Post 19 Lobby Group

The Impact of Transition on Family Life

Research Report

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Foreword

My nephew Henry was born on 19th January 2002. The initial joy of welcoming a new member into our family was quickly replaced by worry and concern when it became clear that a supposed problem with reflux was actually a series of seizures which, in turn, were symptomatic of much more serious underlying disabilities. At eleven weeks Julie, my sister, had a confirmed diagnosis of epilepsy and more ambiguously was informed that Henry had a global developmental delay. From a medical perspective the physical, social and emotional prognosis was not good and Julie was told to take Henry home and love him. To date there has been no formal diagnosis offered with regard to Henry's condition and it has become slowly, and incrementally, clear that my sister's assumption that global developmental delay meant that at some point Henry's development would catch up to the 'norm' is not going to be the case.

Henry's epilepsy is managed by medication and he experiences difficulties in respect of mobility, communication, awareness of pain and spatial awareness. He is slowly achieving a range of developmental milestones, for example walking by 5 years and at 10 using makaton to communicate his needs and desires with a vengeance. It is easy to think of Henry in terms of the symptoms and care he requires however, this belies his mischievous personality and his infectious delight in watching cbeebies, trips in the car, going out for a walk, riding his bike, bouncing on the trampoline and trying to open each and every door that he encounters. His greatest passions are eating (no one's plate is safe not even complete strangers) and being sung to (my sister has become adept at combining singing with conversation, trips to the supermarket and eating out). His dislikes extend to sitting still, shopping and sharing his Mum's attention with his siblings or indeed anyone else.

Notwithstanding, the very clear advances Henry has made and the fact he is much loved member of our family, his severe learning disabilities also provide constant and profound cause for concern. At ten years Henry is still very much a little boy who requires constant care, supervision and safeguarding. Moreover, it is increasingly clear that he will never be able to live independently nor to fully and pro-actively engage or contribute to decisions regarding his future life choices, opportunities and transitions. At the moment Henry attends, enjoys and is stimulated by his attendance at special school and his monthly overnight respite placement. However, my sister as a single mother is his prime carer devoting many hours to the task without complaint, alongside holding down a full time job and caring for and nurturing her three other children. Indeed, my sister's devotion to Henry is admirable and profoundly moving. However, it is accompanied by physical, emotional and social costs which impact on the family life of Henry's siblings and my sister's ability to have any semblance of a personal and social life. My sister's main source of help and support is our retired mother who travels 60 miles on public transport at least once a week to look after Henry and his siblings while my sister is at work. Our brother and I no longer live in Northern Ireland and hence we provide little by way of the direct care or support required on a day to day basis.

As Henry becomes older his personal, physical, emotional and social care needs become more (not less) demanding. This means I constantly worry about the demands placed on my sister and her children, and, of course, what the future might hold for Henry as he progresses inexorably to the key transitional age of 19 years. These personal worries inform my responses to the findings, conclusions and recommendations of the Post 19 Lobby Group's research report. On the one hand, I am overwhelmed with respect and awe for the efforts and sacrifices made by carers, parents and families to attend to the needs of their children with severe learning difficulties. On the other, I am aghast and angered that their efforts lack sufficient and appropriate state support and resources and that a bleak future awaits both these families and children with severe learning difficulties as provision and services ebb and finish on the basis of the young person's attainment of the chronological age of 19 years rather than a holistic consideration of their learning and developmental needs.

Ultimately, the needs of children and young people with severe learning disabilities demand creative, compassionate and caring responses. The Post 19 Lobby Group's research report provides rich and fascinating insights with regard to the possibilities and challenges that securing a happy, fulfilled and stimulating adulthood for these young people poses. I commend this research paper undertaken voluntarily by the Post 19 Lobby Group as it provides a compelling argument for change.

Janet

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Executive Summary

This report on the impact of transitions on family life with a severely learning disabled member has been conducted by the Post 19 Lobby Group. The lobby group is made up of parents/carers and 21 severe learning disabled schools from across Northern Ireland.

The report examines a number of key areas in order to provide a snapshot of family life in Northern Ireland in 2012. It also seeks to provide examples of best practice from Europe and Great Britain to suggest changes to the current system and structures of post transition care, particularly for those young people with profound or complex disabilities. The key areas examined include:

- Family demographics
- Caring responsibilities
- Transitional arrangements
- Impact of caring on the family

The picture of family life emerging from the research paints a very grim picture indeed. Some 62% of parents are caring upwards of 70 hours per week for their child/young person with severe learning disabilities. This is all the more disturbing given that the majority of survey respondents still have children who attend special schools across Northern Ireland, and as such are still contained within wrap-around children's services. Care needs associated with severe learning disabilities clearly outweigh those suggested by Carers NI as average - approximately 50 hours per week.

Overall 77% of parents/carers state that their caring responsibilities have had an impact on their health, with one quarter of this number stating that depression, stress and anxiety are now an integral part of life. Of the 63 families who responded to the electronic survey, 17 had been through the transitional process. Some 82% of the eligible respondents stated that they did not receive enough advice or support through the process. Despite, the recent £3.8 million investment in transition planning processes from the Department of Education in 2007.

Some 76% of eligible respondents indicated that they had to give up or reduce hours of employment as a consequence of transition. Still a further 17% of parents/carers from across the whole respondent group stated that they had been unable to work since the birth of their child with severe learning disabilities, such was the extent of their child's' needs. When evidence would suggest that the cost of raising a disabled child is three times higher than that of a non-disabled child, it is significant that 82% of eligible respondents indicated a decrease in their household income as a consequence of caring and transition.

Social isolation is a common theme for families with a severely learning disabled member. This is compounded when there are two or more children with severe learning disabilities within the family. When parents/carers were asked to identify the personal skills and services which were essential to their young people with severe learning disabilities they were very clear that independent living-skills and opportunities for life-long learning MUST continue beyond the school environment however, profound the disability. There is a real fear amongst all the participating parents/carers of

> "*What will happen to [him/her] when I die?"*

Parents/carers feel strongly that opportunities for life-long learning, particularly for those with more profound and complex disabilities, are essential. This is especially clear if these young people are to stand any chance of coping when their parents/carers are no longer able to manage their caring responsibilities or have passed away.

It is this grim reality of life with a severely learning disabled member that the lobby group seek to raise awareness of. Parents/carers are coping with a challenging set of circumstances with very limited formal support. Unfortunately, with the transition to adults' services the situation continues to deteriorate. The aim of this research is not simply to complain about the non existent provision for those with profound/complex disabilities, or about gaps in current service provision, about ready access to transition planning processes, about accessing direct payments or even the anomalies between health and education which impacts on respite provision- this list is not intended to be definitive. Indeed the issue is not with the process of transition planning in itself, rather with the lack of services and ongoing post transition placements across the board.

The lobby group appreciate that the publication of this report is timely. The report comes at a time when change is on the horizon. Notwithstanding, the lobby group wish to suggest some examples of best practice which could be incorporated into this changing market place. These suggestions acknowledge the flaws and shortcomings of the current provision but seek to ensure an improved system is feasible.

The lobby group sought information on the recent introduction and strategy on care farming in Northern Ireland. Care farming is a growing movement to provide health, social or educational benefits through farming for a wide range of people, including those with severe learning disabilities. Care farming provides a concrete example of the current view of health care provision in that it moves care from the institutional setting to a community setting and promotes the integration of service users back into society by providing them with life-long skills.

Upon the discovery that the cornerstone of disability policy in Scandinavian countries is that everyone is of equal value and has equal rights, the lobby group chose to review this disability experience when considering best practice from Europe. Sweden was the focus of the research as the services available there were broadly representative of its' Scandinavian neighbours. January 1, 2007 marked the introduction of the right to basic adult education for intellectually disabled people who do not have the skills that compulsory social schools are designed to provide, but are capable of benefitting from such an education. Although it is acknowledged that people with severe learning disabilities very seldom have a regular job, municipalities are responsible for ensuring that people with disabilities who do not have a job are provided with a meaningful occupation or daily activities up until the age of 65 years. However, as with everything the system does not come without its critics and there are disparities between the rhetoric and its practical application. Notwithstanding, it is this right to a basic adult education and access to daily activities up to the age of 65 years enshrined within disability policies which are of particular interest for replication.

When seeking examples of best practice closer to home, the work of the Kingwood Trust drew attention. The Kingwood Trust have long been pioneers of housing, support and services for those with autism and Aspergers in the Reading area. The organisation had been receiving an increasing number of requests from the parents of school leavers who are keen for them to embark on a programme of skills training and education which prepares them for the world of work, however profound their disability. To this end Kingwood Trust are in the final stages of developing their latest venture - the Kingwood College - a residential college for young people aged 18-25 years. The Kingwood College will open its doors to its first students in September 2012 and aims to be the blueprint for the future of quality educational and development services for those with autism and Aspergers.

Northern Ireland is not without its own examples of best practice. These can be found in the range of community and voluntary sector organisations providing supported employment opportunities and in a small number of social firms. These organisations provide meaningful work-based and skills development experiences for young people with a range of learning disabilities, including some with severe learning disabilities. Moreover they ensure that young people gain qualifications. The organisations seek to promote independent living skills, such as independent travel skills, money management and personal and emotional well being. Unfortunately, these organisations do not have the resources to provide the support required for those young people with more profound or complex disabilities. Yet, it is clear from the research findings that parents/carers of such young people want to secure similar educational and personal development opportunities. The research report inspires the lobby group to explore the feasibility of establishing a severe learning disability college to extend the positive work towards independent living, so ably carried out by the special school sector in Northern Ireland. The severe learning disability college would seek to provide life-long learning opportunities appropriate to the needs of the adult learners. The college could also double up as a centre of excellence for the training of allied health professionals (AHPs).

So despite the discouraging picture emerging of life with a severely learning disabled member in Northern Ireland the lobby group are encouraged by the possibilities identified as part of the research report. It has been clearly identified that the hopes and aspirations of the young people with severe learning disabilities and their parents/carers appear to have been lost in the complexities of the transition process. For too long, young people with severe learning disabilities and their parents/carers have witnessed an erosion of services and this has been reinforced by the findings of the Appleby Report 2011. In reality, this report suggests that expenditure in social care services in relation to need in Northern Ireland as compared to the United Kingdom has been subject to a cumulative under-spend of 36% over the last three years. Yet the voices of parents/carers are not heard protesting about this, or if they are heard, they are told that because of a lack of resources it is not possible to accommodate their needs. Equality is a crucial issue which has been side-stepped and ignored through community care policies; paying lip service to equality issues fudges the need to take real action. If anything, this report by the Post 19 Lobby Group demonstrates that the time for action is upon us.

Introduction

This research paper will consider the impact of transition on family life in Northern Ireland with a severely learning disabled member. To establish the parameters for this research paper there must first be an examination of the definition of severe learning disability, before moving onto a consideration of the transition process and its potential impact on family life.

There is no definitive definition of severe learning disability; the best fit relies upon a combination of both the medical and social models of disability. Mencap (2009),[1] a leading charity for those with learning disabilities, suggests the following definition:

> *A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.*

Mencap goes on to outline the particular difficulties encountered by those with profound and multiple learning disabilities, which can manifest as follows:

- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- need high levels of support with most aspects of daily life
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviours that challenge us

Whilst the term learning disability can seem somewhat ambiguous the World Health Organisation [2] and, in turn, the British government are quite specific on the use of this term. In the UK, the term 'learning disability' is used to encompass the following traits in both children and adults alike:

- A state of arrested or incomplete development of mind
- Significant impairment of intellectual functioning
- Significant impairment of adaptive/social functioning

A person with a learning disability may experience difficulty in undertaking and coping with social interaction, as well as difficulty in recognising potentially dangerous situations that can leave them vulnerable. Other difficulties may pertain to effective communication, and the ability to take care of oneself. However, the extent of a learning disability varies from person to person, and can depend on the severity of the particular

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[1] http://www.mencap.org.uk/all-about-learning-disability/about-learning-disability/profound-and-multiple-disabilities-(PMLD)

[2] www.aboutlearningdisabilities.co.uk/types-disabilities/what-is-a-learning-disability

condition or syndrome. Most importantly a learning disability is an impairment that exists from childhood. It does not describe a difficulty that is developed in adulthood and does not occur as a consequence of accidental injury or the result of the aftermath of adult illness.

To give the subject of learning disability some contextual setting it is important to examine the available statistical information. It is estimated that 2% of the population in Northern Ireland has a learning disability. This equates to a prevalence rate of 9.7 persons per 1000 of the population[3]. The organisation, Working with Diversity NI[4] states that figures are increasing and estimates that 2 babies are born each week with some form of learning disability. The 2005 Equal Lives Report[5] presents the following table to give a valuable insight into the numbers and age groups of those with severe learning disabilities:

Age range	Severe Learning disabilities	Total Mild, Moderate & Severe	Prevalence per 100 of population
0-19	1718	8150	16.30
20-34	1047	3551	
35-49	949	2438	
50+	753	2226	4.54

(Table adapted from Equal Lives Report 2005)

The Equal Lives Report concurs with the earlier suggestion about the numbers of those with learning disabilities, however as the figures above suggest there is a significant dip between 0-19 years and 20-34 years. This dip would suggest some doubt as to the fate of those with severe learning disabilities between leaving formal education and moving out into adult and community services. It would seem that when no longer in receipt of disability and/or other statutory services people with learning disabilities can become lost in the system not re-emerging until further services are required at a later point. The Equal Lives Report concludes that there could be an additional 16,000 people with learning disabilities not known to services. So from the outset the case in relation to those people with learning disabilities can seem ambiguous and misleading. There are clear care pathways. However, it seems that access to these can prove problematic for those outwith the statutory support networks.

This leads us on to the second proposition for examination, that of transition. For young people with learning disabilities transition is the process which marks the end of education with the move over to adult services. For young people with severe learning disabilities (hereafter referred to as slds) this happens at 19 years. The process of transition is commonly understood as leaving school and moving onto further education and training or employment. It can also result in leaving one's family of origin, living independently and establishing a family of one's own.

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[3] http//www.dhsspsni,gov,uk/prevalencestudy.03.september 2003

[4] http://www.workingwithdiversity.org/div/disability/learningdisability/facts&statistics.php

[5] Equal Lives Report: Review of Policy and Services for People with a Learning Disability In Northern Irelands (DHSSPS 2005)

Within this understanding adulthood can be defined as

> *".... an emergent status realized through the gradual acquisition of certain rights privileges and responsibilities...such a natural progression cannot be taken for granted for young people with learning disabilities*."

MacIntyre (2009)[6] states that the process of transition has become increasingly complex for all young people. Newman & Blackburn (2002)[7] maintain that compared to earlier generations, children appear to have become less able to cope with and overcome stressors and obstacles, partly because of their being sheltered from challenging opportunities. Transitional periods are also periods of heightened risk, illustrated, for example, by the frequent decline in academic performance of vulnerable children on transfer from junior to senior schools. MacIntyre (2009) continues that for young people with learning disabilities the transition process is likely to be problematic. Furthermore the transition to adult status should not be confused with transition from children's to adult services. Young people with learning disabilities can expect to make transitions that involve local educational authorities, children's social services and adult social care. This transition is a complicated business that occurs at different ages and involves different eligibility criteria, depending on which organisation is involved. In Northern Ireland this complication is particularly apparent when young people are treated as adults for health and social services at 18 years yet remain a child within education until they reach the age of 19.

The impact of transition points in life is undeniable, and for young people with learning disabilities this process is of extreme importance. MacIntyre (2009) argues that the transition to adulthood for young people with learning disabilities can be wider in scope, of longer duration and filled with attenuated experiences. These experiences can threaten to slow down the transition or result in it not happening at all. For young people with slds the situation can be compounded for a number of reasons, including their capability to make informed choices, or indeed their perceived incapability to make any choices about their future. Newman & Blackburn (2002) continue that transitional periods in the lives of children and young people are times of threat but also of opportunity for change. If children possess adequate coping skills, are in environments that protect against excessive demands, but also have opportunities to learn and adapt through being exposed to reasonable levels of risk, then a successful transition is likely. If neither coping skills, nor an environment that is likely to promote them, are present then periods of transition may become points in the child or adolescent life span where serious developmental damage may occur. For children and young people with slds the transition period is of

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[6] Gillian MacIntyre Chapter 4, Alison Petch ed, Making Transitions: Support for individuals at key points of change, The Policy Press, Bristol 2009

[7] Tony Newman & Sarah Blackburn, Transition in the lives of Children & Young People: Resilience Factors 2002 No78 Interchange Series ISSN 0969-613X Barnardos Policy Research & Influencing Unit

particular importance and ongoing opportunities for education and development are crucial to their continued achievements outside the special education system.

Within the special education system in Northern Ireland young people with slds begin preparing for transition from children's to adult services at 14 years through the annual special educational needs statement review process. This is designed to ensure that all agencies and services involved with the young person can feed into the process with the full input from parents, carers and most importantly from the young person themselves. The outcome of this process is primarily the identification of and pathway to the most appropriate ongoing placement for the young person with slds. Available placements can include Further Education College, supported employment opportunities, employment, volunteering opportunities, day opportunities or the day centre. In April 2008 during Private Members Business[8], a debate on further education provision for young people with disabilities was held in the Northern Ireland Assembly. As part of the discussion MLAs were informed that statistics released by the National Bureau for Students with Disabilities indicated that about 100 young people with disabilities and /or learning disabilities leave special schools in Northern Ireland each year. About 20% of those are classed as having complex or multiple disabilities, and for those young people, there is often no option other than day care provision. There are few opportunities and too few support systems to enable them to enter further education. Indeed this suggestion would be supported by research carried out by the Bamford Monitoring Group in 2011[9] which states that choices for people with learning disabilities [leaving school] do not really exist. It is simply a matter of fitting in with the provision that is available.

The premise for this research paper is a consideration of the impact of transition on family life in Northern Ireland for families with a severely learning disabled member. Parents and carers came together through the Post 19 Lobby Group in 2010 to lobby elected representatives and statutory agencies for changes to the status quo which could provide more meaningful and appropriate placements for precisely those young people with complex and/or multiple disabilities. This research has been undertaken on a voluntary basis by the Post 19 Lobby Group, no funding has been obtained and the results reflect a snapshot of life with a severely learning disabled member in Northern Ireland in 2012.

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[8] Assembly-Official Record Monday 7th April 2008
http://www.niassembly.gov.uk/record/reports2008/080707htm

[9] Bamford Monitoring Group August 2011-“My Day, My Way Research Paper”-Patient Client Council and Mencap

The Post 19 Lobby Group

The Post 19 Lobby Group is made up of parents, carers and sld schools from across Northern Ireland and is supported by a range of organisations working in the field of disability rights. The origins of the group can be traced back to 2009 when Hill Croft School Parent Teacher's Association (PTA) decided to prioritize the post 19 transition issue as part of their body of work. Hill Croft School, which is situated in Newtownabbey, had long been involved with advocating for change to the crucial transition process for young people with slds with other sld schools. Local politicians have also supported parents and carers by raising the transition issue within debates in the Legislative Assembly at Stormont. However despite this strong focus from parents/carers and support from the local elected representatives, with hindsight it is clear that the lobbying process prior to 2007 was essentially flawed. Principally, in the sense that the power sharing executive within the devolved Northern Ireland Assembly had been dissolved on a number of occasions. The power sharing executive re-emerged following the Northern Ireland (St Andrews Agreement) Act 2006 (c.53).[10]

It was during these periods of Assembly dissolution from 2002-2007 that tribal politics have prevailed to the detriment of local issues, such as those of education and health. However by 2009 the political institutions had stabilised under the leadership of the First and Deputy First Minister, Rev Ian Paisley and Martin McGuinness respectively, and the process of power-sharing was consolidated.[11] Against this political backdrop Hill Croft PTA, having prioritised post 19 transition, moved to organise a Question Time event in April 2010. The event was designed to allow parents and carers to question Members of the Legislative Assembly (MLAs) about transition opportunities. Hill Croft PTA invited a panel of South Antrim MLAs-including David Ford (Minister for Justice), Rev Dr William McCrea, Ken Robinson and Dr Colin Harper from Disability Action's Centre for the UN Convention on the Rights of People with Disabilities (UNCRPD). The event was chaired by Helen Ferguson, C.E.O. of Carers NI. Hill Croft PTA had invited 5 other special schools from the North Eastern Education & Library Board (NEELB) area to the event and had 54 parent/carer representatives from:

- Sandelford Special School, Coleraine
- Riverside Special School, Antrim
- Roddensvale Special School, Larne
- Kilronan Special School, Magherafelt
- Castle Tower Campus, Ballymena

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[10] Explanatory Notes to Northern Ireland (St Andrews Agreement) Act 2006 Chapter 53. The text of this internet version of the Explanatory Notes which is published by the Queen's Printer of Acts of Parliament has been prepared to reflect the text in printed form and as published by The Stationery Office Limited as the Northern Ireland (St Andrews Agreement) Act 2006, ISBN 0105653063.

[11] www.**guardian.co.uk**/uk/2007/may/08/northernireland

This event instigated the drive to harness parent power and to develop the Post 19 Lobby Group across Northern Ireland. The lobby group was able to avail of training from Disability Action through the Centre on Human Rights for People with Disabilities and make links with the NI Commissioner for Children and Young People, Mencap and Carers NI. Since meeting with parents and carers from Hill Croft School in December 2010 the NI Commissioner for Children and Young People has commissioned a scoping paper on transition. This paper is due to report in autumn 2012. More significantly the Lobby Group has, over the intervening period of two years, built a 21 strong special school/parents and carers lobby from across Northern Ireland.

The lobby group now has parent/carer and special school representation from the following areas:

- Antrim-Riverside Special School
- Armagh- Lisanally Special School
- Ballymena-Castle Tower Special Schools
- Banbridge- Donard Special School
- Bangor-Clifton Special School
- Belfast-Tor Banks Special School
- Coleraine-Sandleford Special School
- Downpatrick-Knockevin Special School
- Dungannon-Sperrinview Special School
- Enniskillen- Willowbridge Special School-amalgamation of Elmfield & Erne Special Schools
- Larne-Roddensvale Special School
- Lisburn-Parkview Special School
- Londonderry-Belmont House Special School
  Foyleview Special School
- Lurgan- Ceara Special School
- Magherafelt-Kilronan Special School
- Newry-Rathore Special School
- Newtownabbey-Hill Croft Special School
- Omagh-Arvalee School & Resource Centre
- Strabane-Knockavoe Special School

The lobby group communicates primarily by email through the school principals but has direct links to parents associations where they exist. The lobby group has 104 active members on its email list - 28 of this number relates to special schools and the remaining participants are parents/carers and other interested parties.

From a review of the current literature the Post 19 Lobby Group identified a gap in information available on families with severely learning disabled members. The lobby group decided to undertake their own research to identify the impact of transition on family life. The Post 19 Lobby Group acknowledges that the possibility of generating meaningful dialogue with young people with slds could prove problematic. Foremost is the understanding that verbal communication can prove difficult for many such young people. For non-verbal young people there are a variety of communication systems depending upon their particular skill or need, such as Makaton, PECS (picture exchange communication system) or TEACH (treatment and education of autistic and related communication-handicapped children). However the complexities of using these systems with non-verbal young people to generate a meaningful contribution would have required a degree of specialism and resource that the lobby group simply did not have.

To this end the Post 19 Lobby Group decided, following a Question Time event in October 2011, to circulate an electronic questionnaire to parents and carers from across Northern Ireland seeking their views on the transition process, its impact on family life and their hopes and aspirations for the lives of their young people with slds.

In the interim, and more recently using the preliminary research findings, the Post 19 Lobby Group has continued to raise awareness of the transition issue with further Question Time events in Parkview Special School, Lisburn (March 2011) and Hill Croft School (October 2011). The Post 19 Lobby Group has also been invited to make presentations to Lisburn City Councils Corporate Services Committee (February 2012) and the Minister for Health and his departmental staff (May 2012) on preliminary research findings.

Research Aims

This research had a number of aims:

1. To investigate family life with a young person with severe learning disabilities. and consider the impact of caring
2. To consider the impact of transition upon the family
3. To ascertain the personal development skills which parents and carers feel are essential to the life long learning needs of young people with severe learning disabilities.
4. To provide alternative solutions to the day centre model of care for those with more complex or profound disabilities

The timing of this research has been purposeful; the report was designed to complement the findings of other research papers published in the latter part of 2011, and into 2012, and to take cognizance of legislative requirements for the monitoring on the rights of people with disabilities.

The Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission have been jointly designated under Article 33(2) of the Convention on the Rights of People with Disabilities as the Independent Mechanism for Northern Ireland to "**promote, protect and monitor implementation**" of the United Nations Convention on the Rights of People with Disabilities (UNCRPD). [12]

This research paper reported on a two-way process of investigation, consisting of an examination of current policies and programmes supported by adding evidence to the picture of life with a disability within Northern Ireland. Key research findings suggested that across the wide range of articles considered there were gaps in policies and programmes that needed to be addressed. Three priority areas were identified: awareness raising; participation in political and public life and statistics, data collection and access to information. The report recommended that urgent action by the State [in this instance Great Britain & Northern Ireland] is required to address gaps in policies and programmes, not least in these three priority areas.

The Convention[13] is necessary in order to have a clear reaffirmation that the rights of persons with disabilities are human rights and to strengthen respect for these rights. The Convention articles of particular interest to the lobby group are Articles 24 on education of persons with disabilities which must foster their participation in society, their sense of dignity and self worth and the development of their personality, abilities and creativity and Article 27 Work and Employment which recognizes the rights of persons with disabilities to work on an equal basis with others. However, it is at this point that the rhetoric and reality deviate as the State [GB&NI] has ratified neither Articles 24 nor 27,

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[12] Disability programmes and policies: How does Northern Ireland Measure up? Research Summary Equality Commission for Northern Ireland, January 2012.

[13] The United Nations Convention on the Rights of People with Disabilities-Centre on Human Rights for People with Disabilities Disability Action May 2008

and sadly equal access to education remains resource and not needs led, while opportunities for work and employment are often hindered by the benefits trap.

The Bamford Monitoring Group reporting for the Patient and Client Council produced the ***"My Day, My Way"*** [14]research paper which investigated the views and experiences of people with learning disabilities and their parents/carers. The report states that choices beyond transition for people with learning disabilities do not really exist. It is simply a matter of fitting in with the available provision. Education courses are limited and some people have spent several years in college repeating the same courses. There are few opportunities to secure paid employment. Those people availing of day opportunities (a mixture of day centre, college and supported employment) are afraid to question access to placements for fear of not receiving any. Some are even fearful that if they give up one day in the day centre to explore alternative activities it may not be replaced if the alternative activities do not work out. This report acknowledged that people with severe learning disabilities were not included within the participant cohort and additional information needs to be sought from this group.

In the ***"My Day, My Way"*** research paper there was a feeling amongst parents that sometimes services are based on what is available rather than on the individual needs of the client. A "one size fits all" approach is not appropriate in these circumstances. Some parents highlighted the need for person centred planning, as advocated by the Bamford Report 2007,[15] and the continued need to challenge and stimulate young people with learning disabilities through life-long learning opportunities. These are not aspirations in isolation. All of the requests made by parents/carers as part of the research are contained and enshrined within the Bamford Review Recommendations for Government departments and their agencies. There was even some suggestion within the research paper that for some parents/carers there was a fear of protesting too loudly about the inadequacies of the service they were receiving in case they lost it all together, an indication of the anxieties faced by families moving through the transitional process.

Another of the key issues arising from the research papers is the lack of any real or meaningful engagement with employers. Most of the people with learning disabilities who had managed to get employment were doing so on a voluntary basis. There was a real fear around benefit entitlements and work. For people with learning disabilities, as for anyone else, there would have to be a reasonably paid full-time position which would allow them to come off the benefits they currently receive and still be able to manage financially. However, the big draw back to this is that part-time employment, which may be a more realistic expectation, does not pay enough to take them out of the benefit system. Furthermore part-time employment, while having a significant impact on their benefit entitlement can be compounded by the administration required to keep their benefits on track. The current administrative complexity would frighten even a university graduate never mind a young person with limited literacy skills.

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[14] "My Day, My Way" Bamford Monitoring Group on behalf of the Patient & Client Council supported by Mencap Northern Ireland August 2011

[15] The Bamford review of mental Health and Learning Disabilities (Northern Ireland) 2007 http://www.dhsspsni.gov.uk/bamford.htm/

John Compton, Chief Executive of the Health & Social Care Board in Northern Ireland has led a comprehensive review of health and social care services within Northern Ireland at the request of the Minister for Health, Public Safety & Personal Social Services, Edwin Poots. ***"The Transform Your Care"*** report[16] has investigated and sought the views of users from across Northern Ireland on a range of health and social care services. In respect to the learning disability services there is an acknowledgement within the report that this provision requires a multi-agency and integrated approach. Provision for people with learning disabilities is not solely a health issue. With reference to day services it is stated that a one-size-fits-all service will be less relevant in future.

Further information on the subject of transition to adult services will be contained in the scoping paper currently underway for the Northern Ireland Commissioner for Children and Young People. A full copy of this report is anticipated in the autumn of 2012. Finally, there is a consultation paper on the Northern Ireland Disability Strategy entitled ***"A strategy to improve the lives of disabled people – 2012 to 2015***" open for comment through the Office of First and deputy First Minister until 25.08.12. All the information contained within this brief literature review points to the need for change to current services. However, what is lacking is a framework within which a change can occur. With this research paper the Post 19 Lobby Group seek to provide a snapshot of family life in Northern Ireland with a severely learning disabled member and present some examples of best practice which may have the potential to meet and/or match the hopes and aspirations of young people with slds and their families.

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[16] www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf December 2011

Methodology

Post 19 Lobby Group piloted an electronic questionnaire from ***Kwik Surveys*** [https://www.kwiksurveys.com?s=OHKILM_40b05ec5] between October 26, and November 11, 2011. Minor adjustments were made and the questionnaire was re-launched on November 14, 2011, remaining online until December 12, 2011. The electronic questionnaires were designed to capture:

- Demographic information
- Impact of caring on parental health
- Transition arrangements and impact on family
- Consideration of personal skills essential to ensure life long learning development for young people with severe learning disabilities.

Emails containing the electronic questionnaire link inviting responses were sent out to 22 Special School principals on November 10, 2011 and to a number of disability and community organisations for link inclusion on websites. A press release was distributed to 25 regional newspapers across Northern Ireland calling for all parents and carers to participate in the research.

The lobby group was confident that information about the electronic questionnaire would be readily distributed amongst transition classes in special school, however there were no easy routes to reach out to those families with a learning disabled member who had moved beyond the school system. Letters were distributed to 84 day care centres across Northern Ireland. Unfortunately a number of these were unable to distribute the information to service users until the relevant Health Trust had given its approval. Contact was made with Carer Co-ordinators across the five health trusts to distribute the electronic link information amongst support groups.

Preliminary findings from the first electronic questionnaire were used to facilitate focus groups in 4 special schools on February 21, 2012. Focus groups were held via video conferencing in the following schools:

• Erne/Elmfield Schools, Enniskillen	34 people in attendance
• Hill Croft School, Newtownabbey	13 people in attendance
• Kilronan School, Magherafelt	8 people in attendance
• Sandleford School, Coleraine	6 people in attendance

The electronic questionnaire re-opened on February 21, and remained open until April 3, 2012. Special Schools and parents were also asked to email through their experiences of transition through the 104 member strong email forum. These experiences have taken the form of case studies and have been inserted at relevant points throughout the research paper.

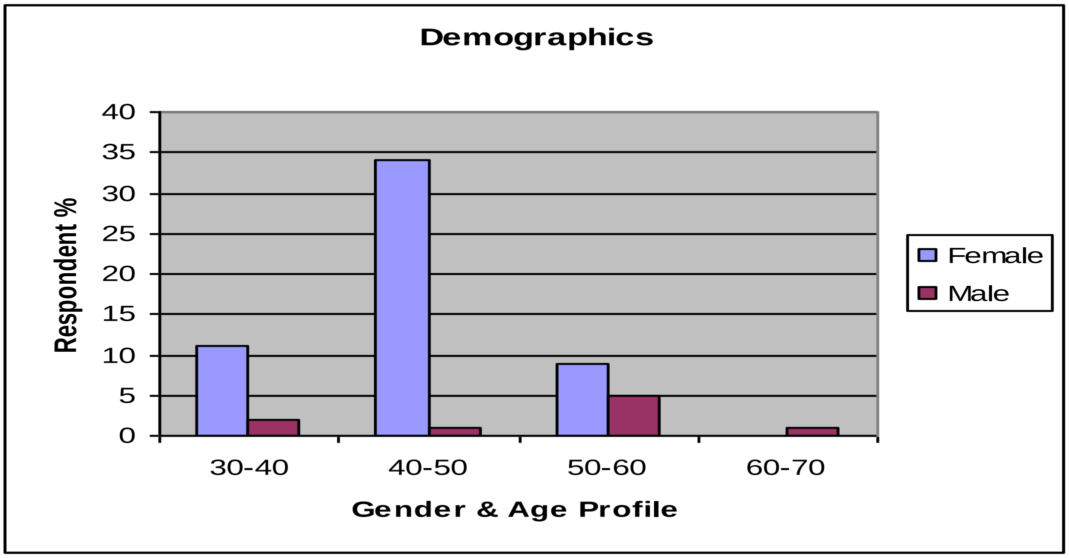
Research Findings

A total of 64 electronic questionnaires were completed, 61 parents and carers took part in focus groups and eight parents and one school principal submitted case studies of transition experiences.

Demographics

The first set of findings relate to demographics. The following graph depicts the gender and age profile of the 64 respondents to the electronic questionnaire.

Figure 1



Just over half of parents/carers responding to the electronic questionnaire were aged between 40-50 years, some 54%. Respondents aged 30-40 years accounted for 24% of the cohort, closely followed by respondents aged 50-60 years at 20% of the total cohort. Overall 83% of the respondents were female, and 34% of this figure were within the most common age range of 40-50 years. Overall 17% of respondents were male and the largest majority of males (5%) can be found in the 50-60 years age range. Whilst these gender percentages show a larger differential between male and female carers overall they concur with Carers NI statistics which identifies 64% of carers as female and the remaining 36% as male.[17] It must be noted, however. that the statistical gender breakdown detailed by Carers NI (2009) does not specifically refer to carers of family members with learning disabilities but constitutes a generic statistic to cover all caring relationships.

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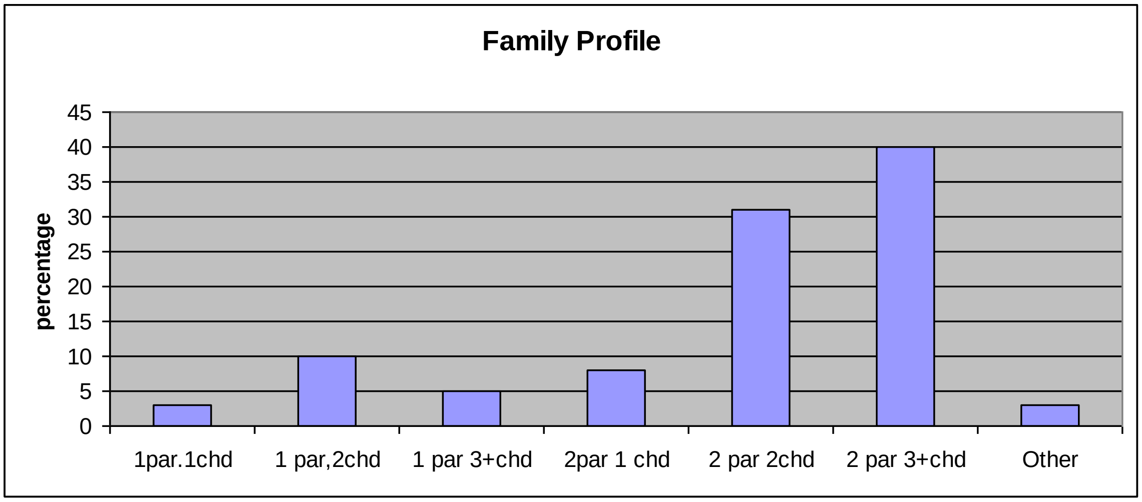
[17] http://www.carersuk.org/about-carers-northern-ireland/facts-about-carers-ni

Family Profile

Figure 2



The majority of respondents was comprised of families with 2 parents and three children (40%). Indeed family units led by 2 parents totaled some 74% of all respondents. Single parent led families made up 18% of all respondents, with 3% of families indicating 2 or more disabled children. These findings would contradict the findings of Buckner & Yeandle[18] which states that in the UK 32% of families with disabled children under 16 years live in lone parent families. However, Clarke & McKay [19] report that there is limited evidence available concerning the impact of impairment and disability on family forms. The authors continue that couples who have a disabled child may experience an increased risk of separation, particularly during the very early stages of parenting a disabled child.

Additionally it is clear through the Audit on Learning Disability in Northern Ireland[20] that Northern Ireland may have a higher prevalence of learning disability than Great Britain, but it is broadly comparable with that of the Republic of Ireland. Upon further investigation it becomes clear that this comparability also translates to family caring relationships. Within the information available from the Republic of Ireland's Census in 2006 nearly 2/3 of those identifying themselves as family carers indicated they were married with the remaining 38% single, separated or widowed. The findings here are indicative of families providing stability and support to their children/young people with slds. This in the face of a society where lone parent led households and poor parental performance seem to dominate the media and more recently in government policy with

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[18] Lisa Buckner & Sue Yeandle "Managing more than most: Statistical Analysis of families with sick or disabled children in England & Wales." University of Leeds November 2006

[19] Harriet Clarke & Stephen McKay "Exploring disability, family formation and break up: Reviewing the evidence." Department of Work & Pensions Research Report No 514 2008 ISBN 978 1 84712 4005

[20] Audit on learning disability in Northern Ireland 2001
http://www.carealliance.ie/publications.php/familycaringinireland.pdf

the Prime Minister David Cameron[21] advocating the establishment of the NHS Information Service for parents and piloting free parenting classes for all children under five years of age in three trial areas. In a speech made to Parliament in December 2010, The Prime Minister stated,

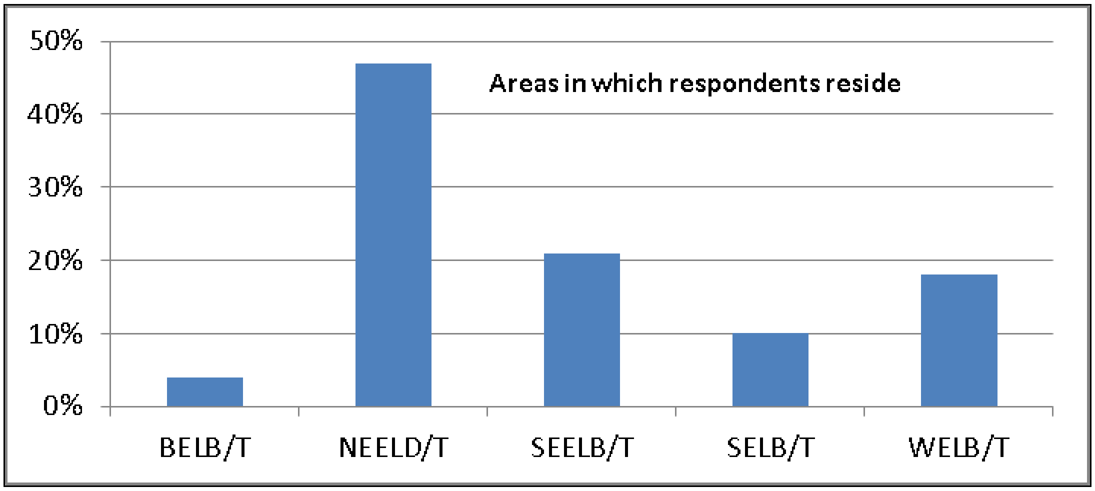
> *The government wants to tackle some of the country's deepest societal problems, and the massive economic costs that they bring. And it has not got a hope of doing so without understanding the importance of the family - the seeds of so many social problems are sown in the early years*

This recognition that support for strong and stable families may help to address some of the country's societal problems is admirable, especially when it also articulates the economic savings that this may bring. The same level of commitment must be demonstrated for families with severely learning disabled members trying to manage under severe pressure.

Families Geographical Location

The next question focused upon the geographical location of the respondents, seeking to ascertain in which Health Trust and Education and Library Board area they reside. As will be clear from the figure 3 below, the majority of respondents - 47% - resided within the Northern Trust/North Eastern Education & Library Board area. This will not be too surprising given that this is the area from which Hill Croft School has been leading and facilitating the work of the lobby group and in which it has developed strong relationships with other special needs schools and consequently parents/carers. Overall 21% of respondents resided within the South Eastern Trust and Education & Library Board area and 18% resided within the Western Trust and Education & Library Board area. The Southern and Belfast Trusts and Education & Library Board respondents accounted for 10% and 4% of the total respectively. The majority of respondents did not consider themselves to be disabled.

Figure 3



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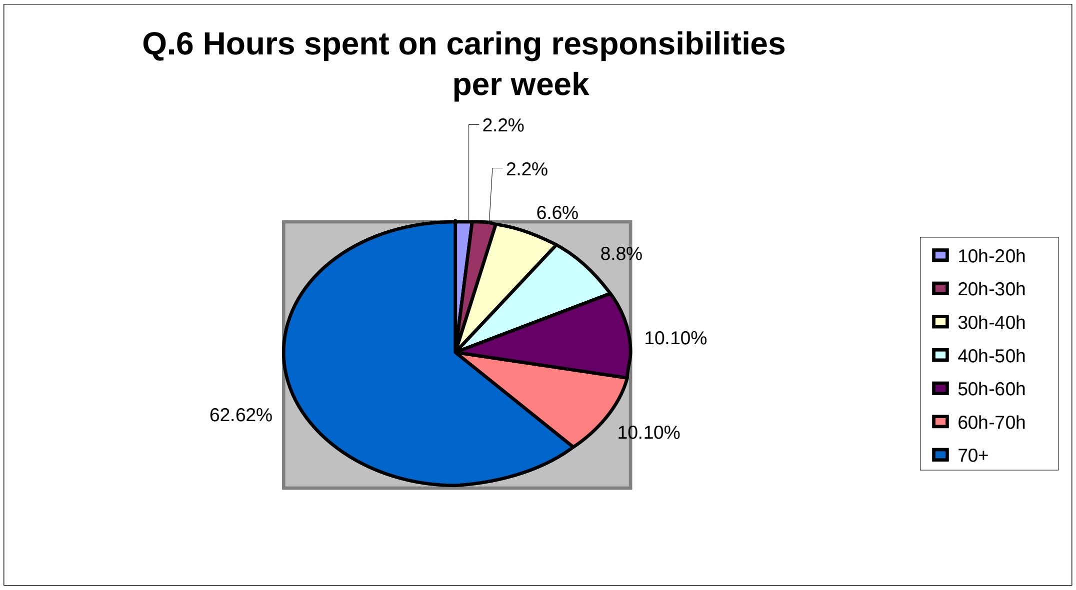
[21] http://www.education.gov.uk/.../pm-announces-family-support May 2012

Caring Responsibilities

Attention now turns to the caring responsibilities of the respondents.

Figure 5



The majority of parent/carer respondents, 62%, indicated that they spent upwards of 70 hours per week on caring responsibilities for their child or young person with slds. A further 20% of respondents indicated spending between 50-70 hours on caring responsibilities each week. The remaining 18% of respondents indicated spending up to 50 hours per week on caring responsibilities. In comparison to figures available from Carers NI[22] that state that one quarter of all carers provide over 50 hours of caring per week, these figures would indicate a significant increase in caring responsibilities for those with slds than is apparent within generic trends.

Sources of assistance with caring responsibilities

Parents/carers were asked about the help they receive with their caring responsibilities from a variety of formal and informal sources. Just over a third of respondents (37%) indicated that family and friends were the major source of caring assistance, closely followed by social services with 28%. The figure of 28% noted with regard to social services is probably more indicative of the age group of the young people with slds whose parents/carers responded to the electronic questionnaire rather than an accurate measure of social care services as a whole. A further 15% indicated assistance from community and voluntary sector organizations such as Sense NI and Mencap. Only 10% indicated a formal care package as a source of support whilst 5% indicated privately funded respite. A further 5% indicated "other" as a form of respite which when further extrapolated indicated no other source of caring assistance. Over half (57%) of all sources of caring assistance are arranged informally with family members and/or community and voluntary sector groups or through private arrangements. When

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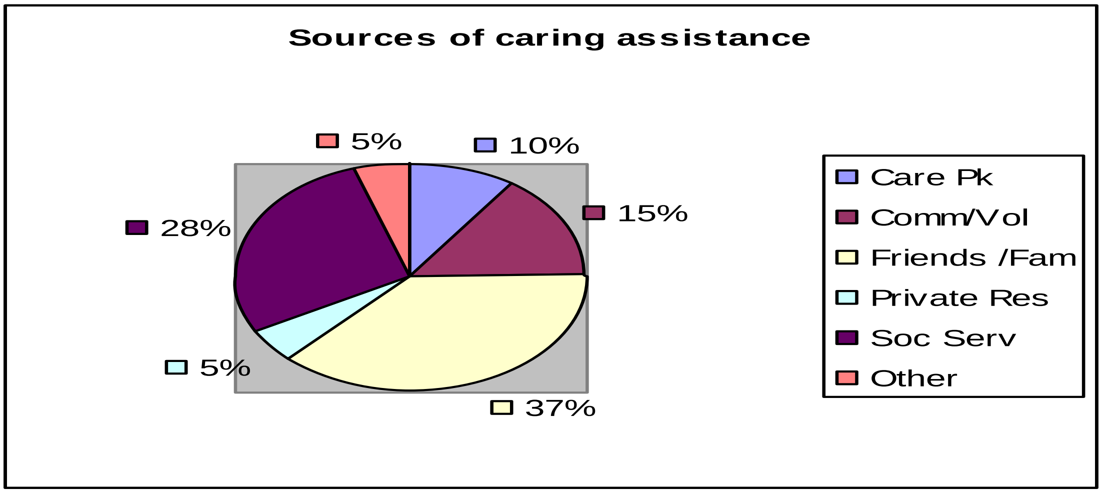
[22] http://www.carersuk.org/about-carers-northern-ireland/facts-about-carers-ni

compared to the 28% of respondents in receipt of formal respite services, it begs the question as to why this is the case? Are formal services difficult to access? More worrying is the 5% of respondents who indicated that they received no other source of caring assistance.

Figure 6



Impact of caring on parental health

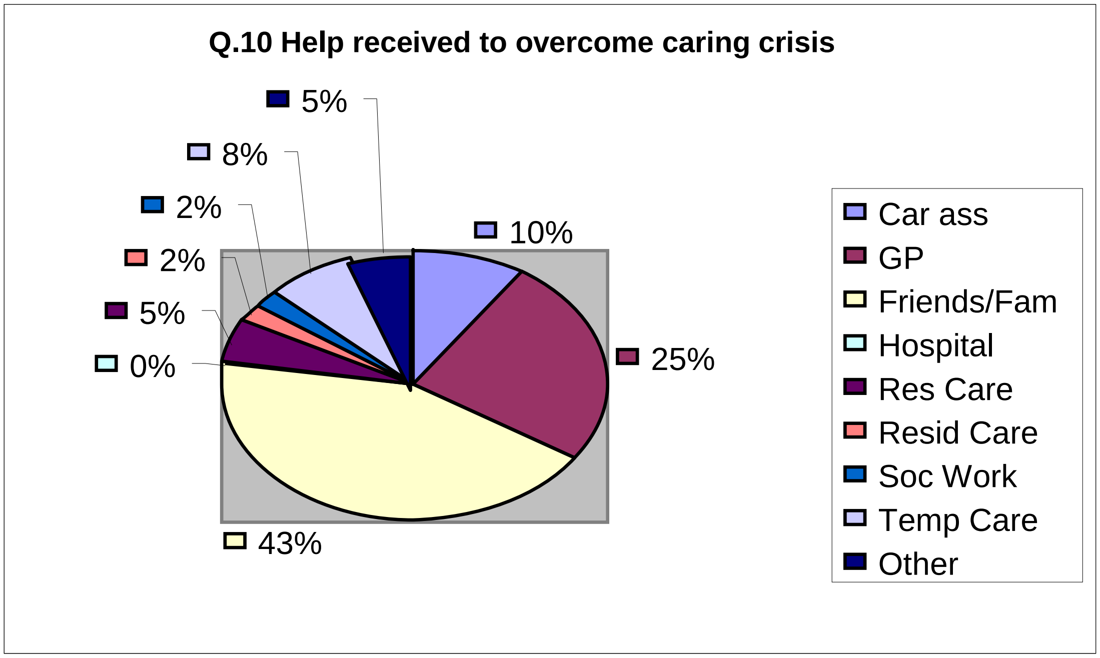
When asked about the impact of caring on health and whether there had been occasions when caring arrangements had broken down because of the carers' ill health. Overall 77% of parents/carers indicated that caring responsibilities have had an impact on their health. One-third of all respondents took the opportunity to provide additional information on health issues, and 25% of these parents/carers acknowledged that depression, anxiety and stress played an integral role in their lives as carers. Some of the comments made by respondents on the electronic questionnaire in response to question 8 are detailed below:

> "The amount of time and mental strain put into caring leaves me exhausted. I find it takes longer to do simple tasks just because I am too tired to think straight. I hurt my back when struggling to keep my son safe when he was displaying challenging behaviour. This was at a stage when I was pleading his case for help, DLA[Disability Living Allowance] etc as we had to wait on a diagnosis. That was four years ago and I'm still having problems." Female 50-60 years
>
> "I have suffered two strokes through stress, also major back problems." Female 50-60 years
>
> "My daughter is completely reliant on my husband and myself for everything. The pressure is relentless, depression and stress are part and parcel of normal life." Female 50-60 years

Notwithstanding the strength of the above statements when respondents were asked if caring arrangements had ever broken down because of ill health, only 43% indicated that this was the case. Figure 7 overleaf illustrates the responses when parents/carers were asked to outline all sources of help received to overcome a caring crisis 43% indicated that it was from family and friends, a further 25% indicated their General Practitioner. 27% of respondents indicated assistance from a variety of statutory sources including a carers' assessment, respite care, hospital and a temporary care package.

Help received when caring crisis occurs

Figure 7



Again respondents took the opportunity to outline the difficulties they experience; some comments from the electronic questionnaire are detailed in the following section:

"I was hospitalised with pneumonia last year and as a widow with a grown up son with severe learning disabilities I was so worried about what would happen to him if I was laid up for a week or two. I had to rely on family to help us through. Eventually we got some help from social services to keep everything going." Female 50-60 years

"You don't have time to be sick; his need is greater than mine so I just get on with things, sometimes better than others. I rely on my family a lot. My daughter is a great help but she is young so she shouldn't have to do too much." Female 40-50 years

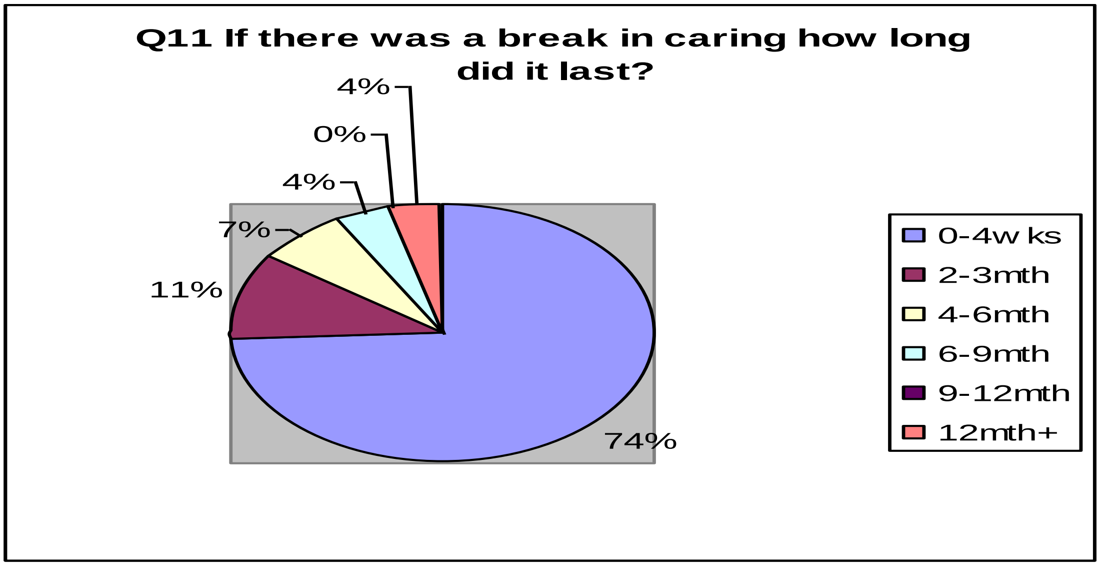
"Can't afford to be sick. No one to help with my son's needs." Female 40-50 years

"Too busy with caring to be sick. If I am ill my husband mucks in and my daughter is a great support but it is unrelenting as my son has personal care needs." Female 40-50 years

So far the picture that is emerging from the electronic survey is bleak, with one-quarter of the respondents suffering from stress and depression because of their demanding caring responsibilities. The majority of respondents are providing upwards of 70 hours of caring per week with limited assistance. It is hardly surprising then that their worries and concerns are magnified by their circumstances.

Breaks in caring

Figure 8



Overall 77% of respondents indicated in Question 8, that caring responsibilities have had an impact on their health. Now, some 74% of that cohort indicated that any break in caring lasted up to 4 weeks. As has already been made clear the main source of help and support during a caring crisis comes from friends and family. This begs the question why are parents/carers so reluctant to seek statutory support?

It is clear that many parents/carers are under an enormous amount of pressure in carrying out their caring roles and whilst statutory support is available the uptake appears to be limited. In a sense this defies the earlier findings of Question 7 in which 28% of respondents indicated they received help from social services. It was pointed out in the Question 7 response that social services could be more involved than was otherwise the case because the children and young people involved were still contained within children's services. At the focus groups, which took place via video conferencing on February 21, 2012 respite was the first topic discussed. Parents and carers discussed access to and flexibility of respite services. One parent, female aged 60-70 years with a 17 year old son, stated:

> *My son is settled at home. He doesn't like the hassle of respite, but I can't get direct payments which would allow me to provide his respite in his own home. I think there should be more opportunities for supported living in rural areas.*

Another parent outlined a very positive experience with direct payments which gave her the flexibility she needed to manage her situation. However, for the most part parents had reservations in regard to respite provision. A male parent with a 16 year old son found services inflexible and unresponsive to his family needs commenting:

> *I work full time so my wife is at home with our son. My wife was quite unwell recently and in hospital for some time. We did request help from social services. They were too slow to respond so we had to draft in family and friends to bridge the gap. Not good enough!*

At part of the focus group discussion on respite a parent flagged up the fear that many parents/carers have of the transition to adult services:

> *Some parents find it hard when their young people are 18 years old. At this point they move over to adult respite services and transport can no longer be provided between respite accommodation and school*

As was pointed out in the introduction it is at this point, when the young person with slds is 18 years old, that the complicated nature of managing transition really begins to impact on families. In Northern Ireland at 18 years the young person is regarded as an adult for health and social care services but remains a child until 19 years within education. This can be a frustrating time for families to negotiate as respite systems change at 18 years as it is part of health and social care services. With the move to adult services families lose out on transport between home, respite facility and school, previously enjoyed within children's services as the health and social care transport cannot take the young people to an educational facility. To this end parents/carers can find it difficult to avail of mid-week respite services because they would then have to transport their young person to respite after school- a round-trip journey of up to 40 miles- and then collect them the following morning to transport them to school. As Northern Ireland is predominantly a rural country a 40 mile round trip can take a considerable time depending on the location of the respite accommodation and the road network. Even parents/carers of children receiving respite provision have to transport them to and from the respite accommodation over weekends and during school holidays. This can be especially problematic if parents/carers do not have access to their own form of transport and have the added expense of public transport or taxis and the additional timing involved in either. To an extent this serves to diminish the respite element of the activity.

Transition Arrangements

The next set of questions was specifically designed for those parents/carers who have been through the transition process. Just over a quarter (17 families) provided responses in respect of their experiences of transition. Transition is probably one of the most important aspects of life with a severely disabled young person as they leave the security of children's services and school and move over to adult services. For many of the young people routine is key to their lives and so change can be difficult to manage, it takes time and preparation. Transition planning[23] is initiated at 14 years through the annual statement review process which considers the continued appropriateness of the school placement. From the age of 14 years best practice dictates inclusion of a transition plan within the annual review process. The plan should involve all the proposed services both within and beyond the school to plan coherently for the young person's transition to adult life. This process should be inclusive of parents, carers and most importantly the young

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[23] www.**cafamily.org.uk**/pdfs/**transition_ni**.pdf.

person. A representative from the careers services should be in attendance at the first transition plan meeting and thereafter annually to update and ensure the transition plan remains appropriate to the needs of the young person with slds.

On 25th October 2011 the P19 Lobby Group asked the Minister for Education, John O'Dowd, via Danny Kinahan MLA to consider working with other Ministers to develop a strategy to expand the opportunities for life-long learning for young people with severe learning disabilities when they leave school at 19 years. In a written response the Minister for Education outlined the collaborative work going on in this respect and detailed that the Department of Education has provided the education and library boards with approximately £3.8 million to improve transition planning process through the appointment of education transition co-ordinators and for appropriate skills/training for independent living. The Minister concluded by acknowledging the importance of the issue and gave his commitment to continue to work with Ministerial colleagues to enhance opportunities for these young people as they make the transition from school or college to adult life.

Availability of Support and Information through the Transition process

In Question 12 parents/carers were asked if they felt that there was enough support and/or information to guide them through the transition process, 83% indicated that this was not the case. Some comments from the electronic questionnaires are detailed below:

"It was haphazard. Only found out about FE lifestyles programme through the grapevine. I was informed that daycare was most likely option as there was nothing else." Male 40-50 years

"There was little or no input from the Transition officer who had never met my daughter yet felt capable of making decisions on her behalf" Female 50-60 years

"Our oldest of 2 boys is 19 and in transition and it has been a nightmare and still full of uncertainties" Female 40-50 years

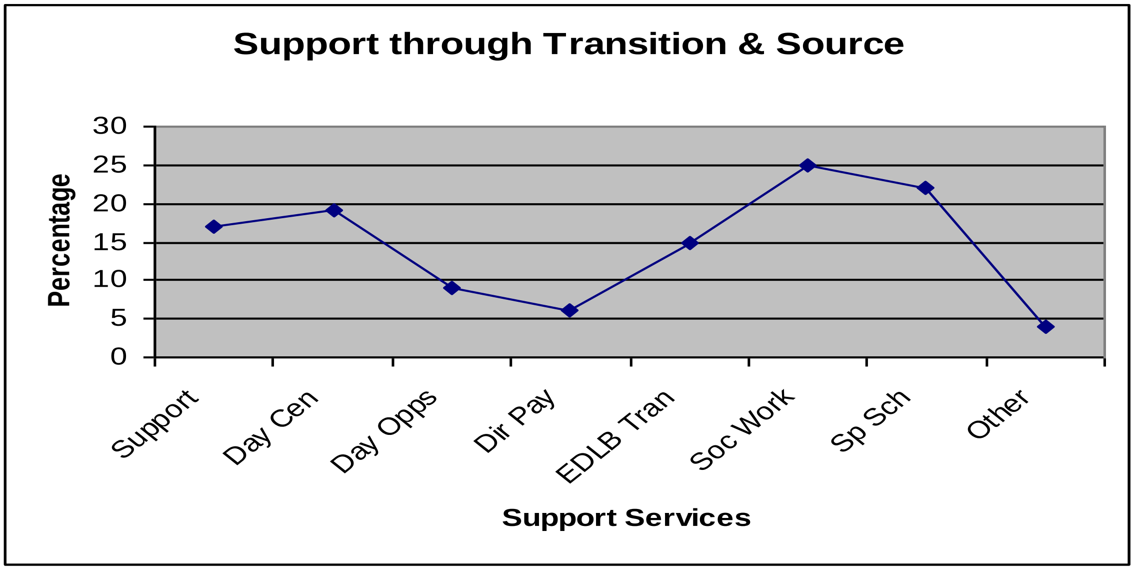
"We never felt in control of the situation yet we were going to have to face the consequences of any decision made. Took everything too long to get sorted." Male 50-60 years

Identification of support from the various agencies

In Question 13 parents and carers from the 17 families which had been through transition were then asked to identify the support they had received from the various agencies. Figure 9 overleaf illustrates that parents and carers could indicate a combination of support sources in response to this question. Some 25% of the respondents received advice and support through the transition process from social work departments; this was closely followed by transition staff in special schools. A further 19% of respondents received advice and support from the Day Centre, with 15% receiving assistance from education & library board transition staff. Finally 6% of the respondents indicated direct payments as a source of advice and support, whilst none of the respondents indicated further education colleges or supported employment placements.

In figure 9 the findings illustrate that many of the parents and carers responding to this question had children or young people with more complex or profound disabilities and thus the day centre was their only option. However, given the comments in response to question 12 and the figures here which indicate that only 15% of this cohort received advice and information from education and library board transition staff it is clear that whilst a huge investment into the transition planning process has been made by the Department of Education, the practical reality of that advice and support has yet to be felt by the families of young people with slds. Furthermore, the ethos of person-centred caring detailed in the transition plan, and advocated by the Bamford Review, has not been the experience for some parents and carers according to the parental comments recorded in the above section.

Figure 9



There is a real issue around the self-determination of disabled people in general and in this case for those with slds. Manifest in all this is the assumption that learning disabled people are incapable of making choices and are therefore dependent on those around them to make choices on their behalf. Susanne Berg,[24] when examining personal assistance reforms in Sweden, states that:

> *Reinforcing the principle of need for care, as in taking care of instead of caring for, confirms orthodox ideals of service provision by a variety of professional experts. These commonly held assumptions actively undermine self-determination on the part of disabled people.*

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[24] Susanne Berg Ch 3 “Personal Assistance Reforms in Sweden: breaking the assumption of dependency” (Adapted from Barnes C & Mercer G (eds) 2005: The Social Model of Disability: Europe and the Majority World; Leeds: The Disability Press, pp32-48)

It could be the case that the practical application of the theory actually serves to diminish the rhetoric on disability.

As outlined in the methodology section parents/carers and staff within sld schools were asked to send through information about transition experiences in the form of case studies, the following piece illustrates the situation in Dungannon.

In Sperrinview [Special School Dungannon] situated within Southern Education & Library Board we cross 2 [health & social care] trusts, Southern and Northern. In both trusts we used to have a situation where pupils commenced a transition programme with the post 19 providers in September of the year they left school. This may have started out as a visit for an hour, gradually building throughout the year, so that by June the pupil was spending at least 1 full day a week with the post 19 service. Staff in school had time to gradually impart important information to staff in the new setting, and relationships between the new staff and the pupils gradually formed. Approximately four years ago this changed.

Now we are lucky if we know what provision a pupil will have post 19 by Easter of the year they leave – this means that the transition period is minimal, if at all. Pupils and their parents are left highly anxious and distressed e.g. this year this led to a pupil with extremely challenging behaviour having a very difficult beginning to her post 19 provision. Staff at the new placement were not properly prepared and she had not had sufficient time to form relationships with them. We had been talking to the service provider about this young person's needs since her 13th birthday, as we realised how difficult the transition was going to be. Staff in the new provision, like ourselves, saw the value in a longer preparation time, however did not have the power to progress this.

Provision is similar across both trusts, however Northern Trust have improved slightly in that the pupil moving to them in September 2011 commenced his transition period in February 2011 – still not enough, but better than the previous year when a pupil still had not commenced her post 19 provision in the October after leaving school due to a transport problem!

Paula Jordan
Principal

Some additional comments from the electronic questionnaire are detailed below:

"My son has limited communication skills and challenging behaviour and it was always going to be difficult to get something sorted for him. Yet nothing was finalised before he finished school and it took some months before a place finally became available in the day centre." Female 40-50 years

"Information is available through transition fairs etc but it is general and not specific to my daughter. The real transition experience happens too late to have much parental input and for fear that if we don't take what's offered we won't get anything, we take it." Male 50-60 years

Our daughter has complex needs and we were pressing school for the last few years to get things sorted in good time mainly so that she had time to get used to the idea. Change is very difficult for her." Female 40-50 years

Whilst issues around direct payments were not a significant finding from the electronic research results with only 6% of the cohort identifying it as a source of advice and support, it was a recurring feature of the focus group discussions. The current situation around direct payments may be seen as another example of practice failing rhetoric. Direct payments were a result of the Carers and Direct Payment Act 2002[25], which as well as making new provisions for carers gave health trusts the power to make direct payments. Direct payments are cash payments made by the health trust in lieu of services that would otherwise have been arranged by the health trust, so that those in receipt of direct payments may arrange the provision of their own services. However, in practice this does not seem to have been the experience of some of the focus groups participants as will be clear from the following comments;

> *My son is 19 and in transition, he is an outdoor kind of guy and has been volunteering on Kilcreggan Urban Farm for a few years we thought this would be a great placement for him when he left school. In order to avail of this service we have applied for direct payments. But have been told by the social worker that there is a long waiting list for them and even if he gets to the top of the list there is no money available. In real terms it will cost about £50 per day for him to attend there.* Female aged 50-60 years
>
> *I rang my social worker to find out how to get direct payments and she said that they could no longer be accessed by the carer, the person who needs the money has to apply. But before they can apply they have to be assessed by a doctor who will decide if the person with slds is aware of what the money is for and how it will be spent. As most of the children who need this money are learning disabled they will probably fail the assessment and be turned down. To me this sounds like another cop-out by the government (a money-saving exercise)…. So as a result there was a court case and this has affected accessing direct payments in all of Northern Ireland* Female aged 40-50 years

The Post 19 Lobby Group sought additional information on the issue of direct payments and received the following information from the Law Centre NI:

> There was a judgment made in the High Court in 2011 *(2011)NIQB20*[26]which ruled that it had never been the intention of the Carers and Direct Payment Act 2002 for direct payments to be awarded on behalf of those requiring. Direct payments should only be paid to those capable of understanding the contractual arrangements they were undertaking. If there was an issue around their capability to understand these arrangements then family members were

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[25] www.dhsspsni.gov.uk/carers_directpay_guide_march04.pdf

[26] http://www.worthingtonslaw.co.uk/downloads/challengingtimesht.pdf

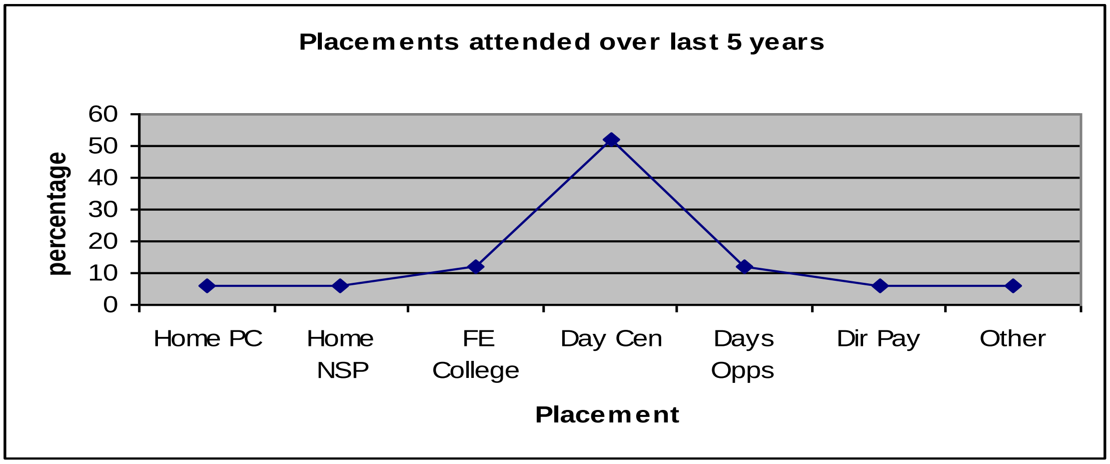
> unable to act on their behalf. Essentially the direct payment request would have to be passed to the Office of Care and Protection and future arrangements made through that office.

The five Health Boards have been enacting this legislation over the past 12 months and the consequences of this decision have yet to fully play out. It is clear that this case law has opened a vacuum which has resulted in a freeze of direct payments at parental level and stalemate as to how to take things forward. There is ambiguity as to the impact of this decision for the Office for Care and Protection. It will see a dramatic increase in its workload as this case law will not only impact on those with learning disabilities but also for those with dementia or severe mental ill health.

Post Transition Placements

In Question 14 parents and carers were asked to indicate the placements that the young person with slds had attended over the last five years; the results are illustrated in figure 10 below.

Figure 10



Overall, 52% of respondents indicated the Day Centre as the placement source. This placement would indicate that the young people with slds being cared for have more profound or complex needs. The day centre is a health trust service for those with learning disabilities, it provides respite and a range of general activities such as gardening, outings, cooking, art and music therapy. Further Education Colleges and Day Opportunities each accounted for 12% of the response rate. FE Colleges offer a combination of mainstream and discrete courses for those with learning disabilities. Day Opportunities is a recent health trust led initiative established following recommendations of Equal Lives Report 2005 and provides four areas of opportunity -recreational, vocational, volunteering and further education. A 6% response rate was recorded against those at home because their placement was completed or because no suitable placement was offered A similar percentage was recorded against direct payments and other. There follows, overleaf, some comments from the electronic survey:

"Nothing has been put in place yet although we have said our son will leave school next Easter 2012 and we still know nothing." Male 50-60 years

"My daughter currently attends day opportunities but it's not very structured and she can be bored. I don't think there's much educational stimulus for her and that's what she needs." Female 40-50 years

"He's at home, placement didn't work out he couldn't manage. Hopeful of getting him into day centre for 1-2 days. He could probably manage more than that but its better than nothing." Female 50-60 years

Time spent at placement

The next question sought to ascertain the amount of time spent on the placement each week 34% of respondents indicated that 4-5 days per week was spent on placement, with 24% indicating 3-4 days per week. The remaining 42% of respondents indicated 0-3 days per week at placement. Generally most day centre or day opportunity placements operate between the hours of 10am-3pm; travel time has to be factored into this. So for 42% of respondents the minimum placement offered to young people with severe learning disabilities would be 6 hours. It is estimated that 24% of young people could receive between 18-24 hours per week whilst the majority of young people at this point would receive between 24-30 hours placement time per week.

Impact on the Family

This final section of the electronic survey seeks to ascertain the impact of transition on family life, from employment to social activities and parent/carer views on the continued life long learning development for their young people with slds. Question 16 found that 76% of respondents stated that as a consequence of transition they had to reduce hours of employment or give up completely. Question 17 (see figure 11) went on to explain the impact of transition on parental/carer employment. 60% of respondents gave up employment whilst a further 23% reduced hours of employment. The remaining 17% of respondents indicated under Other that they had been unable to work since the birth of their child or young person with slds for a variety of reasons; some comments included on the electronic survey are detailed below:

"I had to give up my employment as my son didn't settle into his placement and as he is now at home full-time my employers couldn't hold my job open indefinitely." Female 4-50 years

"Gave up work full-time when my son was 2 as I couldn't get the right child care for him that was 18 years ago, as a result our income halved and has stayed the same since." Female 50-60 years

"My wife has had to give up her employment to care for our daughter full-time." Male 40-50 years

Parents/carers were able to contribute case studies to the research paper to give a fuller explanation of their situations, some parental comments are made below:

One of the major points I would like to make about this issue is the cost to everyone, of not providing care for our sld adults. As an example, my wife is a fully trained nurse and had reached ward sister status. She is also fully trained in cardiac and stroke issues: a major health problem in the province. She has had to give up work to look after our son, so 30 years of experience and training go down the drain! And how much is it going to cost to get a replacement with this level of experience? Now think about all the other people in similar positions and ask the powers that be, why they think they are saving money when they continue to cut services for our kids! Male 50-60 years

Although Michael is only 13-transition is looming. I currently work 25 hours per week and have negotiated a term-time contract. I am one of the lucky ones: I am employed in the public sector (for many this type of contract is not feasible or in fact permitted if in the private sector.) This is all based on the concept that Michael is out of the home on a structured learning routine. What happens when he is 19? Do I take a further hit to my income as he could potentially only be offered 2/3 days per week in a day centre with "older" people? Female 40-50 years

Parents/carers discussed their experiences of juggling work and caring responsibilities at the focus groups. One parent commented,

> *Employers have no concept of how overwhelming caring can be, and consequently limited compassion or even understanding.*

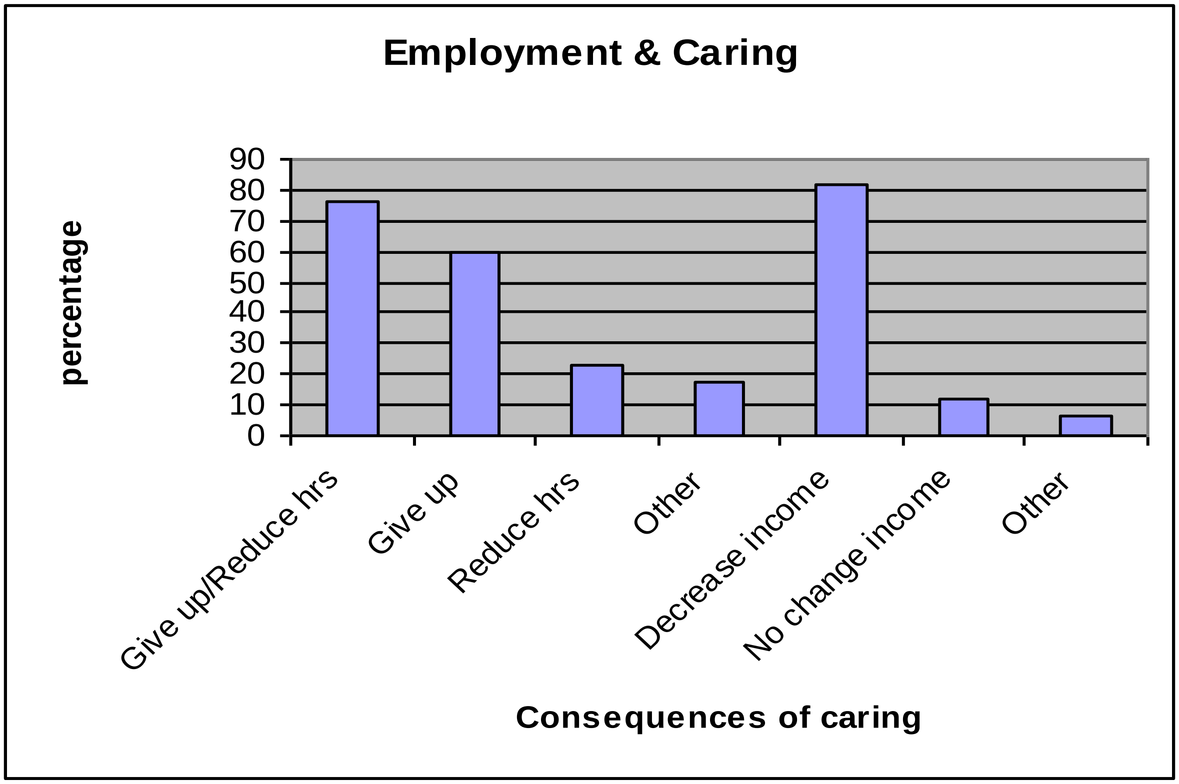
Families have to find ways of making things work for them, in two parent families the general consensus was that one parent worked whilst the other took the main caring role as illustrated in the following comment;

> *My husband is the full time carer whilst I work part-time, we have two young boys with severe learning disabilities. My husband manages a care farm offering work on therapeutic placements to four young adults in horticulture and animal husbandry. There are plans for supportive residential placements in the future.*

Household Income, Employment & Caring

Question 18 seeks to ascertain changes to the household income as a consequence of transition. As 82% of households detail a decrease in household income it is clear that transition does have a significant impact on family life, and particularly for those parents/carers who have been able to work. However, whilst the significance of transition cannot be understated for many parents/carers it has been their caring responsibilities that have been greater and enduring. Many parents from two parent families stated that one went to work and one stayed home, such was the nature of their child's condition. It was usually the mother who remained at home, with a few exceptions. Yet according to the Papworth Trust[27] that annual cost of bringing up a disabled child is three times greater than for a non-disabled child. The Papworth Trust goes on to state that the average income of families with a disabled child is £15,270 some 23.5% below the UK mean income of £19,968 and 21.8% of families have incomes that are less than half of the UK mean. The Post 19 Lobby Group electronic survey findings would support the statement that 84% of mothers with disabled children are not working as compared to mothers of non-disabled children. Only 3% of mothers with disabled children work full-time and 13% work part- time.

Figure 11



The Disability Alliance in their position paper "Employment for People with Disabilities in Tough Economic Times"[28] states that disabled people are twice as likely to live in poverty than other citizens and are more likely to be hit first, hardest and longest by the current recession. Yet statistics[29] show that 1 in 5 disabled people in the UK are unemployed but want to work. This compares to 1 in 15 of non-disabled people. Carers UK[30] are warning of a care crisis in costs to business. A survey of over 4,000 carers by the charity found that 31% of working-age carers gave up work or reduced their working hours in order to provide care because local care services were unsuitable. A new study published in May 2012 from the London School of Economics estimated the public

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[27] www.papworth.org.uk

[28] www.disabilityalliance.org

[29] www.efd.org.uk/disability/disabilityfacts

[30] www.**carersuk.org**/newsroom/item/115

expenditure cost of families quitting their jobs to care is a staggering £1.3 billion a year in carers' benefits and lost tax revenues.

The focus group discussion did touch on the welfare reform changes that would impact upon families with a disabled young person with severe learning disabilities. It was likely that some people may be affected by the change in working hours criteria for Working Families Tax Credits. The changes which came into effect on 5th April 2012 saw an increase in employment criteria from 16 hours to 24 hours of employment for couples. For many families increasing hours of employment is not an option, not only because they only work part-time to fit around caring responsibilities but also because the economic climate in which businesses are operating means there are limited opportunities to make these increases on the part of employers. However, following campaigning from Carers UK[31] and other groups including the Low Incomes Tax Reform Group and the union USDAW, the government has announced that couples including someone on Carer's Allowance will be exempt from this increase from 16 to 24 hours. This means that a couple with at least one dependent child, where one partner is entitled to Carer's Allowance, will continue to be able to receive Working Tax Credit if one parent is working for at least 16 hours a week. This includes people with an 'underlying entitlement' to Carer's Allowance, where you are entitled to the benefit but it is not being paid to you because you receive other benefits which are seen to 'overlap' with Carer's Allowance.

In the PSE UK Response to Northern Ireland Draft Budget paper[32] it states that a proportionately higher number of households in Northern Ireland will see their income diminish as the £18 billion benefit cuts are implemented for 2 reasons. Firstly, there is a higher number of households with children (26% of households in Northern Ireland are in receipt of child benefit) and secondly a higher number of households are reliant on welfare benefits as their main source of income (10% as compared to 6% in England). Overall 3% of total household income in Northern Ireland comes from disability-related benefits which are a particular target for change.

The change process which will see the change from the high cost Disability Living Allowance (DLA) to the Personal Independent Payment (PIP) is already underway and immediately following its introduction in April 2012 it was thought that its impact would be felt by current children/young people claimants by 2015. In Northern Ireland there is a higher percentage per head of the population in receipt of DLA (10% as compared to 6% in England) and the proposed welfare reforms will mean that the very people that the state has a responsibility to protect will be losing out. Even allowing for the 0.5% of wrongful/fraudulent claims there will still be, under these new proposals, a 19.5% decrease amongst people currently qualifying for DLA.[33] Over the period 2006/07 to 2008/09, 30% of disabled working-age adults in Northern Ireland were living in low-

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[31] http://carersuk.org/newsroom/WorkingTaxCreditchanges:whatyouneedtoknow

[32] http://www.drdni.gov.uk/poverty___social_exclusion_in_the_uk_project_-_queens_university_belfast___economic___social_research_council.pdf)

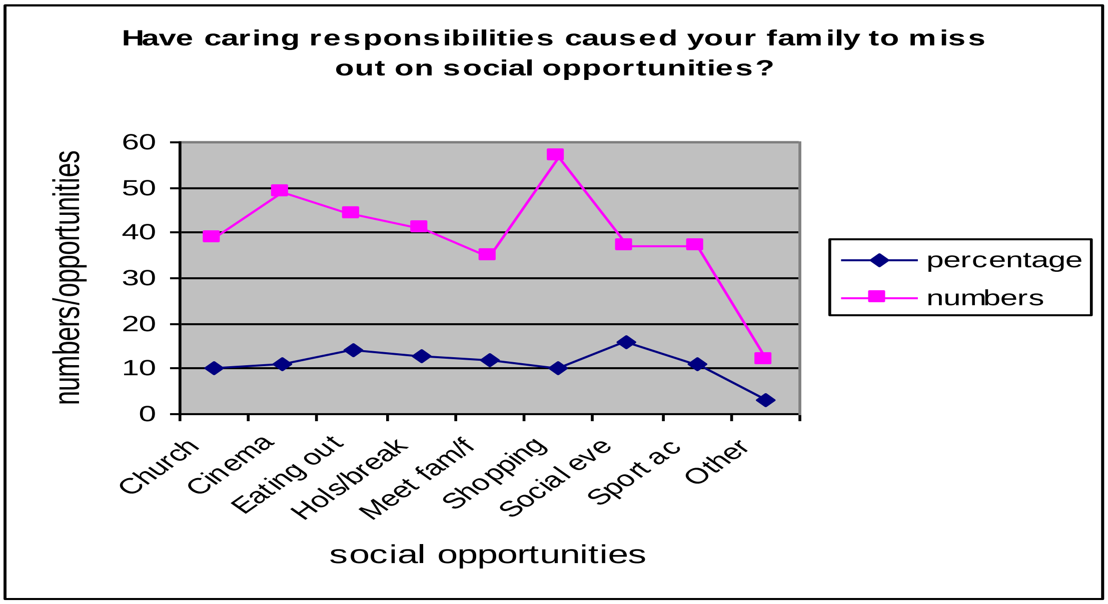
[33] www.poverty.org.uk/i40/

income households (around 40,000 people). This was twice the number of low-income households with non-disabled adults. This would suggest that welfare reforms will hit heavily on those who can afford it least. There are real concerns, too, that those with learning disabilities or limited literacy will not understand the impact of these changes and not be able to protect themselves and their rights adequately. Ultimately there could be many who will lose out and slip further into the poverty. At this point the Coalition Government[34] has no plans to implement PIP's changes in respect to disabled children currently in receipt of DLA. However, this may prove to be an option at a later date.

Social Opportunities

Question 19 moves onto the impact of caring responsibilities on social activities. Parents/carers were given a list of social outings, including church services, social outings, shopping, sports and recreational activities, which they may have missed because of caring responsibilities from which they could choose as many as appropriate.

Figure 12



Comments from parents/carer are probably the best illustration of the difficulties of having a social life when the majority of respondents report having caring responsibilities which are in excess of 70 hours per week.

"Impossible to bring my two very disabled children with autism to social outings which has a very negative impact on my other child who does not have a disability and on us as a family," Female 40-50 years

"Because of unpredictable behaviour it can be difficult to plan anything." Male 50-60 years

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[34] www.**number10.gov.uk**/news/speech-on-**families**-and...relationships

"As a family we have missed out on all of the activities listed. Particularly hard for other children without disabilities." Female 50-60 years

"All activities have to be planned with military precision. Nothing happens spontaneously. Family members lead very separate lives." Female 50-60 years

"Your life changes completely when you have a disabled child. It can be difficult to go out as he is very routine-bound and new places can cause a sensory overload so often its not worth the hassle." Female 30-40 years

Mencap's 2012 study ***"Stuck at home- the impact of the day care service cuts on people with a learning disability"***[35] exposes the heavy impact of cuts and increased charging for services on disabled people-leaving them feeling isolated, lonely and cut off from their communities. From these responses in regard to attendance at social events it is clear that families with children and young people with slds find that the opportunity to attend social functions is severely curtailed.

An emerging issue from the focus groups was the particular difficulties faced by families with two or more disabled young people, a parent commented:

> *Well life for us is certainly hectic with one child in children's services and the other child in adult services. Our respite dates don't match up so we are now getting respite at different times. This is of no use to us as a family to spend time with our other son or to spend time as husband and wife. We haven't had sleep for 19 years as the boys need care night and day, with one boy getting up at 5am every morning. Children's and adult services don't communicate and we are the in-betweeners all the time. How are we expected to charge our batteries when we can't get a weekend off. Yet, we as carers of two disabled children get the bare essentials of help. There is no planning or structure put in place for families like us.*

Essential Services for those with sld's

The service/activities which parents/carers feel are essential to support the life-long learning needs of a young person with severe learning disabilities are illustrated in *figure 13* overleaf. Overall, 55 respondents (18%) felt that a combination of learning/life skills opportunities were essential to supporting the life-long learning needs of a young person with severe learning disabilities. Parents/carers also indicated new opportunities for learning and exploring best practice from Europe, with 43 respondents (14%) and 41 respondents (13%) respectively. Supported employment and educational opportunities were next to poll with 39 respondents (13%) on the electronic survey. Day centre opportunities only accounted for 24 respondents, or 8% of the choices given.

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[35] Mencap "Stuck at home-the impact of day care service cuts on people with learning disability" May 2012 www.mencap.uk.org/publications

Figure 13

Some parental comments from the electronic survey are noted below:

"He needs to be continually developing his learning and with the best will in the world the day centre does not necessarily have the time to do that. He does receive therapies, music and arts & crafts but they are not designed for him individually. He can choose to participate and if he doesn't join in there is limited encouragement as it would mean time and effort on the staff's part which they are ill-placed to provide. I'm not knocking the staff. They do all they can with limited resources and heavy workload." Female 50-60 years

"Learning does not stop for young people at 19 years. It is the same as it is for everyone else. It continues and my son needs to be stimulated and encouraged to continue his learning and developing independence." Female 40-50 years

"We need all the help we can get to make his life worth living." Male 40-50 years

"I am an occupational therapist and mum to two young boys who have severe autism. Last year I looked into what opportunities would be available to them post 19 and was very disappointed with the lack of services available. I did a bit of research into what was available in other countries which would possibly meet my boys' needs into the future. This research brought me to care farming (www.carefarming.org). In September this year [2011] I am pleased to say that my husband and I started the first Care farm in Northern Ireland dedicated to adults with learning disabilities and a member of Care Farming UK. It is called Annagh Care farm, based in Aughnacloy Co Tyrone and provides a different sort of day opportunities in a supportive natural environment." Female 30-40 years

"Day Centre not equipped to cope with individual needs therefore specific package needed to ensure social interaction, exercise outings, i.e. swimming, beach drives. Possibility of direct payments to ensure best possible package in conjunction with supported living package. Original supported living package can not be maintained due to level of care young person requires. Adult services have asked for the revised package to include day care, even though all individuals working with the young person are in agreement it would not be an option. Revised package is already in the process of being agreed with no input from family. Family have had no contact with social worker since the beginning of August despite written request to arrange review and provide specific information." Male 40-50 years

At the video conferencing focus groups which took place on February 21, 2012 parents/carers took the opportunity to consider the essential services those with slds would require. Further Education Colleges offer a number of mainstream and discrete courses designed for those with learning disability. The entry level required for these courses is usually based on ASDAN certifications gained within the school system. However, parents felt that it should be possible for the colleges to do more at entry level as there was a huge gap between this and levels 2 and 3 which young people with learning disabilities find hard to negotiate. Parents were keen to share positive experiences of day care arrangements. One parent gave the following example:

> *We've had a great experience with Fresh Focus [Western Trust]and intervention for adults with learning disabilities within a day care setting for a number of years they spent time concentrating on travel and independent living skills.*

Parents/carers were in agreement that young people with slds needed to have ongoing support and assistance with their learning in social and life skills and so training and employment services needed to be more responsive to them as an individual as should public expenditure levels. The Bamford Report emphasised person centred caring and parents were keen for this principle to receive a practical application. One parent noted that:

> *Employers should receive training on learning disability and how our young people learn and about their capabilities. Our young people need to learn but they need to do so in the right environment. We need a more holistic approach to ensure their health and emotional well being.*

The biggest fear for parents/carers was,

> *Who will look after our children when we are gone?*

Parents/carers want to protect their vulnerable young adults as much as possible, life-long learning is the ultimate goal. However, this may be an understatement of the range of emotions at play as there remains a reluctance in parental understanding to overcome over-protection. Over-protection can be as much of a hindrance to the development of independent living skills. Whatever the case it is clear that parents/carers do want more opportunities for learning for their young people so that when the inevitable happens the young people will be better placed to cope.

Personal development skills and services essential to those with slds

The final question of the electronic survey sought parental/carers input into the personal development skills and services which are essential for young people with slds, they could choose one or more of the options. In figure 14, 53 respondents (14%) felt that personal care was essential to young people with slds. 51 respondents (13%) indicated that independent living skills were essential. A point of clarification is required at this point. Independent living skills do not, as they may for non disabled 19 years olds, mean living independently. Rather independent living skills should be appropriate to the ability of the young person with slds, which might be as basic as the ability to communicate their needs. A further 50 respondents (12%) identified both assistance to attend placement and personal development as essential. Some 46 respondents (10%) felt that communication skills and 48 respondents (11%) identified social opportunities as essential services.

Figure 14

Some of the comments recorded on the electronic survey are detailed below:

"All these things are provided as part of school. Now with the move to the day centre I am once again on the phone trying to get all the things he needs sorted. It's a full-time job. You speak to one person, give them your details then when you phone back you have to go through the same thing again with someone new. It's so frustrating." Female 50-60 years

"Activities to promote independence as much as possible." Male 50-60 years

"Young people with learning disabilities need to be challenged to get on with whatever life throws at them." Male 40-50 years

"More joined-up and appropriate post-transition opportunities must be made available." Female 50-60 years

"It all comes down to money really. It's unlikely that my son will have a job and contribute to society through taxes etc. However, he does have skills and abilities that can be utilised. So whilst his contribution may not be financial that doesn't mean the world has to ignore him. It just has to appreciate his unique contribution. The world is a better place for him being in it." Female 40-50 years

There follows the final case study provided by a parent located in the Western Board illustrating frustrations with the transition process;

As a parent of a post 19 who has been through the system. Three years later parents are still in the same position. No places for their young people. We are meeting with local politicians, MLAs and the Western Health and Social Care Trust and most importantly the parents who are distraught at the thought of having their young people at home on a 24/7 basis. When will politicians realise that under-spending in learning disability will lead to an overspend in Mental Health due to the stress the parents and carers are under? Female 50-60 years

As the current economic downturn shows no signs of abating it can be easy to conclude that there are no available resources with which to influence change. However, for those with a disability it is clear that resources under the social care budget have not been forthcoming for many years. In the Appleby Report (March 2011)[36] it was stated that in the Review of Health & Social Care 2005 need in Northern Ireland was 9.5% higher than for England, implying a 9.5% per capita spend in Northern Ireland. The equivalent updated figure would now be in the region of 11.5%.

The draft budget for Northern Ireland for 2012-13[37] sees the Department of Health, Social Services and Public Safety receive the highest proportion (41%) of current expenditure available to Northern Ireland 2012-13. This amounts to some £4,427.7 million. Of this figure 77% has been protected for health-related services, with the remaining 23% (to include personal social services) subject to efficiency savings as per every other department. Furthermore, the department will receive £278.8 million in capital investment. The Department of Education will receive £1857.3 million in current expenditure and £100.4 million in capital investment, while the Department of Employment and Learning will receive £767.4 million in current expenditure, with £32.3 in capital investment. Bearing these figures in mind, the Post 19 Lobby Group would be identifying these key governments departments as having a specific remit for those with slds and seeking their co-operation to consider investments in alternative care solutions. It is of particular note that carers save the NI economy upwards of £4.4 billion each year which is more than the annual National Health Service spend in Northern Ireland (Carers NI[38], 2011)

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[36] www.dhsspsni.gov.uk/final_appleby_report_25_march_2011.pdf
[37] http://www.northernireland.gov.uk/website_-_draft_budget.pdf
[38] http://www.carersuk.org/about-carers-northern-ireland/facts-about-carers-ni

One of the key messages arising from this final section of the report is that ongoing stimulating and meaningful educational input into the lives of young people with slds is essential to their personal development and progress towards independence. Health Trusts across the province have over the last few years been mindful of the recommendations from the Equal Lives Report 2005[39] and the Bamford Report which both indicated the need for the wider use of a range of community-based opportunities and options for those with learning disabilities and a reduced reliance upon the traditional adult day centre. There have been some moves to reduce this reliance on the day centre model with the introduction of the day opportunities services. The experience of survey respondents has illustrated that there is still some way to go in terms of providing meaningful opportunities, particularly for those with more profound and complex disabilities.

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[39] Equal Lives Report: Review of Policy and Services for People with a Learning Disability In Northern Irelands (DHSSPS 2005)

Conclusions

This research paper had a number of aims and in pulling together the conclusions drawn from the research, the aims should be restated and conclusions developed.

1. To investigate family life with a young person with severe learning disabilities. and consider the impact of caring.
2. To consider the impact of transition upon the family.
3. To ascertain the personal development skills which parents and carers feel are essential to the life-long learning needs of young people with severe learning disabilities.
4. To provide alternative solutions to the day centre model of care for those with more complex or profound disabilities.

To investigate family life with a young person with severe learning disabilities. and consider the impact of caring:

This research provides a rich and insightful overview of family life with a severely learning disabled member before going on to explore the impact of transition on that family. To begin investigations on family life with a severely learning disabled member demographic information was sought from parents and carers: the majority of respondents to the electronic survey were female (84%) and of that nearly half (34%) were aged between 40-50 years. Two-parent led families with variations on the numbers of child dependents, made up the majority of respondents (74%). These findings would support Clarke and McKay's[40] suggestion that there is limited evidence to suggest that impairment and disability has any significant impact on family forms. In terms of geographical location, respondents from all areas of Northern Ireland participated in the electronic survey, and this overarching geographical response was reinforced through the video conferencing focus groups and case studies. Overall, 13% of parents/carers identified themselves as suffering from a disability in the final demographic question.

When seeking clarification of hours spent on caring responsibilities it is clear that caring for a child or young person with slds has a significant impact on family lives with 62% of respondents spending upwards of 70 hours per week on caring responsibilities. Another 20% were caring between 50-70 hours per week, whilst a further 18% were caring for up to 50 hours per week. When taken in context with findings from Carers NI[41] which states that one quarter of all carers provide 50 hours per week on caring responsibilities, it is apparent that parents/carer respondents were providing care, at least on a comparable level with Carers NI figures. But, for the majority there is a substantial increase in caring responsibilities in line with the additional needs equating to slds.

Bearing in mind the hours spent each week on caring responsibilities it is disappointing to find that the main source of support to assist with caring responsibilities is drawn from family and friends (37%). Social Services do provide formal support service to 28% of

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[40] Harriet Clarke & Stephen McKay "Exploring disability, family formation and break up: Reviewing the evidence." Department of Work & Pensions Research Report No 514 2008 ISBN 978 1 84712 4005

[41] http://www.carersuk.org/about-carers-northern-ireland/facts-about-carers-ni

respondents. However, as previously stated this is probably more indicative of the age group of the children and young people with slds whose parents and carers responded to the electronic survey who receive respite services rather than an indication of statutory support services as a whole.

As 77% of respondents indicated that caring responsibilities had impacted on their health the proposition of unrelenting caring pressure can be extrapolated further. One-third of respondents went on to provide additional information about the nature of their health difficulties- a combination of physical problems as well as high stress levels. Some 25% stated that depression, stress and anxiety were an integral part of family life. However, when asked if their caring arrangements had ever broken down because of carer ill health, only 43% indicated that this was the case.

A bleak picture of family life with a severely learning disabled member is emerging from these research findings. This substantial caring undertaking occurs with limited formal assistance, mostly based upon a reliance of family and friends to cover any gaps. In addition to the 77% of parents/carers indicating that caring responsibilities had had an impact on their health. Some 74% of that number went on to assert that any break in caring arrangements because of carer ill health only lasted between 0-4 weeks. During that period the majority of respondents (43%) relied upon informal support mechanisms, namely family and friends. With their unrelenting schedules for caring upwards of 50 to 70 hours per week parents/carers need to be able to access support services quickly and without detriment and sadly this research shows that this support is clearly not forthcoming from formal statutory services.

Respite was one of the contentious areas for discussion at the video conferencing focus groups held on 21st February 2012. The difficulties with respite provision seem to peak when the young person with slds reaches 18 years and the anomalies in departmental criteria for respite arise. In Northern Ireland the Department of Health recognizes a young person with slds as an adult when they reach the age of 18. However, within the Department of Education the young person with slds is deemed a child until adult services transition begins at 19 years. This anomaly is reinforced by MacIntyre[42] as she states that the transition from children’s to adult services is a complicated business, occurring at different ages and involves different criteria, depending on the organisations involved.

The second aim of the research was to investigate the impact of transition on family life. As explained in the opening paragraphs the process of generic transition has become increasingly difficult for all young people. The change of status from childhood to adulthood marks, for all young people not only those with slds, a time where choice and responsibility for the choices made are deemed to rest with the individual. Newman and Blackburn[43] state that transitional periods can be considered a time of threat but it can

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[42] Gillian MacIntyre Chapter 4, Alison Petch ed, Making Transitions: Support for individuals at key points of change, The Policy Press, Bristol 2009

[43] Tony Newman & Sarah Blackburn, Transition in the lives of Children & Young People: Resilience Factors 2002 No78 Interchange Series ISSN 0969-613X Barnardoes Policy Research & Influencing Unit

also be a time of opportunities for change. If all protective and risk factors are in place it is likely that a successful transition may be made. However, if the child acquires neither the coping skills, nor is placed in an encouraging environment, then periods of transition may become points in the lives of children or young people where serious development damage may occur. If, as we are led to understand, transition is difficult for all young people, how much more difficult must it be for those young people with a limited understanding of the world around them and often limited communication skills to make their choices understood?

To consider the impact of transition upon the family:

The next set of findings in relation to transition should begin to tease out some of these issues. Some 26% of the respondents to the electronic survey felt equipped to answer the next set of questions as they had moved through the transition process with their young person. Parents/carers were unimpressed by the support provided through the transition process, with 82% of eligible respondents indicating that they did not receive enough support. The case study provided by the Principal of Sperrinview Special School in Dungannon outlined the situation for a number of young people with less than satisfactory transition experiences. This despite the substantial investment of £3.8 million in 2008 by the Minister of Education to education and library boards to improve transition planning process through the appointment of education transition co-ordinators and for the development of appropriate skills for independent living.

Parents/carers identified social services as the key provider of support through the transition process. This is probably more indicative of the limited availability - currently only day care opportunities - for those young people with more profound and complex disabilities. Despite the aforementioned investment in the transition planning process only 15% of respondents indicated this as the source of their support.

Self-determination has continually been an issue and cause of dispute for young people with slds. The fault lies not only in the lack of ongoing opportunities for those with more complex and profound needs but often with parents/carers who, having provided such intense and prolonged assistance to their children, often find it difficult to take a step back and defer to the choices of the young people. This is not intended as a criticism. It is as much a symptom of a changing society focused on risk management as identified in the research introduction as parents/carers managing under very difficult circumstances. Essentially the information coming from the research findings is that transition planning process is at best patchy and sporadic and at worst non existent, with many placement arrangements not secured until the last minute and some postponed until transport arrangements could be made, often with the consequence that young people have left school and are at home until the placement can be scheduled. It is understandable then that this situation in addition to the unrelenting nature of their caring responsibilities, can prove frustrating for parents/carers. There is a real fear, endorsing the findings of the "***My Day, My Way Report***"[44], articulated by parents/carers that if they do not take what is

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[44] Bamford Monitoring Group August 2011-“My Day, My Way Research Paper”-Patient Client Council and Mencap

offered from the available transition opportunities they may receive nothing. In this instance it is all too easy to see how the Equal Lives Report 2005[45] records an estimated 16,000 people with learning disabilities not known to or in receipt of statutory services.

Another alarming finding arising from the electronic survey is the 76% of parents/carers who have had to give up or reduce hours of employment as a consequence of transition. Whilst this in itself can seem difficult to comprehend it does not end there, as a further 17% of respondents indicated an inability to hold down employment of any form since the birth of their child with slds. It is unsurprising then, but equally disconcerting, that 82% of parents/carers indicated a decrease in their household income as a consequence of transition. Set against the suggestion from the Papworth Trust[46] that raising a disabled child is three times more expensive than for a non disabled child it is a very worrying statistic indeed.

Social isolation is clearly an overwhelming factor of life for families with a severely learning disabled member. Many families indicted their inability to attend a range of social opportunities from church attendance to sporting events to shopping or even nights out, the activities taken for granted by society as a whole. A particular problem has been identified by the families with two or more disabled children/young people. Social isolation is one thing but for them even managing some semblance of family life is quite another, especially when trying to negotiate coordinating respite care with two different providers.

To ascertain the personal development skills which parents and carers feel are essential to the life-long learning needs of young people with severe learning disabilities:

In response to the third stated aim of the research parents and carers were given the opportunity to identify the services and/or activities which they felt were essential to the life-long learning needs of their young person with slds. The majority of parents/carers were able to choose from a number of services and activities and make comments about their choice. The consensus being, learning does not stop for young people with slds at 19 years, so opportunities for ongoing learning are essential. This is particularly true for those young people with more profound and complex needs who are generally placed within day care centres as there are few opportunities and too few support systems to enable them to enter further education. Furthermore, there is recognition that the onset of puberty and continued learning can prove a difficult time for young people with slds. It is as if these two aspects work in direct competition with one another and learning proves to be a struggle during puberty. Wright and Zecker 2004[47] concur that the onset of puberty coincides with a halt in learning disabled children's development. It is then possible to assume that as the young person reaches the age of 19 years, despite their mental capacity, the physical changes and hormones which have been surging during puberty

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[45] Equal Lives Report: Review of Policy and Services for People with a Learning Disability In Northern Irelands (DHSSPS 2005)

[46] www.papworth.org.uk

[47] Beverly A. Wright and Steven G. Zecker "Learning Problems, Delayed Development and Puberty," Science Daily (June 22, 2004) — EVANSTON, Ill. www.**sciencedaily.com**/releases/2004/06/040622021222.htm

will begin to ease and they can refocus with their learning capacity given the right opportunities. Parents/carers were very clear that independent living skills must continue for young people with slds in which ever placement they receive. Unfortunately day care environments, in which 20% of young people with more profound and complex learning disabilities are entering every year in Northern Ireland, are simply that – day care. There is little educational focus. Parents and carers are clear that more opportunities are essential, especially for those with more profound and complex needs, so that young people with slds are better placed to cope if and when parents/carers are no longer able to manage the care requirements or have passed away.

The third and fourth aims of this research paper are inextricably linked. The lobby group was clear that whilst it wanted to provide a warts-and-all snapshot of life with a severely disabled family member, it also wanted to provide meaningful alternatives to the current structures for life-long learning and to promote additional educational measures which could be introduced to day care settings for those with more profound and multiple disabilities. Parents/carers indicated that exploring new opportunities for learning and considering best practice from Europe was a way forward in seeking an alternative model of education and care.

To provide alternative solutions to the day centre model of care for those with more complex or profound disabilities:

In the first instance the lobby group looked to Care Farming when seeking meaningful alternatives to the current post 19 options. Care farming (also called ‘social farming’ or ‘green care farming’)[48] can be defined as the use of commercial farms and agricultural landscapes as a base for promoting mental and physical health, through normal farming activity. It is a growing movement to provide health, social or educational benefits through farming for a wide range of people. This may include those with defined medical or social needs (e.g. psychiatric patients, those suffering from mild to moderate depression, people with learning disabilities, those with a drug history, disaffected youth or elderly people) as well as those suffering from the effects of work-related stress or ill-health arising from obesity. Care farming is therefore a partnership between farmers, health and social care providers and participants. Across Europe, especially in the last 15 years, the utilisation of farms as Care farms has become well established. Care farming provides a concrete example of the current view of health care provision in that it moves care from the institutional setting to a community setting and promotes the integration of service users back into society by providing them with life-long skills.[49] Currently there are two National Care Farming Initiative (NCFI) registered farms in Northern Ireland and exploratory funding opportunities from the INTERREG Social Farming Project are proposed to take place in Northern Ireland and the border counties in 2011-13. It is the intention that social farming becomes a viable activity that brings a high quality social support and health services onto Irish and Northern Irish farms.

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[48] Social Farming An Opportunity for Northern Ireland 2010 Department of Agriculture and Rural Development: Adam Harbinson DARDNI Rural Policy Division NI

[49] (Hassink & VanDijk, 2006; Hine, Peacock & Pretty, 2007; Great Britain. Department of Health, 2010b; 2011c; b).

Upon the discovery that the cornerstone of disability policy in Scandinavian countries is that everyone is of equal value and has equal rights the lobby group chose to review their disability experience when considering best practice from Europe. It is the aim of the policy to close the gap between disabled and non-disabled people. Scandinavian countries rely upon the social model of disability favoured by Great Britain in recent years. For the purposes of this research report an examination focused on the situation in Sweden, as policies there are broadly reflective of disability policies across Scandinavian countries including Denmark and Norway. In Sweden the rights and responsibilities of disabled people are prescribed through the Social Services Act (SFS2001:453) and the Act concerning Support and Services for People with Certain Functional Impairments (LSS1993:387)[50]. January 1, 2007 marked an introduction of the right to basic adult education for intellectually disabled people who do not have the skills that compulsory social schools are designed to provide but are capable of benefitting from such an education. Although it is acknowledged that people with severe learning disabilities very seldom have a regular job, municipalities are responsible for ensuring that people with disabilities who do not have a job are provided with a meaningful occupation or daily activities up until the age of 65 years. The daily activity must suit the differing needs and preferences of the participants. It must be developmental. Berg 2005[51] argues that the Swedish reliance on the social model of disability simply seeks to reinforce dependency and undermine self-determination. It promotes self-determination on one hand yet serves to diminish it with a lack of resources to provide for disabled citizens' rights.

So whilst the lobby group can acknowledge that there are flaws within the system and the rhetoric may not be matched by the reality it is this right to a basic adult education and access to daily activities up to the age of 65 years that are enshrined within disability policies which are of particular interest. Whilst Great Britain, and as a consequence the Northern Ireland Assembly have signed up to the UNCRPD it remains a fact that Articles 24 & 27 in relation to education and work and employment, respectively, have yet to be ratified. Thus the duty to provide appropriate life-long learning opportunities is optional rather than essential. In reality, the Appleby Report 2011[52] suggests that expenditure in social care services in relation to need in Northern Ireland as compared to the UK, has been subject to a cumulative under-spend of 36% over the last three years. This cumulative under-spend reflects the latest figures in the long-running tradition of scarce resource availability for social care.

There are very positive examples of supported employment opportunities and social firms operating in Northern Ireland. These include community based/voluntary led organisations such as Cedar Foundation, Loaf, Mencap, Orchardville, Stepping Stones and Triangle, as well as social firms such as Acceptable Enterprises. These organisations provide meaningful work-based and skills development experiences for young people

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[50] The Study of specific risks of discrimination against persons in situations of Major Dependence or with complex needs. Report of European Study. Volume 3: Country Reports and Stakeholders Interviews ISBN2-87460-095-4 www.**leeds.ac.uk**/disability-studies pp 367-398

[51] Barnes C & Mercer G (eds.) 2005:"The Social Model of Disability: Europe and the Majority World":Leeds:The Disability Press, Ch3 pp32-48.

[52] www.dhsspsni.gov.uk/final_appleby_report_25_march_2011.pdf

with a range of learning disabilities, including some with slds. In addition they ensure that young people gain qualifications and promote independent living skills, such as independent travel skills, money management and personal and emotional well being. These organisations do not have the resources to provide the support required for those young people with more profound or complex disabilities and it is clear from the research findings that parents/carers of such young people want to secure the same educational and personal development opportunities. The only option for these young people is the day centre and it is unfortunate that these do not have an educational focus. The Health & Social Services Boards which oversee these facilities across Northern Ireland are aware that the "one size fits all" approach is no longer relevant and changes have been made to day care provision in recent years. If the endorsements of Equal Lives and Bamford are to be fully embraced then further changes are required.

The lobby group began to seek information on innovative organisations that were doing things differently to see the potential for future opportunities. The Kingwood Trust[53] in Reading has provided critical support and development services to people with autism and Aspergers for many years. Kingwood enables people with autism and Aspergers to live in their own homes and enjoy full and active lives in the community. The Trust plays a pioneering role in developing new ways of supporting people with autism to realise their potential by concentrating on the individual and focusing on what's positive and achievable in their lives. For several years Kingwood Trust had been receiving an increasing number of requests from the parents of school leavers who are keen for them to embark on a programme of skills training and education which prepares them for the world of work, however profound their disability. To this end Kingwood Trust are in the final stages of developing their latest venture the Kingwood College, a residential college for young people aged 18-25 years. The college will continue to develop partnerships the Trust has with local authorities, between health and education departments and with Reading Further Education College. The college will open for its first students in September 2012. The college represents a major development in the services that Kingwood provides and it is intended that Kingwood College will provide a blueprint for other post-school establishments, where experienced teams of professional staff will deliver the support and life-skills training young learning disabled people deserve. The Chief Executive Officer of Kingwood Trust, Su Osborn, has invited the Post 19 Lobby Group and Northern Ireland Assembly members to come over to Reading to visit the college upon its opening in September 2012.

So despite the discouraging picture emerging of life with a severely learning disabled member in Northern Ireland the lobby group are encouraged by the possibilities identified in this final section of this research paper. It has been clearly identified that the hopes and aspirations of the young people with slds and their parents/carers appear to have been lost in the complexities of the transition process. For too long, young people with slds and their parents/carers have witnessed an erosion of services and this has been reinforced by the findings of the Appleby Report 2011. Yet their voices are not heard protesting about this, or if they are heard, they are told that because of a lack of resources it is not possible to accommodate their needs. Equality is a crucial issue which has been side-stepped and

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[53] www.**kingwood.org.uk**

ignored through community care policies; paying lip service to equality issues fudges the need to take real action. It is all too easy for health trusts and education boards to walk away from the complex needs of young people with slds stating there is not enough money to accommodate these needs within current structures. Surely the whole reason and point of focus for the introduction of the Disability Discrimination Act - recently replaced by the Disability and Equality Act 2010 - the UN Convention on the Rights of People with Disabilities and UN Convention on the Rights of a Child were to ensure there was a legislative framework to uphold the rights of a disabled person. It is a disgrace in the 21st century that any person with slds and their parents/carers are still being told that, despite a need having been assessed, that there is not enough money to make appropriate provision. That is not a good enough reason for the opportunities not to be realised and best practice would dictate that it is not even adequate.

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