'Close the door on your way out': parent perspectives on supported transition planning for young people with Special Educational Needs and Disabilities in Ireland

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Students with Special Educational Needs and Disabilities encounter complex and circuitous transitions from post-primary settings to Higher Education. In Ireland, inequitable access to Individual Education Plans, and a lack of policy infrastructure to provide formal transition planning, means that these journeys are varied and uncertain. This study presents findings from surveys completed by parents supporting students with disabilities in their final 3 years of mainstream secondary school (n = 69), and in-depth interviews with a self-selected subset of parents (n = 8). Results point to: (i) disparate levels and quality of support and guidance, (ii) fissures in communication channels between parents and schools, (iii) insufficient awareness and understanding of the interplay between disability and successful post-school outcomes, and (iv) high levels of stress, anxiety and frustration experienced by students, parents and carers.

Introduction

Well I just think that as a society we aren't open to people with a disability, maybe we don't like to look at them, maybe we don't like to think they exist? And I think it is just society as a whole kind of tries to shut the door behind them. (Parent of a pupil with a Mental Health Condition attending a state school)

Transitions from school are a normative part of development, often premised on the notion that these follow highly structured and linear life stage models, where there is a normative progression from dependence to independence (Jeffrey, 2010). However, the emotional and practical factors attached to transitional events, are not experienced by all pupils and parents in the same way (Lohaus, Elben, Ball, et al., 2004; Wagner, Newman, Cameto, et al., 2005). Therefore, transition is subjective and must acknowledge the cultural genealogies and schemas experienced by individual pupils, parents and families. Educational transitions for young people with Special Educational Needs and Disabilities (SEND) are connected to: (i) legal constructs surrounding SEND and educational provision, (ii) competing models of disability that obfuscate how systems and policy-makers should respond, (iii) attitudes towards inclusion and exclusion within the education system, and (iv) personal bioecologies (Doyle, 2015). Each of these represents a potential enabler or barrier to transition.

Transitioning from home to primary school, from primary to secondary school and upwards to 'real world' situations, is fraught with psychological, physiological and practical junctures (Gillan and Coughlan, 2010; Lefever and Currant, 2010; McCoy, Smyth, Watson, et al., 2014; Smyth, Banks and Calvert, 2011; Stewart, Freeman, Law, et al., 2010). There may be separations between the culture of the family and the culture of school, and conflict may arise in relation to trust, beliefs and commitments. This is magnified by individual differences, family resources, curriculum access and socio-economic/socio-geographic variables (e.g. Daly, Keogh and Whyte, 2007; McCoy, Byrne, O'Connell, et al., 2010; Unwin, LeMesurier, Bathia, et al., 2008; Wray, 2013).

The role of the family is a significant one in the lives of young people with SEND, in particular because they rely on support and guidance from parents or carers for longer than their peers (Dovey-Pearce, Price, Wood, et al., 2012). Parents are a child's first teachers, and the home their first school (Berger, 1995), however, the delegation of this role to other adults once formal education begins, may in itself cause difficulties (Crozier, 1999). Further tension is created when this conflicts with cultural values,

as in Ireland, where the principles of family and education are set out in the Constitution (Government of Ireland, 1937), where the family is the fundamental unit of society (Article 41), and is also the primary educator of the child (Article 42).

Parents of young people with SEND face significant hurdles in the pursuit of inclusion for their children (Daly, Keogh, and Whyte, 2007), and frequently '... the family provide students with additional support not offered by the institution, and students who do not have access to such support, may well be at particular risk' (Weedon and Riddell, 2007, p. 6). Although this evolution of dependence is understandable and perhaps inevitable, it may inadvertently constitute a barrier where the desires and aspirations of parents and students diverge, and can impede the requirement to function independently in Higher Education (HE) (Dee, 2006; Mc Guckin, Shevlin, Bell, et al., 2013; Scanlon, Shevlin and Mc Guckin, 2014). At the moment of transition to post-school settings, parents must relinquish some of their influence over their child's life. This power exchange has the potential to be traumatic, as there are specific anxieties and concerns associated with transition to an environment which has radically different structures, systems, and expectations (Checchi, 2006; Gillan and Coughlan, 2010; Hill and Tyson, 2009; Mc Guckin, Shevlin, Bell, et al., 2013; Rose, Shevlin, Winter, et al., 2010). This may have a significant effect on the first crucial weeks of the HE experience, thus the transfer of responsibility for support must be handled with sensitivity and understanding (Mc Guckin, Shevlin, Bell, et al., 2013).

Pre-transition barriers and associated risk factors for students with SEND (Scanlon, Shevlin, and Mc Guckin, 2014) must be observed in tandem with the emotional significance of transition (Barnes-Holmes, Scanlon, Shevlin, et al., 2013; Darmody, 2012; Evangelou, Taggart, Sylva, et al., 2008). At a school level, serious discrepancies exist between the aspirations of pupils and the expectations of practitioners, affecting the level of encouragement and guidance provided (Mc Guckin, Shevlin, Bell, et al., 2013; Smyth, 2013a,b; Smyth and McCoy, 2013; Watson, 2009; Wray, 2013). Unequal educational outcomes for young people with SEND are connected to the ethos of the school and the attitudes and expectations of teachers (Shevlin, Winter and Flynn, 2013; Smyth, 2013b). By extension, this bleeds into provision of resources and dissemination of opportunities and access routes, meaning that for some pupils, particular choices cut off particular pathways well before the end of formal education (Smyth, 2013b). Equal access to educational opportunities and outcomes is the cornerstone of inclusive education (OECD, 2011; Winter and O'Raw, 2010), and by extension, planning for transition journeys is a critical element of social inclusion (Dee, 2006). Therefore, a failure to provide access to appropriate transition support and guidance, is exclusionary (Shevlin,

Kenny and McNeela, 2004; Unwin, LeMesurier, Bathia, et al., 2008).

In Ireland, sections 3, 9, 11 and 12 of the Education of Persons with Special Educational Needs Act (2004) describes the preparation, content, review and appeals in relation to Individual Education Plans (IEPs), however, this statutory obligation is yet to be enacted, meaning that formalised assessment of individual need and preparation of transition plans, are not available to all young people with SEND (Cosgrove, McKeown, Travers, et al., 2014; Mc Guckin, Shevlin, Bell, et al., 2013). Guidelines for the implementation of IEPs acknowledge that 'School leaving represents the final transition envisaged by the Act', and that 'transition planning should take place one year in advance of the young person leaving school' (NCSE, 2006, p. 51) including an exploration of the full range of post-school pathways, however, Irish students report the lack of a formal IEP as a barrier to transition (OECD, 2011, p. 83).

Listening to the narratives and viewpoints of young people and their families as active participants in transition, is critical (Beauchamp-Pryor, 2012; Byers, Davies, Fergusson, et al., 2008; Redpath, Kearney, Nicholl, et al., 2013; Rose and Shevlin, 2004), and in Ireland, investigation of parent perspectives in this area is under-researched. Consequently, this present study sought to explore the narratives of parents supporting young people through the final 3 years of secondary school, in Ireland, designated as Transition Year (age 15–17 years), 5th year (age 16–18 years) and 6th year (age 17–19 years). Thus, the stated research objectives were to: (i) document access to initiatives, advice, support and guidance using online surveys made available to pupils, parents/carers and practitioners, embedded within a dedicated transition website; (ii) investigate personal perceptions of transition and disability via in-depth interviews with pupils, parents/carers and practitioners; (iii) examine transition experiences of young people with SEND at the conclusion of their first year of undergraduate education; and (iv) use an emancipatory methodology that permitted pupils with SEND and associated stakeholders to voice their experiences of transition. Research questions extracted from this conceptualization of the research problem were identified as:

- Are young people with SEND, their parents/carers and other stakeholders in the transition process, provided with access to disability-specific transition advice and guidance?
- Do all stakeholders have equal access to the same quality and quantity of transition support?
- How useful/effective is this advice and guidance, what form does it take and who provides it?
- What are the enablers and barriers to transition identified by young people with SEND, their parents/carers and practitioners?

- Is there a need for dedicated, transition-specific resources, for post-primary pupils with SEND in Ireland?

Method

Participants

Probability and purposive sampling was used to recruit 69 participants with the purpose of: (i) statistical reporting; (ii) achieving a representative sample using a method whereby participants are randomly selected; and (iii) minimising sampling bias (Teddlie and Yu, 2007). This mixed method sampling technique has been used successfully in a number of studies within educational settings (Day, Sammons and Gu, 2008; McCoy, Byrne, O'Connell, et al., 2010). Survey participants were drawn from parents supporting pupils from within 11 disability categories (see Table 1), three school years (Transition Year, 5th year and 6th year), and three types of secondary school [state, DEIS (state designated disadvantaged) and private]. Disability categories conformed to groupings utilised by the HE Authority and the Disability Access Route to Education (DARE) scheme, an initiative that applies reasonable accommodations to the offers and admissions process.

Methodological instruments

The study used a mixed method (Creswell, 2009; Creswell and Plano Clark, 2007, 2011) in that qualitative and quantitative approaches were used simultaneously with no priority given to either method of data collection or analysis; results being converged in the presentation, interpretation and discussion of findings to provide a complementary inference (Östlund, Kidd, Wengström, et al., 2011). An online self-administered survey comprising 10 questions examined: (i) demographics (disability, school type and school year), (ii) access to IEPs, (iii) depth and quality of transition support and guidance, (iv) sources and quality of transition guidance, and (v) the value of transition planning tools. Questions were

Table 1: Abbreviation codes for disability categories

Code	Disability category
AS/ASD	Asperger's Syndrome/Autistic Spectrum Disorder
ADHD	Attention Deficit or Attention Deficit Hyperactivity Disorder
B/VI	Blind or Visually Impaired
DCD	Dyspraxia
Df/HI	Deaf or Hearing Impaired
MHC	Mental Health Condition
NC	Neurological Condition
PD	Physical Disability
SOI	Significant On-going Illness
SLC	Speech, Language and Communication Disorders
SpLD	Specific Learning Difficulty

partially based on previous measures used in studies investigating SEND and transition to Further Education FE/HE (Elliot and Wilson, 2008; Mc Guckin, Shevlin, Bell, et al., 2013), and partially distilled from the principal research questions.

Interview data provided a deeper understanding of access to, and quality of, transition support and the personal experiences of parents supporting young people with SEND through transition. A set of 18 pre-interview trigger questions were distilled from the original survey questions, designed to explore the themes of: (i) perceived enablers and barriers to transition (e.g. 'What changes are required to practices within schools and colleges to support the transition from school to college?'), (ii) access to school-based support and guidance (e.g. 'What sources of information are available to families for planning the transition from school?'), and (iii) advice and guidance from Higher Education Institutions (HEIs) in the form of print and multi-media information, and transition events (e.g., 'How well did access initiatives such as DARE assist with the transition process?'). Descriptive statistics were extracted from survey questions constructed as multiple choice, Likert scale, and matrices of choice items. Inductive content analysis (Elo and Kyngäs, 2008) dissected the data from free response text survey comments and the text corpus of interview transcripts, to identify emergent themes.

Procedure

The survey was embedded within a publicly accessible website, and an invitation to participate circulated to national community and parent support groups within each of the 11 disability categories. Sixty-nine parents responded to the survey, of these 16 indicated a willingness to be interviewed, and eight parents subsequently agreed to participate, receiving a copy of the trigger questions by email, with the option of the interview being conducted either by telephone or in person. These were digitally recorded and transcripts provided to parents for comment in line with a participatory approach, and to ensure trustworthiness of data. The text corpus retrieved from free response survey items and interview transcripts was thematically coded using a hard copy, human coding method as advocated by Saldana (2009). Data was first coded in an exploratory analysis to gain a sense of perspectives within the data set, and subsequently re-coded using an open coding system which identified 18 a priori themes (see Table 2).

The second and third coding cycles not only identified emerging themes, but also involved the merging or absorption of similar themes and separation of dominant themes, resulting in six principal transition motifs: (i) sources of transition advice, (ii) quality of transition advice, (iii) awareness, understanding, and attitudes towards SEND, (iv) the influence of parental support, (v) factors that enable transition, and (vi) factors that represent barriers to transition.

Table 2: Survey comments and interview corpus frequency of themes

Theme	Frequency (n = 370) (%)
Access to information, support and guidance	44 (12.0)
Course and/or college choices	12 (3.0)
Post-primary school support and guidance	43 (12.0)
Support from external professionals	13 (3.0)
College application process	8 (2.0)
Links, outreach and information from HEIs	23 (6.0)
Supports provided at third level	19 (5.0)
Understanding, awareness and attitudes towards disability	32 (9.0)
Factors associated with successful transition	2 (0.5)
Factors that constitute barriers to transition	21 (6.0)
Independence, self-awareness, and self-determination	37 (10.0)
Formal transition planning	27 (7.0)
Support from peers	1 (0.2)
Family and parental attitudes, guidance and input	53 (14.0)
Disclosure	9 (2.0)
Emotional/disability factors affecting transition	30 (8.0)
Aspects of the DARE scheme	23 (6.0)
Pathways transition resources	6 (2.0)

Research findings

Merged results for quantitative and qualitative findings from surveys and interviews with parents are reported here, including thematically coded data which was quantified to establish a frequency of themes. Half of survey respondents (52.7%, n = 36) were supporting pupils attending state schools, 31.9% (n = 22) attended private schools and 10.2% (n = 7) were enrolled in DEIS schools. The majority of parents supported pupils who were enrolled in 6th year (64%, n = 44), 21% (n = 14) in 5th year, with 15% (n = 10) attending Transition Year. Pupils with SpLD were the most frequently supported group (21.5%, n = 15), followed by ASD (17.7%, n = 12), ADD/ADHD (13.9%, n = 10) and DCD (12.7%, n = 9).

Access to transition advice

Of the agencies or stakeholders perceived to have expertise in transitions from school, the most frequently cited sources of advice were HEI access programmes and Guidance Counsellors (GC) (second level teachers with an additional professional Masters qualification in educational guidance and counselling), although 15% (n = 10) stated that nobody had provided them with this guidance. Consultations with Special Educational Needs Organisers (SENO: the Irish equivalent of a SENCO) were held significantly less frequently than any other advisor, and 48% (n = 33) of parents had never discussed the IEP in relation to transition with any educational practitioner. Survey comments described high levels of frustration and inadequate access to transition information, with 13 parents (19%) stating that no IEP existed for their child, 11 of whom (16%) attended state secondary schools (including DEIS institutions). Guidance Counsellors and Resource Teachers were the main providers of transition information and guidance, although none of the parents were aware of any formal transition planning programmes provided in school. Reduced GC support due to cuts in education spending (Mc Guckin and O'Brien, 2013) means that class teachers were often the only providers of advice to parents, but consultation opportunities were not always easy to access:

> . . . I can honestly say, he never saw a Guidance Counsellor like. . . when you go to approach teachers. . . they are kind of. . . they're busy in their classes and class subjects and teaching, it's very hard to get them outside a lot of the time. I don't know whether they want to, or whether they haven't got the time, but it's very hard to. (SpLD, 5th, DEIS)

Consequently, parents felt forced to step in and demand support from the school, sometimes resulting in a confrontational stance affecting school/teacher relationships: 'So it was like trying to pull teeth to get help for him at that stage. I think they just sit there and listen to me and "Yeah, this is another parent," but I am actually feeling. . . I am telling the truth. I don't think it's getting through' (SpLD, 5th, DEIS).

Quality of transition advice

Although many parent comments described support in positive terms, 51% (n = 35) stated that they had received no advice with respect to transition. For example, identification of support and resources in HEI was a significant factor for pupils with SEND, while 30% of parents (n = 21) had received guidance on this, an almost equal number felt that the quality of the guidance they had received was poor, with 27% (n = 19) stating that they had never received advice in relation to potential supports at third level. Comments expressed disappointment and disillusionment with the standard of guidance provided by schools and feelings of isolation. Additionally, parents believed that the amount and quality of disability-specific transition advice and guidance was dependent upon the conscientiousness with which practitioners sourced information from HEIs and access programmes, and the level of accuracy and clarity of that information. These fissures in communication create feelings of mistrust and uncertainty, which detract from opportunities to work together to support the student: 'Lack of awareness for parents and students at second level, everything is a fight, information is not shared freely or perhaps schools are not aware' (SpLD, 5th, State).

Awareness, understanding, and attitudes towards disability

A quarter of parents drew attention to the importance of awareness and understanding of the difficulties

experienced by young people with disabilities within a competitive environment. Inadequate knowledge or understanding within school, both generally and specifically, accounted for 14.5% of themed comments: 'If they don't know or understand they should at least support, at best find out. I received little or no support from any of the three schools they attended' (ADHD/MHC, 6th, State). This knowledge base was identified as being particularly important in respect to identifying post-school pathways: 'She has no idea how to proceed, how to prepare for a future with a disease, what career path is right for her' (SOI, 6th, Private). School culture and staff attitudes were identified as having a cumulative effect on the self-perception and confidence of pupils themselves: 'The fear of being different, not being cool enough or together enough to cope. Fear of everybody finding out that they are (in my child's words) a Freak' (ADHD/MHC, 6th year, State).

The experiences of parents whose children had a 'hidden' disability described this as a particular barrier, despite the existence of an IEP replete with recommendations: 'When he went to [post-primary school] for the first six weeks he could see nothing, because everything was whiteboards, and the glare on the whiteboards, he couldn't see' (VI, 6th, State). Mental health conditions in particular are susceptible to lack of understanding, sometimes with disastrous consequences: 'The principal of the school, she just had no interest. She thought it was all crazy and "Pull yourself together" she said to him in front of me one day. But it went on from there that he didn't leave the house for a year and a half' (MHC, 6th, State).

The feeling of being different exacerbated by lack of understanding from peers and school staff, can result in an escalation of anxiety: 'He couldn't attend school. He went for two months in 5th year and then he would ring me crying from a toilet cubicle, crying, saying "I can't go in. I can't breathe"' (MHC, 6th, State). Similarly, when teachers are unaware of how a specific learning disability manifests itself within the framework of academic skills, young people may often be the target of unfair or unrealistic expectations: 'For spelling, her reading, her grammar, her writing, her working memory problem, they criticised her all year and sent home bad notes' (PD/SpLD, 6th, State).

Parents reported a lack of recognition that difficulties and barriers are unique to the individual in terms of the range and impact of medical conditions, physical disabilities, mental health conditions, the scale of treatment, and the long-term effects of interrupted schooling. The language used by parents to describe the intensity of their child's journey illustrated significant levels of longitudinal stress across the post-primary cycle, together with anxieties connected to the need for young people to equip themselves with the skills to meet these challenges independently. The additional impact of personal crises such as changes in diagnosis and prognosis cannot be underestimated.

Influence of family support
The financial and personal resources at the disposal of parents and guardians, coupled with familial expectations and aspirations, are an important factor in transition pathways. Parents described high levels of commitment required to support their children, which was entirely dependent upon the skills, resources, and circumstances of individual families, representing an uneven 'playing field' in post-primary education. Parental input spanned diverse situations (diagnosis and intervention, supports in school, reasonable accommodations), and the financial burden of sourcing interventions to compensate for an inaccessible curriculum or absences from school, was an additional stressor: 'We tried, we scraped together to get Maths grinds and English grinds [private tuition] for him every week' (SpLD, 5th, DEIS).

Parents also expressed high levels of commitment to any action that would make a difference: 'I would be trying to help in whatever way I can, and do anything I can' (SpLD, 5th, DEIS), often for fear of the consequences that lack of support might lead to: 'I don't think if I did that, I would hate to think of where he is, where he would be' (ADHD, 5th, State). For one parent, this meant taking extreme action: 'I have fought, I have battled for two years to get him into another school, this is the first school who would take him' (ADHD, 5th, State).

Parents experienced self-doubt and anxiety particularly where they felt they were working alone on behalf of their child: 'I'm hoping I'm doing the right job, I'm not sure whether or not I am, but I'm trying' (SpLD, 5th, DEIS), and the emotional consequences were palpable: 'It's a big stress and strain on us' (SpLD, 5th, DEIS), 'I would be very supportive of my children, but I just couldn't do it. I just couldn't do it any more' (ADHD, 5th, State). Parents expressed this emotional burden in terms of 'stress' and 'fatigue', often connected to a lack of understanding of the struggle that their child experienced, sometimes emanating from within the family unit: 'Even my husband wouldn't understand, he goes "God" he says, "This is crazy," he said, "What is the matter with him?"' (MHC, 6th, State).

Barriers to successful transition
Accounting for 9% of coded text, the tendency to manage young people with disabilities as a homogenous group, and not as individuals, represented a barrier:

> My honest opinion of this, being a DEIS school, the students who are excellent are up at the top, the students who are disadvantaged are here <gesture towards the bottom>, and then my son is somewhere a bit up from them, and his kind of level… are just kind of… left there? (SpLD, 5th, DEIS)

Parents alluded to the complexities of inclusivity and integration, and a failure to acknowledge specific needs relating to the learning environment and curriculum: 'They

have huge problems and, and in some ways I think they're kind of expected to fit in with everybody else, and they're not like everybody else' (ADHD, 5th, State), together with a failure to acknowledge individual differences: 'I obviously wish that the [Department of Education] itself was more supportive to students with disability. I believe their supports are geared towards a general norm' (SpLD, TY, Private).

Consequently, the emotional stress of managing an indifferent school environment represented 8% of comments. For some young people, progress through school was a lonely place: 'I think he's covered it for years, from the teachers. He's just battled away himself' (SpLD, 5th, DEIS), a situation that is all the more difficult in adolescence: 'She just feels such a NUISANCE at this stage. She just, like her eyes glaze over, it's awkward enough being a teenager, besides being "special," as she says herself' (PD/SpLD, 6th, State).

Enablers of successful transition
Guidance Counselling in school, including support for parents, was identified as the most important enabler of successful transition, accounting for 35% of comments. Additional enabling factors included identifiable responses to barriers, including the implementation of formal transition planning, increased awareness of SEND and individual differences within the post-primary environment, and more transparent communication with pupils and parents. Although parents were aware of HEI access schemes and resources, delivery of this information appeared to bypass parents as stakeholders. Such activities have the potential to reassure parents and young people with SEND, providing them with confidence that HEIs are aware of individual needs and potentially disabling environments, and can provide supports that will ensure a smooth transition.

Conclusion
This study explored the relationship between disability and transition to HEIs in Ireland, with a focus on investigating the experiences and viewpoints of parents and carers supporting young people with SEND in their final years of secondary school. Data were submitted by parents in response to an invitation posted to a dedicated transition website for pupils with SEND, and it is acknowledged that this may limit generalisation of results to wider contexts.

Findings established that the quantity and quality of disability-specific transition advice and guidance available to secondary pupils with SEND and parents/carers, was variable and disparate. A lack of disability awareness in secondary schools at a conceptual and individual level contaminates attitudes and expectations. The recent increase in provision of resource teachers to work at an individual level with young people with SEND is an ideal opportunity to address this, and to foster new understandings to support successful transitions. Currently, the CPD

service for teachers provides resources for literacy, numeracy, ICT, and anti-Bullying, and as a matter of urgency, similar provision should be made for disability awareness training to all school staff.

Findings also emphasise the role of family – especially where young people depend upon parental input for longer than their peers. Parents play an integral role in filling the support gap, and there was recognition for the vulnerability of pupils who do not have access to such support. Although it is imperative that young people take ownership of their own transition and associated tasks and actions, greater recognition of the need for scaffolded approaches to independence for pupils with complex needs, is essential. Family support is pivotal, particularly where support is not available in school, but the intensity of seeking appropriate guidance can result in fractured relationships with schools, and decreased opportunities for young people to develop independent skills. The ethos and culture of the school influences the level of importance placed on inclusive practices, affecting teacher attitudes towards achievable goals for pupils with SEND.

In an environment where dedicated guidance in post-primary schools is rapidly diminishing, formalised transition planning that includes collaboration between pupils, parents, school and HEI staff, is more important than ever. Aspirations and intentions to progress to HEIs are dependent upon the influence and interplay of agents and agencies in the near social community as providers of information and resources. Transition partnerships require the active involvement of young people with SEND, their families, schools and providers of post-secondary education. There are opportunities to develop action plans that acknowledge the identities and needs of young people, for example, the increased use of interactive online tools to create accessible and portable e-portfolios that capture strengths and challenges, and the acquisition of hard and soft skills. In this way, there are possibilities to engage these solutions to create Individual Transition Plans that fulfil the same function as an IEP, representing continuously evolving documents that are transferable to post-secondary settings. However, robust research is required to determine uptake, retention and abandonment rates for such resources, before significant financial commitment is made by State agencies and schools.

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