

The Review of Mental Health and Learning Disability (NI)

Learning Disability Committee

***Consultation for people with a
learning disability and for carers on
the Committee's draft report
'Equal Lives: Review of Policy and
Services for People with a
Learning Disability in N. Ireland'***

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Background to the consultation

The Learning Disability Committee, set up as part of the Review of Mental Health and Learning Disability (NI) commissioned by DHSSPS, has published its recommendations for learning disability in a report 'Equal Lives: a review of policy and services for people with a learning disability'. This has been issued for consultation until 31st December 2004.

I was invited by the Committee to facilitate an independent consultation process, to validate their findings and recommendations for change by holding a small number of consultation events for people with a learning disability and their carers across Northern Ireland. The Committee wished the facilitation to be led by someone not involved in their work to date and I undertook this work.

Methodology

The participants

It was decided to hold three events for people with a learning disability and three for their carers at a range of locations throughout Northern Ireland. Consultation events - each lasting over two hours - for people with a learning disability were scheduled for Armagh, Antrim and Derry; events for carers were scheduled for Cookstown, Armagh and Belfast. The carers' event in Armagh and the event for people with a learning disability in Derry were cancelled due to lack of response. An accessible version of the report 'Equal Lives' was widely distributed to stimulate debate amongst audiences of both people with a learning disability and carers. It was also encouraging to note that a number of those who attended, including a group of people with a learning disability, Enable NI, had previously discussed the issues in the report and presented their views at one of the sessions.

The events were advertised in the local press, promoted through contact with the established list held by the committee, and specific efforts were undertaken to ensure participation from people with a learning disability in hospitals. Publicity was secured for the events through local media.

The events were well attended with 84 people in total attending – 22 carers and 62 people with a learning disability.

The methodology

It was considered that the most appropriate means of facilitating the sessions was to ensure that the consultation concentrated on the major themes highlighted in the 'Equal Lives' report and the recommendations associated with these:

- Children, Young People and their families
- Living a full life
- Housing & support
- Feeling healthy and well
- Growing older

The brief for the consultation was to check if the user groups agreed with the proposals, if anything had been missed, or if they would like to emphasise any particular issues. Small groups were used to facilitate meaningful discussion. The assistance provided by all those who facilitated small group work, and those who took a record of the discussion of the groups, is duly acknowledged. Consultees were also specifically given the opportunity to raise any further issues they wished in their groups, in private at the end of each session or through a Freephone Message Line. (The latter comments do not form part of this report.)

This report

This report summarises the comments made through the consultation sessions and is structured around the five key themes highlighted above, with a general section at the end covering a number of further specific issues raised.

Values

The five values outlined as core to the 'Equal Lives' report were readily accepted throughout the consultation process as highly relevant, reflected areas of current concern in the way policy and services were developed and delivered, and were essential for building a more effective culture in which to deliver effectively for people with a learning disability and their carers.

The value '**social inclusion**' recognised the strong need to move away from separate provision where possible and ensure that the services provided should as far as possible be the same.

The value '**citizenship**' is regarded as key because people with a learning disability frequently cited examples of less favourable treatment – for example in relation to dental health care – compared to the services received by everyone else. There was a strong sense in which rights should be shared by everyone and not dependent on the quality of life presumed by others. The view was clear - fundamental rights should be fairly shared.

The value '**empowerment**' was also a recurrent theme during discussions. Frequently people with a learning disability stated that they did not have a say in what – in particular – leisure activities they engaged in – and certainly not when. The evidence presented very strongly was that too often the views of people with a learning disability were presumed. A massive culture change was needed in this area, including in many cases from health, social services and other public service professionals. It was also recognised that there was an inherent conflict here between protection and empowerment, which had to be better balanced.

The value '**working together**' again is a priority for carers and people with a learning disability. Many instances were given where carers did not know which public body to approach to identify help, and there seemed to be limited co-operation between different agencies for example in progression from pre-school to school, from school to college, and from home to a formal establishment when

parent carers are no longer available to care. There needed to be a greater clarification about who does what.

The '**individual support**' theme also was affirmed strongly in the consultation. Too often it emerged that a 'one solution fits all' approach was adopted by service providers and the very specific needs of different individuals were ignored. It was evidenced most particularly in the example of people with a learning disability who sometimes engaged in 'challenging behaviour'. The system, health professionals in mainstream health services and carers were all particularly ill-equipped to meet these needs.

The endorsement of these values during the consultation is further evidenced through the key themes that follow.

Children, young people and their families

The key theme in this area is how children with a learning disability and their families are supported through education, after-school activity and transition.

This theme relates to the first two objectives cited in the 'Equal Lives' report – and the associated 13 recommendations.

Objectives:

1. To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society.
2. To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.

Consultation comments

Early diagnosis

There was widespread support for the view that parents have the right to go to a single clear support service to identify the help that is available if they have children with a learning disability.

The people attending the consultation sessions strongly stressed the importance of as much support as soon as possible after a child was diagnosed with a learning disability. The specific suggestion of one (or maybe two) key worker(s) early on was discussed and generally supported, provided they were given additional training. However most participants felt that it was more important to have the support of family members – properly funded. The proposals for Early Intervention Plans were welcomed, although it was noted that waiting lists for assessment were too long and that services did not speedily follow these assessments.

Carers support

There was strong agreement that parents with caring responsibilities needed more financial and professional support – and in particular respite opportunities, especially in emergencies. There was also strong agreement on the need for a ‘one-stop shop’ advice and services centre to help carers and parents, which it was clearly felt – despite some advances – was still a major problem.

Some evidence of good practice in joined-up working from public bodies eg health, social services and education were cited eg ‘Wraparound Project’ in the SHSSB and it was felt that this model should be extended to all of Northern Ireland. The proposals for significantly enhanced funding for a Family Carer’s Support Fund were strongly supported.

Some concerns were expressed that the terminology of carers in the report did not always draw a distinction between ‘professional carers’ and family carers. A strong view was expressed that carers were made to feel like second class citizens compared to ‘professional carers’. Whilst all carers needed training and it was noted that most ‘professional carers’ were generally ill-equipped to deal with challenging behaviour, it was emphasised that the person who best knew the wishes of the person with the learning disability was the family carer; carer-directed plans should focus on them.

Schools

Carers cited examples of many delays in the past in assessment by a psychologist to enable children to get to ‘special school’. It was contended by the participants that this often resulted in poor experiences of not being able to cope with work in school.

Different views were expressed on the experience of people with a learning disability at school – some favoured attending mainstream schools, sometimes because of family support from other siblings. Others described how they were lonely, marginalised, bullied and ‘tormented’ in mainstream schools and preferred ‘special school’ environments where there was perceived to be better staff support. There was strong support for the view that all schools needed to be

trained in how to deal with bullying against children with a learning disability. Pupils with a learning disability also needed training in how to cope with bullying and how to stay safe.

A number of people said that they found it difficult to 'keep up' in mainstream schools, specific needs were better met in special schools and there was less bullying or teasing. However, one teenage girl indicated that she had been the only female in an otherwise all-male class in a 'special school' and this had specifically led to bullying.

There also was a feeling that teachers tended to 'look down' on people with a learning disability in mainstream schools; there were difficulties in dealing with challenging behaviour and much of the problem derived from teachers not having the necessary training.

The availability of other specialists in 'special schools' eg Speech and Language therapists was an important strength in the current system.

People with a learning disability also claimed that they were excluded from work experience while at school.

Clubs and extra-curricular activities

There was strong support for the view that children with a learning disability needed proper support and to be included in mainstream clubs. Youth leaders needed disability awareness training. It was also noted that there were limited leisure facilities for younger children. Multi-agency services in the community and an integrated response was needed to lead the change. The Departments responsible for Education, Health Services, Social Services, and Councils (leisure centres, play areas etc) should all be required to work together to make this happen.

A group of young adults with a learning disability argued that leisure centres, youth clubs, libraries etc should do more to make sure they have interesting activities to offer them and that they should feel comfortable making use of these places – it is not currently the case that they can be accessed without assistance. They also need to be asked what activities they want.

In conclusion it was noted that all the recommendations for Children, Young People and their families were 'excellent', but participants needed confidence that there would be sufficient funds and incentives for the public bodies to effectively implement these recommendations.

Living a full life

The key theme in this area is concerned with how we can be sure that people with a learning disability have a full day and choice in what they want to do.

This theme relates to the third and fourth objectives cited in the 'Equal Lives' report – and the associated 12 recommendations.

Objectives

3. To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.
4. To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods, have access to a wide range of social work and leisure opportunities and form and maintain friendships and relationships.

Consultation comments

Transition arrangements

There was general support for the view that there should be more help available when moving from school to adult services. Most of the participants noted that they did not have any plan for the transition, and especially where school was a positive experience, this was a source of considerable concern since the practices beyond school were not as well developed.

There was a strong feeling that there should be more Further Education College courses with proper certificates for those that pass the course, and that they should also develop courses which meet peoples' specific needs. There was support for a dedicated course for people with a learning disability.

The evidence presented suggests that further education provision for people with a learning disability varies regionally. Instances were presented of people at college for 10 years with no evidence of progress. Some regions seem to have little or no provision except Day Care or Trust Services. A specific concern was raised about the lack of transition support for dealing effectively with challenging behaviour.

There was a strong recommendation of training for a range of 'life changing events' eg learning to drive, living a full life – engagement, marriage, and setting up home.

Work

Work was regarded as extremely important for meaningful integration and dignity in society. Day Care Centres should not be seen as the only option – further education and work options also had to exist. Participants felt that they should have the right to look for work full-time or part-time – whether in or out of hospital.

Work provided a sense of fulfilment and allowed people with a learning disability to meet others and allowed people to contribute at home (towards housekeeping costs). However, more help was needed to assist people in finding work. Supported employment was generally regarded as successful, but more resources needed to be spent on it.

It was strongly recommended that people should receive the proper pay, holidays etc in their work and not be discriminated against if they were able to do the job. People with a learning disability stated that they had problems with interviews and application forms, and that they should receive training in this. More staff were needed to facilitate work placements with employers. It was emphasised that information needed to be provided personally to people with a learning disability by advisers, rather than depending on promotional literature.

The problems of losing benefits whilst working was identified – 'the benefits trap' - so that there was a limited incentive to work. Most people felt that whilst this had been consistently raised over time, nothing had been done about it.

Transport

It was agreed that there should be better local transport which people could afford and which they felt confident to use. It was recommended that courses should be available to explain how to use buses, taxis, trains. It was noted that many only travelled by taxi at the moment, because of lack of awareness of how to effectively use the transport system.

Participants stated that there tends to be a presumption that people with a learning disability cannot be trained to use public transport on their own. But many indicated that what was needed was for staff to accompany them a few times and show them what to do. The cost of public transport was also cited as a barrier – frequently some people were now sent by taxi.

People with a learning disability in hospitals stated that it was difficult to get out because buses were not big enough and the hospitals were short-staffed. It was strongly recommended that more information about transport options was needed from social workers and community staff.

Improvements were also needed in rural areas, and general provision for 'out of hours' courses was poor. It was noted that people with a learning disability experienced a lot of 'name-calling' and bullying in the community when travelling on public transport.

Relationships

It was agreed that more information and courses about friendships / girlfriends / boyfriends / marriage etc. was still needed. Some participants stated that they had real difficulty in gaining acceptance either from carers or in hospital when they wanted to get engaged. Their perception was that even to raise the issue generated a lot of fuss. These participants stated that they felt that social workers asked too many questions – they wanted to know every detail of the relationship even when this was not relevant. There was a strong

sense in these cases of an abuse of their human rights and this was contrary to the key values of citizenship and empowerment.

It was noted that whilst people with a learning disability were receiving education on sexuality, they were not being facilitated to make decisions on their own – they feel that parents and professionals interfere too much. Some indicated that parental restrictions, although positively motivated, stopped people with a learning disability from making friendships and more choices.

A number of participants said that they had ‘special friends’, but that they would like to meet new people.

Socialising opportunities

The general response from participants with a learning disability was that they would like to socialise more than they currently did, and have a greater say in choosing where to go, when and with whom. People wanted to do ‘normal’ things eg going to the cinema, going out for dinner more, shopping and having a coffee in town. This required more one-to-one training on every day skills such as spending money on things of their choice, cooking their own tea and making phone calls. People also stated that they wanted to go to the theatre, play sport, go to pantomimes and other outings.

It was considered that Councils needed to provide clubs / meeting places. Youth clubs and church clubs also needed to become more inclusive. People with a learning disability should not just be automatically sent to Gateway Clubs, they should have a chance to join ‘ordinary’ clubs. A number of participants felt alienated because they were in groups largely dominated by people of different ages; they argued that they needed to go places with people of their own age. The group mix in recreational activities was frequently wrong, in the view of many of the younger participants. Development Plans for Day Centres were therefore strongly supported.

The emerging view from participants was that social outlets varied considerably – with limited outlets in some areas.

Leisure Centres were singled out for criticism – very few people with a learning disability had attended events there. Where they had, they had been the subject of bullying and the stigma of arriving in a ‘special’ bus had caused further marginalisation.

In general people wanted to make their own choices and have the support they needed to make informed choices.

Housing and support

The key theme in this area is how we make sure that people with a learning disability have a real choice about where they live.

This theme relates to the fifth and sixth objectives cited in the 'Equal Lives' report – and the associated 8 recommendations.

Objectives:

5. To ensure that all men and women with a learning disability have their home in the community and that, where they live with their family, their carers receive the support they need.
6. To ensure that an extended range of housing options is developed for men and women with a learning disability.

Consultation comments

Relocating from hospitals to the local community

A number of the participants at events in Antrim and Armagh stayed in hospitals, which stimulated debate around the issue of whether it was better to aim for housing and support in the community or the current model where significant numbers still stayed in hospitals.

A large number of people currently in hospitals did not wish to leave. This was based on the fact that previous experiences of some of them going back to the community had not worked because there was insufficient provision to support their carers or, for example, to deal with 'challenging behaviour' in this context.

It was claimed that some people with learning disability had 'played up' so that they would be sent back to hospitals where they had a close group of acquaintances (if not friends) and where there were many more opportunities for recreational activities and socialising. It was noted that these activities simply did not happen in the local community for people with a learning disability.

It was also noted that a significant number of carers (notably older parents) considered that their children needed the specialist help that was only provided (at least currently) in hospitals; and that the 'risk' of living in the community should not be taken when their relative was perfectly happy and safe in a hospital. If the recommendation were to be pursued, many argued, then there needed to be a very careful risk assessment carried out. In the future they wanted what they considered they had at the moment – a supported environment where they knew their dependants were safe and well-cared for in a family-friendly environment.

A number of older people with up to 30 years spent in a hospital stated that they considered that the hospital was their community and were strongly against the disorientating process that resettlement would cause, especially given that they were 'very happy' in the hospital. It was noted by many that it was important to meet the needs of each individual, not to treat everyone the same, and the report's recommendations in this regard were inconsistent with its stated values of individual support and empowerment.

Some younger people living in hospitals or residential homes had reservations about some of the homes. They indicated that they were to receive training on money management, but had not received this, and when they wanted to access their own money staff would not hand it over.

A number of the younger people with a learning disability also said that they did not want to live with their parents all their life – and despite their best intentions sometimes families do not always give enough support to be independent. It was considered that Social Services should provide more advice in helping to plan for this. The younger people who participated were more keen to see the closure of hospitals as a mode of accommodation, and the establishment in their place of community housing for small numbers of similarly aged people with support to help fill in forms, pay bills, manage money, and own their own homes.

They took the view that it was very important not to be hidden away, and noted the strong sense of dignity from 'having your own front door'. They felt that people with a learning disability could never lead

a full life if they were restricted by ward lives etc. They agreed, however, that support in the community was lacking – people feeling they did not have enough help in their homes, for example only being able to have meals when there was someone to make them.

Models for accommodation in the community

Some older people with a learning disability in hospitals were very concerned by the recommendation (26) in the report that by 2010 all people with a learning disability living in a hospital should be resettled in the community.

It was considered by many of the participants that there would always be a need for a facility for some people (not as many as currently, but still some) who require a hospital for long-term care. To this end some of the participants wanted more information on the number of people who had been moved out, but who had to be re-admitted because it had not worked out.

A number of younger carers for children with autism, whilst very critical of the lack of joined-up support they had received in relation to their children, and understanding the feelings of many in hospitals that that was where the best quality support had been given, did not want to see this for their children in the future. They wanted to see a system where there could be real meaningful support in the community. This, however, would involve massive training exercises, restructuring of how services were delivered in a multi-agency way, and enhanced funding. There was general concern that the quality of care in hospitals at the moment might not be replicated in the local community because of funding constraints and different power relationships.

‘No more than 5 in a house’ model

The recommendation (29) that there should not be more than 5 people in new accommodation for people with a learning disability by 2012 met with some queries. It was argued that the most important issue was choice for the people themselves – one instance was given of where this had worked well for eight people who moved together to

a residential unit and stayed together. Others argued that an odd number - 5 - was inappropriate as it allowed more dominant alliances within the group to 'gang up' on individuals or smaller numbers. A group of younger people with a learning disability argued that the five people should be of similar age. In reality current practice suggested that it often took more than two years to find such a place. The key issue for all was that the people themselves had a say in who they would share with.

There was some criticism of Objective 4 (dealing both with fuller lives and housing) in that the aspiration for people with a learning disability to lead full and meaningful lives 'in their neighbourhoods' needed to be more precisely defined. It was stated that an area of 100,000 for a neighbourhood was too large – neighbourhoods needed to be smaller, delivering local support. (One example was provided of someone wanting to live in Derry, but the social worker wanted them to move to Kesh). Some argued that it was an unrealistic aspiration for all people with a learning disability to lead independent lives, but nonetheless should be pursued.

Changes in the community

In these scenarios inclusion in the community was seen as particularly important and this involved much contact and training for the local community to address prejudice. Disability awareness training for potential neighbours was considered particularly important to allay the potential for hostile petitions etc.

A number of participants argued that the draft report was not clear on the level of support that would be provided in the new proposed community-based housing eg would this involve person-centred planning, diagnosis and assessment? How was 1:1 support, 24 hour care to be dealt with and what standard of assessment would be used? Quality of life, vulnerability, safety and transport within the community all needed to be prioritised. There was concern about the need for separate space for the individual to go to when displaying challenging behaviour. All of which led to significant concerns about the cost of the proposals on housing and support. It was also noted that too many of the housing designs at the moment were not fully

integrated in the community and were set apart, which encouraged exclusion or targeting in certain instances.

The recommendation that where possible people with a learning disability should be able to buy their own homes was strongly supported.

Feeling healthy and well

The key theme in this area is concerned with how we can be sure that people with a learning disability get good healthcare services in the community and in hospitals.

This theme relates to the seventh objective cited in the 'Equal Lives' report – and the associated 14 recommendations.

Objectives

7. To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the needs of people with a learning disability.

Consultation comments

There was widespread agreement that much more work needed to be done to ensure that health professionals in the general health system were better equipped for meeting the needs of people with a learning disability. Training should involve people with a learning disability themselves. One example of this was the need for staff to communicate with people with a more severe learning disability in different ways. One participant cited a friend whom he knows has a health problem, but will not tell anyone about it because he is patronised. Health professionals should also be taught not to use technical language where this is not necessary.

People with multiple disabilities experienced specific problems when it came to accessing services – this tended to create difficulties in getting an appropriate social worker because of the way the system was organised.

The proposal of a health plan for everyone was strongly welcomed : this must be seen to address the issue of communication and informing. Equally, having an individual responsible for the person was welcomed although this may need to be more than one, or a 'multi-disciplinary' person if the patient has multiple disabilities. There

was also support for the view that more social workers, nurses, occupational therapists, physiotherapists, chiropodists, dentists, dieticians, experts on mental health, anorexia etc. were needed. In particular, many of the participants stated that they did not have access to a social worker when they needed one. In short it was stated that whilst there was a strong need for more community services, specialist hospital services would always be needed.

General health

General health issues were considered to be very important and many accounts were provided of instances where there were considerable delays to standard general health issues because of the person's disability (one child with a learning disability had to wait for 2 years to have an abscess in a tooth dealt with). Access to health professionals such as dieticians, dentists seemed to be particularly problematic. There was general support for people with a learning disability being treated for these conditions in the mainstream health system.

Better information and monitoring of general health was highlighted as a priority that was often forgotten especially as a person grew older and the perception often was that any key consequences of the disability diagnosis had already been dealt with.

There was a strong feeling that people with a learning disability were often talked down to by health professionals and talked into things rather than being allowed to make their own choices about health care and the options available. Participants observed that if someone else is present at a medical examination or other health meeting, the professional tended to direct the conversation to them.

There was also a feeling that people with a learning disability could not always confide in or tell staff members that they did not feel well.

One example was cited of a health care day centre where 93% of clients needed some form of follow-up – which highlighted the major need for regular health checks. Major efforts needed to be undertaken to deliver a significant uptake of screening for people with a learning disability.

Specific concern was also expressed about how a GP knew that a person had a learning disability and the difficulties around diagnosis.

Growing older

The key theme in this area is concerned with how we meet the needs of carers and people with a learning disability as they get older.

This theme relates to the eighth objective cited in the 'Equal Lives' report – and the associated 3 recommendations.

Objectives

8. To ensure that men and women with a learning disability age well in their neighbourhoods.

There was general agreement that this is an area that people were reluctant to discuss for understandable reasons; this was reflected by most participants spending less time on this issue.

However it was agreed that systems should be put in place to ensure that provisions for older people with a learning disability should be made through specific planning. These should be developed in conjunction with the people with a learning disability themselves.

Consultation comments

Older people with a learning disability

The problem was put succinctly – 'Where do we go when our parents get older or are no longer there? – we want somewhere to go to give the help and support needed when the Day Centres do not want us'. Participants with a learning disability noted that they wanted someone to support them and help them make decisions but not to have others coming in and making decisions for them.

It was noted that with people with a learning disability living longer - in line with the trend in the general population – there were growing expectations across the board on quality of life. The major concern was that any specific care for the general population eg for those with Alzheimers' disease should be made available for the population as a whole. An identified need was also raised for training of staff who

worked with older people who had a learning disability, which was rarely the case at present.

Older carers

Many participants identified concerns around provisions for people with a learning disability when their carers (often parents) became too old to care for them. It was considered essential that plans for older people with a learning disability should also include the arrangements for caring and support so that everyone with an interest knew what to expect.

Who will take over?

Because people with a learning disability are living longer there was now a need to move people from homes for people with a learning disability to homes 'for the elderly' – staff needed to receive the necessary training for this.

An example of the problems faced was: a sister aged 23 had poor communication skills and a learning disability and her parents are ageing. The parents believe that it is not fair on her siblings to continue the caring they have been providing, but she would not be happy in a residential home. The parents want to know what will happen when they are no longer around.

They emphasise the need for greater respite for older carers and the need to begin the process of familiarising older people with a learning disability with different environments / experiences.

Some participants also raised the issue of, whilst wishing to not place the responsibility for care on siblings, wanting clarity as to who would be approached for consent to medical interventions – operations, new treatment etc in these circumstances. Some quoted a circle of trusted friends who could be relied on and should be consulted; some wished this to be the siblings. It is clear that there is no one preferred approach, but this issue is a source of major concern for ageing carers, which they would like to see specifically addressed in the report, alongside detailed plans for when carers are no longer available.

General issues

A number of other issues which include matters raised in the 'Equal Lives' report are included in this final section and cover the final four objectives in the report (and the associated 23 recommendations).

Objectives:

9. To enable people with a learning disability to have as much control as possible through developing person-centred approaches in services and ensuring wider access to advocacy and direct payments.
10. To ensure that health and social services staff are confident and competent in working with people with a learning disability.
11. To ensure that staff in other settings develop their understanding and awareness of learning disability issues and the implications for their services.
12. To promote improved joint working across sectors and settings in order to ensure that the quality of lives of people with a learning disability are improved and that the Equal Lives values and objectives are achieved.

Consultation comments

In addition to the comments under the five principal headings the following points were made.

The person-centred approach to service delivery as outlined in Objective 9 was strongly supported. Person centred planning for each child through to older people was essential to delivery on the value of individual support. There also needed to be family support plans where the person with the learning disability lived with their family.

Again there was strong support for Objectives 10 and 11 – as has already been identified throughout this report the lack of awareness

of the needs of people with a learning disability or how to work effectively with people was a major barrier. The evidence did not suggest that health professionals were as informed in this area as many supposed. It was key that extensive training as indicated in earlier sections should involve people with a learning disability themselves. Very specific skills training on how to deal with challenging behaviour was also a priority.

The 'WrapAround Manifesto' was promoted as an example of best practice, which should be implemented across the Boards – many felt there was currently a vacuum in community-based services.

It was also recommended that direct payments be better promoted and should be made available to parents so that respite can be given at home.

Most participants did not consider they were qualified to say which systems and structures needed to be in place to ensure more equal or fair lives for everyone. They felt that the recommendations outlined in Objective 12 were appropriate, but there was common consent that the key factors for change would be committing the necessary resources and the necessary political will for change. Some participants expressed considerable scepticism as to whether this would happen.

There was a general concern that the recommendations did not say enough about the need for individual advocacy to deliver on the empowerment value by allowing people with a learning disability to make informed choices.

Conclusion

The consultation process engaged people with a learning disability and carers in lively discussion on the policies and services which affected their lives.

In overall terms there was very strong endorsement for the values, objectives and recommendations contained in the report 'Equal Lives' prepared by the Learning Disability Committee.

The most significant area of concern was in relation to the commitment to not having people with a learning disability living in hospital accommodation by 2010. This is of real concern to many older residents in hospitals (and their carers) who see these places as their natural communities with much higher levels of support and recreational opportunities than they have ever experienced in the community.

There is considerable fear around this proposal and if the Committee is to maintain this as a proposal much work needs to be done to ensure that the necessary support mechanisms are provided in the community.

It should be noted that younger people with a learning disability and younger carers wanted a community-based system of accommodation. Both groups, however, shared significant scepticism as to whether the government would make sufficient funds available to provide adequate support in the community.

As a concluding observation most participants welcomed the specific recommendations but the overriding concern was the extent to which funding and effective joint working would materialise to deliver on them.