An Irish Study of the Perspectives of Special Class Teachers and Special School Teachers of Toileting Differences Experienced by Children and Adolescents on the Autism Spectrum

Toileting is a critical life skill essential for day-to-day independent living. It is not uncommon for children on the autism spectrum to begin the process of toilet training later than their peers. Children on the autism spectrum may continue to have challenges with toileting throughout their childhood and into the adolescent and adult years. Although often referred to as a skill deficit, the terminology used in this study will be toileting differences. Examples of toileting differences include an extended length of time to acquire toileting skills, an inability to generalise the skill and significant sensory sensitivities in the bathroom itself. While toileting differences have been recognised as a frequent area for development in individuals on the autism spectrum, it is unclear how this impacts children on the autism spectrum in a school setting and if these differences are recognised amongst the teaching profession. With an increase in the number of children being diagnosed with autism and a move towards total inclusion i.e. more learners with autism attending mainstream schools, it is important to explore teachers' perspectives on this topic. At present there are no studies available relating to autism and toileting differences in an Irish school setting. This article focuses on a number of findings from a master's dissertation, exploring the perspectives of both special class teachers and special school teachers regarding toileting differences experienced by children and adolescents on the autism spectrum. The factors that aid teachers in supporting children when they present with toileting differences in the school setting were also examined.

Keywords: Autism, ASD, special education teacher, toileting, self-help skills, daily living skills, life skills

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INTRODUCTION

Children who are being educated in autism spectrum classes either within a special school setting or mainstream school have individual additional needs that often require specific supports. Children with autism can present with a large array of complex strengths and needs and display a diverse range of abilities in terms of adaptive function, cognitive and language abilities and neurological co-morbidities (Jeste and Geschwind, 2014). Skill differences in the area of life-skill and self-care activities such as toileting has been identified as a significant challenge (Cocchiola *et al.*, 2012). This is not a new phenomenon; researchers 30 years ago realised the significant impact this was having on both children with autism and their parents. In 1992, a survey of toileting, drawn from a population of parents with children nine years of age or older, reported that five percent of the sample (N= 100) with a mean age of 23.8 years were not toilet trained (Dalrymple and Ruble, 1992). In an Irish study of 127 children and adolescents with autism (age five - 17 years), 81% of the sample presented with at least one gastrointestinal symptom i.e., constipation or diarrhoea, within the previous three months (Leader *et al.*, 2018). The most common toileting problems reported in the study were, "Does not independently perform most self-help tasks", "Has toilet accidents during the day", and "Parent/caregiver notices smears in underwear". Significant predictors of these toileting problems included gender, presence of intellectual disability, gastrointestinal symptoms and comorbid psychopathology.

In the current study, variations in toileting were not considered or referred to as a skill deficit or disorder but acknowledged and referred to as "toileting differences". Terminology regarding autism is also a widely debated issue. According to the Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5), Autism Spectrum Disorders (ASD) are diagnosed on two domains: persistent deficits in social communication/interaction; and stereotyped or restricted, repetitive behaviours (American Psychiatric Association, 2013). To help categorise the level of support required by individuals on the autism spectrum, severity level descriptors are provided by the DSM-5 ranging from level 1 ("requiring support") to level 3 ("requiring very substantial support") (Weitlauf *et al.*, 2014). Even though the diagnostic criteria of autism refer to it as a disordered way of being, many professionals, researchers and settings see autism as a difference and refuse to use the word disorder (Guldberg, Bradley and Wittemeyer, 2019). Additionally, there are ongoing debates whether to use 'person first' language or the term autistic, with some individuals seeing autism as a core part of their identity. In a large scale survey with members of the autism community (N=3470) in the United Kingdom, the terms 'autism' and 'on the autism spectrum' were the most highly

endorsed terms (Kenny *et al.*, 2016). Thus, individuals on the autism spectrum is the terminology used predominantly throughout this article. However, other terms such as individuals with autism or ASD may be used when reviewing literature or other reports where this was the terminology used.

Although one accepts that toileting may be a sensitive or difficult topic, adaptive life skills such as toileting are associated with positive quality of life outcomes and need addressing (Francis, Mannion and Leader, 2017). It is central to supporting inclusion for students on the autism spectrum as research has shown that improving adaptive life skills help to facilitate and support community inclusion (Gray *et al.*, 2014). Aspirations of full inclusion in the education system and in the community is possible if we give the children the tools necessary to live a life of dignity. At the time of the research there were no studies available relating to autism and toileting differences in an Irish school context.

Reports have outlined that special school and special class teachers focus on addressing children's holistic development through the provision of a wide range of learning areas and experiences, listing toileting programmes as one of those areas of learning (Daly *et al.*, 2016). The focus of the study being reported was the exploration of teachers' experiences of teaching children on the autism spectrum who present with toileting differences in the school setting. By recording the perspectives of teachers in mainstream special class settings and special school settings the aim was to develop a greater understanding of the nature of their experiences.

BACKGROUND

In the last three decades, within the Republic of Ireland, significant change has been made regarding the educational provision for pupils with special educational needs (National Council for Special Education, 2019). A number of inter-related developments resulted in a policy shift from parallel systems of mainstream and special education towards an inclusive education system. The publication of the report of the Special Education Review Committee (SERC 1993) was the first significant milestone. It advocated a continuum of educational provision for students with educational needs favouring 'as much integration as is appropriate and feasible with as little segregation as is necessary' (Department of Education and Skills, 1993, p.22). There has been a gradual transition towards inclusion since the publication of the SERC in 1993. In line with the Education for Persons with Special Educational Needs (EPSEN) Act 2004, the National Council of

Special Education (NCSE) advised that the best way forward was the provision of special classes in mainstream schools or special schools situated on mainstream campuses. Furthermore, in a recent policy advice report, 'Progress Report – Policy Advice on Special Schools and Classes' the NCSE revealed their vision for 'Total Inclusion' within mainstream school classes for children with additional needs (National Council for Special Education, 2019). The inclusive school reflects a shift in educational practices from a medical model to a biopsychosocial model, where teaching is differentiated for all students as opposed to teaching to the "normative centre" (Howe and Griffin, 2020).

The Irish education system currently has a multi-track approach regarding the provision for children on the autism spectrum, providing education in either special autism classes in mainstream schools or otherwise special schools and autism specific schools (Kenny and McCoy, 2020). In 2016, the NCSE published a report on supporting students with autism in schools and noted that 1 in 65 or 1.5% of the school going population in Ireland had a diagnosis of autism (Daly *et al.*, 2016). At that time provision included 19 dedicated special schools for students with autism, 95 special classes at pre-primary level, 378 special classes at primary, 152 special classes at post-primary and multiple special schools with classes for students with autism. The figures have increased significantly since this report, with Máirín Ní Chéileachair, Director of Education, Research & Learning, stating that in the 2022-2023 school year there are 1,548 classes for autism across all primary schools (Irish National Teachers' Organisation, 2022). Given the rapid pace of demographic change within the education system in Ireland, teachers undoubtedly have a key role in ensuring the experience of children on the autism spectrum is both successful and inclusive.

A strong link between teacher expertise and a positive experience in special classes for children has been highlighted in research (Banks *et al.*, 2016). There has been contradictions between studies with regards teacher allocation, with one study reporting excellent commitment by principals to recruit experienced staff to teach children with autism (Daly *et al.*, 2016). This was compared to a more recent study which highlighted that the majority of special class teachers (n=50) within the study had "little or no training" before beginning their role as a special class teacher (Horan and Merrigan, 2019). Continuous professional development (CPD) for teachers has been emphasized as a means for improving teacher expertise and competency (O'Gorman and Drudy, 2010). However, access to CPD for teachers either taking up new positions in special classes or accessing CPD has been highlighted as a major area of concern (Daly *et al.*, 2016). Teachers have consistently emphasized the requirement for CPD that is accessible as specific

needs arise (Corkum *et al.*, 2014). In the area of adaptive and daily living skills, CPD courses and access to resources for teachers would therefore be necessary.

METHODOLOGY

From an initial literature review, it was found that much of the research regarding children on the autism spectrum and toileting had been conducted using quantitative research. It was reported that 82% of children on the autism spectrum experienced toileting challenges, as identified through parent report (Szyndler, 1996). Furthermore, the frequency of toileting problems in individuals on the autism spectrum from a number of countries (e.g. Ireland, United Kingdom, Australia, United States and Canada) ranging from 5 to 17 years reported that 53.54% (n=68), had challenging behaviours when toileting (Leader *et al.*, 2018). However, the view and voice of teachers had not yet been given consideration. Qualitative exploration would enable the teacher's perspective to inform the study. Semi-structured interviews were carried out with special class and special school teachers, both primary and post primary, who had experience of working with children on the autism spectrum. This allowed for deep, contextual understanding and incorporation of multiple perspectives (Creswell, 2009). Criteria of selection of teachers were that they were teaching children on the autism spectrum at the time of the interview, that those children were in the age range 3-18 years and that the teachers would have a minimum of five years' experience in this role. While teachers were not required to be educating students with toileting differences at the time of the study, teachers with a minimum of 5 years' experience were recruited with the aim of capturing a particular level of insight into the topic. The following research questions were explored in the study:

1. What are the perspectives of special class teachers and special school teachers regarding toileting differences experienced by children on the autism spectrum?

2. What factors aid teachers in supporting children on the autism spectrum that present with toileting differences in the school setting?

Data was collected from five special class teachers and nine special school teachers in Ireland. Ethical issues were given appropriate consideration from the outset of the study and approval was received from DCU's Faculty Ethic Review Panel (FERP). Pseudonyms were used to identify the participants. Teachers were referred to as Teacher A, B, C etc. The interview schedule for semi-structured interviews contained approximately eight questions. The questions were a guide as

the interview was designed for open dialogue on the topic of toileting differences in children on the autism spectrum. The interviews were approximately thirty to sixty minutes. Each of the individual semi-structured interviews was conducted using the online platform, Zoom adhering to DCU data protection protocols. All interviews were transcribed and sent to the participants for member checking. Data analysis of the interviews was a continuous, iterative process, which followed a data-led thematic analysis approach based on six phases according to Braun and Clarke. This six-step framework offers a systematic, yet flexible approach enabling researchers to identify patterns and themes when analysing qualitative date (Braun and Clarke, 2006). The process began by transcribing data and reading this data repeatedly, followed by coding, searching and reviewing themes, providing definitions, and finally naming the themes which will be discussed in the findings and discussion section.

FINDINGS AND DISCUSSION

Following analysis of the data, one of the core themes uncovered was: teaching and learning in the inclusive school. The subthemes within this theme of "teaching and learning in the inclusive school" were roles and responsibilities, teachers' awareness, training and self-efficacy, and building the foundations. According to AsIAm, inclusion is not solely about the school in which the child attends, it is about the child being accepted, valued and able to completely participate in their learning environment (Inclusion in Our Special Classes and Special Schools, 2020). The inclusive school environment and factors which enable the group of teachers interviewed to support children with toileting differences was a topic that was discussed frequently.

Roles and Responsibilities
Within this study there was a vast discrepancy between teachers regarding whose role and responsibility it is to assist a child on the autism spectrum when toileting differences are apparent. Interestingly, there were no patterns evident in any particular setting. Several teachers understood it to be the responsibility of the teacher to put the plans in place for the child, but it was ultimately the SNAs who assist the child one-to-one in the bathroom "The buck stops with the teacher but from what I have seen in early intervention in school, it's the SNA with that child, I would give 99% of the credit to," (Teacher D). In 2014 a circular entitled, *The Special Needs Assistant (SNA) Scheme to Support Teachers in Meeting the Care Needs of Some Children with Special Educational Needs, Arising from a Disability* (DES, 2014), the Department of Education and Skills recognises that the classroom

teacher is responsible for educating all pupils in his/her class and the work of the SNAs should be focused on supporting the particular care needs of the children with special educational needs at the principal or teachers direction. Within this circular, assistance with toileting and general hygiene where the children with special needs cannot independently self-toilet was given as an example of a care need which might require SNA support. However, the inconsistent practice and the lack of clarity around roles reported within the study being reported here was concerning.

There was a varied response regarding the support available from external support personnel i.e., psychologists, occupational therapists, and other members of the multidisciplinary team. "The OTs were a very big help and obviously as well, speech and language has been really important, just around getting the visuals right" (Teacher E). However, the inconsistent practice and the lack of clarity around roles reported within the current study was concerning. "I've looked for help from the OT and been given the generic stuff that I've tried, like the playdough, the sensory stuff" (Teacher C). Consequently, if support from services is poor or non-existent and the responsibility is ultimately lying with the teacher, it would be critical that teachers working in an autistic spectrum (AS) classroom are aware of the differences that the children may be faced with.

Teachers' Awareness, Training and Self-Efficacy
Teacher self-efficacy refers to the beliefs teachers hold regarding their capability to bring about desired instructional outcomes (Ruble, Usher and McGrew, 2011). When questioned on their self-efficacy regarding working with children on the autism spectrum facing toileting differences many of the teachers spoke about their lack of awareness when first working in the field. "Being trained as a mainstream teacher, it has taken me a while to realise the importance of targeting toileting in school. It's only now that I'm in this school that I see that it is actually part of the one two threes and the ABCs of this child, this is a child's learning" (Teacher L). Teachers alluded to the importance of gaining practical experience: "I would feel reasonably confident that I have a few things to try. I would know where to go and who to ask. But that comes with experience," (Teacher K).

Teachers noted that training was inadequate despite toileting having huge implications for children on the autism spectrum. They reported receiving little autism related content during their initial teacher training. Furthermore, they acknowledged the absence of CPD courses or specific training, recognising the need for courses which focused on information for all adaptive life skills including,

the management and support of toileting differences. Teacher C noted that they just "get this generic template that's been sent out to all of us. We need courses, even for Croke Park hours. I know a lot of children in our school have toileting issues. CPD courses, anything at all. There is nothing.". Although it appears awareness in the area is poor and CPD courses in the area of adaptive life skills are virtually non-existent, teachers discussed ways in which they ensure that the children on the autism spectrum who experience toileting differences can be supported.

Building the Foundations

Teachers referred to the importance of collaboration within schools and furthermore between schools when a child is transitioning to a new setting. Connecting with teachers who had worked with the children previously was commonly alluded to across several interviews. For some teachers, connection with the previous teacher was particularly important and proved to be beneficial for the student. Teacher K detailed the difficulties that may arise if the communication between teachers fail or a smooth handover does not arise. One example given was sharing information on the use of existing reward schemes for toileting as discontinuation of this in a new class would be very challenging for pupils. According to this teacher "I can understand what she was trying to communicate. Where is the treat that I used to get for behaving myself? And if I'm not going to get it, I won't comply." Furthermore, building a a relationship of trust with the child was an essential component before strategies were implemented.

Teachers were adamant in their beliefs that at any of the stages of toileting there should be a foundation built prior to interventions or strategies being implemented. These foundations included the teacher's development of a positive relationship with the child, understanding the needs of the child and ultimately knowing each individual child's personality. Teacher E, an early intervention teacher in a special school, described it as the ability to get the balance right when implementing strategies "Some kids, maybe I pushed a little bit too much. We did have to pull back because they started getting nervous of going to the toilet. It's like everything in special ed. It's the balance of push and pull". Teachers, more so those working with adolescents, considered the importance of having a good rapport with the child for any interventions regarding toileting to succeed. A special class teacher in a mainstream secondary school briefly mentioned that when implementing any strategies, the teacher should be aware of the age of the child and their needs. "It's how it's very discreetly done, I suppose, from a teacher's perspective. To be very cognizant of their needs."

CONCLUSION

The perspectives of special class teachers and special school teachers regarding the toileting differences experienced by students on the autism spectrum was explored and the factors that can aid teachers to support children were uncovered. According to research, "toileting problems" have been recognised as an area for development that affect those with autism (Mannion and Leader, 2013). Moreover, it is regarded as a critical life skill for independent living (Leader *et al.*, 2018). In both the special school and mainstream school setting, teachers are often required to provide specialised educational provisions for children including the provisions for self-care skills; toileting being one of these. However, whose role and responsibility this is, is regularly questioned, in addition to the lack of support from external agencies. Overall teachers voiced a huge level of disappointment regarding the resources, training, and awareness in the area, given that it is such a huge area of need for the children they teach. With the imminent move towards 'Total Inclusion' for all children within the education system including those on the autism spectrum, it is essential that teachers have the knowledge, skills and confidence to support all children within their class.

IMPLICATIONS FOR PRACTICE

The findings from this study have implications for practices within the inclusive school and provide several practical suggestions to support children on the AS with toileting differences.

1. The roles and responsibilities that lie with the teacher, and the support received from SNAs, external supports and colleagues were discussed. Some schools adopt an intimate care policy in respect of students who require care such as toileting, however this is not mandatory. Further clarity in school policy and familiarisation of these policies for all staff is required. Good communication between the SNAs and teacher is also key to determine the support role of the SNA under the guidance of the teacher.

2. This study questions the awareness, knowledge and training of teachers with regards the necessary skills when working with children on the autism spectrum. Prior to taking up roles in special classes or special schools, it would be beneficial for teachers to have access to appropriate training and CPD programmes. This would help raise awareness of differences experienced by children on the autism spectrum and deliver appropriate teacher education. This may ensure that teachers

beginning their work in autism specific classes come to the role with a stronger knowledge base, more awareness of differences children on the autism spectrum experience and improved confidence to support the children in their care.

3. Teachers in this study highlighted the importance of a foundation or relationship being built with a child when toileting differences arise, and additional supports are required. In the literature, teacher aides in preschools in Israel, working with children with developmental difficulties, highlighted the efforts required to create a supportive and close atmosphere during the toilet training process e.g. reading stories and remaining physically close to them (Shoshani and Schreuer, 2019). In the Irish context, the NCSE has acknowledged the significance of building relationships with children on the autism spectrum (Daly *et al.*, 2016). A relationship of trust between the child and teacher or SNA is therefore of fundamental significance and strategies to build these relationships as well as the time required need to be encouraged.

The findings of this study generate several questions for further research. Future recommended quantitative and qualitative studies should incorporate the views of the students themselves, SNAs and parents. Future research is also required to investigate which strategies are most effective for supporting specific stages of toileting. While understanding the individual learners and building relationships was a clear focus for teachers, broadly there is still a medical model based approach to implementing supports for learners on the autism spectrum – training must include autism affirmative approaches building on teachers' knowledge and relationships with the learner.

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