



Review of Mental Health and Learning Disability (Northern Ireland)

Learning Disability Committee Newsletter No. 3 December 2003

Welcome ...

to the 3rd newsletter from the Learning Disability Committee.

- In the 1st Newsletter we explained that the Learning Disability Review is seeking to answer 3 questions:
- Where are we now in relation to policy and services for people with a learning disability and their families?
- Where do we want to be in 10 years time? and

- How will we get there?

In this newsletter we will comment on the first question. Although we have not yet completed the initial consultations and information gathering, we thought it would be useful to share our thinking at this stage. We hope that this will encourage discussion on the key issues affecting the lives of people with a learning disability in NI. Further issues will be discussed in the next newsletter in January.

We would be interested in hearing your views on the issues raised in this newsletter. If you would like to comment please write or email the address on the back cover or phone the Review Free phone and leave a message.

We look forward to hearing from you.

Key Messages

- Learning disability services have been under-developed in Northern Ireland compared to Great Britain and the Republic of Ireland.
- Existing service structures and practices do not match modern expectations and they are inadequate to meet increased demands, which will continue to grow for at least 15 years.
- In future, more learning disability services must be planned and funded on an inter-departmental basis at governmental and sub-government level.
- A small inter-agency team should be established to guide and facilitate the implementation of the recommendations of the Review from mid-2004.

See inside for a detailed overview of the key issues currently being considered by the Learning Disability Committee

Changed Concepts of Learning Disability

In recent years there have been profound shifts nationally and internationally in our conception of learning disability. No longer is it seen as a medical condition inherent in the person but rather the label is an indication that extra supports are needed to enable the person with a learning disability and their families to be full and active participants in society.

Learning disability is the most common *handicap* in our society for people under 65 years of age. It is best thought of as an umbrella term that encompasses a wide variety of disabling conditions both biological and social. Hence there is wide variation in the needs of people but most will require help and support throughout their life span – from birth to death.

Learning disability affects all aspects of human development and functioning – physical, social, emotional as well as cognitive - but its effects can be reduced by appropriate interventions and supports. This group has a long history of social exclusion. Few people with a learning disability are in paid employment, many lead lonely and friendless lives and many of those living away from their families, reside in group care settings with a quality of life that the rest of the population would find unacceptable. Their needs extend beyond health and social services and embrace education, housing, employment, recreation and culture.

A significant failing to date has been the lack of a holistic approach to meeting the needs of this group of citizens and the failure of Government to provide a strategic direction for the development of services. It is incumbent upon all government departments and agencies to ensure shared responsibility and accountability in terms of promoting the rights of people with a learning disability. This will be a key recommendation of the Learning Disability Review.

Although an increased proportion is at risk of experiencing some form of mental illness during their lifetime, the majority makes no call on mental health services.

Northern Ireland appears to have a higher proportion of people with a learning disability than Great Britain. This may be linked to larger family sizes and higher rates of deprivation. Research suggests that 2% of the UK population have some form of learning disability, from mild to severe. In Northern Ireland this translates to over 30,000 people. Information on people with a moderate and severe learning disability is more accurate – approximately 13, 000 people in Northern Ireland who are known to services fall into this category.

The number of people with a learning disability in Northern Ireland is growing and will continue to grow until at least 2020. This is mainly due to the medical advances that have increased their life span. Many now outlive their parents, who to date have provided the bulk of the care and support at relatively little cost to the Exchequer. Older people with a learning disability are at a vulnerable transition stage and many will develop complex needs.

In addition more children with very complex conditions are now surviving into adulthood and they demand more sophisticated care, which includes access to the benefits of technological advances. Thus there will be increased pressure on services to meet these new needs.

Recent Human Rights Declarations and Disability Legislation bestows on people with a learning disability equal access to services. These will place greater obligations on statutory agencies.

Accommodation

The learning disability programme of care accounts for 7% of Health & Social Service Board Expenditure (£105.7 million at 31 March 2002). This equates to approximately £62.9 per person of the total population. Comparable figures for England at 2001/02 rates were £3,335million: £67.9 per person – 8% higher than in Northern Ireland.¹

Nearly 30% of this is spent on hospital provision, which accommodates an estimated 4% of the adult population of persons with a learning disability. DHSSPS has recently announced capital building programmes and increased revenue provision at two hospitals in Northern Ireland at a time when all long-stay hospitals in England are to close by 2005 and in Scotland by 2006.

Whilst accepting there is a need for some hospital-based assessment and treatment services for people with a learning disability, the Learning Disability Committee is keen to ensure that the scale of such developments is closely monitored. It is anticipated that the Learning Disability Review will take future services towards a person' centred, community based, inclusive model that will target resources on strengthening the seriously under developed community support infrastructure.

Northern Ireland has an estimated 1,900 persons in some form of residential provision. This is 700 places short of the *minimum* number of places recommended by the Department of Health for England and Wales.

At present, the Republic of Ireland has twice as many places in residential accommodation than Northern Ireland.

This suggests a marked under-investment in alternative living options for people from Northern Ireland who have learning disabilities. Moreover two-thirds of people in existing residential provision have either come from long-stay hospitals or another residential facility. Many continue to be funded through transferred social security payments (preserved rights) which are now defunct. Past developments have been largely finance-driven with comparatively little investment by NI Health and Social Services.



By contrast, in Great Britain funding has been available through Local Authorities as

well as NHS funding.

In future more people with learning disabilities who require accommodation outside of the family home will have additional needs that will require more intensive supports.

¹ These figures are taken from a ministerial answer by Jacqui Smith (17 December 2002) given to a parliamentary Question for gross costs in England and from returns made by Trusts in NI on their spend in the learning disability programme as at 31 March 2002. In her answer the Minister also gave a commitment that in England "the overall level of funding for social services, including that for learning disability will increase, by on average, 6 per cent in real terms over the next three years."

Children and Young People

The efficacy of early intervention in preventing secondary disabilities and ameliorating the effects of disability are well established but not reflected in policy or service priority. Early intervention services



are fragmented, under-resourced and not easily accessed. Parents report that they often do not know where to go for help and have to wait while professionals talk to one another and decide who needs to be involved in assessing the

child's needs. Only a minority have access to Specialist Child Development Teams. Children waiting to be seen by various professionals lose valuable development time. After a lengthy assessment process there is frequently little intervention to offer.

Delays in the supply of assistive aids and equipment are a common experience. Children have sometimes outgrown the equipment specified before it is issued. Shortages in Occupational Therapists and administrative barriers contribute to unacceptable waits causing real hardship to children and their families.

Play and childcare services, which are essential to the child's development and to enabling parents to continue to work, are available only on an ad hoc basis. There is an over-reliance on short-term funding. The needs of children with complex needs and of older children are not met by existing provision. Services to meet their needs simply do not exist. The lack of suitable and affordable childcare can curtail parents' employment prospects and add to the financial pressures. Many disabled children live in poverty.

Difficulties with accessing sport, arts, leisure and youth provision increase the dependence on family and contribute to social exclusion

and feelings of isolation. Young people often do not have the social or friendship networks to draw them into the life of the community. In addition they can experience name-calling and other forms of verbal and physical harassment in which the perpetrators are often other young people. The extreme social marginalisation that occurs increases the risk of mental illness in a population already vulnerable to mental health problems. Investment is needed in preventative informal social education and personal development to foster citizenship skills in young people.

The absence of natural recreational breaks exacerbates the need for respite and leads to some children being inappropriately placed in order to give their parents a break from caring.

There is a lack of suitable provision in Northern Ireland for children and teenagers who cannot remain with their families because of severe behavioural problems. Many are accommodated in long-stay hospitals - some are on adult wards - or in adult residential care homes in contravention of the Children (Northern Ireland) Order. Similar situations arise in accessing respite breaks. The development of residential options for these children and teenagers must be matched by corresponding developments in the adult years.

Children and young people are too often not given a say in the choices made for them. In services and within families decisions are made in the best interest of the child but without the child's views always being heard. Appropriate methods of consulting young people need to be developed. At school and importantly in informal settings young people should be encouraged to develop their ability to express themselves. A range of measures including advocacy are needed to ensure that children and young people are heard.

Family Support

The bulk of caring in Northern Ireland has been, and continues to be undertaken by families. From the time the child's disability is recognised the family may need support. Appropriate support in the early years is critical to the child's development and to the family's capacity to care in the longer term. Without adequate support there is a risk that families might breakdown, with severe personal and social consequences. The numbers of families in crisis due to lack of support is not known as there is no mechanism for recording the unmet need. Few carers know about their right to an assessment.

Nearly one-third of adults are now cared for by a single carer. Many people with a learning disability live with aging relatives.



This 'demographic time-bomb' is common to other countries in these islands but Northern Ireland is arguably worse prepared than elsewhere to provide alternative caring arrangements.

A sustained commitment must be made within the Supporting People Programme to increase accommodation and support packages for people with learning disabilities. In addition an increase in care-managed packages will be necessary for the growing numbers of people with complex needs. Moreover the social circumstances of families have changed dramatically in recent years with an increase of working mothers, single parenting and the break down of extended families living in close proximity. These factors have also increased demand on

services to provide extra services in the form of domiciliary support, evening and weekend activities and short (respite) breaks. Cash-limited budgets have meant these services are stretched ever more thinly over larger numbers of people. A 'postcode lottery' also operates regarding their availability. Increased funds are required to sustain family-centred care, which is by far the most cost-effective means of looking after this vulnerable group.

Adulthood

There is an unacceptably wide variation across Northern Ireland in the standards expected in transitional support to assist teenagers and their carers make good career choices and pathways.

Post-school provision is still mainly in the form of day care centres; many of which are now out-dated, over-crowded and under-staffed. Vocational training and employment schemes in Northern Ireland have been funded mainly by short-term European monies. People with learning disabilities require training programmes of longer duration and ones that tackle a wider range of social and vocational skills, e.g. independent travel training, money and time management. Life-long learning opportunities for people with learning disabilities are very limited in Northern Ireland. For people with profound and multiple there is little beyond day centre attendance.

The majority of school-leavers also aspire to have some form of employment. Experience in these islands and internationally has demonstrated that this is attainable if appropriate supports are given. The Republic of Ireland allocates around £4 million per annum specifically to supported employment schemes for people with learning disabilities.

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Adulthood

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In addition the regulations governing social security payments need to be reviewed in order to encourage more people to partake in employment opportunities.

An increased life expectancy has meant that people with a learning disability are now living into older age. The increasing numbers of older people with a learning disability are creating new challenges for service provision.

A minority of people exhibits severe challenging behaviors. Specialist professional supports are required in community settings to devise appropriate intervention and support packages along with appropriately staffed short-stay accommodation options. These services would help to ensure that hospital admissions are only for acute short-term assessment and treatments.

The experience of people with a learning disability is that they have few choices. Their options are limited by lack of information on what is available, entry requirements or eligibility criteria, transport difficulties or their personal support requirements. A common complaint is of not being treated with respect nor afforded adult status.

Awareness of rights such as those protected by the Disability Discrimination Act is low amongst people with a learning disability many of whom continue to feel that they are second class citizens.

Other people's attitudes are a bigger hindrance than their disability. Advocacy and self-advocacy are under developed in Northern Ireland although there is growing awareness of its value. Leadership development and initiatives to build the confidence and skills of people with a learning disability are required alongside a review of how people are supported to express their views. Equality training and public awareness programmes should promote positive understanding of learning disability.

Health



Primary health care services do not appear to adequately meet the needs of people with learning disabilities. GP and nursing services need to be more proactive

in promoting the health and well being of this patient group. Subsequent secondary care treatments that are available are often not geared to meet the general needs of people with a learning disability and their carers when they are physically ill.

Service Delivery

Health and Social Services have been seen as responsible for people with a learning disability and have developed services to meet a wide variety of needs some of which may be better served by other statutory authorities. In addition people's needs cross boundaries and many services require cross-agency working. Inter-departmental planning and funding must feature in the future but the mechanisms for doing this are not in place at either governmental or sub-governmental level. This issue requires urgent attention.

Many of the staff working in either residential or day services for people with learning disabilities tend to be employed on low hourly rates of pay and unattractive working conditions. This is a consequence of capped funding to non-statutory organisations in particular. Most of the staff are unqualified and there are few career pathways open to them. Consequently staff turnover can be high and many posts remain unfilled. This is an urgent problem in many areas in Northern Ireland with the growth of more attractive employment options. Greater investment is required in staffing and accredited training if increased service quality is to be attained.

More regulatory and monitoring systems are being created for social care services. Education, housing or other authorities employ separate and different regulatory systems. There are concerns that there will be duplication and an over emphasis on the development of complex, bureaucratic systems that may be at variance with the service principles that will be proposed within the Learning Disability Review. There is an urgent need for assurances that the heightened regulatory requirements will not divert money from direct support activities and increase the administrative burden on service personnel. International experience suggests that these systems per se do not result in better services. Increased emphasis needs to be placed on the outcomes that services achieve for their users.

The Review is likely to recommend major initiatives in service development over a 10 to 15 year period. In England and Scotland, implementation teams were established to guide this process following their reviews. Arrangements should be put in place now to ensure that a comparable team is established in Northern Ireland that could be operational from mid 2004.

Other News From The Review...

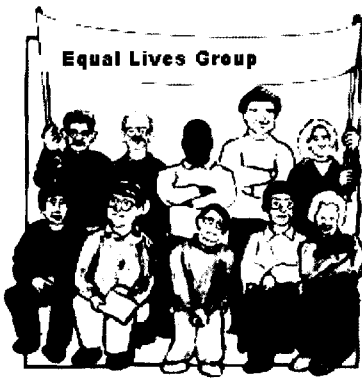
Workforce Issues



All the committees in the Review have identified a need to ensure that issues related to staffing are addressed. These issues will be considered initially by a Workforce Planning Group that is being established separately by David Bingham in DHSSPS.

Workforce planning can be described as *work to ensure that we have enough people with the right skills, knowledge and values, in the right place at the right time.*

There will be representatives from across the Review on the Workforce Planning Group including 2 members of the Learning Disability Committee- Brendan Mullen and Agnes Lunny. Brendan and Agnes are currently planning a meeting in January with those who would like to share ideas on the workforce issues in learning disability services that should be raised with the Workforce Planning Group.



New Free Phone Launched!



Members of the Equal Lives Group have been meeting with other people with a learning disability to hear how they think things should change. The Group will have more meetings in North Belfast on 1st December, Omagh on 3rd December and in Belfast in the evening of 7th January. We will then write a report for everyone in the Review. The Report will help them to learn from what people with a learning disability have told us.

On 1st July 49 family carers met with members of the Learning Disability Committee to advise how family members might best be involved in the Review. At that meeting one suggestion was that the Review should set up a Free Phone that anyone could ring and leave a message to be given to the appropriate person on the Review. Carers felt that this would open up a new opportunity to those who could not attend meetings or who did not wish to share their views in public. The free phone has been set up and already a number of people have left messages commenting on issues raised by the Review.

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For more information on anything in this newsletter contact

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