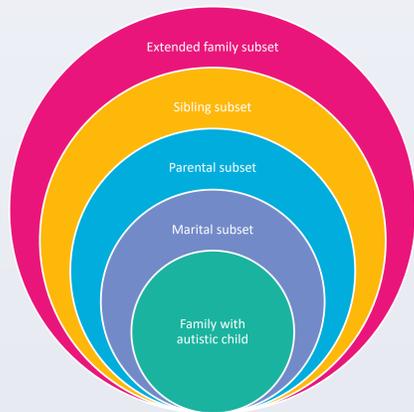




### Abstract

Family Systems Theory, nested in a bioecological systems model (Bronfenbrenner, 1979) emphasises the existence of sub-systems within the family. The functions of the systems are considered to involve support, regulation, nurturance and socialisation. Family interactions are the processes in the conceptual framework that include the marital subsystem (interaction between spouses), parental subsystem (interaction between parents and children), the sibling subsystem (interaction among siblings), and the extended family subsystem (interaction between the nuclear and extended family). Families of young children with autism experience higher levels of stress that present challenges to the interdependency of the family system. This paper presents the findings from three Irish research projects including Project Iris (Rose, Shevlin, Winter & O'Raw 2015).



This paper provides a discussion platform for parents, siblings, and other family members, educators and policy makers from an international perspective. In particular it calls for and invites more intense research on language and communication for families with members identified as being on the autism spectrum. The emerging finding provides evidence to support learning and language development through a 'whole' child perspective and argues for a substantial improvement in supporting parents as leaders of learning. Attention is drawn to the seriousness of horizontal and vertical stresses that families experience and how these stresses impact on their functional relationships.

### Parenting a Child with a Disability

Research literature on families of children with disabilities suggests that these families experience significant patterns of stress that impact on the traditional functioning roles of family members (S. Donaldson, Elder, Self, & Christie, 2011 and McStay, Trembath & Dissanayake, 2014 and McGoldrick, Carter and Garcia-Preto, 2014). It is evidenced within their research that families experience difficulties in vertical and horizontal life stressors that may create a 'dysfunction of the system' or break that family life cycle (Carter & McGoldrick, 2005). McGoldrick et al. (2014) contend that it is vital to respond to the life-long implications that a child with a disability has on the siblings of the family.

#### Family systems theory (Bowen, 1978)

This theory of relationships provides a conceptual framework for exploring the data on the lived experiences of families as they experience sensitive and difficult times. It draws attention to concepts of the self as an individual and as the emotional and functional aspects of the nuclear and extended family. A particular focus of this theory is on 'triangulation' where a third person enters a dyad in support role for one of the family members. Another focus within this theory develops as the family experiences a trauma and enters into a cycle of projection.

**Intergenerational Learning Framework (Gadsden, 1998)** positions the family and the cultural context of the family at the centre of the language learning process. In particular, it focuses on parent perspective of literacy and being literate and the values and roles of the extended family in the development of language and communication. A critical indicator for our consideration within these research projects was how parents and guardians of the families involved used literacy activities to generate a meaningful world for the children within the nuclear and extended family structure. Parents and guardians also learn from the children of the family and this bidirectionality supports the literacy practices and communication styles of the family system over time and generations.

### Perspective Taking

A social constructionist paradigm provides the theoretical perspectives guiding the exploration of the phenomenon of language and communication for pupils with autism. Constructionism provides 'multiple realities' by engaging in conscious construction of meaning (Crotty, 1998). In a social-constructionists view, the realities of communication are dependent on the knowledge of, engagement with and interpretation of communication by people involved within the social environment of the child and the influence our culture has on us. Qualitative and mixed methods were used to provide a depth of understanding of the lived experiences of families and young people with autism. In all projects case studies were used to allow for unique engagement and to provide an overview of experiences and provision.



### Research Project 1: Literacy Practices of Children with Autism (O'Síoráin, C. A. 2017)

Twenty one families were involved in this qualitative research project. Mothers (n21) Fathers (n3). An intergenerational learning framework for 'being literate' was emphasised by parents in this study, by reference to their own learning of language and communication. Parents spoke emotionally about the missed intergenerational opportunities for family fun and games with their autistic children because family members are challenged to cope and manage in ways that are different from their expectations. Mothers also related the financial difficulties they experience in seeking additional therapies to support their child. In all families involved in the study the family system was evidenced as fractured.

#### Loneliness and Isolation:

##### Penny's story

'When you have a child with autism you're on your own a huge amount'. Her family refer to 'Ewan's autism' as 'her business' and they can't relate to her situation because they 'don't walk in my shoes'.

##### Anita's Story

Anita talks about her challenges of having two autistic children and how she had to isolate herself from her family to protect herself. 'Your locking the world out until you get yourself into a better place'. She spoke about the responsibility role her 4 year old daughter had taken on in trying to support the family. She said her daughter sees herself as her equal and that she 'parents' her autistic brothers.

#### Guilt

Many mothers felt guilty that they 'didn't pick up' on the lack of progress of their child at an earlier stage, they referred to being overwhelmed by exhaustion and frustrated by a lack of help from the extended family. Extended family couldn't manage the feeding and changing issues and couldn't soothe the babies. Mothers felt robbed of the 'fairyland' (Lulu) ideology of family.

#### Family Status

While no question was asked relating to marital status in this research project, parents volunteered information about their relationships. Parents stated that the diagnosis of autism had exacerbated already existing issues in relationships and 30% of these parents volunteered that they were legally separated from their partner.

### Research Project 2: Spaces, Places and Identities (Twomey, M. 2013)

#### 'Triangulation'

Through the course of the research, Callum remained silent. Callum's difficulties with social interaction suggested a slower development of self. Callum was not connected with others and occasionally appeared emotionally fragile. He occupied his time playing with a small finger puppet. Observed closely by a very popular sociable peer Rosie, Callum reluctantly joined the research project. The classroom became a 'place' of belonging.

#### Valuing Voice

Parents in this research valued an opportunity to speak about their experiences. Helen referred to the lack of appropriate services. She described "parents' levels of 'loss' of identity". She explained that parents were experiencing the loss of the child they had anticipated but also loss in terms of experiences, interactions, and reciprocity with their child. Referring to lack of professional support during the challenges of assessment and diagnosis, another parent explained "There's no 'someone' to turn to and say... can you explain to me please - what this is? Amy described her experiences and the effects on family life: "you know we were literally, as a family we were at breaking point".

#### Puppets for Developing Relationships

The researcher employed role-play with two puppets, and began the focus group by talking through the puppets. Children joined in the narrative, telling the puppets about themselves, who they were, what they liked doing and who their friends were. Rosie was encouraged to invite Callum to join in and stay with him during the research visits. Callum's Mum referred to her desire to improve her relationship with her son. Callum preferred to engage in solitary activities. Callum's ongoing neurological diagnosis created challenges for his parents in terms of their emotional journeys. They would have benefited from interventions to improve their relationships.

#### An Emerging Sense of Self

At the latter stages of the research, when the puppets introduced a microphone during questioning, Callum quickly responded: "My name is Callum and that is where I go" Callum raised his quiet voice; he was intent on talking about something else... "Farmer Pickles says go down to the pond...we all go down to the pond - that is where we see ducks". Callum was recounting a story of a Bob the Builder character Farmer Pickles from a video he had recently seen. This was confirmed by his Mum, who believed that his affinity with these characters enabled and enhanced his literacy. She read Bob the Builder books to Callum at home. Callum was recounting his sense of place - as he interpreted it through a familiar and well-loved character.

### Research Project 3: Project Iris (Rose, R., Shevlin, M., Winter, E., & O'Raw, P. 2015)

This project was a longitudinal study of the experiences and outcomes achieved by students with a special education need in Ireland. Findings indicate that learners made significant progress in domains such as happiness, engagement and independence. However, findings also demonstrated some of the frustrations parents experience in seeking assessments for resource allocation, access to therapeutic support and the need for great levels of understanding and training for professionals on supporting the educational needs of their children. Post-primary placement was complex and parents experienced additional stressors as they had to raise the level of support and take responsibilities the learning and engagement of their children.

### Conclusion of Findings

The findings from these research projects add significantly to the research on family life and the emotional, financial and relationship hardships that impact on the processes and communication practices of families. Building a sense of belonging and community of support with peers adds to positive interventions in schools. The evidence from these projects highlight the plight of the family as a unit within a community and provides a picture of the needs of the family at different transitioning places across education. As stated in the findings of Project Iris (2015), barriers such as access to service and support are evident from early years not just within the school setting but within the family and community.

This paper calls for **URGENT INTERVENTION AND SUPPORTS** from the moment of diagnosis to enable families to maintain an intergenerational framework to family support and education and to limit the stressors that undermine the structure and function of the family.