



Committee for Employment and Learning Inquiry into post
Special Educational Need Provision in education, employment
and training for those with Learning Disabilities

Submission by the Association for Real Change (NI)

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Background Information

Association for Real Change (ARC) is a leading umbrella body representing service providers in the learning disability sector. Our purpose is to improve the quality of life for people who have a learning disability. We achieve this through supporting anyone who is involved in the planning or delivery of support and services for people with a learning disability.

ARC is committed to promoting best practice within the learning disability sector and we work with others such as the Department of Health, Skills for Care, Big Lottery Fund and Comic Relief through a range of projects. Additionally, ARC provides a range of services such as high quality information sharing, networking opportunities, training, qualifications, publications, and Enhanced Disclosure checks.

One of the lead projects within ARC is Telling It Like It Is (TILII), which are advocacy groups of men and women with a learning disability who come together to speak out on a diverse range of issues that matter most to them. TILII groups currently work in the areas of Belfast, Lisburn, Bangor and Downpatrick as well as, a group in Muckamore Abbey Hospital with a view to extending to two groups within the hospital.

TILII offer training sessions to decision makers, regulators, funders and staff across the Belfast and South Eastern Health and Social Care Trust. The training is based upon the views provided by TILII Trainers on what is needed from people who are interacting with people with learning disability, or more importantly, those who are in a position of influence within their lives.

TILII members offer a unique and personal insight into living with a learning disability; they know first-hand the important issues that staff and service providers need to be aware of. Issues discussed throughout the training include Person Centred Planning, Respect, Privacy and Communication.

TILII have established a new group called the TILII Forum, which contains representation from each of the main groups. The Forum examines the strategic planning of TILII and the development of new ideas. The Forum will improve and strengthen all the TILII groups with a focus to review and monitor the work that TILII carries out.

ARC's mission is to champion the development of high quality, person-centered services for everyone with a learning disability. ARC UK believes that every

person with a learning disability should be in control of their life, as well as, be actively engaged and included within their community, and have access to a range of high quality services to help them achieve this.

1. Transitions from school for young people with learning disabilities

The teenage years are an important time of development and self-discovery for any young person. Leaving school and moving forward into adulthood is often a challenging period of decisions and change. For young people with disabilities and their families this can be an extremely anxious time. The person with the learning disabilities and their families/cares want to know what choices exist and will they help the young person to lead a fulfilling life?

School is often viewed as a safe environment due to the parent/carer support groups and a safety net of people and services, which the families may have been privy to and enjoyed. It is vital that schools work with each young adult and their parents/carers to initiate a person-centred plan for the future.

However, a local school survey in 2012 highlighted that the majority of parents described experiencing a significant level of ambiguity in regards to their rights within the transition planning process

For the young person who is emerging into an adult life, “leading a fulfilling life” could be characterised by a wide variation of roles and experiences related to employment, independent living, friendships, and day opportunities. The transition period is not a finite period of time in the lives of any individual as we continue to live and learn, and grow. It is crucial the planning process and exploration of opportunities and choices begins early and is an integral aspect of the personal development of students within schools.

2. Statement of Special Educational Need.

The Special Educational Need inclusion and provisions are currently under review. Legislative proposals have been drafted by the Department of Education, and it is indicated that current statements will be replaced with an Education, Health and Care Plan (EHCP). A focal point within the new Plan will be education: a child or young person with health and social care needs will only get a Plan if these aforementioned needs have a direct impact upon their education. This shift in criteria and focus is causing some concern that the shift will result in a likely reduction in statements being issued.

It is clear that reforms to the current SEN system are vital for the improvement and development of the infrastructure of Special Educational Needs, and therefore, improvement and development of the quality and format of support being received by people with a learning disability. A fundamental question to be answered is whether the proposed amendments will address the real and tangible challenges and problems within the current system.

There are a number of issues and criticisms with the current Special Educational Needs Statement; many have argued that they are simply a token gesture, as opposed to an enforceable and useful supportive tool. For example, the wording is not always specific and often does not determine or quantify the exact format of support required by an individual child or young person. As such, a growing concern in regards to the proposed legislative reforms would be the potential for reduced levels of provision and statutory protection for those who will no longer be eligible under the new criteria to receive a statement of SEN.

3. Current Range of Choice and Opportunities

The range of choice and opportunities available to school leavers with learning disabilities could be described in layman's terms as a postcode lottery; different opportunities are available based upon the area in which the person lives. This is a significant area needing to be reassessed and reformed. Location of residence - where you live should not have an effect upon opportunities available to a person with learning disabilities or their family; equitable and equal opportunities must be ensured for everyone.

Furthermore, it is important that there is sufficient quality provision at every level. These are issues to be considered in regard to both special schools and mainstream schools; there have been significant cases of young people with learning disabilities being overlooked and continuing unsupported throughout their scholastic career, failing to receive appropriate advice, guidance or support on the suitable options available to them.

Young people with a learning disability and their families /carers must have access to the information and advice they need in relation to the full range of **real options** available to them. Information must be in an accessible format and it is necessary to consider the support that the person with a learning disability will need to access these resources and information.

Additionally, it is vital that realistic and appropriate measures are implemented to ensure access to the opportunities, for example an individual may require support to travel and transport has proven a constant issue in particular for person who are living in rural locations. These will potentially give rise to funding implications and challenges, particularly given this continuing difficult economic climate. Nonetheless, it is important that money is allocated in order to ensure this much needed support.

Currently there is a statutory process for planning the transition from school for young people with a statement of special educational need, however, there is a misconception that people only “transition” once in their lifetime and in regards to people with learning disability this is considered to be completed upon leaving school. As mentioned above, there are many moments in life when we change jobs, activities, social circumstances etc and therefore, this current framework is failing to meet continual transitional needs.

As mentioned above, times of change can prove a difficult time for any young person, however, there are additional challenges and barriers to be addressed when that person has a learning disability. For example, transitioning from college, it is recommended that there is a development of links with a wide range of employers. It cannot be reiterated enough that they must have the person-centred support needs met.

Once again, it is crucial that the young person and their family/carers are provided with all the information, guidance and support to help the young person make an informed decision. There needs to be more provision in further education to meet the needs of people with learning disabilities and again this brings huge funding implications, to help them move into meaningful and sustainable opportunities.

Life long learning opportunities are fundamental and must be accessible and available to everyone, including people with profound and multiple learning disabilities. It is crucial that there is consistency of provision and approach across Northern Ireland. This means addressing the funding implications in addition to making sure that staff are trained with the necessary skills to address the multiple barriers to participation and in order to fully engage and support people with a learning disability.

4. Best Practise in Post School Provision

Despite the lack of consistency, funding and barriers, it is important to note that there are a number of the good practises. There are schemes delivered by statutory bodies and charitable organisations addressing much needed support and career pathways for the young person with learning disabilities, for example, progression pathways for school leavers provide appropriate person-centred support to help young people work towards achieving recognised qualifications. Additionally, there is a plethora of evidence in relation to good practise provision for Post 19 individuals with learning disabilities in the fields of catering and horticulture.

Further Education Colleges provide courses for people with learning disabilities, offering life skills and work preparation courses, however, it must be noted that they are only available part time and there are limited vocational choices. On the remit of best practice, it is common for a young person to received continuous support throughout the day at school, and may be in a position whereby they receive support within classes at college.

Nevertheless, young people with a learning disability often struggle with the social aspects of attending college. Participation and integration into the full remit of college life including extra curricular activities and developing relationships with other students, is a challenge. Young people with a learning disability need to be offered a wide range of realistic choices in both Training for Success and further education; it is imperative that the support offered enables individuals both academically and socially.

There are good work placement schemes, however, it is unfortunately too common an occurrence that they do not result in paid work. In 2010 an evaluation of the Workable NI Programme indicated that only 9% of participants moved to unsupported employment. Many barriers exist to employment; these are not simply social or skill based. Often economic issues arise particularly in regards to the effect paid employment will impact upon the persons benefits. This has resulted in very low numbers of people with a learning disability being able to secure paid work.

Day opportunities and their community links where designed to encourage inclusion and integration, and are an on-going process and developing area. There have been a number of barriers in particular, due to safeguarding

remaining a contentious issue for parents and carers. Furthermore, this is often on a part-time basis and most of the young people and their families would prefer opportunities to be on a five-day per week basis.

5. 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.

In reporting for the Patient and Client Council, the Bamford Monitoring Group produced the “My Day My Way” research paper. This paper investigated the views and experiences of people with learning disabilities as well as those of their parents and carers. The report states that the choice beyond transition for people with learning disabilities could be classed as relatively non-existent. Education courses are limited and it was noted that there were a number of cases whereby, individuals have spent several years in college simply repeating the same courses with few opportunities for progression, especially towards paid employment.

There is a variation across Northern Ireland in terms of supported employment opportunities, the availability of suitable work experience placements and the impact of part time working on social security benefits. It is often not possible for a person with learning disabilities to secure a job let alone enough money for them to no longer need benefits to pay for the care and support they need. Roy McConkey (Professor of Learning Disability at the *University of Ulster*) researched the views of people with learning disabilities at an international level which highlighted that this issue was endemic at not only national but at international and global level.

Furthermore, there is also a need for the opportunities to be centred around the young persons strengths and interest. Without this person-centred provision, there is a double edged sword and it is the danger that the opportunities provided are not centred around the persons interests and strengths. This may result in young people not being stimulated, particularly if there is nothing else available in their area. The lack of full time courses, work placements and day opportunities mean that some young people with learning disabilities are at home four-five days a week. This is not appropriate, nor conducive to living a fulfilling life.

Research has shown that people with learning disability often cite their daily lives containing significant periods of boredom and frustration. Mental health is a growing area for concern and being subjected to monotonous, unfulfilling days or opportunities has a direct correlation on the mental well being of people. In some cases these negative experiences and emotions sparks a negative cycle producing inappropriate behaviour which places additional challenges for the family/carers, which in turn places more pressure, frustrations and negative emotions within the household.

6. Recommendations

There is a need for an integrated service between education and health and social care. Though there is communication and cooperation between them this needs to be a more integrated approach to multi-disciplinary interaction and work. Greater consistency across Northern Ireland is fundamental in order to ensure that the teams work together with the young person at the centre. Person centred approach is crucial as it is the young person's voice that should be heard most frequently and at the heart and focus of all team meetings and decisions. There needs to be a shift from opportunities being based primarily on what is available in the young person's place of residence area. The key question to be answered by everyone is what is in the best interest of the young person?

It is important to take into account that the term "learning disability" encompasses a diverse and wide range of needs and abilities ranging from someone with a mild learning disability to someone with profound and multiple learning disabilities. Some young people with learning disabilities leave school at 16 and others remain in school until they are 19 years of age. It is important to take into account the different ages and routes from school. It is important that we make the transition process a positive experience for the young person, focusing on what they can do as oppose to what they cannot and to make sure that we are working to offer them a path that that is tailored to their strengths and interests. Finally, it is vital to recognise that transition is not a one time event, people continue to learn and grow and develop and change – this must not be denied to people with a learning disability. Their person-centred plan must be consistently and conscientiously reviewed and implemented.