“Being special”

Intellectual disability, Stigma and Special Schools

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In August 2012 the two-week EASP summer school was hosted at the University of Limerick. I consider myself extremely fortunate to have attended the workshop, “The role of intergroup boundaries in shaping social inclusion, integration and wellbeing” and benefited from the expertise available. This workshop was led by, Professors John Dixon, Kevin Durrheim and Orla Muldoon.

Awards and Honors

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Declaration

The substance of this thesis is the original work of the author, and due reference and acknowledgement has been made, where necessary, to the work of others. No part of this thesis has been submitted in candidature of any other degree.

Statement of the candidate’s contribution to co-authored papers.

The three studies included in this thesis were written up in three papers for publication. The substantial contribution to the co-authored papers was made by the candidate, including data collection, statistical analysis, thematic analysis, interpretation of results and framing of arguments and writing. While the candidate is fully responsible for the work presented in this thesis, where the first person is used in the plural (i.e. “we” rather than “I”) as in the original peer reviewed papers, to reflect the collaborative efforts guiding the research process. Since each paper is meant to stand alone some information may be repeated.

Clara O’Byrne_______________________________
Nomenclature

The acronym PWID will be used throughout this thesis to refer to people with intellectual disability. The term intellectual disability will be used throughout this thesis and can be understood to refer to individuals whose FSIQ has been assessed by a suitably qualified professional as being within the range of 50-70 (DES 2002). For the purposes of clarity the term intellectual disability will be abbreviated to ID or PWID and use of the terms does not imply acceptance of its validity or usefulness.
Acknowledgments

A very special word of thanks for Professor Orla Muldoon, my patient, challenging and understanding supervisor, thank you for teaching me the importance of setting ones standards high, striving for excellence and campaigning for social justice. Thank you for taking a chance on me, for encouraging me, advising me, and most importantly being supportive in a myriad of ways. I often hear young people say when I grow up I want to be like... well when I grow up I want to be like Orla.

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Thanks also to my work colleagues in the National Council for Special Education (NCSE) who demonstrated great patience as I often shared with them what I perceived to be exciting research papers and always gave me useful feedback about the gap between policy and practice, the academic world and the world of practitioners.

Thanks to my dear friends, whose unwavering support saw me through some tough times in this long journey from an idea to a completed thesis.

I reserve my final thanks to Jerry, whose patience has been truly tested, as the long nights and months dragged into years. Our little family grew from just us to the four of us during this journey and I am thankful for your support and loyalty and most importantly believing in me.
Dedication

Emer and Daniel

You weren’t even a twinkde in my eye when I began this journey but like all journeys the unexpected happens and brings with it great joy. You have made me stronger and happier and so proud to be your Mum.
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<td>General Learning Disability</td>
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Abstract

This project is concerned with exploring the experiences of and understanding of stigma amongst adolescents who have been given a diagnosis of intellectually disability. This thesis explores how social comparisons, multi dimensional self-perception and perception of stigma are variables in the negotiation of stigma. Specifically the study will focus on adolescents who have been given a primary diagnosis of Mild General Learning Disability (M/GLD, IQ 50-70) and who are in their first year of a second level special school. This study combines quantitative (longitudinal) and qualitative (focus groups) methods.

The first study is a cross sectional analysis of the Time 1 data from the longitudinal dataset. This study finds that the level of cognitive function and gender are key variables on the perception of stigma in PWID who attend a segregated special second level school. The study also finds that reports of stigma impact self-perception and social comparison with others. Discussion focuses on the heterogeneity of those who have received a diagnosis of intellectual disability and how this impacts their experience of stigma.

The second study is a longitudinal study which examines the changes that occur in multi dimensional self concept of PWID across gender and level of intellectual disability. Findings indicate that gender and level of cognitive function are important variables in changes in self-perception across time highlighting the heterogeneous nature of the special school population.

The third study is a qualitative design which examines how disability is constructed by significant adults in the lives of PWID. This study examines whether stigma is recreated or sustained within family and school settings through a thematic analysis of focus group data. Discussion orients to the dilemma faced by parents and teachers as they position themselves as advocates for PWID whilst at the same time recreating pervasive and subtle distinctions between child with disabilty and those without.

This thesis provides an insight into the literature of stigma and disability through the lens of a social identity approach and has implications for policy and practice which will be discussed throughout the thesis.
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Introduction

Research Context

In Ireland, educational provision for children and young people with special educational needs is available in special schools (4 to 18 years), special classes in mainstream primary and post primary, and in mainstream classes with support. SEN or special educational needs is the term given to education for children with diagnosed or undiagnosed learning needs and takes place instead of or in addition to the general classroom. The 1998 Education Act provides the statutory basis for education provision for children with disabilities and The Education for Persons with Special Educational Needs (EPSEN, 2004) Act represented a milestone in terms of embedding inclusion as a core principle in the legislation. However the EPSEN Act 2004 has not yet been fully enacted (Rose, Shevlin, Winter, & O’Raw, 2015). Inclusive rather than segregated provision has been advocated internationally and nationally for over two decades (McConkey, Kelly, Craig, & Shevlin, 2015). A continuum of provision is available for students with special educational needs ranging from full-time placement in a mainstream class to full-time placement in a special school. It has been noted that movement along the continuum of need is not value free (Rix, Sheehy, Fletcher-Campbell, Crisp, & Harper, 2013) as the move from special to mainstream is seen as a success but the move from mainstream to special can be viewed as a failure.

The locus of this research is in special schools in Ireland. In the academic year 16/17, there were 135 special schools in Ireland catering from 8114 students, (DES 2018). Within that category 30 schools are designated as schools for students who have been diagnosed with mild general learning difficulty, (M/GLD). The government statistics differentiate only by gender not by age. Special schools in Ireland are administered as primary schools and as such a breakdown of the age profile in the schools is not nationally collated. The administrative status of special schools as primary, is not without consequence for persons with disabilities as in practice this means that schools, regardless of the age cohort they serve, are run on a primary school calendar, (shorter days, longer year) and are staffed by a mix of primary and post primary trained staff, and access to a full
post primary curriculum is limited (Motherway, 2011, Smyth 2009).

Ware et al (2009) reported that special schools often cater for a wider range of needs than the school’s particular disability/SEN designation. Special schools are not evenly distributed throughout the country and tend to be mainly in the larger urban centres.

**Segregation, Intellectual disability and Special Schools in Ireland**

All children are have a right to education, (UNESCO 1994) but how and where that education may take place is not defined. In Ireland, the EPSEN Act (Government of Ireland 2004) committed to ensuring the education of people with special education needs would take place where possible in an inclusive environment. Generally speaking education policy in Ireland has promoted greater inclusion of children who have been identified with special educational needs in mainstream provision (McCoy, Frawley, Smyth & Shevlin 2014). However the gap between policy and practice is highlighted in an extensive review by (O’Mara et al, 2012) which found there are knowledge gaps in the areas of curriculum design and adaption for students with special educational needs. Additionally this review paper found the homogenising effect of the generic label SEN led to inconsistent research findings which do not reflect the diversity of students with SEN.

An examination of trends in enrolment in special schools in Ireland (2003-2013) found that special schools have a higher proportion of students of secondary school age, despite higher proportions of students with disabilities attending primary schools (McConkey et al 2016). This trend for persons with ID transferring from primary to special school at second level is also noted by Ware et al 2009. Mconkey et al (2016) in a comprehensive review paper of the current position of education for persons with ID in Ireland makes the following key points; There has been an increase in the number of students formally diagnosed with ID, it is hypothesised that the requirement for assessment to access resources influenced this increase. This point is alluded to in the NCSE guidelines on Circular 0014/2017 which advised schools of new allocation of resources model for mainstream secondary schools. The NCSE guidelines acknowledge that
if access to resources is diagnosis driven it has the potential for increasing stigma and further disadvantaging those without access to funds to pay for assessments. McConkey et al (2016) notes that special schools now have a greater proportion of female students and students of secondary school age although no reason is hypothesised. This study also notes that geography is a significant predictor of placement in a special school, which underlines the inequitable distribution of educational choices for both parents and students. This variable of geography is alluded to in Conway, Amberson and O'Sullivan (2011) in a vignette which describes a child (10 years) travelling 7 miles each day to a special school, one wonders would the local national school be closer?

A study which examined the experience of young people with physical disabilities as they moved from special school to a mainstream school found that their experience was mixed with reports of name calling but also reports of “being normal” (O’Donnell, 2003). A study which examined the experiences of young people with hearing impairments, found that outside the structured classroom settings social interaction with peers remained a challenge (Rooney, 2003).

In an Irish context the diagnostic label of ID for adolescents is synonymous with being identified as ‘special’ or having special educational needs, (SEN). Terminology within special education is contested, conflicting and problematic (Meegan & McPhail 2006). Often access to educational resources is highly dependent on a diagnostic label, raising concerns from many advocacy groups about the ‘sticky label’, i.e. once a label is received it is very difficult to remove or deny this label. Current practice in terms of provision of support reflects the deficit model which is grounded in the medical model of disability (Motherway 2009). In many cases the concept of ‘special’ is complex and contested, Rix, Sheehy, Fletcher-Campbell, Crisp and Harper (2013) found that across 55 educational administrations there was no consistent definition of SEN. However as with all evolving descriptive words it is not the word itself that is the problem but rather the negative associations that the term develops which underscores the stigmatising nature of the condition. Walker (2005) argues that such cultural constructions are active agents in
psychosocial development. Indeed in everyday discourse there is an implicit assumption that being disabled or ‘special’, is a dominant identity and it can alter access to macro social resources such as health and education services. Additionally micro social processes can be transformed by social cues and practices that serve to disempower the labelled individual, (Antaki, Walton & Finlay 2007).

Access to specialist educational resources such as in a special school are dependant on a diagnostic label, raising concerns for many advocacy groups about the ‘sticky’ nature of some labels. However from Sept 2017 resource allocation in mainstream schools are not diagnosis dependent. Students are assigned supports based on the needs both transient and enduring which the school allocates. Banks and McCoy (2011) note that ‘need ’ is itself a deficit based term with implications of normality and abnormality. However a formal diagnosis is still required for entry to a special school thus underlining the requiremnt to formally identify and publicly disclose ones disability. The dilemma of disclosure has been noted also at the transition from post primary to HE as in order to access support one has to disclose one has a disability (Kubiak 2015).

The move from primary to post primary is a challenging one for all young people, and research has found that the quality of the school environment at second level has a significant impact on the well being of the young person (Meece & Daniels 2008). Transition can be a time of great challenge for PWID and is explored in greater detail in chapter 3. There are two key transitions for PWID, from primary to post primary and from post primary to further education/post school placement. Transition from primary to post primary is a normative event and whilst experienced uniquely by the individual is one shared with his/her peers. In Ireland primary to post primary transition typically occurs between the ages of 11 and 12. There is a consensus that transition from primary to post primary is time of anxiety for young people (Topping 2011; Smyth, McCoy & Darmody 2004). Some of the concerns include getting lost in larger school buildings and not being able to cope with increased workload, (Hughes., Banks & Terras, 2013; Maras & Aveling, 2006).
At the next typical transition from post primary level students have a mixed experience. A 2011 study (O’Brien, et al) of transition planning from post primary for PWID found that special schools are more likely to have post school transition plans in place and that the students themselves have only a limited understanding of what transition will mean for them. Doyle,McGuckin & Shevlin (2017) report that persons with disabilities experience a inequitable access to further education. Looking specifically at PWID, a longitudinal study by McConkey, Kelly, Craig, & Keogh (2017) found that over a 10 year post school period over half of the participants are no longer know to support services and of those who do begin a post school training placement, most end up in care centres within 10 years. Thus the outcomes for PWID are inequitable across the most critical phases of transition.

Research has found ambivalence towards the inclusion of young people with disabilities, parents favor the inclusion of young people with physical disabilities in schools but are concerned about the inclusion of young people with ID (Rafferty, Boettcher & Griffin 2001). Cooney et al (2006) found that students in mainstream schools report more difficulties than those in special schools, and Cummins & Lau (2003) found that some teachers resent the inclusion of children with ID. Advocates for special schools for PWID argue that many of the disadvantages experienced by PWID, can be lessened by special school, rather than caused by it, (Zigmond & Kloo 2011). Indeed a recent study by Banks and McCoy, (2018) question if the mandatory inclusion in a special class within the mainstream setting is just another form of exclusion. It has been argued that special schools can provide a safety net for students who struggle and who need a more controlled learning environment (Kauffman & Hallahan, 2005). Conversely the argument is that segregated education on the basis of disability contributes to marginalization and stigma, (Pfah & Powell, 2011, Lalvani, 2015).

Teacher training is itself lacking in terms of empowering young teachers to deal with complex issues of disability, (Purdy & McGuckin 2012), in particular teachers lack guidance around disablist bullying, a very real risk factor for young people with disabilities (McGuckin, 2014). In the context of Irish society, over half the respondents (55%) in a
survey on public attitudes to disability felt that individuals with disabilities are treated unfairly (NDA, 2007). However only 36% of respondents felt that children with ID should be educated in mainstream schools, indeed 8% stated they would object if their child were placed in a class with a child with ID. Contrasting with the position of the general public, a survey of adults with ID (NDA, 2006) found that the majority (75%) would not avoid doing something because of the opinion of others, suggesting either a lack of awareness or a choice to ignore their low status. Benicasa, (2012) argues that social exclusion is shaped by the social structures e.g. schools, and thus education policies that direct resources towards segregated education can be powerful determinants in perpetuating inclusive or exclusive practices. Special schools can be viewed as a means of normalizing negative values, discriminatory attitudes and exclusionary practices, a message which is also conveyed to PWID by parents and teachers and typically developing peers (Slee, 2012, Lipsky & Gartner, 2013). This othering of PWID is discussed in greater detail in chapter 4.

Models of disability

Models of disability provide a framework for positioning ID. Traditionally the dominant paradigm for discussion about ID was a medical model of disability which located the ‘problem’ of disability within the individual (Oliver 2013). This model focuses on a deficit approach that highlights individual pathology. Thus intellectual disability is viewed as having biological causality which are related to identifiable genetic, neurobiological and traumatic injuries in the antenatal and perinatal period. For example Downs syndrome is attributed to trisomy 21. Intellectual disability has long been viewed as having a biological based causality and as being “incurable”. Adherents to this position fail to appreciate the difference between intellectual disability as a socially defined construct, and intellectual disability, which is the outcome of a diagnosable biological impairment or medical condition (Bray & Grad, 2003). The medical model does not allow space for the social and cultural factors that isolate, alienate and disempower the individual with disability. It views
the cause of the problem as arising from functional limitations. Special education provision tends to reinforce this model through promoting an within child deficiency (Norwich 2008). This approach to disability is also dominated by a positivist paradigm (Thomas & Glenny 2005). This focus on an empirical quantitative objective reality tends to privilege the power of the professional and assign labels. Proponents of the medical model tend to ascertain that special school have a role to play in terms of providing a ‘continuum of provision’ (Ware et al 2009) and as noted by Rix et al (2013) moving along this continuum of provision (e.g. mainstream school to special school) is not judgement free.

The social model of disability has been articulated in many ways (Oliver 2013, Shakespeare & Watson 2001) but in essence takes the perspective that disability is socially constructed and people are disabled by social barriers. The social model of disability which focuses solely on societal level oppressive barriers does not fully account for the complexity of the ID experience. Critics of this model argue that disability does cause limited functioning and to deny this is somewhat reductionist (Motherway 2011). Advocates of the social model are critical of the existence of special schools, arguing that discrimination is fostered and sustained by their very existence, (Oliver 1995). The social model has been criticised for both focusing solely on socio cultural barriers and also for viewing disability as an homogenous issue. The social model does not fully explore the rights of children or individuals with ID and thus PWID are somewhat neglected (Conors & Stalker 2007). Special education through this lens is seen as a social construct, with power resting with the professionals (Danforth 2002, Oliver 1996).

Thomas (1999) proposes a social relational model of disability which proposes that persons with disabilities will experience restrictions in activity which result from impairment but also experience disability as result of oppression which excludes them from full participation in society. The social relational model of disability shares many of the key tenets of a social constructivist tradition, disablity as a socially constructed phenomenon that means different things to different people (McLaughlin & Mertens 2004).
Models of disability are often constructed as opposing ends of the same spectrum—medical/social but more current argument acknowledges that the lived experience of PWID encompasses both a need for medical labelling and a recognition of social barriers (Manago, Davis & Goar 2017). The concept of disability is moving towards a socio ecological person-environment fit conception (Buntinx & Schalock 2010) these multidimensional models of human functioning are exemplified in the bio-psycho-social model (WHO 2007) which creates a framework that encompasses impairments, restrictions and environmental and personal factors. The biopsychosocial model is useful because it tries to integrate both the medical and social models. However Norwich (2016) notes that there remains a lot of work to be done in terms of embracing these changing concepts of disability in the special education field. The influence of Lewin’s Person-Environment model (Dunn, 2010) is clear in the move towards a more biopsychosocial model which seeks to examine disability in relation to interactions amongst biological, psychological and social systems factors.

The move toward bio-ecological models of disability reflects a move towards similar models in the field of developmental psychology. Current thinking about development examines the interaction between heredity and the environment (Berk, 2001) and there is a consensus that development is best understood as a product of a dynamic interaction between the child and their environment, a bidirectional model of environmental and social influences. Developmental models which emphasise environmental influences draw heavily on Erikson’s theory of psychosocial development. Erikson’s stage theory of lifespan development is a useful framework for positioning the developmental needs of young people in school settings (Woods, Littleton & Oates, 2002). Erikson emphasises the importance of a young persons environment (Meece & Daniels, 2008), arguing that the stages of development are played out through interactions with others and there is a large body of evidence to suggest that ethnic and gender identities are influenced by social interaction in school settings (Meece & Daniels, 2008, Slavin 2003).

Bronfenbrenner’s ecological model (Bonfrenbrenner, 1977, Bonfrenbrenner &
Morris (2006) which is generally depicted as a series of concentric circles, see Figure 1, underlines the importance of the ecology or environment in which development takes place. In this framework the development of child or person with disability is influenced by four nested systems, (microsystem, mesosystem, exosystem and macrosystem). Each of these systems interact with each other to a greater or lesser degree. The developing child or PWID, is surrounded by layers of relationships like a set of nested Russian dolls. The inner circle, the microsystem, describes each setting in which the child has direct, relationships with significant people such as parents, friends, and teachers. This is where PWID live their daily lives and this is where they develop. Additionally there are cross relationships between these small settings e.g. parents talk to teachers; these lateral connections are called the mesosystem. Beyond this is an outer circle of people who are indirectly involved in the child’s development, which in the case of many PWID would include charities which run many special schools, parent employers, who may be called on to fundraise for the 'special school', etc., this is called the exosystem. Bronfenbrenner also described a macrosystem (the prevailing cultural and economic conditions of the society), so for example the structural inequity embedded in a system that views all special schools as primary schools, and a chronosystem which examines issues across time. This a useful model to inform decision making allowing space for the different spheres of influence on the young person to be considered.

Epsteins work on spheres of influence (Epstein, 1987, Epstein, 2011) also draws on the bio-ecological model and invites us to consider the context in which special education occurs. Epstein sought to shine a spotlight on the role of family engagement at home and in school and in the community. This model posits that there are external forces (home, school and community) and the student is the central actor in the learning but has complex and dynamic interactions across the varying spheres of influence. Epstein’s School-Family-Community-Partnership Model has two main components. The first depicts the partnership of schools, families, and communities as overlapping spheres. The spheres represent that school, family, and communities of the child. These partnerships are influence by time and
experience. For example, typically parents are more involved in school when their children are young (Epstein 2001). So this then can be usefully applied to specially school which would typically see greater parental involvement even at post primary.

The second component of the Partnership Model is concerned with the interpersonal relationships and patterns of influence that are most important in a child’s education. The child is both changed by the interactions and produces change in others (Espstein, 2001). These varying models of disability offer lens with which to view intellectual disabilily and special schools.

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**Macroystem**: attitudes and ideologies of the culture in which the individual exists, for example, equal rights and lifelong learning.

**Exosystem**: institutions and contexts which may impact directly or indirectly on the microsystem, for example, support systems, social welfare, educational policies.

**Mesosystem**: links / interactions between different agencies or ‘actors’ within the microsystem, for example, home-school relationships.

**Microsystem**: immediate social context, for example, family, school, peers, church, play group, local area, family health service.

**Chronosystem**: socio-historical life conditions, life events across time.

*Figure 1.* Interpretation of Bronfenbrenner’s (1989) bioecological theory.
**Terminology**

The terminology used to describe and categorize PWID can be problematic and often reflects their marginalized status (Griffin & Shevlin 2007). Prejudice is created and recreated in every day banal interactions and the social constructs that the individual brings to the stigmatising experience may change the nature of that experience. Language exerts a powerful influence on how people think (Clark & Marsh, 2002) and PWID are largely described in terms of their disability as their defining attribute. This concept can be viewed as upholding an ‘ableist’ ideology by which the term ‘disability’ reflects the notion that the person with a different ability is the opposite of ‘able’ (Harpur, 2012) and thus acts as the cornerstone of social inequality. Stereotypes of PWID are generally negative and they are constructed as ‘helpless’ or in need of charity (Funk 1987). It is easier to problematise the individual who does not conform to normative expectations than it is to problematise practises which exclude those who do not conform. The definitions of labels used to describe intellectual disability are not static. There is a regular revision of socially acceptable labels, for example the change of the American Association on Mental Retardation to the American Association for Intellectual and Developmental Disabilities, (Sinason 1992, Schalock 2011) yet the ‘otherness’ of intellectual disability remains firmly ingrained in discourse. Indeed the changing of socially acceptable terms for intellectual disability is mirrored by the speed at which these terms become used as forms of insult, e.g. retard, spastic, etc.

The ‘cut off’ point for intellectual disability has varied at different points, for example when the American Association on Mental Retardation (AMMR) moved the cut-off point from IQ 70 to IQ 75 in their 1992 definition and classification of intellectual disability it meant that twice as many people were eligible for a possible diagnosis of intellectual disability (Schalock & Luckasson 2004). The belief that an intellectual disability is fixed and immoveable can result in discrimination against PWID such as the withholding of services e.g. educational and vocational services (Corrigan & Watson, 2002). The stigma associated
with having an ID stems from this ‘othering’ of those who are different and has both internal and external consequences.

Language is central to the process of social construction as we use language to construct our world through participating in competing discourse (Tizard & Phoenix 2002, Williams 2011). Discourse are the ways of thinking and talking that are available in our cultural context. Within this perspective identity is actively constructed through language. Group membership then cannot be separated from the context in which it is produced. Additionally the construction of PWID as a coherent homogenous group gives rise to a lack of acknowledgement of the individuality of PWID and is a means of perpetuating social distance. In reality PWID are a very heterogeneous group that span a wide spectrum of ability and the label ID tells us only about one dimension of difference. To further complicate the issue some people with an intellectual disability fail to define themselves as members of the group (Finlay & Lyons, 2002, Ali, Hassiotis, Strydom & King 2012). For example, Davies and Jenkins (1997) found that a large cohort of participants in their study of PWID (60 young people with a range of abilities and communication skills) showed a complete lack of application of terms associated with ID such as ‘learning difficulties’ and ‘mental handicap’ to themselves). Finally the label of intellectual disability disempowers group members in a way that few other labels do. According to Bray & Grad (2003) the effects of their label, with which the majority were familiar, were the power and control exercised over them by other people in virtually every part of their lives. Even when they could not explain what a particular label meant or how it might apply to them, they had a view of themselves as dependent and lacking in a say in most of the areas in their lives, including very simple decisions (Bray & Grad, 2003). Once labeled with an ID parents and caregivers often take a controlling role in the life of their offspring and attempt to filter the stigma of the label and to minimize its effect on the person with ID.

The label of ID as a diagnostic term is an example of the power dynamic between professionals, parents and young people with ID. Generally speaking there is an imbalance of power between parents and children irrespective of ability status. However in cases of
disability parents are relatively more powerful and within this family context there is an assumption, rarely interrogated, that parents act in the best interest of their children. However parents can only act within the confines of their own cultural context. If there is systemic devaluing of individuals with ID and persistent lack of investment in the necessary therapeutic service it falls then on parents to seek a diagnosis to secure services rather than for the diagnosis itself.

A diagnosis of ID is externally imposed, is not sought by the individual to whom it is assigned and is generally made in early childhood. However children with ID have reported feeling stigmatized as early as elementary (primary) school (Salmon 2013) and in a study of adolescents with ID the majority of participants reported experiencing stigmatized treatment from non-disabled peers (Cooney, Jahoda, Gumley & Knott 2006). The diagnosis of ID has real consequences for the children to whom it is applied yet is undertaken without their consent and is it ‘for their own good’ or is it for the efficient provision of services? There is a dilemma here around agency. PWID are not agents of their own destiny in terms of choosing to identified as ‘intellectually disabled’, and when social structures such as schools require such a label, this undermines the power of the individual young person to determine their own life choices. Brown & Millar (2016) comment that the rights of young people with ID are the same as the rights of young people generally, but this key point is often overlooked. When PWID are involved in self advocacy movements the outcomes in terms of wellbeing and sense of control in everyday life are much improved, (Tidemann & Svenesson 2015). A study which examined, the key concerns of Irish PWID, (Garcia-Iriarte, O’Brien, McConkey, Wolfe & O’Doherty 2014) found that PWID value and aspire to have agency, with regards to living options and relationships amongst others but they feel they have limited opportunity for decision making. A major theme of this study was that PWID lack control over their lives, this is interesting in light of the recent ratification of UN Convention on the Rights of Persons with Disabilities and specifically Article 12, which recognizes legal capacity. This restricted agency for people with ID is a
common theme (Antaki, et al 2007, Rapley, 2014) and underlines the insidious nature of stigma towards individuals with ID.

**Stigma and marginalized groups**

*Stigma*

Stigma is a trait or attribute, which marks an individual as undesirable or possessing a ‘spoiled’ identity (Goffman 1963). Stigma is a social construction that involves an awareness of difference and the consequent devaluation of the person. It is a complex concept, involving cognitive, emotional and behavioural components (Corrigan & Shapiro 2010). Stigmatization occurs when erroneous attitudes cause prejudice and discrimination with the consequence of magnifying the effect of the original impairment (Corrigan & Penn 1999). If we consider that most differences are acceptable e.g. red haired people are generally not segregated from the general population and people who have green eyes are not housed in institutions, then we can see that those differences that cause discrimination e.g. skin color, race, cognitive capacity are salient only in a particular context. The stigmatization of marginalized groups is considered to be a socially constructed process that varies according to time, culture and context (Arboleda-Florez, 2005). It occurs in the presence of an imbalance of power between different groups and is fuelled by social, economic and political differences (Link & Phelan, 2001). Within the stigma paradigm, disability is a deficit and PWID can struggle to reconcile this deficit with a sense of identity. This internalized message of deficit is a social production created by the interaction with others who view the person as disabled. Stigmatizing reactions which can lead to prejudice and discrimination are often simple a response to normative psychological processes which enable people to categorize quickly into “us” and “them” (Dovidio & Gaertner 2010). However such categorizing can lead to problematic outcomes, which has costly social implications.
The consequences of stigma for the individuals affected have been demonstrated across key areas of functioning. Students with disabilities are at greater risk of bullying (McGuckin, 2014). Stigma has been demonstrated to have serious negative effects in the areas of mental health, physical illness, academic underachievement, infant mortality, low socio economic status, and reduced access to housing, education and employment (Allison, 1998, Braddock & McPartland, 1987, Major & O’Brien, 2005). The processes used to negotiate, understand and challenge stigma have an impact on the lived experience of individuals who are thus stigmatized. Stigma is evidenced in many ways through prejudice, stereotyping and discrimination, at many levels; societal, interpersonal and intrapersonal and manifestations include public stigma, self-stigma, and stigma by association and structural stigma (Pryor & Reeder, 2011, Bos, Pyror, Reeder & Stuttheim, 2013). Public stigma refers to the social and psychological reactions to the individual from the marginalized group (Werner, 2015). The effect of public stigma on the individual can be described as either enacted stigma, that is the experience of negative treatment and felt stigma, the anticipation of negative treatment (Gray 2002, Lundberg, Hannsson, Wentz & Bjorkmann 2009, Bos, et al 2013). Public stigma is grounded in the notion that a particular type of intelligence and functioning are socially valued. Labeling someone in terms of their deficit, as in the case of intellectual disability, is stigmatizing (Eayrs, Ellis & Jones 1993) and this social stigma ‘spoils identity’, disqualifying individuals ‘from full social acceptance’ and reducing them ‘from a whole and usual person to a tainted, discounted one’ (Goffman, 1963). Public stigma is the process by which the general public endorses stereotypes and act in a discriminatory manner. Public stigma is widely acknowledged to have deleterious effects on an individual’s mental health (Corrigan & Shapiro 2010)

Self-stigma is concerned with the impact of having an identity deemed to be stigmatized through social consensus (Jones & Corrigan 2014). The psychological well being of stigmatized individuals is affected by the consequent social devaluation (Mak & Cheung 2010). Self-stigma is widely researched in the field of mental health (Ditchman, Werner, Kosyluk & Jones 2013) and applying knowledge from this field to the ID field is
proving fruitful. Ditchman et al propose that self-stigma may lie on continuum with self-stigma at one end, internalizing the negative stereotypes and empowerment at the other, which involves rejection of the negative stereotype. Of course this model was developed in the mental health field where the cognitive capacity to recognize that one is a member of a devalued group is more likely. Courtesy stigma examines negative reactions of family and friends of the stigmatized individual. Research has demonstrated that merely being associated with a stigmatized group causes devaluation (Pryor, Reeder & Monroe 2012, Mak & Cheung 2008). Structural stigma examines how stigma is tied to the stereotypes created and sustained by social institutions and structures (Corrigan, Major & O’Brien 2005). Link and Phelan (2001) argued that stigma could viewed in components, which are; labeling, stereotyping, separation, status loss and discrimination. By identifying stigma as process with multiple components we can see then that it is a process that affects multiple domains of an individuals life. These direct and indirect consequences of stigma can be seen in the position of marginalized groups such as people with disabilities or social welfare recipients. Link and Phelan (2001) further argue that power is a key component of stigma. Only some groups and people in society have the power to select who becomes stigmatized and have the resources to make this belief the norm.

Stigma is a process that involves stereotyping. Goffman (1963) argued that stigma is the result of relationship between ‘attribute’ and a ‘stereotype’. In other words when a feature of human difference is deemed socially significant and judged to be deficient this label becomes a valid way of categorizing people. A stereotype is a collectively agreed (usually negative) statement about a person or group of persons. Prejudice then is the endorsement of these negative beliefs. Stigma is grounded in negative stereotypes about a group that are specific to a cultural context and thus culturally transmitted. Public attitude surveys demonstrate mixed results about PWID, Scior (2011) reports that most people broadly agreed with the right of PWID to be included in society but PWID are consistently selected as one of the least desirable groups to interact with.
Stereotypes are not just a negative evaluation of a group but have a multidimensional aspect (Fiske, Cuddy, Glick & Wu 2002). The content of group stereotypes can lie on two separate dimensions of liking and interdependence (Dixon, Levine, Riecher & Durrheim 2012). The first dimension relates to how much the group is liked or disliked and respected or disrespected. This liking or respect is contingent on the second dimension, interdependence that relates to how a group is viewed in terms of warmth, competence or status. Some groups are viewed as low on both stereotyped dimensions (members of the travelling community) or high on both (the middle class). However groups are often judged ambivalently as having a mixture of less socially desirable traits. Disabled people and the elderly are judged to be high on warmth but low on competence (Fiske et al 2002). This stereotypical judgment can result in paternalistic attitude to such groups. Such benevolent stigma is hard to identify and challenge, as it is at first glance, kindness, albeit a kindness masquerading as pity. This subtle form of stigma is evidenced in denial of opportunities that are, within an individuals capabilities, by well meaning family members (Jahoda, Wilson, Stalker & Cairney 2010). Thus stigma and PWID is complex, varied and motivated by many factors. There is a paucity of information about the impact of stigma on young people (Heary, Hennessy, Swords & Corrigan 2017). Young people are perhaps more vulnerable to stigma as they have less power, their development is not complete, indeed for adolescents, identity and peer relationships are of critical importance (Kroger, 2007).

A number of psychological theories have been proposed to explain stigma and its correlates of stereotype, prejudice and discrimination.

*Social identity approach*

A social identity approach, including both social identity theory (Tajfel & Turner, 1979) and self-categorization theory (Turner, Hogg, Oakes, Reicher, & Wetherell, 1987) is a useful framework for understanding group based discrimination. A group perspective is useful as stigma is a created in a social context by social groups. The approach details the
psychological processes of self-categorization and intergroup behavior. The social identity tradition has been at the forefront of theory that articulates the relations between groups and the consequences of group membership for individuals. Groups and group membership are an essential part of life, through group membership we gain a sense of belonging and stability and these group membership inform our social identity (Haslam, Jetten, Postmes & Haslam 2009). Social identity is about the groups we belong to, believe we belong to and how we evaluate and are evaluated for the group membership. The social identity framework invites us to consider the consequences of personal and social identities for the individual and the group. Neither the individual or social takes precedence over the other, psychological processes are context dependent, variable and flexible (Reicher, Spears, & Haslam, 2010). However being connected with a group or groups is a source of social support, and a wide range of positive effects such as protecting against stress, improving health behaviors and reducing depression (Gallagher, Meaney, Muldoon 2014, Cruwys, South, Greenaway, Haslam 2014, Haslam et al 2009) Social identity theory explores the issue of social boundaries, which impact, on groups with low social status.

Social categorization

Social categorization; the tendency to label others and ourselves according to group characteristics (‘normal’, ‘special’), is a pervasive social process. Tajfel (1979) argues that individuals have multiple ways of categorizing themselves and an individual’s belief about the groups to which they belong is fluid and context dependent. Research using the minimal group paradigm has found the people favor the in-group over the out-group, (Gross & McIlveen 2016). Categorization creates a “them” and “us” mentality, which is enough to cause prejudice. Extrapolating from that position then inter group conflict is inevitable as society is made up of social categories that have differential power and status. This choice of in-group or out-group is a form of social comparison and of categorization and crucially in-group preference is contingent whether that group membership is significant for ones self concept (Tajfel & Turner 1979). Social Categorization theory
(Turner et al 1987) extends the question of the salience of category membership and emphasizes the individual’s hold multiple group memberships. SCT contends that personal and social identities are not opposing ends of a spectrum but rather personal and social identities function at different levels depending on context (Gross et al 2016). The salience of an identity then is activated in the context in which those identities are embedded (Haslam et al 2009). Deaux (1992) points out self-categorization, as a group member does not always follow from being externally labeled as a member of a low status group. Categorization does not have to be static. Social mobility encourages individuals to seek acceptance from higher status groups, social change and creativity allows for change in category values. A critical aspect of this approach is the crucial role of individuals 'buy in' or identification with social groups in identity processes and intergroup relations (Reicher et al., 2010). Marginalized groups may take a social creativity approach to enhance positive aspects of their in group. One self-protective mechanism for dealing with the stigma is to reinforce group identity and that sense of group belonging can offset the some of the negative consequences, (Schmitt, Branscombe, Postmes & Garcia 2014). But the challenge then is what if they do not identify as a member of that marginalized group?

**Coping with discrimination**

A limitation of the SIT framework is that it does not deal with issues of social injustice to low status groups. The rigidity of some social boundaries precludes any chance at social mobility. Central to the marginalization and associated stigmatization of groups is the issue of power. When a group is perceived to possess an attribute or characteristic that is valued this group becomes powerful (Crocker, Major & Steele 1998). Thus for example in modern western society the rich and highly educated carry disproportionate power and influence (Kennedy & Power 2010). In contrast groups which have limited restricted opportunities to earn large amounts of money or experience educational success are most likely to be devalued. A number of empirical studies have concluded that identification with a stigmatized group does not always correlate with low self esteem, coping strategies include attributing negative reaction to prejudice or devaluing dimensions on which the
group performs poorly, Sani & Bennett 2004). Identity theorists argue that individuals seek through multiple strategies, such as social mobility, social creativity and social comparison to derive positive social identity from group membership. Often the strategy chosen will be informed by the perceived permeability of the group boundary and if one feels prototypical of the group category.

**Social Constructionism**

Social identity theory assumes individuals have multiple ways of describing and categorizing themselves (Billig, 1995). Gergen (1999) offers a contrasting position, arguing that our descriptions of self are limited only by the discourse available in our cultural context. Social constructionism suggests that the way in which we understand the world is constructed through everyday interactions. Language is central to the process of social construction as we use language to construct our world through competing discourses (Phoenix 2002). Social constructionism acknowledges the existence of categories but argues that they are socially produced. Within this perspective identity is actively constructed through language and knowledge claims are socially produced. Thus identities are a fluid construct, context dependent and capable of being constructed and deconstructed. Within this perspective language is not merely an act of cognition it is a resource with which we construct our world. The social model of disability sits within this perspective as the individual attributes, that make up disability, cannot be detached from the environment or context that makes them meaningful (Gallagher, Connor & Ferri 2014).

The social identity approach may be considered a metatheory (Haslam, Cornelissen & Werner 2017) and is a useful lens for reflecting on other theoretical approaches. Haslam et al (2017) note that although the Social Identity approach is sensitive to the context dependent nature of the categorization process, this point has been lost in some research, they argue the boundaries between the social constructionist and social identity approaches are fuzzy at best. The social constructionist perspective invites us to consider that at any one time there are different knowledge claims competing for dominance and what we know and accept to be true of ID now, is unlikely to be valid in the future.
(Nunkoosing 2000). Our current understanding of ID is socially constructed and embedded in the socio cultural context. At the core of both approaches is the comparative nature of identity, an identity that is fluid, strategic and contextual (Haslam et al 2017).

**Social Comparison**

Festinger's class studies (1954) demonstrated that there is a predisposition within the individual to compare themselves to similar others. In the absence of objective performance measures we look to other people to determine a basis for evaluating ourselves. Social comparisons are used to establish group norms and structure (Hogg 2000) and enables one to determine the social standing of a group. Classrooms and schools are an extensive source of social comparisons. Social comparison has been found to have three motivations; self enhancement, self improvement and self evaluation, (Dijkstra et al 2008). Thus depending on the motivation of social comparison one may choose to engage in comparison with a better off, worse off or simliar other. This is termed upwards, downwards and lateral social comparison (Gibbons & Buunk 1999). One of the consequences of social comparison is a robust effect called the big fish-little pond effect (Marsh 1987). In school settings this can be described as an effect whereby equally able students have lower academic self-concepts where the achievement level in the class is high than in classes where the achievement level is low. In extensive review paper Dijkstra et al (2008) comments that social comparison in the classroom may lower academic self-concept particularly among low achieving pupils and this negative effect may be more acute for students with special needs in regular classes rather than special classes. Social comparisons therefore are selective and context dependent. Social comparisons are a social cognitive mechanism by which a person can validate aspects of self. Whilst age is a factor in the motivations for social comparison there is a general consensus in the literature that social comparisons take place for typically developing children from 7-8 years, (Dijkstra et al 2008). As such social comparison requires a level of cognitive ability. This the cognitive capacity or ability to do social comparison may be crucial to the impact of felt stigma.
The social identity approach orients to a group level analysis of behavior, which is critical for this thesis as regardless of the individual responses to stigma experiences, the consequences of being so labeled by society are the similar. Social structures homogenize PWID through the imposition of an ascribed identity. The social identity approach allows one to explore the extent to which group identification hinders or facilitates a sense of belonging.

**Stigma and marginalized groups**

Power imbalances are critical to the creation and persistence of stigma, (Link & Phelan 2001, Bos et al 2014). Studies examining discrimination associated with gender have found that obese women are less likely to have their college education paid for by parents than young women of average weight (Crandall 1995). Gender based stigma also affects boys, they are less likely to access mental health services due to perceived stigma (Chandra & Minokovitz 2006). This intersection between low status group membership and gender also influences and enhances stigma experiences. Armstrong and Hamilton (2014) found that gender and social class intersect in relation to stigma around sexual activity on college campuses (slut discourse). Women who have multiple stigmatized identities (mental illness, gender, ethnicity) have an increased HIV risk (Collins, Unger, & Ambrister 2008). Purdie, Vaughan and Eibach (2008) hypothesize that possessing multiple marginal group identities can create an ‘intersectional invisibility’.

However membership of stigmatized group does not always lead to negative outcomes and can have a self-protective function (Crocker & Major 1999). Crocker and Major (1999, 2005) concluded that individuals do not inevitably suffer low self-esteem as a consequence of being a member of stigmatized group. Identity threat arguments would suggest that if an individual is aware that they are devalued in the eyes of others through membership of a devalued social category that this poses a threat to ones self-esteem. Crocker et al (1998) suggested that an individual could deal with an identity threat posed
by membership of a low status group, by disengaging their self esteem from certain domains associated with poor performance. In effect they stop judging their performance in certain domains so for example a PWID may diminish performance in academic areas, an area that would typically be expected to perform poorly in.

Conversely embracing a collective identity can buffer the negative effects of a stigmatized category because group members can attribute negative treatment to their group rather than their personal failings (Branscombe, Schmitt & Harvey, 1999). Branscombe et al (1999) proposes a Rejection Identification Model in which minority group identity can enhance well- being through the support of a collective identity. The rejection identification model suggests a positive relationship between discrimination and identification suggesting that the awareness of a shared negative experience leads to feeling of inclusion that mitigate the harmful effects of discrimination. This model has been tested with various stigmatized groups, those with body piercings (Jetten et al 2001), gender (Schmitt et al 2002). However this model arose following studies of identities where the boundary between groups was seen as illegitimate (e.g. related to race in the US). Crabtree and Haslam (2010) found that identification with a stigmatized group, (e.g. mental health problems), could buffer one against the negative impact of stigma. In this case the permeability of the stigmatized boundary is important as ‘recovery’ from the mental health problems is seen as more viable than ‘recovery’ from ID.

**Stigma and Intellectual Disability**

*Cost of stigma for people with ID*

Despite significant advances in disability rights legislation and policy, negative associations with the term ‘intellectual disability’, are enduring and as a group PWID continue to be one of the most socially excluded groups in western society (Ali et al 2012). As noted by the European monitoring and advocacy group discrimination against people with ID is deeply rooted and widespread, undermines their fundamental rights and stands in the way of positive change (European Union Advocacy Programme report 2005). In
comparative studies of attitudes to social interactions with members of different groups, PWID consistently emerge as one of the least desirable groups (Jones & Corrigan 2014, Westbrook, Legge & Pennay 1993). Intentions toward people with ID are more negative than those with physical disabilities, (Brown, Ouellette-Kuntz, Lysaght & Burge 2010, Katz Shemesh & Bizman 2000) and a significant minority believes that PWID should lead segregated lives (Gilmore, Cuskelly & Campbell 2003, Tachibana & Watanabe 2004). ID is an identity that is externally imposed when the individual in question deviates from the ‘norm’, in most modern contexts this means having an IQ score in the bottom 2% of the population. IQ testing is not an exact science yet Harris (1995) suggests that the label is a ‘hard’ boundary, a ‘dominant identifying label’, (Beart Hardy & Buchan 2005). This rigidity of the ID boundary makes boundary transgression unlikely. Individuals with ID are a stigmatized group in society and are aware of the stigma associated with the label ID, (Jahoda, Wilson & Stalker 2010, Dagnan & Waring 2004). The stigma associated with having an intellectual disability stems from an ‘othering’ of those who are different and has both internal and external consequences. It can create stigmatisation through the imposition of a negative identity and inclusion in a low status group. It can result in lower levels of self-esteem and self-efficacy, greater social embarrassment (NDA 2006), increased social rejection and maintenance of higher levels of social distance towards persons with disabilities (Olkin et al 1994). Discrimination towards PWID is evidenced by segregated education and limited employment opportunities (Corrigan and Werner 2012). Adolescents with ID report higher rates of peer rejection (Zetlin & Turner 1985, Cooney et al 2006).

Another direct but rarely considered cost to the young person is the external imposition of a label by a professional. A diagnosis of ID is usually made in childhood, when power to make decisions is given to parents. When a delay or deficit is suspected parents seek professional help or are perhaps advised to seek professional help. Within these family contexts it is assumed (and rarely interrogated) that parents always act in the best interests of their children. Generally assessment, diagnosis and intervention occur without
the explicit consent of the child and without any input from them on its future implications in terms of psychological wellbeing, education and social relations. Heyman and Swain (2010) note that a learning disability diagnosis is associated with powerlessness and control by the professional who is positioned as the expert. In an exploratory study of using autobiographical accounts to inform ASD diagnosis, Woods (2016) found that the age at which young people can actively participate in giving their views is younger than previously thought (5 years) and raises questions about deficit focused clinical practice. Bradley, Caldwell and Korossy (2015) call for a more focused approach to understanding what people with ID are trying to communicate that moves beyond traditional diagnostic frameworks. It is also possible that negative consequences of getting a diagnosis may be a less pressing concern for parents than securing access to resources.

Responses to stigma

There are number of responses to stigma identified in the literature. Denying the ascribed identity is one strategy (Edgerton 1967). Goffman (1963) coined the term ‘passing’, to describe the strategies of PWID to pass as ‘normal’ when outside an institutional setting. An example of this, in a special school setting is reported by Cheston (1994). Students leaving special school settings denied their history of segregated education or explained it by reference to physical factors such as being left handed. There is also a hypothesis concerning limited cognitive capacity as a factor in response to stigma. This draws on developmental literature and posits that an individual must have achieved a certain level of cognitive maturity in order to recognize social categories, usually 7-8 years (Harter 1983, Beart et al 2005). Although some studies place the age of capacity for discrimination against peers as young as 4 years (Bigler & Liben 2007) it remains a feature of developmental maturity. There is evidence that some research participants have only a partial awareness or limited understanding of the meaning of the ID concept (Finlay & Lyons 1997). In a study with parents and young people with Downs Syndrome, (DS) Cunnigham, Glenn and Fitzpatrick (2000) found that parent telling was significantly related to their offspring’s developmental level measure through verbal
mental age (VMA). Parents whose offspring had a VMA of less than 5 years had not discussed this ID and these young people had no awareness of DS or ID. For young people whose VMA was above 5 years parents oriented discussion towards what was pertinent at the time with increasingly detailed explanations developing over time and in accordance with offspring’s questions and experience. Only a small percentage (5%) of their sample of parents had deliberately shielded their children from potential hurt by not discussing ID with them (Cunnigham et al 2000).

Other research uncovered a hierarchy of impairment (Deal 2003, Szivos-Bach 1993, Zetlin & Turner 1985) where individuals with ID used social comparison strategies to derogate other stigmatized group members for example individuals with more significant disability. However it is unclear from the literature if individuals with ID foreground the ID identity to the same extent as is assumed. Individuals with ID are not passive participants in discourse about stigma, they can and do choose how and with whom to compare themselves (Cooney et al 2006). A number of explanations have been identified through qualitative studies as to why an intellectually disabled identity may not be salient and self-defining to someone labeled as such. One such explanation may be that the perceived entitativity of the ID group is problematic. The construction of a group –intellectually disabled- demonstrates lack of acknowledgement of the within group differences for people with ID. Often people with ID identify as a person with Downs rather than a broad more homogeneous term. Research suggests that PWID often fail to actively identify themselves as intellectually disabled, as they don’t see it as salient to their everyday lives. For example Davies and Jenkins (1997) found that a large cohort of participants in their study showed a complete lack of application of terms associate with ID, such as mental handicap to themselves. The practice of benevolent stigma is another; parents and loved ones, in an attempt to protect their intellectually disabled offspring from hurt and confusion, may avoid talking about their disabilities (Davis & Jenkins, 1997) and ‘toxic’ identity (Todd & Shearn, 1997). Todd and Shearn, (1997) argue that this avoidance leads to blindness in the person with intellectual disability, that they are literally ‘invisible to
themselves'. This assertion however has been, challenged by researchers taking a constructionist approach (Finlay & Lyons, 2005, Rapley, Kiernan & Antaki, 1998; Scior, 2003). Rapley et al., (1998) reanalyzed Todd and Shearn's data and agree that in managing a 'toxic' identity PWID may actively attempt to 'pass' as 'normal'. However they differ by stating that identity categories are essentially fluid and worked up in interaction, that 'doing being ordinary' is a common feature of social life for everybody and no less so for people with intellectual disabilities. In focusing on their achievements and competence rather than the things they find difficult, PWID demonstrate they have characteristics that are valued in society (Kittlsaa, 2013).

People with intellectual disabilities do not deny their disabilities and varying needs for support but are aware of and often try to distance themselves from the stigma attached to the label and seek acceptance from society. Concern over stigma is only a partial explanation for the lack of category salience however (Finlay & Lyons, 2005). Finlay & Lyons (2000) note that PWID engage in social comparison strategies to maintain a sense of self. Studies have found that downward comparisons with people who are profoundly disabled suggest to less disabled people that they do not belong to the category (Craig, Craig, Withers, Hatton & Limb, 2002; Jahoda & Markova, 2004). When profound disabilities are perceived as prototypical of the category less disabled individuals are unlikely to perceive a normative fit with the category (Finlay & Lyons, 2005). Finlay and Lyons (1998, 2005) found varying levels of identity salience, some people expressed low levels of identification, others psychologically distanced from the category Finlay and colleagues (2003) challenge the assumption that PWID view the category, themselves and their peers negatively. They found their participants had positive self-concepts, supportive relationships and important friendships with their peers. Significantly, the participants recognized the diversity of the category in terms of widely varying cognitive and physical abilities and needs, and only distanced themselves from the behavior of people who were challenging. Although emotionally aware of the stigma they experienced in interactions
they did not view the category negatively, however the category was rarely salient and not drawn on as an explanation for the painful experience of stigma.

Rapley (2004) in a thought provoking book on the social construction of ID argues that the denial of category membership is not evidence of lack of awareness of ID but rather can be construed as evidence of a strong awareness of the low value of such category membership and denial is a form of self protection. Nevertheless, even though PWID may not assume this label or accept that it applies to them, this hard boundary does exist and means that others may label them. This distinction relates to the fundamental distinction between felt and enacted stigmatisation. Abrahams et al (2002) comments that in addition to experiencing classic prejudice, individuals with ID also experience benovolent stigma. Walton et al (2007) explores this aspect of stigmatised identity in their work on the power relations in residential settings for individuals with ID. They outline evidence of disempowered interactions in everyday life even in cases where care workers are ostensibly seeking consent and consensus from those with ID. These are examples of enacted stigmatisation.

In summary, this section has clarified the use of terminology and models of disability. An outline of the context in which this research was conducted, has been presented. Finally this section reviewed the theoretical perspectives with which to examine and discuss the findings of this thesis. It establishes that the Social Identity approach is a useful framework for exploring our understanding of intellectual disability in special schools through a novel contribution to the literature.

**Ethical considerations**

Ethical approval was granted for this research by the University of Limerick Ethics Committee¹ and ethical approval was also granted by COPE Foundation, the disability

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¹ Approvals: 2012_06_172_EHS, 2012_05_150_EHS
services provider that oversaw one of the schools in the study. Additionally approval, was granted by the Board of Management of each school.

The main ethical issues raised concerned the use of self-report measures used in the study. There was a concern raised about the length of time that it would take the students to complete multiple questionnaires. The number of measures proposed was reviewed to ensure that the student interviews would take no more than 40 minutes or one class period. Additionally as the study was focusing on experiences of stigma, there were concerns that recalling stigmatizing experiences may cause distress to the participants. These concerns were addressed in the following ways; The participants had verbal and written information about the study and an opportunity to think about whether or not they wished to participate. The voluntary and confidential nature of the study was emphasized in student appropriate language and was informed by Mencap’s accessible language principles (Mencap 2008, Nind 2008). The participant data was kept in a secure location. Participants were made aware of their right to refuse or withdraw at any time without negative consequences. All the questionnaires were completed in a familiar setting and students had access to staff at all times. The researcher was familiar with the support procedures in each school e.g. pastoral care team and agreed to refer students to relevant staff if they became distressed. Mindful of ongoing assent as well as consent students were reminded that they had to right to withdraw at each data collection phase.

In accordance with best practice guidelines (DCYA 2012) the researcher is Garda vetted, versed in child protection measures and skilled and experienced in interacting with persons with ID. I was mindful that consent is an ongoing process, which allows for the participants to withdraw at any time (Cresswell 2003). I maintained a deep sense of responsibility to the data and the participants throughout this research. This extended beyond maintaining confidentiality to ensuring that all elements of the research were methodologically sound, valid and reliable and that this thesis is an accurate representation of the data.
Methodology

This thesis contained a mixture of qualitative and quantitative methods. An integrated mixed methods approach was chosen because the triangulation of data will provide insight into multiple perspectives of the lived experience of adolescents with ID. A mixed method approach combines the strengths of both approaches and minimizes the weaknesses (Johnson & Onwuegbuzie, 2004, Creswell 2014). Qualitative methods are useful for exploring banal discourse and to better understand the social construction of disability. Quantitative methods provide a counterpoint to the qualitative data and strengthen the overall validity and trustworthiness of the findings. There is a particular challenge in researching a vulnerable population such as PWID because of lack of clarity about the most effective research methods, (Nind 2008, Beail & Williams 2014). Multiple methods validate findings as no one method is perfect and a variety of methods provide a more nuanced insight by looking at different aspects of the same issue. Mixed method approaches collect both quantitative and qualitative data and draws interpretations from the combined strength of both. As this thesis is made up of three empirical papers the convergent design with both quantitative and qualitative elements will be explored in the discussion section. This combined approach has been chosen to gain a comprehensive understanding of the lived experience of adolescents with ID. There is paucity of information about the individual experience of stigma in the literature, (Werner et al 2012) with most research focusing on the attitudes of the public and family rather than the individual. It is our intention to highlight the experiences of a marginalized group and in doing so will be informed by elements of a social justice or transformative paradigm (Mertens 2014)

The paradigm or worldview (Guba & Lincoln 1994) of the researcher is influenced by the social relational model of disability (Thomas 1999, Reindal 2008), that is that disability is a socially constructed and contested concept, which means different things to
different people, (Rapley 2008, Rix & Sheehy 2012). A constructivist stance also influences this research and in keeping with this stance asserts that both the researcher and the participants are involved in the meaning making. It is important to interrogate the assumed knowledge that ID is an observable fact or that our current understanding of ID is fixed. The epistemological position asserted here adopts a pragmatic middle ground that is reality is socially constructed but constrained by cultural and structural conditions. By adopting this position, which combines the traditions of positivism (reality is objective and fixed) and a social constructionist position (reality is socially constructed) ensures that our findings are grounded in data (Madill, Jordan & Shirley 2000).

Due consideration has been given to the need for research design and methods of data collection to be appropriate to the research questions. A combination of qualitative and quantitative methods is useful for answering related questions, (Willig 2013). The use of questionnaires can demonstrate differences between groups and the use of focus groups extends our understanding about the differences.

Focus groups were considered appropriate for the data collection of the views of parents and staff. A focus group is a type of group interview where the interaction between the participants is the source of data (Willig 2013). An advantage of focus groups is that it allows the researcher to examine how meanings can be jointly constructed. The focus groups contained in this thesis have high ecological validity as they are conducted in ‘real life’ setting and the participants in both styles of focus group were known to each other. Two types of focus group were used; a small number focus group and a World café style focus group. The World café style focus group is designed to for large numbers of people and to encourage participation and engagement. It has been found to be more effective than a traditional focus group method with larger numbers (Fullarton & Deakin 2008). This was chosen as an effective way of collecting data from the large group of school staff in an inviting and collegial manner. World café encourages dialogue around critical questions in relaxed setting and is particularly useful for connecting diverse perspectives (Fouche & Light 2010, McFarlane, Galvin, McInerny, Meagher, Burke 2017). The second style of focus
A group was used to collect data from the parents of young people with a diagnosis of ID and the numbers were smaller (n=10). Focus groups are useful for exploring how points of view are constructed and expressed and are useful for collecting a range of data simultaneously (Barbour & Kitizinger 2001).

Quantitative data from people with ID is relatively rare in the literature (Nind 2008, Werner 2012), although given the challenges of comprehension this is perhaps not unsurprising. The self-report measures used in this study were designed for and adapted for use with a population of individuals with ID. There is limited choice of self-report measures that are suitable for ID populations (Finlay & Lyons 2001, Werner 2012). Some have been designed in consultation with individuals with ID and some not. Finlay & Lyons (2001) caution that because an population with ID varies so widely in terms of ability it may be impossible for any one questionnaire to be completely valid. For the purposes of this study it was decided to use measures that had already been successfully used in empirical research with an ID population. These measures utilize a range of formats such as photographic cues, visual analogues and require individual administration. The tests for internal validity for the quantitative components of the study ranged from $\alpha = 0.46$ (General ability) to $\alpha = 0.79$ (Behavior) for the Self Perception Profile for Learning Disabled students (Renick & Harter) and $\alpha = 0.78$ for the composite Stigma scale. Social Comparison was measured twice using an adapted version of the Social Comparison Scale and responses ranged from $\alpha = 0.53$ to $\alpha = 0.46$. The measure of perceived stigma (Ali et al 2008) was found to a high internal consistency, $\alpha = 0.83$.

The participants were recruited from three segregated special needs secondary schools located in the south of the Irish Republic. The participant ages ranged from 12 to 14 years. The schools are classified by the Dept of Education as schools for students with a primary diagnosis of General Learning Disability, (GLD) as assessed by a suitably qualified individual (Dept. of Education 2002). The students were drawn from a wide catchment area rather than one distinct community. All participants have a primary diagnosis of general learning difficulty (GLD). Participants level of cognitive capacity ranged from mild
to moderate GLD in accordance with their IQ score, in accordance with DSM-IV criteria. Additionally many of the participants have a variety of secondary/comorbid diagnosis underlining the heterogeneity of the special school population. However all these students experience the same segregated 2nd level education and thus share the same potentially stigmatizing experiences.
Reflection: the researcher in the research

The genesis of this thesis is grounded in my own personal and professional encounters with segregation and discrimination. My first ‘grown up’ job, when I was 17, was working in a residential care setting for individuals with intellectual disability. Comments such as ‘aren’t you great’, ‘that’s Gods work’, and ‘shur God help us’ were common place and seemed to be meant as a compliment yet I understood that they were in fact achieving an ‘othering’ of an entire group of people. When I began teaching young people with a diagnosis of ID, I was frequently obliged to explain why they would be suitable for a post school training course, as the label ID and the name of the special school they had attended dominated the conversation far more than satisfactory results in state exams.

From a young age I knew that certain labels were unwelcome and although the list of things that were judged be socially unacceptable in rural 1980’s Ireland was very long, being remedial or special was one of them and it applied to me. I was diagnosed with a specific learning disability at the age of 7 and my parents were advised to move me to a larger urban national school where remedial support was available. I was withdrawn from my local rural community and then from class for remedial support. When time came to make the transition to secondary school I was offered remedial support and allowances for state exams. Keenly aware of the low expectations of teachers, and wanting desperately to be ‘normal’ I refused all offers of help and worked very hard at ‘passing’ for normal and fine, a skill that has both merits and flaws in adult life.

My experiences during this time were not unique or unusual and I experienced many of the social difficulties that arise from being identified as different. My future aspirations were dictated by family background as much as ability, 3rd level education was an assumption so ingrained that any alternatives were simply not discussed. It was assumed that I would just have to work harder to get to where I was expected to go. In contrast diminished expectations were set out for my fellow remedial students.
By the time I got to third level, by way of a gap year working in a residential home for adults with intellectual disabilities, I was determined to reject any attempts to label me and challenge the ease with which others were labeled. I trained as a teacher and discovered that I had an affinity for working with students who were classed as difficult. As I gained experience in special education settings, working with a variety of students classed as ‘at risk’ youth, special and challenging and as I became familiar with the veritable alphabet of disorders that accompanies these young people I found myself questioning the system and structures that relied so heavily on labels and segregation. I had achieved a number of post-graduate accreditations by my early 30’s, a testament partly to my determination not to be defined by the low expectations of my early years but also a keen interest in how groups function and the role of individuals in those groups and questions of social justice and equality. I continued to work full time for much of my PhD journey, although being awarded a Department of Children and Youth Affairs scholarship enabled me to devote a invaluable two years to data collection and preliminary analysis. My job has evolved during the time I have been working on this thesis, from teacher to regional advisor for teachers and so I am very much embedded in systems and structures that frame the social and educational experiences of young people with intellectual disabilities. I began this PhD to gain a greater understanding of the experiences of young people with disabilities and as I had direct access to special schools it made sense to focus on young people with intellectual disabilities.

An unexpected but much welcomed twist in the journey came with the birth of my two children and I found myself viewing issues of disability through the lens of a parent. My son (8 months at the time of writing this) was diagnosed with bilateral moderate hearing loss when he was 2 days old. I found myself experiencing first hand the frustration of multiple assessments, I observed the power and privilege accorded to the professional, expert voice and I gained a small insight in to the complexity of emotions that arise when your child is different. Additionally during this last year I was diagnosed with a progressive connective tissue disorder, Ehler Danlos (Heds), which did offer an explanation for a life
time of soft tissue injuries and frequent ‘niggly’ joint issues, and it also deepened my interest in and understanding of being ‘different’. My thinking about labels has evolved to consider their explanatory power, the way in which they act as shorthand for dialogue with professionals and they way in which they can manage expectations.

However given the embedded position I find myself in terms of disability and special education it was critical that I engage in reflexivity about my biases and influences during the research process. I am more conscious of the need for a more individualized approach to disability issues, an understanding that the group ‘disabled’ is made of individuals with disabilities. I have a greater understanding of the complexity of many of the issues, the tensions between finite resources, administrative systems and structures. I find myself more aware of the language I use, I still occasionally catch myself falling into the easy professional jargon used in special education settings but I am more mindful of the impact of my words. I am more comfortable suggesting alternative phrases for professionals about the language they use to describe young people. I have a greater understanding of the heterogeneity of the special school population and I apply that knowledge to policy documents and advice to schools. I have become very aware of my own bias in terms of a heightened sensitivity to being ‘different’ and I am conscious that this is my lens with which to view the world and is not shared by all individuals with disabilities. My views on labeling, segregation and disability have evolved indeed are evolving, perhaps the problem is not the label or the consequent specialist intervention but rather the diminished expectations and negative stereotypes that accompany the label. The question then is how do we change the discourse around and the perceptions of difference.
Thesis road map and rationale

Previous research has highlighted that stigma has negative consequences for marginalized groups. The extent to which people with ID perceive stigma is under-researched, as is the resistant nature of stigma and ID population (Morris 2007, Werner 2012, 2015). It is unhelpful to assume that the self-concept of young people with ID is determined solely by the low status of ID category membership. However the developing social identity may be heavily influenced by this group membership, the extent of which is an under-researched area. Werner (2012) argues that people with ID may experience a stigmatized identity in a similar way to those with mental health issues and notes that there are few studies that look at the impact of stigma on the individual with ID. Research in the social identity tradition has explored the position of marginalized groups extensively (Jetten et al 2009, Cruwys, Haslam & Dingle 2014, Purdie-Vaughns & Eibach 2008), but an exploration of the complexities of stigma in the group-intellectually disabled is under-researched. A number of studies have called for greater understanding of stigma in the area of intellectual disabilities (Werner 2012, Werner 2015, Corrigan 2014, Dagnan & Waring 2004,) and examining the perspective of the powerless is a critical addition to our evolving understanding how members of disadvantaged groups respond to discrimination. The perspective of mainstream society regarding those with ID is reasonably well understood but it is unclear if the ID identity is dominant for individuals who have been assigned the label ID. It is also unclear what are the societal influences on identity and self concept on adolescents with ID and to what extent does ID group membership have on their identity. There is conflicting research about outcomes of the young people with ID in inclusive or segregated settings. On one hand the argument against labeling implies that special education reinforces stigma and foster negative self concept and on the other hand social comparison theory would suggest that special education allows comparison with similar ability ability ability peers and is therefore more protective of self concept.
This thesis set out to answer the following research questions;

- Are young people with ID exposed to stigma in their families and communities?
- Are young people with ID restricted in terms of opportunities to explore their identity?
- How do young people with ID experience stigma in a segregated school?
- How do we do ID?

This thesis consists of three empirical papers, which extend our understanding of the complexity of stigma and intellectual disability in special school settings.

Paper 1 considers the role of the level of intellectual disability and gender on perception of stigma in individuals with intellectual disability who attend a segregated special secondary school and whether reports of stigma impact self-perception and social comparison with others. Each participant completed self-report measures in a cross sectional survey design. The degree of intellectual disability and gender were found to influence experience of stigma and respondents social comparison with others. Category of intellectual disability (borderline, mild, moderate) was also associated with differences in self-perception of physical appearance and perception of global self-worth. Social comparisons were also negatively related to experience of stigma. Discussion focuses on the heterogeneity of those affected by intellectual disability and how this impacts on their experience of stigma.

Paper 2 is a longitudinal study which examines the changes that occur in multi dimensional self-concept of adolescents with a diagnosis of intellectual disabilities, across gender and category of intellectual disability (borderline, mild, moderate), groups. Stability and change in multiple domains of self-perception were examined. Findings indicate that gender and level of cognitive function are important variables in changes in self-perception across time, highlighting the heterogeneous nature of the special school population.

Paper 3 examines how disability is constructed by significant adults in the lives of young people with a diagnosis of Intellectual Disability (ID). We examine whether stigma is
recreated or sustained within family and school settings by analyzing in focus group interviews thematically. Discussion orients to how parents and teachers, see themselves as advocates for those with ID highlight, whilst at the same time recreating pervasive and subtle distinctions between children with and without ID.

The introductory chapter outlines the place of stigma and ID in the wider context of social identity framework as well as examining the theories underpinning research into prejudice and discrimination. The discussion section outlines some of the limitation of the research, makes suggestions for further research and integrates the findings from the three papers.
Chapter 2

Stigma, Self-Perception and Social Comparison in young people with an Intellectual Disability
Abstract

Whether individuals who have a diagnosis of intellectual disability perceive and experience stigma has been a matter of some debate. In this paper we consider the role of the level of intellectual disability and gender on perception of stigma in individuals with intellectual disability who attend a segregated special secondary school and whether reports of stigma impact self-perception and social comparison with others. Each participant, (N=54) completed self-report measures in a cross sectional survey design. The degree of intellectual disability and gender were found to influence experience of stigma and respondents social comparison with others. Category of intellectual disability (borderline, mild, moderate) was also associated with differences in self-perception of physical appearance and perception of global self-worth. Social comparisons were also negatively related to experience of stigma. Discussion focuses on the heterogeneity of those affected by intellectual disability and how this impacts on their experience of stigma.

Keywords: Intellectual Disability, Stigma, Special Education, Self perception
The diagnosis of Intellectual Disability (ID) is a powerfully stigmatizing label that is routinely perceived as a negative and low status. Beart, Hardy and Buchan (2005) refer to ID as a ‘dominant identifying label’ and it has been described as a ‘toxic’ or ‘spoiled’ identity (Todd & Shearn 1997, Goffman 1963). Individuals with ID experience stigma as a consequence of their devalued social identity, (Bogdan & Taylor 1994, Edgerton 1993). Stigma is both the direct experience of rejection (enacted stigma), for example discrimination through the provision of segregated services and education, (Werner, Corrigan, Ditchman & Sokol 2012) and the fear of encountering rejection (felt stigma), (Lundberg, Hansson, Wentz & Bjorkman, 2000; Link & Phelan 1997). There is some evidence that the experience of stigma impacts directly on the individual with ID. Individuals with ID experience social exclusion (Abbott & McConkey 2006) and have a greater vulnerability to mental health issues (Moss, Emerson, Kiernan, Turner, Hatton & Alborz 2000; Gannon & Nolan 2005; Dagnan & Waring 2004), but it is unclear to what extent the stigma arising from the label, ‘intellectual disability’ has consequences for the individual with ID.

In general research tends to view individuals with ID as a homogenous group. However within the population of those affected by ID there are subsets, those with concealable stigmas, those with severe, moderate and mild levels of functioning and these factors may influence the strategies used to negotiate the stigmatizing experiences. Research has found that some individuals with ID appear to be unaware of their disabled
status. It is unclear if this is because of the level of developmental delay and thus they cannot recognize the devalued social category, (Cunningham & Glenn 2004), or the protectiveness of offered by protected environments such as segregated schools, (Todd & Shearn 1997; Beart, Hardy & Buchan 2005) which makes individuals with ID ‘invisible to themselves’ or indeed a denial of and resistance to the ID label (Jahoda & Markova 2004; Kittelsaa 2013, Rapley 2004). A first factor then that may influence the experience of stigma is a person's level of intellectual disability. Cunningham and Glenn (2004) suggest that the level of awareness and understanding of is associated with the severity of the disability. Their studies found that the cognitive capacity to recognize stigmas was an important factor. Perception of discrimination occurs along a consistent and predictable developmental trajectory (Brown & Bigler 2005; Bradshaw, Jay, McNamara, Stevenson & Muldoon 2016) with children engaging in social comparisons from 7 years. Individuals with ID follow a delayed developmental trajectory (Silon & Harter 1985, Brown & Bigler 2005), and in typically developing population's children younger than 7 tend to be very positive about their own abilities (Harter 1993, Cuskelley & de Jong 1996). Cunnigham and Glenn (2004) found that participants with a level of ID comparable to a typically developing young child were the participants who were least likely to engage in meaningful social comparisons. Todd and Shearn (1995, 1997) concluded that individuals with ID could be ‘invisible to themselves’ because the social cognitive capacities are more akin to those available to young children. Equally studies have found that family members (Davies & Jenkins) 1997 and special school staff (Todd 2000) can create a 'protective capsule', to
keep individuals with ID from the knowledge of their devalued social status. This protection may be more likely to occur when disability is more profound.

Social Comparison processes then would appear to be central to understanding stigma. Social comparison theory (Festinger 1954) argues that individuals engage in social comparison strategies as a basis for self-evaluation. Social comparisons are a social cognitive mechanism by which a person can validate aspects of self, and as such social comparison is linked to an individual’s capacity to make appropriate comparisons, within a context that allows for different comparisons. Social comparisons influence self-evaluation and consequently self-perception. Patterson, McKenzie and Lindsay (2012) argues that there is a link between high perceptions of stigma, negative social comparison with others and low self-esteem. Research with typically developing school populations has found that young people will engage in social comparison, suggesting a drive towards self-improvement. However this finding was not consistent in intellectually disabled populations (Crabtree & Rutland 2000). Finlay and Lyons (2000) demonstrated that individuals with ID often made social comparisons to those without intellectual disability, which focused on attributes such as kindness and helpfulness, which resulted in their viewing themselves positively.

On the other hand, Jahoda and Markova (2004) found that people with ID used downward social comparison when comparing themselves with intellectually disabled peers, which they argue had a self-protective function. Djikstra, et al (2008) in a review of social comparison research in schools found that young people with intellectual disability
felt more competent in environments such as special schools where they can compare themselves with similar ability peers. Adolescents with ID in mainstream school settings however can use differentiated social comparisons so that it is protective of self (Cooney et al 2006). Social comparisons with similar ability peers in segregated school/class settings have been found to be protective of self-concept (Zeleke 2004; Renick & Harter 1889). In community settings individuals with ID are of course more likely to compare themselves with typically developing peers and therefore this comparison to those in community rather than a segregated school setting may have a different consequence.

In short, individuals with ID are not necessarily passive in response to their devalued social status and can play an active role in maintaining a positive identity. Interestingly, the experience of stigma can, but does not always result in a diminished self-concept as research has found that individuals with ID can be selective about the domains of competence which they focus on. Crabtree and Rutland (2001) in a study comparing adolescents with and without learning disabilities found that students with learning disabilities devalued academic domains of self-perception and placed a higher importance on non-academic areas such as physical appearance and athletic competence. Muldoon and Trew (2000) found that the perception of physical appearance is a key variable in the successful adjustment from childhood to adolescence in a standard school population. Physical appearance and social acceptance also seem to be significant predictors of global self worth for adolescents with ID (Kloomok & Cosden 1994). These findings can be seen to reflect Crocker and Major (1989) position that people in stigmatized groups protect
their self-concept by using socially creative strategies such as selective comparison with in-group or devaluing dimensions of comparison in which they perform poorly.

Comparative context then is important because the experience of stigma is not limited to one setting such as a school but exists in all areas of social life for individuals with ID. Cooney et al (2006) found differing stigma experiences between mainstream and special school students. Special school pupils reported more bullying in their home locality than mainstream pupils (Norwich & Kelly 2004). Equally, membership of two devalued social categories such as female and disabled has been found to create a ‘double discrimination’ effect for women with intellectual disability. For example people report a greater desire for social distance from women with intellectual disability than women with physical disability (Coleman, Bruner & Haugen 2014). Gender effects have also been found in studies on special schools. Norwich and Kelly (2004) found that boys expressed fewer concerns about attending special school and Malimvarra (2012) found that overall boys in special education classes were happier than girls.

Generally understanding of the influence of gender in intellectual disability research is limited (Umb-Carlsson 2006). Very few studies of people with intellectual disability examine gender (Burns, 2000, Scior 2000) but it seems valid to question if gender plays a role in the shaping the stigma experience of ID.

Taking this literature together it would appear the severity of ID is a factor that may be crucial to the stigma experience. Social comparison processes would appear to be linked to ID, though these processes are also driven by comparative contexts, which include school
and community reference groups and gender. It is also possible that young people with ID use such socially creative strategies such as devaluing dimensions of disadvantage (for example academic competence) to protect their self-esteem, (Szvios 1991; Crocker & Major 1989). It is possible that comparison with similar ability peers shields young people for experiencing stigma and it is possible that they take an active role in managing their ‘toxic identity’ through socially creative strategies. Young people with intellectual disability are amongst the most marginalized groups in society and it is vital that empirical research is conducted to inform policy and practice (Carpenter & McConkey 2012, Watson 2012). Research needs to focus on the heterogeneity of young people with disability and look at factors beyond the ID diagnosis. The present study therefore investigates how stigma is understood and negotiated by adolescents with a diagnosis of ID.

Method

Design

The data presented in this study were collected as part of larger longitudinal study, which tracked changes in self-perception, stigma and social comparison over one year. This paper reports on a cross sectional analysis of Time 1 of the longitudinal data set. Cross sectional analysis allows us to compare data from respondents that differ on key characteristics such as gender or category of learning disability at a single point in time. This point tends to be at Time 1 where the sample size is large and no attrition has occurred. This cross sectional
study allows us to focus on the diversity of the disability within the sample looking specifically at impact of gender and severity of Intellectual disability (borderline, mild, moderate) on our outcome measures. The outcome measures were stigma, social comparison with others in home/locality and social comparison with others in school, self-perceptions across 9 domains. Cross sectional design is therefore very useful for establishing associations between the variables. In this study we have three specific hypotheses:

- There will be significant differences in the experience of stigma, self-perceptions for reported across gender and category of learning disability (CLD).
- There will be significant differences between the social comparisons made with others in home/locality and with social comparisons made with others in school.
- Gender, CLD, stigma and social comparison processes will predict self-perceptions in those affected by ID

Participants

The participants were 54 students (33 male, 21 female) attending three segregated special needs secondary schools located in the south of the Irish Republic. The participant ages ranged from 12 to 14 years (M=13.1, SD=.67). The schools are classified as schools for students with a primary diagnosis of General Learning Disability, (GLD) as assessed by a suitably qualified individual (Dept. of Education 2002). These schools cater for three categories of GLD, borderline mild general learning disability, (IQ range 70-79), mild...
general learning disability (IQ range 50-69) and moderate general learning disability (IQ range 35-49) (Carey 2005; Ware et al 2009). The general learning disability term is used by the Dept. of Education and Science and refers to what is internationally known as Intellectual Disability (Schalock 2011). The majority of the participants (76%) had previously attended mainstream primary school for 6 or more years. This is keeping with Irish Government policy of inclusion of pupils with special needs (NCSE 2011). Inclusion in this instance refers to the students with diagnosed intellectual disabilities being educated alongside their peers in mainstream schools. Inclusion in second level education is not widespread in the Irish Republic and many pupils move from mainstream primary schools to segregated special schools at the beginning of second level (Ware et al 2009). There is a trend in Irish special schools, which has seen an increase in the numbers of post primary aged students attending special school for the first time at 2nd level. Approximately 60% of students in special schools are aged 12+, (NCSE 2011, NAMBSE 2010) and all special schools in Ireland are administered as primary schools regardless of the age cohort of pupils. The parents of 65 students were invited to give consent and 54 (83%) accepted and 11 declined. No data were available regarding the characteristics of the 11 children whose parents refused except that they attended a special school. Participant characteristics are illustrated in Table 1.
<table>
<thead>
<tr>
<th>General Intellectual Disability</th>
<th>Male %</th>
<th>Female %</th>
<th>Total %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borderline</td>
<td>40%</td>
<td>14%</td>
<td>30%</td>
</tr>
<tr>
<td>Mild</td>
<td>42%</td>
<td>48%</td>
<td>44%</td>
</tr>
<tr>
<td>Moderate</td>
<td>18%</td>
<td>38%</td>
<td>26%</td>
</tr>
</tbody>
</table>

Measures

Participants completed a series of measures investigating their experiences with regard to self-perception, social comparison and stigma. The measures used have been adapted or designed for use with a disabled population. There is limited choice of self-report measures that are suitable for ID populations (Finlay & Lyons 2001, Werner 2012). Some have been designed in consultation with individuals with ID and some not. For the purposes of this study it was decided to use measures that had already been successfully used in empirical research with an ID population. These measures utilize a range of formats such as photographic cues, visual analogues and require individual administration. The measures were chosen to tap into both enacted and felt stigma, multi dimensional self-perception and social comparison in two social settings.
Experience of Stigma. Stigma was measured using a composite score from the Experience of Stigma checklist, (Cooney et al 2006) and the Measure Self Perceived Stigma (Ali, Strydom, Hassiotis, Williams & King 2008). The Experience of stigma scale was developed specifically for use with young people with intellectual disabilities in a school context, although the authors did not consult young people with ID when designing the measure they report reliabilities of $\alpha=.63$ to $\alpha=.48$. It is made up of an 8-item subscale, which explores the frequency with which participants experience stigmatized treatment from key figures. Five items concerning non-threatening experiences are interspersed with the stigma items. Participants are presented with a series of questions, for example ‘have other pupils in the school made fun of you?’ and their response is marked on a five-point scale (0=Never, 1=Seldom, 2=Sometimes, 3=Often, 4=Very Often). The Measure of Perceived Stigma (Ali et al 2008) is a 10 item self report measure specifically designed for use with individuals with mild to moderate intellectual disability. The authors consulted with Multi disciplinary teams working in the ID sector as well as individuals with ID. Participants are presented with a series of statements, for example ‘people on the street make fun of me’, an explanatory photo accompanies each statement. Responses are recorded by ticking a box yes or no (1=no, 2=yes). During the analysis a composite scale for Stigma was made up from 18 items from the two scales and the Cronbach’s Alpha coefficient for the composite Stigma scale was $\alpha=.78$

Self-perceptions. This study is grounded in multi dimensional self-concept model and a measure, which tapped multiple dimensions of self-concept was appropriate. Measuring
self-competence perceptions in young people with ID is challenging (Huck, Kemp, & Carter 2010) due to developmental delay and possible language impairments. For this reason, domains of self-competence were measured using Harter’s Self Perception Profile for Learning Disabled students (Harter & Renick 1988). This is a 46 item self-report measure that assesses domain specific and global perceived competence. This measure has been used successfully in special school settings and with adolescents with ID, (Crabtree & Meredith 2000; Crabtree & Rutland 2001). On this occasion self-perception was measured in nine domain specific areas, general intellectual ability, reading competence, writing competence, spelling competence, math competence, social acceptance, athletic competence, physical appearance, behavior and in one global area, global self-worth. The administration and scoring procedure followed that outlined by the authors (Harter & Renick 1988). For each item participants are asked to select which of two statements is most true for them. For example, one item states: “Some kids are sure they are pretty smart in school BUT other kids are not so sure they are all that smart in school”. The participant then decides by ticking a box whether the selected item is “really true” or “sort of true” for them. The response to each item was scored from 1 to 4. Cronbach’s Alpha coefficients ranged from \( \alpha = 0.80 \) for the reading subscale to \( \alpha = 0.63 \) for behavioral conduct subscale to \( \alpha = 0.44 \) for physical appearance subscale.

Social Comparison. Social Comparison was measured twice using an adapted version of the Social Comparison Scale, which has been successfully used with an ID population (Dagnan & Sandhu 1999; Cooney, Jahoda, Gumley & Knott, 2006; Paterson 2012). It was
designed for use with individuals with ID by Szivos (1999). Paterson (2012) further adapted it by specifying the target comparison group. This is a 6-item scale and is designed to assess participant comparison of themselves to others. In this study two target comparison groups were specified, (Paterson 2012) and the participants completed the scale twice, first using ‘when I am with others in school I generally feel”, then using ‘when I am with others in my home/locality I generally feel”. The participants understanding of ‘others in my school” and ‘others in my home/locality’ was discussed prior to completion of the measure to ensure that they had an understanding of who they were comparing themselves to. Response options were scored 1 to 3. In this study the Cronbach’s alpha coefficient for the full scale with people in my school was α= .53. The Cronbach’s alpha coefficient for the full scale with people in my town was α=. 46.

Procedure

Ethical approval was granted in accordance with University of Limerick research guidelines and ethical approval was granted by the Research Ethics Committee of the Intellectual Disability services provider involved in the management of the schools participating. Participants were recruited by way of letter of invitation to the parents of first year students in each school and parental/guardian consent was obtained on an opt-out basis, whereby parents/guardians returned forms only if they did not wish their child to take part in the study. Consent to contact the parents was obtained from the Principals and Governing bodies of each school. Participation was voluntary and the participants were not given reward or incentive to take part in the study. The students were given an
appropriate information sheet about the study and consent from the students was obtained verbally. Many of the students have limited literacy skills and motor skills delays, for this reason it was decided to focus on providing information but not obliging the students to write unnecessarily. The researcher has an extensive professional background in special education, is trained in child centered practice and comfortable engaging with ID youth. The ethical guidelines of the Dept. of Children and Youth Affairs, and the Intellectual Disability Services provider were adhered to at all times.

The researcher liaised with the teachers and principal in each school to ascertain when data collection would cause the least disruption to school schedules. Questionnaires were completed with each student individually in an empty meeting room in each school, the student was visible at all times and were reminded that they were free to withdraw at any time. Each participant (N = 54) completed a series of pen and paper self-report measures with the support of the first author. The measures were read aloud to each student and student’s comprehension was periodically checked during the session and they were assured of confidentiality throughout. The duration of each session was between 30 and 45 minutes.

Results

Statistical Analysis

Descriptive statistics were calculated to obtain the mean scores of each participant in on the various measures, See Table 2. This was followed by Multivariate (MANOVA) and
Univariate (ANOVA) analyses which were conducted to examine the influence of Gender (male, female) and category of Intellectual disability; Borderline, Mild, Moderate, (CLD) on the dependent variables; Stigma, Social Comparison and Self-Perception. Multiple regression analyses were performed to examine the role of Gender and CLD on the variables. Preliminary assumption testing was conducted to check for normality, univariate and multivariate outliers, homogeneity of variance matrices and mulitcollinearity.

Table 2 Descriptive Statistics for all measures used in the study

<table>
<thead>
<tr>
<th>Measure</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception of Stigma</td>
<td>54</td>
<td>10</td>
<td>18</td>
<td>15.12</td>
<td>2.4</td>
</tr>
<tr>
<td>Experience of Stigma</td>
<td>54</td>
<td>0</td>
<td>28</td>
<td>6.96</td>
<td>6.7</td>
</tr>
<tr>
<td>Social comparison school</td>
<td>36</td>
<td>6</td>
<td>15</td>
<td>11.91</td>
<td>2.1</td>
</tr>
<tr>
<td>Social comparison community</td>
<td>36</td>
<td>5</td>
<td>15</td>
<td>11.66</td>
<td>2.0</td>
</tr>
<tr>
<td>Self Perception Global Self worth</td>
<td>53</td>
<td>4</td>
<td>15</td>
<td>11.00</td>
<td>2.1</td>
</tr>
<tr>
<td>Self Perception General ability</td>
<td>53</td>
<td>8</td>
<td>16</td>
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<tr>
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<td>Self Perception Behaviour</td>
<td>51</td>
<td>4</td>
<td>16</td>
<td>10.54</td>
<td>2.2</td>
</tr>
</tbody>
</table>
How do social comparisons with others in school and social comparisons with others in home/locality differ?

A MANOVA demonstrated significant main effects of gender and CLD on the dependent variables, social comparison with others in school and social comparison with others in home/locality. There was a significant main effect for gender, $F(2,29)=10.07, p=.0004$, Wilks Lambda= .59; $\eta^2_p =.41$. There was a significant main effect for CLD, $F(4,58)=3.54, p=.01$, Wilks Lambda =.64, $\eta^2_p =.19$. To explore this finding in more detail follow up ANOVA’s were conducted to explore the impact of Gender and CLD on the social comparison with others in school and social comparison with others in home/locality. Levene’s test indicated unequal variance for social comparison with others in school so the alpha level was adjusted to $p<.01$. There is a significant main effect for gender, $F(1,36)=11.99, p=.002, \eta^2_p =.28$ and CLD, $F(2, 36)=6.16, p=.006, \eta^2_p =.29$. Males reported a higher mean score ($M=12.15, SD=1.76$) than females ($M=10.88, SD=2.97$) on social comparison with others in school, indicating that males report more positive social comparisons with others than their female counterparts. Post hoc comparisons using Tukey HSD revealed that the moderate group ($M=13.10, SD=1.37$) reported higher social comparison with others in school scores than the mild group ($M=11.20, SD=2.40$), suggesting that students in the moderate ID group report more positive social comparisons
with peers in school than the students in the mild ID group. The borderline group 
\((M=11.81, SD=2.40)\) did not differ significantly from either of the other groups. The 
interaction effect was not significant, \(F(2,36)=4.01, p=.02, \eta_{p}^2 = .21.\)

There was a significant interaction between Gender and CLD on the social 
comparison with others in home/locality, \(F(2,36)=3.63, p=.03 \eta_{p}^2 = .19.\) The significant interaction was investigated further by evaluating the simple main effects of CLD for female and male students. A simple effects analysis indicates that gender is a significant variable for the borderline group, \(F(1,10)=17.81, p=.002\) and the mild group, \(F(1,14)=4.91, p=.04.\) The males in the borderline group \((M=12.60, SD=1.26)\) and the mild group \((M=11.81, 
SD=1.66)\) scored higher than the females in the borderline group \((M=7.00, SD=)\) and mild group \((M=9.00, SD=3.36).\) There was a significant main effect for gender, \(F(2,36)=13.39, 
p=.001, \eta_{p}^2 = .30\) and for CLD, \(F(2,36)=3.47, p=.04, \eta_{p}^2 = .18.\) Overall males are reporting a 
tendency to more favourable social comparisons with others than females. Social 
comparison also differs by CLD with students in the moderate group reporting more 
positive social comparisons than the students in borderline and mild groups 
Do stigma, and self-perceptions differ, depending on category of intellectual disability and 
gender?

A MANOVA demonstrated significant differences in the domains of Self Perception 
for the variables Gender and CLD. There was a significant interaction effect, \(F(20.64)=1.7 
p=.04, \text{Wilks Lamda}= .402, \eta_{p}^2 = .36.\) The main effect for CLD was significant, \(F(20,64)=1.7, 
p=.04, \text{Wilks Lambda}= .402, \eta_{p}^2 = .36\) suggesting that category of Intellectual disability is a
factor in self perception. The main effect for gender was not significant. To explore this finding in more detail follow up ANOVA analyses on the domains of Self Perception found significant effects for:

Global Self-Worth. The main effect for CLD reached statistical significance, \( F(2,47) = 3.65, p = .03, \eta^2_p = .13 \). Post hoc comparisons using Tukey HSD reveal that the mean score for the borderline group (\( M=12.25, SD=1.29 \)) is significantly higher than the mild group (\( M=10.21, SD=2.55 \)) and moderate group (\( M=10.85, SD=1.46 \)), i.e those with a learning disability in borderline category have more positive self-worth scores. No other significant effects were observed.

Physical Appearance. The main effect for CLD reached statistical significance, \( F(2,47) = 5.76, p = .006, \eta^2_p = .19 \). Post hoc comparisons using Tukey HSD reveal that the mean score for the borderline group (\( M=12.25, SD=1.69 \)) is significantly higher than mild group, (\( M=10.17, SD=2.10 \)) and moderate group, (\( M=10.64, SD=2.00 \)). No other significant effects were observed. No significant effects were found in relation to the following subscales; General Intellectual Ability, Reading, Writing, Spelling, Maths, Athletic, Social acceptance, Behavior.

This finding suggests that CLD does impact on some domains of self-perceptions. The students in the borderline group report significantly higher scores in the domains of global self-worth and perception of physical appearance than the moderate and mild groups.

Stigma. An ANOVA was conducted to examine group differences for gender and CLD on Stigma. There was a significant main effect for gender \( F(1,48), p = .03, \eta^2_p = .08 \). The males (\( M=17.12, SD=7.17 \)) reported significantly lower experiences of stigma than
females (M=21.52, SD8.94). The interaction effect between gender and CLD was not significant and the main effect for CLD did not reach statistical significance. Gender is a significant variable in the experience of Stigma with males reporting fewer stigma experiences than females.

A multiple regression analysis was performed in order to determine if the scores on the subscales for Global Self Worth could be predicted as a function of Gender, CLD, Stigma and Social Comparison, results are displayed in Table 3. Multiple regression is useful for providing information about relative contribution of each of the predictor variables to one outcome, in this case global self-worth. Gender and CLD were entered at step 1 explaining 7.5% of the variance in perception of global self-worth scores. At step 2 the remaining variables were entered, (Social comparison with others in school, social comparison with others in home/locality, Stigma), the total variance explained by the model as a whole was 37.5%, F (4,28) =4.50, p= .01. In the final model three of the variables were significant predictors of self-worth, Category of learning disability (β=. 47 p=. 008), Social comparison with others in school (β=. 46, p=. 01) and gender (β=. 37, p=. 04). These finding suggest that the category of intellectual disability, whether you are male or female and how you compare yourself to others in school all influence global self-worth.

Multiple regression was also used to predict if stigma and social comparison scores could predict scores for the physical appearance scale. Gender and CLD were entered at step 1 explaining 14.5% of the variance in perception of physical appearance. After the entry of the remaining variables (social comparison with others in school, social
comparison with others in home/locality, Stigma) the total variance in physical appearance scores explained by the model was 33.5 %, F (3,28)= 2.66, p= .06. In the final model two variables were significant, Category of Learning Disability (β= .53, p=.004) and social comparison with others in school (β= .43, p=.02). This finding indicates the degree of Intellectual disability as well as the nature of the respondent's comparisons with others in school are both important factors in predicting young peoples perceptions of their physical appearance.

Table 3 Summary of regression analysis

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Global Self Worth</th>
<th>Perception of Physical Appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>R²Δ R² β</td>
<td>R² R²Δ β</td>
</tr>
<tr>
<td>Step 1</td>
<td>.075 .075 .37*</td>
<td>.145 .145 .18</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
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<tr>
<td>CLD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>.369 .294 .78</td>
<td>.335 .190 .46** .43*</td>
</tr>
<tr>
<td>Stigma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social comparison with others in school</td>
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</tr>
<tr>
<td>Social comparison with others in home/locality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>33</td>
<td>33</td>
</tr>
</tbody>
</table>

* P<.05  **P<.001
Discussion

This study aimed to explore the relationships between stigma, social comparison and self-perceptions in adolescents with an intellectual disability. The data indicate that category of intellectual disability and gender, are significant factors, determining young peoples sense of self-worth and physical appearance. These factors are also important in determining their experience of stigma and social comparison processes.

There was an association between stigma and fewer positive social comparisons such that those who reported greater stigma also reported fewer positive social comparisons with their peers in their special segregated school.. This is consistent with a body of research that demonstrates that people with ID experience stigma in community settings, (Jahoda & Markova 2004; Beart et al 2005; Cooney et al 2006). Not only that it would appear that this experience of stigma has consequence even in segregated settings as social comparison effects in school settings are linked to this experience of stigma.

This study demonstrated that for a subset of individuals with ID, that is young people in the moderate CLD group (i.e. those with the lowest ability) more positive social comparisons with others in school than the mild and borderline groups were evident. This finding may reflect the level of developmental delay, (Todd & Shearn 1997). In their study examining self-awareness of young people with Down’s Syndrome, Cunningham & Glenn (2004) found that the cognitive ability to categorize is important in becoming aware of ones disability. In their study of adolescents with Downs Syndrome they found that level of
awareness of disability was linked to the level of developmental delay. This would support Todd (1995) suggestion that some people with more severe ID are ‘invisible to themselves’.

Equally this finding suggests that young people in the borderline and mild CLD are not protected from the ill effects of social comparison even in their segregated school settings. For others with ID it could be that they work at the establishing their identity in a strategic and self-protective manner (Rapley 2004, Finlay & Lyons 2000). Attending a special school may afford the young people a context in which they have the opportunity to engage in social comparison with similar ability peers. This raises questions about the drive for inclusion in schools, and our findings suggest that for those in the mild and borderline CLD, the segregated education does not protect young people from the negative portrayal of ID in the wider social world.

The degree of ID also appears to influence students in other domains. The data indicates that adolescents with Borderline line ID report higher scores in perception of global self worth and more positive perception about their physical appearance than adolescents with mild and moderate ID. The results from the multiple regression analysis indicate that category of intellectual disability as well as social comparison strategies influences self-perceptions such as perception of global self-worth and perception of physical appearance. In short this finding suggests that those with milder learning disabilities are at risk by virtue of their disability but also as a consequence of their ability to do social comparison. We know from social comparison theory that individuals compare themselves socially to determine their status (Dagnan & Sandhu 199; Dagnan & Waring
2004; Link & Phelan 2006) and the ability to do this comparison means that mildly impaired individuals understand and internalize to some degree their relative status position. Current practice in schools focuses on categorizing pupils into broad category of special educational need (SEN), such as intellectually disabled, and this broad categorization influences school placement. There is little or no discussion about the type or degree of intellectual disability and how this may influence the individual student’s experience of segregated education.

Gender was found to be a significant factor in this study. Males reported more positive social comparisons with others than females and females reported a greater experience of stigma. This suggests a greater vulnerability of females to stigma experiences, which is consistent with research that has found that girls will perceive discrimination more frequently than boys, (Brown & Bigler 2005). Research has found that females in low status groups are more at risk for developing low self esteem, (Munford 1994; Moradi & Subich 2003). McDonald et al (2007) in a study on gender and ethnicity found that having a learning disability exacerbates negative gender outcomes. It would suggest that females with ID are experiencing the psychological effects of a double minority status.

Conclusion

Overall these findings support previous research, which has found that individuals who experience stigma do not always have a poor sense of self worth (Crabtree & Rutland 2001, Heath & Ross 2000). However the difference in the reported experiences of the
moderate ID group (positive social comparisons with others in school) and the borderline group (positive global self-worth and perception of physical appearance) suggests that the mechanisms for dealing with stigma are complex in those affected by ID and merit further study. It is possible that the students in the borderline group have a greater awareness of their low social status and are thus more proactive in engaging in strategies to enhance positive self-evaluations whereas the students in the moderate group may have insufficiently developed cognitive capacity to do so. A longitudinal study could establish if students use socially creative strategies to deal with stigma.

Young people with ID are not passive in their response to their educational setting or label. It is likely that they engage in socially creative comparison strategies to protect their sense of self. However the heterogeneity of the group Intellectual Disabled means that some individuals are more vulnerable than others to the negative effects of discrimination such as females. Social comparison has been found to have a self-protective function but if the experience of stigma and/or cognitive function impedes the utilization of such self-protective strategies then it is vital that additional supports are put in place for these vulnerable young people. Additionally the responses of those with moderate ID, suggests that the developmental trajectory of each individual should be considered. Possessing a stigmatized identity does not meant that the stigma status is central an individuals self-concept, there is a lot of individual variation in response to stigmatized identity (Quinn & Chaudoir 2009). Individuals with ID are not a homogenous population and functional and
cognitive limitations vary and a more nuanced and individual approach to education and socialization may have a more lasting impact than a one size fits all approach.

Limitations and future research

The present study had a number of limitations. The sample size (n=54) is comparable to other studies (Werner 2012) with an ID population however greater numbers would have supported a more fine-grained analysis of the data. The visibility of stigma may influence how stigma is experienced e.g. Downs Syndrome (Goffman 1963, Cunnigham & Glenn 2004) but this was not investigated due to sample size. The social comparison procedure used presents some limitations, as it is impossible to know, if the participants compared themselves with a specific person or general group of people, (Paterson 2012). However the measure has been used successfully with an ID population (Dagan & Sandhu 1999, Dagan & Waring 2004). Nevertheless the choice of instruments to measure concepts in an ID population is limited (Werner 2012). The developing social identity of adolescents is heavily influenced by social group membership and extending our understanding of what membership of an intellectually disabled or special school group means for young people is critical to inform both policy and practice. Future research directions could include longitudinal studies of young people with ID as they move through the special school system, additionally gathering data from parents and teachers would be helpful in building a comprehensive picture of the social experiences of young people with ID.
Chapter 3

Changes In Domain Specific Self-Perception Amongst Young People With Intellectual Disability: A Longitudinal Study
Abstract

This study examines the changes that occur in multi dimensional self-concept of adolescents with a diagnosis of intellectual disabilities, across gender and category of intellectual disability (borderline, mild, moderate), groups. A sample of 54 young people completed the Harter Self-Perception Profile. Using a three-wave longitudinal study conducted during their first year in a segregated special second-level school, stability and change in multiple domains of self-perception were examined. Findings indicate that gender and level of cognitive function are important variables in changes in self-perception across time, highlighting the heterogeneous nature of the special school population.

Keywords: Intellectual disabilities, self-perception, gender, special school,

Inclusion for students with special educational needs including intellectual disabilities (ID) is an increasingly common trend globally and nationally (UNESCO 1994; Banks & McCoy 2011). This move to ‘mainstreaming’ is driven by a greater acceptance of the social model of disability which views disability as socially constructed and draws attention to the physical and social barriers in society (Rapley 2004). In Ireland inclusive education has been generally successful at primary level and overall numbers of students in segregated special schools are decreasing (McConkey et al 2015; Kelly & Devitt 2010). However, the
profile of students attending special schools is changing. A greater proportion of secondary school aged students are now in special schools (McConkey et al. 2015), some studies indicate that over 60% of students in special schools are aged 12+, (Kelly & Devitt 2010). This may be in part driven by a need to access specialist resources and teaching which are often available in special schools and it may be that mainstream secondary schools are less equipped to deal individual needs of students. McConkey et al (2015) in a review of current education provision for students with intellectual disabilities notes that the proportion of girls in special schools is increasing although no explanation for this phenomenon is available. The transition experience from primary school to secondary school for typically developing (TD) young people is well documented (Topping 2011; Smyth, McCoy & Darmody 2004) but the transition experiences for pupils with ID is less well understood (Barnes-Holmes et al 2013) and the transition experience for young people with ID moving to a segregated special school for the first time at second level is wholly under researched. Extending our understanding of the experience of young people with ID at this critical phase in their lifespan is a central aim of this study.

Transition to secondary school is a complex and challenging time for typically developing young people: fears about bullying, making friends and new teachers are combined with the excitement of new possibilities for responsibility and independence (Topping 2011; Hargreaves & Galton 2002). Most students settle well into their first year in secondary school (Topping 2011) but some groups are more vulnerable than others, and
there is potential for the transition and the new environment to affect young peoples sense of themselves (Muldoon 2000).

Eccles (2004) proposes a model called Stage Environment Fit and argue that a mismatch between the needs of the young person and their school context can explain many of the challenges of adolescence. Symonds and Galton (2014) reviewed over 100 transition studies and hypothesize that individuals are influenced by individual school environment. They point to the changes in school transport, changes in staff and peer relationships and expectations of autonomy as factors. The environmental changes that occur at transition such as larger physical space, less teacher-student interaction and shifts in social support networks influences students perception of their self competence and motivation (Zanobini & Usai 2002).

Transition to secondary school is a ‘normative’ change and the factors, which help and hinder this process, are well documented. However transfer to a segregated special school at second level is an atypical experience. Not every student with a diagnosis of ID transfers to a special school, as places are limited in these schools. A recent study (Rose et al 2015) notes that special schools in Ireland tend to be located in large urban areas meaning that many pupils have long distances to travel to attend secondary school. Thus the transition experience for some young people with ID is further complicated by a profound shift in social context into a segregated education setting outside of their community. Gender would also appear to be a factor. Girls are more vulnerable to negative
outcomes in the areas of self-esteem and friendship than boys during the transition and transfer period, (Anderson et al 2000). Gender differences are consistently found amongst young people in secondary school settings and often these differences are related to domain specific competencies e.g. transition to second level appears to have a positive effect on the performance of boys in maths and science, (McGee et al 2003). In short, transition from primary to secondary school is a critical event in adolescent development and successful transition is important for psychosocial well being (Hughes, Banks & Terras 2013). It is important that research clarifies and extends our understanding of how young people, both boys and girls, with intellectual disabilities experience this transition.

The context of a special school can be considered more nurturing and responsive to the needs of students with disabilities during their first year (Hughes, Banks, & Terras 2013), although this may be a function of high staff/student ratios rather than something unique to special schools. Norwich and Kelly (2004) and Crabtree and Rutland (2001) compared students in mainstream and special settings and found that overall students who attend special schools had a more positive perception of academic ability and that general self-perception did not differ by placement. Arguably segregated education allows students to have the opportunity to engage in social comparison with similar ability peers thereby fostering academic self-competence. This position is supported by Djikstra et al (2008), they found that young people with intellectual disabilities reported feeling more competent in special schools where they could compare themselves with similar ability peers.
Conversely being identified with a stigmatized group by virtue of type of school attended is stressful and associated with poor self-concept, (McCullough, Muldoon & Dempster 2009). Buckley, McDonald and Byrne (2002) found that mainstream education had better outcomes for students with Downs Syndrome than their peers in a special school. Conley, Ghavami and Foulkes (2007) report that students in special schools have lower global self-esteem than peers in mainstream settings. In this way it remains unclear as to the impact of segregated settings on self-perceptions.

The complexity of the issue is likely related to the multi dimensional nature of self-concept, (Harter 1999; Marsh, Green & Martin 2007). Self-concept or how one perceives oneself overall and in specific areas is a multidimensional construct and domain specific evaluations occur when an individual evaluates their efficacy in different domains such as physical appearance or athletic competence. Much of the research that examines transition to secondary school for typically developing young people has identified varied patterns in domain specific self competencies such as bias towards athletic competence for boys (Tubic & Dordic 2015), bias towards literacy for girls (Pajares & Valiante 1999, Jacobs et al 2002) and both decline (Cantin & Boivin 2004) and increase across school transition (Proctor & Choi 1994) in the domain of global self-worth has been identified.

There is limited research on the factors that may influence multi dimensional self-concept young people with intellectual disabilities and it tends to focus on comparative
studies (Begley 1999; Crabtree & Rutland 2001; Gans, Kenny & Ghany 2003). The results are mixed. Szumski and Karwowski (2015) compared the academic self-concept of students with ID in mainstream and special settings and found that the academic self-concept of students in special schools is higher, suggesting that social comparison with similar ability peers is protective of academic self-concept. This finding echoes earlier studies (Crabtree & Rutland 2001, Norwich & Kelly 2004) that report that students attending special schools have a more positive perception of academic ability than their peers in mainstream settings. In contrast, Conley et al (2007) found that students in special schools have lower global self-worth than peers in mainstream settings and Buckley et al (2002) found that students with Downs syndrome in mainstream had more positive overall perceptions of education than their peers in special school. In a review of comparative studies (n= 41) between typically developing young people and young people with ID, Zeleke (2004) found that academic self-concept is more negative for students with ID but there is no significant difference between social self-concept and global self-concept scores for typically developing and ID children. Taken together the evidence appears to suggest that academic self-concept is protected in special education settings but the evidence for self-concept in the global and social domains is mixed. The lack of clarity would suggest that longitudinal research which examines self-concept trajectories, as a multi dimensional construct is needed.
There is also the question of the heterogeneous nature of students who are classified as having an intellectual disability; these young people are not homogeneous. We know that the type of disability one has can impact on school experience, McCoy, Banks and Shevlin (2012) found that students with intellectual disability are more likely to report that they like school less than their peers with physical disabilities. In addition to type of disability, the level of cognitive capacity or category of intellectual disabilities may also be a pertinent factor in increasing our understanding. Cunnigham and Glenn (2004) have argued that self-concept is in part influenced by cognitive capacity. Huck, Kemp and Carter (2003) investigated the self-concept of children (9-11 years) with ID in mainstream classes and found that overall they had a positive general self-concept but this decreased as age increased. They argue that cognitive capacity may be a factor suggesting that the more positive perception of their ability may be because they have not yet reached the developmental age to use their peers as a ‘frame of reference’, an effect seen in typically developing young people.

Gender and disability also interact to influence social experience. Coleman, Brunell and Haugen (2015) found that women with intellectual disability were the most negatively judged group comparing gender and physical disability and intellectual disability. This is consistent with the concept of intersectionality, which examines the intersection between multiple subordinate identities such as race and gender (Purdie-Vaughn & Eibach 2008), which appears to amplify disadvantage. Bjornsdottoir and Traustadottoir (2010) examined the intersection between disability, class and gender and found that disability interacts
with other social factors to perpetuate the exclusion of people with intellectual disability. This would suggest that young women with ID have the potential to be a particularly vulnerable group.

This study sets out to examine the specific impact of the transition into segregated secondary school on self-perception of boys and girls with differing levels of intellectual disabilities. We investigate how domain specific self-perceptions change over the course of one academic year for male and female young people with intellectual disabilities who attend a segregated special 2nd level school.

This study will:

- Examine the patterns of change and stability over time of domain specific self-perceptions
- Examine the influence of gender and category of intellectual disabilities on multiple domains of self-perception and global self worth.

Method

Design

This is a longitudinal study from the beginning of 1st year in secondary school to the end of 1st year in secondary school for young people with a diagnosis of Intellectual disability. Participants completed The Self Perception Profile for Learning Disabled
students (Harter & Renick 1988) at three time intervals during the school year, September, January and June. The measured independent variables are boys and girls and the category of intellectual disabilities (CID); moderate (IQ range 40-54, mild, IQ range 55-69, and borderline IQ range 70-79). The dependent variables are the scores across time on the various domains of self-perception.

Participants

The participants were 54 students (33 male, 21 female) attending three segregated special needs secondary schools located in the south of the Irish Republic. The participant ages ranged from 12 to 14 years (M=13.1, SD=.67). The schools are classified as schools for students with a primary diagnosis of General Learning Disability, (GLD) as assessed by a suitably qualified individual (Dept. of Education 2002). These schools cater for three categories of GLD, borderline mild general learning disability, (IQ range 70-79), mild general learning disability (IQ range 50-69) and moderate general learning disability (IQ range 35-49) (Carey 2005; Ware et al. 2009). The school populations are made up varying levels of cognitive capacity and classes are not streamed by ability or gender. The majority of the participants (76%) had previously attended mainstream primary school for 6 or more years. This is keeping with Irish Government policy of inclusion of pupils with special needs (Banks and McCoy 2011). Inclusion in this instance refers to the students with diagnosed intellectual disabilities being educated alongside their peers in mainstream schools. Inclusion at second level is not widespread in the Irish Republic and many pupils move from mainstream primary schools to segregated special schools at the beginning of
second level (Ware et al 2009). The parents of 65 students were invited to give consent and 54 (83%) accepted and 11 declined. No data were available regarding the characteristics of the 11 children whose parents refused except that they attended a special school. Participant characteristics are illustrated in Table 1. Attrition rates across the data collection period were minimal, T1 n=54, T2 n=52, T3 n=52 and were related to attendance issues.

Table 1
Participant Characteristics as a percentage of total cohort (N=54)

<table>
<thead>
<tr>
<th></th>
<th>Male % (N)</th>
<th>Female % (N)</th>
<th>Total % (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Intellectual Disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Borderline</td>
<td>40% (13)</td>
<td>14% (3)</td>
<td>30% (16)</td>
</tr>
<tr>
<td>Mild</td>
<td>42% (14)</td>
<td>48% (10)</td>
<td>44% (24)</td>
</tr>
<tr>
<td>Moderate</td>
<td>18% (6)</td>
<td>38% (8)</td>
<td>26% (14)</td>
</tr>
<tr>
<td></td>
<td>33</td>
<td>21</td>
<td>54</td>
</tr>
</tbody>
</table>
Table 2
Characteristics of participants with prior segregated experience (transfer mid or late primary to special school) N=13

<table>
<thead>
<tr>
<th>General Intellectual Disability</th>
<th>Male % (N)</th>
<th>Female % (N)</th>
<th>Total % (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borderline</td>
<td>37% (3)</td>
<td>0</td>
<td>24% (3)</td>
</tr>
<tr>
<td>Mild</td>
<td>62% (5)</td>
<td>60% (3)</td>
<td>62% (8)</td>
</tr>
<tr>
<td>Moderate</td>
<td>0</td>
<td>40% (2)</td>
<td>15% (2)</td>
</tr>
</tbody>
</table>

8
5
13

Measures

Domains of self-competence were measured using The Self Perception Profile for Learning Disabled students (Harter & Renick 1988). This is a 46 item self-report measure that assesses domain specific and global perceived competence. This measure has been used successfully in special school settings and with adolescents with ID, (Crabtree & Rutland 2001). On this occasion self-perception was measured in nine domain specific areas, general intellectual ability, reading competence, writing competence, spelling competence, math competence, social acceptance, athletic competence, physical appearance, behavior and in one global area, global self-worth. The administration and scoring procedure followed that outlined by the authors (Harter & Renick 1988). For each item participants are asked to select which of two statements is most true for them. For
example, one item states: “Some kids are sure they are pretty smart in school BUT other kids are not so sure they are all that smart in school”. The participant then decides by ticking a box whether the selected item is “really true” or “sort of true” for them. The response to each item was scored from 1 to 4. Reliability across the three time periods ranged from; T1 $\alpha= .46$ (General ability) to $\alpha= .71$ (Maths competence), T2 $\alpha= .59$ (Global Self Worth) to $\alpha= .84$ (Maths Competence) and T3 $\alpha= .45$ (Athletic Ability) to $\alpha= .79$ (behavior).

Procedure

Ethical approval was granted in accordance with University of Limerick research guidelines and ethical approval was granted by the Research Ethics Committee of the Intellectual Disability services provider involved in the management of the schools participating. Participants were recruited by way of letter of invitation to the parents of first year students in each school and parental/guardian consent was obtained on an opt-out basis, whereby parents/guardians returned forms only if they did not wish their child to take part in the study. Consent to contact the parents was obtained from the Principals and Governing bodies of each school. Participation was voluntary and verbal consent was obtained from the students at each data collection time period, the participants were not given reward or incentive to take part in the study.

The researcher liaised with the teachers and principal in each school to ascertain when data collection would cause the least disruption to school schedules. Questionnaires were completed with each child individually in an empty meeting room in each school.
Each participant (N = 54) completed a series of pen and paper self-report measures with the support of the first author. The measures were read aloud to each student and student’s comprehension was periodically checked during the session and they were assured of confidentiality throughout. The duration of each session was between 30 and 45 minutes.

Results

Statistical Analysis

The changes in the self-perception profile, in each domain from Time 1 to Time 3 and the influence of Gender (male, female) and category of intellectual disabilities (CID) were examined using repeated measures MANOVAs. The categories are borderline, mild and moderate. Preliminary assumption testing was conducted to check for normality, univariate and multivariate outliers, homogeneity of variance matrices and mulitcollinearity. Post hoc tests were performed as follow up tests on all significant interactions to determine the group means. Regression analyses were conducted to assess the influence of gender and category of intellectual disabilities on the domain of Global Self worth.

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2 Non-parametric tests were run to examine if previous school attended was a significant variable. The results were not significant.
Group differences in self-perception profiles

A repeated measures MANOVA was conducted to assess the impact of between subjects variables, gender (male, female) and category of intellectual disabilities (borderline, mild, moderate) on within subjects variables, participants scores on ten domains of Self-Perception across the three time points (T1, T2, T3). Cell sizes of the within subjects factors were deemed appropriate for parametric testing. The MANOVA indicated a four way interaction (time x gender x CLD x domain score) effect, $F(36,16)=3.095, p=.009$. This finding indicates that the variables of time, gender and category of intellectual disability are influencing self perception in multiple domains. To explore this finding in more detail the effects of time, gender and CID were examined again using follow up ANOVAs for each domain of self-perception separately.

Writing Competence. The mean writing competence scores at Times 1, 2 and 3 were (M=10.56, SD=2.13), (M=11.04, SD=2.48) and (M=10.00, SD=2.55) respectively. A within participants interaction was identified relating to the influence of gender on perception of writing competence, $F(1.66,58.24)=7.36, p=.003, \eta_p^2 =.17$. Post hoc analysis using simple effects found significant differences for females across time, $F(1.4, 23.98) =9.11, p=002, \eta_p^2 =.36$. Female scores from Time 2 (M=11.11, SD 2.44) to Time 3 (M=9.11, SD 2.57), $p =.001$ decreased significantly and from Time 1 (11.17, SD 2.03) to Time 3 (M=9.11, SD 2.57), $p=.01$. The results reveal that female participants show a significant decrease in perception of writing competence across time. No significant effects were observed for the males, $F(1.9, 44.06)= 1.69, p=.19, \eta_p^2 =.06.$, see figure 1. No other main effects were observed.
Spelling competence. The mean spelling competence scores across Times 1, 2 and 3 were $(M=10.80, SD=2.44)$, $(M=11.24, SD=2.86)$ and $(M=10.46, SD=3.13)$ respectively. A within participants interaction was identified relating to the influence of gender on the perception of spelling competence $F(2,34)=3.31, p=.04, \eta^2_p = .16$, across time. Post hoc analysis using simple effects found significant differences for females across time, $F(2,15)=4.00, p=.04, \eta^2_p = .34$. Females perception of spelling competence decreased significantly from Time 2 $(M=10.41, SD= 2.95)$ to Time 3 $(M=8.94, SD =2.88)$, $p=.05$. The effect from Time1 $(M=10.82, SD 2.37)$ to Time 2 $(M=10.41, SD 2.95)$ approaches significance, $p=.09$. The results indicate that female participants report a decrease in perception of spelling competence across time. No significant effects were observed for males, $F(2,22)=1.91, p.17, \eta^2_p = .14$, see figure 2. No other main effects were observed.
Figure 2. *Mean scores for perception of spelling competence for male and female. Error bars denote one standard error around the mean*

Physical appearance. The mean physical appearance scores at times 1, 2 and 3 were \((M=13.84, SD=2.15)\), \((M=15.45, SD=2.61)\) and \((M=15.02, SD=2.72)\) respectively. Two main effects were observed. There was a significant within subjects main effect for time, \(F(1.45, 55.30) = 7.40, p=.004, \eta^2_{p} =.16\). Post hoc analysis using pairwise comparisons found a significant increase from Time 1 \((M=13.84, SE=.32)\) to Time 2 \((M=15.45, SE=.39)\), \(p=.001\) and from Time 1 to Time 3 \((M=15.02, SE=.41)\), \(p=.03\). The perception of Physical appearance increased across time from September to June. There was a significant between subjects main effect for CID, \(F(2,38) = 12.23, p=.000, \eta^2_{p} =.35\). The borderline group \((M=16.35, SE=.418)\) scored significantly higher than the mild \((M=13.98, SE=.395)\) and the moderate \((M=13.66, SE=.52)\) groups using Tukey HSD. Overall results indicate that perception of Physical appearance increases across time and the borderline group report the highest scores in perception of Physical appearance.
Global Self Worth. A significant main effect in relation to time was observed $F(2,36)=3.41, p=.04, \eta_p^2 = .15.$ in relation to global self-worth. The mean global self worth scores at times 1, 2 and 3 were $(M=13.86, SD= 2.06), (M=15.37, SD=2.85)$ and $(M=14.39, SD=2.60)$ respectively. Post hoc analysis using pairwise comparisons found a significant increase from Time 1 $(M=13.86, SD=2.06))$ to Time 2 $(M=15.37), p=.003,$ and a significant decrease from Time 2 $(M=15.37, SD =2.85),$ to Time 3 $(M=14.39, SD=2.60), p=.02.$ Time 1 to Time 3 did not differ significantly. The results reveal that perception of Global Self-worth increased from September to January and decreased from January to June. No other main effects were observed, however there is a between subjects main effect approaching significance for CID, $F(2,37)=2.52, p=.09, \eta_p^2 = .12.$ The borderline group scored the highest in perception of self-worth $(M=15.20),$ followed by the Mild $(M=14.25)$ and then the moderate group $(M=13.34).$

Social acceptance. There was a significant between participants interaction effect observed relating to the influence of gender and CID on social acceptance scores, $F (2,37) =6.79, p=.003, \eta_p^2 = .26.$ Post hoc analysis of this effect revealed that the Male borderline group $(M=15.16, SE .38)$ scored significantly higher than the Male moderate $(M=12.44, SE .76)$ group, $p=01.$ The results indicate that participants in the male borderline group report the highest scores in the domain of Social acceptance. The differences between the other
groups were not significant. There was no significant difference between the female groups.

Anovas were conducted to explore the impact of Gender and CID across time on the remaining subscales; general ability, reading, maths, behaviour, athletics and spelling. The results were not significant. Non-parametric tests (Friedman and Mann Whitney) were conducted to examine if difference between the participants prior school experience is an influencing factor. The results were not significant.

The influence of gender and category of intellectual disabilities on Global Self worth

Regression analyses were undertaken to assess the ability of Gender and CID to predict Global Self worth at Time 2 after controlling for scores at Time 1. Multiple regression is useful for providing information about the relative contribution of each of the predictor variables to one outcome, in this case Global Self-Worth. Global Self Worth Time 1 was entered at step 1, explaining 4% of the variance in Global Self-Worth at Time 2. After the entry of Gender and CID at step 2 the total variance explained by the model is 18%, $R^2 = .18$, $F (3,46)=3.34$, $p=.02$. In the final model only one measure, CID, is statistically significant, (beta=.30, p<.04). This finding suggests the category of intellectual disabilities influences perception of Global Self-Worth.

Regression analyses were undertaken to assess the ability of Gender and CID to predict Global Self worth at Time 3 after controlling for scores at Time 1 and Time 2. Global Self-Worth Time 1 was entered at step 1, explaining 24% of the variance in Global Self worth at
Time 3. After the entry of Gender and CID at step 2, the total variance explained by the model is 28%, $R^2=.29$, $F(4,38)=3.62$, $p=.01$. In the final model only one measure is statistically significant, Global self worth Time 2, (beta=.45, $p=.006$). This suggests that the perception of Global Self-Worth at the mid point of the year influences perception of Global Self worth at the end of the year.

Table 3. Regression Analysis Global Self Worth and Gender and CLD

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Time 2</th>
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<th>Time 3</th>
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</thead>
</table>
|                        | $\Delta R^2$ | $R^2$ | $\beta$ | $\Delta R^2$ | $R^2$ | $\beta$
| Step 1                 |         |       |       |         |       |       |
| Global Self worth T1   | .04    | .04   |       |        |       |       |
| Step 2 Gender and CLD  | .12    | .18   | .30*  |        |       |       |
| Step 1                 |         |       |       |         |       |       |
| Global Self Worth T1   |        |       |       |        |       |       |
| Global Self Worth T2   | .25    | .25   | .45** |        |       |       |
| Step 2 Gender and CLD  | -.03   | .24   |       |        |       |       |

• $p=.05$, ** $p=.01$
Discussion

One of the aims of this study was to examine the influence of gender and category of intellectual disabilities on the domains of self-perception. Our analyses indicate that female perception of writing and spelling competencies decrease over time from September to June. The results show that young males in the group of borderline ID scored higher in the perception of social acceptance than their peers in the mild ID and moderate ID groups. The findings with regard to female perceptions of writing and spelling competencies are unexpected because although gender differences favouring males are consistently found (Muldoon & Trew 2000), the domains in which the differences are found unexpected.

Writing and spelling are usually viewed as female domains. Previous research has found that literacy domains tend to favour girls (Pajares & Valiante 1999; Jacobs et al 2002). It is possible that the negative effects on self concept of transitioning and attending a special school (Conley et al 2007) are seen here but in specific domains. Research has found that young people with intellectual disabilities attribute less importance to academic domains such as writing and spelling (Nader-Grosbois 2014; Harter 1999). Crabtree and Rutland (2001) in a study comparing adolescents with and without learning disabilities found that students with learning disabilities devalued academic domains of self-perception and placed a higher importance on non-academic areas such as physical appearance and athletic competence. The negative trajectory for writing and spelling for girls in this sample could reflect a strategic devaluation of academic domains by the girls and although
previous studies have not found a gendered strategic devaluation of academic domains this may be due to an overlooking of gendered responses in research to date. Individuals with intellectual disabilities are viewed as people with ID first, and other identities such as gender and ethnicity are often not considered (Bjornsdottoir & Traustatoddoir 2010; Barron 2002).

Data indicate that category of intellectual disabilities effects self concept, the young males in the group of borderline ID scored higher in the perception of social acceptance than their peers in the mild ID and moderate ID groups. The borderline group also scored higher in perception of physical appearance than the mild and moderate groups. This is an unexpected finding as previous research would suggest that the ‘weaker’ groups would be more likely to be positive about themselves in terms of social acceptance and physical appearance as they less likely to have the capacity to engage in realistic social comparison with peers (Begley 1999; Huck et al 2010). Begley (1999) found that individuals with a delayed developmental trajectory tended be very positive about themselves. However it is possible that this result means the borderline group and males in particular are benefitting from segregated settings as they can evaluate themselfe in relation to similar ability peers (Festinger 1954) which is protective of their self concept. The gender difference may suggest that girls are less willing or less able to evaluate themselves positively in the domain of social acceptance. Muldoon and Trew (2000) found that gendered identities have an adverse effect on girls and this is of particular concern for female students with ID.

One of the ways in which transition to secondary school can be made easier is by
encouraging existing peer relationships from primary school (Topping 2011), girls in particular have been found to prefer primary school identified peer groups (Hargreaves & Galton 2002; Smyth et al 2004). This raises questions about the lack of protective factors for girls with ID who are moving from mainstream primary (with a familiar peer group) to a segregated secondary school (unfamiliar peers). The intersectionality perspective highlights the cumulative vulnerability of having a double minority status. Purdie-Vaughan and Eibach (2008) hypothesizes that women with multiple subordinate identities e.g. female ethnic minority, become ‘invisible’. This is particularly concerning in light of recent research which shows that the number of females attending special schools is increasing (McConkey et al 2015).

A second aim of this study was to investigate stability and change in domain specific self-perceptions in young people with a diagnosis of Intellectual disability across one academic year. The pattern in the domain of Global self-worth is one of initial increase from September to January and then decrease as the year progresses and the pattern in the domain of perception of Physical appearance indicates a steady increase but this is most pronounced from September to January. The data indicates that in the domain of Global self-worth there is a significant increase from September to January and a significant decrease from January to June. The regression analysis found that at Time 2 January, Global self-worth is significantly predicted by CID although the influence of both gender and CID account for 14% of the variance in scores at Time 2. At Time 3, June Global self-worth was
significantly predicted by scores at Time 2, accounting for 25% of the variance in scores at Time 3.

Segregated schools create a social context which augments the evaluation of self with peers of similar ability. Ninot, Bild and Delignieries (2005) examined integrated and segregated physical education and found that in segregated settings adolescents with ID tended to overestimate their athletic competence. It is possible that initial increase in Global self-worth is linked to social comparison with similar peers and the decrease from January to June reflects a growing awareness of low status of a special school. The significant prediction of global self-worth by the category of intellectual disabilities supports this.

In the domain of Physical appearance there is an increase across time from September to June and particularly from September to January. There is a slight but non significant decrease from January to June. This is partially similar to findings by Cantin & Boivin (2004) in typically developing population who found that domain of social acceptance increased over time but most rapidly during the initial transition period. Muldoon and Trew (2000) found that the perception of physical appearance is a key variable in the successful adjustment from childhood to adolescence in a standard school population. Physical appearance and social acceptance were also significant predictors of global self-worth for adolescents with ID (Kloomok & Cosden1994).

Before considering the implications of these findings it is important to acknowledge the study limitations. The strengths of the current study include; longitudinal data, standardized measures and appropriate statistical analyses. The limitations include small
sample size, lack of comparison group of young people with intellectual disabilities in mainstream and lack of data from parents and teachers. The possible influence of previous school experience is a factor that would be worth exploring with a larger sample size and it would be useful if future research gathered data on prior school experience. Additional factors may influence changes in self-perception during this time period and were not addressed in this study. Future research could examine the contributions of parent views on special education and student teacher relationship in addition to exploring the influence of prior education experiences.

The implications of these findings are important as they highlight the heterogeneous nature of students attending special schools. Many studies examining the issues surrounding special schools and special educational needs focus only on the very broad category of special educational need (Cambra & Silvestre 2003) and the diversity within this category is not being examined closely. These findings are useful for professionals in applied settings as they are an evidence based reminder that the cohort of young people with intellectual disabilities are a diverse group and that factors such as gender and cognitive capacity do influence their self perceptions and consequently their self-concept. It is vital that special schools are encouraged to put in place structures that would help overcome gender and level of intellectual disability differences.

Targeted support, which involves parents, teachers and peers, would be helpful. The vulnerability of girls to transition effects suggests that girls in particular may benefit from
social support networks such as peer mentoring (Akos & Galassi, 2004, Wang & Eccles 2012).

Special schools in Ireland are administered as primary schools and consequently not all special school staff have access to in-service training aimed at second level. The provision of targeted in-service training aimed at supporting teachers to help students make a successful transition would be beneficial. It is important that schools recognize and understand the vulnerabilities of young people with intellectual disabilities prior to admission. Many mainstream school put in place transition and transfer programmes for students transferring from mainstream primary to mainstream secondary (Anderson et al 2000). A similar structured transition from mainstream school to special school may be beneficial.
Chapter 4

The construction of Intellectual Disability by parents and teachers
Abstract
This study examines how disability is constructed by significant adults in the lives of young people with a diagnosis of Intellectual Disability (ID). Specifically we are interested in how do parents and teachers construct ID in talk. We examine whether stigma is recreated or sustained within family and school settings by analyzing in focus group interviews thematically. Parents and school staff construct disability as negative, (Theme 1), emphasizing difference from the ‘norm’, which they claim drives social isolation (Theme 2). A lack of agency is also attributed to those with a diagnosis of ID in Theme 3. Discussion orients to how parents and teachers, see themselves as advocates for those with ID highlight, whilst at the same time whilst at the same time recreating pervasive and subtle distinctions between children with and without ID.

Keywords: Intellectual disability, Social construction, Stigma

Points of interest:
• Parents and teachers hold complex and contradictory views about disability
• Despite seeing themselves as advocates, parents and teachers can inadvertently disempower those affected by ID

The pervasive stigmatization of those with ID is evident in the talk of parents and teachers charged with their care
Introduction

A diagnosis of Intellectual Disability is not sought by the individual with ID, yet is a label that will mark the individual as different for a lifetime. Young people with disabilities experience impoverished social lives (Baker & Donelly 2001). Individuals with ID and their families experience both felt and enacted stigma, through social exclusion and prejudice (Ali et al 2012, Werner, Ditchman, Kosyluk & Jones 2013). Individuals with ID are afforded greater social distance and associated with more negative stereotypes than individuals with physical disabilities (Werner 2015). Parents of young people with ASD report both public stigma in the form of enacted (overt discrimination) and felt stigma (fear of rejection) (Gray 2002). However research in the field in limited, (Scior 2011, Werner 2015) and there is little evidence about how and whether stigma is applied to young people with the label of ID, either advertently or inadvertently by significant adults in their lives such as parents and teachers. This paper aims to fill this gap in the literature.

Background to the Study

Research has found that low status out groups such as individuals with ID elicit predictable reactions (Fiske Cuddy & Glick 2002, Phelan & Dovidio 2008), which are often negative. People evaluate others and their position in the social world along dimensions of warmth and competence (Fiske et al 2002). Individuals with ID are generally viewed as warm but incompetent leading to a position where individuals with ID can be constructed as worthy of pity. Whilst this is likely to reduce overt hostility towards those affected by ID, this type of stereotyping is likely to have important implications. The role of language in sustaining and creating
stigma is believed to be critically important. Language can empower or devalue and when language is used to create a social category-the disabled- it creates a low status category that minimizes individual differences and facilitates stereotyping (Dunn 2015 & 2010, Harpur 2012, Rapley 2004).

For many individuals the source of stigmatization is in the label of disability (Chen & Shu 2012, Phelan & Dovidio 2008), underscoring the power of language to delineate difference. For others the language of disability presents a dilemma; parents both resist and embrace the ID label (Russell & Norwich 2012, Lalvani 2015). Parents for example have been shown to use talk to construct multiple meanings of disability (Avdi, Griffin, & Brough 2010). Family is a powerful social influence on a young person’s social experiences (Baker & Donnelly 2001). Parents act as gatekeepers to information about disability and their understanding of disability influences how they present this information to their children (Cunnigham, Glenn & Fitzpatrick 2000, Resch, Mireles, Benz, Grenwelge, Peterson & Zhang 2010). Parents can unwittingly transmit messages about ability to children (Doren, Gau & Lindstrom 2012) and when to they orientate to difference and disability they inadvertently highlight a disabled identity.

In the same way, parental expectations can impact on children's academic achievement. A recent longitudinal study has found that parental expectations were a significant influence on academic outcomes for children with disabilities (McCoy et al 2016). Whether the parent views the young person as an active agent of their own lives or a passive agent in receipt of support also has very real consequences for outcomes for that young person. Academic achievement has been found to be influenced by a sense of agency and self-determination for young people with ID, (Erickson, Noonan, Zheng, Bruscow 2015). Renshaw & Choo (2014) found that a disabled identity was accomplished for students by the everyday talk of both parents and teachers. Again in
this way, teachers’ as well as parents’ talk can be seen as important to the educational and social experiences of young people affected by ID.

Significant people in the lives of young people provide a filter on the world. Teachers can inadvertently use language that highlights the powerful nature of the deficit model of disability (Lalvani 2013, Kang 2009). Indeed teacher’s talk about disability is heavily influenced by a deficit model of disability and they often view their students through a disabled lens (Lalvani 2013, Kang 2009). This paternalistic model of ‘helping’ students constructs students as objects of pity or charity, a construction that draws on the Fiske et al (2002) stereotype content model of warmth but low competence. Teacher attitudes to and relationships with students, are influenced by labels (Avramidis & Norwich 2010, Blacher, Howell, Littin, Reed & Languesa 2014), they use them to differentiate learning outcomes but they are also used to frame conversation about and expectations of the young person with the label. Whilst teachers do interrogate the dominant discourse around disability (Gallagher, Connor & Beth 2014, Norwich 2013), the deficit model remains a powerful framework for talking about disability for teachers (Lalvani 2015).

Present study

The aims of the present study are to examine the discourse around ID by special school staff and parents of young people with an ID diagnosis. The category of ID is not an objective reality but rather there is a social consensus about what is to be Intellectually Disabled. The language used to describe ID is contested and fluid. Although words such as ‘handicapped’ and ‘retarded’ have fallen out of favour, there is no reason to assume that their replacements, Intellectual Disability (USA) and Learning Disability (UK), (Schalock 2011), do not carry the same difficult connotations. (Corrigan
We argue that discourse around disability is an important focus of study because it can sustain and recreate stigma. As such we are also interested in the ways in which talk can be active in sustaining disempowering and exclusionary practices. The question we are concerned with interrogating here is: what are the discourses in family and school communities surrounding young people with a diagnosis of ID?

**Method**

*Participants*

Two facilitated discussion groups form the basis of this study. In the first, twelve parents (3 males, 9 females) from the target group of all parents of young people attending a segregated second level special school located in the Republic of Ireland, participated in a focus group. The young people all shared a primary diagnosis of general intellectual disability, the entry criteria to the school, in addition to more specific disorders. Focus groups were chosen as the method of investigation because focus groups are a useful method for exploring how points of view are constructed and expressed, (Barbour & Kitizinger 1998). In the second, staff of a segregated second level special school (N=30, 6 male, 24 female), were invited to participate in a World café style focus group. World Café is a form of enhanced focus group, which promotes the sharing of ideas through evolving rounds of discussion. It is useful method for facilitating large group discussion (Fullarton & Palermo 2008).

*Procedure*

Consent was obtained prior to the focus groups taking place. Ethical approval was obtained from the University of Limerick Ethics committee and the Ethics committee of the Disability services provider. On a pre-arranged day the parent focus group was conducted on the school premises, in a large meeting room. Participants were invited to sit around a table and an audio recorder was placed on the table to record the conversation and participants were asked to introduce themselves to aid
distinguishing individual voices from the tape however participants were reassured regarding their anonymity. The discussion was guided by an interview schedule (see Appendix A) and was orientated around themes such as: labels, diagnosis, difference and challenges. The focus group with parents lasted approximately 80 minutes.

On a day pre-arranged with school principal the World Café with the staff also took place on the school premises. The creation of a hospitable space is a critical feature of world café (Fouche & Light 2011) so light refreshments were provided. Participants were invited to sit in small groups at a series of tables and an audio recorder was placed on each table to record the conversation. Participants were reassured regarding their anonymity. The researcher explained the World café procedure to the participants. Discussion was orientated around themes; labels, difference and participation in community. Questions (See Appendix B) were written on tables, and a host participant remained at the table for the duration to anchor the discussion. Participants were free to move to tables in the order of their choice and duration was approximately two hours.

Analytic Strategy

The data were analyzed using theoretical deductive thematic analysis with a discursive orientation (Braun & Clark 2014). Thematic analysis is a flexible method, which facilitates a rich description of the data. It is flexible in that it is not tied to an epistemological framework and can be used within a constructionist framework, as it is here, where language is understood to construct and create meaning, (Braun & Clarke 2014). In this instance the approach focused on the participants’ construction of disability and how discourse can sustain and recreate stigma. These constructions are socially produced in talk, so a discursive approach, which focuses on the action orientation of talk was considered suitable. During the analysis particular attention was paid to language but not all the analytical tools specific to discourse analysis were used.
Thematic analysis lends itself to a rich description of the data set (Braun & Clarke 2006) and provides opportunity to interrogate the data at both surface (semantic) meaning as well the assumptions underpinning the discourse (latent). Analysis was carried out in six phases reading the data, coding, collating the codes into initial themes, reviewing the themes, defining the themes and writing the report. The digitally recorded discussions were taped and transcribed verbatim, by the first author, using an abridged form of Jeffersonian convention, (Jefferson, 2004) including identification of pauses greater than a second (.), overlapping talk ( ) and speaker emphasis, see Appendix for Glossary. In an iterative process the transcripts were read and each instance of talk was assigned a code in a systematic manner, which recorded those features of the data that were potentially relevant to the research question. These candidate themes were reviewed, defined and named. After this process extracts for subsequent analysis were identified. This led to a final set of 7 extracts, which the authors believe exemplify the core themes identified. An overarching theme of Difference was identified and this can be further subdivided into; (1) Being Different (2) Social Isolation as result of being Different and (3) Lack of agency.

Findings

Our research question is concerned with how disability is constructed in talk, by those individuals (parents and teachers), who are tasked the care and development of young people with ID. Theme 1, examines how difference is highlighted and the segregation of young people with ID is normalized. Theme 2 relates to the issue of social isolation arising from the segregation. Theme 3 examines how works to construct the young people as passive. Below, each theme is presented in turn and accompanied by exemplar extracts.
Theme one: Difference: categorizing Intellectual Disability as Other

In the first extract the parents are responding to a question about the time their child was diagnosed with an Intellectual disability.

Extract No 1: “they think they have a perfect child”

1. Parent 10: I think maybe that Downs syndrome has its advantages and disadvantages in that you know it does hit you from day 1 whereas a lot of other people they think they have a perfect child until year 1 or 2 or 3 or whatever I dunno (.) but maybe then they have time to get used to it, a gradual thing you know so am em I suppose and the other thing is you know with downs syndrome, that they that they (.) are you know they are easily identifiable

2. Parent 2: Yeah

3. Parent 1: Yes

4. Parent 10: You know there is no chance of cure,((smiling, group laughter)) or whatever and so you just accept I suppose really but I presume well

5. Parent 1: I suppose that most of us were kind of devastated by it at the time

6. Parent 2: I think that’s right, it was devastating at the time hits you all at once ....

Downs syndrome is characterized as a global categorization from the outset and the use of the verb ‘hit’, (line 2) is active and violent. Downs syndrome hit them from the outset of their journey as a parent, ‘from day 1”, (line 2). The image constructed is negative and shows the unwanted nature of the diagnosis, parental loss and disappointment. This disappointment is clear in a distinct othering of a child with a diagnosis of Downs Syndrome as not perfect, “they think they have a perfect child”, (line 3), the diagnosis underscores difference between them and other, presumably perfect children. This negative imagery is picked up in line 12, ‘most of us were kind of devastated”. The reference to ‘a lot of other people’, (line 3) works to draw all children with a diagnosis of ID into the ‘not perfect’ category, even if their parents are unaware of this in the early
years. The use of ‘they’ serves a dual purpose, individuals with Downs syndrome are constructed as a homogenous group ‘they’ with a visible marker of difference and also places distance between them and the family, the talk does not refer to ‘we’ or ‘us’ being easily identifiable but rather ‘they’, a distinct outgroup. The creation of social categories serves a function, creating in groups and out groups (Brewer & Brown 1998). The parents work together to co-construct a narrative of loss, repeating each others words and phrases, parents 10 and 2 echoing each other with “hit” and “devastated”. This repetition and echoing gives strength and legitimacy to their construction of the children as a group who have ‘no chance of cure’ (line 10) and are ‘easily identifiable”, (line 7) and are thus Different. These markers of difference are constructed as the disadvantage of Downs syndrome, (Lines 1-7). The opening statement invites us to consider both advantages and disadvantages, (line 1-2), with the advantage being presented first, and then the disadvantages. Downs syndrome is a life-long and visible disability, with ‘no chance of cure’, (line 10), a statement that implies that a ‘cure’ is desirable. This is another example of othering, the parent indirectly wishes their child to be cured. The visible nature of the disability is also constructed as disadvantage, indirectly implying that having an invisible disability may be more desirable. Goffman (1963) talks about ‘passing’, passing as normal is a form of impression management (Goffman 1963, Corrigan 2014) which allows the stigmatized individual to conceal their deviant characteristic. Parent 10 indicates that knowing about the disability from the outset is an advantage, (line 2-3). A common coping strategy for low status groups is to engage in upwards social comparison, (Dunn 2015). Here she positions herself as better off than the parents who find out later but is equivocal on this, wondering aloud if getting used to it (line 4-5) is an advantage.
In the next extract the parent is contributing to a conversational thread about challenges experienced by the young people with ID. The parents discuss the challenges experienced when attending mainstream school.

Extract No 2: “*I am happier that he is coming to a school where everybody is the same as him*”

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<tr>
<td>1.</td>
<td>Parent 1: <em>I think up to about 5th class its ok</em></td>
</tr>
<tr>
<td>2.</td>
<td>Parent 5: <em>yeah yeah 5th class yeah</em></td>
</tr>
<tr>
<td>3.</td>
<td>Parent 2: <em>yeah yeah yes its grand</em></td>
</tr>
<tr>
<td>4.</td>
<td>Parent 1: <em>my son went to mainstream school and he was grand but</em></td>
</tr>
<tr>
<td>5.</td>
<td>once the other kids get the idea that oh look he can’t do</td>
</tr>
<tr>
<td>6.</td>
<td><em>what I can do that’s when the trouble starts its like even</em></td>
</tr>
<tr>
<td>7.</td>
<td>when they are out on the street playing they are allowed to</td>
</tr>
<tr>
<td>8.</td>
<td><em>play with the other kids until then but at that stage (2) I am</em></td>
</tr>
<tr>
<td>9.</td>
<td><em>happier that he is coming to a school where everybody is</em></td>
</tr>
<tr>
<td>10.</td>
<td>the same as him</td>
</tr>
<tr>
<td>11.</td>
<td>Int <em>Mmmm</em></td>
</tr>
<tr>
<td>12.</td>
<td>Parent 1: <em>because I feel he can challenge himself better because he is</em></td>
</tr>
<tr>
<td>13.</td>
<td><em>competing with people who are like him</em></td>
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The speakers co construct a narrative which presents 5th class (age 9-10 years in Irish schools) as cut off point for mixing with peers in their own community. By setting a boundary, 5th class, the discourse suggests that the individual with ID is behaving outside the range of normal development, not keeping up with their peers. The problem of decreasing social interaction is located within the young person with ID, *"he can’t do what I can do’,* (Line 2). The difference between special school and mainstream school is again underscored by the explicit naming of mainstream school in Line 1, “*mainstream school*”. Rather than simply refer to school, the type of school is specified and the existence of one implies by extension that a school that is not mainstream is different. There is an interesting attempt to homogenize all people with ID as ‘the same’ in Lines 6-7, *“he is coming to a school where everyone is the same as him”*. This Othering of her son, as one of a homogenous group also contradicts earlier statements from this parent and other parents, which identify their children by differing diagnostic labels,
such as Downs Syndrome, Autism, ADHD and Learning Disability. Members of an in-group generally see members of an out-group as more homogenous that they actually are, so ‘everybody is the same as him’, (Line 10) places the emphasis on the disability category primarily and does not acknowledge the diversity of this social category. The group label is also used in line 7 where ‘they’ is used to describe young people with ID playing with their peers. The group label creates a ‘spoiled identity’ (Goffman 1963), the lack of ability and being different is central to the description of the young person, it is a pervasive categorization. Thus the talk works to construct the young person as different from his peers in mainstream but somehow the ‘same’ as every other young person in the special school. The assumptions underpinning this extract are grounded in the stereotyping of both the young person with ID, focusing on lack of competence, and stereotyping his peers as predatory, “when the trouble starts”, (line 6) and untrustworthy.

In the next extract from the staff focus group, the categorization of the young people as other or different focuses on visible difference.

Extract 3: “they have the ah shur God love us...

1. F11:   Well the Downs
2. F4:   I think the more able bodied their peers wouldn’t have any time for
3.   them like well those with a more visible disability like the Downs kids or you
4.   know the
5. F5:   They have the best of it really
6. F11:   They are treated kindly by people
7. F4:   Those with an obvious disability
8. F5:   They have the ah shur God love us (.) I think if you talk about their home
9.   community one would assume that their home community would know
10.   them but often they don’t know them
The speakers are contributing to a conversational thread about how the students from the school mix in their communities. The use of the term ‘the Downs’, (line 1) is a classic example of a feature of the stigma process where social labels create an ‘us’ and ‘them’, (Link & Phelan 2001). By describing a group of children who have a diagnosis of Downs Syndrome as ‘the Downs’, (lines 1 and 3), the speakers delineate difference, by implying they are Downs, a different type of person, rather than having Downs, a person with a syndrome. In creating a social category of ‘the Downs’ the speaker is defining the young people as the disability. Downs syndrome as a diagnostic label is a medical term which defines a chromosome disorder but individual experiences of Downs syndrome are varied, however by categorizing individuals with Downs syndrome as ‘the Downs’, the speaker is creating a classic homogenous outgroup. The discourse creates categories at two levels, there is the level of ‘the downs’ and also ‘able bodied’, (line 2), this also works to create a hierarchy within the category of disability, the visible nature of Downs Syndrome is worked up as something that earns sympathy and compassion, “they are treated kindly”, (line 6). Stereotypes of individuals with intellectual disability fall into a category of prejudice that is pity, a warmth but no respect, an assumption of incompetence and minimal agency (Cuddy, Fiske, et al 2009). There is also an implication that unless the disability is obvious, that sympathy and compassion is missing, “the more able bodied their peers wouldn’t have any time for them”, (line 2). Line 8 uses a phrase, ‘ah shur God love us’, which is used commonly to demonstrate compassion to individuals, in this instance it demonstrates a paternalism or benevolent stigma. This type of paternalism draws on stereotypical understandings of individuals with intellectual disability as incapable, (Corrigan & Watson 2002), which are collectively endorsed at a societal level.
Theme two: The Intellectual Disability category as Social

This theme continues the theme of difference but examines the ways in which a diagnosis has social consequences. Young people with ID are perceived to have trouble accessing opportunities to engage with peers in social or school activities in their local communities. The othering continues in both school and community settings. In this extract Parents 6 and 7 are a couple and there is overlapping speech between both parents as they work together to co-construct a narrative about their son. They are responding to a request to describe their child.

Extract 4: “socially wise he don’t go out”

1. Parent 6: well my son is John (1) is his name, he is 15 years of age
2. and eh he is in 2nd year and em (.) and he was in:: a few
3. different schools and (2) he was falling behind he’s got em add and
4. 5. Parent 7: [“autistic spectrum”]
6. Parent 6: oh the the autistic spectrum again you know, but em, he
7. weren’t a happy child in some of the schools he went to
8. Parent 7: [“he was but he knew he was different”]
9. Parent 6: and em you know like from the advice we got, we felt that
10. the longer he stayed in mainstream school (.) you know the
11. more he’d fall behind and he might get bullied and picked
12. on what have you (.) so (.) since he’s come here he’s-
13. Parent 7: ‘much happier in himself”
14. Parent 6: he’s much happier in himself you know but eh...
15. Parent 7: “socially wise he don’t go out”
16. Parent 6: no socially wise he don’t mix and he have no one in the
17. area cos the school is so far away, he have no friends in the
18. area

The talk here works to emphasize different through the use of multiple labels, “he’s got add”, (line 4) and “the autistic spectrum”, (line 5), and in line 8 the parent explicitly names his son as different, “he knew he was different”. We learn that their son is different because of academic failings, ‘he was falling behind”, (line 3) The parents take the position that a negative experience in mainstream school is inevitable, “he’d fall
behind and he might get bullied and picked on”, (lines 11-12) this extreme case formulation works to explain the choice of special school. The maximum quantity invoked (Pomerantz 1986) claims that mainstream school would have been damaging academically and socially. The parents engage in script formation to tell their story, they followed advice to send their son to special school, they talk of multiple school placements and diagnostic labels are used to underline their sons difference. Script formation (Edwards, 1994) is used to present a scenario as factual and alternative versions are rejected. There is explicit identification of school as mainstream, which creates a binary- special and mainstream. The special school is constructed as a distinctly different space and place. The talk works up a claim of incremental social isolation. Social isolation is named explicitly, “socially wise he don’t mix and he have no one” (line 13) yet this contradicts their claim that he is happy, ” he’s much happier in himself”(line 14). A restricted social life is a common in the adult ID population (Umb-Carlsson & Sonnader, 2005) and the parents talk about social isolation would seem to support this. There is a group consensus about social isolation, multiple voices echo their position. This group consensus forms part of fluent conversation with multiple overlaps. The special school can be thus viewed as place of inclusion and exclusion. The parents differentiate between happiness in school and lack of happiness outside of school, “much happier in himself”, (Line 13) and “he have no friends in the area”, (line 17). The parents construct a claim that they rejected mainstream school for their son to prevent social and academic failure for their son (line 11) however their description of the current school placement is also characterized by social isolation. The talk reveals that the parents consider or have chosen to consider happiness and social interaction in school as more important than outside of school. There are multiple claims of difference from peers in this extract, the young man is named as different through his diagnosis, he
is constructed as different by virtue of the multiple school placements and he is socially isolated within his own community.

In the next extract from the staff focus group the theme of difference from peers continues, with the staff discussing some of the challenges experienced when the young people try to get involved in their local communities.

Extract 5: “they find it hard to integrate into clubs”

1. M3: I suppose football helps but they find it hard to integrate into
2. clubs like even the good footballers that we have here like James he still
3. has to play on a special team, like he wouldn’t get onto the local team
4. F17: That’s wrong
5. ...
6. M2: But you also have the special Olympics
7. F14: But is that identifying them more as special like
8. M2: That it could be positive or negative
9. M3: Yeah yeah (.) like if they are trying to integrate into their
10. community as normal and then they are part of the special Olympics
11. that is different
12. F18: That is singling them out

The word ‘they’, (line 1) groups all the young people with ID into a homogenous group, additionally the language used ‘they find it’, (line 1) works to put the responsibility of integrating into a club onto the young person with ID and not the club. The young people are positioned as excluded and different within their communities, regardless of ability. This exclusion is experienced by ‘even the good footballers’, (Line 2) suggesting that paradoxically, ability, here talked about as football skills is not sufficient to overcome an intellectually disabled identity. This then is an example of the pervasive and global nature of the ‘spoiled identity’, that is Intellectual Disability. The phrase in ‘their community as normal’, (lines 9-10) works to highlight difference, by implying that
the person with ID is not normal. The Special Olympics is characterized as emphasizing difference, (lines 9-12) with the speaker offering an example of the dilemma faced by young people with ID in terms of community based recreational opportunity. On the one hand they can try to integrate into their local community ‘as normal’ (line 10) and on the other hand there is the Special Olympics which is positioned as not normal. The speakers take opposing positions about the Special Olympics, with M2 offering it as a solution to the problem of not getting on local teams, (line 6), but F18 argues that this differentiates even further, (line 12) and F14 suggesting that would identify them ‘more as special’. The construction of the word special here is in the form of a category that is different. Being different then has social consequences in that it restricts recreational opportunities even when the individual may have sufficient skills to compete with their peers.

Theme three: Lack of agency and passivity

In this theme we examine talk the highlights a lack of agency associated with ID. Things are are done to and for young people with ID. There is a contradiction evident here, as on one hand we have parents and staff frustrated with the othering and isolation of the young people yet they also engage in constructing young people in their charge as passive, outside the decision making process and as in need of protection from themselves.

In the next extract the parent is contributing to a conversational thread about the meaning of special needs.

Extract 6: “I have no name for what is wrong with John…”

1. Parent 1:  I have no name for what’s wrong with John only that he’s
got mild to moderate learning disability, he’s (.) I’ve never
been told he’s autistic (.) we started in the cerebral palsy, we
started him in the L______ centre and then we transferred
when he was three but all I’ve ever said to him is
that it takes you twice the length to get something done but
From the outset her son is constructed as having something ‘wrong’ with him. The use of ‘wrong’ to describe her son is negative, implies a flaw in his person and works to identify him as different. The pronoun “we” is used frequently, “we started him in the L___ centre”, (Line 4) suggests a lack of agency for John. We, the parents decide choose the schools, the centres, the age he will learn to drive. The listeners are told of decisions ‘we’, make about him. There is a passivity to her construction of John, his decisions are not his own to make, for example, “why don’t we wait until you’re 21”, (Line 8). This construction positions John having to wait until the parent is ready for him to learn to drive, John is doing the waiting rather than doing the driving. John is different from his brothers but he wishes to ‘do’ like his brothers, this is evidenced by the statement, ‘his brothers did’, (line 8). The parent uses humour, and indeed presents Johns driving ambitions as comical, “unless I had a crash helmet”, (line 13) The reference to need a ‘padded suit’ and ‘crash helmet’ is an example of extreme case formulation, used to work up an argument by introducing a maximum or minimum quantity (Pomerantz 1986). The notion of her son driving is dramatized to include an inevitable negative outcome and the group response of laugher legitimizes this position. The parent’s claims that he is not ready to achieve, indeed even attempt this developmentally appropriate task underscores the extent of his difference from his siblings. There is an inherent contradiction between positioning him as differently abled to his brothers, ‘he
doesn’t know left from right” (line 11,) and her position that she reassures him that he can achieve his goals, “you still get it done”, (lines 5-7).

In the next extract we examine again the contradictory positions and how in particular they appear in conversations around agency and autonomy. This parent is responding to a question about the language used about special needs.

Extract 7 “its derogatory I mean we all have our abilities and our disabilities”

1. Parent 9: as I say Mark thinks he is normal, that is the first thing anyway, we
2. never made () well special but special in a good way right
3. ...
4. Parent 9: so if you call a child handicapped or perhaps special needs
5. which covers a multitude handicapped to me would be like
6. a red bull (,), a red rag to a bull
7. Int: Mmm Ok in what sense
8. Parent 9: its derogatory I mean we all have our abilities and our
9. disabilities none of us (2) like I would always have Mark
10. never to be compared to anyone else the way we were
11. compared as children
12. Parent 5: yeah you weren’t as good as your sister or your cousins

This extract forms part of a conversation thread in which the parents discuss language and labeling, and it was an animated and free flowing moment in the conversation. The opening statement in this extract works up a description of the young person with ID as not normal, “thinks he is normal”, but rather special. By implication then being special is not normal nor is it necessarily a good thing, as the parent feels obliged to add the explanatory note of ‘special in a good way’, (line 2). He goes on to state his position, he objects strongly to his son being labeled (lines 1-3) handicapped although he acknowledges the term special needs, ‘covers a multitude”. The analogy he choose to use
is associated with anger and his anger is specifically directed at the word ‘handicapped’ but not at special needs, it is “derogatory”, (line 5). There is evidence of stigma resistance here and there is some interesting work going on in managing this dilemma, on one hand he objects to his child being assigned a negative label but on the other hand he accepts another type of label, although he does reframe it as ‘in a good way’. The socio-cultural context of the terms used is important, at one point in time the word handicapped would have been acceptable. However over time as it became associated with individuals with intellectual disability it became a pejorative term. In this parents estimation the word ‘special’ does not yet fully have the same negative connotations although his explaining of the word as ‘in a good way’ suggests that he is aware that special needs is itself becoming associated with a stigmatized group. The young person with ID is drawn into the group through the use of the phrase, ‘we all have our abilities and disabilities,” (lines 8-9), in this instance being different is not othered, it is part of ‘us’, (line 9). Interestingly he does not want his child compared with other children but the very act of describing him as ‘special’ marks him as different, this othering is by its very nature a comparison, he is special, and other children are normal. The emotive and negative aspect of being labeled is alluded to, “we were compared as children”, (line 11) and this is echoed by parent 5 at line 12. There is a clear contradiction in the position taken by Parent 9, he constructs his child as Other, an individual who is ‘special in a good way”, yet also objects to him being labeled describing it as derogatory.

Discussion

This analysis was concerned with exploring staff and parent talk to ascertain if stigmatizing discourse surrounded young people with ID. Our findings indicate that disability discourse amongst families and teachers of those affected with ID is very complex. Engaging in a process of categorization was evident in our data. Orientation to
ID as a deficit and the young people as objects of pity was also in evidence. Both parents and teachers are unwittingly complicit in reproducing a model of disability, which is a powerful and structural ‘ideology of deficit’, (Kang 2009), concerning intellectual disability. Parents and staff demonstrated contradictory positions about disability. This creates uncertainty about the place of disability, and facilitates legitimacy of the stigma surrounding ID. The complexity of parent and teacher talk about disability extends our knowledge about how disability is represented and framed in the lives of young people with ID.

There are contradictions and ambivalence around views of ID and school evident in the participants talk. Schools for those with ID are discursively constructed as both a place of inclusion and exclusion (Goodefellow 2012). Schools are social institutions and are thus integral parts of local communities, they are both a space for education and a place that young people go to. On one hand a special school is seen as a place where those affected by ID can socialize and be amongst similar ability peers. By the same token special schools act to exclude students with ID from the mainstream community of students. Schools are significant influence on the quality of social experiences. The physical barrier of geographical distance from others puts the young person with ID at a disadvantage (Baker & Donelly 2001). This exclusion from mainstream school and community is compounded by the fact the many parents report that their children with ID were excluded in mainstream schools during earlier years and are excluded in extracurricular activities because of their ID. Paradoxically, parents hope that segregated schooling might serve to counteract the problems of exclusion.

There is also evidence of contradictory positions amongst the staff around the access to recreational activities such as the Special Olympics. Opposing positions on the role of the Special Olympics are reflected in the literature. Storey (2004) argued that the Special Olympics sustains segregated sports practices and can lead to infantilization of
adults with ID. Conversely research with parents suggests that they find Special Olympics to be an important space for meaningful social interactions (Goodwin, Fitzpatrick, Thurmeier & Hall 2006). Conflicting opinions about ID have been found in research with service providers (Craig, Withers, Hatton & Limb 2002 and this uncertainty has implications for identity development for people with ID.

In constructing their competence as limited and thus justifying the protectiveness of parents and staff, the young person with ID is restricted from opportunities to learn from the trial and error of life, an opportunity routinely afforded to their siblings and peers. By focusing on what they can’t do the burden of proving their competence is placed on the young person, (Ollie et al 2012). Our data also suggested that young people are constructed as passive rather than agentic in situations where learning opportunities arise. The impact of this construction, as passive rather than active agents of their own learning, is likely to be undermining in family and school environments. Agency is facilitated when young people are afforded opportunities’ to make choices. As in the previous literature (Rapley 2004) the power asymmetry in favor of teachers and parents who themselves are influenced by a deficit model of disability appeared to reproduce and sustain the characterization of the person with ID as incompetent. When parents and teachers orientate to disability as a homogenizing characteristic they overlook other aspects of difference such as gender or personal interests which creates barriers for to pursue their own interests, (Ollie, Vehkakosi, Salantera 2012). Browne & Millar (2015) argue that the exercise of agency requires that the young person with ID is engaged in decisions about their lives in order to facilitate social inclusion. However our data shows that young people have decisions made for them rather than with them.

These findings are limited to the conditions of the study. The data were collected from a small sample size in a specific geographic location. The site of the data collection was a
school that had access to an urban transport network and specialist services, the experience of individuals living in a rural community may be different. This study focused solely on the experiences of parents whose children attended a segregated special school. A larger sample size would have permitted a comparative analysis between the views of parents who chose to send their child to mainstream and those who chose to send to their child to special school and may have yielded interesting results and is an area for further study. The participants shared a common experience of working and living with individuals with a primary diagnosis of mild intellectual disability and it is likely that the experience of living and working with individuals with moderate or severe intellectual disability would be different. The visibility of certain disorders such as Downs syndrome was evidenced in preliminary data analysis but we were unable to explore it further due to limited sample size and time constraints. This is an area that would be worthy of further exploration.

This study was conducted in Ireland where the promotion of inclusive education for young people with disabilities is government policy. Indeed the numbers of young people with disabilities attending special schools is decreasing overall (McConkey, Kelly, Craig & Shevlin 2016). However despite advances in inclusion at primary level (Banks, McCoy & Frawley 2017) the numbers of young people attending segregated schools at second level are increasing (McConkey et al 2016). This tension between successful inclusion in mainstream at primary level but not at secondary level is reflected in our data. Future research could explore why do parents make a choice to move from an inclusive setting to a segregated setting and to what extent are they supported and facilitated during the transitional phase between primary and secondary school.
In conclusion, it appears that the deeply embedded nature of the deficit model of disability is evident in parents and teachers talk around ID. This raises questions about teacher training both in-service and pre-service as well as educational supports for those parenting children with ID. Teachers and parents need to be assisted to understand the inadvertent messages thought everyday talk within their families, schools and communities. Talk reveals normative ways of thinking and therefore can create barriers for young people that others the vulnerable and denies them social and educational opportunities that all are minded and keen to deliver.
Discussion and Conclusions
Discussion

Summary of work

This thesis consists of three discrete empirical studies, which set out to answer 4 research questions. This discussion chapter is a reflection on the totality of the work presented. Each chapter will be briefly summarized, then the findings discussed with regard to the research questions. Additionally the findings will be placed in the context of the 'big picture', this section also speaks to the fourth research question, "How do we do ID". Finally there will be an account of scope and limitations and suggestions for future directions and policy and practice.

The introduction sets the scene for this thesis through a review of literature. Through identifying a gap in the literature this thesis sets out to raise awareness of and increase understanding about how PWID in special school settings experience stigma. The theoretical framework, the social identity approach, for this thesis is also outlined.

The cross sectional study presented in chapter 2 examined the data from N=54 students attending segregated special schools at second level. This study examines the role of the level of intellectual disability and gender on the perception of stigma in PWID. This study also examines how stigma impacts on self-perception and social comparison. The findings indicate that level of intellectual disability and gender influence experience of stigma and social comparison.

A longitudinal study builds on the cross sectional data and is presented in chapter 3. This paper focuses specifically on the changes that occur in multi dimensional self-perception over time. The findings support the earlier findings that gender and level of intellectual disability are key variables in the changes to self-perception over time.

The final paper takes a qualitative approach to examining data from parents and teachers. This paper examines, how parents and teachers, of PWID, construct disability.
The data supports the view that disability is viewed as negative, constructed as ‘other’, and drives social isolation. A lack of agency is also attributed to PWID. The findings invite us to consider the ways in which parents and teachers can find themselves in contradictory and complex positions with regard to PWID.

Research questions

Are young people with ID exposed to stigma in their family and communities?

The findings outlined in this thesis support the argument that students in a segregated setting are aware of the low status of special school and this has consequences in the domain of global self-worth for some students. The findings outlined in chapter 2 demonstrate that young people do experience stigma in both school and community but these experiences are impacted by the level of intellectual functioning, with those in the moderate category reporting the most positive social comparisons. This finding supports previous research, which has found that PWID do experience stigma but this experience is influenced by cognitive capacity, (Cunnigham & Glenn 2004). Crucially the experience of stigma is also impacted by gender as evidenced by the analysis presented in study 1 and study 2, with males reporting more positive social comparisons than females. This finding supports previous research, which finds that psychosocial variables such as gender and class interact to influence the development of self-concept (Barron 2002, Muldoon & Trew 2000). The results presented in the third paper, the focus group study also support the view that young people experience stigma in both family and community settings. This qualitative study examining the constructions of intellectual disability by parents and teachers found that disability is constructed as negative and a factor in driving social isolation. This finding supports previous research (Lalvani 2015, Mcoy et al 2016), which has found that parental expectations influence academic and social outcomes for PWID. This thesis presents new findings about the complexity of the mechanisms for dealing with stigma
amongst PWID. The variables of cognitive capacity and gender and how they interact to influence development of self-worth have not been examined to date and the influence of key stakeholders discourse around ID has also been under researched.

*Are young people with ID restricted in terms of opportunities to explore their identity?*

The findings outlined in this thesis indicate that key individuals in the lives of young people with ID, parents and teachers, can unwittingly restrict opportunity and diminish agency. The data demonstrates that individuals with ID are constructed as disabled, different from the norm, and placed in situations, which drive social isolation. Socialisation into the identity of being intellectually disabled is largely carried out by others and is imposed after a professional diagnosis. Orientating to the structural processes involved in the construction of ‘special’ requires us to examine the agency of those receiving the identity of ID and those requesting the diagnosis of ID. The findings presented in this thesis ask us to consider is the ID identity assumed or ascribed? If it is assumed by PWID how then can we support then in finding their collective voice? How can the teachers and parents empower PWID to engage in advocacy and support then in the exercise of agency? If the identity of ID is ascribed what are the consequences? Is there a cost to stigma? These questions are important for creating a roadmap of responses at the level of policy and also a suggested path for future research. The findings presented in chapter 4 support previous research which has found that parental understanding of disability influences how they present information to their children (Cunnigham et al 2000). The strong influence of the medical or deficit model in the structure of the education system is highlighted and the embedded nature of inequality is supported by previous research (Lalvani 2015). The data asks are parents and staff colluding with the consensus of deficit by working up a disabled identity for the young person?
How do young people with ID experience stigma in a segregated school?

The evidence outlined in this thesis support one critical point, that experience of stigma is varied and individual. The evidence invites us to consider both gender and level of intellectual functioning as impacting on adolescent students transitioning into special schools. The findings outlined in the longitudinal study demonstrate that males in the borderline group have greater perception of social acceptance than their peers in mild and moderate groups. In another gender specific finding, the data indicate that female perception of writing and spelling competencies decrease across time. In the cross sectional study the data demonstrates that both gender and level of intellectual functioning are significant factors in determining a young persons sense of self worth and physical appearance across time. The data outlined in the cross sectional study indicated that gender is variable in the experience of stigma with females reporting a greater experience of stigma.

Both gender and level of intellectual functioning as key variables are evidenced in the longitudinal study, where the data demonstrates that males in the borderline group report higher scores in the domain of social acceptance than the mild and moderate groups. Across time the borderline group also reported higher scores in the domain of physical appearance, a finding which echoed that of the cross sectional analysis presented in chapter 2. The longitudinal data presented is of critical importance as longitudinal data is lacking in the field of ID research, (Werner 2012). These findings support previous findings about domain specific self-perceptions in the mainstream population (Muldoon & Trew 2000, Tubic & Dordic 2015), and add to our knowledge base about the nature of domain specific self-perception in young people with ID.
How do we do ID?

The findings of this thesis asks questions about the structure and systems that privilege the diagnosis of ID over the individual needs of the person with the ID diagnosis. By framing disability as a social and political construction we can see that disability privileges ability, normal etc. The label of intellectual disability disempowers group members in a way that few other labels do. Due a dominant culture of individualism in western society we can underplay the role of group influence in our lives. If we orientate to structural factors we must look at impact of group identity. These findings contribute to debate in a number of key areas which will be explored below. Firstly the findings concerning gender bring attention the concept of the intersectional invisibility. Secondly the findings with regard to the differing experiences dependent on level of cognitive capacity shed light on the hierarchy of impairment. Thirdly this research supports the view that parents and teachers unwittingly and with the best of intentions restrict opportunity and diminish agency. It is critical to explore how this barrier may be lessened. Finally the resistant nature of stigma for individuals with ID and its implications for policy in terms of inclusive education and empowering advocacy are discussed.

Intersectional invisibility

The findings with regard to gender are particular interest in light of recent evidence that the number of girls in segregated special schools is increasing (McConkey et al 2015). Disability is a gendered issue (Fine & Asch 1988, Mohammed & Shefer 2015), and disability status can in many cases ‘eclipse’ other statuses (Fine & Ach 1988). Disabled women are more vulnerable to domestic violence (Thiara, Hague & Mullender 2011), are more vulnerable to sexual abuse (Szollos & McCabe 1995) and participate
less in education and employment (Hann & Ragovosky 1991). Women with ASD face barriers to social inclusion (Saxe 2017). Crenshaw (1989) proposed a theory of intersectionality, which argues that an individual who has several marginalized identities will have a different life experience to an individual with just one oppressed identity. The concept of intersectionality emphasizes that the axis of disadvantage e.g. female and disabled, do not occur independently but rather simultaneously. Disability intersects with other forms of social disadvantage (Liasidou 2013, Purdie-Vaughan & Eibach 2008), thus for women with ID who come from deprived socio economic backgrounds their disadvantage is compounded.

Ferri & Connor (2010) study notes that girls have to negotiate the stigma of disability in addition to economic disadvantage and sexism through using multiple social identities e.g. claiming to have behavior disorder rather than ID or denying the label in non-school settings. Whilst such actions lend support to Rapleys (2004) thesis that ID is an identity that is contested and ascribed it also underlines the work that goes into being a girl with ID. The findings presented in this thesis suggest that females have a greater vulnerability to stigma experiences. This is supported by research; a meta-analysis by Gentile et al (2009) found that girls are more vulnerable to the adverse effects of lower self-perceptions than boys. The lens of intersectionality highlights the flaws in an individualized deficit model. A girl with ID is not limited by merely one factor but the disability label intersects with other factors, which compounds adverse effects. This interplay between gender and disability and indeed class affects right to participation at many levels (Bjornsdottoir & Traustadottoir 20xx)

Research has found that people desire the most social distance from ID women suggesting that women with ID have to contend with sexism and ableism (Coleman et al 2014). Barron (2002) makes an interesting point when she points out that women with ID are at once invisible, not present in regular community, work etc. and visible but
'other', attending specialist services for work and recreation. So if we look at the female participants in this study, these girls (N= 21) are invisible to their communities as they are not present in their community, and identified as ‘different’ through accessing of specialist services. Many studies of young people with ID in school settings report no findings in relation to gender, the disabled girl is largely invisible, (Cooney et al 2006, Crabtree & Rutland 2001, Avramidis 2013) which highlights the substantive contribution of this research to the field.

Hierarchy of impairment

Within the SIA framework, prototypicality of group membership is important. This concept refers to how much an individual is typical of or shares with group members (Hogg et al 2004) Thus if a child feels that they ‘fit’ a special school type they are more likely to have a greater sense of belonging than if they believe themselves to be less typical of a special school group member, in this case they will have a lesser sense of belonging. People with ID tend to make lateral and downward social comparisons, viewing themselves the same or more favourably than other individuals who are perceived as less competent (Finlay & Lyons 2000). In an extensive review paper, Deal (2003) finds evidence for a hierarchy of impairment within the disabled community, which further perpetuates oppressive practices. Understanding why a hierarchy of impairment may exist would expand our knowledge about the degree to which PWID view themselves as a homogenous in group, in which they ‘fit’. Szivos-Bach (1993) findings support the notion of a hierarchy of stigma where one member of a disadvantaged group will derogate more disadvantaged member of the group. In this study it was the students with the greatest awareness of stigma reported feeling the most different. This supports the findings in chapter 2. Ironically the individual with
sufficient cognitive capacity to be aware of their difference can also be the one who can most successfully pass for ‘normal’.

The assumption embedded in the homogenization of services for PWID assumes that ID is a global delay across all aspects of cognitive functioning. However individuals and individual disorders have unique cognitive profiles. The data presented in this thesis highlights this critical point. By creating a simplistic category of ID the opportunity to tailor provision is lost as is the opportunity to empower advocacy. An extensive review by O’Mara, Conway et al (2012) supports this point, individuals with SEN and PWID are not a homogenous group and by grouping students together under this umbrella term it leads to inconsistent research findings and knowledge gaps. This thesis goes some way to remediating this. There is a tendency to view disability as a homogenous category yet even with the field of disability advocacy ID is stigmatized (Chappell 2001). It is important to recognize that within this category the varying levels of cognitive function present a challenge to understanding the existence of oppressive social practices (Dowse 2001). It is unclear if individuals with ID have difficulty conceptualizing their disability or have difficulty in articulating their understanding of their disability.

**Consequences of stigma through restricted opportunity**

Thomas (1999) refers to disability as a ‘barrier to being”, in which being different is constructed to be of lesser value. This barrier to being can also be a barrier to doing, as the costs of stigma include diminished social networks and barriers in terms of housing, education, employment etc. (Link & Phelan 2001, Corrigan 2014), thus the restrictions placed on individuals with ID are numerous but subtle. The young people who participated in this study are on the cusp of adolescence. A central task of adolescence is to increase autonomy from parents and peer relationships become more
important (Kroger 2007), however the nature of ID can complicate and delays this.

Parents can restrict social networks to protect their child, limiting contact to those who will understand him/her (Gray 2002), this type of passing could be understood as a form of benevolent stigma. Social psychological literature demonstrates that the application of a group label, in this case, ‘special’, is central to the stereotyping of that group by others (Tajfel & Turner 1979). The paternalistic discourse, which underpins the talk about ID by parents and teachers as outlined in chapter 3, is an example of the Stereotype Content Model (Fiske et al 2002) in which disabled people elicit disrespect because they are perceived to be high on dimensions of warmth but low on dimensions of competence. Compassion or benevolence is not helpful if it diminishes autonomy. Protecting someone from the risk of failure is not enabling but disabiling, indeed could be construed as infantilizing.

The young person with ID is an individual in a system, which is designed for groups. The homogeneity of the provision of services such as education does not match the heterogeneous nature of the population as evidenced in the findings of this thesis. Restricted opportunities also extend to the access to higher education. There are courses for PWID at third level and interestingly these courses have seen an increase in the numbers of younger people (20-25) taking this opportunity when they transition from mainstream education, in contrast older applicants tend to have attended special schools (Kubiak 2015). However in general PWID are under represented in higher education (Scanlon, Shevlin & McGuckian 2014), which raises questions about the reality of the educational choices afforded to PWID. Transition to post school services has been found to be a time of stress for parents who are tasked with negotiating this critical time (Gillan & Coughlan 2010). This is an example of parents taking on the task of advocacy for their children when the question remains, to what extent can PWID be empowered to advocate for themselves?
Another consequence of attending special school is a physical removal from the community in which one resides. A recognized trend for special schools admission in Ireland is increasing numbers of students transferring to a special school setting at post primary level (Ware et al. 2009, Kelly & Davitt 2010, McConkey et al. 2015). Whilst there is a lively debate about the merits of inclusive practices in schools (Banks & McCoy 2017, Ware et al. 2009), I argue that the debate is too narrow and focuses primarily on the academic outcomes for children. Parents orientate to the increased chance of academic success in special schools (Ware et al. 2009), and there is conflicting evidence about the merits of special schools in the area of social and emotional supports (Swan 2000, Kelly & Davitt 2010, McCoy & Banks 2012.) However the consequences of lack of visibility in their communities has not merited discussion to date. McConkey et al. (2015) comments on the lack of research into the regional variation of placement in special school or mainstream school and comments that in areas where the choice of special school does not exist, mainstream schools are the alternative. An examination of the intersection between these two variables would be helpful, is there a difference in the social inclusion in the local community of PWID who attend the local school or those who do not? An examination of the literature about young adults with ID identifies concerns about choice of living place, control over money and access to transport and building social connections (Abbot & McConkey 2006, Iriarte, O’Brien, McConkey et al. 2014, Leonard, Foley et al. 2016). PWID experience social isolation and social networks tend to be made up of families and professionals (Forresster Jones et al. 2000, Lippold & Burns 2009). Ideally socially inclusive practices would enable PWID to contribute to society and combats social exclusion (Simplican, Leader et al. 2015). A recent Irish study (Iriarte et al. 2014) of PWID concludes that they lack control over their lives and have limited opportunities for decision-making. The findings presented in chapter 4 in this thesis highlight this trend beginning at second level, a time of life when for most other
young people embracing decision-making is part of the normative adolescent development process.

Another area of restricted opportunity is that of research into the lived experience of individuals with ID. One of the consequences of benovolent stigma is that the overprotective nature of those tasked with caring for PWID can restrict access to the point that research is limited. Werner et al (2012) demonstrate a paucity of accurate measures of stigma in the ID field and call for further research in this area. They hypothesize that the limited research could be a result of the belief that PWID are protected from an awareness of stigma (Todd 2000). Certainly there are some obvious gaps in the literature, for example in an extensive meta-analysis of transition literature Symonds & Galton (2014) explicitly excludes all studies involving special needs children. Interestingly their study found that gender was a crucial variable in successful transition, this thesis extends that finding somewhat but clearly more research is warranted. In an extensive review paper of social comparison in the classroom (Dijkstra et al 2009) 125 papers were examined. Findings include that relevant variables for social comparison are race and gender but of the 125 papers examined only 9 refer to students with what they refer to as ‘academic handicap’, a useful example of the complexities of labeling. None of the 125 papers examined explored the intersection between ID and gender and social comparison. O’Mara, Conway et al (2012) specify that there is a knowledge gap in terms of how young people with SEN can be supported in the transition from primary to post primary settings. Brook et al (2014) conclude that the evidence base concerning PWID in terms of public health is inadequate. A recent paper (Rose & Shevlin 2017) argues that there is a need for longitudinal research about the lived experience of children with special educational needs in Irish schools. This thesis goes some way to extending our knowledge about the experiences of PWID.
**Consequences of stigma and institutional nature of stigma**

Normal is not a benign category it is a powerful construct that defines who is in and who is out (Gallagher, Conor & Ferri 2014). The data presented in chapter 4 supports the view that teachers are embedded in a deficit model of disability with its implicit stereotypical representations of PWID as incompetent and not normal. How can we ensure that at the very least teachers presume competence?

In order for teachers to combat the strongly embedded deficit model (Lalvani 2015) they must be taught about ablism and disablism. Purdy & McGuckian (2015) use the term disabilist bullying to highlight the interaction between bullying and SEN. In a study of NI trainee teachers they found little or no training in this area although the teachers were largely in agreement that this was something they wanted to learn. A recent study (Damiandiou & Phitiaku 2017) found that teacher attitudes to ID in particular were problematic, with evidence of stereotypes and prejudice. They suggest that teachers are specifically trained to view the person not the disability category. Given the narrow syllabi provided during initial teacher education (Darmody & Smyth 2016) it is not surprising that teachers adapt to the institutional mores. Even when studies examine how teachers deal with ‘other’ the othering of PWID is only briefly alluded to. In an interesting recent paper Kitching, O’Brien, Long, Conway, Murphy and Hall examine how student teachers respond to Other. There is an implicit assumption that ‘other’ is race and class and there is limited discussion about the other ‘Other’, of students with special needs. There is a valid point made also that just as it is unfair to assume homogeneity of students it is unfair to assume homogeneity of teachers. However there is scope for change, a 2014 (Tindall et al) study of Irish pre service physical education teachers, found that when teachers were exposed to a ‘lived’ experience of working with PWID there was a positive change in attitude. Conway et al
(2011) in a technical report to the NCSE recommends that in order for teachers to facilitate inclusive curriculum planning they must become aware of the impact of stereotyping students with SEN. Beijaard et al (2004) comments that context is an integral part of identity formation, schools are the teachers ‘landscape’, and teachers conform to the values associated with that landscape. Flores and Day (2006) refer to this aspect of identity construction as adaptive strategic compliance. New teachers adopt a strategy of been seen to be compliant with school expectations regardless of personal beliefs. Beijaard (2000) points out that school culture invariably encompasses the values and expectations of the whole community and as such determines the professional story of each teacher. Cohen (2008) found that the identity possibilities for teachers are limited by the normative beliefs and practices associated with teaching. In the context of special educational needs this suggests teachers are influenced by society’s expectations of and perceptions of special needs and disability.

Norwich and Kelly (2005) used the term dilemma of difference to describe the catch 22 of special schools, on the one hand there is the positives of the differentiated curriculum and similar ability peers and on the other hand there is lower status, stigma and social exclusion. There is an opportunity to encourage teachers to reflect on this concept and its consequences perhaps during initial teacher education. The support services tasked with providing CPD to teachers such as the NCSE school support service could also facilitate reflection on these issues.

Consequences of stigma and the resistant nature of Stigma

Outside the externally imposed group of special school, PWID are not a distinct group and thus lack the protection that could be offered by a collective identity. Stigma has a negative effect on psychological well being (Branscombe et al 1999) however unlike other low status identities e.g. race, Pwid do not draw on a collective group identity as positive resource to buffer negative effects of stigma.
The resistant nature of stigma is grounded in the diverse responses of PWID, resistance, rejection, acceptance, lack of understanding (Olin & Jonsson 2009), and also the complex and contradictory positions adopted by those charged with empowering and advocating. The broad all encompassing nature of the label ID is problematic because while it serves a purpose at societal level in terms of distribution of resources, facilitation of communication amongst professionals, it does not serve a positive purpose for the person labeled. Herein lies the core of the resistant nature of stigma and ID. Although being a member of a stigmatized group can have negative impacts (Major & O’Brien 2004), a strong social identity can be a source of collective strength (Branscombe et al 1999). Effectively ill treatment and the associated sense of injustice can be used as a powerful psychological resource to deal with adverse social and educational challenges (Muldoon & Downes 2007).

As noted earlier, PWID are perceived to be a coherent homogenous group. For many individuals with ID they identify more closely with their particular diagnostic category e.g. Downs syndrome which is more in keeping with the heterogeneous reality of the category. Consistent with this is the evidence that often PWID fail to actively define themselves as intellectually disabled as they don’t see it as salient or relevant to their everyday lives (Finlay & Lyons 2000, Todd 2000). For example Davies and Jenkins (1997) found that a large cohort of participants in their study of PWID showed a complete lack of application of the terms associated with ID such as ‘learning difficulties’ and ‘mental handicap’ to themselves. This could be viewed as lack of awareness about the ID label, they are ‘invisible to themselves’, (Todd & Shearn 1997). Alternatively it has been argued that the denial of category membership is evidence of strategic devaluing or denying of a low status identity and in this way is a form of self-protection. Both interpretations lead to a situation where PWID do not identify as PWID
and therefore reduce the collective power of the group. PWID can be viewed as uniquely disadvantaged because they cannot challenge the identity ascribed to them.

Coping with stigma is generally acknowledged to improve when one 'buys into' a group identity, which promotes a psychological sense of community (Major & O'Brien 2004). Group membership is a powerful determinant of psycho-social well being, it is an integral part of our social identity (we and us rather than me and i), provides social support, belonging and agency. A shared social identity is essential for collective action (Haslam 2004). Collective action such as advocacy is informed by shared values and category membership. However if PWID do not identify as a collective, this limits the potential for collective self–advocacy. One area to be considered is that collective movements can be difficulty to create and maintain amongst PWID due in part to the heterogeneous nature of the population but also due to their impoverished social networks, (Forresster-Jones 2000). Thus we can see here a link between the consequences of segregation and stigma at 2nd level, which impedes the development of social networks and can subsequently impede the development of a collective group identity as young adults.

Scope and Limitations.
The study was limited by time and resources factors. A comparative analysis between students with ID in mainstream settings and students in a special school was considered but would have made the project too large for its current purpose. It was intended to collect qualitative data from the students also to act as a counterpoint to the views expressed by parents and teachers. This would have added greater depth to the study and indicated where there was consistency and variance in the views held but there was not enough time to explore this fully.

In terms of locating the researcher in the research there was scope to engage in a more narrative inquiry. The reflective piece contained autho-ethnographic accounts of
the researchers experiences with disability. Preeze (2008) uses the term “parenthetical considerations” to refer to that contextual information that informed the research but did not form part of the research. These experiences allowed me to be informed but sufficiently detached. The visible and invisible nature of ID and consequent stigma were not explored but there was a trend in the data to suggest that this would be a fruitful area for further study.

Questionnaires designed for the general population are not appropriate for use with a population of individuals with ID, however there is a considerable gap in the literature of specifically designed self report measures (Finlay & Lyons 2001, Werner 2012). Additionally even with the cohort of PWID there are a sub groups of individuals with receptive and expressive language difficulties, cognitive capacity varies considerably and acquiesce bias or yea saying is acknowledged as a challenge when conducting research with PWID (Finlay & Lyons 2001), although the existence of such a bias is challenged by some e.g. Rapley 2004. Research has found that questionnaires can be an ineffective method of collecting data from individuals with ID (Ottmann & Crosbie 2013), although this same study advocated studies, which used multiple methods of data collection. Often the efficacy of self-report measures is judged based on an individual with ID completing the measure without any support. However the self-report measures used in this thesis were either designed or adapted for use with an ID population and as such recommended researcher support for the individual completing the questionnaire as well as other adaptations such as visual prompts. In keeping with strategies recommended in existing research (Finlay & Lyons 2001, Nind 2008, Hartley & McLean 2006) language was simple and concrete, choices were binary, visuals accompanied scales where possible and plenty time was allowed to complete the measures. From time to time the researcher used open-ended questions to elicit examples to check interviewee understanding. Silon & Harter (1985) argued that the
self concept of children with mild gld develop in similar manner to their typically developing peers but along a longer trajectory. The sample size was small and it is unclear to what extend the results can be generalized to a broader ID population especially as this population is diverse. It is quite telling about the relative neglect of this area of research that the Finlay and Lyons 2001 paper concludes that it may be impossible to design a robust and valid questionnaire for this population given the diversity of need. The world café style focus group is useful for facilitating meaningful collaboration and dialogue but the responses can lack the depth that one may find in other methods such as interview (McFarlane et al 2017).

**Future directions for research**

The label of ‘intellectual disability’ is objectively speaking neutral it is the stigma associated with it, therefore how do we reframe the term ID as an example of diversity? Schalock (2011) make an interesting case for redefining ID in a manner that is consistent with a multi dimensional view of intellectual functioning in contrast to ‘intelligence’, a somewhat arbitrary and unitary concept. Of course such a shift would require the elite professionals to design new methods of measurement. This focus on the professionals is also highlighted by Dunn and Andrews (2015) who recommend that psychologists enhance their cultural competence, through utilizing both person first (people with disabilities) and identity first (disabled people) language.

A recent paper by Heary & Hennessy & Swords & Corrigan (2017) proposes that stigma models developed in the mental health field may be effectively applied in the ID field, specifically they argue that theoretical frameworks developed for stereotypes and prejudice could guide future research. The specific developmental needs of young people (Kroger 2007) are different to that of adults, for example peer relationships are highly salient in adolescence and as such stigma related constructs may have different effects at different life stages. Werner et al (2013) conclude that not only is stigma an
issue of social justice for PWID but there is no systematic framework applied to the understanding of stigma for this group. One of the challenges in understanding stigma and ID is underlined in this thesis, that is the heterogeneity of ID, and whilst there is variation in the population with mental health issues, functional communication is largely possible.

The national research strategies of Department of Children and Youth Affairs (DCYA 2011) recognizes a substantial deficit in current knowledge about factors impacting on educational attainment of children with ID and early school leaving. The data presented in this thesis clearly evidences the importance of examining the variables of gender and level of cognitive capacity when planning the educational pathway for a young person with ID. The data raises questions about the some of the possible reasons why early school leaving may be an outcome for young people with ID, such as experience of stigma, awareness of the low status of special school, the varied and individual responses to special school. The DCYA (2011) also recommends that further investigation is needed to be better informed about children’s social support networks and participation in their community. The data presented in this thesis clearly demonstrates that young people with ID are restricted in terms of agency and opportunities to develop networks in their communities. The research also evidences the complex and contradictory positions about disability taken by those who are tasked with empowering and enabling these young people (parents and teachers). The research strategy of the National Council for Special Education (NCSE 2017) outlines states that its goal is to support schools in enabling students with SEN to achieve better outcomes, although this is not further specified. However the findings from this thesis would suggest that the outcomes examined need to be broader than academic attainments and include an examination of social networks, visibility in the community and exposure to ‘othering’ discourse. In a comprehensive review paper Vaughan and
colleagues (2011) concluded that school placement decisions for young people with disabilities should include variables such as social functioning as well as academic ability. Additionally they recommended that the decision should be informed by the students own opinions on which education context they would prefer.

Policy and practice implications

This thesis has implications for policy and practice in three main areas.

Firstly supporting parents in making informed choices about education. An advantage of special schools is access to specialist resources, and access to resources is not guaranteed in mainstream settings. Parents are made aware through first contact with the schools that the resources will have to be applied for and may or may not be granted (Griffin & Shevlin 2007). Recent changes (DES 2017) to a generalized allocation model for all additional needs in mainstream schools still puts the onus on the parents to draw attention to their child’s unique needs. This is the choice presented to parents if they are in geographical proximity to a special school. Olsson et al (2015) in a comparative study of students with SEN in special and mainstream schools found that students in mainstream schools were significantly less likely to access support service that students in special schools. This suggests that there is scope to educate families about the social services available in a more integrated way. If the government department tasked with managing the deployment of resources for education could utilize an existing service that makes regular contact with parents, for example the NCSE school support service, and use this empower and educate parents about school choice.

The factors that drive parents to choose one type of educational setting over another merit research. The question must be asked – are parents given choice or concession? Geographical proximity to the limited special school network in Ireland is one factor (McConkey et al 2015) and socio-economic status of the parents is also a
factor. Casey et al (2006) found that parents in the occupational groups A and B were significantly more likely to send children with SEN to mainstream rather than special schools. Support for parents in terms of information, communication and choice is inadequate (Rose et al 2010).

There is a lack of empirical studies about the efficacy or otherwise of inclusive practices (Hardiman et al 2009). One could argue that the agency of parents in making a school choice is restricted both in terms of information given to them about the short term and long term outcomes of their choice and also the lack of flexibility of inclusive options, for example dual enrollment, where a young person attends both a mainstream school and a special school, is rarely utilized despite recommendations for its use (Ware et al 2009).

Secondly, promoting the social inclusion of PWID by challenging stigma in the community. Stigma change is needed to promote the social inclusion of people with ID (Werner & Roth 2014, Jahoda & Markova 2004). In order to reduce the stigmatization of PWID it is essential that interventions that focus on changing societies attitudes are employed and not just focused on 'integration'. To date many attempts by care providers to integrate PWID into mainstream society have been for the most part informal local level initiatives aimed at educating and informing the public about PWID, these include workplace shadowing, open days, sibling support workshops etc. but research about the efficacy of these measures is limited (D'Arcy, Flynn, McCarthy et al 2005). As an intervention contact with out-group members is often viewed as a route to reducing prejudice, stereotypes and stigma. This is a view held in psychology since Allport (1954) proposed the contact hypothesis. A large body of research has focused on testing the contact hypothesis in various inter-group situations. Contact is seen as an important factor in improving attitudes towards PWID, finding ways in which to educate the general public about PWID is also an important aspect of tackling stigma.
Increasing the information available about the capability of PWID can improve attitudes, (McDonald and McIntyre, 1999). Given the trend toward community integration contact between PWID and their neighbors in a community has been the subject of a number of studies. Dijker, Alphen, Bos et al (2011) found that a complex picture emerges, with factors such as the severity of the ID and size of the group impacting on attitude change. They suggest that successful community integration may be improved by educational efforts in the community prior to contact occurring, as the anticipation of contact aroused more fear than actual contact. The question remains would the efficacy of these interventions with adults with ID be improved or diminished if young people had a more visible presence in their communities during second level schooling?

Social networks help protect mental and physical health (Jetten Haslam, Dingle & Jones 2014). Having diverse social networks is protective therefore how can policy makers ensure that marginalized groups (those most vulnerable to the negative effects of stigma) have access to wider social networks and encourage more social connectedness? If group membership can be used a social and psychological tool (Jetten et al 2014) then it is critical that policy makers consider the implication of imposing group membership on individuals. Social inclusion in community settings could be supported by access to sporting initiatives such as Unified sport, an initiative of the Special Olympics, which matches PWID with people without ID. Although the Special Olympics movement has been criticized (Storey 2014) there is some research to suggest that this initiative may support greater social inclusion (McConkey, Hasson 2012).

Thirdly, support PWID in engaging in advocacy. Involvement in self-advocacy has been shown to have positive benefits for PWID (Lundstrom 2008, Gray & Jackson 2002). Goodley (2000) found that effective advocacy can empower individuals with ID to step out of the passive role assigned to them by society. The contemporar
emphasis on user participation and person centred planning has emphasised the importance of dialogue with and offering choice to individuals with ID. However these interactions can be unbalanced (Jingree, Antaki 2006, Antaki, Young and Finlay 2002, Gilmartin 2009). In order for self-advocacy groups to overcome internalized oppression and challenge the stigma attached to ascribed labels, service providers, families and professionals have a responsibility to help identify the barriers to resistance such as slow pace of change in societal attitudes and the pervasive nature of the social oppression. A first step in the Irish context would be to ratify the UN convention on the Rights of persons with Disabilities, (at the time of writing this, March 2018, the Irish government had promised to do this). This would mean persons with disabilities; included PWID would be legally protected against discrimination.

Conclusion

The data demonstrates that a cohort of young people with ID can be viewed as homogenous by the systems and structures, which support them and in this way each member can become defined by their category of disability (Atkinson 2002). Thus the young people who participated in this study are defined as people with intellectual disability by parents, teachers and the education system. However the participants in this study varied in age, gender, cognitive functioning and also in their range of interests, experiences and family backgrounds as might be expected of any group of young people. What they share in common is attendance at a segregated special school, which is located outside of their community. This aspect of their lives, while it is only one aspect of their lives, does not define them any more than their disability defines them. However it is does have a significant influence on many aspects of their lives. The direct consequences of stigma are quantifiable e.g. restricted employment and housing and have been noted elsewhere (Corrigan 2014).
The SIA framework is a useful approach because it seeks to unpick the experience of the individual person when placed in the group ‘intellectually disabled’. This thesis highlights the loss of the individual to the group and questions the assumptions we make about capacity and competence.

The data demonstrates that the individual with ID becomes part of the group of people with ID. The concern of this thesis was to highlight the indirect consequences of ascribed group membership, a cost which, can only be examined by focusing, on the experiences of the marginalized group and those who claim to advocate on their behalf.

The data demonstrates that those tasked with empowering and advocating for people with ID do so from a position of benevolence and this may not be in the best interests of the young person with ID.

The limitations of the research parameters raised questions, which can act as a useful roadmap for future research. I will conclude by slightly paraphrasing Rapley (2004, p.197),

“diagnostic definitions of Intellectual disability have used the language of medicine to give us an homogenous disorder where in practice there is heterogeneity, diversity and uniqueness”.

A diagnosis may be necessary but is not sufficient to inform the path of a young person with ID, an individual is more than a label, and the stigma associated with that label has consequences. The individuals charged with supporting young people in planning their education and career should be educated about the consequences and supported to embrace advocacy and inclusion.


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Appendices
Appendix 1

Focus group Schedule

Parent focus group interview schedule

1. Describe your child
2. Does your child know what special needs means
3. What does special needs mean in your family
4. How did you feel when you found out your child had an ID
5. If you had one wish for your child what would it be
6. Where do you see them in 5 or 10 years time
7. What would be a perfect school for your child
8. What challenges does your child face
9. Do you think the language we use to describe the children is important

Appendix A1

Staff World Café Questions

1. What are the challenges that the students face
2. How are the students perceived in the community
3. Is special the main way students identify themselves
4. Are students aware of difference between themselves and their peers
Appendix 2

Information and consent forms
Dear xxx,

Further to our conversation earlier this summer concerning my postgraduate studies at the University of Limerick I would like to take this opportunity to give you more information about the proposed research. I am a full-time class teacher in xxx and I am currently on a career break to complete a PhD in Psychology. As part of these studies I wish to conduct some research in xxx school. The research that I wish to complete is a longitudinal study, over the next academic year 13/14. The Dept of Children and Youth Affairs fund this research. This research is also taking place at xxx and xxxx

The focus of my research is exploring the social experiences of adolescents with intellectual disability and ascertain if actual and perceived social experiences could be characterized as negative. I am interesting in finding out more about how they negotiate their identity as an Intellectually disabled adolescent.

Study 1 will be a longitudinal study documenting the attitudes of incoming students at three intervals over the next 12 months. It will require each student complete a series of paper and pencil tests at three time periods, each time period will take approximately 30 minutes per student.
The Ethics Committee of COPE Foundation has approved this research.
The Ethics Committee of the University of Limerick has approved this research.
Approved research is indemnified by the University of Limerick and I will be adhering to the Child Protection guidelines recommended by the University of Limerick, Dept of Education and Science, Dept of Children and Youth affairs and COPE Foundation.

Your support in this matter is greatly appreciated and I hope that the findings will be of benefit to the school community. I would appreciate it if we could schedule a meeting to discuss a data collection schedule.

Yours sincerely,
Clara O’Byrne

Contact Details:
Email: clara.obyrne@ul.ie
Information and Consent form for Study 1: Student version

Dear Students,

My name is Clara and I am in a teacher in XXX. I am doing a project in college I would like to find out more about what you think about your primary school and your secondary school.

What is the study about?
I am also interested in finding out more about what you think about people your own age and your friends. I am also in interested in finding out more about what you think their opinion of you is.

Why are you asking me?
I am asking all the new students. You will start XXXX in September and I would like to find out what you think before you begin the school. I will ask you for your opinion two more times, once in the middle of the year and once at the end of next year, when you will be nearly finished your first year in XXXX.

What do I have to do?
I will sit down with you and have a chat and ask you to fill out some forms.

Do I have to take part?
No. It is up to you whether you want to take part or not. If you decide to take part and then change you mind that is okay.

What are the benefits (good things) about this project?
This may help you to figure out how you feel about starting a new school and it may help to talk about your feelings.

What are the risks (bad things) about this project?
Some of the questions I will ask might make you feel sad or cross but you do not have to answer any question you do not wish to.

What happens if I take part?
I will ask you to sign a consent form. I will also ask your Parent/Guardian if it is ok for you to take part.

**What happens to the information?**

All the information you give me will be kept private and stored on a computer protected with a password. It will be deleted after 7 years.

**If you would like more information or are worried about something these contact details may help.**

**Contact details of Project Investigators.**

Principal Investigator:
Professor Orla Muldoon, Psychology Dept, UL
Email: [orla.muldoon@ul.ie](mailto:orla.muldoon@ul.ie)

Other Investigator:
Clara O’Byrne, Phd student, Psychology Dept, UL
Email: [clara.obyrne@ul.ie](mailto:clara.obyrne@ul.ie)

If you have any concerns about this study and wish to contact someone independent, you may contact The EHS Research Ethics Contact Point of the Education and Health Sciences Research Ethics Committee, Rom E1003, University of Limerick, Limerick, Ireland.
Tel: 061-234101 or Email: [ehsresearchethics@ul.ie](mailto:ehsresearchethics@ul.ie)
Consent form for students for Study 1

Please circle yes or no

Have you read the information sheet?  Yes  No
Do you understand what the project is about?  Yes  No
Do you have any questions?  Yes  No
Do you understand that it is ok to say no?  Yes  No
Are you happy to take part?  Yes  No

Sign either A or B below.
A: I agree to take part in Study 1 of Clara O’Byrne’s research project in June 2012

- ___________________ Signed (Student) : Date_______

B: I do not agree to take part in the Study 2 of Clara O’Byrne’s research project in June 2012

- ________________Signed (Student) :Date__________
Dear Parents/Guardians,

My name is Clara O’Byrne and I am currently studying for a postgraduate degree in Psychology at the University of Limerick. As part of this degree I am completing research on the social experiences of adolescents with Intellectual Disability. I am interested in finding out about what students think of themselves, their friends and the schools they have attended and currently attend. I am interested in finding out about how they feel about themselves and what they think their friends think about them. I am particularly interested in exploring the transition to XXXX and how they adapt to their new school environment.

This research will take place over the next 18 months. As well as contributing to my degree it is hoped that this research will help us understand how students with learning disabilities negotiate the transition to special school.

I am inviting all new pupils to XXXX to participate in this study and I am now inviting you to consider letting your son/daughter participate in this study. This would involve your child completing some questionnaires with me during normal school hours. Completion of the questionnaire will take approximately 45 minutes. Child protection guidelines will be adhered to all times. The responses will be confidential and seen only by my University of Limerick supervisor and myself. When I am finished my research I will give a presentation on my findings to the Parents Association.

You are under no pressure to participate in this study and I appreciate you taking the time to read this information sheet. If you do not wish for your son/daughter to take
part in this study please sign the enclosed form. If I do not hear from you over the coming days I will contact you by telephone to ask if you are ok with your son/daughter participating in this project.
If you would like more information these contact details may help.

Contact details of Project Investigators.
Principal Investigator:
Professor Orla Muldoon, Psychology Dept, UL
Email: orla.muldoon@ul.ie

Other Investigator:
Clara O’Byrne, Phd student, Psychology Dept, UL
Email: clara.obyrne@ul.ie

If you have any concerns about this study and wish to contact someone independent, you may contact The EHS Research Ethics Contact Point of the Education and Health Sciences Research Ethics Committee, Rom E1003, University of Limerick, Limerick, Ireland.
Tel: 061-234101 or Email: ehsresearchethics@ul.ie

Thank you very much for considering this matter
Yours sincerely,
Clara O’Byrne
Parental Consent Study 1

I have read the information sheet concerning Study 1 of Clara O’Byrne’s research

If you do not wish your son/daughter to participate in this research please sign below.

I do not give consent for my son/daughter to take part in Study 1 of Clara O’Byrne’s research.

Parent/Guardian of__________________________

Signed:______________________________

Date:______________________
Information sheet for Staff: Discussion Group

Dear Colleagues,

I would like to invite you to take part in a discussion group, called World Café, to chat about your perceptions of the social experiences of XXX
This discussion group forms part of my ongoing research for a postgraduate degree in Psychology at the University of Limerick. The focus of my research is to examine young peoples transition from primary school to special school and the challenges that this transition may present.

As education professionals you can provide an insight into the issues that may concern adolescents with Intellectual Disability and it will be most beneficial to my research to listen to your opinions about this. The methodology, which I intend to use, is informal and relaxed, it is called a World Café approach and is designed to connect diverse perspectives and encourage everyone’s contribution.

This World Café discussion group will take place in Monday 22\textsuperscript{nd} May. The discussion group will take approximately 2 hours and light refreshments will be served. The event will take place in the school, during school hours. In addition to collecting data through observation and written notes, I will tape record the conversation. This is purely for my own benefit to assist me in a more accurate recollection of the conversation when I am analyzing the data. The audio recordings will be stored securely and the participants will not be identified in the transcription.

There is no pressure to participate; the choice to participate is entirely up to you.
If you would like more information about the study these contact details may be useful.

\textbf{Contact details of Project Investigators.}
Principal Investigator:
Professor Orla Muldoon, Psychology Dept, UL
Email: orla.muldoon@ul.ie

Other Investigator:
Clara O’Byrne, Phd student, Psychology Dept, UL
Email: clara.obyrne@ul.ie

If you have any concerns about this study and wish to contact someone independent, you may contact The EHS Research Ethics Contact Point of the Education and Health Sciences Research Ethics Committee, Rom E1003, University of Limerick, Limerick, Ireland.
Tel: 061-234101 or Email: ehsresearchethics@ul.ie

I appreciate you taking the time to read this information sheet and if you have any questions please do not hesitate to ask me.

Clara O’Byrne
Consent Form:

I have read the information sheet about A World Café Discussion group. I understand that an audio recording will be made of the discussion group.

I agree to take part in A Word Café Discussion group in XXXX

Signed___________________________________________________

Date:____________________________________________________

Thanking you for your consideration,

Clara O’Byrne
World Café Discussion Group @ XXXX

Instructions to Participants:

Welcome and thank you. Please help yourself to refreshments.
The format for today's discussion is the World Café approach. It is designed to be informal, relaxed and hospitable. Please be seated wherever you wish and make yourselves comfortable.

As you can see there are 7 tables with five chairs at each table. There is a question written on a sheet in the centre of each table.

As you can see each table is covered in paper tablecloth, with pens, markers etc. This is to facilitate you in recording through text or picture any key points.

As I outlined in the information sheet there is also a tape recorder on each table. This is solely for my benefit to help me recall the key points of the discussion and I hope that you find them unobtrusive.

The format of the discussion is as follows;

There are five conversation questions in total, one at each table. Each table group will be asked to focus their discussion around the question written on their table. This is called a conversation round. There will be five conversation rounds each last approximately 20-30 minutes. Please feel free to draw, doodle or write key ideas on the paper tablecloth.

After approximately 20 minutes discussion I will direct you to change tables.
However I would ask that one person volunteers to stay as 'host' at each table to provide continuity of ideas from group to group.

The remaining group members are free to sit at whatever table they wish to begin the next conversation round, and so on for five rounds.

At the end of conversation round no. 5, we will share our insights and discoveries in a whole group conversation.
Café Etiquette: Focus on what matters, Speak your mind and your heart, Contribute your thinking, Listen to understand, Link and connect ideas, Play, Doodle and draw- Have Fun!

I am a Table Host what should I do?
Remind the people at your table to jot down key ideas and deeper questions as they emerge
Remain at the table when the others leave and welcome participants from other tables
Briefly share the key insights from the preceding conversations so that others can build on these ideas.

Café Guidelines:

1. Clarify the purpose- the purpose of today’s conversation is to explore your perception of the social experiences of the adolescents who attend Scoil Bernadette

2. Create a hospitable space- I hope that you find today’s venue safe and inviting. Feel free to help yourself to refreshments

3. Explore questions that matter- the questions for today’s Café Discussion are; How are the students perceived in the wider community? What are the challenges that face students in their lives outside of school? What are the positive and negative outcomes of being labeled with ID? Is ‘special needs’ the dominant identifying label for the students? Are the students aware of a difference between themselves and their peers?

4. Encourage everyone’s contribution- Please feel free to contribute your ideas and perspectives but remember that you are free to contribute through simply listening also.

5. Connect diverse perspectives- Each one of you brings a unique insight and knowledge to the conversation, please actively contribute your thoughts and link the essence of your discoveries to the ever widening circles of thought as we progress from table to table.

6. Listen for Insight and Share Discoveries- Through practicing shared listening and paying attention to insights it is hoped that you may sense a connection to a larger whole.
Appendix 3
Data collection instruments
Experience of Stigma Checklist – Cooney et al., 2006

For Qs 1,3,4,5,6,8,9,10,11 :

→ Never/Once or twice/sometimes/often/a lot

- What do they do?
- How does that make you feel?
- How do you think they’re treating you?

1. Have other pupils in the school made fun of you?
2. Do you like where you live?*
3. Do your parents treat you as if you’re different from other people?
4. Have people in the local area ever made fun of you?
5. Have other people ever made you laugh?
6. Do teachers treat you like you are different from other young people?
7. Do you like to go into town?**
8. Have people in your family ever made fun of you?
9. Do people in (local area) treat you like you’re different from them?
10. Do you like the school you go to?
11. Have teachers ever made fun of you
12. Do you like to go to the cinema *
13. Do pupils in the school treat you like you’re different from them?

0
Not at all

1
A little

2
Moderately

3
Quite a bit

4
Extremely
### Questionnaire about the way other people treat people who have learning disabilities

These questions are about how people act towards you because you have a learning disability.

Please read each question and tick one of the boxes.

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>People talk down to me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People on the street make fun of me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People on the street look at me in a funny way</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-----</td>
<td>----</td>
</tr>
<tr>
<td>people laugh at me because of the way I look</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>people treat me like a child</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>people laugh at me because of the way I talk</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>the way people talk to me makes me angry</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>people make me feel embarrassed</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----</td>
<td>----</td>
</tr>
<tr>
<td>![Image](72x378 to 487x778)</td>
<td><img src="201" alt="Thumb Up" /></td>
<td><img src="201" alt="Thumb Down" /></td>
</tr>
<tr>
<td>I keep away from other people because they are not nice to me</td>
<td></td>
<td></td>
</tr>
<tr>
<td><img src="201" alt="Image" /></td>
<td><img src="201" alt="Thumb Down" /></td>
<td><img src="201" alt="Thumb Down" /></td>
</tr>
<tr>
<td>I worry about the way people act towards me</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

thank you for filling this in
Social Comparison Scale

How I feel around other people (A).

Name:_____________ Date_____________

These questions are about how you feel when you are with other people in school. We will do a practice run first. I will read a statement with you and then I will ask you to point to a block to show how you feel. Put a circle around the block that best describes how you feel.

Procedure:
Show the example question and read out the question and responses. Ask the participant to point to the ‘taller than’ block, to the ‘shorter than’ block, and then to the ‘same height’ block. Then ask ‘which block would a tall person point to?’, ‘which block would a short person point to?’, and ‘which block would they point to if they were the same height as other people’.

Practice question
When I am with other people I generally feel:

Taller than other people  The same as other people  Shorter than other people

-----------------------------------------------
When I am with other people in school I generally feel

- Worse than other people
- The same as other people
- Better than other people

When I am with other people in school I generally feel

- Better at things
- Just as good at things
- Not as good at things

When I am with other people in school I generally feel

- More friendly than other people
- Just as friendly as other people
- Less friendly than other people
When I am with other people in school I generally feel

More shy  The same as other people  Less shy

Part of the group  A bit part of the group  On my own

The same  A bit different  Different
Social Comparison Scale (B)

These questions are about how you feel when you are with other people in general, such as the people in your park or the people in your town. We will follow the same procedure as the last time, I will read the sentence and you can point to the block that sounds like how you feel.

**When I am with other people I generally feel**

- Worse than other people
- The same as other people
- Better than other people

**When I am with other people I generally feel**

- Better at things
- Just as good at things
- Not as good at things

**When I am with other people I generally feel**

- More friendly than other people
- Just as friendly as other people
- Less friendly than other people
When I am with other people I generally feel

- More shy
- The same as other people
- Less shy

When I am with other people I generally feel

- Part of the group
- A bit part of the group
- On my own

When I am with other people I generally feel

- The same
- A bit different
- Different

Thank you
Scoring Procedure for Adapted Social Comparison Scale

<table>
<thead>
<tr>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant number:</td>
</tr>
</tbody>
</table>

### Interviewer score sheet

**Adapted social comparison scale**

**Q1.** When I am with other people I generally feel… worse than other people or better than other people?

<table>
<thead>
<tr>
<th>Worse than other people</th>
<th>the same as other people</th>
<th>Better than other people</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Q2.** When I am with other people I generally feel … not as good at things or better at things?

<table>
<thead>
<tr>
<th>Not as good at things</th>
<th>Just as good at things</th>
<th>Better at things</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Q3.** When I am with other people I generally feel … less friendly or more friendly?

<table>
<thead>
<tr>
<th>Less friendly than other people</th>
<th>Just as friendly as other people</th>
<th>More friendly than other people</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Q4.** When I am with other people I generally feel … less shy or more shy?

<table>
<thead>
<tr>
<th>Less shy than other people</th>
<th>Just as shy as other people</th>
<th>More shy than other people</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

**Q5.** When I am with other people I generally feel … on my own or part of the group?

<table>
<thead>
<tr>
<th>Part of the group</th>
<th>A bit part of the group</th>
<th>on my own</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

**Q6.** When I am with other people I generally feel … the same or different?

<table>
<thead>
<tr>
<th>The same</th>
<th>A bit different</th>
<th>Different</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

| 207 |
MANUAL
for the
SELF-PERCEPTION PROFILE FOR LEARNING
DISABLED STUDENTS

Mari Jo Renick and Susan Harter
Appendix 4

DCYA Briefing note
“Being special: Intellectual disability, stigma and special schools”

What is the study’s background?
This study was the subject of a PhD thesis (2018) by Clara O’Byrne, Department of Psychology, University of Limerick, with funding from the Office of the Minister for Children and Youth Affairs (now the Department of Children and Youth Affairs) under the National Children’s Research Scholarship programme.

What is the study’s purpose?
The aim of this study was to develop a richer understanding of stigma amongst adolescents who have been given a diagnosis of intellectually disability. This study explores how social comparison, self-perception and the strategic use of identity may be employed by adolescents to negotiate the impact of stigma. Specifically the study will focus on the social experiences of adolescents who have been given a primary diagnosis of Mild General Learning Disability (M/GLD, IQ 50-70).

How was the study undertaken?
This study combines quantitative (longitudinal) and qualitative (focus groups) methods to explore the social experiences of adolescents with ID.

In the quantitative study, 54 students from special schools completed self-report measures in a longitudinal survey design. The degree of intellectual disability and gender were found to influence experience of stigma and respondents social comparison with others. Category of intellectual disability (borderline, mild, moderate) was also associated with differences in self-perception of physical appearance and perception of global self-worth. Social comparisons were also negatively related to experience of stigma.

A qualitative study examined how disability is constructed by significant adults in the lives of young people with a diagnosis of Intellectual Disability (ID). Specifically how do parents and teachers construct ID in talk. The question of whether stigma is recreated or sustained within family and school settings was explored by analyzing focus group data thematically.
**What are the key findings?**

1. Findings indicate that gender and level of cognitive function are important variables in changes in self-perception across time highlighting the heterogeneous nature of the special school population.
2. Parents and school staff construct disability as negative, emphasizing difference from the 'norm', which they claim drives social isolation
3. A lack of agency is also attributed to those with a diagnosis of ID by parents and staff
4. A dilemma is highlighted as those who see themselves as advocates for those with ID highlight, also recreate pervasive and subtle distinctions between children with and without ID.

**What are the conclusions?**

The diversity of the group ‘intellectually disabled’ has consequences when system and structures construct them as a homogenous group. Variables such as gender and level of cognitive capacity are significant in contributing to the understanding of and experience of stigma. However the powerful nature of the discourse around ID and the ‘othering’ of individuals with ID means that parents and teachers are themselves complicit in recreating a homogenizing effect. This homogeneity means that the individual with ID is lost to the group of people with ID. Thus this thesis examines the group in the individual rather than the individual in the group

**Implications for Policy and Practice**

Parent Advocacy and information: An advantage of special schools is access to specialist resources, and access to resources is not guaranteed in mainstream settings. For many parents the choice of a special school is made because of a perceived access to multi disciplinary resources (NCSE 2011). The factors that drive parents to choose one type of educational setting over another merits research. The question must be asked – are parents given choice or concession? Geographical proximity to the limited special school network in Ireland is one factor (McConkey et al 2015) and socio-economic status of the parents is also a factor. Casey et al (2006) found that parents in the occupational groups A and B were significantly more likely to send children with SEN to mainstream rather than special schools. Support for parents in terms of information, communication and choice is inadequate (Rose et al 2010). This suggests that there is scope to educate families about the services available in a more integrated way.
Recommendation 1

a. Give parents information about choice of school and the implications of those choices both in school and community settings,

b. Explain the implications of those choices in terms of access to future post school placement and planning

c. Help parents to understand the strengths and challenges presented by their child’s unique profile and family support structure

d. Resource schools with access to a multi-disciplinary school support service so that parents do not have school choice constrained by availability of resources

School support and training:

There is a lack of empirical studies about the efficacy or otherwise of inclusive practices (Hardiman et al 2009). There is also a lack of flexibility of inclusive options, for example dual enrollment, where a young person attends both a mainstream school and a special school, is rarely utilized despite recommendations for its use (Ware et al 2009). Initial teacher education needs to encourage pre service teachers to reflect on diversity and stereotypes (Purdy & McGuckin 2013, Conway 2011). NCSE (2011) recommended that CPD should be structured in such a way as to build a range of competencies.

Recommendation 2

a) Review the efficacy of current ITE and CPD provision particularly with regards to an understanding of key psychological principles about stigma and stereotyping.

b) Encourage and incentive teachers to engage in reflective practice about students who are different and what are the strengths and challenges of diversity in their school context.

c) Consider more formal links between special and mainstream schools to minimize difference and share expertise. This was recommended by the NCSE (2011) and dual placement arrangements would certainly go some way to remediating the ‘othering’ of PWID.

Inclusion and Advocacy:

Stigma change is needed to promote the social inclusion of people with ID (Werner & Roth 2014, Jahoda & Markova 2004). In order to reduce the stigmatisation of PWID it is essential that interventions that focus on changing societies attitudes are employed and not just focused on ‘integration’. To date many attempts by care providers to integrate PWID into mainstream society have been for the most part informal local level initiatives aimed at educating and informing the public about PWID, these include
workplace shadowing, open days, sibling support workshops etc. but research about the efficacy of these measures is limited, (D’Arcy, Flynn, McCarthy et al 2005). As an intervention contact with out-group members is often viewed as a route to reducing prejudice, stereotypes and stigma. Would the efficacy of these interventions with adults with ID be improved or diminished if young people had a more visible presence in their communities during second level schooling?

Social networks help protect mental and physical health (Jetten Haslam, Dingle & Jones 2014). Having diverse social networks is protective therefore how can policy makers ensure that marginalized groups (those most vulnerable to the negative effects of stigma) have access to wider social networks and encourage more social connectedness? If group membership can be used a social and psychological tool (Jetten et al 2014) then it is critical that policy makers consider the implication of imposing group membership on individuals. Social inclusion in community settings could be supported by access to sporting initiatives such as Unified sport, an initiative of the Special Olympics, which matches PWID with people without ID. Involvement in self-advocacy has been shown to have positive benefits for PWID (Lundstrom 2008, Gray & Jackson 2002). Goodley (2000) found that effective advocacy can empower individuals with ID to step out of the passive role assigned to them by society.

Recommendation 3
   a) Promoting inclusive practices in the community e.g. unified sport
   b) Promoting and enhancing social networks for PWID
   c) Promote avenues to advocacy roles e.g. student councils

Links to National Data and Research Strategy 2011-2016

Outcome No.2

There is a recognized substantial deficit in current knowledge about factors impacting on educational attainment of children with ID and early school leaving. The data presented in this thesis clearly evidences the importance of examining the variables of gender and level of cognitive capacity when planning the educational pathway for a young person with ID. The data raises questions about some of the possible reasons why early school leaving may be an outcome for young people with ID, such as experience of stigma, awareness of the low status of special school, the varied and individual responses to special school.
Outcome No 3

Further investigation is needed to be better informed about childrens social support networks and participation in their community. The data presented in this thesis clearly demonstrates that young people with ID are restricted in terms of agency and opportunities to develop networks in their communities. The research also evidences the complex and contradictory positions about disability taken by those who are tasked with empowering and enabling these young people (parents and teachers).

Dissemination Plans:

Local and regional level:
I gave a synopsis of the research findings to the Board of Management and staff from each of the schools that participated in the research. I am currently organizing a suitable date to present my findings to interested parties (staff, parents etc) in COPE foundation, the site of most of the data collection.

National level:
I am currently working for the NCSE (National Council for Special Education) and as such will present an overview of the research findings to the Director of School Supports and Operations for dissemination to senior management with responsibility for policy.

Conference presentations include;

International level:
Two chapters of the thesis have been published and the third has been accepted subject to revisions. Copies of the published papers have been given to COPE Foundation, the Principals of each of the schools that participated and NCSE School Support Service research staff.

List of papers:
O’Byrne C., & Muldoon, O.T., “Constructions of Intellectual Disability by parents and teachers”, Revise and resubmit Disability and Society, March 2018

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