes, prior research recommendations and personal experience.

Inclusive Policy and Practice

In relation to Early Childhood Care and Education (ECCE), the introduction of the *Access and Inclusion Model* (AIM) by the Department of Children and Youth Affairs (DCYA, 2016) has greatly reformed the approach to inclusion in the early childhood field (Moloney and McCarthy, 2018). Recent policy reform underpins current inclusive practice at primary school level, including the *Revised Special Education Allocation Model* (Department of Education and Science [DES] 2017), as well as the *Comprehensive Review of the Role of Special Needs Assistants* (National Council for Special Education [NCSE] 2018). Consequently, the need to create a culture of inclusion has become dominant across the discourse on inclusive education internationally (United Nations Educational Scientific and Cultural Organisation [UNESCO] 2005; European Parliament 2017; Council of Europe 2018). However, in spite of the child-centred ideology espoused across education policy within the ECCE and primary sectors nationally and internationally, research into the experiences of families as they help their child on the autism spectrum navigate within and across their educational settings emphasises the stresses and challenges involved in this process (Denkyirah and Agbeke 2010; Quintero and McIntyre 2011; Lilley 2014; Connolly and Gersch 2016; Moloney and McCarthy 2018). The present study argues that such challenges relate to tensions that arise between the multitude of narratives relating to inclusive education presently. It also emphasises the importance of recognising the significance of the lived experiences of children on the autism spectrum and their families. Lived experiences that the researcher and her family are also immersed within.

Lived Experience of the Researcher

The final component of the rationale behind this study is the researcher's own lived experience as parent of a child on the autism spectrum and educator within the Irish education system. While a researcher's declaration of positioning is an important element of every study (Bryman 2008; Creswell 2009), within this study, researcher positionality defined the entire inquiry from the beginning. In previous years, as the researcher and her young son co-navigated the wider world together, it became clear that there was ambiguity surrounding the information available on autism. Without doubt, various, and oftentimes conflicting, narratives of autism existed. Each narrative related directly to the central philosophy behind the multitude of groups and agencies providing information. As each group interpreted autism differently, their conclusions drawn in relation to families' experiences of autism and inclusion, were also entirely different. It became evident that this lived family experience was entirely relational and, indeed, this research developed from that interpretation. While at the centre of this relational matrix stands a young boy on the spectrum, the experiences of other individuals on the autism spectrum were also relevant and warranted exploration. Thus, the researcher's lived experience and narrative was recognised as embedded within wider experiences and grand narratives. These narratives inform the research throughout and are presented ecologically, recognising the many interconnected social systems of children on the autism spectrum and their families.

1.2. Aim and Objectives

The central aim of this research is: *to understand how the lived experiences of children on the autism spectrum and, their parents as they co-navigate the Irish early years education system together, relate and contribute, to narratives of autism and, inclusion across social contexts.*

The following key objectives were fundamental to realising this overarching aim:

- *To examine the roles, actions and narratives that positively and negatively impacted the experiences of these children and parents as they co-navigate wider social contexts together.*

- *To include the voices of these young children on the autism spectrum in this exploration of experience, through the adoption of innovative methods that recognise the important relationship between the inclusion of voice and the development of self-identity.*

- *To determine the dominant narratives informing inclusive education policy in Ireland currently, and, to explore the impact of the actions arising from these on both the children's and families' experiences of inclusive practice.*

- *To reconstruct stories of the phenomena explored that encompass the narratives, experiences and actions central to this inquiry.*

1.2.1: Central and Embedded Research Questions

Derived from the central aim and associated objectives, this research is guided throughout by the following central and embedded questions:

> *How can the lived experiences of children on the autism spectrum and their parents as they co-navigate the Irish Early Years education system together relate and contribute to narratives of autism and inclusion across social contexts?*

1. What are these parents' experiences of accessing both early years and primary school education for their child on the autism spectrum and, what factors enabled or impeded this?

2. How are the voices of these young children on the autism spectrum constructed and included in their homes, educational settings and beyond?

3. What roles and actions were central to the realisation of inclusion in education and beyond for these young children on the autism spectrum?

4. How do the dominant narratives informing inclusive education policy in Ireland impact these children's and families' experiences of inclusive practice?

1.3: The Power in Narrative: The Significance of Language Throughout the Study

The power inherent within narrative is evident throughout this research. The influence and impact of narratives on the experiences of these children and parents underlies the central research question, the review of both literature and policy, the theoretical framework, methodology and the findings that emerged. The tension and conflict between narratives is a dominant thread across the study and, is outlined here in relation to the narratives surrounding autism, the child on the autism spectrum, inclusion and finally, care and education.

1.3.1: The Narrative of Autism

The issues and tensions arising from the multitude of narratives surrounding autism are a recurring feature of this study. The widely accepted pathological view of autism is critiqued in terms of its emphasis on the associated deficits and struggles. This research argues that the acceptance of a negative stance on autism impacts the development of identity within the individual on the autism spectrum, generally positioning them as the cause of challenges within homes, education settings and beyond. Consequently, the majority of attention, efforts and finances invested in autism focus on the uncovering of possible causes, cures and preventions. From this perspective, autism is interpreted as a source of stress and trauma (Gray 2002; Hall and Graff 2011; Bitsika *et al*. 2015; Gorlin *et al*. 2016). Indeed, families' experiences have even being compared with war victims whose symptoms of Post-Traumatic Stress Syndrome result from their attempts to cope with chronic traumatic and adverse circumstances (Mount and Dillon 2014; Whitehead *et al*. 2015; Pruit *et al*. 2016).

The present study aligns with the work of those who suggest that understanding and accepting autism as difference can reduce, or even remove, the trauma from the lived family experience (Field and Hoffman 1999; Bachraz and Grace 2009; Petalas *et al*. 2009; Holder 2013; Hoogsteen and Woodgate 2013; Hart 2014). In promoting the acceptance of autism as a different, rather than abnormal, way of being, this study draws on historical and philosophical influences. Within the realm of such influence, the lived experiences of children on the autism spectrum and their families are understood in reference to the experiences of minority groups who struggle to realise their human rights as a result of the differences between them and the dominant majority (Broderick and Ne'eman 2008; Owren 2013; Donaldson *et al*. 2017). This study recognises, values and prioritises the rights of these children and families. It therefore endorses a social model of autism and disability. Throughout the study, an optimal narrative of autism is symbolised using the metaphor of the tribe. Such an approach draws on the experiences and actions of tribal and indigenous groups over time, valuing the way that these inter-dependent communities recognise, and live in harmony with, difference (Basso 1996; Walsh 2007; Kapp 2011; Bodley 2015). The positive impact of such an approach on the development of the young child on the autism spectrum is also a central vein throughout.

1.3.2: The Narrative and Voice of the Child on the Autism Spectrum

The earliest definition of the word 'child' traces back to the early Latin *infantem*, translated as one *unable to speak* (Skeat 1993, p. 146). This ancient description of the child continues to bear relevance on the present study as it embodies the experiences of young children on the autism spectrum in two ways. Firstly, these children typically experience challenges regarding receptive and expressive communication (Crosland and Dunlap 2012; Weitzman 2013; Gilroy *et al*. 2018). Secondly, their voice is often excluded from research concerning their own lived experiences; as autism is viewed as a limiting condition, rather than part of their identity (Hart 2014; Demer 2018; Hens 2019). In keeping with Article 12 of the *United Nations Convention* *on the Rights of the Child* (UN 1989), children on the autism spectrum have the right to have their voices included, listened to and acted upon in all matters concerning them. Nevertheless, there remains an absence of voices representing the perspectives of children on the autism spectrum in research. Thus, reflecting much research relating to autism where the voice of the individual on the autism spectrum is often omitted (Broderick and Ne'eman 2008; Mottron 2011; Krcek 2013).

However, due to communication difficulties, genuine challenges do exist in relation to the direct inclusion of these children's voices in research (Lloyd *et al.* 2006; Boggis 2011; Teachman and Gibson 2018). Within the Irish context, due to lengthening waiting periods between referral, autism diagnosis and intervention, many children with communication needs are typically of school-going age before they begin to use alternative or augmentative communication methods (Connolly and Gersch 2013; Gilroy *et al.* 2018; Moloney and McCarthy 2018). In such instances, communication becomes a shared, inter-dependent experience where the significant people in the child's life are of paramount importance. The present study recognises the necessity for and value of this co-construction of narrative and, therefore, interprets these children's voices within the families' inter-related experiences and narratives. As this study sought to understand the roles, actions and narratives that influence and impact these children and families' experiences, consideration was given to times in the children's and families' lives when other social actors had the most significant impact. In terms of this research, the shared co-navigation from home to pre-school, and pre-school to school, constituted this phenomenon, while offering insight into the interpretation and implementation of inclusive action in the Irish early years education system.

1.3.3: The Narrative of Inclusion

The central focus of this research is the inclusion of children on the autism spectrum in the Irish early years education system. In order to provide a socio-historical context to this relatively recent phenomenon, the inclusion of individuals with additional needs in Irish education is examined over time since the establishment of the State. An international context for inclusive education is provided through an exploration of literature and policy. At present, a variety of international organisations share common definitions of inclusion and inclusive education. For instance, the Council of Europe, the European Union and the United Nations all define inclusion in terms of the realisation of every child's right to education and prioritise the values of participation, quality, equality and justice (UNESCO 2005; European Parliament 2017; CoE 2018). Some studies have analysed the interpretation of inclusion and inclusive education internationally and found that multiple dimensions and levels of inclusion exist in practice (Ainscow *et al*. 2006; Göransson and Nilholm 2014; Haug 2017). These researchers argue that the placement of children with additional needs in mainstream education constitutes the lowest level or dimension of inclusion. They maintain that following a child's placement in, for example, a school, inclusion must embrace both their social and academic needs. They further emphasise that authentic inclusion involves partnerships with parents and all relevant stakeholders. The present study embraces the importance of such partnerships, but acknowledges the issues and tensions present in the establishment and development of same.

Against the backdrop of UNESCO (1996), this research argues that the phenomenon of including children on the autism spectrum in education, and wider society, encompasses the seven main tensions affecting education around the world in the 21st century (see Fig. 2). When the narrative surrounding inclusive education is interpreted in terms of these potential tensions, a multifaceted view of inclusion can emerge. Consequently, the tensions within each binary relationship are imbalanced and non-reciprocal. Instead, through the ideologies and actions of the powerful, one side of the connexion typically dominates the other, thus creating increased tension.

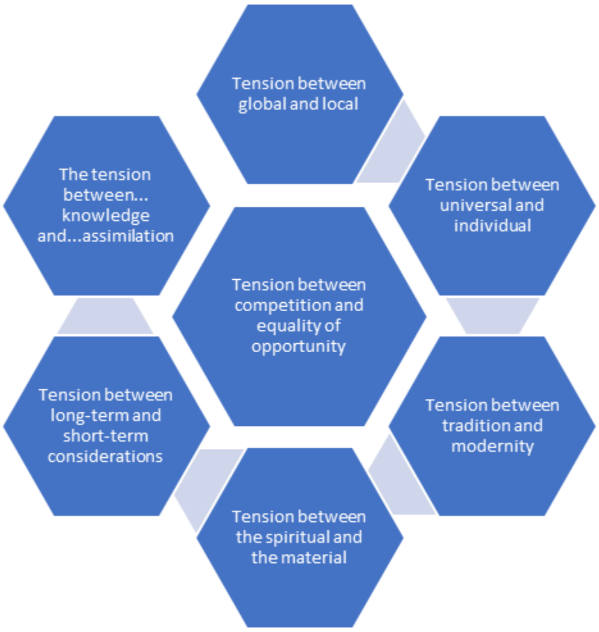

Figure 2: Tensions Affecting Education in the 21st Century

When the tensions within inclusive action are overlooked issues can arise that manifest as counterintuitive to a vision of authentic inclusion. Hodkinson (2011, p. 179) argues that such oblivion could locate inclusion as ‘a guise of truth’ that seeks to adorn the ‘cultural cloak of equality’ in order to create and nurture tensions or ‘double binds where performativity [is] pitched against presence, standards against segregation and ableism against absence’. Likewise, Zizek (2009, p. 25) draws on these dichotomies of tension when he presents the paradoxical nature of inclusion where ‘freedom’ equates with ‘forced choice’ and the success of inclusive measures rely on the capacity of the child with additional needs to ‘do exactly what they are expected to do’. Within such paradoxical practice ‘inclusion and exclusion became entwined in a false dichotomy’ (Hodkinson, 2011, p. 182) when criteria for inclusion are not met and the child who is unable to perform or compete is segregated or rejected. In this study, the dichotomy of inclusion and exclusion are inextricably linked to the relationship between care and education in the Irish early years education system.

1.3.4: The Narrative of Care and Education

The tensest dichotomy permeating this study is between care and education across the Irish early years education system presently. Through an exploration of the care-education divide issues arose surrounding the inclusive policy guiding the ECCE and primary education sectors. The right of all children to avail of free primary education was stated in Article 42 of the *Irish Constitution* in 1937 (GoI 2015). However, the reference to ‘primary education’ within Article 42 led to the creation of a distinct divide between education and care in Ireland. Thus, primary education manifested as formal schooling and did not encompass the care and education of children who were not yet school going age. As a result, children younger than four years old were ineligible to realise this constitutional right (Hayes 2007; Moloney and McCarthy 2018; Stembridge 2019). The traditional view that children's education did not commence until entry to primary school remained throughout the 20th century. Indeed, access to free ECCE is a relatively new phenomenon in Ireland as it was not introduced until 2010 in a comprehensive and systematic way (DCYA 2019). While a growing recognition of the importance of a continuum of education is gradually emerging within the national context, the care and education divide appears to remain. Because of this divide, interpretations of early childhood care and education vary. According to Hayes (2007, p. 6), in Ireland 'there is not, nor should we expect there to be, one universal agreed understanding of early childhood education and care'. While accepting this reality, Hayes explains that it is 'challenging, as it requires a continuous interrogation of policy and practice against the dynamic and changing reality of everyday life' (ibid.). The present study can be considered an example of such an interrogation. The definition of early childhood within this study is congruent with that within *Aistear: The Early Childhood Curriculum Framework* and, includes all children 'from birth to six years' (National Council for Curriculum and Assessment [NCCA] 2009a, p. 6).

Although this age range encompasses children in ECCE settings and infant classes in primary schools, a certain tension between care and education is evident. This tension is due to governance structures in both domains. In Ireland, primary school settings are governed by the Department of Education and Skills (DES) and are seen as 'having a traditionally understood educational role' (Hayes, 2007, p. 6). However, ECCE settings have, in the past, been governed by multiple Government Departments. Currently, they are under the auspices of the Department of Children and Youth Affairs (DCYA) and inspected by the Child and Family Agency: TUSLA. While Hayes (2007) suggests ECCE settings have 'a predominantly welfare or caring role', Moloney (2015) indicates that their educational role is becoming increasingly evident. The *educational role* of the DES is clear throughout the introduction to the Primary School Curriculum (GOI 1999). However, the relationship between education and care is referenced just three times within the entire curriculum document: twice in relation to a child's prior pre-school care and once in relation to the provision of care to children with additional needs:

> Effective education for children with special needs involves a balanced provision of education and care, the nature of which can vary as the child develops and progresses. It is essential, therefore, that it is flexible enough to accommodate both ease of movement between special and mainstream education (GOI, 1999a, p. 29)

It is important to note that central to the ‘balanced provision of education and care’ to children with additional needs in primary education is the distinct and separate roles allocated to ‘special and mainstream education’. Clearly, the relationship between care and education has been interpreted differently in ECCE and primary education settings. Indeed, the NCCA (2009b, p. i) states that ‘particular understandings of education and care impact on children’s experiences during early childhood education’. Moreover, Hayes (2007, p. 4) describes the processes of care and education in the Irish early years education system as ‘two recurrent, interacting and often contentious concepts’. Unfortunately, within the formal education system in Ireland, it appears that the act of caring is seen as separate from education and requiring specialist intervention. Drawing upon the White Paper on Early Childhood Education: *Ready to Learn* (DES, 1999), this research argues that care and education are inextricably linked. It further argues that embracing both as a holistic process is critical to inclusive practice.

1.4: The Ecological, Critical and Philosophical Role of the Researcher

Exploring the experiences of young children on the autism spectrum and their parents as they co-navigate the Irish education system can offer certain insight into the issues and, tensions arising from the variety of narratives informing inclusive education in Ireland presently. The current research interprets these experiences ecologically, critically and philosophically (see Fig. 3). The ecological stance, that emphasises the influence of social actors within and across social contexts on child development, underlies the study throughout. A critical lens is also applied to this ecological view of experience to determine the power structures present within these social contexts. The philosophical perspective that accepts autism as a different way of being permeates the study from the outset.

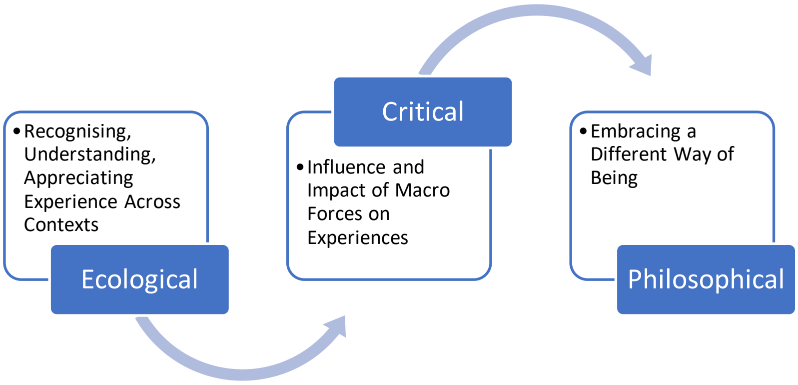

Figure 3: Applying Ecological, Critical and Philosophical Lenses

1.4.1: An Ecological Interpretation of the Educational Experiences of Children on the Autism Spectrum

The central theory guiding this study; Bronfenbrenner's Ecological Theory of Development, demands a deep understanding of all the social systems that impact the child's development (Bronfenbrenner 1979; 1986; 1992). While much of the research on navigating education systems with children on the autism spectrum cites the use of either an ecological or a systems-based theoretical model, it generally focusses on the child's immediate social context (microsystem) and the relationships and interactions present within this (mesosystem). Thus, presenting these times of change from the perspective of the microsystem and mesosystem, and foregoing the opportunity to deconstruct the forces of the governing macrosystem. Forces that many have long argued, underlie and inform our immediate social context (Freire 1970; Bourdieu 1979; Foucault 1991). According to Parthasarathy (2008), gaining an understanding of socio-cultural context is an integral part of any narrative study and the subsequent knowledge created. This socio-cultural perspective concentrates on the way that social life is organised. Therefore, examining the social and cultural narratives that influence the roles and relationships within our homes, schools and communities is an integral element of this ecological study. The division of power, and potential inequalities between these families and others, are also essential to any critical interpretation of narrative (Hickson 2016).

Thus, a critical-ecological stance can reveal the divisions of power that create a social order while exploring the impact of consequent inequalities on the development of, for example voice or identity within the oppressed group. The inclusion of a critically reflective lens throughout the research eliminates the need to choose between the micro or macro perspective. On the contrary, it allows one to effectively interpret the narrative ecologically, with micro and macro contexts in mind. Therefore, similarities can be drawn between critical interpretations of grand narratives and Bronfenbrenner's ecological system, namely the impact of macro actions in wider society on micro experiences. Interpreting the grand narratives within the micro level requires an analysis of the language of narratives. In this respect, meso-level interpretation focusses on the way these narratives are constructed and understood within the education system, of which, the child engages. This critical understanding of experiences within the mesosystem focusses on the division of power and subsequent inequalities between various groups, an integral point of any critical interpretation of narrative (Hickson 2016). While the exposition of inequalities is a central element of any critical inquiry, combating such injustices is also a necessary element of this approach and effectively connects the micro to the macro, the individual to the social.

1.4.2: A Critical Merging of the Micro and the Macro

The central research question explores the lived experiences of these young children and their parents as they co-navigate the Irish early years education system together. It also encompasses the influence of dominant narratives within the discourse on autism and inclusion. Therefore, this research question encompasses the social realms of both micro and macro. It focusses on the experiences of these families as their child moves from the immediate context of their microsystem (home) to a wider social system (ECCE setting and primary school) that is representative of the ideologies of the macrosystem. Consequently, this study includes a critical examination of the power relations that are created within the microsystem and mesosystem of children on the autism spectrum as a result of governing elements of the macrosystem, with particular consideration given to inclusive education policy. Within a critical narrative inquiry, it is essential that what emerges from a micro and meso-level of analysis is framed against a backdrop of the broader macro context of grand narratives (Peterson and Wetzel 2015; Cannella and Lincoln 2018; Lessard 2018). A grand narrative can be defined as a narrative about narratives (Clandinin and Connelly 2000; Kim 2016). The grand narrative is so called because of the significant knowledge, meaning and moreover, experience present within it when located against a backdrop of history. Thus, understanding the macro or grand narratives that inform inclusive action is a crucial element of this research and constitutes the act of building a bridge between the micro and macro contexts (Schiller 1994; Wan and Chew 2013; Campano *et al*. 2016).

Macro-level analysis requires continued engagement and scrutiny of the relationships of power present within the micro systems of the child on the autism spectrum, and their families. The application of a broader lens of macro analysis, creates and projects a multifaceted representation of the narratives (McAllister 2001; Hendry 2009; Cardiff 2012). Multilevel analysis therefore enables this narrative inquiry to generate discussion around a significant issue in the national context of education. As discussed, this process requires the researcher to become authentically involved in the experience with a view to bringing about social and political change. It is also central to the researcher's positioning. The importance of the researcher's own positioning in relation to autism and inclusion, is therefore paramount as it also acts as a bridge between the micro and macro narratives of difference. Thus, integrating a philosophical stance into the ecological and critical approach.

1.4.3: A Philosophy of Storytelling and the Metaphor of the Tribe

This research focusses on the lived experiences, relationships, desires and beliefs of the individuals involved and therefore must emphasise the importance of the 'self' (Denscombe 2007; Creswell 2009; Punch 2009). Indeed, this study argues that interpretations can only arise if there is a critically reflective synthesis of the lived contexts of the children, parents and researcher and the life texts created within and between these. Phenomena are understood in a new way through an interpretive approach that incorporates the philosophical, critical and ecological elements inherent within the grand narratives underlying these children's and parents' lived experience. Thus, conceptualising these personal narratives within a new wider context of meaning. The present study maintains that this reconceptualization can lead to possibility, therefore resonating with Bakhtin's (1981) notion of *unfinalisability;* where people's circumstances do not necessarily dictate their future but can lead to the creation of different truths.

Central to narrative inquiry is the philosophical concept of experience as truth and the overarching role of identity in the relationship between both. In fact, the construction and acceptance of both truths and identitie**s** has been a central vein of this research throughout. The concept of colonisation, pertaining to the domination of minority social groups by the majority, was also drawn on philosophically throughout the research. It was invoked as a metaphor and historical backdrop that can encompass the lived experience of the individual on the autism spectrum (Walsh 2007; Kapp 2011). The decolonisation of knowledge is central to this concept and focusses on recognising and appreciating the value of alternative narratives, knowledge and truths to the wider, macro context. These alternative narratives are often excluded from wider macro agendas as they are deemed different from, and therefore contradictory to, a typically singular and universal vision of knowledge (Mignolo 2000; Medina 2003; Michaelsen and Shershow 2007). The narrative of *autism as difference* is an example of such and, within this study, is integral to a philosophical interpretation of equality, diversity and inclusion that can move past established colloquial or stereotypical norms (Barbour 2010; Dennis 2010).

As mentioned, early communities and societies, and in particular the metaphor of the tribe, have become a recurring motif throughout this research. This metaphor reflects the lived experiences of individuals on the autism spectrum and their families, who like their tribal counterparts, are connected to their community through shared experiences and narratives. Experiences and narratives that do not typically represent the dominant majority (Walsh 2007; Bodley 2015). As with Bronfenbrenner’s Ecological Theory of Development, the importance of the relationships forged between the individual and their significant others saturates every aspect of the study. These relationships begin within the child’s family, where the process of caring is central and extends to include those within the wider social contexts with which they interact. The importance of being an active participant across social contexts; homes, schools and communities, as carers, educators or activists also resonates throughout. This approach reflects the philosophical values associated with a social model of autism that embraces difference and inter-dependence and, moves away from the traditional medical model of autism that emphasises deficits and isolation. It is hoped that adopting this philosophical approach could have a very real impact on the narrative surrounding autism and, perhaps, manifest as a positive force of change for these young children and their families.

1.6: Conclusion and Summary of Chapters

This chapter presented the central and embedded research questions that guided this study throughout. The need to gain a deeper understanding of the experiences of children on the autism spectrum and their families as they co-navigate the Irish early years education system together was emphasised. The multitude of narratives associated with the central research question were outlined in relation to autism, the child on the autism spectrum, inclusion and care and education. The adoption of a triangulated stance that incorporates ecological, critical and philosophical lenses of interpretation was described.

Chapter Two presents the literature review that begins with an examination of the wider narrative of autism and the historical landscape of inclusive education. The lived family experience of both autism and inclusion is a central vein of the review throughout. Thus, major issues or tensions emerging from this examination are explored further in terms of the divides identified between the State and the family, care and education, quality and inclusion and, the needs and rights of children on the autism spectrum. The need for a critical and ecological exploration of the experiences of young children on the autism spectrum and their parents as they co-navigate the Irish early years education system is highlighted.

Chapter Three outlines the theoretical framework that guides the entire study: Bronfenbrenner’s (1979) Ecological Theory of Development. The multi-dimensional nature of this theory encompasses all the social contexts that influence and impact the individual child's development and acts as a fitting lens through which these children's and families' experiences could be deeply understood. The interconnected concepts of caring as action, and action as critical stance, are presented ecologically in terms of their role in the creation of these children's and parents' unique identity and voice. The development of voice and identity is argued as encompassing all such interconnected concepts within the wider ecological theoretical framework.

Chapter Four demonstrates how narrative inquiry as the chosen methodology facilitates an interpretation of these families' experiences and their consequent development of self-identity. The importance of adopting a critical stance is highlighted in effectively deconstructing the power relations present in both the research and wider lived experience. The effective merging of the ecological and critical approaches to interpretation is portrayed through an account of the methodological tools employed. The immersed role of the researcher in the processes of *analysis of narratives* and *narrative analysis* incorporates the essential philosophical perspective also.

Chapter Five presents the findings that emerged from the initial *analysis of narratives*. These findings are structured ecologically to represent experience and action within the microsystem, mesosystem, exo and macrosystem. They are organised under the wider narratives of *challenge*, *change* and *choice* as voiced by the parents across all phases of the research. Central to this framework are the underlying grand narratives that informed such experiences: *care and action*, *management of outcomes*, *social norms* and the all-encompassing *equality in education*.

Chapter Six comprises the findings that emerged from the *child-centred narrative analysis*. This chapter emphasises the recognition and appreciation of child voice as being central to the children's and parents' lived experiences of co-navigating the Irish early years education system together. Again, this construction of voice and self-identity is structured ecologically, encompassing the microsystem, mesosystem, exo and macrosystem. The social and educational experiences of these nine children are presented under the lens of each social system.

Chapter Seven presents the reconstructed narratives, written in the folktale genre. These tales merge the individual experiences and stories of the parents and children with the underlying grand narratives that inform and impact their experiences. The narratives of autism and inclusion and the issues, divides and controversies within these, are portrayed through the use of metaphor. The journeys these families make across the education system are portrayed within a shift in the understanding of difference. The divisions between care and education, rights and needs, and quality and inclusion, provide a backdrop to all of the folktales. The researcher adopts the persona of The Storyteller throughout.

Chapter Eight discusses the findings from both the *analysis of narratives* and the *child-centred narrative analysis*. It therefore incorporates the findings pertaining to the challenges, changes and choices that saturate the parent narratives with the act of recognising, understanding and appreciating the voice of the child on the autism spectrum across social contexts. This chapter is divided into three sections, structured to represent the findings as they relate to each of the social contexts that impact these children's and parents' experiences. It begins with the children's microsystem, where families' personal experiences and the recognition of the child's unique voice comes to the fore. Next, findings regarding the mesosystem are examined, incorporating the children's and families' experiences within, and between, educational settings. Finally, the macro forces influencing and impacting these children's and families' experiences are explored.

Chapter Nine concludes the study. It returns to the central and embedded research questions and describes how the research explored, and answered, these. It presents a synopsis of the findings in response to each question and the conclusions drawn from these. Recommendations, arising from these findings and conclusions, are made for research, practice and policy. The contributions of this study to knowledge are highlighted in relation to the chosen research area, the innovative methodologies employed and the unique approach to interpretation throughout. The limitations of this study are discussed in terms of the different ways they can be interpreted. The thesis concludes with a reflection, written in the genre of the folktale, once more. Within this, the study's contribution to knowledge is again highlighted, with particular consideration given to the potential impact on the lived experiences of young children on the autism spectrum and their families.

Chapter Two

Literature Review

2.1: Introduction: Road to the Research Question

The road to this research question was carved from the researcher's lived experience of autism and change. Changes to life circumstances brought with them changes to family identity. While such changes were triggered by the delivery of an autism diagnosis, this only represented the very beginning of a journey. A complete immersion within the literature pertaining to autism resulted in a multitude of changes to the researcher's emotions, cognition and perspective. From the outset, the inclusion of narratives from those who had a lived experience of autism became a central pillar of the study. Such experiences permeate this review throughout, beginning with the narrative of autism and families' experiences of same and the inclusion of the child on the autism spectrum in education. A historical overview of inclusive education in Ireland is presented, within which these children's lived experiences are embedded. A variety of tense dichotomies emerge, namely between care and education, quality and inclusion and, needs and rights. The central research question therefore evolved from an inquiry into the lived experience of autism, an exploration of the lived experiences of individuals on the autism spectrum, and their families, as they navigate through these turbulent times.

2.2: Initial Literature Search

According to Oliver *et al.* (2017) clarifying and refining the research question is a prerequisite to a good literature review. Furthermore, Liabo *et al.* (2017, p. 252) argue that it is in this stage of the research process that one must consider the 'review's ability to address a research problem'. Therefore, the studies included, and the review method adopted, dictate the quality of evidence produced. In the present study, an electronic search was performed using EBSCO, an online research database, as the primary database. Other databases were selected within this host search engine, namely: Academic Search Complete, Social Sciences Full Text, ERIC, Education Source, British Education Index, PsychArticles, Applied Social Sciences Index and PsychInfo. This ensured a broader scope of literature on the topic. The term 'autism' was first inputted to the search engine. This search yielded thousands of articles and offered a broad overview of the dominant research topics, and narratives, within autism literature. The inclusion of wider literature on autism was integral to framing the landscape within which the research pertaining to the lived experiences of individuals on the autism spectrum, and their families, are situated.

2.3: The Narrative of Autism in the Wider Literature

The prevalent narrative of autism in the literature emphasises its manifestation as a pathological issue (Robertson 2009; Rutter and Schopler 2012; Willey 2014; Schmidt 2018). Within this narrative, research on autism typically focusses on the alleviation of symptoms and impact of a medical condition. While this view of autism as deficit has saturated the literature on autism for decades, more recently, it is contested by researchers who promote a narrative of autism that draws on the social model of autism and disability, contrasting starkly with the deficit or pathological model. Rather, the social model of neurodiversity presents *autism as difference* (Jaarsma and Welin 2012; Cascio 2015; Schmidt 2018). Within the researcher's own lived experience, autism is accepted as difference, rather than deficit, as this stance can potentially enhance the quality of life of individuals on the autism spectrum and their families (Petalas *et al*. 2009; Mottron 2011; Hiersteiner *et al.* 2017). In fact, these researchers, and others within the neurodiversity movement, argue that the development of the identity of the individual on the autism spectrum relies heavily on the views that those closest to them hold in relation to autism. Interestingly, there is an absence of research pertaining to the development of identity within the child on the autism spectrum, instead, the issues surrounding atypical childhood development and autism are generally emphasised.

2.3.1: A Focus on 'Childhood Autism'

In an international review of literature relating to autism, Parsons *et al.* (2009), reported that almost half of all research focussed on the presentation of autism in toddlers and young children. As such, research of this nature is fundamental in highlighting developmental concerns and identifying symptoms of autism in the early years (Moss *et al*. 2013; Rao *et al*. 2014; Özçalişkan *et al*. 2015; Muratori and Maestro 2018). When these indicators are recognised and understood, early intervention strategies can be implemented to enable the child to have the best possible outcome (Barbaro *et al*. 2013; British Autism Study of Infants Siblings Team 2013; Cascio 2015; Clark *et al.* 2018). However, many of the studies undertaken in relation to early development and autism, seek to find answers as to why autism occurs, with some researchers studying the ways in which irregular brain development can cause autism (Courchesne *et al*. 2013; Mak Fan *et al*. 2013; Di Martino *et al*. 2014; McKinnon *et al*. 2019). Whereas, others hold the mutation of human genes in autism as their primary focus (Neale *et al*. 2012; O' Roak *et al*. 2012; Sanders *et al*., 2012; Brundson and Happé 2014; Lossifov *et al*. 2014; Ronemus *et al*. 2014; Buja *et al*. 2018). Undoubtedly, enormous amounts of money are invested annually in this pathological research internationally (Pellicano *et al.* 2014; Fletcher *et al.* 2018). Some argue however, that it may be more beneficial to invest in research that concentrates on the improvement of services and quality of life for children on the autism spectrum (Pellicano and Stears 2011; Wiggins *et al.* 2013; Marrus *et al.* 2014; Vohra *et al.*2014; Barrett *et al.* 2015).

Currently in Ireland, families can wait between nine and eighteen months to be seen by an autism team and may be told upon assessment completion and diagnosis that services will not be provided (Gilroy *et al.* 2018; Roddy and O' Neill 2019). The impact of this on families cannot be overstated. While the development pattern in a child with autism typically manifests as the primary worry for families initially, the social, behavioural and emotional issues observed in children on the autism spectrum typically become an increasing concern over time (Ozsivadjian *et al.* 2012; Silversten *et al.* 2012; Eussen *et al.* 2013; Stewart *et al.* 2013; van Steensel *et al.* 2013; Mazefsky *et al.* 2014; Raza *et al.* 2019). As families wait for their children to be seen, these concerns grow, resulting in significant increases in the stress levels of family members (McStay *et al.* 2013; Weitlauf *et al.* 2014; Raza *et al.* 2019; Tarver *et al.* 2019). However, research into the impact on parents, siblings and grandparents of raising a child on the autism spectrum, generally credits the presence of autism in a family with such negative experiences and gives little or no consideration to influential factors from social systems outside of the family unit (Thomas *et al.* 2012; Timmerman *et al.* 2012; Wright *et al.* 2012; Giallo *et al.* 2013; Malesa *et al.* 2013; Crane *et al.* 2015; Gnanasekaran *et al.* 2015; Navot *et al.* 2015; Nguyen *et al.* 2015; Hori *et al.* 2016; Benson 2018; Benevides *et al.* 2019). When such a narrative prevails in autism research, authentically including individuals on the autism spectrum in education, and moreover, society, becomes a more difficult task.

2.3.2: Autism and Inclusion in Education

Over the past decade, policy in Ireland relating to children with additional needs in early years education has strongly emphasised the benefits of integration in mainstream early years educational settings (GOI, 2004; National Childcare Strategy, 2006; National Disability Authority, 2011). The enhanced outcomes for children on the autism spectrum in inclusive early childhood settings feature prominently in research internationally (Allen and Cowdery 2014; Mozolic-Staunton *et al.* 2015; Lee *et al.* 2015; Gunning *et al.* 2019; Odom 2019). A dominant theme throughout the research relating to inclusive early childhood education is the essential role of intervention for young children on the autism spectrum. These studies typically evaluate the intervention programmes used in various early years settings, mostly pre-schools, with overall findings focussing on the effects of such interventions on children on the autism spectrum (Eikeseth *et al*. 2012; Wilson *et al.* 2012; Dykstra *et al*. 2013; Goods *et al.* 2013; Katz and Girola-Metto 2013; Twomey 2013; Odum 2019). However, there is little emphasis placed on the role of educators in the creation and development of such inclusive early years environments. In recent years, the NCSE has conducted extensive research into the integral role of the teacher in the effectiveness of inclusive primary and post-primary education (NCSE 2011; 2015). One could argue that the presence of inclusive education frameworks and policies are not enough to effectively establish, and nurture, inclusive learning environments, the role of the educator is crucial (Casserly and Padden 2018; Tiernan *et al.* 2020). Yet, in recent studies of inclusive experiences in Irish schools, teachers' insufficient skills and knowledge in relation to the inclusion of students with additional needs was reported, often by the teachers themselves (Rose *et al*. 2015, p. 7; Daly *et al.* 2016). Another cause for concern was the decreasing availability of supports for children with additional needs in mainstream classrooms in Ireland (McConkey *et al*. 2016; Kerins *et al*. 2018; Leonard and Smyth 2020)

Children on the autism spectrum attending mainstream schools in Ireland, may be entitled to some or all of the following supports: specialised teaching in an ASD class, access to special education teaching and/or a special needs assistant, assistive technology etc. (DES 2004, 2006, 2017; DES/NEPS 2007). Families, schools and national agencies report that these supports are integral in facilitating the inclusive education of children on the autism spectrum in mainstream settings (Parsons *et al*. 2009; Health Service Executive 2013; Rose *et al*. 2017). However, Crosland and Dunlap (2012) assert that when asked, families state that though their main priority is to have their child's basic needs met at school while accessing the curriculum, their child's social inclusion at school is of paramount importance to them. Indeed, contrary to traditional beliefs surrounding the lack of interest across the autistic population in engaging in social relationships, children on the autism spectrum, view the forging of friendships in school as important (Calder *et al*. 2013; Schroeder *et al*. 2014; Locke *et al*. 2015; Bennet *et al*. 2018; Bottema-Beutel *et al*. 2019).

2.3.3: Autism and Inclusion in Society

Research surrounding the quality of life of individuals on the autism spectrum generally reports significant challenges in relation to social integration (Byers *et al.* 2013; Kammio *et al*. 2013; Andersson *et al*. 2014). Moreover, experiencing these challenges on a daily basis can lead to loneliness, anxiety and depression. Indeed, many individuals on the autism spectrum have reduced functionality in several aspects of their lives because of mental health issues (Kammio *et al*. 2013; Fung *et al.* 2015; Moss *et al.* 2015). Many argue that such reduced functionality results from these individuals' social experience of the world around them and is, therefore, not specifically associated with autism (Hebron *et al*. 2013; Moss *et al*. 2015; Sterling *et al*. 2015). Worryingly, recent statistics in relation to adults on the autism spectrum, who are considered 'high-functioning' in their daily life, indicate that the risk of suicide is substantially higher than that of their peers (Cassidy *et al*. 2014; Richa *et al.* 2014). Clearly, while the inclusion of individuals on the autism spectrum in education appears to have been established in functional terms, issues remain regarding the effectiveness of inclusive action on the understanding and acceptance of autism in wider society.

The present study examines the role of education systems in enabling access to education for individuals on the autism spectrum but also in the promotion of acceptance of these individuals in homes, schools, communities and wider society. Through authentic inclusive practice, families can more greatly understand autism as an aspect of human variation (neurodiversity) that warrants respect and recognition (Krcek 2013). Broderick and Ne'eman (2008) discuss the importance of acceptance further in relation to the dominant narratives surrounding autism and the possibility of inclusion for individuals on the autism spectrum. They explore both the narrative and counter-narrative of this argument concluding that it is imperative to direct autism research away from the interminable investigation of causes and treatments towards a commitment to examine, and enhance, the quality of life of individuals on the autism spectrum. This conclusion is echoed by many others (Jaarsman and Welin 2012; Pellicano *et al.* 2014; Donaldson *et al*. 2017). The futility of continued investigative research into autism has been highlighted in recent years by those within the autistic community who resolutely advocate for the phenomenon of autism to be explored instead as a human rights issue (Broderick and Ne'eman 2008; Robertson 2009; Kapp *et al.* 2013; Hart 2014; Willey 2014). Such advocates argue that the relentless scrutiny of causes and searches for cures within autism research, is as useful as studying the genetic causes of differences in race and sexuality, rather than working towards the acceptance of difference in society (Jaarsman and Welin 2012; Shakespeare 2013). All within the autism rights movement emphasise the importance of the lived experience, rather than impact, of autism in any discussion relating to it.

2.4: The Lived Experience of Autism: Inclusion of the Family Narrative

To reiterate, the researcher's personal experience of autism in her family has led to her recognition and appreciation of autism as a lived experience: a different way of being-in-the-world. However, early engagement with literature on the lived experience of autism revealed that while much of the qualitative research available on autism advocates the importance of exploring the lived experience, the primary focus of many studies was on the impact of either autism or autism interventions. Studies rarely presented the experience of the individual on the autism spectrum. From 252 journal articles citing the lived experience of autism as their research focus, just 35 presented the experience of the individual on the autism spectrum. While the title of these 35 studies implied an exploration of these individuals' lived experience, further examination indicated that many emphasised the deficit model of autism, in terms of its negative effects on psychological and social functioning, or focussed on the ways in which individuals on the autism spectrum experienced social, educational and psychological supports and interventions.

Only two articles adopted a philosophical lens, where the lived experiences of individuals with autism was presented with the aim of understanding autism as a way of being in the world (DePape and Lindsay 2016; Powell and Acker 2016). This is remarkable as research within psychology has long advocated that any exploration of the human mind should value the importance of the individual's narrative of their lived experience (Polkinghorne 1988; Bradley 2005), rather than the reduction of this experience to the observation of behaviours in controlled settings (Levine 1983; Barrett 2011; Di Paolo *et al*. 2014). While all 35 articles adopted an interpretivist worldview of the lived experience of the individual on the autism spectrum, these two articles alone mirrored the researcher's ontological and epistemological views, presenting them through a philosophical lens. Nevertheless, while an integral element of the present study is the inclusion of children's experiences of navigating the Irish early years education system, it quickly became apparent that the age, and level or mode of communication of this group, would make their views, and voice, difficult to access. Accordingly, the researcher turned towards accessing family narratives with regards to the collective family experience, accepting that the exploration of such narratives could also offer great insight into the lived experience of each child, and moreover, the ecological development of their identity (Bronfenbrenner, 1979). Hence, the following section explores a range of literature pertaining to individuals and families' collective lived experiences.

2.5: Researching Families' Experiences of Autism: Defining and Refining the Search

In order to gain a deeper understanding of families' experiences of autism, the following key terms informed the literature search: 'autism' and 'family'. Initially, the recovery of these terms relied on their presence in the article title. This search returned 297 articles, 118 of which focussed on the family as a means of scientific inquiry in relation to genetic mutations, cognitive impairment and heritability of medical conditions. The term 'experience' was added as a title word in order to direct the search towards literature that presented the lived experience of autism. This yielded 23 articles. This practice is commonplace in the early stages of literature reviewing. In fact, Rapley (2007, p. 12) describes it as 'a hit and miss affair' where 'common sense' must prevail as searches are frequently adjusted to yield more relevant literature. With the intention of broadening the search, the term 'autism' was retained as a title word while 'family' and 'experience' could be present within the authors' stated subject terms, abstract or keywords. The search included peer reviewed journal articles over the past 25 years. 336 articles contained the terms 'autism' 'family' and 'experience'. Of these 336 articles, 143 researched the role of the family as early interveners in their child's autism, 52 focussed on autism in healthcare, 33 presented findings relating to autism service provision in specific countries, 9 explored the relationship between families' religious or ontological beliefs and autism and, 99 articles presented the family experience of autism.

These 99 articles were further divided on the basis of the representation of the collective family experience [see Appendix A]. The title of 49 of these articles explicitly highlighted the negative experience of having a child on the autism spectrum in the family and were set aside for use as a point of reference where necessary. The 50 remaining article titles they did not specify whether families' experiences had been negative. Each of these articles was reviewed in terms of main findings, theoretical underpinnings and research methodologies. Gaining an ecological understanding of the literature required a more in-depth analysis that did not simply focus on research findings but instead, explored the significance of the nature of interventions, the research participants' profiles, the theoretical approaches adopted and the research methods used (Sutcliffe *et al*. 2017). Thus, ensuring a criticality regarding the evidence accessed, interpreted and applied resulting in a literature review of enhanced quality (Rumsey 2004; Gough *et al*. 2017).

The importance of social systems in understanding and evaluating the lived experiences of families saturated the literature. Thus, emphasising the interacting systems present in each individual's, and indeed family's, social construction of their world. Much of the literature that highlighted the significance of social systems focussed on the immediate context of the individual on the autism spectrum, and did not explore the impact of wider society as a social system that the family engage with (Fong *et al*. 1993; Margetts *et al*. 2006; Cridland *et al*. 2014; Gorlin *et al*. 2016;). The lived experience of individuals on the autism spectrum and their families cannot be evaluated without acknowledging that their development is impacted by interconnected factors present in wider social contexts (Broderick 1993; Siller *et al.* 2014; Mittal *et al*. 2018), which create a particular narrative of autism.

2.6: Towards an Ecological View of Autism and Inclusion

The present study adopts and advocates an ecological view of autism and inclusion throughout. Bronfenbrenner (1979) presented an ecological system of development, which comprised of the microsystem, mesosystem, exosystem and macrosystem. The groups and institutions that directly impact an individual's development are referred to as the microsystem, consisting of the family, school, peers, religious groups and neighbourhood. The interactions and interconnections between these microsystems, and the people within them, can be defined as the mesosystem. The links that exist between social settings where the individual does not have a functional role and the direct context of the individual constitutes the exosystem. The wider cultural context is described as the macrosystem. The transitions experienced over the course of an individual's life, together with their socio-historical context, comprise the chronosystem. All of these systems must be taken into account when researching family experiences of autism and are elaborated upon further in Chapter Three: The Theoretical Framework. The importance of a 'family-systems' model of understanding the lived experience of neurodiversity was first outlined in Murray Bowen's (1993) extensive research with families of adult schizophrenic children. This work led him to focus his research on interpreting human interactions rather than observing symptoms in clinical settings, which, he argued, focussed on diagnosis and treatment and was therefore limited. He suggested that the lived socio-historical experience of his clients must instead be interpreted. This perspective bears particular significance in any research carried out pertaining to the lived experience of autism.

2.6.1: Autism as Trauma within the Family

The concept of trauma in the family's experience of autism emerged as a dominant theme throughout much of the literature with many research teams basing their studies on the belief that the presence of autism in a family equated with trauma (Gray 2002; Hall and Graff 2011; Bitsika *et al*. 2015; Gorlin *et al*. 2016). Consequently, the 'devastating' impact of autism on the quality of family life was frequently reported (Hutton and Carron 2005, p.182; Reid 1999, p.63; Fung *et al*. 2015). Much literature drew comparisons between the reactions of family members, particularly mothers, to autism and Post Traumatic Stress Syndrome (Mount and Dillon 2014; Whitehead *et al*. 2015; Pruit et al. 2016). One of the first researchers to adopt this analogy was Reid (1999), a psychologist who carried out a retrospective study of cases of autism over a thirty- year period, paying particular attention to the psychological well-being of families. She argued that families were 'imprisoned' by autism (ibid., p.72), and moreover, by the child on the autism spectrum, who 'takes more and more of the family resources' but 'is unable to give' (ibid., p.66). This negative view of the child on the autism spectrum was widely accepted twenty years ago, when research into autism steadily built upon the earlier foundations laid by Kanner (1943), Rimland (1964) and Lovaas (1993). The perspective of these pioneers presented autism, first, as a form of schizophrenia in childhood and consequently highlighted for families, a lack of hope for both their relative and themselves.

Unfortunately, recent literature into family experiences of autism still portrays this lack of hope resulting from the associated trauma (Quintero and McIntyre 2010; Mouzourou *et al*. 2011; Bekhet *et al*. 2012; Benson 2018). While families' feelings of hopelessness and despair were frequently voiced throughout the literature, some studies reported on the importance of hope in these contexts. Hutton and Caron (2005, p.181) for instance, concluded that their 'most surprising finding' was the presence of hope in these families who lived in constant 'intense and extreme stress'. Other researchers were not as shocked that these families held hope for their relative on the autism spectrum. Sirota (2010, p.559) who collected narratives from seventeen individuals on the autism spectrum and their families, reported that 'the role of hope [was] paramount' in their lives. Connolly and Gersch (2013), who explored family experiences of autism within an Irish context, also reported feelings of hope among parents, once they had been empowered through education to accept their family circumstances. Having an acceptance of autism, seemed to reduce the trauma within the family experience as it enabled individuals on the autism spectrum and their families to grow together as they cope with challenges, while learning to appreciate aspects of the lived experience of autism (Field and Hoffman 1999; Bachraz and Grace 2009; Petalas *et al.* 2009; Holder 2013; Hoogsteen and Woodgate 2013; Cridland *et al.* 2014).

2.6.2: Autism, Alienation and Stigma

Families' experiences of alienation manifested differently throughout the literature. While some families explicitly discussed their lived experiences of alienation (Cridland *et al.* 2014; Gorlin *et al.* 2016; Kinnear *et al.* 2016), other studies suggested a fear of alienation present among families (McCabe 2007; Connolly and Gersch 2013; Whitehead *et al.* 2015). A deconstruction of the concept of alienation within these families' experiences revealed the importance placed upon normality by wider society, and its impact on their lives. Theorists on alienation argue that deviation from accepted social norms can result in the isolation of the different by the majority group who adopt and adhere to society's doctrine with ease (Goffman 1963; Becker 1973). If this doctrine is wholly capitalist in nature, an individual's potential to produce capital becomes the primary marker for acceptance in society (Victor 1973; Bourdieu 1977). Many families across the literature demonstrated this reality and emphasised the importance of their child's independence and the possession of a job as a measure of a meaningful life (Fong *et al.* 1993; Mouzourou *et al.* 2011; Chamak and Bonniau 2016). However, many also went on to explain that this may not be a possibility for their loved one on the autism spectrum, perceiving alienation as a consequent inevitability (Fong *et al.* 1993; Kinnear *et al.* 2016; Tait *et al.* 2016).

As well as the possibility of alienation, the presence of stigma surrounding autism emerged a dominant theme across the literature relating to families' lived experiences (Iobst *et al.* 2009; Banach *et al.* 2010; Connolly and Gersch 2013; Kinnear *et al.* 2016; Mitter *et al.* 2019 Grinker, 2020). These studies found that the stigma surrounding difference can act as a pervasive barrier to opportunities that define a good quality of life. Furthermore, they argued that stigma typically involved many factors, including stereotypes, prejudice, and discrimination. Suggested stereotypes about individuals on the autism spectrum and their families were centred on perceived incompetence. Unfortunately, research into stigma in wider literature found that professionals sometimes endorse negative stereotypes present among the general population (Burk and Sher 1990; Stier and Hinshaw 2007). One review indicated that professionals' beliefs were, in fact, more negative than the general population (Schulze 2007). The impact of professional perspectives on families of children on the autism spectrum cannot be overstated and are integral to a family's capacity to cope (Avdi *et al.* 2000; Mulligan *et al.* 2012; Lilley 2014).

2.6.3: Autism and Coping

Coping is defined as the behaviours adopted by individuals to prevent psychological damage. The coping strategies adopted by families of individuals on the autism spectrum have been explored extensively (Higgins *et al*. 2005; Koydemir-Ozden and Tosun 2010; Kahana *et al*. 2015; Hussain and Vallikad 2019; Reddy *et al*. 2019) and are typically classified along an 'approach-avoidance continuum' (Snyder 1999, p.108). Approach strategies are commonly referred to as active coping, while avoidance strategies are widely known as passive coping. Much research has reported the use of passive coping, through avoidance strategies, by family members of individuals on the autism spectrum (Mount and Dillon 2014; Whitehead *et al*. 2015; Tait *et al.* 2016). According to Snyder (1999), when individuals or families have experienced trauma, and possibly developed the symptoms of post-traumatic stress disorder, they will inevitably adopt avoidance strategies in order to cope.

While avoidance strategies are used in order to effectively distance the individual from the problem, this often results in the individual withdrawing inwards and generally negatively impacts both themselves and their family. Avoidance coping strategies include self-blame, denial, substance abuse and disassociation (Hutton and Caron 2005; Mouzourou *et al.* 2011; Hoogsteen and Woodgate 2013; Mount and Dillon 2014; Tait *et al.* 2016). All findings relating to avoidance strategies linked this coping method to the development of mental health issues, which seems to be ubiquitous in families of individuals on the autism spectrum. While most of this research focusses on mothers (Meirsschaut *et al*. 2010; Fung *et al.* 2015; Kahana *et al*. 2015), other studies have suggested the onset of depression among other family members as a result of their relative's autism (Mount and Dillon 2010; Bitsika *et al*. 2015). However, some of the literature suggested that the adoption of a different method of coping would significantly decrease the levels of depression among such families (Hall and Graff 2011; Atkin and Tozir 2014; Whitehead *et al.* 2015; Zaidman-Zait 2020). While an 'approach' strategy of coping was evident in much of the literature on family experiences of autism, the majority of studies presented this active approach as a way to deal with the problem of autism. A small number of articles suggested that changing one's view of the lived experience of autism can be an effective means of coping (Banach *et al*. 2010; Connolly and Gersch 2013; Holder 2013; Lodder *et al*. 2019). This change in perspectives on autism, has long been advocated among the autistic community, who promote a strengths-based approach to autism, and highlight the ways in which the adoption of this positive view can develop resilience in both individuals on the autism spectrum and their families (Mottron 2011; Heirstiener *et al*. 2017).

2.6.4: Autism, Resilience and Empowerment

The development of resilience in families emerged as an issue of great significance, and while many research teams set out to investigate families' levels of stress, emotional and psychological well-being and coping strategies, the development of resilience in families of individuals on the autism spectrum simultaneously came to the fore (Corcoran *et al.*, 2015; Kahana *et al.*, 2015). Resilience was generally presented as how a person can constantly and effectively think, plan and act during and after adverse circumstances. However, when one is in a constant state of stress, his/her ability to cope is greatly impacted and relies on significant support (Matsen and Obradovic, 2008; Werner, 2012). In such instances, viewing the development of resilience as being confined solely within the internal capacity of an individual becomes an issue (Joseph, 2013; Gates, 2019). While the literature regularly emphasised the need for partnership between families and others to build and maintain resilience, the responsibility for such partnerships was often presented as an internal family process that was necessary to overcome the adversity generally conceived to be associated with autism (Higgins *et al*. 2005; Koydemir-Ozden and Tosun 2010; Bekhet *et al*. 2012). Partnerships that resulted in the empowerment of families and individuals on the autism spectrum were under-represented in studies generally.

Although the concept of empowerment arose in literature pertaining to families' experiences of autism, again, it was typically viewed from a needs perspective. Thus, empowerment was promoted as a means of reducing the negative impact of autism on the quality of family life (Banach *et al*. 2010; Sullivan *et al*. 2012; Pruit *et al*. 2016). Irrespective of the objective, it is important to consider the central tenet of such processes of empowerment. In all cases, parent and family education, was seen as integral to empowerment and relied on effective collaboration between all involved in the care and education of the child on the autism spectrum (Banach *et al*. 2010; Mulligan *et al*. 2012; Webster *et al*. 2017; Baixauli *et al*. 2019). The role played by professionals in empowering families and, consequently, individuals on the autism spectrum emerged paramount also (McCabe 2007; Koydemir-Ozden and Tosun 2010; Sansosti *et al*. 2012). Again, the perspectives held by professionals in relation to autism, and how they conveyed this, had a major impact on families' consequent responses and actions (Hutton and Caron 2005; Mouzourou *et al*. 2011; Connolly and Gersch 2013). Many families based their reaction to the delivery of their child's autism diagnosis on the attitude of the professionals they were receiving it from. Essentially, when professionals equated an autism diagnosis with poor outcomes, the well-being of families was impacted. But when professionals promoted understanding and acceptance of autism, families reported feelings of empowerment (Mulligan *et al*. 2012; Webster *et al*. 2017). It is evident that while professionals must identify the needs of individuals on the autism spectrum, the rights of this group must also be acknowledged in order to effectively empower the whole family (Kapp *et al.* 2013; Boshoff *et al.* 2019). Although making a compromise between needs and rights in narratives relating to empowerment may appear paradoxical, many consider it critical to realising the potential of empowering partnerships (Rappaport 1981; Field and Hoffman 1999; Banach *et al*. 2010). As discussed in the following section, such partnerships are integral to the child and their families' co-navigation of the education system.

2.7: The Mesosystem: Families' Experiences of Navigating the Education System Together

Times of transition in the lives of young children have long been the focus of educational research, with many studies examining how such transitions impact children with additional needs and their families (Alexander and Entwistle 1988; Fowler *et al*. 1988; Carta *et al*. 1990). Seminal studies within this area include the work of Chadwick and Kemp (2000), Jewett *et al.* (1998) and Wesley and Buysse (1996) which underscored the importance of having increased supports in place, to cater for both the physical and learning needs of these children during, and following, their transition to pre-school or school. The lived experiences presented throughout this earlier literature focussed on whether or not necessary supports were in place and the impact of the presence or absence of same (Reiss 1994; Powell and Batsche 1997; Erwin and Schreiber 1999). At this time, research was also undertaken in relation to certain differences in the experiences of families of children on the autism spectrum and families of children with a developmental disability. Studies in this area generally reported increased challenges among families of children on the autism spectrum, with particular reference to social, emotional and behavioural difficulties (Lowe *et al*. 1998; Volkmar *et al*. 2004).

2.7.1: Families' Experiences of Navigating Early Years Education Systems with their Child on the Autism Spectrum

In 2004, Forest *et al.* explored, in particular, the challenges associated with the process of educational transition for children on the autism spectrum, their families and educators. This pioneering research heavily advocated the adoption of a collaborative transition partnership to ease the challenges that can arise for a child on the autism spectrum during this transition. It encompassed the perspectives of many of the stakeholders involved in this process, the family, preschool staff and kindergarten staff. This is noteworthy, given that the inclusion of the experiences of multiple stakeholders was not typical across similar research within this area (Stoner *et al.* 2007; Denkyirah and Agbeke 2010; Fontil and Petrakos 2015). Continued co-operation among stakeholders emerged as the central, integral factor in successful transitions. Much of the research in relation to early years educational navigations, however, concedes that the success of transitions ultimately depends on the unique needs of each child on the autism spectrum (Denkyirah and Agbeke 2010; Quintero and McIntyre 2011; Starr *et al.* 2016). Moreover, the widespread omission of the navigational experiences of children on the autism spectrum with more significant needs is heavily criticised by members of the autistic community and their families (Lester 2012; Thomas and Boellstorff 2017; Broder-Fingert *et al.* 2019). As a result, the importance of research representing the experiences of children across the autism spectrum became a priority for the present study throughout.

2.7.2: Parents' Perspectives of Early Educational Navigations with their Child on the Autism Spectrum: National and International Contexts

Although Connolly and Gersch's (2016) research on the transition to school for children on the autism spectrum within the Irish context, mirrored previous research in the field, it included the experiences of children across the autism spectrum. Again, the many stresses and challenges experienced by these children and their families in the transition to primary school were highlighted. The dominant themes that emerged centred on the importance of parents' experiences being believed, the impact and experience of being labelled and, their anticipation and preparation for the future. Similar to other research, parents were presented as an underutilised resource in these educational navigations and as sources of valuable information oftentimes overlooked (Denkyirah and Agbeke 2010; Starr *et al.* 2016; Thomas and Boellstorff 2017). Another key finding centred on the need for professionals to be aware of the power they hold over parents as they are deciding on appropriate school placements for their children, a point reiterated by others (Quintero and McIntyre 2011; Fontil and Petrakos 2015; Starr *et al.* 2016). Acknowledging the power that professionals exert in their role, these researchers urge those offering expertise to be aware of the power relations present in such exchanges.

2.7.3: Voices of the Powerful and Powerless in Families' Co-Navigational Experiences

Few studies exploring the transition to school for children on the autism spectrum focus on the possible power relations present in this navigational exploit. Instead, such power relationships are generally revealed to be an incidental finding, usually in relation to the inclusion or exclusion of a particular group's voice (Stoner *et al.* 2007; Fontil and Petrakos 2015; Nuske *et al.* 2019). One study however, explicitly set out to critically examine such processes of power during these times of transition. Lilley (2014) focussed on mothers' experiences of the transition to primary school for their children on the autism spectrum. The professional guidance they received throughout this process was emphasised. This professional expertise was critically explored and presented as varied epistemological stances on autism. Multiple, and oftentimes conflicting, funds of knowledge regarding autism are reported. These funds of knowledge are informed by many and varied disciplines that have all become integral to the lived experiences of children on the autism spectrum and their families. This point is regularly reinforced throughout literature on the lived experience of autism, where a critical approach to knowledge regarding autism is recommended (Broderick and Ne'eman 2008; Brownlow 2010; Russell and Norwich 2012; Gillespie-Lynch *et al.* 2017). All such research promotes a widespread shift in our understanding of autism to ensure the experiences of individuals on the autism spectrum are enhanced.

Once viewed from a wholly pathological perspective, autism is now beginning to be interpreted through an inherently social model of understanding (Baker 2006; Kapp *et al.* 2013; Krcek 2013; Pellicano *et al.* 2014), where experiences across social settings and systems offer great insight. Lilley (2014, p.513) credits a 'democratisation of autism expertise' between individuals on the spectrum, their parents and professionals with this shift. Although this democratisation is said to provide a balanced power relationship between families and professionals, Lilley claims that this may not be the case. Rather, she argues that professionals continue to hold substantial power and influence regarding the school placement of children on the autism spectrum within the remit of wider governing policy. Parents typically 'do their best to manoeuvre within, and sometimes around, the limited, and often limiting, possibilities' (ibid.). The reference to governing policy within Lilley's research has particular significance for this study as the navigational experiences of children on the autism spectrum and their families depends on the nature of such policy, and the way it is implemented, in individual education settings. Accordingly, the next section explores the evolution of inclusive education policy within the Irish context since its inception, while applying a critical lens to the inherent power relations within this evolvement.

2.8: Autism, Inclusion and the Macrosystem: The National Context

It is impossible and inadvisable to attempt to represent the development of a wider understanding of autism and inclusion nationally, without exploring the factors that enabled or impeded the creation and development of the concept of inclusive education historically. It is important to note that the term 'autism' is a relatively new concept in historical terms and is therefore absent from much literature and policy pertaining to individuals with additional needs prior to the 1990s. Thus, it is inferred that reference to an individual with additional needs, or disabilities, includes those on the autism spectrum.

2.8.1: Understanding the Chronosystem: The Emergence of Inclusive Education Policy in Ireland

Article 42 of the *Irish Constitution* encapsulates the right of all children to free primary education (Government of Ireland, 2015). This right to education appears certain and transparent and does not seem to warrant any further deconstruction. However, a critique of current Irish education policy reveals many issues in terms of the inclusion of young children (0-6 years old), particularly those with additional needs, in the Irish education system. A critical point in the aforementioned constitutional statement is the reference to 'primary education'. In Ireland, this equates with children's formal schooling and does not encompass early years care and education settings. Thus, children younger than the former school going age have been ineligible to realise their educational right. While recent government action represents an initial step in recognising the value of educational provision within the ECCE sector (OMCYA 2009) and the inclusion of young children with additional needs (DCYA 2016a), an obvious care/education divide continues to exist. This divide impacts greatly on the possibility of authentic inclusive practice in Ireland, to an extent much greater than that of many of our European counterparts (Kennedy 2001; Dineen 2012; Moloney 2015). The deep-rooted cause of such fragmentation within the Irish education system is discussed in section 2.8.2 in relation to the historical relationship between the State, the institution of the family, and the inclusion of children with additional needs in education.

2.8.2: The State and The Family: Public vs Private

Santerini (2010, p. 183) argues that the dominant view with regards to one's right to education in Ireland has steadily evolved from a 'mercantile understanding of the person' at the turn of the century. Henceforth, having a commercialised role in society became synonymous with an individual's 'appropriate functioning' (ibid.). However, interpretations of appropriate functioning have varied, depending on the values held by those in power. Ireland's fight for independence was centred upon citizens' rights to equality and inclusion, with the Irish Proclamation demanding 'equal rights and equal opportunities' and committing to 'cherishing all the children of the nation equally' (Department of An Taoiseach 2017). However, Fleming (2016, p. 127) states that, following Ireland's independence and acceptance of this inclusive proclamation, the education policy-making structure 'remained unchanged' as the Catholic Church, rather than the Irish Government, assumed 'the dominant position in education'. Many argue that much inequality in Ireland, is a direct result of the power of the Catholic Church, who have held ultimate responsibility for education in Ireland, promoting a hierarchical system that traditionally placed children at the bottom (Murray 1939; O' Neill 1949; Akenson 1975; Ó Buachalla 1988). While Catholic doctrine explicitly acknowledged the rights of children, this was exclusively in relation to their 'sacred right' to religious education. In fact, Abbott notes that the Catholic Church 'earnestly entreat[ed] all who exercise government over peoples or preside over the work of education to see that youth is never deprived of this sacred right' (1966, p.639-640). Through the Department of Education, the Irish Government embraced and indeed advocated the prioritisation of the sacred right of children to receive an education that holds religious indoctrination as its central vein. This stance is encapsulated in the following excerpt from the Rules for National Schools, (DES 1965, p. 38):

> Of all the parts of a school curriculum Religious Instruction is by far the most important, as its subject matter, God's honour and service, includes the proper use of all man's faculties, and affords the most powerful inducements to their proper use. Religious instruction is, therefore, a fundamental part of the school course, and a religious spirit should inform and vilify the whole work of the school'

Because the Church and the State considered a child's right to religious instruction as paramount, it follows that all other rights, including a child's right to inclusive education, were of secondary importance. Unfortunately, children with additional needs were oftentimes perceived as ill-equipped to receive religious instruction, and therefore, were traditionally locked out of the primary education system (Booth and Ainscow 1998; Rose *et al*. 2017). The needs of these children were interpreted as being outside of the remit of formal schooling and would, therefore, have to be addressed outside of the education system.

2.9: Care and Education Divide

Literature and policy regarding the inclusion of young children with additional needs in the Irish education system revealed a distinct divide between care and education in Ireland that impacts the experiences of children on the autism spectrum and their families in two significant ways. It encompasses the historic care-education divide in Ireland that permeates the early childhood period (birth to six years) since the foundation of the State. With the *Irish Constitution* focusing on the rights of all children to free primary education (GOI 2015), effectively rendering children who fell outside of this domain irrelevant to education policy, as previously mentioned. Again, it was not until 2010 that the free pre-school year in ECCE was introduced as 'a key step towards equality of opportunity for all young children in Ireland at the most important developmental stage of their lives' (NCCA 2009b, p.4). For the first time in the history of the state, universal access to education would include access to ECCE settings where all children (from two years and eight months old onwards) could benefit from early childhood methodologies (for example, an increased focus on child-led play) and low adult/child ratios. However, for children with additional needs, the care-education divide within the Irish education system continues to bear negative consequences. For these children, this divide has impacted their treatment within the formal education system which traditionally manifests as providing inclusive mainstream education for most and segregated special education for some. The importance of including children with additional needs in the education system is a central vein throughout the next section. As is the integral role that families can undertake in the realisation of this inclusive vision.

2.9.1: Responsibility for Children's Care and Education in Ireland: Role of the Family

The United Nation's Committee for the Convention of the Rights of the Child published their *Second Periodic Report on the Holy See* in 2014. This report reiterated its concern regarding the Catholic Church's reservations in relation to the Convention, which, the committee felt 'undermine[s] the full recognition of children as subjects of rights' (CRC 2014, p.3). While the Church recognises the individual's 'inalienable right to an education', regardless of 'condition', Abbott argues that it depends upon how those who govern education, view an individual's 'proper destiny' (1966, p.639). Therefore, it seems that both the Church and State not only recognised, but nurtured, the unmitigated power each held over children's education.

Regardless of the central role afforded to parents in the Irish Constitution, such mutual acknowledgement left little room for parental involvement in their child's education (Akenson 1975; Whyte 1980; Kitching 2013). Thus, while parents are credited with having the 'first and the inalienable duty and right to educate their children', this right and duty was limited to enrolling their child in the primary school (Abbott 1966, p. 644). Family involvement within the national education system was traditionally frowned upon by the Catholic Church, which did not recognise parents' capacity to prepare their children for the ultimate realisation of their religious goals (Chubb 1970; Whyte 1980; Titley 1983). According to Akenson (1975, p. 148) the voice of the parent, and consequently the voice of the child, were 'all but eliminated' from the process of education. Ultimately, childrearing was perceived by the State as a 'private family matter' while education was accepted as the responsibility of the Church and State (Moloney 2014, p. 72). This polarisation of care and education, and concomitant fragmentation in Early Childhood Care and Education provision, persists to the present day, effectively overlooking the potential benefits of an education system that encompasses the early years (Duignan 2005; Moloney 2014; 2015) and special education (McConkey *et al.* 2016; Rose *et al*. 2017).

2.9.2: Creating a Care- Education Divide in Ireland

The development of family patterns in Ireland appear unique in comparison to its European counterparts. A significant increase in the number of mothers participating in the Irish workforce throughout the 1990s led to an urgent demand for the provision of childcare outside the family home in Ireland. This change in family pattern occurred much later in Ireland than in other European countries as the ideology of motherhood, that held child-rearing as the destined role of the mother and optimum level of care for the child, had an exceptionally long-lasting impact on Irish social and economic policy (Mooney and Munton 1997; Kennedy 2001). This is not surprising, as the role of mother as primary caregiver was explicitly enshrined in the Irish constitution and the importance of its protection strongly emphasised:

> The State shall therefore endeavour to ensure that mothers shall not be obliged by economic necessity to engage in labour to the neglect of their duties in the home.
>
> (Government of Ireland, 1937, Article 41.2.2)

This depiction of motherhood in Irish legislation aided the unequivocal acceptance of the role of the male, or more specifically, the husband as the primary ‘breadwinner’, thus, cementing the view of the mother as the most competent and appropriate caregiver (Kennedy 2001, p. 92). Accordingly, a longstanding tradition in Ireland. where almost all mothers of very young children stayed out of the labour market, persisted up until the late 1990s and early 2000s. This tradition consolidated the previously mentioned care-education divide which permeates the early years Irish education system to the present day. In the latter half of the 20th century, when other countries perceived ECCE as a common good, and were investing significant resources in the sector, the Irish Government showed minimal interest in the care and education of children outside of school-going age (Mahony and Hayes 2005; Dineen 2012). Furthermore, when the status of women in Ireland was beginning to be explored, a government appointed Commission reported that they were ‘unanimous in the opinion that young children…should, if at all possible be cared for by their mother at home’ (GOI 1972, para. 310). The chance of any unity between the care and education sectors in Ireland had received a major blow. Consequently, many young children, especially those with additional needs, have long been marginalised in early childhood and beyond.

2.9.3: Ongoing Impact of the Care-Education Divide

Regardless of policy trends towards inclusive education in recent years, the deeply entrenched divides highlighted earlier, mean that for many families in Ireland, accessing mainstream education for their young children has been stressful and problematic (Moloney and McCarthy 2010; Rose *et al*. 2017). In fact, it has been suggested that early interventions that could benefit children with additional needs are simply unavailable outside specialised settings because ‘assistance and support to create continuity for children is not comprehensively put in place’ (Murray and Urban 2012, p. 63). This situation, which further marginalises children with additional needs and their parents, is again characteristic of the traditional care-education divide in Ireland. Education has not been seen as a priority for these children, rather, the predominant focus has been upon their care needs, which have been identified, interpreted and addressed by the Department of Health, rather than the DES (DH 2012; HSE 2012). Attempts to ascertain the feasibility of realising the rights of these children to education have been extremely rare. In the early 1980s for example, a report commissioned by both governmental departments called for adequate facilities for the provision of education to preschool children with additional needs. Although a positive recommendation, access to such educational provision was limited to the unlikely possibility of a place being available for a pre-school child within a healthcare setting. While such settings were attached to a special educational facility, they operated entirely separately (DES/DH 1983, p.17). As such early years settings came under the remit of the Department of Health, nurses were typically tasked with providing ‘all treatment services’, including meeting the educational needs of these young children, with the assistance of child care staff, where possible (ibid., p.28). The quality of educational provision for very young children with additional needs did not appear to be a concern for the DES whose attention was firmly fixed on the quality of the formal school system, including its provision of special education to children of school-going age. The experiences of children who fell outside this remit were not included.

2.10: Recognising *Special Educational Needs* in Ireland

In 1959, the first Inspector for Special Education was appointed in Ireland. The following year funding was allocated to the facilitation of teacher and psychologist training in special educational methods (Walsh 2009). While these actions appeared promising, the provision of specialised education within the mainstream education system was consistently deemed either unfeasible or inappropriate (Bennet *et al.* 1998; McConkey *et al*. 2016). According to Bennet *et al*. (1998), the provision of special education in Ireland has remained relatively unchanged since the *Report on the Commission of Inquiry on Mental Handicap* (GOI 1965). A major finding emerging from this inquiry was that irrespective of the arguments made ‘for and against the segregation of handicapped pupils… it is essential in this country to provide education for mildly mentally handicapped pupils mainly in special schools’ (ibid., p. 76). When giving their reasons for this deduction, the Commission explained that the possibility of children with additional needs being included in mainstream education ‘is hampered by the strong academic bias of primary education in this country’ (ibid.). Bennet *et al*. (1998 p. 161) claim that this reality has continued to shape a view of the inappropriateness of including some children with additional needs in education, as they ‘appear to be permanently incapable of benefiting adequately from the instruction in the ordinary school curriculum’ (ibid.).

An inquiry into the educational provision for *Physically Handicapped Children in Ireland* (1982) further reinforced this view. This report stated that while some children with additional needs ‘are incapable of engaging in any productive activity, the development of their limited potential through education can give purpose to their daily lives’ (DES 1982, v). In the past, the DES have also examined the case for educational provision of young children with additional needs (from the age of four upwards), who had been excluded from the formal education system. While the report acknowledged the possible benefits of educating children with special needs in mainstream settings, they found that the education and training needs of many of these children ‘could not be met, in the foreseeable future, by attendance at ordinary schools’ (DES 1983, p.3). Again, the care of these children is emphasised as their primary need while their right to education is dismissed. At the same time as such judgements were passed, developments were occurring internationally in relation to the realisation of mainstream education for all children with additional needs.

2.10.1: Mainstream Integration for Children with Additional Needs

By the 1980s the notion that every child has a right to be educated in the regular classroom, if possible, had been adopted in most developed countries and had heavily influenced international policy relating to *special educational needs* (Pijl *et al.* 1997; Meijer *et al.* 2003). Many studies reported that children with additional needs who were mainstreamed, experienced positive outcomes including enhanced academic achievement and long-term behaviour (Hobert 1980; Johnson and Johnson 1980; Madden and Slavin 1983; Walker 1986). Furthermore, Hobert (1980) and Walker (1986) noted increased levels of confidence and self-efficacy among such students.

Others suggested that educating children with and without additional needs together created an atmosphere of understanding and tolerance that prepares all children, regardless of abilities, for the world beyond school (Johnson and Johnson 1980; Madden and Slavin 1983). A longitudinal study regarding the outcomes of integration into mainstream education in the United States highlighted that, as a result of their inclusion in the mainstream, students with additional needs felt that they were equal to their peers and should not be treated any differently (National Research Centre on Learning Disabilities 2007). With such positive evidence, governments across Europe promoted integration as the accepted placement model for children with additional needs (Gross and Gipps 1987; Ashman and Elkins 1994). Policy development in Ireland in the 1990s gradually followed developments internationally, moving towards increasing levels of integration of children with additional needs in mainstream education. With the enactment of the *Education Act* in 1998, the right to mainstream education for children with an additional need or disability was realised in Ireland (DES 1998). While this long-awaited policy change received much commendation, there remained a strong emphasis on segregated special education in Ireland.

2.10.2: The Possibility of Mainstream Education Access for Children with SEN in Ireland

Throughout the international push for integration of children with additional needs into mainstream education, separate classes for these children continued to be established across Ireland (Commission of the European Communities 1992; Fleming 2016). A review of provision for children with additional needs, by the *Special Education Review Committee* (SERC 1993), reported that over two thousand children were being educated in such classes. The SERC report, which dealt extensively with the educational implications arising from additional needs, recommended a continuum of support encompassing full time integration in a mainstream setting, full or part time placement in a special class or school, or fulltime placement in a residential special school. However, Bennet *et al*. (1998, p. 150) argue that while SERC recognised the need for a range of educational provisions, there was an overemphasis on the appropriateness of special schools and special classes and the infeasibility of integration into mainstream education. Indeed, this lack of support for integration in mainstream education was openly criticised by the Psychological Society of Ireland (PSI 1994), who argued that the continuum of provision described was effectively excluding many children from being integrated into mainstream classrooms.

The following year, the White Paper on Education: *Charting our Education Future* (1995) explicitly dealt with the issue of access and integration in mainstream education in Ireland. Accordingly, *Charting Our Education Future* proposed that: 'all students, regardless of their personal circumstances, have a right of access to and participation in the education system according to their potential and ability' (DES 1995, p. 26). While this guarantee of access appears to rely on an evaluation of a child's ability, reference is also made to a commitment from Government to provide intervention at all levels to ensure equality of access to all children. With regards to intervention for children prior to school, three principle considerations are set out:

1. Early childhood experiences are paramount to the overall development of the child.
2. Entering the formal school system is a major transition for children, particularly those who may have additional needs.

3. Early disadvantages affect the child's long-term experience within formal schooling (DES 1995, p. 16).

However, the White Paper fell short of explicitly stating how such tailored mainstream education would be provided for preschool aged children with additional needs. Yet again, the focus remained upon facilitating special educational needs predominantly within the domain of the formal school system, with limited concern for younger non-school going children.

2.10.3: Moving from a Narrative of ‘Special Needs’ to ‘Special Educational Needs’

Although the *Education Act* (1998) focussed upon access to education for school going children, it nonetheless, marked a significant paradigm shift in education from the traditional mainstream model to an integrated alternative. The importance of providing inclusive special education is clearly outlined in its preamble, which presents equal rights to education as integral to ‘the common good’ (GOI 1998, Section 1). It further emphasises that this ‘common good’ encompasses ‘any person with a disability or who has other special educational needs’ (ibid). Contrary to previous Government documents relating to special education, the *Education Act* (1998) makes no assumptions with regards to children’s capability to learn or whether education is or is not of benefit to them. Instead, educational provision for children with additional needs is presented as a policy priority. While this provision is highlighted as central to many of the responsibilities of the Minister of Education (i.e., establishment of support services, individualised education models, collaboration with parents etc.), the extent to which these actions are developed, again relies on whether the Minister considers them to be ‘appropriate’ (GOI 1998, Section 7).

Therefore, ambiguity remained surrounding the interpretation of the act. In practice, the most significant element of interpretation within the *Education Act* was a logistical change in terms of language. Up until this point, the Government had been somewhat vague in terms of explicitly stating which public service had ultimate responsibility for addressing the additional needs of children in Ireland. Thus, the paradigm shift, from *special needs* to *special educational needs*, placed primary responsibility for these children’s education with schools/Department of Education (O’ Sullivan 2005; Barry 2009). However, as the ECCE sector remained outside the parameters of the DES, a corresponding shift in the understanding of *special needs* to *special educational needs* did not occur, at either a policy or practice level in ECCE (McCarthy and

Moloney 2010). Consequently, responsibility for the *special needs* of these children remained with the Department of Health, further cementing the fragmentation and inconsistency within such services, rendering the possibility of quality education for some young children with special educational needs even further out of reach.

2.11: Providing an Education System for All in Ireland

The *United Nation's Policy Guidelines on Inclusion in Education* (2009) advocate strongly for adopting authentic inclusive practice in order to achieve high-quality education for all. Indeed, the primary goal of inclusive education is the strengthening of the education system 'across all levels, provisions and settings to deliver on the promise of a quality education for all' (Opertti, *et al.* 2014, p. 150). As mentioned earlier however, there are barriers to delivering inclusive education *across all levels* in Ireland. The clear care-education divide in Ireland seriously impedes the reality of quality education for all (Mahony and Hayes 2005; Dineen 2012; Moloney 2015). Interestingly, policy relating to the ECCE sector emphasised the centrality of quality from its inception, whereas it took almost a century for the issue of quality to emerge as a dominant factor in educational policy in Ireland.

2.11.1: Inclusion Across the Irish Early Years Education System: The Lens of Quality

The relationship between inclusion and quality in early years educational provision for children aged from three to six years featured prominently in *Ready to Learn: The White Paper on Early Childhood Education* (DES 1999). Some argue that this relationship is influenced by international policy in the field of early years education, that highlighted the long term social and economic benefits to providing high-quality education in the early years (Cleveland and Krashinsky 1998; Blatchford and Wong 1999; Alexander 2009). Prior to the publication of *Ready to Learn*, ECCE was viewed primarily in terms of providing childcare to facilitate the ever-increasing number of mothers who were entering the Irish workforce (Hayes 2007; Moloney 2014). Within the ECCE sector broadly, the concept of 'quality' has been outlined and evaluated by a variety of sources (e.g., DJELR 2002; CECDE 2005; DES 2009). As a result, many and varied quality measures and standards have been produced and implemented into ECCE settings. According to Opertti *et al*. (2014, p. 150), any ambiguity surrounding the meaning of 'quality' in education can lead to conflicting opinions on best practice which consequently creates 'piecemeal approaches or evidence gaps between and within the policy…and practice levels'. A fragmented and disjointed understanding of quality can therefore act as a barrier to the achievement of effective inclusion for all. As a result, the relationship between quality and inclusion across the Irish early years education system warrants in-depth examination.

Now more than ever, the importance of quality assurance dominates public policy in Ireland, especially in education, including early childhood education. Quality and governance go hand in hand. In this respect, Governance of the formal education sector is straightforward with one single body, i.e., the DES with support from the NCCA, responsible for developing, implementing and overseeing curriculum developments. A different picture emerges in the field of ECCE where both the DES and the DCYA currently govern the sector, as well as determine the core constituents of quality. In addition, a range of bodies and organisations including TUSLA, the *Child and Family Agency*, *Early Childhood Ireland* and *Better Start*, for example, all define quality from their respective perspectives. More than a decade ago, the Centre for Early Childhood Development and Education (CECDE 2006 now disbanded) developed *Síolta: The National Quality Framework for Early Childhood Education and Care*, arising from one of the main objectives of *Ready to Learn* (DES 1999). From the outset, the CECDE recognised the possible ramifications of the ‘multiple and competing perspectives on quality in ECCE’ (Duignan 2005, p. 168) and thus, ensured that the twelve principles of quality within Síolta were developed in collaboration with the many stakeholders involved in ECCE. *Síolta* was intended to bridge ‘the traditional divides between the care and education and between the formal school sector and the informal ECCE sector’ (Duignan *et al*. 2007, p.40). As such, it was designed for use across a variety of ECCE settings, caring for and educating, children aged from birth to six years. The role of *Síolta* in the relationship between quality and inclusion across the Irish early years education system is significant. While it is a quality assurance framework, it also encompasses many of the fundamental elements of inclusion, for example, the prioritisation of the child, the importance of equality and diversity and the central role of parental partnership. These aspects of quality, which are integral to this study, are explored in detail in the remainder of this review and, across the entire study.

2.11.2: Inclusion and Quality in the Early Years: The Role of *Siolta*

While the twelve *Principles of Síolta* (DES 2017c) are integral to the achievement of quality early years education in Ireland, their pivotal role in inclusive practice is also clear. Indeed, it appears that in attempting to bridge the gap between the ECCE and primary education, the

Principles of Síolta contain elements that are crucial to the realisation of inclusion for all children in early years education across preschools and the infant classes of primary schools. As Figure 4 outlines, these principles stress the importance of valuing the experiences of young children and their parents, developing relationships to enable equality of opportunity for all children, and creating inclusive spaces and cultures where collaborative and child-centred methodologies can be implemented with ease.

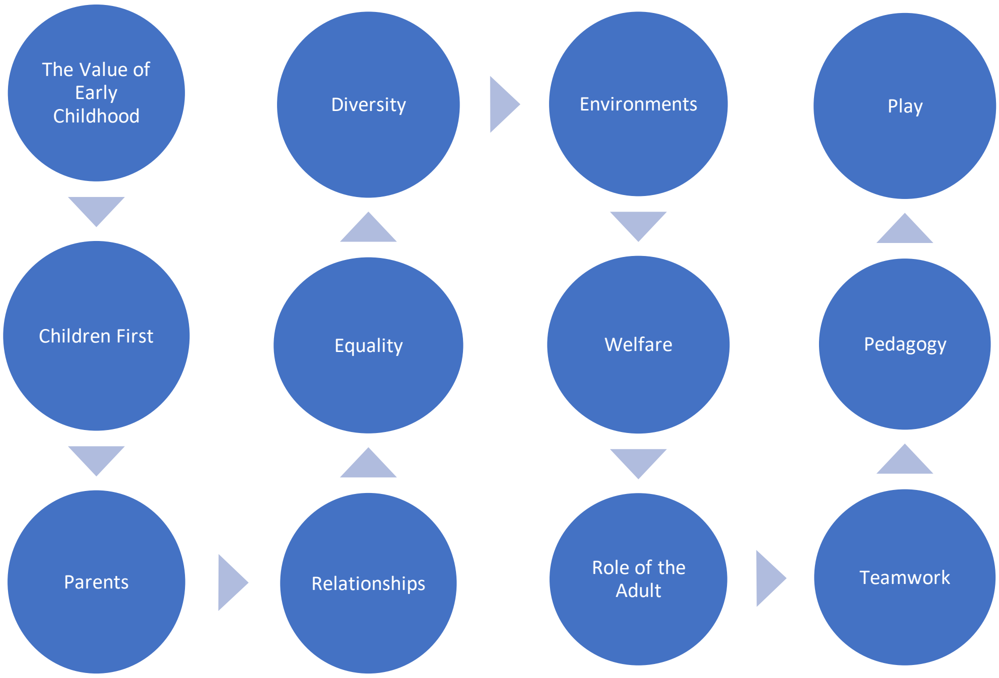

Figure 4: The Principles of Síolta

These, principles, however, are especially important in determining whether the navigation of a young child on the autism spectrum across the Irish early years education system is a positive or negative experience for them and their families. The *Principles of Síolta* represent dynamic indicators of quality that align closely with an ecological stance, within which interactions, relationships, values and perspectives are pivotal. The fact that this dynamic nature of quality is difficult to measure means processes considered central to the concept are often overlooked, with attention given, instead, to its static, and more easily measured elements (Walsh 2005; Dahlberg *et al.* 2007; Opertti *et al.* 2014). Therefore, while the wider narrative on quality early years education argues that dynamic factors are quintessential (Blatchford and Wong 1999; Walsh 2005; Alexander 2009), the prioritisation of static indicators of quality, such as compliance, the achievement of standards and assessment results, prevails (Gerwitz 2000; Hayes 2006; Hanafin 2016).

In 2005, when the delivery and support of quality ECCE began to emerge as a dominant narrative, the importance of cohesiveness across the sector was highlighted as being a 'prerequisite of quality services' (Walsh 2005, p.189). However, it was still considered 'advisable to build any assessment infrastructure on the existing statutory systems in operation within early years settings' (ibid., p. 189). Therefore, the pre-school inspection system would remain under the aegis of the DH, while infant classes in primary school would continue to be inspected by the DES Inspectorate. While the *Child Care Act* (1991) had previously outlined some connections between the Departments of Health and Education in the provision of childcare, the explicit and continued involvement of different governmental departments has resulted in multiple, and varied, systems of inspection which expose the sector to unrelenting governance and scrutiny (Moloney 2010; 2015; 2018). Moreover, the involvement of different departments affects the realisation of the symbiotic relationship between quality and inclusion, as envisaged within the *Principles of Síolta* across ECCE and primary education (Hanafin *et al.* 2009; Hanafin 2016). Within the scope of the present study, the key role of parents within processes of quality and inclusion across the Irish early years education system warrants particular consideration.

2.11.3: The Role of Parents in Quality and Inclusion in ECCE

As mentioned earlier, since its inception, ECCE policy has been saturated with references to quality measures and standards. Research exploring the impact of this unremitting emphasis on quality assurance on practitioners within ECCE settings can offer further insight into the lived experience of such policy changes (Moloney 2015; Hanafin 2016). Internationally, the perspectives of early years practitioners on quality measures and standards, reveal that an over-emphasis on static indicators of quality have impacted negatively on dynamic indicators of quality, for example, parental partnership (Hujala *et al*. 2009; Cottle and Alexander 2014; Whyte 2015). According to Mahony and Hayes (2005, p. 199), the voices of parents and children were typically 'less evident' in the 'extensive debate within the ECCE sector regarding what constitutes quality'. The authors attributed this to 'power dynamics' within the sector that prioritise the wider macro-agenda of Government that continues to exist across both the care and education sectors. Within this macro-agenda, parental involvement in education is equated with parental satisfaction with education, an interpretation that can prove problematic for parents of children with additional needs who view quality education differently (Brain and Ivan 2003; Brooker 2010; Cottle and Alexander 2014). These parents define quality education in terms of the possibility of access, resources, social inclusion and acceptance of their child (Frederickson and Cline 2002; Connolly and Gersch 2013; Lilley 2014). However, ensuring their child's access to such quality education means that they often have to accept alternative ECCE placements and compromise on what they had initially planned for their children (Moloney and McCarthy 2010; Connolly and Gersch 2013). It appears that the element of choice, so central to the wider quality agenda, may be removed for them

2.11.4: The Possibility of Quality ECCE for Children with Additional Needs

In a historic development, the Government in 2016 first recognised the rights of young children with additional needs outside of formal education, to benefit from quality ECCE on an equal basis with all other children. The seminal *Access and Inclusion Model* (AIM) (DCYA 2016a) incorporated numerous significant policy developments that have occurred within the ECCE sector in relation to inclusive education in recent years. The introduction of *Aistear*: *The National Early Childhood Curriculum Framework* (NCCA 2009) and the Free ECCE scheme (DCYA 2019) indicated a crucial move towards equality of opportunity and outcome for all young children in Ireland. The guidelines and objectives of both reiterate the importance of diversity, equality and inclusion throughout. At the same time, McCarthy and Moloney's (2010) *Framework for Action for the Inclusion of Children with Special Needs in Early Childhood Education Settings* provides a comprehensive review of current policy and practice in relation to *special educational needs* in the early years in Ireland, and makes important recommendations for policy, practice and research. Such recommendations were an essential pre-requisite to both the interdepartmental report on *Supporting Access to the Early Childhood Care and Education (ECCE) Programme for Children with a Disability* (2015) and the development of the *Diversity, Equality and Inclusion Charter and Guidelines for Early Childhood Care and Education* (DCYA 2016b). Moreover, it is evident that the design of the *AIM* (DCYA 2016a) was premised upon the recommendations for policy and practice within the *Framework for Action*.

While these policies and legislative documents present an important charter for inclusion in the early years, the *AIM* is a particularly integral development within the inclusive policy landscape of ECCE in Ireland. It promotes and prioritises the rights of young children with additional needs to be meaningfully included within mainstream ECCE settings. Through its establishment of universal and targeted support systems [see Appendix B1], it strives to ensure that children with additional needs can access and, moreover, authentically participate in the ECCE Programme. It also encourages the empowerment of ECCE staff to fulfil their role in inclusion through increased expertise and quality assurance measures. A critical element of the AIM is the development of *The Leadership for Inclusion in the Early Years* programme (LINC), which enables the development of the knowledge, understanding and skills of participants to be empowered to facilitate and support inclusion in early years settings (MIC/ECI/MU 2017). It appears that, through the AIM, the relationship between quality and inclusion in ECCE settings has become more harmonious. However, the AIM relates to ECCE settings and not primary schools, though its abundant references to dynamic indicators of quality is informed by the *Principles of Síolta* (2006; 2017), which was designed to encompass both. It is therefore, crucial to gain an understanding of how the relationship between quality and inclusion has developed within the primary education sector.

2.12: Assuring Quality for Children with Additional Needs in Schools

The importance afforded to the rights of young children with additional needs to quality educational experiences is a core aspect of *Ready to Learn* (DES 1999). This is seen as ‘necessary to ensure equality of opportunity and equitable treatment’ (DES 1999, Section 3.7) and to combat any differences in attainment as early as possible, such action is more ‘effective and cost-efficient than later intervention’ and should ‘maximise the private and social returns on investment’ (ibid., Section 3.6). *Ready to Learn* explores the capacity of ‘quality early childhood educational interventions’ to alleviate, or indeed prevent, some of the ‘handicaps and difficulties’ children with additional needs may experience. However, in spite of advocating for early intervention, the ‘remedial’ education provision, implemented in September 1999, was directed solely at ‘children in the early years in national schools’ (ibid., Section 6.4). With regards to parents, the White Paper advocates for providing the support families may need in ‘adjusting to having a child with special needs’: an issue that remains a concern within special education provision today (Banach *et al.* 2010; Connolly and Gersch 2013). However, there was a vagueness surrounding who held responsibility for this high quality, 'seamless provision of care and education' for all children from birth to six (DES 1999, p. 44). It seems that while the DES accepted the responsibility for ascertaining the quality of mainstream education provided to children in the early years, this would be limited to those in infant classes in primary schools. The quality of the formal school system remained their priority.

2.12.1: Focus on Quality Measures in the Irish Education System

In Section 13 of the *Education Act* (1998), the revised and extensive role of the DES inspectorate is elaborated upon, with particular reference to their evaluation and regulation of quality education and their understanding of special educational needs. It was envisioned that the Inspectorate would have the capacity to advise schools and collaborate with parents on best practice in education for their children with additional needs. Hislop (2012) however, holds that in putting the *Education Act* into practice, the majority of the Inspectorate's work focussed on the evaluative and regulatory elements of its role. In their critique of quality measures in education, and congruent with the narrative of marketization, Hoy *et al.* (2000, p.13) conclude that the widespread emphasis on quality assurance in education evolved from a climate of mass consumerism. Within this context, quality is defined and evaluated in terms of consumer expectations and how they are met. Consequently, within education policy, parents seem to be presented as consumers who should develop their evaluative and regulatory role through collaborative partnerships with educators.

Within the Irish context, Hislop (2012, p.25) claims that there has been a tendency for parents to be 'protective of their schools when external inspection occurs'. He concludes that this 'is a pity' as parents essentially 'fail' to carry out their role as effective partners in quality education. This representation of the parents' role as educational critics can be problematic as it fuels the perspective that governmental advocacy for parental partnership in education policy is driven by a desire for increased efficiency and accountability (Crozier 1998; Brain and Reid 2003; Cottle and Alexander 2014). While the widely accepted view that increased accountability and transparency results in improved educational provision, international evidence suggests, that for some marginalised groups, the opposite can be true (Blatchford and Wong 1999; Gerwitz 2000; Osgood 2006). These authors argue that within this marketized model of education, the quest for accountability and transparency can negatively impact the culture of schools and consequently hinder the authentic inclusion of children who may be perceived as being incapable of achieving accepted quality standards.

2.12.2: Identifying Strengths: A Prerequisite to Delivering Quality Education

The central importance of identifying the strengths and abilities of children with additional needs, as a prerequisite to authentic and effective inclusive practice in education, permeates the literature on inclusion (Parsons *et al*. 2009; Moloney and McCarthy 2010; 2018; Murray and Urban 2012; Roberts and Simpson 2016). The perspectives that all involved in education hold in relation to additional needs and disability are paramount to this positive, strengths-based approach to inclusion (Casserly and Padden 2018; Leonard and Smyth 2020; Tiernan *et al.* 2020). The Education Act equated 'disability' with medical needs, and presented it in terms of deficit, describing, for example: 'the loss of a person's bodily or mental functions…, chronic disease or illness… malfunction, malformation…disfigurement…disturbed behaviour' (GOI 1998, Section 2). Six years later, the State introduced a child centred model of disability through the *Education for Persons with Special Educational Needs Act* (EPSEN 2004). Crucially, EPSEN focusses upon all children's right to education and the importance of all children's strengths. While the possible 'restriction in the capacity of the person to participate in and benefit from education' echoes Governmental documents from the previous decades, the definition concludes by reinforcing the notion that children with additional needs 'learn differently' (GOI 2004, p.6). Thus, a social model of diversity rather than deficit was introduced to inclusive education policy in Ireland for the first time.

This bore a significant impact on practice in Ireland as special educational provision now had to take differentiated learning into account and individualise education plans accordingly. The fact that children's skills, talents and abilities were advised to be foremost in this plan implied an adoption of a strengths-based approach to special educational needs. Thus, realising a central and long-standing element of inclusive education (Frederickson and Cline 2002; Thomas and Vaughan 2004; Moloney and McCarthy 2010; Murray and Urban 2012; Tiernan *et al.* 2020). However, according to Kinsella (2009, p. 88) inclusive practices in schools can only ever be achieved if there is genuine interaction between the strengths and needs of individual learners and the strengths and needs of our education system, concluding that 'to date the focus has been on the former rather than on the latter'. Effective inclusion, therefore, can only occur when there is genuine understanding and collaboration between the child, their family, and their educators, but also between all sections of the education system.

2.12.3: Measuring Quality in Special Educational Provision

Following the implementation of the *Education Act* (1998) there was ambiguity surrounding the evaluation and regulation of quality in special educational provision in mainstream schools. Hislop (2012) indicates that this ambiguity was related to the practice whereby the Inspectorate delegated the task of advising on the provision of special education (and regulating practice in this) to other parties and agencies, namely the NCSE, the National Educational Psychological Service (NEPS) and, the Special Education Needs Organisers (SENO). The SENO, employed within the NCSE, has primary responsibility for the distribution of support and resources to individual schools, based on the identified needs of individual children (GOI 2004). Consequently, quality measures in the Irish education system began to focus primarily on the delivery and receipt of mainstream education, while educational provision that did not fit this description would be under the domain of other Government agencies or departments.

In keeping with the traditional care-education divide, the provision of quality inclusive ECCE to pre-school children with additional needs would remain the concern of other Governmental departments and organisations (McCarthy and Moloney 2010). It is noteworthy, however, that home tuition, which is provided by the DES to meet the educational needs of children who are unable to attend primary and secondary school, can also be availed of as ‘early educational intervention for children on the autism spectrum who meet the [home tuition] scheme’s eligibility’ (DES 2017a, p. 3). Clearly, the Government is cognisant of international research findings that point to the long-term social and economic benefits of early educational intervention for children on the autism spectrum (Rutter and Schopler, 2012; Weitzman, 2013). However, issues have arisen regarding the actual availability of such early educational intervention (Gilroy *et al.* 2018; Roddy and O’ Neill 2019). Especially as children on the autism spectrum are only eligible for a six-month period of tuition when they are between 2.5 and 3 years of age. This timeframe in their young lives generally coincides with ongoing waiting for assessment and diagnosis, without which they are deemed ineligible (Connolly and Gersch 2013). Again, the need for cohesion between governmental departments in realising these children’s rights to education are highlighted. Such cohesion is also necessary between the stances adopted within the design and implementation of inclusive education policy. The sometimes-conflicting positions of quality and inclusive education must be recognised and negotiated through dialogue, otherwise, issues regarding the implementation of such policy will continue.

2.12.4: Achieving Quality or Becoming Inclusive

The NCCA combines both quality and inclusion in their definition of inclusive education, stating that it is ‘concerned with creating quality education for all students, including those with a disability’ (2002 p. 2). Effective inclusion must evolve from a worldview that accepts the potential of each child, emphasising their strengths and abilities in every aspect of day-to-day life in the educational setting, rather than their needs or weaknesses (Frederickson and Cline 2002; Thomas and Vaughan 2004; Ainscow *et al*. 2006). This perspective contrasts with what Hoy *et al*. (2000 p. 13) described earlier as the ‘consumerist dogma’ that occurs in education today. When education systems prioritise quality in an attempt to improve consumer choice they can, instead, remove the element of choice in education placement for families of children with additional needs.

If quality education systems continue to focus solely on academic attainment as a measure of achievement, the inclusion of children with additional needs again becomes problematic (Blatchford and Wong 1999; Ainscow *et al*. 2006; Fullan 2016). Therefore, while parents are often presented in education policy as the primary consumers in education, such consumerist terms bear little weight for families of children with additional needs. In this respect, these families face many challenges in terms of accessing education for their children because of an over-emphasis on achieving high-quality standards in education settings (Frederickson and Cline 2002; Lilley 2014; Rose *et al*. 2017; Byrne *et al*. 2018). Thus, equality of quality outcomes become irrelevant to those who are unable to access the system in the first place. Lynch and Lodge (1999) argue that the concept of equality in education has for many years, been based on a ‘distributive’ model of social justice that focusses primarily on addressing needs. It has been assumed that if a particular group were given greater access to different forms of education, then equality in education was being achieved. What has become clearer in recent years, however, is that working from a distributive model of justice for the promotion of equality in education, while necessary, is no longer sufficient. Policy must instead focus on children’s rights rather than constantly emphasising children’s needs (Children’s Rights Alliance (CRA) 1989; UNESCO 1994; United Nations 2006).

2.13: Managing Under the Macrosystem: Interpreting Inclusion

The recognition of the human rights of individuals with additional needs in Ireland has been a recurring topic within the social justice discourse for the past decade. However, in 2008, as the impending recession was becoming more apparent, the Irish Government distanced itself from its quoted socially just ideals, suspending the implementation of numerous elements of inclusive policy because of economic constraints (CECDE 2008; Drudy 2009; Roche *et al*. 2017; O' Connell 2019). The ongoing creation of, what Tormey and Haran (2003, p. 32) describe as, 'equality infrastructure' in Government policy means little if there is an absence of partnership between policy stakeholders in the implementation of these. This absence of partnership between stakeholders in inclusive education may emerge as its detrimental flaw. If increased efficiency and quality assurance remains the primary goal of Government, then policies that are saturated with the ideals of social justice and inclusive partnerships, are conflicting, impracticable and have the capacity to reproduce unequal power relations (Drudy 2009; Devine and Luttrell 2013; McConkey *et al.* 2016; Lynch 2017).

2.13.1: Inclusion as Recognising the Rights of All Children and Families

In the thirty years since the introduction of the *United Nations Convention on the Rights of the Child* (1989) there has been a dramatic increase in exploring the rights of children, rather than limiting our understanding of them to an evaluation of their needs. This focus on children's rights has led to the widespread promotion of inclusive education for all children. The convention states that children with additional needs have the right to 'access to and receive[s] education…in a manner conducive to the child's achieving the fullest possible social integration and individual development' (UNCRC 1989, p.23). The centrality of children's rights within the narrative of inclusion effectively brought the provision of special education from a segregated and isolated field to an integrated process. However, integration was not viewed as an end in itself, but rather, a prerequisite to inclusion. As previously stated, since the 1980s, there has been a worldwide movement towards the inclusion of individuals with additional needs in education and wider society. This movement began with the *United Nations' World Programme for Action Concerning Disabled Persons* (United Nations, 1983) and includes: *The Salamanca Statement* (UNESCO, 1994), *Dakar Framework for Action*

(UNESCO, 2000) and, the *Convention for the Rights of Persons with Disabilities* (UN, 2006). However, it was 2018 before Ireland ratified the *United Nation's Convention of Human Rights for Persons with a Disability* (2006), the last country in Europe to do so and many years after the rights of these individuals were recognised in the vast majority of nations across the world (Lennon, 2017).

While the EPSEN Act emphasises the rights of children with additional needs to 'avail of, and benefit from, appropriate education as do their peers who do not have such needs' (DES 2004, Section 13), Ireland's failure to ratify the *Convention of Human Rights for People with A Disability* for such a long period of time is problematic. It undermines the significance and impact of this legislation. EPSEN is however, clear in the rights it allocates to parents of children with additional needs. It seems that parents are viewed as integral stakeholders in the process of special education provision and that their increased involvement would ensure successful implementation of the Act in schools. Indeed, ascertaining the wishes, experiences and knowledge of parents is deemed an integral aspect of the role of the school, the SENO, the NCSE, and the Minister for Education (DES 2004, Section 15). Nevertheless, the needs of the child are framed within the needs of wider society throughout, a common occurrence in more recent national and international Government documents pertaining to children (OECD 2009; DCYA 2014; NCC 2016).

2.13.2: Inclusion as Meeting the Needs of Society

A central concern of national and international Governments presently is the transmission of knowledge, attitudes and skills through the education system that will result in the creation of long-term behaviours that develop and maintain a productive, sustainable and inclusive society. Within this view of social justice, the education system immediately becomes an outlet for the distribution of equality policies, that generally also emphasise the importance of quality and efficiency (Devine 2000; Wright 2012; Devine and Luttrell 2013). While such policy appears to focus predominantly upon children's rights, the needs of the State appear to be prioritised. For example, many aspects of the EPSEN (Sect.13(3)a) act remain unimplemented as the provision of the necessary resources was not deemed to be 'consistent with the common good'. The common good therefore, is defined and based upon international economic trends (Kennedy 2001; Harvey 2005; O' Connell 2019). Surrendering certain elements of this inclusive education policy is seen by, for example, the EU, as an opportunity for all member states to work effectively together in order to 'emerge stronger from [a] crisis and turn the EU into a smart, sustainable and inclusive economy, delivering high levels of employment, productivity and social cohesion' (Day 2013, p.19). This reinforces what many describe as a neoliberal governmentality that draws on the modern economic role of the market, rather than the traditional sociological role of the state, when constructing knowledge about education (Douglas 2010; Lynch *et al.* 2012; Stangvik 2014).

In a neoliberal society, the central aim of government policy is the construction of independent, self-regulating individuals and groups (Arestis and Sawyer 2005; Harvey 2005; Davies 2014; Moloney *et al.* 2019). However, such an agenda reproduces inequalities, as the more powerful and privileged identify the needs of the less powerful while prioritising the needs of wider society and distribute provisions accordingly (Clark 2005; Kinsella 2009; Mladenov 2015b). In her work, on the effective inclusion of children on the autism spectrum in education, Douglas (2010, p. 105) argues that some countries have designed 'new mentalities of rule around educational inclusion'. These new mentalities represent a form of 'neo-liberal governmentality in schools, circulating together with discourses around parent involvement and teacher practice, as well as illiberal forms of power, in complex and contradictory ways' (ibid.). Such contradictions appear to be evident in inclusive education policy governing the Irish early years education system currently, the impact of which will now be explored.

2.13.3: Managing Inclusion in the Education System Effectively

Many who have examined educational change stress the importance of a strong, seamless and transparent education system in realising an inclusive vision (Morrison 1998; Ainscow *et al.* 2006; Fullan 2016). The obvious divide between ECCE and primary education in Ireland therefore acts as a barrier to effective inclusion. According to Fleming (2016, p.397) there has been a 'reluctance or failure' by the DES 'to develop a role for itself beyond mainstream schooling'. The ECCE sector is not acknowledged as part of the formal Irish education system, and consequently, obvious and impacting fragmentation exists (Hayes 2007; Moloney 2014; 2015). Again, this division is clearly distinguishable in the introduction of recent inclusive education policy in both settings. Namely the AIM (DCYA 2016a) in the ECCE sector and, Circular 0013/2017 *Circular to the Management Authorities of all Mainstream Primary*

Schools Special Education Teaching Allocation (DES 2017a) which now governs inclusive practice in primary schools. As mentioned earlier, the recent introduction of the *AIM* (DCYA 2016a) holds the rights of children with additional needs, together with their families, at its centre. Its primary goal relates to empowering ECCE providers to deliver a quality inclusive pre-school experience to children who may not have been able to participate and receive such education previously. While this aspiration can be problematised in terms of the reduced role of Government, dynamic indicators of quality education, as outlined in relation to *Síolta* (2006; 2017) earlier, saturate the policy. Again, the role of parents emerges an integral feature, the strengths and abilities of the child are represented as paramount and the importance of an increased understanding of diversity, equality and inclusion among ECCE service providers is emphasised throughout. By contrast, *Circular 0013/2017* approaches inclusive education from a needs perspective, where the needs of the education system and society, rather than those of children, families and educators, are prioritised.

2.13.4: ‘Governmentality’ or ‘Inclusion’ in Current Irish Education Policy

The tenets of governmentality, for example, reduced role of government, increased self-government, efficiency, cost-effectiveness, quality, expertise, inspection etc. permeate *Circular 0013/2017*. Little reference is made to elements central to inclusive education: partnership, appreciation of strengths and abilities of children, and the increased understanding of inclusion among teachers (DES 2017b). While the need for expertise is referenced, in this instance, it manifests as a means of self-government. This stance on inclusive practice is less associated with the collaborative empowerment of educators and more closely linked to the increased responsibility for inclusion among individual teachers (Casserly and Padden 2018). Foucault (1991, p. 102) highlights governmental representation of self-government as an integral value of individual citizens within a neoliberal state, referring to such as necessary ‘apparatuses of security’. The central feature of effective governmentality is the fostering of these individualised apparatuses by Government. Foucault (1991) posits that individual expertise is essential in the creation of distance between self-regulating persons and reigning Government. Such an emphasis renders collaborative power sharing among the stakeholders of inclusive education impossible. To ensure a fair balance between, for example, self-government and inclusive education, power-sharing must occur between all stakeholders involved (Wright 2012; Brown *et al.* 2015; Graham 2016). Representatives of minority groups, for example individuals with additional needs and their parents, must be given a voice in the social justice dialogue, especially when their ‘needs’ are so often a central theme. Without the contribution of marginalised groups, the goals of social justice could be interpreted as being unethical, unattainable and contradictory (Lawton 1977; Tormey and Haran 2003; Shields 2014).

In Irish education policy, the social justice argument has been interpreted and presented as equal opportunity for all people to become productive citizens (DES 1995; DCYA 2014; NCC 2016). Within such policy if a student achieves well throughout their school career it is generally accepted that they will be successful in wider society in adulthood. Equality of outcome has, therefore, long been a central tenet in educational and sociological research. However, equating the delivery of increased access to different forms of education with equality in education has been presented as a major misassumption due to the emphasis placed on needs (Daun 2001; Kenny *et al*. 2009; Lynch and Lodge 2009). Central to the implementation of a distributive model of social justice for the promotion of equality in education is the act of addressing needs rather than recognising human rights (Drudy 2009; Lennon 2017). This ‘needs’ discourse is typical in education policy in much of the western world, where difference is often viewed by policy makers as a challenge which must be overcome in order to succeed in society (Walsh 2007). Nevertheless, recognising the rights of young children with additional needs is critical to realising an inclusive education for them. However, education policy in Ireland tends to focus primarily on the needs associated with inclusion, needs that pertain more closely to the State than the child. The impact of this macro-micro relationship on the development of the individual child’s identity cannot be overlooked. It is crucial, therefore, that the experiences of children on the autism spectrum and their families be understood in relation to a wider social context where macro-narratives in relation to difference and inclusion are acknowledged.

2.14: Conclusion

This literature review began with an exploration of the wider narrative of autism, which consequently informed the examination of research relating to the relationship between autism and inclusion in both education and society. The lived family experience of autism was interpreted, and presented, in terms of the concepts that typically dominate literature in this field. These include trauma, stigma and the capacity to cope, with the significance of developing resilience with a view to empowerment of both individuals on the autism spectrum and their families. Families' experiences of navigating early years education systems with their child on the autism spectrum were explored within both the international and national context, with the need for the adoption of a critical stance regarding this experience emphasised. As this study centres on inclusion across the Irish early years education system, the evolvement of inclusive practice in both ECCE and primary education was extensively examined. Within this examination, certain divides emerged, between the State and the family, care and education, quality and inclusion and needs and rights. The influence and impact of such divides on the experience of children on the autism spectrum and their families is integral to both this research and to any ecological interpretation of such experiences. The next chapter, the Theoretical Framework, focusses primarily on the adoption of such an ecological stance and its relevance to the children and families involved in this study.

Chapter Three

Theoretical Framework

3.1: Introduction

Creating, implementing and reflecting on a theoretical framework provides the researcher with the structure, knowledge and skills to 'philosophically, epistemologically, methodologically, and analytically approach the dissertation as a whole' (Grant and Osanloo 2014, p.13). This statement thoroughly aligns with the experience of engaging with this research process from the outset. The central theory guiding this research, Bronfenbrenner's *Ecological Theory of Child Development* (1979), has influenced all aspects of the study and is embedded in its design, implementation and evaluation. In essence, ecological theory recognises the importance of relationships, interactions and values on the child's personal development within their microsystem and other directly (micro and meso), and indirectly, (exo and macro) connected social systems (Bronfenbrenner 1979, 2005; Moen and Adler, 1995). This central theory will be elaborated on in detail in Section 3.2. In the context of this study, it was critical to explore and understand all social systems encompassing the child on the autism spectrum. Much consideration was given therefore to the significance of other, interconnected theories encompassed within this ecological research design.

3.1.1: Background: An Ecology of Theoretical Influences

Exploring and interpreting the microsystems of children on the autism spectrum required an in-depth understanding and critique of the central concepts and theories associated with these experiences. As mentioned in Chapter Two: Literature Review, the concepts of stress, trauma and alienation, intertwined with the strategies of self-efficacy, coping and resilience emerged dominant in research surrounding families' experiences. In order to acknowledge and consolidate the variety of influences on the present study from the outset, two wider realms of theory, incorporating both care and action, were drawn upon. In fact, the central guiding Ecological Theory of Development demonstrates the importance of both caring and action in the experiences of young children, and their families, across settings and wider social systems (Bronfenbrenner 1979; 2005). The relational nature of caring and action, together with the attention given to the voices involved in these processes, also connects closely with the central premises of narrative theory and narrative inquiry; the chosen methodology (Bakhtin 1981; Bruner 1986; Clandinin and Connelly 2000). Therefore, narrative theory permeates this research, placing participants' experiences and stories at the centre of the study. Figure 5 provides an overview of the theoretical framework, demonstrating the centrality of ecological theory, within which care and action are pivotal, across the micro, meso, exo and macrosystem.

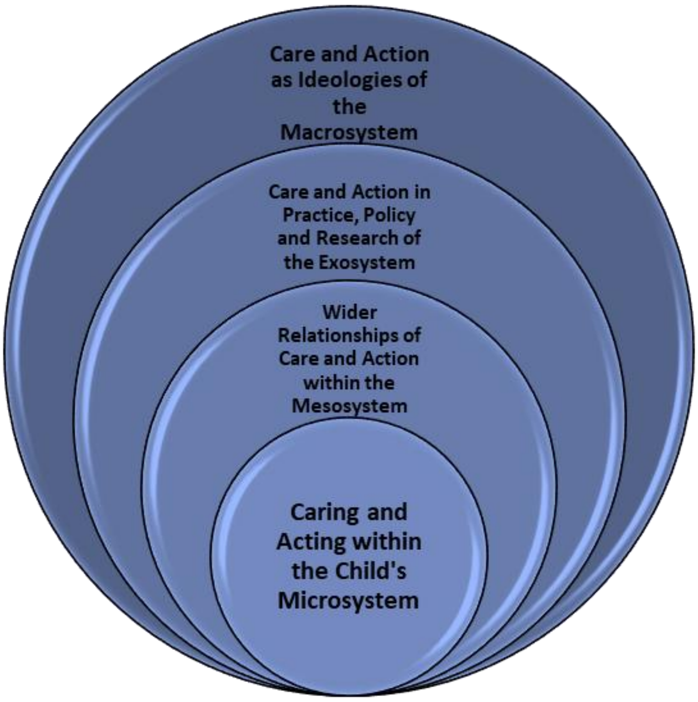

Figure 5. Overview of Theoretical Framework

3.2: Bronfenbrenner’s Ecological Theory of Human Development

The importance of an Ecological Theory of Development in understanding and evaluating the lived experiences of young children on the autism spectrum, and their parents, cannot be overstated. Ecological theory emphasises the interacting systems present in each child’s social construction of their world. The system within which the child is centred is referred to as the microsystem, and is defined by Bronfenbrenner (1979, p. 22) as ‘a pattern of activities, roles and interpersonal relations experienced by the developing person’. It typically represents the child’s home, and as they get older, their educational setting. The relationships that result from the child’s participation in different microsystems constitute the mesosystem, an example of which are the interactions between a child’s home and preschool or school. Central to the child’s mesosystem is the importance of partnerships, built on mutual trust, understanding and shared power, between their home and educational setting (Bronfenbrenner 1976; 1979; 2005). The exosystem comprises of the interconnected processes occurring between two or more settings, in which the child is not physically present, but nonetheless, is influenced by, for example, education policy or school practice. It is through the recognition and interpretation of such external factors that the value of an Ecological Theory of Development can be appreciated as a ‘critical link’ (Bronfenbrenner 1999, p. 3).

3.2.1: A Historical Chronosystem of the Ecological Theory of Human Development

Talcott Parsons (1922, 1996), one of the most influential sociologists of the twentieth century, first outlined the relationship between systems theory and the social context. He critiqued the concept of human behaviourism, presenting it as a linear process of development which assumes a singular view of both the individual and the world. From Parsons' perspective, the world should be viewed as a collection of interconnected social settings, which together become the social system. Many sociologists (e.g., Bronfenbrenner 1961; Habermas 1990; Pinney 1992) critiqued his positivist stance whereby he presented the social system with a particular emphasis on its scientific aspects. Prior to introducing his Ecological Theory of Development, Urie Bronfenbrenner (1961) presented his critique of a Parsonian social systems theory. His particular point of criticism was Parson's representation of identification among families in the 'social system'. Bronfenbrenner (1961) elaborated further on this process of identification, arguing that it occurs through relationships with others and contrasting it with the product of identification, the creation of the individual's identity. While Bronfenbrenner credited Parsons with acknowledging the 'complex role-relationships between the self, parent and ultimately, society' (1961, p. 205), he questions the ambiguity around the development of these role-relationships, and concludes that a general lack of attention is given to the individual's family, school, peers, community etc. For Bronfenbrenner, the creation of a valid, applicable ecological theory required a deep understanding of development across the life span and the interconnected role-relationships. This constituted his life's work (1979; 1983; 1995; 1998; 1999; 2000; 2005).

3.2.2: Locating Autism within an Ecological View of Development

As mentioned, Bronfenbrenner's (1979) Ecological Theory of Development comprises of the microsystem, mesosystem, exosystem and macrosystem. The transitions experienced over the course of an individual's life, together with their socio-historical context, comprise the chronosystem (Bronfenbrenner 1976; 1977; 1979). The current study argues that Bronfenbrenner's original Ecological Theory, rather than his revised bio-ecological theory (Bronfenbrenner and Morris 1998), is most relevant to an interpretive narrative study of the lived experiences of children on the autism spectrum and their families. The reason being that it emphasises the shared family experience, rather than concentrating on, for example, 'geneenvironment interactions' specific to the development pattern of a young child (Bronfenbrenner and Morris 1998, p. 993).

Earlier, Bowen's (1993) *family-systems* model of understanding the lived experience of neurodiversity outlined the insight gained by interpreting human interactions, rather than observing symptoms in clinical settings: a point made by Bronfenbrenner (1974) almost twenty years prior. Thus, encouraging a shift away from the objective and pathological context where the neurodiverse were traditionally studied (Feinstein 2010; Grinker 2020). In fact, Bronfenbrenner (1974, p. 1) heavily critiqued the approaches that interpreted developmental difference as 'strange behaviour of children in strange situations for the briefest possible period of time'. This perspective has borne immense significance in the present study as it pledges to understand the educational experiences of these young children on the autism spectrum within a continuum of past and, future experience, all the time prioritising voice, identity and, these children's narratives. Accessing the shared family experience enables an understanding and appreciation of autism as difference to emerge, which is a central tenet of the neurodiversity movement (Broderick and Ne'eman 2008; Mottron 2011; Kapp *et al*. 2013).

3.3: An Ecological Narrative Stance

The chosen methodology, narrative inquiry, rests upon the premise that experience must be interpreted as a continuum, where every interaction is shaped by what has happened previously, and consequently, influences what follows (Dewey 1938). According to Mishler (1995, p. 121) 'historically, studies of stories and their meanings were marginalised, excluded from the positivist hegemony' in research. The fact that every lived experience and every human action constructs its own narrative, particular to the social actors or social systems involved, was first emphasised by Roland Barthes (1988, p. 95) who highlighted that 'narrative is simply there, like life itself'. This research embraces the view that the lived experiences of each and, every child facilitate the construction of their own unique narratives, their personal theories of their shared world. These life experiences and subsequent theories are communicated to others through their voice. According to Bakhtin (1981, p. 138), the process of voice consists of the realisation of self 'through others'. Indeed, he outlines the importance of the role of significant adults from the child's perspective, stating that 'from them I receive words, forms and tonalities for the formation of the initial idea of myself' (p. 138). Furthermore, Bakhtin (1986) presents voice as dynamic and ever-evolving in space and time, through the constant interactions with others who impart significant influence based on the particular social eras within which they exist. Therefore, applying Bakhtin's concept of dialogism to the family narratives of young children on the autism spectrum helps us to understand their lived experience in a deeper sense. Within this process, the shared narratives are listened to, nurtured and negotiated, thus creating a space wherein multiple voices can be co-constructed, rather than simply co-existing. This shared narrative space saturates the ecological underpinnings of this study throughout and again, holds the child on the autism spectrum at the centre. Within this theory, all utterances, whether verbal or non-verbal that take place in the presence of others, must be interpreted as inherently social, and accepted as an authentic attempt to communicate one's own narrative.

3.4: An Ecological Approach to Caring

As mentioned, the present study is premised upon an ecological theoretical framework that encompasses many interconnected contexts and social systems. It therefore includes other interconnected and relevant theoretical stances also. Thus, theories of *caring* (Noddings 1984, 1992) proved integral in gaining critical insight into the particular experiences of these children and parents. Early in the research process, it became evident that there were many interrelated concepts that constituted an ecological theory of care or caring regarding the experiences of young children on the autism spectrum and their families. For the most part, research focussed on the impact of caring on the carers for individuals on the autism spectrum. The wider view of this caring relationship within the family and wider society also emerged significant, with caring often interpreted in terms of the associated stress and trauma. The following section explores theories related to this positioning, and centres on the importance of self-efficacy, values and an inter-relational stance within the act of caring.

3.4.1: Self-Identity, Self-Efficacy and Caring

Traditionally, a child's autism diagnosis came with a certain amount of blame attached, specifically towards the mother, or 'refrigerator mother' who was characterized as being emotionally cold (Kanner 1954, p. 378). The differences or deficiencies observed within children on the autism spectrum were typically traced back to something lacking within the child's microsystem, especially in the mother-child relationship (Bettleheim 1950; Kanner 1962). Instead of working to develop and nurture this relationship, all familial ties were severed. It is not surprising then that many mothers experienced 'a deep sense of anguish and resentment toward child psychiatrists who often made them feel as if they were to blame for their children's autism' (Cohmer, 2014, p. 1). The value traditionally placed by communities on care and wisdom were disregarded in traditional treatments of autism in the Western world (Kapp 2011, p. 583). Instead, the microsystem of children on the autism spectrum was considered an ‘emotional refrigerator’ (Kanner 1949, p. 416) which had damaged the child. Consequently, such children were removed from their familiar worlds and placed in controlled, clinical environments (Kanner 1966, Willey 2014; Silberman 2015). The legacy of this negative view of these families’ lived experiences is still somewhat evident in recent literature. Indeed, many studies continue to focus on the damage, stress and trauma associated with the perceived burden of caring (Dale *et al.* 2006; Fung *et al.* 2015; Benson 2018; Arellano *et al.* 2019). The present research argues, however, that factors other than the physical presence of stress or trauma, should be included in any study related to caring. Drawing upon Richard Lazarus (1966), who was one of the first to widely advocate the significance of narrative in any appraisal of stress, the inclusion of families’ narratives across settings, rather than the isolation of symptoms within the family context, is therefore, paramount.

Many studies of families’ experiences of autism suggest that the view held by individuals of themselves (their self-identity) and their capacity to adapt to their circumstances were integral to a reduction in the presence and impact of stressors and the achievement of effective adaptive functioning (Bachraz and Grace 2009; Sirota 2010; Hall and Graff 2011; Sullivan *et al.* 2012). This reiterates the central point of Lazarus’ stress theory while encompassing the fundamental principles of ‘self-efficacy’ theory also. Researchers such as Banach *et al.* (2010) Field and Hoffman (1999) and Kapp and Brown (2011) reiterate the importance of self-efficacy in families of individuals on the autism spectrum. Bandura (1997, p. 2) defines self-efficacy as the way in which an individual perceives their capabilities to plan, and implement, the ‘courses of action required to manage perspective situations’. In essence, he argues that people approach challenges in their lives based upon their belief in their power to affect circumstances. This perceived self-efficacy relies completely on both the individual’s experience and ‘self-perception’ or self-identity (ibid., p.80). According to Rogers (1989), while self-perception or self-concept can lead to growth, it depends on the creation of a climate of authenticity and understanding where people feel accepted. Clearly therefore, how society perceives caring and difference is critical to the development of positive self-perception and requires exploration.

3.4.2: Caring as a Relational Narrative Theory

Deeply embedded within these interconnected theories are the relationships constructed and developed between individuals and groups. As the young child on the autism spectrum is at the centre of this study, their direct relationships with significant others (and their indirect relationships with interconnected social actors and social systems) warrant thorough analysis. Employing elements from Buber's (1923, 1970) concept of *I-Thou*, central to Nel Noddings' (1984) theory of *caring*, facilitated an unwavering focus on these relationships while engaging with these children's and families' experiences and narratives. Noddings (1984) depiction of the cared-for and the one(s)-caring represents the very essence of her theory of *caring*. Understanding the ways that each of these parties interact with, and relate to, each other is essential in order to authentically interpret the narratives that they construct together. Noddings presents the process of caring as relying on three prerequisites: engrossment, motivational displacement and, the response of the cared-for (1984, p. 69). Engrossment can be defined as having a deep commitment to gaining an in-depth understanding of the one who is cared-for. If we are to participate in authentic caring, we must understand an individual's particular personal situation before we can determine the appropriateness of any of our actions impacting our cared-for. Although it is crucial that we understand the position of those we care for, the perspectives of those-caring too often dominate. It follows, therefore, that significant others in the lives of children on the autism spectrum must deeply understand the lived experience of autism. This knowledge can only be attained by engaging with the narratives of the autistic community, thus recognising and validating the perspective of the cared-for, rather that prioritising the experience of the one-caring.

Giving precedence to the lived experience of the cared-for over the self-interests of the one-caring is referred to as motivational displacement, which it is thought, ensures that the actions of the one-caring are positive, acceptable and determined by the needs and rights of the cared-for (Noddings 1984, p.71; 2003a, p. 16). On its own, motivational displacement would also be insufficient for ethical caring. The final requisite of caring, is the need for recognition from the cared-for of the actions of the one-caring, and is integral to the process, as it enables it to be effectively 'completed in the other' (Noddings 1984, p. 4). When exploring the lived experiences of children on the autism spectrum and their families, this aspect of caring can become problematic because of the challenges, whether experienced or perceived, that often surround the development of social relationships. While Noddings ceaselessly emphasises the fundamental correlations between ethics and the process of caring (1984; 1992; 2003a/b, 2006), she also outlines potential scenarios where, even she, could not advocate a commitment to caring. In doing so, she presents her definition of the spectrum of disability, and the actions she would recommend us take, in circumstances where one might interpret their caring as not being 'completed in the other' (1984, p.4);

> Disabled people may be thought of at a distance because we have difficulty in either eliciting or recognising forms of response with which we are familiar... Those people who work lovingly and successfully with the severely retarded usually find other forms of human response that are as valuable as reason. Laughter, smiles, hugs and touches of affection are also valuable human responses. . . If our knowledge comes only from books and lectures it is easy to sentimentalise the disabled and suppose that we need only avoid prejudice, in actuality the range of disabilities is enormous. Some are so small that we should ask ourselves whether we have invented them to keep our specialists in business. some, managed sensitively, may be converted into new forms of creativity. Some are so severe and pervasive that most of us would be unable to detect a characteristically human response. Questions arise then about the wisdom of sustaining such lives. (Noddings, 1992, p. 124)

It follows, that within the present study, Noddings' work regarding the disability community, and their inclusion in education, cannot be a stand-alone theory as her views on the spectrum of disability warrant critique. While the value she places on the inclusion of a variety of human responses in interactions has influenced the study design, her description of challenges to care could be construed as damaging for many who are considered *severe* or *profound* on an externally measured scale of disability. Questioning whether such a life should be sustained could be considered as a type of validation of the abuse, sometimes fatal, that disabled individuals who are categorised as either *severe* or *profound* have endured at the hands of others (Declercq *et al*. 2017; Swenson 2019). Somewhat ironically, the stance adopted by Noddings in relation to caring, and levels of disability, emulates what she and Bandura describe as *moral disengagement* where 'we can, with spurious good conscience, permit acts against those at distance that would appal us within our chosen moral community' (Noddings 1992, p. 112). However, the concept of moral disambiguation remains relevant to the present research as Noddings' close association between it and the actions of Governments can relate to its focus on recent education policy in Ireland. Thus, the relationship between caring and action becomes even more pertinent.

3.4.3: Caring as Action: An Ecological View

It became evident that while a theory of caring was relevant and appropriate within the scope of the study, conflicts could arise if this theory was applied blindly. With such conflicting application of Noddings' theory of caring on the lived experiences of individuals with different needs, a further analysis of caring as a multi-dimensional mode of action was necessary. This research argues that if caring is viewed as action, rather than labour, empowerment becomes a possibility for both the cared-for and the one-caring. That is, if authentic caring occurs, and if the process of caring is viewed as a mode of action, caring can become an empowering experience for all involved. Inextricably coupled with this view of care and caring was the concept of action, as outlined by Hannah Arendt in her philosophy of the human condition. Using Arendt's theory of action, embodied within her *Vita Activa* (1958), helped to facilitate further an ecological approach to the narratives. This theory of action served as a multi-dimensional lens through which the roles adopted, and actions implemented, by the child's significant others, were interpreted and represented. The central premise of this act being, if the parents'/family's responsibility for care is limited to being understood in terms of labour alone, or indeed work, then issues will arise. Rather, this care must be seen as the highest level of the *Vita Activa*; action, and it must be in partnership with the other social systems involved.

3.5: An Ecological Approach to Action

Again, an overarching purpose of the present research is to interpret families' experiences as they and their young child on the autism spectrum navigate the world of early childhood education together. Central to gaining an ecological understanding of these experiences are the roles and actions of social actors within and across social settings. Within this ecological approach to understanding experience, coping, resilience and action are presented as significantly impacting the experiences and narratives of individuals on the autism spectrum, and their families, within homes, schools, communities and society.

3.5.1: Coping as Positive or Negative Action

Coping is defined as the behaviours adopted by individuals to prevent psychological damage as a result of trauma (Carpenter, 1992; Snyder, 1999). As mentioned earlier, research that explores families' experiences of autism tends to focus upon the impact of autism on families. From this standpoint, autism is often equated with trauma (Hall and Graff 2011; Bitsika *et al.* 2015; Gorlin *et al.* 2016). The coping strategies adopted by families in relation to autism feature prominently in research studies (Higgins *et al.* 2005; Koydemir-Ozden and Tosun 2010; Kahana *et al.* 2015) and, it is thought, that adopting a positive and active method of coping is an optimal action for these families (Hall and Graff 2011; Atkin and Tozir 2014; Whitehead *et al.* 2015). Approach Strategies for example, are considered to be most effective in reducing stress, trauma and the negative behaviours associated with both (Carpenter 1992; Snyder 1999).

These strategies require the individual to be active in their coping. Generally, this would mean removing or changing the problematic circumstances, if possible. However, some have suggested that an individual can actively cope by changing the way they perceive an experience, or their position within an experience (Carpenter 1992; Bandura 1997). Thus, revealing the inextricable connection between one's voice, or self-identity, and their capacity to cope and become resilient.

3.5.2: Resilience as Individual or Social Action

Resilience is generally presented in terms of having the capacity to continuously and effectively cope during and after adverse circumstances. However, it is accepted that when one is in a constant state of stress, their capacity to cope effectively is greatly impacted (Masten and Obradovic 2008; Werner 2012). Therefore, the development of resilience must not be viewed as relying solely on the internal capacity of individuals. Rather, external factors must be accepted as being integral to its development. According to Lerner *et al.* (2012), the views and actions of institutions, within their community and wider society, dictate the level of resilience among individuals and families. While the literature highlighted the need for the establishment of partnerships within families in fostering and maintaining resilience, this was perceived as an internal family responsibility, necessary to overcome the adversity typically perceived to be associated with autism (Higgins *et al.* 2005; Koydemir-Ozden and Tosun 2010; Bekhet *et al.* 2012). Thus, the development of resilience can further pressurise and isolate the vulnerable and marginalised (Joseph 2013; Chandler 2014). In his extensive work on alienation, Victor (1973) outlines the ways that people are typically left alone to respond to their experience of difference, and subsequent marginalisation. Victor (1973, p. 13) holds that this alienation can only be directly or indirectly changed when the 'terms of society' are rejected, and movements are established, in an attempt to reconceptualise the status quo. Again, emphasising the importance of both individual and social action.

3.5.3: 'Action' as a Critical Theory

This research includes a critical examination of the power relations that are created within the microsystem and mesosystem of children on the autism spectrum. Such power relations result from governing elements of the macro-system, for example, education policy. Central to this research, therefore, is the necessary application of the critical lens. The primary stance of philosophers and sociologists, namely Adorno, Marceuse, Benjamin, Gramsci and Habermas, who created and shaped critical theory, was the direct opposition of any interpretation of life stories that lacked an element of criticality regarding the hegemonic relations that underlie experience (Best and Kellner 1991; McCarthy 1999). The present research accepts prior arguments that suggest that these issues of power are reproduced culturally in the lived experience of society, homes, schools, communities and beyond (Freire 1970; Bourdieu 1990), and interprets such relational contexts as such. It is essential, therefore, to identify and critically deconstruct, the power relations present in the narratives constructed within these interconnected social contexts. For the purpose of this research, Arendt's theory of action (1958) is integral in gaining this critical understanding.

Arendt's *Between Past and Future* (1954, 2006) offers a particular lens of critique using our understanding of action in our immediate and wider experience, individually and collectively. Similar to the work of many critical theorists, Arendt urges us to question, and deconstruct, what we perceive to be autonomous human action (Foucault 1970; Bourdieu 1977; Habermas 1987). However, rather than advocating for the sole critique of modernity, and its associated values and actions, Arendt encourages us to locate our understanding of autonomous action against a historical and philosophical backdrop. Within this socio-historical context, Arendt queries whether autonomous action is, or ever was, a truth. She defines it instead, as an 'axiomatic assumption' upon which 'laws are laid down in human communities… decisions are taken… judgements are passed' since the earliest times of civilisation (1954, 2006, p. 142). In her later writings on *The Human Condition* (1958), she argues that human action is the essence of human existence, and furthermore, that our and others' inevitable judgement of the significance of our actions illuminates the meaning of the lived experience. This meaning creates and fosters active perception, leading to a deeply socio-historical interpretation. Such interpretation is critical to any study of the individual and collective experience, and associated narratives (Arendt 1954; 1958; 1978). Thus, aligning closely with Bronfenbrenner's Ecological Theory.

Arendt places particular significance on understanding the role that our individual and collective action plays in active socio-historical interpretation. This role is presented as a vital category of the human condition, which is realised in its ultimate form in the *Vita Activa* (1958). Arendt presents the *Vita Activa* as comprising of three categories, each of which correspond to our being-in-the-world; labour, work and action. Labour is the ability to meet the needs of humanity, whereas work is the capacity to create, and uphold, a world that can be used appropriately and adequately. Action, however, is achieved when the identity of the agent is recognised, their lifeworld affirmed, and their capacity to attain the freedom to act is realised (Yarburgh and Stern, 1981; Whiteside, 1994). While all three categories of being are autonomous, they must also be interpreted as relational, with a particular emphasis placed on the importance of macro forces (Arendt, 1958; 2006). Arendt argues that historical changes in the relationships between action and labour have been connected to changes in the relationship between public and private realms. She explores the reality of modernity from this standpoint and concludes that modernity is equated with the loss of the world. She further explains this loss as the abolishment of the public sphere of action, and a prioritisation of the private world of introspection and personal economic welfare (1954, pp.147-148). Again, evoking the relationship between the macro and the micro.

Identifying and interpreting changes to human action of such significant historical importance requires the use of a critical lens that incorporates both the micro and, macro experience. Within critical theory, such a stance enables one to understand and, interpret changes within family life and education. This research stresses the importance of exploring and understanding the action of families, while being acutely cognisant of action on families, in any analysis of change in the social landscape of education and wider society. As changes within families reflect wider social changes, it follows that the ways these families communicate such changes bear particular significance. Valuing such narrative action in any inquiry into family life, allows us to understand change ecologically and, further reinforces the point that an ecological understanding of family life, and the changes it experiences, not only highlights the present dangers it may face from a macro point of view, but can also stimulate social change in families, education settings and, potentially, in wider society.

3.6: Conclusion

This chapter presented an ecological theoretical framework, within which the significance of caring and action were emphasised. This framework facilitates an exploration of the lived experience of the child on the autism spectrum, and their families, as they co-navigate the Irish early years education system. The concept of caring as action and action as a critical stance connects the direct and indirect experiences of the child on the autism spectrum across social settings and systems, inclusive of the micro, meso, exo and macrosystem. This theoretical framework therefore requires a methodology that acknowledges, and can engage reflectively and critically within, the various social systems of the child on the autism spectrum. It must also take into account the social actors within these systems, while recognising and appreciating all unique narratives and identities. Chapter Four presents the adoption of critical narrative inquiry as the optimum methodology through which this research was undertaken.

Chapter

Four

Methodology

4.1: Introduction

This qualitative research is positioned within an interpretive stance. It is in fact, a critical narrative inquiry as the importance of narrative (families' experiences) and grand narratives (wider social issues) permeate the methodology and associated methodological tools. This chapter provides the rationale for adopting critical narrative inquiry as the chosen methodology. It follows the major developments within narrative inquiry, exploring its possible roots in phenomenology and highlighting the significance of its evolvement and establishment on this qualitative research study. This chapter further discusses the essential research components in relation to the study's sample, ethical considerations, data collection and analysis, with particular emphasis placed upon the importance of participants' individual lived experiences within their collective social context. The epistemology central to narrative research is explored extensively, concluding with its possible, and powerful, connections to a critical researcher stance. Thus, the concept of critical narrative inquiry manifests, and is presented, as the optimum methodology for this study. Through this critical narrative positioning, the researcher challenged the grand narratives present. The employment of an in-depth method of understanding of individual narratives within a wider exploration of social life made this possible. This ecological approach encompassed the central aim of this study: *to understand how the lived experiences of children on the autism spectrum and their parents as they co-navigate the Irish Early Years education system together, relate and contribute, to narratives of autism and, inclusion across social contexts*.

4.2: Paradigmatic Traditions in Autism Research

As outlined previously, much research related to autism over the years has focussed on its the causes and effects. Such research is typically positioned within a positivist stance and, has generally been conducted under the lens of the medical model. It therefore presents the deficits associated with autism and how these can be alleviated to benefit society in the long term (Robertson 2009; Pellicano *et al*. 2014). Thus, the lived experiences of individuals on the autism spectrum are often interpreted in terms of behaviours that are atypical or warrant change. Research undertaken within the positivist paradigm is characterised by the centrality of science as the ideal of knowledge. Generalisability, validity and reliability are integral to this stance. Moreover, an objective ontological position is emphasised, as the world is conceived to exist as an entity separate from the 'being' (Bryman 2008; Creswell 2009). Institutions, for example, homes, schools and communities, are viewed as instruments of society with their own particular objectives, independent of the people within these organisations and, their diverse experiences of reality. Indeed, this positivist and abstract view of social reality became central in the development of behaviour analysis and modification: now an established element of the lived experience of most children on the autism spectrum in the Western world (Lovaas 1993; Keenan *et al*. 2010; McPhilemy and Dillenburger 2013). Because the importance of society's needs tends to outweigh the lived experience of the child, the child and family experiences of such treatment are typically overlooked. By contrast, this study embraced the social model of disability, which defines autism as a different way of being. It also emphasises throughout, the role of the family in co-constructing the voice and world of the child on the autism spectrum. Crucially, it is concerned with the families' lived experiences of autism and their navigations of the wider world.

4.3: Paradigmatic Positioning: Emerging from the Cave to View the World

The importance of understanding lived experiences within the wider world is central to the methodological stance of this research. In Socrates' philosophical writings, Plato presented an allegory of a cave where people had been kept since infancy, chained so that they were forced to gaze at a wall of shadows. The cave inhabitants' shackles could only be broken if reality was observed in its truest forms through in-depth study and, analysis of the world (Allen 2006). In the years that followed, many ventured out of the cave to look upon the sun and developed laws based on their enlightenment. Central to such laws were objectivity, realism, validity and generalisability of theory: the keystones of the positivist worldview (Berlin 1979; Beiser 1999). The stance adopted throughout this research is critical of the potential negative impact of such social laws, based on positivist fundamentals, on the lived experience. Essentially, this study argues that the reduction of social experiences to formulae has many implications, especially for those who are not included in the common unity, a point long contended by sociological researchers (Benedict 1934; Lister 1990). Such sociologists state that those who are unable to trade off against the social contract of the common unity are always excluded, thus creating an 'exclusive society' (Lister 1990), where 'the conditions of possibility', for example, the marketized concept of choice, have become, for some 'the conditions of impossibility' (Van Manen 2014, p. 158). Echoing this statement, the current study explores, in particular, the significance of inclusive (and exclusionary) action on the lived experience of young children on the autism spectrum and, their families as they navigate the Irish education system.

4.4: Philosophical Foundations of the Research Methodology

Within interpretivism, the central meaning of the lived experience can emerge through an ontological and epistemological lens that values diverse ways of being and knowing. It allows those who have emerged from Plato's cave not only to view the world, but also, to understand theirs and others' experiences within it. Within this interpretivist perspective, there are many different ways of being and experiencing reality. However, the way in which knowledge about these different ways of being is constructed, transmitted and assimilated, determines the way in which diverse groups, for example, individuals on the autism spectrum and their families experience the world. The philosophical underpinnings of this research are simultaneously, intertwined with many theoretical influences. The following discussion explains the decision to adopt narrative inquiry as a methodology that reflects such philosophical and theoretical connotations.

4.4.1: An Ecological Ontology

The genesis for this study lies in the collective experience of reality. Thus, the inter-contextual and ecological nature of the lived experience has framed this inquiry from the outset (Bronfenbrenner, 1972; 1979). It is grounded by an ontological understanding of reality as co-constructed among social actors and within and between social contexts. Within this ecological ontology, the lived experience and identity of every individual is collectively co-constructed. Both rely on the relationships, interactions and grand narratives experienced by, and impacting on, the individual in his/her microsystem. This ecological ontology can offer valuable insight into the creation of reality experienced by those who identify as *different* or *other*. According to Dreyfus (2014, p. 164), society depends for its 'stability and efficacy upon certain norms being accepted as natural'. Indeed, Bourdieu (1977, p. 82) contends that power relations are created on the basis of the socialisation of prevailing norms and, are saturated with the 'imperceptible cues of the body hexis'. Dreyfus (2014, p. 164) elaborates further on these indiscernible social catalysts of power as being 'different styles of eye contact, intervention in conversation, [and] deferential of defiant posture'. He concludes that such norms 'determine who commands and who obeys' within society. Thus, it appears that individuals on the autism spectrum, by their innate nature, are at a social disadvantage (Willey 2014; Silberman 2015).

An ontological reality that recognises the experiences of those that identify as 'other' must also appreciate the strengths present within difference, for example, within individuals on the autism spectrum (Lewiecki-Wilson *et al*. 2008; Kapp 2011; Ong 2014). Moreover, it is paramount that the disadvantage experienced by this group, together with their families, in wider society is also recognised. This critically reflective perspective seeks to understand the negative conditions present for some as they experience reality. An understanding of the ontological reality of groups that identify as *other* can only develop if the social conditions which created their experience of reality, and consequent construction of voice and identity, are examined.

4.4.2: From a Phenomenology of *Being* towards a Narrative of *Being-in the-World*

Initially, it was envisaged that a phenomenological approach embodied a fitting set of principles to guide an in-depth interpretation of the lived experiences of these children and parents. Within this approach, the individual experience of the *self* is prioritised. Immanuel Kant, a pioneer of the phenomenological approach, argued that one could only search for and, discover true concepts of self through a deep and thorough analysis of our understanding of experience (Zweig 1970). Kant proposed a transcendent, reflective philosophy where meaning, and therefore validity would be guaranteed through such penetrative thought. Husserl further developed the phenomenological process by introducing the concepts of essence, bracketing (the suspension of any a priori concepts or theoretical assumptions) and intentionality and argued that, as a result, philosophy could finally be considered rigorous (Moran 2000). However, in highlighting the importance of interpretation in phenomenology, Heidegger (1998) shifted the existential focus away from the transcendental ideals of Husserl's 'being' towards a methodology grounded in the lived experience of 'being-in-the-world' (Langan 1959; Caputo 1987; Moran and Mooney 2002). In fact, Heidegger (1988, p. 275) reconceptualised phenomenology with this interpretive and social stance on inquiry and emphasised that: 'in whatever way we conceive of knowing, it is…a compartment toward beings'.

Research outlining the importance of both experience and interpretation in narrative inquiry have highlighted the relationship between it and phenomenology. While some argue that the association rests with the common goal of exploring and interpreting phenomena (Potter 2013), others emphasise the phenomenological aspects and, insights intertwined throughout the narrative inquiry approach (Bamberg and Damuth 2016). While the present study acknowledges the importance of phenomenological concepts, it also adopts a social interpretation of 'being', as a wider understanding of 'being-in-the-world' (Heidegger 1994).

Within this wider understanding, Heidegger emphasised the importance of the socio-historical perspective, labelling such interpretation as 'the vital medium of man's historical *being-in-the-world*' (Palmer, 1969, p. 125). Thus, the ecological and socio-historical theories of both Bronfenbrenner (1979) and Arendt (1958) become increasingly relevant to the parents' and, children's experiences of co-navigating the education system representing their unique and, collective 'being-in-the-world'. This shared sense of 'being in the world' accentuates the way that these families' identities are not only co-constructed but are ever-evolving in response to the influences of the many interconnected social systems within which they engage. A methodology that recognises the sociological nature of being is therefore essential.

4.4.3: A Socio-Historical Epistemology: Our Lived Experience of Knowing the World

Epistemological debates surrounding the ways human beings construct knowledge have occurred since ancient times. In St. Augustine's *Book of Confessions* (AD 401, 2008) a type of socio-historical epistemology is presented that merges the individual's experiences and consequent knowledge as immersed within a broader social context. Within this view, the knowledge one constructs of the self is influenced by the values, beliefs and ideologies of wider society. However, many years, or indeed centuries, passed before St. Augustine's concept of the socially constructed knowledge and experiences of individuals was accepted as valid among both the scientific and, philosophical community. While acknowledging these inter-connected pillars of enlightenment within theology, philosophy and scientific inquiry, Wilhelm Dilthey emphasised the necessary interpretive element of any inquiry into the lived experience (Palmer 1969). He argued that underlying the structure of human life experience, were categories of living, inseparable from categories of meaning, and thus, hermeneutics was forged. For Dilthey, the socio-historical context was quintessential to the hermeneutic process (Makkreel 1999). For the purpose of this research, it is important to explore the associations between hermeneutics and, the development of the narrative inquiry method. Central to the hermeneutic method is the interpretation of life texts (Burns 1992). There is, therefore, a hermeneutical element in every narrative inquiry. However, there is a significant difference between hermeneutics and narrative inquiry comprised within the role allocated to the author.

The storyteller is integral to the process of narrative inquiry (Delgado 1989; Cavarero 2000; Coulter *et al.* 2007; Hyvärinen 2008). The narrative therefore cannot be viewed simply as a product to be interpreted, but as a way of knowing, an epistemology in itself. Bruner (1986) elaborates further on this narrative way of knowing. In his words, 'our sensitivity to narrative provides the major link between our own sense of self and our sense of others in the social world around us…'(p.69) In place of the hermeneutic circle then, the narrative inquirer is guided by the 'full circle' of stories of 'overlapping lives' (Bateson, 2000, p.1). In this study, the *full circle* encompasses and emphasises the ecological development of our lives. Thus, highlighting the importance of understanding identity in relation to ourselves, our families, our communities and, our changing world.

4.5: The 'Turn' of Narrative Inquiry

Many research disciplines have acknowledged narrative as a legitimate way of knowing both the world around us and our experience of being in this shared world. In fact, a broad range of inquirers, some identifying as positivists, many as interpretivists, have embraced narrative as both a medium through which phenomena are interpreted but also as a phenomenon in itself (Andrews *et al*. 2013). According to Goodson (2013), a turn towards narrative as a central means to understanding is often in response to a particular change within the inquirer's experience of the world. This change in their own experience, and associated narrative, leads them to inquire into the manifestation of this change in the experiences and narratives of others. A narrative inquiry stance focusses on making meaning of these stories of change, in order to better understand the changing issues and changing bodies of knowledge that are actively in flux on a wider experiential level (Polkinghorne 1988; Clandinin and Connelly 2000; Kim 2016).

4.5.1: Experience and Action as Narrative

Narrative inquiries into human experience and action have existed simultaneously with the life history of humankind. Stone (2000, p. 254) presents the revival of narrative as a necessary and relevant interpretation of 'a new old history', especially due to the changes in life stories as a result of modernity: a dominant theme throughout this study. Many argue that narrative inquiry has become particularly valuable because it connects lived experiences with social action and, through a juxtaposition of such experiences and action, a deeper, more comprehensive and authentic narrative emerges (Mishler 1986; Lyons 2007; Andrews *et al*. 2013). An awareness of the relationship between social action and the lived experiences of these children and parents proved integral to this narrative inquiry. For Arendt (1998), active perception and socio-historical interpretation is critical to the individual and collective lived experience. It acts as an elemental aperture to the lifeworld. Interpretive methodologies, such as narrative inquiry, emerged from this primal perceptiveness and have always strived, to ‘involve the voice in an original singing of the world’ (Merleau Ponty 1973, p. 13). The socio-historical context of the experiences and voices of the marginalised is paramount in this research. Such an interpretation of context is both a central element of narrative as well as an integral factor in the formation of identity (Holstein and Gubrium 2000; Freeman 2003; Medina 2003). Therefore, the researcher’s and, participants’ previous experiences and knowledge is embedded in the entire process and is an integral component of interpretation (Clandinin and Connelly 2000).

4.5.2: Adopting a Narrative Inquiry Stance: Narrating Experience and Action

According to Lyons (2007, p. 604), the ‘dramatic development’ of narrative as a mode of insight and knowledge was stimulated by changing views and, spreading disenchantment with, the traditional ‘guiding postulates’ of inquiry and the ‘disciplinary barriers’ associated with it. As outlined earlier, the longstanding conflict concerning the relationship between the truth of lived experiences and the methods used to access and interpret these truths resulted in the division of interpretive research into an array of possible paths: all of which contain some element of narrative (Polkinghorne 1988; Freeman 1997). The pioneering work of Clandinin and Connelly (1998, 2000) in the development of narrative inquiry as a stand-alone methodology reiterates the importance of narrative in every experiential inquiry. Prior to this, those who acknowledged the process of narrative inquiry understood it simply as a methodological tool employed by a variety of qualitative researchers in the field (Hendry 2009; Andrews *et al*. 2013; Kim 2016). Others dismissed it entirely, based on its very essence: the complete immersion of the researcher within the narrative (Kim and Latta 2009; Juzwik 2010; Byrne 2017). While Clandinin and Connolly (2000) were presenting narrative inquiry as the storying of experience, Conle (2000a, 2000b, 2001) was exploring the ways that narrative inquiry could include a critical element that accounted for the power relations present in each and every narrative. She advocated the adoption of a critically reflective interpretive method based on communicative action (see Habermas 1990) to effectively resolve the perceived conflict between narrative and criticality. This study argues that combining such critical and interpretive perspectives can result in the ‘conjunction and the articulation of three theories: a theory of meaning, a theory of action, and a theory of experience’ (Roberge, 2011, p. 6). This stance enables an all- encompassing interpretation of personal narratives and grand narratives (present in wider society) through critical narrative inquiry.

4.5.3: The Centrality of Action in the Family Narrative

In explaining their concept of inquiry as stance, Cochran *et al*. (2009, p.119) describe a theory of *action* that is firmly 'grounded in the dialectic of knowing and acting'. Accordingly, all inquiry must recognise the importance of action (ibid.). It appears, however, that much of the research reviewed on families' experiences of autism does so from a contemplative position, often setting out to explore the potential trauma, stress and alienation, and rarely examining the actions of families and others. The significance of the actions taken by these families as they co-navigate the wider world with their child on the autism spectrum was fundamental to this inquiry. In *The Human Condition* (1958), Arendt argues that human action is the essence of human existence and, furthermore, that the inevitable judgement of the significance of our actions illuminates the meaning of the lived experience. She suggests that while scientific inquiry is traditionally viewed as the most capable of human action, it only investigates nature's existence. It does not recognise the importance of human lived experiences and relationships: the history of action (Hogan, 1995, p. 233). She advocates the adoption of an interpretive lens on lived action as the only means of understanding 'the life of the mind' (Arendt 1978; Bernasconi 1999). This research suggests an inextricable link between the actions of significant others and wider society and, the lived experiences of children on the autism spectrum. Recent work on the relationship between action and narrative inquiry reinforces this connection and, indeed defines action as the essence of narrative, bearing the most significance on the life texts of the marginalised: the central priority of this research (Lessard *et al*. 2018); Tamboukou 2018).

4.6: Storying Experience: Voice and Narrative

The active co-construction of voice is clearly integral to this research throughout. In fact, Bronfenbrenner's Ecological Theory of Development (1979) emphasises that the lived experiences of significant others within the child's microsystem significantly affects the formation of the child's identity and, in essence, voice. In 1992, Ireland ratified the *United Nations Convention for the Rights of the Child* (1989), thus explicitly declaring the importance of listening to the voice of the child. However, while international policy has emphasised the recognition of voices too often unheard, some have heavily critiqued the emphasis currently placed on voice in qualitative research. They argue that focusing research on exploring or giving voice is 'politically self-defeating…[and] intellectually incoherent' and caution those within the sociological research community to work harder to 'produce knowledge in the strong sense' (Moore and Miller 1999, p. 191). This research contests these arguments. Rather it recognises and promotes the capacity of narrative research on voice to contribute to knowledge in the most powerful sense, with a view to bringing about epistemological and social change.

4.6.1: Experience and Voice

In his work on narrative, storytelling and selfhood, Cavarero (2000, p. 34) presents the inextricable link between an individual's experience and the development of their inner voice as a 'narratable self'. A self that is recognisable only to themselves, a self that is present in all experiences, thus, infusing a unique but 'familiar sense in the temporal extension of a life story that is this and not another' (ibid.). As mentioned in Chapter Three: Theoretical Framework, Bakhtin (1981) argues that this development of inner voice and self-identity must recognise the significant influence of interactions within the child's social context. Without this recognition of the inextricable link between the shared lived experiences of children and the development of their voice and identity, there is a risk that an identity could be imposed on a child based on the perceptions of those around them, with disregard for this child's interactional lived experience. The American philosopher Hazel Barnes (1997, p. 1) discussed the impact that certain adult narratives had on the construction of her inner voice as she reflected on the interactive process of 'being a child':

> I was not the kind of child anyone would have chosen, and in the network of cause and effect, my early self-image naturally reflected such negative judgements…

This representation of the co-construction of the child's voice proved particularly relevant to this research as the child on the autism spectrum interacts with, and is impacted by, a multitude of adult narratives that are incredibly influential in terms of the child's development of identity. Where the child on the autism spectrum is concerned, adults' views and beliefs in relation to autism also bear significant influence and can represent 'developmentally instigative conditions characterizing the lives' of children' (Bronfenbrenner 1979, p. 101). The following researcher journal entry highlights this point:

> My epistemological position has evolved as I began to question if systems of knowledge can be oppressive beginning within my own micro system and my son's where the knowledge surrounding developmental milestones greatly impacted our lived family experience. This micro narrative reflected a broader grand narrative in relation to what is accepted as normal and what is rejected as abnormal in modern society… a grand narrative that could construct or deconstruct his unique voice and identity…
> (14th March, 2017)

This entry also references the connection between narrative and voice. Consequently, emphasis is placed on both the creation of personal narratives within the microsystem and the influence of narratives that exist in other social contexts, particularly the macrosystem. The value placed on a particular line of narrative is integral to the development of voice (Polkinghorne 1988).

4.6.2: Narrative and Voice

In *Storied Selves: Identity through Self Narration* (Eakin 1999), the relationship between narratives, our inner voice and identity is explored deeply, culminating in the paralleling of narrative with identity. Eakin elaborates on this association stating that ‘narrative is not merely an appropriate form for the expression of an identity: it is an identity’ (ibid. p.100). It is essential, therefore that any examination of experience, identity or voice includes the narratives of those at the centre of the experience. In a systematic review of literature that purports to include the voice of the child, Zhang (2015) reported four broad interpretations of such inclusion: pseudo voice, inferred voice, surveyed voice and co- constructed voice. For Zhang, co-constructed voice reflected the optimum option, as the other interpretations of voice were adult led and typically fulfilled adult intentions. As mentioned earlier in relation to research into families’ experiences of autism, the child’s experience is often overlooked, with their behaviour instead presented as their narrative (Keenan *et al.* 2010; McPhilemy and Dillenburger 2013). Conversely, within this research, every effort was made to include the narratives of children on the autism spectrum. Narratives that, together with their family, were listened to, nurtured and negotiated, thus creating a space wherein multiple voices did not just co-exist, but were co-constructed.

4.6.3: Inclusion of the Silenced Voice

Much research in recent years reports that children’s perspectives, especially those with additional needs, are often marginalised, resulting in their voices being silenced (Morris 2003; Cameron and Murphy 2007; Boggis 2011). Such research argues that these children’s voices have been silenced by our widespread adoption of developmental theories. Consequently, adults are urged to actively listen to the voices of children for whom we are making decisions, to develop a deep awareness of the ways in which our views of child development can effectively limit children. Children who present with communication issues face further challenges as they attempt to construct their voice within a society that typically devalues any form of communication that is not spoken or written (Lloyd *et al.* 2006; Boggis 2011;

Teachman and Gibson 2018). Warming (2011, p. 50) equates the reality faced by these children as a form of symbolic violence and critiques attempts made to implement inclusive strategies ‘designed to cater to children’s different preferences and abilities’. He argues that such strategies ‘still risk favouring verbally inclined children, and thus reproducing symbolic violence towards less verbal children’ (ibid.). The importance of acknowledging, including and valuing the voices of those who do not communicate with speech is critical to research that explores inclusion. Teachman *et al.* (2014) present augmentative and alternative communication [AAC] systems (e.g. visuals, hand signs, ICT etc.) as a narrative form that warrants deeper understanding. Continuing their examination into the inclusion of voices that for so long had been dismissed or deemed inaccessible, Teachman and Gibson (2018) found that AAC forms of communication were not interpreted as reliable narratives in themselves.

There are certain issues preventing any guarantee of the authentic and ethical inclusion of the voice of the young child on the autism spectrum in research. In order to receive a diagnosis of autism, a child must present with communication issues (DSM-5, 2013). Unfortunately, in recent years in the Irish context, waiting periods between referral, diagnosis and intervention are lengthening (Connolly and Gersch 2013; Roddy and O’ Neill 2019). Therefore, many children with communication needs are older before they begin to use AAC methods (Teachman *et al.* 2014; Gilroy *et al.* 2018). Indeed, in discussing their inclusion criteria for sampling in later research, Teachman and Gibson (2018) gave reasons for including 15 to 24-year olds, who communicated using AAC. They revealed that this age group would be ‘more likely than their younger peers to have developed the requisite communication skills to support participation in the study’ (ibid. p. 3). This represents what Zhang (2015, p.102) describes as ‘a realistic, honest approach’ in explaining the absence of independent narratives from a particular group. In fact, he states that it is ‘good practice to acknowledge the difficulty’ in including the independent voices of some children in research (ibid.), rather than making claims of giving voice which can lead to misrepresentation and, is therefore unethical. For these pragmatic reasons, but moreover, for the associated ethical concerns, the children’s narratives were not included directly in the data collection processes of the present study. Instead the shared dialogism of family life, including the experience of the child on the autism spectrum, was accessed through interaction with the parents as gatekeepers of the family narrative.

4.7: Co-constructing Children's Voice through The Family Narrative

Greder *et al*. (2004) discuss the importance of accountability among professionals who explore the marginalised voices of families. They urge researchers and others to take responsibility for implementing action based on the interpretations of narratives. Without this necessary element of action, they argue that we are failing to hear the voices of these vulnerable families and children. The present research argues that in hearing the voices of families on the margins we are, in a sense, including the voices of the children within these families.

4.7.1: The Role of Family in the Construction of the Child's Voice and Identity

Dialogic pedagogy, as described by Whyte (2015), presents relationships as the curriculum where all human learning takes place. Within such relationships, the development of the child's voice and identity is intertwined with their experiences within the family and, from an ecological perspective, the family's wider experiences. The present study suggests that the voice of young children on the autism spectrum can be effectively and authentically included when the family narrative is embraced, rather than omitted to remove its perceived impact on the independent voice of the child. The work of Teachman and Gibson (2018, p. 3) offers insight into the role of families in the co-construction and representation of the voice of the child, particularly the child who may not communicate using speech. They reflect on the lived familial experience of these children and, conclude that the family's involvement in the child's narrative is optimal as families have typically developed 'idiosyncratic, situated systems of communication that are more reliant on non-verbal gestures, facial expressions, dysarthric speech, and non-speech vocalizations' (ibid., p. 3).

While the present study stands firmly in solidarity with the research recommendations of the autistic community, it acknowledges the methodological and ethical issues preventing any guarantee of the direct inclusion of the voice of the very young child on the autism spectrum in research. Consequently, the present study aimed to access the young children's voices through engagement with the narratives of the most significant people in their lives, their parents. Narrative inquiry, in particular parental narrative, was utilised as a means of including the voice and experience of these young children on the autism spectrum, as they and their families co-navigated the Irish early years education system. In this respect, the present study also resonates with the work of autism advocates, who promote the inclusion of the collective voices of the autistic community, their family members and immersed practitioners in research as a methodological imperative, thus, representing the need for a co-constructed narrative. This research recognises and embraces authentic co-constructed voice and narrative within the family's shared lived experience of education by using visual elicitation methods and, the integration of artefacts. It illustrates how these methodological tools are an effective means through which the voice and experience of children on the autism spectrum can be constructed and embedded in research.

4.7.2: The Family Narrative as 'Polyphony'

The term *polyphony* is typically used when discussing the texture of music, defined as multiple concurrent lines of independent melody coming together as one (Waite, 2012). In his writings on voice, Bakhtin (1986) evokes this term as a metaphor for the individual lived experience within shared socio-cultural contexts. Kim (2016) explains Bakhtin's concept of polyphony further and outlines its significance for narrative inquiry. A narrative inquiry that involves multiple voices is only considered polyphonic when no single voice enjoys privilege, including that of the author. It is therefore, the author's responsibility to allow 'different consciousness (conveyed in each voice) encounter each other as equals and engage in a dialogue' (ibid. p. 74).

Ironically, Zhang's (2015) systematic review of literature on children's voice in research reported a widespread dearth of these children's voices regarding their own care. This is reflective of Noddings' (1984) concept of motivational displacement, where the perspectives of the *cared-for* are often overlooked. The inclusion of all voices and perspectives are viewed as integral to understanding the identity of children on the autism spectrum and essential to the shaping of the identity of the one-caring also (Gilligan 1982; Noddings 1984). Furthermore, Byrne (2017) recently examined the problem of representation in narrative inquiry and the 'giving of voice' to participants (p.36). She suggests that hierarchical issues surrounding representation can be reduced if the researcher honestly aspires to 'evoke the participants' experience' rather than making claims in relation to giving voice (ibid.). This study was primarily concerned with presenting the reality of children's and families' experiences of navigating the education system together. While the concept of voice is a dominant subject throughout, critically evaluating the construction of voice, rather than making claims of giving voice, became a central goal. Consequently, hierarchical issues surrounding this evaluation warranted in-depth examination.

4.7.3: Researcher Voice and Critical Reflection

The researcher’s identity and voice has gradually developed in a dualistic sense from years of experience practicing within the education system and, most importantly, her immersed stance within the lived experience of autism as a parent of a young child on the autism spectrum. Within the remaining sections of this chapter, the inclusion and negotiation of the voice of the researcher within this study will be evident in the reflective excerpts of researcher narrative incorporated into the presentation of research design, data collection and data analysis processes and the reconstruction of narratives. The centrality of critical reflection in including and negotiating the researcher’s voice cannot be overstated.

Critical reflection holds critical theory at its centre. Both encompass the principle aim of social theory: the critique of society with a view to bringing about change (Fook and Gardner, 2007). Creswell (2007, p. 25) outlines how such critical reflection is integral in focusing ‘on changing ways of thinking’ by identifying and addressing the ever-present social conditions of ‘hierarchies, power and control’. According to Creswell, exploring such conditions requires an interpretation of different narratives where the perspective of marginalised groups can emerge. The researcher identified and reflected on the possible imbalance of power between her and the research participants, together with the wider interconnected power relationships within and between their social contexts, endeavouring to interpret the meaning behind such hierarchical conditions (Fischer and Anushko 2008; Gray 2014). Researcher reflections emerged essential within this critical narrative inquiry as it demonstrated and reiterated ‘how language and interactions are used to construct reality in social situations’ (Potter, 1996, p.43). The socio-historical significance of language in such reflections was clear and is portrayed in the emphasis on the etymology of the words and narratives. Understanding the etymology of a particular word or narrative enables its meaning to be interpreted over time and place with particular consideration given to the power structures behind such changes (Skeat, 1993). In acknowledging the power issues that may have been present in the narrative interviews with parents, the researcher identified the potential risk of jeopardising the authenticity of the data through the ‘Hawthorne effect’ (Cohen *et al*. 2000; Robson, 2002). The researcher’s immersion within the parents’ lived experience of autism, and the corresponding navigation of the Irish education system also helped to counteract this effect.

4.8: Reflection and Reflexivity in Narrative Inquiry: Seeking, Constructing and Critiquing Truths

Reflection and reflexivity are essential components of both interpretive and critical studies. The importance of reflection in an attempt to deeply understand our experiences is reiterated throughout the writing of significant influences of narrative inquiry (Clandinin and Connelly 2000; Lyons and LaBoskey 2002; Kim 2016). The transformative capacity of reflection within narrative inquiry has frequently been the focus of studies regarding its use as a methodology (Coulter *et al.* 2007; Hardy *et al.* 2009; Salter 2017). The need for critical reflection or reflexivity on the power relations inherent within social action has also been embraced by those within the sociological field (Freire 1970; Holstein and Gubrium 2000). This research embraced the reflexive process of deconstructing and reconstructing story through the prioritisation of criticality throughout. This reflexive awareness within and surrounding the narratives, referred to by Clandinin *et al.* (2007, p. 21) as ‘wakefulness’, was fundamental to the entire critical narrative process. Indeed, any reference to critical reflection throughout this study holds reflexive action at its centre, which, according to Bolton (2012), enables the researcher to recognise issues of power within her own role and the wider social context within which all roles and actions are constructed.

4.8.1: An Ecological Critical Narrative Inquiry

The central critique of narrative inquiry as a methodology is that it can be limiting due to its over-emphasis on the individual narrative. Brushwood and Granger (2013, p. 21) argue that narrative inquiry does not consider the ‘unexpected’ and ‘unconscious’ elements of the narrative as critically as other methods do. In a sense, Juzwik (2010, p. 375) argues the opposite, suggesting that researchers should be cautious in relation to narrative inquiry and avoid ‘over-stating claims for story’ by applying general interpretations to the wider social context. Byrne (2017) instead focusses on the problem of representation in narrative inquiry and the risks associated with giving voice. She problematises the narrative inquirer’s aspiration to make meaning on behalf of another and highlights the importance of critical reflective methods in overcoming this issue. Employing critical reflection techniques throughout a narrative inquiry acknowledges the action involved in creating and sharing narratives and analyses how this is shaped by social structures (Fook and Gardner 2007). This ecological approach takes into account both the reproductive and the constructive power of narratives.

Critical reflection on these narratives enables the study of grand narratives produced in society and has the capacity to influence, and perhaps, constitute them.

McAllister (2001, p. 391) states that a critical narrative perspective ‘helps to illuminate multiple dimensions to…complex issues’. Likewise, in earlier writings, Hones (1998) argues that a multi-layered or ecological approach to narrative inquiry opens up definite and unique interpretations of the self, the diversity of others and the relationship between their actions, interactions and experiences. This ecological view of narrative inquiry has since been embraced by many. Atkinson (2016) presents this ecological quality as the very foundation of narrative inquiry as it emphasises the contextual and discursive influences of experience, whether micro or macro. This critical narrative methodology afforded the researcher the opportunity to work at the micro-level, focusing on the structural elements of the narratives; the significant words and inferences, while drawing upon encompassing philosophical concepts present within the narrative. The study therefore incorporated both critical theory and ecological theory with a view to providing an overview of the power structures faced by these children and parents as they co-navigate through education and wider social systems.

4.8.2: Identifying *Grand Narratives* through an Ecological and Critical Inquiry Stance

The concept of the ‘grand narrative’ is contentious within the narrative inquiry community. Some would argue that analysing narratives at the intimate micro level and then reinterpreting them in terms of the grand narrative can divide the data (Cortazzi 1993; Reissman, 1993). Clandinin and Connelly (2000) however claim that they learned the craft of research within the context of grand narratives. They deconstruct the concept of the grand narrative in terms of the boundaries it passively creates and maintains, referring to such division as the creation of ‘boundaries between thinking according to narrative inquiry and thinking according to the grand narrative’ (ibid., p. 29). They encourage us to imagine a physical boundary line where people on either side seem blurred, incoherent and somewhat irrelevant to each other. While Clandinin and Connelly (2002, p. 134) argue that the prioritisation of the grand narrative can potentially ‘set up a reductionist boundary’, the critical researcher would argue that the passive transmission of society’s grand narratives into the lived experiences and narratives of individuals warrants deep exploration, especially in relation to the impact of these on the lives of marginalised groups (Foucault 1970; Freire 1970; Bourdieu 1990). Therefore, the present study sought to gain a deep analytical understanding of both the child-centred narratives and the grand narratives underlying these. The use of in-depth, informal interviewing was central to ascertaining this multifaceted understanding.

4.8.3: The Interview: At the Centre of an Ecological and Critical Narrative Inquiry

The potential that narrative inquiry holds to provide a richer understanding of our contexts has been widely documented (Mishler 1995; Lyons 2007; Kim 2016). While narrative inquiry is often associated with individual stories, the potential associated with collective narratives has also been highlighted (Hones 1998; Atkinson 2009; Hendry 2009). A central goal of this study was the inclusion of collective interwoven narratives. This enabled a broader range of stories and breadth of experience to inform the data collection and analysis process. These stories were accessed through the interview method. According to Cohen *et al*. (2000, p. 267), the interview is the optimal method through which participants can ‘discuss their interpretations of the world’. Its narrative nature can lead to a ‘contextually bound and mutually created story’ (Fontana and Frey 2008, p. 116). The associations between narrative inquiry and the interview method are therefore inextricable. In fact, Atkinson (2007) places the interview at the centre of every narrative inquiry, emphasising its capacity to bring the lived experience to the fore. In their historical overview of the interview process, Savin-Baden and Van Niekerk (2007, p.459) conclude that interviews were first used in research to ‘question meanings of experience’. While the researcher’s interpretation of meaning is of importance, the focus of interviews is to develop understanding and interpretation of others’ perspectives on their experiences. Priority is always given to the voice of those at the centre of the experience. Bagnoli (2009, p. 547) explores the elements of narrative and voice in research interviews and suggests that in order to represent voice authentically, interview methods require significant consideration. He emphasises the importance of integrating artefacts into the process, highlighting the capacity of such methods to effectively stimulate narratives, elicit voice and acknowledge the contextual formation of identity. The importance of the contextual formation of identity is also emphasised by McCormack (2004, p. 219), who associates the process of active listening as fundamental to any inquiry that adopts a multiple lens view to explore and interpret ‘both the individuality and the complexity of a life’. As Bronfenbrenner’s Ecological Theory of Development is integral to this research, implementing a research design that would effectively access an inter-contextual narrative was imperative.

4.9: Research Design: Creating a Space for Critical Narrative Inquiry to Evolve

The importance of creating a suitable space within which narrative inquiry could evolve was a recurring point across the literature in this field. Clandinin *et al.* (2007) focus on the importance of navigating the narrative inquiry space effectively. They recommend gaining a deep understanding of place and the action within it. It is essential, therefore, to give deep consideration to the 'tensions and connections, differences and similarities, contrasts and disparities' of the narrative inquiry space prior to, during and following the action within it (Smith, 2007, p. 391). In presenting the sampling and ethical considerations of this study, particular attention is given to the creation of a narrative inquiry space that understands and appreciates the value of the experiences and actions that occur or are represented within it.

4.9.1: Sampling: Finding Our Tribe

For her renowned work *Composing a Life* (1990), Mary Catherine Bateson, collected five life stories that connected with her own. While taking a sympathetic yet candid position as narrator, she embraced an appreciative inquiry stance (Ryan *et al*. 1999; Fry 2002; Filleul 2009), focusing on the qualities that enabled each participant to experience such success in their fields. Such an approach influenced heavily the decisions regarding sample selection for the present research. The value of gaining a deep and personal understanding of a shared lived experience through engaging with a smaller sample was recognised. Six parents participated in multiple, in-depth interviews over a period of eighteen months [June 2018-December 2019], thus giving them the opportunity to talk extensively about their lived experiences of navigating the education system with their child on the autism spectrum. While small, this sample allowed for continual, in-depth interpretation of the stories of these parents; an integral element of narrative inquiry (Clandinin and Connelly 2000; Kim 2016; Chase 2018).

A non-probability purposive sampling technique was utilised to select the parent participants. While parents were invited to participate in the research, their involvement depended entirely on self-selection [see Appendix C1]. Purposive sampling involves the selection of research participants based on their particular characteristics (Bryman 2008; Creswell 2009). Although it is a commonly used sampling technique, purposive sampling has its limitations in terms of, for example, the generalisation of findings (Bryman 2008; Creswell 2009), not typically an aim associated with the narrative inquiry stance. However, determining the presence of essential inclusion criteria among the participants from the outset helped to ensure the collection of relevant and rich data (Bernard 2000; Gray 2014).

Each of the research participants were parents/guardians of children on the autism spectrum who were aged between three and six years old. Of the six participating parents, three engaged in an existing parent network within which the researcher herself engaged. The three remaining parents expressed their interest in participating having seen information relating to the study online through autism community forums. As five parents had more than one child on the autism spectrum, the study represents the experiences of nine children, aged three to six years old[1] (see Figure 6). Each child presented with various modes of communication, including verbal (n=6) and non-verbal communicating through AAC (n=3): methods such as PECS (Picture Exchange Communication System) (n=2), Lámh[2] (n=1) and an AAC device (n=1).

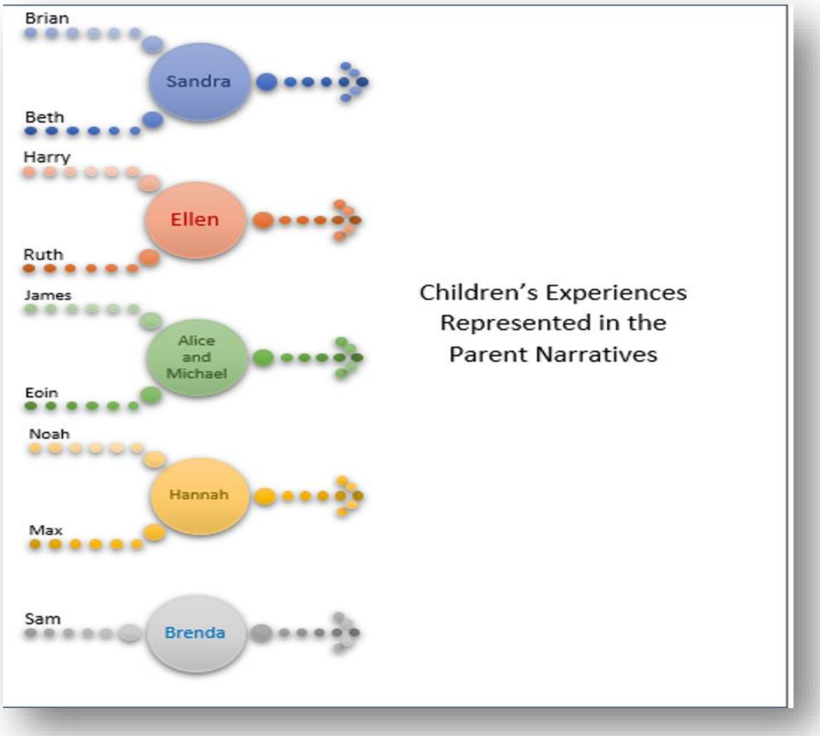

Figure 6: Children's Experiences Represented in Parent Narratives

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[1] 98% of three-year olds in Ireland attend ECCE. All six-year olds are legally obliged to attend primary school.

[2] Lámh is a sign language programme developed for children with developmental delays and disabilities.

4.9.2: Ethical Considerations: Prioritisation of all Voices

Bearing in mind the stringent data protection guidelines governing access to the details of children with a diagnosis of autism, families were identified and selected informally and purposively through the channels outlined earlier. While this alleviated any ethical concerns surrounding the direct involvement of these children, it also raised certain issues regarding the various challenges and responsibilities arising from the inclusion of their voices within their parents' narratives (Cameron and Murphy 2007; Cridland *et al*. 2015). The challenges associated with visual elicitation methods have been well documented, typically in relation to the increased workload for the research team (Low 2006; Drew *et al*. 2010; Allen 2012). However, the main concern surrounding the use of visual elicitation methods in the present study centred on authentically including these young children's experiences and voices without creating increased challenges for them or their parents. This issue was discussed with the six parents prior to data collection and it became immediately evident that the inclusion of their children's perspectives was a priority for all involved. It was also agreed that the children's agency in the visual elicitation process was paramount and, therefore, their engagement in the process was entirely voluntary. The concept of child-centred narrative analysis was also discussed to highlight how the children's voices (as opposed to the researcher's) would emerge an integral vein of the findings. Thus, reinforcing the relationship between such methodologies and the children's 'construction of self' (Croghan *et al*. 2008, p. 345).

At this time the researcher provided the parents with a detailed information sheet and, informed consent form [See
Appendix C2] Both documents stressed the voluntary nature of participation and explained that participants had the right to withdraw at any time, without reason or consequence during the research process. It was also outlined that anonymity and confidentiality would be protected by using identification codes or pseudonyms. This ensures that no child, parent, pre-school or primary school, can be identified by anybody other than the researcher. These pseudonyms and random ID codes are stored with the data. Participants were also advised that any information provided would be used for the purpose of the doctoral thesis only, with quotes from interviews presented in isolation and anonymously. Furthermore, if data is to be used for reports or research papers, pseudonyms and ID codes will continue to be used to maintain confidentiality and anonymity.

Informed consent represented a communicative process that enabled participants to make an informed and voluntary decision regarding their acceptance or refusal to participate in the research (Hennink *et al*. 2011; Gray 2014). The principle of informed consent stresses the researcher's responsibility to completely inform participants of different aspects of the research in comprehensible language (Robson 2002; Bryman 2008; Creswell 2009). Relevant information included the following: the nature of the study, the participants' potential role, the identity of the researcher, the objective of the research, and how the findings would be used/published. Information concerning what would happen to the data upon completion of the research was further provided, with participants advised that all information gathered would remain confidential and would not be released to any third party. The provision of this open, honest and transparent information was central to ensuring that consent was both freely and voluntarily given.

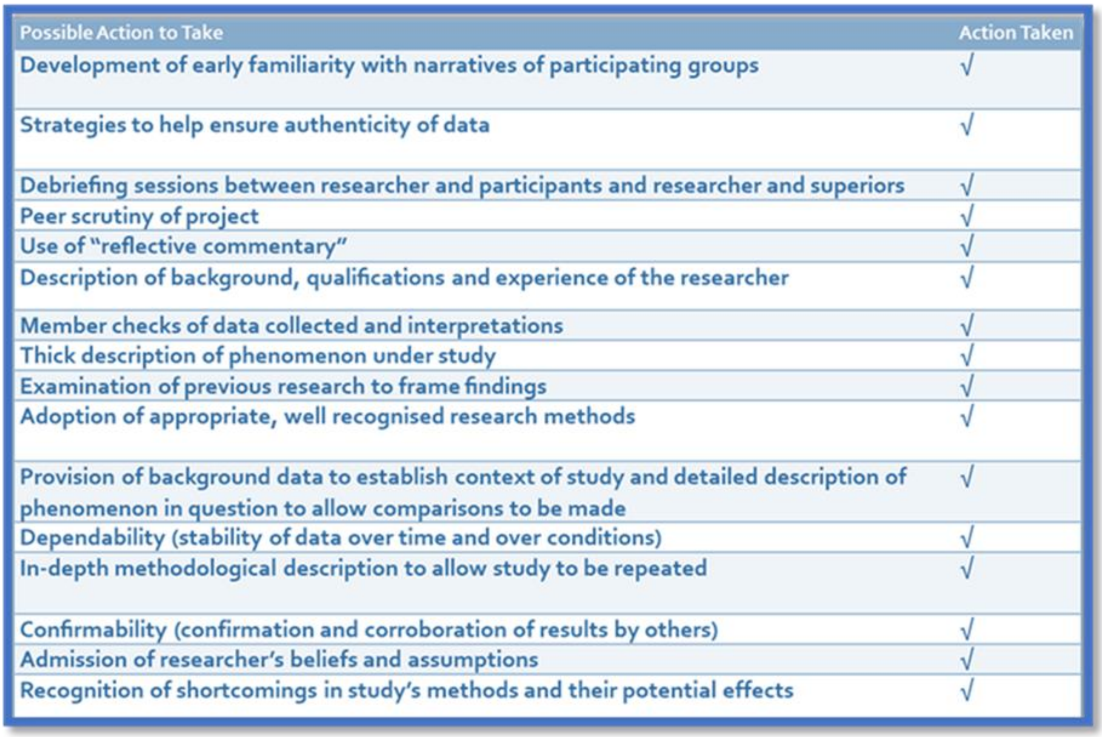
Moreover, no coercion or inducement was used to obtain participants' consent to participate in the research study. In addition, participants were given sufficient time to consider whether to participate and, were given every opportunity to ask questions about the research before confirming their involvement. The social and ethical issues that can arise when processing, storing, retrieving and retaining data were evident to the researcher. Her awareness that even a simple error on her part could have a major impact on the participants within the research, and those outside the information system, encouraged her to give this aspect of her study considerable consideration (Robson 2002; Creswell 2009). The researcher adopted ultimate responsibility to ensure that the information system created through the research took account of all potential social and ethical issues. Data (audio recordings and transcripts) were password protected and stored electronically on an external hard drive in a physically secured environment. The use of the external hard drive eliminated any risk of data duplication through Wi-Fi, Bluetooth, I-cloud capacity on devices etc. While the researcher alone has access to the data, her doctoral supervisor had access to the data on a need to see basis throughout the research process. Other than this, the research data was not shared with any third party. In accordance with Mary Immaculate College's Record Retention Schedule, anonymised data may be retained indefinitely by the researcher, if this is deemed necessary.

4.9.3: Role of the Researcher: Trustworthiness

The aforementioned ethical considerations increased the trustworthiness of the research. This emphasis on truth and trust manifested as the achievement of rigor as the study progressed. The following journal account details the relationship between rigour and narrative inquiry in the early stages of the study:

> At the outset of this journey, I believed that the concept of rigor, traditionally accepted as the quality assurance of quantitative research, stood almost in opposition to my immersed narrative stance…as I reflect on my earlier writing I am met with the recurring argument that because qualitative research did not lend itself to rigid boundaries, there was a paradoxical relationship between rigor and such research... rigor was not my concern…
> (7th November 2017)

However, congruent with Connolly (2007) and Petrone (2017) the need to redress the conflict between such opposing stances in and around the field of narrative inquiry quickly became apparent upon entry into the field. As the research developed, rigor came to be understood as a type of trustworthiness (Fereday and Muir-Cochrane 2006; Amankwaa 2016; Stewart *et al.* 2017). A series of actions were taken to ensure this commitment to trustworthiness and to consequently increase the integrity and validity of the research. Figure 7 outlines how these actions manifested throughout all phases of the research process.



Possible Action to Take	Action Taken
Development of early familiarity with narratives of participating groups	√
Strategies to help ensure authenticity of data	√
Debriefing sessions between researcher and participants and researcher and superiors	√
Peer scrutiny of project	√
Use of "reflective commentary"	√
Description of background, qualifications and experience of the researcher	√
Member checks of data collected and interpretations	√
Thick description of phenomenon under study	√
Examination of previous research to frame findings	√
Adoption of appropriate, well recognised research methods	√
Provision of background data to establish context of study and detailed description of phenomenon in question to allow comparisons to be made	√
Dependability (stability of data over time and over conditions)	√
In-depth methodological description to allow study to be repeated	√
Confirmability (confirmation and corroboration of results by others)	√
Admission of researcher's beliefs and assumptions	√
Recognition of shortcomings in study's methods and their potential effects	√

Figure 7: Increasing the Trustworthiness Surrounding the Role of Researcher

These actions acknowledged and, in a sense, validated the presence of the researcher's subjective, immersed voice. While this validation is not synonymous with concepts of validity and reliability that saturate positivist research, it does present the capacity of trustworthiness as an example of rigor, rather than an alternative to it. The trustworthiness of the findings was further increased through a ‘systematic approach’ to gathering and understanding the narratives (Gioia 2013, p. 15). For this reason, the recurring processes of data collection and analysis demonstrated a certain type of rigor that accepted the embodiment of the researcher as the primary tool in this reflective method (Fereday and Muir-Cochrane 2006; Amankwaa 2016; Stewart *et al.* 2017).

4.10: Data Collection: Gathering Life Stories

Given that the primary aim of the research was to explore and interpret the experiences of these young children and their parents, data was collected through narrative interviews over a period of eighteen months [June-September 2018, May-July 2019, October-December 2019] that would encompass the children’s and parents experiences of co-navigating the educational landscape between home, pre-school and primary school together. While the parents’ narratives comprised the main data, developing an understanding and interpretation of the children’s experiences of the Irish Early Years Education system was paramount. Consequently, data collection was viewed as a shared experience where the voices of these young children and their parents were continually prioritised.

4.10.1: Eliciting Voice and Co-Constructing Narratives: Visual Storytelling

The use of artefacts to elicit voice was a central feature of this research. Artefacts of importance to the parents and, associated with their experience of navigating the education system, were included in both the second and third phases of the data collection process [May-July 2019 and October-December 2019]. The inclusion of artefacts relating to the children’s lived experience of education thus far (e.g. photos or drawings of their pre-school/school etc.) was strongly advocated and the value of these contributions to the narrative was emphasised to ensure that parents would offer their children the opportunity to have their voice included in the narrative. The capacity of such strategies to include voices that are often deemed inaccessible or irrelevant has been reiterated throughout the literature (Croghan *et al.* 2008; Allen 2012; Teachman *et al.* 2014; Teachman and Gibson, 2018). The use of artefacts has long been promoted within the narrative inquiry community. In 2002, Clandinin and Huber highlighted the effectiveness and significance of integrating artefacts into their three-dimensional narrative inquiry space as a means of including the ‘aesthetic and artistic dimensions of experience’ (ibid., p. 161). The inclusion of artefacts recognises and embraces the multitude of forms that the human voice can take.

4.10.2: Role of the Researcher in Data Collection: Creating a Balance of Power

Bagnoli (2009) considers the process of interpretation in, for example, photo elicitation strategies, and concludes that this method has a significant impact on the role of the participant. He argues that it ‘opens up’ their interpretations and, enables the researcher to authentically respond to ‘participants’ own meanings and associations’ (ibid. p. 547). The challenges inherent in visual storytelling or photo elicitation methods have also been documented with much research citing the related ethical considerations (Drew *et al.* 2010; Meo 2010; Allen 2012). These considerations will be explored further regarding ethical considerations. The recognition of the dominant role of the researcher in the process, and the power imbalances that may exist, was secondary in importance to the possibility of causing stress or anxiety for the children. Therefore, as outlined earlier, these children’s experiences would be included within the wider family narrative. From birth, their voices had been co-constructed, communicated and interpreted within and by their family and so, this aspect of the research methodology was a fitting choice, rather than alternative.

While this research embraces this shared narrative process, significant consideration was given to the potential implications arising from the immersed researcher role. Informal, in-depth interviewing techniques, verbatim transcription, continued member-checking and purposeful reflection all facilitated the reduction of any biased selectivity of data. Early in the research process, Chenail’s (2011) *interviewing the investigator strategy* proved extremely beneficial in increasing the integrity of data collection methods when a pilot study was not undertaken due to issues surrounding sample access and the longitudinal nature of this study’s data collection period. Chenail (2011, p. 258) argues that assuming ‘the role of interviewer and interviewee’ within this process can lead to more responsible and ethical research as one becomes immersed within the experience of the research participant and the potential ethical or hegemonic issues that may have otherwise gone unnoticed. This process also supported in-depth critical reflection on the multifaceted role of parent of a child on the autism spectrum, practicing educator and all-encompassing researcher. While this strategy highlighted any potential bias that could underpin particular questions or narratives, the potentially neutralising effect that this triangulated positioning had on the production of bias during interviewing or reflecting also came to the fore. In her first interview, a parent, Ellen effectively articulated this somewhat neutralising effect:

> I suppose you are in a great position really…you're a parent, a teacher, a researcher. You get it. You're not going to fall into the trap of blaming one side for any problems that might arise. You can see both sides.

A devotion to critical reflection also helped to reduce the potential bias on the researcher's part. Such continual reflection enabled the researcher to identify the issues that could arise in terms of power relations and, the consequent value and representation of voice. Figure 8 outlines the approach taken during all phases of data collection to recognise such power relations while effectively bringing the voices of the children on the autism spectrum and, their parents to the fore. Through active listening, memoing, member checking, transcribing and reflecting, the hierarchical structures within the narratives were gradually revealed. A commitment to recognising all forms of communication and, the use of visual elicitation methods and artefacts ensured that the voice of the child on the autism spectrum was always prioritised.

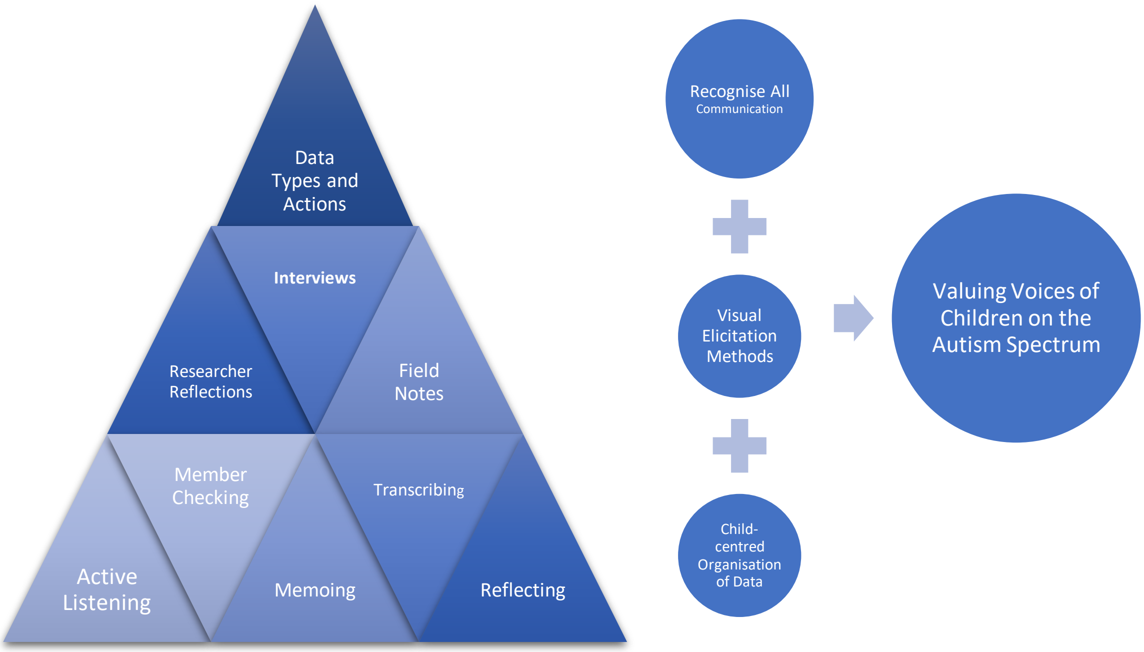


Figure 8: Overview of Approaches Adopted to Enable a Balance of Power

4.10.3: Overview of the Data Collection Process

In order to ensure the well-being of all involved in this research, the parents were asked to include their child's voice in their narrative, if possible, using informal, familial methods prior to each of the interviews. The data was collected in surroundings familiar to the participating parents, with a view to enabling them to reveal their authentic experiences. In this study, the primary goal was to understand the lifeworld of parents of children on the autism spectrum.

Many researchers (see Hermanns 2004; Hennink *et al*. 2010; Brinkmann 2018) highlight freedom to talk about lived experiences in a broader sense as a central element of narrative inquiry. The integration of artefacts of meaning as stimuli, through which parents and children's experiences could be narrated, was representative of this broader approach to the narratives of life experience. Consequently, an informal style of interviewing proved the most appropriate means of accessing and interpreting life stories (Clandinin and Connelly 2000; Kim 2016; Chase 2018). The idea being that the narrative interview encourages and stimulates the interviewee to talk about some important event in his/her life and social context (Muylaert *et al*. 2014), leaving the researcher to reconstruct social events from the point of view of the participants (Clandinin and Connelly 2000).

The parents were encouraged to use any or all of their preferred modes of communication with their children, including facilitation by familiar communication partners. Parents were advised that this engagement was optional and would be negotiated on the child's terms. If any signs of distress or anxiety developed within their child as they interacted, it was recommended that the parents discontinue. This process of shared narrative elicitation and formation was based on the *initiating parent voice* concept, advocated by Whyte (2015) in response to the aims of New Zealand's *Te Whāriki Early Childhood Curriculum*. According to Whyte, (2015, p. 10) the initiating parent voice concept effectively places the young child at 'the forefront of the child–parent narrative, using a photo… the parent engages in co-constructing the narrative response with the child'. Through this shared, active engagement, the responses of the parent are integral as they must ensure that their child's voice, together with their own voices, is evident throughout the narrative. The importance of actively listening to and documenting their child's voice was highlighted to the parents involved following our first interview.

As mentioned previously, parents participated in three phases of interviews between June 2018 and December 2019, at a time, date and place of their own choosing. Parents were thus, encouraged to reveal their authentic experiences within a safe environment where their anonymity and confidentiality would be ensured (Cohen *et al*. 2000; Hopf 2004; Bryman 2008). Each interview was between one and two hours long, yielding rich data that would require in-depth analysis. Immediately after each interview, the researcher listened to the audio and made notes and memos. Following this, each interview was transcribed, with the researcher paying particular attention to the participants' non-verbal communication also. If hesitations were made, sentences broken, sighs exhaled or tears shed, emphasis was applied within the transcript, to ensure such modes of communication would be recognised and understood each time the transcript was revisited. Table 1 offers an overview of the data collection phases of this research.

Table 1: Overview of Data Collection Phases

Participants	Data Collection 1 **June-September 2018**	Data Collection 2 **May-July 2019**	Data Collection 3 **During term 1 2019 (Sept.– Dec.)**
Parents (6): **5 Mothers & 1 Father representing experiences of 9 children**	**Focus**: Parents' and children's experiences prior to attending pre-school	**Focus**: Parents' and children's experiences co-navigating pre-school and/or accessing primary school	**Focus:** Parents' and children's experiences co-navigating primary school

4.11: Data Analysis: Analysis of Narratives and Narrative Analysis

The manner in which narratives are analysed features strongly in debates within the narrative inquiry community. The forefathers of narrative inquiry make a clear distinction between *analysis of narratives* and *narrative analysis* in narrative inquiry (Polkinghorne 1988, Mishler 1995). Some are critical of an *analysis of narratives* approach, where codes, categories and themes are sought, due to the fact that the individual narrative is deconstructed and taken apart to be understood (Cortazzi 1993; Kim 2016) and promote a *narrative analysis* approach in any research that claims to be positioned within the narrative inquiry stance. While much research in the field of narrative inquiry adopts a *narrative analysis* approach, where an in-depth interpretation of story, rather than a summative overview of content is preferred, the present study drew on both methods of analysis. An initial *analysis of narratives* ascertained the common narrative threads and patterns that comprise the paradigmatic features informing and influencing the stories of the six parents involved. Nevertheless, the importance of child-centred *narrative analysis* informed the research throughout and prioritised the voices of the young children on the autism spectrum.

4.11.1: Analysis of Narratives: Coding and Categorising as Action

Kim (2016, p. 196) argues that a paradigmatic *analysis of narratives* is 'derived from the predetermined foci of one's study'. He goes on to portray the process involved in such analysis, stating that ‘findings would be arranged around descriptions of themes that are common across collected stories’. Clandinin and Connelly (2000, p. 131) offer extensive guidance on the ways that such analysis can, and should, be conducted. They describe the conversion of field texts into research texts as complex, but necessary, especially in the case of early career researchers. They highlight the importance of careful coding strategies in this transformative process; a conclusion accepted by many within the field of qualitative research (Braun and Clarke 2006; Bryman 2008; Creswell 2009).

In this study, the advice of Clandinin and Connelly (2000) regarding the interconnectedness of themes and issues within and across narratives was enormously influential. It enabled codes to evolve to become narratives as the researcher endeavoured to ‘look for patterns, narrative threads, tensions and themes, either within or across an individual’s experience and the social setting’ (ibid., p. 132), all the while interpreting these narrative aspects within, what Polkinghorne (1988 p. 35) describes as a ‘realm of meaning’ where all the aforementioned elements are encompassed as a ‘dialectic integration of its [meaning’s] parts’. Through this analysis of the meaning within and influencing parent narratives, preliminary findings emerged. Polkinghorne’s (1988; 1991) *Analysis of Narratives*, which focusses on paradigmatic influences, was then employed to reveal the wider discourses, or grand narratives, that may relate to and underpin the parents’ stories. Figure 9 offers an ecological overview of this process incorporating, for example, the phenomenon of choice across contexts.

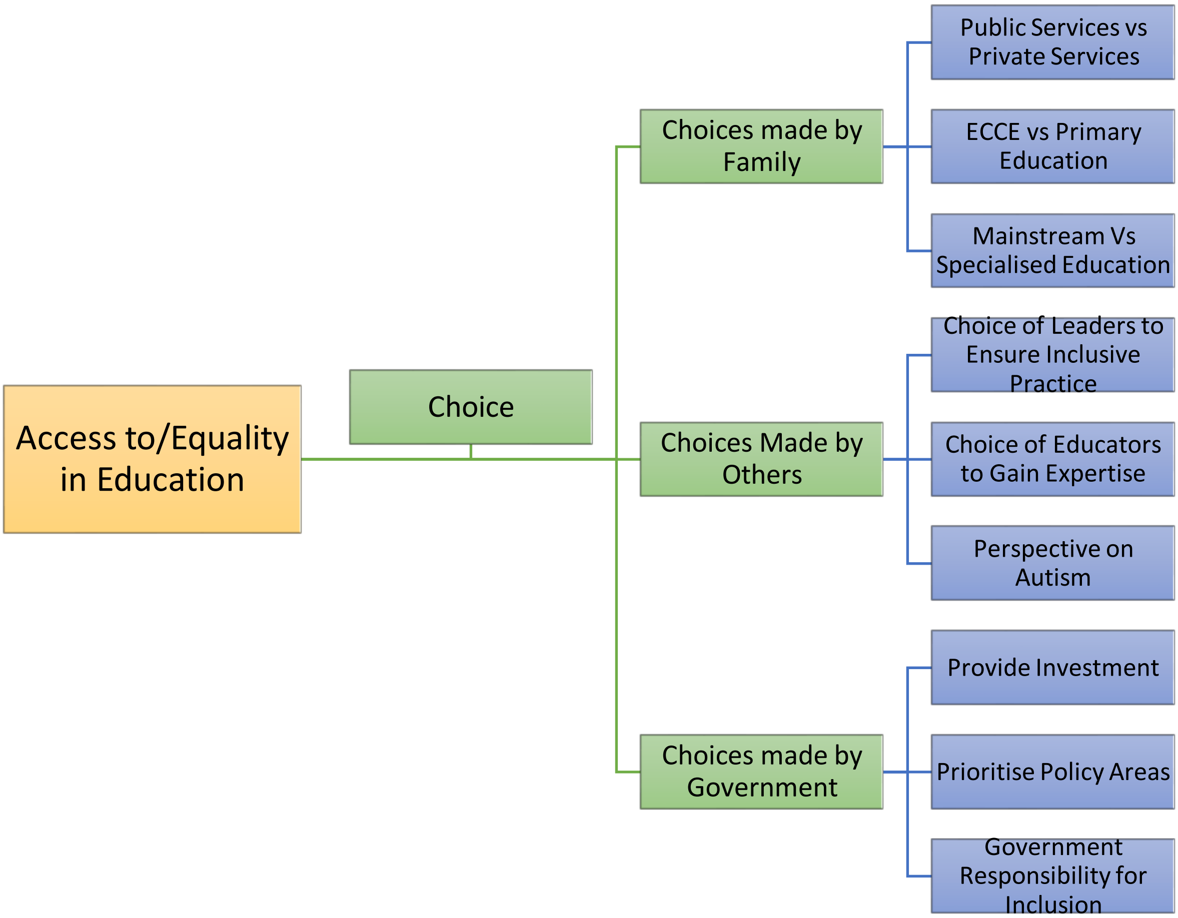


Figure 9: The Journey from Codes to Narratives

To understand the everyday experiences within the families' microsystems, recognition was given to the impact of wider, governing narratives upon these micro experiences, thus the analysis of narratives was both ecological and critical in nature [see Figure 10]. Through this process of critical and ecological analysis, the grand narratives present within the parents', and consequently children's, stories gradually became apparent. This process was entirely reliant upon the triangulation of data from certain sources. These sources encompassed the verbatim transcripts of the interviews, the reflections that continuously evaluated prior fieldwork and informed future work in the field and, finally, the critically reflexive journal entries and memos that identified and interpreted the explicit and implicit power relations present.

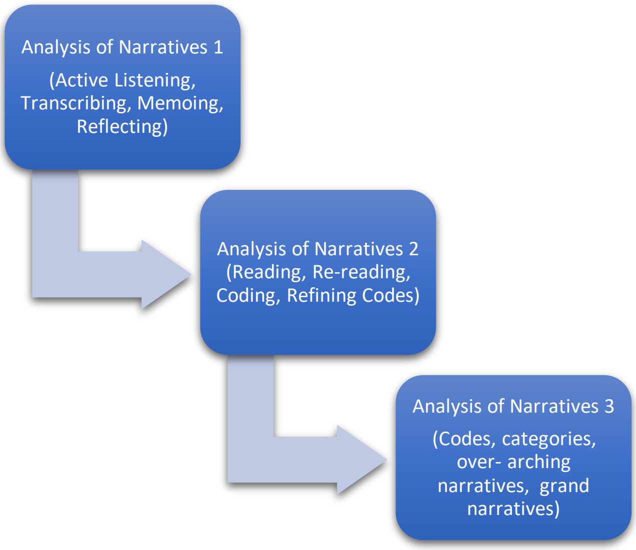


Figure 10: Analysis of Narratives

As Figure 10 illustrates, the preliminary codes or issues were initially engaged with, reflected upon and grouped under wider narratives or themes, based on common or associated elements. A total of 192 codes were created during the first phase of the analysis. During the second and third phases, these were refined further enabling a merging or collapsing of minor codes to create 144 final code categories. Such categories were then further refined and grouped together to establish broader over-arching narratives, which in turn were categorised to create the dominant grand narratives [see Appendix D 1-3].

4.11.2: Role of the Researcher in Data Analysis

The study adopted a human-as-instrument processes of analysis where the notion of subjectivity was deeply and personally embraced, while maintaining its link to an informed theoretical perspective (Pezalla *et al*. 2012). This study reiterates the views of other narrative researchers who value deep engagement as a methodological strength and appraise researcher voice as an asset (Clandinin and Connelly 2000; Lyons and LaBoskey 2002; Andrews *et al*. 2013; Kim 2016). Gaining insight into the field of narrative inquiry revealed the significance of appreciating researcher identity while also prioritising the participants' voices. The following journal extract illustrates how this tension between researcher identity and participant voice was identified and resolved early in the research:

> My own identity, my voice as a parent of a young child on the autism spectrum, as a teacher within the Irish education system, must be recognised among the multitude of voices involved. This recognition can strengthen the research. It embraces shared trust, understanding and power; the central tenets of partnership… myself and the six participating parents are storytellers who share a narrative. Our stories

> represent what many would accept as the very fabric of narrative inquiry and embody the essence of this study. The communal relationship built around the construction and re-telling of our stories, this almost tribal experience of narrative, has become a metaphor throughout… (Reflective Journal: 3rd February 2018)

Indeed, understanding the development and influence of all dominant voices was a critical aspect of the entire research process, increasing its scope to include a broader analysis of the collective life stories and, revealing the multitude of voices moulding each child-centred narrative. Within this study, this narrative fabric was manually created and interpreted using interwoven strands of meaning. This meaning is enmeshed with the many issues and bodies of knowledge that are actively in flux within these children's personal and wider stories; a central tenet of narrative inquiry (Cavarero 2000; Coulter *et al.* 2007; Hyvärinen 2008). Thus, highlighting the importance of understanding identity in relation to ourselves, our families, our communities and our changing world. While the use of manual, rather than automated processes of coding during the initial analysis of narratives could be viewed as a significant limitation within other methodologies and disciplines, many argue that for the researcher who acknowledges and embraces their immersed positioning, such methods are in fact, optimal (Polkinghorne 1991; Hatch 2002). Within the narrative inquiry process and, especially within the early analytic phases (analysis of narratives), broad paradigmatic content were identified in order to better understand the unique stories explored in later narrative analysis methods, thus combining, what Saldana (2013, p. 40) describes as ‘the art and craft’ of narrative research.

4.11.3: Child-Centred Narrative Analysis

An I-Thou and I-It (Buber 1923, 1970) framework of analysis allowed a separate *child-centred narrative analysis* to be conducted, the findings of which were understood both ecologically and critically in terms of the influences of important interactions, relationships and actions on the children’s experiences. The first way in which the children’s experiences were identified and interpreted was through the comprehensive ‘I and Thou’ association which focusses upon the wider world of relational contexts and, the connections between the ‘I’ and ‘Thou’ in every living relationship (Buber 1923, 1970). The second interpretation of each child’s relational experience encompassed an ‘I and It’ relationship between the individual child and their experience of a phenomenon, for example, their experience of inclusive practice (see Noddings 1992; 2006). As parents provided the main accounts of both their child’s and their own experience, the term *I* typically referred to their immediate personal experience, whereas, the use of children’s names and the pronouns: *he*, *she*, and sometimes, *them*, were typically used to denote particular reference to their child. The I-Thou analytic framework incorporated all such references, ensuring the placement of the child at the centre of all identified relational contexts [see Figure 11].

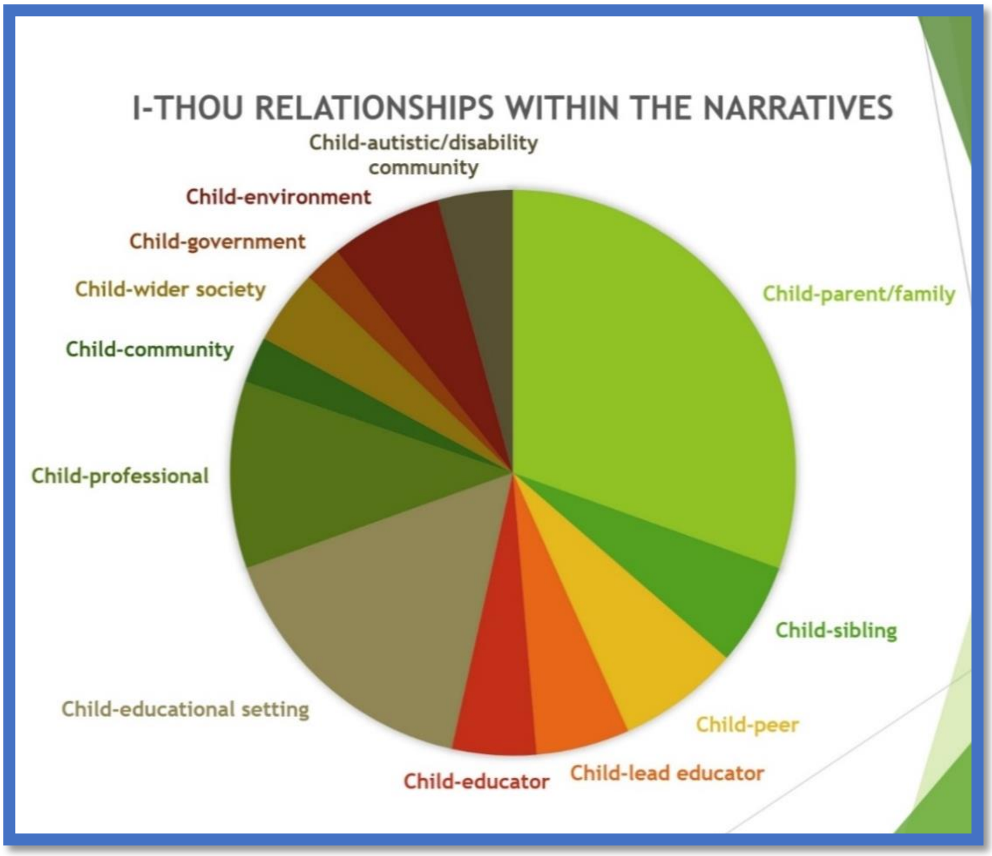


Figure 11: Child-Centred Positioning within the Narrative Analysis

However, the child remained an *I* within a complex, interconnected system of *I-Thou* and *I-It* interactions and relationships [see Appendix J]. The employment of an *I-Thou* and *I-It* relational framework of analysis enabled an overview of voice to emerge that took into account the concept of autism and inclusion as phenomena (*I-It*). Such phenomena are entirely experiential and relational and rest on the perspectives and narratives of the significant others (*I-Thou*) within the child's microsystem and beyond. This *I-Thou* and *I-It* framework of analysis was integral to the restructuring of the narratives as folktales, as explored in the following section.

4.12: Storytelling: (Re)Constructing the Voice of the Tribe

In his work on *Rewriting the Self*, Freeman (1993, p. 20) describes the process of reconstructing the narrative as paradoxical, explaining that within such action the 'beginning leads to end' but, ironically the 'end leads to beginning, the outcome in question, serving as the organising principle around which the story is told'. The significance of this premise frames the final phase of this research: the (re)construction of the narratives. The primary outcome of this critical process being the creation of 'stories to engage, transform and catalyse social action' (Carmona and Luschen 2014 p. 1). While the personal growth associated with a (re)storying of life stories has been explored extensively (Kenyon *et al*. 1997; Eakin 1999), the power of these stories to bring about wider societal change is less well documented and has emerged as a dominant theme with regards to the reconstruction of the narratives.

4.12.1: (Re)Constructing the Narrative: The Researcher as Storyteller

A commitment to critical reflexivity across all phases of data collection was integral to embracing and validating the immersed researcher role. Purposeful reflection allowed researcher subjectivity to be 're-viewed as a resource that can be tapped in order to contextualize and enrich… research process and its products' (Gough and Madill 2012, p. 374). The importance placed on reflection in understanding all the facets of the story of our experience is central to narrative inquiry (Clandinin and Connelly 2000; Lyons 2007; Kim 2016). This research embraced such authors' avocation of deconstructing and reconstructing story while considering the emotive element of the narratives and associated reflection. It therefore supports the notion of 'positioning our own emotional responses as legitimate research data' (Morris and Davies 2018, p. 229). Accordingly, reflecting upon emotions that emerged within, for example, privilege, resulted in a shift from researcher privilege and guilt as a 'troubling experience' (Clarke 2016, p. 26) towards an acceptance of its capacity to encourage 'crucial interrogation of the place of the self in the research process' (DeLuca and Maddox 2016, p. 284).

Two simultaneous goals guided the reconstruction of the narratives. First, was the need to carefully consider form, structure and function. Mishler (1995, p. 88) discusses the prominence of structure in the reconstruction of narratives, defining it as 'the linguistic and narrative strategies through which different types and genres of stories are organised'. Kim's (2016) adaptation of Mishler's Topology highlights the importance of structure in the process of narrative reconstruction but extends this to include three central elements in this process: temporality, structure and function. Temporality involves a reconstruction of the ‘told’ in and from ‘the telling’, while exercising caution that a ‘told’ is not imposed on the ‘telling’ (Kim 2016, p. 200). The narrative, rather than identified common patterns, must be prioritised. The structure includes the mode of representation of the narratives. Particular consideration was given to the language associated with folktales as the metaphor of the tribe permeated this study. Finally, the function comprises of, what Kim (ibid.) describes as the ‘narrativisation of experience’. Within this *narrativisation*, certain components of experience were brought to the fore. Thus, self, culture and the underlying power relations that impact these could be emphasised [see Appendix K].

4.12.2: Fictive Representations: *The Folktale*

The value of reconstructing narratives in a way that might encourage increased levels of engagement from wider audiences is highlighted throughout narrative inquiries into education (Clandinin and Connelly 1998; Coulter *et al*. 2007; Bignold and Su 2015). Such researchers argue that accessible narratives can have a greater social impact than research presented solely towards an academic audience. Moreover, Denzin (2018, p. 3) equates narrative and story with fictive representation, asking explicitly ‘is there only fiction?’ According to Khan (2018, p. 1059) the importance of representing life stories in their fictive form is an integral aspect of our shared lived experience. By doing so, the narrative inquiry space can evolve into a type of historical ‘public space[s] where raconteur and poets recited the popular tales… for the general public’. The present study adopted the folktale genre as a fictive representation so that these children’s and parents’ stories could be told beyond the realm of academia.

Vladimir Propp (1984), a pioneer in narratology and self-identified folklorist, suggested that all stories fit within a folktale typology that encompasses cumulative, pourquoi, trickster and fairy tales. Cumulative folktales begin with a particular incident that sets a chain of events in motion. Folktales defined as *pourquoi* explain the possible reason(s) for a phenomenon of interest. Trickster tales have a central character who has some strengths but many weaknesses that lead to the creation or disruption of social harmony. Finally, the fairy tale presents many varied, yet interconnected events that ultimately lead to a happy ending (Forrester 2012). The present study is influenced by each of these. In *The Morphology of the Folktale*, Propp *et al.* (1968, p. 81) argue that character functions are central to generic folktale types. In the present study, reconstructing the narratives helped to prioritise the character’s experience of the phenomenon rather than the phenomenon itself. The character categories, rather than folktale types, became the central vein of the reconstructed narratives. The character narratives created represented important members of traditional tribes including *The Elder*, *The Warrior*, *The Clan Mother*, *The Miner*, *The Chief* and *The Chieftain*, with the researcher's own story, told through *The Storyteller.*

4.12.3: Narratives of the Tribespeople

Through reflection on theory and literature in the field, the researcher gradually started to craft the stories of the children and parents involved in the research. The metaphor of the tribe was central to this act of storytelling, in both social and critical terms. Tracing the narrative of the children's, parents' and researcher's individual and shared lived experiences also bolstered this metaphor of tribe. Since the beginning of time, relationships between small groups who share experiences have developed in this way and communities have been created on these relational foundations. In fact, Kapp (2011) and Lindblom (2014) draw similar comparisons between the lived experience of the individual on the autism spectrum and their families with the historical experiences of Indigenous communities. The following journal entry (9/1/19) emphasises the connection between this social reality and the critical stance adopted throughout this research:

> The relevance of the tribal metaphor throughout this line of inquiry led me to discover a fund of knowledge in relation to the modern colonisation of thought and narrative by those who dominate and typically represent a globalised social view focussed on the creation of a productive knowledge economy. The importance and potential empowerment attached to a decolonizing of knowledge through embracing traditional or even tribal ideologies became a central vein and metaphor throughout this research and located the child on the autism spectrum within a close and safe environment among their significant others where knowledge and understanding of the individual child informed every interaction

Kapp (2011, p. 583) credits the Navajo philosophy of *Hozho*, which venerates the concepts of harmony and beauty in all things, in meeting the needs of people on the autism spectrum in a more inclusive and dignified way than the widespread concept of making progress in autism through research based on causes and treatments. It is within this philosophy that the stories of the children, parents and researcher are told.

4.13: Conclusion

This chapter began by presenting the philosophical underpinnings of this study and outlined how the lived experience informs the methodology throughout. The paradigmatic positioning of this research was shown to embrace both the importance of the lived experience but also the fact that such experience is ecological and relies upon the interactions, relationships and narratives that the individual engages with within the microsystem and beyond. The centrality of voice in both this view of experience and development resonated throughout the chapter and is inextricably linked to narrative inquiry, the chosen methodology. The role of the family and the researcher in both the co-construction of voice, and indeed identity, was also examined with particular consideration given to the importance of adopting a critical stance that enabled an awareness of the power relations present in both the research and wider lived experience. The methods of data analysis employed help to merge this ecological and critical position, while recognising the immersed role of the researcher. The chapter concluded with an explanation of how the narratives will be reconstructed, and the significance of both the genre of folktale and the metaphor of tribe. The next chapter presents the findings that emerged from the analysis of narratives, where common threads and patterns were identified and reflected on to reveal the grand narratives influencing and affecting the lived experiences of these families.

Chapter

Five

Analysis of Narratives

(Findings)

5.1: Introduction

This chapter presents the dominant narratives within the stories collected from the six parents as they co-navigated the Irish early years education system (both pre-school and primary school) with their young child on the autism spectrum. The present chapter provides comprehensive accounts of the parents' experiences, including details of the challenges they faced as a result of changes in both policy and practice, which impacted upon their choices for their children's support and education. The *analysis of narratives* revealed a definite overlap between these unique life stories adding further weight to the concept of the shared narrative or voice of this group. While there is diversity among the storytellers; their backstories, their families, their circumstances, their lives: commonalities prevail throughout their stories, all of which is represented in the dominant grand narratives to emerge from the study [see Appendix D 1-3]. As discussed in Chapter Four: Methodology, four dominant grand narratives were identified following an in-depth analysis of narratives: *Care and Action*, *Management of Outcomes*, S*ocial Norms* and, *Equality in Education*. Through continued critical reflection and analysis, *Equality in Education* emerged as a meta narrative that encompassed all grand narratives. The creation of this meta-narrative does not imply an imposed agenda upon the individual life stories. Rather, it allows these stories to move beyond the parameters of their telling and provides a more defined socio-historical context for the narratives. Reflective memos regarding the etymology (or socio-historical nature) of some of the language used in the parent narratives are also interspersed throughout the chapter

5.1.1: Care and Action

Undeniably, the act of caring was forefront in the lives of all six parents. This was evident in a literal and practical sense, with three of the parents adopting the role of full time carer to their child or children on the autism spectrum, while the parents who had continued to work holding an integral role in the provision of care to their children, together with spouses, extended family members, au pairs and friends. A more in-depth analysis of the narratives of caring involved positioning this action within the grand narratives associated with it in wider society.

While it is widely accepted that the act of caring is central to the lives of families' of children on the autism spectrum, within the wider narratives of societies, this lived experience of caring, can often be equated with the action of carrying burdens, a meaning derived from the old

English term *Caru*[3] but that still lingers today. In the present study however, parents presented the act of caring as the essence of family life and, of love. Within this research, the dominant grand narrative of *Care and Action* (see Figure 12) manifested throughout the parent narratives in the threads and patterns that related to (1) coping (2) responsibility (3) support and (4) relationships.

Figure 12: First Grand Narrative: Care and Action

The grand narrative of care and action, and the narratives that comprise this [Figure 12], are incorporated into various components of the meta-narrative of equality in education. This chapter, therefore, maintains the focus on the children's and parents' experiences of navigating the Irish early years education system while recognising and, accepting the integral nature of caring as a necessary action within both their microsystems and their journeys. The challenges faced, changes experienced and, choices made by these families saturated the data and, warranted interpretation within and across the social contexts that engage or impact them.

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[3] Etymology of Care: CARU/ CEARU [Old English], KARŌ [Germanic]. The *weight of many burdens*. *Burdens of the mind/ sorrow, lament, anxiety, grief.*

5.1:2 Management of Outcomes

The second grand narrative identifies the *Management of Outcomes* as an essential act of the families' microsystems and beyond. The efforts made by families to manage outcomes, whether positive or negative, on a daily basis were obvious. However, further reflection and analysis revealed the management of outcomes across other social contexts. Crucially, while there were clear contrasts between the act of managing and, the act of leading, the parent narratives presented experiences that typically emphasised the families' capacity to manage and, the Government's interpretation of their experience as something that had to be managed. A deconstruction of the direction behind, or aspiration to control such management, through (1) intervention (2) role of Government (3) inclusive policy and practice and (4) leadership was conducted, as illustrated in Figure 13. Each of the four separate lines of narrative factor heavily in the challenges, changes and choices experienced and, navigated by these parents and children and are interpreted not just within their immediate social context of home, but extending to the wider social contexts of educational settings, public services, community and society.

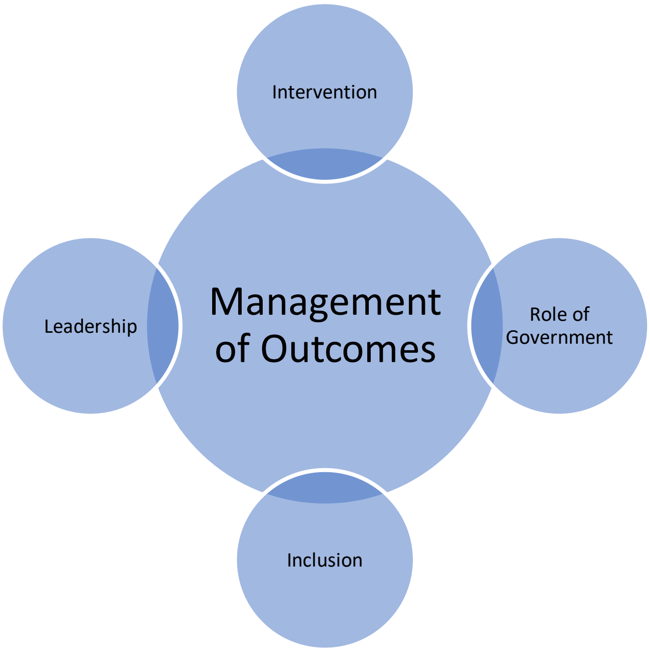


Figure 13: Second Grand Narrative: Management of Outcomes

The commitment of parents and, their obligation to protect their children's welfare underlies the parents' narratives across all phases of data collection. The actions associated with this multi-faceted role were initially interpreted within the immediate family experience. They were then located within the wider realm of social experience to include the broader social systems of educational settings, public and private services, Government and society. Each of the four separate lines of narrative [see Figure 13] factor heavily in the challenges, changes and choices experienced and navigated by these parents and children and, are interpreted not just within their immediate social context of home, but extending to the wider social contexts of educational settings, public services, community and society.

5.1.3: Social Norms

The concept of social norms permeated the parent narratives throughout. Indeed, the widespread acceptance or potential reconceptualization of such norms emerged as actions that were integral to whether these young children on the autism spectrum, and their parents, had positive or negative experiences, interactions and relationships across social contexts. The description of autism as a 'different way' of being became a recurring motif within the narratives and was closely associated with an appeal from the parents for their children's differences to be accepted as an example of diversity. The importance of challenging the prevailing social order and, particularly the universal acceptance of '*normal*' development was reiterated, time and, time again. Positioning the central research question within the *social norm* narrative enabled a deeper understanding of the far-reaching influence of such norms on the journeys of these children and parent as they navigate the Irish early years education system together. Consequently, the grand narrative: *Social Norms* encompasses four wider narratives [see Figure 14], namely (1) Universality of Childhood vs Autism (2) Disability vs Difference (3) Perspectives (4) Values.

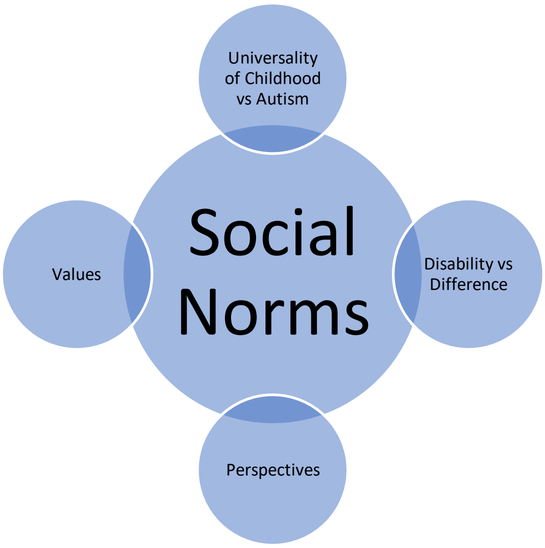


Figure 14: Third Grand Narrative: Social Norms

The wider narratives illustrated in Figure 14 were identified and interpreted further in relation to their presence, and indeed role, within the challenges, changes and choices that exist in and between the micro, meso, exo and macrosystems of the parents and children involved. This action focusses the inquiry on the central research question relating to the experiences of parents and, their children on the autism spectrum, as they co-navigate the Irish early years education system.

5.2: Equality in Education: A Meta-narrative of Experience and Action

As mentioned earlier, in answering the central research question, the grand narratives of *Care and Action*, *Management of Outcomes* and *Social Norms* were brought together to constitute a meta-narrative of *Equality in Education* [see Appendix E, Appendix F]. This meta-narrative not only related directly to the questions asked by this research, it also reflected closely the lived experiences of the families involved. The narrative threads and patterns, wider narrative and grand narratives were interpreted further within the domains of challenge, change and choice across social contexts. The most dominant finding to emerge from this study relates to how the inclusion of these young children on the autism spectrum has been impacted because of significant changes across the landscape of inclusive early years education in Ireland. Parents were acutely aware that their child's inclusion in education relies now, not only on the availability of supports, but also on the level of understanding of autism within the educational setting and beyond. In spite of such challenges, the families still spoke about the positive aspects of their experience of navigating the education system. The importance of developing positive relationships: the significance of interactions, relationships and values emerged an incredibly dominant narrative. Through the research process, the choices, roles and actions of social actors underpin the focus upon relationships across the interviews. Thus, interconnected narratives of challenge, change and choice are presented in relation to the social systems of family [Appendix G, educational setting [Appendix H], Government and society [Appendix I].

5.3: Experience and Action within the Microsystem of the Family

This section presents the experiences of challenge, change and choice within the child's and parents' microsystem. Particular emphasis is placed on the actions taken by the parents in response to the challenges, changes and choices they faced. The main challenges within the microsystem are presented in terms of the children's challenges regarding engaging in their social and sensory world and how others interpreted these. The parents' perspectives on the challenges within their family life also emerged significant. The concept of change is considered for both the children and parents and is presented as a process, rather than an experience alone. Finally, the choices made by families, as they and their children move outside of their microsystem to navigate the Irish early years education system are explored.

5.3.1: Challenges Faced Within the Family

The primary challenges faced within the family unit were discussed across three domains as follows:

1. Challenges experienced by the children as they navigate the sensory and social environment around them and others' interpretation of thes.
2. Challenging experiences for the parents in relation to their family life.
3. Challenging emotions felt by the parents in relation to their particular lived experience.

The role of professionals in the families' initial experiences of co-navigating through this new and different phenomenon also emerges significant.

Challenges for Children

Each interview began with the parents describing their autism journey thus far. While parents initially recalled feelings of '*shock*' (Brenda, Sandra) and '*devastation*' (Ellen), it quickly became apparent that the children on the autism spectrum were the central characters in their parents' stories. The challenges associated with autism as identified by the parents were often described in terms of how their children experienced these, rather than how their families were affected. This child centred approach to autism appeared to enable the parents to better understand their child and, prioritised the children's experience of the world around them. Alice, mother of James and Eoin, explained that '*it's all in your mind-set*'. She articulated how:

> *It's not about us. It's about him, do you know what I mean? So, I could sit here and say [pretending to lament] 'oh I don't want him to have autism' but that's about me. I don't have autism, he has. So, the way I see it it's up to me.*

All six parents had referred their children to professionals because of concerns in relation to their development prior to the age of two. The challenges their children presented with were common across the narratives and included communication, social and sensory issues. Typically, professionals working with the families during the referral and assessment stages observed such challenges and either diagnosed or suggested autism. Section 5.6.3 discusses this process in detail in relation to choosing between public and private services. When recollecting this process, Sandra, mother of Brian and Beth, fondly remembered the impact a social worker, whom she considered to embrace a child centred approach to autism, had had on her. She described this woman as:

> *Totally different…* [because]*…she looked at Brian and she saw his little quirks, the things I was nervous of people seeing, and she didn't judge him.*

The way that others, primarily professionals, judged the children, was often remarked upon by the parents who saw it as a challenge for their children. Another parent, Ellen, mother of Harry and Ruth, voiced her experience of judgemental attitudes towards Harry. She described how '*they* [other parents and professionals] *were all looking at him and me*' and how she felt she:

> *Had to explain his behaviour during therapy so that they would know that this isn't what he's normally like…and wouldn't be judging him.*

Hannah (Max and Noah's mother) discussed the challenges for her children in terms of the affect that the language used by professionals had on their lived experience, describing diagnostic terms as '*loaded*' and delivered in a '*matter of fact way*'. Hannah presented her reaction to the word 'profound' and how it contrasted so strongly with her interpretation of her sons:

> *It took me three days to get over the word profound. All I could see and hear and do, just that particular word…I was questioning am I not seeing what everyone else is seeing? Am I the one who's wrong here? Am I wrong to be thinking they're not… And then I broke it down to what tests were… they didn't capture the real them…*

When asked to expand upon her reference to testing, Hannah mentioned the effect that sensory over-load could have on a child on the autism spectrum within a clinical setting. She explained how, on the day she took Max and Noah for their cognitive tests, this may have been interpreted:

> *They went into this bright room they'd never been in before. Everything was new. Everything was potentially frightening. They just kept looking only at me and smiling at me for reassurance… sure of course, they weren't engaged with anything she wanted…Look maybe they're profound from a professional point of view… but when you actually get to know them and see that they have an understanding, they're aware, they're present in the room, their eye contact is amazing. That's the real them.*

Equally, each of the other parent narratives highlighted how such tests appeared to scrutinise the weaknesses of children on the autism spectrum, while dismissing their strengths as unimportant or irrelevant. Brenda and Alice both referred to this approach to assessment as '*a waste of time*' and a '*torment*' for their children. Both Sandra and Ellen advocated for the children's home life to be meaningfully incorporated into such assessments in order to show professionals what their child '*was really like*'. Indeed, the importance of gaining an understanding into the family life of these children and parents emerged significant as a means of alleviating the challenges surrounding these interpretations.

Challenging Experiences and Family Life

While the parents frequently outlined their increased responsibility for, and obligation to, their child or children on the autism spectrum, they positioned this commitment as characteristic of any loving family relationship. Thus, interpreting the narrative of obligation as it was originally intended; a binding pledge rather than a burden borne: '*our duty*' (Michael, Sandra). A commitment to the duties of family life was clear for the six parents involved, all of whom had more than one child. Four of the five participating families had more than one child on the autism spectrum. Some parents were raising their family alone. All families had one or both parents working. Therefore, the impact of challenges on family life was clear with multiple references made throughout the interviews to financial and time constraints, both of which were somewhat intensified by the parents' commitment to provide therapies and interventions for their children on the autism spectrum, as Alice highlighted:

> *Everything James needs we do it. I always had this thing in my head 'what if someone came back when he was older going …if you had done this'… so no one can say that to me because I literally do everything possible no matter the cost…*

Three of the parents spoke about the lack of awareness of others, oftentimes professionals, in relation to the challenges that they, as a family, experienced on a daily basis. Sandra described the harmful impact of a lack of awareness on her, as a mother stemming from a support worker, describing her family life as '*too challenging*'. She seemed overwhelmed by the support worker's comment, stating that she '*couldn't get it out of [her] head*'. She asked:

> *How would you feel…if you were at home… 24/7 every day of your life, and next minute someone comes in for 2 hours and says oh I can't do this anymore? And yet I'm ok to do it but you are not... It's awful. It's hurtful…*

Interestingly, each of the six parents suggested that professionals who have a loved one on the autism spectrum or with additional needs, not only recognised these challenges, but in fact alleviated many of the families' challenges through their understanding and supportive approach. Sandra, Hannah, Brenda and Ellen all strongly emphasised how professionals who shared in their lived experience '*get it*', with Michael and Alice explaining that it '*changed everything*'. As a result, the actions and perspectives of these professionals enhanced the learning experiences of their young children. Whether it was Harry's home tutor, Eoin's pre-school educator, James' speech therapist, Brian's play therapist, Max and Noah's public health nurse or Sam’s junior infant teacher, the message was the same. When a professional had a lived experience of autism or additional needs, they were better positioned to build partnerships with the children and their families, built on mutual trust, understanding and a shared balance of power. Hannah articulated this clearly, stating that:

> *When you meet someone who says, I have a child with special needs. Oh my god the difference… they have a huge advantage because you can connect, you have that common ground.*

This sense of connection and common ground seems to establish a positive experience between the professional and the parent from the outset.

Challenging Feelings

As parents began to describe their autism journey, they reported feelings of ‘*shock*’ and ‘*devastation*’. However, in all cases, these emotions dissipated as parents came to understand autism and their child’s unique lived experience of it. The most challenging feelings that parents dealt with on an ongoing basis derived from their experiences of navigating the wider world with their child. While parents reported feeling frustrated and angry about accessing services, the most common emotions reported were worry, anxiety and fear. Generally, these emotions were associated with waiting for long periods without knowing what the future held for their child. Brenda, who had an older child on the autism spectrum, reflected on her previous experiences and the time she spent worrying:

> *All those hours I gave worrying, I will never ever get them back. I wasted a lot of time worrying about things that might never happen.*

Ellen and Hannah reiterated this point and highlighted the challenges they both endured due to intense and prolonged worrying about whether their children would be ‘*able to go to mainstream*’ primary school. This concern, that has since dissipated for both mothers, had proved a significant challenge for them for years until they both deduced that their children’s happiness ‘*was all that matters*’. While feelings of frustration, disappointment and anger were commonly reported by the parents in relation to particular interactions or experiences, Sandra, Ellen, Alice and Michael all spoke of the hurt they felt when their child was judged or presumed incompetent by people ‘*that don’t even know*’ them, with all three pledging to ‘*fight harder*’ for their children, as a result. Thus, at times, facing such challenges brought change about within the family.

5.3.2: Changes in the Family

A narrative of change at multiple levels underscored all parent interviews. This narrative was expressed in terms of changes in children, in parents and, in the families' values and priorities. These changes occurred over the course of the research and were in response to both positive and negative experiences in the lives of the children and parents. The importance of understanding, acceptance and happiness resonates throughout.

Changes in Children

Initially, parents discussed changes in children in terms of developmental issues that arose in infancy. However, as the interviews continued, parents equated the changes they recognised in children with progress. For the most part, these positive changes within the child were in response to a person, environment or activity that '*got it*' (Michael, Hannah, Brenda) and engaged their child in ways others did not. On the other hand, Sandra provided an account of changes in Brian's behaviour during his developmental reviews, his respite hours, and his initial assessment with CAMHS (Child and Adolescent Mental Health Services). All of these resulted in the reduction or termination of subsequent services, with one of the professionals involved stating that they:

> *Can't deal with him because his autism is too out of control… like because Brian is supposedly too hard work that she's just not going seeing him anymore… just like that*

As Sandra became increasingly worried about the potential consequences of professionals' interpretations of her son, she reflected on the advice of a close friend who suggested:

> *You know the way they're saying Brian is this and Brian is that? Get the play therapist involved the one that has an amazing relationship with him.*

Sandra's explanation of Brian's interactions with the play therapist portrayed him in a different light, allowing others to '*see the progress he can make… with a person who understands'*. A person who embraces child-centred practice by making her interaction '*all about him'*, which Sandra surmises '*must be so refreshing for him'*.

Noah and Max' experiences replicate Brian's with regards to the significance of having '*people who understand'* (Hannah) the lived experiences of these children and families. Following a meeting where the teacher and principal of her sons' autism specific preschool unit stated explicitly that Noah would '*not be able'* to continue attending, Hannah brought her sons to visit a special school in the next county. Moving to a setting where educators '*know exactly what to* *do*' stimulated a major change within her sons and, interestingly, within herself, leading their family, to '*become so happy'*. Hannah elaborated on the happiness that emulated from seeing Noah and Max '*in their element'* as being:

> *Able to put that perspective on it… to be delighted that they are going where they are, because they are happy and adored. It's like a safe haven for them, where they just feel totally accepted…*

The fact that Noah and Max being '*totally accepted*' led to changes within both boys and Hannah was representative of how the concept of change manifested within all six parents. This phenomenon will be examined further in the next section.

Changes within Parent(s)

The parents often discussed the ways that they themselves had changed since setting out on their families' co-navigations together. The most common change noted within the parents was the development of resilience against the challenges they faced in the outside world. Within Hannah and Ellen's narratives, such resilience manifested as having the capacity '*to keep going… no matter what'*. Alice also presented resilience as her only viable response when faced with unreliable or unavailable supports, concluding that:

> *You are better off just knowing that you are pretty much on your own and getting on with it….*

However, Brenda cautioned against viewing resilience as a solution to the many issues experienced by her family now and in the future. She stated:

> *It can't be enough on its own. What good will [it] be when our boys are trying to go it alone out there? There needs to be more than just knowing the parents will keep on going… what about after we… what about when they are on their own?*

In reality, most changes occurred within the parents in direct response to the fact that they felt they had assumed sole and ultimate responsibility for their children's outcomes. With repeated allusions made to being left alone since their child's diagnosis, it appeared that the development of resilience, therefore was not just an option for them; it was an integral necessity. It is noteworthy that both Sandra and Ellen brought letters to the final interview as their chosen personal artefacts, the content of which emphasise the importance of becoming resilient and having a positive approach to the change, or indeed constant flux, that navigating the wider world with a loved one on the autism spectrum can bring. Both letters, written to their younger selves, opened with the recognition that life '*is different'* but reassured that everything '*will be ok'*. The central theme of both letters was that of change. Both began by describing the way their lives changed the day their child was diagnosed, mentioning '*shock', 'devastation'* and '*fear*'. Both concluded by mentioning the transformational power intertwined with such change drawing on the theme of moving from darkness to light. Ellen's words articulated this transformation further:

> *When it was confirmed that Ruth had autism, I felt like the bottom had fallen out of my world, she had no future, everything I had planned and hoped for was gone. When Harry was diagnosed even though I knew what to expect, I almost felt worse. Now two children on the spectrum. If only I had been able to glance into my future and realise their lives weren't over, everything wouldn't be dark and depressing but instead we would have a happy home full of love and laughs. Sure, there would be some rough days and some things that others take for granted. It might be a bit tougher for us but it's just a different way of living. Different not less*

Changes in Values and Priorities

Although the parents' priorities focussed entirely on meeting the needs of their children on the autism spectrum, as they navigated the wider world together, they reported a change in their fundamental values and priorities. As mentioned previously, all six parents had initiated the diagnostic process and engaged in early intervention with a view to aiding their child's development, especially in relation to language and communication. Yet, as time went on, their priorities changed. As such, the principle priority became their child's access to appropriate education. Brenda succinctly illustrated this change in priorities:

> *When Sam was diagnosed, I did take it bad but I knew that I had that brilliant preschool and that the chances were that they would take him. It made it easier knowing that…*

In the first phase of data collection, preschool and school placement emerged the parents' central priority. All six parents valued mainstream education, citing it as the most appropriate and desired setting for their child on the autism spectrum. In fact, Hannah outlined how the responses of others were also gauged in terms of the value they held for mainstream education as a social norm, and the child's capacity to attend. She recollected other people sympathising with her, saying, '*oh God and the two of them have it, oh I'm so sorry to hear that'*. But Hannah reported a visible change in people when she would respond *'it's fine, I expect they'll be mainstream'*, stating that '*then they* [the public] *would be grand'*.

Each of the parents narrated similar experiences, presenting the interactions between theirs and others' values as typically ending with an agreed view of '*mainstream*' or the '*norm*' as optimal. However, over the course of the research, all of the parents began to cite their children's happiness as their top priority and identified the availability of specialist support as providing the best possible educational experience for them, while fostering their happiness. For the parents, attending and completing mainstream education was intertwined with the perceived value of their child by others, who '*judged you in terms of how able you were*'

(Michael). Although special or ASD classes came to be viewed as an option for some of the children, they were generally located against the landscape of mainstream education. Parents described ASD classes as '*technically…mainstream'* (Sandra), '*the best of both worlds'* (Hannah) and '*more about teaching children in a different way'* (Alice). Each of these parents expressed hope that their children would be integrated into mainstream education over time, if they were '*able*'.

5.3.3: Choices Made by the Family

As previously stated, a dominant grand narrative throughout relates to the children and parents' experiences of being granted or denied access to education. When access issues arose for children, their families generally faced the following binary choices: (1) mainstream or special education and (2) early years or primary education. Typically, the act of finding the *best place* for their young children was a recurring motif across the parent narratives.

Mainstream Education vs Specialised Education

The division between mainstream and special education, and the suitability of either for their child, emerged a recurring theme across the parent narratives. While parents appeared to accept this division during the first phase of data collection, over time some of them began to question this divide. Hannah urged those within the field of education to refrain from:

> *…presenting mainstream as amazing and special education as this place that people are put… because actually for a lot of children it's the opposite. Mainstream can be a terribly exhausting and kind of excruciating place for the child to be. And then special education is like a safe haven…*

She commends any attempt to gather family narratives, believing that they can '*show that actually for a lot of children it's the other way around. Special education is the optimum*'. Three parents also touched upon the evolving narrative surrounding the term *special.* While Ellen, Brenda and Alice did not support the use of the word '*special*', describing it as '*negative*', Sandra demanded a return to the original meaning of special as '*better than ordinary*' rather than something '*unusual*' or '*less*'. She suggested that such a shift would reduce the clear '*them and us*' divide between special and mainstream education and dispel any negative associations. However, it appears that in these parents' experiences, this divide remains and continues to influence the choices available concerning their children's education.

From the outset, in the months prior to enrolment in pre-school, parents voiced their concerns for their child in relation to the pressures associated with attending mainstream school and the apprehension surrounding whether their child would be deemed suitable. The parent narratives suggested a significant gap between the reality of practice and the ideology of inclusive policy. While the benefits of inclusion permeate policy, three parents questioned whether these aspirations were '*realistic*' (Sandra, Brenda, Hannah) in practice, given recent cuts to special education and the '*nature of primary schools*' (Ellen) in Ireland. Indeed, this dichotomy between ideology and practice represents a recurring theme throughout the data. Brenda emphasised this point regarding her son's denial of access to a Special Needs Assistant (SNA) in mainstream education and her consequent decision regarding the '*best place*' for him. She explained that while '*technically [Sam] doesn't even really need to be in a unit because he's fine'* the denial of access to supports in the context of large class sizes in primary schools, meant that '*it was a huge worry'*. The consequences of this reality are further outlined in Sandra's statement pertaining to Brian's enrolment in primary school:

> *He can't go to mainstream without an SNA because it's so busy workwise and crowded in there…even though he is well capable…*

Sighing in exasperation, she declared '*this is what I'm up against…They* [education system/Government] *have you backed into a corner…*'. In other instances, parents described specialised settings as a '*better fit*' for their children because they would have the opportunity to '*be themselves*' (Hannah). Drawing these conclusions represented a significant shift in Hannah's stance in relation to special education, as she explains how she had resigned herself '*to the facts that frightened* [her] *so much at the beginning*'. She spoke about her panic at the prospect that her sons '*wouldn't be interacting with any mainstream children*' before concluding that her opinions were leading her towards decisions '*for the wrong reasons*'. The following interview excerpt illustrates fluctuations in Hannah's stance with regards to being forced to choose mainstream or special education and, her realisation that special education can be viewed and experienced positively:

> *You'd be saying sure, there's no picking, I'm forced to… but special education is an amazing thing that shouldn't be constantly viewed as the alternative, the last resort. It understands different ways of learning and the whole establishment recognises all that is different, rather than everything and everyone having to be the same.*

This acceptance of special education as a place where children on the autism spectrum would potentially, be understood and accepted was also central to Sandra's narrative where she discussed Brian's transition from a specialised preschool to a mainstream primary school. Recalling a time when Brian:

> *…had to get a cognitive development test… I remember nearly crying because he had to leave the special pre-school because he wasn't diagnosed with an intellectual disability [ID] I was in bits… imagine…*

While afraid that it would '*sound terrible'*, Sandra explained that at the time of Brian's transition she was '*half hoping'* he would be diagnosed with an ID so that he could remain in the specialised pre-school '*because it was his world'* , and she was '*very scared of what his next chapter would be'*. Similar concerns regarding the '*the next chapter*' featured within all parent narratives, where the pressures of '*school readiness'* (Ellen) expectations were clear. Ellen was concerned that her children's '*development wouldn't be where it should be'* whereas Brenda explained that:

> *Your heart would be in your mouth… hoping and praying that each teacher, each year will have a positive enough approach to* [Sam].

It is hardly surprising therefore, that Sandra deduced '*that anyone would see why you would try to push out the primary school another bit'*. The following section further elaborates on how primary education was viewed as significantly different to early years education with Brenda noting that '*one gives you roots, the other?... Wings*'.

Early Years or Primary Education

While the first phase of data collection took place prior to the children beginning preschool, at this early stage in their educational journey, all six parents expressed apprehension about their child's subsequent transition to primary school. This highlighted both the perceived differences that families recognised between preschool and school and, the differing strengths in relationships between home and preschool and home and school. All six parents chose to avail of the second ECCE year, sometimes applying for an over age exemption to do so. Parents cited school readiness as a deciding factor in this choice and, expressed a desire for their child to stay where they were known, understood and included and, where '*they show the same love and attention… as we do as parents*' (Michael). With Michael's son, James, '*so included*' within his ECCE setting, his parents decided that they would apply for an over-age exemption so that he could attend preschool for a third year. They rationalised this choice in light of the fact that James was '*going to spend the rest of his life in school*', a prospect that made '*the [over-age] exemption*' necessary to ensure that '*he'll be ready for school then, …hopefully…*'.

As mentioned earlier, the perception of school readiness was influential for the parents who decided that their child '*would have to*' (Alice, Sandra) extend their time in pre-school. However, in all cases the decision to either remain in pre-school or attend primary school involved the input of other educational stakeholders. When issues surrounding support-allocation arose (e.g. '*reduced*' or '*withdrawn home tuition'* (Hannah, Sandra), '*refusal of over-age exemption*(s)' (Alice, Michael) or a *lack of school places* (Brenda), parents sought advice from national agencies.

Professionals, and especially SENOs, recommended that Sandra, Alice and Hannah enrol their four-year old children in primary education rather than extend early intervention or education in homes and pre-schools. Such recommendations were met with confusion and worry, as the children were deemed to be '*too young*' (Sandra), '*not ready*' (Hannah) and to '*need more time*' (Alice). Leaving the familiarity, care and safety of home or a pre-school setting and entering an education setting chosen by external agencies emerged a cause for concern. In her second interview, Brenda presented her son, Sam's experiences within the preschool setting, outlining that '*he wanted to stay there forever*' and that, she '*would never worry*' if he could. The following excerpt from her narrative depicts her '*roots and wings*' analogy:

> *I often think of this plaque I gave my parents once that said: "parents give you two things, one is roots, the other, wings". That saying just doesn't work when you have a child with significant needs. The thoughts of the wings part can keep you awake at night. You have to focus instead on the roots and that's inclusion. And his preschool is like that. It's all about him and helping him fit in.*

She, together with Ellen and Sandra described primary education as being '*a different ball game*'. In her opinion, school was '*all about the wings of the students and the great heights they can reach*'. Signifying her worries for Sam's future she asked:

> *What if you have a broken wing, what then?*

This metaphor can be used to illustrate the many challenges that the families experienced at the prospect of their loved one on the autism spectrum entering social contexts that were unknown or unfamiliar to them. Such navigations will now be explored.

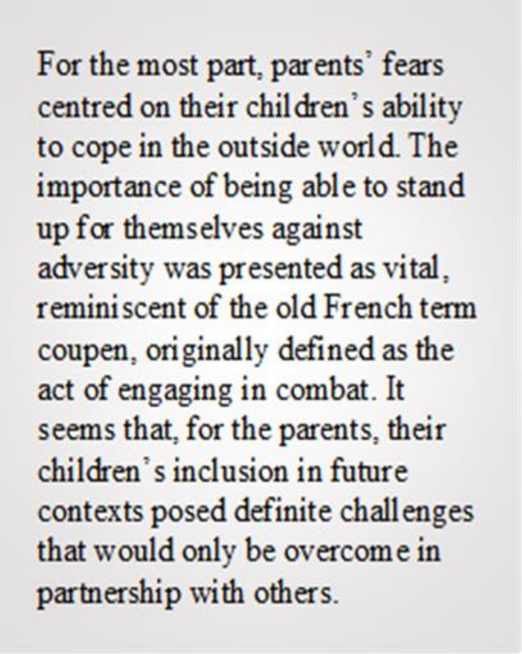
5.4: Experience of Actions and Narratives of Other Social Contexts

This section presents how these parents', and consequently their children's experiences, were influenced and impacted by the actions of others within the social contexts that they engage in as a family. As discussed, this study is concerned with educational settings as the principal social contexts within which the family engage. Thus, the mesosystem encompasses experiences and action in the home and the child's education setting. This section outlines the main challenges and changes experienced within the mesosystem, with particular consideration offered to the choices of the principle social actors within such contexts, for example, educators and educational leaders.

5.4.1: Challenges in Other Contexts

The prospect of their children entering into different social contexts posed a variety of challenges for the parents, each of whom expressed concerns relating to their child navigating settings other than their home or preschool. This section demonstrates how these concerns are associated with fear in other contexts, the influence and impact of others' opinions and, difficulties with accessing support/education.

'Fear' and Other Social Contexts



For the most part, parents' fears centred on their children's ability to cope in the outside world. The importance of being able to stand up for themselves against adversity was presented as vital, reminiscent of the old French term coupen, originally defined as the act of engaging in combat. It seems that, for the parents, their children's inclusion in future contexts posed definite challenges that would only be overcome in partnership with others.

For Brenda, at the beginning of her journey, '*the big things [she] feared were the social side of it: the parties, the invites, the playdates… things that turned out to be the small things really*'. Alice also referenced her '*big fear*' regarding James leaving the familiar social context of his preschool, stating that '*the only thing [she is] always afraid of is when he leaves Anna's. It keeps me awake*'. The main fear expressed by Hannah, and also voiced by the other parents at one point or another, related to the prospect of her children entering into the wider context of society in the future, stating '*I think it's the fear of it that's the worst part, fear of the world*'.

The very tangible fear surrounding their children entering into society or the wider world was not solely indicative of concerns the parents' held with regards their children's capacity to cope[4]. A far greater source of fear was the possibility that their children would be treated badly by people that '*did not love*' (Brenda) or '*understand them*' (Ellen) and '*their little ways*' (Hannah). Interestingly, while the parents admitted that this aspect of their child's future may be outside their control, they did recognise the potential that positive contributions to the wider narratives of autism and disability could have on their children's future experiences. While the importance of entering into open dialogue about autism, difference and inclusion was often touched upon, Sandra explored the concept of '*fear around talking about autism among the staff and everyone*' within the school context, and suggested that this extended to '*even the parents of other children*' on the autism spectrum. She reflected on a time when she and the other parents of children in the ASD class were repeatedly excluded from the narratives surrounding whole school activities and events. Sandra felt that:

> *It was the way it had always been there, and no other parent had ever come forward and said anything until I did. It was like they were afraid…*

When asked what they might have been afraid of, Sandra responded that they probably did not want to cause any '*trouble'*, stating that '*even though change came about*' following her speaking out about how they and their children were treated, the school '*saw me as a trouble maker… and still do*'. The importance of others' opinions in relation to their children, and themselves, emerged a dominant narrative.

Opinions of Others

The parent narratives explored the impact that others' opinions regarding autism have on theirs', and their children's, daily experiences. While there is no doubt that there are many and varied opinions in relation to autism among people in wider society, in this study, the opinions encountered by the parents were classified into three distinct categories. 1) Some opinions were, treated as just that, characteristic of the early Latin definition of *opinionem*[5] where one's

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[4] Etymology of Coping: COUPEN which was defined as engaging in combat or *coming to blows* in the 1300s. By the late 1700s the meaning of coping had evolved to mean the capacity to *handle yourself or something successfully*, to *deal with something*.

[5] Etymology of Opinion: OPINIONEM [Latin] In 1100s defined as *conjecture, belief, fancy, appreciation, esteem*. Etymology of Judgement: originally equated with *opinion*. By 1530s *judgement* began to be used to describe a *sense of discernment*. By the 1600s, discernment was often associated with *displeasure*. Etymology of Blame: BLASTEMARE [Latin] meaning to blaspheme. By 1200s became more widely used in relation to the act of finding fault. In the 1300s a narrower definition came into use: *to lay responsibility for something deemed wrong*.

beliefs about a topic were acknowledged but not argued. 2) Other opinions could be more accurately defined as judgements, associated with knowledge rather than opinion and, differentiated further by the embedded discernment that often portrayed displeasure. 3) Finally, and expressed by the parents as most damaging, were the opinions that constituted the distribution of blame. In Brenda's experience, there was an undercurrent of blame present in some of the judgments made by others. Consequently, Brenda felt '*anxious and afraid*' because she found it:

> *...so hard to cope with [her] child being judged, I will never forget the way people would sympathise with you when they heard he had autism…it was awful.*

Brenda's account was similar to the experiences of the other parents, however, Michael's view on how children approach autism and difference provided an interesting contrast. Emphasising how an absence of judgement or bias can be instrumental in the inclusion of children on the autism spectrum, Michael commented on their acceptance of a child responding differently to them, stating that '*kids have no judgements in their eyes*'. He highlighted a significant difference between how children and adults respond to, and interact with, a child on the autism spectrum, noting '*an adult needs it and wants the eye contact and stuff*' and when this is not a realistic expectation both '*your child and you are judged*'. While the opinions of the public factored as significant in each parent narrative, the issue that emerged most dominant, and unanticipated, was the range of opinions held by leaders of educational settings in relation to autism. Ellen spoke about this extensively, making the discomforting deduction that '*there is a stigma about autism, and I see now that I actually had that stigma myself*'. She further explained how the presence of such stigma can influence the educational experiences of young children on the autism spectrum because:

> *The minute you tell a person that* [child is on the autism spectrum] *in pre-schools or things like that, it can change everything*.

All six parents touched on the impact of such stigma or negative opinions on their families' navigation of the Irish education system, across pre-school and primary schools. For Sandra and Hannah, the impact on their children's educational realities was undeniable. They experienced first-hand, the pain of having their child refused entry into primary education, based on the opinions of the school leaders. Sandra articulated the significant hurt and anger felt regarding educational leaders who stigmatised autism. Signifying her immense hurt, at one point, Sandra resorted to:

> *…actually, writing out the part of the constitution that said every child has the right to education. I stood there reading it out to them crying…*

Sandra was '*angry…tired from it*'. Adding to her sense of hurt and frustration, the leaders responded with '*nothing*'. Although others' opinions emerged a central thread of the parent narratives, the final decisions regarding their children's educational placement relied heavily on the possibility of accessing the relevant supports.

Difficulty Accessing Support/Education

The difficulty that parents experienced in accessing support for their children emerged a dominant theme throughout their narratives during all three phases of data collection [June-September 2018, May-July 2019, October-December 2019]. Brenda and Ellen presented an interesting comparison between prior engagement with support services with their older child on the autism spectrum some years ago and their experiences in recent years. Both mothers referred to their prior engagement with support services as '*different'* and '*fortunate'* when compared with their present experience. Both reported shorter waiting periods between initial referral and final diagnosis for their older child and praised the amount of intervention and therapies provided subsequently. While Hannah praised services in her initial interview, she explained that she had been encouraged to seek a private diagnosis to ensure her children's immediate access to services:

> *She* [psychologist] *warned me that it could take a year or more. But I said I don't think I can wait that long to get them the help they need…*

It emerged that such services were not provided following receipt of her sons' private diagnosis; a scenario that Alice was familiar with. Alice too had been encouraged to seek a private diagnosis to access services. However, having taken this action, she too was still waiting. All six parents questioned the justice of this, especially when immediate '*early intervention*' is considered to be '*everything*' (Ellen), '*so important*' (Sandra) and '*the be all and end all*' (Brenda) to the progress of all children on the autism spectrum. Consequently, all nine children attended private intervention and therapies in an effort to ensure such progress.

While the difficulties associated with a widespread lack of early intervention and support services saturated the narratives in our initial interviews, during the second and third interviews, the parents' concerns, regarding '*little or no support*' (Ellen, Sandra, Brenda) for their children, centred on their educational setting. As mentioned earlier, guaranteed access to supports was the deciding factor in these children's school placement. In the absence of an assurance of supports within their preferred choice of educational setting, Sandra, Alice, Michael and Hannah all voiced how they '*had to*' contemplate '*going somewhere else*'. Sandra elaborated on this reality further:

> *And it was like they* [SENO] *was saying that it's my choice not to send her to that school. So my choice in other words… caused all that. I chose that apparently, chose that she would have no place? I was choosing that for her, they said…but sure there was absolutely no choice.*

It became evident that as the parents navigated the transition from pre-school to primary school with their children, the issue of support allocation and provision emerged most dominant. Each of the parents reported meeting with leaders of educational settings and discussing the matter of support with them. The outcome of some of these conversations are noteworthy as they provide insight into, not only the difficulties surrounding the availability of individualised support and the consequent impact on some of the families involved, but also the impact that this reality had on some of the educational leaders. In one of the seven schools, Sandra approached to enrol Brian, the actions and voice of the principal epitomises this emotional impact:

> *…she said under the new system he was seen as having no care needs… that meant then that we probably weren't going to be successful in getting an SNA for him. She was as shocked as me and said "look it is still totally up to you, but if it was me, I wouldn't send him here". She was fit to cry.*

Hannah and Alice gave accounts of pre-school managers who made an authentic commitment to provide one-to-one support to their sons within their setting, as they believed this level of assistance was necessary to ensure James', Noah's and Max's happiness and to help them reach their potential. However, with policy advising against such individualised support, and the logistics of such provision becoming more difficult as a result, this commitment became a source of frustration and upset for the educators. The parents credited the main cause of such upset to the fact that the educators '*wanted to help'* these children in every way but, their '*hands were tied*' in relation to accessing physical support and resources. It is noteworthy, that Ellen and Brenda, both of whom had previously worked in the early childhood sector, met the Government's advocation of educators gaining expertise on inclusive practice (rather than applying for supports to facilitate inclusive practice) with scepticism and mistrust. While both women recognised the clear benefits of such expertise, they deduced that expertise alone is not enough. Brenda asks: '*if expertise solves everything why can't a speech therapist have 25 children in a session*?' While commenting that '*there would be loads of therapy for everyone*' the reality would be different, '*it would be an actual disaster'*. To bolster her point, she presents an account of her sister, an educator who, in this scenario, is affected by the difficulties accessing support in education at present:

> *My sister is a teacher and is so clued in about autism and she's coming home nearly crying because she can't help the child the way she would want to if she had another adult in the room or a smaller class.*

Certainly, such testaments solidify the argument that changes to inclusive policy in Ireland are adversely affecting inclusive practice in particular circumstances. Such changes to policy, and subsequently to accessing support, therefore, warrant further exploration.

5.4.2: Changes Related to Other Social Context(s)

While the exploration of changes within the microsystem focussed upon changes within the children and parents, the concept of change within other social contexts manifested as something experienced or endured by the social actors within the settings of home and pre-school or school. Therefore, the family's mesosystem represents social experience and action in flux, especially in terms of changes to accessing support, changes to support provision and, the changing role of educators.

Changes to Accessing Support

The recent changes to the ways that supports and resources are now allocated to children with additional needs in schools appears to have altered the way that the word *support*[6] is now received, reducing it to its original definition as assistance in tolerating, bearing or enduring a phenomenon. Interestingly, some of these exact terms featured in the parent narratives when describing their child's educational experience without the possibility of what they deemed to be adequate resources. Brenda expressed her distrust in the practicality of the Government's future plans regarding the *School Inclusion Model* proposed by the Government for 2020/21. This model proposes that all children are educated in their local mainstream school, irrespective of level of disability, an undeniable socially just charter. However, Brenda argued that the Government '*won't realise what a disaster of an idea it is until there has been a lot of damage done*'. When asked to elaborate on such damage, Brenda replied:

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[6] Etymology of Support: in the late 1300s held generally negative connotations *to prop up/put up with/tolerate/to bear/endure*. Early 1400s, evolved to describe *that which supports, one who provides assistance, protection, backing*. Mid to late 1400s support became typically equated with the *bearing of expense*. In 1953 support as *services which enable something to fulfil its function and remain in operation* was introduced.

> *Damage to our children… damage to us…having to send them off every day to endure that… that kind of a set up….*

From the perspective of the parents in this study, the introduction of a *School Inclusion Model* requires significant increases in investment in special education in schools, rather than the current trend of decreases in spending to achieve '*value for money*' (Michael, Brenda, Sandra). Brenda went on to share her fears for parents, for teachers and, most importantly, for children on the autism spectrum in the event that this model does not receive adequate financial investment:

> *Parents will blame the schools for not being able to manage properly and then teachers will blame parents… instead of being seen as a cry for help because of the lack of support, the children will be seen as bold and unmanageable they'll be put on shorter days or worse still expelled.*

The five other parents shared Brenda's fears, voicing their concerns about the level of inclusion their child could experience without such supports in place in mainstream education. In our first interview, Hannah discussed the fact that, because of policy changes, her children would only have access to an SNA to facilitate their care needs at particular intervals during the day. She felt that '*even if [her sons] are showing the ability for mainstream*' she would still opt for a specialised setting to ensure that the school could '*give them the supports they need*'. The parents' and children's experiences of recent changes in the provision of special education support within primary schools therefore warrants further exploration.

Changes to Support Provision

A recurring thread throughout the interviews, especially during the second and third phases of data collection [May-July 2019, October-December 2019] was the recent trend observed by parents with regards the establishment of ASD classes within mainstream schools. Parents typically viewed this initiative positively, interpreting it as the '*only option*' (Sandra, Hannah, Alice) for six of the children, because of reduced levels of access to SNA support within mainstream settings. While all six parents appreciated the level of investment necessary to establish units across the education system, some were critical of the philosophy behind the creation of special classes and, its impact on inclusive practice in mainstream settings. Ellen's primary concern related to the fact that while autism is accepted as a diverse spectrum of representations, the government '*just put all autistic kids in a unit*'. This deduction was further solidified by both Michael's and Sandra's experience, where on receipt of diagnosis, '*the unit*' was presented as their children's only viable option. Michael recalled the psychologist giving them '*the bit of paper*' and saying '*he should just go to a unit*' When he explained that Eoin's preschool had said he was ‘*capable’* and recommended enrolling him ‘*straight into mainstream and get his hours*’, he was simply told this would not be possible as ‘*things had changed*’. For the parents, ‘*the unit*’[7] represented a separate educational setting where supports were ample, but where the possibility of authentic inclusion for their children relied heavily on the philosophy of the leaders of both the ASD class and the school. Under the guidance of the right leader, Brenda suggested that *units* could represent an ‘*option of specialised education within the mainstream in every community*’. However, she then added softly ‘*but are they though*?’. The negative connotations surrounding the word ‘*unit’* were clear and elaborated upon further by Alice in our second interview. She articulated her sense of disquiet about ‘*that word*’ noting that ‘*there is this dark shadow over the unit*’. She described the term unit as being ‘*so clinical*’ suggesting that ‘*it sounds like you are going for a medical procedure*’. She therefore called upon the Government to stop ‘*calling them units*’.

Alice’s observation aligned with earlier findings that highlight the stigma that can surround the medical model of autism, where, in this instance, an autism class becomes equated with a hospital ward. Conversely, Sandra suggested that ‘*the unit*’ can be viewed as an integral fabric of the school where difference is celebrated and, the term unit can evolve towards its original definition of *unity*. However, she warned that:

> *If the unit is going to be totally cut off from everything else it will be very segregating… still very much ‘them’ and ‘us’. Just like long ago.*

Critical to this process of unification is the act of valuing the children that access the ASD class in their own right, rather than evaluating them in terms of how they do or do not fit within the education system. The role of educators in this process is pivotal.

The Changing Role of Educators

All six parents discussed the role of educators in bringing about change in the educational experiences and lives of these young children on the autism spectrum. However, the changeable role of educators in inclusive practice currently also became evident. For the parents, the role of educator was multi-faceted, encompassing the central pillars of teaching and learning but also, incorporating the field of caring. Over the course of the study, parents had built positive relationships with at least one of their children's educators. When discussing the impact a given

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[7] Etymology of Unit: derived from MONAS [Greek] and translated over time to mean a *single number regarded as an undivided whole* (1500s) and *single thing regarded as a member of a group.* In 1893, the term *unit* was first officially recorded as referring to a *group of wards in a hospital.*

educator had on their children's educational experiences, the emphasis was always placed on the relational and, caring aspect of the educator's role. In fact, it was the interactions that parents had with educators outside of the educational context that resonated with them most. When Sandra travelled in bad conditions to attend a course on autism by night, she described feeling moved at the sight of Brian's class teacher '*sitting there with a chair kept*' for her. When Hannah had to contend with her children being '*sent home on a reduced day*' from their autism specific preschool unit, she spoke about being '*close to tears*' when the manager of their previous preschool '*welcomed them with open arms*'. When Michael collected Eoin from preschool and, saw him walking through a field hand in hand with his teacher, laughing while counting pigs, he remembered '*just standing there*' watching '*what education should be like*'. The case was the same for Alice, Breda and Ellen who all presented accounts of educators who had touched theirs and their children's lives simply by interacting with and caring for them. All three mothers employed the same phrase to highlight how these educators had treated their children '*as if they [were] their own*'.

5.4.3: Choices Made by Others

The choices made by others within social contexts outside of the home greatly influenced the experiences and subsequent actions of these families. In terms of the children and, parents' co-navigation of the education system, the choices of educational leaders and educators had the most significant impact. These individuals' chosen perspectives on autism and difference also emerged important.

Choice of Leaders to Ensure Inclusive Practice

Parents regularly reiterated the significant role of educational leaders in making inclusion possible. They perceived these leaders as facilitators of, or at times barriers to, inclusive education. While it became evident that a leader with a positive vision of inclusion was quintessential in guiding inclusive practice, it became equally evident that the leaders of educational settings were solely responsible for translating inclusive policy into practice. In this regard, the term responsibility shifts from its intended meaning, as the recognition of one's *obligation for the welfare of another*[8], towards a more modern interpretation of responsibility

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[8] Etymology of Responsibility: RESPONDER [Latin] meaning to back or to pledge something. 1590s: being "answerable" to another for something. 1640s: "accountable for one's actions". 1690s: being responsible became defined as being reliable or "trustworthy", the responsible party would recognise and act on their "sense of obligation for the welfare of another"

as defining who is answerable or accountable for one's actions. While the latter definition seems to correlate to the role of educational leader currently, the former description closely relates to the accounts given by parents throughout the narratives. Within such accounts, parents emphasised the importance of the actions of leaders concerning the welfare of their children, leaders who treated these children '*like their own*' (Michael), '*adored them*' (Hannah), and simply '*as children first*' (Brenda). Nevertheless, the children's experiences varied based on the individual qualities of the leaders within their educational setting and, their interpretation of inclusive policy and practice.

Ellen, a pre-school manager, herself, highlighted the significance of the leader's personal philosophy of inclusion on the children's experiences and, positions this against the anomalies associated with the Access and Inclusion Model. According to Ellen, there is scope within the implementation of the AIM for leaders to say:

> *Let's take the child with special needs because that means we'll be getting an extra pair of hands for the service. We'll have plenty use for them…*

Ellen therefore questioned whether the AIM '*is being used to give that child the best learning experience in the preschool*'. She concluded that this is her '*problem with AIM*', that in the policy, '*they are blatantly saying that…this is not for the child this is for the service*'. Sandra felt that this ambiguity within inclusive education policy resulted in a strained relationship between her and pre-school staff. In fact, it prompted her to voice her dissatisfaction with the policy direction to one educator:

> *Its management telling you what to do, what he decides is important… A guy with a business background…come on*

In the next interview, Sandra again touched on the issue of policy implementation in relation to enrolling her child in local mainstream primary schools. Here she witnessed how various principals '*used*' policy differently, explaining that:

> *There I was making these appointments to see if the school would be suitable for our son and they were there to see if he was suitable for their school.*

As Sandra described the barriers to her son's inclusion, her upset was evident, and reminiscent of the exchanges she had with such leaders where ambivalence towards her upset was equally palpable:

> *One of them just said that on the ground policy didn't make much difference… she told me that her hands were completely tied that the Board of Management were against a unit and wouldn't budge on it. They wouldn't budge, no way.*

Sandra was totally dismayed that this attitude came from '*other teachers, other parents, respected people in the community, a priest for God's sake…*'. On the other hand, Brenda's experience pointed to positive relationships with leaders as underpinning Sam's authentic inclusion. She referenced the AIM and Aistear, noting that in accordance with both:

> *The only way inclusion can happen is if you will gain an understanding of a child and that can only be through their parents. It's the relationships on the ground that matter*.

Indeed, for all six parents, the prospect of their children attending an educational setting, where leaders did not encourage or implement inclusive practice, instilled fear and anguish. Certainly, the possibility of their child being authentically included rested on the role executed by the leaders of educational settings and the educators within these.

The Concept of Choice in Educators' Implementation of Inclusive Policy

As mentioned earlier, the definition of *choice* has evolved to symbolise a variety of meanings over the years. The parent narratives suggest that their children's educators were restricted to making limited choices within the constrained policy-practice context of inclusion. Nevertheless, parents frequently highlighted the potential role that educators could adopt in making inclusion possible. Indeed, Alice's and Michael's accounts were saturated with references to how one educator dramatically changed the life of their son James and, the entire family, stating that without her, they would be '*totally and utterly lost*'. Moreover, across the narratives, the impact of educators' choices on the parents and especially the children's experiences were clear. Hannah presented the desire to teach children with additional needs as a fundamental choice inherent in the practice of inclusive education. She explained that when it came to her sons she knew '*how to love them… how to accept them… adore them*' but conceded that she did not know '*how to teach them*'. Consequently, she emphasised that '*you need teachers who want to do that*'. Michael's portrayal of Anna, James' and Eoin's pre-school teacher, exemplified someone who has made this fundamental choice:

> *She is just one person who views autism differently and has no fear of anything. She's not an I can't person she's an I can… she has changed so many lives.*

It gradually became evident that intrinsic to educators' inclusive practice was a devotion to the children in their care, which in some cases, superseded autonomous choice and was presented as the educators' only viable option. Brenda offered insight into this notion of devotion in

Sam's pre-school and, her decision to give money to the staff towards petrol expenses to express her appreciation for their efforts on his behalf:

> *They want to learn about Sam rather than make him do things the same as everyone else. They went off in their own time and did classes about communication and autism, I actually felt so bad for them I gave them a few bob to cover their petrol. I mean they get nothing for that. That's just wrong. And they wouldn't complain. They are so devoted to the children.*

While the significance of knowing that staff had participated in continued professional development regarding autism was mentioned by each of the parents, some were critical of the value placed on expertise. Parents often spoke of educator's priorities aligning more closely with '*academics*' (Michael, Hannah, Ellen, Alice) rather than the inclusion of children on the autism spectrum. Sandra suggested that while prioritisation of the academic is a concern, the probability of inclusion rests on the '*individual teacher*', rather than their level of expertise in any one area. In her opinion, '*you could have a great teacher and they mightn't know much about autism themselves*'. Brenda provided a contrasting scenario, warning that if teachers '*feel that autism isn't anything they need to know*' there is a risk that the child on the autism spectrum will be interpreted as '*the child who can't row in with the way school works'*. In some instances when this happens, Brenda suggested that children and their families may be told that '*they can leave… and they do, some are even expelled*'. Unfortunately, both Sandra and Hannah's narratives confirmed the veracity of this harsh reality, as both mothers '*had to take* [their children] *out of school*'. Nonetheless, while there appeared to be ambiguity surrounding the possibility of educators implementing inclusive policy, this was typically seen as being '*outside of their control*' (Hannah). In fact, all six parents located educator practice within a larger '*system'* that either had their '*hands tied*' (Sandra, Michael) or had left them '*on their own*' (Ellen, Brenda). Their narratives suggest that Government action (or inaction) with regards the implementation of inclusive policy can manifest in varied and, conflicting views and experiences of inclusion emerging.

Perspective on Autism and Difference

Attention cannot be turned towards the *one who is included*[9] without also considering, the one who includes. Within inclusive education policy and practice in Ireland, this role is devolved to the individual educator. In order to be able to adopt such a responsibility, choices must also, be made in terms of deciding on or accepting a particular stance or perspective regarding

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[9] In 1839, the language of inclusion came to be adopted as a noun, describing the one who "is included"

inclusion and, by association, autism. As mentioned earlier, the importance of educators having a '*positive perspective*' (Brenda, Hannah) on inclusive practice features prominently within parent narratives. In fact, as previously cited, this was the deciding factor in parents' choices regarding their child's educational placement. The parents' perspectives on autism and difference were accepting and understanding. However, in these families' interactions with others, autism was usually discussed in terms of the deficits associated with it. Sandra emphasised this stance, stating that '*every bad thing is put down to autism*'. All six parents referred to and welcomed the recent efforts made by those who promote a narrative of autism that draws on the social model of disability. All six parents described autism as '*a different way*' of being, rather than a condition that manifests in a multitude of deficits. While it did not emerge a recurring thread, it is important to note that two of the parents (Sandra, Michael) highlighted the potential risks associated with looking at autism from a *disability versus difference* stance, if '*needs started to be ignored*' (Sandra). Instead, an approach that recognises the presence and, importance of both, is advocated to ensure that the challenges associated with the lived experience of autism, are not dismissed and, the rights of their children to supports is not disregarded.

Within every finding presented in this chapter it is clear that underlying the parent narrative was the significance of the perspectives that they themselves, their children's educators and therapists, and the public, held in relation to autism. Parents spoke about positive approaches to autism and inclusion and compared it with their own choice to adopt a strengths-based approach to autism. This approach appeared to enhance the daily-lived experience of their families by '*accepting* [their children] *as they are*' (Hannah, Alice, Brenda). Extending this concept to their child's education settings, parents articulated how educators' perspectives on autism, whether they '*get it*' (Michael, Ellen, Sandra) or not, were the central keystone of their child's inclusion in, or exclusion from, education. A point introduced earlier in relation to families' experiences of stigma. As previously outlined, the stigma surrounding autism among professionals, many of whom were educators, appeared paramount. While some leaders of educational settings displayed an implicit stigma in relation to autism, one such educator, a primary school principal, explicitly voiced hers to Sandra, stating '*oh aren't you great to tell me straight out about the autism, another one would be hiding it*'. Sandra described being '*so hurt, so angry*'. She further elaborated that:

> *The worst part was she* [the principal] *was in charge of all the other teachers, all the staff, no wonder they are like that as well, having an actual problem with including children with autism.*

Accordingly, parents expressed a need for the development of positive perspectives towards autism and inclusion among all educators and, referenced professional development as a means to '*helping people understand*' (Ellen) and '*helping our children be included*' (Michael). Sandra attributed such professional development to an apparent transformation within Brian's teacher:

> *In the beginning, she did not want to be in the unit at all she was petrified and in the space of a year she had totally changed. She is living and breathing autism now, doing courses non-stop. She is actually taking a year out this year because she is going off doing a Masters in autism, I think. So, there you go like it changed her completely and for the better like. And I've heard that loads of times, this teacher in a panic in the unit and they get to love it and they only want to work in autism after.*

Alice further stressed the magnitude of professional development, outlining that she could accept '*the whole public not understanding autism*' but that different standards should apply within education where '*people who are working with autistic children every day need to have autism specific training done*'. In the absence of informed and positive perspectives within educational settings, Alice suggested that such educators are:

> *Tirelessly trying to make our children meet the same milestones or do the same schoolwork as everyone else in the same way as everyone else.*

She urged such educators to realise that '*it has to be about more than results. It has to be about life*'. Hannah also offered an account of the importance of educator perspective, not just on autism but also on the act of providing special education, which she stated, is '*totally down to how the people, the professionals usually, view inclusion or difference*'. She became emotional as she recollected a teacher telling her friend that being allocated to a specialised setting '*is just so unfair*'. Her response added further weight to the parents' concerns surrounding the negative perspective associated with ASD class when she stated:

> *They are putting me into the unit…the unit…as punishment because I was out on maternity leave. It's just so unfair…*

Without doubt, this educator's negative perspective on both autism and inclusion could have a detrimental impact on the children whose care and education she views as her '*punishment*'. Following this account, Hannah reiterated how '*the people…that run them* [units] *can make all the difference*' oftentimes, in negative terms. Essentially, she argued that those who manage ASD class have much more power and consequence than '*the SNA, with the smile on her face or the bus escort who is in great form every morning*' (Hannah). However, Brenda problematised the emphasis placed on educator perspective in inclusive education in Ireland currently and, again, voiced her criticism of policy direction particularly in relation to reduction in the numbers of SNAs. Therefore, while she acknowledged that perspective '*is so important and it does make a difference*', she believed that educators:

> *Will be the scapegoats now and if inclusion all goes pear shaped it's in the news as being totally their own fault…*

This was not the only time that parents referenced Government responsibility for inclusion and exclusion. In fact, the '*contradictory*' (Michael, Sandra) social and economic choices of Government, in both policy and practice, emerged, not only as a recurring narrative pattern, but as a significant factor in the daily lived experiences of these families.

5.5: Experience of Actions and Narratives of the Exosystem and Macrosystem

It would not be possible to effectively explore the experiences and actions within the child's family and education setting without positioning such challenges, changes and choices within the wider realm of macro-experience and action. Thus, locating our understanding of how such experiences, roles and actions within the children's and parents' micro and mesosystems are constructed and impacted by certain macro-forces, for example, social norms, the media, modernity, and most significantly within this study, Government policy and action.

5.5.1: Challenges in Wider Society

The embedded nature of the human experience was evident across the parent narratives. Many challenges mentioned by parents regarding their own lives, and the life of their child on the autism spectrum, were also positioned in relation to wider society. This effectively compares two representations of the narrative of *challenge*: the challenges associated with macro forces and ideologies and the action taken by the parents in challenging these. The present section explores the challenges of macro-contexts identified by the parents, in terms of society's norms, online engagement and the influence of modernity.

Challenging Society's Norms

As each parent narrated their experience, they repeatedly contemplated how different theirs and their children's stories could be if the prevailing norms of society were to change, if '*being different was ok*' (Ellen). Predominantly, the interpretation of difference as wrong or not right, especially among professionals, was highlighted as a recurring issue that should be challenged. Brenda was the first to voice her reservations about this, with regards to the autism assessment process, suggesting that it '*should be way more positive*'. When asked how this could be achieved, she replied:

> *It's simple really just look at it as a different learning style rather than a wrong or flawed learning style.*

All six parents problematised the concept of '*normal*' development, questioning the motivation behind the widespread acceptance of a single, correct way to develop. Interestingly, Alice's interpretation of normal, as the way '*you're conditioned to think that your child should be*' rested firmly on the child's ability to '*follow rules created by others*' for the benefit of greater society. Again, Alice recommended challenging the premise behind and the promotion of '*normal'*, urging parents instead to defend difference by declaring '*no…our child is working at his own pace*'. Michael also referred to the process of '*conditioning*', linking the emphasis on universal development with the goals of a productive society where adults are '*conditioned to progress in your career*' with competitiveness encompassing such normative progression and reinforcing the belief that:

> *You have to do this… you have to do that…but to what end. That's what people need to be asking. That's the way people need to look at it*

As mentioned earlier, the pursuit of happiness, rather than success, was actively encouraged by the parents. References to the importance of their children's happiness as being '*the main thing*' (Sandra), '*all that matters*' (Hannah) and '*everything*' (Ellen) greatly outweighed mentions of their development or productivity. However, jeopardising the possibility of such happiness was the presence of inaccurate of negative perspectives on autism among wider society.

Each parent discussed the ways that negative or misinformed perspectives were, not just damaging to them as a family but could, in fact, be internalised by their children who were '*incredibly aware*' (Sandra), '*intuitive*' (Michael) and '*sensitive*' (Brenda). The danger and futility associated with such negativity was closely aligned to the need for positive perspectives to become the norm. Critically, all six parents explicitly referred to their involvement in the present study, as an opportunity to address the negative connotations that they felt were typically associated with their families' lived experiences, to '*have their say*' (Ellen) and '*get their stories out there*'(Alice). While they also saw the research as a potential forum to highlight the actions or events that negatively affected theirs and their children's lives, in the end, the importance of promoting a positive perspective prevailed. Even, in Sandra's case, after surmounting endless barriers and engaging in countless fights to ensure her son had access to education, the importance of focusing on positives rather than negatives comprised the concluding comment of our final interview:

> *But I really don't want to leave things on a negative note because do you know what? There might have been negatives along the way but they were always down to a lack of understanding or a fear of the unknown, when people actually met our children and got to know them all that went away…*

Indeed, the importance of close contact with people who took the time to get to know their children and to appreciate their unique family life was a common thread across narratives. Therefore, it is understandable that parents discussed their engagement in online communities, with whom they did not have this relationship, in terms of its associated risks rather than as a network of support.

Risks of Online Engagement

As outlined earlier, the parents spoke of their fear at the prospect of their children entering into unfamiliar social contexts, both now and in the future. However, another type of fear identified by the parents centred on the potential dangers associated with engaging with others online in relation to families' experiences of autism. While the benefits of this interactive process were outlined by parents, this typically referred to the information-sharing opportunities associated with this forum in the earlier stages of their journeys when they felt they '*had no information*' (Alice), '*had to find out about autism*' (Hannah) or simply '*wanted tips*' (Ellen) . This initial information-sharing generally consisted of parents exchanging advice following their child's diagnosis and beyond, for example, the recommendation of particular procedures for accessing support. However, underlying every reference to such online interaction was an awareness of the associated risks as '*it could be a dangerous place*' (Brenda). For the parents, an over-emphasis on negative experiences represented a very real danger for them and their children, with particular emphasis placed on how being immersed within a negative narrative of autism would significantly impact their families' ability to cope and could manifest as '*a slippery slope*' (Alice) of '*doom and gloom*' (Hannah). In order to cope proactively, Alice pledged to never '*read anything online again*' stating that '*people can be too negative*'. Ellen explored the way that families' negative experiences are widely accepted as the '*typical*' experience of someone who has a child on the autism spectrum. She incorporated an image from the internet into her narrative showing three different pictures of parents, explaining:

> *This is someone without kids, this is someone with kids and this is someone with autistic kids… supposedly…they look like they've been pulled though a ditch… come on like*

Her disappointment was apparent as she studied the image, shaking her head, while adding '*it's not right'*. Sandra also questioned the fact that the experiences of parents of children on the autism spectrum were often set apart or othered, revealing that while she had '*witnessed challenging children who don't have autism*' and presumed that '*those parents might go to bed pulling their hair out*' she wondered why '*no one makes a show on the internet about that*'. Ellen implied that this particular representation in the media further ingrained negative stereotypes into people's minds. She also expressed her surprise that sometimes '*parents welcome this*', alleging that they '*almost thrive on this sympathy*'. Brenda also referred to the connection between the sharing of negative experiences online and the subsequent outpouring of sympathy. She mentioned '*woe is me blogs*' emphasising the negative impact of '*the list of one hundred comments saying, "oh my heart breaks for you"*', especially following a child's diagnosis as '*people are so impressionable in the early days… people can feel alone*'. Brenda also deduced that online interaction can help to relieve this feeling of isolation, suggesting that an emphasis on the negative could result in a greater yield of interaction. She concluded by saying she could:

> *…almost understand it because that's what people are looking for…shared experiences or a feeling of community. If you get that through negativity and the likes… then I suppose what can you do*

Hannah reinforced this point. She admitted that she could '*see why people would go online*', again reiterating their need for '*support that is otherwise unavailable to them*'. The next section examines this feeling of isolation, in relation to its creation and development within modernity.

Challenges of Modernity

The isolation associated with modernity manifested as an underlying current throughout the parent narratives. The '*pressures*' (Sandra, Alice) of modernity that lead to this isolation and increased individualisation also emerged a dominant thread. Both implicitly and explicitly, parents revealed a deep awareness of the impact of modernity on families presently, especially those whose experiences do not represent the '*perfect life*' (Ellen, Alice) or '*successful lives*' (Hannah) as defined by modern standards. Alice portrayed her family's life as a '*different type of normal*', outlining how she not only accepted this, but also actively worked to '*normalise the different*' for her family every day. She elaborated on how striving for a '*perfect life*' could be potentially damaging, linking this to the fact that '*suicide rates are so high in this country*', as a result of the ideology of '*this perfect life…that just does not happen for people*'. Alice made a deduction that four of the six parents (Sandra, Ellen, Hannah, Michael) alluded to, the fact that '*we can't all have that*'.

While accepting the different path in life that they now navigate with their families, each parent touched on the pressures that people feel to stay on the path to success, rather than focusing on family. Michael asserted that '*long ago there wasn't that pressure*'. The multiple references to the pressures felt by families '*nowadays*' suggested that demands of modernity posed particular challenges to these families who identified as different or other. Interestingly, the very definition of modernity, as a deviation from the traditional, bore negative undertones, eventually evolving into a central metaphor within which, the strengths of family and community emerged fundamental. In her examination of the depiction of mainstream and special education in Ireland at present, Hannah also evoked the aforementioned metaphor stating that while:

> *Every mother wants their child to be able for the real world… we should not assume 'the real world' means 'real school'… whatever that is*

Hannah asserted that people have always had '*their own versions of the real world*' and urged others to recognise that '*this is okay*'. Each of the parent narratives voiced the widespread change that Hannah advocated. Section 5.6.2 explores this in relation to the ideology, influence and impact of change at macro level.

5.5.2: Government Action and Ideology as Choice

In this exploration, the choices of government to change or prioritise particular policy areas and, responsibilities for inclusive education, became an undercurrent throughout the narratives. These choices are pivotal to gaining an understanding of the impact of macro-action and, ideologies on the experiences of these children and parents as they co-navigate the Irish early years education system.

Changes to Policy

The changes to inclusive education policy in Ireland, first mentioned in the introduction to this thesis, became tangible in Brenda's comparative account of both her sons' early educational experiences. Having '*travelled this road before*' with her fifteen-year old son on the autism spectrum, Brenda often cited Government policy changes as the most significant difference between both of her experiences navigating the education system. She suggests that changes at policy level might not have the desired positive, inclusive impact and, lead to '*exclusion rather than inclusion*'. Brenda became overwhelmed with emotion when she discussed the possibility that her younger son, and other young children like him, would be unable to enter mainstream education because of their diagnosis of autism, even though his older sibling had been attending mainstream schools for eleven years. She proclaimed that:

> *Now no one child is entitled to anything. There's no such thing anymore. A child doesn't have their own resources.*

The most discussed change in policy, as perceived by parents, was the shift from their children traditionally being granted resources from the Government '*in their own name*' (Sandra, Brenda, Hannah) to a general allocation of resources to educational settings. The biggest concern expressed by the parents regarding this change to policy was the '*fairness*' (Ellen, Hannah) and prudence of '*handing over*' (Michael) the responsibility for identifying and facilitating the needs of their children to the leader of each individual educational setting, irrespective of whether '*they are able to or not*' (Brenda). As mentioned earlier, Sandra and Ellen also expressed their concern in relation to how the responsibility for implementing the AIM in ECCE settings has been administered. Ellen critiqued such change and advised '*putting the person with them* [child with additional needs], *helping them, working with them*' instead of with the service as '*that's how it should be*'. Certainly, the way changes in inclusive policy had manifested in practice raised concern among the parents in relation to governmental priorities.

Prioritise Policy Areas

An important narrative that emerged strongly was the parents' views on the motivation behind recent Government action in relation to inclusive education. Some parents saw this as the Government's response to the economic '*recession*' (Brenda, Michael). Brenda perceived recent Government action on inclusion in schools as '*getting rid of SNAs*' something that she deduced was not '*about inclusion*' but related to '*saving money*'. Looking sadly towards her son as he played, she suggested that '*our children are still paying for the recession that they caused…*'. As she reflected on her children's future, Alice's narrative referenced the negative impact of designing inclusive education policy around short-term economic goals, rather than having a long-term social vision of inclusion. She questioned what she perceived as, '*misguided*' policy prioritisation, asking why '*they're fighting over pennies*' when in the long term:

> *…if children like our boys aren't facilitated in their community… they're going to cost probably millions to the country. Imagine if you could actually get a child independent in their community, they need to be with their peers from the beginning for that*

Alice's long-term inclusive vision rested on giving James, Eoin and '*others like them*' the chance to '*get to know others*'. However, the Government's role in inclusion over the life span appears, instead, fragmented, distant and, as Michael emphasised, focussed on '*the economic aspects*' of inclusivity. He argued that '*the state…instead of actually providing support to people… give the allowance and that's it*'. When asked to extend on this distributive role, Michael responded, saying:

> *It's cheaper… there are no services, no help, no support just here's a bit of money, go private if you can. We can do nothing for you…*

Brenda also argued that the Government have retained '*total power*' with regards the allocation of supports and resources for children on the autism spectrum, while responsibility for these children's inclusion rests with the child's significant others within their microsystem, as Sandra articulated: '*the ones who care*'.

Reduced Responsibility for Inclusion

Throughout the research, each parent, at some point, referred to being '*on your own*' in terms of responsibility. As mentioned earlier, while all parents and children had developed shared partnerships of responsibility with particular professionals, these alliances were typically forged in response to the '*reality*' (Sandra, Hannah) faced by each party in terms of their roles in inclusion. During the first and second phases of data collection [June-September 2018, May-July 2019], the narrative of responsibility was generally presented with reference to its manifestation within the children's and families' microsystems. Michael spoke of the complete responsibility he assumed in his own fight for his child, stating that '*at the end of the day*' he would not '*have any regrets*':

> *…when I'm on my death bed at least I can say I did what I physically could for them, emotionally from a father perspective, from a financial perspective, we were on our own… but we did all we could…*

The manifestation of responsibility within the macro was first discussed, in terms of the immediate impact on the lived experiences of the children and their families. However, by the final phase of data collection [October-December 2019], the responsibility assumed by the Government for inclusive education was being referenced in a broader sense, with the dialogue often concentrating on the creation and, implementation of policy nationally. The main reason for this narrative shift was the Government announcements of, and the media response to, a *School Inclusion Model* in education. Some found the aspirations of such a policy initiative '*admirable*' (Hannah) and '*well-intentioned*' (Ellen). For others, the ideology that all children, irrespective of level of disability, could attend their local mainstream school stimulated scepticism, worry and fear among others who questioned how this '*could be possible all of a sudden*' (Sandra) or '*how it could work*?' (Brenda). The findings have shown that accessing supports for their children within mainstream education proved challenging for all of the parents, with some abandoning their vision of inclusion in mainstream education in order to, instead, find the '*best place*' for their child (Hannah, Sandra, Alice).

Special classes or special schools were chosen (or recommended), as the best place for six of the nine children in this study. The families' realities were integral to understanding their apprehensive and negative response to a *School Inclusion Model*. For two parents (Sandra, Brenda), a '*sudden move*' to turn away from specialist settings towards universal inclusion within mainstream, represented an urgent requirement for increased and, intensive investment in inclusive education and, an immense commitment from the Government and education system. In fact, Michael described such efforts as '*impossible*' because '*Ireland is not like that*'. Brenda elaborated on this, stating that as she read about the model, she learned that the countries whose policy the Government was emulating '*have around fifteen in each class, two adults in every room and as much resources as you need*'. She suggested that significant fiscal '*investment is needed*' for best practice in inclusive education and warned against those in power '*using it as a way to save money*'. It appears that, for total inclusion to become possible nationally, these parents felt significant change was necessary.

5.5.3: Change at Macro Level

The manifestation of change within the macrosystem, and its consequent impact on the families in this study, was multidimensional. This final section examines the concept of change with regards to Government investment in children on the autism spectrum with a view to achieving change. The changing role of, what the parents referred to as, the system, is explored. Finally, this section also highlights the need for widespread change in relation to the inclusion of voices often unheard, It is fitting that this narrative of change comprises the concluding section as it, in a sense, presents a chronosystem or representation of change over time in the life-span of individuals on the autism spectrum. Beginning with the emphasis on change in the earliest years of these children's lives and ending with the need for change to include these children's voices in the narrative of autism and inclusion.

Investing in Change

Parents mentioned the action taken by the Irish Government regarding investment in autism throughout their narratives. While access to services and education was reiterated throughout as a source of concern by parents, early in the process, each parent referred to the positive impact that the government's provision of home tuition, ECCE and, in some cases, the domiciliary allowance, had on their, and moreover, their children's lives. While Hannah initially stated that she '*couldn't fault the support*' she received, over time, her stance changed as she began to feel concern and frustration at aspects of this investment that were '*very wrong*'. When asked to elaborate. Hannah explained that she felt the Government were '*essentially penalising*' her children for being twins by not providing the same level of support and intervention, as they would, to children on an individual basis. The '*agenda*' (Brenda, Alice) associated with intervention emerged significant throughout all phases of data analysis, oftentimes representing the Government's investment in change for these children. Some parents critiqued the fact that early intervention, for example, home tuition, was heavily invested in up to the age of four but as children got older '*less and less supports were offered*' (Sandra) to those who struggle. Both Brenda and Michael suggested that failure to progress during early intervention or a perceived lack of '*potential*' for the future caused a reduction or complete cessation of investment. Hannah offered an account of this stark reality in response to her children '*getting older*' but not being '*entitled anymore*':

> *I explained the whole thing to them* [DES] *that look they've Autism, they've special needs…But home tuition just stopped abruptly. It was probably a factor in what happened to Noah* [regression, distress] *for a few months... And they said 'look we get it, it's awful, you're being discriminated against, but we get funding from the Department with certain rules and we can't go outside them, there is nothing we can do for you.*

For Michael, Brenda and Alice, who also had an older child on the autism spectrum, this type of investment had proven problematic as it focussed on '*how much they* [the children] *could achieve*' (Brenda) or '*if you can pay back*' (Michael). These parent statements essentially portrayed the Government's interpretation of their children on the autism spectrum in terms of their potential economic capital. For the parents that had younger children on the autism spectrum, the importance of investing in such capital was also highlighted with a view to '*a better future*' (Ellen) where '*anything could be possible*' (Hannah). However, it became clear that in order for such visions to be realised, Government action, for example, investment, had to be reflective of an effective, functioning system, rather than a response to aspects of '*the system*' that were '*failing*' (Alice). Again, the call for change resounded.

The Changing System

The '*system'* was frequently mentioned by parents and portrayed under a sceptical or dubious light. Throughout the narratives, *the system* encompassed two meanings. Usually, it referred to the role of the Government, but sometimes, it implied the prevailing social order. References to a '*broken'* (Alice) or '*flawed'* (Hannah) system manifested as a strong narrative thread across the parent stories. Michael, the first to identify '*the way the system is*', questioned the morality behind the actions of government who:

> *…tell you like your child is like this and f**ked if you don't get intervention. And then… they don't provide it.*

Michael expressed his worry that his son James would suffer because of the inadequacy of '*the system*'. Unfortunately, James' story was typical of all nine young children represented. Across the narratives, the waiting periods for early intervention seemed almost paradoxical to the parents involved. The urgency surrounding the '*assessment of need*' was described as '*pointless*' (Brenda) and '*a joke*' (Alice). The clear stipulation in Government policy outlining that any diagnosis made following assessment would not be equated with access to services was interpreted by the parents as '*unfair*' (Sandra and Michael), unfolding as a clear source of frustration and perplexity. Alice hypothesised further about the Government's stance on this matter. She maintained '*the whole system*' acted in response to the commands of a wider economic manifesto. She envisaged the ideology underpinning this manifesto as saying:

> *Moneywise only diagnose ten kids every six months or whatever because we can't afford to be taking them on. That's all that matters to them…*

The changes to the system of diagnosis were frequently discussed, not only in relation to the recent shift from the public domain to private '*family responsibility*' (Sandra), but also with the changes to diagnostic processes and terms.

Brenda associated the '*huge problem of trying to find places in schools*' with the fact that all Autism Spectrum Disorders are now encompassed under *Autism* as an umbrella term. Alleging that '*the word Aspergers was always associated with high academic achievement*', Brenda stated that under the '*new system*', inclusion can become somewhat problematic if educators '*hear the word autism*' and '*automatically go to another place*'. When asked to define this place, Brenda suggested that '*they picture children who are going to need a lot of help*'. When looking for a primary school for Brian, Sandra experienced this perspective first-hand, identifying it as '*the biggest roadblock*' to accessing six of the seven schools she approached.

She felt that the word ‘*autism*’ was typically rejected, especially when principals learned that Brian had attended a specialised preschool setting. These principals had all cited ‘*changes to the system*’ and specifically to the allocation of supports for children with additional needs, as the primary factor in their decision not to enrol Brian. This left Sandra hurt, in despair and questioning such a system. A system that could make her feel:

> *…actually ashamed, ashamed that that was the system, our country’s system.*

This harsh reality suggests that there was an over-emphasis placed on Brian’s perceived needs, with his right to be included emerging as secondary in importance. The next and final section examines the concept of need and, how it manifested across the parent narratives as a potentially transformative phenomenon, a catalyst of change.

Need for Change: Including All Voices

Sandra’s narratives problematised the way in which the concept of need could be used in an act of exclusion, ironically, in response to changes within Irish inclusive education policy. Thus, suggesting that in certain instances the needs and rights of children in relation to education manifest as separate entities. The parents spoke about this divide, with particular reference to the primary sector where ‘*the emphasis on care needs*’ (Brenda) was interpreted as dividing staff within educational settings into categories of those who provide care and those who provide education, when ‘*it should be both*’ (Hannah). Sandra pondered this point on the care/education divide also, identifying the fact that the voices of children’s SNAs were often absent from any dialogue concerning their child. She argued that SNAs ‘*have a right to be there too*’. Highlighting the significance of the care relationship in her children’s and family’s life, Sandra developed this point further, asserting that ‘*they actually know your child even better than the teacher*’.

The old Irish phrase *naunae*, meaning famine or shortage, was once used to describe a lack of something that was deemed necessary. Throughout our engagement it became evident that for the parents, the need to have all relevant voices heard represented something necessary that was lacking in their experiences.

Certainly, the need to recognise and appreciate a variety of voices in the narrative of autism and inclusion was a common request across the parent narratives. Typically, these recommendations emphasised the ‘*value*’ of parent and child voice (Ellen, Brenda). At times however, the importance of including the voices of older individuals on the autism spectrum, representing the autistic community, came to the fore also. Alice's account, further outlined below, concerning the inclusion of teenagers and young adults on the autism spectrum in any conversation about their lives, did not go unnoticed. It signified a deeper understanding of the oftentimes, conflicting opinions regarding the inclusion of the voices of this demographic. While attending a course regarding the social and educational experiences of adolescents and adults on the autism spectrum, Alice observed, that '*by right the teenagers and young adults should have been there*'. However, following interactions with their parents, Alice deduced that '*if they didn't actually know they were autistic, how could they go*?'. This reality poses many questions relating to families' engagement with the narrative of autism and, the consequent impact of this on individuals on the autism spectrum. Here, Alice presented autism as a phenomenon experienced across the entire lifespan, thus, recognising adolescents and adults on the autism spectrum as having valuable funds of knowledge derived from this life-long experience. Hannah reiterated this stance when, following the diagnosis of her sons, she critiqued her family's experience stating that '*there's too much paper, too much talking*'. She suggested that instead, professionals should '*show how these children developed*' into adulthood. She explained that:

> *We're all aware of the children that struggle, that's the autism they keep pushing… but if we could learn from adults who know… imagine.*

For the past number of years, one did not have to imagine, because in reality, adults on the autism spectrum gained more and more opportunities to have their voices heard '*on TV, the internet and lots of places*', as Sandra observed. Worryingly, however, Alice highlighted how a return to issuing the antiquated category of '*childhood autism*' diagnoses could effectively silence this group in the future:

> *I was so angry when they diagnosed Eoin with childhood autism. I have never heard anyone mention the childhood autism diagnosis before that or since that. It must be a new thing now, because of the money I suppose… but what is going to happen with it…where will they stand in the future?*

Alice's analysis of this single act by Government implied a potential loss of identity for an entire minority group going forward. It also presented the identity and voice of individuals on the autism spectrum across the chronosystem (encompassing their childhood and entire lifespan) as something that should be accepted and appreciated rather than diagnosed using a short-term prognosis. The latter change can only increase the challenges experienced by these children and families and further limit their choices going forward.

5.6: Conclusion

This chapter presented the dominant findings that emerged from the ‘analysis of narratives’ phase of the research. These findings were presented ecologically to represent the microsystem, mesosystem, exo and macrosystem. The challenges, changes and choices voiced by the parents across all phases of the research were framed as experiences and actions relating to the microsystem of their family, the mesosystem of interactions and relationships with their child or children’s education setting and the macrosystem of Government action and the tenets of wider society. Throughout this chapter, and indeed the entire research, the parents positioned their child or children on the autism spectrum at the centre of their own experiences and actions. The inextricable connection made between autism and identity is a central vein of this research. In recognising this, the experiences of these children and parents can be greater understood in terms of the construction and appreciation of the voices of these young children on the autism spectrum. Chapter six presents the prioritisation of these children’s voices, which are a central vein of this research.

Chapter Six

Child-Centred Narrative Analysis

(Findings)

6.1: Introducing the Children

This chapter presents the voices of the nine young children on the autism spectrum at the centre of this study: Beth, Harry, Eoin, Sam, Noah, James, Max, Brian and Ruth. While it was not possible to access these children's narratives directly, through visual storytelling methods with their parents and an in-depth process of child-centred narrative analysis, their voices gradually came to the fore. Such action meant that the children were given a certain amount of agency in the retelling of their experiences co-navigating the Irish early' years education system with their parents. The inclusion of these children's voices not only facilitated the development of their agency within the construction of their families' narratives, but also centred the focus on the self-identity of these young children on the autism spectrum. At the beginning of the study Beth, Harry, Eoin and Sam were three years old, Noah, James and Max were four and Brian and Ruth were both five. This group represented four sibling relationships: Beth and Brian, Harry and Ruth, Eoin and James, and Noah and Max. While Sam had an older brother on the autism spectrum, he was outside the age threshold for the study, however, his mother Brenda often referred to his prior educational experiences within her and Sam's narrative.

Without doubt, the value placed on these children's voices throughout the research was clear. The study embraced a variety of modes of communication to include both verbal and non-verbal voice. Therefore, an excited flapping of the hands, an energetic leap across the room or a protective covering of the ears in response to a photo of, for example school, could potentially offer as much insight into a child's experience as a verbal response might. It is also important to reiterate that by the final phase of the research just Ruth, Sam and Harry were attending a mainstream primary school setting. Brian and Beth were both enrolled in ASD class. James and Eoin had both remained in their ECCE setting for an extended period of time and, Noah and Max had transferred from an early intervention ASD class to a special primary school setting. By contrast, eight of the nine children had attended mainstream pre-school settings prior to enrolling in primary school. Therefore, the children's comparative experiences in ECCE settings may appear to be more dominant throughout the data. However, the discussion takes the children's experiences across a variety of settings over time into account.

6.2: Valuing the Experiences of Children on the Autism Spectrum as they Navigate the Irish Early Years Education System: Time, Place and Voice

This chapter presents the children's experiences in two ways. Firstly, the narrative excerpts directly represent these children's responses to visuals and artefacts, relating to their experiences of co-navigating the Irish early years education system with their parents. These responses are presented collectively in relation to *place* and *time*, thus encompassing both the fundamental elements of Bronfenbrenner's Ecological Theory of Development and, the central research question that includes the children's experiences spanning both pre-school and primary school. Secondly, presentation of these children's narratives focusses on the dominant findings arising from the child-centred narrative analysis. Again, such findings are structured ecologically, comprising of Beth, Harry, Eoin and Sam's experiences within the micro-system, Noah, James and Max's experiences within the mesosystem and, the influence of the macrosystem on the experiences of Brian and Ruth. This section emphasises the construction, understanding and appreciation of these children's voices, with particular reference to the development of each child's self-identity. Central to this process of identity formation are the interactions and relationships that these young children have with their parents, siblings, educators, other professionals and peers. The views held by such significant others in relation to autism, disability and difference emerge as paramount in the construction of either positive or negative self-identity as the navigate within and between social contexts.

6.3: Presenting the Voices of Young Children on the Autism Spectrum: Across Places and Over Time

The children's responses to visual storytelling methods based on stimuli representing their experiences of pre-school and/or primary school, offered insight into their emotional connections to their educational settings and, the educators within these. As the children engaged in this shared narrative process with their parents, their individual experiences of enjoyment and acceptance could gradually come to the fore, as could, at times, their upset and exclusion. The findings across place and, over time suggest that while some children's navigations across the education continuum were successful, others experienced significant stresses and barriers that inhibited their inclusion. Again, the significance of interactions, perspectives and relationships in enabling inclusion is palpable.

6.3.1: Children's Perspectives on Place

The concept of place featured strongly in each child-centred narrative. As the central research question sought to understand the experiences of young children and their parents as they navigated the Irish early years education system, gaining the children's perspectives in relation to the places where their educational experiences occurred was of paramount importance. The ways that children were understood varied in respect of the place they or their parents occupied at any given time. Understanding the importance of place, within and surrounding narratives, emerged an integral element of these stories.

The importance of place was clear in Alice's account of James' preschool, which she discussed while holding the photo, showing the front of a brightly coloured building, that her and James had used. The photo of the building acted as a stimulus with which the relationships between her son James and those who care for him within the setting, could be explained. As illustrated in the following excerpt, the staff '*love James as a child, as himself*'. Looking closely at the photo and smiling, Alice reflected that:

> *James just runs in the door. You see there's never an issue about autism with them. They're not coming over to you with every small thing because they get it, they understand it… They show the same love and attention to James as we do as parents. They love him as a child, as himself. No wonder he gets excited when he sees the place.*

Michael referred to an image of his youngest son, Eoin's, preschool. He spoke in admiration of its remarkable structure asserting that '*the actual physical structure of the playschool is amazing*', while elaborating further to make an association between the physical aspects of this place and the educational philosophy behind it:

> *The name of the place even, it has its philosophy there in the title: freedom. Eoin gets that freedom there... They have geese on the farm, chickens, like Eoin feeds the pigs and stuff. Look at it like. No wonder he loves it.*

Like Alice, Michael too referenced the interactions within Eoin's setting noting that '*there's just more interaction rather than being stuck in your typical classroom*'. At other times, parents recollected their children's responses in particular, locating these within the wider child-centred narrative, to include their own perspectives also. An extract from Sandra's narrative presented her son, Brian's reaction to the ASD specific preschool he attended the previous year. Sandra incorporated both an image of the preschool and, a DVD of Brian's memories collated by the preschool when he was leaving, into their collective story of educational navigation. She spoke of the profound impact the pre-school had on her, recollecting how: '*I still remember* *when I first saw it*'. She then recounted how, in spite of his long day from the time he left home in the morning until he arrived home again, he '*absolutely loved*' his pre-school:

> *He left here at twenty past eight in the morning and he didn't get home till three every day… and he loved it he absolutely loved it. He loved the bus, he loved the staff, he still cries when I show him the DVD they did for him. He loves looking at all his memories. Do you know he actually said: "why did I have to leave, why mammy?".*

Later, Sandra used an image of an empty primary school classroom to highlight the differences between hers and Brian's perspective on place. For Sandra, the empty classroom was representative of deeper issues preventing the inclusion of her son in primary education. It highlighted for her, some of the differences between early years and primary school settings. It also portrayed the divide between special and mainstream education provision, culminating in what she felt was a complete lack of understanding of her son, and other children like him, by certain educational professionals:

> *I was like, there's nothing in there like nothing, not even books or anything…I was shocked, I wasn't expecting it… I started bawling crying, I was there shaking saying "my son is a person you know". I said "come on you have a school there you could surely go in and get a few tables and chairs or books" and the principal said it had to be specialised equipment for them and I said it didn't. they just needed something, anything…*

From Brian's perspective however, the same empty classroom was simply '*his school*' and invoked only positive reactions within him. When Sandra showed Brian the photo again, she recollected that '*he just loved it*'. Thus, spurring her to declare *that 'this was bothering me and not bothering him at all'*. Upon further reflection, she concluded that Brian's happiness was paramount. She therefore '*took a leaf out of his book and I said at the end of the day if he's happy that's all that matters*'.

The images that portrayed the inside of the children's preschools and schools all included stills of the children at play, eating lunch, working at tables etc. Therefore, the children's interaction with these places, rather than the places themselves, became the clear and immediate focus of the resulting narrative. Ellen's discussion surrounding an image of her son, Harry, completing puzzles at preschool demonstrated this. As she skimmed through different photos, she stopped on one in particular, her expression becoming more animated as she spoke, before a look of concern crossed her face as she contemplated his future beyond preschool:

> *I knew he would just soak it up, he is so clever, he is like a sponge. He can read words already, you can hear him at the numbers and stuff. He loves academic type things, so I know he'll excel along those lines in school. That's my big thing like. If he had to go to a unit because of his autism that that would affect his education. That's my worry because I think he's really clever and will probably do very well academically.*

As Ellen's narrative indicated, photographs depicting the children among their peers appeared to hold significance for the parents. Moreover, such images encouraged parents to examine their children's inclusion in these educational places. Brenda also explored this concept further in relation to her son, Sam's, preschool experience, highlighting in particular how important it was for her and, for him, to know other children who would be starting school with him. She explained that while Sam '*didn't really have any major reaction to most of the images he did keep pointing at his preschool*':

> *…Especially at Elaine, the manager. You see we're half connected to her, so it made all the difference for him. She knew him since he was a little baby… so then there wasn't all this drama about him having autism or whatever…And he did so well there. You see he was with the other children who were going to be in school with him in Junior Infants, that meant everything to us, and I think, in his own way, it meant a lot to Sam.*

One of the parents, Hannah, used images given to her by the principal governing the early intervention ASD unit, to help her twin sons, Noah and Max, make the transition from home to preschool. A photo of her sons' classroom elicited an extensive response from her, relating especially to the prospective inclusive educational experience of her children:

> *They gave us these images* [showing buildings, classroom, teacher, SNAs etc.] *in advance to make things easier for them going in. See here, the classroom has everything labelled, they have their own areas... I think they will bring other pupils in every week to be with them and the whole school learns about autism…They will know their names and that they have autism and they will all understand what that means.*

Hannah's words highlighted a central feature of many narratives; a gradual move from their function representing the background to a story towards the creation of a new foreground. The importance of time emerged dominant across the narratives and therefore, warranted further exploration of the children's perspectives in this regard.

6.3.2: Children's Perspectives Over Time

As with every narrative, temporality was an integral factor in both understanding and critiquing the co-construction of these children's voices. This temporal approach emphasised the sentiment of the moment narrated, ensuring the moment could be interpreted as active rather than passive, thus presenting the socio-historical context of the children's current educational experiences over the course of the research and beyond. *Change over time,* so deeply encompassed within the chronosystem, emerged as a central tenet in all the child-centred stories.

Alice discussed her son, James' reaction to an image of his preschool, highlighting how this response has changed over time. She credited his educators for the development of his positive perspective:

> *I mean he didn't say or do anything but he looked at it, and looked happy. That's because he associates it with things he likes doing. Before, he wouldn't have stood and looked, he wouldn't have acknowledged it. I mean James is gone from kind of doing nothing…that sounds horrible but he did nothing...he didn't play with anything, he didn't like anything, you wouldn't be able to say 'James loves…'. He didn't like anything. And now it's like he loves Sesame Street songs and rhymes, he can clap his hands and stomp his feet with the songs. He's saying parts of the alphabet like 'a' and 'h' and 's' and that's all from school. Like I'd love to be here saying 'oh I did that' but I didn't.*

An excerpt from Hannah's interview echoed Alice's deeper understanding of her child's responses and, emphasised the importance of artefacts in her own realisation of this. She used an image of her son, Noah, completing a matching activity as a stimulus to discuss both his, and her own, positive educational experience:

> *One day one of the tutors commented that Noah was doing really well with matching pairs. Now at the time, Noah wasn't responding to his name, he was in his own little world… I was thinking, how could this be Noah? Then she sent me the video and there he was matching absolutely everything, based on size, based on colour. It was unbelievable. It was like I was after getting a smack into the head. I was shocked. I was looking at it and looking at it and saying "oh my God"… To look at these pictures, to see the stuff he can do is just unbelievable and to see the little face of my son and he absolutely loving it.*

Over time, the photo-elicitation methods led Sandra's son, Brian, to speak about happy and sad times in his school. He had always told his mother that he did not like break times. However, on this occasion, he elaborated further on the reasons for this, while repeatedly referring to the gate that surrounded his school's ASD class:

> *So he picked up the photo of the outside of school and then I was kind of quizzing him about playtime and about the breaks and he said they would be in but if they were out that there is a gate around them and they aren't allowed pass the gate to go out and the other children aren't allowed pass the gate to go into them. I nearly died, I nearly dropped there and then.*

Sandra rang the school asking why children on the autism spectrum were not allowed to play with the other children. As indicated through the following narrative, she was further shocked by the principal's response to her question. It seemed that the rational for separating the children was based on nothing more than the children on the autism spectrum were in the ASD class.

> *So I rang the school and I said "when it's break time why can't they be out playing in the yard with the other children?" and he [the principal] was like "sure they can't be out around the yard with everyone!" and I was like "are you serious? Why can't they like?!" and he actually said "because they are in the unit".*

Sandra continued to speak without averting her gaze from the photo, while describing how she was left '*stunned*' by the principal's response. While she also affirmed the principal's concerns regarding Brian's '*health and safety*', she concluded that, irrespective of this, she viewed this opportunity as the time to '*fight for the rights of the children*' within the ASD class '*over* *everything else*'. She recalled urging the principal, through her tears, to '*let them play with the other children for God's sake*'. Because of her actions '*Brian ended up going in and he absolutely loved it*' which led to an increase in dialogue with his family about his social experiences, something Sandra had '*never heard before*'.

This excerpt highlights the importance of incorporating the children's own perspectives into the parent narratives and also, demonstrates how these children's voices can be represented to bring about social change. With such excerpts, it was important to move beyond the didactic *I-Thou* relationship to encompass *They*, thus, enabling a critical and ecological narrative analysis that focussed upon, not only relationships, but the actions that impacted these, oftentimes involving the 'othering' of children on the autism spectrum. This multi-relational approach accounted for both the reproductive element of such imbalanced power relations but also represented the potential constructive power of these child-centred narratives in relation to voice.

6.3.3: I-It, I-Thou and The Relational Nature of The Construction of Voice

The employment of an *I-It* and *I-Thou* relational framework of child-centred analysis enabled an overview of voice to emerge that took into account the concepts of autism and inclusion as phenomena (I-It) and the roles and actions of those in constructing, or indeed destructing, the voice of the child on the autism spectrum. Figure 15 demonstrates how the phenomena of autism and inclusion across places and over time could affect the development of the children's voices.

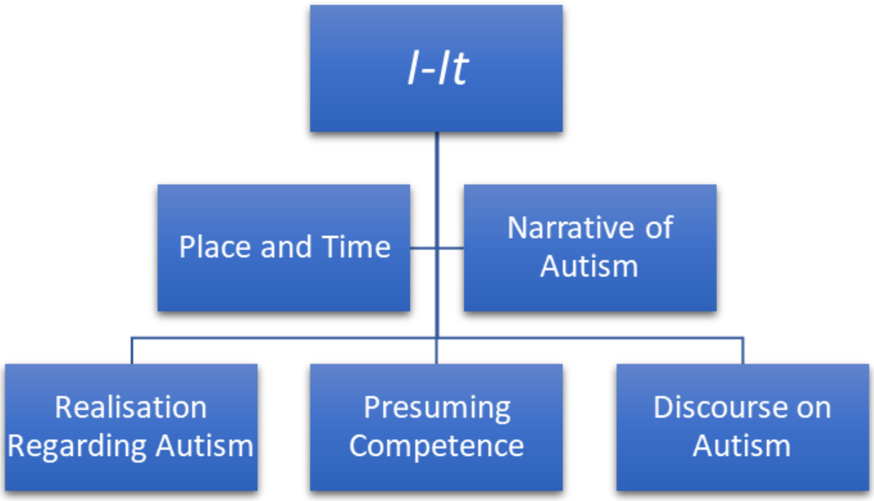


Figure 15: I-It Analysis: Autism and Inclusion as an Experiential and Relational Phenomenon

It is important to note that for this purpose, autism, and indeed inclusion, are not viewed as phenomena in themselves, but are interpreted as an entirely experiential and relational. Thus, the perspectives and narratives of the significant others within the child's microsystem and, beyond become crucial. These experiential phenomena are most clearly understood in the family's realisation regarding autism within the microsystem, the presumption of the child's competence or incompetence within their mesosystem and, the impact of the discourse or grand narrative of autism present within the child and family's macrosystem.

As previously stated, the *I-Thou* analysis emphasises the roles and actions of the child's significant others in the construction of their voice. Central to this analytic framework are the relationships that exist between the child and others across social settings, and the understanding and appreciation of child identity and voice within these relationships. As Figure 16 outlines, the three areas explored in terms of these relational roles and actions are the gaining and sharing of knowledge within the child's microsystem during diagnosis and beyond, the value placed on all types of communication within the child's mesosystem and, the acceptance of these children's 'different way of being' as wider socio-cultural action .

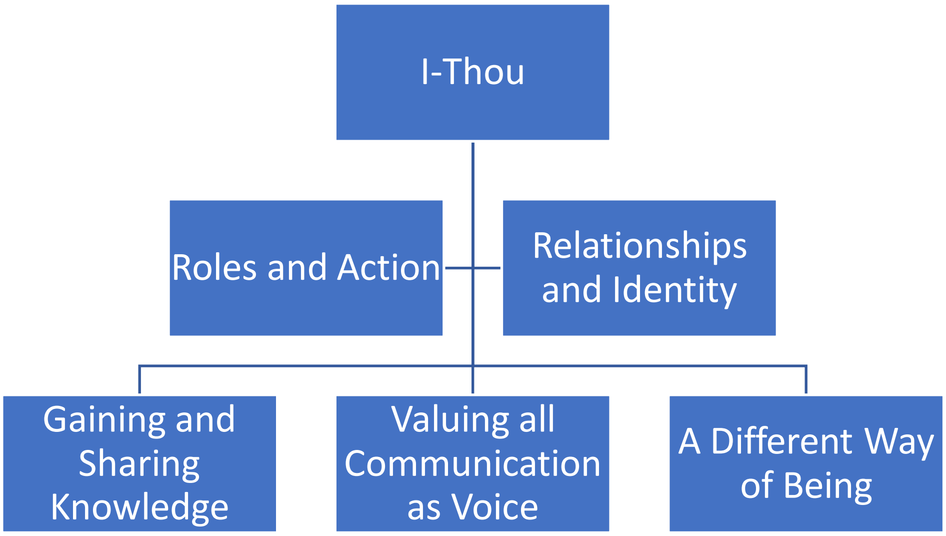


Figure 16: I-Thou Analysis: Relationships, Identity and Voice

This child-centred *I-It* and *I-Thou* analysis revealed certain commonalities across the narratives of the nine children represented. Reflection upon these similarities in the construction of voice enabled an ecological reconstruction of the children's experiences. Therefore, the stories of Beth, Harry, Eoin and Sam are presented collectively, to portray the recognition of their voices within their microsystem. The roles and actions of others in understanding and valuing the voices of James, Noah and Max within their mesosystem have been jointly reconstructed. Finally, merging the narratives of Brian and Ruth, demonstrates the potential impact of wider macro forces on the development of the voices of children on the autism spectrum.

6.4: Beth, Harry, Eoin and Sam: Realisation Regarding Autism. Child Voice in Gaining and Sharing Knowledge

While the parents reported moments of epiphany regarding the realisation that their child may be on the autism spectrum, the child-centred narrative analysis of Beth, Harry, Eoin and Sam's stories revealed a common and significant thread [see Figure 17]. All four were the second child in the family to receive a diagnosis of autism. All four children also communicated verbally. Their narratives suggest that the prior lived experiences of these families and, the depth of understanding they had developed in relation to their older child on the autism spectrum, led to the construction of wholly positive narratives of autism surrounding their second child's diagnosis. As with the diagnosis of their first child, the knowledge constructed by parents during the recognition that their second child was on the autism spectrum had the potential to lead to their and their families' consequent empowerment or disempowerment.

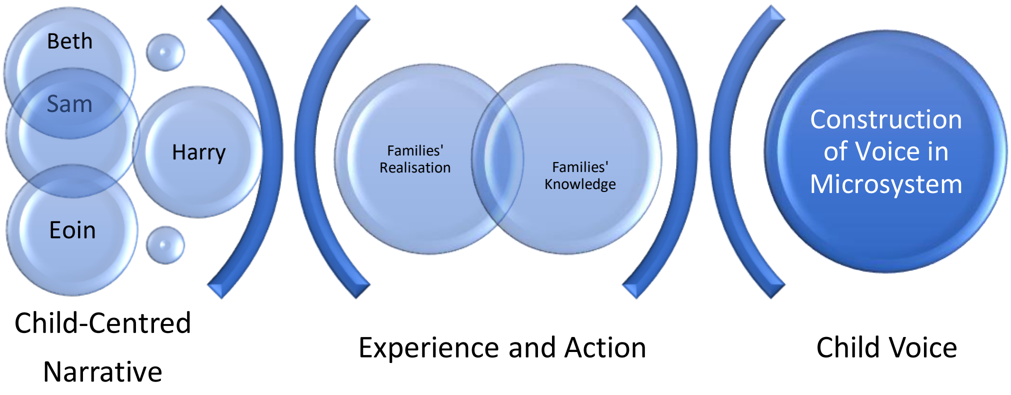


Figure 17: Construction of Child Voice in the Microsystem: Beth, Harry, Eoin and Sam

While Ellen and Sandra mentioned an initial struggle to cope with this development within their family, they also spoke about how they were better equipped to understand and appreciate this reality for Harry and Beth, due to their lived experience with Ruth and Brian and their maternal pride in '*how well they had turned out*' (Ellen). However, while Beth, Harry, Sam and Eoin each had older siblings on the autism spectrum, there was an inextricable link between parents' realisation that their younger child was on the autism spectrum and, the recognition of this child's unique, individual voice.

6.4.1: A Second Epiphany of Difference

Alice reminisced about Eoin as a new-born baby and, how she interpreted some of the difficulties he was experiencing as the early presentation of his voice. She spoke about giving him his bottle in the neo-natal ward, nodding knowingly as she recollected:

> *That was when Eoin needed me, even though anyone could have fed him. The nurses couldn't believe it, they said he was being tube fed when I wasn't doing it. At that age like, if that wasn't a sign.*

For Harry, the change he experienced at eighteen months, from a typically inter-dependent, social toddler to a more introverted infant, led Ellen to worry that '*he was slipping away from [her] a little bit*'. However, while commending the way that this difference had been fostered as individuality within her older daughter, Ellen recounted her and her husband's pledge:

> *To get everything she possible could for Harry… not to change him' but to help him develop and express his voice, just as his sister does.*

Certainly, having older children on the autism spectrum made the process of realisation in the stories of Beth, Harry, Eoin and Sam more straightforward. However, it also emphasised how, within the realm of autistic experience, action and identity, there can be such a spectrum of difference. When professionals were telling Sandra that Beth was just '*copying her older brother*', Sandra reiterated the importance of recognising Beth's individual voice as part of her diagnostic process, saying: *But she's nothing like her brother, she's completely the opposite. She is herself…*

This diversity within difference was also central to Brenda's epiphany moment with Sam, whom she accepted '*was very different to Billy in so many ways*' while also realising that '*he was very like him in many ways too*'. This acceptance of difference, during the parents' moments of realisation, was critical to the construction of their children's voices as they grew socially, emotionally and cognitively and their different way of learning came to be recognised.

6.4.2: Accepting and Appreciating A Different Way of Learning

In each of the four children's narratives, their particular special interest acted as a gateway into their unique learning style. The parents often began by talking about what their children were '*in to*', usually described as what they were '*obsessed with*'. Whether it was Beth's princesses, Sam's letters and nursery rhymes or Harry and Eoin's numbers, the children's connection with their chosen interest was undeniable. As the parents spoke, they referred proudly to the strengths and ability of their children that was most evident when they were engaging with or discussing their special interest, explaining that their children could '*see things that we don't see*' [Eoin]. The fact that during the diagnostic process and beyond, their children's special interests were often dismissed, as fixations, rather than passions, frustrated the parents, who felt these were inherent aspects of their children's identity. Brenda discussed how uplifting it was when the staff at Sam's preschool also looked at his special interest (Nursery Rhymes) as a strength:

> *You see Sam was always into nursery rhymes, he learned to talk that way. It was just repetition of rhymes all day. I now know that that is called echolalia and is seen as a major red flag. So, you can see why it was so lovely to have this habit of his interpreted as a skill rather than a flaw or whatever….*

By contrast, Brenda found the professionals involved in diagnosing Sam to be dismissive of his abilities, claiming they were '*irrelevant to them*'. She felt that the professionals were '*kind of saying: oh don't be fooled because Sam has words, he doesn't have the right words*'. Harry's language development had also been the main concern for the professionals that worked with him and, while he had made clear progress in speech therapy, '*issues*' remained regarding his speech. Ellen explained that a person would '*know straight away that there's something when Harry starts speaking because he has a very formal way of speech*'. After conceding that Harry was '*not where he should be*', Ellen leaned a little closer and said softly that '*his language is something that [she] absolutely love[s] about Harry… it's really endearing*'. For her, it was about his individuality. However, as the narrative unfolded, she grew somewhat concerned, asserting that '*he knows how to talk, kind of, and if people are going to be nice to him, then I wouldn't care if he speaks a little differently*'. For Ellen, it was '*the worry of others*' and how they would treat Harry, that was '*the hard part*'. It seems that while Ellen accepted Harry's unique way of interacting with others and the world, she feared that others would not.

Yet it was Beth's passion for Disney princesses that earned her numerous invites on play dates with her peers:

> *They* [children from mainstream junior infant class] *see her as a friend so… she got invited to the cinema, ten of us altogether; five mothers and five girls. Beth was the only one from the unit.*

However, Beth had developed a way of dealing with the issue of others' expectations regarding communication in a way that made her mother, Sandra, '*a little uneasy*': She described Beth's actions in terms of a performance to mask her autism.

> *But if you see her, it is like watching someone with Schizophrenia the poor little pet…, it's actually, I don't know how she keeps it up. She literally will talk to one of them in a certain way, she'll put on a different voice and all like and then she'll turn over and she'll change her voice for you like and then change. And I'm like it must be exhausting. The masking that autistic girls do… I suppose it takes a long time to realise who you are yourself.*

Sandra's deduction that '*it takes a long time to realise who you are yourself*' is not just relevant to Beth's experience. Indeed, the importance of nurturing, rather than impeding, the process of realising oneself was central to all the children's narratives. For Beth, Harry, Eoin and Sam however, the significance of play and, their particular way of playing, emerged as integral to the positive development of one's voice and identity.

6.4.3: A Right to Play or A Right Way to Play?

As their parents discussed their approach to play, a clearer picture of Beth, Harry, Eoin and Sam's individual voices and, how they were either fostered or impeded, emerged. Over the course of the research, Brenda referred to the development of Sam's individual identity, placing particular emphasis on play as an integral aspect of this process. She explained that '*Sam has his own little ways*', but as he gets older, '*you can actually see that personality shining through*'. Sandra noticed his '*little personality the most when he's playing*'. Even when he is on his own therefore, Sam '*talks away to himself and he really come through in the little running commentary he does during play*'

Alice often discussed Eoin's desire and ability to play. She described with pride, how he '*plays in his own way*'. However, the role of play in the diagnostic assessment of professionals drew criticism. As mentioned in Chapter Five, the expectations that psychologists held in relation to play and, their interpretation of it as a compartmentalised activity that a child should complete, was particularly upsetting for parents. Alice asked how a professional carrying out an assessment:

> *Could expect Eoin, a three-year-old child supposedly on the spectrum, to go into a room and play and have great fun… and then the very next day to go in to the same room and not be allowed play.*

Alice went on to explain that the '*way that Eoin played*' on the first day was seen as problematic and that by the end of the two-day assessment Eoin was reported as '*doing no imaginative play in the play session and in the cognitive session… just ignoring her*'. She concluded however, that she 'saw it differently' describing how Eoin had '*taken the psychologist's folder and was driving the car through it… like it was the tunnel*'. She frustratingly conceded '*but that wasn't part of the test*'. The importance of recognising the play of young children on the autism spectrum as part of their identity, rather than symptomatic of a particular condition, was a common narrative thread across Beth, Harry, Eoin and Sam's experiences. Ellen's role as a pre-school manager meant that she could offer an account of how an increased appreciation of the value of free play in '*quality early years education*' could benefit all children, including her son Harry:

> *Harry, like all children, will benefit from quality early years education. Like at the moment the big emphasis is on free play and choice. Giving children choice within limits. I think because it's become so much more play based and you are taking away that whole "school readiness" side to it, it automatically becomes more naturally inclusive for kids like Harry or any kid with special needs. They have more freedom to roam around and do what they want.*

Nevertheless, within this portrayal of quality early years education, Ellen also emphasised the importance of the knowledge and understanding of staff, without which, for Harry:

> *Free play becomes, I suppose "I'll just kind of wander around". He might be like "oh God, what am I going to do here now" you know. It can be hard for him…*

The importance of educators understanding and appreciating, not only the perceived struggles that young children on the autism spectrum may display in play environments, but also their unique play experience, came to the fore in Beth's experience also. Sandra frequently mentioned the value of exploratory play in helping Beth regulate during or following an instance of sensory overload. She explained how '*Beth loves sand, she's really sensory and it really calms her, she loves colouring too*'. However, Sandra also highlighted how children's voices and needs can be ignored by staff who opt for passive activities that are of '*no benefit to the children*'. To illustrate this point, she articulated her experience of telling the staff in Beth's crèche about the benefits of '*using the AIM resources*' to help her regulate. Rather than using the AIM resources however, Sandra found that all the staff would do when Beth found it difficult to regulate was to '*put her watching DVD's till she'd zone out. It's heart-breaking*'. The heartbreak experienced by families when their children's voices were not acknowledged or understood was also very evident in the stories of Noah, James and Max, who all communicated non-verbally. These young boys' experiences illustrate how child voice can effectively, or ineffectively, be constructed and included in the mesosystem.

6.5: Noah, James and Max: Experience and Action in the Mesosystem: Presumptions, Assumptions and The Value of the Lived Experience of Autism

The experiences of James, Noah and Max emphasise that if the significant others within the child's mesosystem presume competence (or incompetence) on the part of individuals on the autism spectrum, then that particular child's voice will be positively (or negatively) impacted [see Figure 18]. It follows, therefore, that accepting or refuting competence can have either a positive or negative impact on inclusive practice. The stories of these three young boys reiterate a point highlighted in earlier chapters: that the level of understanding and lived experience of professionals, leaders of educational settings and educators, dictate whether young children on the autism spectrum, especially those who communicate non-verbally, experience positive outcomes. The foremost of which, as noted by their parents, is happiness.

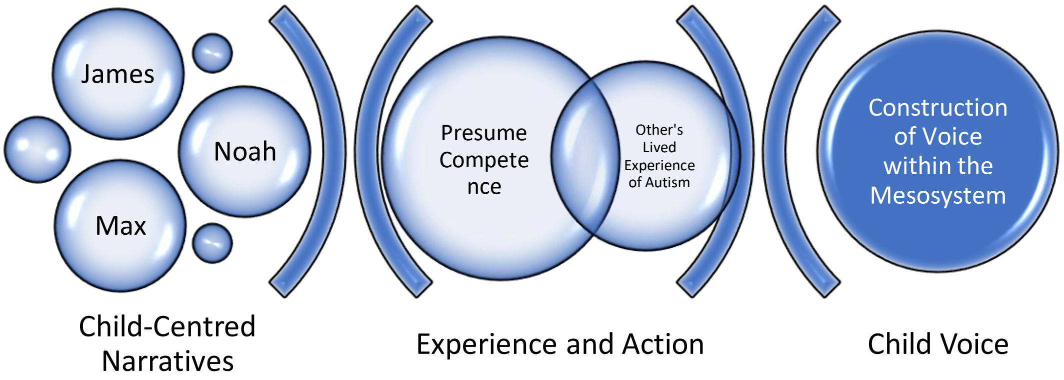


Figure 18: Construction of Child Voice within The Mesosystem: James, Noah and Max

6.5.1: Presuming Competence/Incompetence and Including the Silenced Voice

The importance of presuming competence emerged a dominant narrative thread across James, Noah and Max's stories. The fact that all three children communicated non-verbally was central to their parents' emphasis on others' presumption of their competence, or more often, incompetence. One of the keystones of the parent dialogue was the relationship between their sons' absence of verbal communication and their perceived position as either '*severe*' or '*profound*' along the autism spectrum. Alice questioned the application of '*severe*' as a classification for James:

> *Ok fine language-wise James is severe, but I am telling you in other ways he's totally not… James can be so easy… He's a great boy.*

This echoed Hannah's earlier point in Chapter Five when she discussed the *'life changing*' impact of Noah and Max's positioning within the '*profound*' category of disability and how it almost led her to question her own view of her sons, until, through a deconstruction of the assessment process she accepted this was '*just the conclusion she [psychologist] drew… based on her knowledge and expectations*'. The knowledge used by professionals when drawing '*conclusions*' was also a cause for concern for Alice who felt that infrequent access to services and, a lack of continuity in therapists led to circumstances that were '*so upsetting for James*'. In her opinion, this type of assessment was inappropriate as:

> *Nothing is play-based just all tasks and it's just new face after new face not even knowing who your child is or what help they need… and then they're drawing conclusions, based on what*?'.

Across all our interviews, Alice spoke about the hurt she felt when professionals working with James '*had no faith in him*' or '*discredited*' the strengths she would highlight to them. Michael also expressed his frustration at how the professionals that worked with James would '*talk about him as if he wasn't there*'. In an attempt to include James' voice in his interactions with those outside of his family his parents invested in assistive technology for him. Although they were '*excited*' to show his progress to the therapists working with him, that too led to further frustration for both them and James. Michael described how they had set up the device:

> *… to show them, with his favourite things because James will only look for something that he likes. That's beneficial to him. He's not going to do something that's completely pointless to him…*

However, Michael felt that the therapists '*only wanted James to say his name using it. So, he had to press 'name' and then find James. He couldn't do it'*. Expressing his frustration, James '*ended up hitting himself in the face*'. Michael concluded his account by asking '*are they trying to irritate a child*?'

In the case of Noah and Max, however, the risks that professionals may associate with a presumption of competence came to the fore. Both boys had been placed on a reduced day in their ASD early intervention unit because Noah had been showing signs of struggling. The fact that Max '*would have been able for it*' did not affect the school board's decision to '*send them both home after an hour and a half every day*'. Hannah described this as '*a terrible time*' for her family and, offered an abundance of praise to the crèche that accepted the boys for the remainder of the day, every Monday to Friday. During this time, a professional who visited the early years setting raised concerns that '*they weren't learning a lot*' and that the staff '*presumed*' they were '*taking it all in*'. Hannah responded with a statement that showed the trust she placed in the voices of her non-verbal sons:

> *You should see them in the car when they're going to the creche and they see where they're going. They're jumping out of it. They're gone. Crying because I'm bringing them home. I said, 'That's all I want. I just want them happy'.*

James, Noah and Max's parents all mentioned the importance of their sons' relationships within their early years setting and how, the actions of their children and the other children in the setting, highlighted the connection between acceptance and the presumption of competence. Alice explained that the other children in James' preschool understood that James did not communicate verbally but that '*they are fine with that. They accept James for who he is*':

> *They're like oh, there's James, he doesn't talk. That's it. There's no more to it. I often see them, all the kids would come in and they'd be like, 'Hi James'. James is not going to say hi back like but they are fine with that*

Hannah reiterated this point when she stated that the thing she '*loves about mainstream creche*' is the other children's interactions with her twin sons, who they refer to as '*The Maxs*'. Again, she focussed on the children's acceptance of difference. Accordingly, '*they take no notice because they know that's just The Maxs' way*'. Michael offered further insight into the differences they observe in James across settings. This provided a direct contrast between clinical settings and James' preschool, when he suggested that '*James seems to be an excellent judge of character… [who] can read people so well*'. He concluded that the reason James is so happy in his preschool is because '*he just feels safe*'. It appears that for James, Noah and Max, being with people who understand them, value their communication and contribution, and accept them as they are, is integral to their happiness.

6.5.2: Valuing All Communication as Voice

Because James, Noah and Max did not physically use their voice to speak, their parents, instead recognised the value of the other modes of communication they utilised. Their first goal was to ensure that everyone within their home accepted and valued their children's various forms of communication. Alice explained that this is '*what I'm teaching my children because I can't have James being different in his own home, these are his own siblings*'. She demonstrated this to her youngest child as she left James '*throw a blanket over [her] head because that's how James interacts*'. She turned this act of communication into a family game for everyone to ensure that no one was interpreting it as: '*God James is a bit strange*'. Hannah also emphasised the importance of family members accepting her sons' actions as communication, recollecting her daughter looking at Max moving his hands and then '*saying "look he's doing his little bird dance" and getting us all to row in with him*'. This led Hannah to remember another similar occasion where the acceptance of her sons' actions was prioritised:

> *You know when they might stare into their hands or look at their fingers at different angles. I was here one day and a relation of mine who works with children was like "put down your hands now Noah, put down your hands Max" and she kept putting things into their hands to distract them and I was here going "that's fine". That's telling me that they need to do that. I don't mind.*

Within their homes, the three boys were described as being able to '*communicate very well'* [James] *and as 'great communicators really*' [Noah and Max]. In fact, Hannah highlighted the importance of recognising all of her sons' actions, whether positive or negative, as communication in an effort to '*build up the trust*'. Across the children's mesosystem, as they had interactions with a variety of professionals, the significance of recognising and valuing all forms of communication as voice became apparent. After having a negative experience at an occupational therapy (OT) session where Alice felt James '*was judged*' rather than helped, she attended an OT who specialised in autism, privately. She described how the OT '*listened to*' James' voice:

> *So, if James is thrown there and doesn't want to do anything almost like 'go away from me'. She just closes the blind and turns on the flashing lights. And suddenly he is loving it. He's like laughing and running up and down and he'll go on then to do whatever with her.*

Hannah also stressed the importance of her sons being '*listened to*' as she gave an account of a particular difficult time in her family's life. The role that one professional played in alleviating her situation by interpreting Noah's actions as his voice, rather than a consequence of autism, emerged significant. She spoke about being '*reduced to tears about autism*' and being unable to '*deal with it*' on one occasion '*when the head banging started*'. She graphically described how:

> *Out of nowhere, Noah just started doing it, he would be kneeling and with full force whacking his forehead or the back of his head off the walls or the cot and screaming and this placid, gentle little boy changed.*

Although '*all the specialists said it was autism*' Hannah listened to his voice and her own instincts, bringing Noah to a doctor who took a different approach, telling her '*this boy is in pain and he gave me this anti-biotic. And whether it was coincidence or not I'd a new boy*'.

Hannah concluded by stressing the importance of understanding and listening to children on the autism spectrum, explaining: '*you see they are great boys when they are understood, when they are listened to*'.

As outlined, James, Noah and Max's parents oftentimes expressed their frustration and regret at the way their children's strengths were sometimes overlooked. Their differences or challenges were sometimes defined as symptoms of autism, rather than their expression of voice. Having their children's unique voice recognised and understood was of central importance to their children's and their own lives, especially within their microsystem. James, Noah and Max's parents committed themselves to accepting and valuing their voices within their homes. However, as they interacted in other contexts as a family, ensuring this inclusive practice occurred in their son's educational setting emerged somewhat outside of their remit. Rather, it relied on the understanding and actions of individual leaders and educators.

6.5.3: Understanding All Children's Voices in Education

The significance of James, Noah and Max having their voices recognised and listened to within their educational settings proved integral to, not just their learning experience, but their experience of happiness across settings. Michael credited '*how happy James is*' at his pre-school to the ability of Anna and her staff to interpret and value his actions as the expression of his individual voice. He reflected on a time when a staff member working with James declared that '*being non-verbal doesn't mean they can't communicate or have nothing to say*' before asserting that '*James is actually a good communicator*'. However, the interpretation of negative actions within educational settings as voice was particularly relevant to Noah's, and consequently Max's, story. In Chapter Five, Hannah recalled how little support she received from her son's early intervention unit and how, she was essentially, left to deal with his behaviour herself. She describes how the '*only strategy*' the staff of the ASD early intervention unit had '*was the note home and then deal with it yourself. There was nothing else'*.

The next time we met, Hannah had been asked to meet the principal to discuss the '*reality*' of Noah and Max continuing to attend the unit. Following that meeting, Hannah began to explore special education as a placement for her sons, suggesting that it represented a place where their voice would be recognised and developed. She declared that '*Noah and Max are just fabulous little guys with a great temperament who laugh and smile and are very happy'*, expressing her belief, that the boys had the right to '*go to a school where they would be understood*'.

The central role that leadership and the development of an inclusive school culture had in the nurturing of child voice was evident across James', Noah's and Max's stories. The responsibility of the leader to ensure that the educators working with children on the autism spectrum, especially those who communicated non-verbally, yet again, emerged as fundamental. Hannah was not the only parent within this study who described the teacher appointed to the school's ASD class as '*terrified*' or '*frightened*'. Neither was she alone in recognising that, with increased knowledge and experience, an educator could '*grow into the role*' anticipating that while the ASD class might become '*a better place for children… though at the moment that teacher is very much in a learning role to do with Autism.*':

Michael and Alice's portrayal of Anna's role in the construction of James' voice represents the opposite scenario, where lived experience has positioned this educational leader in the optimal role to include young children on the autism spectrum, to provide the '*best place for James*':

> *We knew it would be the best place for James. We knew that if this lady has a daughter with autism then she has knowledge in it and she would get it.*

And it would seem that their inclination was correct, as they proudly referred '*James' love for Anna's'.* Certainly, Anna's role in James' inclusive education, was obvious but so too was her role in including James and his family in the local community, and in particular the wider autism community. A family evening held at Anna's became a hub for sharing knowledge and experiences, subsequently, the particular and unique construction of the voices of children on the autism spectrum. Alice stated that, prior to this occasion:

> *They [the parents] had never crossed paths it was just fantastic… I was like 'oh he's having a little trouble with whatever' and they'd be like 'oh my little fella was the same don't worry. That's their way like.*

To have the '*way*' of their children recognised and, accepted in education led to positive outcomes, not just for the children involved, but for their significant others also. While Noah and Max had to be officially positioned within the severe to profound category of disability in order to gain entry into a special setting, their happiness in response to their placement eclipsed all the '*worry and fear*' that Hannah had felt in relation to this classification. A visit to their new educational setting verified this for her:

> *Noah came over to the glass, gave me a smile and turned and walked away, they were so happy. They didn't care and I was there going "oh my God". And every day they came home they were dead happy and they're as happy going off... It was everything to me.*

Certainly, the understanding and acceptance of James, Noah and Max's differences was pivotal to their experiences across settings, and to the construction and development of their voices. While the issue of difference, and its acceptance or rejection, was a common thread across all of the children's and parent narratives, it emerged particularly dominant in Brian and Ruth's stories.

6.6: Brian and Ruth: Narratives, Experience and Action of the Macrosystem: Let's Talk About A Different Way of Being

For Brian and Ruth, the impact of macro influences on the construction and development of their voice was more evident. There were similarities across Brian and Ruth's experiences [see Figure 19]. Brian and Ruth were the oldest children represented in the narratives. They were also the first of two or more siblings in their families to receive an autism diagnosis. Both Brian and Ruth communicated verbally. However, there were also some differences in how each child had been impacted by, for example, the wider discourse that exists in relation to autism.

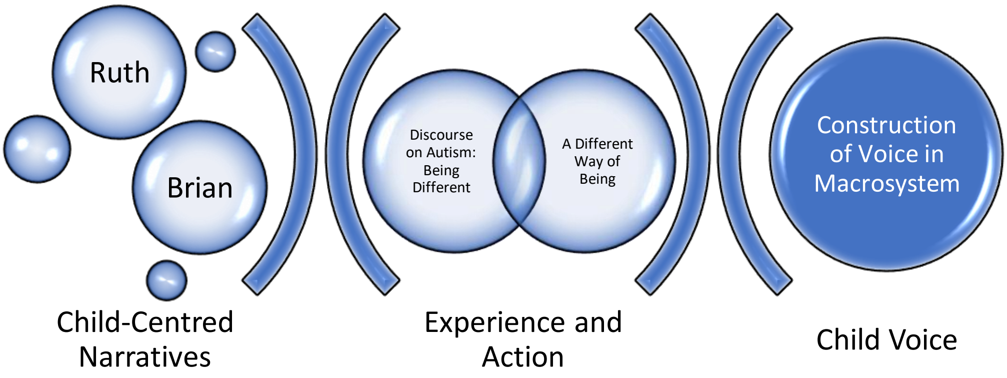


Figure 19: Construction of Child Voice and the Macrosystem: Brian and Ruth

As mentioned in Chapter Five, all six parents revealed how their narrative of autism had changed over the course of their lives. However, a deeper understanding of the relationship between narratives of autism and child voice was necessary, to effectively interpret how the children's own perspectives on autism were constructed. This in-depth relational analysis revealed that the concept of difference manifested in two ways for Brian and Ruth: *being different* and a *different way of being.*

6.6.1: Early Childhood and Access to Education

Both Brian and Ruth's stories were saturated with examples of the impact that macro narratives of autism had on their educational and wider lived experiences. While their mothers, Sandra and Ellen, both acknowledged that their own view of autism had changed following their lived experience with their children, they expressed their upset at the fact that some leaders of educational settings, in a time when inclusive practice is universally advocated, still displayed wholly negative perspectives on autism and inclusion. In Brian's case, the vast majority of principals that Sandra approached demonstrated this negative perspective. Of the seven schools she approached, Sandra felt that '*six of them had that "he won't be coming here anyway" attitude*'. Furthermore, while the remaining school said: '*Brian would be very welcome*', they also stressed that '*he would have no supports because of not having care needs*'. Although Sandra had '*stopped trying to figure out why*' people in this position would refuse access to Brian, she suggested that his prior enrolment in a specialised pre-school setting led to him being judged as '*unsuitable*' for mainstream primary education. Such negative assumptions surrounding the enrolment of a child on the autism spectrum was not limited to Brian's narrative or indeed to primary education. Ellen also revealed her surprise that an educational leader '*in this day and age*' would portray an adverse attitude towards the inclusion of a child on the autism spectrum in mainstream preschool:

> *When I went to the local pre-school when Ruth was small, just asking about enrolling her, everything was fine at first but the minute I mentioned she was diagnosed with autism she was like "oh…oh…well I don't know if we can facilitate that"… that's actually the way she phrased it.*

Fortunately for both Brian and Ruth, their mothers responded to these poor views of their children's ability with an increased fervour to find an educational setting where their children's strengths and individuality would be recognised, where the leaders would take the time to '*get to know*' their children. Sandra described refusing access to education on the basis that a child has autism, not just as '*unjust*', but also as '*so blatantly incorrect*'. To make such an immediate judgement when '*they didn't even know Brian, didn't even know my son*' led Sandra to pledge that he would go '*where he was wanted*' where his voice would be recognised. Ellen gave a similar account of her reaction to Ruth's denial of access to education, concluding again, that she '*would never send her somewhere where she wasn't wanted*':

> *I was like "you haven't even met Ruth". I mean you [to me] can see how good Ruth is. Like to not have even met her and then to…I was just like "screw you, you haven't even met my child and you're judging her already". I decided that even if she came back to me and said she could take Ruth that I would never send her somewhere where she wasn't wanted.*

6.6.2: Experiences within Inclusive Education: Construction or Destruction of Child Voice

By our second interview, both Brian and Ruth had been, accepted into educational settings. Ruth was attending a mainstream preschool and, Brian was enrolled, in an ASD class within a mainstream primary school. Neither of these educational settings were the families' local preschool or school. It became clear that after Brian and Ruth's initial placement in these settings, their paths began to diverge somewhat. Ellen's account of Ruth's new preschool was praiseworthy and, clearly depicts an authentic culture of inclusion:

> *Where Ruth ended up going, they are just the opposite. They welcomed her with open arms. They are like that with everyone, there were children with a whole variety of special needs and they were all welcomed, every one of them; lots of children with autism as well… there's just no treating any different.*

Unfortunately, Brian's experience of inclusive education was very different and, while Sandra had some initial concerns herself, it was not until Brian voiced his experience that she realised how inclusive practice was manifesting or not, within the setting:

> *Brian used to come home kind of sad and say I 'm always looking out at the other children in the school. He'd be like "why am I out here and not in there". You see they were completely separate. The four of them were treated differently to the rest of the school. They were just left in there*

These contrasting school cultures bore significant impact on the construction of Brian and Ruth's voices within their mesosystem. For Ruth, her inclusive pre-school environment was credited for the clear progress she was making, especially in terms of having the confidence to use her voice. Ellen reported that '*Ruth was doing great, chatting, talking, socialising, people were saying when I'd tell them she had autism…that they didn't believe it*', Ellen went on to suggest, that Ruth had become '*the model child*'. Brian, however, was struggling with school and his separation within the unit. He had started to refuse to attend. Sandra observed a '*huge change in him*', compared to his experience of preschool. She described how '*for the first time, Brian started saying he didn't want to go to school anymore*'. She felt this was because '*he was totally separate in the unit'*. She found this situation frustrating, as '*for the whole two years of preschool he literally ran out to the bus every morning*'. Now, however:

> *Brian was crying from the minute he got up in the morning, shouting "no school, no school, no school, I don't like school anymore" over and over… I could not get over the change in him…*

In a bid to encourage Brian to return to school, a process of integration into his corresponding mainstream junior infant class, was initiated. Brian was perceived to integrate so well that within a few weeks, he was spending more time in the mainstream classroom than in the ASD class. However, Sandra grew concerned when Brian began to '*refuse support so he would be treated exactly like everyone else*'. She became especially concerned when his teacher said he was '*disengaging and looking away*'. Sandra described Brian's disengagement as a means of coping that she had not seen before. She asked if Brian would '*ever say no for anything*?' the teacher and special needs assistant responded '*never, not once*'. They viewed this as a sign that Brian was making '*excellent progress*'.

Ruth's teacher offered a similar description of '*a super quiet child*', also interpreting this behaviour as '*excellent*'. Ellen, however, worried when she heard that Ruth '*covers her mouth when she's talking... that she doesn't want to talk*', concluding that she had not seen this '*change in her at home*'. Sandra presented her argument against equating silence with attainment, highlighting the relationship between child voice and agency. In her opinion:

> *saying nothing doesn't mean he's good, that means he's just compliant to everything they say... of course you have to say no for something, do you want this or that? He's not making any decisions. That's not progress.*

6.6.3: Narratives of Autism and Child Identity: Being Different or a Different Way of Being?

As Brian and Ruth were the oldest children represented in the study, their stories were more reflective of the influence of macro-forces. The concept of difference emerged as central to their narrative and, was evidently a dualistic term encompassing both the experience of *being different* and, the perspective of autism as *a different way of being.* In Ruth's case, her progress was typically demonstrated in how people no longer recognised her as different. Her mother Ellen explained how '*now she's fully verbal and she's so sociable*', she did not feel it was necessary to '*even tell people anymore that Ruth's diagnosed with autism anymore*', emphasising that she '*wouldn't be volunteering that information to anyone*'. When asked why, she explained that she was '*not sure of how others would react*'. Certainly, the reactions of others had a significant impact on Brian, who, as our research drew near its end, had been referred to CAMHS (Child and Adolescent Mental Health Services) for what his mother Sandra, described as '*crippling anxiety*'. Sandra elaborated further on how Brian presented with, what she considered to be, '*symptoms of depression*' and how CAMHS responded:

> *When I think of CAMHS like and they dismissing it. I said, he won't even bath or shower anymore, doesn't want to do anything. If he was an adult and you put all the symptoms in and it would be like chronic depression that's what his symptoms would be… a loss of interest in everything… not playing with anyone… not talking… withdrawn, not sleeping, sometimes not eating, sometimes overeating. Everything he loved he regressed. It was so obvious that he had changed. And CAMHS are just not taking it seriously, they keep saying that that is autism.*

Sandra suggested that the suppression of Brian's individual voice, in an attempt to be the same as everyone else, had caused him to start focussing more and more on the ways that he was different. Just like Beth, in her attempts to mask her autism, in relation to Brian, Sandra again asserted that '*it must be so hard to keep that up*'. While Ruth was doing very well in primary school and was perceived as '*not standing out*', Ellen explained that now, when Ruth came home from school, she was '*acting different*' to how she was before:

> *I mean, not in a very bad way really but like hyper and acting different… real silly you know so maybe it's because she isn't getting any of the supports, that on paper she was supposed to be getting. It's a really hard one to call I think because she doesn't really want to be singled out, but she probably does need a little bit of something.*

Because of the changes in Ruth's behaviour, Ellen and her husband Liam had discussed if they '*should tell her*' she was on the autism spectrum. Ellen further explained that this was something that they were unsure about but admitted that they had always resigned themselves to the fact that '*if the time was right*' they would. The importance of Ruth's voice in discerning when the right time arose was clear:

> *I don't actually tell Ruth she is diagnosed. That's another thing me and Liam have discussed, are we right or wrong or what. It's a hard one isn't it. I'm kind of thinking if Ruth's like "why is this like this?" or "why am I feeling this?" or whatever, then we will talk to her about it. If we ever get to that point where she has aroused an interest in it. Then we will. We'll talk it out with her.*

The importance of talking about difference with Brian also became clear to Sandra who, even though she knew it was necessary, worried that she would '*say something wrong and make him worse*'. She described how difficult discussing an emotive and abstract concept such as difference was for Brian but highlighted that his acute awareness of this difference was tangible:

> *…He doesn't talk about it at all, he freezes up. When he does talk, he says: "it's too hard…the pressure" and he just keeps saying "the pressure of everyone and people looking at me and I don't like it". And I was like, they are not. He just has a dark cloud over him. You see Brian's actually more aware than anybody. And that's what scares me…*

When we met again, it became evident that Sandra had been right to feel scared about how Brian was coping with the experience of being different. She explained that, in the weeks prior to us meeting, '*things were not good*'. She became emotional and, began questioning her ability to '*help Brian*'. She gave the following account, which Brian's voice strongly permeates, to explain how the family's circumstances had worsened

> *A few weeks back we were bathing Brian and he literally* [becoming emotional], *me and my husband, we were bawling crying, not in front of him. But he literally turned around and said, "Mum, ye would be better off if I was dead. It's just too hard. I just can't do it any more mum. I just need to die now. I'm just so tired, I can't do it anymore". To hear your seven year old say that like. And like, I said, 'I need to know what to say to him.*

In this meeting, Sandra again referred to CAMHS and stated that '*there was no help' nothing…telling us to hide the knives and watch him*'. She angrily declared '*Like come on like, I can't live like that. I have to be able to know how to help him*'.

It seems that while CAMHS psychologists dismissed the emotional struggles that Brian was going through as symptomatic of autism, both he and his parents believed that the changes within him could have been in response to his experience of being different. Brian and Ruth's experience of being different, and their views on difference, warranted further exploration. The fact that both children also had younger siblings on the autism spectrum meant that they had the opportunity to voice their perspective on difference within their immediate microsystem. In the first phase of data collection, both Brian and Ruth began to associate the difficulties they observed their siblings having with their diagnosis of autism. Neither Brian nor Ruth knew at this point that they too were on the autism spectrum. When Ruth asked: '*why Harry can't talk and why he can't do what other four-year olds are doing*', she proceeded to answer her own question saying: '*oh it's his autism isn't it*?'. After Sandra had read a story to Brian explaining that some people have different brains, he related the challenges that Rosie, the main character, was having with the lived experience of his younger sister, '*but not himself*':

> *He was like, 'now I know why Beth does it', you see there was a part with Rosie's brain, it was a child that cries constantly and wants to be picked up and he was like, 'So, that's why Beth does that, that's because she has a brain like Rosie's'. And I was like yeah, that's right. He was able to interpret that way. But he was able to see Beth but not himself.*

As the research progressed, it appeared that Brian and Ruth both recognised autism as being different and both made the clear distinction that they were not a part of this diverse group. Neither child identified with what they perceived to be the negative aspects of autism. Ellen described a time that Harry had coped very well during a family excursion to a busy environment. She recollected that '*it was amazing for a kid with Autism, not a peep out of him and it must have been stressful*' and Ruth's memorable response that '*well I was fine so I definitely don't have Autism, thank God*'. Ellen's discomfort at Ruth's deduction was similar to how Sandra was feeling, as she elaborated on why Brian had '*turned against his ASD class*'. She shook her head, while a concerned expression drew across her face, as she recounted Brian's declaration that the other children in the ASD class were '*weirdos*' and that he didn't '*belong there*'. While she took consolation in the point that '*he doesn't see himself as different*' she conceded that '*he is like them, but he doesn't want to be*'. The actions of both Ellen and Sandra in response to the developing perspectives of their children had an entirely positive impact on the construction of their children's voices. Both mothers recognised autism as a part of their child's identity and therefore developed discussions around the concept of autism as difference, rather than deficit, with their children. Ellen recalled Ruth '*looking confused and worried*' when she found out that she was on the autism spectrum and by way of gentle reassurance said:

> *You know what Ruth, so what. It doesn't mean anything. It doesn't make you any different to the person you are today it's just a part of you.*

Sandra also chose a direct and concise way of explaining to Brian that she believed autism was an aspect of human diversity, likening it to the colour of one's hair, eyes or skin. Knowing that Brian was very interested in technology she opened with a metaphor she felt he would appreciate and, explained that autism meant that '*your brain is like an iPad and my brain is like an android tablet*'. Having noticed that their children seemed to be giving this new information much contemplation, both Ellen and Sandra adopted a strengths-based approach to emphasise the fact that being different '*isn't a bad thing*' (Ellen). Sandra chose to make a list of her own strengths and challenges and went through these with Brian, explaining that:

> *Every type of brain has a different power and we're good at certain things. And we are bad at certain things too. You might be good at something and I'm not. And he turned to me and said 'I know what my super power is I'm really good at remembering, I have a really good memory', because he has a photographic memory for detail…and I definitely don't* [Laughing]

Ellen also gave an account of a conversation she and Ruth had about autism that resulted in a transformed perspective within her daughter. This highlighted for Ellen that children '*base their opinions one hundred per cent on what you say or how you react in a given situation*'. She was thankful that she had decided to have this discussion with Ruth:

> *I could have said nothing, but I said "Ruth Autism isn't a bad thing. Look at Harry, isn't he amazing how he's able to read and do his numbers and he's so clever" and then she had a complete turnaround and said: "I love Autism". So, I was like" it just means that he and you learn things in different ways". And I said: "look how amazing and creative you are".*

The appreciation of difference within Brian and Ruth's families was clear and, as a result, both children began to express themselves in their unique voices with confidence within their homes. While navigating other social contexts still posed certain challenges for them, their complete acceptance within their families made them more equipped to cope with these. In fact, on an occasion when Sandra had observed Brian running back and forth across the room in response to his feelings of anxiety, she didn't classify it as symptomatic of autism but, instead, saw it as an opportunity to learn about his different way of being. She watched, and waited and then asked about this self-regulatory action:

> *I asked him one day, 'What does it feel like when you're doing your running?', and he was like, 'Oh Mum, it feels amazing… you know when I go to bed and my head is like, all these things, my pictures keep coming through my head and I'm not able to turn it off', he said, 'When I'm running it helps it, it puts it all into place', and I was like "wow". It was incredible insight.*

This simple action allowed Brian's voice to come to the fore and represented an interpretation of his self-regulation as an essential aspect of his being, rather than an atypical cause for concern. It highlights for us that placing the voices of children on the spectrum at the centre of the roles and actions of their significant others is paramount.

6.7: Conclusion

This chapter clearly emphasised the recognition and appreciation of child voice as being central to the children's and their families' lived experiences of co-navigating the Irish early years education system together. Positioning the child at the centre of both the data collection and analysis prioritised their voice in this navigation. As mentioned at the outset, child voice in this study is understood as encompassing the many ways that a child's experiences, perspectives and ideas can be communicated, through for example, gesture, facial expression, laughter, and bodily movements. It is clear from the findings that using photo elicitation and, child-centred narrative analysis, helped to activate the voices of the nine children on the autism spectrum at the centre of this research. Thus, gathering and embedding their voice in this study. This chapter not only recognised the significant influence of interactions within the child's social context, it also emphasised the role of parents, educators, peers and professionals in the symbiotic shaping of the child's identity and consequently, their voice as they co-navigate other social contexts together. A failure to recognise the inextricable link between the lived experiences of children on the autism spectrum and the co-construction of their voice and identity, increases the risk of imposing an identity on these children based entirely on the narratives and perspectives of others. The next chapter presents the reconstructed narratives as folktales and, embraces the unique lived experiences of these children and parents as they co-navigate the wider world, while recognising the dominant values and perspectives that influence and affect this navigation.

Chapter

Seven

Reconstructed

Narratives

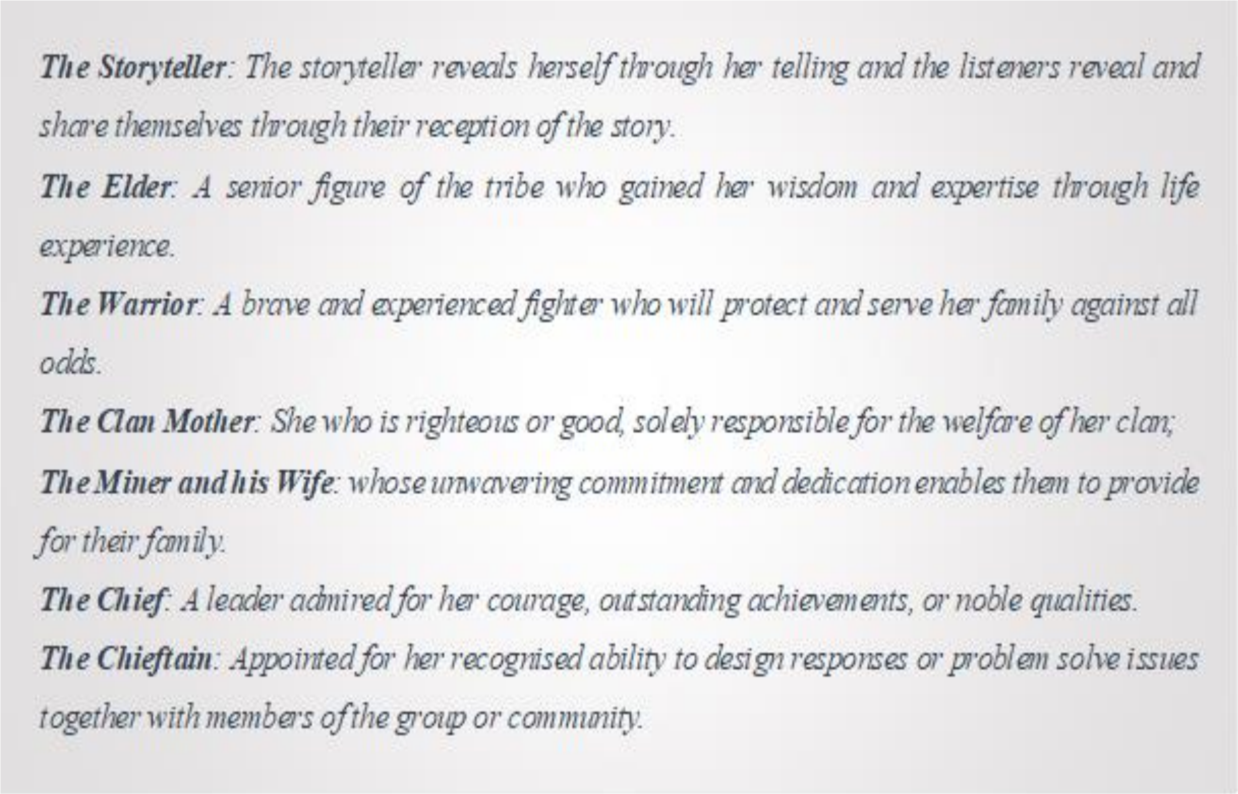
Folktales

7.1 Reconstructing the Narratives

In introducing this reconstruction of the narratives, one returns to Bakhtin’s *Dialogic Imagination* (1981). While the significance of this work has already been emphasised in terms of voice and, the storying of experience, the potential power of our stories to change the sociocultural landscape should not be understated. The transformative aspect of narrative inquiry is evident across the literature but typically refers to changes within the storytellers. The possibility of wider societal change is often deemed outside the scope of a narrative study, or may be, referred to in aspirational terms. However, the relationship between an individual narration of experience and tangible changes in society can become more credible through the adoption of an Ecological Theory of Development that explores the possible influences of the microsystem on the macrosystem, rather than vice versa.

7.2: Character Profiles: The Self Through Story

Enabling the children, parents and researcher to tell their ‘story of self’ in this way can enhance further the construction of their identity. The use of story to portray the lived experiences of people, who may be classified as a minority identity by society can be effective, as it presents the minority experience in an accessible way to the majority, thus shaping their identity within a wider social context. Catherine Walsh’s (2007) work on shifting the geopolitics of knowledge echoes the importance of enabling a shift in identity through empowerment of the minority. She also draws upon the role of the tribe and community in helping us to embrace and, empower difference within our micro contexts. For it is through the creation and development of such tribal communities that our personal identities unfold within the wider story of the community. The following characters are represented in and across the folktales [see Figure 20]: The Storyteller (Sarah), The Elder (Brenda), The Warrior (Sandra), The Clan Mother (Hannah), The Miner and his Wife (Alice and Michael), The Chief (Anna) and The Chieftain (Ellen).



The Storyteller: *The storyteller reveals herself through her telling and the listeners reveal and share themselves through their reception of the story.*

The Elder: *A senior figure of the tribe who gained her wisdom and expertise through life experience.*

The Warrior: *A brave and experienced fighter who will protect and serve her family against all odds.*

The Clan Mother: *She who is righteous or good, solely responsible for the welfare of her clan;*

The Miner and his Wife: *whose unwavering commitment and dedication enables them to provide for their family.*

The Chief: *A leader admired for her courage, outstanding achievements, or noble qualities.*

The Chieftain: *Appointed for her recognised ability to design responses or problem solve issues together with members of the group or community.*

Figure 20: Folktale Character Profiles

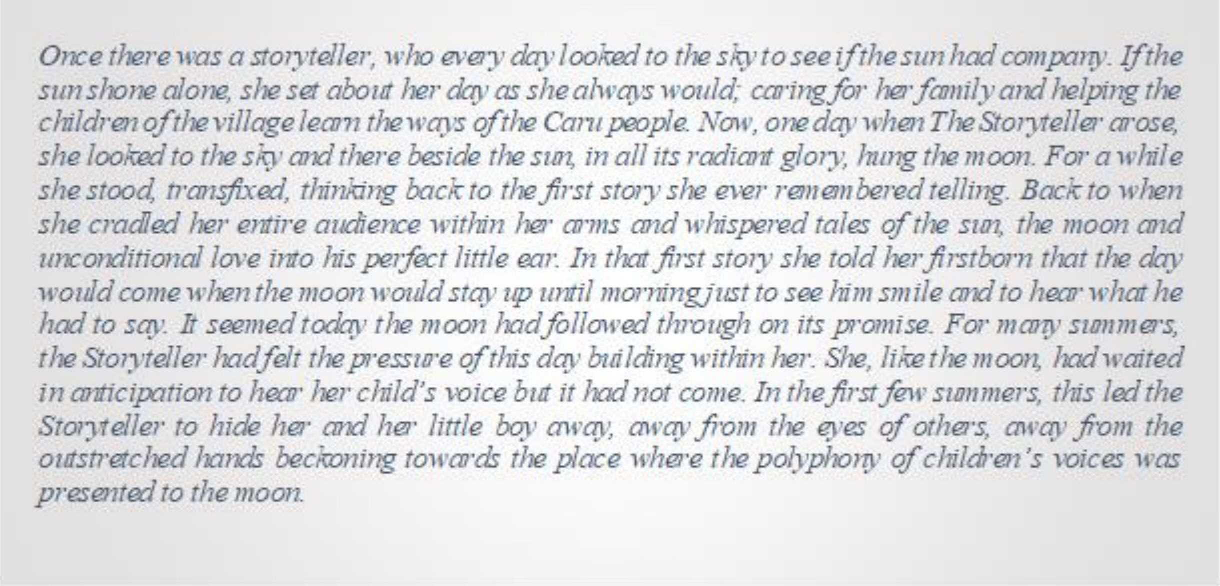
7.3: Metaphors Used Throughout the Folktales

The narratives of autism and inclusion and the issues, divides and controversies that arose as these children and their parents co-navigated the Irish early years education system together are portrayed through the use of metaphor. The social model of autism and disability represents a philosophical stance that accepts *autism as difference*, reflected within the children who *speak and move in Their Own Way*. The contrasting medical/deficit model of autism and disability is represented as *the ways of The Other*. The care/education divide provides a backdrop to all of the folktales and is symbolised by *The Caru* and *Ducera* mountain ranges, the names of which derived from the original terms for care and education. Table 2 further outlines the metaphors evoked throughout the reconstructed narratives.

Table 2: Metaphors Used Throughout the Folktales

Glossary of Terms
Caru Mountain= Care
Ducera Mountains= Education/Formal schooling
Canyon Especialis= Special Education
Giant Dynamikos the Powerful- Guards the gateway to the Caru mountain range. [Representing the relational nature and power of dynamic indicators of quality]
Giant Statikos the Balanced- Guards the gateway to the Ducera mountain range. [Holds *The Universal Child* as a measure of achievement. [Representing the imbalanced power relations implicit within static indicators of quality]
Speaking and moving in the ways of The Other: Medical model of autism and disability [deficit approach]
Speaking and moving in their own way: Social model of autism and disability [strengths-based approach/rights-based approach]
Tree of Knowledge: Dominant narratives
The Morning/Midday Moon: Perceived judgement/Cultural acceptance
Elder's Swirling Track: Infinity symbol of the autistic community
Cabins at the entrance to Ducera= ASD classes/ 'units'
The Lustrous Metal= Money/economy
The Wagon=Public services
The Universal Child= Predicted Development (Childhood as meeting developmental milestones etc.)
The Scrolls of Ducera= Academic/Performance/Assessment data
The Scribes = Government/Government policy
The Trickster and The New Way= Neoliberalism

Researcher Vignette: The Storyteller and The Midday Moon (Part I)



Once there was a storyteller, who every day looked to the sky to see if the sun had company. If the sun shone alone, she set about her day as she always would; caring for her family and helping the children of the village learn the ways of the Caru people. Now, one day when The Storyteller arose, she looked to the sky and there beside the sun, in all its radiant glory, hung the moon. For a while she stood, transfixed, thinking back to the first story she ever remembered telling. Back to when she cradled her entire audience within her arms and whispered tales of the sun, the moon and unconditional love into his perfect little ear. In that first story she told her firstborn that the day would come when the moon would stay up until morning just to see him smile and to hear what he had to say. It seemed today the moon had followed through on its promise. For many summers, the Storyteller had felt the pressure of this day building within her. She, like the moon, had waited in anticipation to hear her child's voice but it had not come. In the first few summers, this led the Storyteller to hide her and her little boy away, away from the eyes of others, away from the outstretched hands beckoning towards the place where the polyphony of children's voices was presented to the moon.

The Tree of Knowledge and The Elder

Now, since the beginning of stories the immense and dominant tree of knowledge has stood in the centre of the village. Upon this revered tree, collections of accepted symbols were often attached. Only those who held valuable knowledge could add to the tree if they saw fit. However, all the people of the village were welcome to approach the tree and check if any of the symbols were relevant to their particular lived circumstances. Many did. To this day sketches are made of the chosen symbols and, these are displayed with pride within the settlements of the people. The Storyteller came to the tree on a few occasions in those earlier years but could never find a fitting symbol for hers' and her family's life, in fact most symbols provoked tears. One day, after such a pilgrimage, the hurt overwhelmed her, and she fell to her knees on the ground. It was on that day that she first saw the tracks. Now, the Storyteller had probably walked over these tracks a thousand times before but, on this occasion, something about them seemed entirely remarkable. From this lower vantage point, the swirling tracks were obvious and reminiscent of a symbol she had once seen as she passed by a smaller settlement within the Caru mountains. At first, she followed these coiling tracks with her eye alone and her gaze was guided to a colourful dwelling nestled into the side of a hard rock face. At the door of this dwelling stood a silhouette with one hand raised in salute. The Elder.

The Elder had been watching this woman for some time now. When she finally rose to her feet, The Elder immediately recognised her from her previous visits to that looming tree. She was the one who searched in hope and always made her return journey, dispirited. Now, she had changed her course and was making her way up the steep incline towards The Elder’s dwelling. At times she lost her footing and regressed a little but after each set back she persevered until she eventually made it to the clearing just before The Elder’s home. It was as she got to the edge of the clearing that the Storyteller saw him. A boy, a grown boy. He was so like her own son it took her breath away. He expressed himself freely in the voice and movement of The Other. That was until he saw her and in response, froze. She smiled in salutation, but he quickly averted his gaze and disappeared around the back of the multi-coloured abode. She was just about to follow when she heard The Elder speak: “you’re not going to find the symbols of our lives on that tree”. The Storyteller turned around and there stood The Elder, holding the hand of a little boy who also moved in the ways of The Other, another boy just like The Storyteller’s son. The Storyteller felt an instant connection with The Elder and her boys and nodded acceptingly at the declaration. The Storyteller had long known this deep inside, her husband had told her time and time again. But as she finally accepted this reality in the clearing outside The Elder’s house her body felt weightless. Together they proceeded to the back of the brightly coloured dwelling. It was there, while they both stood watching the little boy and the grown boy move majestically in the sunlight that The Elder told her that she had often travelled to the tree of knowledge, many years ago but that she had instead turned towards her sons to show her the symbols of their family’s different life. The Storyteller knew that it was this decision that had made The Elder wise, made her strong. They spoke until the sun fell low in the sky and when they parted The Elder placed a note in The Storytellers hand, it read “Tell their story. Sketch their symbol”. The Storyteller could hardly keep a steady foot on the path home. Her heart raced and her breathing quickened. This was the story that she was destined to tell. A story, not just of The Universal or The Other, but of her son and other children just like him.

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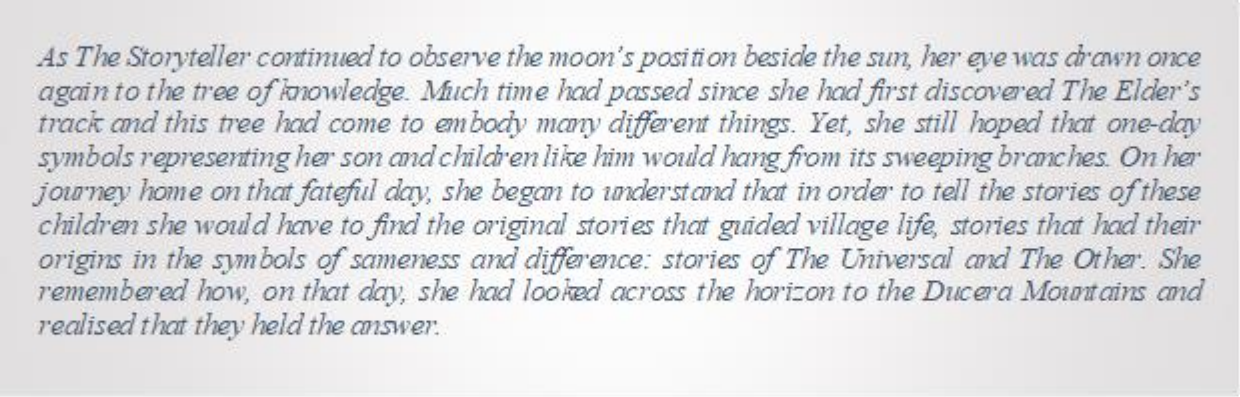
Researcher Vignette: The Storyteller and The Midday Moon (Part II)



As The Storyteller continued to observe the moon's position beside the sun, her eye was drawn once again to the tree of knowledge. Much time had passed since she had first discovered The Elder's track and this tree had come to embody many different things. Yet, she still hoped that one-day symbols representing her son and children like him would hang from its sweeping branches. On her journey home on that fateful day, she began to understand that in order to tell the stories of these children she would have to find the original stories that guided village life, stories that had their origins in the symbols of sameness and difference: stories of The Universal and The Other. She remembered how, on that day, she had looked across the horizon to the Ducera Mountains and realised that they held the answer.

<u>The Ducera Mountains and the Warrior</u>

For as long as anyone in the village could remember the children of the Caru region had been tasked with surmounting the Ducera Mountains and journeying through its undulating valleys. The children who would emerge from this task victorious would be allowed to leave the Ducera region, equipped to compete individually against other victors that they would encounter on their independent journeys throughout the wider land. The Warrior was aware of the significance of this task. In fact, this task was fundamental to her family's decisions from the very beginning. When choosing a place to lay down her family's roots, the Warrior and her companion decided to leave their native home and their many clansmen to live closer to nature, where their future children would have a greater chance at conquering Ducera. As children, when they were tasked with scaling its towering interface, they had struggled and so now, they wanted more than ever for their children to succeed. They arrived upon a small settlement where the tribes people knew each other's names and happily made a home. At this time, the Warrior did not know the extent of her strength and fortitude; indeed, she was not aware that within her a Warrior lay; awaiting emergence. Prior to becoming a brave warrior, this mother had a simple vision. She yearned for her and her family to be included among the local tribespeople. For her, a pivotal aspect of this vision was that her children would learn from the most knowledgeable of the Ducera community. Indeed, this had been the main reason they had said a difficult goodbye to their beloved clanspeople.

A few years later, she welcomed her first born into the world. His cries echoed out in the night, and the day. For days, these cries rang out, unyielding. The days turned to weeks and the weeks to months. The Warrior began to worry and looked to others for help. She knew and loved her child and therefore feared for him, but others failed to see what she saw. She held and comforted him, becoming his rock; a rock he clung to for security and predictability. Then the day came for her to welcome her second child. Her first born struggled. It was difficult for him to share his rock, to find his own place there when another needed care, security and protection. His cries rang out once more until they became recognised as the voice of The Other. Some years later, her second child's cries received similar recognition. The Warrior accepted this acknowledgement as her family's identity, their symbol, and pledged that her children would still journey into the Ducera region. The Warrior prepared herself and her family for the uncertain road ahead. She sought and mastered the knowledge and skills to nurture and develop her children's voices, to better equip them, not just for the challenge of Ducera but also for the unknown land beyond. Together they worked hard and did very well. One day The Warrior looked upon her children, saw how they had blossomed and was impressed with the great skill and determination they displayed. She gathered them around her and told her firstborn that it was time. The next morning, she would journey to the entrance of the Ducera Mountains and request entry for her son.

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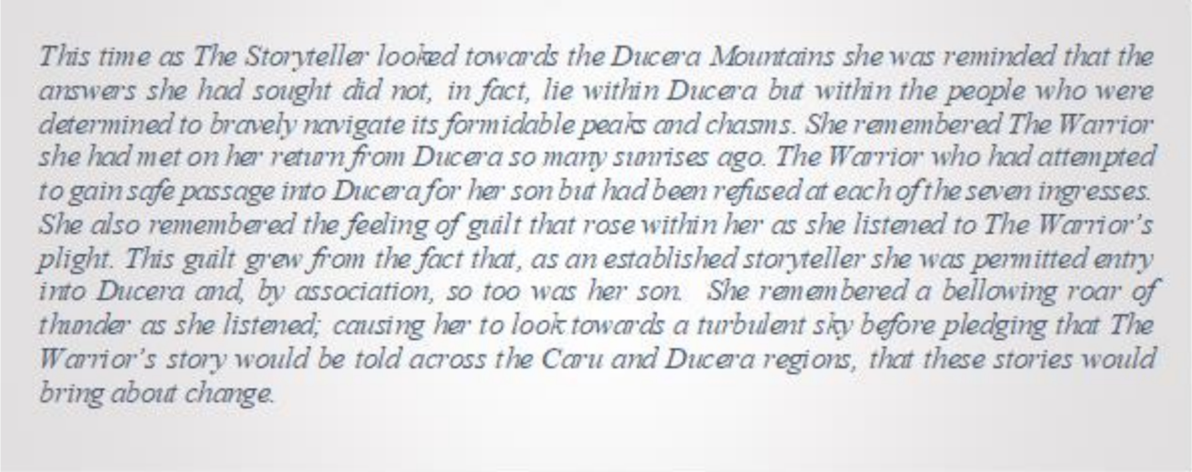
Researcher Vignette: The Storyteller and The Midday Moon (Part III)



This time as The Storyteller looked towards the Ducera Mountains she was reminded that the answers she had sought did not, in fact, lie within Ducera but within the people who were determined to bravely navigate its formidable peaks and chasms. She remembered The Warrior she had met on her return from Ducera so many sunrises ago. The Warrior who had attempted to gain safe passage into Ducera for her son but had been refused at each of the seven ingresses. She also remembered the feeling of guilt that rose within her as she listened to The Warrior's plight. This guilt grew from the fact that, as an established storyteller she was permitted entry into Ducera and, by association, so too was her son. She remembered a bellowing roar of thunder as she listened; causing her to look towards a turbulent sky before pledging that The Warrior's story would be told across the Caru and Ducera regions, that these stories would bring about change.

The Clan Mother, The Storms and The Canyon Epecialis

A loud crack of thunder woke The Clan Mother with a start. It was almost dawn and her children would awake soon so she decided to rise and begin her day. She had a lot to do. The Clan Mother had raised her children alone for many years now. She alone protected them from the many storms that had shaken their home on the tempestuous side of the Caru Mountains. She knew that this storm season would probably be no worse than the ones that had raged before but this morning's thunder had signalled her to leave sooner than she had anticipated, to gather provisions that would see her family through. The Clan Mother worried about leaving and knew she would have to find someone to take care of her children while she was gone. But at least now she felt she had an answer. At the village well the day before she had heard people talking about cabins that were being built at the entrances to the Ducera region. She hadn't really been listening until she heard them mention children who spoke and moved in the ways of The Other. Children like her children. As the people of the village filled their water vessels, they discussed these children further, children who were unable to defeat Ducera, children who were instead, given access to these cabins. So, on the morning that the first sounds of thunder crashed she started preparing her family for their journey.

The road was unknown to her but together they followed its meandering turns all the way to the front door of a newly erected cabin. As they left down their belongings to stretch their weary backs, the door opened to reveal a pleasant and smiling face. The Clan Mother breathed a deep sigh of relief and was reassured to hear that her children would be welcome in the cabin. She left on her quest, but not before agreeing to watch the sky every day that she was away for the cabin owner's signs. Now, The Clan Mother's task was difficult and exhausting, but she took solace in the fact that on the first day a white plummet of smoke filled the sky around the little cabin. Her children were well. On the second day, however, the smoke grew darker and by the third day, black smoke swathed the sky above the cabin where her children stayed. She bundled what she had gathered into her arms and ran. She ran without stopping towards the flumes of black smoke. She ran until her feet hurt and her chest burned. She ran and ran until finally she found herself at the door of the little cabin. There outside the door stood her two little boys, their belongings left on the porch beside them. They cried when they saw her and so did she. She put her arm around them and pushed against the door with her other hand. It was locked. She turned and holding each of her sons' hands, set off back towards their home on the tempestuous side of the Caru Mountains.

They hadn't gone very far when she saw it. The Canyon Especialis. It was much more beautiful than people had described. Its land stretched as far as the eye could see and from every orifice sprang blossoms in a multitude of variety and colour. In the farthest corner, she could almost make out the figures of children and adults playing in the puddles formed by the flurries of rain, but she was too far away to be sure. Now since The Clan Mother was a little girl, she had heard whispers of The Canyon Especialis. In a rhyme chanted by her and her friends, it was called "the place where we don't go". Certainly, The Canyon had always been off limits but now, as she gazed upon it and smiled, she could no longer remember why. She had distant memories of some children leaving to go to The Canyon years ago, but she had no memory of seeing them again after that. She was immensely curious but acutely aware of the worsening weather and so turned her attention to finding shelter. It was there, as she carried her boys into a cave to wait out the showers, that she met The Storyteller. They sat together and spoke about their lives and their sons until the rain finally stopped. They emerged from the cave to the heartening sounds of laughter resonating from The Canyon Especialis. They walked together in the direction of the merriment. When they got close The Clan Mother gathered her sons in her arms and made her way towards the jumping and dancing figures. The Storyteller waited behind and watched. She watched, as they got closer to the gathering of children and adults. She watched as the little boys outstretched their small and delicate palms to receive the brand necessary to guarantee their entry. Knowing that this aspect worried The Clan Mother most, The Storyteller studied The Clan Mother's face, but all signs of worry and fear were replaced with relief, happiness and hope.

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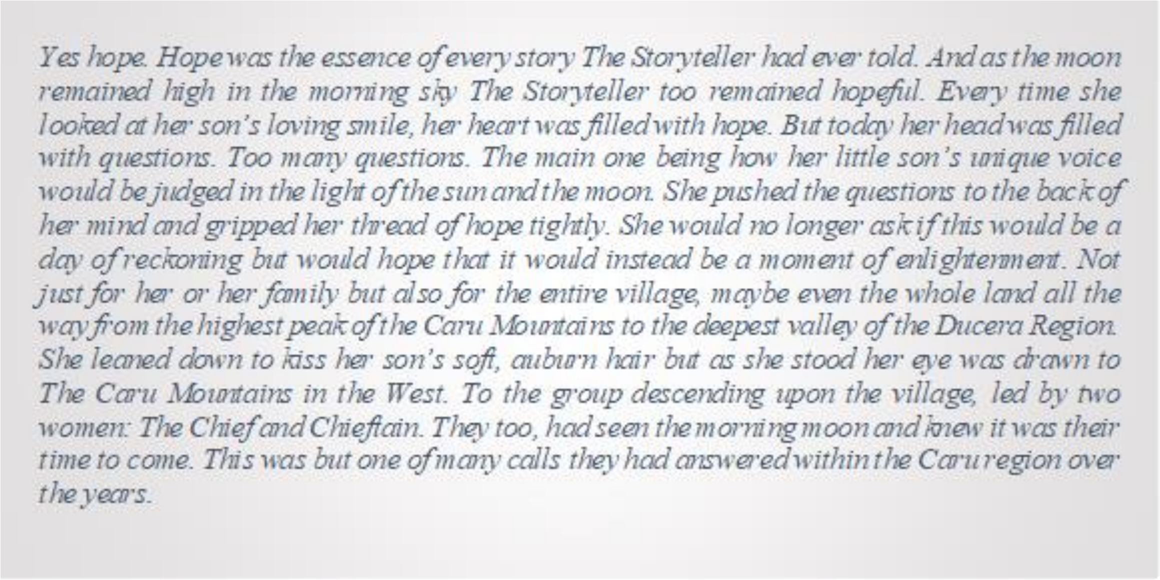
Researcher Vignette: The Storyteller and the Midday Moon (Part IV)



Yes hope. Hope was the essence of every story The Storyteller had ever told. And as the moon remained high in the morning sky The Storyteller too remained hopeful. Every time she looked at her son's loving smile, her heart was filled with hope. But today her head was filled with questions. Too many questions. The main one being how her little son's unique voice would be judged in the light of the sun and the moon. She pushed the questions to the back of her mind and gripped her thread of hope tightly. She would no longer ask if this would be a day of reckoning but would hope that it would instead be a moment of enlightenment. Not just for her or her family but also for the entire village, maybe even the whole land all the way from the highest peak of the Caru Mountains to the deepest valley of the Ducera Region. She leaned down to kiss her son's soft, auburn hair but as she stood her eye was drawn to The Caru Mountains in the West. To the group descending upon the village, led by two women: The Chief and Chieftain. They too, had seen the morning moon and knew it was their time to come. This was but one of many calls they had answered within the Caru region over the years.

The Chief and The Miner's Family

Stories of The Chief were well known among the families of children who spoke and moved in the ways of The Other. Indeed, one of the tribesmen, The Miner, often spoke of her worth when gathered around the village fire. Now, The Miner was also very well known among the community. The people of the village respected him, as he was an incredibly hard worker. Every morning he would rise with the sun and descend into the mine where he would dig all day till sunset for the lustrous metal his family needed. It was no secret that this lustrous metal held value for the people of the village, but for The Miner's family, its value was immeasurable. You see The Miner and his wife had four children, three of whom displayed the ways of The Other. And, as all the villagers knew, a child who exhibited these different ways required the help and support of many in building their strength. When their first child's voice was recognised as different, The Miner and his wife were told about a wagon that would regularly come to the village operated by those who would offer ample help and support. Every day, while caring for her children, The Miner's Wife would watch for this wagon, but it never came. Once she thought she had caught a glimpse of it and gave chase only to come upon the wagon crashed against the rock face broken and empty. That day she returned to her home dejected and tearful. The Miner comforted her, placed his pickaxe on his shoulder and headed towards the mine once more. He would continue to mine the valuable metal that could procure the help that his family needed. This was the darkest day. The day before they met The Chief.

Then The Miner and his wife were growing up, getting to know each other as a young couple, experiencing the world together, contemplating the future, making their decision to commit to each other forever, the Chief had long been navigating the world for her youngest child, helping the world to hear her daughter's unique voice. Helping the world to see her different ways. She was resolutely carving a path for her child and herself, a path along which she would lead so many other families within the Caru region. For years, The Miner and his wife had passed the Chief's foundation for care and learning. The surrounding grounds captivated them, drawing not only their eye but also, many a pair of little exploring hands or feet, they surmised. Animals grazed happily in the adjoining paddocks, unaware of their significant role in the Chief's vision. They both knew that this was where their children would embark on their learning journey, under the guidance of the Chief. As the couple had envisaged, The Chief's foundation proved the optimum experience for their firstborn and, consequently, The Chief changed the lives of The Miner's family, replacing fear and worry with hope and happiness. With the help of The Chief, their dream for their children was unwavering. As their other little boys grew, as they laughed and cooed, crawled and toddled and showed their different ways of communicating, of experiencing the world; their parents never released their grip on their dream. They had faith in the Chief and their faith was bolstered every time she would tell them that their children did not speak or move in the ways of The Other but in their own way. And when The Miner spoke of The Chief around the village fire it was her powerful words that The Storyteller could not let go of: "yes our children are different but this does not make them The Other. It simply makes difference a beautiful and important part of all of us". Our children did not have the way of The Other, they had their own way.

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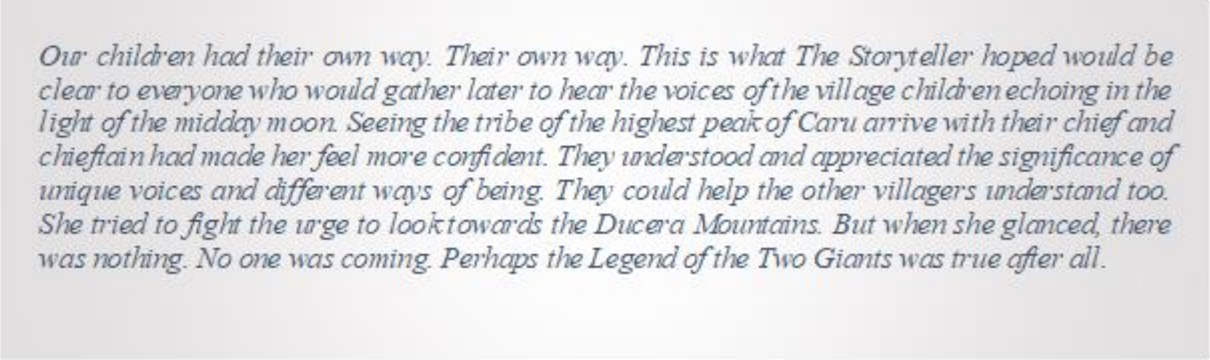
Researcher Vignette: The Storyteller and The Midday Moon (Part V)



Our children had their own way. Their own way. This is what The Storyteller hoped would be clear to everyone who would gather later to hear the voices of the village children echoing in the light of the midday moon. Seeing the tribe of the highest peak of Caru arrive with their chief and chieftain had made her feel more confident. They understood and appreciated the significance of unique voices and different ways of being. They could help the other villagers understand too. She tried to fight the urge to look towards the Ducera Mountains. But when she glanced, there was nothing. No one was coming. Perhaps the Legend of the Two Giants was true after all.

The Chieftain, The Giants and The Scribes

The Storyteller had known The Chieftain of the highest peak of Caru long before she was appointed by The Chief and, her tribe. They had walked similar paths that had crossed on occasion. They had both spent many years helping young children to learn the ways of their people. They both had borne children who spoke and moved in their own way. In fact, The Chieftain's children were currently making their way across the mountains and valleys of Ducera. But the thing that connected them more closely than any other was their knowledge of the fabled giants that watched over the regions of Caru and Ducera. The Chieftain could often be heard talking about Giant Dynamikos the Powerful, the overseer of Caru. She would explain that, historically, Giant Dynamikos was most pleased when he saw tribespeople interacting, building and developing relationships and partnerships that improved and strengthened the lives of all the people in their community. The Storyteller too loved to tell stories about Dynamikos the Powerful and the villagers loved to hear them. However, when The Storyteller spoke about Giant Dynamikos she always felt it was important to give the enthusiastic ears around her both sides of the story. This was when she would introduce Giant Statikos the Balanced, usually to a resounding chorus of boos from her veteran listeners.

Legend has it that since the birth of the sun, Statikos the Balanced has guarded the Ducera region. Giant Statikos earned his name as The Balanced during Ducera's earliest days. All within Ducera and beyond have heard tales of Statikos' balance, upon which The Universal Child stood. Children who wished to enter the Ducera region would first have to step upon Statikos' balance to ensure that they were equal in measure to The Universal Child. Those that did not balance the scales were refused entry. When one season would end and another begin, leaders from across the many mountains and valleys would read aloud the scrolls of Ducera to

Giant Statikos. Nothing pleased him more than when the scrolls detailed the myriad of accomplishments of those who had successfully navigated the precarious terrain of Ducera, defeating all other opponents. Now, The Scribes who lived in a citadel beyond the mountains and valleys of Ducera could clearly observe Giant Statikos' gratification as he listened. And they, being positioned too far from the Caru Mountains to discern the action of Giant Dynamikos the Powerful, decided that they would base their writings on the penchants of Giant Statikos. And they did. The Scribes regularly despatched important parchments to places of learning across the Ducera region. Indeed, these parchments reached many settlements within Caru also. This troubled Dynamikos the Powerful who was concerned about much of what was written within these parchments and their impact on his people. He rose to his feet imposingly and started out towards the citadel of The Scribes.

From the highest window in the highest tower within the citadel The Novice Scribe watched as the giant slowly made his way towards their holding. The closer the giant came, the more clearly he contrasted with Statikos the Balanced. The more quickly The Novice Scribe's fear dissipated. This giant did not exude a cold or distant demeanour. His features were soft, and his expression was one of worry. Down his vast cheek rolled a gargantuan tear. The Novice Scribe hurriedly descended from his viewpoint to inform the others that he believed this caller did not pose a threat. He raced down the winding stone staircase and across the courtyard to give the signal to the watchmen but ground to an immediate halt when he saw them. The Head Scribe and The Trickster. Now upon his entry into the citadel, The Novice Scribe had been given the tedious task of replicating all the ancient parchments that lay deep within the annals of the scribes. It was from these ancient parchments that he recognised The Trickster. Unfortunately, he was the only one to do so. As he drew closer, he could hear The Trickster whisper about A New Way and the many benefits of rewarding the most successful competitors of the Ducera region with the valuable lustrous metal of the mines. He spoke of the freedom of miners to work ceaselessly and the autonomy of Ducerian children and their leaders to contest their opponents incessantly. He explained that it would be wrong of The Scribes to intervene in this New Way as it would be essentially taking freedom away from the miners, children and leaders. With this, he turned to leave, but not before pointing towards the approaching giant and saying: "Beware of this titan who could harm our New Way".

It was this line in The Storyteller's tale that caused The Chieftain to rise by the light of the fire and exclaim "but Dynamikos would have only made things better!". The Storyteller nodded in agreement and when other villagers spoke about how The New Way was making their lives worse, she again shook her head knowingly. For she knew more than anyone how her people had suffered within this New Way. She lay in the dark at night thinking of all the children that spoke and moved in their own way and how there was no place for them in this New Way. Ducera was moving farther and farther out of reach for them as their ability to compete successfully was widely questioned. But she had made a promise to herself in the dark on one of those nights. A promise to share the stories of these children, their families and their plight within this New Way. For now, that was all that she could do.

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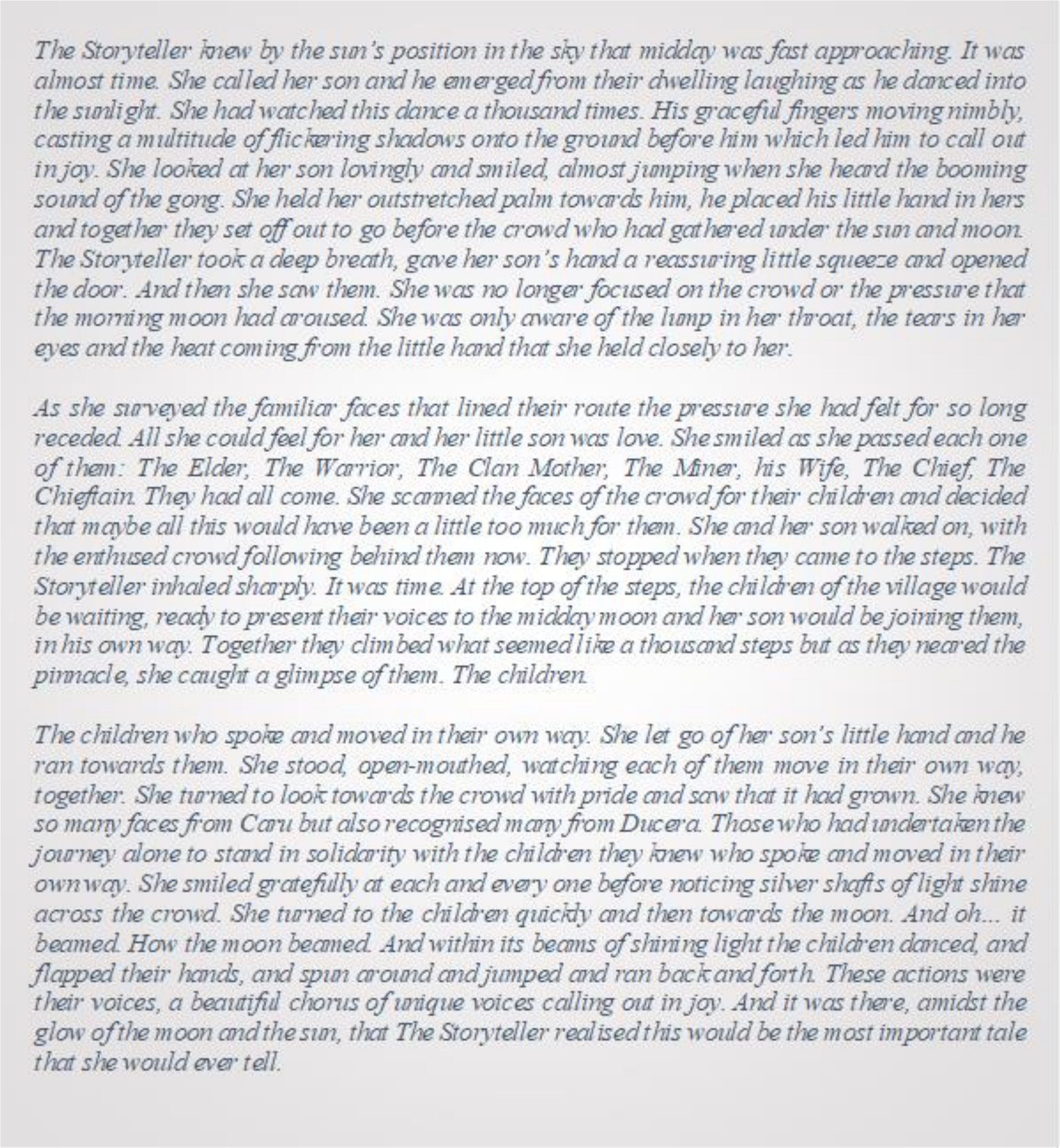
Researcher Vignette: The Storyteller and The Midday Moon (Epilogue)



The Storyteller knew by the sun's position in the sky that midday was fast approaching. It was almost time. She called her son and he emerged from their dwelling laughing as he danced into the sunlight. She had watched this dance a thousand times. His graceful fingers moving nimbly, casting a multitude of flickering shadows onto the ground before him which led him to call out in joy. She looked at her son lovingly and smiled, almost jumping when she heard the booming sound of the gong. She held her outstretched palm towards him, he placed his little hand in hers and together they set off out to go before the crowd who had gathered under the sun and moon. The Storyteller took a deep breath, gave her son's hand a reassuring little squeeze and opened the door. And then she saw them. She was no longer focused on the crowd or the pressure that the morning moon had aroused. She was only aware of the lump in her throat, the tears in her eyes and the heat coming from the little hand that she held closely to her.

As she surveyed the familiar faces that lined their route the pressure she had felt for so long receded. All she could feel for her and her little son was love. She smiled as she passed each one of them: The Elder, The Warrior, The Clan Mother, The Miner, his Wife, The Chief, The Chieftain. They had all come. She scanned the faces of the crowd for their children and decided that maybe all this would have been a little too much for them. She and her son walked on, with the enthused crowd following behind them now. They stopped when they came to the steps. The Storyteller inhaled sharply. It was time. At the top of the steps, the children of the village would be waiting, ready to present their voices to the midday moon and her son would be joining them, in his own way. Together they climbed what seemed like a thousand steps but as they neared the pinnacle, she caught a glimpse of them. The children.

The children who spoke and moved in their own way. She let go of her son's little hand and he ran towards them. She stood, open-mouthed, watching each of them move in their own way, together. She turned to look towards the crowd with pride and saw that it had grown. She knew so many faces from Caru but also recognised many from Ducera. Those who had undertaken the journey alone to stand in solidarity with the children they knew who spoke and moved in their own way. She smiled gratefully at each and every one before noticing silver shafts of light shine across the crowd. She turned to the children quickly and then towards the moon. And oh... it beamed. How the moon beamed. And within its beams of shining light the children danced, and flapped their hands, and spun around and jumped and ran back and forth. These actions were their voices, a beautiful chorus of unique voices calling out in joy. And it was there, amidst the glow of the moon and the sun, that The Storyteller realised this would be the most important tale that she would ever tell.

Chapter Eight

Discussion of Findings

8.1: Introduction

This chapter discusses the findings from both the *analysis of narratives* and the *child-centred narratives* and locates these against an ecological, critical and philosophical backdrop. The chapter is structured ecologically to encompass findings relating to these children's and parents' experiences within their microsystem, mesosystem and macrosystem. It therefore incorporates the *challenges, changes* and *choices* experienced by families across social contexts. Central to this chapter is the importance of *recognising*, *understanding* and *appreciating* the voice of the child on the autism spectrum across these interconnected social contexts. Therefore, this chapter is divided into three sections, representing how each social context (and the dominant narratives inherent within it) influence and impact these children's and parents' experiences. The first section examines the children's microsystem, where families' personal experiences, and the recognition of the child's unique voice, come to the fore. The next section explores the findings regarding the mesosystem, incorporating the children's and families' experiences within and between educational settings. The final section focusses on the macro forces influencing and impacting these children's and families' experiences. Again, the relationship between such forces and the development of self-identity is highlighted, with particular consideration given to the experience of *being different*, and the contrasting action of accepting one's experience as *a different way of being*.

> Existing theory and research point to the importance for the child's development of the nature and strength of connections existing between the family and the various other settings that a young person enters… this event can markedly alter attitudes, expectations, and patterns of interaction within the family, especially in relation to the child.
>
> Bronfenbrenner, 1986, p. 734

* * *

8.2: Experience and Action Across the Microsystem

The inextricable relationship between experience and action has been emphasised throughout this research and is a fundamental element of ecological, narrative and critical theory. The experiences of the children and parents in this study are more deeply understood, when particular consideration is given to the actions that were central to these experiences. While the child's development is typically the focal point of ecological theory, developments within the child's family are also regarded as particularly significant. This section presents the interplay between both of these. It particularly highlights the recognition of the unique voice of the child on the autism spectrum, and the consequent development of self-identity, within the children and their parents. Within the microsystem of the family, experiences of challenge, change and choice are also presented, with the actions taken by the families in each of these regards demonstrated. Figure 21 outlines the main lines of narrative comprising each of the areas explored. The recognition of the child's unique voice is examined in relation to the parents' realisation regarding autism, and their consequent action regarding gaining and sharing knowledge. The impact of professionals' actions on life within the microsystem is highlighted throughout. The main challenges within the microsystem are presented in terms of the children's navigation of their social and sensory world, and the parents' stances on their daily family life. The concept of change as process, rather than experience alone, is considered for both the children and parents. Finally, this section discusses the choices made by families, as they and their children move outside of their microsystem to navigate the Irish early years education system.

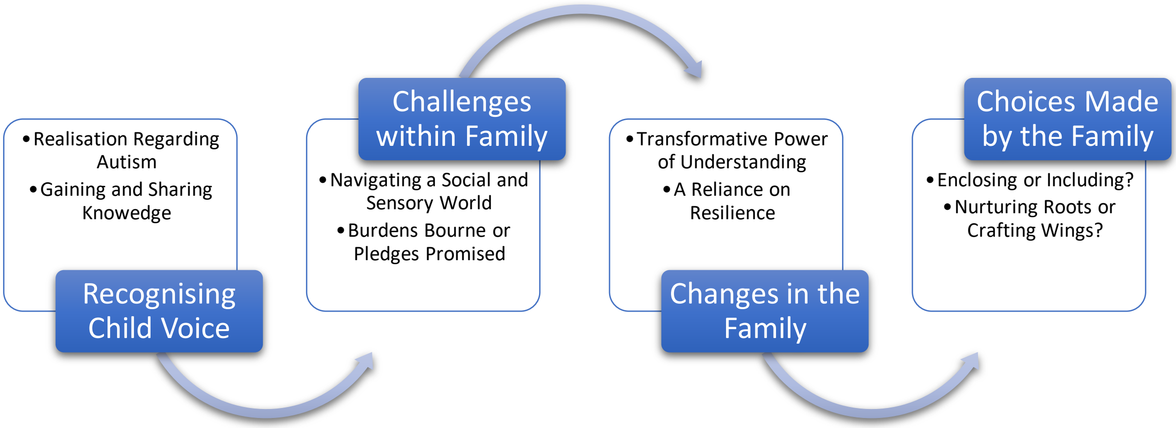


Figure 21: Experience and Action Across the Microsystem

8.2.1: Recognising the Voice of the Child on the Autism Spectrum

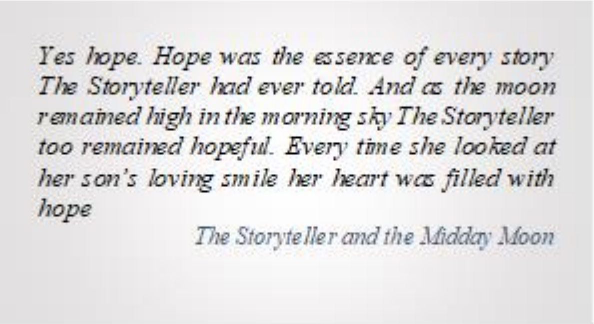
The recognition and inclusion of the voices of children on the autism spectrum was a central vein of Chapter Six which presented the findings of the child-centred narrative analysis. The prioritisation of these children’s experiences by their parents throughout their accounts allowed the significance placed on child voice to emerge. The following section discusses the initial recognition of this unique voice in relation to the families’ realisation regarding autism, and their consequent engagement in knowledge gaining and sharing processes.

Realisation Regarding Autism: Epiphany in Adversity

The significance of parental stance in relation to autism and the consequent construction of voice within their children became evident during the child-centred narrative analysis. The action taken by parents in the earliest part of their journeys determined their consequent positions and perspectives relating to their lived experience. The six parents involved referred their own children for assessment due to communication, social and sensory concerns. However, variance existed among parents regarding the realisation that their child was on the autism spectrum. As mentioned earlier, when presenting the child-centred narratives, moments of epiphany were regularly reported before, during and after this referral. Aligning with Denzin’s (1994; 2009) extensive work on the possibility of epiphany in research, parents’ realisations in relation to autism emerged as significant moments of truth. Through the autonomous narration of theirs and their children’s journeys, the revelation of such truths occurred spontaneously, without the confines of structured formats of inquiry. Clandinin and Connelly’s (2000) and Kim’s (2016) emphasis on the act of backgrounding and foregrounding narratives encompassed the children’s and parents’ lived experiences prior to, during and following this shared life-changing event.

As indicated through the findings, both family structure and professional perspective were integral to the outcomes following these families’ moments of epiphany. Similar to previous research, the children and parents who had close family networks, often inter-generational, retained a more positive outlook during the process of realisation, whether before or after referral and diagnosis (Mouzourou *et al.* 2011; Kahana *et al.* 2015; Sicherman *et al.* 2018). The actions of professionals during this time emerged critical to the consequent narratives of autism constructed by both the parents and children. Congruent with previous research, the experiences represented in this study also indicate that the possibility of parents constructing positive or negative narratives of autism, following moments of realisation, rely on whether professionals themselves held a positive or negative understanding of autism (Avdi *et al.* 2000; Osborne and Reed 2008; Abbott *et al.* 2013).

Evidently, the knowledge constructed by parents at this time lead to empowerment or disempowerment of both themselves and their children on the autism spectrum. It emerged that the process of empowerment occurred when the voice of the child on the autism spectrum was valued by the family. This value was first evident in the parents' recognition and appreciation of their child's individual learning style and approach to play. Parents were unanimous in their identification of strengths within their children's learning styles and play behaviours. This often led to disagreement between parents and professionals who generally interpreted these differences as deficits. This echoes the work of Sirota (2010) who presented the transformative capacity of families' positive personal interpretations of difference in shaping the identities of individuals on the autism spectrum, and in constructing their families' trajectories of hope. The importance of positioning the experience of the child on the autism spectrum at the centre, rather than peripheral, of the narrative was also emphasised. Within this stance the 'children's experiences and self-conceptions pertaining to well-being, disability, and difference are configured and shaped via discursive practices carried out within the family sphere' (ibid., p. 544). Thus, hope emerges central, and contrasts with the trajectories typically presented for individuals on the autism spectrum, where their levels of independence are examined and their interdependent experiences oftentimes critiqued (Henninger and Taylor 2013; Chamak and Bonniau 2016). In the present study, in sharing positive personal and interdependent experiences trajectories of hope also emerged. Thus, illustrating the potential impact that the construction and sharing of knowledge regarding autism can have on these families' lived experiences (Sipos *et al*. 2012; Holder 2013).



Yes hope. Hope was the essence of every story The Storyteller had ever told. And as the moon remained high in the morning sky The Storyteller too remained hopeful. Every time she looked at her son's loving smile her heart was filled with hope

The Storyteller and the Midday Moon

Gaining and Sharing Knowledge of Autism: Empowerment in Education

As outlined in Chapters Five and Six, all six parents reiterated the direct link between gaining knowledge in relation to autism and feeling more empowered to understand and help their child. The benefits for families following participation in parent training and education programmes specifically related to autism, has long been highlighted across research. Particular emphasis was placed on developing parents' ability to recognise potential issues and deal with these accordingly (Rao *et al.* 2014; Özçalişkan *et al.* 2015; Muratori and Maestro 2018; Spikol *et al.* 2019). This research, however, reflects more closely the findings of Banach *et al.* (2010), Mulligan *et al.* (2012) and Webster *et al.* (2017), all of whom suggested a significant increase in positive outcomes for families who had participated in affirmative and empowering educational partnerships with professionals following a child's diagnosis. Similar to the findings of Boshoff *et al.* (2019), 'the foundation for all future relationships' during navigation and advocacy rested on parents' positive exchanges with professionals (ibid., p. 143). Such partnerships were 'transparent', encouraged 'hope' and resulted in 'empowerment' for both children and parents (Mulligan *et al.* 2012, p. 311).This reinforces the point, that the stance adopted by those the parents sought, or received, information from proved critical to the construction of their families', and consequently children's, identity following diagnosis. Thus, echoing Hays and Colaner (2016, p. 143) who highlighted the significance of this aspect of information-sharing, crediting it with families' later 'tribulations' or 'triumphs'.

As reiterated throughout the presentation of findings, the perspectives or worldviews of the children's significant others were central to the construction and sharing of empowering knowledge within the microsystem. When professionals interpreted autism as an aspect of diversity rather than demonstrating a medical or deficit approach, parents consequently constructed their own positive ontologies that also viewed autism as difference. The benefits of this philosophical stance are outlined by Hart (2014) who explored the impact of parents' ontological view of autism and found that their acceptance of *autism as difference* enhanced the lived experience of their children on the autism spectrum. As with this doctoral study, Hart (2014, p. 284) promotes the recognition and appreciation of child voice as the 'embodiment' of 'personhood' and the foundation of positive lived experiences. Thus, positioning the child at the centre of family empowerment efforts. This child-focussed action is distinctive from the role of empowerment strategies as highlighted across other literature on families' experiences of autism, which generally views such action from a needs perspective where empowerment is promoted as a necessary response. In such instances, the empowerment of families of individuals on the autism spectrum was advocated as a means of reducing the negative impact of autism on the quality of family life (Banach *et al.* 2010; Sullivan *et al.* 2012; Pruit *et al.* 2016) rather than a philosophical outlook that enhanced the lived experience of children on the autism spectrum, and their families. Within the present study, the children and parents' capacity to cope with challenges within their microsystem rested on the development of a positive ontological position in relation to autism.

8.2.2: Challenges Faced Within the Family

Certainly, the parents involved in this study experienced a variety of challenges on a daily basis, many of which are attributable to circumstances and contexts outside of the immediate family unit. Such challenges feature in later sections relating to the *meso*, *exo* and *macrosystems*. The principle challenges within the home can therefore be classified into two categories: challenges for children and challenges of family life. The pivotal role that personal perspectives play in coping with these challenges is fundamental.

Challenges for Children: Navigating a Social and Sensory World

As outlined in Chapter Six, the parents prioritised the experience of their child or children on the autism spectrum throughout and centred this within their narratives. Without doubt, this child-centred approach to autism enabled the parents to better understand their child and their experience of the world around them. Positioning the child on the autism spectrum at the centre of the families' immediate and wider experiences is integral to Bronfenbrenner's *Ecological Theory of Development* (1979). This ecological action allowed the challenges reported by families to be reframed, thus presenting challenges experienced, rather than caused, by the children on the spectrum. This shift in representation and understanding is deemed by many as essential to any inquiry into the lived experience of individuals on the autism spectrum (Broderick and Ne'eman 2008; Pellicano *et al.* 2014; Potter 2016). The challenges the children presented with, e.g. communication, social and sensory issues were referenced with regards to their recognition by parents and professionals during the referral, assessment and diagnosis stages. The deeper understanding of such challenges that emerged over time, suggested that communication, social and sensory differences were accepted by the parents as part of their children's lived experience. This contrasts with the deficit approach to the children's challenges, oftentimes displayed by professionals who worked with them.

The adoption of either a social (autism as difference) or deficit (autism as medical condition) approach was central to how these children's challenges were perceived across settings. Echoing findings by others (Mulligan *et al.* 2012; Sansosti *et al.* 2012; Webster *et al.* 2017). This study also indicates that professionals who were understanding and accepting of the challenges experienced by children on the autism spectrum played a pivotal role in the children's and families' capacity to cope with such. Unfortunately, however, parents also reported the negative impact of their children's challenges being apportioned to autism when they believed and argued that other causes may be responsible. In the instances where James, Noah, Eoin and Max were in pain or distress, the underlying causes articulated by their parents as being potentially responsible were either overlooked or explicitly dismissed by the professionals they were attending. For these professionals, autism manifested as a complicated medical condition with varied and multiple symptoms. Again, indicative of a deficit approach that can create negative repercussions (Kapp *et al.* 2013; Krcek 2013; Hardy and Woodcock 2015). James, Max, Eoin and Noah's pain and distress subsided when professionals, who understood autism as their particular way of being, listened to their voices and worked with them and their parents to ascertain what was wrong. For Brian however, psychologists repeatedly assigned his anxiety to autism in, what his mother Sandra perceived as, complete disregard for his well-being and mental health. While anxiety is accepted as being a common co-morbidly occurring condition with autism (Eussen *et al*. 2013; Scahill *et al*. 2014), research into experiences of anxiety within children on the autism spectrum, highlight its ecological nature as it develops within the child in response to events, settings and, the wider world around them (Ozsivadjian *et al*. 2012; Simpson 2019). It was clear that Brian related his feelings of anxiousness, and consequently despair, to his experience of being different. In fact, this relentless experience of being the *other* led Brian, at six years old, to wish that he was dead. Rather than accepting this change as a symptom of autism, Brian's parents saw it as his lived experience, which warranted in-depth understanding to help them support him in coping with the challenges he was facing. In listening to his voice amid their turmoil, Brian's parents exemplified the stance of all six parents in this study, who pledged to be there for their child in the face of all challenges and adversity.

Challenges of Family Life: Burdens Borne or Action Pledged?

The common differentiation made between typical family life and the family life of children on the autism spectrum was referenced throughout the data. While certain differences in families' daily lives were recognised and accepted, the perceived othering of their familial experiences stimulated hurt and frustration within the parents. All six parents rejected the notion that their family life was lesser or demanded pity. Instead, the parents reported the importance of recognising that their family life was 'a different kind of normal' (Bachraz and Grace 2009, p. 317) and revealed a desire for people to appreciate that families can be diverse while acknowledging the many similarities that they also share. On the other hand, there was an identified struggle with the lack of awareness that people sometimes displayed regarding the intensive commitment made to overcome the families' challenges. Challenges which were oftentimes dismissed by professionals with whom they engaged. This reinforces findings which, point to the presence of a disconnect between those that are and are not immersed in the lived experience of autism (Pellicano and Stears 2011; Boshoff *et al.* 2018). Throughout the research, the parents offered accounts of when the challenges of daily life experienced by the family were more clearly understood by professionals, who themselves, had a family member with additional needs or on the autism spectrum. Thus, underscoring the centrality of such interactions in reducing the impact of challenges.

Both the parents and children developed significant relationships with professionals who had personal experience of families' intensified commitment to ensuring, and enhancing, the well-being of children with additional needs. The families made a commitment to care, pledged from a position of love and devotion, a stance seldom researched in relation to the development of children on the autism spectrum (Mittal *et al.* 2018; Richardson 2018). The findings of this research suggest that such action should be recognised and appreciated within the narrative surrounding autism and care. In fact, parallels can be drawn between a life of caring and a life of action, or the *Vita Activa* as it were (Arendt 1958). Within contemporary civilisation, devotion to a life of caring is typically equated with a life that is destined to remain inactive, reducing the *Vita Activa* to merely a false and, frustrating hope for the carer. Some would argue that the devaluing of the act of caring in modern times has led those who commit to a life of caring, to have a reduced level of self-efficacy and self-worth (Noddings 1984; Kapp 2011; Boshoff *et al.* 2018). Thus, rendering the respected role of carer, in its original and truest sense, impossible and creating multiple challenges for families for whom the act of caring is central to their interdependent lived experience (Factor *et al.* 2019).

This study argues that if caring is understood as a form of labour that must be endured because the alternative vision of independent living is not feasible, neither the *one-caring* nor the *cared for* will be able to foster and develop the positive and fulfilling relationship at the heart of the act of caring (Noddings 1984; 1992). Another option would be to interpret caring as *work* or an inevitable part of life, representing the second element of Arendt's *Vita Activa* and, redefining the act of caring as an element of reality, rather than a burden to be borne. However, if caring is considered and understood to be a process of action, then both the one-caring and, the cared for, are empowered. Valuing the process of caring as action is reflective of Arendt's third and final level within the *Vita Activa*. The role adopted by the parents in this study, as they cared for their children on the autism spectrum, encompassed advocate and activist and demonstrated how one can exercise their power of agency within circumstances where too often, people feel utterly disempowered. Moreover, this can enable those *cared for* to gradually become more empowered also. Thus, a change in ones' view of caring can bring about change for all involved.

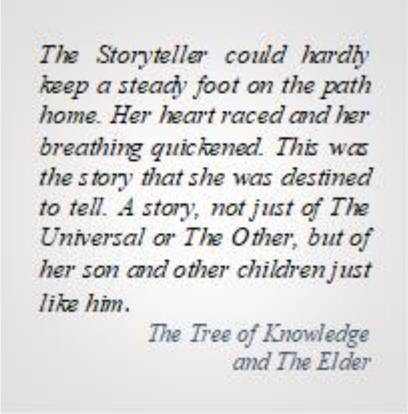
8.2.3: Changes in the Family

Again, while the parent narratives oftentimes demonstrated family life in flux, the process rather than experience of change was central to the children's and parents' lived experiences. These processes of change were reported over time and included changes in the children, and in the parents. For the children, having their unique voice recognised and understood, resulted in marked changes within them in their homes, while changes within the parents were generally connected to their development of resilience. In both cases the significance of self-perception, and consequently, self-identity is evident.

Changes in Children: The Transformative Power of Understanding

Earlier, when discussing the challenges that children on the autism spectrum experience, changes noted over time were almost always positive, with the exception of the manifestation of anxiety in some children as they got older. The more commonly referenced positive changes in children typically focussed on the progress they were making emotionally, socially, behaviourally, physically, cognitively and, especially on the development of their self-identity: an immensely underexplored area in research relating to children on the autism spectrum. For the most part, these positive changes within the child were in response to a person, environment or activity that engaged them in ways that others did not. This epitomises Bronfenbrenner's Ecological Theory of Development that emphasises the roles of significant others in children's development. Moreover, it rebukes widespread adherence to a linear model of child development that has a tendency to be viewed as a process independent of, rather than dependent on, the roles of other social actors (Bronfenbrenner 2005; James *et al*. 2005; Murray and Urban 2012).

More recently, there has been a shift from the traditional interpretation of childhood as a predictable and systematic stage, towards a more socially ecological view of childhood as embedded in wider human action, a point reiterated in both the parent and child-centred narratives where such interdependent action proved integral to the co-construction of child voice. Indeed, this shift is most clearly visible in Aistear, the early childhood curriculum framework in Ireland (NCCA, 2009), where children's relationships with their significant others are central to all learning experiences and child identity. However, the fundamental nature of developmental psychology, from which primary school curricula have been moulded (GOI 1999a), endorses the viewpoint that children enter and exit these stages sequentially, giving much less consideration to the formation of identity within young children. Unfortunately, when developmental milestones are accepted and promoted as the prevailing social norms, those that do not progress in the anticipated way are often othered and, a fragmented identity is instead constructed (Bronfenbrenner 1979; Kitching *et al*. 2014; Hays and Colaner 2016; Byrne *et al*. 2018).



The Storyteller could hardly keep a steady foot on the path home. Her heart raced and her breathing quickened. This was the story that she was destined to tell. A story, not just of The Universal or The Other, but of her son and other children just like him.

The Tree of Knowledge and The Elder

The individual adults, whom parents credited for some of the positive changes within their children, shared two common traits. They all built relationships with the children and families that were entirely child-centred and, they all viewed autism as an example of difference, rather than deficit, and adapted their practice accordingly. Such action is representative of best practice in the field of autism and inclusive action (Hall and Graff 2011; Andersson *et al*. 2014; Boshoff *et al.* 2018) and emerged critical to the recognition and development of the voices of the young children represented in this study. These children construct their view of themselves, others and the world around them in line with the narratives they experience daily in their local environment. It follows, that the level of inclusion or exclusion experienced by a child in, for example, an educational setting, depends on the interaction patterns of that child with significant others within that micro-context (Devine 2008; McCarthy and Moloney 2010; Murray and Urban 2012; Moloney and McCarthy 2018). According to Devine (2009a, p.57), these interactions are always framed along a continuum of either 'sameness' or 'difference' that is informed by wider macro values. It is along this continuum that voices are constructed, identities shaped and a sense of belonging is either developed or damaged. The next section discusses changes that occurred within parents in response to this continuum of sameness or difference.

Changes within Parents: A Reliance on Resilience

As previously noted, the most common change observed within the parents was their development of resilience over time. The outlook they held regarding their valuable role in both the act of caring and in advocating for their children's rights was integral to their development of resilience within their home. This finding emulates other studies of autism and family experiences that reported effective adaptive functioning as relying heavily on the view the individual held of themselves and their role (Dale *et al*. 2006; Sirota 2010; Hall and Grace 2011; Sheridan *et al*. 2012; Sullivan *et al.* 2012). The parents' capacity to cope was evident in how they proactively adapted their environments and family life to effectively reduce the presence and impact of stressors on everyone in the home. In doing so, they chose happiness over adherence to social norms. This represented a transformative change in the parents' values and priorities over time. Initially parents' priorities began to change in relation to their original aspirations regarding the outcomes of early intervention or therapies. Over time, this priority was typically replaced with an appreciation of the value of becoming empowered to act on behalf of their children irrespective of any anticipated outcome or external measure of progress.

In his seminal work on coping, Dreyfus (2014) explores the philosophy behind the actions of people as they cope with daily circumstances, promoting an active method of coping based on a personal experiential philosophy. The parents' experiences illuminated the process of active coping within which personal experience and a transformed and positive outlook is integral. This positive, strengths-based approach also reiterates a key point of Lazarus' Stress Theory (1966), that is often overlooked in research pertaining to autism and families' experiences, as it emphasises the deep connection between the emotions and outlooks of the individual and, the action they take in response to stressors. Thus, providing a more insightful account of these families' experiences, rather than just simply suggesting that the presence of autism in a family automatically equates with the development of high levels of stress across all family members (Fung *et al*. 2015; Pozo and Sarriá 2015).

The significance of the parents' personal positioning within the development of resilience also encompassed the fundamental principles of Self-Efficacy theory (Bandura 1997), which emphasises the characteristics and perspectives of the individual in all action. Indeed, the parents' unequivocal acceptance of their role of responsibility gave them the capacity to continuously and effectively think and plan, even when they experienced adverse circumstances as they navigated other social contexts. However, as mentioned earlier both in the presentation of findings and the literature review, the development of resilience should never depend entirely on the internal capacity of individuals alone. Rather, it is critical to recognise the important role played by external factors also. Although partnership is critical to the development and maintenance of resilience (Bayat 2007; Bekhet *et al*. 2012; Lerner 2012; Sheridan *et al*. 2012), in this research, resilience presented as an internal family process necessary to overcome the adversity faced by the families. It appeared that the development of resilience became the only solution to the immediate needs of individual families, rather than a shared process of empowerment between individuals, families and wider society. This reinforces criticisms of the promotion of individualised resilience as it represents an unequal power relationship that can negatively impact vulnerable families (Joseph 2013; Chandler 2014; Lamont *et al*. 2016). In such situations, there is no other choice than to develop resilience from within, against the hardships endured externally. Certainly, the concept of choice, which was critical to the development of these parents' resilience, also influenced their decisions regarding their children's educational placement.

8.2.4: Choices Made by the Family: Navigating Deep Divides

In order to access the '*best'* education for their child, five parents accepted alternative educational placements and compromised on what they had initially planned for their children. While it is evident that in some instances, the element of choice was essentially removed from these parents, the value they placed on their children's acceptance and consequent happiness outweighed much of the regret regarding roads not travelled. The main choices inherent within these families' navigation of the Irish early years education system were between mainstream and special settings and, between early years and primary education.

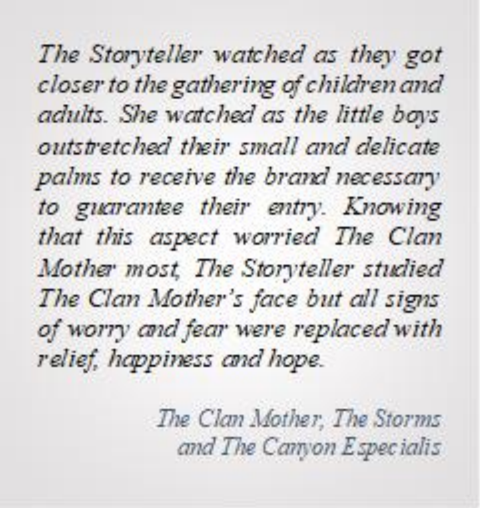
Mainstream or Specialised Education

As reiterated throughout Chapter Five, the distinct division between mainstream and special education, and the suitability of either for their child, emerged a recurring theme across the parent narratives. This division was less discussed in relation to the children's pre-school, with eight of the nine children attending a mainstream ECCE setting. The introduction of the *AIM* (DCYA 2016a) meant that the way in which their child was included in preschool had changed. Such changes were typically viewed as positive by the parents. While the increased focus on expertise and the provision of relevant materials was welcomed, parents were more apprehensive about the reconceptualization of support as a reduced ratio within the setting rather than the traditional one-to-one model of support provided by a pre-school assistant (PSA) from an external agency. These changes did not result in a reduced level of access for the children represented in this study. The successful inclusion of these children relied on the knowledge and understanding of the leaders and educators within ECCE settings, in relation to this organisational change. This echoes the findings of Ring and O' Sullivan (2019) and Stembridge (2019) in their examination of the role of educators in the creation of inclusive educational settings through the implementation of the AIM policy. In the present study, the creation of such inclusive spaces was presented as a more isolated or fragmented process in relation to primary education. The parent narratives revealed a significant gap between the reality of practice in primary education and, the recommendations of inclusive policy for most of the children represented in the study. Harry, Ruth and Sam were the only children who entered or planned to enter a mainstream classroom setting. The six remaining children were either enrolled in or attended special classes and schools.

National policy relating to children with additional needs has strongly emphasised the benefits of integration in mainstream education settings (DES 2004; Office of Minister for Child and Youth Affairs 2006; National Disability Authority 2011). Nevertheless, these parents' stories suggest that this is not a choice available to all families. Over twenty years ago Booth and Ainscow (1998) portrayed a divide between *them* and *us* in inclusive education internationally and envisaged the capacity of combined action in inclusive education policy and practice in abridging this division, effectively leading the narrative *from them to us*. Unfortunately, some of the children's educational experiences suggest that over twenty years later this bridge is yet to be built, with Sandra explicitly stating that in six of the seven primary schools she approached to 'take Brian' it was 'still very much them and us'. This reality echoes Lynch's (2017, p. 61) argument that the Irish educational system has consistently 'failed… to include all children' due to its fragmented nature.

Lynch (2017) acknowledges that Ireland was one of the first countries to attempt to include all children in their local mainstream school through a continuum of support encompassing integration in a mainstream setting, placement in a special class or enrolment in a special school. However, the fact that this continuum remains within the Irish education system today is presented as a concern, shared by many over the years (Psychological Society of Ireland 1994; Bennet *et al.* 1998; Barry 2009; Kinsella 2009; McConkey *et al.*, 2016; Banks and

McCoy 2017). This not only impacts the rights of these children but also infringes upon the rights of parents who, as outlined in the *Irish Constitution*, 'should enjoy true freedom in their choice of schools' (Abbott 1966. p. 644). For the parents involved in this study however, the choice was not between particular schools, rather it was between distinct philosophies of education and inclusion within the education system. Mainstream education was perceived as focusing on measurable academic achievements as the principle educational outcomes for the children. The capacity of the children to cope in such an environment was the determining factor in parents' decisions to enrol their child in a specialised setting, even if this meant they would have to seek diagnosis of severe or profound autism or intellectual disability. The fact that these children's inclusion in mainstream education was identified as a phenomenon that they would have to cope with or even '*endure*' (Hannah) is an extremely worrying issue, especially when a model of total inclusion in mainstream education is being espoused at government level for every school-age child with additional needs in Ireland (DES 2019). This study shows that in the same year that the proposed *School Inclusion Model* was announced, six of the nine children represented in the present study were either attending or enrolled in specialised settings. In these children's experience, mainstream primary education manifested as the provision of a certain level and type of schooling, determined by, and requiring specified standards upon entry, as well as departure. This representation contrasts starkly with a view of inclusive education where all children, irrespective of level of ability or disability, can participate meaningfully (UNESCO 2005; European Parliament 2017; CoE 2018). It is because of this traditional stance on the role of mainstream education that the parents in this study struggled when faced with deciding whether their child should remain in ECCE settings or start school. This struggle will now be further examined.

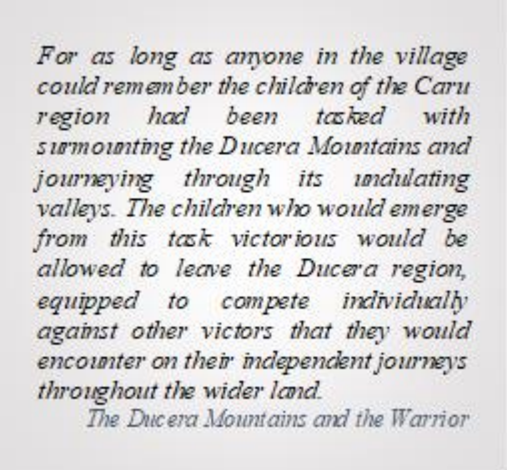

The Storyteller watched as they got closer to the gathering of children and adults. She watched as the little boys outstretched their small and delicate palms to receive the brand necessary to guarantee their entry. Knowing that this aspect worried The Clan Mother most, The Storyteller studied The Clan Mother's face but all signs of worry and fear were replaced with relief, happiness and hope.

The Clan Mother, The Storms and The Canyon Especialis

Early Years or Primary Education: One Gives you Roots: The Other? …Wings

In Chapter Five, Brenda's opinion that school is '*all about the wings of the students and the great heights they can reach*' is stark. She acknowledges the importance of school in preparing children for their future roles, however, signifying her deep worries for Sam's future, she asks: '*what if you have a broken wing, what then*?'. Research has reported enhanced outcomes for children on the autism spectrum who have been included with their peers in early years settings (Allen and Cowdery, 2014; Mozolic-Staunton *et al.*, 2015; Lee *et al.*, 2015). The main goal for the parents in this study, following their child's inclusion in ECCE settings, was that they would be ready for school. Such was the importance of this goal, that four of the six participating parents applied for an over age exemption to enable their child to remain within their ECCE setting for an extended period of time. Each of these four parents cited school readiness as the deciding factor.

Research on school readiness and autism generally centres on strategies and interventions to increase the capacity of the child on the autism spectrum to cope in school. Nonetheless, some have exposed the many stresses and challenges experienced by parents as their young child on the autism spectrum leaves pre-school to enter primary school (Quintero and McIntyre 2011; Fontil and Petrakos 2015; Starr *et al*. 2016; Nuske *et al*. 2019). Such studies reported parental concerns surrounding the importance of family experiences being understood, the impact and consequence of being othered and, their apprehension for the future. Though, similar research within the Irish context, places greater emphasis on the definite distinctions that exist between care and education (Connolly and Gersch 2016; Byrne *et al*. 2018). As suggested in Chapter One, the care/education divide that exists within the Irish education system is unique: therefore, the parents' and children's experience of navigating this division proved incredibly significant, especially as children on the autism spectrum typically present with having increased care and education needs. For four of the parents involved, traversing the chasm between care and education within the Irish education system was perceived as unfeasible for their child until they effectively demonstrated school readiness.



For as long as anyone in the village could remember the children of the Caru region had been tasked with surmounting the Ducera Mountains and journeying through its undulating valleys. The children who would emerge from this task victorious would be allowed to leave the Ducera region, equipped to compete individually against other victors that they would encounter on their independent journeys throughout the wider land.

The Ducera Mountains and the Warrior

However, as previously outlined, for some of the children, the time when they would be deemed *ready* for mainstream school never came. Thus, the concept of school readiness, widely accepted as an indicator of success in both education and society, could be accountable for the exclusion of these children who were perceived as not being able to achieve particular educational standards and outcomes (Lebowitz 2016). According to Tager (2017), the concept of school readiness must be challenged in order to prevent damage to the self-perception and identity of children and families who are unable to compete in either education or the economy. In fact, across the narratives, the parents did challenge the social and ethical implications of holding a child’s school readiness as a prerequisite for inclusion rather than evaluating the readiness of a particular school to include a child. Such a challenge required a critical awareness of the power relations implicit within the concept of school readiness, effectively recognising what Brown *et al*. (2015, p. 138) refer to as an agenda that informs policy to portray the learner as ‘one who becomes an earner and consumer rather than an active member of the larger democratic society’. The parents embraced the latter vision of their child and, in doing so, averted their gaze away from school readiness and economic productivity, towards happiness and acceptance for their children. This redefined focus meant that parents wanted their children to remain in settings where they were accepted for who they were, and their happiness prioritised. This resulted in the children attending pre-school for extended periods of time. Parental accounts of the children’s pre-school settings were saturated with references to how their children were meaningfully included by educators who recognised and valued their unique voice. Accordingly, their children’s navigation into other social settings became a more positive experience for all.

> The developmental potential of settings in a mesosystem is enhanced if the role demands in the different settings are compatible and if the roles, activities and dyads in which the developing person engages, encourages the development of mutual trust, a positive orientation, goal-consensus between settings, and an evolving balance of power in favour of the developing person
>
> Bronfenbrenner, 1979, p. 212

8.3: Experience of Action in Other Social Contexts

The first part of this chapter examined the experiences and actions of the families within the microsystem of their home. The present section considers these children's and parents' experiences of the actions of others within the social contexts that they engage in as a family. In this study, such social contexts typically manifested as education settings, i.e. the mesosystem, encompassing experiences in the home and the child's education setting. Figure 22 provides an overview of the section, beginning with the importance of the voices of children on the autism spectrum. The principle challenges presented relate to the emotive experiences of the families regarding their child's navigation of other social contexts and, the difficulties experienced during such navigational attempts. The issue of support, or lack thereof, emerges dominant with the recent changes pertaining to this. Finally, the roles, actions and perspectives of educators and leaders of educational settings are examined, with emphasis placed on their relevance to the realisation of inclusion for these children in education currently.

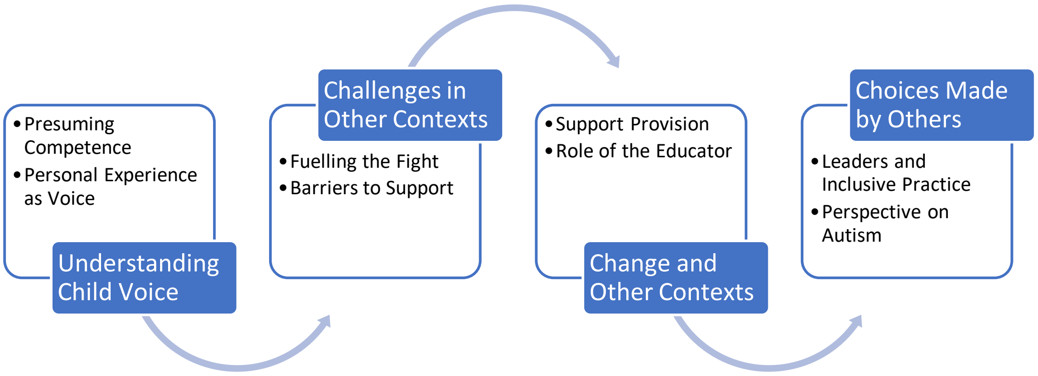


Figure 22: Experience of Actions and Narratives of Other Social Contexts

8.3.1: Understanding the Voices of Children on the Autism Spectrum in Other Contexts

In order to authentically include the voices of these young children in other social contexts certain actions emerged as integral. Within the children's microsystem and mesosystem, presuming their competence, rather than incompetence, led to more positive outcomes for children and parents alike. Gaining a deeper understanding of their unique voice commanded a deeper appreciation of the voices of others on the autism spectrum. Thus, the connection between presumed competence and, the valuing of all voices encompassed both micro and macro experiences and narratives.

Presuming Competence or Incompetence

While the importance of presuming competence is not an explicit element of Bronfenbrenner's Ecological Theory, inherent within it are the interactions, relationships and perspectives that influence the child's development. It follows, that if the significant others within the child's microsystem and beyond assume incompetence on the part of individuals on the autism spectrum, then that particular child will be negatively impacted. The point, reiterated by the parents in this study and across research from within the autistic community, is that competencies are not universal or standardised. Strengths that exist outside the scope of typical development deserve recognition. In fact, it is upon this very premise that Ogbu (1981) based his cultural-ecological theory on human competence. Similar to the work of Bronfenbrenner, Ogbu recognises the significance of various social contexts on a child's development. However, he considers in particular, the ecological development of minority groups and how their development differs from that of children within dominant groups in society. Central to his theory is the importance of identifying and developing competence.

Unfortunately, the competencies of minority groups are oftentimes not recognised as such by the majority (Douglas 2010; Devine and Luttrell 2013; Mladenov 2015b). This was evident across the parent narratives, especially in relation to the suitability of assessments used on their children during the diagnostic and, intervention stages. It was evident that in the treatment of some of the children (e.g., James, Noah and Max), that a proportion of professionals that worked with them failed to recognise their competence or the capacity they had to express their voices in different ways. It appears that these professionals were adhering the advice of those within the medical and scientific field who are sceptical of the concept of *presumed competence*. O' Neill and McCarthy (2018, p. 10) express their concerns surrounding the adoption of presumed competence as 'an anthem' by professionals working with people on the autism spectrum. They argue that it is 'not rooted in sound evidence' and presents the assumption that an individual on the autism spectrum may have 'significant untapped… capacities' as a major 'pitfall'. Travers and Ayres (2015, p. 371) built upon this critical stance, rejecting the act of assuming a philosophical, rather than scientific, stance to the evaluation of inclusive practice. They view such an approach as being 'based on presumption rather than evidence, hope rather than data', suggesting instead an alternative model of inclusive practice 'built on empiricism to pursue the best possible educational outcomes for individuals with autism' (ibid.).

Within Travers and Ayers' narrative on competence, experts and professionals are described as being best placed to monitor the pursuit of the 'best possible educational outcomes' for individuals on the autism spectrum. Some argue that a prioritisation of the measurable data of academic achievement over the philosophical hopes of inclusion has been evident in recent policy changes within inclusive education in Ireland currently (Lynch 2017; Rose *et al*. 2017). Some of these changes have been informed by prior audits of supports that were evaluated in terms of their ability to improve the academic outcomes of children with additional needs efficiently, rather than their effectiveness in realising authentic inclusion (DES/DF 2011; DOH 2012). By extension therefore, accepting or refuting competence can have either a positive or negative impact on inclusive practice. The findings of the present study align closely with the beliefs of individuals on the autism spectrum with regards the presumption of competence. For this group, anything other than its acceptance, dismisses their personal experience and, excludes their voice (Broderick and Ne'eman 2008; Kapp 2011; Hart 2014).

Valuing the Voices of Individuals on the Autism Spectrum: Dancing in the Midday Moon

In the folktale: *The Storyteller and the Moon*, the joy shared by the onlookers as they watched *the children who spoke and moved in their own way,* dancing together in the shimmering light, represents the positive outcomes that can be achieved for all, when the voices of individuals on the autism spectrum are recognised and appreciated. Across the data, stories were told of professionals who built relationships with the children and their families, centred on the importance of recognising the children's individual voices. By demonstrating this respectful and accepting position within their practice, they enhanced the interactions and relationships of these children and their families This is a key feature of inclusive practice, where the rights, rather than simply the needs, of individuals on the autism spectrum are prioritised (Mottron 2011; Heirstiener *et al*. 2017; Demer 2018). Praise was given to professionals who themselves had a loved one on the autism spectrum and, as a result, immediately respected and appreciated the voices of these children. Indeed, it was due to this intersubjectivity that the researcher felt the parents spoke so openly and freely in her presence (Finlay 2003; Pezalla *et al*. 2012; Morris and Davies 2018). However, to avoid a dominance of parental narrative, the experience and voice of the child was constantly emphasised, with innovative methodologies employed to ensure that no child's voice was silenced. The prominence given to the findings relating to the ecological construction of child-voice represent a ‘strengths-based approach to partnering with the autism community’ (Donaldson *et al*. 2017, p.56).

The present study argues that acknowledging this unique voice is a critical first step in inclusive education and, moreover, society. In their research on autism rights and voice, Ashby and Causton-Theoharis (2009) present their lived experiences of having their needs relentlessly identified, rather than their rights unanimously recognised. They deduce that this life-long practice has effectively rendered them and others like them ‘disqualified in the human race’ as a direct result of ‘living in a culture where autism is considered deviant, deficient and outside the range of normal human experience’ (ibid., p. 501). Within the present study, the simple act of recognising and appreciating the play activities of young children on the autism spectrum was critical to the positive construction of their voice, a point underrepresented across the literature in relation to autism and childhood.

Such practice is central to a more inclusive notion of, for example, child development or competence, and is entirely relationship-based, relying on the actions of individual people rather than empirical evidence (Goodley and Runswick-Cole 2010; Kernan and Devine 2010). The prioritisation of empirical data and accepted norms, rather than the child’s relational experience, has often resulted in the voices of individuals on the autism spectrum being excluded from dialogue relating to their own lived experiences as their competence to effectively communicate is questioned (Boggis 2011; Teachman *et al*. 2014; Zhang 2015). The present study indicates that such a dismissal is unfounded and, that the voices and personal experiences of children on the autism spectrum can be included in dialogue, if one adapts their mode of communication without giving precedence to oral or written contributions. Incorporating child-voice into the study enabled the development of, what Belek (2015, p. 12) describes as, ‘a nuanced appreciation of the particular characteristics and histories’ of children on the autism spectrum. Connections with their bodies, their experiences, with others and the world around them came to the fore. It was imperative to approach the narratives with this awareness in order to ‘ask what it might reveal’ (ibid., p. 12) but also to locate the emotions and feelings that parents were experiencing within the ecological realm of the child.

8.3.2: Challenges in Other Contexts

The process of navigating other social contexts created many challenges for the parents and their children. The foremost of these were challenges the parents perceived to be outside of their control and consequently unsurmountable. In contrast to the challenges within their family that were alleviated somewhat through the development of resilience or a commitment to changed perspectives and values, the challenges arising from their child's engagement in other social contexts remained a constant source of concern. Such challenges were both abstract and tangible, encompassing the emotive difficulties experienced by parents as their children navigated certain social contexts alone and, the substantial difficulties encountered in accessing support and education for their children.

Challenging Emotions and Other Social Contexts: Fuelling the Fight for Families

Mirroring the work of Fung *et al*. (2015), Hutton and Carron (2005) and Reid (1999), as parents began to describe the beginning of their journeys following their children's autism diagnosis: feelings of shock and devastation were typically reported. However, this doctoral research and other literature in the field, found a reduction in such emotions over time as parents came to understand their and their children's lived experience of autism (Andersson *et al*. 2014; Woodman *et al*. 2015; Boshoff *et al*. 2018). However, the parents did experience other challenging feelings related to their experiences of co-navigating the wider world with their young child. Reflective of the more interpretive literature, parents' feelings of worry often subsided to be replaced with frustration, hurt and anger, because children on the autism spectrum suffered as a result of a reduction in or refusal of access to supports and education (Parsons *et al*. 2009; Keenan *et al*. 2010; Lilley 2014). It became evident that the experience of such challenging feelings was often a prerequisite of decisive parent action, spurring them to continue to fight for their children to ascertain what they deserved, especially in terms of their education.

Too often, when the term 'fight' is used in a narrative of autism, it relates to a fight against autism rather than a fight for autism rights (Broderick and Ne'eman 2008; Sarrett 2012; Demer 2018). The ecological action fundamental to this inquiry positioned the child on the autism spectrum at the centre of both the narrative and the family experience, thus, prioritising their human rights. This allowed parents to acknowledge their challenging feelings while framing them as an aspect of the child's lived experience. This action centred on the recognition and development of their child's rights, and by association, the rights on the individual on the autism spectrum. Again, evoking Arendt's (1998) *Vita Activa*, with parents' 'fight' for their children representative of the uppermost level, within which caring is not viewed as labour or work but action. However, was when the act of caring fell outside the domain of the parents' actions that feelings of fear were aroused.

Fear emerged as one of the most dominant emotions throughout the parent narratives and was always connected to their children's experiences in other social contexts. The parents' primary fear centred on their child's ability to cope, not just within the context of educational settings but in wider society also, with each parent admitting that their greatest fear was their child's outcome after their death. Such strong, and oftentimes overwhelming, feelings, are in fact reflective of literature on parents' experiences of raising children on the autism spectrum (Connolly and Gersch 2016; Byrne *et al*. 2018; Vincent 2019; Sheinkopf 2020). However, the aforementioned literature also highlights that as children on the autism spectrum and their parents grow together, parental fear can be gradually replaced with feelings of hope. Integral to the development of such hope is the authentic inclusion of the child on the autism spectrum within their family, their educational setting, their community and beyond. Regrettably, due to an increased difficulty in accessing supports in education, this encompassing experience of inclusion was not a reality for some of the children within this study.

Difficulty Accessing Support/Education: Barriers, Boundaries and Bridges

As previously outlined, the struggles faced by parents in accessing supports were typically discussed in relation to the manifestation of a public versus private realm of services and agencies. Indeed, in three instances, the process of diagnosis could not be provided publicly due to staff shortages and increased workloads within the public sector, a problem commonly reported in research into Irish citizens' experience of austerity and recovery following our economic recession (Roche *et al*. 2017; O' Connell 2019; Roddy and O' Neill 2019). All nine children represented in the study were accessing private supports and therapies due to the lack of public provision in this area. This shift from public to private services will be further explored in later sections relating to investment and responsibility within the macro context. However, the families' micro-experience of the challenges associated with the adoption of these responsibilities require significant consideration. The historical relationship between the family and the State in Ireland featured in the literature review in relation to the perceived responsibility of the family in providing care and, the State's role in providing education. The experiences of the families within this study reinforce the point made by Moloney (2014, p. 72) in relation to caring and its interpretation as a 'private family matter', with all six parents reporting that, following their child's diagnosis, they had been left alone in this regard. This study argues that neither caring nor inclusion is a private issue. It is the very opposite and, relies on the acknowledgement and acceptance of its public nature. However, within these families' experiences, failure to recognise public responsibility for care had clear repercussions, not just on the families' capacity to physically and financially provide care and support, but on their children's later access to public education.

Because of this divide, and in spite of the policy trend towards inclusive public education, the reality for the families involved, revealed numerous issues regarding accessing support in public education for their young children. The main reason cited within the Government's refusal of supports or resources to these families derived directly from their view of care as separate from education, rather than care and education being recognised as intertwined in the holistic process of teaching and learning. It appears that, in some of the parents' experiences of accessing education for their child on the autism spectrum, the process of caring has been almost stigmatised. Recalling the negative responses of some leaders of educational settings on hearing that their child was on the autism spectrum, Sandra, Brenda, Alice, Ellen, Michael and Hannah claimed that in every case, this reaction related to the assumed care needs of the child and, the presumed impact of such on theirs and their peers' education. The negative impact of stigmatised stances on autism features prominently across the literature in relation to families' experiences (Gill and Liamputtong 2009; Sansosti *et al*. 2012; De Grace *et al*. 2014; Corcoran *et al*. 2015; Kinnear *et al*. 2016; Gates 2019).

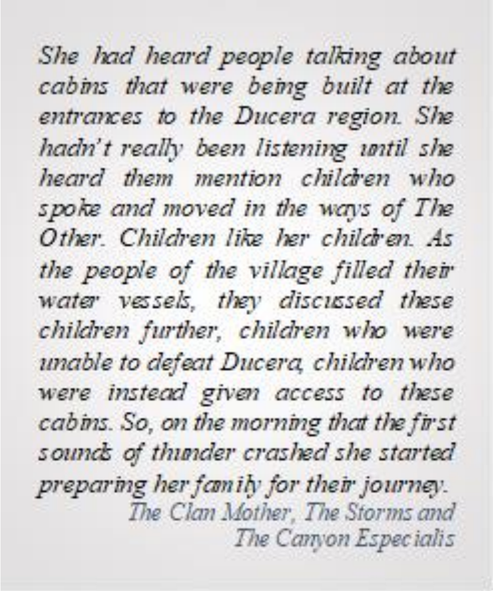
However, in order to understand the effect of, for example, the stigmatisation of caring within inclusive practice in education, a more comprehensive examination of support provision and change was necessary. This resulted in a reconceptualization of the traditional theories of stigma that lead to exclusion, isolation or alienation of those who are different (Goffman 1963; Hunt 1966) towards a more multi-dimensional understanding of the micro-experience of exclusion as action reflective of the macro-ideologies of, for example, caring. Thus, if inclusive policy in schools now formally separates the care and education needs of children and, allocates responsibility for each area to different parties (DES 2017b; NCSE 2018), has an interpretation of support as the minimum requisite necessary to cope with the perceived burden of caring emerged? Rose *et al*. (2017) argue that this is the case and that, as a result of this view, the gap between inclusive policy and practice has widened even further. This study argues that positive change is necessary to close this gap and, move from a distributive model of social justice that temporarily meets the transient needs of children on the autism spectrum, towards an inclusive social justice model that is founded upon the realisation of these children's rights over the life-span. Recent changes to support provision in inclusive education feature in the following section.

8.3.3: Changes Related to Other Social Contexts

The main changes discussed in relation to other contexts referred to changes observed by the parents within the education system. The recent changes to the provision of support for inclusion were most frequently referenced, particularly in relation to the more distinct division created between their children's care and education. Encompassed within this change, was the current role of individual educators in inclusive practice across ECCE and, primary school settings. The capacity of such educators to bring about change in these young children's lives is also highlighted.

Changes to Support Provision: Dividing the Caru and Ducera Regions

The findings of this study suggest that the families involved have experienced much change in recent years in relation to gaining access to education for their children on the autism spectrum. This was particularly apparent in the cases of Brenda and Ellen who were able to provide a comparison between the experiences of their older and younger children. The biggest change voiced by the parents was the establishments of ASD or special classes in mainstream primary schools to provide increased support and specialised education to children on the autism spectrum. Earlier, in Chapter Five, the problematic nature of the almost clinical language surrounding 'the unit' was explored, so too was the parents' interpretation that for Brian, James, Noah, Max, Eoin and Beth, '*the unit*' was presented by professionals and educational leaders as the only viable way that these children could access mainstream education. The parents generally accepted this reality for their children, but they also recognised it as a major change within the landscape of inclusive education in Ireland where, since 1998, children with additional needs were integrated into their local mainstream class with the support of a Special Needs Assistant (DES 1998b; DES 2002). An examination of the literature, however, suggests that such changes may instead be the resumed adoption of a prior stance on inclusive education in Ireland. Before the



She had heard people talking about cabins that were being built at the entrances to the Ducera region. She hadn't really been listening until she heard them mention children who spoke and moved in the ways of The Other. Children like her children. As the people of the village filled their water vessels, they discussed these children further, children who were unable to defeat Ducera, children who were instead given access to these cabins. So, on the morning that the first sounds of thunder crashed she started preparing her family for their journey.

The Clan Mother, The Storms and The Canyon Especialis international push for integration of children with additional needs into mainstream education, separate classes for children with additional needs had been established across Ireland (Commission of the European Communities 1992; Fleming 2016), a process that continued, but to a lesser degree, during this international drive for inclusive education. The doubling of ASD or special classes in Ireland since 2012 seems to be further evidence of segregation within an international era of inclusion (Banks and McCoy 2017). However, for the parents, having access to an ASD class meant that their children's care and education needs could be met simultaneously. Nevertheless, McConkey *et al*. (2016) argue that criticality is necessary in any examination of such provision within inclusive education in Ireland currently. They caution that the allocation of support to increasingly segregated and specialised settings within the education system has resulted in children with more significant needs now being 'at greater risk of being excluded from mainstream education' than before (ibid., p. 96). They suggest that this landscape of change is based on the needs of the education system rather than the rights of the child. Likewise, parents in this study, all accepted their child's enrolment in specialised settings as the only option when inclusion within the mainstream education system was considered unrealistic. The most common reason cited by parents for their child's exclusion from mainstream was their ability, or perceived inability, to achieve the expected educational outcomes associated with quality primary education currently.

The relationship between parental decision making and quality in education was highlighted earlier in the literature review, with the concept of quality emerging as a wholly subjective entity and therefore best understood regarding its relationship to inclusion in its dynamic form (CECDE 2005; Dahlberg *et al.* 2007; Alexander 2009; Opertti *et al.* 2014), where relationships, well-being and acceptance of difference are fundamental. The parents' experiences were reflective of a subjective stance on quality education. Their prioritisation of dynamic, rather than static indicators of quality is congruent with the literature on inclusive education in the early years (Quintero and McIntyre 2011; Fontil and Petrakos 2015; Starr *et al.* 2016). For the parents, their child's happiness outweighed any objective or static evaluation of their quality educational outcomes. Thus, a significant finding relates to the change within parents regarding their vision of quality education. As previously outlined, all six parents began their journeys with the goal of mainstream primary education for their children. However, four parents faced barriers that impeded this realisation. What emerged significant from this stark reality was the perspectives and experiences of the parents in relation to the alternative education settings they and their children were redirected to. Therefore, for these families, the resurgence of specialised settings within and outside of mainstream education (e.g. special classes and schools) began to represent optimal quality in terms of inclusive education, with the lack of supports and static view of quality educational outcomes in mainstream education being presented as a grim alternative that their children would have had to endure rather than experience. It is important to note, however, that fundamental to the parents' perception of quality educational settings across the education continuum was the role of individual educators.

Role of Educators in Bringing About Change: Leading Out or Locking In?

Throughout this study, the role of educators in inclusive education, and the subsequent changes within this role at present, were regularly discussed. Before locating the educator within this tumultuous domain, consideration must be given to the manifestation of the term educator as a recurring narrative motif across the parent stories. When educators, as a group, were positively referenced, they embodied elements of a strong educational partnership across the entire setting. For example, the collective group of early years educators that Alice and Michael so often credited for their role in their sons' inclusive educational experiences. For the most part, however, educators were typically presented as lone social actors, who themselves were experiencing change rather than bringing such change about. In fact, the parents also identified the somewhat unrealistic expectations surrounding the role of educators in inclusive education in Ireland at present. It appears therefore that there is a distinct contrast between the interpretation of the role of educator within these parent narratives and the treatment of this role within current education policy. Certainly, they are not alone in this evaluation of educators' roles.

In 2017, when the revised *Circular 0013/17* on special education allocation in schools was implemented, Young *et al*. examined the possibility of authentic inclusion as a result of such policy and concluded that it represented 'utopian thinking' (2017, p. 1). Central to such policy, and indeed to this study, is the immense importance of the perspectives and attitudes of educators towards inclusive education. However, congruent with Young *et al*. (2017), Sandra, Brenda and Alice, highlighted that while the educators they engaged with, held positive attitudes towards inclusive education, they cited multiple external barriers to inclusion, the foremost of which was availability of resources. Leonard and Smyth (2020) further, and more specifically, explored educators' attitudes towards the inclusion of children on the autism spectrum in mainstream education in Ireland in the years following the implementation of the revised circular and found that adequate resources were pivotal to both the facilitation of inclusion and the sustainability of educators' positive attitudes to inclusive education. This resonates with Brenda's account of the individual educator who experiences self-blame due to his or her inability to meaningfully include a child or children with additional needs in the mainstream setting, as a result of the 'tension' experienced by teachers as they attempt 'to meet the needs of class groups while ensuring that all students receive[d] an appropriate education' (Casserly *et al*. 2019, p.626). Such circumstances are cognisant of the work of Shay (2002) on the moral injury experienced by those on the ground as they observe the damage that can occur through their implementation of the commands of those in power. Levinson (2015) applies the concept of moral injury to the discipline of education, rather than its original field of military roles and action, and examines the emotional guilt and self-blame experienced by educators as a result of injustices within the education system that are largely outside of their control. In essence, the urgent need for a shared commitment by all stakeholders, to ensure inequalities and injustices were not reproduced in practice, was stressed.

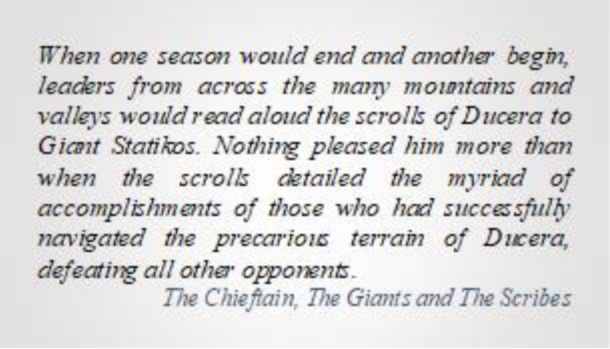
Unfortunately, as voiced by the parents earlier, because of issues relating to the provision of adequate resources, educators are tasked with filling the gap that has emerged between policy and practice in inclusive education. Ironically, the act of *filling in* or *filling up* comprises the original meaning of implementation, a term that by the mid-1400s had come to represent the act of completing a repayment. However, the capacity of lone educators to undertake their present task appears uncertain and unjust. As a result, such an approach to inclusive education can hinder rather than help children on the autism spectrum, and their families, who are directly impacted by the implementation (or lack, thereof) of inclusive policy. The parents accepted the need for educators to enhance their expertise, however, they also felt that this was not wholly effective in closing this gap. Indeed, parents drew conclusions similar to Kitching *et al.* (2014) and Blum *et al*. (2015) who found that while increased levels of expertise are critical to the success of inclusive practice, each educator's action can only be understood within the socio-cultural context of the setting and those who manage and govern it.

8.3.4: Choices Made by Others

The concept of choice within this study has manifested as a multifaceted entity. Choice is typically interpreted as free will or having the power to choose. Within this research a recurrent representation of choice as accepting the only alternative or viable option became a significant feature of the narratives. While this reality was explored earlier pertaining to the parents' choices, it is now examined in relation to the choices available to leaders in making inclusion a reality for these young children on the autism spectrum.

Choice of Leaders to Ensure Inclusive Practice: Managing?... Almost

Across the children's, parents' and researcher's narratives it became evident that there must be a clear distinction made between educational leadership and educational management if authentic inclusive education is to become a real possibility. It is widely accepted that inclusive education relies upon leaders who have the capacity and the resources to lead and to guide others towards shared goals of importance (Shields 2014; MIC/ECI/MU 2017; Moloney and McCarthy 2018). In her overview of the evolution of inclusive education, Lynch (2017, p.61) highlights that instances of good practice relied on the leader of an educational setting recognising and accepting their role as 'an important agent of change'. Similar to Ellen's pledge that she would do '*everything*' to ensure her setting would be authentically inclusive. However, Shields (2014, p. 333) explains that leadership can only be considered an effective tool in the creation of socially just education systems and societies if leaders of settings critically transform both their philosophy and practice through gaining a deep understanding of their role in 'perpetuating or addressing disparities and inequities in the world'. The importance of criticality in inclusive leadership is therefore clear. All six parents spoke about individual educators whose personal philosophy enhanced the inclusive practice within their setting, Nonetheless, they each referred to leaders who struggled to facilitate inclusion due to external constraints, for example, the availability of supports as inputs and the emphasis on measurable educational achievements as outputs. In some instances, the impact of this struggle was palpable with leaders visibly suffering because of the conflict between their belief in inclusion and the limitations of their capacity to realise authentic inclusive practice. Ebert (2016, p. ix) presents this scenario as a process of individualisation in public work, where the 'conditions of marketisation' transform the 'emancipatory qualities and motivations' that may be present in individual leaders reducing their role to the 'reproduction of systemic imperatives'.



When one season would end and another begin, leaders from across the many mountains and valleys would read aloud the scrolls of Ducera to Giant Statikos. Nothing pleased him more than when the scrolls detailed the myriad of accomplishments of those who had successfully navigated the precarious terrain of Ducera, defeating all other opponents.

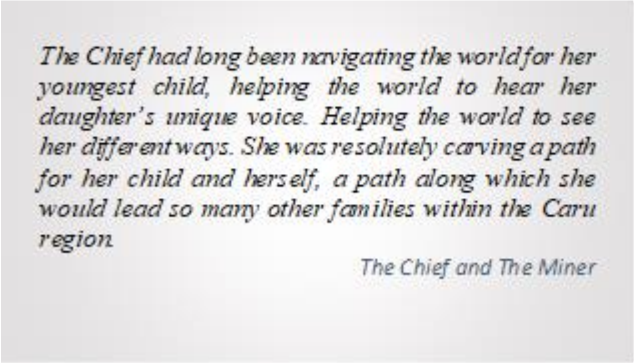
The Chieftain, The Giants and The Scribes

Across early years and primary education in Ireland over the past number of years, leaders of educational settings have been tasked with roles and responsibilities more fitting of managers, with the act of directing and controlling becoming central to their occupation (Lynch *et al*. 2012; Devine 2013; Devine and Luttrell 2013). This is not a natural evolvement of their role but a divisive act that has been interpreted as ‘reconstructing educational leaders to enact new managerial forms’ in a bid to ‘curb their power’ (Lynch *et al*. 2012, p. 5). When such power imbalances exist within the education system the reality of authentic inclusive practice moves further out of reach. Instead, there is the risk of equating inclusive practice with the placing of children in educational settings under the direction and control of leaders who may neither have the resources nor the power to make authentic inclusion a possibility for all. When such power imbalances exist, the act of inclusion can manifest within the child’s *micro* and *mesosystem* as a negative experience, which in turn becomes inseparable from the evolving view of the child who is being included. Such experiences and views can also contribute to the wider narrative of autism within the field of education and beyond. A narrative that, this research argues, informs the perspectives of all involved in inclusive education.

Perspectives on Autism and Inclusion

As mentioned previously, the issue that emerged both dominant and unanticipated, was the range of opinions that leaders of educational settings held in relation to the inclusion of children on the autism spectrum in education. The diversity of opinions among these leaders highlighted the varying levels of experience and expertise held by those in charge of educational settings. However, it also reflected the fact that for inclusive education to become a reality, the pre-existing assumptions of those involved in education require deconstruction (Devine 2013; Blum *et al.* 2015; Leonard and Smyth 2020). The present inquiry examined the construction and impact of such opinions ecologically, essentially exploring the difference between the construction of opinion in other contexts and the impact of judgements on those within the microsystem. Evident within the parent narratives was the acceptance of people’s opinions on autism and inclusion as being typically reflective of their own individual experiences. However, judgements constituted generalisations in relation to autism and inclusion, that can be damaging to many groups across settings, especially young children on the autism spectrum and their families. The judgements that bore the most significant impact were those that comprised of the inevitable laying of blame, for instance, the view that parents, like Sandra and Hannah, should have known better then to pursue enrolment when a child is perceived as unsuitable for a particular educational setting.

As outlined earlier, the choices available to educators in relation to their role in inclusive practice appear somewhat limited. They do not hold power in relation to policy design and the consequent administration of responsibility. However, they do have the capacity to adopt a perspective that bolsters, rather than blockades, the inclusion of children with additional needs. Looking at autism and wider disabilities as aspects of difference, rather than deficit, can be of huge benefit to leaders who are responsible for inclusion and, the children and families who hope to be included. The language used by some of the leaders and educators when discussing autism could reveal their philosophical position regarding the inclusion of individuals on the autism spectrum in education (Ripamonti 2016, p. 56). The rejection of terms with negative connotations, for example, disorder or deficit, as evident in Anna's practice is presented as a 'humanising' action that enhances the well-being of the person on the autism spectrum and their significant others (ibid.). This study does not suggest that a change in a leader or educator's perspective on autism will guarantee the effective inclusion of children on the autism spectrum across the Irish education system, the present issues surrounding the provision of and access to supports have undeniable repercussions for inclusive practice (Lynch 2017; Rose *et al*. 2017). But it does argue that while educators must take a critical stance within their practice in terms of the reality of their role, the significance of also adopting a philosophical position that appreciates the differences of children on the autism spectrum and champions their right to inclusion in education.



The Chief had long been navigating the world for her youngest child, helping the world to hear her daughter's unique voice. Helping the world to see her different ways. She was resolutely carving a path for her child and herself, a path along which she would lead so many other families within the Caru region.

The Chief and The Miner

Without such educators these families' trajectories would have been quite different. Underlying every parent narrative was the significance of the perspectives that parents, teachers and the public held in relation to autism. But the parents involved specifically spoke about educators whose perspectives on autism showed that they understood, that they 'got it' and consequently was presented as a fundamental keystone of their child's inclusion in education. Such educators certainly emulate the power highlighted by Bronfenbrenner (1979) in terms of how a single adult could change the life of a child. However, it is critical to understand the macro-forces influencing and impacting the actions of such adults and the consequent experiences of children on the autism spectrum and their families. The next and final section will examine in detail such experiences and actions, interpreting these in relation to macro-forces and contexts, namely, the grand narratives of difference in society, prevailing social norms, the media, Government action and policy.

If the children and youth of a nation are afforded opportunity to develop their capacities to the fullest,

if they are given the knowledge to understand the world and the wisdom to change it,

then the prospects for the future are bright.

Bronfenbrenner, 1974, p. 1

8.4: Experience of Actions and Narratives of the Exosystem and Macrosystem

In exploring these children's and families' experiences within their home and across the Irish early years education system, the challenges and changes they have faced and endured, and the subsequent limited choices available to them, have become evident. The emphasis, thus far, has been placed on the experiences, roles and actions of the significant others within the children's micro and mesosystems. However, in order to effectively interpret and discuss these children's and families' experiences ecologically and critically the influences and impact of their exosystem and macrosystem must be extensively examined. This section is introduced and framed by an exploration of the grand narrative of difference in wider society. This culminates in an appraisal of these children's and families' experiences and actions as evidence of challenging prevailing social norms across a variety of contexts and platforms. As the choices of families within their microsystem and adults within the mesosystem have been presented, the choices of Government in relation to the distribution of investment and responsibility will now be examined, the outcome of which informs the final segment regarding the adoption of an ecological stance to policy and change.

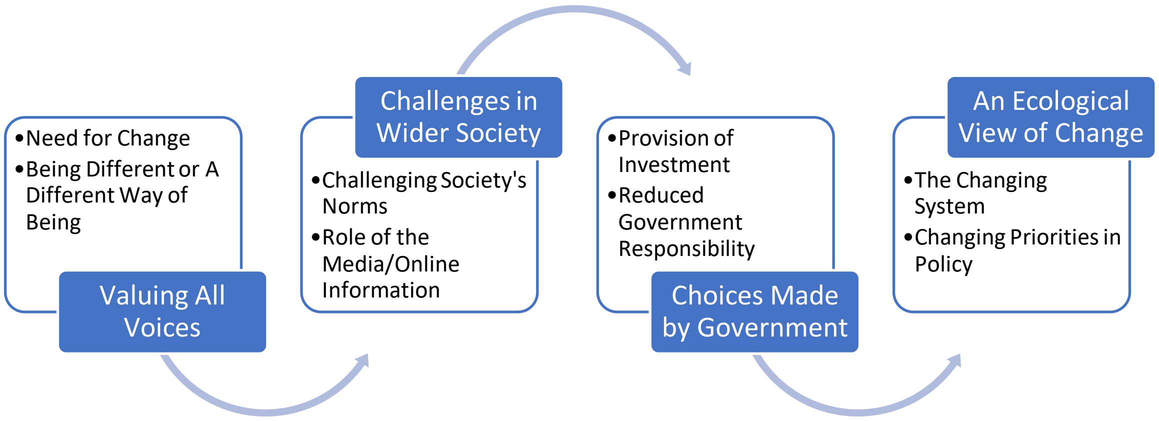


Figure 23: Experience of Actions and Narratives of the Exosystem and Macrosystem

8.4.1: Appreciating Remote Voices

The ecological stance adopted throughout this study recognises and appreciates the voices of children on the autism spectrum and their families beyond the micro and meso system. Without such recognition and acceptance within the macrosystem these children's and families' experiences continue to be '*othered*' and the construction of their collective identity, and individual self-perception, is negatively impacted. This study's call for change relies on the inclusion of voices, so often silenced, in the dialogue surrounding the creation and development of inclusive education and society.

> *Now, since the beginning of stories the immense and dominant tree of knowledge has stood in the centre of the village. Upon this revered tree, collections of accepted symbols were often attached. Only those who held valuable knowledge could add to the tree if they saw fit.*
>
> From The Tree of Knowledge and The Elder

Need for Change: Listening to All Voices

While it is widely accepted that expertise is promoted as integral to inclusive education, this study questions the voices that are either included or excluded from any given field of expertise. It argues that the expertise garnered from the lived experience of autism or disability in the family must be recognised as a vital fund of knowledge available to any educator with responsibility for inclusion (Lilley 2014; Connolly and Gersch 2016). While parents regularly identified the importance of their children's, and their own, voices in any inclusive action, they also spoke about the issues that can occur when conflicting perspectives or voices come together. For some of the parents such conflicts resulted in they or their child having to leave a particular setting or space, or not being granted access there to begin with. The conflicting agendas that emerged across the parent narratives comprised of (1) needs or rights-based models of inclusion, (2) the somewhat diverging philosophies of care and education and, (3) the opposing ideologies of inclusion as education for all or as optimum educational outcomes for all. Such 'mentalities of rule around educational inclusion' (Douglas 2010, p. 105) each have their own associated expertise which impact the possibility of inclusion for these children in any given setting, with exclusion often occurring as a result of 'immanent conflicts' that often leave 'non-abled' children behind 'in spite of promises of the opposite' (Stangvik 2014, p. 91).

When individual parents offered encouraging accounts of the inclusion of their families' voices in a particular education setting, it was just that. An account of a particular education setting that had chosen to include their lived contribution. The multitude of models, philosophies and ideologies continued to exist, but the individual setting, and those within it, had created their own inclusive space that welcomed the voices of children on the autism spectrum and their families. This research therefore argues that for authentic inclusive education to become the reality, rather than the exception, in Ireland, all relevant voices must be recognised and given equal weight. The voices of children on the autism spectrum are integral (Conn *et al*. 2020). Thus, creating a Bakhtinian power-sharing 'polyphony' where each voice can 'encounter each other as equals and engage in a dialogue' (Kim 2016, p. 74). However, in this study where the experiences of nine children were represented, five were excluded from a particular educational setting as a result of conflicting positions surrounding autism, inclusive practice or both. Brian, Noah, Max, Ruth and Eoin all at some point were judged as having needs that could not be met within a particular model or were viewed as posing challenges to care or education, that could not be overcome. However, it was usually these children's autism diagnosis that led some professionals to decide that they would not attain a positive educational outcome and were, therefore, unsuitable for certain settings, causing substantial hurt and damage. This study found that such hurt and damage subsided when those involved in inclusive education accepted autism as a different way of being and indeed appreciated this diversity. In some instances, this action lead to, what Bakhtin describes as a carnivalesque celebration of voice, where those typically excluded or silenced are not just welcomed, but their knowledge and experiences are valued (Bakhtin 1981; Holquist 2003).

The Grand Narrative of Autism: Being Different or a Different Way of Being [construction or destruction of voice]

As outlined in the literature review, much research has explored the variety of narratives that are associated with autism in a bid to determine the optimal language with which to describe or discuss the phenomenon (Broderick and Ne'eman 2008; Rutter and Schopler 2012; Pellicano *et al*. 2014). It appears, however, that an ultimate decision has not been reached. Indeed, Kenny *et al*. (2016, p. 442) suggest that there remains considerable 'disagreement about the way autism is and should be described'. While it may seem of little consequence whether the term *autistic*/*on the autism spectrum* or *person with autism* is used, the impact of this simple language choice can be considerable. Some argue that it can reveal whether the social actors within the microsystem of children on the autism spectrum and beyond, understand autism to be an aspect of diversity or a category of disorders (Mottron 2011; Owren 2013; Hart 2014).

The parents promoted a narrative of autism that drew on the social model of disability which recognises disability as an aspect of diversity similar to race, gender or ethnicity (Abberley

1987; Campbell 2009; Anastasious *et al*. 2016), representative of the acceptance of the concept of neurodiversity. This was significant as the children represented in the study were diversely positioned along the autism spectrum.

Baker (2006, p. 15) critiques the feasibility of individuals across the realm of disability adopting such neurodiverse stances and differentiates between the concepts of neurodiversity and neurological disability. He states that neurodiversity is associated with the acceptance of neurological difference as ‘individual or community identity’ whereas neurological disability describes the ‘impairment of socially determined major life functions caused by observable, diagnosable difference in an individual’s brain’. This distinction has manifested as a criterion for inclusion in or exclusion from many groups comprised of either individuals on the autism spectrum or members of the wider autism community (Lewiecki-Wilson *et al*. 2008; Sarrett 2011; Hays and Butawski 2018). However, the parents in the present study did not make this classification at all. For them, regardless of any perceived or diagnosed ‘impairment’ within their child, autism was accepted as integral to their identity and viewed as an integral feature of their voice.

The parents’ recognition and appreciation of their children’s unique voice and experience is, in fact, a prerequisite in changing such socially determined norms. The power of parents of children on the autism spectrum to act with their children, and the wider autistic community, in bringing about change, relies on this very point (Hays and Colaner 2016; Webster *et al*. 2017). Therefore, the actions of Alice, Sandra, Hannah, Michael, Brenda and Ellen can be located within the neurodiversity movement. Central to which is the critique of the medical model of autism while simultaneously recognising the struggles that children and families experience, thus endorsing ‘a deficit-as-difference conception of autism wherein neurological conditions may represent equally valid pathways within human diversity’ (Kapp *et al*. 2013 p. 59). It seems, however, that while the parents portrayed a wholly positive approach to autism and difference, some of the children represented in the study still developed a negative perspective towards autism, and their experience of difference, in wider society. With Brian and Ruth’s parents suggesting that their children had perhaps internalised the accepted norms of society and identified that their lived experience and identity conflicted with these. The next section examines such norms and presents the children’s and parents’ challenge of these.

8.4.2: Challenges in Wider Society

It could be argued that many of the challenges experienced by the families represented in this study are derived from neoliberal ideologies espoused at a macro level. In neoliberal societies, government policy and collective social action, aims to construct independent, self-regulating individuals and groups, who will ultimately benefit the future economy and, generate a profit from the investment made in them in their earlier years (Harvey 2005; Brown *et al.* 2015). While the child on the autism spectrum does not typically enter the exosystem, much consideration must be given to its influences and the encompassing macrosystem on their development of voice and identity and the actual possibility of their and their families' authentic inclusion in wider society.

Challenging Society's Norms

Earlier, this chapter highlighted the presence of fear within families, in relation to the ability of their child to cope in other social settings. All six parents demonstrated their commitment and capacity to cope 'actively' through the adoption of a positive, and proactive, 'approach', rather than 'avoidant' stance throughout their family's experience of autism (Snyder 1999, p. 108). This greatly reduced their risk of experiencing the mental health struggles often associated with those who passively cope with such circumstances, for example, self-blame, denial, disassociation and substance abuse (Mouzourou *et al*. 2011; Hoogsteen and Woodgate 2013; Mount and Dillon 2014; Tait *et al*. 2016). Instead, it emerged that the mental well-being of the older children in the study was negatively impacted due to their adoption of passive coping strategies in other social contexts. Ellen for instance, described Ruth's changed behaviour as '*wired*' and '*hyper*' whereas Sandra indicated that Brian presented with '*the symptoms of chronic depression*'. With both children's differences being accepted and appreciated within the home, a deeper analysis into the impact of wider social settings on the development of their voice and identity was vital. It appeared that while their parents' actions were representative of our modern understanding of coping as the ability to bend without breaking, both Brian and Ruth's behaviour in other social contexts suggested that they, instead, had embraced the original definition of coping as the act of providing someone or something with a cloak (or cope)[10]. Brian and Ruth's silence in Chapter Six, which examined the

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[10] Etymology of Coping: By the late 1700s the meaning of coping had evolved to mean the capacity to handle yourself or something successfully, to deal with something. Possible derived from the architectural process of forming "a cope" that can bend as an arch or the medieval process of providing someone with a cloak or "cope"

construction of voice, embodied their attempt to blend in and remain unnoticed in certain social settings. Worryingly, their perception of difference as ‘other’ represented a ‘disidentification’ among those who are different, but do not identify as such (Medina 2003, p. 655). While Bronfenbrenner’s (1961) concept of identification is an inter-personal process, where the developing individual relates to other identities as they construct their view of themselves or their voice, disidentification as a process is more influenced by the prevailing social norms and what the developing person perceives to be acceptable or unacceptable, normal or abnormal.

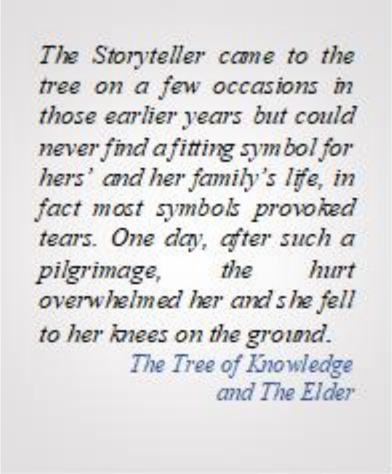
Normality, and indeed abnormality, is always defined culturally and ultimately based on the most accepted or unaccepted social behaviours of a society (Benedict 1934; Foucault 2003). If an individual does not exhibit the prevailing social norms of a particular society, they are immediately viewed as the deviants or outsiders: ‘disqualified in the human race’, (Ashby and Causton-Theoharis 2009, p.501). Such social norms are integral to the sustainability of a society. In fact, neoliberalism depends on the widespread acceptance of these norms to create and maintain a productive and efficient society (Harvey 2005; Davies 2014; Brown *et al*. 2015). These norms are continually reproduced across society and have long been identified as penetrating the institutions of family, educational setting and community (Foucault 1970; Freire 1970; Bourdieu 1977; Habermas 1990), the micro and mesosystems within which children on the autism spectrum engage. One must deduce that such regimes of alleged truth and observed power are ‘embedded in the process of identity formation through the dominance and evolution of particular discourses and norms’ (Lynch *et al*. 2012, p.106). They therefore impact the ways that children on the autism spectrum construct their voice and identity.

As this study was influenced by the fields of philosophical and narrative thought, the interpretive understanding of such norms was necessary. Drawing on Bakhtin’s ‘unofficial truths’ (Kim 2016, p.75) and Arendt’s ‘axiomatic assumptions’ (1954 p. 142) the parents’ actions, in response to their child’s identification of disidentification, enabled the inclusion of the voices of these children on the autism spectrum in the polyphonic harmony of difference (Bakhtin 1981). When Brian and Ruth’s parents spoke to them about autism as an aspect of diversity and an important part of their identity, they effectively offered their children a positive counter-narrative. This empowered them to actively cope with the experience of being different in a society where the standards of universality are upheld. However, such an approach can be limiting if wider acceptance and appreciation of difference does not permeate the macro-forces of society and their associated funds of knowledge (Joseph 2013; Runswick-Cole 2014;

Lamont *et al*. 2016). Therefore, the funds of knowledge influencing such norms warrant exploration.

Risks of the Media/Online Information: A Tree of Knowledge?

Earlier, the challenges that families faced were explored with reference to the influence of the opinions of others on their lives. The most regularly referenced opinion was the negative or uninformed perspectives on autism among some of the wider public, and the impact this had on both themselves and their children. Indeed, it is important to note that all six parents treated their involvement in the research as an opportunity to address this issue on a wider forum, thus, their participation can be viewed as critical action that could influence wider socio-historical interpretation (Arendt 1958). The association was made between the presence of such negative views in society and the potential damage to the construction of child-voice and identity, with all of the parents discussing the ways that these perspectives can be internalised. Thus, highlighting the need to examine the range of opinions and perspectives that could potentially destruct, rather than construct, the voices of children on the autism spectrum.



The Storyteller came to the tree on a few occasions in those earlier years but could never find a fitting symbol for hers' and her family's life, in fact most symbols provoked tears. One day, after such a pilgrimage, the hurt overwhelmed her and she fell to her knees on the ground.

The Tree of Knowledge and The Elder

As touched on in Chapter Five, the variety of conflicting information in relation to autism and disability that is available online can be problematic, even dangerous, especially as those seeking information online may be at their most vulnerable (Sarrett 2011; Leatherland and Chown 2015; Ben-Sasson *et al*. 2016). The risks associated with the availability and quality of online information for parents, have long been identified by researchers concerned with 'pseudoscience' (Riggot 2005, p. 55). Other concerns relate to medicalisation of children on the autism spectrum in a bid to treat or, moreover, cure what was presented to parents online as a serious medical condition (Brent 2013; Conrad and Tan 2014, Crisponi *et al*. 2015). It follows that if autism is presented in the media and beyond, as a disease or condition that warrants intensive treatment or cure, all methods will be deemed necessary and acceptable (Fox and Mulick 2015). Crucially, success will be measured in terms of the level of indistinguishability between the child on the autism spectrum and their typically developing peers (Lovass 1993). In their online content analysis of information relating to autism, Lewiecki-Wilson *et al*. (2008, p. 314) described a type of 'autism wars' emerging between individuals on the autism spectrum who viewed autism as a part of their identity and, parents and professionals who viewed autism as a medical condition requiring treatment. The central bone of contention dividing these groups was the use of Applied Behaviour Analysis (ABA) as a treatment for children on the autism spectrum (Owren 2013; Bowman and Baker 2014; Donaldson *et al*. 2017). Nevertheless, within this doctoral study, engagement in ABA therapy was generally presented as a positive experience for children and parents alike. Again, these experiences relied on the role of individual professionals, their view of autism and their interpretation of the philosophy behind such intervention.

In 2016, as part of the present study, an online content analysis was carried out on information circulated by agencies across Ireland and, the UK who state that they offer support to parents of children on the autism spectrum. This analysis found that while there were similarities across the agencies' names (e.g. Autism Alliance, Autism Action, Autism Partnership etc) there were vast differences between each agency in relation to their views of autism. Two such agencies: Autism Alliance UK and Autism Partnership UK, while seemingly analogous, demonstrated how conflicting these 'Autism' agencies positions could be. While Autism Alliance (2016) described their role in a 'vision of a better world… as an alliance [who] hold shared beliefs and values relating to the individual potential of people on the autism spectrum', Autism Partnership (2016) quoted the prior work of ABA pioneer Ivor Lovaas and emphasised the importance of parents committing to 'consistent' and 'intensive' ABA treatments to ensure 'successful outcomes' for their children. Success relied on the 'proper dosage of treatment', encouraging parents to imagine 'if you have cancer, the oncologist might say that to increase the likelihood of remission, you need to receive the appropriate level of chemotherapy over a certain period of time'.

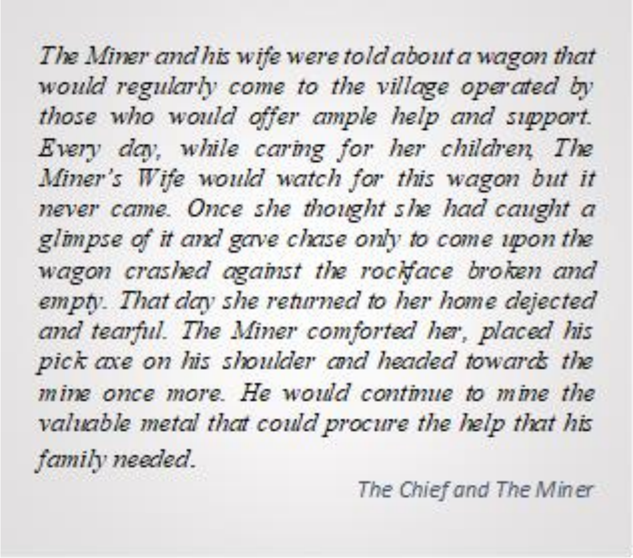
With such information potentially permeating the homes of children on the autism spectrum and their families, it is hardly surprising that the parents in this study often gave accounts of 'coming off' the internet or social media due to the abundance of negativity they observed. However, in the case of Autism Partnership, individuals on the autism spectrum and their parents raised their concerns in relation to the damaging comparisons made between autism and cancer. Consequently, the excerpt was replaced in 2019 with 'if you are suffering from a serious medical condition' (Autism Partnership 2019). While this statement still reflects their deficit approach to autism, it is not as harmful as their previous declaration. Such parental action reinforces the findings of Langan (2011, p. 205) who suggests that while parents of children on the autism spectrum have 'played a prominent role in controversies' associated with autism for example, beliefs in relation to vaccinations and searches for treatments, cures etc., a significant proportion of parents have ‘rejected this approach, making common cause with people on the autism spectrum’. Thus, contributing positively to ‘the evolving official discourse around autism’ (ibid.) and, perhaps, creating their own symbol fit for hanging on the metaphorical *Tree of Knowledge*.

8.4.3: Choices Made by Government: The New Way

The aforementioned positive contributions made by parents to the narrative of autism were highlighted as significant as they shared a common cause with individuals on the autism spectrum. Such power-sharing partnerships are of paramount importance to both inclusive education, and wider social inclusion, as they allow parents to transition from simply wanting successful outcomes for their children towards the more holistic action of working in partnership, to ensure a better life for their loved one. However, this research argues that placing value on the realisation of a better life rather than simply focusing on the possibility of achieving successful outcomes must be a vision shared among all stakeholders in education and society, not just among these parents and their children. The role of Government in such inclusive partnerships is paramount and will now be explored with particular emphasis placed on its provision of investment and responsibility for inclusion.

Provision of Investment: Better Outcomes or a Better Life?

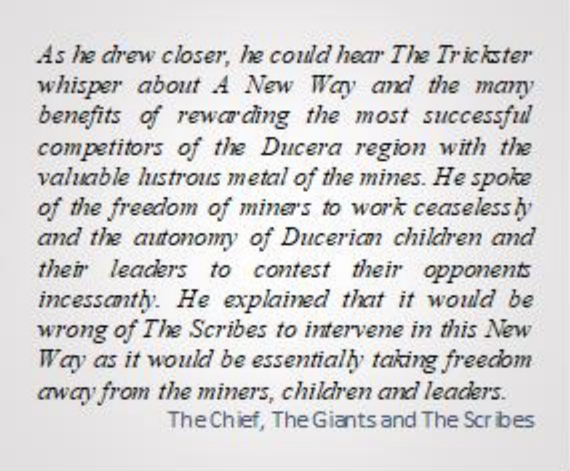
In recent years, the Irish Government has invested considerable amounts of money in certain areas where autism-related needs have arisen (DF, 2019). All six parents in this study acknowledged the investment placed in their child’s home tuition, specialised education or transport to a school further away. Nevertheless, they interpreted such investment as reactive rather than proactive. They reasoned that, in their cases, such investment was made when the families’ original choices for their children’s support or education proved unfeasible. Recent research within the Irish context reinforces the parents’ perspectives. Roddy and O’



The Miner and his wife were told about a wagon that would regularly come to the village operated by those who would offer ample help and support. Every day, while caring for her children, The Miner’s Wife would watch for this wagon but it never came. Once she thought she had caught a glimpse of it and gave chase only to come upon the wagon crashed against the rockface broken and empty. That day she returned to her home dejected and tearful. The Miner comforted her, placed his pick axe on his shoulder and headed towards the mine once more. He would continue to mine the valuable metal that could procure the help that his family needed.

The Chief and The Miner

Neill (2019, p. 1106) for instance, suggest that the economic burden of therapies and supports for children on the autism spectrum falls on parents because of a ‘significant level of unmet need’ across services. The parents, when discussing their applications for domiciliary allowances, mentioned basing their decision on the recommendation of professionals within the early intervention field. These professionals gave advice to seek financial support in order to pay privately for services their children were entitled to publicly but could not receive because of staff shortages and, a widespread lack of resources. Similar issues regarding the availability of supports in the children’s local, mainstream school were recognised as being fundamental to the significant increase in investment in ASD/special classes. Equally, Rose *et al*. (2017, p. 379) cited a lack of ‘adequate resources’ in making authentic inclusive education possible across the Irish education system. The present study argues that issues surrounding access to mainstream primary education in Ireland have become more evident since 2017, when policy changes to Government investment in special education provision were introduced (DES 2017a). Certainly, the narratives of Brenda and Ellen, both of whom had previously navigated the Irish education system for their older child on the autism spectrum referenced how ‘*different things are now*’.



As he drew closer, he could hear The Trickster whisper about A New Way and the many benefits of rewarding the most successful competitors of the Ducera region with the valuable lustrous metal of the mines. He spoke of the freedom of miners to work ceaselessly and the autonomy of Ducerian children and their leaders to contest their opponents incessantly. He explained that it would be wrong of The Scribes to intervene in this New Way as it would be essentially taking freedom away from the miners, children and leaders.

The Chief, The Giants and The Scribes

As mentioned earlier in relation to changes in support provision, it seems that priority is given to investing in long-term economic sustainability, with the resulting social inequalities being dealt with on a short-term basis, reflective of neoliberal government action (Brown 2015; Graham 2016; Burch 2018; O’ Connell 2019). Such governing action embraces the modern economic role of the market, rather than the traditional sociological role of the state, with the primary goal of education being reduced to the production of independent and competent citizens who are accepted by society (Harvey 2005; Kinsella 2009; Mladenov 2015a). When it comes to the education of children on the autism spectrum, the parent narratives suggest that the same rules apply. In an overview of the educational provision for pupils on the autism spectrum based on the *Task Force on Autism* (2001, Section 2.4), the primary goal of inclusive education was cited as attaining a ‘good outcome’ for children on the autism spectrum. This outcome was defined by their capacity to ‘reach full potential, and an appropriate level of independence and social competence through acceptance within society'. Echoing the earlier declaration in *Ready to Learn* (DES 1999, section 3.7) which highlighted the importance of quality early childhood education in addressing any additional needs in young children, as such early intervention, would be more 'effective and cost-efficient than later intervention' and, should 'maximise the private and social returns on investment'. Indeed, if one applied Bronfenbrenner's (1979) concept of *bidirectionality* or Noddings' (1984) notion of *response in the cared-for* to the relationship between the Government and the young child on the autism spectrum, the latter would be assuming the majority of the responsibility to ensure that such a partnership yielded an economically successful outcome.

Sociologists, such as Bourdieu (1977), have long critiqued the definition of education as a process of investment in capital due to the consequent inequalities created. The parent narratives suggest that present Government action in Ireland has tasked the education system, and those working within it, with ultimate responsibility for the elimination of such inequalities (DES 1998; 1999; 2001; 2004). In doing so, educators potentially become guarantors for the successful outcomes of every child. In 2016, the NCSE published their guide to educational provision for students on the autism spectrum and their parents, offering a more multifaceted view of the 'better outcomes' they envisaged for children on the autism spectrum within schools (p.11). Such outcomes were based upon the findings of an in-depth study carried out by Daly *et al.* (2016), which evaluated the provision of education for children on the autism spectrum across mainstream and, special settings in primary and secondary schools and, typically defined outcomes in terms of a child's learning or progress. Findings from this study, regarding (1) including the voices of children on the spectrum, (2) the role and experiences of parents, (3) the relationship between autism intervention and, theories of early childhood and, (4) the lack of partnership between stakeholders and across sectors impacting these children's and families' lives, echoed that of Daly *et al.* (2016). The present study responds to these issues by promoting the adoption of an ecological, rather than economical, role by Government in inclusive education, that will be further outlined in the concluding chapter. While such a shift is critical to the realisation of inclusive education for all children in Ireland (Murray and Urban 2012; Rose *et al.* 2017; Moloney and McCarthy 2018), the parent narratives suggest, the Government are distributing responsibility for inclusive education in both impracticable and unacceptable ways.

Reduced Government Responsibility for Inclusion

As mentioned earlier, in relation to the choices and roles of leaders in educational settings, the children's and parents' experiences of the recent changes within inclusive practice in education, indicate a shift in the way that responsibility for social inclusion has been distributed by the State. While the language used in explaining the positioning of the state within neoliberalism centres on the sanctity of citizens' individual freedom or autonomy (Harvey 2005; Brown 2015) in the parents' experience, such action was interpreted as being '*left to your own devices*' (Michael) and '*on your own*' (Sandra and Brenda), with a lack of support from Government reported by all six parents involved. The way that the parents perceived the Government's distribution of responsibility to other parties suggested the presence of unequal power relations among the stakeholders of inclusive education in Ireland. Leaders and educators in educational settings were oftentimes described as having their hands tied or being on their own. Such experiences align with the work of Douglas (2010, p. 105) who argues that some countries have designed 'new mentalities of rule around educational inclusion' that represent a form of 'neo-liberal governmentality in schools… as well as illiberal forms of power, in complex and contradictory ways'.

Within the present study both the *AIM* (DCYA 2016a) and *Circular 0013/2017* (DES 2017b) were analysed in order to understand the different approaches taken to inclusive practice in ECCE settings and primary schools. This analysis suggested the presence of a 'neoliberal governmentality in schools'. An initial *analysis of narratives* (Polkinghorne 1991) of the policies implied similar positions with both treating inclusion as a social justice issue throughout and drawing on the language of marketized education (e.g. quality, efficiency, accountability etc.) to ensure successful implementation. However, a deeper *narrative analysis* (Polkinghorne 1988) highlighted a significant divergence in the distribution of responsibility and power in each, with the centrality of partnership emerging a dominant aspect of the AIM. In this policy, the individual child, their parents and the relational process of inclusion were each mentioned ten times more than within Circular *0013/17*, where the process of inclusion was mentioned four times throughout. Three of these references were made to the minimum or baseline of resources that would be allocated to make inclusive practice possible, the fourth referred to achieving 'effective inclusion' in an 'efficient and timely manner' (DES 2017b, p. 20). 'Responsibility' was mentioned twice, both relating to the role of the individual classroom teacher. These narrative deductions align with the parents' stories, which were saturated with accounts of educators who had made an impact on their children's and their own lives.

However, as outlined earlier in relation to the ‘choice’ between early years and primary school, inclusive education was described as a more collective practice, even culture, in ECCE settings, a point emphasised by Brenda, Ellen, Alice, Hannah and Michael throughout their narratives. Within primary schools, the role of the individual teacher, like Múinteoir Paul, came to the fore. Paul built a partnership with Sandra based on mutual understanding, trust and power to ensure Brian’s inclusion in his class. Central to this partnership was the construction of shared knowledge and expertise.

Earlier, in the literature review, the promotion of expertise by Government was located within the realm of neoliberalism where expertise is equated with self-government, less associated with empowerment of individuals (for example educators and parents) and more closely linked to governmental control. Thus, rendering the necessary power sharing among the stakeholders of inclusive education unachievable in neoliberal times (Douglas 2010; Stangvik 2014; Chong and Graham 2017; Hardy and Woodcock 2018). This study criticises a neoliberal approach to the promotion of expertise as an alternative to the necessary supports traditionally provided by the state; a key feature of governmentality (Foucault 1991; Lemke 2001). Nonetheless, it recognises the importance of expertise in the authentic inclusion of, not just the children represented in this study, but all children on the autism spectrum. In fact, the importance of gaining a deeper recognition of the voices included in the construction of autism expertise or ‘different epistemological ways of knowing about autism’ (Lilley 2014, p. 513) has been fundamental to this research throughout. However, while continued professional development in diversity, equality and inclusive practice is advocated across policy as being integral to inclusive education (DES 2001, 2004; 2017; DES/NEPS 2007; NCSE 2011; 2016; 2018; DCYA 2016a, 2016b), the presence of conflicting narratives jeopardises the possibility realising the potential of expertise across the Irish education system. If ‘effective inclusion’ is to be achieved in ‘an efficient and timely manner’ (DES 2017b, p. 20), and the successful educational outcomes of children with additional needs continue to be measured in terms of their academic attainment (DF/DES 2011), then the collaborative co-construction of expertise, that includes the voices of children on the autism spectrum and their parents, becomes a less viable option. In this way, change remains a phenomenon designed by the macro and experienced, or endured, by those within the micro and mesosystems.

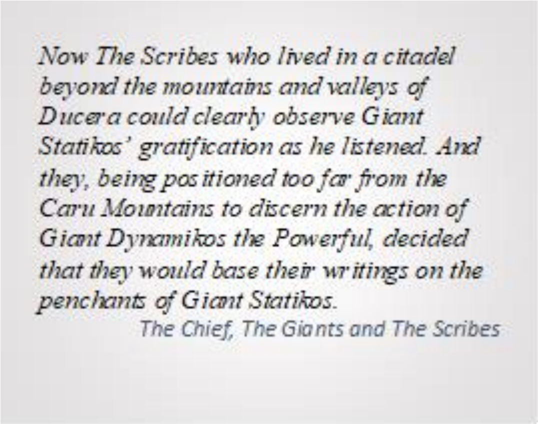
8.5: Change: The Need for An Ecological Stance to Inclusive Policy Development and Implementation

In order to explore the concept of change as it manifests within the macrosystem of these children and families, a dualistic position has been adopted wherein, the changes experienced by families as a result of macro forces are critically deconstructed and, located against a reconstructed narrative of change as political, social and philosophical action. The importance of merging such concepts is further exemplified in suggestions to merge our understanding of the rights and needs of the individual on the autism spectrum, the fields of care and education within the Irish education system and, the processes of static and dynamic quality across society. Without such unity, any attempt to achieve inclusive education for all could continue to reproduce inequalities.

The Changing System: Uniting the Caru and Ducera Regions

It is important to return to Bakhtin’s (1981) notion of the evolution of truth from the carnival of polyphonic voices, a process through which each presented their own unofficial truth in a bid to co-construct a truth together. Each stakeholder involved in inclusive education adopts their own epistemological stance on autism and inclusion. Individuals on the autism spectrum, their families, peers, educators, leaders of educational settings, professionals from different fields, government agencies, policy makers and members of society all hold particular truths based on their own experience. All such positions are therefore founded on unofficial truths, or again what Arendt (1954, p. 142) would describe as ‘axiomatic assumptions’. In modern society, the most powerful stakeholders typically decide on what should be verified as a truth. Therefore, individuals are evaluated in terms of their competence and capacity to be included in the dominant truth.

The needs of individuals who appear to be incompatible with this truth are identified and addressed quickly and efficiently, otherwise their inclusion within this truth is unfeasible (Orsini 2012; Graham 2016; Burch 2018; Hardy and Woodcock 2018). This long-identified action, again representative of a neoliberal ideology, has been described broadly as ‘the individualisation of the social’ (Ferge 1997) and more acutely as ‘the politics of production’ (McKinlay and Taylor 1998). In this transferal of responsibility from the social to the individual, from public to private production, those that struggle to produce and compete suffer. Such suffering was evident in the challenges and choices of the children and families represented in this study. While these families also spoke of their increased resilience to these adverse circumstances, it is the views and actions of the most powerful in wider society that dictate the nature of the resilience within individuals and families (Lerner *et al*. 2012). That is, whether it is a positive, empowering experience or the only possible option within a system that has excluded you. For Sandra, Hannah, Alice and Michael their truths described the latter. They all referred to a 'system' not fit for purpose and, built on truths that were far removed from theirs and their children's present or future lived experiences. The role that these children and parents could (and should) have in making inclusion a possibility for all, is evident throughout this study. Indeed, their collective voice seems to urge those with power in the system to 'privilege interdependency over liberal concepts of the autonomous self' (Mitchell *et al.* 2014, p. 7). They place immense value on the act of caring, a truth that they believe should be embedded in 'the system'.



Now The Scribes who lived in a citadel beyond the mountains and valleys of Ducera could clearly observe Giant Statikos' gratification as he listened. And they, being positioned too far from the Caru Mountains to discern the action of Giant Dynamikos the Powerful, decided that they would base their writings on the penchants of Giant Statikos.

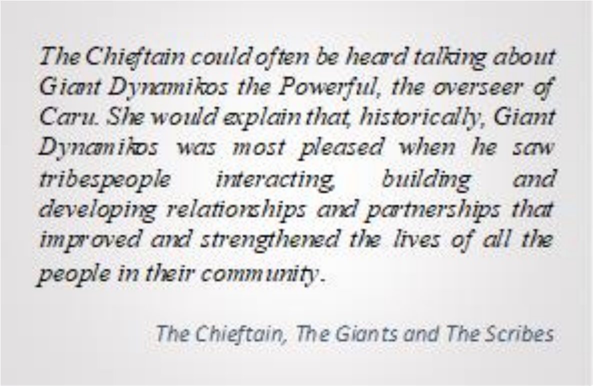
The Chief, The Giants and The Scribes

The clear care-education divide has been highlighted throughout this study. In Chapters One and Two a socio-historical interpretation of this divide was presented against which the research evolved. This evolution encompassed the relational experience, within the micro and mesosystem, of a young child on the autism spectrum transitioning from early years to primary settings, while also presenting a more critical understanding of this ecological experience and action embedded within the macrosystem. Within both dimensions of experience, the divide between care and education in Ireland was unequivocal with the way that access to support is now viewed in current inclusive education policy permeating both lenses of interpretation. Earlier, the difficulties families experienced accessing support, and consequently education, were discussed in relation to such change within the mesosystem. The care and education divide within the Irish education system was integral to this change. While there have been many changes at policy level to make inclusive education possible, the positive impact of these changes on the lived experiences of the children represented in this study were difficult to discern, especially in relation to their access to primary education. It appears that changes to policy are oftentimes not reflected in practice due to conflicting or contradictory stances and priorities present within these governing documents.

Changing Priorities in Policy: The Battle of Dynamikos and Statikos

As outlined in Chapter One, Irish education policy has gradually been redefined to combine both socially just and economic ideals, presented as the provision of equal opportunities for all Irish people to become productive and competitive citizens (DCYA 2014; NCC 2016). Furthermore, the key policies and policy advice on inclusive education within the primary sector have been designed with the importance of ensuring social justice for all children while increasing the economic efficiency of our education system (DES 2017b; DES/NCSE 2018).

As previously stated, while the Government have retained power regarding the design and distribution of these policies, responsibility for their implementation has been handed over to educators. It appears that educators have been given the autonomy to include all pupils who wish to attend a school but are cautioned that supports and resources cannot be allocated to the school, based on the needs or rights of these pupils. Recommendations have also been made regarding a reduced role for the Special Needs Assistants scheme following a review by the DF (2011) that found it did not achieve value for money. Essentially, it reported that while children with additional needs were successfully included in the education system, they did not achieve a high enough level of educational outcome to deem the scheme efficient. The key conclusion relating to the economy and efficiency of the scheme suggested that 'the SNA Scheme could achieve its objectives and the associated level of output with fewer inputs and thereby achieve greater value for money' (DES/DF 2011, p. 11). Such language conceptualises the experiences of young children on the autism spectrum in education, in terms of their projected productivity or output, by placing a fiscal value on the process of caring. It also devalues this critical aspect of inclusion which is so intertwined with the process of education. Viewing caring through the lens of economy and efficiency could be described as the act of moral disengagement (Noddings 1992) and reverts our understanding of caring to its original definition as, *Karō: the weight of many burdens*. Separating the process of caring from education negatively impacts both the cared-for and the one-caring (Noddings 1984), as does an over-emphasis upon a child's care needs, rather than holistic education. It was this accentuation of identified care needs, or their absence thereof, that determined whether the children represented in this study would be included or excluded in primary education. Inclusive policy and practice must evolve from a worldview that accepts that each child has the right to education, rather than granting or denying access based on how efficiently and timely their needs can be addressed. This study argues that when education systems prioritise these static components of quality in an attempt to improve consumer choice they can, instead, remove the element of choice in education placement for families of children with additional needs. When quality systems that focus on academic attainment are used as a measure in education systems, the inclusion of children with additional needs becomes problematic (Blatchford and Wong 1999; Ainscow *et al*. 2006; Fullan 2016) and, the policy goal of ensuring equality of outcomes become irrelevant to those who are unable to access the education system in the first place. Children like Brian, James, Noah, Eoin and Max. The findings of this study relating to parents' choice between mainstream and specialised settings, underscore the way in which market-based principles in education can prove paradoxical. It is evident that the marketisation of education, and the introduction of rigorous and unrelenting managerial reforms, can undermine the right to quality education and, further promote segregation of those who are deemed incompatible with this truth (Drudy 2009; Wright 2012; Ebert 2016). For inclusive education to become a real possibility, dynamic indicators of quality (e.g. the lived experiences of individuals on the autism spectrum, their families, educators and communities) must be valued and accepted as truths in their own right (Devine and Luttrell 2013).



The Chieftain could often be heard talking about Giant Dynamikos the Powerful, the overseer of Caru. She would explain that, historically, Giant Dynamikos was most pleased when he saw tribespeople interacting, building and developing relationships and partnerships that improved and strengthened the lives of all the people in their community.

The Chieftain, The Giants and The Scribes

While launching Ireland's 'first ever autism plan' in 2019, Minister Simon Harris, who himself has a family member on the autism spectrum, outlined how such dynamic, relational processes of understanding would saturate the proposed policy. He stated that 'improving services includes increasing knowledge and changing attitudes' while emphasising the power of the 'language we use to discuss autism'. Drawing on his own family's lived experiences, he rejected the concept of autism as a childhood medical condition, presenting it instead, as encompassing the entire lifespan. Furthermore, he observed that currently 'we see a generation of young people age out of our school system and into adulthood we must ensure our adult services become truly inclusive, accessible and equitable'. It appears that for this group, the definition of successful educational outcomes has already changed. Bakhtin's (1981) *carnivalesque* of shared truths, from equal sources of power, may have already begun to come into effect within the Irish landscape of inclusion. However, it also leads one to ask about the future for young children on the autism spectrum currently navigating the Irish education system and beyond. A question with no certain response as Sandra, Hannah, Ellen, Michael, Alice and Brenda repeatedly noted. A question that must be asked of every stakeholder in inclusive education if such a vision is to be realised.

8.6: Conclusion: Choosing A Different Way of Being, Accepting the Challenge of Change

This chapter incorporated and discussed the findings that emerged from both the *analysis of narratives* and the *child-centred narrative analysis* processes. The findings arising from the *child-centred narrative analysis*, regarding the recognition, understanding and appreciation of the voices of these young children on the autism spectrum, framed each section of this chapter. The three sections of this chapter were structured to offer insight into these children's and parents' experiences within the microsystem of their families and the mesosystem, incorporating relationships between home and these children's educational settings. Finally, these experiences were then examined in relation to the dominant narratives within each social context, that influenced and impacted the children's and parents' experiences. Restructuring the findings in this way constituted, what some within the field of narrative inquiry refer to as, the representation of experience within a narrative past, narrative present and a narrative future (Mishler 1995; Kim 2016). Thus, the narratives of challenge, change and choice were presented in terms of the past, present and future. However, the emphasis placed on the construction of voice and identity, offered an alternative vision going forward, where change becomes the only choice in defeating such challenges. The next, and final, chapter explores this vision further in terms of the main conclusions and recommendations derived from this study.

Chapter Nine

Conclusions

and

Recommendations

9.1: (Re)Introducing the Central Research Question: The Thesis as Call and Answer

This final chapter returns to the central and embedded research questions that guided this study throughout. From the outset the need to gain a deeper understanding of the experiences of children on the autism spectrum and their families as they co-navigated the Irish early years education system together was voiced. The wider social aspect of this educational phenomenon was also outlined, with its interconnectedness informing the design of the study's conceptual framework. This framework incorporated five fundamental areas (1) The Narrative of Autism (2) Families' Experiences (3) Inclusion in Education (4) Reconceptualising Quality and (5) Conflict in Practice. Each of these areas were examined in detail across the research with particular prominence given to the divides present within each. Such divides represented a recurring motif throughout the thesis and encapsulated the central research question that asks:

> *How can the lived experiences of children on the autism spectrum and their parents as they co-navigate the Irish Early Years education system together relate and contribute to narratives of autism and inclusion across social contexts?*

9.1.1: Exploring the Central Research Question in Literature, Policy and Theory

The central research question was formulated following a review of the literature and policy relevant to the research using an ecological framework. This review began with a broad scope of reference, initially encompassing the wider narrative of autism and the historical landscape of inclusive education. Through a process of deductive reasoning the focus became more refined as the review progressed. Thus, placing the lived family experience of both autism and inclusion, at the centre of the review. This immersed their experience within the major issues or controversies that emerged from this examination, namely the influence and impact of divides between the State and the family, care and education, quality and inclusion and, the needs and rights of children with additional needs.

The findings of this review also further bolstered the theoretical framework employed throughout the study: Bronfenbrenner's (1979) Ecological Theory of Development. This theory proved the most fitting lens through which these children and families' experiences across social contexts could be deeply understood. The interconnected concepts of caring as action, and action as critical stance, enabled the experiences of these children on the autism spectrum and their families to be interpreted in terms of the narratives and actions that influence the development of their unique identity and voice. Indeed, the development of voice and identity encompassed all interconnected concepts within the wider ecological theoretical framework. The voices of the *one caring* and the *cared for* (Noddings 1984), the voice of action within the *Vita Activa* (Arendt 1958) and the shared construction of voice as *dialogism* (Bakhtin 1981) were all consolidated within the ecological stance that guided this research in its entirety.

9.1.2: Inquiring into the Central Research Question

To effectively inquire into this research area, critical narrative inquiry was adopted as the chosen methodology. This choice evolved from a paradigmatic positioning that aligned closely with an ecological understanding of the lived experience. The centrality of voice within narrative inquiry facilitated an interpretation of both this experience and the consequent development of identity within these young children on the autism spectrum. Within this examination, the importance of adopting a critical stance enabled a deconstruction of the power relations present in both the research and, wider lived experience. The methodological tools employed helped to merge this ecological and critical position, while recognising the immersed role of the researcher in the processes of *analysis of narratives* and *narrative analysis*. An overview of the reconstructed narratives closed the chapter, with the significance of both the genre of folktale and, the metaphor of tribe coming to the fore. Consequently, the present study aimed to include the young children's voices through engagement with the narratives of their parents. Parental narrative was employed as a means of including the voice and experience of these young children on the autism spectrum, as they and their families co-navigate the Irish early years education system. The role of families in the co-construction and representation of the child's voice was integral to the methodological choices of the study and enabled their shared experiences and narratives to come to the fore.

9.1.3: Answering the Central Research Question

In answering the central research question, findings that emerged from the initial *analysis of narratives* of the parent stories and the subsequent child-centred *narrative analysis* were presented. The findings arising from the *analysis of narratives* were structured ecologically to represent experience and action within the microsystem, mesosystem, exo and macrosystem and organised under the wider narratives of *challenge*, *change* and *choice* as voiced by the parents across all phases of the research. Central to this framework were the underlying grand narratives that informed such experiences: *care and action*, *management of outcomes, social norms* and the all-encompassing *equality in education*. These grand narratives emerged following a collective analysis of the parent stories. While there was diversity among the storytellers' backstories, families, circumstances and indeed lives: commonalities prevailed throughout their narratives. These common narrative threads and patterns were grouped to form a reconstructed overview of the parents' shared experiences before, during and following their co-navigation of the Irish early years education system with their child on the autism spectrum.

The findings that emerged from the *child-centred narrative analysis* offered insight into the development of voice and self-identity within these nine young children on the autism spectrum. This chapter clearly emphasises the recognition and appreciation of child voice as being central to the children's and their families' lived experiences of co-navigating the Irish early years education system together. Within this co-navigation, the construction of voice was presented as a shared experience between these young children on the autism spectrum, their families and social actors within other contexts, for example, educators. Positioning the child at the centre of both the data collection and narrative analysis prioritised their voice in their navigation across the education system. Again, this construction of voice and self-identity is structured ecologically, encompassing the microsystem, mesosystem, exo and macrosystem and the social and educational experiences of these nine children under the lens of each.

9.1.4: Reconstructing the Narrative around the Central Research Question

The reconstructed narratives were written in the folktale genre. These tales merged the individual experiences and stories of the parents and children with the underlying grand narratives that informed and impacted their experiences. Thus, merging the ecological and the critical once more, while drawing on the philosophy of these early communities [see Appendix L] The narratives of autism and inclusion and the issues, divides and controversies within these were portrayed through the use of metaphor. The medical/deficit model of autism and disability was represented as *the ways of The Other*. The social model of autism and disability manifests within the children who *speak and move in Their Own Way*. The climactic scene involving celebration under *The Midday Moon* illustrated a shift from the perceived judgement associated with the deficit model of autism and disability towards the imagined cultural acceptance of autism and disability as difference. The journeys these families made across the education system were encompassed within this shift in the understanding of difference. The division between care and education provided a backdrop to all of the folktales and was symbolised by *The Caru* and *Ducera* mountain ranges, the names of which derived from the original terms for care and education. The repurcussions of this divide permeated these families' experiences and are evident in the depiction of special education as the *Canyon Especialis* and the tension between dynamic and static indicators of quality, represented in *Giants Dynamikos* and

Statikos. The potentially problematic relationship between quality and inclusion in neoliberal times is demonstrated within the role of *The Trickster* and his promotion of *The New Way*. The present chapter concludes with a reflective commentary in the folktale genre, illustrating the role of this research in terms of contributions to knowledge and the potential impact of this on young children on the autism spectrum and their families.

9.2: Conclusions Drawn in Answering the Embedded Research Questions

The main conclusions drawn from the findings will now be outlined. The nature of this narrative study was to understand the common and unique elements within the experiences of these children and their parents. Therefore, the conclusions are not intended to be applied generally. However, the following sections demonstrate how the over-arching and grand narratives that emerged from the analysis can create opportunities for new narratives to evolve in research, practice and policy. The main conclusions drawn from the findings will now be presented in answer to each of the embedded research questions.

9.2.1: Concluding Synopsis: Co-Navigating the Irish Early Years Education System

The first embedded research question examined the experiences of these children and parents in terms of accessing both ECCE and primary school education. It focussed on the equality of opportunity (to attend) rather than on the equality of outcome and asked:

> *What are these parents' experiences of accessing both ECCE and primary school education for their child on the autism spectrum and what factors enabled or prevented this?*

The focus on equality of opportunity rather than equality of outcome related to the fact that these young children's early navigational journeys across the Irish early years education system were the phenomenon under study. However, this proved a fitting emphasis, as access to education emerged a dominant issue for the children and parents involved. Recent changes to Irish education policy on the inclusion of children with additional needs in mainstream education clearly impacted the lived experiences of these young children on the autism spectrum and their parents, in both positive and negative ways. With the inclusion of these children now relying, not only on the availability of supports, but also on the level of understanding of autism within a particular preschool or school. For six of the nine children represented in the study, this meant an absence of choice typically associated with educational placement and posed many challenges. Indeed, the narratives of challenge, change and choice saturated the findings throughout. Within the microsystem, the challenges for children were discussed in terms of the broader realm of the challenges associated with daily family life. The concept of change pertained to transformations within the children and parents. While the element of choice was explored, firstly, in relation to mainstream or special educational settings and then, concerning early years or primary education. Within the mesosystem encompassing these children's homes and other related social contexts, for example, educational settings, challenges and changes regarding the availability and provision of supports and the roles and actions of social actors came to the fore. The narrative of choice further emphasised the role and actions of educational leaders and located such within a wider macro-context of governance. Indeed, the role of macro forces in the experiences of those within the micro and mesosystem arose a fundamental feature of the findings throughout, particularly concerning the development of voice and self-identity within these children and families.

9.2.2: Concluding Synopsis: Constructing and Including the Voice of the Child

The second embedded research question illustrated a point that became a central vein of this study throughout; the recognition and understanding of the voices of these young children on the autism spectrum. It focussed on the construction and inclusion of these voices and asked:

> *How are the voices of these young children on the autism spectrum constructed and included in their homes, educational settings and beyond?*

The present section outlines how the voice of these children on the autism spectrum were fundamental to the findings and were revealed through the adoption of an ecological approach to understanding experiences. These conclusions will also inform the later recommendations made concerning the development of identity, and particularly, the role of research going forward. The study was designed to ensure that prioritisation was given to the voices of these young children as, too often, research into autism omits the perspectives and experiences of the individual on the autism spectrum (Broderick and Ne'eman 2008; Pellicano and Stears 2011; Kenny *et al.* 2016). A deeper understanding of these children's lived experiences was gained as a result of the emphasis placed on the microsystems of these young children on the autism spectrum. The role of the family in this research was therefore paramount. The inquiry into life within these children's homes encompassed a broad realm of experiences to represent positive aspects of this unique family life.

Adopting such an ecological and inductive stance when inquiring into the lived experience of, for example, autism and inclusion allowed a more holistic interpretation of voice and identity to evolve. An interpretation that included the strengths, hopes, successes and transformations within these families. An interpretation that does not just access these voices but respects, understands and appreciates them. In this respect, the present study also resonated with the work of autism advocates who promote the inclusion of the collective voices of the autistic community and, the autism community (their family members, educators and immersed practitioners in research) as imperative (Robertson 2009; Holder 2013; Pellicano *et al*. 2014). This research promoted the need for an ecological positioning in understanding the experiences of children on the autism spectrum and their families throughout and was critically aware of the ramifications of a stringent adherence to a predominantly macro or micro vision for the future. As a result, the power relations inherent within the roles and actions central to inclusive education were more deeply examined.

9.2.3: Concluding Synopsis: Roles and Actions in Inclusive Practice in Education

The findings relating to inclusive education practice emphasised the importance of the roles and actions of educational leaders and educators in making inclusion possible for these young children. The embedded research question relating to practice asked:

> *What roles and actions are central to the realisation of inclusion in education and beyond for these young children on the autism spectrum?*

The key conclusions made regarding inclusive practice in education encompass these young children's experiences of inclusive education in the Irish early years education system. Evident within these experiences were the integral roles played by educational leaders and educators. The findings of this study suggest that in spite of significant changes to the landscape of inclusive education policy towards a *School Inclusion Model* in primary education, the reality of every child with additional needs accessing their local mainstream primary school may be more difficult to bring to fruition than is anticipated. It argues that in order for such inclusive visions to be realised significant change may have to occur within mainstream educational settings. As previously mentioned, six of the nine children represented in this study were either enrolled in or attending a special setting as their local mainstream primary school had proved unsuitable. Indeed, in the cases of Brian, Max, Noah and Eoin, it was they who had been deemed unsuitable for inclusion within the mainstream primary education setting. The fact that eight of these nine children had attended a mainstream ECCE setting suggests that, for these families, inclusive practice has manifested differently in ECCE settings in comparison with primary schools. The divide between both sectors of the Irish early years education system is very evident in these children's and parents' co-navigation across the education system. It appears that the relationship between inclusion and quality in ECCE settings has been more harmonious, with the ideologies of both saturating the guidelines for high-quality inclusive practice. With the *Access and Inclusion Model*, *LINC* (Leadership for Inclusion) *Síolta* and the *ECCE Scheme* sharing similar visions in relation to the inclusion of all children in quality early years education. This study argues that for inclusion in mainstream to become a reality for all children across ECCE and primary education settings, visions of inclusive and quality education must complement, rather than contradict each other.

The relationship between inclusive practice and quality education presented differently in relation to the formal school system, where conflict between the vision and reality of inclusion was reported by the parents. Similar to the ECCE settings discussed, the creation of an inclusive culture, where equality and diversity were respected and appreciated, relied on the actions and perspectives of the leaders of individual educational settings. The positive impact of certain leaders on the lives of these children and families was clear. As was the impact of leaders whose actions negatively impacted or indeed impeded these children's and parents' navigations across and within the education system. However, this study interpreted and located these leaders' actions ecologically and revealed an underexplored area within the national context: the impact of assuming responsibility for inclusion on the educational leaders and educators. In some instances, during this study, the impact of this struggle was palpable with leaders visibly suffering because of the conflict between their belief in inclusion and, the limitations of their capacity to ensure inclusive practice in terms of the provision of adequate support and resources. This scenario warrants further exploration and deeper analysis, the outcomes of which should inform future changes within the field of inclusive education in Ireland.

9.2.4: Concluding Synopsis: Experiences of Inclusive Education Policy

The final embedded question related to inclusive education policy and the narratives that inform it. It explored how underlying narratives in policy contribute to the children's subsequent experience of inclusion and asked:

> *How do the dominant narratives underlying inclusive education policy in Ireland impact these children's and families' experiences of inclusive practice?*

This section reiterates the issues surrounding the promotion of a singular, macro-identity in policy relating to inclusive education. It subsequently stresses the need for the inclusion of all voices through the establishment of dynamic partnerships of action where knowledge concerning difference and inclusion can be co-constructed together. In presenting the conclusions arising from this study, the importance of including the voices of children on the autism spectrum, together with their parents and indeed, educators, came to the fore. This study argues that if certain voices and experiences are not recognised and valued within inclusive education then negative experiences will prevail for individual children, parents and, indeed, educators. When one voice dominates a particular narrative, a singular identity is typically advocated, which can repress the inherent differences of groups deemed unsuitable or inadequate (Ackroyd and Pilkington 1999; Walsh 2007; Banks 2014). The findings suggested that, within inclusive education policy in Ireland at present a singular, globalised identity may be being promoted where positive outcomes for pupils are defined in terms of their capacity to become productive, competitive citizens within a global economy (DES 2001; DES/DF 2011; DCYA 2014; NCC 2016).

The present study's emphasis on the construction of voice also relates to this process of globalisation which, some argue, has its own epistemology: the efficient construction of a macro identity comprised of quality knowledge (Daun 2001; Chertoff 2009; Barth *et al*. 2015). Embracing such an epistemology promotes and values the inclusion of the individual who adopts this macro ontology and becomes an independent and productive citizen (Kjeldgaard 2003; Kenny *et al*. 2009). The experiences presented in this study suggest that this worldview underlies inclusive education policy currently and is problematic in spite of the fact that it claims to place equal precedence on the economic and sociological aspects of this construction of identity. Reconceptualising traditionally economic terminology, for example, quality, assurance, performance, standards etc. as socially inclusive narratives does not mean that the negative meanings of historical categories of otherness disappear. This study argues that they instead take on new forms. It is intended that the recommendations arising from this study may work towards the creation of socially inclusive narratives that do not create further categories of otherness.

9.3: Recommendations for Practice, Policy and Research

If all voices and narratives involved in such partnerships are given equal power and trust than dominant forms of knowledge that promote a singular identity are replaced by, what Bakhtin (1981) would describe as new or unofficial truths, crafted from a variety of valuable funds of knowledge and experience. This new truth evolves from dialogues that are not just polyphonic in nature but can be described, using Bakhtin's terminology, as 'carnivalesque' where ‘everyone is an active participant, openness is celebrated, hierarchy is invisible, and norms are reversed (Kim 2016, p. 76).

9.3.1: Recommendations for Practice

Microsystem

It is important that children on the autism spectrum (together with their families, educators and peers) are exposed to a positive narrative of autism within their microsystem in order to eradicate the stigma, sometimes associated with difference, that can negatively impact the development of children’s self-identity. The role of parents in this process is paramount and must go beyond granting consent to professionals with accredited expertise to lead the discussion. This study recommends a shared, strengths-based approach to talking about autism that embraces the social model of autism and disability.

Mesosystem

Professionals, including educators, should interpret the challenges experienced by children on the autism spectrum ecologically, taking a multitude of factors and variety of social contexts into account. This would require a shift away from the traditional treatment of autism as an isolated phenomenon at the root of such challenges. Valuing the lived experience of autism is fundamental in making this shift. An appreciation of this unique voice is necessary to ensure that authentic inclusion, based on intrinsic rights and not simply identified needs, can become a reality for every child on the autism spectrum. Again child-centred partnerships between the child on the autism spectrum, their family and the professionals working with them are central to this vision.

Exo and Macrosystem

The inclusive experiences of these children and parents as they navigated the primary education sector suggested an individualised, rather than ecological and socially connected, approach to inclusive education currently. Such an approach focusses on the inclusion of individual children in isolated settings and the practice of individual educators and educational leaders and contrasts starkly with the widely accepted view of inclusive education as a collective, inter-relational experience with shared responsibilities and equal power relations. This shift towards an ecological stance in inclusion, from the more economic and individualised nature of Government practice currently, would move such macro-action beyond reactive fiscal contributions towards a dynamic and sustainable contribution to developing proactive partnerships between children, families, care and education settings, communities, government agencies, services and policy makers within the Department of Education, Department of Child and Youth Affairs and the Department of Health.

9.3.2: Recommendations for Policy

Microsystem

This study recommends a sustainable, child-centred mode of Government investment, rather than the reactive, problem-oriented action described by the parents. This would involve collaboration between all relevant Government departments and, in some instances, would encompass the lifespan of the child on the autism spectrum. The goal of this type of sustainable investment is to ensure that the child can be included in their home, educational setting, community and wider society. The capacity of the child to become an independent, productive and competitive citizen is less emphasised. Within this model, resilience develops naturally within children, families and communities and is not a forced response to adverse circumstances. In valuing and sustaining these families' inter-dependent way of life, they may be empowered to live together, without the need for segregation at any point in their child's life.

Mesosystem

The findings that emerged throughout this study in relation to inclusive policy and subsequent practice in the Irish early years education system revealed a number of divides within the system. All such divisions are encompassed within the broader care/education divide that permeates ECCE, mainstream and special settings in Ireland. This study recommends the development and implementation of mandatory inclusive policy that facilitates increased collaboration between ECCE settings, primary schools and relevant Government services and agencies before, during and after the child on the autism spectrum transitions into primary education. The findings from this study also suggest that lessons may be learned from the implementation of policy in ECCE settings through the implementation of AIM. Such policy focusses on the creation of an inclusive space and culture through the provision of equipment, materials, continued professional development (LINC) and extra personnel on a staged approach as necessary. While the continuum of support in primary education also follows a staged approach, the focus is solely on the individual child's needs rather than the creation of an inclusive culture throughout the school. This study recommends, therefore, that inclusive policy in primary education must place a greater emphasis on the creation and development of inclusive school cultures if all children are to be accepted, irrespective of their level of need.

Exo and Macrosystem

The findings of this study recommend a dynamic, rather than static, approach to inclusive education policy that recognises and includes all voices involved, and measures its success in terms of the lived experience rather than the performance of either children or the economy. This approach to inclusive policy requires a move away from the narratives of individual competitiveness and productivity towards a model of collective social justice, where each stakeholder is responsible for the welfare of the other. If all stakeholders (children, families, educators, educational leaders, relevant professionals and government agencies) are seen as equal partners with shared responsibility for inclusion then the narrative of inclusion can become about realising rights rather than supporting needs alone. Central to this recommendation is the role of special education. This study argues that if special education continues to be provided in segregated settings, for example, ASD classes and special schools, the possibility of authentic inclusion in education and society is reduced. These recommendations recognise the value of and need for specialised knowledge and methodologies but stress that these cannot be seen as separate from or alternate to mainstream education. Inclusive policy must encompass both.

9.3.3: Recommendations for Research

Microsystem

Without doubt, further research into the lived experiences of children on the autism spectrum and their families is warranted. It is recommended that an ontological view of *autism as difference*, rather than deficit, is adopted. Within this approach, the voice and identity of the child on the autism spectrum can come to the fore, as can the strengths and hopes of their family. This study also recommends that researchers continue to utilise innovative and creative ways of including children on the autism spectrum in research studies, so that they are not the subjects of research but an integral part of the process. Thus, recognising and valuing the interdependent processes and narratives of action within these children’s and families’ lived experiences

Mesosystem

Within the findings of this study, the simple act of recognising and appreciating the play activities and unique learning styles of young children on the autism spectrum proved critical to the positive construction of their voice, a point underrepresented across research in relation to autism and childhood. Further research into this area would require an understanding of autism and childhood as a diverse and all-encompassing lived experience, rather than an example of atypical development or a failure to achieve universal milestones or standards of achievement. A reconceptualisation of the concept of *school readiness* could manifest within this paradigm shift, where the capacity of educational settings to include, rather than the capacity of the child to be included, becomes the focus.

Exo and Macrosystem

This study argues that research into the presence or prevalence of autism within society must pay particular consideration to the lived experiences of individuals on the autism spectrum. The human rights of this group should be central to such inquiries. Indeed, the enhancement of their quality of life and happiness should be prioritised over the identification of autism causes or cures. Crucially, an ecological stance should be adopted, informed by a social model of autism and disability, where diversity rather than deficit can be interpreted. In essence, research focusing on autism in the macro-context must recognise that the lived experience of autism creates its own ideology and culture, which is also impacted by the ideologies and cultures of the dominant groups of society. Further research into the navigations of individuals on the autism spectrum within and across the prevailing power structures of society is also necessary.

9.4: Contribution to knowledge: Tree of Knowledge

This research set out to share the experiences of nine young children on the autism spectrum and their six parents as they co-navigated the Irish early years education system together. The stories of this small group cannot be generalised, nor should they be. They represent the unique journeys of these children and their parents. However, this narrative inquiry espouses the power of such stories to potentially influence the wider narrative as they filter across social contexts. In essence, it is through sharing these stories around that tribal fire pit that this group's alternative symbol or unofficial truth may eventually be added to *The Tree of Knowledge*. This study's impact is therefore multifaceted and comprises of contributions to knowledge through research area, innovative methodological approaches and a unique interpretive stance.

9.4.1: Contribution to Knowledge through Research Area: Shared Experiences, Journeys and Voice.

As outlined earlier, much research relating to the lived experiences of children on the autism spectrum and their families focusses on either the negative impact of autism on their quality of life or the positive impact of interventions on reducing the challenges associated with autism

(Keenan *et al*. 2010; Hall and Graff 2011; Pellicano *et al*. 2014). Consequently, research also tends to present parents' experience in terms of how they are affected by their children's autism (Whitehead *et al.* 2015; Gorlin *et al*. 2016; Benson 2018), leading to typically homophonic findings where the affected parents' perspective emerges as the singular dominant voice (Hays and Colaner 2016; Benevides *et al.* 2019). This study explored and presented these children's and parents' experiences in terms of the interactions, relationships, values and narratives that influenced and impacted their journeys across social contexts. The findings arising from this exploration represent valuable funds of knowledge that illustrate the holistic experiences of these children and parents, rather than isolated aspects of their lives.

Central to this holistic representation was the shared nature of these children's and parents' experiences and narratives. This study's recognition and appreciation of the lived familial experience of these young children on the autism spectrum demonstrated that the family's involvement in the children's narrative was not just acceptable, but in fact proved optimal. This stance also enabled the inclusion of these children's experiences and perspectives, irrespective of their mode of communication. In this respect, the present study resonated with the work of advocates who promote the inclusion of the collective voices of the autistic community, their family members and immersed practitioners in research as an imperative. Thus, representing the need for a co-constructed narrative of autism and inclusion (Pellicano and Stears 2011; Holder 2013): a keystone of the present study.

9.4.2: Contribution to Knowledge through Innovative Methodological Approaches

This study shows that children on the autism spectrum, face considerable challenges as they attempt to construct their voice and identity within a society that can often devalue any form of communication that is viewed as typical. Consequently, there is an absence of voices representing the perspectives of children on the autism spectrum in research. Unfortunately, this is reflective of much research relating to autism which often omits the voice of the individual on the autism spectrum (Broderick and Ne'eman 2008; Mottron 2011; Krcek 2013). From the outset, this study was cognisant of concerns raised by these advocates regarding the empowering or disempowering nature of certain methodologies used in autism research. Such advocates have argued that methodological designs that exclude the voices of individuals on the autism spectrum can be deemed unethical and unreliable. Careful consideration was afforded therefore, including the voice of the young child on the autism spectrum in the study. While direct access to these children was not possible for ethical and pragmatic reasons, gaining the perspectives of these children in relation to their educational experiences remained of paramount importance throughout the research. Therefore, innovative and creative methodologies were employed to authentically integrate their voices throughout the study.

This interpretation of voice emphasised the significance of how these experiential elements have been socially constructed (Bakhtin 1981; Whyte 2015) and goes beyond a child's capacity to communicate verbally. Thus, parents were encouraged to document their children's responses, whether verbal or non-verbal. The importance of noting sensory expression (e.g., excitedly hand-flapping or anxiously covering ears) was emphasised also. Parents incorporated their children's responses to visual elicitation methods into the interview process. As a result, children's experiences and narratives were gradually revealed. In this way, the study reached and authentically included the voices of these nine young children on the autism spectrum; a group typically defined as remote or hard to reach (Croghan *et al*. 2008; Bagnoli 2009; Allen 2012; Teachman *et al*. 2014). The integration of visuals and artefacts relating to the children's educational journeys allowed the child-centred narratives to be co-constructed, bolstering the processes of shared narrative, elicitation and formation. The subsequent employment of child-centred narrative analysis enabled these young children's voices to come to the fore and included them in the creation of knowledge pertaining to their lived experience (O' Leary and Moloney 2020a).

9.4.3: Contribution to Knowledge through Adoption of a Unique Interpretive Stance

This study included a critical examination of the power relations that are created within the microsystem and mesosystem of children on the autism spectrum as a result of governing elements of the macrosystem. Within this research the influence and impact of inclusive education policy was evident. The present study suggests that these families' experiences of stigmatisation, exclusion and a sense of powerlessness were often as a result of conflict between the principles guiding macro-action and therefore underlying their narratives. Through the incorporation of both critical theory and ecological theory, this study provided an overview of the power structures challenging these children on the autism spectrum and their parents, as they co-navigated the Irish early years education system and beyond. Thus, this critique of these children's and parents' micro experiences exposed the influence of wider forces that significantly influence the development of identity of the 'other' (Van Bark 1961; Goffman 1963; Victor 1973; Wilson 1974).

Through this critical stance, this study explored the formation of identity as a direct derivative of the ‘norms that prevail in the society at large’ (Devine and Kelly 2006, p.136) and found that the children and parents whose experiences did not relate to this socially validated way of knowing were othered. The emergence of the *Social Norms* grand narrative reinforced how dominant funds of knowledge, constructed within the macro context, made the fostering of these children’s and parents’ self-identities a thoroughly challenging, and sometimes isolating, experience. Inherent within this critical stance was the ecological positioning of the child on the autism spectrum. Through this child-centred approach issues that arose over the course of the research in relation to the development of these children’s self-identities were interpreted by the parents in terms of the child’s experience, central to which was their identity as an individual on the autism spectrum and the acceptance of this. In turn, central to this acceptance were the perspectives held by the children’s significant others within their microsystem and beyond in relation to autism. Indeed, such perspectives proved pivotal to these children’s inclusion in or exclusion from the Irish early years education system and contribute to the wider narrative of autism currently. It is hoped that this study’s emphasis on the promotion of positive perspectives, the value of voices and the acceptance of diverse identities has not only contributed to knowledge, but will contribute positively to the wider narrative of autism and inclusion going forward and potentially enhance the lived experiences of children on the autism spectrum and their families (O’ Leary and Moloney 2020b).

9.5: Limitations of the Study

The size of the study sample and the nature of its selection constitute the primary limitations of this research. The small sample of six parents was selected using a non-probability sampling method and therefore does not reflect the experiences of the general population, i.e. all parents of young children on the autism spectrum. While small, the sample size (n=6) proved to be a considerable strength of the study as it a) enabled a deeper engagement with the families and their narratives over a prolonged period of time and, b) allowed continual, in-depth interpretation of the stories of these parents and their children: an integral element of narrative inquiry (Clandinin and Connelly 2000; Kim 2016; Chase 2018). Moreover, the nine children represented within the study demonstrate the diversity encompassed within the autism spectrum. Consequently, the six parent narratives include a broader realm of experience.

The researcher's immersed positioning had the potential to limit the impact and relevance of this research considerably. Substantial consideration was therefore given to this possibility. Rather than viewing the immersion of the researcher throughout the narrative inquiry and analytical process as a weakness of the research, theorists in the field argue that this deep engagement is in fact, a strength (Clandinin and Connelly 2000; Lyons and LaBoskey 2002; Andrews *et al.* 2013; Kim 2016). The researcher's voice has gradually developed from this immersed stance, within both the lived experience of autism in her family and her role as a practicing teacher within the Irish education system, was recognised among the multitude of voices involved. Indeed, it was this dualistic positioning that enabled a deeper understanding of the development of voices and the influence of narratives within both realms of experience. However, to further ensure the prioritisation of the children's and parents' voices and experiences, the researcher adopted the role of storyteller throughout.

9.6: Concluding Reflection

The Storyteller smiled as she slowly and carefully folded the cloth around the finished piece. She lifted the parcel closely to her chest, holding both arms across it protectively and watching as it moved quickly and steadily in response to her hastened breathing. Her anticipation was palpable as she cautiously placed it in her satchel and secured it tightly across her. She reached out and took her son's hand and together they left. As she held his hand within hers, she noticed how it had grown over this past while. She rubbed her thumb back and forth softly on the palm of his hand as they made their way along the winding path. Her son often struggled during this journey as it contained many inclines. But together, hand in hand, they climbed to the top of each one. They stood for a moment when they reached the top of the last hill. The view from this standpoint never disappointed.

The vista encompassed the Caru and Ducera Mountain Ranges, the Canyon Especialis, The Citadel of the Scribes and everything in between. From here it seemed as if these landmarks all encircled one particular entity… The Tree of Knowledge; standing so tall, almost majestic, with its many symbols catching the sun's rays. The Storyteller and her son began their descent, scarcely able to keep their footing as they navigated the downward slope excitedly. Their brisk walk almost evolved into a canter upon seeing the group gathered by The Tree. There stood The Elder, The Warrior, The Clan Mother, The Miner and his Wife, The Chief and Chieftain and all their adored children who spoke and moved in Their Own Way. The Storyteller reached *into her satchel and retrieved the parcel. She placed it down in the shade under The Tree, her heart pounding in her chest as she willed her hands to steady enough to allow her to unwrap the cloth. As she uncurled the threaded knot, she noticed that the others had joined her, and now, together, they formed a small circle sitting in the shade of The Tree. All eyes were on her as she moved the cloth back to reveal the hand-carved symbol inside.*

As she slowly lifted her head she was greeted with warm smiles and nods of agreement. She lifted the colourful symbol gently and passed it to The Elder on her left, who in turn studied it and passed it around the group. Though it was quite a simple piece, it represented so much for these children and their loved ones. A small circle encompassed within another, and another and another: symbolising the inter-related and inter-dependent nature of their existence. The centrepiece comprised of ten unique, precious stones, the value of which had long gone unrecognised by the inexperienced eye. A stone for each of their children who spoke and moved in Their Own Way. When the piece worked its way back to The Storyteller once more, they stood. The Storyteller took in a deep breath, turned towards The Tree and attached their symbol to the branch upon which the sun shone the brightest. She stepped back and turned to the group with a smile and together they watched with pride as the precious stones caught the sun's light and dispersed a spectrum of colourful beams. Within this carnival of colour, they and their children came together in joyful song and dance… unaware of the mother who watched in the distance while clutching the hand of her little child, who spoke and moved in Their Own Way. Unaware of how this mother and child's feelings of fear were dispelling as they slowly walked towards this celebration of difference.

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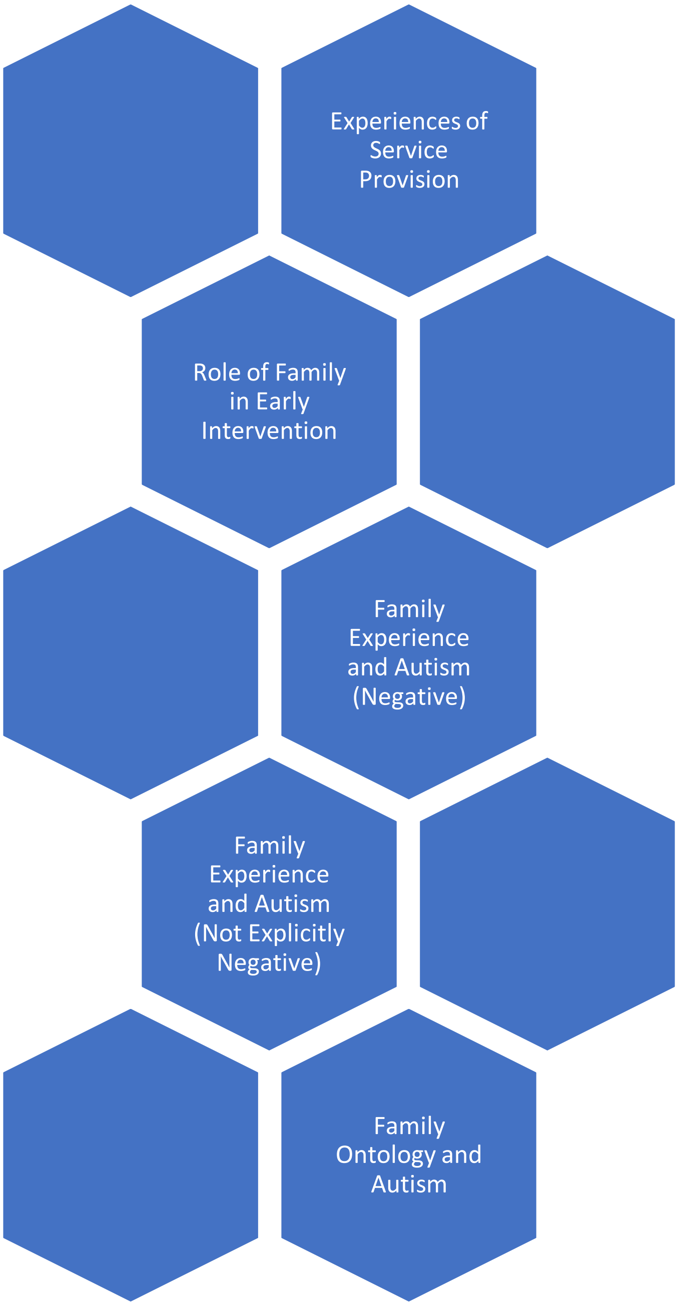
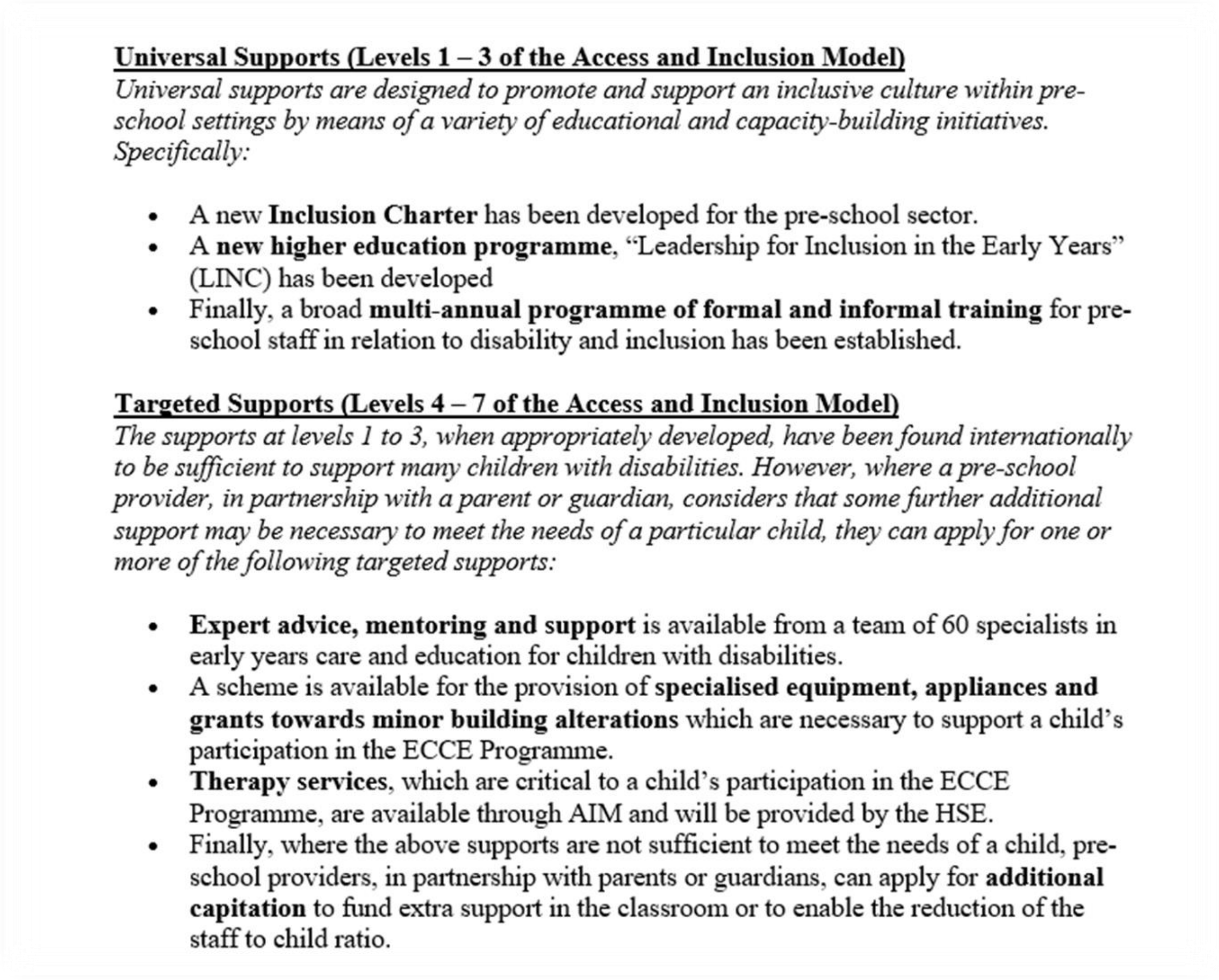
Appendix A

Overview of Literature on Families’ Lived Experiences of Autism



Appendix B1

Overview of the Access and Inclusion Model (DCYA, 2016)



Universal Supports (Levels 1 – 3 of the Access and Inclusion Model)

Universal supports are designed to promote and support an inclusive culture within pre-school settings by means of a variety of educational and capacity-building initiatives. Specifically:

- A new **Inclusion Charter** has been developed for the pre-school sector.
- A **new higher education programme**, "Leadership for Inclusion in the Early Years" (LINC) has been developed
- Finally, a broad **multi-annual programme of formal and informal training** for pre-school staff in relation to disability and inclusion has been established.

Targeted Supports (Levels 4 – 7 of the Access and Inclusion Model)

The supports at levels 1 to 3, when appropriately developed, have been found internationally to be sufficient to support many children with disabilities. However, where a pre-school provider, in partnership with a parent or guardian, considers that some further additional support may be necessary to meet the needs of a particular child, they can apply for one or more of the following targeted supports:

- **Expert advice, mentoring and support** is available from a team of 60 specialists in early years care and education for children with disabilities.
- A scheme is available for the provision of **specialised equipment, appliances and grants towards minor building alterations** which are necessary to support a child's participation in the ECCE Programme.
- **Therapy services**, which are critical to a child's participation in the ECCE Programme, are available through AIM and will be provided by the HSE.
- Finally, where the above supports are not sufficient to meet the needs of a child, pre-school providers, in partnership with parents or guardians, can apply for **additional capitation** to fund extra support in the classroom or to enable the reduction of the staff to child ratio.

Appendix B2

Quality Across the Irish Early Years Education System (ECCE and Primary)

QUALITY in Irish EYE System	**ECCE Settings**	**Infant Classes in Primary Schools**
Adult-Child Ratio	1:11	1:27
Educational Experience	Learning dispositions across four themes of Aistear (Not mandatory)	-12 Subjects of Primary School Curriculum (Mandatory) -Learning dispositions across four themes of Aistear (Not mandatory)
Minimum Qualification Level	QQI in Early Childhood Care and Education (Level 5)	Bachelor of Education (Level 8)
Health and Safety	Health and Safety Statement as outlined by the Safety, Health and Welfare Act (2005) is mandatory.	Health and Safety Authority have published *Guidelines on Managing Safety, Health and Welfare in Primary Schools*
Floor Space	0-1 year-3.5m², 1-2 years-2.8m², 2-3 years-2.35m², 3-6 years-2.3m²	Not applicable
Introduction of Inclusive Policy for children with SEN	Better Start Access and Inclusion Model (2016)	Education Act (1998) EPSEN Act (2004)
Provision of Resources for SEN	Prior to the AIM Policy, PSNA support was available for children in preschools with SEN but public funding for this was the responsibility of the DoH and was not guaranteed. This was often supplemented by families' private incomes and charities.	SNA model widely adopted since 1998. Funding for this has been provided by the DES. Circular 0013/2017 marks a move away from the traditional SNA model of support. Resource teachers provide supplementary teaching and in-class support for x no. of hours per week as granted by SENO

*Information compiled from various documents from DES, DCYA, DoH.

Appendix C1

Appendix C1 – Participant Information Sheet

Understanding Parents' Lived Experiences of Navigating the Irish Early Years Education System (Preschool and Primary School) with Their Child on the Autism Spectrum.

What is this study about?

This study is concerned with parents' lived experiences of navigating the Irish early years education system (preschool and primary) with their child on the autism spectrum.

Who is undertaking the study?

My name is Sarah O' Leary. I am a Postgraduate student at Mary Immaculate College undertaking a PhD within the Department of Reflective Pedagogy and Early Childhood Studies under the supervision of Dr. Mary Moloney. The current study will form part of my thesis.

Why is this study being undertaken?

Recent research on autism highlights two important points: the increased prevalence of children diagnosed with an autism spectrum disorder in Ireland and the need to increase our understanding and inclusion of parental experiences of autism within the Irish education system. It is hoped that this study will enhance our understanding of parental experiences of navigating the educational system for their child with autism and provide insights into how best to support children on the autism spectrum in the Irish early years education system.

Exactly what is involved for the participant?

As the parent of a child with autism, you are invited to participate in this study. This involves participating in three separate audio-recorded interviews between June 2018 and December 2019. The first interview (between June and September, 2018) will focus on your experience of accessing pre-school for your child, the second (between May and July, 2019) will focus upon your experience of accessing primary school for your child, while the third (between September and December, 2019) will focus upon your experience of primary school during your child's first term in school. Each interview will last for one hour approximately. Interviews will be undertaken on a date, time and location of your choosing.

Right to refuse/withdraw

Participation in the study is entirely voluntary and you have the right to withdraw at any time without giving a reason, and without consequence.

How will information be used/disseminated?

Any information provided will be combined with that of the other participants in this study and used to form the findings of my thesis. Summary data only will appear in the thesis, individual participant data will not be shown. Any information provided by you during the interviews will be coded, so that you, your child, his/her pre-school setting or school cannot be identified by anybody other than the researcher. The information will not be shared with any third party, and it will only be used for the purposes of my Ph.D. thesis. If it is to be used for research papers or presentations, confidentiality and anonymity will be maintained through the use of pseudonyms and codes.

What will happen to the data after research has been completed?

In accordance with the Mary Immaculate College Record Retention Schedule, all anonymized research data can be retained by the researcher as such documents will not contain any identifiable factors.

Benefits for participants

There are no material rewards for participation, but you might find the study interesting. This study will potentially make an important contribution to our understanding of how parents navigate the Irish Early Years Education system for their child in the autism spectrum.

Risks for participants

The risks associated with participation are minimal. In the unlikely event that participation raises any concerns, you can discuss these with the researcher.

Contact Details

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Ph.: xxx-xxxxxxx

Dr. Mary Moloney
Research Supervisor
Mary.Moloney@mic.ul.ie
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If you have concerns about this study and wish to contact someone independent, you may contact:
MIREC Administrator
Mary Immaculate College
Ph.: 061-204980
mirec@mic.ul.ie

Appendix C2

Appendix C2- Informed Consent Form

Understanding Parents' Lived Experiences of Navigating the Irish Early Years Education System (Preschool and Primary School) with Their Child on the Autism Spectrum

Dear Participant,

As outlined in the **participant information sheet**, this study explores parents' experiences of navigating the Irish Early Years Education System (preschool and primary school) with their child on the autism spectrum. Please read the participant information sheet fully and carefully before consenting to take part in the study.

Please read the following statements before signing the consent form.

- I have read and understand the **participant information sheet.**
- I understand what the project is about, and what the findings will be used for.
- I am aware that my participation involves three audio recorded interviews between June 2018 and December 2019.
- I am aware of any risks and benefits associated with the study.
- I know that my participation is entirely voluntary and that I can withdraw from the study at any stage without giving a reason and without consequence.
- I am aware that any information given by me, will be treated with the utmost confidentiality, and that codes will be applied to the data to maintain anonymity.
- I am aware that the findings from my interview will form part of a doctoral thesis.
- I am 18 years of age or older and agree to participate in this study.

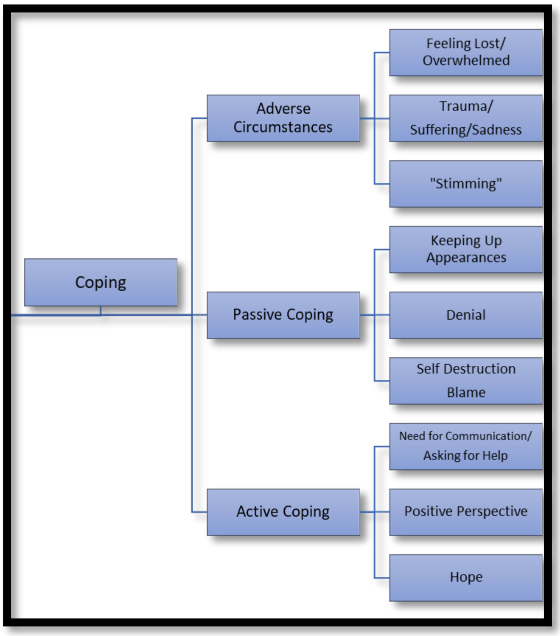
Name (PRINTED): ____

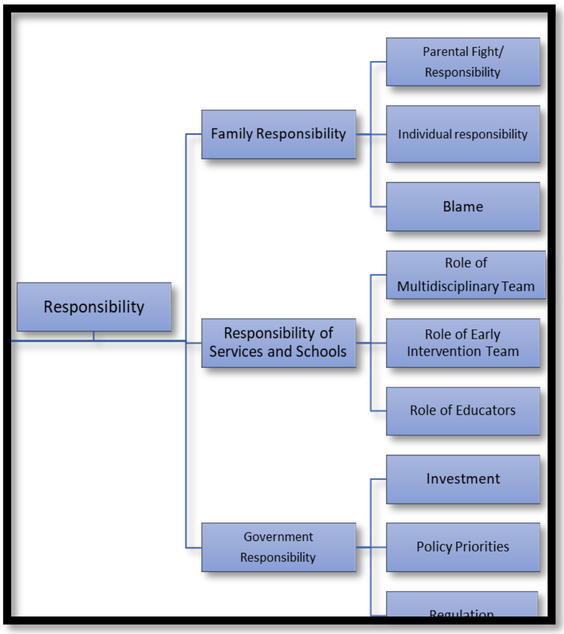
Name (Signature): ____

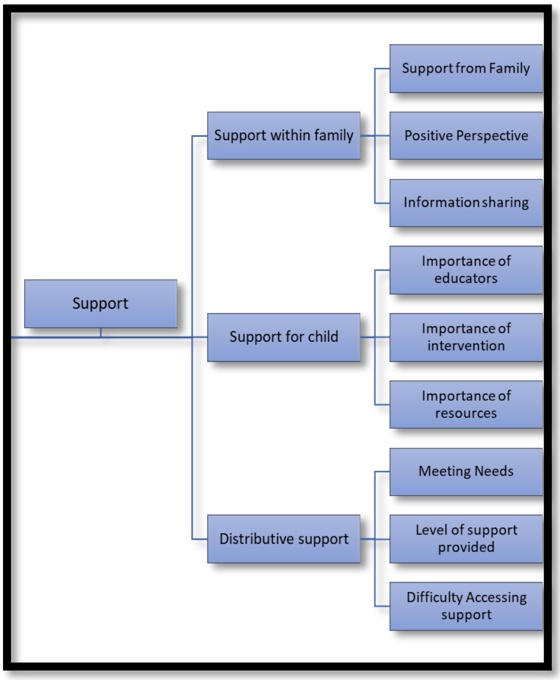
Date: ____

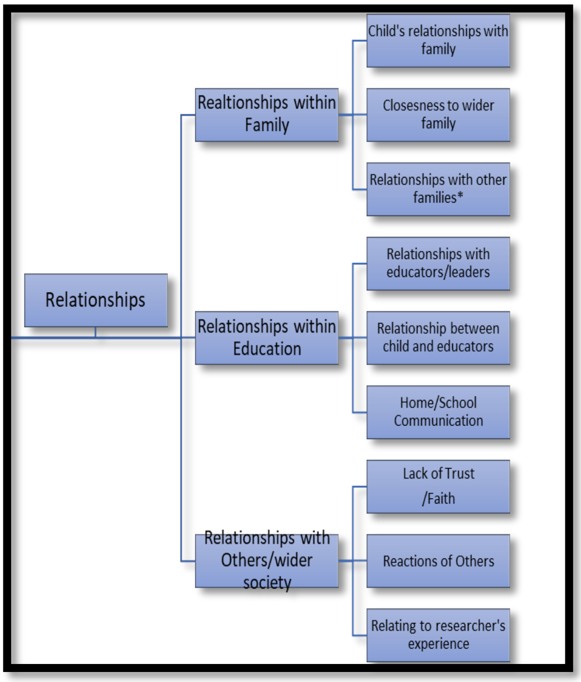
Appendix D 1-3

D1: Dissemination of *Care and Action* Grand Narrative

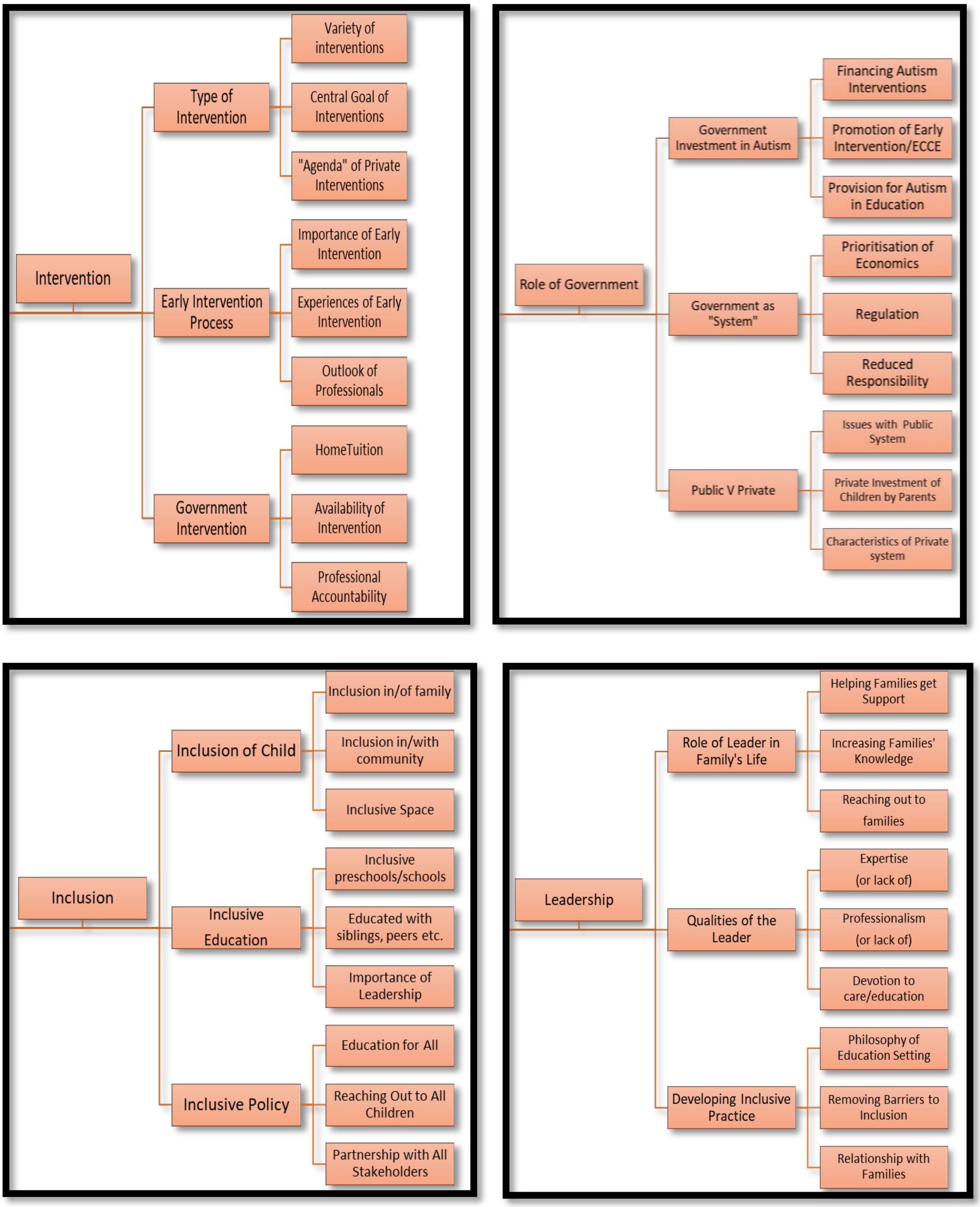




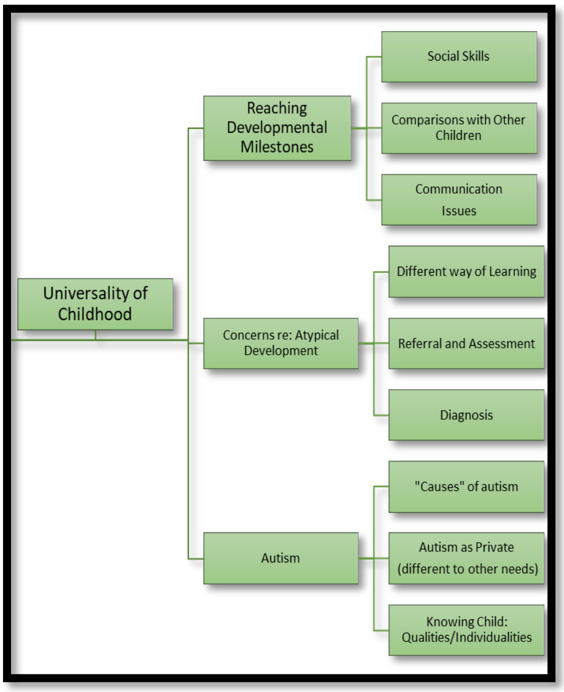


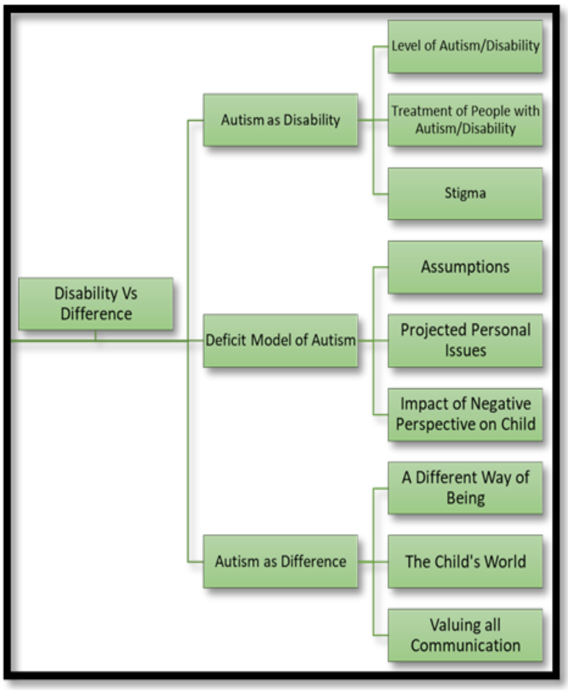


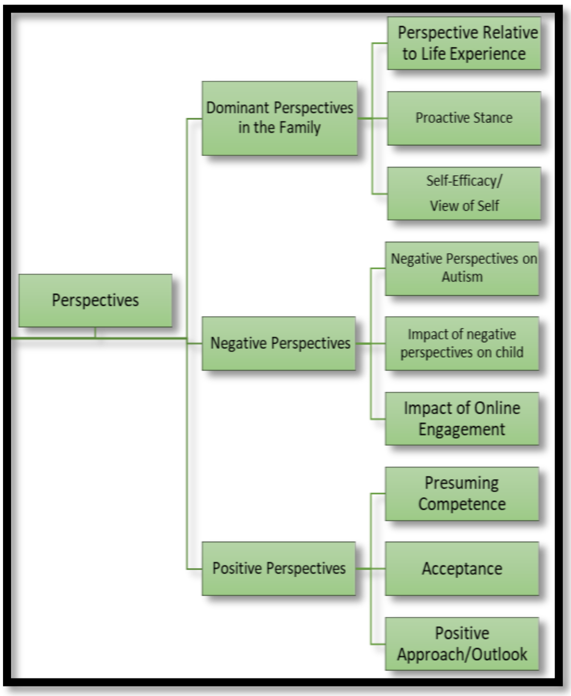
Appendix D2: Dissemination of *Management of Outcomes* Grand Narrative

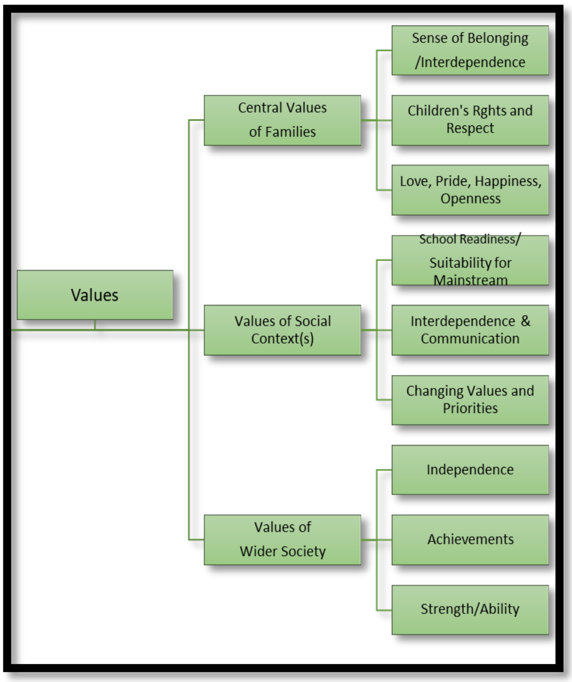


Appendix D3: Dissemination of the *Social Norms* Grand Narrative



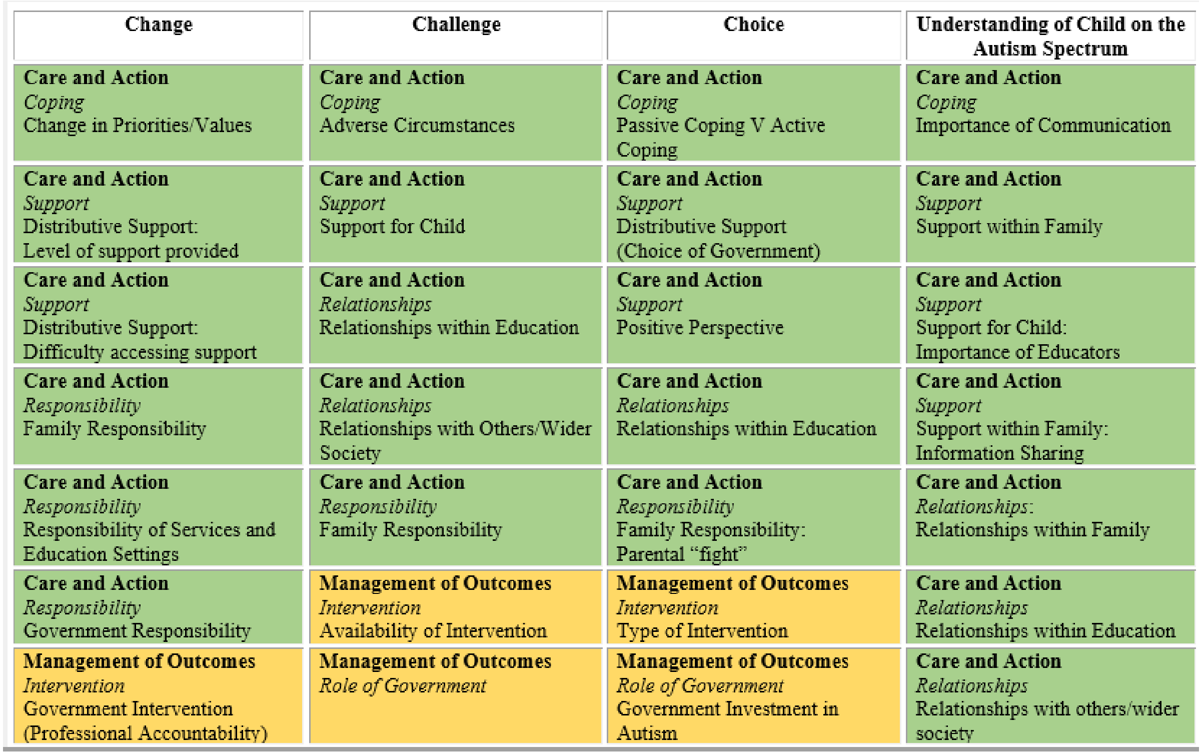






Appendix E

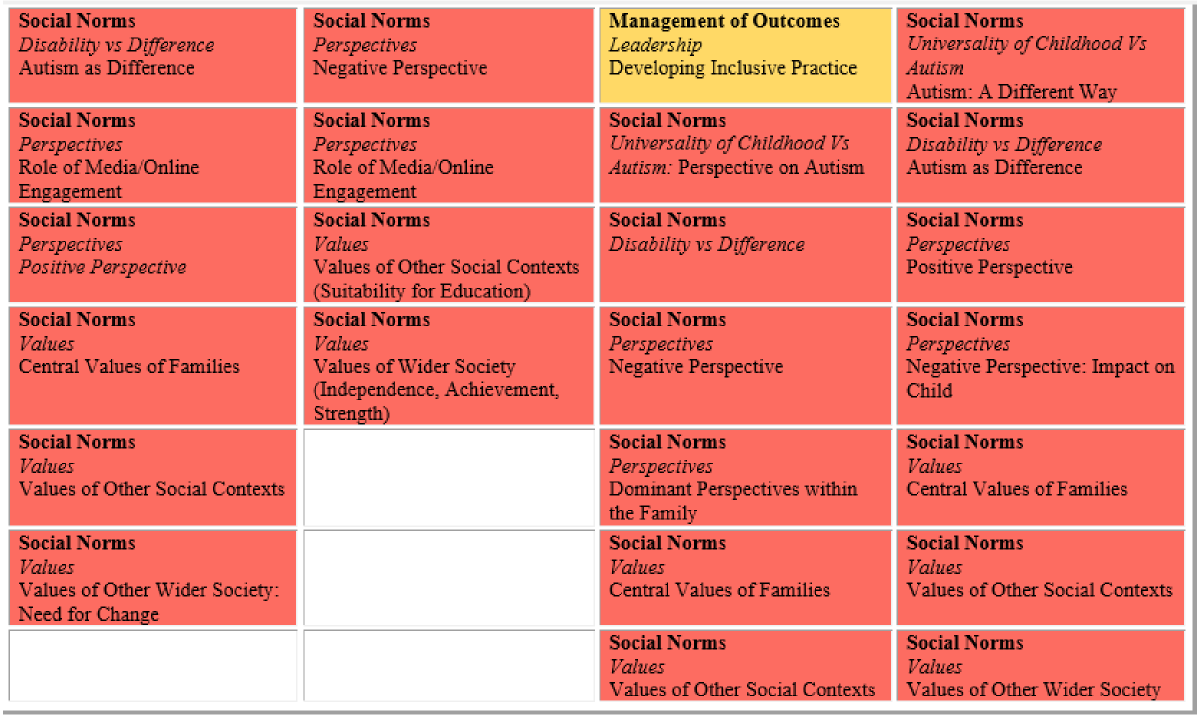
Developing the Meta-Narrative [Equality in Education] from the Grand Narratives of *Care and Action*, *Management of Outcomes* and *Social Norms*




Change	Challenge	Choice	Understanding of Child on the Autism Spectrum
Care and Action *Coping* Change in Priorities/Values	**Care and Action** *Coping* Adverse Circumstances	**Care and Action** *Coping* Passive Coping V Active Coping	**Care and Action** *Coping* Importance of Communication
Care and Action *Support* Distributive Support: Level of support provided	**Care and Action** *Support* Support for Child	**Care and Action** *Support* Distributive Support (Choice of Government)	**Care and Action** *Support* Support within Family
Care and Action *Support* Distributive Support: Difficulty accessing support	**Care and Action** *Relationships* Relationships within Education	**Care and Action** *Support* Positive Perspective	**Care and Action** *Support* Support for Child: Importance of Educators
Care and Action *Responsibility* Family Responsibility	**Care and Action** *Relationships* Relationships with Others/Wider Society	**Care and Action** *Relationships* Relationships within Education	**Care and Action** *Support* Support within Family: Information Sharing
Care and Action *Responsibility* Responsibility of Services and Education Settings	**Care and Action** *Responsibility* Family Responsibility	**Care and Action** *Responsibility* Family Responsibility: Parental "fight"	**Care and Action** *Relationships*: Relationships within Family
Care and Action *Responsibility* Government Responsibility	**Management of Outcomes** *Intervention* Availability of Intervention	**Management of Outcomes** *Intervention* Type of Intervention	**Care and Action** *Relationships* Relationships within Education
Management of Outcomes *Intervention* Government Intervention (Professional Accountability)	**Management of Outcomes** *Role of Government*	**Management of Outcomes** *Role of Government* Government Investment in Autism	**Care and Action** *Relationships* Relationships with others/wider society
Management of Outcomes *Role of Government* Government as "system"	**Management of Outcomes** *Role of Government* Government as "system"	**Management of Outcomes** *Role of Government* Government as "system"	**Management of Outcomes** *Intervention* Outlook of Professionals
Management of Outcomes *Role of Government* Public Services vs Private Services	**Management of Outcomes** *Inclusion* Inclusive Education (Educated with siblings, peers)	**Management of Outcomes** *Role of Government* Public Services vs Private Services	**Management of Outcomes** *Inclusion* Inclusion of Child
Management of Outcomes *Inclusion* Inclusive Education	**Management of Outcomes** *Inclusion* Inclusive Policy	**Management of Outcomes** *Inclusion* Inclusion of Child: Inclusive Space	**Management of Outcomes** *Inclusion* Inclusive Education
Management of Outcomes *Inclusion* Inclusive Policy	**Management of Outcomes** *Leadership* Qualities of the Leader (Expertise, Professionalism, Devotion)	**Management of Outcomes** *Inclusion* Inclusive Education	**Management of Outcomes** *Inclusion* Inclusive Policy
Management of Outcomes *Leadership* Role of Leader in Families' Lives	**Management of Outcomes** *Leadership* Developing Inclusive Practice	**Management of Outcomes** *Inclusion* Inclusive Policy	**Management of Outcomes** *Leadership* Role of Leader in Families' Lives
Management of Outcomes *Leadership* Developing Inclusive Practice	**Social Norms** *Universality of Childhood Vs Autism: Concerns*	**Management of Outcomes** *Leadership* Role of Leader in Families' Lives	**Management of Outcomes** *Leadership* Qualities of the Leader
Social Norms *Universality of Childhood Vs Autism: Atypical Development*	**Social Norms** *Disability vs Difference* *Deficit Model of Autism*	**Management of Outcomes** *Leadership* Qualities of the Leader (Expertise, Professionalism, Devotion)	**Management of Outcomes** *Leadership* Developing Inclusive Practice

Appendix F

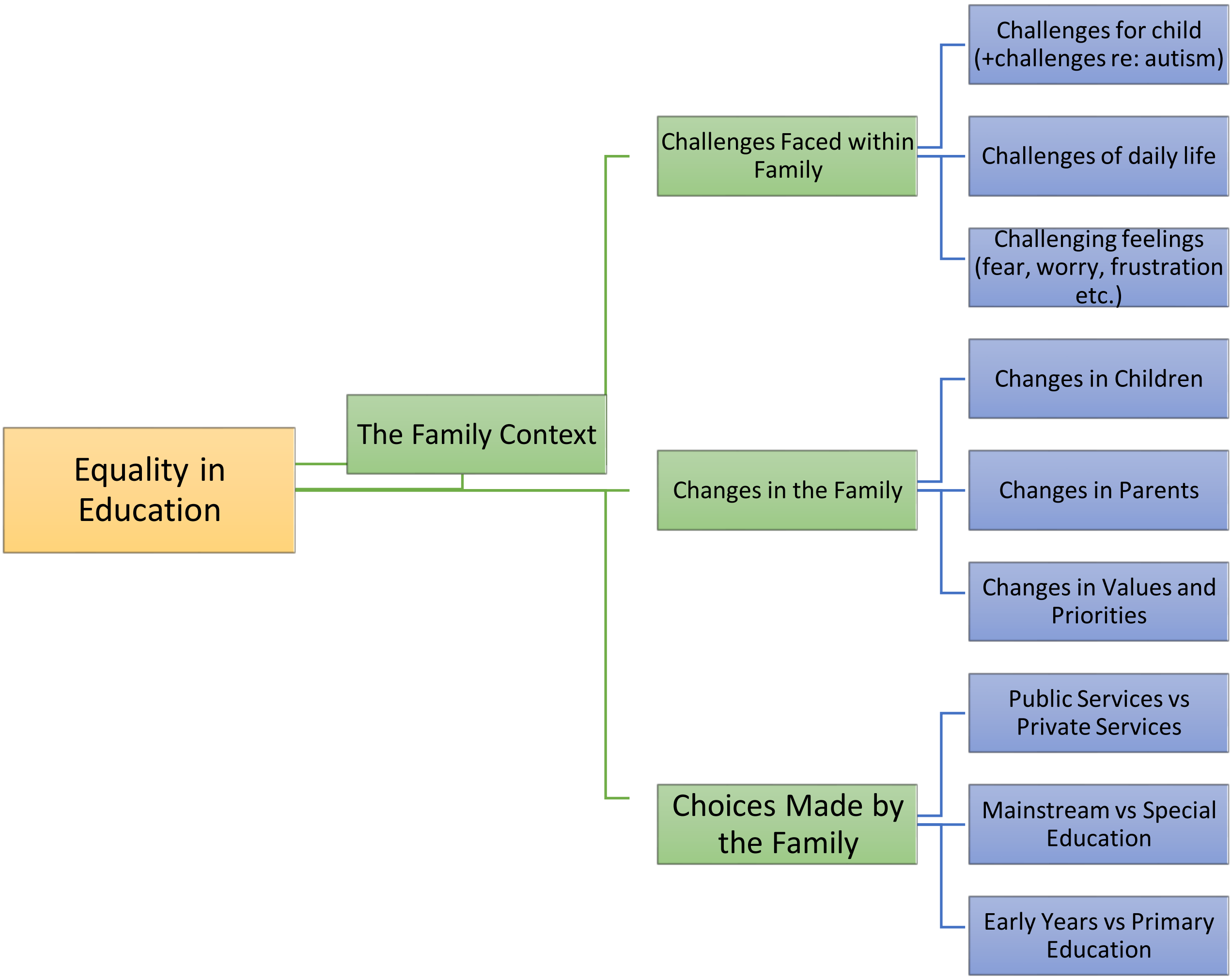
Developing the Meta-Narrative [Equality in Education] from the Grand Narratives of *Care and Action*, *Management of Outcomes* and *Social Norms* [continued]



Change	Challenge	Choice	Understanding of Child on the Autism Spectrum
Social Norms *Disability vs Difference* Autism as Difference	**Social Norms** *Perspectives* Negative Perspective	**Management of Outcomes** *Leadership* Developing Inclusive Practice	**Social Norms** *Universality of Childhood Vs Autism* Autism: A Different Way
Social Norms *Perspectives* Role of Media/Online Engagement	**Social Norms** *Perspectives* Role of Media/Online Engagement	**Social Norms** *Universality of Childhood Vs Autism:* Perspective on Autism	**Social Norms** *Disability vs Difference* Autism as Difference
Social Norms *Perspectives* *Positive Perspective*	**Social Norms** *Values* Values of Other Social Contexts (Suitability for Education)	**Social Norms** *Disability vs Difference*	**Social Norms** *Perspectives* Positive Perspective
Social Norms *Values* Central Values of Families	**Social Norms** *Values* Values of Wider Society (Independence, Achievement, Strength)	**Social Norms** *Perspectives* Negative Perspective	**Social Norms** *Perspectives* Negative Perspective: Impact on Child
Social Norms *Values* Values of Other Social Contexts		**Social Norms** *Perspectives* Dominant Perspectives within the Family	**Social Norms** *Values* Central Values of Families
Social Norms *Values* Values of Other Wider Society: Need for Change		**Social Norms** *Values* Central Values of Families	**Social Norms** *Values* Values of Other Social Contexts
		Social Norms *Values* Values of Other Social Contexts	**Social Norms** *Values* Values of Other Wider Society

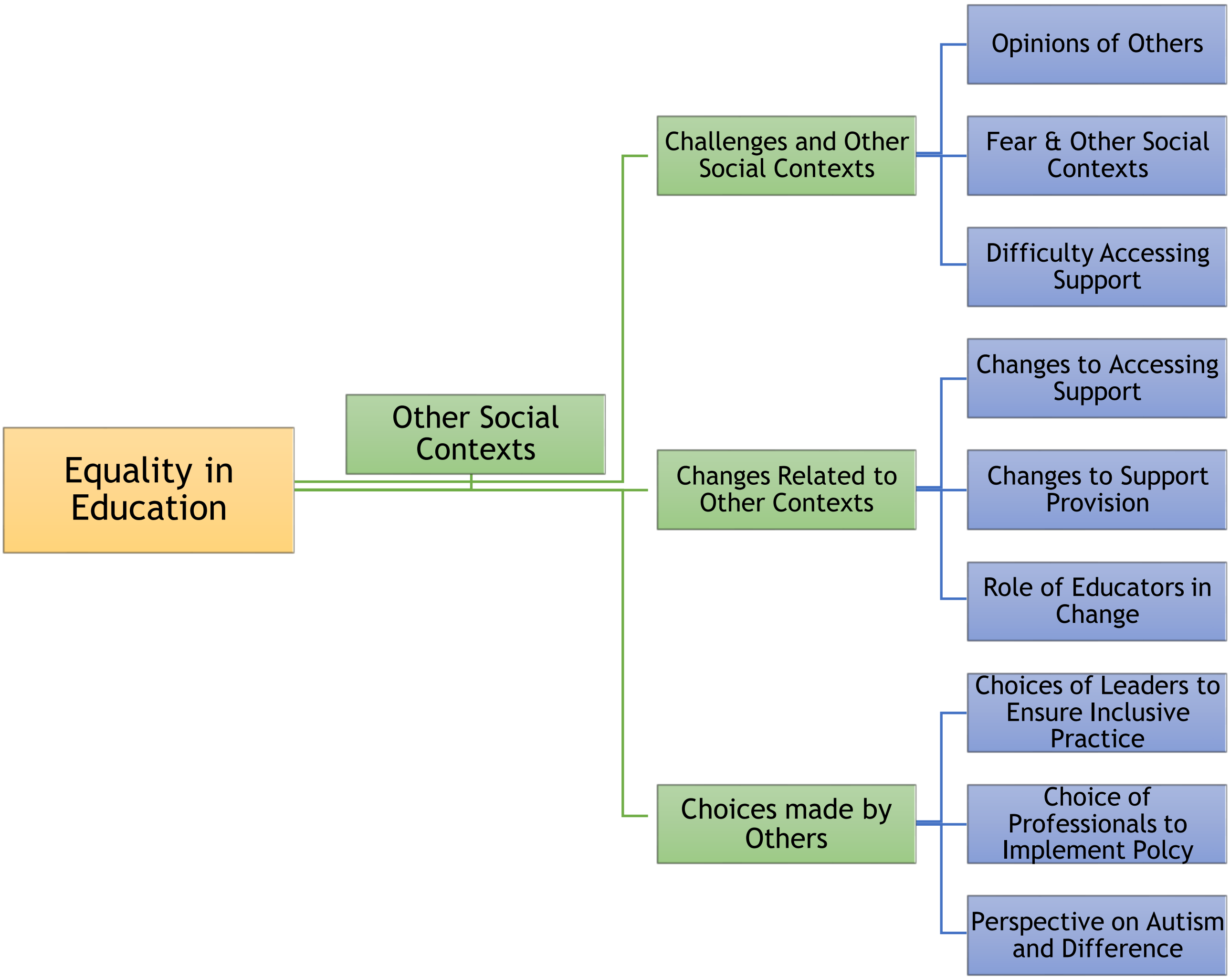
Appendix G

Dissemination of the *Equality in Education* Narrative in the Microsystem



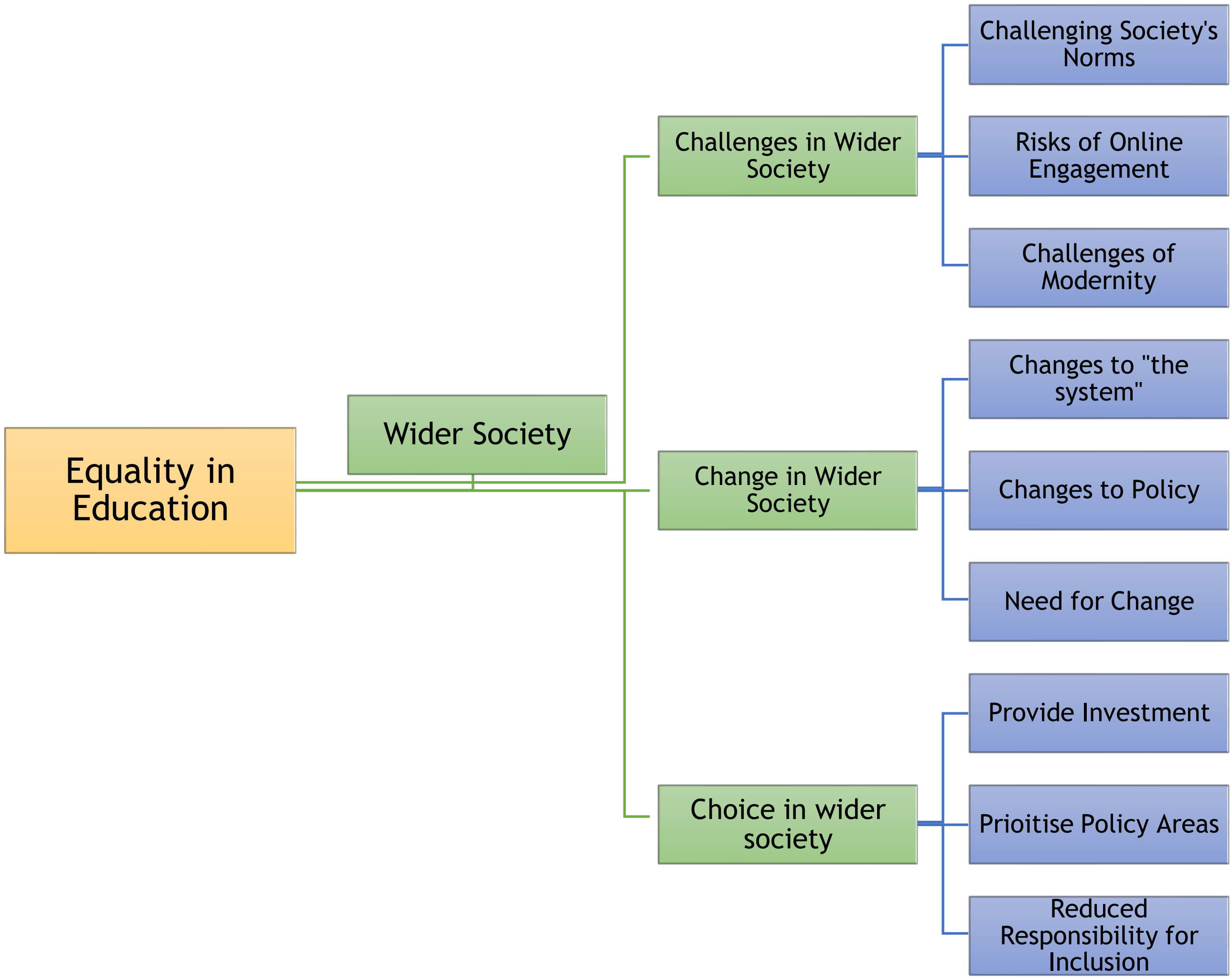
Appendix H

Dissemination of the *Equality in Education* Narrative in the Mesosystem



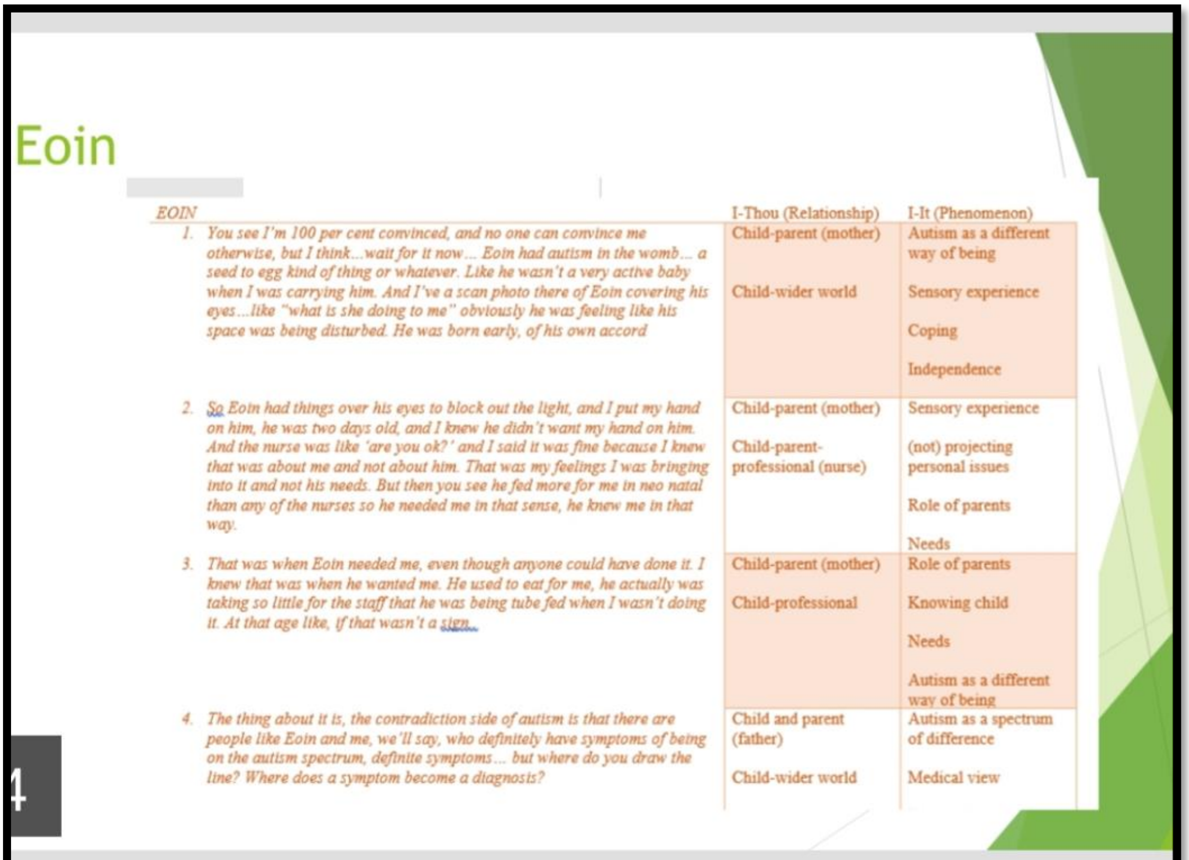
Appendix I

Dissemination of the *Equality in Education* Narrative in the Macrosystem



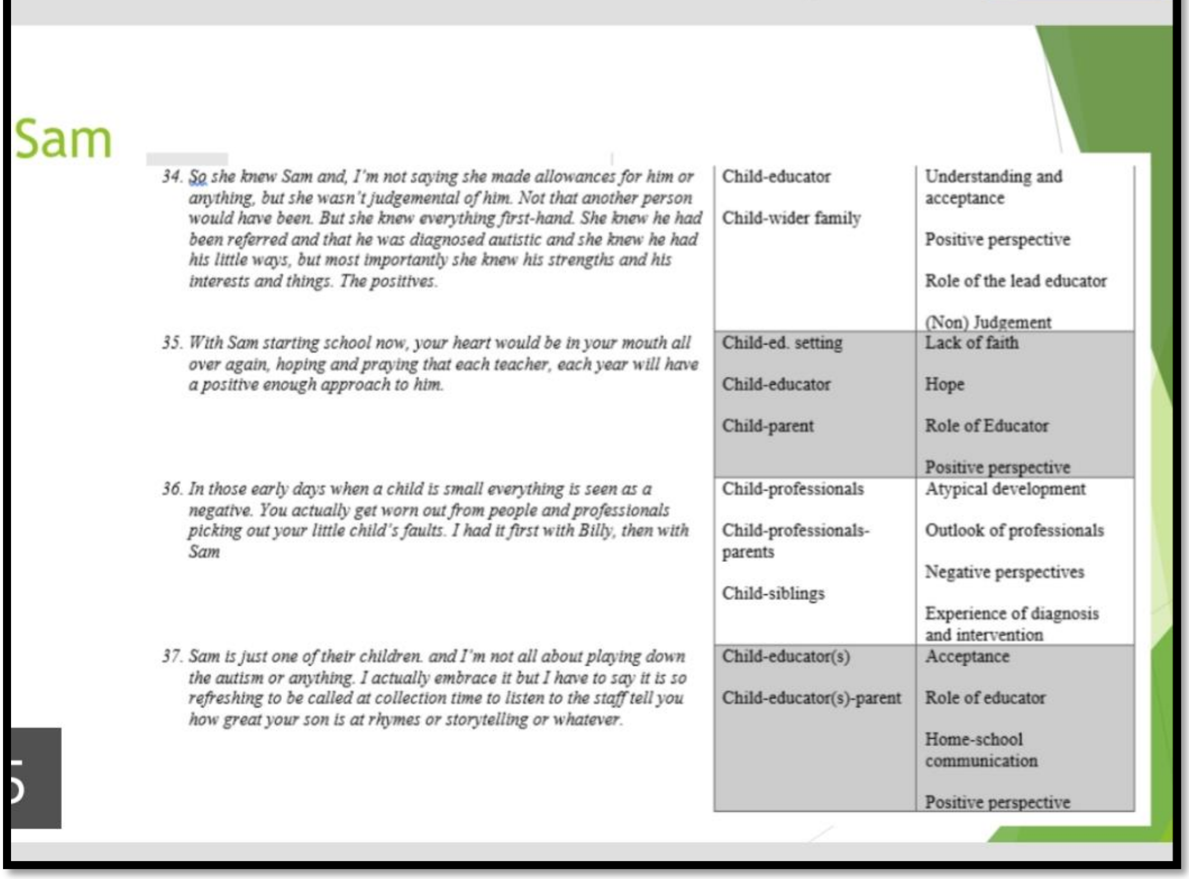
Appendix J

Child-Centred Narrative Analysis [Samples]



Eoin

EOIN	I-Thou (Relationship)	I-It (Phenomenon)
1. *You see I'm 100 per cent convinced, and no one can convince me otherwise, but I think…wait for it now… Eoin had autism in the womb… a seed to egg kind of thing or whatever. Like he wasn't a very active baby when I was carrying him. And I've a scan photo there of Eoin covering his eyes…like "what is she doing to me" obviously he was feeling like his space was being disturbed. He was born early, of his own accord*	Child-parent (mother) Child-wider world	Autism as a different way of being Sensory experience Coping Independence
2. *So Eoin had things over his eyes to block out the light, and I put my hand on him, he was two days old, and I knew he didn't want my hand on him. And the nurse was like 'are you ok?' and I said it was fine because I knew that was about me and not about him. That was my feelings I was bringing into it and not his needs. But then you see he fed more for me in neo natal than any of the nurses so he needed me in that sense, he knew me in that way.*	Child-parent (mother) Child-parent-professional (nurse)	Sensory experience (not) projecting personal issues Role of parents Needs
3. *That was when Eoin needed me, even though anyone could have done it. I knew that was when he wanted me. He used to eat for me, he actually was taking so little for the staff that he was being tube fed when I wasn't doing it. At that age like, if that wasn't a sign..*	Child-parent (mother) Child-professional	Role of parents Knowing child Needs Autism as a different way of being
4. *The thing about it is, the contradiction side of autism is that there are people like Eoin and me, we'll say, who definitely have symptoms of being on the autism spectrum, definite symptoms… but where do you draw the line? Where does a symptom become a diagnosis?*	Child and parent (father) Child-wider world	Autism as a spectrum of difference Medical view



Sam

34. *So she knew Sam and, I'm not saying she made allowances for him or anything, but she wasn't judgemental of him. Not that another person would have been. But she knew everything first-hand. She knew he had been referred and that he was diagnosed autistic and she knew he had his little ways, but most importantly she knew his strengths and his interests and things. The positives.*	Child-educator Child-wider family	Understanding and acceptance Positive perspective Role of the lead educator (Non) Judgement
35. *With Sam starting school now, your heart would be in your mouth all over again, hoping and praying that each teacher, each year will have a positive enough approach to him.*	Child-ed. setting Child-educator Child-parent	Lack of faith Hope Role of Educator Positive perspective
36. *In those early days when a child is small everything is seen as a negative. You actually get worn out from people and professionals picking out your little child's faults. I had it first with Billy, then with Sam*	Child-professionals Child-professionals-parents Child-siblings	Atypical development Outlook of professionals Negative perspectives Experience of diagnosis and intervention
37. *Sam is just one of their children. and I'm not all about playing down the autism or anything. I actually embrace it but I have to say it is so refreshing to be called at collection time to listen to the staff tell you how great your son is at rhymes or storytelling or whatever.*	Child-educator(s) Child-educator(s)-parent	Acceptance Role of educator Home-school communication Positive perspective

Appendix K

Character Profiles and Glossary of Terms

The Storyteller (Sarah), The Elder (Brenda), The Warrior (Sandra), The Clan Mother (Hannah), The Miner and his Wife (Alice and Michael), The Chief (Anna) and The Chieftain (Ellen)

The Storyteller: The storyteller reveals herself through her telling and the listeners reveal and share themselves through their reception of the story.

The Elder: A senior figure of the tribe whose wisdom and expertise has been gained through life experience.

The Warrior: A brave and experienced fighter who will protect and serve her family against all odds.

The Clan Mother: She who is righteous or good, solely responsible for the welfare of her clan.

The Miner and his Wife: They whose unwavering commitment and dedication enables them to provide for their family.

The Chief: A leader admired for her courage, outstanding achievements, or noble qualities

The Chieftain: Appointed for her recognised ability to design responses or problem solve issues together with members of the group or community

The Storyteller and The Moon-Written as vignettes that are intertwined with the following folktales

The Tree of Knowledge and The Elder

The Ducera Mountains and The Warrior

The Clan Mother, The Storms and The Canyon Especialis

The Chief and The Miner

The Chieftain, The Giants and The Scribes

Glossary of Terms
Caru Mountatin= Care/Early years education
Ducera Mountains= Education/Formal schooling
Canyon Especialis= Special Education
Giant Dynamikos the Powerful, guards the gateway to the Caru mountain range. [Representing the shared relational power of dynamic indicators of quality]
Giant Statikos the Balanced, guards the gateway to the Ducera mountain range. [holds the universal child as a measure of achievement. [Representing the imbalanced power relations implicit within static indicators of quality]

Speaking and moving in the ways of The Other: Medical model of autism and disability [deficit approach]

Speaking and moving in their own way: Social model of autism and disability [strengths-based approach/rights-based approach]

Tree of Knowledge: Dominant narratives

The Morning/Midday Moon: Perceived Judgement/Cultural Acceptance

Elder's Swirling Track: Infinity symbol of the autistic community

Cabins at the entrance to Ducera= ASD classes/ 'units'

The Lustrous Metal= money/economy

The Wagon=public services

The Universal Child= Predicted Development (Childhood as meeting developmental milestones etc.)

The Scrolls of Ducera= "Big data" (academic testing etc.)

The Scribes = government/government policy

The Trickster and The New Way= Neoliberalism

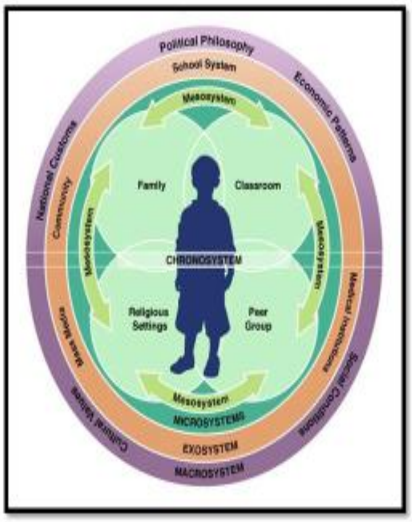
Appendix L

The Ecological Theory of Development as a Reconceptualisation of Ancient Symbolism

Ecological Development of Identity

Navajo Sand Painting

A circle around other Native American symbols signifies family ties, closeness & protection. The wider governing forces impact individual directly.



Bronfenbrenner's Ecological Theory

Incorporating the microsystem, mesosystem, exosystem and macrosystem.