

# making us count



Identifying and improving mental health support  
for young people with learning disabilities

A RESEARCH REPORT

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the  
Foundation for People  
with Learning Disabilities

## **making us count**

Identifying and improving mental health support for young people with learning disabilities

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# Preface

Approximately one-third of a million young people in the UK have learning disabilities.<sup>1</sup> Of those, 40% are likely to develop a mental health problem.<sup>2, 3</sup> In 2001 the Foundation for People with Learning Disabilities convened an inquiry to explore a very neglected area: the mental health needs of young people with learning disabilities. The result of the year-long inquiry was the 2002 *Count us in* report<sup>4</sup>, and a two-year programme of research in which the Foundation funded four research projects aimed at improving access to high quality services.

The *Count us in* Inquiry and report confirmed that the range of mental health problems experienced by young people with learning disabilities is similar to the general population. However, young people with learning disabilities are far more inclined to develop emotional difficulties such as depression and anxiety and these conditions often go unrecognised and untreated.

Some of the most common messages the inquiry and the researchers heard were the difficulties young people faced in accessing suitable college or work placements, accessing leisure opportunities and maintaining friendships or relationships. This lack of opportunities, which other young people take for granted, were often the triggers to mental health problems. For those requiring help we heard that young people encountered difficulties in getting appropriate services and those pathways to referral for help and support were vague. There were often long time delays to access assessment and interventions; young people were shunted between mainstream and specialist services or did not 'fit in' anywhere.

It is clear that services need to change in order to reach this vulnerable group of young people. There is a favourable policy climate at the moment, with a number of policy documents setting standards for young people with learning disabilities to be supported by mainstream mental health services.<sup>5</sup> The Foundation is also pleased to be working with the Department of Health's National Child and Adolescent Mental Health Services (CAMHS) to develop managed care approaches.

This report offers some practical advice that practitioners and commissioners can take on board to improve the range of services available to young people with learning disabilities who experience mental health problems.



**Dr Andrew McCulloch**  
**Chief Executive**  
**The Foundation for People with Learning Disabilities**

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# Executive summary

## Aims of the report

The report has been written with care managers, senior service managers, commissioners of services and interested practitioners in mind. Its aims are to:

- explore the issues of mental health needs as understood by young people themselves and their family carers
- present their views about the gaps in services, what they find helpful and what kinds of support they would like to be available
- highlight some new and exciting approaches to addressing the mental health needs of young people with learning disabilities
- recommend ways in which services and support can be improved for both young people with learning disabilities and their family carers.

## Terminology

Following the Foundation's *Count us in* report, the research programme views mental health as a 'positive sense of well-being', which is an essential component of general health. Throughout the report reference is also made to 'emotional well-being'.

The report uses the term mental health problems as defined in the national service framework for children, young people and maternity services<sup>1</sup>:

*Mental health problems may be reflected in difficulties and/or disabilities in the realm of personal relationships, psychological development, the capacity for play and learning and in distress and maladaptive behaviour. They are relatively common and may or may not be persistent.*

## The research programme

The projects conducted their research between autumn 2002 and 2004. All four projects were highly individual, ensuring that the needs of a wide range of young people with learning disabilities were addressed, including those with profound and multiple learning disabilities, those with mild to more severe learning disabilities, and those from two minority ethnic communities.



The focus of most of these projects has been on the experiences of young people. Some previous research studies had not really taken into account the views of young people with learning disabilities who experienced anxiety, depression and other forms of emotional distress, thus not giving them a voice to explain how existing services do or do not help them. The projects also involved and considered the needs of family carers, who often undertake the complex role of caring with little support.

A team from the University of Strathclyde led research into what young people with learning disabilities understand by anxiety and depression and its impact on their lives. A team from the University of Bradford studied the needs of Pakistani and Bangladeshi young people with learning disabilities and mental health problems, where language and cultural differences make it harder to access services. A partnership between the Norah Fry Research Centre in Bristol, the joint commissioning team and the Connexions service in Somerset identified and overcame barriers for those young people making the transition to adult services. Finally, a team from the University of Dundee researched how mental health problems in young people with profound and multiple learning disabilities manifest themselves.

## **The findings**

Despite each of these four projects being unique, there were some key messages that were interwoven through most or all of them.

### ***Mutual support for young people***

The young people who attended a series of peer support workshops preparing them for adulthood spoke about how useful it was to meet other young people in the same position and to gain skills that will help them make new friends, use leisure facilities and cope with emotional stress. It is not just isolation and boredom that causes stress; attempts to cope with life alongside non-disabled peers whilst working or in managing relationships can create great anxiety and often young people are not fully equipped for this. Running such workshops are a good investment because when support networks are formed they can be long lasting, unlike many health interventions which are costly and often time-limited.

### ***Family support***

Family carers need assistance to find avenues of mutual support, which can often improve their emotional well-being. The stress of caring can be an enormous burden – several family carers experienced physical and mental stress, with some having to cope with aggressive or violent behaviour from their son or daughter. Two different groups for parents in the research both found mutual support for family carers very effective, particularly when such networks were maintained after the groups had finished their course.

### ***The need for someone to talk to***

Many of the young people and family carers appreciated having a professional who was able to spend time with them. This was often time-limited yet many young people have no-one else to turn to after the intervention had ceased. Again, this is another low cost, low level intervention that can have cost-effective results. Those young people who had a specialist transitions worker valued the person-centred approach. Person-centred approaches that incorporate attention to health can identify and address some of the causes of mental health problems, including isolation, boredom and physical health problems.

### ***Single referral point***

Young people and family carers want a single point of contact to which they can be referred for other sources of help. Most are unaware of the services available and get frustrated at the lengthy waiting times when they are referred. A single contact point would create clear pathways to support.

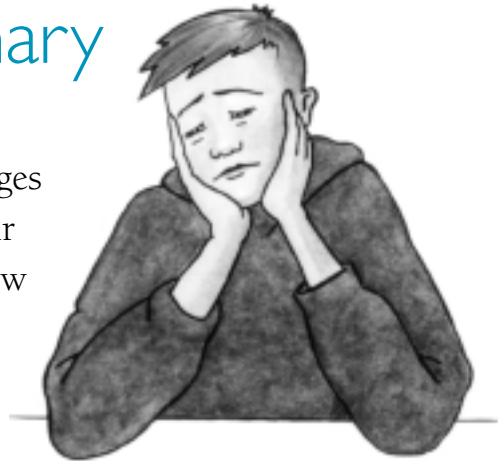
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## Easy to read summary

As young people grow up, lots of changes happen. They will have changes in their bodies, leave school, may move to a new home, get a job or go to college.



All these changes can be fun and exciting but they can also feel strange, confusing and scary. Feeling up and down, happy or sad, is part of being a teenager. Some teenagers can feel very down or sad. Sometimes this can be really serious and can be called a mental health problem. They may need extra help from other people to make them feel better.

*Making us count* is a report about how four teams worked with young people with learning disabilities who had mental health problems. They all had good ideas about how we can make things better for young people and their families.

Here is what we found out.

The Glasgow project team spoke to lots of young people who were feeling very sad and stressed out. The young people took photos of people, places and activities that were important to them. Some also used a cam-corder to make a video of themselves. The researcher asked lots of questions about the photos and videos, which helped the young people talk about how they felt. They were sad because they did not have any friends and did not have jobs. They wanted someone to talk to regularly who wasn't their mum or dad.

A project in Bradford wanted to find out why families from Pakistan and Bangladesh do not use many services for people with learning disabilities. Many of the people told them that they do not know what help there is because they do not speak English. The project team got a woman who spoke their languages to let families know what help they could get and help them get in touch with services. The young people and their families were pleased with the support they got and began to use more services.

In Somerset, young people helped to run a support group for other young people about growing up, leaving school, making friends and how to deal with feeling sad or stressed. They gave the young people lots of ideas and they all made lots of friends by going to the group. The project also ran a support group for parents, as they can feel very stressed too when their son or daughter is growing up.

The project in Dundee worked with family carers to find out if people who need a lot of support and who cannot speak feel sad or stressed. People with high individual support needs do feel sad and stressed, often because of changes in their lives or if they are unwell. Sometimes they may not want to eat or sleep, may hurt themselves and not make eye contact. The family carers helped to run some training sessions to let other parents know about this.





## What can help?

This is what young people, parents and services can do.

- Do not think that you are the only person to feel sad, unhappy or stressed. Many young people feel this way. But make sure you get support when you need it.
- Young people should be told about ways to cope with their feelings, like the young people from Somerset. Find out if there are any groups nearby, where you can meet friends and share how you feel.
- Family carers should be told about the services available locally that can support them and their son or daughter.
- GPs, teachers, nurses, transition workers and social workers must be told about the mental health needs of young people with learning disabilities so that they can help them.
- Learning disability and mental health services need to help those with serious problems.
- Support needs to be person-centred so that the young people are in control of their future.
- Professionals should find out the best time and place to arrange meetings with young people.



## CHAPTER ONE

# Involving young people and their families in research

*“I change my mind all the time, but I want the support there when I want it. And I want to use it for whatever I want to use it for, and when I have finished with it, I put it back down.”*

### Introduction

One of the ways in which planners, policy makers and practitioners can work towards more effective services for young people with learning disabilities and mental health needs is to ensure that the voices of these young people and their families are heard and supported. This chapter shows how the projects presented in this report were able to demonstrate the value of directly involving young people and families in research and its outcomes.

Historically, people with learning disabilities have found it hard to make their voices heard. They have been both physically excluded from society and excluded from all forms of decision-making which affect their lives. Even though people with learning disabilities are now present in our communities, participation in those communities has proved harder to achieve. Recently, there have been new national policy initiatives in all four countries of the UK with the goal of ensuring that people with learning disabilities are fully included as active citizens within the mainstream of society. For example, in England the government's white paper *Valuing people*<sup>1</sup> states that participation in planning one's own future is to be matched by participation in policy and planning. At the local strategic level, the government expects:

*“...people with learning disabilities and their carers to be fully involved in planning, monitoring and reviewing services.”*



## Spectrum of involvement

Listening to the views of young people and family carers was central to all the strategies employed by the researchers. A fundamental part of being a citizen is the right to be involved in making decisions about one's own life, and many researchers have taken this to include participation in the research process itself.<sup>2, 3</sup> The four projects included in this report have taken this premise to heart, using innovative ways to elicit the views and direct involvement of young people in research. For example, the *Mind the gap* project in Somerset took an action research approach, in which both the young people and their families were involved in determining the main outcomes of the research. Action research ensures full participation: that is, it enables the participants to be present and active in defining their own needs and problems. Researchers act as a resource to participants in planning interventions, taking action, and evaluating outcomes. One major aim of action research is to ensure that research findings are both relevant and practical, and perceived as such by those who are affected by the research.<sup>4</sup>

The action research project in Somerset benefited from the involvement and support of a wide range of service providers and a research advisory group. It was carried out as a partnership between Norah Fry Research Centre and stakeholders in Somerset, who included learning disability commissioners and policy makers, Connexions managers, health and social services professionals, members of the community learning disability teams, parents and young people themselves. A stakeholder group was formed, hosted by the transitions sub-group of the learning disability partnership board. This provided a forum for regular discussion and feedback of research findings, and joint planning for action.

There were many phases (or mini-cycles) within the action research cycle in Somerset, with results from the research being fed back to stakeholders. In the final stage of deciding which direction to take, a consultation paper was drafted by the commissioning manager and circulated to all the key professionals.

In Somerset the young people involved in the initial research went on to set up and facilitate a peer training course, while in both Somerset's and Dundee's projects, the family carers were fully involved in designing and running a course for parents.

## Listening to the views of young people and their families

Despite the ever-increasing interest in recent years on views of carers of disabled children, little has been published on what young disabled people have to say, and the voice of disabled people from minority ethnic communities is virtually silent.<sup>5</sup> Young people's opinions have consistently been ignored by researchers and practitioners, and services and interventions for young people with learning disabilities have been instigated without consulting the young people themselves. However, there is a growing recognition of the importance of listening to all people with learning disabilities, to gain insight into their

lives and to discover the issues that concern them, as well as their views and perceptions about the service provision available to them.

As professional awareness of mental health needs in young people with learning disabilities has increased, so too has an interest in young people's subjective well-being. Previous research has shown that people with mild or moderate learning disabilities are well able to reflect on their experiences and give cogent accounts of their emotions.<sup>6</sup> In many cases they are likely to be a more reliable source of information than their parents or carers whose perspectives may differ.<sup>7</sup> One aspect of the design of all four projects has been about listening to the experiences of young people with learning disabilities who have suffered emotional distress, including the impact of such distress on their feelings, actions and day-to-day lives. The projects were able to demonstrate the importance and value of listening to both young people's direct accounts, and to their family carers' perspectives, which often included the perceived impact of the young person's distress on their own well-being.

## The challenge of communicating

The projects were able to introduce a number of additional methods of involving young people which took into account the diverse range of communication abilities within the groups. One of the projects summed up the challenge as follows:

*“At one end of the scale, for instance, the sample included a young man who had attention deficit disorders, and a range of specific learning disabilities, together with ongoing bipolar problems. When interviewed during the first stage of the project, he talked fluently and irrepressibly for about an hour and a half. At the other end of the scale, a young person of the same age, 18, had no speech at all. He was a young man with Down's Syndrome and an autistic spectrum disorder, and often communicated by screaming, turning away or throwing objects. What these two young people had in common was that they had both fallen into the gaps between services. In both cases, the combination of their needs had meant that transition to adulthood was a complex and disturbing process, both for them and those around them.”*

The following sections describe ways in which young people and their families were able to communicate their feelings concerning emotional distress, together with their needs for support and services.

### **Pictorial interview questionnaire**

The Somerset project used a pictorial interview questionnaire to ask young people about their feelings and needs for support. This questionnaire was designed and refined in an inclusive way with the young people in the research group. Many of the traditional questions about emotional problems included in psychiatric interviews were discarded

at this stage as being too intrusive. Instead, they were replaced by the kind of questions young people felt that they could ask each other – questions about the places they liked to go out to, friendships, how feelings were expressed, and who they turned to for help.

The following excerpt was used as a way of evaluating any changes or improvements in their emotional well-being and day-to-day lives before and after the course. The symbols used are from Somerset Total Communication, a system of common language devised to make a consistent and positive difference to people's lives.

## Helping yourself

### **How can you get better when you are under stress?**

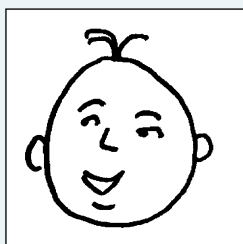


Do you do any of these things?

- Go for a walk?
- Listen to music?
- Talk to someone?
- Have some food?
- Have a rest?
- Go for a holiday?
- Relaxation exercises?
- Anything else?

How do you feel right now about helping yourself?

Happy



OK



Not sure



Really bad



### **Using photo and video diaries**

The *What's happening* project in Glasgow made use of photo and video diaries to involve the young people in recording their lives and expressing their feelings. Below is an extract from an interview, based on looking at a photograph, that demonstrates the value of this approach. Gary took a number of photographs both in and around his home. This photograph depicted a lounge with no-one in it. It provided a basis for him to discuss his feelings and also gave an indication of how he coped with his emotions at the time.

Discussion:

*(Interviewer) 'So you're in the house again?'*

**(Gary) 'Aye.'**

*'Do you like being in here?'*

**'Naw, sometimes, but sometimes it drives me nuts.'**

*'Cause you're like, in here, you only go out to work the two days and the rest of the time....?'*

**'In here... it drives you nuts.'**

*'Hard going?'*

**'Aye. That's why I'm going for the drink.'**

Several of the participants in the Glasgow project used a video camera very effectively to communicate their feelings. For the researcher the video diaries proved a rich source of information. The cameras captured the young people's changing emotions and the impact of particular situations. Gary used the camera regularly during a period of depression that culminated in an eight-week stay in hospital. His routine involved filming at night before he went to bed and then again when he woke up the following morning. Gary spoke directly into the camera and described exactly how he felt at that time. His sense of desolation, anger and acute boredom were very evident in his video diary. For the researcher, the video was particularly revealing as Gary did not display these emotions during the interviews.

### **Focus groups**

Focus groups are a way of listening to people and learning from them. These were employed by the projects in Somerset and Bradford as a method of eliciting the views of young people and their families, and of those involved in providing services. Focus groups are group interviews, guided by a group moderator, in which small groups of six to eight people (usually with similar backgrounds) discuss topics that the interviewer raises. Focus group guidelines are available for those interested in using them.<sup>8</sup>

In Somerset themes and issues raised by young people and their families were explored further in focus groups and taken back to the stakeholder group. The overall aim of the focus groups was to find practical ways to translate findings into action.

Focus groups proved a means of gathering rich data about the experiences and concerns of young people and their family carers, including those from south Asian communities. For many, the focus group was a rare opportunity to share the stresses, both for young people and for family carers.

“Getting services is difficult, so I don’t ask for help. To get that help, you have to be a very clever person, know how to approach them and get info... people like us can’t do that...” (Family carer, Bradford project)

The involvement of practitioners and service providers in focus groups, for example as in the Somerset project, helped to explore the difficulties involved in ‘labelling’ conditions and in providing appropriate services, building a coherent picture of the kinds of support received and required by young people with learning disabilities and mental health problems.

### **Peer group approaches**

Young people with learning disabilities need more than good opportunities for skills learning. They need opportunities to develop their own self-advocacy, their ability to take the initiative, and to become responsible members of society. The Somerset project directly involved young people with learning disabilities in establishing and facilitating a peer group approach as a way of providing other young people with these kinds of opportunities. A peer training course they developed, *The strongest link*, also enabled participants to reflect on themselves, to be more open about their feelings, and to think of ways they could get support for themselves, all attributes which might stand them in good stead for adulthood. The model could be used as part of the educational curriculum in schools and colleges for all young people with learning disabilities.

The feature of *The strongest link* which is probably most significant in marking it out as ‘different’ is that the young people were actively leading sessions that they planned, and were offering support and friendship to other young people. Young people were supporting other young people and so one of the most important factors in success was to get the facilitation right, and make sure that young people really took the lead.

The researchers reported that sometimes it was necessary to prompt people to take over in the sessions, and at other times it was really important to simply remain silent. Tape recordings of the sessions reveal some of the strategies taken by the researcher, who was the main facilitator for this initiative.

“Instead of leading activities myself, we had usually decided which group member was going to lead, and had this written in our plan. However, people often needed prompting. Instead of simply announcing something to the whole group, I often prompted the relevant group member.”

Val (researcher): ‘We are going to go on to talk about growing up’ (to Emily)

Emily: ‘We are going to talk about growing up. Being a child is being told what time to go to bed, by Mum. I don’t like that, because I am 21, and I don’t want to be told what time to go to bed.’

The qualities that needed to be nurtured in the research group were the ability to overcome nerves, to rise to the occasion and to trust each other in the team. Teamwork was a very important theme, and it was essential to build up that level of mutual trust before the peer group sessions started. In fact, good and structured preparation was essential to the success of the sessions. One young man described his feelings during the first session of the course.

*I felt nervous at the start, but when I got in there and saw everyone – my mind just went whoof, and I managed to talk and I felt confident about myself.*

Another important feature of the course was the basis of fun and flexibility. Young people had many good ideas about how to ensure the right atmosphere was kept up. These included:

- playing music during sessions
- having drinks and snacks available at frequent intervals
- going out on social visits, as well as staying in for ‘talk’ sessions.

Being entrusted with running a peer support course gives young people a sense of responsibility, and this can spring from quite small and practical choices. In the case of *The strongest link* these experiences fostered a sense of taking responsibility for the direction of the sessions, and this was illustrated clearly when things went wrong. For instance, in the second session a new person came to the group who had never been before. This meant that she was unaware of the basic purpose of the group and started to upset the balance by playing tricks on a member of the group running the session. People got quite cross with each other, and amongst all this the visiting participants (those *on* the course as opposed to those *leading* the course) felt left out and confused. Later on, the group discussed exactly what had happened, and what they should (collectively) have done about it. One member said:

*Basically we would tell them to get into the group, and ask them what they felt. Make them feel more accepted.*

Rather than the facilitator stepping in and taking control, it was far more valuable for group members to think about the progress of the group, take responsibility and think of solutions for themselves.

Evaluation of the course further demonstrated ways in which people with learning disabilities can be fully involved in the process, and included evaluation questionnaires, individual interviews and group discussions. The questionnaire for visiting participants was designed in an inclusive way with the young people in the research group, incorporating questions they felt they could ask each other. This was used both at the beginning and the end of the course as a basis for individual discussion with each of the young people in the visiting group.

Additionally, group discussions were held with the young people in the research group at various points during the process, with a final feedback session at the end. Tape recordings were made during parts of sessions, comments were collected after sessions from research group members, and notes were made by the researcher after each session.

From the experience and evaluation of *The strongest link*, the following factors seem to be important in setting up and running peer support courses:

- a facilitation style that encourages young people to run the sessions for themselves
- nurturing by the supporter of self-confidence and teamwork amongst the young people running the course during the preparation phase, as well as during the course
- good preparation
- a fun atmosphere
- stepping back by the supporter, encouraging the young people to speak for themselves
- allowing young people to take responsibility, even when things go wrong.

### ***Interviewing family carers***

Listening to young people with learning disabilities and emotional distress poses particular challenges where those people have profound and multiple learning disabilities. The Dundee project focused on this group and based its research on involving family carers who had reported that their son or daughter was experiencing, or had experienced, emotional or mental well-being problems. A semi-structured interview schedule was designed to ask questions about the possible causes and effects of changes in emotional and mental well-being, as well as what help was available to the family carers if a change was identified.

The study found that changes in the emotional and mental well-being of young people measured by standard diagnostic instruments were, in fact, consistent with the specific signs reported by family carers, based on their understanding of the young person.

*“Scott changed. He was listless and just sat in the chair with his head down. During this period he started to be sick and his seizures increased. He slept a lot and it felt like he was sleeping his life away. This went on for one-and-a-half years in total.”*

The interviews yielded rich data about the kinds of external and internal changes which had triggered changes in emotional and mental well-being, for example bereavement, changes in care staff, parental stress, puberty and physical illness. They also provided valuable information about the way in which changes in mental well-being may be expressed, for example through changes in facial expression, vocalisation, disruptive behaviour, self-injury or changing sleep patterns.

During the information-gathering process, consideration had to be given to the sensitivity of the topic and the high healthcare needs of the young people. Often the interviews were interrupted because of the need for healthcare intervention, or because the young person had to be brought home unexpectedly from their day service. This meant that in most cases several visits were needed to complete the interview process. Another consideration was the amount of time the interviewer had to spend with families in order to gain insight into their emotional and mental well-being. The family carers were often very stressed and had few people available to listen to their problems. In that respect, the interview process offered a valuable opportunity to talk about their concerns.

*“During this very difficult time there was no one to help and there were problems with his respite as well. He didn’t eat, he was living on Weetabix and milk fed through a funnel cup. At this time his sleep pattern was broken and he would often bang on the wall at one or two o’clock in the morning.”*

All four projects showed how family carers themselves struggled with physical ill-health and stress in supporting their sons and daughters through difficult and challenging phases of their lives. The Somerset project used an assessment index<sup>9</sup> to help family carers explore their own issues and ways of coping before and after the training course they attended.

## Support groups and training for family carers

Families are a vital part of the emotional support for young people with learning disabilities. In order to provide this support, family carers need to be strong in themselves. This requires establishing a very firm sense of their own self-identity, self-confidence and social support. As part of both the Dundee and Somerset projects, parents were able to develop and facilitate their own courses for parents as a way of developing this emotional resilience. The Somerset course, *Our link to the future*, provided rare opportunities for them to give vent to their emotions and to share coping strategies. It also provided practical help on managing stress and developing assertiveness.

Another need expressed by parents was around increasing their understanding of the mental health needs of their growing children. For example, the Dundee two-day training workshop was designed and developed by some of the parents who participated in the research, in partnership with the White Top Research Unit and PAMIS, a voluntary support organisation. The workshops were interactive and used case studies from the research to raise awareness of changes in, and maintenance of, emotional and mental well-being of people with multiple and profound learning disabilities. The Somerset course included useful sessions on communication, behavioural management and reacting to stress.



The Dundee project also identified that family carers are unable to find appropriate help and advice in caring for their young people, a finding which was echoed in the other projects by those involved. The parents involved in the Dundee training course made sure that it also offered an opportunity for family carers to identify possible pathways of help.

## Conclusion

One key finding of the research projects was the high degree of isolation experienced both by young people with learning disabilities suffering emotional distress and their family carers. The methods of involving and listening to both groups of people which the projects introduced can help to reduce this sense of isolation, and offer opportunities to build self-confidence and meaningful relationships, recognising the differences and diversity which exist within the communities concerned. Furthermore, they can be used to give people who have been marginalised by disability and other factors like poverty and ethnic background a louder voice, involving them in self-advocacy, in research and in other forums which can improve the support and services available in the future.

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# Towards better support

## Introduction

*“They’re OK whilst the young person is at school but what will happen after he leaves school?”*

Moving from adolescence to adulthood is daunting for most young people. Many suffer a lack of confidence and experience confusion as to where their future lies. The process may be even more daunting for young people with learning disabilities because many lack a local peer group or have communication difficulties that make it hard to express their feelings.

Transition from childhood to adulthood is a stage when young people are most vulnerable to developing mental health problems, yet it is also a time when it is most difficult to obtain help. In 2002 *Count us in*<sup>1</sup> reported a wide variation in patterns of service delivery for young people with learning disabilities across the UK. A teenager presenting with a mental health problem could be referred to the local community paediatric service, the child and adolescent mental health service (CAMHS) or the learning disability service, depending on where he or she lived. In many areas there are gaps in the age range for accessing such services so some young people receive no service at all. It can be particularly difficult for young people with moderate and mild learning disabilities and they too may not be seen by any service. Young people attending residential specialist schools away from home may experience difficulties in being relocated into a local service when they leave school.

In this chapter we look at some of the issues, gaps and obstacles which young people themselves and their family carers identified in accessing services and support; some new kinds of support and interventions which the research projects implemented and evaluated; and some pointers for future development.

## Features of a good service

The *Count us in* report described the features of a good mental health service. It should:

- be centred on the young person and the family
- provide early diagnosis and a prompt response
- have clear referral routes
- be adequately resourced
- have specialist skills in communication
- provide accurate information to young people and their carers
- be holistic in its approach
- work in partnership with other agencies
- provide a proper handover at transition to adult services.

Two of the key recommendations from this report are that mainstream services should develop the resources and expertise necessary to respond to young people with learning disabilities, their families and networks and should not exclude people because they have a learning disability; and that specialist learning disability services should be retained and developed both as a resource for mainstream mental health services and to support young people with the most complex needs.

## Definitions and labelling

A major issue which arose early on in the research projects was that of defining a 'mental health problem'. It was clear from those young people who took part in some of the studies that many had not been professionally diagnosed as having a mental health problem. While many experienced feelings of disorientation and confusion at transition and were quite aware of these problems, some clearly had difficulty in recognising their emotional distress as a mental health problem. The young people, families and support professionals alike were unused to discussing young people's needs for mental health support. Furthermore, it seemed that many were suspicious of the label of 'mental health' because it emphasised a need for separate mental health services, rather than the kind of support which could, in many cases, be provided from within primary care or learning disability services. Some families felt that there was a stigma associated with mental health services.

The *Mind the gap* project in Somerset set out to separate the issue of labelling from that of recognition by not simply focusing on those with a dual diagnosis of learning disability and mental health needs. It aimed to include all young people with learning disabilities who had mental health support needs whether recognised or not. By exploring the kind of language used by young people themselves and their families to describe their whole range of needs, they were able to decide on using words like 'stress' and 'emotional distress' throughout the project.

## Social causes of emotional distress

The medical framework of mental health support needs as ‘problems’ or ‘illnesses’ is the dominant one in mental health service provision. While recognising that some young people will benefit from greater access to prompt and effective psychiatric services in their transition to adulthood, some of the projects highlighted the need to identify and tackle the social causes of emotional distress when addressing affective disorders. For example, in the Somerset project a Connexions transitions personal adviser described a young man who had a number of severe symptoms of distress, including self-harm, and had consistently sought help. The approach to this young person was not to treat him as ‘ill’ but to identify the causes of his emotional distress as including lack of social opportunities, family issues and failure in work-related activities. The adviser felt that the most important thing was to tackle these issues and to create opportunities, together with the young person, to enrich his life, which had a positive effect on his mental health. This was a very clear endorsement of a social approach to some of the affective mental health problems, and was echoed by the other personal advisers in the project.

The Bradford study also highlighted the importance of a social model of disability which recognises that people can be excluded from society because of their disability and social conditions. There is considerable evidence that inequality and exclusion are very much part of the experience of south Asian communities in the UK and that they suffer from discrimination and disadvantage. For example, research has shown that more than 80% of Muslims (mainly Pakistani, Kashmiri and Bangladeshi people) were living in areas classified as ‘struggling’ in 2000.<sup>2</sup> In addition, the prevalence of learning disabilities and chronic illnesses is higher within some south Asian communities. Listening to the experiences of such families can increase our understanding of how attitudes to race and disability, coupled with social conditions, can affect their self-identity and their needs for support.

The Glasgow project *What’s happening?* showed how young people made concerted efforts to develop their social lives, and in some cases to gain employment. However, their efforts to develop their own identities sometimes had the unwanted effect of increasing their anxiety or sense of despair. Experiencing difficulties in sustaining employment, living independently, having a boyfriend or girlfriend, or socialising with peers were all factors that contributed to distress among the participants. Getting out also brought them into contact with situations which were anxiety-provoking. These worries were heightened where individuals lacked a peer group of close friends to talk with.

All four projects demonstrated how young people’s anxieties made most sense when considered in the context of their wider lives. There is a need for professionals, particularly those working solely in a clinical setting, to grasp this broader, social context.

## Current use of services

The projects in this study showed how patchy current use of support services is for many families. The reasons for this included lack of provision, lack of knowledge about what support is available and how to access it, and families' own attitudes to caring and to seeking help.

Somerset's *Mind the gap* project was fortunate in that it straddled learning disability and mental health services and also had a foothold in the Connexions service. Parents reported how supportive the adult learning disability services were compared with the little support they received when their son/daughter was younger.

Young people with profound and multiple learning disabilities and those from the south Asian population were in touch with very few services, and cited voluntary organisations and families as the best sources of support. Some south Asian families looked to schools for support and these provided a good source of referral to services. While there is an over-representation of children from minority ethnic groups in special education, this doesn't seem to follow through into the use of other services. Certainly the families in the Bradford project found that there was little help available when their children left school. There was high usage of primary care and welfare support services and very little referral on to specialist disability services when problems deteriorated.

The families in Dundee's *Well-being project* identified a lack of appropriate pathways of help as there are no dedicated professionals with specialist knowledge to support people with profound and multiple learning disabilities. They relied on a voluntary organisation which specialised in offering families advice and support in this field. Similarly, in the Glasgow project the young people and most of their carers did not know about specialist services they might turn to for support in addressing mental health needs. Most were referred to the specialist services through their school or GP.

## Accessing services: gaps and barriers

Recent national policies in all four countries of the UK have stressed the importance of social inclusion for all people with learning disabilities, and the role of support services in promoting and providing services which enable individuals to lead fulfilling lives within their local communities. Many of the gaps identified by young people and families in these projects related to simple, everyday supports which might facilitate inclusion, rather than to professional or specialist services. In relation to the following findings, the main need was for support services to listen to young people and their families, to be directly accessible to young people, and to broker opportunities for young people to take part in normal, everyday activities. In addition, family carers lacked the support they needed to maintain their own emotional well-being and cope with the challenges of caring.

## **Social isolation**

One of the main findings of the projects was the high degree of social isolation and boredom experienced by many young people which negatively affected their self-esteem and behaviour, and in turn placed extra strain on their family carers. Young people wanted to lead 'normal' social lives and valued friends as a key component of their self-image and self-respect. However, it was clear that many of them were spending long periods of time at home with little to do and with no access to social opportunities. Having opportunities for meaningful daytime activity and a chance to meet with other young people was a big gap in their lives. As the Somerset project concluded:

*“Young people with learning disabilities have the same ordinary ambitions as any young person. They want fun, a good social life, some independence and choices.”*

## **Someone to talk to**

Another gap related to having someone available to listen both to young people and their family carers. Many family carers felt alone in supporting their children. The projects provided rare and much-valued opportunities for both groups to talk about their feelings and about the challenges they faced. Sadly, the social and emotional support available for most participants was limited, with several individuals in the Glasgow study identifying the researcher as one of the few people they could confide in.

The Somerset project raised the need for counselling, both for young people in and outside of college, and for family carers.

## **Knowledge about mental health needs**

Family carers often did not appreciate that the changes they were seeing in their growing children were indicative of emotional distress, rather than a result of their disability. The Dundee study revealed a lack of professional information, advice and help relating to changes in the emotional and mental well-being of the young people with complex needs they were caring for. Because of this family carers felt isolated, stressed and alone. They wanted more knowledge about aspects of mental health needs and about how they could best support their sons and daughters. The Dundee project provided valuable help with this via a training programme for family carers.

Young people themselves showed awareness of their own emotional anxiety and stress and there was a need for them to have information about these issues. The Somerset project showed the value of peer support courses in sharing feelings and finding out what professional help is available.

One particular need which emerged from some of the projects was for both young people and family carers to have an opportunity to explore issues of sexuality, sexual identity and puberty, particularly in relation to their impact upon mental well-being.

## **Barriers to seeking help**

The projects identified a number of barriers for families accessing help and services in addition to lack of knowledge and awareness about what is available.

In Somerset family carers felt that they were branded by services as being 'over-protective' or 'worriers' or just a plain nuisance. At the very time when they were coping with extreme situations at home, they felt they were needing to cope with their growing reputation as 'difficult' parents.

For some families there was a reluctance to seek help. In the Bradford study this was sometimes based upon religious beliefs, for example the belief that the young person's disability was determined by their god and that it was the family's lot to care for them.

*We left it in the hands of Allah... it's our responsibility to look after her.*

Some saw the future very much in Allah's hands:

*We will see what Allah brings... whatever Allah has in mind will be best for all of us.*  
(Sister of young person)

For other carers in Bradford and elsewhere, reluctance to seek help arose from the simple belief in self-reliance – that the family should be the carers and not depend upon others. Some felt that family reputation was crucial, in particular those within the south Asian community, and that they wanted to keep sensitive issues concerning their family members very much within the family.

For south Asian families, language barriers also made it difficult for them to explain their problems to professionals and to get an adequate response. Some of these families and those involved in the other projects also experienced difficulties with transport and waiting times, and with just finding the time to seek help:

*There's a problem with having to look after the family and not having the time to find help...*

Once linked into services, parents in the Glasgow project had mixed views about their effectiveness. While some professionals were identified as particularly helpful, others were described as insensitive or out of touch, making suggestions which were considered irrelevant or impractical.

## **Referral issues**

The Glasgow project demonstrated a number of problems with referral. Like other projects, the majority of young people and their family carers were not aware of

specialist services available to support them and most young people were either referred to services by their school or college or through their GP. This raises questions about how young people are identified as needing help. Some of the participants were clearly referred to services owing to their challenging or aggressive behaviour. However others, who were also suffering distress but had become withdrawn, were not referred. The findings indicate a third group – youngsters who, for a variety of reasons, may not wish to discuss their worries with family members or other carers, particularly issues of a sexual nature. With no evidence of participants referring themselves, access to help in such circumstances seems unlikely.

### **Support for frontline staff**

It was clear from the Dundee study that frontline staff often lack vital knowledge and professional advice in coping with the effects of changes in the emotional or mental well-being of the young people with multiple and complex learning disabilities they were supporting. They tended to look to work colleagues who were familiar with the individuals, rather than professionals whose time was difficult to access. The staff members expressed the strain of caring, together with the need for support and training in mental health issues.

### **The role of services in addressing the gaps**

The projects raised the importance of services providing a flexible, person-centred and rapid response to the mental health needs of young people and their families. The Glasgow study included examples of where both health and social care professionals were able to provide effective help in supporting the well-being of young people. However, the health interventions tended to be confined to episodes of treatment, and there was sometimes a struggle to obtain substantive social support before a crisis point had been reached. Unfortunately, this often meant that the available help was inadequate to meet the needs and aspirations of these young people and their families. The projects highlighted the need for professionals to consult with and listen to the needs both of young people and their family carers frequently and regularly, and to work together to provide better information and service options, not just at the point of crisis.

All projects pointed to the need for services to promote more opportunities to tackle the social barriers and create better life chances for young people, including social and recreational activities. In addition, the projects demonstrated that services and professionals should improve their communication skills, avoiding the use of jargon and finding ways of communicating with people who have profound and complex disabilities. In the case of those for whom English is not their first language, there is a need to ensure that interpretation services are more widely available.



### ***Services for minority ethnic communities***

Despite the complexities which arise from cultural and ethnic differences, the more significant finding from the Bradford study was that minority ethnic families have similar needs and concerns to other families who have sons and daughters with learning disabilities and mental health concerns. These include having needs recognised and responded to promptly and appropriately, knowing what is available, and having access made more straightforward, irrespective of one's cultural status.

While the beliefs and attitudes of the families in the Bradford study tended to place the burden of care firmly within the family, there were services which families wanted but which did not currently take account of their religious and cultural needs. These included female-only day services, a wider range of leisure and recreational services, and culturally sensitive respite services. Family carers wanted to carry on caring for the young person within their own home. Services need to address language barriers and provision of information about what is available.

The Bradford study was able to show that what families often needed most were generic services and practical help which would improve their life conditions, including housing extensions and adaptations, benefits advice, leisure activities, help with transport and support in the home.

The liaison worker model used in the Bradford study showed the usefulness of having a single point of contact for families who are otherwise quite isolated from services.

### ***Services for young people with profound and multiple learning disabilities***

The Dundee project showed how important it is that family carers and services recognise the fact that people with profound and multiple learning disabilities experience changes in emotional and mental well-being and that they convey their responses to these changes through a variety of behaviours. More interventions need to be developed to help prevent and overcome mental health problems in this group and to enhance communication of sensitive events.

Closer working partnerships should be encouraged and developed between families and service providers to ensure that the young people's emotional and mental well-being is not overlooked or neglected by those caring for them. The Dundee project suggested a need for a dedicated specialist professional who family carers and frontline staff can turn to for support in the physical and emotional care of people with profound and multiple learning disabilities.

Training for family carers and frontline staff can help to meet the needs of this group, along with the development of local care pathways where carers can receive ongoing help, advice and information. In particular, there needs to be an improved exchange of information through partnership working between family carers and professionals. This

would ensure that valuable historical information was shared, allowing the development of a more holistic approach to the care of people with profound and multiple learning disabilities.

### ***Collaboration between services***

The projects advocated that services should form partnership networks in tackling social exclusion and in making more opportunities available. Many families mentioned the lack of future planning and that they had to 'take each day as it comes'. An issue raised in the Bradford project was that few services take on families 'long-term', with the result that they have to repeat their stories and have their cases re-opened for someone to help them. Certainly, this highlights a need for professionals and families to work together in making plans for provision, now and in the future.

The need for co-ordinated provision exists, regardless of who takes the major role in providing support. The Glasgow project gave worrying examples of referrals getting lost within the system and of professionals failing to communicate with one another, resulting in young people losing out on the possibility of helpful treatment and intervention. On a positive note, although the two health boards included within the Glasgow project operated different models of overall service provision, both adopted a care management approach, where the care manager had an explicit responsibility for co-ordinating professional involvement.

A related need raised by families was for a single point of contact for accessing support. This could address problems of not knowing what is available or who to contact, in addition to the time involved in visiting or telephoning services. It would also ensure continuity of services across transition, preventing some young people from falling into a black hole. The liaison worker model piloted by the Bradford project demonstrated the helpfulness of having a single person who families could contact to discuss their needs, and who could make initial contact with services on their behalf.

The Somerset project emphasised the need not only for joint working, but joint training for mental health and learning disability professionals. The aim would be to share their expertise and increase their awareness of the emotional and mental health needs of young people with learning disabilities.

## **Existing services**

### ***The role of school and college***

Schools were seen as a valuable support to families and an important point of contact when needs arose. However, the Somerset project highlighted the kinds of problems that many young people with learning disabilities experience at school, including lack of friendships, bullying, and a lack of understanding by individual members of staff. Social

isolation was seen as the worst part of childhood and on leaving school the young people tended to lose touch with the few friends they had made. Some of the young people from the Glasgow project rarely attended their further education colleges because they found the course boring or there was not enough support for them in a busy, crowded college. Increased awareness of different expressions of emotional distress in young people could help colleges make appropriate referrals and work with young people more effectively.

Schools and colleges have a valuable role to play in promoting and sustaining positive mental health in young people with learning disabilities. They need to be made aware of possible triggers to poor mental health and the behavioural responses associated with adolescence and transition, for example onset of puberty, leaving school/college, change of short-term break providers. They might help to raise awareness in young people about mental health issues through supporting the kind of peer group course established by the Somerset project which not only addressed issues around mental health, but ways to establish and sustain friendships.

Schools also have a key role in advising parents on accessing specialist help and in referring. The parents from the Bradford study all reported how the school made all the referrals to other services on their behalf, and some appeared to be more willing to turn to teachers than other professionals. However, this kind of support was no longer available once their son or daughter left school. Schools need to keep families well informed of adult services and key professionals they can contact during the transition period.

Young people attending out-of-county schools and colleges, although not addressed in these research projects, represent an area of concern. Not only are these young people living miles away from their family but their capacity to make friends locally is limited because leisure opportunities are scarce. The transition process is even more challenging because of the distance between the school and the young person's home area, making it difficult for their local authority to seek their views and to co-ordinate planning for the future.

### ***Connexions and other transition workers***

Connexions is a service recently established in England to bridge the gap between school and the adult world for young people aged from 13 years.<sup>3</sup> Through personal advisers Connexions provides young people with information, advice and practical help with all issues affecting them at school, college, work, and personal or family life, and can refer individuals to specialist support if it is needed. In the case of young people with learning disabilities, personal advisers play an important role liaising with the young person and their school on planning for transition to adult life and they provide information about appropriate support services. Despite there being no Connexions service in the other UK countries, the information here can be applied to other professionals supporting young people with learning disabilities during transition.

A key factor to providing good support during this challenging time is the quality of the relationship between the young person and their personal adviser. The Somerset project was able to demonstrate the effectiveness of personal advisers dedicated to young people with learning disabilities and linked to multi-disciplinary teams.

The transitions personal advisers (TPAs) employed by the Somerset Connexions service support young people with learning disabilities who are likely to get social services support as adults. They aim to meet with young people from the age of 14 until they reach 16 years old. A novel feature of the TPA posts in Somerset is their close link with social services teams. Each of the four TPAs is based within a multi-disciplinary team for adults with learning disabilities. This means that they have direct access to a range of professionals, and can share ideas and expertise very easily with colleagues who may be just down the corridor. On the whole, this has made the job of 'linking' far easier in Somerset than elsewhere.

The role of the Connexions transitions personal advisors was shown to offer a holistic approach to supporting the young person's mental health using a person-centred approach which addresses social opportunities, family issues and work related activities. In addition Connexions and other transition workers should keep in touch with young people at college and those living out of their local area and hand over to the Job Centre Plus information, advice and guidance when they reach adulthood. However, the Somerset project pointed to the need for these advisors to receive training in mental health needs, and be given opportunities to share their own knowledge of appropriate support and referral routes for young people with learning disabilities and emotional distress.

### **GP provision**

The GP is often the first port of call for young people and their families, yet mild conditions are not always recognised and treated and GPs do not always refer those with more serious conditions for further help. People with learning disabilities are at more risk of having physical problems, for example epilepsy, hearing and visual impairments, and many family carers, particularly in the Dundee project, were burdened with the strain of coping with complex health conditions.

*“She’s got diabetes, asthma... it’s too hard... she doesn’t sleep at night and upsets us all night...”*

The GP is extremely important for families because s/he is often seen as the main point of contact and referral. GPs need to be able to offer information on mental health and to know the range of services available locally to refer people to. It is vital that they receive appropriate training in learning disability and mental health issues, and in ways of facilitating communication.

Whilst many families are comfortable visiting the GP if their relative is experiencing physical problems, this isn't necessarily the case where mental health issues are involved. In the Glasgow study none of the 16 young people who took part turned to their GP for support and only three of the parents reported visiting their GP. In the Bradford study parents often turned to their GP as the first port of call, but then experienced problems in accessing further support because referrals were passed to and from various teams and waiting lists were too long.

Given the health problems reported by carers in the projects, the GP also has an important role to play in supporting family carers' physical and mental well-being.

### **Voluntary organisations**

The Bradford and Dundee projects discussed the positive support families received from voluntary organisations. The Asian Disability Network in Bradford acted as a one-stop shop for family carers and also provided leisure and social opportunities. Similarly, the Scottish-based organisation PAMIS (in partnership with people with profound learning disabilities and their carers) was often seen as the only source of support for family carers of people with profound and multiple learning disabilities, offering family support, training and a library service.

It is clear that voluntary organisations have a great contribution to the emotional well-being of young people and family carers. Over-dependency on voluntary services can be very problematic as some voluntary organisations may be under-funded and under-resourced to cope with the demands placed on them. They need to be properly funded by local authorities and other grant-giving organisations to maintain such levels of support.

### **Mental health services**

Forty per cent of young people with a learning disability have a mental health problem. While many young people involved in the projects had had no contact with mental health services, others had received psychiatric support which family carers had considered vital. The Somerset project suggested that children with learning disabilities whose mental health needs had been diagnosed early received a better service than those who developed needs during adolescence.

Some of the projects highlighted the difficulty of accessing help and support because of long waiting times, even where referral systems were in place. This was obviously inappropriate for individuals needing immediate help in order that preventative action could be taken.

While for many involved in the project there was a need for general emotional support during difficult times, it was clear that there were some young people who would have

a need for more specialist support. In these cases, the projects suggested a number of ways in which services might be improved, including:

- collaboration and joint provision by learning disability and mental health services, including joint training for staff
- joint working and increased communication between adult mental health services treating family carers and those treating young people
- continuity across transition from child to adult service provision
- increased collaboration between psychiatry and psychology
- greater involvement of psychology services, especially CAMHS and other adolescent mental health services
- better information for young people and families about the nature and purpose of treatment.

*Green light for mental health*<sup>4</sup> provides guidance for local mental health and learning disability services addressing the mental health problems in people with learning disabilities.

### **Assessment of mental health needs**

The projects revealed the capacity both of young people with learning disabilities and their carers to recognise mental health needs in ways which are consistent with formal diagnostic instruments. Even in relation to young people with profound and multiple learning disabilities, family carers were able to identify specific signs that alerted them to changes in emotional and mental well-being, and furthermore the causes and effects of such changes were shown to be no different from those within the general population.

*“Scott can show facially how he is feeling and this is how I can tell if he is upset or down. His eyes appear to sink in his head and there’s terrible black shadows under his eyes.”*

Young people and carers have a vital role to play in the detection of emerging mental health problems, and diagnostic tools which capture the information they can provide, for example the *Mini PAS-ADD*<sup>5</sup>, should be more widely used within learning disability and mental health services.

### **Who provides emotional support?**

Recent reviews and reports of practice have generally referred to the right of all people, including people with learning difficulties, to access generic mental health services. However, with so many young people experiencing mental health problems, it is clear that not all are going to get ongoing support from generic mental health services as they

exist at present. There are now documented examples of good practice in specialist services for this group.<sup>6</sup> Additionally, in the light of the above comments about the social causes of mental health distress, it may well be that all services have to become more effective in providing better emotional support. As one Connexions advisor put it, when asked what support was most effective:

*Time and a human face and loads and loads and bags and bags of reassurance.*

The young people and family carers interviewed by the Glasgow project talked about the value of community nurses in providing emotional support during difficult times, although this supportive contact was generally only available during the young person's course of treatment for a diagnosed mental health problem like anxiety or depression. Some of the young people came to depend on their community nurses for emotional support and this caused difficulties when the nurses withdrew at the end of treatment. Access to emotional support should, therefore, be available on a continuing basis.

Practitioners and families in the Somerset project felt that good emotional support should be offered by *all* the professionals who come into contact with young people with learning disabilities. This was echoed by families in the other projects; in fact, the type of professional providing emotional support was of little significance to them.

In addition to general emotional support, the Somerset project mentioned the need for 'talking therapies' to be available to young people with learning disabilities, rather than simply medication. The Glasgow project identified the usefulness of certain psychological interventions, for example anxiety management, anger management, and bereavement counselling. These had been provided by a number of different professionals including a community nurse, social worker and psychologist.

Finally, the Glasgow project showed the importance of services reaching out to young people and their families in order to offer much-needed emotional support, rather than waiting for a crisis call or assuming that they have access to informal sources of support.

## **New forms of support**

### ***The liaison worker model***

The Bradford project described in this report implemented and evaluated a liaison worker model to provide much-needed support to families in a south Asian population, many of whom were socially isolated. The liaison worker contacted families once every month, or more if required. Their role centred around discussing the family's concerns and the types of help required, and then liaising between services and the family to see how services could respond and what help might be provided. In this way, they provided the role of 'broker', rather than providing any direct interventions.

The study showed that families allocated a liaison worker had more frequent contact with more services, and with more positive outcomes than the group of families who did not have this support. More significantly, it demonstrated that the carers experienced a better physical quality of life, and that the young people had decreased problems on one behavioural measure, when compared with the other group.

The kinds of outcomes reported by the liaison worker for the young people included access to local leisure facilities, sorting out a delay in direct payments and contact with a range of statutory services for funding, advice and support. Outcomes for family carers included getting help from a Punjabi-speaking benefits worker to fill in disability forms, contact with hospital interpreting services and contact with an occupational therapist about installing railings outside the house. Here is an extract from the liaison worker involved in supporting the family of a 17-year-old young man who is still at school but who spends the rest of the time at home, partly owing to his unruly behaviour.

*“I called up social services, who recommended I speak to the Community Learning Disability Team, as Yach was going to turn 18 soon and would be using those services. A social worker has now been assigned to Yach and has been round to do care assessments and says he will help Yach get in touch with leisure and perhaps arrange for a support worker to take him out and look after him.”*

The liaison worker was valued by families as a single point of contact. Other families mentioned the difficulty of getting through to the relevant contact within social services and how much better it would be to have one person who would be readily available.

### **Training and peer support for young people and family carers**

There were three main training and peer support initiatives which demonstrated how important it is to create opportunities for both young people and family carers to build greater emotional resilience, and how effectively they can be involved in providing mutual emotional support. The Somerset project involved young people in developing and facilitating peer support groups to empower them and equip them with ideas to look after their mental well-being. It showed the value of such an approach in providing opportunities for young people to talk about and share their feelings, and to build their self-confidence and friendships. It also built in opportunities to develop useful skills in maintaining well-being, including self-advocacy and management of stress.

Both the Somerset and Dundee projects included the development of training courses run by parents for parents. These provided similar opportunities for sharing feelings, along with valuable information about young people’s mental health needs and ways of supporting the young people. In addition they highlighted the need to recognise the impact of caring on the mental health of family carers, and gave carers a chance to explore coping strategies for themselves. These initiatives are discussed in **Chapter 1** and in the relevant project chapters of the report.



## **Mapping services**

All four projects found that young people and their families lacked vital knowledge about what services and supports may be available and how to access them. The Bradford project included mapping current usage of services by south Asian communities, including:

- support from services – informal and semi-formal groups
- range and type of services
- contact with professionals
- frequency of use
- helpful/unhelpful nature of services
- user satisfaction.

Based on semi-structured interview questions, this mapping study identified important service gaps and barriers to accessing support.

The Somerset project set out to map local services available and went a step further in identifying possible pathways to support for young people and their families. The Somerset project used an interactive exercise which staff from different services can undertake together, based on some scenarios of young people with learning disabilities who are experiencing emotional distress during their transition to adulthood. This exercise is included in **Appendix A**. In addition, they provided the following guidelines for mapping services:

- any map or guide produced must be practical, and based on real situations known to professionals
- it should include an indication of referral time and capacity for various services. This would mean, in practice, that it would need constant updating
- a good way to develop the map and to ensure that it is included in practice would be to work directly with Connexions advisers in interactive exercises, such as the one included in **Appendix A**.

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## CHAPTER THREE

# What's happening? How young people with learning disabilities and their family carers understand anxiety and depression

Alastair Wilson, Dr Andrew Jahoda, Dr Kirsten Stalker and Anja Cairney

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### Introduction

#### Project summary

*Whenever I try something new I'm anxious. That's just the way I am. It's not the way I was brought up, it's just the way I am ... I feel sick a bit, you know what I mean, and it's just one of those things and it really annoys me, it really does.*

This was how one young woman described her feelings of constant worry when interviewed for a project which aimed to fill a significant gap in knowledge concerning the views of young people with learning disabilities who are experiencing anxiety and/or depression. Conducted by researchers from the Universities of Strathclyde, Glasgow and Stirling, the study focused on the way in which young people and their family carers identify and understand emotional difficulties. The project helped a small number of young people to talk about their own experiences of mental distress, how they coped and the support they received. In addition, it explored how family carers and care staff respond to the young people's needs and how well health, social care and other services support them.

The project employed an innovative methodology involving the use of photo and video diaries to facilitate communication and understanding between the researchers and the young people. Findings showed that the young people had varying degrees of insight

into their own feelings and situations. However, the services they and their carers currently access, in the form of prevention, treatment and ongoing support, are patchy and inconsistent.

### **Project aims**

This research project had three primary aims:

- to explore what young people with learning disabilities understand about anxiety and depression, its treatment and impact on their lives
- to study how carers (including family carers and paid staff) have identified and coped with anxiety and depression among young people with learning disabilities
- to examine the response of mental health and learning disability services in assisting young people and their carers to deal with anxiety and depression.

### **The context**

In planning the project, a range of key research findings were taken into account concerning the experiences of people with learning disabilities. These are briefly summarised below.

#### *Subjective well-being*

Along with increasing professional awareness of the vulnerability of young people with learning disabilities to depression and anxiety, there has been a growing interest in young people's subjective well-being. Previous research has shown that people with mild or moderate learning disabilities are well able to reflect on their experiences and give cogent accounts of their emotions.<sup>1</sup> In many cases they are likely to be a more reliable source of information than their carers whose perspectives may differ.<sup>2</sup>

#### *Wider social context*

It is vital that studies of mental health among people with learning disabilities take account of the wider social context in which they live. Individuals are often only too aware of the stigma surrounding disability<sup>3, 4</sup>; many experience harassment and discrimination on a regular basis.<sup>5</sup> In addition, young people with learning disabilities may have fewer and less effective resources than other youngsters for coping with adversity. Research has shown that occupying valued social positions or having a range of achievements can protect against depression<sup>6</sup>; satisfying social relationships and networks help to promote well-being, while difficult or fraught relationships exacerbate stress.<sup>2</sup> Although research evidence is lacking, clinical experience suggests that positive opportunities and life changes can dramatically improve the well-being of young people with learning disabilities.

Nevertheless, environmental improvement alone will not always resolve young people's difficulties; many may continue to be dogged by past experiences and negative perceptions of both self and the wider world. That is why it is so important to explore psychological mechanisms for coping, including young people's perceptions of themselves and their social circumstances, and their potential ability to overcome emotional difficulties and deal with the challenges they face.

The project was set within the context of recent policy and programme developments within Scotland aimed at promoting the well-being and social development of people with mental health needs, although little has been specifically targeted at young people with learning disabilities who have mental distress.

### ***Importance of the project***

As outlined above, this project aimed to give voice to young people with learning disabilities identified as experiencing anxiety and depression. Most previous research has relied on proxy accounts. This project set out to investigate how these young people can regain sufficient sense of well-being to take advantage of real opportunities, where these are available to them.

In addition, the study employed an innovative research method involving the use of photo and video diaries to facilitate communication and understanding between the researchers and the young people. Not only has this approach yielded rich, intimate data, it has also paved the way for a follow-on project, funded by The Foundation for People with Learning Disabilities. This has involved producing a video featuring some of the young people taking part in this study to help disseminate its key messages.

### **How the project was carried out**

The research involved a preliminary phase designed to give an overview of mental health policy and practice in this field, followed by the fieldwork phase where young people were recruited for case studies. The research benefited from the guidance of a research advisory group as well as some informal consultation with people with learning disabilities known to the research team from a previous study.

#### ***Preliminary phase***

In the early stage of the project the research team carried out a mapping exercise of mental health service policy and provision in the central belt of Scotland. This involved the analysis of key policy texts (see **Appendix B**) and a series of 'key informant interviews' with representatives of a range of agencies, including the Scottish Executive and health, social services and voluntary organisations.

## **Fieldwork phase**

Young people were recruited to the study from two health boards in central Scotland, comprising a mix of urban and rural areas. Both health boards contained neighbourhoods with significant levels of deprivation and social exclusion. In one of the health board areas school-aged individuals could obtain support from social services and from child and adolescent community mental health teams (CAMHS) set up specifically to meet the needs of young people with learning disabilities. Adult community learning disability teams co-ordinated the input of a wide range of professionals for people with learning disabilities post-school. Both health boards adopted a care management approach, where the care manager had an explicit responsibility for co-ordinating professional involvement, including social workers, psychiatrists, psychologists, community nurses, occupational therapists and speech and language therapists.

For the purposes of the study, 17 participants were selected from the two health boards, nine from one and eight from the other. Local mental health services for people with learning disabilities helped to identify young people willing to take part in the research, while other participants were recruited through further education colleges, local special schools and voluntary organisations. These various routes of referral to the research team allowed a range of young people to participate in the study. Some were receiving support from health and social services, while others had been identified by their family carers who were concerned about their emotional well-being but, as yet, the young person had not been formally diagnosed or obtained support. Whilst the data for all 17 participants had undergone a preliminary analysis, the research team undertook a more in-depth analysis of eight participants. It is from this group of young people that the findings are illustrated here. *Table 1* summarises their key characteristics and social contexts.

## **Procedure**

Participants were visited regularly over the course of six months to a year, depending on their circumstances. A range of qualitative approaches were used to gain insight into the young people's perceptions of their emotional well-being. These approaches varied according to each participant and the researcher had to remain sensitive to the mental health of the young people. Given the nature of the young people's difficulties, it was crucial to develop a mutual understanding with each participant and to establish a trusting relationship.

## **Interviews with young people**

Locations for the interviews varied. On some occasions the young person and the researcher were comfortable just talking together in the young person's home. At other times they met at the young person's school, college or place of work. The aim was to

build up a more general understanding of the participants' lives before exploring their experience of anxiety and depression. The interviews aimed to identify the following:

- the nature of the young person's distress and its impact on their lives
- what they described as the trigger or cause of their distress
- how the young people coped with their difficulties and what helped them.

In addition to the depth of information obtained about these young people's experiences, the longitudinal nature of the study also allowed the study to examine how events unfolded in their lives.

**Table 1** Summary of participants

Pseudonym	Age	Gender	Circumstances	Type of difficulties	Help and support
Moira	19	F	Lives with parents. Attends college p/t. Seeking employment.	Epilepsy. Symptoms of anxiety.	Treatment for epilepsy. Support from tutors at college.
Sam	16	M	Lives with carer. Attends a special school.	Diagnosed with low mood/depression and impulsivity.	Bereavement counselling. Psychological support. Parenting support for carer. Social work input.
Karen	19	F	Lives with mother. Attends college full time.	Diagnosed with anxiety and depression.	Treatment for epilepsy. Psychological support. Parenting support for carer. Referral to befriending service. Referral to social worker.
Jason	26	M	Lives with family.	Diagnosed with acute anxiety.	Psychological support. Social work input.
Susan	19	F	Lives with mother. Recently left school and attends college.	Psychiatrist noted symptoms consistent with anxiety and depression.	Referred to community team.
Darren	26	M	Lives with family.	Diagnosed with anxiety.	Psychiatric intervention, medication, community nurse support.
Mel	22	F	Lives with family.	Diagnosed with anxiety and depression.	Psychiatric intervention, medication, community nurse support.
Gary	20	M	Living at home with father. Not working, previously had full-time job.	Diagnosed with depression and acute anxiety.	Psychiatric intervention, medication, community nurse support. Period of time in hospital.



### **Interviews with carers and professionals**

With the young people's permission, interviews were also carried out with their family carers and/or care staff, as well as others who were providing support such as social workers, teachers and healthcare professionals. These interviews allowed carers to talk about and reflect on the following:

- their experiences
- how they recognised and coped with the young people's difficulties
- the response made by health and social care services.

### **Use of photography**

The interviews were complemented with the use of photography and video diaries. These innovative approaches provided other means for the participants to express their views and helped to make the research process more engaging.

Each of the young people was invited to make use of disposable cameras and to take photographs of whatever they felt was interesting as a basis for later discussion with the researcher. In general, the young people enjoyed this process as it afforded a means for them to discuss broader aspects of their lives not easily captured in an interview. Equally, it provided the researcher with an insight into areas of the young people's lives that may not necessarily have been raised in an interview. In particular it facilitated communication with those young people who were perhaps withdrawn or had difficulty expressing their emotions, articulating their thoughts and/or engaging with the researcher. More information about using photographs in this way is included in *Chapter 1*.

### **Use of video diaries**

Video diaries were also used to assist young people in talking about their lives and circumstances. Young people were encouraged to use a camcorder to make a video diary of events, places or people which they felt significant. As with the use of photographs, this technique encouraged young people to bring issues to the attention of the researcher, in effect enabling them to take a lead in discussion. This was particularly important as it went some way towards bridging the gap between the researcher's understanding of issues facing the young people and the young people's own understanding. More information about using video diaries in this way is included in *Chapter 2*.

## **Main findings**

This section outlines key themes to emerge primarily from the in-depth analysis of the eight case studies. The four sub-sections relate to: the participants' experience of anxiety or depression; perceived causes of their distress; what they believe to be helpful; and barriers to obtaining help.

## 1. Expressions of distress in young people

### Hurting inside

Young people spoke of feeling terrible sadness or a sense of worthlessness. A number also spoke about their wish to die or that they had not been born. Susan expressed these feelings on several occasions.

*'One day everybody was sitting bawling at us, sometimes for nothing. What's the point in me being here, know what I mean? Just getting pure moaned at. May as well be dead, know what I mean?'*

*'Who's been bawling at you?'*

*'Just my pals an' that. Sometimes my Ma an' that.'*

*'Do you feel like that now?'*

*'Naw. I'm alright now.'*

Several participants described harming themselves; one young man's actions put himself at risk of serious harm, if not death. Sam described his self-injuring in powerful terms: he saw it as a way of escaping.

*'I kept doing it and I thought I would never do it too deep but then one night I was really, I don't know, I was pure pissed off, don't know how and I don't know what made me feel like that, I just felt pure that I didn't want to be in this world any more. And then one night I went in and just sat up in my room in my bed and then I was doing it nice and slow and then I just went pure deep and it went right through my hand and I was lying in my bed pure screaming and then I stopped screaming and I was just like that, shutting my eyes and I was all blood on my quilt and all that, and then my uncle came up the stairs and he ran to the phone, he phoned [the carer].'*

### A wish for change

Other participants talked about less drastic ways of changing their lives. Some individuals just hoped for a change in their circumstances, while others looked forward to events in the future which they hoped might be a watershed in their lives. This wish for new lives, or to become a new person, was characterised by Gary's wish to change his appearance. As his father explained:

*'He wants to dye his hair constantly, wants to dye it black the next time. He's gone to the sunbeds to change the colour of his skin, he's getting new clothes to change the way he looks. He's wanting a complete change so I don't know what this is, God knows what this is.'*

### Worry and panic

Those whose main problems were anxiety-related reported feelings of constant worry or, as one man said, he worried 'on and on and on'. Often the young people were unable to attribute these feelings to a specific cause:

*I am anxious some of the time but whenever I'm in a situation I'm anxious. Whenever I meet people... other people I'm... I try something new, I'm anxious, 'Oh I'm going to fail this'... It's not the way I was brought up, it's just the way I am.*

Participants also talked about the accompanying physical symptoms of panic or an extreme anxiety state.

*'What do you mean when you say you're anxious, how do you feel?'*

*'Nervous, I get sweaty palms, I feel sick a bit, you know what I mean, and it's just one of those things and it really annoys me it really does.'*

These descriptions of physical symptoms varied from general terms like being 'uptight', to those who had received professional help with their anxiety and talked in more detail about their breathing becoming out of control (due to hyperventilation).

### Hitting out

One of the main signs of depression that participants talked about was becoming angry and aggressive. They seemed to recognise that their responses were sometimes unreasonable or that they were 'taking out' their feelings of distress unfairly on people who did not deserve to be treated in such a fashion. This was often a parent or someone who they were close to, as Mel described when prompted by the interviewer:

*'You say that nobody will like you because you're depressed. What do you mean by that?'*

*'It's also a lot to do with my temper especially when I take it out on my mum and dad.'*

*'Take it out?'*

*'On my mum. My mood swings and things like that. She gets me on the wrong side of her.'*

On other occasions the young people talked about reacting very strongly to peers at school or college who they thought were being 'nasty'. One young man, Sam, described how his feelings of despair could turn towards aggression. Following the death of a relative, he went out in the early hours of the morning.

*I was walking about, man, and everybody that went by me I was just pure growling at them and then one mad guy said, 'Who are you growling at?' and I was like that, 'You!' and I went like that, 'Who does it look like?' ... don't know what was up with me that night.*

## 2. Causes of distress in young people

### Emotional difficulties

What became apparent from speaking to these young people was the complexity of their lives. Some participants had experienced a striking number of traumatic life events and many lived in difficult circumstances. Family bereavements were a source of great distress to some, whilst illness and serious family tensions or conflicts were also a source of worry and upset. So while certain participants were guilty about 'taking out' their upset on family members, at other times they felt that their anger and frustration were justifiably vented on their families. Participants reported becoming particularly upset when they felt that parents imposed unfair restrictions. Several individuals were in the position of caring for parents who had their own difficulties, and sometimes resented having to take a supportive role. In a less dramatic fashion, there were reports of falling out between friends. Outside the family home, some young people reported being victimised and bullied. Sometimes they just worried about how other people would see them or felt themselves to be excluded. In the following example, Sam's social worker describes how Sam believed that nobody at his school liked him.

*Sam, at one point, thought that everyone in the school hated him – which was completely untrue because he had a lot of support from the school. He was very introverted and thought that everybody was against him, apart from myself, so we had to work on that one, making him realise that people cared about him...I would say over maybe the last six, seven months, maybe this has been ending because his attitude at school has been a lot better... he accepts challenges, he accepts rebuke, which he wouldn't have accepted before.*

Like many young people, there was also a wish for romantic attachments and several were saddened by their lack of a boyfriend or girlfriend. Sexuality was a major source of concern for one young man who reported having developed a 'terror' of gay people after seeing two men kissing in a gay bar he visited.

### Nothing to do

Many of these young people had very limited daytime or social activities. Whilst it may be difficult to tease out whether they had become more withdrawn owing to their mental health problems, or whether their lack of activity or social contact were contributory factors to their mental health problems, several individuals expressed frustration and despair about the lack of meaningful activity in their lives. Here is an extract from an interview with Moira which illustrates the point.

*'So what did you get up to this weekend?'*

*'Nothing.'*

*'Nothing?'*

*'Sit in the house and my mum an' that's pals were there.'*

*'What did you do when you were in the house, did you watch the telly, listen to music?'*

*'Sleep.'*

*'Sleep – you slept the whole weekend?'*

*'Aye, apart from going to Mass and that's it, slept the rest of the time.'*

*'Do you do that a lot when you are in the house?'*

*'Definitely.'*

Moira benefited from activities organised by her local college which supported her by helping her with independent travel. She benefited particularly from friendships which often provided an independent source of fun and companionship which could be missing in her normal routine.

When her college course was finished, Mel was at home with her mother 24-hours-a-day, seven days a week. Tension between the two of them was a constant source of concern for both Mel and her mother and was frequently the subject of their discussions with the community nurse. However, while finding Mel a suitable work placement was a priority for the social worker involved, this proved difficult to realise. In the course of a year Mel only found part-time work for several weeks during the summer.

Where young people had no access to organised activities and few established friendships, family carers and care staff often had to try and think of ways to occupy them. Karen's mother described how Karen frequently complained of being bored, particularly when college was closed. However, she found trying to motivate her daughter to do things extremely difficult.

*“She does like college aye, she really, really likes college, aye she does. Because even when college is off I will go... ‘Do you not want to go to the shopping centre?’, ‘No, I don’t want to’, then it’s, ‘I’m bored, I hate this’ and I will go ‘But Karen I’m asking you do you want to go somewhere but you don’t want to go, what can I do?’ That’s what I’m saying, when the college is off she gets so bored, know what I mean?”*

### *Physical well-being*

Health problems were linked to anxiety-related difficulties, with epilepsy being cited by two individuals as a source of anxiety. Moira was concerned by the unpredictable nature of the condition, along with the fear of the potential embarrassment of having a seizure in public.

*“You don’t know what’s going to happen to you next. Like, say, I was just sitting here – I wouldn’t know what was going to happen to me next. Like last period when I was in first aid, would you believe it or not I had a seizure like for an hour, like constant shakes and it wouldn’t stop.”*

Bowel conditions and urinary problems had also caused personal hygiene problems for some individuals, which in turn had led to hurtful name-calling by their peers. Karen described her bowel problems and how these cause her embarrassment.

*'Sometimes I can't walk with it, I'm doubled in two.'*

*'Oh do you get like cramps?'*

*'Aye – and I've got to sit in the toilet if I'm out. In the space of one day I'm in the toilet every five minutes probably.'*

*'That's awful.'*

*'Sometimes I can't make it to the toilet. Then my bum gets sore and I walk funny and I'm feart (afraid) to go outside and when I'm in places in case I have it and then I'm looking about – people look at you and think you're stupid.'*

### **Coping with everyday life**

A number of participants also admitted to a lack of self-confidence about aspects of everyday life like independent travel, feeling anxious that they might become lost. Karen, for instance, avoided travelling alone.

*'I'm no really good on the bus because every time I'm on the bus I fall asleep, or when I cross the road sometimes I don't look and I go and I just cross and sometimes my ma's got to pull me back.'*

## **3. Sources of support**

### **Getting help**

None of the young people involved in the study referred themselves to their GP or to mental health services. Family carers had little knowledge of the range of services and help which may have been available to them. Instead, they tended to rely on the assistance of schools, colleges and social work in making referrals to mental health services. Only three parents initiated contact with their GP, feeling they had nowhere else to turn to. When Karen turned 16, her mother felt that Karen 'saw herself as an adult and was no longer biddable'. She found Karen's behaviour very unpredictable and difficult to understand. She was frightened at times as Karen would throw the kitchen chairs around and threaten to hit her with something. She said that while Karen could be very loving, she could also switch from one mood to another in seconds; she would interact well with young nieces and nephews and then lose her temper and be screaming at them the next. She contacted her GP when she felt that she could no longer cope and couldn't 'take any more' of Karen's behaviour.

Darren experienced a period of acute anxiety which worried and frightened his mother.

*“It was really bad, it was really bad because I didn’t know what to do. I’d never experienced anything like that and I probably let it go for longer than I should have because I kept thinking ‘Oh this will go away’ because I didn’t know what it was really. So he went to [local psychiatric hospital] and [name of consultant] said that he might get kept in so that was really upsetting.”*

Darren’s mum was angry about the way she was treated by the psychiatrist who, although understanding at times, made several comments she disagreed with and felt were inappropriate. For example, he asked her ‘Why are you upset?’ and commented, ‘He is lucky to have got to his age without this happening’. On another occasion he said ‘It’s normal in people with special needs’.

Many parents reported experiencing cumulative difficulties with their children over long periods of time. Some said they felt it their duty to cope with their child’s difficulties on their own and that seeking help was somehow an acknowledgement of failure. For example, several years ago Karen’s mother had rejected input from social services, feeling that it was her responsibility to cope.

*“A long time ago they asked me if I wanted a social worker and I said ‘No’ but I felt at the point ‘I’m in denial, she’s mine and it’s up to me to deal with this’.”*

### *Specialist support*

Special schools and FE colleges were generally aware of sources of specialist support. They tended to have strong links with community learning disability teams and were sensitive to changes in young people’s emotional well-being. Thus they were able to make appropriate and prompt referrals, as illustrated by this comment from a college co-coordinator.

*“As we’ve got to know them [the area learning disabilities team] and know what they are able to do, we’ve identified people that we think would benefit from their services so then referred them on. So it’s been a kind of two-way process that’s just developed and it’s a service that we are referring more and more students to.”*

In one health board area the local FE college was a main source of referral of young people to the local adult learning disability team. The child and adolescent mental health service in one area had good links with local learning disability schools and as a result teachers were able to make direct referrals without having to go via the young person’s GP.

In addition to family and informal networks of support, the participants had received help from a variety of social and health care professionals. There was a clear intention on the part of professionals to adopt a variety of medical, social and psychological approaches. In particular, when young people received a drug-based treatment, efforts were made to complement this with social interventions. One of the psychiatrists interviewed cautioned against an over-reliance on medication.

*Sometimes what you do by medicalising it, you actually de-skill them [young people] as it were. And if you could give them something other than a tablet say, some form of self-help that would actually gear up their own coping mechanisms [it would be] an awful lot better.*

### Talking to someone

Most people said that simply having someone to talk to was helpful in addressing their fears and worries or depressing thoughts. Often this would be their assigned community learning disability or mental health nurse or social worker. One person used the saying that 'a problem shared is a problem halved' to describe how talking with someone helped her. Sometimes people felt that it was particularly helpful to have emotional support from a person outside their immediate circle of family or friends, with whom they could talk about feelings of a personal or private nature. For Mel, this included issues relating to sexuality or distress about tensions in the family home.

*'So how often do you have to go up to see him [psychiatrist]?'*

***'I think it's every two months.'***

*'So what does he talk about? Does he ask you how you're getting on or..?'*

***'Aye and I show him my diary.'***

*'What do you think he's trying to do?'*

***'I don't know. He's trying to help me but...'***

*'Trying to help you? Do you think it helps?'*

***'Sometimes.'***

*'Well what way does it help you?'*

***'There is someone there to talk to – like I can't talk to my mum or dad as they start shouting at me. Can't talk to anybody apart from [community nurse].'***

### Support from community nurses and social workers

The support of the community nurse was crucial to Mel's parents. Here her mother describes how regular contact with the community nurse helped her cope with Mel's difficulties.

*It's a relief for me because I can go and say to [community nurse] the problems I've had with Mel and [community nurse] can speak to Mel and find out what's bothering her. That day I said to [community nurse] 'There is something bothering Mel' and that's when I found out she had actually hurt herself. She had tried to break her wrists. It takes the pressure off me, myself. I'm the one with her 24/7 and I have things wrong with me but I would like more [help].*



Several individuals did have an opportunity to address the nature of their anxieties or distress. A social worker and a psychologist provided anger management work and bereavement counselling for one young man. However, while his carer and teachers noticed a difference in his behaviour, he did not indicate that this had been helpful. In contrast, another young man appreciated the guidance and anxiety management treatment provided by his community nurse. He said that he used the breathing techniques he had learned to control his feelings of panic. Most of the young people with community nurses greatly valued this contact. For example, on hearing that an old boyfriend had died suddenly, Mel had periods of anxiety during which she confided in her community nurse. Yet this supportive contact was generally only available during the young person's course of treatment for a diagnosed mental health problem, like anxiety or depression. Some of the young people came to depend on their community nurses for emotional support and this caused difficulties when the nurses withdrew at the end of treatment. Mel described her wish to contact her community nurse when her father was taken ill.

*'You were trying to get hold of [community nurse]?'*

*'Aye to talk to her about it.'*

*'Well, was it just that you were worried about your dad?'*

*'Aye worried about my dad an' that.'*

*'Well, were you able to get in touch with [community nurse]?'*

*'No it was hard to get in touch with anybody.'*

*'What did you do?'*

*'Just coped with it myself.'*

Karen similarly described her annoyance that her nurse therapist was not available to support her.

*“Now my Ma's kicking up with her. She said she was gonna phone and she never. I've had enough of her – she's not phoned. Any time I got a hospital appointment I can't find where I should go and I'm always getting lost if she can't go with me. But every time I was gonna go she said 'Oh I can't come, I've got a meeting' or, 'I've been not well for a couple of weeks so I have to do this' and [she] just keeps cancelling things and not wanting to come out.”*

Darren received support from his community nurse after an episode of serious anxiety. He was visited over a period of eight months on a weekly, fortnightly and then monthly basis. Darren talked to his community nurse on a very personal level and about things that he felt he could not discuss with his parents. While his recovery was steady and both he and his parents were pleased with his progress, there remained an anxiety that he might not have anyone to call on should things go wrong in the future.

At times social workers played a similarly supportive role. Sam started receiving input from his social worker a year after his mother died. His aunt had become his main carer and he was having difficulties adjusting to these changes. Consequently, his relationship with his aunt was deteriorating to the extent that she was not confident that she could continue caring for Sam. It took Sam a few months to trust and confide in his social worker. Both Sam and his carer attribute their improved relationship to working with their social worker. He was also integral in identifying the source of many of Sam's problems and subsequently in initiating referrals to mental health services.

Sadly, the social and emotional support available for most participants was limited, with several individuals identifying the researcher as one of the few people they could confide in. Gary's father explained the level of support he felt his son needed.

*I think wi' Gary I feel as though his confidence and esteem has got to be boosted every day, you've got to build him up, make him feel good, just saying small things or even just talking to him ordinary, trying to invite him into a conversation, you know, trying to get him to talk, you know, but if you don't do that, if you don't make that kinda effort... he's prone... to depression and everything was black, you know.*

### Something to do

Having something to do during the day was welcomed by participants, raising their morale and breaking the monotony of life at home. Therefore, organising meaningful social activities was often a key aim of professionals working with some of the young people. Gary's community nurse gave a personal view about how Gary would benefit from having a job and working.

*I think his structure of activities, his employment... are still the most crucial... that will improve his mental attitude and give him a sense of esteem and self-worth and value. And I think he would become less dependent on alcohol as a result of that, and I think he would have less need for medication to help him sleep at night...*

Families were usually at the core of people's social lives and networks. By and large, the participants had limited social opportunities outside their homes, but enjoyed the activities they took part in. Some enjoyed social clubs for people with learning disabilities, whilst a college's attempt to foster friendships between students proved to be the mainstay of another young woman's social life.

Developing people's social activities or offering a more purposeful life are complex matters, requiring not only good communication between services but also sufficient resources, as this further comment illustrates.

*“I suspect the sort of services I or we will be delivering for Gary won't be in isolation, focused just on him as an individual. We will be trying to work with and encourage and facilitate other people within his social system to help him make some changes, to help him find a niche in the social world where he is more comfortable. It's quite difficult because the resources aren't there.”*

While a social care professional might view a work or college placement for a morning or afternoon a week as a significant achievement, it can be a different picture from the point of view of the individual who is spending the rest of the week with nothing to do, as illustrated earlier. Some of the younger individuals in the study had low attendance at college or school, or had dropped out. Their reasons for failing to attend included boredom and difficulties in coping with FE establishments, where several individuals reported being in conflict with peers. Yet the potential importance of educational experience was highlighted by Susan's expression of pride in passing a first aid exam. She was someone who rarely attended her college courses, but had turned up faithfully for all the first aid classes.

It would be wrong to give the impression that these young people were passive, waiting for services to respond to their needs. Most made great efforts to find day-time occupation or to build a social life for themselves. One man was successful in finding himself work, albeit unpaid, cleaning at a local pub several mornings a week. Several individuals also participated in activities in mainstream settings, and would make regular trips into their local town or city for nights out. While they looked forward to these trips they were solitary outings, with the uncertain promise of meeting individuals whom they knew at the venues. From participants' own accounts and the photographs they took of their outings, there was evidence that their trips could take them into situations they found anxiety-provoking. It was also apparent that they were often on the social margins of events.

Although social care agencies aimed to provide better work and social opportunities for the young people, these had not materialised during the course of this study. Therefore, it is not possible to say what their impact on participants' perceived well-being would have been.

### **Alcohol use**

Several young men said that they had used alcohol to make themselves feel better. However, they acknowledged that they had ended up feeling much worse when under the influence of alcohol.

*'I was out last Thursday – it was like half out of it and it was just scary stuff, man.'*

*'Why, what happened to you?'*

*'I don't know, something happened which I... made me want to fling myself in front of cars again...'*

'On Thursday?'

*'I don't know what's causing it – what it's about ... I drink and then ...'*

### Medication

Several individuals had been given medication to help tackle their mental health problems. In one instance a young man did not feel that there had been any noticeable benefit, despite several changes in his medication, whilst another man remarked that taking the pills had helped him to recover from his 'illness'. Others, who were on long-term medication, were unsure how this had helped.

*'So how long have you been taking those [anti-depressants] Mel?'*

*'About two years now, two years.'*

*'And do you think that has helped?'*

*'A wee bit but not much.'*

There were significant problems for participants who had epilepsy. For one participant with symptoms of anxiety, these were attributed to her epilepsy and the possible effects of related medication. There seemed to be no attempt to investigate her anxiety more fully, despite the fact that it had a significant effect on her well-being, and it was not being addressed either by mental health services or by those treating her epilepsy.

## 4. Barriers to help

The study identified a number of barriers for people trying to access help and support, and these are briefly described below.

### Difficulties with services realising a multidisciplinary approach

The philosophy underpinning multidisciplinary team working is generally intended to help people with learning disabilities to have as ordinary and fulfilling a life as possible. The value of this approach to working with young people with learning disabilities and anxiety/depression was underlined by one of the key informants interviewed.

*'Depression is not one condition, it's a whole spectrum of disorders, from people who are having what we would call a mild depressive episode, usually in response to some sort of social circumstances – entirely understandable – right through to people who have got a very severe, recurrent disorder. I mean it's a multi-faceted problem and you are going to need a variety of different approaches.'*  
(Psychiatrist, Scottish Executive)

However, in the areas studied it was sometimes unclear as to when an individual should receive support from different specialist services. One key informant, a psychologist, commented that while psychiatry and psychology were increasingly working together,

there were still cases in which a young person's treatment may be limited to one or another approach.

*It seems to me that we [psychologists] are picking up a lot of people who are treated by psychiatry with an anti-depressant and there doesn't seem to be any psychological input, and yet you would think surely that's one of the areas where there should be.*

One participant received psychiatric help, in the form of medication, and regular visits by a community nurse while dealing with a period of acute anxiety relating to his sexuality. However, when it came to dealing with his worries, it is interesting that no-one addressed his feelings and thoughts about sexuality. Despite the vital importance of establishing sexual identity in social and emotional development, support was limited to a sex education course at college and being advised by his community nurse to steer clear of gay bars.

While there was often recognition that young people needed the support of social services and other agencies, one community nurse described how this was not always easy to secure. Gary's community nurse commented:

*Certainly social workers were involved but currently he hasn't got somebody allocated at this time because the area social worker has left and we haven't got a replacement, and that's a wee bit of an issue for us as well, because it's useful for ourselves as health workers linking in with other people at that point, you know.*

In such circumstances, community nurses sometimes tried to fulfil a social work role for the young people. However, this was not always viewed as being either within the parameters of their own work or feasible. In addition, finding suitable work and training placements for young people with learning disabilities was often difficult, particularly for those from more rural areas.

### Planning

Working collaboratively to plan a person's treatment also created difficulties, particularly in liaising with families. In some cases, there appeared to be no overall strategic plan for addressing a young person's difficulties, as outlined by one clinical psychologist.

*I think it is difficult for professionals and for families to actually see a plan... we might have a clear plan but... it doesn't always fit with the family's plan or the other professionals' plans.*

This is in contrast with a person-centred approach that links and co-ordinates different contributions to agreed goals.

### Communication

At times, communication between different services was difficult. In some cases, this led to young people missing out on appropriate professional intervention. Sam's input from a clinical psychologist was put on hold while he was being seen by a counselling service. Sam stopped attending the counselling service but no one informed his clinical psychologist. As a result, Sam had no support from services at a time when he was particularly vulnerable. Following concerns raised by her school, Susan was referred to mental health services. She was assessed by a psychiatrist and referred to an adult community learning disability team. This referral got lost in the system and Susan effectively disappeared from services for a number of months. The psychiatrist was not aware of this until interviewed by a researcher for this study.

### Referrals

A further difficulty to emerge was that some mental health professionals expressed concern that they were only contacted by other services when a young person's behaviour became difficult to manage. For example, Sam's clinical psychologist expressed some frustration that school only made contact when Sam was aggressive and not when he was experiencing low mood.

*“He's not a problem for schools and the only reason why they are not phoning us is that he's not been threatening other people or getting into scrapes and things. He's just a quiet young man who's very, very unhappy and I think we want to really engage with what that's about, and if we can be of any help, and how we can organise that.”*

### Young people's awareness of treatment

Participants were frequently unaware of, or unclear about, the reasons they were being asked to attend a mental health service. On occasion, this caused confusion and fear about meeting with professionals. When Sam first attended a mental health service, he and his aunt were seen separately. Sam believed that he was being taken away. His aunt explained:

*“Sam was paranoid cos they were taking him into a different room. He thought he was being put away. An' I asked him why and he says 'Because you're always saying you're putting me away' and I said 'I know I say it but I wouldn't actually put you away, I'm no that type o' person'. And the reason I put up with him for so long is cos I love him, plus I'm doing what his mum would've wanted me to do for him.”*

Susan had been referred to a psychiatrist by her school. However, she did not understand how the psychiatrist could help and was unaware why the referral had been made. She assumed that it was due to her behaviour at school.

*'Why did you see the psychiatrist?'*

*'Just to see, eh, how I act and how I act in public – public places and also in school. She spoke to us about how I got on in school, about my behaviour an' that.'*

### **Family carers' unease at meetings**

Some family carers were uncomfortable meeting with professionals, particularly when this involved large interdisciplinary meetings. Gary's father described his feelings.

*'I think that last meeting – I felt it was my opportunity to eke a bit of information out of them, because what I wanted to say to them was how I was dealing with it and I would have hoped that maybe they would suggest that I could deal with certain things maybe a different way... or maybe even just to reassure me that I'm having the right attitude towards Gary when he does things – I don't know. I was hoping for something like that, but the upshot of it was there was a crowd of them there and I'm no' a good speaker amongst a crowd. One to one I'm OK. I couldn't think of anything that I could say, so it was a wasted opportunity for them.'*

Other family carers expressed frustration that some meetings seemed to be called only when the young person's behaviour had caused difficulties.

### **Mental health of family carers**

Three of the participants' family carers reported having their own mental health problems, and also anxiety and depression, for which they were receiving professional treatment. At times, their well-being was linked to that of their children, as the following example illustrates.

*'I suffer from the panic attacks mostly as well. It's nothing to do with Sam, I've suffered panic attacks ever since I've had my daughter, but Sam wasn't helping at the time cos he was making my nerves worse. But now that's quietened down a lot, it's been a lot better.'*

However, despite this link there was little evidence of co-operation between the professionals working with the family carers and those providing support to the young person. For example, Karen's community nurse felt that Karen's mother required extra support and was concerned about her well-being. With permission, she wrote to the mother's psychiatrist in an attempt to develop some joint working that would benefit the whole family. No response was ever received.

### **Difficulties in maintaining contact and attending appointments**

Several of the participants found services helpful. However they stopped going to these services due to difficulties in getting there, finding the time to fit in appointments when

attending several different services, working or going to school/college, or forgetting appointments.

Some participants lived at a number of different addresses and had several mobile phone numbers as contact numbers. Services struggled to keep in touch with these young people, as writing formally to one address seldom found the right person.

## Conclusions

This section returns to the three main aims of the study, addressing each in turn.

### **Aim 1** To explore how young people with learning disabilities understand anxiety and depression, its treatment and impact on their lives

#### *Young people's understanding of their situations*

Not surprisingly, the young people did not discuss their understanding of mental health issues in abstract terms, but tended to use descriptive terms often linked to unpleasant emotional and physical sensations. They used words like 'temper', 'panic' 'bored', 'feart' [frightened], 'fed up' and 'things wrong with me', and described the physiological symptoms of anxiety and depression, such as sweaty palms and hyperventilation. Sometimes they used phrases which seemed to have been picked up from others, like 'mood swings' and 'in a huff'.

In most cases, their understanding extended to the perceived causes of their feelings, notably loss and bereavement, family conflict, troubled relationships with peers, social isolation and worries about specific health conditions. The young people also referred to difficulties achieving the recognised milestones of transition to adulthood, although some were less explicit in linking these to their anxiety or depression. Overall, the young people had varying degrees of insight into their own situations.

#### *The effects of the wider, social context*

The young people's problems need to be considered within the wider context of their lives. They are not passive individuals shaped by external forces; rather they are actively trying to make sense of the world and establish their own identities within it. Some of the participants have achieved limited success in this respect, gaining part-time employment or attending courses at their local FE college. Similarly, with support, some have developed social lives based around college friends, while others have learned how to travel independently, enabling regular outings to pubs and clubs. However, their efforts to develop their own identities sometimes had the unwanted effect of increasing their anxiety or sense of despair. Experiencing difficulties in sustaining employment, living independently, having a boyfriend or girlfriend, or socialising with peers were all factors that contributed to distress among the participants. These worries were heightened where individuals lacked a peer group of close friends to talk with.



In conclusion, young people do need to feel empowered to have control over their lives and to develop a sense of self-confidence, but they also need support to achieve their goals, and recognition from others in order to gain a sense of fulfilment. Paradoxically, while participants may be active in pursuing the lives they want, their position vis-à-vis the services that might provide them with emotional support is a passive one. Professionals determine if young people are 'ill' enough to require support.

**Aim 2 To study how family carers have identified and coped with anxiety and depression in young people with learning disabilities**

*The stress of caring*

The findings indicate that, while most families 'wanted the best' for their son or daughter and strove to support them through their difficulties, the effects of doing so could be very stressful. Some parents were unsure what behaviour was a 'normal' part of adolescence and growing up, what might be attributed to 'learning disability', and what indicated real mental distress. Parents whose sons or daughters could occasionally be aggressive or even physically violent faced particular stress, two admitting to feeling frightened at times. Indeed, a few family carers had their own mental health difficulties. Despite these challenges, some parents took the view that it was their duty to cope and were reluctant to seek outside help. In addition, most lacked information about what external support was available.

*Effectiveness of services*

Once linked into services, parents had mixed views about their effectiveness. While some professionals were identified as particularly helpful, and their input was seen as vital in maintaining or improving the young person's current circumstances, others were described as insensitive or out of touch, making suggestions which were considered irrelevant or impractical.

**Aim 3 To examine the response of mental health and learning disability services in assisting young people and their carers to deal with anxiety and depression**

*Lack of awareness of services*

Before considering the kind of help that might be most appropriate, the first question concerns who there is to turn to. None of the participants, nor the majority of their family carers, were aware of specialist services available to support them. Instead, most participants were either referred to services by their school or college or through their GP. This raises questions about how young people are identified as needing help. Some of the participants were clearly referred to services because of their challenging or aggressive behaviour. However others, who were also suffering distress but had become withdrawn, were not referred. The findings indicate a third group – youngsters who, for a variety of reasons, may not wish to discuss their worries with family members or other

carers, particularly issues of a sexual nature. With no evidence of participants referring themselves, access to help in such circumstances seems unlikely. Perhaps primary care and specialist services have to ask themselves what they need to do to reach out to these young people and their families in order to offer much-needed emotional support, rather than waiting for a crisis call.

### *Nature of support*

The next issue is the nature of support that people might require in relation to their emotional distress. As stated previously, participants' worries made most sense when considered in the context of their wider lives. There is a danger that some psychologists or psychiatrists working solely in a clinical setting have difficulty grasping this broader context and will address people's problems in isolation. It is particularly worth noting that coping with epilepsy can invoke considerable anxiety for young people, yet this seems not to be addressed sufficiently by services.

### *Limitations of support*

All the participants benefited from emotional support which came directly or indirectly from their involvement with different forms of service provision. In some cases, this meant developing a close relationship with their community nurse or social worker over a period of time. Often this appeared to be very beneficial to the young people involved and a source of support to their carer. However, such emotional support was not unproblematic. Firstly, few of the participants obtained support around the nature of their thoughts and feelings and they could have benefited from more intensive psychological support than that delivered through their community nurse or social worker. Secondly, such support was consistently framed and provided only within the 'treatment' period of the young person's anxiety or depression. Hence, while its contribution appears to have been crucial in participants' recovery process, there was little or no possibility of such support being provided as an ongoing resource. This concern was identified by participants and their family carers.

The limiting of such support by services may be a rational response to working within restricted budgets. In some cases, professionals may also be assuming that young people have informal sources of emotional support they can draw on when dealing with everyday difficulties, but this may not be so. Young people who struggle with aspects of their everyday lives may be more prone to crises and there is clearly a need to ensure that continuing support is available.

The study points to instances where health professionals provided effective help and where social support played an important role in the well-being of these young people. Yet the health interventions tended to be confined to episodes of treatment, and there was a struggle to obtain substantive social support before a crisis point had been reached. Unfortunately, this often meant that the available help was inadequate to meet the needs and aspirations of these young people and their families.

### PRACTICAL IDEAS FOR ACTION

- Young people need to know where to look for help, and services need to be directly accessible to young people. They need more support in attending appointments. Some young people live at several addresses, and others do not want to miss time at school or college to attend an appointment in the middle of the day.
- There should be an increased awareness of the need to respond to less 'challenging' expressions of distress in young people, rather than wait until the person has really deteriorated.
- Schools and colleges can have a very positive impact on young people suffering distress. Increased awareness in schools and colleges of different expressions of distress in young people could help them make appropriate referrals and work with young people more effectively.
- Rather than relying on the spoken word when assessing mental health problems, try other forms of communication, e.g. photographs, symbols and video. Asking the young person about significant people or places can facilitate conversation around what is making them feel depressed or anxious; for example, 'tell me why you took this photo?'
- The 'episodic' nature of treatment needs to be developed into a model capable of sustaining ongoing emotional support for young people. Young people want someone to talk to, therefore more counselling type services, or availability of professionals young people can talk to is required (particularly relating to sexual problems).
- Increased communication and joint working is necessary between adult mental health services treating family carers and those treating young people. More attention should be paid to addressing the needs of the whole family.
- Young people require more opportunities to go out with friends and be employed as staying at home for lengthy periods can have an adverse effect on their mental health.

### **Project resources**

The research team has produced a video called *What's happening?* It presents the experiences of young people from the study, allowing others to identify with and learn from them. Its target audience is young people and their families and practitioners.

The video is available from The Foundation for People with Learning Disabilities.

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## CHAPTER FOUR

# Supporting young people with learning disabilities and mental health needs from a minority ethnic community

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### Introduction

#### ***Project summary***

*There are so many problems... the girl needs 24 hour help... We have to take it in turns to look after her.*

Two major issues in supporting young people from minority ethnic communities are the family carer's awareness of their child's mental health needs and their perception of what services are available. This research project focused on the needs of young people with learning disabilities from Pakistani and Bangladeshi communities in Bradford and explored some ways of improving access to services. The project included mapping of service use by families; focus groups with service users and service providers to identify the barriers to accessing services; and recommendations for future services. During the project one group of families was allocated a liaison worker for nine months to help them get in touch with the services they requested, whereas another group carried on without this type of support. A comparison was made of service take-up, behavioural issues of the young person, and carer stress. Additionally, a detailed case analysis was made of 10 young people with learning disabilities with behavioural/mental health concerns to gain greater insight into issues affecting the young people.

The findings of this research indicated that young people from Pakistani and Bangladeshi communities and their families experience significant problems in accessing services. These arise from lack of knowledge and awareness about what support is available, language barriers, inability or reluctance to get help, and perceptions and beliefs about caring and the role of the family. Families who had received help from the liaison worker had significantly more frequent contact with a wider range of services and with more positive outcomes than those who had not.

### **Project aims**

The project set out to evaluate the effectiveness of specialist liaison services in ensuring adequate access to services for families from an ethnic minority community. In particular, it aimed to:

- map the level of service use amongst Pakistani and Bangladeshi young people with severe learning disabilities and mental health problems
- examine the processes involved in ensuring adequate access to services
- compare outcomes for Pakistani and Bangladeshi young people with severe learning disabilities and mental health problems either allocated or not allocated to a specialist liaison worker
- develop awareness and consensus around best care for Pakistani and Bangladeshi young people with learning disabilities and mental health problems.

This study was conducted in Bradford city and surrounding areas, where there is a high proportion of people from Pakistani and Bangladeshi communities.

### **The context**

#### *Ethnic diversity and learning disability*

The UK population is gradually becoming more diverse and complex in terms of ethnicity, culture, language and religion. The 2001 Census showed that south Asian communities made up 4% of the UK population with Pakistani and Bangladeshi communities making up 1.8% of this figure.<sup>1</sup> In Bradford, 14.5% of the population is of Pakistani origin and 1.1% of the population is of Bangladeshi origin.

The increase in ethnic diversity is also apparent in the population of people with learning disabilities. Emerson and Hatton<sup>2</sup> reported that the current population suggested a projected 70% increase in the number of non-white people with intellectual disabilities in Great Britain from 1991–2021, compared to an increase of 3% in the white population. There is an over-representation of children from minority ethnic groups in special education, compared to white children, although this does not seem to follow through into use of services. For example, there is an under-representation of people with learning disabilities from minority ethnic groups in residential services and an under-representation of south Asian adults from the UK in the use of psychiatric services.

### *Social inequality*

There is considerable evidence that inequality and exclusion are characteristics of the experiences of south Asian communities in the UK. The fourth national survey of ethnic minorities<sup>3</sup> reported that Pakistani and Bangladeshi communities were one of the poorest groups in the UK. Along with other minority ethnic groups in the UK, British Asians face substantial inequalities, discrimination and disadvantage: they are more likely to live in substandard housing in inner-city areas, be employed in semi-skilled or unskilled jobs, be unemployed and experience discrimination in education, health and social services.<sup>4</sup> Within the south Asian population, Pakistani and Bangladeshi populations in particular are likely to experience inequalities, discrimination, and disadvantage.<sup>5</sup>

### *Needs of south Asian families*

The prevalence of learning disabilities in people aged between five and 34 years is three times higher in the south Asian community compared to the rest of the whole population.<sup>6</sup> Compared to white families with a learning disabled person (who may also face material disadvantage, compared to white families without a disabled child), south Asian families face material disadvantage in terms of housing, unemployment, transport, income and benefits.<sup>7</sup> Many south Asian families may have more than one disabled child in the family, and some of these young people may have severe and complex learning disabilities which place the families under severe stress. Mir *et al*<sup>8</sup> argue that the needs of these communities are often not addressed by health and social welfare services, resulting in inappropriate provision and consequently low take up of services.

### *Importance of the project*

While research has examined the experiences of parents of disabled children from minority ethnic communities<sup>9</sup>, the voice of disabled people from minority ethnic communities is virtually silent.<sup>10</sup> The experiences of disabled children from minority ethnic groups and their families would increase our understanding of how culture and religion, alongside disability, affects their identity and self-image and whether it makes their experiences different from white disabled young people.

## **How the project was carried out**

The project involved three phases, each of which is described below.

### ***Phase 1: Service mapping***

The first phase of the project involved the mapping of service use by families and young people with learning disabilities from Pakistani and Bangladeshi communities. The aims of service mapping were to:



- identify the range and types of support provided by services
- explore families' awareness of the types of services available
- explore the pattern and problems of access to these services by families and their suggestions for improving access.

More information about service mapping is included in *Chapter 2*.

The characteristics of the participants in the study are summarised in *Table 2*.

**Table 2** Characteristics of participants for the mapping study

	Number of young people
Sample size	35
Age range	14–25 years
Gender	26 male, 9 female
<b>Degree of intellectual disability</b>	
Mild	11
Moderate	8
Severe	16
<b>Families</b>	
Pakistani families	31
Bangladeshi families	4
<b>Accommodation</b>	
Living with family	34
Group home	1
<b>Language ability</b>	
Some language/able to communicate	26
No spoken language	9
<b>Conditions known to families</b>	
Behaviour problems	2
Autism	2
Down's Syndrome	4
Cerebral palsy	2
Joubert's Syndrome	1
Epilepsy	5
<b>Language used in interview</b>	
Urdu	14
English and Urdu	1
Bengali	2
English	18

A brief semi-structured questionnaire was developed to collect the mapping information, based on the schedules used by Emerson and Robertson.<sup>11</sup> Prior to the mapping interview all individuals were screened for behaviour and/or mental illness symptoms<sup>12</sup> and individuals who tested positive for mental illness were recruited for this study. Written consent was obtained from family carers of young people below the age of 18, and informed consent from individuals above 18 years old.

All the participants were interviewed with their family carers; four young people were able to articulate their own responses, but in the remaining cases the family carers responded to the questions.

The mapping exercise was followed by focus groups with family carers and service providers to identify barriers that limit access to and uptake of services. The focus groups included family groups (involving 11 family members) and a service provider group (involving four service providers).

## **Phase 2: Liaison worker intervention**

### **Liaison worker role**

The next phase of the project examined the impact of using a liaison worker to raise awareness of existing service provision and help families to get in touch with the services that they requested. The findings from the Phase 1 focus groups provided a basis for defining what the liaison worker role should entail. This included making regular contact with families, advising about the availability of particular services and helping participants access these services. More detailed tasks included:

- liaising with families once every month or more, if required, via home visits and over the phone (liaison worker to keep detailed records)
- discussing the family's concerns and work on the types of help required for the young person and the family
- reflecting on the family's issues/problems and working on ways to move forward
- exploring services required and gaining access to them
- liaising with agencies, teams and individuals who provide services, making them aware of the needs of the family and young person and discussing how service providers could take action to meet them
- communicating information back to the family and helping them get in touch with the services, by networking with family and service providers
- checking if the family acted upon advice given by the liaison worker and/or whether services were able to help and bridge any gaps
- exploring other possibilities for the family and young person
- ensuring families, young people and services are able to link up with each other and maintain appropriate contact, and that help is received or given, as and when required.

### **Randomised controlled trial**

A pilot randomised controlled trial (RCT) was conducted to examine the impact of using a liaison worker in the above ways. Participants were randomly allocated to two groups, one of which was provided with a liaison worker for a period of nine months (the 'intervention group'), whilst the other group carried on accessing services as before (the 'control group'). The study was explained to the young people and their family carers who gave written consent to take part.

Baseline measures and outcome measures were used to assess the following differences over time for all families:

- service access and uptake
- the young person's strengths, difficulties and behavioural issues
- stress and health issues relating to the main family carers.

A total of 12 families took part in the intervention group and 14 in the control group. More information about RCT and the assessment measures used are included in *Appendix C*.

### **Contact with liaison worker**

The liaison worker collected baseline and post-intervention data from the control group, and baseline data from the intervention group. Another researcher collected post-intervention data from the intervention group. The liaison worker visited or telephoned families in the intervention group at least once every three weeks, but did not personally provide any specific interventions. She kept a diary of all the visits and interventions provided for the young person and their family.

### **Contact with services**

At the end of the study all the family carers were asked to report the total number of contacts they had had with services during the study period, the number of contacts with different services and the number of interventions that resulted from their contacts. For participants in the intervention group, contacts with services were also recorded by the liaison worker as a means of checking the accuracy of their self-reports.

### **Phase 3: Case analysis**

In order to gain greater insight into issues affecting the young people, the final phase involved conducting case analyses of 10 young people with learning disabilities with behaviour/mental health concerns. The case analyses were carried out after completion of the RCT with five young people from the intervention group who had been allocated a liaison worker (two with severe learning disability, two with moderate learning disability and one with mild learning disability), and five young people from the control group who had received no liaison worker support (two with severe learning disability, one with moderate learning disability and two with mild learning disability). The characteristics of

this sample highlighted the degree of disability and the nature of difficulties experienced by the young people and their families. The overall analysis explored the access and take up of services for both groups.

Focus groups were also held with families and service providers to feed back the findings of the RCT and look at recommendations for future service provision for this particular group.


## Main findings

### **Findings from Phase 1: Focus groups with family carers**

The following findings are drawn from focus groups held with family carers both before and after the RCT period.

In focus groups prior to the introduction of the liaison worker, family carers discussed issues around their son's/daughter's disability and how other physical and mental health issues also affected the families. Carers felt overwhelmed by their children's behavioural and mental health concerns and desperately wanted service providers to help them with this. They expressed the emotional burden the child's disability places on them and reported high levels of stress.

Some family carers commented on the strain of coping with health complications which were not being addressed.

 *She's got diabetes, asthma... it's too hard... she doesn't sleep at night and upsets us all night...*

Sometimes other members of the family had a disability and family carers also had health concerns of their own.

Stigma was examined and family carers said it was not the stigma that affected them but the fact that other people just did not know how to respond to the disabled young person and viewed them as being childish or naughty, especially the older generation.

### **Problems with support services**

All the family carers agreed that they were not receiving the help or support they required, and some young people were not accessing any services at all. Difficulties in initial diagnosis or late diagnosis were mentioned, and support from clinical specialists and professionals were either lacking or sporadic. Family carers who were actively seeking support to help the young person reported that it took too long accessing any help. For example, there were reported problems in accessing support via their GP, including waiting too long for help and too much 'to-ing and fro-ing'.

Family carers also felt frustrated with repeating the same information to different professionals that they met.

*“That’s what I don’t like, talking about it, because some people come and it’s like you’re repeating the same thing to some people, and they come and they get a pen and write it down and then nothing, you know.”*

Most family carers reported their main source of help was a local voluntary organisation and child and adolescent services. When professional help was provided, carers did not know which professionals were seeing their son/daughter and felt care staff tended to be unqualified to do their job properly.

*“They were sending somebody for my daughter, but she had no training or work with special needs children and so we gave up after two weeks.”*

Another problem highlighted was a need for transport to get to services.

Family carers reported that they felt service providers blamed parents for not looking after their children properly. They also reported that the other siblings were neglected, as the care and support for the disabled young person took up so much time that they could not give the time required to the other family members.

*“We just want more attention and more support for the normal children because it is difficult for the parents when there are other children in the house to give them the attention that they need.”*

Family carers acknowledged that lack of money and resources were a big concern and also that waiting lists were far too long; the young person could be waiting for a long time before being seen by an appropriate service provider.

The focus groups explored issues around service provision that affected both service users and service providers. A number of themes emerged from these about problems of and barriers to accessing services. Each is briefly described here and put in the context of related research findings.

### **Knowledge and awareness**

The biggest barrier to uptake appeared to be a lack of knowledge and awareness of services. Most participants reported not knowing about particular services, or how to access them.

*“No one’s ever explained or told me about the different types of help I could get so I don’t know what’s out there.”*

This finding supports previous research findings, for example Chamba *et al*<sup>13</sup> argue that given the lack of awareness and service support reported, it is not surprising that unmet needs feature so highly in this population.

### Mental health and behavioural concerns

A few of the family carers acknowledged that their son/daughter had some form of mental health concern and/or displayed challenging behaviour that placed a strain on their ability to care for them, and were willing to accept help and support.

*“She’s always trying to get out of the house to play with other kids and if we don’t let her go, she fights with us and hits us. If we don’t let her go out, she gets aggressive with us.”*

However, many family carers were not aware of the mental health and behavioural concerns of their son/daughter. Lack of knowledge about the link between mental health and behavioural concerns, alongside a lack of awareness of the most appropriate help and support in the locality, meant that they were not seeking any therapeutic services. The literature highlights that south Asian people experience high levels of stress and psychological morbidity but make significantly less use of psychiatric services than white people. They are also generally more reluctant to present with mental health problems because of the fear or distrust of psychiatrists and also because of the stigma attached to ‘insanity’.<sup>14</sup>

### Family reputation

The findings from this study indicate that people were worried about how they were perceived by others.

*“Asian people worry about what others will say... people worry about their reputations. ...People talk about your problems and backbite and tell others, that’s why I wouldn’t use services” (Young person)*

Other research has indicated the vital importance of family reputations within close-knit communities and most south Asian people want to keep sensitive issues concerning their family members within the family structure, with carers taking extra precautions to hide any conditions associated with mental ill health.<sup>15</sup>

### Language and communication barriers

An important barrier to service uptake was language and communication. Family carers unable to speak English face particular problems in terms of access. A young person’s sister said:

*“Most services my sister got because of me – my parents can’t speak English so I have to get help on their behalf.”*

Another person commented:

*“Asian people don’t get a good response because they can’t explain their problems properly and are held back when they look for help.”*

These findings link to previous research which showed that interpreter or link worker schemes remain inadequate, with most service users relying on their young children for interpretation.<sup>16</sup> While there is a need for interpreters, the use of their services is very patchy.<sup>13</sup> Even when service users can speak English, poor communication between them and professionals, rather than language difficulties themselves, may limit south Asian families’ understanding of diagnosis and restrict further opportunities for discussion with the professional.<sup>17</sup>

### Self-reliance

The present study shows that the use of services may be affected by particular beliefs and perceptions held by people from south Asian backgrounds. Most families placed a premium on self-reliance and preferred to look after the young person at home.

*“If we look after her at home, we think she’ll be OK. Once she makes friends... it’s a matter of looking after her needs at home and caring for her here.”*

*“How can you rely on others to look after your kids properly...?”*

### Religious and cultural needs

Family carers in this study were of the opinion that the services often overlook the religious and cultural needs of the young person. Previous research has also highlighted the feeling from family carers that services are not culturally and religiously sensitive to the needs of the young people with learning disabilities.<sup>11</sup>

Religious beliefs played a crucial role for most of the families.

*“We’ve left it to Allah...we can’t do anything else...”*

Many had consulted religious or traditional healers in the hope that they would make their child ‘better’.

*“Yeah, we have (used religious/traditional healers abroad) because people said somebody might have done black magic on her... so we went abroad last year. When she was there, she found it difficult because of the different people and surroundings... they thought it was to do with black magic... so they got a religious man to do things... it didn’t work.”*

It should be noted that even though members of the south Asian community make more contact with religious healers, this does not mean that they are less likely to contact medical professionals.<sup>13, 18</sup> Certainly the sample in this study looked to both as a means of getting the help they needed.

*I hope that Allah makes her better... we just want to try to make her better... I've tried to get help from doctors in Pakistan and the doctor there told us we wouldn't get the best help as that could only come from this country. The doctor [local consultant] gives us medication... we use that.*

### Need for daytime and leisure services

Despite their self-reliance, many family carers expressed the need for their son or daughter to engage in day and leisure activities, rather than being stuck in the home all the time. Most of the family carers showed dissatisfaction with the social and recreational activities available and it was clear that their sons and daughters were spending much of their time at home, with resulting boredom and isolation. There was little access to local activities and leisure facilities in the community. Family carers felt there was not enough for the young person to do and wanted more daytime activities, as well as things to do at weekends and in the holidays.

*I need to know more about stuff to help him. Parents need a programme to help and show them how to access help and support for the kids; perhaps start a network of parents to organise outings... We would like him to get as much help as possible as he's gone without for so long. He might have gotten better if he'd got help earlier.*

However, most family carers felt that the future was bleak and that the young people will remain at home most of the time, being cared for by their families. Uptake of day services was low, as parents felt these were either not appropriate to the cultural and religious needs of the young people, or not available. Others just did not know about them. Other research has produced similar findings.<sup>19, 11</sup>

### Breaks for family carers

Family carers wanted respite for the young person, especially at weekends and in the holidays, but were not keen on overnight or long-stay care.

*I wouldn't want anyone to come and take them away for a few days.*

All the family carers still reported the difficulties of coping with the disabled young person because they were not getting any respite themselves and felt under constant stress. Family carers felt that they had to cope, regardless of the difficulties, and provide the necessary care and support themselves.



*“There’s three people looking after her... we have to do everything... sometimes I do it, or Mum does it or her sister does it... all day you’re running after her and you don’t get any time to yourself.”*

It was much harder as the child got older and this had a great impact on other siblings in the house.

### Financial costs

There was concern regarding the transition from children’s services to adult services and family carers felt there was a lack of choice and opportunity, as well as added costs of paying to use certain services.

*“You have to pay to send your child to day centres and if you can’t afford it, then you have to keep them at home.”*

### Future plans for care

The majority of family carers seemed uncertain about the future and felt that they had to take every day as it came, rather than making long-term plans for the young person:

*“It is a worry, we’ll probably [carry on using] day centres at the moment...”*

Lack of future plans post-school were particularly evident. Transition is a very stressful and confusing time, both for the young person and their families, and carers felt unsure about options available to the young person, other than day centres.

*“I want to become a social worker. I’m not too good at studying so might not go too far. If I can look after myself then it will be OK, but if not then my mum will have to do it.” (Young person)*

*“We had a meeting with her school because she’s going to turn 16 soon and they were wondering what she was going to do after that and we have decided she will stay on at school for another two years. She’s not ready to go out on her own so we can’t send her to college...”*

Most family carers agreed that the young person would stay with the family for the rest of their lives.

*“I hope that Allah makes her better...with her being a girl, its a lot harder... if she was a boy, we wouldn’t worry as much... she’ll be staying with us forever...we can’t think of getting her married because that would be wrong... we just want to try to make her better... money comes and goes so I don’t mind spending that to make her better.”*

## **Findings from Phase 1: Focus group with service providers**

The focus group with a range of primary care and specialist service providers highlighted a number of issues in providing appropriate services.

### *Cultural and religious issues*

Service providers felt that south Asian families tended to reject short-term breaks, usually due to the fact that they did not meet their religious or cultural needs, and many family carers tended to look after their disabled son/daughter for many years without additional support, as they felt it was their responsibility to do so.

*“The main experience that we’ve had is that families with kids with challenging behaviour have tried to cope for years without any support. They often say no [to respite care]... they feel it’s their responsibility...”*

In addition, they reported that family carers wanted female-only adult services for their daughters and did not like mixing, which was usually a bigger concern for the father than the mother.

Service providers mentioned the usefulness of a particular voluntary organisation that has provided a one-stop shop for a large number of south Asian families in Bradford. This organisation had been especially useful in advocating and mediating for families and service providers.

### *Awareness of services*

Service providers reported that family carers were more aware of the financial benefits available to them than of the range of support services. Many problems fell around transition, especially the gap between children’s and adults’ services, whereby families and service providers were confused about which service should meet the young person’s need during that period.

### *Service needs*

Service providers suggested that direct payments would be helpful, enabling families to get the money to make improvements as and when they wanted. However, there was agreement that families would find this very difficult to manage and that it might be open to abuse.

### *Contacting services*

Service providers also discussed the issue of social services having a central contact point and directing families to appropriate services, and recognised the stress on family carers caused by having to repeat themselves and not ‘getting very far’.

*...you have a central line to call [social services]... they can take 20 minutes... I found it was better when there was direct contact [to a social worker]... it's a lot harder, especially for Asian parents to contact the relevant person.*

### Long-term support

Another issue raised was that some services do not tend to take on cases long-term, which concerned families, who would have to go through the whole process of having their case re-opened for someone to help them. However, it was acknowledged that adult services were trying to maintain links with families in order to provide support over a longer period. Service providers discussed how sometimes 'you have to know the right people' to get the help you want.

### Young people with complex needs

Service providers felt that young people with mild/moderate disabilities tended to get more help than those with complex needs and challenging behaviour, making it even more difficult to achieve inclusive opportunities for this group.

*People with complex needs do tend to get left out and many organisations are only interested in mildly disabled kids. Inclusion means opportunities to be involved in activities in appropriate settings and there's a huge gap between special provision and mainstream provision...*

Those present also felt that there was more choice of adult services available, compared with provision within children's services.

### Summary of gaps and needs identified

Service providers examined ideal service provision for minority ethnic people with learning disabilities, reporting that failings within current service provision should be identified and improvements made and maintained. They highlighted the fact that no directors of services had been in the focus group and that their presence was needed, as any recommended changes arising from the project would take place through them. Some particular gaps and needs identified included:

- integration of young people with learning disabilities into mainstream services
- multi-agency work around the area of inclusion for these young people
- respite care for young people with challenging behaviour
- greater involvement of psychological services, especially CAMHS
- help for family carers at an earlier stage in the young person's life
- a one-stop shop for all services relating to learning disabilities that family carers could access when required

- greater partnership networks between services
- GP training in the area of learning disabilities and mental health issues, especially as they are the first point of contact by most family carers.

### **Findings from Phase 1: Service mapping**

All participants, except one living in a group home, received most support from their parents and family members, confirming findings from previous research.<sup>11</sup> Schools were highly rated by parents as being a good source of formal support but they were reluctant to use support groups and overnight short-term breaks.

With regard to formal support, there appeared to be high usage of generic and welfare support services, that is the GP and social services, compared to specialist disability services such as psychiatry and behaviour therapy. The reasons for this could include: the nature of the referral system and long waiting times for appointments which may deter south Asian people<sup>20</sup>; difficulties in communicating symptoms effectively<sup>21</sup>; and GPs' perceptions of south Asian patients as presenting with trivial complaints.<sup>22</sup>

### **Findings from Phase 2: Liaison worker intervention**

Results highlighted that families who had received support from the liaison worker felt better-equipped to help their son or daughter, whereas those who did not receive help reported continuing difficulties in gaining necessary access to services, help and support.

#### **Contact with services**

The main outcome measure agreed at the start of the project was number of contacts with services, since this best reflected the aim of the study to determine whether introduction of the specialist liaison worker could enhance access to such services. It was predicted that those allocated to the specialist worker would have more contact, greater variety of contact and more positive intervention outcomes with services than those in the control group.

This proved to be the case. Participants allocated to the specialist worker had statistically significantly more frequent contact, with more services, and with more positive outcomes from such contacts than did those in the control group, as shown in **Table 3**. Please refer to **Appendix C** for further details.

**Table 3** Summary of contact with services during the RCT

Group	No. of contacts with services	No. of different types  of help required	No. of outcomes achieved
Control	40	17	9
Intervention	111	47	33

### Brokering services

During the randomised control trial the families in the intervention group were able to ask liaison workers to access services on their behalf. Most of the help requested was based around access to leisure facilities, interpreting help, benefits advice, care and support for the young person and support for the family carer. **Table 4** is a summary of some of the services requested and subsequent actions: family carers discussed the kind of help they required for the young person and the liaison worker was able to contact appropriate services on their behalf.

**Table 4** Services requested and actions taken by liaison worker

Service requested and reason	Subsequent action and outcome
Leisure facilities	Weekly fitness sessions provided by voluntary group
Railings outside house	Contacted occupational therapy who sent assessment form and are looking into it
Blue badge (old one had lapsed)	Asked social services. Need to re-apply and will be assessed
Mother's need for support (suffers from severe depression and other health concerns)	Support group which she now attends weekly
Mother wants to learn English	Put in touch with local community centre which runs classes
Help with filling in disability forms	Help from benefits worker who speaks Punjabi
Direct payments for a support worker	Delay has been sorted out
Mother's difficulty in understanding what was said at hospital appointments	Hospital contacted about interpreting services
Transport to hospital appointments	CTLD looking into it but has not been sorted out
Concern about dental hygiene	Referral to local health centre – on waiting list
Advice about building a play area	Social worker asked to contact family
Medication decreased, then stopped for a young person which mother did not understand reasons for	Contact with psychiatrist and social worker to explain, via interpreter: Psychiatrist recommended video on autism for mother – not arrived
Safety adaptations to the home	Contact with social worker who helped get them
Incontinence problem	Contact with nurse to advise
Leisure facilities	Social worker trying to arrange funding – ongoing

After the RCT period the intervention group reported that they had found the liaison worker to be invaluable in helping them get the support they required for their young person.

*“Any time I needed [liaison worker] with any problems with school, I used to ring her up and she would ring that person... it has helped... knowing you can ring someone straight away when you need help.”*

In contrast, the control group reported that not much had changed in the past few months, as they were still struggling to get access to services:

*“We didn’t get anywhere... there was nothing. My son’s 18 now and he’s going through transition and it’s very difficult not having anyone there.”*

### Services needed

Findings showed that many family carers did not know what clinical services are available and they said that the schools often referred them to services. The consequence of this is that families rely on schools to help their child, thus offloading their concerns, and it is possible that they do not fully know and understand who the child has been referred to and why. Also, once the young person leaves school there is little help available to them if they need their son or daughter to be referred to appropriate services, apart from going to their GP.

Only two parents from the intervention group asked for psychiatric help for their son or daughter during the RCT period. For most families, there were other issues to be dealt with first, such as getting better housing, culturally sensitive short-term breaks/leisure activities and benefits. More specifically, the most common issues raised by the families were the need for leisure activities, housing extensions/adaptations, benefits advice, day services/activities and support in the home. However, it is worth noting that providing help in these areas may benefit the mental health, emotional and social well-being of the young people, as well as their family carers.

There are different perceptions about what help statutory services can offer families and clearer information is required from services and professionals about what is available. In terms of this study, most of the families sought help from a local voluntary organisation, recommended by others in a similar position, who felt that the organisation would help meet their needs in a culturally sensitive manner and communicate with them in their preferred language. The families had very high expectations of the organisation, viewing it as a one-stop shop for services.

In the service providers’ focus group following the RCT, it was reported that family carers required flexibility from services which was not currently available. They reported how a large number of families with disabled children had major problems with home improvement services. However, their feeling was that these services did not have a good understanding of disability, taking a long time to finish jobs and causing delays in work being carried out.

*There's one family with three disabled brothers and it's taken four damn years to get adaptations done to the house... the Home Improvement Service has no understanding of disability and treat it like any other case... these young people are not going to be around longer than 18–19 years and it takes four years to sort that out...*

### *Impact on mental well-being and general health of young people and family carers*

Before the trial period began it was proposed that people in the intervention group would be able to access more services with the help of the liaison worker and would fare better in the outcome measures. It was felt that the short duration of the project would make it unlikely that significant differences on the other measures could be achieved. However, this was only partly the case. While there were no differences between the two groups of young people on one measure of problem behaviours, another measure showed that over time the young people in the intervention group had decreased problem behaviours when compared with those in the control group. No significant differences were found between the family carer groups over time on psychiatric difficulties. However, a further assessment finding indicated that family carers of people allocated to the liaison worker had better physical health. Statistical details of these findings are given in *Appendix C*.

### **Findings from Phase 3: Case analysis**

The 10 case analyses gave a greater insight into the young person's social and personal life and issues surrounding health, support and service uptake. The young people included in the case analysis presented a number of complex and additional conditions and needs, for example autism, self-injury and epilepsy. Behaviour problems were often severe, including fighting, arguing, anger, tantrums, making noise, breaking, throwing and setting fire to things, and physically attacking family carers.

### *Family support*

Strong family support was evident, especially from parents and siblings. Though immediate family support was evident, none of the parents mentioned support from extended family networks, despite previous research emphasising strong extended family support in south Asian families. In these circumstances, it would be important to know what may happen if family support was no longer available and how this would affect the young person.

### *Impact on family carers*

An important issue raised was family carers having to give up work to look after the young person. The financial burden of looking after a disabled child was further aggravated when the family carer was not working. Most carers reported psychological and emotional strains of looking after the young person who often required 24-hour supervision, regardless of whether they were getting support or not. This may be because the help is not seen as sufficient and young people and family carers still require more support.

### Services received

Some of the professional services young people had received from time to time included:

- psychiatry
- speech therapy
- clinical psychology
- paediatrician/child and adolescent consultant
- physiotherapy
- district nurse
- social worker
- social worker from community learning disability team.

Other support services which had been used include:

- school support worker
- respite care
- home carer for a few hours per week
- voluntary organisations for support, advice, trips out of the house, finding a new place to live, finding a carer
- sports centre
- female-only day service
- religious healer.

### Problems in accessing services

Most of the young people displayed mental health concerns and behavioural issues. However, the majority of young people's needs in this area were not being addressed and the care and support given by the family carers might not be appropriate or adequate, which could result in things getting worse.

While it was evident that families in the intervention group were in touch with more services than those in the control group, the case analyses showed a number of common problems and issues in accessing services, many of which had already been highlighted by the focus groups of family carers. These are discussed in the section on focus groups in *Findings from Phase 1*, page 69 and include general lack of support from services, waiting times, language barriers, lack of awareness of services, health concerns of both the young person and the family carer, and lack of leisure facilities. The case analyses also raised a number of additional, social issues which are discussed below.

### Social networks and relationships

Friendships for the young people were usually based solely at school or at a day centre. Those not accessing help or those who stayed at home all the time did not have local friends. Family carers discussed underlying issues regarding sexual matters. However,



most carers might feel uncomfortable talking about this and not regard it as a priority or as a problem that needs addressing.

### *Marriage*

Marriage was discussed and most family carers wanted the young person to get married. However, most recognised that this may never happen and felt saddened by this, especially as they felt their child deserved all the same opportunities as a non-disabled young person. It is important to compare south Asian carers' desires for their young son or daughter to get married to those of family carers from non-south Asian backgrounds. Studies in the past have concentrated on perceptions about marriage and learning disabilities from a south Asian perspective.<sup>23</sup>

### *Future care*

As indicated by earlier findings, all but one of the family carers wanted to take care of the young person at home and would not consider residential care at all. It was reported that the carers would look after the young person and, if they could no longer do that, the siblings or other relatives would care for them as long as necessary.

## **Conclusions**

The findings highlight some of the key issues that affect access and uptake of services for young people with learning disabilities and mental health concerns by members of the south Asian community. They also shed light on the problems faced in trying to obtain appropriate help and support, confirming the findings of other studies in this area which have shown that there is a lack of service receipt by south Asian people with learning disabilities.<sup>11</sup>

### **Cultural and religious issues**

Past research has emphasised the need for culturally and religiously sensitive service provision. This study highlights the bigger picture, within which families are not even aware of what is available and may not be accessing services because of this, rather than because of any cultural insensitivity in services. The dimension of culture and its impact on access to, and take-up of, services is a complex one. Culture changes over time, and in addition, there may be different positions and points of view held by people who share ethnic and religious affiliations. However, this study has confirmed that culture does shape some of the parameters of what is considered acceptable and frames some of the language of expression around needs and wants. For example, most family carers do not wish to consider short-term breaks or residential care because of an anxiety that the care offered will not be culturally specific and because it conflicts with a belief that the family should care for the young person. Seeking care from others that involves the young person being away from home contradicts this belief. In terms of the language of cultural expression, it is important to have a shared understanding of what it means to have a mental health problem.

### **Common concerns**

Despite the complexities which arise from cultural and ethnic differences, the more over-reaching finding is one of a similarity of expressed needs with other families who have sons and daughters with learning disabilities and mental health concerns. Having a young person with these problems creates areas of common concern that transcend cultural difference. There is a shared need to have the burden of care recognised and responded to promptly and appropriately. There is a shared need to know what is available and have access made more straightforward irrespective of one's cultural status.

### **Key findings for service provision**

The project has shed light on some of the key issues for young people with learning disabilities and mental health problems from Pakistani and Bangladeshi communities. These include:

1. Young people with learning disabilities and mental health problems from Pakistani and Bangladeshi communities experience problems in accessing services. The mapping study indicated language barriers, lack of information about services, belief systems of families and inappropriateness of services to be key factors which contribute to the access and use of services.
2. Transition from school to adult services continues to remain a major problem for young people from Pakistani and Bangladeshi communities, with the majority of family carers expressing concern and anxiety about services post-school. There is a lack of service provision for young people in the 16–18 age group.
3. Moving out of the family home is not considered an option for the young person by family carers, who would rather carry on caring for them within their own home. Furthermore, overnight respite care and other short-term breaks do not appear to appeal to south Asian carers, owing to the fact that these do not meet their cultural and religious needs. Where such issues are taken into consideration by service provision, waiting lists or lack of resources are a major hindrance to obtaining the necessary support.
4. A lack of leisure opportunities for the young people caused great concern to them and their family carers. Despite the fact that Bradford has many different facilities aimed at young people with learning disabilities, resources are a barrier, especially with the increasing numbers of young people requiring help. Issues surrounding transport, location, support workers and costs, amongst others, inhibit the young person from experiencing the mental, physical and social benefits that these facilities can offer.
5. Families are requesting more help with practical matters. Requests for help fall mainly in the areas of leisure activities, support for parents, support for the young person at home and outside, home improvements due to physical disability of the young person and information and advice on benefits.

6. Families are not aware of the ways to seek help with behaviour and mental health issues of the young person, and may be concerned about the impact of mental ill-health on family reputation. The need to seek help for these issues is recognised as a concern for the emotional well-being of the young person but appears to be overshadowed by more pressing issues like leisure facilities or benefits advice.
7. The focus groups also highlighted the difficulties and problems faced by families in caring for the young person at home, the lack of support and the resulting high levels of family carer stress. Despite all the difficulties families continue providing care within the home. Given this, the liaison worker model was found to be useful by families and its effectiveness clearly demonstrated by the randomised controlled trial. Families receiving input from the liaison worker had more frequent contact with more services than did families not receiving this input and had more results from such contacts. There was also some indication that families receiving the input had a better quality of life and their son or daughter experienced less behavioural problems.

#### PRACTICAL IDEAS FOR ACTION

- Easily accessible and understandable information about services is needed for young people and families from minority communities. Services should explore innovative ways of providing this information, for example through local radio stations or through other audio formats.
- Schools are a good source of information and support to families and should play a major role in helping families through transition by linking families to key services for adults.
- A single point of contact (for example a liaison worker) should be considered as a way of supporting families from ethnic minority communities. The person should preferably be someone from that community so that they can speak their language, and someone with whom they can build trust. In this study a relatively modest input made a useful difference to families.
- Services should be sensitive to the religious and cultural beliefs of the young person and their family. In this study we found that most families preferred support in the home rather than using services out of the home such as short-term breaks.
- The liaison worker in this study had to deal first with other issues affecting families before addressing mental health problems, for example finances, housing, and leisure opportunities. By using this approach families may then have some trust in that person to begin to address the mental health needs of their son or daughter or themselves.
- Consider the contribution of culturally based voluntary organisations and the resources they require to support families.
- There is a stigma attached to mental health problems within certain cultures, therefore practitioners may need to adapt terminology when working with such groups of people.

## Project resources

A CD called *Meeting the emotional needs of young people with learning disabilities from minority ethnic communities* has been produced in Urdu, Punjabi, Sylheti and English for family carers.

A video about the research called *Linking with families* has been produced for practitioners and service providers.

Both are available from The Foundation for People with Learning Disabilities.

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# Mind the Gap: improving emotional support for young people with learning disabilities

Dr Val Williams and Dr Pauline Heslop

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## Introduction

### ***Project summary***

*“I was mixed up between school and college. I wasn’t in one head – I was in both.”*

These were the words of one young person who took part in *Mind the gap*, an action research project that aimed to improve the emotional and mental health support for young people with learning disabilities as they move into adulthood. It was carried out by the Norah Fry Research Centre, Bristol, in partnership with those involved in service provision for people with learning disabilities in Somerset, between September 2002 and August 2004.

The project explored the views of young people and their families about the kind of emotional and mental health support they wanted, and involved them in establishing their own forms of support through action research. Based on the good practice that already exists in transition support within Somerset, the outcomes included a peer support course facilitated by young people themselves, and a course in emotional support facilitated by parents.

## **Project aims**

The main aim of the project was to investigate together approaches that help to achieve better emotional support for young people with learning disabilities, including:

- mapping the current strategies, provision and pathways for young people who have a learning disability, and may have a mental health need, as they move from children's services to adults' services
- identifying the gaps in supports and services from the point of view of young people themselves, their families, and key professionals
- developing, implementing and evaluating some interventions to address these gaps.

## **The context**

Somerset is a large, rural county in the south-west of England. Support services within the county are quite widely spread, with local social services offices in each of four administrative areas and well-established community teams for adults with learning disabilities (CTALDs) providing a well co-ordinated, multi-disciplinary service.

The *Mind the Gap* research project coincided with an initiative based at Connexions Somerset, which created four transitions personal advisor posts (TPAs), and this provided an ideal starting point for the research. These personal advisors are dedicated to supporting young people with learning disability through transition to adult services, and have in-built partnerships with a range of professionals through the multi-disciplinary social services teams. The TPAs were involved in the project and their views are described later in this chapter.

## **Partners in the project**

The initial research partnership was at managerial level, engaging the involvement of the commissioning manager for learning disability services and the team manager for the Connexions special needs service throughout the project. This commitment from senior management proved to be a very important factor in the success of the project, as many other researchers have found.<sup>1,2</sup> A project stakeholder group was established under the auspices of the local partnership board for learning disability services, and this continued to meet and discuss the project until its end. There were regular opportunities to discuss and share developments within other service forums and further afield.

## **The role of young people and families in the project**

The project took an action research approach, which meant that a whole range of stakeholders were actively involved in the research process. The major stakeholders, however, were the young people with learning disabilities themselves, together with their parents and families. They not only defined their own needs and problems, but

were centrally involved in developing the subsequent interventions that would be evaluated.

The inclusion of people with learning disabilities in research is an important part of work carried out at the Norah Fry Research Centre, and within Somerset the project was able to build on other projects and initiatives, where young people and their families had acted as equal partners. It was felt that the area of mental health and learning disability would benefit from the same empowering approach. More information about action research is included in *Chapter 1*.

### **Importance of the project**

The project set out to address several important issues concerning the mental health needs and support of young people with learning disabilities at the challenging time of transition. Each is briefly summarised below as context for the project. *Mind the Gap* was able to bring valuable insights into these issues and some detailed information is included in the introductory chapters of this report.

#### *Social causes of psychological distress*

The medical framework of mental health support needs as ‘problems’ or ‘illnesses’ has dominated mental health service provision. While recognising that greater access to prompt and effective psychiatric services is going to be helpful to some young people at certain points in their transition to adulthood, the key project partners had strong views that the social causes of psychological distress be addressed. Like other projects in this report, *Mind the Gap* aimed to find out how services could respond in a holistic way, in providing both social and emotional support to people with learning disabilities and in helping individuals to overcome the social barriers facing them.

#### *Definitions and labelling*

One of the first steps for *Mind the Gap* was to discuss how best to define the target group of young people. This led immediately to issues about terminology. The very fact that mental health needs go undiagnosed means that professionals, families and young people alike are very unused to discussing young people’s needs for mental health support. Furthermore, it seemed that many people were suspicious of the label of ‘mental health’, including young people with learning disabilities, families and professionals in the learning disability field. In particular, professionals who work in learning disability services felt that their services cover all people with learning disabilities, and that the label of ‘mental health need’ refers only to people who also need a separate mental health service.

The *Mind the Gap* project aimed to separate out the issue of labelling from that of recognition. The aim was not to focus simply on those with a dual diagnosis of learning disability and mental health needs. Instead, the project aimed to include all young people



with learning disabilities who had mental health support needs, often unrecognised. For this reason, the project set out to find language that was used by young people themselves and their families to describe their whole range of needs; words such as 'stress' and 'emotional distress' emerged, and were used throughout the project.

### *Collaborative support services*

Another issue which was addressed was the extent to which services for people with learning disabilities and those for mental health support are able to collaborate and provide jointly for those who may have both a learning disability and a mental health need. In Somerset, there are strategies for ensuring that these services do work jointly, and *Mind the Gap* was fortunate in straddling both sets of services (learning disability and mental health), and in having a foothold in the 'neutral', generic Connexions service. Therefore, it was in a good position to investigate alternative ways of providing support. It was also able to explore the importance of emotional support being available not only through generic mental health services, but also as a central part of all services.

### *The Connexions service*

Connexions is a service for all young people (in England), to guide them along the path to adulthood. Recent research about Connexions<sup>3</sup> however, has pointed to continued gaps in meeting the support needs of young people with learning disabilities. A key to providing good support is the relationship between the young person and their Connexions personal adviser, and so the transitions personal advisers in Somerset were able to provide an invaluable insight into the development of individualised support for this group.

### *Addressing the gaps*

*Mind the Gap* set out specifically to find out what support was effective, from the point of view of young people with learning disabilities themselves and their families. This was a project in which young people were central to the process and product of the research, and in which a direct form of action was built in to the design. As will be described below, families were also empowered to pilot a new, person-centred approach to establishing their own peer support. In all these ways, the project probed the strategies that are available to everyone for building greater emotional resilience in young people with learning disabilities.

## **How the project was carried out**

One of the initial actions in this project was to establish a small, central research group of young people, who called themselves the *Mind the Gap* research group. This group continued throughout the project, and played a very important role in one of the major interventions described below.

There were two main phases in *Mind the Gap* which followed a typical action research cycle (see *Chapter 1* for more information about the action research process).

### **Phase 1: The current picture**

The first phase lasted for nine months and sought basic information about what kind of emotional and mental health support young people and their families wanted. This was done both through semi-structured interviews with the young people using pictorial booklets where appropriate, their families, and the key professional involved with each family at transition, exploring their stories in a holistic fashion. Interviews were followed by focus groups to explore issues raised in more depth.

#### *The young people who took part in the research*

The first period of data collection aimed to seek the views of young people with learning disabilities and mental health support needs who had already experienced transition. The aim was to interview 10 young people between the ages of 18 to 25, their principal parent, carer or supporter, and the key professional who supported them through the transition phase.

These young people had a range of communication needs and levels of impairment, both in terms of their learning disability and their mental health needs. Amongst these young people, signs and symptoms of mental health distress were commonplace, including aggression, anxiety about going out, obsessive behaviours, lack of concentration (ADHD) and withdrawal.

Parents who took part in interviews were family members of the young people who had been identified and who had agreed to give interviews. They were approached with the permission of the young people concerned, and after the interview with their son or daughter.

#### *Focus groups*

The families who eventually took part in the focus groups, the planning for the intervention, and the intervention itself, were all parents who had contact with Somerset Impact, a local support organisation. There were two focus groups involving the young people (a total of 22) and three involving the family carers (a total of 22). Again, they were self-selecting, and the young people were aged between 12 and 19. Some of those youngsters had recognised needs for mental health support, but the majority did not. Some 50% of family carers who came to the focus groups had youngsters with autistic spectrum disorders, and three of the parents who took part in the intervention had sons or daughters with multiple support needs (physical impairments, as well as learning disability).

This was a diverse and self-selecting sample, both of young people and of parents. What they all had in common was a recognition that emotional support matters, that service

provision is often inadequate to meet their needs, and that by taking action to support each other, they could build up their own resources and choices in life.

### **Phase 2: A time for action**

After the first project phase and discussion of findings in focus groups with young people, parents and professionals, the research moved into its second phase, which was planned as a time for 'action'. This phase lasted for 15 months, during which interventions were planned, carried out and evaluated by negotiation with all the key players in Somerset.

#### **Mind the Gap research group**

During the second stage of the project, the main participants were the young people in the college-based *Mind the Gap* research group, and those who took part in the sessions run by the group. The research group members were self-selecting, having responded to initial publicity in their college, and the visiting participants in the group sessions all came from a local residential college. Research group members had a range of ability levels, but most were able to communicate verbally with each other. Those who came from the residential college had, on the whole, a higher level of need in terms of communication and independence.

Two of the six young people who attended the research group had identified mental health support needs. Both were receiving support for depression. The others, however, had all experienced periods of emotional distress, and all had ongoing problems that they discussed and worked out during the group sessions. The students from the residential college had autistic spectrum disorders, and, to varying degrees, they all needed support for emotional and mental health distress.

#### **Project outcomes**

The research project aimed to put something in place within Somerset that would make a difference, and that would continue to make a difference by being embedded within the support services already available. There were two main practical outcomes planned, implemented and evaluated:

1. *We are the strongest link*: training for and by young people.
2. *Our link to the future*: a course provided for and by parents.

The details and findings of each are included in the following sections of this chapter.

A final stage of the project involved a conference, providing an opportunity for professionals, policy makers and providers in Somerset to hear the messages from the research and the interventions, and to make plans to take forward the findings into their own practice.

## Phase I: The current picture

### 1. Young people's views

#### Feelings

The first finding from the interviews in Phase 1 was that feelings of disorientation and confusion are commonplace at transition, and need to be recognised. Young people talked about the trauma they experienced, both on leaving school and when moving on from college. They talked about crying out for help, and about testing out the system. In one case, this had resulted in an attempted suicide. As one young person said:

*I don't talk to anyone – I just bottle it in. If I get angry, I just bottle it in, and then it explodes.*

Some of these young people were quite aware of their problems, and talked about anger management. However, others clearly had difficulty in recognising their emotional distress as a mental health need. This included one young person who had high support needs and occasionally displayed challenging behaviour. He had been involved in an accident in the swimming pool, and afterwards found it hard to accept having a bath: he reacted in ways that those around him interpreted as 'challenging'. As one member of staff explained, it was hard to work out what was due to his emotional distress, and what was due to the fact that he had challenging behaviour.

#### Friends

When asked about the person they would turn to for support, friendships were frequently mentioned. However, young people needed stable situations where friends did not suddenly disappear. Most of the young people who spoke with us in the interviews were anxious to have a 'normal social life', while acknowledging a degree of tension in the establishment of friendships. Several people had been bullied at school, and one person clearly said that she wanted her own friends, but had to be content to socialise with the friends of her siblings. Social isolation was considered the worst part of childhood, and every effort was made to compensate by being as 'sociable' as possible.

On leaving school, the young people tended to lose touch with close friends, and this was frequently mentioned as a source of problems.

*I will tell you what I didn't like, that was making new friends again. I found it really difficult.*

Having friends is a key component in building self-respect and a positive self-image in all young people. It was clearly very important for those interviewed to receive respect, admiration and affection from people around them.

## Families

Families remained an extremely important component of the support networks of these young people, although the relationship with families was, understandably, rather different from the relationship with friends. Some young people had evidently experienced great stress and tension in their home life, and had already left home. In these cases, distance appeared to foster greater harmony. One young person could turn back to her parents for support, once the tension of living at home had gone. This young woman expressed her feelings eloquently.

*“I even put on my Christmas cards to her, ‘Thanks for everything mum. You are not only my mum you are my best friend too.’”*

## Emotional support

Above all, young people wanted emotional support that they could trust and which was flexible and friendly. They wanted supporters who cared about them, who knew them well, and who listened well – rather than speaking for them. They also wanted a relaxed atmosphere and a bit of fun. One person spoke of ‘having a good laugh’ and forgetting about his problems, and another said that his favourite social worker was someone who was very lively and humorous. Young people spoke of needing support that was readily available, and that they could call on when they wanted.

*“I change my mind all the time, but I want the support there when I want it. And I want to use it for whatever I want to use it for, and when I have finished with it, I put it back down.”*

## Summary

In summary, the key findings from the young people in Phase 1 included:

- young people with learning disabilities have the same ordinary ambitions as any young person. They want fun, a good social life, some independence and choices
- the young people identified emotional distress as a significant threat to their mental health, which can be triggered by a variety of factors at the transition stage, but is often unrecognised by others
- above all, young people value the support they receive from their friends
- most of them also want to keep a good link with their families
- they want professional support that they can trust, that is flexible and friendly, and that is always available for them.

## 2. Parents' views

### Expert knowledge and advice

Parents and other family members have detailed knowledge of the day-to-day behaviour and the changes in their own children. In the main, parents who took part in this study advocated for better access to any service that would help them understand and support their son or daughter. There was a recognition that it is all too easy to assign any complex mood changes to 'the disability', as this parent reflected:

*“Nobody ever said anything about it, and we just took it as part of her disability.”*

### School life

It might have been expected that schooldays represented a safe haven for these families, at least providing some stability for their children and respite for themselves. However, this was not by any means true for all families. Many had experienced problems during their children's schooldays, including:

- problems relating to lack of achievement in their children
- lack of friendships
- bullying
- unhappiness of their son or daughter
- lack of understanding and insensitivity by a particular teacher or member of staff
- exclusion from school.

The particular triggers that had caused problems all related to change or frustration caused by bad management of a changeover period. In such situations, parents had to take on roles that they did not relish, so that in addition to providing care for youngsters with very complex needs, the parent became the organiser, advocate and 'fighter'.

*“It was not something I set out to do. It was only because I was pushed into a corner.”*

### Service responses

Despite the parents' evident sensitivity to their children's needs, they often felt alone in supporting the young person. One parent said:

*“It is very difficult to know why my son can be comparatively easy, or he can be an absolute nightmare.”*

Not only were there many gaps in support for these families, but in many cases, the parents felt they were branded by services as being 'over-protective' or 'worriers', or just a plain nuisance. At the very points when they were coping with the most extreme

situations at home with their offspring, they were also forced to cope with the growing reputation they were acquiring as 'difficult' parents.

Most parents in the interviews reported that no mental health services had been involved during the childhood years, although extreme events, such as outbursts of aggression, did result in psychiatric interventions. However, at the point of crisis psychiatrists were simply not able to provide the level of intensive support that families needed. One young person, for instance, had been given medication for depression but often refused to take it. The practical support he received from his social worker was seen as being of far greater benefit to his mental well-being than the medication.

These views, however, have to be balanced by those of several parents whose children are now in their early teens. For them, the services provided by psychiatry were considered vital and the consultant psychiatrists involved were described in glowing terms. This may suggest that children with learning disabilities whose mental health problem is diagnosed early on do in fact receive a better service.

## Summary

In summary, these are the kinds of support that parents wanted:

- professional advice to help them cope at home
- peer support from other parents
- person-centred planning, that involves families centrally
- access to day and residential services that are person-centred and have the expertise to deal appropriately with those with challenging behaviour
- a system of resourcing that is more open and to which families have greater access.

### 3. The views of the *Connexions* personal advisers

Towards the end of the first year of *Mind the Gap* some information was gathered from the *Connexions* TPAs via interviews. This was also the end of the first year for these postholders, and an internal evaluation was conducted by *Connexions*.

#### *Emotional distress*

The TPAs all felt that the majority of young people they saw experienced some kind of emotional distress. Among the reasons they could perceive were:

- the move to college, change, lack of stability
- expectations of being an adult
- peer group changes.

As one TPA said:

*“Young people feel they have lost control over their lives, and they do things to gain control over one area of their lives at least.”*

Asked about the kinds of emotional distress problems they saw, in the main TPAs mentioned behavioural challenges. One young person was described as being ‘out of control, and self-harming, swearing, violent towards staff and just being stuck somehow, and not being able to move on.’ Another young woman had become anxious on leaving a residential school and college, and began to self-harm. Her parents were not coping with this, and so it became a crisis situation. Eventually she had to move into a residential home.

### *Support needs*

Despite some individual differences between the postholders interviewed, they all had broadly similar views about what was needed in supporting these young people. They felt that a person-centred approach, in which young people were supported to ‘get a life’, was the best way of ensuring that problems were minimised or avoided.

In particular, TPAs were adamant that labelling someone as having a mental health need and referring them to psychiatric services was not always the answer. For instance, one TPA described a young man who had a number of severe symptoms of distress, including self-harm, and had consistently sought help. The TPA recognised the causes of the emotional distress as including lack of social opportunities, family issues and failure in work-related activities. She felt that the most important thing was to tackle these issues and to create opportunities, together with the young person, to enrich his life. This was a very clear example of the need for a social approach to mental health distress, and was echoed by all the TPAs involved in this research.

### **Summary**

In broad terms, findings from the Connexions TPAs echoed what the young people and their parents had said. They did recognise emotional distress, and they could also clearly appreciate the frustrations and problems that triggered it. Their approach to support was to work with the young person and their family, spending as much time as possible listening and finding out, so that a plan could be put in place to overcome some of the social barriers they were facing.

This set of findings presented a coherent picture of what young people, parents and practitioners wanted at transition. It was a picture that informed the action phase of the project, as will be described in the next section.



## **4. Mapping local service provision**

A further objective of the project was to produce a map of referral routes to mental health services. However, this did not prove possible, partly because the small sample of people involved in the project had not all been 'referred' to mental health services. In addition, the direction which is taken in an action research study of this kind is dictated by all the partners, and their perspectives. In this project, the partners, as discussed, were chiefly interested in positive emotional support for all young people with learning disabilities. The very necessity to refer people to mental health services was contentious.

During the second phase of the research, however, attempts were made to remedy this gap in the research. In discussion with the key liaison personnel, a draft guide based on individual scenarios ('typical people') was produced in the form of a flowchart, to show some of the possible routes to obtaining emotional support. This map is of course specific to Somerset, and so is not reproduced in this report. However, the scenarios and general points which emerged from the exercise are provided in **Chapter 2** and **Appendix A** to help others map out referral routes and local services.

## **Phase 2: A time for action**

### **1. We are the strongest link: training for and by young people**

#### **Aims and course content**

Since young people had spoken about the value they placed on friendship and on peer support, the young people's research group suggested a peer support course about emotional support. They adopted the group name *The strongest link* for this course, in which they were to be the key facilitators, and called the course *We are the strongest link*.<sup>4</sup> The plan to take this forward was agreed with all research partners.

The course aimed to help young people to talk about and share their feelings. Sessions in the course were:

1. Friendships
2. Feelings
3. Growing up and relationships
4. Getting support
5. Helping yourself.

The *We are the Strongest Link* course materials and session plans can be found on the Foundation for People with Learning Disabilities website at: [www.learningdisabilities.org.uk/strongestlink](http://www.learningdisabilities.org.uk/strongestlink).

The aim was for the young people in the *Mind the gap* research group to lead these sessions. By way of preparation, it was agreed to try out each session within the group (referred to below as the 'host' group) in order to decide together on precisely what would work and how they would conduct each session with a visiting group of young people from a residential college. More information about how to involve and prepare young people in running a peer support course is included in **Chapter 1**.

The course was evaluated through pre- and post-course questionnaires, designed by young people in the research group, and used in individual discussion with participants. There were also tape-recorded group discussions with research advisory committee members (see **Appendix D**). From these sources, the following themes emerged.

### Confidence

A central purpose of the project was to put these young people in the driving seat, enabling them to be facilitators themselves, and there was plenty of evidence that this did in fact happen during the sessions. When asked about their own experience of preparing and running the *We are the strongest link* course, the host group mainly spoke about increased confidence and the ability to speak up for themselves. As one member commented:

*I have felt changes. I feel more confident. When I started... I was sort of shy and embarrassed. But I can look into a camera straight now, like I'm looking at you. I can do a lot more things, and I am more confident about myself. Yes, I feel more confident than I ever have.*

They also spoke of the sense of achievement they felt in running the course, and in seeing it go successfully. They felt a real sense of pride that some of the visiting group members had visibly grown in confidence too.

### Talking about feelings

A primary aim of the *We are the strongest link* course was to enable young people to talk about their emotional needs, and there was evidence that this was successful. It was clear that young people became more fluent in talking about their feelings.

*I was relaxed and chilled.  
I will be sad to leave my girlfriend.  
I will be upset and sad sometimes.*

Some of the young people from the host group felt that the *We are the strongest link* course had given them the opportunity to share their feelings with friends, which was indeed the central purpose of the project. They spoke particularly of the negative effects

of 'bottling things up', and how good it was to share and release feelings. This is what one young person said:

*I feel sad, upset and depressed when I keep things in. I've done that for two years.*

The visiting group also talked about the course as an opportunity to meet new friends. It was clearly helpful for young people to find that their friends took them seriously, and that there was a space to share concerns and secrets.

### *Friendship and teamwork*

Another important factor for host group members was the feeling of being part of something. By the end of the course they all felt that they had bonded well, and some of them spoke about being part of a team.

*It's changed quite a lot for me. Since I've been in Mind the gap, I've met Chris, Mary and Em, and got on perfectly about work. It's good to be part of a team. I'm often a bit of a loner.*

Towards the end of the course, visiting professionals identified teamwork as an observable outcome, saying that they admired the trust which had built up amongst group members.

Other individual changes were harder for members to identify and to verbalise. However, they occasionally picked out issues about each other, and in particular one member spoke movingly about her presentation partner. She had noticed how he had moved from being disruptive and loud to joining in, facilitating and behaving responsibly.

### *Going out with friends*

Young people in the visiting group had many activities and clubs arranged by their college, but seldom seemed to have time to go further afield. However, at the end of the course, two of the four were talking more about how they liked to go out with friends.

*I like going out with my girlfriend. I like going to the pub of a night. It's very good.*

They both demonstrated an increased awareness of the value of their own friends, perhaps partly because they were due to leave the college and move on into other activities. One of them recalled an evening out with his girlfriend as being something which would help him relax.

*I was relaxed and chilled. Me and my girlfriend had a drink. My girlfriend is very nice to me.*

### Self-advocacy

There was some evidence that the course participants gained in self-advocacy skills and in thinking about their own identity. For instance, during the group feedback session one participant started to talk spontaneously about her own life story. Others also talked about themselves in quite revealing ways. They were very aware of the strengths they possessed, and what made them individual. For example, one young man commented:

*“We do drama on Wednesday evening, and we get together on Saturday nights at the disco, and I always do all my funky moves, and... I’m trying to learn a bit more dancing.”*

### Getting support

In the fourth session of the course, four professionals were invited in to meet with the young people: a college counsellor, two mental health liaison social workers and a Connexions advisor. All the young people spoke up and took the opportunity to question them. Visiting group members had also been accompanied by their own support person from their college throughout the course. It was therefore natural that they had started to think about the things they wanted from good supporters. As one young man said, ‘They’ve got to have the right qualities’. He felt that staff should be responsive, and be ready to provide support when it was asked for by young people.

Prior to the start of *The strongest link*, members of the research group had interviewed three other professionals, and so they did have the opportunity to find out for themselves what support was available. In particular, they talked about the value of being assured of confidentiality when talking with a counsellor. However, none of them were at all sure about how they would access confidential counselling once they had left college.

### Managing stress

The final session of the course was called *Helping yourself*, but throughout other sessions as well some activities were geared towards young people exploring how they might help themselves if they felt stressed. The booklet *All about feeling down*<sup>5</sup> was useful here to help people think and talk about positive strategies. These discussions were extremely useful, and afterwards some of the participants from the residential college spoke of relaxation techniques, of pursuing hobbies and activities they enjoyed, and of finding friends to talk with.

## 2. Our link to the future: a training course for parents

Like the *We are the strongest link* initiative, the parents’ course also emerged from listening to the experiences of those concerned. At every stage, when the problems for the young person escalated, parents reported that they too suffered increased stress, and in some cases desperation. Nevertheless, parents in the focus groups still wanted to grasp the

nettle and to find out about all the latest initiatives, legislation and services that would be available for their son or daughter. They had certainly not given up hope that they could be instrumental in bringing about change, and many of them were clearly ‘fighters’. This came, though, at a cost. More than one family talked about the mental health issues that had faced parents and siblings of the disabled child. Two fathers who came to the second focus group were unemployed because of long-term sickness.

### **The inspiration**

At a planning meeting for parents the issues mentioned focused very much on the young person, his or her communication needs, and on understanding the sources of support, future support options, and the way that these are all resourced. Parents spoke of wanting to understand their rights, so that they could campaign for change.

However, it was the drive and inspiration of one parent in particular which led to the local project initiative *Our Link to the Future*. This parent, who had two sons with autism, felt that parents needed to focus on their own needs and identity. They do not just need information to enable them to fight the system. As she commented:

*“Parents in our situation get so weighed down by all the responsibility, and loss of identity, that we need a push.”*

### **Aims and course content**

The aim of *Our link to the future* was to provide a forum for parents to pursue their own goals, rather than those that are forced onto them simply by virtue of the fact that they have a disabled child in the family. These ideas were both very relevant to the theme of emotional support and were exciting and different enough to be tested out as part of our action research.

The course content emerged from the wishes of participants and comprised the following sessions:

1. Introductions, what people want from the course. Our dreams for the future.
2. Working out what people want to achieve, and analysing barriers that are stopping them. Writing our own plans.
3. Counsellor on managing stress and assertiveness.
4. Communication.
5. Group session: going out for a picnic. Half-way evaluation.
6. Behavioural management and reacting to stress.
7. Group path: a tool for change.
8. Final re-cap of what has been achieved. Individual progress and evaluations.

Seven people came to the sessions. Although they all wanted to attend regularly, the numbers fluctuated, as parents were often busy, ill, or had other commitments. The course was evaluated through pre- and post-interview, either face-to-face or by telephone, and the following issues emerged.

### Feelings

As for the young people, emotions loomed large in parents' lives and the theme of 'letting your emotions out' was of major importance to them. More than one parent was in tears, both in pre-course and post-course interviews. The parents who talked about emotions before the course, however, always made excuses for their behaviour, explaining that they felt embarrassed, or they apologised for themselves. The following comments were typical.

*It's embarrassing to let your emotions out. Usually I don't!*

*I do let emotions out, but I don't always do it in the right way. It comes out, all guns blazing.*

When interviewed half way through the course, one man in the group felt that parents, and especially men, are not given the permission to express their emotions, and he said he was benefiting from the course very much for that reason.

The course gave people the permission to let themselves go, and that seemed to help change their attitude towards emotions. Emotional release became a bond that drew them together in the group, and the feeling of letting go was still with most of them some six weeks after the end of the course.

### Confidence and assertiveness

In post-course interviews, the most commonly mentioned positive outcome for parents was increased assertiveness. One parent spoke of her shock when she realised she had said 'no' to someone.

*Someone asked me to do something, and I said 'No I can't', and she heard me and accepted me. I was so shocked, that had never happened before.*

Assertiveness was linked with a positive feeling about self, which made it alright to look after your own needs and to keep time for yourself. The word 'confidence' was also mentioned in the post-interviews, and parents felt that their new level of assertiveness would stand them in good stead when dealing with professionals.

*It's given us the confidence to go and ask people – professional people – yes we do... we are not going to accept no help this time.*

## Coping strategies

The life of a parent of a disabled child is never easy. Parents in this small sample, at different times during the project, experienced:

- severe upsets due to health changes in their child
- periods of time when they had to care for their child at home, in isolation
- a sense of loss and confusion, when left on their own to organise services and make links with providers.

Before the course, parents who were interviewed spoke of losing their own life and identity, 'because your life isn't your own'. They were frustrated at not being able always to communicate well with their own child, and this frustration was compounded by professionals not listening to them. The difficult life circumstances faced by these families sometimes took over, and left them floundering, no matter how much emotional support they were offered.

For the two parents who completed interviews based on an index for coping strategies<sup>6</sup>, there were many similarities between their responses, both in the pre- and post-interviews. For instance, both mentioned 'seeing the humorous side of something' as a strategy they adopted, and both also said that they tried to talk with family or friends about any problems that arose. However, after the course, more parents mentioned active interests that they were pursuing, and in other cases these interests brought them into contact with other people, thus reducing their social isolation. One parent spoke about going to the gym, and of learning German, since he wanted to take his daughter to Germany. The language learning had become quite a social activity. When asked about coping, another parent at the end of the course said that she had started to 'keep a little time for myself', and that she sought opportunities to talk things over with other people.

## Summary

The evaluations during and after the course showed that the most appreciated aspect of the course was the opportunity to meet other people in the same position as oneself. The course nurtured an atmosphere in which it was 'OK' to talk about personal things, and parents felt that this was the most valuable feature for them.

*“There were chances to talk about personal things on the course, and this has helped me to open up to other friends now.”*

The single best session was the counselling session. Everyone who spoke about this wanted more, and said that in particular the activities about dealing with stress had been useful. However, they also felt that regular, individual counselling would be extremely valuable for them.

*continued...*

Other aspects that were appreciated included having fun together, reawakening interests and making plans for the future, and being encouraged to think about yourself.

When asked about what could have been better on the course, most spoke of needing more time, and having more of the same. Some parents expressed an additional need for ongoing, better information, and a more practical approach to solving problems they were facing within their families.

## Conclusions

### ***Continued work in Somerset***

The *Mind the Gap* research project has shown the possibilities of a ‘bottom-up’ approach for effecting change, in which groups of people were enabled to support themselves, and to have a voice in articulating their needs. Both young people and parents in this project said that they want:

- better options and information at all stages
- emotional support that they can trust
- support that is available when they need it, not just at a crisis point
- the opportunity to have a life for themselves.

Policy-makers in Somerset are planning to develop and continue the project initiatives locally and have held a conference to discuss plans. Apart from the offer of emotional support, local initiatives will help service users and family members to have a more cohesive group voice. This is especially important for those young people who have both a learning disability and a mental health support need.

### ***Learning disability and mental health professionals working together***

*Mind the Gap* has found continuing problems for people with learning disabilities in accessing mental health services. There is still a need for services and professionals to take a more positive approach towards the issues for young people with emotional distress. Practitioners and families felt that good emotional support should be offered by all the professionals who come into contact with young people with learning disabilities. Additionally, there may be some young people who have a need for a very specialist kind of support, which could well be provided by specialist outreach services that could be jointly set up by learning disability and mental health services. There are many ways of working that would promote this kind of re-think of emotional and mental health support, including:



- joint training for mental health and learning disability professionals
- joint work for certain service users
- opportunities to listen: both groups of professionals consulting with and listening to the needs of young people and their families
- a greater emphasis on person-centred approaches, which can tackle the social barriers and create better life-chances for young people
- more opportunities for young people with learning disabilities to benefit from ‘talking therapies’, rather than simply medication.

### ***Emotional support and resilience***

Resilience has been an important theme throughout this research. The project established a model whereby young people could be helped to provide support to each other, which they felt was a vital way of building their own strength and emotional resilience. Likewise, parents were on the whole very positive about the opportunity to have an initiative for themselves as people. They too need to find their own identity, and to build their emotional strength.

Both the peer group course and the parents’ course provided important opportunities for doing this, including:

- personal reflection and opportunities to develop a stronger sense of identity
- the building of personal confidence and assertiveness
- the opportunity to develop friendships and to share feelings with friends.

All young people need to develop a degree of resilience, particularly as they approach adulthood. The ability to talk about personal feelings and to speak out about themselves is an essential ingredient of emotional maturity, and is especially valuable when young people move from college into the wider world and are attempting to get help for problems. It is hoped that the ideas developed in this study could be disseminated more widely in schools, youth groups and elsewhere.

From the point of view of parents, emotional resilience was also an important concept. *Our link to the future* gave them a rare opportunity to stop and think about themselves, and it proved also how valuable this could be. A course such as this could perhaps be best placed within a wider package for parents, where a person-centred approach to parents is followed up with more information on how to ensure their child receives a person-centred support service, and plan for the future.

## ***The role of Connexions***

In many ways, the evidence that we gained during this project showed how very successful the transitions personal advisor initiative is in Somerset. Compared with many other areas, this small project is proving that targeted, specialised support delivered by personal advisors who have strong and structured links with social services teams, can be a lifeline for young people and their families.<sup>3</sup> This in itself should alleviate many of the problems associated with learning disability and mental health distress.

However, time needs to be built in to the Connexions schedule for some development work about the various routes for emotional support. Some useful routes identified by young people themselves included the following:

- counselling, both at college and outside college
- psychotherapeutic interventions
- creative approaches to relaxation and self-help (e.g. music groups, art)
- one-to-one support on a regular basis from someone that can be trusted, is familiar, and is 'always there' if you need them
- support through friendship groups.

## ***Wider implications for services***

The project in Somerset has shown how emotional distress can spring directly from frustrations, lack of opportunities and lack of friendships. If a person-centred approach can help the individual achieve some of his or her ordinary ambitions for an independent life, that will of itself help that individual to achieve more stable emotions.

Emotional distress is quite clearly widespread in this group of young people, as a direct cause of their social exclusion. What is needed to tackle social exclusion generally will be more than simply patching over the cracks. It will involve a re-think of the whole system, so that young people with learning disabilities are enabled to have a greater level of control and autonomy in their lives, while their families are given greater recognition and support, as a matter of right.

## PRACTICAL IDEAS FOR ACTION

- Many young people and their families do not like terminology such as mental health or mental illness. Find out what language they feel comfortable using and work with that.
- This project has demonstrated how young people with learning disabilities can be involved in mutual emotional support. *We are the strongest link* can be delivered in schools, colleges, youth clubs and through voluntary organisations.
- Similarly, structured support groups or training workshops can provide family carers with knowledge and emotional support.
- Mental health services, learning disability services, child and adult mental health services, the local authority and voluntary organisations need to work together to map local care pathways.
- Connexions personal advisers (or other similar transition professionals) are seen as key people to bridge the gaps between child and adult services. However, they need more training and opportunities to share their own knowledge of appropriate support and referral routes for young people with learning disabilities and mental health problems.
- When considering the provision of mental health support to young people with learning disabilities, take account of the social model of emotional distress, as well as recognising mental illness.
- When developing new services speak to young people and family carers to find out what they want from them.

### **Project resources**

Two web-based resources are available:

- *We are the strongest link*. A pack to help young people with learning disabilities support each other. [www.learningdisabilities.org.uk/strongestlink](http://www.learningdisabilities.org.uk/strongestlink)
- *Linking up*. A Connexions guide to the emotional support needed by young people with learning disabilities. [www.learningdisabilities.org.uk/linkingup](http://www.learningdisabilities.org.uk/linkingup)

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# The well-being project: Identifying and meeting the needs of young people with profound and multiple learning disabilities and their carers

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## Introduction

### Project summary

*I know it's difficult to describe the changes in her facial expressions, because you know the changes are so subtle, but very noticeable. When she's happy you certainly know she's happy and she lets everybody know she's happy, because she sings at the top of her voice. The tone changes with changes in her emotional and mental well-being, just a slight difference; it's like the difference between somebody singing a lament and singing something happier.*

There is a growing awareness that young people with profound and multiple learning disabilities suffer from depression, anxiety and stress, as do many other individuals. Because they cannot talk about their difficulties these may be overlooked by those who care for them.

This project was carried out by The White Top Research Unit, University of Dundee, to investigate how family carers and care staff identify and respond to changes in the mental and emotional well-being of these young people, using diagnostic instruments to help identify psychiatric indicators, together with carer interviews. The project also explored what service support was sought by and available to family carers and care staff.

The study found that the majority of the carers were able to identify specific signs that alerted them to changes in emotional and mental well-being and some of the reported symptoms were consistent with psychiatric indicators contained in standard diagnostic instruments. Furthermore, it showed that the causes and effects of changes in the emotional and mental well-being of people with a profound and multiple learning disability were similar to the causes and effects in the general population. However, carers were unable to find appropriate advice and support once changes in emotional and mental well-being had been identified.

The research findings highlighted key areas in which information and training for family carers and care staff are required. These provided the basis of a training workshop which was designed and run for family carers and care staff by parents in partnership with the White Top Research Unit and PAMIS, the voluntary agency in Scotland representing individuals and parents and families of people with profound and multiple learning disabilities. The workshop is interactive and uses case studies from the research to explore sensitive and emotional areas of well-being, as well as possible pathways of support.

### **Project aims**

This study set out to:

- understand how family carers and care staff identify and respond to changes in the emotional and mental well-being of young people with profound and multiple disabilities
- explore what help is available to carers who identified changes in emotional and mental well-being
- use the findings to provide the basis for a training workshop for both family carers and care staff.

### **The context**

#### **1. Definitions**

In this chapter the term ‘profound and multiple learning disabilities’ refers to people characterised developmentally as having abilities typical of the sensorimotor period. This period covers the first 18 months of a typical child’s life, from birth to the very early stages of spoken language, although for a young adult with profound and multiple learning disabilities their life experience makes it inappropriate to think of them as a small child.

Sixty-six per cent of children and adults with profound and multiple learning disabilities have epilepsy, which in turn increases their vulnerability to mental health problems. Respiratory, eating and nutritional difficulties are also very prevalent.

The project focuses on affective disorders, that is, emotional disorders such as anxiety and depression.

## 2. Research

While the past decade has seen a burgeoning of research into the mental health difficulties of people with learning disabilities<sup>1</sup>, only limited attention has been directed to those with profound learning disabilities. There is, however, a growing view that people with profound learning disabilities and those who also have multiple disabilities can experience significant mental health problems, particularly with respect to affective disorders. Barriers to communication can create additional obstacles in diagnosing such individuals, for example in relation to using standard instruments for psychiatric diagnosis.

### Summary of recent research findings relevant to this project

#### *Occurrence and diagnosis of affective disorders*

Work in the early 1990s pointed to the occurrence of mental health difficulties, particularly depression, in people with this degree of disability.<sup>2, 3, 4</sup> Subsequent work has confirmed the feasibility of diagnosing affective disorders (such as anxiety and depression) in people with profound learning disabilities.

#### *Environmental influences*

This work also led to considerations of the causes of such disorders. In explaining mental health difficulties, the importance of environmental influences was noted.<sup>3</sup> This author suggested that stress arises because of the inability of people with profound multiple learning disabilities to control their environment through prevention of, or adjustment to, threatening situations.

#### *Symptoms of depression*

Attention has also been drawn to the possibility that depression may be manifest not through 'classic symptoms' of depression, but through what have been referred to as atypical symptoms or 'depressive equivalents', including aggression, self-injury and irritability.<sup>5</sup>

#### *Response by carers*

An evaluation of specialist day services in Scotland identified a failure on the part of carers to act on their judgement that a mental health problem has been identified. Studies of staff responses to mental health difficulties in the wider field of learning disabilities have indicated a similar lack of response.



## **Importance of the project**

The studies above tend to focus on professional diagnosis of the psychiatric conditions under review. However, it is frontline staff and family caregivers who will be most sensitive to changes that may indicate an alteration in emotional and mental well-being, or mental health problems. This factor, coupled with lack of carer response to such changes, provided the focus for the project and for the carer training programme.

The project outcomes have implications for improving the lives of young people with profound and multiple learning disabilities and their families in a number of ways.

These include the need to:

- raise awareness of mental well-being among family carers
- increase awareness of the implications for support and treatment for identified changes in emotional and mental well-being
- develop specific strategies for identifying changes in the emotional and mental well-being of people with profound and multiple learning disabilities
- identify gaps in service provision and the training needs of frontline staff
- develop a model of training for family carers and frontline staff.

## **How the project was carried out**

### ***Phase 1: Identification and interviewing of family carers and care staff***

The first phase of the work was to identify people with profound and multiple learning disabilities living in the Tayside region of Scotland who were experiencing, or who had previously experienced, emotional or mental well-being problems. This was achieved through approaching family carers who had indicated the presence of such problems in their sons or daughters as part of the Tayside Profound Disability Survey, a 10-year follow-up survey of 150 children and adults with profound and multiple learning disabilities who were identified in 1993.<sup>6</sup>

Because of the small number of individuals identified by this survey who met the necessary criteria regarding age range (13–29 years), who had experience of changes in emotional and mental well-being and were willing to participate in the research, the study had to be extended to the Fife region of Scotland. This proved successful, resulting in a total of 13 young people participating in the study. Eight parental interviews and eight care staff interviews were completed (for three young people, both their parent and member of the care staff from a residential home or day service were interviewed).

Visits to family homes and day services were arranged and carers who agreed to participate in the study were asked to complete the Mini PAS-ADD assessment schedule for the detection of mental health problems in adults with developmental disabilities.<sup>7</sup>

Completing this assessment schedule gave the carers an opportunity to think about and discuss the concepts of emotional and mental well-being before being interviewed. Once the assessment schedule had been completed, the carers were interviewed using a semi-structured interview schedule. The interviews were recorded on tape.

The semi-structured interview schedule was designed to ask questions about possible causes and effects of changes in emotional and mental well-being, as well as what help was available to the carers if a change was identified. It was felt that questions relating to the availability of help would be beneficial to identifying clear pathways of help for the carers. Interview responses, together with data from the PAS-ADD assessments and workshop sessions, were analysed and four categories emerged: cause, how the symptoms of affective disorders are demonstrated, available help and future help.

During the information-gathering process consideration had to be given to the sensitivity of the topic and the high healthcare needs of the young people. Often the interviews were interrupted because of these needs, which meant that in most cases several visits were required to complete the interview process. Family carers are often very stressed and find that few people have time to listen to their problems, so for them this project offered the opportunity to talk about their concerns. We have complemented information from the interviews with further insights from discussions during the workshop.

### ***Phase 2: The training***

The training workshop for carers was designed and developed by some of the parents who participated in the research, in partnership with the White Top Research Unit and PAMIS. The workshop sessions offered the opportunity to raise awareness of emotional and mental well-being and the causes and effects of changes in the emotional and mental well-being of people with profound and multiple disabilities. They also offered an opportunity to help identify possible pathways of help.

Family carers involved in the research attended a strategy and planning meeting to agree on a framework for the development of the training workshop. This meeting led to the forming of a group of parents who would deliver the training.

Four areas identified from the research analysis as causing changes in emotional and mental well-being were chosen as themes for the workshop sessions. It was decided that the workshop sessions would be interactive and use guided tasks and case studies from the research to illustrate identification, and causes and effects of changes in emotional and mental well-being.

## Main Findings

### ***Findings from Phase 1: Identification and interviewing of carers***

The study found that the indicators of poor mental health in the young people reported by carers were similar to those employed in psychiatric diagnosis. Furthermore, it showed that the causes and effects of changes in the emotional and mental well-being of people with a profound and multiple learning disability were no different from the causes and effects in the general population. However, the difficulties for people with profound and multiple learning disabilities are compounded by their lack of verbal communication.

The investigation also revealed that carers are unable to find appropriate help and advice once emotional and mental well-being changes have been identified. There is currently no suitable and appropriate pathway of help available to families caring for a daughter/son with profound and multiple learning disabilities.

### ***Causes and effects***

The analysis identified a number of factors responsible for changes in the emotional and mental well-being of young people with profound and multiple learning disabilities. These were divided into external and internal causes before then being subdivided into specific causes. These are listed in **Table 5** and each is briefly described in the following section. The analysis also revealed a number of reported behaviours which were specific to each individual. These included:

- changes in facial expression
- increased crying
- withdrawal
- biting (self and others)
- grinding teeth
- increase in repetitive hand movements
- increase in sexual behaviour
- increase in seizure activity
- changes in appetite
- changes in posture
- lack of response
- decrease in vocalisation
- increase in vocalisation
- disruptive behaviour
- thumb-biting
- self-injurious behaviour
- changes in sleeping pattern.

**Table 5** Causes of changes in emotional and mental well-being

External causes	Internal causes
Bereavement	Physical illness
Moving house	Pain
Change in staff	Puberty
Change in routine	Menstruation
Parental separation	
Parental stress	
Transition	
Lack of stimulation	

The next section describes the findings in relation to the causes and effects of changes in emotional and mental well-being, carers' responses, and sources of support.

## External causes and effects

### Bereavement

Four people interviewed reported bereavement as a cause of major changes in the emotional and mental well-being of people with profound and multiple learning disabilities. From the analysis it became obvious that loss and bereavement had a profound effect on the lives of these young people and their families. No specialist help was available and in many cases parents who were struggling with their own grief reported feeling guilty for not acknowledging the grief their daughters/sons might be suffering. One mother described the reactions of her son at the funeral of his grandmother.

*“He loves churches, he loves singing and he loves everything like that... it was at the crematorium that he just went really quiet. His head was bowed down and after we came out of the crematorium there was definitely tears in the eyes. He really had noticed that something sad had gone on and he wasn't going to see his gran again. I think that was when he sort of realised that was that and when he come home he was very quiet but very tearfully quiet and just wanted lots of cuddles and reassurance.”*

Another parent noted his son's behaviour which continued for a year following a bereavement.

*“When my dad died my son didn't understand that he died – it was just the disappearance. He would come home on the bus and he would go to my mum's house and my father would have been sitting in the lounge in a chair looking out at the valley, and for a whole year after my father died he ran into the house and went through to the lounge and looked at the chair...”*

The analysis clearly revealed that, as for other causes, the emotional impact of loss and bereavement often affected the physical health of the young person. The study also revealed that carers often underestimated the length of time it took a young person with profound and multiple learning disabilities to recover from changes affecting their emotional and mental well-being.

The workshop session on loss and bereavement for family carers substantiated these findings and highlighted a lack of appropriate ways of explaining emotional changes to a young person with profound and multiple learning disabilities. It was also reported that for individuals and families of people with profound and multiple learning disabilities there was no professional help available during times of loss and bereavement. The following comments from a parent illustrate these points.

*“Scott is normally a very happy person and laughs a lot with people he is familiar with. Scott’s mental health problems began when his father became ill. His problems were compounded because, during this difficult time, his day service was withdrawn. Scott changed. He was listless and just sat in the chair with his head down. During this period he started to be sick and his seizures increased. He slept a lot and it felt like he was sleeping his life away. This went on for one-and-a-half years in total, eight months of this when my husband was alive.*

*During this very difficult time there was no one to help and there was problems with his respite as well. He didn’t eat, he was living on Weetabix and milk fed through a funnel cup. At this time his sleep pattern was broken and he would often bang on the wall at one or two o’clock in the morning. I eventually turned to PAMIS for help and now have a day service for Scott six days a week. However, I would like to emphasise that it is only now, almost four years later, that Scott is returning to anything like his normal self.*”

### *Moving house and other changes*

Change in environment and routine also had a major impact on the emotional and mental well-being of people with profound and multiple disabilities, as the following account by a parent illustrates.

*“His first experience was changing from childcare respite to adult care respite. The first night he stayed away he seemed to be okay up at the new adult respite unit... I noticed that when he came home that he was really withdrawn, he wasn’t his usual happy-go-lucky self. He’s usually quite a loud guy, he roars and gets excited with things, but after that weekend he was really very quiet and withdrawn. He started thumb-biting quite a bit, he was really thumb-biting and wanted to be on his own in his own room quite a bit and also... he would give me horrible, horrible looks. I suppose that was his way of trying to describe to me that he was just not feeling great at all.”*

There were a number of changes which affected emotional and mental well-being, each of which is briefly described below:

- moving house (reported by 4 individuals)
- transition from school to adult services (reported by 2 individuals)
- change in staff (reported by 5 individuals)
- change in routine (reported by 5 individuals).

One member of staff gave a powerful description of how a young man reacted to a change of environment within the residential service.

*“We began to notice a change in Sandy when he began to refuse to join in activities and found it very obvious that he didn’t want to interact with staff or his fellow clients, whereas before, even though it took a bit of coaxing to get him to join in, he would appear to be quite happy to sit in the middle of a gathering and be okay with being there. Then he began to lash out occasionally in this environment if folk tried to coax him too far, and also in the ambulance going to the day service we noticed he became a bit more agitated as we got nearer the building.*

*The practice of his interactions also changed. He began to isolate himself totally... sitting in the toilet or bathroom all the time on his own with the lights out. If anybody else entered the room at that time he would just take off very quickly, roaring loudly and constantly until he got to another environment that he would consider to be suitable, then again the staff would go back and try to interact with him, but he would cover his head with his arms completely which we took as a sign of him opting out and very much a plea to leave him alone.*”

### *Parental separation and parental stress*

Three individuals reported parental separation as an indicator of changes in emotional and mental well-being, as illustrated by the comment below.

*“Her mum and dad split up and her sister had left home recently, and her behaviour has been increasingly difficult since then. She’s just become more prone to scratching and biting and she’s just not a very happy person sometimes.”*

The study revealed that parental stress had a major impact on the lives of both the carers and the young people they cared for. It was reported that caring for someone with profound and multiple learning disabilities was very demanding both physically and emotionally. The high healthcare needs of young people with profound and multiple learning disabilities created stress for carers. Further reported causes of stress included the lack of appropriate information, advice and help, and lack of appropriate services. In turn, carers’ stress had a direct impact on the person they were caring for.

*“My daughter’s well-being is very much dependent on my well-being and if I’m having a particularly difficult time, then I’m not really capable of looking after her. If I can’t look after her she has to be taken somewhere else to be looked after at tremendous cost to the State and everybody else. So I think that there should be a service to help people like me who are carers of people like my daughter so that our mental well-being is improved, or is as good as it can possibly be, and that we’re in a better position to look after somebody like my daughter, because if you’re under constant stress and pressure, especially during the really bad time when she was doing all that nipping and scratching and not sleeping, I felt that I was at breaking point and ready to crack up, and at the same time having another child to be responsible for and working full time, you know, it was an absolute nightmare. So I think there should be some psychological services for carers, whether it’s a self-help group or somebody that would come out and see you in the house or whatever, but there needs to be something.”*

### *Lack of stimulation*

Boredom and lack of stimulation were reported by the majority of the individuals interviewed as another cause of changes in emotional and mental well-being.

*“Boredom has a big effect on Andy. If we’re rushing about trying to get everybody else to the toilet... he’ll try and get in the toilet with the other person. Again he’ll maybe pick up his frame and chuck it. Again, this isn’t all the time, it just tends to be when he’s down, you know when he’s had enough. You know he’s been coming here for 10 years day in, day out. You know it’s no wonder. I mean we get fed up doing the same thing and I sometimes think it would do him good not to be here five days a week [and] doing something different.”*

The majority of participants stressed that lack of appropriate stimulation had an impact on the emotional and mental well-being of the people they cared for. This view was substantiated in discussions during the workshop. Both family and paid carers agreed that boredom was a major cause of changes in the well-being of people with profound and multiple disabilities. The paid carers also indicated that they were aware of the lack of appropriate stimulation but emphasised that staffing levels had a direct impact on this.

### **Internal causes and effects**

The study found that in many cases, because the healthcare needs of people with profound and multiple learning disabilities are complex and carers are alert to and aware of any physical changes in the people they care for, they often overlook the emotional and mental well-being of the individual.

Changes in physical health were reported as resulting in a change in emotional and mental well-being, whereas the analysis revealed that emotional and mental well-being

was in fact often responsible for causing changes in the physical health of people with profound and multiple learning disabilities. Pain was also responsible for changes in emotional and mental well-being of individuals.

### *Physical illness and pain*

Carers reported that in many cases they are so busy looking for a physical reason to account for changes in the young person that they often do not consider the emotional and mental well-being of the individual.

*“After a sustained period of illness which meant he had to endure frequent stays in hospital, and about the time Craig was going through puberty, he ended up with pneumonia which obviously affected his health seriously and he was in and out of hospital. This had a tremendous effect on Craig’s sense of well-being and on his general state of mind. Having said that, I didn’t recognise it... I thought it was all around his health issues. What I thought was him ailing or sickening again could, I think, have been him sinking lower and lower down and absolutely being totally fed up and depressed, but I certainly wouldn’t have recognised it being that. Looking back I do, but at the time, no, I thought he was probably sickening again.”*

Another carer gave a graphic account of the effect of pain on mental well-being.

*“If he’s in awful pain and does not have painkillers or get it controlled, he’ll just run about the house thumping stuff, pulling things down off the top of the wardrobes. There was a bit of glass in the front of that video unit there and he came through and hit his knee on it and broke it.*

*Often he was running about screaming with his wisdom tooth and I didn’t have a clue what it was, I could have done with somebody then – somebody to come in, professional, unprofessional, whatever, just to help me fathom out what it was. I just didn’t know what it was and that’s torment, more torment on Aiden. That was the hard bit about it, because he was trying to tell me what was wrong, but how did I know?... it’s probably that it had got Aiden down but he hadn’t shown it.”*

### *Puberty and menstruation*

During the interviews a number of carers indicated that at the onset of puberty the young people they cared for experienced the same hormonal changes as most young people.

Carers were also aware that young people with profound and multiple learning disabilities were unlikely to understand what was happening to their bodies during puberty.



*“He was masturbating more often as well. You know, being a young guy he does have sexual needs but at that time it was five days a week, whereas normally it can maybe be once every two weeks.”*

Carers also reported an increase in seizure activity at the time of puberty.

*“Up and down, I’d say he has been up and down in the last few years. He has been unsettled, more fits, I think it was just part of him growing up.*

*I think when he went into puberty, Craig started to have an increase in his seizure activity and this meant that he had quite a lot of hospital stays during that period.”*

Two individuals interviewed stressed that menstruation had an impact on emotional and mental well-being, as illustrated by the following account.

*“I think principally, the problems that we have experienced with Lauren in the last couple of years has been difficult behaviour, really to do with nipping and scratching and hitting and occasionally biting. She has always had an element of that type of behaviour but it really increased dramatically around about the onset of puberty, and her behaviour seems to get better or worse depending on what stage of her cycle she’s in.”*

### **Carers’ responses, available help and support needs**

During the interview process both family carers and care staff were asked to report how they responded to an identified change in emotional and mental well-being. They were also asked what help was available to them and what future help they would like to access.

Most family carers reported that there was no help available to them. Care staff relied on work colleagues to help plan strategies that might alleviate the effects of changes in emotional or mental well-being. Care staff also reported that while psychiatric and psychological advice was available to them, it was felt that due to their workload these professionals did not have the time to devise appropriate strategies. Most of the carers interviewed agreed that the most helpful strategies were devised by people who knew the individual well.

#### **Care staff**

Care staff reported that they would seek help from colleagues who worked with individuals on a daily basis and were familiar with them, rather than from a professional. It was felt that they were best placed to detect and act upon any changes in emotional and mental well-being. Staff also felt that there was not enough professional help given to people with profound and multiple learning disabilities because of communication problems.

*I think I would be fairly loathe to bring in psychologists' help for someone who had no verbal communication. I feel that it is vastly important that you know the person very well to have any kind of link with them and I'm aware of how long it took me to have a good working relationship with her. I do feel that often psychologists, perhaps because of their time limitations, would see the person for a short time or would see them out of their normal environment in the centre, and I'm not convinced that's really a helpful way or gives a true picture of the person.*

*There is not really a psychologist available without jumping through huge referrals and by the time that happens he's okay again and I think they struggle because he doesn't have any communication as well. It's a struggle for them to come up with anything and quite often they'll say, 'Well, it's just them you know', which can be quite frustrating.*

Another keyworker described the available sources of support at work.

*The other staff within the team and the unit and the team in the building [are a support]. We did tend sometimes to be short due to staff holidays and sickness and it did get quite wearing on me personally, it did, and sometimes there wasn't a lot of other staff to look upon to help you, and bearing in mind we always had the other service users in the building as well. The unit manager was very supportive and did what he could, but directly that was who was involved in the way of support.*

*The other thing I thought would be to get training. I would discuss things with my manager, the dietician and physio, the people who know her very well and her mum and her mum's partner.*

### Family carers

Most of the family carers interviewed reported that in relation to a recognised change in emotional and mental well-being, there wasn't one specialist professional available with an overall knowledge of the needs of people with profound and multiple learning disabilities to support the young person, except for other family members.

*There's not usually anybody here with me when I'm looking after her. Maybe my mum but my mum's in her 70s now so she's not really able to do as much or very much at all now. Lauren's a good head bigger than my mum now...*

Family carers also valued the support they received from PAMIS. This included:

- practical help, advice, training and information
- individual support and contact with other families
- assistance with achieving better access to community resources, whether mainstream or specialist
- the opportunity to influence local and national policy and services.

One family carer described the difficulties of responding to her daughter's needs until she attended a PAMIS workshop on managing difficult behaviour.

*Well we're through the worst of it now but I have to say the help that I got from PAMIS was outstanding. It made a huge difference both to mine and my other daughter's lives because we were under such stress. I mean life was really, really difficult, it was awful, it was an absolute nightmare, and also Lauren wasn't sleeping particularly well although I had been attending a sleep clinic for her for about a year, and after we used the strategies that we devised with help from the PAMIS workshop [on difficult behaviour] things improved dramatically. Should I be in the position again where I did need help, that to me would be the best option, if there was something like that available.*

### Accessing professional help

The study revealed a lack of professional information, advice and help relating to changes in the emotional and mental well-being of the young people they were caring for. Because of this family carers felt very isolated, stressed and alone. Care staff reported that there was a referral system in place but the waiting time for psychology and psychiatric services, which in some cases was six months, was inappropriate when the individual obviously needed help immediately in order to take preventative action.

One family carer illustrated the difficulty and time involved in accessing help, and also the benefits of attending the project's training workshop.

*There was a spell a number of years ago when her behaviour was very difficult and the school managed to obtain the services of an educational psychologist who we had one meeting with. It wasn't particularly helpful... it was just a one-off. I made approaches again, I think via the school, and I did have a visit from a psychologist... but by the time she came to see me here, I had already attended the PAMIS workshops and her behaviour was significantly improved so that wasn't taken any further. So it was months and months and months that I had to wait for that help and the previous time it had taken some months to get the educational psychologist to see me as well, so it's not particularly easy to get assistance.*

One of the fathers in the research study illustrated the difficulty of getting a 'normal' response in relation to a serious health condition.

*Some of them didn't even actually sound her chest, they just took one look at her and didn't want to know. But then people are out of their depth... but we knew that if we just phoned for an ambulance we probably wouldn't get one so you had to phone for a doctor and he came out, and sent for an ambulance, either that or you took her in yourself and you weren't wanting to take her in yourself.*

Another family carer commented on the absence of support in relation to emotional difficulties.

*I don't think I've ever asked for professional help when Stephen's low although we do have a community learning disability nurse, but we've never sat down and talked about anything like this, it's mainly been nappies and incontinence pads.*

### Proposals for future pathways of help

All the individuals participating in the study agreed that the referral system was inadequate and that no appropriate pathway of help was available. Both family carers and care staff were in agreement that there was no dedicated or qualified worker with the specialist knowledge necessary to support individuals with profound and multiple learning disabilities. As one keyworker commented:

*Just to have somebody there I suppose, that you can turn to just to know you are doing the right thing and it really needs to be somebody that's got the time to get to know them and take the time.*

### Support for family carers

The study indicated that parental stress had a direct effect on the emotional and mental health of the person being cared for, and so any pathway of support should include support for the carer.

*I do not want my son to go into residential care, I do not want him to go anywhere, neither does my husband or my son. He would die without his brother, and as I say, as long as I have the support, we're just like any other family. We want to look after him and if we are not mentally well he is not mentally well because we have not got the energy to look after him. I would like to have access to a qualified professional to offer advice on mental well-being, working within the community learning disability team.*

It was also emphasised in the workshop sessions that this support should be ongoing and continuous for the family.

### Advocacy

One carer noted the importance of advocacy for young people with multiple and profound disabilities.

*An independent person would be better for that, just to be aware. That seems to be more of an up and coming thing and I think that it is something that has to be welcomed because an independent point of view and some kind of discussion is always useful.*

## Training

A member of the care staff commented on the need for training in mental well-being issues.

*“People think because people have got special needs they don’t maybe suffer from mental health problems but we don’t know that. Even some mainstream clients have got mental health problems and we’re not trained for any type of mental health. We should be because if somebody comes to us with some problems and we can’t help them, what would they think of us? They think that we should be here to help them and we’re not... We should be getting trained or we should be getting people working here that are trained. I mean any type of training in that form is good for everybody and I know all the staff that work here would gladly go for any training.”*

## Individuals’ history

Both the research findings and the feedback from the workshops emphasised the importance of knowing the individual’s history in both providing adequate healthcare needs and identifying the most appropriate care package for the individual.

*“Well, like I said earlier, a lot of the staff that I work with have been nurses for a lot longer than I have and they have known Sandy on a more constant basis in the past, probably since he was a little boy, so a lot of my observations are based on asking them and drawing everything in... they have a much more historical perspective of him.”*

## Findings from Phase 2: The training

The two-day training workshop offered the opportunity to share the findings of the research with both family carers and care staff and raise awareness of the mental well-being of people with profound and multiple learning disabilities in ways which would help to ensure that it is not overlooked, neglected or forgotten. The workshop sessions were attended by family and care staff, occupational therapists and teachers and were held in both Fife and Tayside.

The workshop aims included:

- to raise awareness of changes in emotional and mental well-being of people with profound and multiple learning disabilities
- to explore how carers detect and respond to changes in emotional well-being
- to investigate how people with profound and multiple learning disabilities react to changes in their emotional and mental well-being
- to identify clear pathways of help.

The first phase of the project had identified several causes and effects of changes in emotional and mental well-being. Four key topics were chosen for inclusion in the workshop which best incorporated the areas of the research findings that caused major changes in emotional and mental well-being: change and transition; health issues; loss and bereavement; and supportive therapies. In addition to the four main sessions, the workshop included a brief introduction at the beginning of Day 1, and discussion time and evaluation at the end of both days.

During a preparatory training workshop, where family carers were trained as workshop trainers and facilitators, it was decided that the guided discovery method would be adopted for the interactive training sessions. An underlying principle of the guided discovery method is that it is more effective for people to take on board what they have thought out and discovered for themselves, than being told by someone else. The combination of case studies and guided discovery tasks used in the workshop enabled the participants to build on their existing knowledge and understanding.

### Training workshop

Learning objectives	Content
<p><b>Session 1: Change and transition</b></p> <p>To understand the impact of change and transition on emotional and mental well-being, and how changes in these are recognised and responded to.</p>	<p>Exercises and case studies to illustrate how periods of change and transition can cause changes in emotional and mental well-being and how these changes are recognised and responded to. 'Change' refers to changes in routine, staff, peer group and moving house, as well as the transition from child to adult services. Combining change with transition in this session meant that more of the research findings could be incorporated into the workshop. Session ended with participants being asked to identify possible avenues of help.</p>
<p><b>Session 2: Health issues impacting on the emotional and mental well-being of people with profound and multiple learning disabilities</b></p> <p>To understand how physical health can impact on emotional and mental well-being and how poor mental well-being can affect physical health.</p>	<p>Two case studies used to demonstrate these impacts:</p> <ol style="list-style-type: none"> <li>1. Young person who had left home to live in a group house where his family thought he might gain more independence, but this turned out to be an extremely negative experience and as a result, the young man had suffered severe emotional and mental illness as well as a loss of mobility.</li> <li>2. Young person who had developed poor emotional and mental well-being as the result of a physical illness, leading to a prolonged hospital stay.</li> </ol> <p>Participants then asked to think together about how the two individuals might have been feeling at the time of their experiences and what could have been done to avoid a deterioration in their emotional and mental well-being. Session ended with participants being asked to identify possible avenues of help.</p>

Learning objectives	Content
<p><b>Session 3: Loss and bereavement</b></p> <p>To identify the ways in which a person with profound and multiple learning disabilities expresses feelings of loss.</p> <p>To identify how families and professionals can support a person who is bereaved.</p>	<p>Group discussion about how we feel when talking about loss and bereavement.</p> <p>Short talk about the grieving process and what happens when we grieve, including some loss and separation theories and the 'stages of grief'. The psychological aspect of grief, what happens to us when we lose someone important and how we cope with that loss was discussed.</p>
<p><b>Session 4: Supportive therapies</b></p> <p>To explore the use of supportive and alternative therapies and complementary medicines.</p>	<p>Discussion of two case studies from the research are used to illustrate positive and negative affects of music. Video used to illustrate how one family uses music as a medium to identify changes in the emotional and mental well-being of their daughter.</p> <p>The use of complementary therapies was also discussed and exercises provided.</p>
<p><b>Evaluation</b></p>	<p>Before and after the workshop session participants were asked to evaluate, on a scale of 1–10, how confident they felt about helping a person with a profound and multiple learning disability who had experienced a mental health problem.</p>

### Evaluation

The workshop sessions proved very successful. The workshops will continue to be held for family carers and care staff, and the workshop programme is also available from the Foundation for People with Learning Disabilities. In the overall evaluation participants indicated that they found the sessions very helpful, as the following comments illustrate.

- It made me think about how a person with profound and multiple learning disabilities might be thinking. I very much enjoyed the two days. It is very encouraging.*
- Hearing how other people cope... and although there are no text book answers I found it very interesting. Have found both days very interesting and enjoyed meeting with others at these sessions and exchanging views with them.*
- Learning about the real life experience of grief and how we can deal with it. Learning from personal experience of parents.*

## Conclusions

This research project has clearly identified that people with profound and multiple learning disabilities do experience mental health problems, often for reasons similar to other people. However, identifying those signs and symptoms that indicate changes in the emotional and mental well-being of people with profound and multiple learning disabilities is a learning process. Key triggers for developing mental health problems can be divided into external and internal causes. External triggers include bereavement, changes in routines, environments and staff, whilst internal triggers include pain, physical illness and puberty.

Using an already existing assessment tool (the Mini PAS-ADD) has proved to be extremely useful in identifying mental health problems in people with profound and multiple learning disabilities with carers, providing the interviewer can give carers the time to address these issues.

The shortage of professional staff, the referral system and the feelings that family carers don't want to take up professionals' time seems to be a significant factor in not getting the help they want. Closer working partnerships should be encouraged and developed between families and service providers to ensure that the emotional and mental well-being of people with profound and multiple learning disabilities is not overlooked or neglected by those caring for them. Training for family carers and care staff can help achieve this, along with the development of local care pathways where carers can receive help, advice and information.

### PRACTICAL IDEAS FOR ACTION

- Recognition should be given to the fact that people with profound and multiple learning disabilities experience changes in emotional and mental well-being in a variety of ways but it can take time to understand their individual means of expression.
- Discussing changes in mental health with family carers needs to be handled with great sensitivity. A number of the family carers interviewed as part of the study said they were so pre-occupied with their son or daughter's physical needs they did not think about their emotional well-being.
- The Mini PAS-ADD assessment has proven to be a useful diagnostic tool in identifying mental health problems in people with profound and multiple learning disabilities. The assessment can take longer to administer to family carers of people with learning disabilities due to time constraints linked with their caring role.
- There is a need for a dedicated specialist professional to whom family carers and frontline staff can turn for support in the physical and emotional care of people with profound and multiple learning disabilities.
- Training for family carers and care staff should be offered, particularly at the time during adolescence.



## **Project resources**

The well-being workshop *Ensuring the emotional and mental well-being of people with profound and multiple learning disabilities: a training resource for family carers and support staff* is available on multi-media CD from The Foundation for People with Learning Disabilities.

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# Conclusion

The work of the *Count us in* inquiry and the research programme report, *Making us count*, have drawn attention to the emotional and mental health needs of young people with learning disabilities. The inquiry reported that one in four young people with learning disabilities will experience mental health problems each year. This may even be an underestimate, so it is essential that there is a range of approaches and services to respond to their needs.

It has become very clear from the research that opportunities within the community for friendships, social and leisure activities, education and employment will enhance the self-esteem of young people. It is also important that they have the chance to be at the centre of planning for their own futures and to influence practice. This has been exemplified in the *Mind the gap* project in Somerset, where the peer training course had such positive results.

Another theme emerging from the research was difficulty with the language that is used for describing mental health problems. Young people, and indeed families, often did not recognise their poor emotional well-being as a mental health problem. Parents in particular felt they did not want their son or daughter given yet another label. There needs to be language sensitivity in talking with young people and their parents about mental health needs.

In the four countries of the UK the learning disability policy papers *Valuing people* (England), *Fulfilling the promises* (Wales), *The same as you?* (Scotland) and the *Northern Ireland review* have focused both on health needs and transition. The National Service Framework for Children (for England and Wales) includes standards specific to the needs of young people with leaning disabilities, including:

- a range of services should reflect the needs of those with learning disabilities
- adequately resourced Tiers 2 and 3 learning disability specialist CAMHS
- access to Tier 4 services providing in-patient and outreach units.

The Foundation's four research projects have demonstrated ways in which services should develop if they are to meet the needs of young people with learning disabilities who experience mental health problems. The wishes of young people and their families are modest – they need a single referral point, mutual support and someone to talk to. These are low-level interventions with cost-effective results that all local areas should be offering.

The following recommendations from The Foundation for People with Learning Disabilities are addressed to the UK as a whole.



# Recommendations

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## Mental health education and promotion

- From a young age children should be encouraged to communicate about their emotional well-being at school and at home.  
**Action:** pre-schools, schools and agencies working with children.
- Young people need to be better prepared for adulthood and feel emotionally strong. Some young people should be involved in training other young people for this (as discussed in *Chapter 5*).  
**Action:** schools, colleges, advocacy groups and agencies working with young people.
- Family carers need to be informed about ways of supporting their young people emotionally and how to access support for the range of mental health and emotional problems their sons or daughters may experience, through training, support groups or other means (as discussed in *Chapters 5* and *6*).  
**Action:** primary healthcare services, schools and colleges, voluntary agencies working with or led by family carers.

## Person-centred approaches and transition

- Person-centred approaches should be used as a tool for planning ahead with young people and families. It is particularly beneficial if this starts from the year 9 transition review and encompasses all aspects of a young person's life. Health action planning should be a key element of person-centred planning and can be used to explore and take action on physical and mental health problems.  
**Action:** schools.
- Young people should benefit from the continuity of a transition worker (this could be a care manager, community learning disability or psychiatric nurse or social worker) who is linked to education and adult services to ensure there are no gaps in service provision at this time. The Connexions personal advisers in England have proved to be a key support. They need extra time to work with young people with complex needs.  
**Action:** social services, primary health care, Connexions services in England and agencies working with young people.

## Identifying mental health problems and providing appropriate support

- Primary healthcare services should be educated about ways of promoting the emotional well-being of young people with learning disabilities, including those with profound and multiple learning disabilities, and about how to identify at an early stage the emergence of any mental health problems.

**Action:** medical and nursing training schools, professional bodies, national training organisations, in-service training provision, for example from specialist learning disability and mental health services.

- Young people with complex needs should receive appropriate support with mental health problems, with clear referral routes/pathways to care.

**Action:** primary healthcare, learning disability and mental health services.

- All child and adolescent mental health services should have support in developing competencies and confidence to support young people with learning disabilities through the use of managed care approaches.

**Action:** health departments throughout the UK. In England, The Foundation for People with Learning Disabilities in partnership with the Department of Health and the National CAMHS Support Service.

- Families should have regular contact with a link person who can help them access services. There is a need for a specialist person to support people with profound and multiple learning disabilities and those from minority ethnic communities (as discussed in *Chapters 4 and 6*).

**Action:** primary care and voluntary organisations employing health liaison workers or family advisors.

- Young people with learning disabilities should have equal access to a range of mental health services that should be non-stigmatising and sensitive to the needs of young people.

**Action:** primary healthcare, child and adolescent mental health teams, community learning disability teams and adult mental health services.

# Mapping exercise

### **Who can help a young person with learning difficulties who also has emotional support needs?**

The mapping exercise below can be carried out by a team or group of professionals and service providers involved in providing support to young people with learning disabilities and their families.

People are individuals, and they do not fit neatly into boxes. However, in Somerset we found that there were certain typical ‘scenarios’ that might help to think about the referral routes that people can follow.

#### ***The scenarios***

Jack has a mild or moderate learning disability, and shows signs of aggression or challenge during adolescence. Perhaps has had a rough deal, and has a range of social factors stacked against him.

Paula is someone with a severe learning disability. She can communicate verbally, and has always been considered compliant and easy. During adolescence, starts to show signs of anxiety, depression (or maybe even psychosis).

Srikant has had episodes of depression or anxiety throughout his childhood. He has a learning disability, but has been to mainstream school. He has received services from CAMHS, and saw a consultant psychiatrist when a child.

Sue has a history of behavioural challenges. She communicates largely non-verbally, and can become very distressed when she is not understood. She has been diagnosed as having an autistic spectrum disorder.

With these four scenarios in front of you, as a team write on different pieces of card or sheets of sticky notepad your ideas about which people and/or services might get involved with each of these young people.

Then, taking one scenario at a time, talk through the path which that young person might follow. Use your cards or sticky sheets to graphically map out the route, using a wall or flipchart to display them, and arrows to link them together. Remember that there are probably many routes and many outcomes. However, the rules are to:

- listen to each person in the team
- base your mapping exercise on real people and real referral routes
- remember that any map can be changed, and you can constantly update your expertise with new information.

## Policy in Scotland

Recent years have seen a raft of policy initiatives in mental health and learning disability in Scotland. A detailed framework for mental health services was published by the Scottish Office in 1997.<sup>1</sup> The Mental Health (Care and Treatment) Act 2003<sup>2</sup>, to be implemented in 2005, gives local authorities a duty to promote the well-being and social development of everyone in their area who has a 'mental disorder', not only through social, cultural and recreational activities but also training and employment.

Current national programmes aim to raise awareness of mental health issues (see [www.seemescotland.org](http://www.seemescotland.org)), promote mental health and well-being, and support recovery (see [www.wellontheweb.net](http://www.wellontheweb.net)). A national review of child and adolescent mental health<sup>3</sup> (NHS Health Scotland, 2003; see also [www.phis.org.uk](http://www.phis.org.uk)) recommended that mental health promotion, prevention and care be integral to all agencies working with young people, the main thrust coming through their communities, schools and families. The report acknowledged young people's rights and the role they can play in their own health. The Child Health Support Group is charged with taking forward these recommendations.

In relation to people with learning disabilities, *The same as you?* report<sup>4</sup> sets out a national strategy for Scotland. It also recommends health promotion and joint working in relation to mental health. Its 29 recommendations are currently being taken forward by a national implementation group. Very few policies, however, are specifically targeted at young people with learning disabilities who have mental distress. How far the initiatives described above will prove relevant and effective for them is not yet clear.

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## Randomised controlled trial (RCT)

A randomised controlled trial (RCT) is a study design used to evaluate the effectiveness of health care intervention. RCTs are not only used to evaluate pharmacological treatments, but also physical and psychological therapies, diagnostic tests or preventive and public health measures. RCTs are the most rigorous way of determining whether a cause-effect relation exists between treatment and outcome and for assessing the cost-effectiveness of a treatment.<sup>1</sup> In a controlled trial randomisation ensures that allocation of patients to treatment is left purely to chance and the characteristics of participants that may influence outcome are distributed between groups so that any difference in outcome can be assumed to be due to the intervention.<sup>2</sup> In this study participants were randomly allocated by computer randomisation to receive either normal interventions or the help of the specialist liaison worker in accessing relevant services.

### **Assessment measures**

All participants were assessed at baseline and at the end of the study using standardised measures. For the young people, these were measures of problem behaviours and included the strengths and difficulties questionnaire SDQ<sup>3</sup> and the problem behaviour inventory PBI<sup>4</sup>. Family carers were assessed using a standardised measure of mental ill health for use in non-psychiatric settings, the general health questionnaire GHQ30<sup>5</sup>, and a standardised measure of quality of life, the short form health survey SF12.<sup>6</sup>

### **Data analysis**

Data was analysed using SPSS to perform statistical tests appropriate to the comparison of two groups (treatment and control) over time. Specifically, two-way analysis of variance and independent groups tests were used.

### **Service contact**

The treatment group had statistically significantly more frequent contact ( $t=5.528$ ,  $p=0.001$ ), with more services ( $t=4.058$ ,  $p=0.002$ ) and with more outcomes from such contacts ( $t=3.745$ ,  $p=0.002$ ) than did the control group.

### Assessment measures

GHQ30, PBI and SF12: No differences between control and treatment groups.

SDQ: Significant differences ( $F=8.003$ ,  $p=0.009$ ).

Physical subscale of SF12: Significant differences ( $f=5.925$ ,  $p=0.022$ ).

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We use our research and projects to promote the rights of people with learning disabilities and their families.

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- Communicating our knowledge to a wide range of people.
- Turning research into practical solutions that make a real difference to people's lives now and in the future.

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