

Patient and Client Council

My Day, My Way

What I do during the day

What people with a learning disability said

August 2011

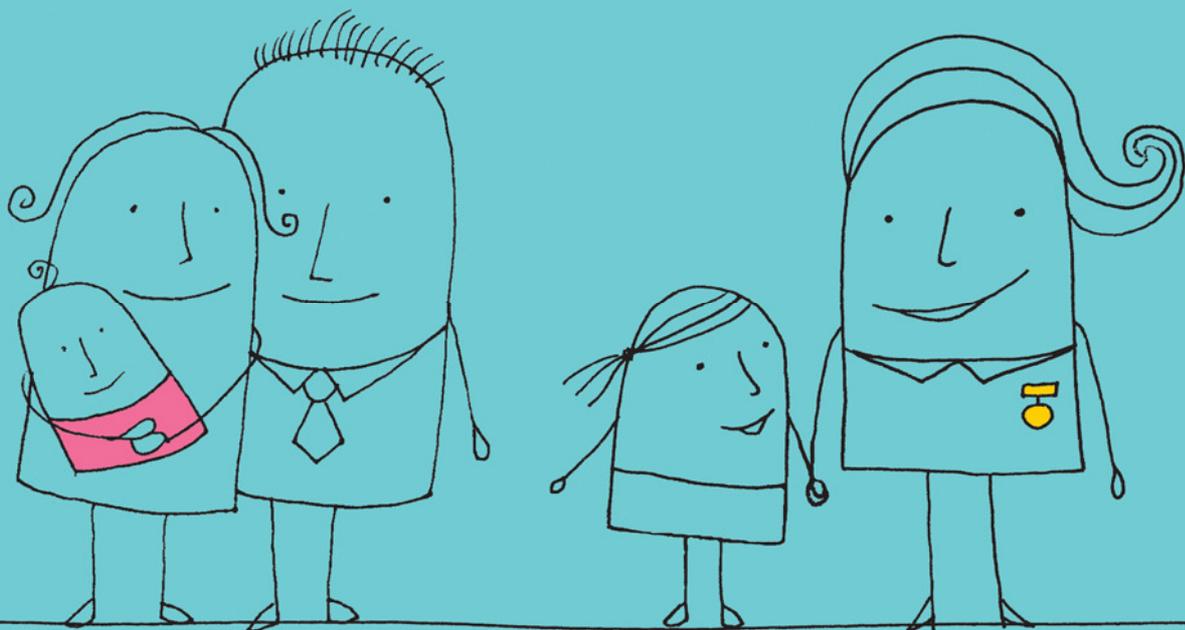


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Foreword

It is important for people with a learning disability to know what's out there for them to do, to enjoy the opportunities they have and to have fun. Through day opportunities people with a learning disability get the chance to meet lots of new people, to make new friends and to have a good time.

Good day opportunities give people with a learning disability the chance to meet up with other people, to say what they want to do, to decide where they want to go and to try out new things in their community.

The Bamford Monitoring Group has talked to people with a learning disability about their day services – whether staff listened to them and helped them to do what they wanted to do or told them what they were doing during the day. Day opportunities are important to people with a learning disability. They help them become more independent and learn how to make decisions and to support each other by working as a team and doing things together.

Thank you to all of the people with a learning disability who talked to the Bamford Monitoring Group about how they spend their day.

Lisa Jane Henry

Bamford Monitoring Group Member

Summary

The purpose of this report is to give people with a learning disability the chance to voice their opinion on the ways in which they spend their day and on the range of day services and opportunities available to them.

A total of **1190 people** with a learning disability, parents, carers and family members took part in this process.

874 people took part in small discussion groups at day facilities and centres, **120 people** attended the 'Our Stories' conference, and **196 people** attended local 'Our Stories' workshops across Northern Ireland. Through these discussions with people with a learning disability and with their parents, families and carers, some clear themes have emerged.

The **majority of people** with a learning disability **said they were happy with how they spent their day** and whilst they raised some issues and concerns they had many positive things to say about both day care services and 'day opportunities'.

The **most positive** response came from people who have **variety in their week** and divide their time between work, college, social enterprise, work skills training, drop-in or day centres.

However, the concept of choice seemed to be difficult for people with a learning disability. While **most people** felt that they had a **choice of activities** when at the day service or centre they attended, **few identified** that they had a **choice in where they actually spent their day** or were aware of the full range of options available to them.

This is extremely important as having **real choice** means knowing the range of day opportunities that are available locally and being able to choose what you want to do. This **does not seem to be the experience of most people** with a learning disability we spoke to.

Most people in employment really value their job and like to work, but many are concerned that jobs for people with a learning disability are limited and that paid employment will affect their benefits.

Response from people in education was similarly positive, however some did question the range of courses open to people with a learning disability and suggested that a lack of alternatives mean that people are often repeating courses. Parents and carers supported this opinion; they said that college, work skills training and social enterprise should be significant preparation of the future and aimed a progression into the workplace and that employment needs to be meaningful and paid not just tokenism.

The majority of people who attend a day centre spoke positively about this experience. However, across all Health and Social Care Trust areas people are unhappy about an apparent decline in the number of trips and outings. Some also felt that organised activities do not always take place because of staff shortages. Parents and carers raised concerns about poor staffing levels, the limited range of stimulating activities and lack of access to key therapies within the day centre. Transport to day centres and day opportunities can also be an issue, especially in rural areas where long journeys and an unreliable service often result in short days.

In some areas, parents and carers feel that local opportunities for people with a learning disability are particularly limited. There is a sense amongst many that services are sometimes based on what is available rather than on the needs of the individual, and parents and carers highlight the need for person-centred planning.

Planning for the transition from Children's to Adult Services is something which people believe must start early, as this appears to be a particularly stressful period for the parents and families of people with a learning disability.

Some parents and carers also feel that there is a distinct lack of opportunities for people with more severe and complex disabilities and they highlight the need for properly equipped and staffed centres to provide the necessary care and stimulation.

Parents and carers believe that there is a lack of information about the day opportunities and services that are available to people with a learning disability across all Health and Social Care Trust areas. This is also evident amongst people with a learning disability, especially when asked about choice.

Most people with a learning disability really enjoy how they spend their day. It is clear that in some areas changes to day services and day opportunities are in progress. However, more needs to be done to inform people about the options available and to provide them with the support they need when making choices. It is important that the development of day opportunities continues so that people with a learning disability can realise their potential.

1.0 Background and Purpose

1.1 The Patient and Client Council

The Patient and Client Council provides a powerful, independent voice for people. The Patient and Client Council has four main duties. They are to:

- listen and act on people's views;
- encourage people to get involved;
- help people make a complaint; and,
- promote advice and information.

1.2 The Bamford Monitoring Group

In 2002 the Department of Health, Social Services and Public Safety (DHSSPS) carried out an independent review of mental health and learning disability law, policy and service provision. It was called the Bamford Review of Mental Health and Learning Disability, now known as the 'Bamford Review'.

Between June 2005 and August 2007 the review produced a series of 10 reports that made over 700 recommendations to improve mental health and learning disability services. It represented a far reaching vision for reform and modernisation of mental health and learning disability services in Northern Ireland. The Equal Lives report (DHSSPS, 2005) focused on reviewing policy and services for people with a learning disability.

In October 2009, the DHSSPS published the report 'Delivering the Bamford Vision: The response of Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability. Action plan 2009 – 2011' (DHSSPS, 2009). This sets out the specific actions that Government Departments and their agencies are committed to take during the period 2009-2011 to improve mental health and learning disability in line with the Bamford Review recommendations.

The Bamford Monitoring Group has been set up by the Patient and Client Council to monitor how changes being made to law, policy and services arising from the Bamford Review of Mental Health and Learning Disability are affecting people and communities.

The role of the group is to find out from people with mental health needs, learning disabilities, parents, carers, family members and communities whether these changes are making a positive difference to them.

We want to know if people have experienced any changes to services in their area, if so what has been the effect of the changes on their health and wellbeing. We aim to make sure that the voice of people who have mental health needs, learning disabilities, families and carers is heard and acted upon.

The Bamford Monitoring Project Team of the Patient and Client Council carried out the field work for this project, information about the team is in Appendix 1.

1.3 What do we mean by ‘day opportunities’?

Traditionally, most people with a learning disability leaving school have gone directly to a ‘day centre’. The Equal Lives Report¹ identified the need for alternative provision and the development of a wide range of innovative day-time activities for people with a learning disability, including supported work placements, vocational training, social, educational and leisure opportunities.

This ‘alternative provision’ is what is being collectively referred to in this report as ‘day opportunities’.

1.4 What is the purpose of ‘My Day My Way’?

The purpose of this report is to ensure that people with a learning disability have a voice and the opportunity to say what they think about how they spend their day and

¹ Equal Lives Report: Review of Policy and Services For People with a Learning Disability in Northern Ireland (DHSSPS, 2005)

the choices they have available for meaningful day-time activities. This report also contains the views of some parents, carers and family members.

During the period August 2010 to May 2011 the Bamford Monitoring Group project team at the Patient and Client Council met with people with a learning disability, and some parents, carers and family members from across Northern Ireland. What follows are their views about 'day opportunities' available in their area. The aims of this project were to:

- provide the opportunity for people with a learning disability, and also parents, carers and family members to voice their opinions regarding 'day opportunities' and also day services in Northern Ireland;
- determine what changes people with a learning disability have seen to provide alternative 'day opportunities';
- identify concerns regarding 'day opportunities' and day services available;
- produce a report based on what people with a learning disability, parents, carers and family members say;
- use the findings in the report to advise policy and decision makers, if and how changes to 'day opportunities' and day services are being realised and making a positive difference in the lives of people with a learning disability, and to parents, carers and family members.

Currently, there is a cultural shift away from a reliance on day centres, towards alternative options for people with a learning disability. This new model of 'day opportunities' should be based on social integration and encourage people with a learning disability to fully participate in community life, and ensure they have greater choice and more control over their own lives.

“increase the provision of person-centred day opportunities (including employment provision) for people with a learning disability that facilitate integration into the community”.

(DHSSPS, 2009, p.130)

People with a learning disability should be able to choose what they want to do each day. They should be able to access various activities tailored to their aspirations and needs.

This report is necessary to find out what people with a learning disability think about how they spend their day and if there are more person-centred day opportunities available to them.

2.0 Our Approach

In order to hear the views of people with a learning disability, the Bamford Monitoring Group project team met with groups of people with learning disabilities, and also some parents, carers and family members. We asked people to tell us:

- how they spend their time each day;
- what sort of things they do and where they go;
- what they liked about these things and what they didn't like;
- if they got to choose what they did and where they went; and
- if they would like to try something different.

In this report we outline what people told us about their day. However, it is recognised that a separate study will be required to fully reflect the views and experiences of people with severe and profound learning disabilities, including those with challenging behaviours.

It is important to remember that, just like you and I, the lives of people with a learning disability are wide and varied. Therefore, the provision of meaningful 'day opportunities' are NOT just the responsibility of health and social care, but the responsibility of other government departments and agency partners such as education, and employment and learning.

“The goal is to help individuals with a learning disability to use their individual strengths to reach their full potential. In doing so, provision of services for people extend far beyond traditional health and social care services and require cross departmental and interagency action.”

(DHSSPS, 2009, p. 8)

2.1 Discussion groups

During the period September 2010 to June 2011, the team met with 85 groups of people with a learning disability, parents and carers. These small discussion groups were held in those local facilities / centres where day opportunities and services are provided, and also within community venues.

The total number of groups met in each Trust area across Northern Ireland is contained in the table below. A more detailed list of these groups is contained in Appendix 2 of this report.

Table 1: Number of groups met, by Health and Social Care Trust area

Area	Groups	No. People
Belfast HSC Trust Area	15	143
Northern HSC Trust Area	19	226
Southern HSC Trust Area	13	132
South Eastern HSC Trust Area	16	90
Western HSC Trust Area	22	283
TOTAL	85	874

2.2 'Our Stories' conference and workshops

The Bamford Monitoring Group hosted a conference in November 2010 called 'Our Stories'. This conference was attended by 120 people with a learning disability, parents, carers, family members and people involved in supporting adults with a learning disability.

During the conference, people with a learning disability, parents, carers and family members embraced the opportunity to speak out about several key issues including, day opportunities and day services. People then formed small groups to share their views and experiences in greater detail.

Following the success of the conference, the Bamford Monitoring Group took the decision to reach out to people in their local areas. The team went on the road and hosted a series of nine 'Our Stories' regional workshops in various locations across Northern Ireland. Locations were chosen to be close to where people live.

The 'Our Stories' regional workshop were attended by 196 people and were particularly important in reaching parents, carers and family members of people with a learning disability. Details of the nine workshops are provided below; attendance across these varied greatly.

Table 2: Attendance at 'Our Stories' Regional Workshops

Workshop	Parents / Carers	People with a Learning Disability	Staff / Support workers / others
Downpatrick	4	2	1
Bangor	12	8	4
Cookstown	5	48	21
Belfast	1	13	7
Ballymena	15	41	26
Armagh	6	3	4
Newry	0	3	1
Londonderry/Derry	12	11	10
Enniskillen	5	7	10
TOTAL	60	136	84* <i>(not counted in total attending)</i>

In total **316 people** took part in 'Our Stories' events, including the conference and regional workshops.

3.0 Our Findings

874 people with a learning disability, parents, carers and family members who were part of small group discussions completed the questionnaire and **316 people** took part in 'Our Stories' events. This section summarises their responses.

The small group discussion format for meeting with people gave an opportunity for more in-depth conversation about the issues. Given the nature of this approach, it has not always been possible to assign numbers, percentages or weightings to quantify the numbers of people who raised specific issues. However, as a general guide the following definitions will give the reader an indication of the frequency of occurrence during group discussions:

WHEN WE SAY:	WE MEAN:
"few"	= 10 % or less
"some"	= 11 – 25 %
"many"	= 26 – 50 %
"the majority"	= 51 – 75 %
"most"	= 75% +

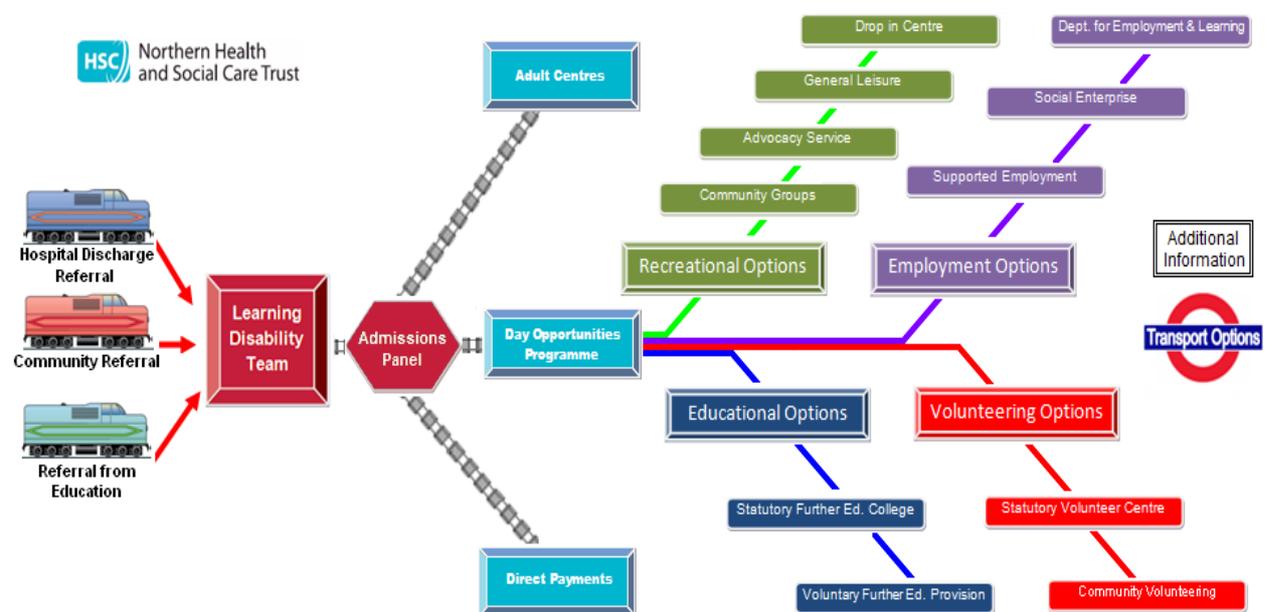
3.1 Northern Health and Social Care Trust Area

The Northern Health and Social Care Trust (Northern Trust) is geographically the largest health and social care trust in Northern Ireland. It operates from approximately 150 locations across the local council areas of Antrim, Ballymena, Ballymoney, Carrickfergus, Coleraine, Cookstown, Larne, Magherafelt, Moyle and Newtownabbey and serves a population of 443,079 people. The Northern Health and Social Care Trust directly employs approximately 12,000 people and has an annual budget of £619 million.

3.1.1 Current provision for people with a learning disability

This section 3.1.1 details the current provision of day services including ‘day opportunities’ provided by the Northern Trust for people with a learning disability. This information has been provided to the Bamford Monitoring Group by the Northern Trust.

Figure 1: Northern Health and Social Care Trust Rail Track Model



This resource produced by Alternative Angles, Ballymena North Business & Recreation Centre, Cushendall Road, Ballymena

The Northern Trust's **Day Opportunities Programme** was established to modernise and reform day services to enable adults with a learning disability to access community based day services instead of buildings-based day services.

Community-based day services are coordinated through the Day Opportunities Programme. The programme covers four areas of community based opportunities:

- Recreational activity (through the Base 'Drop-In Centre')
- Supported employment
- Volunteering
- Further education

Day Opportunities coordinators work with the individuals and their families/carers to provide a "package" of community based opportunities tailored to the needs and aspirations of the individual and, wherever possible, within the participant's home area. The Northern Trust has developed working partnerships with community and voluntary sector providers and with other government departments to provide a range of locally-delivered services and opportunities for the participants. Almost **500** participants are involved with the Northern Trust's Day Opportunities to date.

Base ("Drop-in" Centre)

The Northern Trust's Day Opportunities Programme has developed a number of Base ("Drop-In") centres, many in partnership with independent sector providers, across the Trust to provide facilities to enable adults with a learning disability to meet and to make friends. There is a Base coordinator at each Base 'drop-in centre' to act as support and coordinator of the centre and its outreach activities. Generally, people attend a Base as part of a package of community-based day services.

Supported Employment Provision

The Northern Trust's Day Opportunities Programme, with the Department for Employment and Learning, has developed partnerships with supported employment providers across the Trust to place, train, maintain and progress adults with learning disabilities in vocational opportunities. The supported employment

provider assesses the individuals' needs and places the participant into a vocational opportunity.

Volunteering

The Northern Trust's Day Opportunities Programme, with the Department for Social Development and the Association for Independent Volunteer Centres, has developed partnerships with Volunteering Providers across the Trust to match and maintain adults with learning disabilities in volunteering opportunities.

Accredited Further and Higher Education

The Northern Trust's Day Opportunities Programme has developed partnerships with the Northern Regional College, South West College and with Independent Sector Providers to provide accredited Further Educational courses for adults with a learning disability across the Trust. The range of courses include; employability skills; independent living skills, travel awareness training; community living skills; numeracy and literacy development, ICT and personal and social development. The educational provider assesses individual student learning needs, and then supports are put into the learning environment to help the student achieve their qualifications.

Adult Centres

The Northern Trust operates a total of nine Adult Centres. Places are prioritised for people who are immobile, who require all their personal care needs to be met, or who have other major health needs. These are outlined in below:

Table 3: Northern Health and Social Care Trust Adult Centres

Name
Antrim Adult Centre
Broadway Workshop Adult Centre
Cookstown Adult Centre
Drumross Adult Centre
George Sloane Centre
Hawthorns Adult Centre
Larne Adult Centre
Magherafelt Adult Centre
Mountfern Adult Centre

3.1.2 What people said...

In total 315 people with a learning disability and 20 parents and carers shared their views and experiences of day services and day opportunities in the Northern Health and Social Care Trust Area.

People with a learning disability told us about their day. Some people do more than one activity in each week; 169 people attend a day centre, 145 people attend a Base drop-in centre, 52 people go to a social enterprise, 93 people access education and 116 people are in employment, either voluntary or paid.

Day Opportunities

The majority of the people we spoke to said they were happy with how they spend their day. One group who all had a varied week of work, college and the Base drop-in centre said they liked that *“you can mix and match your week”* and one person added *“we make our own decisions”*. One person was happy with the move to day opportunities, *“I’m happier now I’m busier, I used to just go to the day centre”*. One person who split their week between college and social enterprise agreed that they liked being busy and enjoyed the hard work, *“I’m flat out!”*

Another group felt that people with a learning disability were being more involved in the decision making process. As one person who attended a workshop at the ‘Our Stories’ conference exclaimed, *“don’t ask me again what I want to do – too many people ask me that!”* However many people welcomed the opportunity to have their say, another person said that they enjoyed taking part in ‘Our Stories’, *“I’m happy you were talking to me and me talking back”*.

“I like to talk to other people at meetings and take part”

The Base

“It’s brilliant”

“You can do more at the Base”

“It’s better than the adult centre. At the adult centre you were looking around at four walls”

145 people said they attended the Base. Feedback was very positive; in fact the majority said that they would not change anything about the Base. Some people said that they would like to go to the Base more days in the week and a few people who did not go to a Base said they would like to have that opportunity.

Most agreed that *“there are lots of things to do at the Base”* and listed the activities they enjoyed such as computer games, pool, watching DVDs, the gym, keep fit and circus skills. Activities outside the centre organised by the Base were also popular, such as trips to the leisure centre, cinema, driving range, library and bowling. More casual outings like going for lunch with friends or going for walks *“down the town”* were just as popular because many people felt that they had more freedom and independence at the Base.

“I like getting out and about by myself”

“I go out for walks, I go out on my own”

Some people even felt that arranged outings were more flexible at the Base; for example one person said they liked that there was no time limit on trips so you did not have to rush back to the centre, *“you can come and go as you want”*.

Having more choice and freedom was one of the most popular things about the Base.

“You get to make your own decisions about your day”

“It’s just brilliant, you can do whatever you want”.

Some people talked about the steering groups within each centre where people discuss what they want to do and activities are put to a vote. Many also felt that there was more flexibility at the Base, for example it was fine to change your mind about an activity if you felt you no longer wanted to take part. People liked that they could speak out there, *“you say what you want”*, and many felt they had more freedom to make their own choices, *“you can do your own thing”*.

People were proud of this sense of independence and individuals mentioned that coming to the Base made them feel *“useful”*, *“part of things”*, *“independent”* and that it *“makes others proud of me”*. A few people also mentioned that coming to the Base made them feel like part of the community, *“it gets you out into the community”*, *“I like communicating with the public”*.

Socialising and meeting people was another positive aspect about coming to the Base and most people mentioned that spending time with friends and making new friends was important to them. Many people said that they enjoyed helping out at the Base, doing chores, cleaning up and generally keeping their centre tidy. Some talked about the different educational programmes they accessed through the Base such as independent travel training, the pharmacy programme on lifestyle choices and personal hygiene and the volunteer service, which people felt helped boost self-esteem. Others just enjoyed getting out of the house and having somewhere to go, as one person said about the Base *“it gives you a reason to be tired at the end of the day”*.

Some people talked about what they did before they came to the Base. 25 people shared that they had previously attended a day centre. A few commented further on this; one person said that he found the day centre *“boring”* and is happier in the Base where he feels he makes decisions about day activities for himself. Another person agreed that they did not like the day centre *“one bit”* and much prefers it now that

they work three days and spend a day at the Base. One person said that they “*wouldn't go back*” to the day centre. 5 people stated that they just stayed at home before the Base opened. One person added that they felt “*lonely, bored and frustrated*” at home before coming to the Base and another person said that two years earlier the day opportunities co-ordinator “*pulled me out of the house*” and encouraged her to try new things like social enterprise, volunteering and the Base.

“There are more opportunities for me at the Base than at the adult centre”

People with a learning disability want more Bases. People and parents from Ballymena and Coleraine frequently voiced the need for Bases in these areas. They felt that there was a shortage of day opportunities in their area and that Ballymoney was too far for some to travel to attend a Base. A few people said that they felt they were “*missing out*” because there was no Base closer to home.

However, while feedback was mostly positive, there were some negative comments. Two people did say that they preferred the day centre to the Base and two others said they left the Base because they did not like it, although they did not offer any explanation as to why. One group felt that while they had lots of choice when in the Base, they had no choice of when they could attend the centre as everyone was assigned certain days. One person said that because people do not go to the Base everyday they are sometimes not notified about new things and can miss out on information. A few people also complained about the decision making process for choosing activities within the Base; one said that if not enough people choose to do the same activity it might not take place and another felt that the group can be indecisive. A group at one Base felt that there were too many rules and that they were no longer allowed in the centre unless there was a staff member present, which made them feel that they were being treated like children. This group also said they had asked for more space in their centre and for a pedestrian crossing outside the building as the road was very busy but were told this was not a priority. Individuals mentioned that they wanted to go on more educational outings, they did not like the

circus skills classes and that it can be expensive when they go on a lot of trips from the Base.

A group at one Base was very concerned because a nearby day centre was closing down and new people would be joining the Base. Some people were worried that, as a result, the Base would just turn into “*another day centre*”. Those who had previously attended this day centre were particularly worried that this would happen. The group felt that the centre would get too noisy and they would lose space if too many new people joined. They were also frustrated that they were not consulted about this development, “*just told*”. This seemed to be something of a mixed message; people did feel that the Base offered more choice and independence but on the other hand they had no say in who comes and who goes through their centre or any choice in what days they can attend.

Social Enterprise

“It’s good fun, we make t-shirts and staff help us”

“I love it, I love meeting up with friends and working there. I hope to get a job out of it”

The 52 people we spoke to who take part in a social enterprise were mostly positive about this experience. Many people said they like the different tasks they do there such as making candles, t-shirts, boxes and bath bombs, sticking labels, cutting and putting folders together. Some people said that they liked the variety of tasks, that the jobs were interesting and they like being busy. Supportive staff and good friends were other positive aspects about going to social enterprise. A few people said they liked getting paid and having responsibility training for work.

There was some negative feedback on the social enterprise. Three people had attended a social enterprise for almost three years but there had been no mention of progressing on to a work placement; one person described how this made her feel like she was being “*overlooked*” and was frustrated with the lack of information. One

person who had recently moved on to a work placement was only working one day each week where they previously had three days at social enterprise, leaving them with two free days with nothing to do. Some people also complained that tasks can be repetitive and boring, as one person said *“it’s the same mundane tasks all the time”*. A group of people at a day centre who used to go to a social enterprise felt that there was *“nothing positive”* about this experience and that they got *“fed up”* doing the same things as there was not a big selection of contracts. This group also complained about the lack of transport to their social enterprise and felt that it was not a nice atmosphere to work in. A few others agreed; individuals mentioned that when there were too many other people to work with there can be personality clashes and the atmosphere between clients can be unfriendly.

Day Centre (Adult Centre)

169 people attended a day centre. Feedback on day centre experience was mixed. The majority of those who responded did have good things to say about the day centre. Some people said that they looked forward to coming to the centre each day. People enjoyed meeting their friends there, *“I like having fun with my friends”*, and talking and mixing with different people, *“I enjoy the craic”*. People said they enjoyed a range of activities such as gardening, arts and crafts, puzzles, sports, computer games, cookery, reading, writing and making scrap books. Pool was very popular in some day centres and the annual pool competition between different centres in the area was a big event that many looked forward to. People also enjoyed trips out of the centre, swimming, bowling, shopping, horse riding, walks, theatre trips and eating out. Some people enjoyed pampering and relaxation sessions. Courses in cookery, drama and reception skills run by a tutor from North West Regional College were popular in one centre and people there said they enjoyed learning new things. Some people said it was just nice to get out of the house and do different things, *“it’s very busy here”*, *“we do a wee bit of everything”*.

Another common response from people at day centres was that they liked the staff. Most people said that staff members were supportive, helpful and easy to talk to. Many said that they liked to *“help out the staff”* at the day centre and they talked about the jobs they carried out around the centre such as helping on reception, in the kitchen, checking fire alarms and cleaning. At a few centres people carried out

contract work; packing, making mats, labelling food, woodwork and cutting sticks. Some people shared that they like to help and support other people in the centre, such as wheelchair users or those with more complex needs. Many people mentioned the incentive rewards they received for activities in the centre as something they looked forward to each week. People very much regard this as their “pay”, so much so that one person complained that other people in the centre were sleeping instead of doing activities and yet they still got paid. Some people also said that they liked having their say when at the day centre and that they did this by sitting on the committee for user groups or taking part in discussion groups.

However, there was negative feedback on day centre experience. Some people stated that they can also feel “*bored*” and “*fed up*” at the centre and that there were not enough opportunities. One person said that they feel “*stuck in the day centre*” and that they would rather be “*out and about*” and another said “*I don’t do anything new anymore*”. One person said that he did not like the centre at all, that it was just “*somewhere to go*”. Some others felt that there were too many rules and said they did not like being told what to do by staff; one person maintained that she feels she is treated like a child in the day centre, that she is not given any responsibility and has nothing to do there.

Many people also complained about cutbacks and staff shortages. Several groups felt that day trips and outings had become very limited due to staff shortages and money constraints. One group said that some things in their centre were broken, “*but we have been told there isn’t enough money to get new things we want*”. Other groups complained that activities were sometimes cancelled because there were not enough staff. This was particularly upsetting for people who liked routine and did not like it when plans were changed at short notice. One group said that they used to go swimming but there is no longer enough staff to take them. Some people mentioned that this lack of money and staff meant they had little choice at the centre.

A few people also felt that the needs of others can limit choice at the day centre. One person felt that it was “*one rule for one and one for another*” and another felt that some people in the day centre “*get their way too much*”. Some others said that people in the day centre could behave badly, fight, shout, use bad words and as a

result the centre could become very noisy. Several people said that they would like somewhere quiet to sit in the day centre when things became too noisy. A few people mentioned that issues with transport could also restrict their choice of activities at the day centre; for example, one person complained that their bus did not arrive until very late each morning as it had to collect several people across a large rural area. One person voiced his opinion that things at the day centre “*are just getting worse*”.

Some people at day centres said that they would like to be more independent, as one person explained “*I feel like my independence is being taken away*”. One person who used to spend one day each week in a day centre said that Wednesday is now her day off, “*I used to go to the adult centre. I stopped going cause I didn't like it. I didn't like what they were giving me to do. I really wasn't happy*”. Another person also felt unhappy at the centre, even though they only attend one day each week, “*I don't like it, I'm going to give it up and go to work on a Wednesday*”.

Some people talked about past experiences of going to a day centre. One person who left the day centre highlighted that it was “*just not for me anymore*” and that people with needs more suited to the care provided by the centre took his place. He now goes to the Base, where he has more interesting activities to do and a lot more friends. Two people who used to spend all week in the day centre both said they much prefer their week as it is now split between work and the drop-in centre. Another person who used to attend the day centre stated that she did not like it there and she now volunteers and goes to the Base. Her message was that “*independence is important*”.

Education

“I like going to Tech ... I like everything ... PSD [Personal and Social Development] is brilliant”

“I love everything, meeting up with friends and doing courses and learning how to work computers”

“I've been going two years ... I love it. It's so interesting what teachers tell us. I meet new people”

93 people spoken to currently attend college and feedback was mostly positive, in fact a common response was *"there is nothing I don't like"*. Many people talked about the *"helpful and friendly"* staff and meeting friends, *"my favourite thing is making new friends and stuff"*. Many people said that they simply liked being a student and enjoyed learning new skills, *"I love to learn"*, *"the work is easy peasy"*. Some said that they valued getting qualifications, *"passing tests makes me feel good"*. Others said they enjoyed the Wider Choices and Personal and Social Development courses. A few people talked about the importance of college as preparation for independent living, as someone in supported living said *"I can carry the skills from PSD into Supported Living, its geared for what I am doing and helps me be independent as well"*. One person described sitting down with a support worker from college and choosing PSD from a range of courses; she was happy with her choice. Just being at college made some people feel more independent. Things like getting the bus to college on their own and choosing their own lunch in the canteen made people feel more responsible. Individuals mentioned the relaxed atmosphere, social evenings at college and holidays with the rest of the class as other things they enjoyed about going to college. One person said that sometimes they are given too much work, *"but I have to do it, it's good to do work"*.

The most common complaint about college was that there were no new courses available which meant that people could end up repeating courses, *"I have done lots of the same courses, there is nothing new for me to do, I am bored"*. A few people stated that they had been going to college for almost six years, going over much of the same material. One person said they had attended college for nine years and had no desire to go back. Some people asserted that they were *"fed up"* repeating courses; for example, one group in a day centre used to go to college but left due to repetitive courses and the lack of any new options. They all agreed that if things improved they would like to go back. Some people were unhappy about the choice of courses more generally and felt that free courses available to people with a learning disability were limited. A few others talked about the lack of courses available locally which meant long and expensive journeys to college.

Some people said that they could feel intimidated by the college environment; people talked about the noisy canteen, people pushing and shoving, the building being so

big that it was hard to find rooms and there being no tutor to help outside the classroom. As one group said *“we’re just students like everybody else”* and this lack of extra support could sometimes be difficult. A few people said that other students in the college could be unkind and call them names. While most people said that college staff were supportive, some individuals did have issues with their tutors. One person felt that the tutors *“don’t have time for us”* and another said she had to leave her course because she did not like the tutor, *“it was her attitude. She wasn’t nice to us, I didn’t like her attitude. She was being very rude”*. Colleges changing timetables at the beginning of term was also criticised by a few people, especially as this could impact on other day opportunities. A few people said that they found college boring; two people said that they watched TV and DVDs instead of learning things and another said *“I get bored, you don’t really do anything”*. One group felt that some college courses were too easy, the message they wanted to send was that *“people with a learning disability like a challenge too!”*

Employment

“I feel like an adult”

“Staff are happy to have me there, it makes me leave work happy”

“I got this job myself. I spoke up for it myself and asked for it at a meeting”

“I enjoy it, I’m going to stick to it ... I do washing and brushing the floor, I like it the best”

116 people spoken to were currently in a work placement. Most people were very happy at work; one person who worked in a nursery said *“I love it”* and another said they wanted to continue working in the café *“until retirement”*. Many people said that getting paid and meeting people were the best things about going to work, *“if you don’t go out you don’t make friends”*. Some people felt they were well supported by colleagues *“the staff are good, the supervisor is good too”*, *“they are really understanding”*; one person talked about how much they enjoyed going for lunch with other staff when she was at work. A few people said that they liked meeting customers, providing good customer service and helping others, *“I like working at the hospital, looking after patients and helping people”*.

Some people said that being employed offered more independence; individuals described how work made them feel “*useful*”, “*more confident*”, that they could “*speak out more*”, that it gave them a sense of “*purpose*” and greater “*freedom*”. One person described how work helped him to live more independently; after undertaking independent travel training he now goes to work by train each day and he saves the money he earns in his own bank account which he can then access. This person felt that working helped him to develop these basic skills. Some people said they had a degree of choice when it came to getting a work placement. One person described how he got his job “*it was organised through my Supported Employment Officer. I made a CV and went around employers with my SEO asking for a job*”. One person said that they focussed on what they wanted, studied for a Child Care qualification and now work in a nursery every day. Some people who were not in employment said that they would like to get a job and identified gardener, painter/decorator, farmer, hairdresser or in an office as work they would like to do in the future.

“I wouldn’t mind getting another job but they’re not easy to get around here, you’re better sticking with what you have. They’re hard to get and there’s not many jobs around where I live”

Some people felt that employment opportunities for people with learning disabilities were very limited and that some employers were reluctant to employ someone with a learning disability. One group suggested that pressure should be put on large companies to employ learning disabled people and that it was important that employers ensure people were not bullied at work. Some people said that they would like to get paid but that a lot of the work on offer was voluntary. A few felt that people with a learning disability are not paid in case it will affect their benefits and that this issue also restricts people from applying for any “*good jobs*”. Some said that they would like to work more hours. A few people complained that it took a long time to organise their work placement and others said that it can be difficult to change a work placement if things are not working out.

Individuals shared some issues they have with their work placements. One person felt that their job was too busy and they said they were often working “*flat out*”, while another person complained that their job was boring and that they often had nothing to do. A few people felt that they were being overlooked at work; one person said that he has to empty bins every time he is at work even though he has said how much he dislikes this task and another person said that he would like to be trained to use the forklift but felt he was always passed over for this type of work and he also complained that he had not been given a uniform like everyone else. One person had their hours at work dramatically reduced as a result of cutbacks in their workplace and another person who loves his work is worried that the current financial situation means his job is uncertain.

Do you enjoy what you do during the day?

The overwhelming majority of people said they were happy with their day and felt that they would not like to change anything. On a few occasions people answered no to this question and went on to explain that this was because they do not like change in general.

While most people said they were happy with their day, when questioned further many did identify different things they would like to try. Some who attend day centres said that they would like “*a bit more variety*” and would like to get out of the centre more. Many people in day centres said that they were happy but then voiced things they would like to change about the centre such as “*a big dining room so we can all eat together*” or “*a bigger car park for staff*”.

Some people with work placements said they would like to be paid or would like more hours at work and some not in employment said they would like to get a job. A recurrent concern was that working or paid employment would affect benefits and a few said they did not want to take this risk.

People do want to access more day opportunities; a few said they would like to progress to a job through a social enterprise, others voiced that they would like to go to the Base and some felt they would like to go to college, especially if new courses

were made available. A few felt that they were missing out on day opportunities, for example one person said that they had three free days each week which they would like to fill with other day opportunities. A person who lives in supported housing said that they stay at home all week as there are currently no day opportunity or day centre places available.

Some people talked about becoming more independent; a few said that they would like to live independently, others said they would like to get married and one person said they would like to learn how to drive. One group said that they would like to visit different places and meet new people and one person said they would like to socialise with different people at the weekends.

When asked whether they would like to try anything different most said they would not change anything about their day. However when further questioned some said that they were unsure about other things they could do or get involved in. Some people said they would like to try different things but were not sure what.

“You don’t know if you like something until you’ve tried it”

“We would just like to be busier and try new things but we don’t know what, because we don’t know what’s available to us”

Do you get the extra help/support you need to do what you want to do?

Most people felt that they did get the support they needed to do what they wanted to do and that staff at the day centres, social enterprise and bases were helpful and easy to talk to. One group identified day opportunities staff, the day opportunities co-ordinator, their social worker and family as their support network and this was quite reflective of response as a whole. Two people agreed that you can always go to your day opportunities co-ordinator if you want to try something new, *“no one is stopped from doing what they want to do”*.

There was very little negative response to this question. Some day centre users felt that staff shortages could at times prevent them from doing planned activities. A few people at social enterprises and the Base felt that staff were too strict and imposed too many rules. A few felt that “*some staff don’t listen*” and one person felt that they were not “*taken seriously*” by their social worker.

There was also some concern voiced that budget cuts could prevent people from doing the things they would like to do. One person said that he was “extremely” concerned that the day opportunities budget would be cut; he described how he wrote a letter to Stormont explaining his concerns, received a response within a week and was happy with the outcome. One group discussed budget cuts; they thought that money was being cut in the wrong places and they would like to see more money for respite services.

Do you get to choose where you go and what you do during the day?

Most people who responded felt that they did have some choice in the activities they take part in during the day. One group were of the opinion that people with a learning disability were becoming more involved in the decision making process. One person said that with staff encouragement they now had the confidence to make their own decisions. Another person agreed that people with a learning disability can “*be their own boss*”. However, only some people said that they had a choice in where they actually went each day and only a few talked about making a choice from a range of day opportunities.

Most people at day centres felt that they have some choice over the activities they do each day. Individual groups did mention that this choice was limited by transport, meal routines, staff shortages and the needs of other people in the centre. People recognised that there was a lot of structure in their day and understood that they could not always choose what to do on an individual basis. Some people said they were happy with this structure and did not mind if things were organised for them, but others felt that there was “*not enough choice at the day centre*”. A group at one day centre felt very strongly about this; they said that they would like more

independence, to make their own decisions and choices, to be treated like adults and to have the same opportunities as everyone else.

People at the Base felt that they had more independence and variety. Some said that they could go out of the base whenever they liked, just as long as they informed a member of staff. People enjoyed having this freedom of choice, "*we can do whatever we want*", "*we make our own decisions*".

Several groups which consisted of both day centre and Base users helped to highlight the different degree of choice available. Four members of one group divided their week between the Base and the day centre; they felt that they had a lot of choice at the Base but that their day was more structured at the day centre and all four said that they preferred the Base. Another group agreed, they said that activities were organised for them at the day centre but at the Base staff encouraged them to make their own choices. In a third group, half attended a day centre where they felt that their choice was limited and the other half went to the Base where they felt they had a good level of choice. People felt that they had more say about how they spent their day when they went to the Base.

Many people talked about the importance of independence. Individuals described travelling short distances independently after taking a travel awareness course and, with a little support, going to the bank and managing their own budget.

A few people felt that their choice was limited when it came to other day opportunities. Issues of choice around college courses were mentioned by some groups. A few people who had previously attended college said that they were not given the choice to continue on to another course, they just had to return to the day centre. Two groups of people whose college courses were coming to an end were not sure if they had the choice to return the next year, but some felt that they would like this option. A few people from these groups were worried that no provision had been made for after college; for example one person said they will have two free days when college ended and they did not know what, if anything, they could choose to fill these days. On the other hand, one person said that they wanted to give up their college course and return to the day centre they previously attended, only to be

told that there was no longer a place at the centre. They felt that they were given no choice and were now “stuck” at college repeating courses.

A few people also felt that there was not enough choice when it came to work placements. People felt that there were limited work opportunities available to people with a learning disability, that they had little choice over the number of hours they worked and that, once in a work placement, it could be difficult to change to something new.

Change

It is clear from some individual comments that changes to the provision of day opportunities has had a big impact on the lives of some of the people we spoke to in the Northern Trust Area. The question of change was often a difficult concept for people to grasp and many found it hard to recall what they used to do and to compare past with present. However, about 30 people did talk about how they used to spend their week before becoming involved in day opportunities, which gives some indication of how things have changed over the past few years. The overwhelming majority of those who did respond to this question felt that things had changed for the better. Most people said they much preferred going to the Base, work, college or a social enterprise to spending all week at the day centre or at home as they had done two or three years earlier. They shared that they enjoyed having more variety and independence, a positive sign that some people with a learning disability now feel that they have more opportunities. However, there are still some people in day centres who said they felt “*stuck*” there and shared that they were “*fed up*” with the lack of stimulating activities, independence and responsibility.

Views of Parents and Carers

Many parents had good things to say about day opportunities. For example two parents agreed that their experience of day opportunities had been very positive; they felt that their family members had been well supported by their care workers and had become more independent as a result.

Most parents felt that the Base gave their family member the chance to develop a sense of independence. One said that their son had left the day centre three years ago and now spends two days at the Base. This parent felt that the Base offered more “*scope*” and encouraged independence. A few parents called for more Bases, especially in the Ballymena area. Two parents with family members who each spend four days in the day centre and one in the Base agreed that the option to spend a day each week at the Base was a welcome opportunity; one parent said “*the opportunity came up and its good for her to learn to go on her own*” and the other felt that the Base would be “*further learning*” for their son. However, while both parents said that their family member “*loved*” going to the Base, they expressed concern that if something happened to the Base there would no longer be a place back at the day centre. They were worried about the financial position of the Base and were wary about giving up a place at the day centre until they felt confident that the Base was there to stay. One parent, while praising the Base for encouraging independence, said that people with a learning disability continue to be vulnerable and can still be taken advantage of and that this remains a barrier to independence. However she also acknowledged that, as a parent, you should not prevent your child from becoming more independent. Only one parent spoke negatively about the Base their daughter used to attend; they felt that “*all she did was watch TV*” so she now spends these days at home.

Parents agreed that social enterprises should be aimed at preparing people for the workplace and two parents felt that the social enterprise their family member attended did just that. One parent described their daughter’s social enterprise as an “*excellent environment*” and they felt that the “*can’t say no*” principle was a good way of teaching the discipline necessary for the workplace.

Parents had very positive things to say about their family member’s experience of work. One parent said that their son volunteers three days each week; they felt that he benefits from the shared experience of work and from meeting other people and that the job gives him a sense of purpose, although they did say that their son would ideally like to get paid for the work. Another parent spoke of her son’s employer describing how happy he was with her son’s work and that he was pleased to have him working there. One parent said that their daughter loves going to work more

than anything else, “*when she is not there she phones to make sure everything is ok*”. This parent added that they would like their daughter to have more work or education that would lead to employment. However, as another parent said, employment for people with a learning disability needs to be meaningful not “*tokenism*”.

One parent felt that people were often repeating courses at college because the curriculum for people with a learning disability was so limited. This parent suggested that courses are sometimes offered to people because they feel they “*must be doing something*”, which again brings up the idea of “*tokenism*” rather than meaningful education.

One parent described how he removed his daughter from the day centre she previously attended because he felt she was “*regressing*” as he felt there were no interesting or stimulating activities there.

Concerns about the facilities available at the George Sloan Centre were raised by another parent. He felt very strongly about the poor condition of the building; he said that it met only the minimal environmental requirements and needed to be modernised in order to provide for the basic needs of those who use the centre. He felt that people with a learning disability were being overlooked.

One group of carers felt that there were not enough opportunities for people with severe learning disabilities. They felt that the day centre was the only post-school option, but there were questions as to whether centres had the necessary staff or equipment to provide for complex needs. Staff shortages meant that some were missing out on the one to one attention they needed; in one example given, just one member of staff was left to feed five people at breakfast time. They felt that people need more stimulation and one to one assistance. This group felt that while the Bamford Report had improved the circumstances of some, those who are less able for work or training are “*forgotten*”.

A few parents also felt that there was little support for people with autism after school and they suggested that people with autism can struggle to fit into a work environment.

Some parents identified transport as a big issue. They said that transport from rural areas was no longer provided and when it was in the past it was not consistent. They said that transport needs to be reliable as routine is important for people with a learning disability and they can become anxious about being late and getting into trouble. One parent shared that the transport to their son's day centre is often unreliable and can be very late, if it comes at all. They have had to take their son to the centre on a number of occasions.

A few parents did highlight some general concerns about day opportunities. One parent felt that there was an "*illusion of services*" rather than any real provision for people with a learning disability. It was suggested that parents are often reluctant to speak out because they fear that they will lose the services they have or are too proud to ask for help. One parent said that information about the opportunities available to adults with a learning disability needs to be presented to parents and carers in a simplified way. Another said that they were not made aware of what was available for their son but had found things out by default. This highlights the need for what one parent described as "*local networking and a united community*". Communication was an issue; parents felt that people just do not have the information and that they need to be informed in order to have a voice. It is felt that coherent information about what is available and more support in accessing day opportunities would make things easier for the families, "*unless you have someone in your family with a learning disability you don't appreciate how hard it is*".

Key Points:

- **The majority of people with a learning disability we spoke to said they were happy with how they spend their day;**
- **Most people who talked about how they used to spend their week before becoming involved in day opportunities said they preferred going to the Base, work, college or social enterprise to spending all week at the day centre or at home as they had done two or three years earlier;**

- **People with a learning disability want more Bases;**
- **People like to work but some are concerned that jobs for people with a learning disability are limited and that paid employment will affect their benefits;**
- **Employment for people with a learning disability needs to be meaningful, not “tokenism”;**
- **Many people are repeating college courses due to a lack of alternatives;**
- **Some people find tasks at social enterprise repetitive and boring;**
- **Education and social enterprise should be meaningful preparation for the future;**
- **Feedback on day centres was mixed. The majority of people did have good things to say about day centres and the staff, however some people said they felt bored, day trips and outings are becoming limited, due to cutbacks and staff shortages.**
- **Transport can prove problematic; long bus journeys to day centres can cut the day short;**
- **More opportunities for people with more severe learning disabilities are needed – the day centre was the only post-school option. Parents questioned whether the centres had the necessary staff, equipment or stimulating activities to provide for complex needs;**
- **Many parents and carers had good things to say about day opportunities but feared that if funding was reduced these would be at risk and their relative would not be accommodated back at the day centre;**
- **Parents felt that they do not have the information about what is available and require more support in accessing day opportunities.**

3.2 South Eastern Health and Social Care Trust Area

The South Eastern Health and Social Care Trust (South Eastern Trust) is an integrated organisation, incorporating acute hospital services, community health and social services and serves a population of approx 345,000 people, and covers the local government districts of Ards, North Down, Down and Lisburn.

3.2.1 Current provision for people with a learning disability

This section 3.2.1 details the current provision of day services including 'day opportunities' provided by the South Eastern Trust for people with a learning disability across its 3 geographical sectors. It also includes services funded by the Trust and provided by voluntary and independent sector providers. This information has been provided to the Bamford Monitoring Group by the South Eastern Trust.

Geographical Sector	Statutory Day Centre	Voluntary Independent Sector
Lisburn sector	Registered 120 places per day in:	<ul style="list-style-type: none"> Stepping Stones – Pathway to Employment Service – 25 places per day YMCA – 5 places per day Beeches – 14 places per day
Down sector	Registered 121 places per day in:	<ul style="list-style-type: none"> Autism Initiatives – 33 places per day Orchard Grove – 18 places per day Down Residential Project – 52 places per day South Eastern Regional College Employability Scheme – 15 to 20 places per day Daisies Café – Accept Care – 5 day care places / 10 work placements
North Down and Ards	Registered 219 places per day in: Ards TRC Ravara TRC Balloo TRC	<ul style="list-style-type: none"> Action Mental Health, Conlig – 35 places per day in 2011 (this will increase by 15 places per year for 3 years). Fold Avondale – 20 places per day. Glenraig – 5 places per day. Conlig Work Skills – Praxis – 27 places per day.
Across the South Eastern Trust		<ul style="list-style-type: none"> Mencap Pathways- 70 trainees

Statutory day care services provide 65% of all day care support provided to people with a learning disability with 35% commissioned by the Trust from independent and voluntary sector organisations. The Trust also commissions day opportunities from Providers of supported living schemes, nursing and residential facilities also.

The South Eastern Trust's Reform and Modernisation Plans for Disability Services were approved by the Department of Health, Social Services and Public Safety in February 2011. The Trust identified the need to review the provision of services with a greater strategic emphasis on the rights of disabled people to enjoy the same opportunities as all citizens. The plans have been extensively consulted upon from June until September 2010, involving users, carers and the wider public. They were accepted by the Trust Board and supported by the HSC Board in November 2010 before being submitted to the Department.

The South Eastern Trust has developed a project team to:

- (1) Reprofile statutory day care services to provide care to users with the most complex need;
- (2) Develop a Business Case seeking capital funding to replace the current 3 Training and Resource Centres in the North Down and Ards Sector which are not fit for purpose to create two premises to enable the needs of complex individuals to be met;
- (3) Engage with the community, voluntary and independent sectors to develop a flexible range of day opportunity services.

The Trust proposes to use a person centred approach to enable current users and their carers to explore day opportunities outside of their existing day care service. The Trust will seek to work with stakeholders to create a flexible continuum of day opportunities to ensure that individuals can move across services to ensure the best outcomes for the service users and best value for money.

3.2.2 What people said...

In total 100 people with a learning disability and 33 parents and carers shared their views and experiences of day services and day opportunities in the South Eastern Health and Social Care Trust Area.

People with a learning disability told us about their day activities. Some people we spoke to do more than one activity in each week; 74 people attend a day centre, 17 access education outside the day centre and 28 are in employment, either voluntary or paid. We also spoke to 19 people who attend social enterprise and work skills training.

Social enterprise and work skills training

“Variety and independence are very important”

The response from 10 people who attend social enterprise was wholly positive; most people said that they would not change anything about it other than coming in more days in the week. People enjoyed the variety of work activities available, in the kitchen, the café, card making and picture framing and some mentioned that the travel training programme at the social enterprise was very helpful. Meeting friends was another positive aspect of going there. One person, who used to spend all week in the day centre, and now goes to social enterprise three days said they much prefer their week the way it is now, *“I have lots of choice”*. One person said that working at the social enterprise feels like a *“real job”*.

Feedback from a group of 9 people at a work skills training centre was more mixed. The majority of people did enjoy the centre, especially taking part in work activities such as baking goods to sell, preparing plant pots and baskets to sell, delivering goods and helping staff. Those who responded most positively were those with the most varied week, such as the person with one day in college, two days in a work

placement and two days at the work skills centre who said that “*independence and variety is very important*”. However, two people were very unhappy with the centre; both disliked the work training activities on offer, one would prefer to be out working and the other preferred the day centre he previously attended. Another person felt that it could get a “*bit boring*” and that they would like more choice of activities. Most people were disappointed that community access trips to different places outside the centre had stopped due to staff shortages. A few people also mentioned problems communicating with staff.

A few people we spoke to took part in a horticultural project attached to one of the day centres and they really enjoyed the work.

Day Centre (Training Resource Centre)

“The centre is like a second home”

“It picks you up when you come here, makes you feel better about yourself”

74 people said they attended a day centre. Most people talked about the activities they enjoyed most such as arts and crafts, gardening, cookery, music, photography, woodwork, keep fit, yoga, drama, sports and games. One person who used to spend his week at home said he much prefers his week now that he comes to the day centre because he can do more “*intellectual activities*” which are very important to him. Others agreed that they enjoyed reading, writing, working on computers, quizzes and book groups. A few people explained that they were completing an ASDAN (Award Scheme Development and Accreditation Network) personal development course at the centre and that they enjoyed doing this at their own pace. Some people said that they enjoyed using the multisensory room and one person said they enjoyed the relaxation programme, “*the more you relax the more colour you see*”. Bus trips and outings, going for coffee and going out for walks were popular with most people. Creative activities with an end product were particularly important to those who took part in them, such as knitting blankets to send to Romania, gardening, selling baskets, preparing potted plants, wooden pallets and

fire sticks and making cards to sell. A group from a day centre that caters specifically for elderly people with a learning disability said they enjoyed knitting, watching television, choir, shopping, drawing and music communication.

Helping out at the day centre was frequently mentioned as something people enjoyed about their day. Many people talked about how much they liked helping with various jobs within the centre such as working in the kitchen and office, cleaning, caretaker duties and acting as a *“meeter and greeter”*, *“I love helping out around the centre”*. Some people also said that they liked to help other people in the centre, such as reading to others or helping those with more complex needs, *“I really enjoy helping others”*.

Most people said that spending time with friends was one of the best things about coming to the day centre, *“I get emotional support from best friends”*, *“friends are very important”*. Many also talked about the support and encouragement of staff, *“it makes it easier to come to the day centre – makes it fun”*. One person liked that staff at the day centre treat him with respect and another said that staff take time to listen. Many people said that they liked coming to the day centre because it kept them busy and some people said they often felt bored at home. When asked what they would be doing if they did not come to the day centre, one person answered that they would be *“stuck”* in a residential facility, *“I’d be there all day, I’d be bored”*. A few said that they would not like to try anything different like a work or college placement, *“it’s not me, I like coming to the day centre. Why change it? I’m happy”*.

However, there was some negative feedback on day centre experience. Some people felt that options were limited at the day centre and that there were not enough interesting activities. A few said that they would prefer to be out working, that they like to keep busy and are frustrated if there is not enough to do at the centre. Many people complained that they no longer went on as many day trips as they used to and that swimming trips had been cancelled. Some people mentioned that certain activities do not take place on days when there is not enough staff. Groups at several day centres felt that they really needed more staff in order to do the things they wanted during the day.

A few people felt that they were not “*taken seriously*” by staff, that staff sometimes did not explain things properly and that it could be difficult to speak up and tell staff they were not happy with something. There could also be problems finding activities that suited the mix of age groups within the day centre; for example a “lazy day” at one centre each Friday was enjoyed by older members of the group who liked taking it easier and having a day of less structured activities, but not by two younger members of the group who said they would rather be out working. A few people had very negative comments on the day centre, the day centre is “*like school*”, the day centre is “*like prison*”, and people are stuck there “*til the day they die*”.

There is concern about the amalgamation of three Training Resource Centres into one centre. People at one centre were very concerned that they might have to move to one of the other centres. Although they recognise that their building is old, they do not want to leave as they are worried they will be separated from friends, they are concerned that the other centre was not near a bus stop, that they will not know the staff there and that there is a young offenders institute nearby – “*it’s a big change for us*”. They felt that they had not been properly informed or consulted about this potential change. Members of an advocacy group at one of the other centres involved were also concerned about the future of the centre. They were really anxious about the lack of information and had asked that someone from the Trust come out and talk to them, even if it was only to explain that they do not know what is happening yet.

Education

17 people spoken to currently attend a course at college and feedback on their experiences of this were overwhelmingly positive. Most people agreed that there was nothing bad about college. The most common responses were that people enjoyed meeting new people and seeing good friends at college and that they liked the chance to learn new things and to get qualifications. Many people said that they liked the tutors. Some said that they would like to do more courses. One person who gained a qualification in money management said that they liked knowing the value of everyday things like a newspaper. Only one person responded negatively; they said that they did not find their course very interesting.

Employment

“You can be yourself”

“The work placement is great as the work is easy and it’s great to meet lots of new people”

28 people spoken to were currently in employment and for those who had a work placement, the response was mostly positive. Most people said they enjoyed the work they did, that they liked helping others and carrying out a variety of tasks, *“I like hard work”*. Many people said they liked the respect that came with working and that they liked feeling valued. Some said the best thing about working was getting paid and others said that they liked to keep busy. Colleagues who understand and meeting lots of new people were other aspects of work that people enjoyed. One person enjoyed renovating tools as part of his voluntary placement because he was working with his hands at a *“manly job”* and his parent added that he enjoyed the good *“working man’s atmosphere”* that existed there. It was common for people not in employment or who had never had a work placement to say that would like to work.

The most commonly voiced complaint about work was that there were *“not enough hours”*. Many people also said that paid employment would be better than volunteering. Some felt that people with a learning disability did not have enough choice when it came to work and a few went further to say they would like a different placement but that there were no alternatives. For example, one person said they were not *“cheeky enough”* to turn down the work placement the social worker offered them even though they would have preferred the option to do something else. Many agreed that more advice and support were needed to help people find suitable work placements.

Several people raised individual issues about work. Two people said they were finding it difficult to find an employer that could accommodate their personal care needs and one person said they would like to work in a supermarket but his mum

questioned if he would get the support he needed there. One person had not enjoyed his previous employment at a fast food restaurant because he felt he was not treated well by other staff and told to do the jobs no one else wanted. One person was disappointed to lose the office job he loved because of financial cutbacks and another person had her request for more hours at work turned down without any explanation why, leading her to feel let down. A few people felt that they had to restrict the number of hours they worked so as not to impact on their other benefits, which they found frustrating.

One person at a day centre said they would like to work but that it was proving difficult to find something suitable, *“they say people have equal lives but they don’t put things in place to support them”*.

Do you enjoy what you do during the day?

Most people who responded said they were very happy and did not want to change anything about their day, one person said *“I’m really, really happy”*. However there were some exceptions; a few people at day centres felt very unhappy there and two people at a work skills training centre also voiced their discontent, one said *“there is nothing good about coming here”*.

While most people said that they did not want to change anything about their day, when questioned further some did identify different things that they would like to try. The most common response from people was that they would like to work or to get back into employment. People identified that they would like to try work in an office, a supermarket, café, mechanics, hairdressers, with children and with animals. A few people said they would like to go to college or work at a social enterprise. Some people felt that they would like to be more independent; one person said they would like to live in the community, another would like to learn how to drive and two people said they would like to learn about money management.

“I would like to learn more about money, to gain more independence and manage my own money”.

A few people mentioned that they would like the opportunity to socialise more outside the day centre. Some others felt that they would just like to have more choice in their day.

Do you get the extra help/support you need to do what you want to do?

The majority of those who answered felt that most staff at day services were friendly, supportive, patient and easy to talk to. Some people also mentioned social workers, family and friends as people they could talk to about their options and about trying new things.

A few people did raise concerns about getting the support they needed. Some said that they would like more help to find a job, fill in application forms and prepare for interviews. One person said that they find it difficult to get the words across when speaking to their social worker and another said that they do not see their social worker very often to discuss options. Several groups agreed that day centres need more staff so that they could do more activities and have more choice. A few people felt that staff at day centres do not always listen to you or explain things properly. There was an issue with lack of communication more generally; people wanted better explanations when services were taken away and they wanted to be informed about change.

Do you get to choose where you go and what you do during the day?

This was a very difficult question for people and most struggled to answer it. If people did respond, they usually talked about their choice of activities when at day opportunities or the day centre but few mentioned having choice about where they actually went during the day. This seemed to be a difficult concept for people. People also appeared to find it difficult to think back to what they used to do before they started attending their current day opportunity or centre, so finding out how things had changed for people proved problematic.

“Variety is very important”

“Lots of things – work, drama, football, I can choose myself from lots of options”

“Very little, I would prefer to be in full-time work”

The majority of people who responded to the question about choice felt that they could choose from a range of activities during the day and were happy with the amount of choice in their day. However while it was clear that most people felt they had a choice of activities at the day service they attend, few mentioned actually making a choice about where they go during the day or said they felt they could choose from a range of day opportunities.

The three training resource centres in the area had advocacy groups to talk about issues affecting their day centre and members agreed that they liked having this forum. However, some members of the TILI [Tell It Like It Is] self-advocacy groups felt that day centre users had no say in what they do and that the activity list was chosen by staff not by the people themselves. They felt that options within day centres were very limited. One member of Bangor TILI felt that he had very little choice over his day and that he would prefer to be in full-time employment.

Some people did complain about the lack of choice when it came to work placements. A few people said they had work placements that they did not enjoy but felt they did not have any alternative or the option to try something different. A few also felt they had no choice over the number of hours they could work. Some agreed that there was just not enough choice of work placements for people with a learning disability.

Three people felt that they had more variety in their week since they moved into assisted living accommodation, including the option of taking up a work placement. One person said they felt that when they were in residential care they could not talk to staff about options but in assisted living you were given more choice and greater independence. Two others agreed that they had more options and independence in

assisted living and enjoyed the responsibility of setting their own timetable with the help of support workers.

These were the most common responses that emerged from the focus groups and workshops but there were exceptions. For example, there were some people who prefer to attend the day centre five days a week, those who want the choice not to work or go to college and others who do not want any more variety in their week. The needs of those with profound and multiple disabilities also need to be considered. This highlights the need for planning on an individual basis.

Views of Parents and Carers

Parents agreed that a good day opportunity placement should provide a safe environment, with caring staff, somewhere a parent or carer can feel confident and content to leave their family member. Day opportunities need to focus on quality of life and be person centred. Forming friendships and having a social life are important but they should also be developmental.

One parent described their daughter's job in a café as "*the highlight of her week*" and another parent said that their son is so happy in his work placement that, in turn, it makes them happy. However, there is a genuine fear amongst parents in this area that work placements are being taken away. One group of parents felt that the jobs for people with a learning disability were just not there and those places that were offered were rarely paid.

Some parents felt that there was a need for ongoing training at college. They felt that local colleges had cut back on extension courses and as a result people were now repeating courses as there was nothing to progress on to. One parent stressed the point that people now at college had to be able to move into a job, not just stay on at college repeating courses or returning to the day centre. Another parent suggested that social and personal skills classes at college might be of more practical use to adults with a learning disability. Last minute changes to college courses at the beginning of term were also criticised for the disruption they cause to an individual's weekly schedule.

Some parents felt that there were limited opportunities for people with a learning disability in the area and that there needed to be more to challenge and stimulate people. One parent felt that not only were options limited, those that were available were not made clear to parents and carers.

Other parents agreed that there was a lack of awareness as to the day opportunities available and that the different organisations involved did not network or work together. This lack of co-ordination amongst organisations was identified as a really negative aspect of day opportunities. Parents also raised the question of equality; compared with a child who does not have a learning disability, parents felt there were very few choices available and questioned why a person with a learning disability should have less choice about how they spend their day. Some parents highlighted the need for person-centred planning.

“Individual needs need to be at the core of service provision and planning”

For example, one parent explained that a social worker offered her son a place in a day centre without advising on the average age of the people there – when they visited the centre they discovered that most people were a lot older than her son. This parent questioned the suitability of this and was able to organise a more appropriate placement at a horticultural project.

There was a feeling amongst parents that sometimes services are based on what is available rather than on the individual needs of the client. Another parent also stressed the need for age and ability appropriate day opportunities, not just have everyone “*clumped together from 19-77*”. This parent felt that there was a “*one size fits all approach*” which does not work.

There is a real concern amongst parents over the quality of provision and the reduction of the number of facilities available for people with a learning disability. One parent said that resources at their son’s day care were stretched, with staff trying to do the impossible under difficult circumstances. This parent felt that staff

can become de-motivated in such circumstances, which leads to absenteeism and more limited resources. Other parents questioned whether, in today's financial climate, there will be as many day opportunity and day care places in the future. Some suggested that best practice, day opportunity models that are working well, need to be shared across the board. Consistency of services is of utmost importance to parents and carers of people with a learning disability.

A few parents praised the care that their family members received at the day centre. One parent said that their daughter who has complex needs spends five days at a centre that is "*a real home from home*". The parent of someone with profound, multiple disabilities said that the care her son receives in the intensive support unit of his day centre is "*second to none*". Her son loves the day centre and she is also very happy with it, especially the way in which different days in the centre are distinguished by colours, smells and tastes. However she feels that going to the day centre each day is not enough for her son and that he needs more activities, although she is not aware of what. She believes the money and resources are just not there for people with more complex needs.

One parent shared some thoughts on day centre care. While they said that their son's day care worker was excellent, they were worried about staffing levels at the centre especially as the centre is using more agency staff. They felt this creates a problem with continuity of care as agency staff do not know of each person's specific care needs. They also said that if a staff member leaves they are not replaced, groups are reallocated which is disruptive and leads to larger groups. Transport to the centre was also identified as a problem; this parent chose to take their son to the centre every day because the bus journey took an hour and a half. They also questioned why the day was so much shorter at the centre as compared to school. This short day meant that "*outings don't exist*" because they can only leave at 11am and have to be back by 12.15pm.

There is a strong feeling amongst parents and carers that day centres are not for everyone. Some parents questioned the level of choice available at day centres and one parent felt there was situation of "*containment*" at the day centre their child attends, which he put down to lack of funding. Another parent commented that there

was “*too much DVD watching*” at the day centre their child attends, which they felt was not a suitable day opportunity. One parent agreed that day centres need to make sure that clients are stimulated, “*sometimes some of the groups are just sitting there*”.

Some parents raised issues about access to key services. One described the provision of speech and language therapy and occupational therapy as “*chaotic*”. Despite the great need for these services she felt that that availability was dreadful. This parent described the difficulty she had getting an OT assessment so that her son could travel by bus to the day centre, a process that took weeks during which time she had to drive her son to the centre each day so that he would not miss out. She suggested that each centre should have its own speech and language therapist and occupational therapist.

A group of parents of children with a learning disability who were still at school voiced their anxieties about the future and about the options open to their children after school. One parent shared their concern about the way forward into the adulthood for their son, “*the future is around the corner*”. They felt that they needed time to prepare for change, especially as the adult world was so “*loose*” compared with the structure their son knows now at school. Another parent felt that the specific needs of a young person are not recognised once they are out of school; they are just classed as adults.

Some parents felt that planning for transition does not happen as early as it is supposed to; one parent said that it was left until their child was just about to leave school. They felt that there should be more preparation and coaching for the next steps after school. One parent described the transition process as a “*complete nightmare*” and felt that this process is particularly difficult for those with profound learning disabilities.

Some parents felt that it was difficult for carers to fight for change; so much time was taken up by the caring role that they could not get involved in the lobbying that was necessary to drive change forward. Some agreed that there was a need for more parents’ forums; “*we all need to be singing off the same hymn sheet*”. One parent

felt that it was difficult to complain, that *“you can’t complain, who would you complain to?”*

Some parents also talked about the challenges facing the families of people with a learning disability. Some feared that so much attention was focused on their child with a learning disability that other children could sometimes miss out or feel neglected. One parent said that caring support from family members allows her a few hours each weekend to spend quality time with her husband and other son. Another parent said that her son’s learning disability meant that *“the baby stage never seems to end”* and the parent role does not reduce with time as it does with other children.

One parent described Positive Futures as a “lifeline”. Through this service volunteers offered support by occasionally taking her daughter out for a few hours, *“if it wasn’t for Positive Futures – I wouldn’t have a social life”*.

Parents felt that there was a great skill base within the community and in the voluntary sector that the Trust should make better use of.

Key Points:

- **Variety is very important. The most positive experiences came from people who mixed their week between college, social enterprise, work or day centre;**
- **Work offers people a feeling of independence, but many feel that there are not enough hours or paid employment available;**
- **Staff shortages in day centres mean that planned activities can not always take place and outings have been removed;**
- **Most people attending day centres talked about the activities they enjoyed, meeting friends and ‘helping out’ at the day centre;**
- **If people with a learning disability talked about choice they usually spoke about their choice of activities when at day opportunities or the day centre, but few mentioned having choice about where they actually went during the**

day;

- **People found it difficult to think back to what they used to do, so finding out if things had changed proved problematic;**
- **Some parents and carers felt that there were limited opportunities for people with a learning disability in the area, and there was a lack of awareness of what options were available;**
- **There was a feeling that sometimes services are based on what is available rather than on the needs of the individual – it is not person-centred;**
- **There was a concern amongst parents over the reduction in number of facilities available;**
- **Parents felt that the jobs and work placements for people with a learning disability were just not there and places that were offered were rarely paid;**
- **Parents felt that people with a learning disability were repeating courses as there was nothing to progress on to;**
- **Parents worried about staffing levels, lack of outings, transport and access to key services such as speech and language therapy and occupational therapy at day centres;**
- **Transition planning and post-school options were a concern for parents.**

3.3 Western Health and Social Care Trust Area

The Western Health and Social Care Trust (Western Trust) provides health and social care services across five council areas of Limavady, Londonderry, Strabane, Omagh and Fermanagh. The Western Trust employs approximately 12,000 staff and spends £459 million annually in the delivery of health and social care services.

3.3.1 Current provision for people with a learning disability

This section 3.3.1 details the current provision of day services including 'day opportunities' provided by the Western Trust for people with a learning disability. Day care and day opportunity services are provided both directly by the Western Trust, and also through voluntary and independent sector organisations funded by the Trust. This information has been provided to the Bamford Monitoring group by the Western Trust.

The Western Trust provides a full range of health and social care services including services for adults with a learning disability on the basis of assessed needs. The Western Trust has said it is fully committed to implementation of the recommendations of Equal Lives (DHSSPS, 2005).

Day care services are provided in twenty five (regulated) day centre settings, a full list of centres is outlined in Appendix 3.

Day opportunities services take the form of social, recreational and vocational outlets and include innovative clubhouse peer support groups, community-based music and performing arts opportunities, horticulture, sheltered and supported employment, volunteering, further education and befriending schemes. These are outlined below:

Table 4: Western Trust Day Opportunity Services

Name of Service and Provider	Location	Nature of service
Lilliput Theatre Group, WHSCT	Playhouse, Derry	Drama and performing arts
Pilots Row, WHSCT	Derry City	Social Inclusion
Sow n' Grow, WHSCT	Gransha Park, Derry	Horticulture and retail
Destined Group, Destined	Derry City	Peergroup Clubhouse promoting social inclusion
Green Gym, Conservation Volunteers NI	Gransha Park, Derry	Health promotion through physical activity in local conservation.
LCDI Garden Centre, Limavady Community Development Initiative & WHSCT	Limavady	Horticulture and retail
New Horizons Garden Centre, New Horizons	Drumahoe, Derry	Horticulture based training and sheltered/supported employment
New Horizons Garden Centre, New Horizons	Glenside, Strabane	Horticulture based training and sheltered/supported employment
Glenside Satellite Group, WHSCT	Strabane Methodist Hall	Social and recreational
Pathways to Employment, Mencap	WHSCT Trust area	Sheltered and supported employment
FVAD Horticulture Centre, Fermanagh Voluntary Association for the Disabled & WHSCT	Mill Street, Enniskillen	Horticultural activities
Fresh Focus, WHSCT	Enniskillen	Social inclusion and promotion of independence

The increasing prevalence of adults with severe learning disability brings significant challenges to the Trust. Provision of day care services for those with high dependency, and significant health and personal care needs enables families and carers to have a life outside of caring. Therefore the delivery of traditional day care services for this group is essential and, as a health and social care provider, the Western Trust has said it will continue to prioritise the needs of this group.

It is also significantly engaged both as a direct provider, and commissioner of day opportunity services. There is a need for further reform and modernisation of services to continue these developments and targeting resources to priority health and social care areas. The “Opportunities for Change” report provides the strategic direction for further development and reform of day services.

3.3.2 What people said...

In total 301 people with a learning disability and 21 parents and carers shared their views and experiences of day services and day opportunities in the Western Health and Social Trust Area.

People with a learning disability told us about their day activities. Some people do more than one activity in each week; 180 people attend a day centre, 44 people access education outside the day centre and 56 people are in employment, either voluntary or paid. We also spoke to 82 people who attend community based projects, music, performing arts and horticultural projects during the day.

Day Opportunities

“Variety in the week is very important”

“Day care is not for everybody – I prefer to be out working”

Response from people with a learning disability who access day opportunities was mostly positive. Some people felt that what they did gave them independence and offered them the chance to do different things. For example, one person described how a group from a project they attend was involved in a conference with learning disabled people from Poland and Germany, *“some of us will go on exchanges”*. Some said they enjoyed getting out and socialising with friends during the day and others just liked knowing that they had *“somewhere to go”* each day. Many people praised the staff that supported them, *“staff help us when we are upset”*, *“everyone’s feelings are taken into consideration”*. As one person said of her key worker, *“she has made so much difference to my day-care”*. However, a few people shared that they were worried about the future of their day services, especially when faced with financial cuts, *“where would that put us?”*

26 people from two community based projects had very positive things to say. At one centre people liked being able to choose their own timetable and decide on what activities they wanted to take part in. People said they enjoyed activities such as computers, pottery, gym, games, photography and putting on exhibitions. Some mentioned that they enjoyed learning to read, write and speak Irish. This choice extended to outings organised through the centre, *“we make our own choice about where we go”*. Holidays with the group from this centre were also very popular. Being with friends and helping others to do things they found difficult were voiced as other reasons why people liked coming here during the day. At another centre people said they enjoyed a varied week of activities which included music, college, art and keep fit classes, many of which took place outside the centre in the community. Everyone said they were happy with the activities they have access to.

Feedback from 27 people on their experiences at a performing arts group and a music project was wholly positive. At the music project members said they enjoyed a range of musical and artistic activities, *“we sing”*, *“we use different instruments”*, *“we have shows in the Playhouse”* and *“we make cards and face masks”*. One person said they would like to put on more shows and another said they would like to make a music video and record their own album. Many members also said they

enjoyed the weekly numeracy, literacy and computer skills classes organised through the centre. Individuals mentioned that they enjoyed meeting different people there and being able to use their own money when out for lunch.

Members of the performing arts company said they really enjoyed creative activities such as drama and creative writing, *“we do sketches for the trust staff to teach them about learning disability”*, as well as organised trips like bowling, shopping and eating out. Holidays with the group were also popular. Some members identified that they prefer to be kept busy and do not like it when they are at home with nothing to do; one person described how they can sometimes feel *“lonely”* at home.

Many felt that these groups provided company and friendship, as well as the *“comfort to know I have something to do”*. The only problematic issue voiced was that of transport and personal care needs; one member in a wheelchair described transport as a *“nightmare”* and they felt they did not have access to the same opportunities as everyone else at the performing arts group because of this, *“there is no wheelchair bus, which limits what I can take part in”*. This person shared that he would also like to attend the music project but that there was no staff there to undertake personal care.

The response from 26 men attending two horticultural projects in the area was overwhelmingly positive. Most agreed that they really enjoy the work; being outdoors, working in the garden, meeting customers and helping them to purchase plants.

One of the gardening projects has a “work crew” that carry out jobs in the community and these contracts are particularly popular. The men working at this project readily identify this as their job. They agreed that they share a good relationship with staff and with each other, *“I like it, it’s great to get out in the fresh air. I keep the other boys right and show them how to do things because I have been here from the start”*.

Day Centre (Adult Centre)

“I like coming here surely”

“It gets you out of the house”

“I feel happy here”

198 people with a learning disability said they attended a day centre. The majority responded positively about their experiences of the day centre. Most said they enjoyed the activities they do there, *“I like the centre”, “you do what you want”, “it’s good fun”*. One person who had recently moved to a day centre from school said, *“It’s very good, I like it, I was a wee bit shy and nervous, everyone made me feel welcome”*. One of the most important aspects of coming to the day centre for most people was meetings friends and socialising with others, *“I like these people”, “I like the centre, like coming here, piles of friends”*. Staff was also mentioned by many as an important source of support, *“staff are great friends to me, they are close to my heart”*.

Almost everyone spoke about the activities at the day centre they enjoyed the most. These could be creative; such as arts and crafts, cookery, knitting, flower arranging, drama and putting on productions, line dancing and writing life story books. One group was particularly proud of the work they had done on these. Sports such as cricket, basketball, tennis, keep fit, curling and walking were also popular. Others enjoyed more practical activities like gardening, reading and writing, woodwork, money management and life skill classes. Courses provided by a tutor from college held within the day centre in subjects such as Healthy Lifestyles, communication, literacy, cookery, music and computers were popular with most people who commented on them. More informal social activities were also enjoyed; puzzles, aromatherapy, massage, pampering sessions, yoga, playing pool, playing cards and watching DVDs. A gardening project for men at one centre and a Woman’s Group for over-50s at another were notable for the passion and enthusiasm of those involved. Trips out of the day centre were particularly popular and most people talked about going for coffee, to the library, bowling, swimming, shopping or trips into

town as something they enjoyed, *“we love getting out and about”*. Helping out around the centre was also important to many people and helping staff on reception, in the kitchen, cleaning and making tea was very much considered a job. Four different day centre groups mentioned “their pay”, incentive rewards received for activities undertaken in the centre, as something that they did not want to lose, *“we’re lucky our pay wasn’t cut, we really didn’t want that to happen”*.

“We had day trips ... why can’t we go on day trips?”

“There is very little choice available”

“We just try our best ... no arguments”

There was also negative feedback on day centre experience. Many said that they were unhappy that outings do not happen as much as they once did. Individuals at one centre were particularly unhappy about this, *“we used to go to Castlearchdale for a quiet walk in the nice summer evening ... that’s all stopped now”, “we went on shopping trips and to the theatre in the evening but staff are not allowed now”, “we used to go shopping ... now there’s too much red tape. We can’t go now, we can’t get”*. This group stressed that they want the choice to have outings because they get bored and annoyed. Two other day centre groups shared that they used to have an annual weekend trip away which has recently stopped because of financial constraints; this was an event people looked forward to all year and they would like to see it back.

A few people felt that there was not enough choice available at their day centre; one commented *“it would be better if you chose different things to do”*. One person who used to attend a day centre all week agreed that there was little choice available, they felt they were *“just sitting there”*. Now this individual only attends a day centre one day each week, has one day at college and is soon to start a work placement. A few other people felt that they would rather be working than in the day centre.

Transport is also a problem at some of the rural day centres. A group at one rural outreach centre said they had a long bus journey to get to the centre and collection

times were unreliable which often disrupted their day. At another day centre there were only three buses to cover a large geographical area meaning that some people could be on the bus for up to an hour and a half each morning. There were other individual comments; a few people said there could be name-calling and bullying at the centre, one group said that staff shortages meant that they did not get to do certain activities every week and some wheelchair users in one day centre felt that the narrow doors in the centre were difficult to get through and that there was a need for more than one disabled toilet. One day centre has an adjacent garden centre which now lies vacant as there is no longer enough staff to supervise individuals in both the day centre and garden centre. This was once a positive outlet for people and many would like to see it used again.

In order that people can spend their day in the community where they live, Omagh day centre has been broken down into various “outreach centres”, satellites of the larger day centre in Omagh town. Some other central day centres rent premises in smaller towns one day each week so people can spend at least one day in their local community – these are staffed by the day centre. One outreach centre, Carrickmore Stepping Stones, was due to close in May because of a decrease in numbers. Those who attend were due to move back to Omagh’s larger centre with some detrimental impacts, such as increased travel times to and from Omagh and the cancellation of the courses these individuals were taking within the centre. When asked about this impending move individuals replied, *“I don’t know what to think”* but it was evident that most did not feel comfortable talking about the move.

Education

“[College] is really enjoyable ... a great chance to make friends”

“I like getting out of the house instead of sitting watching TV all day”

“I didn’t learn as much as I would’ve liked ... there was too much pressure on the course”

44 people currently attend a course at college or a training centre and many others had done so previously. Response was mostly positive; many said they enjoyed their course, liked learning new skills, meeting new people and had a good relationship with their tutor. One group chose to take a course at a local training centre rather than go to college as from previous experiences of college they felt this was a better option. Some others attended essential skills and personal development courses with different mental health agencies and everyone said they enjoyed these.

Only three people said they did not enjoy the course they were currently attending. One person said they would rather work and two people stated that they had been going to college for “a lot of years”. One group who had previously attended college agreed that courses were repeated every year and there was little choice given. The group said that they had requested additional courses be added, such as local history, but nothing happened. As a result they all left college through choice but would consider returning in the future if more courses were made available.

In the Western area college courses tend to be run within the day centres facilitated by tutors from North West Regional College or South West College, rather than people attending college in person. These figures only reflect those who access education outside the day centre.

Employment

“Everybody should get the chance to work like me”

“I like to scrub, scrub, scrub the big pots”

“I get tea and toast, then I go around the offices and empty bins, wash dishes and sweep the floors ... I love it, I like the staff”

57 people spoken to were currently in employment. The majority said they really liked their work, “I know the ones that come in the shop, I like it”, “I like working there surely, I like doing dishes and all and mopping the floors”, “this [my job] makes me

happy". Many people said they liked the variety at work, carrying out different tasks, being busy and getting paid. Many mentioned the other staff as a reason why they enjoy going to work, "*the manager is very nice, you can feel comfortable and talk to the other people who work there*", "*it's good craic, they make you laugh, the staff do*". Others described how they like meeting new people at work and helping customers, "*I'm a helper and like to do the right thing for people*". One person had just started a new job teaching computers to over 50s at a training centre and was very proud to have this opportunity. Some mentioned the sense of freedom and independence that working offered them. One person explained how she wanted to take on another day at work and had asked the manager for this herself. She was very proud of her independence in this instance; her ability to ask for the extra day herself and to achieve it. Another person said they like that they are totally independent on the two days each week they are at work and another prided themselves in walking independently to and from their place of work. When asked if you would like to try anything different the most common response was "work" which highlights that there are many people with a learning disability in this area without employment who would like to access this opportunity.

"I never get no pay. I would like to be paid, naturally enough, anybody would"

The most common complaint about employment was that it was often unpaid, "*we all need to get paid*". A few felt that this was the result of the "*benefits trap*", as one person commented "*I would like to get paid but make sure it doesn't stop my other money [benefit]*". Another person suggested that this issue was stopping him getting into paid work, as he was worried life would be more difficult without benefits. Some voiced their dissatisfaction with the work opportunities available to people with a learning disability. A few said that their work placement was "alright" but that they would like to try something different. Many people without work said they would like a job and a few people who had work placements that had ended said they were not offered anything new. One person who was very involved with children in her spare

time wanted to find work in this area but was unable to access a relevant course or work placement.

Do you enjoy what you do during the day?

Most people who responded said that they were happy with their day and would not like to change anything. When asked if they would like to try anything different during the day the most common response was “work”. People identified that they would like to work in a shop, a hotel, as a cleaner, with children or with animals. One person said, “*I would like to become a politician. I like to help people make things better*”. The second most common response was “go to college”. A few people also said that they would like the opportunity to be more independent.

However, when questioned if they would like to change anything about their day or try anything new most people did not seem to know what else was available or could not identify any other options. What is more, most people in day centres could not remember how long they had been going there and many could not remember ever doing anything different. There was a sense that people did not have a lot of choice in how they spend their day and frequently looked to staff to make decisions for them.

Do you get the extra help/support you need to do what you want to do?

Most people who responded felt that they did get the necessary support to do what they wanted during the day. Most people at both day opportunities sites and day centres felt they had a good relationship with staff and received a good level of support. Some mentioned their social worker as a source of support. One person said that they received great support from Positive Futures and New Horizons and felt there were people at both organisations who you could discuss your options with. It was evident that, for many people, family were a hugely important source of support. One person explained that she was a carer for her own parents who are elderly and in ill-health. She said she was “*trying the best I can*” but added that when she was at the day centre “*I like staff looking after me*”.

Do you get to choose where you go and what you do during the day?

Most people who responded felt that they do have some choice over their day. Those attending the various day centres and projects said they were happy that they had choice in what they do, that they have a say in the upcoming programme of activities at the centre and feel that staff *really* listen to them. However, while they have choice in what activities they take part in, there was no mention or apparent understanding of whether they have choice of where they go during the day.

This was also true of people in day centres, the majority of who felt that, once they are in the centre they have a choice of activities and that they can talk to staff about what they like and don't like, "*staff don't make you do things*", "*you can say no*". Most day centre groups identified the centre's council or student meetings as a place where they could regularly discuss choice and other issues, these were described as meetings where you "*talk about what you like to do*", "*talk about any worries or complaints*" and "*you speak about what you want and say what you want*". Most felt that in these meetings "*staff listen*", "*we talk about what we don't like, we told staff, it changed*", "*we talked about the centre, we need new chairs for the kitchen and got it fixed*", "*sometimes we get to do what we want, we get annoyed if we don't get to do what we want, we can get angry*". Two groups referred to these as a "Members' forum", as one group explained, meetings are chaired by the people themselves and staff are excluded, which provides an open forum through which members can openly discuss issues and make choices. Those involved were very vocal that they liked having this forum, especially as they take ownership of it and "*all issues are talked about*". However, a few people at day centres were less positive about the amount of choice available to them; one person felt that "*we just have to do it ... if everyone is doing something we just all do it together*" and another feared that "*there's always changes coming ... there isn't much out there for people to do*".

There were some issues surrounding the concept of "choice". In one group, despite various methods of wording the question, individuals could not identify means by which they have the opportunity to make their own choices; they did not appear to comprehend what this meant and could not readily identify decision making forums

or opportunities. In another group it was evident that individuals did not wholly understand the idea of choice and did not provide any feedback. A third group felt that they were given choice in what activities they undertake, however the word “choice” or phrase “getting to choose” was not understood by the members and this needed to be further broken down by staff members. Individuals then described ‘choice’ as how they would sit down with the staff and tell them what they would like to do with their day and these activities are arranged where possible.

This type of choice, choosing what activities to do when at the day service you attend, was the one most readily identified by people when asked about the level of choice available to them. This was very much evident from the student councils and members’ forums set up within each of the day centres. However, very few people mentioned what choice they had in terms of where they actually went during the day and what day opportunities they attend.

Views of Parents and Carers

Transition to Day Services

One of the most common concerns raised by parents and carers of people with a learning disability was the transition process from school into adult day services. One parent was positive about this experience and felt their son now had a good balance between college and work and that he felt more “*grown up*”.

However, other parents described the transition process as “*terrible*”. Two sets of parents said that transition officers at school advised that day care was the only option for their children. Both declined this offer, as one parent explained, he “*wanted something different*” for his son and felt that the day centre did not offer “*enough stimulation*”. Both family members now have a more varied week between college, volunteering and work placements. As a result, one of these parents felt that post-school day options had allowed his son to mature a lot and had given him more independence. Despite these positives, this parent said that they still go from “*day to day*”, anxious about the future.

A third set of parents agreed that they were given no choice about post-school options; it took a year for their daughter to settle at the day centre, especially as she was only allowed to spend one afternoon there in advance to prepare her for the move. Another parent described how there were no day care places available at all when their son left school, which affected his first year out of school leaving him demoralised and lacking confidence. A sub-transition stage between school and day services to ease this process was suggested by one parent.

A group of parents of children with learning disabilities who will be leaving school within the next few years voiced their concerns and anxieties about the options available to their child in future when they move into adult services, highlighting a need for more information about day opportunities available in each area. One parent felt that, due to this lack of information, parents of people with learning disabilities do not know how to go about getting what they need.

Day Centres

While most parents and carers agreed that their family member liked attending the day centre and enjoy the activities they take part in there, all but one voiced issues with the level of stimulation, choice and staffing at the centres.

One parent felt that, at times, the day centre feels like a “*babysitting service*” and that more stimulation is needed, “*I feel my son needs a varied programme but there aren’t enough staff to provide a good enough service*”. This parent talked about the importance of day opportunities for their son because his complex needs stopped him attending clubs in the evening. They would like to see better use of the facilities that already exist, such as providing a drop-in centre after 4.30pm. Other parents agreed that day centres need to provide more stimulating and meaningful activities; one said that their son used to work but now spends all week in the day centre where he is “*fed up*”, another parent felt that people in the day centres become too dependent and a third parent felt that their son wanted to work but that the day centre he attends was too social, “*they do bowls and swimming, but that’s not work*”. One parent felt that staffing was a big issue at the day centre and they needed to make better use of volunteers.

Questions were also raised about access to key therapies like Speech and Language Therapy and Occupational Therapy, especially in day centres. One parent said they had to “*fight to get Speech and Language Therapy*” for their daughter.

One parent was very vocal about the lack of day opportunities for people with complex and severe needs. This parent would like to see the range of activities available to those attending day opportunities available to her daughter who has more complex needs. While she described her daughter’s day centre as “very good” she feels her daughter needs more stimulation and privately pays for extra social activities and services such as Befriending. This parent felt that by making the assumption that everyone can speak for themselves, the needs of those with more severe, multiple disabilities can miss out. She also highlighted the need for assessing each person on an individual basis, “*not one fits all*”.

“We have to fight for everything”

There is a feeling amongst parents and carers in this area that “*we have to fight for everything*”. A group of parents attending one workshop said they felt they have had to fight all their lives for facilities and services for their sons and daughters, it was felt that having to endure this for many years was a form of “*emotional blackmail*”. One parent referred to the “*Cinderella service of learning disabilities*”, he felt that there was nothing for people. He referred to the lack of services for people with learning disabilities as “*the greatest scandal in public life in Northern Ireland*”.

Many mentioned the impact this had on the families of people with a learning disability and it was agreed that some parents were suffering from stress due to the demands of the caring role, “*what about the parents with no support network?*”. One parent felt that having to fight for services puts so much pressure on the family, “*families should not have to become unwell to get extra help*”. This parent felt that they always have to ask and beg for help, but if there was consistency in services parents could let their guard down and relax.

Other Issues:

Parents and carers also have real concerns about future care and housing for their family members. One parent felt there should be better future planning, *“so you don’t have to worry about what will happen when you die”*.

One carer said that, in terms of changes to health and social care provision for people with a learning disability, *“I live in hope but I think things are deteriorating by the day”*.

There is a feeling amongst parents and carers that the Western Trust area is underfunded. One group of parents said they feel there is a discrepancy between services in the West and Belfast. Another parent said that when looking at resources, you have to take into account the levels of deprivation in the North West; for example, charges for transport to day services might disadvantage some people. There is a real anxiety about current cutbacks to services, despite the need for more investment, as one parent questioned, how are the aspirations set out by the Bamford Report going to be achieved without funding?

One group of parents praised the support offered by Positive Futures, *“if it wasn’t for Positive Futures we would be lost”*.

One group of parents praised the Rural Lift services; this was felt to be an excellent service with supportive, friendly and familiar staff which did much to reassure parents.

At the ‘Our Stories’ conference it was stated that autism groups were unhappy at being classified under the mental health section of the Bamford Report, the speaker felt that autism should be addressed on an individual basis and not be crossed over into mental health policy or service. It was felt that autism groups were not happy with the implementation of the Bamford Report.

Key Points:

- **People attending projects with a particular focus such as horticulture, music or performing arts were overwhelmingly positive about their experiences there;**
- **The majority of people spoke positively about activities at the day centre, but were unhappy about the recent decline in organised trips out of the centre;**
- **Transport to rural day centres was thought to be problematic; long journeys and an unreliable service;**
- **Most people enjoyed college, but some thought courses were repeated each year and there was little choice given;**
- **People who weren't currently employed wanted to work;**
- **People in employment really like their work but many raised questions about the lack of paid employment and many feared paid employment would affect their benefits;**
- **Most people said they had choice in what activities they take part in during the day but there was no mention or apparent understanding of whether they have a choice of where they go during the day;**
- **Most people did not know what else was available or could not identify any other options where they could go during the day;**
- **Parents are concerned about the transition from Children's to Adult Services, and thought there was limited post-school options;**
- **Some parents questioned the level of stimulation, choice and staff at day centres;**
- **Access to key therapies was a concern for parents e.g. speech and language therapy and occupational therapy;**
- **Parents felt there was a lack of opportunities for people with severe and complex needs;**
- **Parents said the Western area was underfunded to support people with a learning disability and families.**

3.4 Belfast Health and Social Care Trust Area

Belfast Health and Social Care Trust (Belfast Trust) delivers integrated health and social care to 340,000 people in Belfast and part of the Borough of Castlereagh. It also provides specialist services to all of Northern Ireland. With an annual budget of approximately £1bn (spending about £3m each day) and a staff of 20,000, it is one of the largest Trusts in the United Kingdom.

3.4.1 Current provision for people with a learning disability

This section 3.4.1 details the current provision of day services including 'day opportunities' provided by the Belfast Trust for people with a learning disability. This information has been provided to the Bamford Monitoring group by the Belfast Trust.

Belfast Trust Learning Disability services are aware of the Fuller Lives recommendations of the Bamford report and are actively working towards delivery of its key recommendations. The Trust has recently published 'The Big Plan: Learning Disability Services 2010/13' (BHSCT, 2010) which sets out its vision for the lives of adults with learning disabilities and describes how their services can contribute to this. The Belfast Trust confirms its commitment to provide a range of day activities such as employment, training, college, helping out in the local community or going to a Day Centre. The Belfast Trust highlights the following developments as important steps in achieving these aims:

- There is a single transitions planning process in operation across Belfast. This is led by two voluntary organizations; NOW and Orchardville. They work with schools and Belfast Trust staff to ensure that the widest possible range of choice is available to young people making the transition from school to the adult world. NOW and Orchardville both provide a range of training and supported employment opportunities for adults with learning disabilities across Belfast. Both access EU and Trust funding. The Belfast Trust also has a contract with the Mencap Pathways scheme.

- In response to requests from people with a learning disability, The Belfast Trust has established four Club Houses. Club Houses allow people to exercise a greater level of control over services than has been the case in Day Centres.
- Community Day Services have been developed, using Belfast City Council and Library Service buildings as a base for a model of service which seeks to be more community based. In particular this has been developed to meet the wishes of school leavers.
- The Belfast Trust is aware of the need to allow service users a greater opportunity to have a real input into the running and direction of services. There are Service Users groups in all services and an overall Service Users Council which meets on a quarterly basis.

The Trust continues to provide Day Centre provision in eight centres, regulated by the RQIA, spread throughout the Belfast area. These services are responding to increased support needs in particular with regard to complex physical disabilities, autism and support with behaviours.

Table 5: Belfast Health and Social Care Trust Day Centres

Suffolk Day Centre
Orchardville Training and Resource Centre
Mica Day Centre
Everton Day Centre
Edgumbe Training and Resource Centre
Fallswater Day Centre
Fortwilliam Day Centre
Mount Oriel Day Centre

Table 6: Belfast Health and Social Care Trust Day Opportunities

Edging Out
Extending the Choice Club
NOW, Springfield Road
Orchardville Society
Skyways Club
The Junction Club
Whiterock Community Day Services

The Belfast Trust states that it hopes to work on the following areas:

- (1) The Trust has a small number of direct payments in place for Day Services. The Trust wishes to allow this option to be more readily available but face challenges with freeing up funding from existing services.
- (2) The Trust is aware of the development of Personalised Budgets and how these have been used in England and Scotland and is currently exploring this as an option.
- (3) The Trust would like to see more adults with Learning Disabilities engaged in activities beyond day centres. This would allow centre based services to focus on those with more complex support requirements.
- (4) The buildings used to deliver centre based services, while meeting RQIA standards, would require considerable investment to meet the increasing complexity of need of those using them.
- (5) The Trust would welcome more inter agency working at a regional level which would set a template for local co operation.

3.4.2 What people said...

In total 156 people with a learning disability and 16 parents and carers shared their views and experiences of day services and day opportunities in the Belfast Health and Social Care Trust Area.

People with a learning disability told us about their day activities. Some people do more than one activity in each week; 110 attend a day centre, 52 people attend community day services or clubs, 22 people access education and 36 people are in employment, either voluntary or paid.

Community day services

52 people attended community day services, clubs and outreach projects attached to day centres but based in local community centres. Feedback on these day services was very positive. People felt that they offered more choice, flexibility and

opportunity, *“this gives us more choice with what we can do”*. Many said that they liked being out of the traditional day centre environment, *“it gets us out of the day centre”*.

Community Outreach Clubs (associated with day centres)

We spoke to three groups at outreach projects connected to day centres but based at centres within the local community, one of which provides social enterprise activities.

“There should be more clubs like this one. People with learning disabilities should have more opportunities in society and have their own say about what they do with their day”

These clubs are staffed by the day centre but most are charities that rely on fundraising to pay for extra costs. Some clubs are only open to people who attend the associated day centre and some are open to the wider community. Members of one project explained that their club was set up by people in a day centre almost 20 years ago because they felt they did not want to attend a typical day centre. Most people felt that they had more choice and independence at the club, *“we can make our own minds up, we make our own decisions”*. One group talked about committee meetings at the club, *“we talk about things that we have done, things that we would like to do in the future, we decide on new projects”*. Another group said that sitting on the club committee gave them more say over how they spend their day and helped them to work as a team, *“we get nominated by our members and supported by our peer group”*.

Feedback on the community outreach clubs was overwhelmingly positive. People from two clubs talked about different activities and workshops they enjoyed. At one club people said they liked activities such as weaving, circus skills, fitness and photography, *“we had our own exhibition”*. They also enjoyed workshops run by Belfast City Council on recycling and revamping furniture, a digital book reading club, gardening with the National Trust, the Women’s Information group which meets each

month to discuss women's issues and the Men's Group, so popular it currently has a waiting list. One club was particularly focused on artistic and creative projects such as story writing, singing workshops, fashion shows "*we design model and make our own clothes*" and arts and crafts, especially candle and card making "*we sell these for fundraising*". One of the most popular activities at this club was short film making, the group's own interpretations of films like *Ghost*, *The Sound of Music*, *Titanic*, *Ghostbusters* and *Jaws*. The group produced an award-winning version of Willy Wonka's Chocolate Factory, "*we won two awards ... we had to go to Rotterdam to get it, we also got money which we put back into the club for fundraising because we are a charity*". Everyone wanted to continue making films, "*we love it*".

People at both clubs also said that they enjoyed the company of friends and going out for walks and for lunch. Some people mentioned that they liked the change of atmosphere from the day centre and that the club was quieter than the centre. People also agreed that the club "*gets you out of the house*" and "*gives us something to look forward to*". The only negative point raised was in relation to funding. One group said that they would like more help with fundraising, "*we have lots of ideas about other things we would like to do but there is never enough money*". There was also a shortage of funds when it came to equipping the club, "*we would like some new equipment for our area at the club, we need a new table and flooring, we find it difficult to raise money for these sorts of things*".

The third group we spoke to were involved in social enterprise activities at their club. Feedback was very positive, "*we really like it*". People said they enjoyed different jobs such as folding and stamping letters, making address labels, making entry passes for the local racecourse, making up sachets of reindeer food, printing leaflets and business cards. While people enjoyed this work, everyone agreed that they would like more contracts because there were quiet days with little to do and everyone would prefer to be busy. Some people also said they enjoyed learning together and taking money matters and coin recognition classes. People identified this as a work placement and referred to the day centre or drop-in centre which some also attended as more like "social time".

We spoke to one group at a community day service in Whiterock and feedback was mostly positive. Most people felt that it was a very sociable environment, "*we have good fun here*", "*I enjoy being able to meet up with my friends*". People talked about the different activities they enjoyed there such as art, ceramics, computers, music, learning to cook, playing pool, making jewellery and doing other people's hair and nails. Most people also liked trips out to the library, charity shops, swimming, bowling, archery, rock climbing, golf and dining out. One person said that when at community day services, "*I like being able to do my own thing*". While some people mentioned activities they did not like, activities were timetabled in advance and people got to choose how they spent their time. Most people agreed "*there's nothing I don't enjoy*".

We spoke to 9 people who attended at the Junction club during the day and response was very positive. Most people said that there was "*nothing bad*" about the clubs and that they loved going there, "*it's good fun*". As with the community outreach clubs, some people liked having somewhere to go that was not a traditional day centre, one person said "*I'm not keen on day care. The drop-in centre breaks up the middle of the week*". People said they enjoyed a range of activities such as baking and computer classes at the local community centre, safety awareness sessions from the Police and Fire Service and from Disability Action, a healthy eating programme, flower arranging, arts and crafts, singing, drama and bingo. Most people said they also enjoyed going on trips organised by the drop-in centre. The only negative point made was about transport. People complained that the bus was always late, it was very expensive to use public transport to get to activities all the time and it was difficult to book Disability Action buses. Again, like the community outreach clubs, while members did organise their own fundraising events they still felt that lack of funding prevented them from taking part in some activities.

We spoke to 5 people at an employment training project. Everyone said they enjoyed the training opportunities and felt that there was a good selection of work and volunteering placements on offer through the project. Individuals said they enjoyed work placements in a café and a care home and some said that they would like to take part in more training schemes. One person felt that going to the

employment training project was a welcome change from the day centre, *“I go to get away from the day centre”*.

Day Centre (Training Resource Centre)

“I have lots of good friends at the day centre”

“It stops you going mad staring at the four walls”

“Staff say would you not give it a try – they encourage us”

110 people said they attended a day centre and the feedback was mostly positive. Over a third of those who responded said that there was nothing bad about the day centre, as one group said *“we really love it here”*. Most people talked about the activities they enjoyed such as games, gardening, cookery, drama, dance, art and watching DVDs. Some people enjoyed sports like archery, armchair aerobics and pool, while others enjoyed yoga, aromatherapy, the multisensory room and pampering sessions. Many people enjoyed music and one person talked about being in the day centre’s band. Groups from different centres talked about computer classes at the local library and community centre, a newspaper group, a communication group for men and project work – one group talked about a project on famous people from Northern Ireland they were currently putting together. Many people said that trips out of the centre were a favourite activity; swimming, shopping, walks, bowling, going out for lunch or coffee and trips to the seaside. One person said the highlight of each month was having a *“chippy day”* at the centre.

A group with profound learning disabilities from one centre said that they enjoyed activities that helped them express themselves because *“we sometimes have problems getting our points across”*. They liked using makaton, trying fun ways of learning and remembering it, music therapy and singing, *“we show each other and staff that we are happy by singing, taking part in our activities and coming to the centre each day”*. The group said they also enjoyed cookery, especially tasting different foods they would not get at home

Most people mentioned meeting friends and having people to talk to as one of the best things about coming to the day centre, *“I like it because I have friends here”*. Many people also talked about how much they liked the staff, *“the staff are easy to talk to”, “staff help us very much so, they are very helpful”*. Many people said that they liked doing errands for staff and helping out around the centre with jobs such as photocopying, shredding, typing and writing letters. Some people said they liked coming to the day centre because it got them out of the house and kept them busy and others said it was good fun and that they enjoyed the variety. Some people also talked about attending user groups and having meetings in the centre, *“this enables us to have our say”*.

“Day centres should only be for people that need it”

“Stop putting young people in day centres”

There were some negative comments about the day centre. Some people felt that opportunities were limited. A few people said that there were not enough activities or options, *“I would like other things to do”*. One person felt that *“things are organised for you at the day centre, you can’t do what you want to do”*.

A few people now at a club but with previous experience of a day centre shared their feelings on day care, *“being treated like kids”, “being stuck inside”, “having minimal opportunities”* and *“not being able to do things for ourselves”*. Another person agreed that people were given little responsibility or stimulation at the day centre; they felt that the centre only offered nursery or primary school activities and that people just did whatever was set down in front of them. One person who spent ten years at a day centre did not like it at all and felt much happier now that they went to local clubs and groups during the week.

Some people mentioned more practical issues such as staff shortages and lack of transport as having a negative impact on their day, *“there is no staff, when staff leave the room to toilet someone there is no one left to supervise our group”, “sometimes our outings can’t go ahead, this makes us sad”, “there is not enough*

transport to get us out and about". Some people complained that the day centre could be very noisy at times, that there were too many people and a few people said how much they disliked people fighting in the corridors and on the bus.

Education

"I like the work that I do at college, we do reading and writing"

"It made me aware of things I wouldn't normally be aware of"

"You have to do the same things over and over – I would rather do something more interesting"

22 people spoken to currently attend a course at college and most people responded positively about this experience. Many people said they liked everything about college, especially working hard and learning new things. One person said they hoped that the course would train them for employment and they could get a job when it is finished. Many talked about meeting new friends at college and meeting other people in the community. Some said that teaching staff were friendly and helpful, *"tutors are dead on, they talk to you, not at you. They wouldn't walk past you, they stop and speak"*. One person hoped that being a student would help widen their experience of life.

There were some negative comments about college. A few felt that there was not enough choice of courses and that the same things were always offered. They would like more variety and the option to do something different. Two people felt that some courses were too easy and said that they would like something more challenging. A few voiced their individual concerns about college; one person felt that the college was too far away and the journey too long, another felt that college was too noisy, one did not like having to pay for additional courses and one felt he would rather be at university. There were also some issues around college providing for care needs; one wheelchair user felt that the doors at college were too small and that there were too many ramps at the main entrance and another person with a visual impairment had to leave his course because the dark room prevented him from working properly. One group said that they would like more input into the

courses provided for people with a learning disability at college, *“we would also like a say in college courses to improve our choice”*.

Some people said they had previously attended college but that their courses were now finished, *“I got qualifications and certificates. I did all that I can”*. No further courses were offered and people did not want to do the same courses over again.

Employment

“Work is a nice change, it adds variety”

“We would like to get paid for our jobs the same as everyone else”

“I would like to get paid, but I don’t get paid because I know it will muck up my benefits. It is slave labour”

“People can get a job if they want one”

36 people spoken to were currently in employment and the majority said that they really enjoyed their work. A lot of people in the Belfast area had their work placements organised through the Orchardville Society. Most people said they enjoyed the work itself and a few people said that working was *“good fun”*. Many said that they liked to keep busy and that work *“gets you out of the house”* and *“gives you something to do”*. Many others said that they liked meeting people at work, helping people, serving and talking to customers. Some said that they liked the other staff and a few mentioned that they liked getting paid. One person said that they enjoyed going to their job because at work they were *“treated as an equal”*.

However, not getting paid was a big issue for people, *“we would like to get paid for our jobs the same as everyone else, we work just as hard and we don’t see why we should work for less money”*. Some people talked about the impact of paid employment on benefits, *“I get paid but with benefits they give it in one hand and take it out the other. What we do for nothing we are putting money into their pockets”*. A few people with jobs said that they would like to work more hours but again the impact of this on benefits was a concern. Some people felt that work opportunities were limited and that people with a learning disability had little choice

of placements. A few people expressed fear that they were going to lose their work placements and two had already been notified that their placements might not continue, “*we don’t know what we are going to do if that happens, we know that we don’t want to go back to the day centre every day*”. One person said that while he liked his job “*half and half*” he felt that he was not being treated as an equal at work.

“I don’t like it because I got told off about smoking. I think I am discriminated, this is bullying. Everyone else can go out and smoke but I can’t. I’m left out”.

Do you enjoy what you do during the day?

The overwhelming majority of those who responded said that they were happy with their day and felt that they would not like to change anything.

However, when further questioned some people did identify different things they would like to try. Many people said they would like a work placement or to be in supported employment. People mentioned work in an office, hairdressers, Post Office, with children or with animals as something they would like to try. A few people said they would like paid employment and others said they would like to work more hours. Some people said they would like more choice, whether in relation to work placements, college courses or the activities they do each day. One person was particularly vocal about the lack of opportunities open to people with a learning disability. He attended college one day and spent the rest of his week at home, having left the day centre because there were too many people and not enough choice of interesting things to do. He had since failed to find anything suitable to fill these days but would like to be at college more and working towards getting a job.

A few people said that they would like more independence, to travel independently or look after money independently. A few wheelchair users at day centres said that they would prefer to go to the associated community outreach centre but the club

does not cater for their care needs. This was particularly frustrating for one wheelchair user who had previously attended a club before their needs changed and they really miss this outlet now they are back in the day centre. A few people at day centres said that they had been going there a long time and would like to try something new. One group at a day centre said that they would like to “*run the centre ourselves!*”

The need for more information about day opportunities for people with a learning disability is very evident. Many people felt they would like to try something new but they did not know what was available to them or what they could access within their local community. For example, one group said that they did not want to try anything different but if they were informed about new things then they might be interested in trying them. Some individuals also felt that they would like to try something different but could not identify what, as one person said “*not sure what I would like to do but I would like to do something different*”.

Do you get the extra help/support you need to do what you want to do?

Most people agreed that they get the help and support they needed from staff the day services they attend, “*the staff, they’re very good*”. One group identified day support staff, the social worker, friends and family as their support network and this was reflective of responses as a whole.

There were some individual concerns raised. One group felt that the employment training project offered a good selection of training and work placements but beyond this there were very few options and you were left to research your own options. One person said that they could not talk to anyone about their options because their social worker was off sick and had never been replaced and another person agreed that they do not see their social worker enough, only once a year. One person shared that he was the main carer for his elderly father. The wheelchair users who were prevented from attending community outreach clubs because of their personal care needs also raised issues about getting the extra support they needed to do

what they wanted to do. One group with more profound disabilities identified that they would like more sessions with the Speech and Language Therapist.

One person expressed uncertainty about the future now that they were getting older. They did not know what services or what support would be available to them and feared that they would be at home on their own and would become very lonely.

Do you get to choose where you go and what you do during the day?

Most people felt that they had some degree of choice over their day but this was almost always in reference to choice of what activities they did when at a particular day service rather than choice of where they actually went during the day.

Most people in day centres felt that, with help from support staff, the group could decide on activities and the option not to take part was always open, "*you are asked do you want to do it, not made as such*". Most felt that there was a good choice of activities in the centre and that options were always discussed, "*we use working tools, what works and what doesn't, and find solutions*".

Only a few people talked about having a choice in where they went during the day. Two people said that they discussed different day care options with their social worker and were given a choice of different day centres to attend. One person felt that they had no choice in where they go during the day; they spent part of the week in a day centre but did not understand why they were there, they said it had never been explained to them.

People felt that they had more choice at community day services, outreach clubs associated with day centres and drop-in clubs. One group said that the drop-in club "*gets us out of the centre*" and "*gives us more choice with what we can do*". This group said they make decisions together then make a timetable for each week and they agreed that if there was something new they wanted to try they would inform staff who would look at ways they could incorporate it into their day. When lots of different people wanted to do different activities it was put to a vote. Some people

also sat on the club committee which they felt gave them more say. A group from an outreach club associated with a day centre also said that they held committee meetings, *“we talk about things that we have done, things that we would like to do in the future and decide on new projects”*. At an outreach club which focuses on social enterprise activities, people said they had no choice in what they did because this was a work placement, but they identified that they had more choice in the drop-in or day centre because this was “social time” not work. Again this relates to choice of activities when at a particular day centre but not choice as to what day opportunities to attend.

It was clear that people like to be involved in decision-making processes and in setting the timetable for their day, but there was little to suggest that people felt they were actively involved in choosing what day opportunities they took part in or where they went during the week.

Views of Parents and Carers

Parents agreed that balance is important; ideally most would like their family member to have a varied week between college, work training and work placements.

However, some parents felt there was a lack of opportunities for people with a learning disability and one parent suggested that the views of parents on day opportunities were not listened to or taken forward. Some parents also felt that there was little flexibility with the options that were available and that if a placement did not work out it could be difficult to arrange a more suitable option.

Many parents had issues with the work placements available to people with a learning disability. One group of parents and carers suggested that more businesses should be encouraged to offer work placements, even if it was just a few hours each week, and that tax breaks and other incentives should be introduced to facilitate this. One parent made the point that money is important to people with a learning disability too and that good money management skills and proper careers training were essential. One parent suggested that more information on

Employment Support Allowance, which would allow people to work up to 16 hours per week, would encourage more people to look for work placements.

Parents agreed that there was a lack of information in general, "*there is a real information gap in terms of what day opportunities are available*". One person suggested that a file from a social worker with a comprehensive list of options should be handed out to every family. One group of parents agreed that if it was not for the Orchardville Society and speaking with other families you would never find out about any opportunities. These parents felt that they were "clinging" to Orchardville. Parents of children soon to leave school expressed some "*immense fears*" about the post-school opportunities available and felt there was a lack of communication regarding options, "*it is up to the parents to find and fight for day opportunities*". Some parents also felt that there was very little information on the availability of benefits, direct payments and carers' premium.

Some parents agreed that, even if college or work placements were arranged, transport could still be a major problem. They felt that the 'Door2door' transport service could be a good resource but that it needed more drivers and funding in order to be fully effective. One group of parents agreed that more independent travel training was needed. One parent said that transport and a lack of social opportunities big issues for people with learning disability

Parents felt that the gap between child services and adult services was "*huge*". Post 19 options were described as an "*absolute disaster*".

Key Points:

- **The overwhelming majority of people were happy with how they spent their day and would not change anything;**
- **People were very positive about community day services, clubs and outreach projects where they had more choice, flexibility and independence;**

- **Many people said they liked being outside the traditional day centres;**
- **Feedback about day centres was mostly positive but concerns included staff shortages, transport issues, feeling opportunities were limited and not being able to do things for themselves;**
- **People like to work but unpaid employment, the impact of pay on benefits and the desire to work more hours are issues for many;**
- **Not enough choice of college courses;**
- **People like being involved in making decisions about the activities they do each day;**
- **People need more information about opportunities available to people with a learning disability within their local area;**
- **Parents feel that there is a lack of opportunities for people with a learning disability, especially in relation to work placements and little flexibility of arrangements;**
- **Parents said there is a lack of communication about what options are available;**

3.5 Southern Health and Social Care Trust Area

The Southern Health and Social Care Trust (Southern Trust) provides health and social care services to the council areas of Armagh, Banbridge, Craigavon, Dungannon and South Tyrone, and Newry and Mourne. It spends £1.18million per day delivering services to 334,000 local people. The Trust employs approximately 12,000 staff, 77 per cent of whom provide direct care to patients and clients.

3.5.1 Current Provision for people with a learning disability

This section 3.5.1 details the current provision of day services including 'day opportunities' provided by the Southern Trust for people with a learning disability. This information has been provided to the Bamford Monitoring group by the Southern Trust.

Day Care (facility based)

There are currently ten Day Care facilities within the Southern Trust registered with RQIA to provide Day Care for up to 511 adults with a Learning Disability per day.

Table 7: Southern Health and Social Care Trust Day Care Facilities

Day Care Facility	Number of places
Eden Social Education Centre, Portadown	44
Banbridge Social Education Centre	35
Banvale Social Education Centre, Gilford	90
Windsor Day Centre, Newry	40
Crossmaglen Social Education Centre	24
The Laurels Day Centre, Newry	75
Oakridge Social Education Centre, Dungannon	71
Appleby Social Education Centre, Armagh	105
Coalisland Social Education Centre	12
Aughnacloy Social Education Centre	15

The Southern Trust state that a number of significant changes have taken place within Day Care over recent times, these include;

- 1) Registration with the Regulation and Quality Improvement Authority (RQIA);
- 2) Each Day Care centre has a clearly defined statement of purpose;
- 3) Only clients whose needs can not be met within the community are now eligible to attend Day Care;
- 4) Day Care Centre activity now focuses on meeting the needs of clients with high levels of complexity;
- 5) Development of staff expertise in response to emerging complex and high dependency need;
- 6) Person-centred ethos is applied;
- 7) A significant number of “traditional” Day Care attendees have transferred to more appropriate services within the community.

Day services (community based)

Community Access, There are currently three Community Access officers employed to work with adults with a Learning Disability across the Trust, the aim of this service is to;

- 1) Empower the individual so that he/she is able to access and participate in activities independently;
- 2) To participate in a Person Centred Planning approach with clients in assessing, identifying and pursuing individual goals;
- 3) To plan, implement and review appropriate supports to meet client needs and to withdraw supports when no longer required;
- 4) To liaise with other community services and agencies including education/training, social and leisure opportunities and where appropriate work collaboratively.

In June 2009 there were 112 individuals availing of the Community Access service, by June 2011 this had grown to 167.

Day Opportunities, within this scheme sixteen staff enable clients to attend activities within their own communities. Activities are supported by Trust staff and based on assessed need. Activities currently include; conservation work, gym sessions, access to college courses, pottery, information technology, animal husbandry, horticulture, catering.

In June 2009 there were 48 individuals availing of Day Opportunities, by June 2011 this had grown to 267.

Summary:

- Day Care (facility based) is no longer seen as the only option to meet the needs of adults with a Learning Disability.
- The Trust is working towards having only those who need to attend a facility based service actually doing so.
- A range of alternatives have and will continue to be developed within the community to form a comprehensive menu of choice.
- The evolving progress within Day Services has afforded adults with Learning Disability opportunities to gain real life experience in their own community.
- Upwards of 434 clients have been afforded real and meaningful opportunities to be integrated within their own communities.
- A high percentage of this 434 were actual or potential Day Centre attendees.

3.5.2 What people said...

In total 138 people with a learning disability and 7 parents and carers shared their views and experiences of day services and day opportunities in the Southern Health and Social Trust Area.

People with a learning disability told us about their day activities. Some people do more than one activity in each week; 92 people attend a day centre, 49 people access education outside the day centre and 17 people are in employment, either

voluntary or paid. We also spoke to 38 people who take part in a range of day opportunity groups, taking part in activities such as music, sports, arts and crafts and gender discussion groups.

Day Opportunities

“All the activities are great”

“Socialising”

“Working is good – I have plenty to do, it passes the day”

38 people we spoke to attend a range of day opportunity groups and projects, many of which focus on particular activities such as music, sports, art and conservation.

One group described the day opportunities they take part in during the week, which includes activities such as arts and crafts, pottery, gardening, sports, walking and looking after animals. Everyone agreed that they enjoyed these activities; they shared that staff were nice, everyone worked as a team and they all looked after one another. A few members of this group previously worked, one came straight from school and a few people were at the day centre and the group shared that they liked day opportunities better than what they were doing before. While this was true for everyone in the group, one person did share some rather negative experiences of the move from the day centre to day opportunities, *“I’m not too happy about the way they done it, they didn’t explain to us, two ladies just told us – there were no apologies. I like it here now”*.

Members described some of the work they do at the arts and crafts group, *“we learn about 2D and 3D. The tutor took a lot of time explaining. We are making all different things”*, *“we go a walk in the park and look at different sculptures and copy them”*. A few people from this group also take part in a Conservation Group one day each week where they make paths in the forest, build seats, fix hedges, make willow sculptures and build plant beds, as one person shared *“I love getting out every day, getting messed up”*.

Two men who take part in a sports group each week described how they go for walks in the morning and get golf tutorials in the afternoon. One person also attends the conservation group; he liked both groups, especially as they are both outdoors. He enjoyed doing a variety of activities and feels he has made good friends through day opportunities. The other man agreed that he had made new friends at the sports group.

People at the music group talked about the range of activities they take part in such as singing, playing instruments, recording music and learning about rhythm, time and pitch. Everyone agreed that they really enjoy it, *“this group rocks, it’s ace”, “the experience helps you and the amount of stuff you learn is amazing”*. One person shared how much they like spending time with the other people at music group *“we are one big happy family, we are here with friends”*.

Some women from a gender group described what the group was all about, *“it’s a girl thing”, “we are looking at the female, equal rights, history, the division of men and women”, “we learn about women’s rights”, “we learn about our own lives and how we feel”, “we do about self-esteem and confidence”*. Some members also attend an arts group where they *“do trouble and peace murals”* and jewellery making. Everyone shared that they liked coming to the gender group; one lady who is a carer for three children with learning disabilities and behavioural problems said that she heard about the group through her social worker:

“I like everything and anything really. We do stuff about how you feel, art work and about yourself. I like it, it gets me out of the house and I get mixing with friends. I need the break”

Some people at these groups talked about their previous experiences of day care and all agreed that they prefer taking part in the day opportunity groups. One group shared some thoughts on what it was like to be out of the centre and involved in day opportunities; *“I’m happy and relieved”, “I didn’t like [the centre]. There was too*

much noise and too much shouting. You were told what to do and didn't have the time to talk to your friends", "there was nothing to do, you just sit there all day", "I'm not happy there at all, I don't want to go there anymore". A member of the Sports Group explained that this was the only day opportunity group he attends, the rest of his week was still spent in the day centre. He explained that he was unhappy at the day centre, *"I'm far happier out at these groups ... it is far better".* This person had previously worked and he felt there was nothing to do in the day centre, *"I just smoke all day. I have asthma and shouldn't even be smoking but there is nothing else to do. I don't smoke half as much when I'm not there".* He had explained the situation to his social worker who is now helping him *"get out"* of the day centre.

Day Centre (Social Education Centre)

"There are lots of activities to do"

"Staff work so hard to look after us, they are brill, fantastic"

"I would cry my eyes out if I couldn't come"

92 people said they attended a day centre and the majority of those had positive things to say, *"I love it here", "the craic is good", "I have no enemies here".* Most people talked about the activities they like to do at the centre. These could be creative such as arts and crafts, storytelling, crochet, nail painting, dancing and music, or sporting activities such as bocca, football, skittles and exercising. Some people liked working with their hands at woodwork and gardening and others enjoyed more relaxing activities like yoga, the relaxation room, watching TV and having tea. One person said they prefer peace and quiet and love being able to sit in a quiet room at the centre and listen to audio books. Some people enjoyed reading, writing, word searches, watching the news, current affairs, communication skills and discussion groups, such as those at one centre in which people planned the week ahead and talked about what they did at the weekend. Many people also said they enjoy trips out of the centre, to the library, walking, shopping and going out for meals as a group.

One of the most important aspects of coming to the day centre for many was socialising, company and friendships; people said they enjoyed *“talking”*. Staff support was also central to people’s positive experience of day care, *“the staff do a great job”*, *“you can talk to staff here”*. Some people talked about how much they liked helping staff around the centre, cleaning, setting tables, doing the door and greeting people. For a few, coming to the day centre was a nice change from being at home, *“its gets you out of the house”*, *“you would be bored at home”*. One group who used to be in a large day centre but were now in an associated satellite centre within their own community said they preferred the smaller centre and enjoyed being back in their local area, *“we wanted to be in Coalisland, we wanted to come here”*, *“we know Coalisland, its familiar”*, *“its quieter here”*.

“We miss outings – we don’t have as many anymore”

“We would like for them to get more staff. We have low staff. We want to do things and don’t get to because there’s not enough staff”

Some groups and individuals did raise a few issues about the day centre. One group said they would generally like to be more active, to have more activities, to go to the leisure centre and swimming again and to play their musical instruments more often. One person added that they would like to go out more as a group, possibly once a month for coffee. Another group identified things that had changed within the last year that they were not happy about, for example they felt they no longer went on as many outings and they listed activities they no longer do such as walking, golf, canoeing, swimming and shopping. One group also shared that they were *“angry”* that some activities had been removed from their schedule, such as swimming and having their hair done by a hairdresser in the centre, especially as they had paid for these activities themselves. Some people identified staff shortages as another problem, *“we want to do things and don’t get to because there’s not enough staff”*, *“it’s not staff fault. It’s funding. The staff try to do everything”*. A few people felt that the day centre could be too noisy at times, *“it is sometimes too noisy, some people are too rowdy, I prefer peace and quiet”*. Another person said they would like to be paid for the contract work they carry out at the centre. One person who used to go

to a day centre said they left because there were too many people and the games they did were “silly”. One person who currently attends college said that they did not want to go to a day centre but felt people were encouraging this move, “they keep showing me around a day centre but I don’t want to go”.

Education

“We learn new things everyday”

“I really, really enjoy it ... I like learning how to use the computer and do different tasks ... I go along with anything. It takes me out of the house and gives me something to do”

49 people were currently in a course of education and almost everyone responded positively about their experiences of this, “it’s friendly”, “we enjoy it”, “I have a good time”. People liked learning new things, working on computers, writing, cookery and life skills classes. Many felt that the tutors were “good, kind and helpful” and many said they liked seeing friends and meeting new people at college, “I like the company and friendship”. One person said they like getting certificates. Another said that they had to go to college, “I have to go ... it’s my sister’s orders” but added, “I like it, I’m happy”.

There were very few negative comments about college and education. A group from one centre said that some college courses had recently been stopped and they were not happy about this. One person requested more computer courses and more training.

Employment

“I love it. I love seeing other workers. It helps me be more independent”

“I’ve been working there years. I like talking to people and if they are looking help I help them”

17 people spoken to were currently in employment. Most people really liked their work, as one person who works as a gardener said *“I love it, it’s like my second home, I’m part of the furniture”*. Some people particularly liked helping people and talking to customers, *“I like meeting and getting friendly with people. I like helping ladies, I don’t let them lift anything too heavy”, “I like everything ... talking to people ... serving dinner to customers”*. One person who volunteers for a charitable organisation as a bus escort said they loved helping elderly people and those who could not look after themselves. Some people said they liked their colleagues, a few enjoyed the variety at work and one person said they liked getting paid at the end of the month.

“Pathways told me to get a job but everybody wants free labour. If you ask employers for money you are told to go away, to get lost”

While most people liked their work, some people did raise issues of pay and hours. Four people who loved their work admitted that they would like to get paid more, as one person explained *“I don’t get much, I get buttons, £9.20 a week”*. One person complained that they did not get enough hours and another said that their hours had recently been cut. Two people shared bad experiences of previous work placements; one person said of their old workplace *“I didn’t really like it, people telling you what to do, using you”* and another said of their previous colleagues, *“there were the biggest gangsters ever. The staff were nasty and ignorant and scared me”*.

Do you enjoy what you do during the day?

Most people said that they were happy with their day. However, some did identify different things that they would like to try. A few said they would like to get a job; mechanical work with cars, a job in a music shop and being a DJ were mentioned as work people would like to try. One person said they wanted to study childcare so that they could work with children but they were turned down for this course because

of their learning disability. Individuals mentioned that they would like to work more with computers and try new sports like tennis or badminton.

Do you get the extra help/support you need to do what you want to do?

Most people felt that they had a good support network. One group identified support staff, the social worker, parents, family and friends as sources of support and this was typical. Many people in day centres talked about the help they receive from staff, *“we talk to staff, they listen to what we say”* and a few felt that their social worker was a *“good help”*.

However, a few people shared the difficulties they faced getting access to day opportunities. One person felt she had little support at first, *“nobody had time for me. I was trying but they were just talking about me. Mum tried for ages to sort things out. A woman came out to the house and we had a meeting, she was really nice”*. Another person agreed that it took a long time to get access to any opportunities, *“I was sitting in the house for two years getting really down. It was discrimination no matter what way you look at it. Everyone should be treated like everyone else”*.

One person was very vocal about the difficulties involved in accessing opportunities and about the lack of support available, *“if you have a learning disability no matter what type, unless you have someone to fight your corner you have no chance. I done so many courses and went to jobs and benefits and the careers officer and it was all worth nothing”*.

Do you get to choose where you go and what you do during the day?

One group felt that day opportunities were a big change from the day centre, especially when it came to having your say. They shared some of their thoughts as to why; *“we do our own thing”*, *“at the day centre we had to talk about it, instead of staff just letting us do it. We couldn’t do anything without permission”*, *“this is completely different, you are let do what you want to, you ask and you are told to go ahead”*.

Most people felt that they had a good choice of things to do during the week when at the day centre, but few could remember if they had a choice about coming to the day centre in the first place because it was such a long time ago. Many people talked about advocacy and discussion groups they attended and identified these as forums for having their say. One group said that they have a “*funky team*” meeting once a month with a group from another centre, “*people come*”, “*we discuss different things*”, “*we discuss what we are happy with and not*”. This group also had a “Workers Party” at their centre where “*we say how we feel*” and “*we talk about different activities*”. A group from another day centre said they have an advocacy group called “Movers and Shakers” that meets once every two months. This group also felt that they could talk to staff about what they do and they felt that staff do listen. People from one day centre described how once a fortnight a committee made up of members from each group within the centre get together to talk about the centre and to organise outings and coffee mornings.

Views of Parents and Carers

One parent felt that “*things haven’t changed in 14 years*”. Their son still spends all week in a day centre. While this parent said the day centre provides a good level of care and does the best with the resources it has, they felt that there were very few activities on offer and people spent too much time in the “quiet room” relaxing instead of using up energy. This parent said that “*apathy*” had set in and felt that there was “*nothing out there*”. They said that there was a long way to go before there are real alternatives to day care.

Another parent said that their son likes the day centre he attends, especially cookery and looking after a friend in the centre who has more complex needs. However, they said their son would love to get a job or take a cookery course at college; they felt that with the appropriate supervision their son could do so much more.

Several parents highlighted the need for individual person centred planning; one parent felt their son was “*stuck*” in with people who have more complex needs in an environment where young and old were just “*thrown in together*”.

One parent whose daughter has complex needs said that they would be happy with a day care placement but that other young people should be given a more structured plan of activities. Another parent agreed that it is “*not a one size fits all*”, it should be about the people with the disability not the criteria.

One parent described how much their daughter enjoys their work, that it “*gives her a reason to get up in the morning*”, the staff are good to her and she gets to meet different people. They felt that their daughter was “*capable of more than manual work*” and that she prefers the clerical work placement that she has.

A parent suggested that transport can be an issue when it comes to accessing day opportunities.

Some parents wanted more clarification on the position of autism within Bamford. They felt that autism was not provided for unless the person also has a learning disability. One parent went further to describe her personal experiences of this issue. Her son has a learning disability and autism but because he is in a group focusing on his learning disability rather than one specifically for people with autism she felt that he was falling between programmes. She said that they have found it difficult to find suitable day opportunities because of her son’s autism and she felt that he was pushed “*from here to there*”. Her son currently spends a few hours each week at work, one morning at college and two days in the day centre, but she said that, apart from work, he is “*not being stretched*” by his day activities and she felt that “*he is not getting a lot out of life at the moment*”. This parent felt that her son’s specific needs were not being met and that there should be alternatives especially geared for autistic people. She described her son’s situation as being like “*one different sort of fish in a pool with a shoal of other fish*”.

One person said that their daughter was just about to leave school and that they were finding the transition process difficult, even though they had “*wanted to be the first person going through transition without cracking up*”. They felt that nothing happens automatically, there is no fixed path to follow and that they had to personally push for their daughter. They also questioned how parents can access

information about day opportunities if they do not attend the meetings at school. This parent felt that the transition process was so much clearer for children without a learning disability. One parent suggested that the transition process after school can affect families more than the initial diagnosis of learning disability. They said that parents were very wary of day services and they felt that schools provide a high level of care which is not continued through to adult day services.

Other Issues:

Separate Mental Health and Learning Disability – put learning disability under disability “*where it rightfully belongs*”.

One group of parents said “*Bamford was a lie*”. Parents and carers views were not listened to, their voice was not heard. Bamford groups were over-represented by professionals, that they listened more to voluntary and community organisations than the actual parents, carers and people with a learning disability.

Key Points:

- **Most people said they were happy with how they spent their day;**
- **People felt they had more independence, responsibility and choice at day opportunities and it was better than what they were doing before;**
- **There were concerns raised about accessing day opportunities. Some people described how difficult they found it to get involved and to get the support necessary to access opportunities;**
- **Feedback on college experience was overwhelmingly positive;**
- **People like to work but some did raise issues about poor pay and limited hours;**
- **Majority of people had positive things to say about day centres, but were concerned about a reduction in outings from the centre, reduced activities and staff shortages;**
- **Parents highlighted the need for person-centred planning, not a ‘one size**

fits all' approach;

- **Parents suggested there was a need for more information about day opportunities available, particularly during transition.**

4.0 Conclusions

The majority of people with a learning disability said that they were very happy with how they spent their day and whilst they raised some issues and concerns they had many positive things to say about both day care services and 'day opportunities'.

That said, it appears that **'day opportunities' offer people with a learning disability greater choice, flexibility and independence**. People really value having a variety of activities to do and places to go each day, and those who mixed their week had the most positive experiences.

People with a learning disability want to be independent, part of which is being able to make their own decisions and choices about their lives. The majority of people said that they have some choice in their day. However, in most circumstances, people with a learning disability were only able to identify that they had choice in what activities they did at a centre or place where they spent their day, but few mentioned having a choice about which centre or place they went to.

Having **real choice** means knowing the range of day opportunities that are available locally and being able to choose what they want to do. This **does not seem to be the experience of most people with a learning disability we spoke to**. Yes, people with a learning disability were mostly very happy with how they spent their day, but we need to be sure that this is because they are doing what they really want to, rather than being happy with what they've got because they don't know the alternative.

Flexibility is also highly important and people with a learning disability to be able to try, test and see if the options available meet their needs. One person we spoke to describes this perfectly, *"you don't know if you like something until you've tried it"*. Change is not easy for people with a learning disability, and it is often a difficult process. However, people with a learning disability can identify what they want to

do, but they do need good information, support and advice to get there – person centred planning.

In some areas, people were more able to talk about what has changed in relation to day opportunities, and could readily identify what they used to do compared with what they do now. This gives evidence that there have been changes in recent years to expand and offer a greater range of day opportunities.

However, there were several key themes emerging from the feedback from people with a learning disability as well as parents and carers which are important to draw attention to.

- There is an urgent need to fill the '**information gap**' regarding day opportunities and day care services. On many occasions people with a learning disability, parents, carers and family members said they were not aware of what options are available in their local area;
- People with a learning disability really enjoy college, however a common concern was the **lack of new educational courses**;
- Working and **paid employment** are very important to people with a learning disability, parents and carers. People without a job frequently said they would like to work, and those with a job said they would like to work more hours;
- Some felt that job opportunities available to people with a learning disability were limited. However, people were concerned that being paid and working more hours would **affect benefits**;
- Many parents we spoke to were extremely concerned about the future, particularly the **transition** from children's services to adult learning disability services. Planning and preparation for next steps after school and information on the options open to their children was essential, "*the future is around the corner*";

- Parents said that **access to key services** such as speech and language therapy and occupational therapy was problematic; this needed to improve;
- People with a learning disability and parents both stated that they were concerned about staffing levels, transport and the reduction in the number of outings from day centres;
- There is a clear call for a **person-centred approach** to day care services and day opportunities, planning around the needs of the individual;
- **Advocacy** groups and opportunities for people with a learning disability, parents and carers to share their views, get involved and contribute to decision-making about their services are important to them.
- Parents felt there was a lack of opportunities for people with **severe and profound disabilities** and those with **challenging behaviour**. A further piece of work is required to specifically focus on gathering the views and experiences of individuals, parents, carers and family members regarding the provision for and needs of this group.

5.0 Recommendations

The Bamford Monitoring Group plans to undertake a further study to capture the views and experiences of people with profound learning disabilities, including those with challenging behaviours. In addition, the Bamford Monitoring Group recommends that the following actions are taken to address the issues raised in this report:

- The Department of Health, Social Services and Public Safety should further develop day services and day opportunities regionally.
- The Department of Health, Social Services and Public Safety should work in collaboration with government departments delivering the Bamford Vision action plan to identify a clear post-school pathway for people with a learning disability including all the options for education, training, work and leisure that are available.
- The Department of Health, Social Services and Public Safety should work in collaboration with the Department of Education to ensure there is a clear pathway and early initiation of transition planning.
- The Health and Social Care Board and the Health and Social Care Trusts should develop information and advice service regarding day opportunities and day care services provided for people with a learning disability in Northern Ireland.
- The Health and Social Care Trusts should develop advocacy groups for people with learning disability and create a means to regularly involve and communicate with parents and carers.
- The Department of Health, Social Services and Public Safety should liaise with the Department for Employment and Learning to take steps to involve people with a learning disability in developing a range of new further education courses for people with a learning disability, that maintain a focus towards preparation for work, independent living and some leisure options.

- The Department of Health, Social Services and Public Safety should liaise with the Department for Employment and Learning to create job opportunities for people with a learning disability.
- The Department of Health, Social Services and Public Safety should liaise with the Department for Social Development to address the concerns raised in this report in relation to paid work and benefits for people with a learning disability.

6.0 References

DHSSPS (2009) **Delivering the Bamford Vision: The response of Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability. Action plan 2009 – 2011.** Belfast: DHSSPS (October 2009).

DHSSPS (2005) **Equal Lives: Review of Policy and Services for People With a Learning Disability in Northern Ireland.** Belfast: DHSSPS (September 2005).

Word List

Day Centre

There are a number of different terms used to describe day centres across the Health and Social Care Trust areas.

These are as follows; Training Resource Centre (TRC), Assessment and Resource Centre (ARC), Social Education Centre (SEC), Elderly Resource Centre (ERC), Adult Centre or Day Centre.

These terms may be referred to throughout the report.

Social Enterprise

Social firms designed as employment progression opportunities for people with a learning disability

The Base

Drop-in centre in the Northern Health and Social Care Trust

PSD

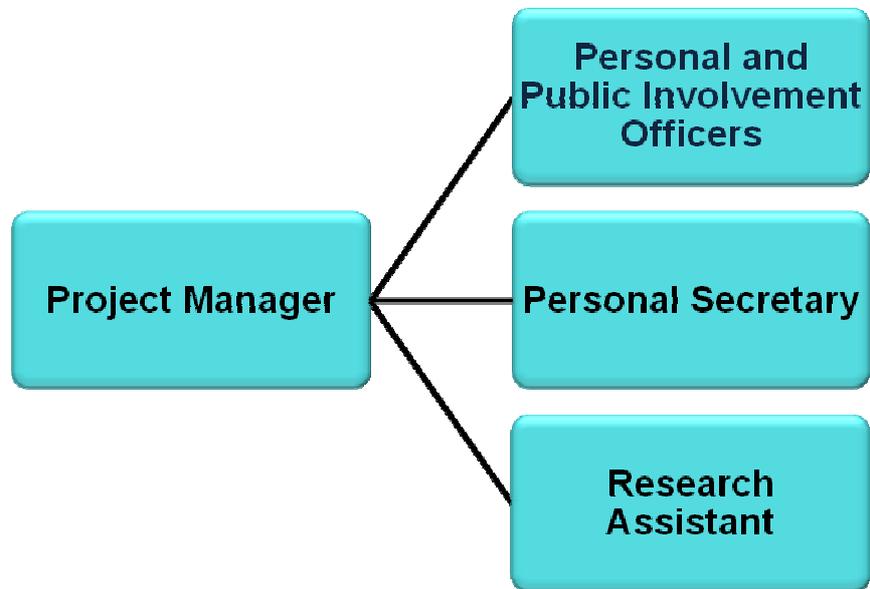
Personal and Social Development

ASDAN

Award Scheme Development and Accreditation
Network personal development course

Appendix 1 – Bamford Monitoring Project Team

The structure of the Bamford Monitoring Group Project Team is as follows:



Appendix 2 – List of Groups Visited Across Northern Ireland

Groups visited in the Belfast Health and Social Care Trust Area:

Group Name
174 Trust
Edgecumbe TRC
Edging Out
Everton TRC
Extending Choice Club
Fallswater Day Centre
Fortwilliam Day Centre
Mount Oriel Day Centre
NOW, Springfield Road
Orchardville Society
Orchardville TRC
Skyways Club
Suffolk Adult Centre
The Junction Club
Whiterock Community Day Services

Groups visited in the Northern Health and Social Care Trust Area:

Group Name
Alternative Angles
Antrim Adult Centre
Carrick Senior Gateway Club
Cookstown Adult Centre
Drumross Adult Centre
George Sloan Centre
Larne Adult Centre
Magherafelt Adult Centre
Millbrook Adult Centre
Mounfern Adult Centre
Rathmoyle Adult Centre
The Base, Antrim
The Base, Ballycastle
The Base, Ballyclare
The Base, Ballymoney (Compass)
The Base, Cookstown
The Base, Magherafelt
The Base, Newtownabbey
Voices for Choices Group

Groups visited in the South Eastern Health and Social Care Trust Area:

Group Name
Ards TRC advocacy group
Balloo TRC advocacy group
Carers Forum on Disability
Down Residential Project
Lisburn ARC
Lisburn YMCA
Mountview Day centre
Positive Futures, Bangor
Praxis, Conlig
Prospects, Bangor
Ravara TRC
Stepping Stones
Stepping Stones
The Beeches, Aghalee
TILI, Bangor
TILI, Lisburn

Groups visited in the Southern Health and Social Care Trust Area:

Group Name
Banbridge Social Education Centre
Coalisland Day Centre
Crossmaglen Social Education Centre
Dungannon Arts & Crafts Group
Eden Social Education Centre
Newry and District Gateway Club
Oakridge Social Education Centre
Sports Group, Loughgall County Park
The ARC, Bessbrook
The Gender Group
The Laurels Day Centre, Newry
The Music Group
Windsor Day Centre, Newry

Groups visited in the Western Health and Social Care Trust Area:

Group Name
Carrickmore Outreach Centre
Destined
Dromore Outreach Centre
Evergreen Centre, L'Derry
Fresh Focus
Gortin Outreach Centre
Haven Unit, Share Centre
Kesh
Lackaboy
Lilliput Theatre Company
Millstreet, Enniskillen
Omagh Buzz group
Pilots Row, L'Derry
Positive Futures, Lisnaskea
Project Buttermarket, Enniskillen
Project Castlederg
Row Leap Group, Limavady
Something Special, L'Derry
Sow & Grow, L'Derry
The Gardening Project, Limavady
The Willow Group, Limavady
Tir Navar Day Centre
Valley Centre, L'Derry

Appendix 3 – Western Trust adult learning disability day care centres

Day Centres	Registered Maximum Number of Clients Attending per day
Benbradagh Resource Centre*, Limavady	56
Willows Group, Limavady	20
The Valley Centre, L'Derry	25
Evergreen Centre, L'Derry	35
Oak Tree Centre, L'Derry	25
Maybrook ATC*, L'Derry	70
Glenside ATC*, Strabane	55
Castederg Centre, Castlederg	18
Gortin Centre, Gortin	12
Strathroy Centre, Omagh	25
Omagh Centre*, Omagh	50
Dromore Centre, Dromore	16
Kesh Centre, Kesh	30
Lackaboy 1, Enniskillen	28
Lackaboy 2*, Enniskillen	18
Lisanskea Enterprise Centre*, Lisnaskea	20
Lisnaskea Share Centre, Lisnaskea	28
Tir na Var Centre, Derrygonnelly	18
	549

6 centres (denoted *) cater more specifically for clients who present with high dependency and have associated health and personal care needs, and challenging behaviours.

Table 2: Western Trust contracted day care services

Provider / Location	Level of Service
Faughanvale Community Project, Greysteel	3 day per week service – 10 places
Glenshane Carers Association, Dungiven	3 day per week service – 16 places in total
Strule Erne, Omagh	3 day per week service – 10 places
Strule Erne, Derrygonnelly	3 day per week service – 10 places
Strule Erne, Irvinestown	3 day per week service – 10 places
Praxis Care Group, Ardess, Kesh	Client specific agreements
Praxis Care Group, Richmond Hall, L'Derry	5 day per week service – 10 places

Day care services delivered through external providers contracted by Western Trust.

More training opportunities and employment for people with learning disabilities

College got me ready for work People are grouped together even though their needs are very individual Encourage

independent thinking *More flexibility regarding getting transport*

Work improved my life Pressure on big companies to employ people with learning

disabilities My job makes me feel good about myself More opportunities within college

Getting out into the community To have a job

like other people *Don't get enough*

support and money More information and planning for older

people with learning difficulties, what happens at 65? Important

to have more options and supported

paid employment More Bases open so

more people can have the choices I have *Enjoy*

the range of classes Meaningful

employment *There are more opportunities for me @*

the BASE than at the adult centre Choices I would

like more to do during the day I'm not

happy that Antrim College is closing. Where do the people with a

learning disability who want to go to college go to? More

choice, "I get to say" A job makes me feel useful. I am contributing and needed **Limited activity in**

day centres Planning our own timetables **More**

social opportunities Worried about my job

going Day centre activities – too much

colouring pages and DVDs Can save for holidays

and pay for personal items *More monies available for*

more services **Earn my own money**

Work colleagues don't understand disabilities or

include person with disability fully in workplace I

want more choices of courses Don't get enough

choices *The Base is nice but prefer Adult Centre* Respect the

person with a disability **More job**

opportunities and better pay to

stop us getting caught in a

benefit trap Should be centred around the person

and not a service **Equal lives for people with**

learning disabilities *Suit the job to the person* **To**

work, real job, PAID **More opportunities in**

leisure for adults with severe learning difficulties

Can't work anymore hours my benefits would be cut I am

worried about the lack of proper and suitable

day opportunities for my son, he is an

individual and should be treated like one

Employers need more training **Base is good**

www.patientclientcouncil.hscni.net

Remember you can contact your local office on
Freephone 0800 917 0222

or email info.pcc@hscni.net

Belfast Area

1st Floor, Lesley House
25-27 Wellington Place
Belfast BT1 6GD

Northern Area

Houston's Mill Site
10a Buckna Road
Broughshane
Ballymena BT42 4NJ

Southern Area

Quaker Buildings
High Street
Lurgan
Craigavon BT66 8BB

Western Area

Hilltop
Tyrone and Fermanagh Hospital
Omagh BT79 0NS

South Eastern Area

1st Floor, Lesley House
25-27 Wellington Place
Belfast BT1 6GD

