

The Post 19 Campaign

The Post 19 Lobby Group is made up of 150 parents, carers and 21 special schools for severe learning disability from across Northern Ireland. The lobby group enjoys the support of 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 severe learning disabilities (sld) 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, the lobbying activity did not prove fruitful. Hill Croft PTA, having prioritised post 19 transition moved with renewed vigour 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

This event proved to be the turning point for the campaign as parents and carers were encouraged to harness parent power from across Northern Ireland through which to advocate for change. The lobby group has, over the intervening period of two years, built a 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 and has direct links to parents associations where they exist. The lobby group has 150 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.

The campaign has successfully sought the support of many Members of the Local Assembly from across Northern Ireland. The campaign has also been recognised by the Shelia McKechnie Foundation [www.smk.org.uk] one of the only UK based organizations designed to support campaigners, as Julie Jamieson was awarded the 2013 Social and Economic Justice award. Julie has been leading the work of the Post 19 Campaign since its instigation in 2010.

Terms of Reference for the Inquiry into post Special Educational Need Provision in education, employment and training for those with Learning Disabilities.

1. To examine the current range of choice and opportunities available for those with Learning Disabilities on leaving full time schooling.

The Post 19 Campaign was established in 2010 to challenge the paucity of post educational placements for young people with severe learning disabilities when they leave school at 19 years. In April 2008 MLAs were told that of the 100 young people leaving special school each year in Northern Ireland, 20% of those with additional complex/profound disabilities would have no choice but to go to the day centre, as there were too few opportunities and support systems to enable their entry into further education. The situation in relation to young people with severe learning disabilities considerably predates the current NEETS dilemma. This situation has been compounded as the most recent consultation on the future of adult disability services carried out by the DHPSSS in the latter part of 2013 indicated a significant increase of young people with severe learning disabilities and additional profound/complex disabilities and that the figure of school leavers requiring such care and support would be 50% as opposed to the 20% detailed in 2008. For parents and carers these represent worrying statistics as under the current system that would result in their placement in social care services with no access to further educational opportunities.

The Post 19 Campaign published a research report “The Impact of Transition on Family Life” in 2012 and this research looked at the range of choice and opportunities for those with learning disabilities on leaving full time education. The findings made for grim reading once the learning disability focus moved to severe learning disability:

- Some 62% of parents are caring upwards of 70 hours per week for their child/young person with severe learning disabilities
- Care needs associated with severe learning disabilities clearly outweigh those detailed 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
- Some 76% of eligible respondents indicated that they had to give up or reduce hours of employment as a consequence of transition
- 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.
- Social isolation is a common theme for families with a severely learning disabled member. This situation was further compounded if there were two or more children/young people with additional needs.
- 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

lifelong learning MUST continue beyond the school environment
however, profound the disability.

Notwithstanding this grim reality the research went on to explore alternative opportunities to improve and expand the current provision which is inclined to move these young people with severe learning disabilities straight over to social care buildings based services. Some of these alternative options will be explored in relation to section 3 of these terms of reference

2. To seek the views of young people, family carers and groups representing children and young people with learning disabilities what services they would like to see in place and how the current situation meets their needs.

The Post 19 Campaign through its research report have been highlighting the views of parents and carers of young people with severe learning disabilities over several years and has a clear view as to the services required for this group of young people.

Formal educational services have not previously been associated with day centre services and if there is still to be a place for day centre activity particularly for those young people with severe learning disabilities and additional profound/complex needs then education is key to the services provided within that environment. The services within the day centre need to build upon the work undertaken in the special school sector by the transfer and maintenance of individual learning plans for all young people with severe learning disabilities and additional profound/complex placements. Individual learning plans would include opportunities for physical and social activities upon assessment from Allied Health Professionals involved in the building's based provision.

The employment of learning support assistants to assist in independent living skills development will be essential to this proposal. A peripatetic team of teachers and learning support assistants could operate on a rota basis delivering individual learning plans for young people with severe learning disabilities within each trust area. In this way individual learning support assistants could maintain learning plans in the interim. This restructuring of staff and resources to deliver this improved service will encourage the development of meaningful independent learning. Essentially this will mean the engagement of additional staff with a different focus from the current care role to learning support assistants with the skills to encourage communication skills-both verbal and non verbal and the support of the Allied Health Professionals to ensure quality and performance levels. Low communication levels place many young adults with severe learning disabilities and additional profound/complex needs at a disadvantage in terms of stating their needs/desires, if there is to be meaningful integration in local communities the continued development of communication skills will be essential.

All proposals will require joint departmental co-operation to ensure resource and management. The Post 19 Campaign is harnessing support for a private members bill to introduce the right to a basic adult education for those with intellectual disabilities, similar to that enacted in Sweden in 2007. Unfortunately it seems that legislation may be the only way to ensure that young people with severe learning

disabilities and additional profound/complex needs access further education in Northern Ireland.

The recent health board led shift towards day opportunities for those able to avail of them is very welcome however, it will also be necessary to ensure that the 50% of young people with severe learning disabilities and additional profound/complex disabilities leaving school in the coming years also have access to good quality services and opportunities to avail of further education within the buildings based approach. When using the term further education, we do not mean education in the strictest sense of qualifications and accreditations rather as previously detailed individual learning plans appropriate to need.

There has been a significant underinvestment in learning disability services in Northern Ireland. In the Appleby Report (March 2011) 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 lobby group are hopeful that the Transforming Your Care policy will redress this underinvestment through appropriate and adequate services for the learning disabled population.

The Coalition government's Draft Children and Families Bill 2013 is seeking to enhance SEN provision from birth to 25 years and this enhancement of joined health, education and social services provision and this would also be a very welcome direction for the NI Assembly to consider. Research would suggest that the impact of puberty on learning has been significant both for non-disabled and disabled learners. Increasing SEN provision to 25 years would allow young adults with severe learning disabilities to continue on an upward learning curve and so enhance their maturity and readiness for other post educational opportunities.

3. To research best practice in post school provision for those with learning disabilities.

The difficulty with the best practice research is not with the available examples rather, it is with the very diverse nature of need within the learning disabled population. For those at the more extreme and profound end of the spectrum the nature of the provision will require a significant human and capital resource. Within the current fiscal climate it's very clear that government departments are stretched however, equality of opportunity cannot continue to be ignored to the detriment of the educational needs of young people with severe learning disabilities.

The Post 19 Campaign has already carried out some preliminary research into best practice in post school provision for those with learning disabilities included within this are the following examples:

- Care farming a growing movement to provide health, social or educational benefits through farming for a wide range of people, including those with severe learning disabilities 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. In Sweden , 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 benefiting 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 Kingwood Trust has 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. These aspirations took physical form as the Kingwood College which opened to its first residents in September 2012.
- Discrete further education courses at level 1 and 2 are beyond the capabilities of most young people with severe learning disabilities-not simply in terms of educational ability but in relation to safeguarding these vulnerable young adults within limited support structures. More emphasis should be placed on pre-level 1 and 2 course criteria in the form of individual learning plans, as discussed in previous sections.
- Day opportunities and their community links are designed to encourage inclusion and integration but safeguarding remains a contentious issue for parents/carers.
- There is a 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. Unfortunately, these organisations do not have the resources to provide the support required for those young people with more profound or complex disabilities.

4. To examine if the quantum and quality of post school provision for those with learning disabilities is meeting the demand and develop recommendations to address the barriers to participation and delivery of high quality provision.

The Post 19 Lobby Group research report carried out a literature review of post educational services available for adults with learning disabilities in 2012 and found that:

The Bamford Monitoring Group reporting for the Patient and Client Council produced the **“My Day, My Way”** 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, 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.

“The Transform Your Care” report 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.

Review of Transitions to Adult Services for Young People with Learning Disabilities
By Professor Laura Lundy, Dr Bronagh Byrne and Dr Paschal McKeown commissioned by NICCY

For young people with learning disabilities attending Further Education (FE) courses, concerns centred on the lack of support for the young person when settling into FE and the lack of genuine options and subsequent opportunities for progression when a course comes to an end. There are no specific statutory obligations to support

young people with learning disabilities on transition into FE and from FE into employment. In the context of employment, again there is variation across NI in terms of supported employment opportunities, the availability of suitable work experience placements, and the impact of part-time working on social security benefits.

The availability of age appropriate and flexible day care and short break services are limited and vary across Health and Social Care Trusts. Parents and young people do not always have access to accurate and/or detailed information on the real options available, including information on the range of accommodation and services, alternative sources of support, and on the eligibility/entitlement for services including direct payments and carers assessments. Young people with learning disabilities are much more likely to experience mental health problems. Concern has been expressed at the potential negative impact of transitions on the mental health and wellbeing of young people with learning disabilities as they adjust to unfamiliar environments.

Families of young people with learning disabilities provide care and support well beyond what is normally expected and over a longer period of time. However, the practical and emotional support provided to families, particularly at times of transition, is fragmented and patchy across Northern Ireland. Uncertainty around the impact and complexity of the proposed welfare reforms is an added source of stress for families. The issues highlighted above are compounded by the lack of suitable transport arrangements and independent travel initiatives, particularly for young people living in rural areas. Nor do young people with learning disabilities have equal access to age-appropriate leisure opportunities on the same basis as rest of their peers. The latter becomes particularly pertinent when young people leave the security of school-based social networks, often outside their own communities.

There is a need for an integrated planning service between education and health and social care. While there have been efforts to improve communication and co-operation between education and health and social care, there are, in effect, two separate planning and delivery processes for transition which often occur at different points in time in a young person's life

There is a need for person centred planning across the transition processes. There is a clear sense that decisions about education, employment, and health and social care are often determined by what is available rather than what is in the best interests of the young person and there is little evidence that they get support to ensure their voice is heard. Consistency in provision across Northern Ireland is limited.

Whilst the literature review would identify areas for concern about the quality of current post educational provision the Post 19 Campaign would also express some concern about the quantity of such provision. Currently there are no guarantees that any post educational provision will occupy a young person with severe learning disabilities for 5 days a week, this is the usual working week for the majority of the non disabled population. The majority of those with learning disabilities attending

day opportunities are allocated 2-3 days per week and in buildings based day centres attendance can range from 1-4 days per week. A significant disparity is readily apparent. Moreover the impact on family life is significant as parents face the prospect of an increase in their caring responsibilities at a time when they are older and their health can be considerably poorer, particularly given the findings of our research report detailed in section 1 of these terms. This of course coincides with a time when a routine bound young person is facing additional time at home, out of their usual activities which can prove frustrating and present problems for parents and carers in managing challenging behaviours without increasing their own stress levels.

5. Given the complex and interrelated needs of individuals in this group to identify barriers to co-ordination across departments-regionally and locally- and to make recommendations for improvement.

Integrated planning lies at the heart of the problem for young people with severe learning disabilities, there is uniform support and sympathy for their situation across all party groupings however, what is lacking is a vision or a framework to turn that support into action.

Joint departmental agreement as to resourcing and managing services and building for the learning disabled community is essential if a sustainable and diverse range of services are to be delivered for people with learning disabilities. Key departments such as Health, Education, Social Development, Regional Development and Employment & Learning must work in close proximity and within agreed parameters to ensure a flawless service. No one department should be more or less responsible for the provision of services.

The good practice and working relationships that are so ably demonstrated within children's services requires the full co-operation and shared resourcing between the Departments of Health and Education which must be carried forward and developed to include the input from Employment & Learning through the transition of young people with severe learning disabilities. Transition does not present, in real terms an additional cost, as outlined in the consultation paper. The learning disabled population have always been in existence but monitoring and tracking has failed families with learning disabled members as it stopped when they left school if these people did not proceed into statutory services. Yes, investment in buildings and services is required, and it may well be substantive in order to meet the needs of this vulnerable group but that doesn't mean that it's not worth doing. Investing in quality services will reduce the stress and ill health visited upon the families as the main carers and ease things at the crisis end of the conundrum. If learning disabled people are appropriately placed within meaningful and stimulating placements the pressure upon their carers ease as they are more fulfilled. This does necessitate properly considered five day per week placements as well as respite opportunities.

This concludes the written submission to the Committee Inquiry into post Special Educational Need Provision in education, employment and training for those with Learning Disabilities in Northern Ireland from the Post 19 Campaign.

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