



NI COALITION
ON LEARNING DISABILITY

Department of Health, Social
Services & Public Safety

An Roinn Sláinte, Seirbhísí
Sóisialta agus Sábháilteachta
Poiblí



A Fair Chance

Report on a consultative exercise

facilitated by

LEAD – NI Coalition on Learning Disability

May 2002



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A Fair Chance

For people with learning disability

"It is very important that people from all walks of life get a Fair Chance. It is important for people with learning disability to have their say."

Joanne McDonald
Self-advocate, Omagh

Funding provided by DHSSPS made **A Fair Chance** possible

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Foreword

The four seminars detailed in this report are a triumph for the equality agenda.

It is important that we acknowledge such achievements not least because the apparent fast pace of changes in legislation can blur their value.

Consultation exercises like this make the bureaucratic systems truly meaningful. The seminars are also a triumph for the men and women with a learning disability who participated and voiced their views and feelings in a markedly responsible manner. Our formal helping structures often end up creating distances between those being served and the care-givers. The very act of listening can dissolve distance between "us" and "them".

Each seminar provided a space for all of us to go beyond our "roles" and deep human qualities came forth: openness, yearning, patience, courage, humour, forbearance. Moved and touched by these qualities we naturally acknowledge and reaffirm our humanity and renew our guiding principles. It is at these moments that we remember what the work is all about.

The spirit of this consultation exercise was that whatever people had to say was of value. We show people that we value them by keeping our agreements with them. The test for service providers now, is can users views be taken account of, no easy challenge in these times of often shrinking budgets and increasing demands. But services must find ways to take on board what was said and this essentially distils down to:

- small is beautiful in terms of structures
- support us to speak for ourselves.

It must also be acknowledged that this was the beginning of a process and with each consultation the process itself was refined and improved. The consultation was only able to focus on those who can verbalise in words, so future refinements will widen the process to include the missing voices of children, those with challenging behaviour and more people with autism and sensory disabilities.

The climate of openness so tangible in these seminars will only endure and expand if self-advocates become more prominent in the organisation and facilitation of future consultation. The emerging advocacy movement here clearly welcomes opportunities to step forward and make a positive contribution. Let's listen to them.

I would like to thank all those who spoke out and made the events so full of life, especially those who contributed formally and introduced topics and so started off discussions.

A special thanks to Paddy Rodgers who facilitated all the events and wrote up the findings, and also to Paschal McKeown in Mencap who was a steady source of good organisational skills.

Finally, LEAD is particularly grateful to Catherine Donnelly and Roy Keenan from the Department for their role in promoting **A Fair Chance** for people with a learning disability.

Copies of this report are available on the Department's website at **www.dhsspsni.gov.uk/publications**

The Department will also make the report available in Braille, Audio Cassette, Irish and Chinese, and will consider requests for translations into other minority ethnic languages.

A handwritten signature in black ink that reads "Miriam Kelly". The signature is written in a cursive, slightly slanted style.

Miriam Kelly

Chairperson, LEAD – NI Coalition on Learning Disability

May 2002

Summary

Section 75 of the Northern Ireland Act 1998 requires public authorities to promote equality of opportunity and good relations. The Department of Health, Social Services and Public Safety fully recognises the importance of consultation in fulfilling its duties under the Act. Consultation with people with learning disability presents a considerable challenge.

In order to engage people with a learning disability in an effective consultative process, the Department asked LEAD - Northern Ireland Coalition on Learning Disability - to conduct a series of consultations with the client group.

In responding to the request, LEAD developed a model for consultation, the aim of which was to minimise the barriers to participation and enable people with a learning disability to have an effective voice in the equality consultation exercise being undertaken by the Department. Four consultation events were held in Antrim, Newcastle, Omagh and Portadown. Statutory, voluntary and private sector service providers were asked to support people to participate, in a purposeful way, in the consultative process.

This report has been compiled from the thoughts, opinions and aspirations of the people who participated in the consultative exercise. People came to the events prepared to talk and listen to others. There was extensive discussion over a wide range of issues.

What was said

There was a widespread acceptance amongst delegates that health and social services provided good support for them as they endeavoured to build meaningful lives and aspire to citizenship. There was, however, room for improvement. Large day centres, many said, are not as attractive as

smaller units. The range of activities in centres could be more imaginative and include more inclusive activities, giving people greater opportunities to engage with communities. Work is seen by many people as a conventional adult activity and they recognise that they need support if they are to have a place in the economic life of the community.

Medical, dental and hospital services are generally good, but service staff should develop more effective communication skills. In particular, they should be more willing to communicate directly with people with a learning disability. Some self-advocates offered to help with training health professionals. Delegates felt that special hospitals should be closed.

The development of skills in self-advocacy was evident at some of the events. However, more opportunities for individuals to develop skills in speaking out need to be developed.

Bullying remains a feature of many people's lives. Delegates felt that it was related to lack of awareness. Many of the delegates would be willing to participate in disability awareness programmes in schools and community groups.

The consultative process was well-received by those who participated and was positively evaluated. The hope was expressed that consultation directly with people with a learning disability would continue and develop.

I. Introduction

People with a learning disability have traditionally been either institutionalised and separated from the wider community or have continued to live with their families well into adulthood. They are people who, compared to those without a disability, have had diminished access to health care, to education, to employment and to leisure. They are people who have tended to have things, good and bad, done to them, rather than enjoying personal rights and choices. They are people for whom participation in the things that affect their lives has been limited due to difficulties faced by people who have problems with communication and understanding, and due to the attitude of others. Consulting with people with a learning disability requires the development of a process which is sensitive to their specific needs and listens and acts on their views.

The majority of people wish to live inclusive lives in which they are part of the community, with choices in work, health care, housing, adult education opportunities and recreational pursuits. Some people with a learning disability are able to access community life without assistance, most require support if they are to pursue their aspirations and interests.

This report has been compiled from the thoughts and opinions expressed by people with a learning disability at a series of consultative events held at various venues throughout Northern Ireland. The report outlines the context in which the consultations took place and details the issues raised. During the four consultative events many valuable points were made by the delegates but, it has not been possible to include them all. The report does attempt to reflect the main points and issues which were raised. The things people said are emphasised and an attempt is made to formulate messages from the participants. The evaluation of the consultative process, which was carried out by delegates, is summarised and information on attendance is appended.

The creation of a format for consultation, which would enable people with a learning disability to speak out and have their voices heard was a challenging task. A key concern of the planners was to develop a model which would ensure that people had accessible information and effective support during the consultative process. The model for consultation which was devised by the organisers, is outlined in Section 3. Others may find it useful as they engage with people with a learning disability.

The report is intended for those with responsibility for promoting equality of opportunity. It will only be of value if organisations determine to listen to what people say, attempt change and check back frequently with service users.

2. Background

2.1. Contacting LEAD – NI Coalition on Learning Disability

Section 75 of the Northern Ireland Act 1998 requires public authorities to promote equality of opportunity and good relations. Under the Act, the Department of Health, Social Services and Public Safety must have due regard to the promotion of equality of opportunity:

- between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- between men and women generally;
- between persons with a disability [including people with a learning disability] and persons without; and
- between persons with dependants and persons without.

The Department wished to communicate with people with a learning disability and include them in the consultation process that they were undertaking on the equality implications of its policies.

The Department approached Mencap in Northern Ireland to facilitate consultation with people with a learning disability. Mencap involved LEAD-NI Coalition on Learning Disability, a coalition of the voluntary organisations working with children, men and women with a learning disability in Northern Ireland. (See **Annex I** for a list of organisations involved in LEAD).

LEAD agreed to organise four events called **A Fair Chance**.

LEAD recognised that **A Fair Chance**:

- could be the beginning of the relationship that must develop between people with a learning disability, and the Department, HSS Boards and Trusts in their area;
- could offer a model for including people with a learning disability in consultative processes;
- could provide an opportunity for all involved to learn about making consultative processes more accessible to people with a learning disability;
- would not be inclusive of all people with a learning disability, of all ages, from all areas; and
- would help identify the groups of people with a learning disability who required more targeted initiatives, for example children, young people, people with profound and multiple disabilities, those with behaviours which challenge, and people with autism.

2.2. Barriers to participation

People with a learning disability face a number of barriers including:

- the attitudes of others about their ability to participate and contribute;
- the absence of information in accessible formats;
- the need for support, usually provided by other people, before, during and after their involvement;
- the absence of accessible transport and the reliance on others for transport; and
- the lack of experience in being included and in being asked to contribute their views.

2.3. Aims of A Fair Chance

In discussions between the Department and LEAD, it was agreed that the aims of **A Fair Chance** would be:

- to raise awareness of Section 75 amongst people with a learning disability;
- to encourage participation by people with a learning disability in a consultative event;
- to provide a supportive environment that would encourage people with a learning disability to contribute their views;
- to collate the views of people attending **A Fair Chance** and forward these to the Department; and
- to offer a model for consulting with people with a learning disability.

3. *A Model for Consultation*

3.1. Principles

The principles upon which **A Fair Chance** was based were:

- i. Partnership
- ii. Inclusion
- iii. Independence
- iv. Consistency and flexibility
- v. Valuing the expertise of people with a learning disability

i. Partnership

Between DHSSPS and LEAD – NI Coalition on Learning Disability

Representatives from DHSSPS and LEAD met four times to agree the approach, briefing materials and outline programme.

DHSSPS agreed to:

- draft a briefing paper aimed at people with a learning disability, outlining the new duty to promote equality of opportunity;
- identify HSSPS speakers for each event;
- draw attention of key staff within the HSSPS Department, Boards and Trusts and Education & Library Boards to **A Fair Chance**; and
- attend and take part in each event.

The DHSSPS also agreed to cover costs incurred in organising **A Fair Chance**.

Organisations involved in LEAD worked together to:

- draft a flyer aimed at people with a learning disability;
- test out accessible materials with a group of people with a learning disability;
- draft a letter aimed at service providers, explaining the background to **A Fair Chance** and requesting that they support individuals with a learning disability to decide if they wished to attend and take part in their local event;
- draft a programme outline;
- organise **A Fair Chance**, identifying an organisation to be responsible for each event and providing essential administrative support;
- identify an independent facilitator and speakers, as well as the leaders, reporters and supporters which were used during the events; and
- send around 300 invitations to service providers about **A Fair Chance** and to promote the events through their membership and service networks.

Organisations involved in LEAD also made an essential contribution towards **A Fair Chance**, largely through making staff available to help with the organisation of each event, and in providing group leaders and reporters for each event. This contribution was not included in LEAD's costing for the four events.

With Service Providers

LEAD is grateful to the service providers in the statutory, private and voluntary sectors for providing transport and support so that people with a learning disability could attend and take part.

ii. Inclusion

LEAD attempted to make the events as inclusive as possible by:

- identifying people with a learning disability throughout Northern Ireland as the primary audience;
- producing information in a more accessible format;
- organising four events to facilitate transport arrangements; and
- ensuring that people with a learning disability played a key role at each event; making sure that delegates were welcomed and knew the location of lunch, groups, etc., and, at two of the events, by being key speakers.

LEAD acknowledges that not all people with a learning disability were included in the **A Fair Chance** events and that alternative methods and initiatives may have to be developed, for example, to ensure the inclusion of children with learning disability, people with profound and multiple disabilities and people with challenging behaviour and autism.

LEAD recognises, too, that parents and carers remain important advocates for the people they care for and support.

LEAD has agreed to forward to DHSSPS issues raised by carers at Section 75 information sessions facilitated by Mencap and Carers National Association.

iii. Independence

LEAD recruited an experienced, independent facilitator, Paddy Rogers, to attend and act as Chairperson for each event, to listen to the points made and to draft an independent report using the feedback reports compiled by reporters.

iv. Consistency and Flexibility

An outline programme was used for each event to ensure consistency of approach.

Written and verbal briefings were provided for group leaders, reporters, and the independent facilitator:

However, the need for flexibility within the programme was recognised by LEAD so that discussions could take place at the pace and with the agreement of the delegates. Delegates were also given alternative options about how they could contribute their views.

v. Valuing the expertise of people with a learning disability

LEAD believes that because of their life-long, multi-agency experience of health and social care, people with a learning disability have much expertise to offer in helping to identify both the adverse impacts of policies and the changes which would result in equality of opportunity.

A Fair Chance demonstrated that people with a learning disability have much to contribute to discussion about promotion of equality of opportunity.

At the end of each session, the views recorded by reporters were confirmed and agreed with delegates.

3.2. Factors for success

The following factors for success were identified as a result of the 4 consultation events:

- i. Location
- ii. Timing of events
- iii. Reaching people with a learning disability
- iv. Targeted information
- v. Support
- vi. Active inclusion of people with a learning disability
- vii. Respect for the views of people with a learning disability
- viii. Support for a consultation process that targets people with a learning disability
- ix. Organisation of the events
- x. Funding

i. Location

Organising four events meant:

- Northern Ireland-wide coverage
- Local venues*
- Relationships could be developed with relevant Boards and Trusts
- Transport difficulties encountered by people with a learning disability were minimised

*LEAD acknowledges that, for some people with a learning disability, the location of the events may still have been too far away.

ii. Timing of events

The events took place during the day to facilitate the provision of transport and support to individuals with a learning disability. Account was also taken of the daytime arrangements of service providers, such as day centres, when devising the timetable for the programme.

iii. Reaching people with a learning disability

Few people with a learning disability are members of community or voluntary networks. Many are not able to read and rely on others for help in understanding written information.

Invitations to people with a learning disability to attend **A Fair Chance** were issued through service providers and Mencap's membership network. LEAD members also actively promoted the events through their own networks.

iv. Targeted information

A letter was sent to service providers outlining the background to **A Fair Chance** and asking for their support so that people with a learning disability could take part in their local event.

Included with the letter was a flyer and a briefing note in more accessible formats, aimed at people with a learning disability.

v. Support

LEAD recognised that people with a learning disability needed support to attend and take part in the events. LEAD asked service providers and other carers to provide this support.

LEAD also tried to arrange additional support such as sign language support, where this need was identified.

vi. Active inclusion of people with a learning disability

LEAD actively included people with a learning disability as supporters at each event and as speakers at two events.

vii. Support for a consultation process that targets people with a learning disability

Service providers and carers demonstrated their belief in the right of people with a learning disability to be included by supporting individuals to attend and take part in their local events and through their comments on evaluation forms.

viii. Respect for the views of people with a learning disability

LEAD tried to ensure that people with a learning disability:

- had some information about the equality of opportunity duty and the **A Fair Chance** events;
- understood what was going to happen to their views; and
- were given the opportunity at the end of each session to confirm the accuracy of what was recorded and to withdraw, change or add to the views recorded. LEAD also intends forwarding, to delegates, a plain English summary of views recorded.

ix. Organisation of the events

The four events would not have been successful without the administrative support of Linda Spence, the participation of members of LEAD as group leaders, reporters and organisers, and the participation of DHSSPS and Board representatives.

The appointment of an independent facilitator was also important in ensuring the independence of the views collated in the report, the consistency of approach between each event and the compilation of a written record of the process.

x. Funding

LEAD is grateful to the DHSSPS for funding **A Fair Chance**.

4. Organising the events

4.1. Inviting people

The primary target audience for **A Fair Chance** was people with a learning disability, although parents and carers were also welcome to attend, as were representatives of local Boards, Trusts and equality officers of Education and Library Boards and other public authorities.

LEAD was keen that people with a learning disability living in a special hospital or using the assessment and treatment services of special hospitals should be invited to attend. The Department of Health Social Services and Public Safety forwarded invitations to the appropriate contacts.

Publicity material prepared in plain English and illustrated by symbols and pictorial drawings [**Annex 2**] was circulated to:

- Service providers in the statutory, voluntary and private sectors;
- Special Learning Disability schools;
- LEAD members;
- Self advocacy groups known to LEAD members;
- Mencap affiliated local groups and Gateway clubs;
- Learning disability teams in HPSS Trusts;
- Equality Managers and Policy Personnel in HPSS Boards and Trusts;
- Equality Managers and Policy Personnel in each Education & Library Board; and
- Policy Personnel in DHSSPS

These organisations were asked to promote the consultative programme and encourage people with a learning disability to participate and have their voices heard.

4.2. The venues

Four venues were selected which would ensure:

- there was a geographical spread across Northern Ireland;
- there was adequate conference space for the events and accessibility.

The venues selected were:

- The Fitzwilliam Hotel, Antrim **Thursday 7 June**
- The Burrendale Hotel, Newcastle **Tuesday 12 June**
- The Silver Birch Hotel, Omagh **Thursday 14 June**
- The Seagoe Hotel, Portadown **Thursday 21 June**

At each venue a conference room and syndicate rooms were reserved. To facilitate independent access to facilities, such as rest rooms, conference rooms and dining areas, signage directions were posted.

Supporters, including LEAD members and people with a learning disability welcomed delegates to the events and helped them find their way around the venues.

4.3. Participation

Altogether 265 people took part in the consultations. Of these 161 were people with a learning disability. Geographical representation was uneven, with some areas being well-represented, others poorly (details of attendance may be found at **Annex 3**). The majority of the delegates were adults. Young people at school did, however, participate in two of the events.

4.4. The programme

The fundamental object of the programme was to provide facilities and create an atmosphere which would enable the delegates to speak and to be heard. At the planning stage it was felt that this was most likely to be achieved if people were in small groups, and if adequate support was provided. A programme outline was devised to ensure consistency of approach. The programme was distributed with the invitation to facilitate support before the event. Throughout there was an emphasis on devoting maximum time to participative sessions.

➤ The morning programme

Each event was opened by a LEAD representative with a welcome and general orientation to the venue and its facilities. Following an introduction to the role of the independent facilitator there was a formal presentation on the current legislation. These were made by Equality personnel, from local Trusts at two of the events, and by representatives from the Department at the remaining two.

The event in Antrim was addressed by Richard West, a self-advocate from London. His main message encouraged people to speak out and have their voices heard. At the Omagh event, Joanne McDonald, a member of the Strule Buzz self-advocacy group, urged people not to

waste the opportunity to say what they liked and what they did not like. The major part of the morning was devoted to small group discussions. Each group was encouraged to focus on daytime activities, work, leisure and support.

➤ **The afternoon session**

The afternoon opened with a resumé of the morning session and the opportunity for delegates to add new comments and views to the morning topics.

Session 2 explored factors surrounding going to hospital, and the final session concentrated on going to the doctor and dentist.

Three of the events closed with the end of discussion time and one had a brief resumé on the topics which were raised during the day.

➤ **The opportunity to speak out**

Although each session had a focus, this did not preclude discussion on other topics which delegates wished to raise. The facilitator and the group leaders stressed to delegates the option of speaking out about other issues. Delegates also had the option of speaking privately to the group leaders, the reporters, or representatives of the Department either at the events or afterwards. A feature of the consultative exercise was that delegates took some time to settle in and feel comfortable with talking. This resulted in the morning sessions being rather slow with a corresponding quickening of the pace in the afternoon sessions.

4.5. Supporting the delegates

An extensive support network was built around the events. Additional needs were ascertained through the application process. Each group had a group leader who was briefed to encourage delegates to tell their own stories, express opinions, compliment services or voice complaints, listen to others or talk about their hopes and wishes for their lives. A reporter was attached to each group with the task of recording as much as possible. Parents, carers and staff from the statutory, voluntary and private sectors also helped support delegates.

Local delegates, mainly people with a learning disability, acted as supporters in the different venues by guiding people to session venues and providing information on the layout of the settings.

A sign language interpreter was engaged for a delegate at one venue. A speech and language therapist from a local HSS Trust was available throughout the day at another venue. At one venue, LEAD was unable to provide a sign language interpreter, and sign language support was provided by a supporter known to the individual concerned. LEAD members were available at all the events to give help and coherence to the process.

5. The Issues

5.1. Introduction

In his introductory remarks, the facilitator emphasised that the main function of the consultative process was to give delegates the opportunity to talk about their lives, to tell their stories and to raise issues which concerned them. The group leaders reinforced this point and provided people with a safe and comfortable environment in which they were encouraged to talk. At the end of each session, the reporters outlined what they had recorded, checked their records for accuracy and offered delegates the opportunity to change, or amend, any part of the record. Some delegates took the opportunity to raise issues outside the group sessions.

5.2. The issues

A large number of important issues were raised by delegates and time was found to discuss these. There was a significant relationship between the issues raised at the four venues, which would seem to indicate that across Northern Ireland people with learning disability have similar experiences and concerns. This will be important to the Department, the Boards and the Trusts as they explore this report and identify where there are challenges to equality in the provision of services to people with a learning disability.

The main issues raised during the consultative process were:

- Daytime services;
- The creation of opportunities for employment;
- Adult and continuing education;
- Leaving school;

- The importance of self-advocacy;
- Bullying;
- Leisure opportunities;
- Going to the doctor;
- Going to hospital;
- Going to the dentist; and
- Support.

The need for choice, independence and respect for people's rights were constant themes across the events. The limitations of the benefits system, the relative lack of potential to earn real wages and difficulties associated with transport were also raised.

5.2.1 Daytime activities

➤ Day centre

The day centre remains an important part of people's lives. A number of people indicated that they were happy with the day centres, particularly when there was a range of activities that engaged them. However, many delegates were critical of the limited range of activities provided by day centres, and some referred to a reduction in the activities offered.

Delegates wanted to see the centres become more purposeful, providing a richer menu of activities from which people can choose. They also would like the day centre to be more active in providing a stepping stone to inclusion in the community. A significant number of people spoke of the possibility of having lunch in local food outlets, where they would have greater choice and could interact with other people.

People have visions of mixing with others in a range of community-based activities in which they could join others in work or art-based activities. Many delegates spoke of sitting in the day centre with nothing to do. Money, or lack of it, is also frustrating. One delegate spoke of receiving £4 per week and pointed out that he had earned that amount in 1968.

A number of delegates expressed their appreciation of the personal support they received from sensitive staff in the day centres. They thought it was important to spend some time in the day centre each week in order to access support and see their friends. A number of delegates felt that if they were to have more choice there would need to be more staff in the day centres.

Some delegates were distressed by having to travel in transport that carried the livery of public bodies. They felt that transport should be anonymised. The inadequacy of public transport was also an issue, particularly in the south and west of the province.

People said

"I like the horticulture and the cooking in the day centre."

"We have choice in the day centre if there are enough staff."

"We would like more opportunities to be 'out and about'."

"It's very annoying when activities we like are stopped. We used to make hanging baskets, now that has stopped."

"I like the day centre but I like my job better."

"Staff listened to me when I wanted to go out alone."

"People outside the day centre don't understand- they don't mix with people from the day centres."

"The centres are overflowing, there are not enough places."

"I only get three days I would like full time."

"When they started day care reviews things changed."

"It's time to move on, I want to earn a wage."

"I am at home doing nothing. I want to go to a day centre. There are no places."

"I would like training in computers."

Message

The day centres are still important to people, but changes are needed.

People are seeking more variety in the activities offered by day centres and they want to see community-based activities as an extension of the day centre programme. People would like to be consulted about day centre programmes. Many stressed that small centres were preferable to large ones. Some people do not have the opportunity to go to a day centre and others would like their attendance to be increased.

Payments made to people attending the centre for their work was felt to be inadequate and out of date. Marked transport can be embarrassing to people.

➤ **Work**

The possibility of work is closely allied to daytime activities and is of increasing importance to people with a learning disability. A significant number of people work for part of the week – very few are in paid employment. There is widespread awareness of the potential effect of earnings on benefits. To many people, work represents the norm. It means they are included in the mainstream and can mix with other people.

People said

"I like the job I'm in. I'm happy with my pay."

"I like what I do. I move trolleys. I would like to work in Tesco's."

"My job ended in June. I don't know why."

"I love working in an office. I hope to get a job. I want to work."

"I would like to do more work. I would like more money."

"I get £5 for ironing two days. I use my money to go to a singing class."

"I am working in the bakery now. I don't want to go back to the day centre."

Message

Many people see work as a natural part of adult life. Some would like work as their principal daytime activity-others would like to have part-time work and go to day services for a portion of the week. People's ambitions, related to work, are realistic and achievable. Having vocational qualifications is important to job-seekers.

➤ **Adult and continuing education**

An increasing number of adults with a learning disability participate in adult and continuing education. Some are enrolled in basic education classes involving studies in English, mathematics, communication and information technology. Others follow vocational programmes and a number have been awarded qualifications. Delegates were aware of the relationship between qualifications and success in finding work.

People said

"I go to a link course in the college."

"I have a NVQ in horticulture."

"I do word processing on the course."

"I like the college. I am treated like an adult."

"I'm doing a City and Guilds course. I am enjoying it. I was asked if I wanted to go, I said yes."

"There are no courses in our local college."

"I like going to the Tech but I wish we could be along with other students and not in a special class."

Message

People enjoy going to Colleges of Further Education. Qualifications enhance opportunities in the job market. Some colleges make no provision. Colleges should develop more inclusive provision.

5.2.2 Advocacy

A number of self-advocacy groups participated in the consultative process. Their self-confidence and skills were evident in the way they could focus on topics and speak for themselves.

People said

"You need to speak up for yourself."

"Sometimes people don't listen-you have to have a strong voice."

"Mary and others went to Stormont last week to speak out."

"We learnt to speak out at the Buzz Group."

"Self advocates should go into the schools to give talks. This would help with the problem of bullying."

"Able-bodied people talk through you."

Message

People still have difficulty having their voices heard. Membership of a self-advocacy group helps people develop the self-confidence and skills required to talk and be listened to. The development of groups should be encouraged. Skilled self-advocates could provide feedback to service providers.

5.2.3 Bullying

Bullying is an important issue for people with a learning disability. It was raised at each consultation. The delegates were insistent that something be done about it. They felt they had a right not to be bullied.

People said

"I feel sad about bullying. I think visits from school would be good."

"Invite schools to the centre to meet people and become friends instead of bullies."

"I went out to get my Dad a paper. A boy threw my bike down and called me names. I was upset and fell off my bike on the way home. There was nobody there to tell. I told my Mum when I got home."

"A boy lit a firework close to my ankle when I was out with my brother. I don't go that way now. It was very scary."

"People called me names like spastic. Sometimes people came at me with matches. I stand up for myself now."

"We can be bullied. Things they say to us are not nice. We can be bullied by other people's attitudes."

"You can be bullied by other people in the day centre. Staff don't always listen."

"Why do ordinary people bully us? Why is there not a law to stop people mocking us?"

"We must be taken seriously. We have a right to complain."

"The new rule can help us."

"We need to involve the police."

Message

Bullying is widespread. People with a learning disability need to be encouraged to report incidents of bullying and given strategies for counteracting bullies. There is a need for greater disability awareness in schools, in the workplace and in society in general. Segregation does not help in the reduction of bullying. Self-advocates are very willing to be involved in disability awareness training for schools and community groups.

5.2.4 Leisure opportunities

Although there is evidence that people with a learning disability are engaging in a wider range of leisure activities, delegates felt that the choice was still very limited. A major obstacle is the lack of transport and the relative lack of skills in using public transport.

People said

"The Gateway Club is very good, I don't go anywhere else in the evenings. I would like to go somewhere I've never been before."

"I have to wait for my brother to take me, he works so he can't always take me."

"I have a volunteer who takes me out, to McDonald's or swimming. I have choice."

"I would like to do things other people do."

"We get away from our parents."

"I get bored at weekends."

"There is a lack of help at the leisure centre."

"I was able to go to America with Special Olympics."

"I like to keep busy, I have a dog. I have a computer, a CD player and Hi Fi in my room. I go out some nights."

"I like to write."

"I clean my room every morning, do jig-saws, collect coins. It's my hobby."

"I would like to do more fishing. I go out with friends and my father takes me out."

"I do swimming. I've got three gold and a silver medal."

"I go out with-----, we go to dances, there's plenty to do where we live. My father leaves me down and we get a taxi back."

Message

People with a learning disability have difficulty in accessing leisure pursuits enjoyed by others. The Gateway Clubs still play an important role in many people's lives. Support and suitable transport are crucial to a fuller recreational life. Lack of opportunities to pursue community leisure activities means that the day centres have to provide for recreational needs.

5.2.5 Going to the doctor

Many delegates expressed satisfaction with their family doctor service. There was, however, some criticism regarding the quality of communication between doctors and patients. There was the excellent suggestion that symbols could be used to label medicines. There was also a strongly felt need for support in going to the doctor. At the Omagh event there was the expressed desire to be involved in the local debate about the local acute sector hospital provision.

People said

"I have a good doctor who listens to me, I like him. He explains things to me."

"I prefer a choice about which doctor I see."

"I had to fight to get off medication I didn't need or want. I should have been listened to."

"People shouldn't be made to do anything against their will - they need all the information to make an informed choice."

"I like company and support going to the doctor, my sister comes."

"If doctors understood more about disability they would treat us with more understanding and respect."

Message

People have good relationships with their general practitioners. They like to have explanations about diagnosis and treatment. They like to be involved, and are resentful when doctors ignore them and talk to others.

5.2.6 Going to hospital

In relation to waiting lists and waiting times, there were complaints which are common to many people who use the National Health Service.

In talking about their hospital experiences, delegates referred to general hospitals and to special hospitals and made a sharp distinction between the two types of service.

By and large, people's experiences of general hospitals were satisfactory, although there was, again, a number of comments about the lack of understanding of people with disabilities and about poor or inappropriate communication.

Talking about the special hospitals aroused a range of emotions, particularly from people who had direct experience. Additionally, a number of people spoke of being traumatised by the threat of admission to a special hospital, as a response to trivial deviations from acceptable behaviour. There was the widely held view that there was no need for special hospitals and, therefore, they should be closed down.

One parent drew attention to the inaccessibility of A&E for emergency procedure for people with a learning disability. Her son, she said, could not wait the 2/3 hours required before being seen, is panicked by the sight of blood and is unable to cope with noise or crowds.

People said

General hospitals

"At the hospital I was treated very well. It helped me."

"The consultant had time for me, he sat down beside me."

"I am a dialysis patient. I am not treated differently because I have a learning disability."

"I went to casualty. I didn't like it. I had to wait a long time."

"In hospital they talk to you, explain things to you. I was very frightened going into hospital."

"I was very frightened. I couldn't eat or sleep. My sister's friend is a nurse and she came to talk to me. I still don't understand why I have it [epilepsy] but I have to learn to live with it. I'm scared of when the next attack is going to come."

"Staff can be cheeky."

"Doctors sometimes talk to the support worker and not to the person."

"I was asked to leave then they talked to my Mum. I didn't like that."

Special hospitals

"I spent days in pyjamas."

"I was bullied in-----"[special hospital].

"I wouldn't like to live in hospital."

"Can they ever take you back to-----"[special hospital].

"I was in -----[special hospital] I didn't like it."

"In the past special hospitals were used as a threat."

"They should be closed down."

Message

Many people have had good experiences in general hospitals. They were appreciative when treated like others. There was the feeling that not all doctors were aware of disability issues, and that medical students would benefit from experiential visits to day centres.

Discussion on the special hospitals raised feelings of anger and fear. The threat of being sent to a special hospital was deeply resented. The special hospitals should not be used for respite-short term breaks. Many people felt that there was no longer a need for special hospitals and that they should be closed. Although there were extended discussions on the special hospitals, many people indicated that they did not wish that their comments be recorded.

5.2.7 Going to the dentist

There was widespread satisfaction with dental services. The majority of people preferred going to a community dentist rather than to the dentists in the special hospitals. The dental hygienists were very popular with many people. One Trust representative pointed out that with the increasing use of community dental services, a significant number of people fail to make or keep appointments. Increasingly, the day centres have to arrange dental appointments.

One parent, however, drew attention to the fact that her son had had to wait 6 weeks, in great pain, to get his tooth out in hospital. Her son does not attend the local dentist.

People said

"I like my dentist. I go once a month. He talks to me, fills my teeth and polishes them. He tells me how to brush my teeth and to eat fruit and vegetables."

"I don't like getting fillings, the dentist explains it to me."

"I have no fear of going to the dentist."

"The dental hygienist is very helpful, she will come to your home if you cannot go to the dentist's surgery."

"I would rather go to my own dentist rather than the dentist in ----- hospital." [special hospital].

"My dentist explains everything to me, he tries not to hurt me."

Message

Dentists are skilled in putting people at ease and willing to explain procedures to them. The use of special hospital dental services are seen as inappropriate.

5.2.8 Support

The need for support was a constant theme across the sessions. As people strive for inclusion in the economic and social life of the community they realise that they need support if they are to improve the quality of their lives. They want support to be appropriate to their needs and they want it focused on opportunities to engage in personal and social activities.

People said

"I need someone with me going to the doctor."

"We need support when we go on the bus."

"We need more staff in the daycentre if we are to do things we want to do."

"You can get help from staff, the staff are very kind and helpful."

"Sometimes you get support when you need it. I would like more support. I would like to change my work. I am not happy."

"My parents give me help and support. I asked them not to wrap me in cotton wool. They are there when I need them."

"I've plenty of support from family and friends."

"I go down town with my volunteer."

"My brother takes me out."

"My sister goes to the doctor with me."

"I would like a volunteer."

Message

Appropriate and discrete support is essential to fuller inclusion. Families are an important source of support. The range of activities in day services is often limited by inadequate staffing. Volunteers are popular as supporters.

6. *The Evaluation*

Delegates at the four events were invited to complete an evaluation form. Support was available for those challenged by reading the text and writing their answers. A number of delegates wrote and submitted separate comments.

There was considerable enthusiasm for the concept of consultation and the opportunity to talk and to listen to others. The programme was highly rated and the venues were seen as ideal. The introductory talk on the new rule was seen as very useful.

A considerable volume of comment, which makes a very valuable addition to this report, enriched the evaluations.

7. Conclusions

The messages from this report are most vividly expressed in the 'voices' of the participants. People's fears, hopes, wishes and aspirations are expressed in temperate language, demonstrating that people had thought about the issues and formulated balanced views. They recognise when services are good and where the reduction of barriers would lead to greater inclusion in society. The report clearly demonstrates that people with a learning disability can and should be included in consultation exercises.

The majority of people who participated in **A Fair Chance** are relatively happy with the service they receive from medical and dental staff. They see a need for an improvement in communication and wish that professionals would speak directly with them and not through others.

Bullying is a grave concern for many people. They attribute this to lack of awareness, particularly amongst young people. They feel that more work needs to be done in schools and in society to raise awareness of learning disability and the desire of people with learning disability to live in harmony with other citizens.

The special hospitals have unpleasant memories for many people who spent part of their lives in them. For others, their very existence can be threatening. There was the widespread opinion amongst delegates that there is no longer a need for special hospitals.

“People with disabilities want to be included and involved like everyone else in social activities, education, training and employment. This should be theirs as a right.”

Self-advocate, Catherine McGuigan speaking at the Portadown event.

Annexes

Membership of LEAD – NI Coalition on Learning Disability

Aaron Curry House

Barnardo's

Carers National Association

Challenge

Craigavon and Banbridge Volunteer Bureau

Disability Action

Downe Residential Project

Down's Syndrome Association

Families in Contact

Karen Mortlock Trust

Kilcreggan Homes

Mencap

Orchardville

SENSE

Triangle Women's Association

Prospects for People with Learning Disability

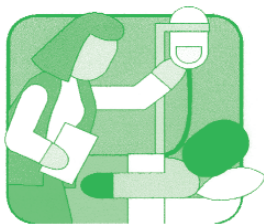
United Response



A Fair Chance

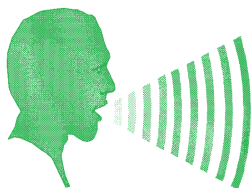
Do you feel that you have A Fair Chance?

A new rule says that you must have a fair chance.



The people in charge of hospitals, days centres, doctors, dentists and social workers want to make sure that you have a fair chance.

They want to know what can be done to make sure that you have a fair chance.



They want to listen to you.

Come and talk on:

Thursday 7th June 2001

Fitzwilliam Hotel, Antrim

10.30 am – 3.30 pm

Contact:

**Linda Spence, Kilcreggan Homes,
Elizabeth Ave.**

Carrickfergus BT38 8BH

Tel/Fax: 028 93 359588

Attendance at the events

Altogether 265 people participated in the four events. Attendance at each event was:

Antrim	–	70
Newcastle	–	70
Omagh	–	72
Portadown	–	53

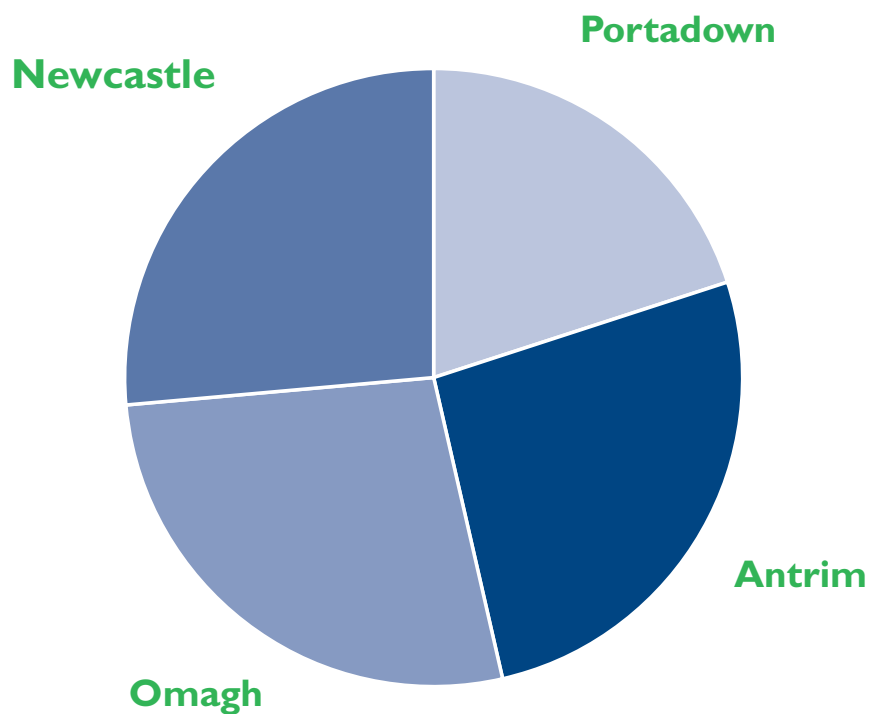


Figure 1: Total attendance by venue

Attendance at the events (cont)

Of those attending, 161 were people with a learning disability. Attendance at each event was:

Antrim	–	55
Newcastle	–	40
Omagh	–	45
Portadown	–	21

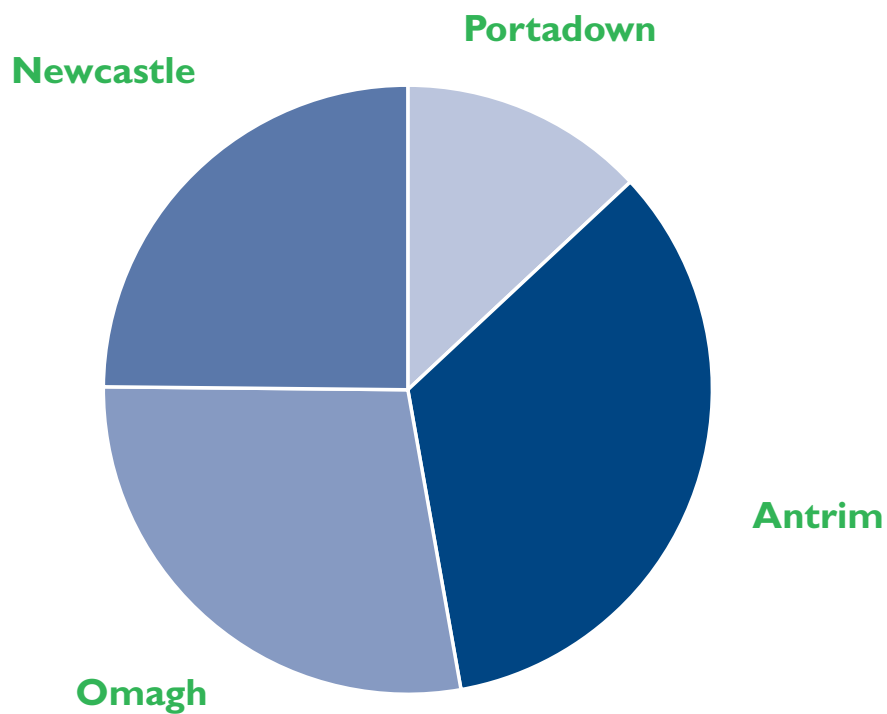


Figure 2: Attendance of people with a learning disability by venue

Breakdown of Attendance – Antrim 7 June 2001

People with a learning disability	Supporters	Parents/Carers
55	30	3

LEAD	DHSSPS	HSS Boards/Trusts	Voluntary/Private Sector	Schools
10	3	10	11	1

Speakers
4

Attendance by:

Broadway
 Carrick Gateway Club
 Compass Services
 Community Living [Bury St. Edmunds]
 DHSSPS
 Drumross Adult Centre
 Everton Centre
 Hillcroft School
 Homefirst Trust
 Kilcreggan Homes
 LEAD
 Mencap Local Society
 Mountfern Centre
 NHSSB
 People first
 Rathmoyle Resource Centre
 Ravara Training and Resource Centre
 Stradreagh
 Triangle Housing Association

NOTE : Because some people appear in more than one category the figures in the tables do not equal to the total number of people attending the events.

Breakdown of Attendance – Newcastle 12 June 2001

People with a learning disability	Supporters	Parents/Carers
40	32	3

LEAD	DHSSPS	HSS Boards/Trusts	Voluntary/Private Sector	Schools
12	2	3	33	1

Speakers
2

Attendance by:

Balloo Day Centre
 Clifton Park School
 DHSSPS
 Downe Residential Project
 EHSSB
 LEAD
 Lisburn Resource Centre
 Mountview Day Centre
 Parents/Carers
 Pathway (Mencap)
 Ruby House
 The Orchardville Centre
 Ulster Community Trust

NOTE : Because some people appear in more than one category the figures in the tables do not equal to the total number of people attending the events.

Breakdown of Attendance – Omagh 14 June 2001

People with a learning disability	Supporters	Parents/Carers
45	27	0

LEAD	DHSSPS	HSS Boards/Trusts	Voluntary/ Private Sector	Private Sector	Schools
10	2	12	11	10	1

Speakers
4

Attendance by:

Ashley House, Mencap
 Barnlea Residential Home
 Camphill Community
 Central Services Agency
 DHSSPS
 Downe Residential Trust
 Drumary House Residential Home
 Galliagh Residential Home
 Kilcreggan Homes
 Killadeas Residential Home
 LEAD
 Mantlin Court Residential Home
 Maybrook Adult Training Centre
 Mencap
 Mullagh House Residential Home
 Railway Court
 Sow and Grow
 Stradreagh
 Strule Buzz Group
 The Omagh centre
 WHSSB

NOTE : Because some people appear in more than one category the figures in the tables do not equal to the total number of people attending the events.

Breakdown of Attendance – Portadown 21 June 2001

People with a learning disability	Supporters	Parents/Carers
21	18	8

LEAD	DHSSPS	HSS Boards/Trusts	Voluntary/Private Sector	Schools
10	1	3	8	0

Speakers
2

Attendance by:

Challenge
 DHSSPS
 Dungannon PNH
 Eden SEC
 Fairgreen, Keady (Mencap)
 LEAD
 Parents/Carers
 Pathway (Mencap)
 Teach Sona, Kilkeel
 The Blood Transfusion Service

NOTE : Because some people appear in more than one category the figures in the tables do not equal to the total number of people attending the events.



NI COALITION
ON LEARNING DISABILITY

A Fair Chance

Programme



10.30 am Registration and Coffee

11.00 am Welcome

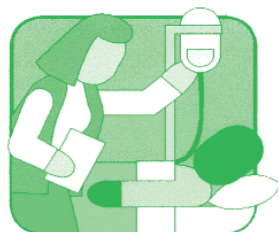
- why we're here
- outline of programme
- housekeeping



11.20 am A Fair Chance

11.40 am Session 1

Daytime activities/support
(work, daycentre, leisure)



12.30 pm LUNCH (to be provided)

1.30 pm Session 2
Hospital

2.30 pm Session 3
Going to the doctor and dentist



3.15 pm CLOSE

3.30 pm Coffee/Tea/Cold Drinks

A Fair Chance

Reports From Workshops

7 June 2001 – Fitzwilliam Hotel, Antrim

Morning Session

Wishes

- Shopping
- Travel
- Swim with dolphins
- Newsletter for carers
- Work with animals on farm
- Get more support/help with many animals
- Like to fly to London
- Talk together clearly with people to make our lives better
- Go to see a friend
- Keep it the same
- Out of the day-centre for lunch, picnic
- More football
- More work, more jobs of our choice, more pay
- More respect for staff
- Help others in mind – using your own head – choice
- More opportunity
- Magic Wand
 - "Listen to me about my feelings."
 - "Staff listened to me when I wanted to go out on my own".

Day Services

What we do in the day

- Out and about
 - College
 - Swimming
 - Work looking after children
 - Computer
 - Knitting
 - Like doing cooking
 - Like doing jigsaws

What are the changes we need?

1. Try to be strong!
2. More money, more staff
3. Better transport
4. More access to shops!

"Choice – we have the choice at the day centre – if there are enough staff."

"I like the day centre, but I like my job better."

"X worked in the bakery, now he is in the farm with others and does not want to go back to the day-centre."

"My brother works in the day-time, so he can't always take me out."

X talked about change in her centre!

"Sometimes people don't listen. You have to have a stronger voice."

"X has a volunteer who takes her out shopping, McDonalds, or swimming."

"I have choice."

"Everybody should have more choice – they need support, help to make choices and do it."

"Sometimes things are very slow, even when people listen."

"Sometimes I'm stuck with nothing to do."

"People sometimes say things I don't like. When people aren't being fair I think about it and sometimes wish I had spoken out. Speak out – it can be hard."

"Going to Broadway – know people there – have to leave friends at school."

"My Mum chose what I did when I leave school with Social Worker."

"During the day – work for Mencap – talk to government."

"Day centre – I get training at day centre e.g. answering phones, photocopying."

"Only see friends when at Centre."

"Don't get enough money."

Garden Centre (placement) – "like feeding the birds."

Drumross – activities include:- cooking, knitting shopping – increased confidence.

"Need more staff."

"Work placement – I would like to work in a hospital after leaving school."

Compass will help people speak up.

Xxxx (Chairman Compass) will help people talk about day-time activities
"to empower people is our main aim."

Xxxx has lots of interests – travels by motorbike.

Direct Payments

"Make your own choice – be strong. Direct Payments help. Sometimes Social Services don't know about it or don't want to listen."

"Direct Payments – means that someone can buy your own services, choose staff."

"Choose how the Health & Social Services is spent on your services."

"It changes your whole life, you can be the boss of your life!"

Going out

"Gateway Club is good, I don't go anywhere else at evenings. I would like to go out more to somewhere I've never been before..."

"I have to wait for my brother to take me."

Main Points – Morning Session

What we do in the day

1. "Our right to be respected, no bullying, abuse, name calling anywhere, at any time, by anyone – human rights (basic)."
2. "Have a break, get out of day centre – for lunch."
3. "More opportunities."
4. "Out of daycentre – more jobs, pay, training."

Afternoon Session

Going to the doctor, hospital, dentist

- "If your health is at risk, sometimes you have to go to the doctor/hospital – lots of people fear the unknown – reassurance would help."
- "If doctors understood more about learning disability or any disability, they would treat us with more understanding/respect."
- "I have to go to hospital for stitches."
- "Sex education for children with learning disability is needed."
- "Explain to us."
- "I don't like going to the dentist but at the hospital I was treated very well – it helped me."
- "I prefer a choice about which doctor I have."
- "People shouldn't be made to do anything against their will, they need all the information to make an informed choice."
- "I like company/support to go to the doctors, my sister comes."
- "I have a good doctor that listens to me, I like him, he explains things to me."
- "One time the doctor didn't come out to see my mother, he was too busy. I want him to listen to me."
- "I am happy with my doctor/dentist."
- "It's not fair to go to hospital when I don't want to – if someone came with me it would help."
- "It's hard to get supplies (shoes) when I need them."
- "I speak to the Consultant/GP and get passed around – complain to the Trust."

- "All my life I'm fighting. I had to fight to get off medication I didn't need or want. I should have been listened to."
- "Parents can smother children by trying to protect them."
- "We have to make mistakes to learn."
- Everybody use own GP/dentist. Brought GPs etc back to centres for screening.
- Prescriptions – should use symbols.
- X talked about a letter (Appointment) – taking someone to the hospital to be told he has Down Syndrome – expect 'bad stomach' – not explained properly.
- Visits to day centre from trainee doctors (Everton Centre).
- X said - woman getting off a serious injection took years – lack of clarity between consultant and GP.
- GPs good access but limited screening etc., re disabilities. Dental screening in workshop.
- People forming into groups to share healthcare e.g. women's groups.
- MLAs – local politics, lobbying, higher than local social services.

Bullied on Bus

"If it happens on a day centre bus, staff have had to contact police."

"Invite schools to centre to meet people and become friends instead of bullies."

"I feel sad about bullying – I think visits from schools are good."

Mixed schools - Bullies – ignorance.

Some people would like it – some people nervous.

Bullying – " If anybody hits you, hit them back. I've been brought up that way."

"Tell someone" – teacher, day centre staff, Mum or Dad.

"Children with learning disability need support to mix with other children – with help anyone can take part – bullying is wrong."

Where people live

Shadow of Muckamore – "what do we do with people."

Ask people first where they want to live – with family, on own. Most people want their own home – denied to most people.

X lives on his own since parents died. "Not the same as being locked up (used to live in Muckamore)". Bullied at work (Shorts), went to GP who contacted social worker – was told he may have gone to a home but went to Broadway where he is happy and has company/friends but now only gets £4.00 per week (same as his first job in 1968). "Benefit affected if we earn more, stops people working."

Advocacy

Advocacy can help! X talks about advocacy in England.

"Now it is coming here."

X and others went to Stormont last Thursday to speak out!

X is good at speaking out.

Social Workers don't always help. "You might as well talk to a brick wall"

"What can be done..."

Five points

1. Choice
2. Support
3. Treated
4. Empowerment – advocacy – direct payments
5. Managing own money

Round up all groups:

- Choice is important
- Family and carers have too much say
- Day services – have some uses – others should have the choice not to go
- People outside of day services don't understand – they don't mix with people that are in the day-centres
- People in mainstream schools have more chance to mix with the community
- Mainstream schools may mean that vulnerable people would be bullied
- More training
- Get out to meet more people
- Enjoy going to workshop
- Don't want to go to workshop – not enough choice of things to do
- Not enough leisure choices – should have more say
- Would like a bigger slice of the Social Services budget
- Everyone should be given a chance to have their say
- More outings
- More staff to offer support so choices can be fulfilled

A Fair Chance

Reports From Workshops

12 June 2001 – Burrendale Hotel, Newcastle

Morning Session

What we do

- Work in café serving food
- Different things on different days
- Do everything
- Sewing
- Make tea
- Art
- Work in Art shop – help shoppers, bring trolleys to shop
- Work in shop
- Gardening at day centre
- Services OK
- Catering Assistant
- College
- Downpatrick UIP Group
- Work in pub yard
- Work in Murlough – strimming grass, putting in posts
- Like cycling
- Work in office
- At home some days
- Downe Residential Workshop – painting, drawing, varnishing
- Work in Newtownabbey Library
- Voluntary work in Barnardo's shop
- Hairdressing

Daytime – What we do

- Answering phones – college on Monday NVQ I
- Balloo and work placement in a school – in school for one more year
- Balloo and office work, gives pay cheques out
- Used to work (VOTE) – wants to work again
- Day care, setting and washing tables
- Day care, makes summer seats and bird tables – likes this
- Did not like day centre, now works in Connswater Shopping Centre
Hires out scooters. People treat her well. Will be writing cheques
- Monday – Saturday – no salary paid, expenses paid – benefits
- Monday – Thursday work experience in library, computer course last year. People are nice, goes on bus, difficult in beginning
- Thursday, work experience (hairdressing), like it, people very friendly
- Monday and Tuesday in day centre. Volunteer in Barnardo's shop
Friendly and fantastic
- Wood workshop and kitchen in day centre likes it
- Monday – catering. Fridays – works in schools office
- X was worried about getting home from Nazareth Lodge. She had
NVQ 1 & 2 in Business Administration
- One nice person was willing to give training but she left. Would like
training in hairdressers
- X has trained people to get jobs
- One person said that they only got one day a week in day centre. They
would like five days

Out-of-work time – What we do

- Friday Clubs, Youth Club. X organises trips bowling etc., her Mum provides list
- At Thursday Club we get away from our parents! We play snooker
- Goes for drive with Mum on Saturday night
- Thursday – go to Gateway. Listen to music – ABBA
- Goes shopping at weekends
- Wednesday night is Gateway. Bored at weekend. Would like to go to disco and cinema
- Helps with shopping. Plays with Megadrive. Sometimes goes out – church fashion show
- Gateway on Monday. Would like to do own shopping but too expensive
- Book stays in Orchardville day centre
- Roadrunning 21 miles over 3 days – cycling sometimes with friends
- Goes to pictures with people from work. Gateway Club on Thursday
- Takes dog walking
- Does not go anywhere at night – Mum is sick and goes to bed early
- Caravan in Newcastle at weekends –
- Gateway Club on Thursday
- Watches TV – supports West Ham
- First Aid Course – gets tired out

Good things

Brilliant

- doing much more work, like gardening/woodwork
- put into more groups

Very well run

- everything well set up
- know what you're doing each day

Like going to job

- meet different people
- get on with other staff

Enjoy people coming in to give talks about different things

- enjoy working with computers
- likes knowing what will be doing
- (coffee shop) sometimes good – people coming in and buying things
- (Wallace Ave) Nice staff, good staff team, good team, low turnover
- learn how to look after own house
- like the staff member who teaches
- enjoy supervising – don't have to be told what to do
- close to home
- enjoy activities – enjoy everything
- some people like having things structured
- can choose courses for college in September

Bad things

- not different age groups
- takes a long time to get into the day centre
- don't do cooking any more – miss that, but there is no "lunch-box" anymore
- would like office work experience – answering phones – computers
- what happens in summer?
- more pay

Going to College

- some people going one or two days a week
- some people doing NVQs
- to do work placements
- link between Colleges, Trusts and Special Schools, locally

Afternoon Session

Bullying

- "I went out to get my Dad the paper and a boy threw my bike down and called me names. I was upset and fell off my bike on the way home. I told my Mum when I got home."
- "Some boys chased me with an iron bar. I was with my cousin. I am still frightened to go out at night. I told my Mum. There was no phone to call the police."
- "A boy lit a firework close to my ankle when I was out with my brother. My brother protects me now – he is a security guard. I was very frightened."
- "People call me names like 'spastic'. I stand up for myself now. Sometimes bullies came at me with matches. Now they don't bother me."

Hospital

- In hospital for back operations – doctors and nurses were nice
- In hospital for eye operations – treated OK
- Needed medicine so had to go to Muckamore for a couple of years. Nurses treated him well in 7A
- City hospital, only saw nurse and doctor once. TV next door too loud
- X-ray showed pneumonia that never goes away. Has to take medicine. Mum's doctor said "you're lucky to be alive."
- In for a week – knows what to do when she gets sick now, in for about a week – no-one to talk to – nothing to do
- Antrim hospital for hysterectomy – “nurses and doctors were good. Explained everything, even though they were busy – Mummy stayed all day with me in the hospital – in for about a week.”
- “I hate hospitals. I'm treated like dirt. They tell you nothing.” Doctors spoke to her brother instead of her. She wanted to speak for herself – brother to sign forms.
- Road traffic accident. Needed pin in shoulder – had morphine
- Teeth out in hospital
- Had pneumonia twice and a hernia
- In Dundonald – doctor tried to look into his ear which made his father very angry. Given drugs which made him very dizzy. They looked in his ears when he was in bed and didn't tell him what was happening
- In the Royal to have eye operation when she was very young (11 or 12)
- Fell off horse and had to have an operation in Downpatrick – in for a day
- New hearing aid – doctors were fine

Going to the Doctor

- “The doctor listens when I have to have blood tests.”
- Open surgery. “Turned out to be a viral infection – took medicine and it got better.”
- Needed ears syringed. “I was brave. The nurses were nice.”
- “I have no worries about my doctor at all. He is good and listens to me.”
- “My Mum’s doctor and my dentist are great.”
- Injections in my arm. “Xxxxx came with me. I was very nervous. It would have helped if the nurse had talked about it a little bit more.”
- Tetnus injection and broken ankle. “They set my ankle the wrong way and it needed rebroken. Typical Antrim hospital.”
- Lazy eye. “Needed tests because I had double vision. After operation, I had to go back to see the doctor. They were all good to me.”
- “Dentist told me not to drink Coke or diet Coke.”
- “I was very sick, my chest was tight and I was vomiting. I couldn’t get out of bed - the doctor said I should go to hospital.”
- “I had wax in my ears. When they took it out I felt drowsy and I couldn’t hear. I had to go to hospital for 10 weeks. When I could hear again I could hear voices, but I did not know what was going on.”
- “I found out I had asthma. I take inhalers.”
- “A boy stabbed my ear. I saw 4 doctors. In the end they put purple superglue on it. All doctors said something different. I was a bit scared of the doctors.”
- “Skin grew over my ear and I need an injection. They ran a bit of thread through my ear at the top. I was very nervous.”

Dentists

- Fear of dentist
- Someone found dentist rude to him about his teeth
- Didn't like treatment given
- "Not all dentists make you feel relaxed."
- Injections hurt – better than suffering pain
- One person liked it – well treated
- Prefer "down in the mouth" – people nice – room not so clinical
- Prefer male dentist

Doctor

- "Does not really explain what he is doing, just does it." (taking blood pressure, etc)
- Doctor says "there's nothing wrong with you"
- Sometime asked to leave and then goes and talks to Mum about him
- Does not see doctor very often – "only when there is something wrong with me."
- "Tell Mum, family, work – whoever I was with at the time if I'm not well"
- Sometimes go on own, with staff member, family – "not as bad as going to the hospital"

Doctors and Dentists

Where:

- Doctor's surgery
- clinic
- health centre
- home
- own GP – sometimes visits in hospital
- not too happy about how treated at times "nothing you can do about it", "not going to take your word for it"
- Downe, Royal, City, Lagan Valley, Musgrave, Ulster (Dundonald) Antrim, Whiteabbey, Ards, Bangor, Belvoir Park, Daisy Hill, Muckamore, Downshire, Purdysburn, Holywell

A Fair Chance

Reports From Workshops

14 June 2001 – Silver Birch Hotel, Omagh

Morning Session

Day Time

- most people go to the Centre everyday. One person goes 4 days. Some 2 days and does work experience on other days
- One lady works in a playgroup in the mornings and then goes to the centre
- a lot of people work one day a week
- some people do a job in the centre
- "you get a bit more money if you work"
- "helpers go to make sure you know what to do and see how you're getting on"
- "the bus leaves me to my town and I make my own way home"
- everyone goes by bus
- in the evening – pub, town, Gateway Clubs, the pictures (but expensive) computer course
- "transport is the biggest problem when we want to go out"
- "in residential care, you have to be in by a certain time and ask permission – staff need to go too"
- " pictures are dear, especially if you have to pay for a taxi too – drinks are expensive"
- "TV, CDs are what we do when we stay in and computer games as well"

- some people go home at the weekends
- washing cars and buses, cooking own dinner; singing, keeping rabbits
- concerts, "Daniel O'Donnell is my favourite"
- moved from daycentre to work project, "too many people" in daycentre, overcrowded. Went to Spain – had information evenings for parents – enjoyed the social side – work at the start was strange – got to know people over time
- working in Tesco's helping people with bags, information, leaflets, wears a uniform and a name badge – working in centre as well (3 days). 2 days in Tesco Centre – gardening – carer -not enough hours in the day – 30 attached to day centre – mixture of mental illness and learning disability – they can help each other.
- I have been trained (NVQ). Hard work – 12 years in centre – previously worked as a porter and involved in Special Olympics
- Enjoys the company – 5 days a week – always plenty to do
- Art, sewing, swimming – involved in cleaning
- Involved in photography – in the centre
- WHSSB – decisions – hard questions to answer on spending money
- I would like training on computers

Support

"I've plenty of support from family, staff and friends."

"Sometimes you get help when you need it. I would like more help. I would like to change my work. I am not happy"

" My parents give me help and support. I asked my parents not to wrap me in cotton wool. They let me go out and do what I want, but they are there if I need them"

Leisure

- Swimming (Tuesday night) go to Youth Clubs, photography (part of YTP)
- Bowling from the centre (alley was blown up), Gateway Club on Thursday
- Learning to speak out "Buzz Group", just talking – helping me to speak out
- School – special needs education officer – move onto course at 16 years
- Go to cookery class in the tech – 1 day a week
- Out and about – bus trips – summer – away for weekends
- Two residents do not get day care – not enough places for everyone
- Centres are overflowing – may only get 2 days a week
- Maybrook – UK conference "Let us talk" – self-advocacy group
- In the past, able to do drama therapy – YTP Programme – express yourselves
- Was able to go to States – Special Olympics

Holidays

- X going to England with Dad
- X may go on exchange
- X went to Ibiza with sister – hard to find facilities for disabled people
- Accommodation may be accessible, but facilities for activities are limited e.g. pool, showers
- X went to England
- Buzz Group go away for team building weekends
- X loves the Buzz Group
- X enjoys all her outings and activities

- X likes to go to Discos
- X likes her social life
- X would like the bus to come later – wants a lie in
- X loves his football
- X values her independence and likes making her own choices
- X likes time away from work to go to pubs
- X likes time out of the office
- X loves her work which is farming

Bullying

- "nobody will challenge people who aren't fair"
- "the police didn't help someone who I know was bullied"
- "there should be someone to help you get your point across"

Out-of-work time – What we do

"In my spare time I watch Gerry Springer, Crossroads, I go up the town, I go to Omagh, not often."

"I like to keep busy. I have a computer, a CD player and Hi Fi in my room. I have a dog. I wash all the clothes. I go out some nights."

"I used to ride horses, but that stopped because of the foot and mouth. I play for the disabled in football and go to the library. I am happy with what I do."

"I knit dishclothes go shopping, watch TV, go to the pub. I love it the way it is."

"I clean my room every morning, do jigsaws, collect coins. It's my hobby."

"I like to write."

"I would like to do more fishing. I watch my brother at Judo. I go to weights. I'm moving into a flat on my own, so I'm decorating at the moment. I go out with friends and my father takes me out."

"I go out with xxxx. We go to dances. There's plenty to do where we live. My father leaves us down and we get a taxi back."

"I do swimming. I've got 3 gold and a silver medal."

"I travel by myself on the bus to Co Meath, to go home, 4 times a year."

What would you like to do?

- "go to the pub myself"
- "learn to drive"
- "go swimming"
- "socialise"
- "mini buses are hard to book and expensive. Each centre should have its own minibus"
- "disabled people should be able to speak up for themselves but there needs to be someone to listen"
- "we keep missing the end of the film, because we have to get the bus. This draws attention to us"

Overall: Most people had a job, some 2 days a week, some 3 days a week. Most were happy with what they did during the day time. One person had been paid off. People were involved in a range of day time activities. Usually people attended a day centre for part of the week.

Some people worked in the kitchen of the local hotel, some in "Sow and Grow", a number in the day centre office, one in a cotton factory, one making sausages. One person referred to being discriminated against because he had epilepsy, one person talked about wanting choice in deciding what job she did. Most said that they were happy with their pay. Some did say that they wanted more pay.

"I like the job I'm in. I'm happy with my pay."

"I am happy in my job"

"I like what I do. I move trolleys. I would like to work in Tesco's."

"I like answering the telephone and I like computers. I don't like art."

"I like my job. I like playing the piano, it's my hobby. I like going for walks, going places— I do enough of it!"

"My job ended in June. I don't know why. I'll be going to a chip shop or a coffee shop. I would prefer to go to the coffee shop – but I probably will have no choice. I would like to get another job and to choose it."

"I am happy where I am. It was not always that way. I used to work for the Council. I was diagnosed with epilepsy. I was not feeling well. As soon as I came round I was taken home. The boss said to my mother that he didn't want me back at work. My father went to see a local councillor and I went back to work. The same thing happened again to me. My father contacted a solicitor, but he didn't want to put me under stress. I am now at tech and am happy, but they shouldn't have got away with it. The government need to do more. They made promises and are not carrying them out."

"I love working in an office. I hope to get a job. I want to work."

"I go to college one day a week. I passed a hygiene course. I worked hard."

"I'm at college, on a special education programme."

Afternoon Session

Hospitals

Royal, Erne, City, Ballyards, Banbridge, Coleraine, Stradreagh, Armagh, Longstone, Muckamore

- Wellwoman clinic in Omagh – no wheelchair facilities, no routine checkups
- Waiting time in A&E or outpatients too long
- "We don't give blood"
- "Questionnaire very difficult and confusing"
- X was in hospital with tonsillitis
- X needs help to make appointments - wants to change her GP but needs help
- Mary has asthma – goes to hospital by ambulance, taxi or a lift
- X has cerebral palsy and uses different hospitals

Overall: Most people had been to hospital. Over 10 hospitals were mentioned as being known by participants. A number of people said that they had been in Stradreagh and that they did not like Stradreagh. They did not elaborate on this point. A number of people talked about the proposals for acute sector hospital closure.

"It was very quiet and peaceful in the Erne. I liked it OK"

"I went to casualty. I didn't like it. I had to wait a long time. The staff were nice, but I didn't like the operation pain"

"I didn't like xxxxxxxx in Dublin. They made you work, making stews. People were smoking. I had a nervous breakdown".

"I like to see the nurses and I like the attention. I don't like being confined to bed and I don't like needles. I have been in hospital a lot. I have great faith in Altnagelvin. The Omagh hospital should not be closed. I would have to travel to Belfast. My experiences have all been good"

"My experience was bad. I fractured my shoulder. The Doctor looked at the x ray and didn't see anything. But 4 weeks after, the mobile rings and I had to go to hospital, there was a crack in my shoulder"

"I was in Erne, Tyrone & Fermanagh and Stradreagh. I was there for 3 years. I had a nervous breakdown. I'm ok now. I didn't like it. I hated it"

"I was in Stradreagh. I didn't like it. I've been in Omagh County. I liked it."

"I was in hospital when I was small. I was sick. I got an operation, pills to settle my stomach. I liked it. I was there for a long time"

"I travelled every day to see my father in the RVH. The nurses are very reassuring"

"I've had an operation. I couldn't sleep because of the pain. I've been in Stradreagh for respite"

"My brother-in-law is very ill and in hospital. The nurses are very good, telling his wife what they're going to do"

"I don't like hospitals. I would rather be in my own bed"

"I've been in and out 3 times. My granny's in Gransha. I didn't like hospital. I would prefer to be in the house"

"In the past the system was very unfair. You were made to do lots of work" (reference to living in Co Longford)

"You can get help from the staff, the staff are very kind and helpful"

"I get help from the people at the day centre, my family, my dad. You get help when you ask"

Good points

- staff, doctors, Longstone, friendly doctors and nurses at Erne

Bad points

- food choice?, older men left alone in Ballyards
- most people in main wards
- "I think Stradreagh (workshops) should be closed down – it's a bad building"
- "I think it's wrong that people should have to wait a long time for an operation"
- "If you're bad, if you misbehave, you have to go to Stradreagh – also if you're not well and you can see a dentist there"
- "There should be a hospital on the Derry side. If you had a heart attack it would take a long time to get to hospital"
- "Need to go to respite after you get out of hospital to give your parents a break – too expensive to bring care to home"
- "We had home-help after my father fell"
- "You need someone to tell you what tablets to take and how many. You need to know what the medication is doing"

Doctors and Dentists

Overall: Most people liked or didn't mind going to the doctor. Two people said that they did not like going to the doctor. One person said that they now had a new doctor and that they preferred the new doctor. One person referred to the fact that doctors tell people not to smoke but smoke themselves.

"Doctors should go out to see you when you're very sick as well as you going to see them."

"They should know (people have a learning disability) from the records in their surgery."

"People don't look forward to the dentist."

"The dentist didn't tell me he was going to stick a needle in my gum!"

"I go to the doctor on my own."

"I go to the doctor's with someone else. They go in and sit with you. The doctor explains things to the person with me and to me."

"I go to the doctor with my mum. The doctor explains it to my mum. I am not allowed to go on my own."

"I go to the doctor on my own. I had to change my doctor when my doctor retired because his daughter took over and I did not want to be seen by a woman doctor. I wanted a male doctor. He is very good. He is very quick. He doesn't cut corners. He is very thorough. I went to the Chief Man to see if I had epilepsy or not. He said that I was just looking for attention. My own doctor asked for an appointment to see the specialist. The specialist wouldn't admit that he was wrong."

"I hate going to the doctor. I can go on my own sometimes. I sometimes go with my father or my sister."

"I'm never sick. I don't see the doctor that often."

"I had an awful pain, the staff didn't listen to me. The nurse told me to go to the doctor with the pain."

Advocates

- "self-advocates should go into schools and talk to kids. This would help with the problem of bullying"
- "people who are part of advocacy groups get experience and then they can start their own groups"
- "a meeting should be held for advocacy groups to talk to the Government"

Orange Group – Afternoon Session

Hospital

- Renal Diagnosis: Very knowledgeable, - aware of transplant procedure including "pager" call – every patient has their own nurse – use taxis (hospital) should be a unit in Derry. Have to travel to Omagh, your journey – up at 7.00am. Dungannon service very good – nurses and consultants "fantastic". Reason Renal Unit is in Omagh - is centralised
- Hip Replacement: "Spoke to GP who listened and referred me to consultant, now waiting for surgery (waiting for months as consultant was off sick)"
- Epilepsy: "Consultant kind to me, medication helps my fits – frightened of injections"
- Took time with me - sat down beside me and asked me "if I was going through the operation"
- Nervous of hospitals –problem with appointments due to post
- Investigations help find out my illnesses – I can talk to them on a one to one basis, explain to me what my problems are
- GP – good back up service
- Demand for respite – Stradreagh used for this – 30 patients only
- Didn't have the security of the hospital when out in the community
- Dad main carer – dad dead – now in Stradreagh – semi-long term respite
- It takes a long time when someone dies to get over it
- School doctor and dentist came into school for children who are statemented – different system for these kids

Doctors and Dentists

- Needs to take their time and talk to the person
- Lady doctors/dentists
- X's doctor doesn't listen to her. In and out as quickly as possible
- Doctors makes you better - dentist cures toothache
- You should be seen straight away
- Bad that you have to pay to go private
- Doctors sometimes interact with the supporter and not the patient
- The specialists can be very full of jargon and less patient
- Maybe with the voice of disability getting stronger, there will be more awareness of learning disabilities
- The waiting time is the worst part of going to doctor/dentist

Overall: Most people were happy going to the dentist and most said that they went to the dentist regularly.

"I like my dentist. He is in Enniskillen. I go once a month. He talks to me, fills teeth and polishes my teeth. He tells me how to brush my teeth and to eat fruit and vegetables."

"I don't like getting fillings. The dentist explains it to me"

"Dentists used to be like butchers."

"Sometimes I don't like the dentist, when he said that I have to brush my teeth or that I had to get a brace on my teeth."

"I like the new dentist, not the old one. I had to change my dentist. He hurt me and I bit him. The new dentist is nice and gentle with the needle."

"Sometimes the dentist comes to Maybrook, sometimes to give a talk. I get a badge. I think that it's ok to get a badge" (Others in the group said that it was childish to get a badge).

A Fair Chance

Reports From Workshops

21 June 2001 – Seagoe Hotel, Portadown

Morning Session

Day Time

Bocombra Work Scheme

- Happy with day centres
- Some paid/some not
- Difficulty with benefits
- Eden – no male staff, 5 female staff , 50 clients
- Son needs male staff member – problems
- Some training for NVQs/some not
- Some would like different work experience
- Bored if sitting doing nothing
- Likes working in shop

Daytime activities/care

- Work skills – learning – more placements required
- Given a choice to do what we want through Challenge and other groups
- Attending day centre – sometimes people are left out in discussion group. Discrimination against individuals in day centre.

- Employment – need for supported employment, difficulty in convincing employers to take people with learning disabilities, problems with pay
- Day centre: clients often bored – why can't we use normal facilities? People should take part in activities in their own community e.g. art groups/sports groups, etc
- Daycare placements: not enough to allow "A Fair Chance/Choice"
- Works 3 days in Body Shop – not paid
- "Benefits trap" – can earn up to £20 and still get benefits
- Not paid in centres – used to get paid £3 per week – felt valued when paid
- When attending day centre have to pay £1.35 for lunch or bring own
- Eden SEC – job for Ulster Carpet Mills – clients don't get money from this
- Staff not trained/not qualified
- Clients sit round doing nothing
- Father would like his son trained to live independently
- Clients need trained e.g. computer training, using the telephone, managing money
- Father worries what will happen to his son when he is gone
- Should not be sitting in day centres drawing silly pictures
- People are not consulted in decision making about provision of services for themselves within the day centre
- Funding for daycare provision prevents total inclusion and provisions
- Lack of staff in day centres does not facilitate good practice for personal care procedures e.g. when on outings. Also impacts on provision in the centre i.e. activities stopped, less opportunities, therefore choice is limited
- At transition stage – like to continue to develop skills in interests that we have learnt in school

Day time activities/support

Overall: Some people in the group worked 2 days a week, others go to college. Most said that they were happy with what they did during the day. A number of people were unhappy with their "pay" or lack of "pay" in the centre. One person that used British Sign Language was teaching British Sign Language to other people at the day centre. A parent mentioned that there were not enough places in the centre and that in the future some people may not be able to attend the centre for 5 days.

"I do ironing 2 days a week. I help in the new day centre, helping in the kitchen, setting the tables, clearing dishes. I enjoy that. I was asked to do it. I am happy to do it. I go to Appleby on Friday. I like talking to the staff. I do education on Friday, learning about different things. I help clean up the dining room."

"I sometimes go to the centre and work in the horticultural department. I'm involved in Special Olympics. I'm doing a City and Guilds course. I enjoy that. I was asked if I would like to go and I said Yes. I sit on a few committees. I'm kept busy."

"I arrive at Bannvale at 10.00 am and stop at 3.30 pm for a cup of tea. It's long enough."

"I want to do art. I've got an O' Level and an A 'Level."

"I work in the garden. I don't do the hanging baskets anymore. I'm not getting paid anymore. I feel sad. I would like to be able to work more with flowers and baskets."

(Note: A supporter said that funding for the work on hanging baskets was stopped which meant that this work could no longer take place, adding that there was a customer base for the hanging baskets. People who had been involved in the hanging baskets were now involved in weeding, landscaping around centres, and the sensory garden).

"I did 'Clips' for Seagoe Technology, flyers about carpets, but not anymore. I like the centre. I started in January. I go out shopping on Friday."

"I feel that I need more help, more choice."

"I would ask for help if I needed it."

"I work in Bocombra (cookie factory). I make cookies 2 days a week. I tidy the kitchen before going out to the shops. I love it."

"I like to go to different places, I like to work. I like meeting different people."

"I would like to do more work. I would like more money."

(Note: A parent asked if people got paid on work placement and the discussion started about what people got paid for working)

"I get paid £5 for ironing 2 days. I use my money to go to a singing class."

"I get £1 in Appleby - reward. This is not enough to buy a cup of coffee or to buy lunch if you are on an outing, or if you go swimming."

"I get £8.50 a week in the factory."

"I feel sad that I don't get money."

(Note: During the discussion that followed, comments were made about money that centres received for contract work, with some centres using the money for a "comfort fund" to benefit everyone. In Bannvale, it was said, the money goes back into the Trust, with the Trust using some of the money to buy stock for the horticultural work.

One centre had taken away £1.50 from people attending the centre and there had been an "outcry" at the time. One supporter said that "people get nothing and that's a sore point").

Choices

- No choice with regard to work/life etc
- The right to retire – what age?
- In house activities available, but people may benefit from getting out of home environment

Employment

- Equality of choice and provision is evident in some areas
- In certain areas – limited provisions for people with learning disability

Advocacy

- Advocacy must be promoted and encouraged

Leisure

- Likes bowling/swimming/holidays
- Likes computer course

Transport

- Picked up early in morning and driven all round the country
- In centre for a few hours – long journey home again
- Should not have name on bus – this is like an advertisement
- People point and laugh and them (degrading/horrible) – stigmatises them
- Problems getting to activities
- Needs supporters

- People with elderly carers cannot access other activities easily
- "I've started travelling by myself. I get the support I need. I know where the bus stop is, I know the time the bus goes at"
- "There are too many clients, they are putting some people out, otherwise they will have to get another bus."

(Note: Discussion followed about the possibility of using public transport. However, the lack of public transport in the area to get people to the day centre was pointed out as a major difficulty).

- "I would like to go on a bus"
- "There is no public transport, so I am not able to do this" (use public transport).

(Note: Discussion also continued about the length of time that people are travelling on the bus before they arrive at the centre).

- "The bus leaves Keady at 8.15 am and I get into the centre at 10.30 am"

Afternoon Session

Hospital

- Patient in Longstone hospital for 4 years in a locked ward with violent people – had nervous breakdown – on medication
- Don't know why they have to have blood tests
- Hospitals smelly
- Doctors don't talk to patients – talks to supporters

Experiences of Hospitals

- No-one would like to live in a hospital
- Feeling nervous and frightened – doctors should not use big words, use simple language
- GPs – waiting list and times too long

Additional note: One parent asked that the following issue be added to the above:

Accident & Emergency

Parent's son had ingrown toenails which were very painful. The waiting list was 6 weeks. Her doctor recommended that she bring her son to A&E for an emergency procedure. She is not able to do this because her son cannot sit still for the 2/3 hours required before being seen, he is panicked by blood, he does not like noise or crowds. She felt that A&E should have special arrangements so that her son can use A&E like everyone else when he needs to.

Doctors

- Not enough time to talk to patient
- Doctors need training to speak to person with learning disability
- Doctor does not understand what I am saying
- "Travellers" get more time than me
- 2 years waiting list for OT
- OT and speech therapy should work together
- Parent said "mistake by doctor on treatment given, long term effect on child"

Dentists

- Long waiting lists
- Not enough dentists
- Good service through day centres

Additional note: A parent asked that the following issue be added to the above:

Dentist services

Parent's son, aged 16, had to wait 6 weeks before getting the treatment he needed in South Tyrone Hospital. He needed to get his tooth out and needed antibiotics. Her son doesn't attend the local dentist and he was in great pain during the 6 weeks. He did receive pain relief. The parent had asked if her son could attend privately, but no one could tell her if this was possible or who she should contact.

Medicine

- Do not understand instructions – need plain English – symbols easy to read

Respite

- Only 2 beds available in Nightingale
- Maybe only get respite once a year
- Parents of Down's syndrome boy – never had a break

Choices

- No choice with regard to work/life etc
- The right to retire – what age?
- In house activities available, but people may benefit from getting out of home environment

Red Group – Morning Session

Day Care/Work

- Person employed for 3 years in Dunnes – not paid – likes to be her own person
- Would like to see disabled people in employment as a right
- Would like to attend day centre more
- Attends Cookie Company 5 days a week – bakes, washes dishes
- Options available for school leavers – what happens if SEC have waiting lists and no places?
- Career advisors required to provide information before people are ready to leave school
- Mainstream/special schools should prepare better for leaving – "need to fight"
- Ballyards is not a nice place to go
- Go to Longstone for misbehaving
- Appears to be different standards around policies required for areas of uncertainty
- Segregation regarding employment, people being labelled

Placements

- Systems may prevent people getting a fair chance
- Planning
- People moved out of hospital but has provision in the community been made?
- Partnership between education and health required

Leisure

- Don't get swimming as much now
- Gateway clubs – stops for summer
- Summer holidays – most residential homes organise holidays, people living at home do not have the same holiday options
- Keep fit at local leisure centre – lack of help at swimming pools

What can we do?

- Communication in ways people can read and understand
- Able to talk to others

Making complaints

- Jargon makes it difficult
- Need better communication
- Taking time to explain
- Use symbols – cost is an issue in preparing literature

Afternoon Sessions

Hospitals

Ballyards (special care – men only), The City *(G), Downshire, Longstone *(LD/MH), Daisyhill (G), Tower Hill (G and special care), Craigavon (G/MH), Manor House (LD children), S Tyrone (G), St Lukes (MH), Royal Victoria (G), Lagan Valley (G)

***Key: G = General, LD/MH = Learning Disability/Mental Handicap**

- Food not good in Longstone
- Curtains drawn when visitors come in

- Hospitals closing down to open as nursing homes
- Doctors rude
- Taken off waiting list

Doctors

- Health checks
- Parents/staff may be asked for the person's symptoms
- Family member usually accompany people with learning disability to GP appointments
- People need to be aware that they can change their doctor or make a complaint
- Transfer of medical history with clients when they move facilities
- The ability to inform people that we are pleased with the service provided

Dentists

- People may require specialist support because of medical issues e.g. epilepsy (difficulty in having this service locally)
- Appears that explanations are usually given about procedures
- Dentists may come to residential/nursing facilities