

# making us count

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

## REPORT SUMMARY

- **What are the mental health needs of young people with learning disabilities?**
- **What are the problems young people encounter in meeting these needs?**
- **What ways forward are there to overcome these problems?**



A Foundation for People with Learning Disabilities research programme and report *Making us count* provide some answers to these questions. This is a brief summary of the research and its key findings. The research was funded by the Baily Thomas charitable fund.

[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

# The research

The research centred on four projects, covering a wide range of young people. The starting point for all the projects was the young people themselves – their thoughts, their feelings and their views. The needs of family carers were also considered. Involving young people and carers in the research was seen to be key. While each project had different specific aims, the common threads were recognising the causes of mental health problems, identifying them, and accessing services to help with them.



## The four projects

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

Researchers in Scotland worked with a group of young people to talk about their own experiences of mental distress, how they coped and the support they received. This project used an innovative methodology involving photo and video diaries to facilitate communication and understanding between young people and the researchers. 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.

### **Supporting young people with learning disabilities and mental health needs from minority ethnic groups**

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, and focus groups with service users and service providers, to identify the barriers to accessing services. During the project one group of families was allocated a liaison worker for nine months to help them access the services they requested, while another group carried on without this support. The young people allocated to the liaison worker experienced fewer behavioural problems and were in contact with more services than the other group.

### **Mind the gap: improving mental health support for young people with learning disabilities**

The Norah Fry Research Centre in Bristol worked in partnership with Somerset Joint Commissioning Team and the Connexions service, focusing on transition and the mental health problems identified by young people around this difficult time. 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. The outcomes included a peer support course facilitated by young people themselves, and a course on emotional support facilitated by and for parents.

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

This study, based in Dundee, 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. The study found that the majority of carers are able to identify specific signs that alert them to changes in emotional and mental well-being and that the causes are no different from the general population, for example life changes, bereavement and illness. However, carers were unable to find appropriate advice and support once changes in emotional and mental well-being had been identified. The family carers helped develop a series of training workshops for other family carers and care staff.

# The findings

## What is 'a mental health problem'?

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

Many of the young people who took part in the research experienced varying degrees of distress, anxiety and emotional stress. Most had not been professionally diagnosed as having 'a mental health problem'. Young people and carers themselves often did not recognise this term, and did not want the stigma they felt was associated with it. They used terms like:

- stressed
- depressed
- distressed
- sad
- angry.

Common symptoms reported by the young people in Somerset were:

- aggression
- anxiety about going out
- obsessive behaviours
- lack of concentration (attention deficit disorders)
- being extremely withdrawn.



## The social context

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

All four projects emphasised the social causes and context of mental health problems and emotional distress. Friends, or the lack of them; shortage of work opportunities; bereavement; exclusion; and boredom are just some of the factors that affect one's state of mind and ability to cope. Clinical experience suggests that positive opportunities and life changes can dramatically improve the well-being of young people with learning disabilities.

Many Muslim, Pakistani, Kashmiri and Bangladeshi people live in areas classed as 'struggling' and people in south Asian communities suffer a disproportionate incidence of learning disabilities and of chronic illnesses. Listening to their experiences increases our understanding of how attitudes to race and disability, coupled with social conditions, can affect their self-identity and their needs for support.

In one of the projects, a Connexions transition worker described a young man who displayed severe symptoms of distress. She recognised the emotional and social factors at work, including work problems and family issues, and worked with him to create opportunities to enrich his life. This is a clear example of a social approach to a mental health need.

# How does emotional distress manifest itself?

“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.”

Young people with mild and moderate learning disabilities may communicate verbally, but may struggle to outwardly express their inner emotions. Others will show how they feel by changes in their behaviour, non-verbal communication or their reactions to people and events. These behaviours are very similar to those exhibited by anyone with emotional problems, not just people with a learning disability.

The better you know the person, as a family member or carer, the more likely it is that you will recognise the signs of mental ill health. The research showed that it was important to know the person and their history in order to provide appropriate diagnosis and care. However, family carers did not necessarily realise that the changes they saw in their growing children were due to emotional distress rather than to their disability, and they too need information and support to overcome this.



## How should services improve?

“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.”

All the projects pointed to the need for services to help tackle the social barriers and create better life chances for young people, including social and recreational activities. It was also clear that services do not always take the cultural and religious needs of minority ethnic groups into consideration.

In Bradford, the experiment of giving some families a liaison worker clearly showed how useful it is for families to have one clear point of contact. All the projects clearly demonstrated the lack of co-ordinated provision; communication between professionals in different disciplines and services; reliable referral routes.

Two of the key recommendations 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
- there should be specialist learning disability services for mainstream mental health services and to support young people with the most complex needs.

Two key concepts trialled in the projects were liaison workers and mapping pathways to support. The liaison worker provides regular, proactive support while the mapping exercise identified local services and identified possible routes through them for different clients and cases.

## How do young people perceive mental health problems and react to them?

“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.”

Although the people in the projects may not identify themselves as having a mental health problem, or even a particular emotional problem, there is no doubt that they experience the same feelings as the general population. They spoke of feeling down and wanting things to change; of boredom and pointlessness; of constant worry. Some even self-harmed. In Scotland the study found young people tended to use descriptive terms often linked to unpleasant emotional and physical sensations. They used words like ‘temper’, ‘panic’, ‘bored’, ‘fear’ [frightened], ‘fed up’ and ‘things wrong with me’.

Anger and aggression towards others was a common response, and one that was often recognised by the person as being ‘unreasonable’ or not the other person’s fault.

It is clear that transition – a period of life on which the Somerset project in particular focused – is a difficult time, bringing with it feelings of disorientation and confusion. While some of the young people were aware of their feelings and the issues that caused them a problem, others did not recognise them as mental health needs. Carers also did not always recognise poor mental health and distress. Mood and behaviour changes were sometimes put down to the person’s learning disability, rather than to a particular mental health need.

## What were the main service issues identified?

“It was months and months and months that I had to wait for 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.”

The current availability and use of support services is patchy. Young people with profound and multiple learning disabilities and those from the south Asian population in particular were found to be in touch with very few services.

The Dundee project identified a lack of appropriate pathways of help with no dedicated professionals with specialist knowledge to support people with profound and multiple learning disabilities. 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 the school or GP.

Many of the gaps identified would appear relatively easy to bridge, through support services to listen to young people and to help them take part in everyday activities.

A number of barriers to seeking help were also identified. These included:

- fear of being branded a ‘nuisance’
- religious belief
- a belief in self-reliance
- language barriers
- lack of awareness of services.



# Issues for family carers

“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.”



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.

Parents plainly felt that they were often coping alone, and were wary of pushing for services for fear of being branded as a ‘nuisance’ or ‘over-protective’. Again, as in the population in general, some parents and carers felt that social support had been more valuable than psychiatric intervention, while others were full of praise for the psychiatrists who had been involved in their children’s care.

The Scottish project found a lack of knowledge among parents about the services available, coupled with feelings of not being able to cope and of confusion at changes in behaviour. When professional help was sought, it could be less than helpful or positive.

In the Bradford study, a major issue for the family carers was their perception of what services were available. None of the families involved felt they were getting the support they needed and they felt overwhelmed by the mental and physical health issues of their children.

Care staff in Dundee would primarily turn to colleagues who knew the individual, rather than seek help from a professional, finding this to be most helpful.

Overall family carers want and need:

- professional advice to help them cope at home
- to be listened to
- peer support from other parents
- access to respite, day and residential services that have the appropriate expertise
- a system of resourcing that is more open and to which families have greater access.

The full report ***Making us count*** is available from  
The Foundation for People with Learning Disabilities, price £17.50.  
Tel: 0207 803 1100, email [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk), [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk).

# Involving young people and their families

All the projects directly involved young people and their families and carers and a number of methods were used. Somerset employed the dynamic of action research in which participants were encouraged to define their own needs and problems and the research outcomes. They also used a pictorial interview questionnaire, with questions the young people felt happy with, in an accessible language.

In Glasgow, photos were used to prompt discussions about feelings and emotions. Video diaries provided some real insights into people's lives, displaying emotions that were not present in interviews with researchers.

Focus groups involving service providers and practitioners brought people together to explore a wide range of issues. The Somerset project used these to explore areas of concern that were raised by individuals. The Somerset group also developed peer group support and training that has resulted in a training resource, *We are the strongest link* (available on [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)). Through this young people share, learn and support each other.

Listening to and hearing young people with profound and multiple learning disabilities has particular challenges, and in the Dundee project family carers were closely involved.



## Conclusions

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

The young people who attended the Somerset peer support workshops 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. 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 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 transition 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.



the  
Foundation for People  
with Learning Disabilities

We use our research and projects to promote the rights of people with learning disabilities and their families.

We do this by:

- Identifying work that is needed to overcome barriers to social inclusion and full citizenship.
- 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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