

# Linking up

**Emotional support for young  
people with learning  
disabilities**



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# Introduction

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## Background

This guide springs from an action research project in Somerset, called *Mind the gap*, where there is very good practice in transition planning and in joint working between Connexions and social services. The study was carried out by the Norah Fry Research Centre, in partnership with Connexions, other service providers and commissioners in Somerset. It was funded by the Foundation for People with Learning Disabilities, as a follow-up to the *Count us in* inquiry (2002).

This inquiry into meeting the mental health needs of young people with learning disabilities confirmed that young people with learning disabilities experience the same range of mental health problems as the general population. However, they are far more inclined to develop emotional difficulties such as depression and anxiety and these often go unrecognised and untreated.

A common message the inquiry researchers heard was about the lack of opportunities for young people with learning disabilities in education, work and leisure. This lack was often the trigger for mental health problems. And when help was needed, the inquiry found that finding and accessing appropriate treatment was far from straightforward.

The subsequent research programme, of which *Mind the gap* was part, aimed to find out what support works best for these young people, and to offer some practical advice.

Young people with learning disabilities should not be put into a separate box, packaged up and labelled as 'special'. They should have the same opportunities, the same thinking and planning, as anyone else. The only difference is that they may need more support to attain their goals.

## About this guide

Young people with learning disabilities have the same needs, hopes and fears as other young people as they move into adulthood. Sometimes these may be expressed or communicated in a different way, but their ambitions are the same - around work and their personal life. The problems they face are also the same: their lives are undergoing huge change. As specialists, Connexions staff have a vital role to play in this transition, in helping it to go smoothly, and in helping the young person know and understand what the future holds. It is because services are not co-ordinated, and transition is not smooth, that Connexions staff and others who give help and advice to young people are needed.

Transition can be a difficult time for any young person, but if you are experiencing mental health problems it can be even tougher and the distress can escalate. The *Count us in* report (2002) found that one in four young people with learning disabilities experiences mental health problems. This needs to be recognised by staff and carers, and the appropriate support given. Connexions staff not only provide this support, but also have a key role to play in helping people along the route to other professional services where there are specific needs.

To quote one transition personal advisor: 'I would say one of the main stresses is not knowing what is going to happen to them. I think if we could get in earlier and sort things out earlier then some of it might be avoided.'

Knowing what that support might be, and the most fruitful way of providing it, is not always easy. This short guide has been written to help Connexions staff - and indeed anyone working with young people in transition - give this support to people with learning disabilities, and to provide some practical advice and examples. The guidelines were developed in consultations with Connexions personal advisors and are based on their experiences and advice.

The publication of *Valuing people* (2001) has put a spotlight on services for people with learning disabilities in England and specifically mentions the role the Connexions service has to play. However, anyone working with young people with a learning disability anywhere in the UK should find these guidelines helpful.

For full details of the project, contact [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk).

# SECTION I

## Issues for young people with learning disabilities

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### Policy and strategies to support people with learning disabilities

#### MAIN MESSAGE

The aims of government policy for all people with learning disabilities are to give them more **choice, independence, and rights**, in as **inclusive** a way as possible.

### Valuing people

*Valuing people: a new strategy for learning disability for the 21st century* ([www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)) is the main government strategy for people with learning disabilities in England and specifically mentions the Connexions service. However, these guidelines should be useful to anyone in the UK working with young people with learning disabilities.

One of the most important goals in *Valuing people* is to make sure that transition to adulthood is managed successfully for all young people with learning disabilities. Connexions staff have a vital role to play.

This is what *Valuing people* says about young people at transition:

- local learning disability partnership boards have a duty to provide a leader for transition planning at local level
- partners such as education, health, employment and council services/relevant services should work together to ensure a smooth transition to adult services
- all young people with learning disabilities in transition should have a person-centred plan by 2003.

### Key objective

As young people with learning disabilities move into adulthood, a key objective of *Valuing people* is 'to ensure continuity of care and support for the young person and their family and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in training, education and employment.' (*Valuing people*).

Connexions personal advisors have a responsibility to attend the first transition review for a young person with learning disabilities at the age of 14, and to assist with the transition plan for that young person. They can then continue to work with the young person until the age of 25 if needed.

Connexions personal advisors need to be able to take the lead for all aspects of the planning for a young person with learning disabilities, including the emotional support to be offered.

## Transition

### MAIN MESSAGE

Young people with learning disabilities may need some quite specific help and guidance on the path to adulthood.

Connexions is a service for all young people, to guide them along the path to adulthood. Young people with learning disabilities have the same problems as all young people:

- they are growing up
- they are developing new identities and interests

- they may well be facing considerable changes (eg leaving school, going to college or work).

These changes may be difficult for everyone, but young people with learning disabilities face additional and complex challenges at this stage (see *Count us in*, 2002).

Some of these are **personal challenges**.

- They may still need to develop their own self-confidence.
- They may need to develop their communication skills.
- They still need to learn many independence skills.

Other challenges are to do with the **social barriers** around them.

- Young people with learning disabilities are often surrounded by people who 'know best'. Their lives are controlled by other people, and it is hard for them to speak up and make their own decisions.
- Transition is a time when young people move from children's to adult services. Co-ordination and planning may be poor. One young person on the *Mind the gap* project, when asked if he knew what transition was, said:

*“ Is it when you pass something on? ”*

That may well reflect how young people feel at this stage. They feel like a package that has been bundled up and is passed from person to person, service to service.

## What do young people with learning disabilities want?

### MAIN MESSAGE

Young people told us that they wanted the same things as all young people: friends, fun and a future.

This is what young people with learning disabilities told us about their ambitions for the future:

*“ I am not sure I can call it a dream or an ambition, but I hope that one day I will be living independently. ”*



*“ I want to get back to work as soon as I can. I want to get into a normal routine as soon as possible. ”*

*“ I just want life to be better. I could do things on my own, and get more independent. ”*

Other ambitions mentioned included those relating to work, such as:

- a job in computers
- working with children
- working in catering
- a job in landscape gardening.

Those who could not speak for themselves could still show what activities and situations they enjoyed by their reactions, their facial expressions and other means of communication. Again, their preferences reflected some very ordinary needs and wishes in life, including:

- the wish to be with friends or familiar people
- the chance to try out exciting sports or physical activities
- enjoying rock music.

## Mental health problems in young people with learning disabilities

### MAIN MESSAGE

*Count us in* found that 1 in 4 young people with learning disabilities will have a mental health support need at some point during adolescence.

Until quite recently, it was thought that people with learning disabilities did not have the same range of feelings and emotional needs as other people. It is now realised that it is very common for young people with learning disabilities to experience mental health distress.

*“ I was mixed up between school and college. I wasn't in one head - I was in both. When I left school, I got used to it eventually - but it did take me a while. ”*

**“ I get stressed out of my mind sometimes - people are always telling me what I ought to do. But I just want to go out with my friends. ”**

*Valuing people* states that people with learning disabilities should have the right to be included in the targets set under the National Service Framework (NSF) for Mental Health. We know that a large number of young people with learning disabilities will experience mental health distress, but we also know that they do not necessarily receive mental health service support (Simons and Russell, 2003). We therefore need to know more about how best to support them through this period.

# SECTION 2

## Identifying mental health problems in young people with learning disabilities

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### Common fallacies

#### MAIN MESSAGE

Signs and symptoms of poor mental health are often put down to a person's learning disability. We need to identify mental health problems in these young people, in the same way as we do for all young people.

When someone shows signs of feeling distressed, it is all too easy to say 'it's just the disability'.

A young woman who did not communicate with words lived in a group home. She had been involved in an accident in the swimming pool, where she nearly drowned. Afterwards her behaviour started to change. She found it difficult to sit down and eat at the table; she also started defaecating in the garden, and reacting in ways those around her interpreted as 'challenging'. As one member of staff explained, it was hard to work out what was due to her emotional distress, and what was simply due to the fact that she had 'challenging behaviour'.

Putting feelings down to a person's disability is particularly likely when someone cannot speak for themselves and tell you how they are feeling.

*“ It’s hard to know - I think it’s probably just part of his learning disability, and of course he’s autistic too. ”*

In our study, all the young people had experienced mild mental health problems such as mild depression and anxiety. These are commonly referred to as affective or emotional disorders. The more severe mental health problems include thought disorders such as schizophrenia, bi-polar disorder, severe depression, anorexia-nervosa, alcohol dependence or substance misuse and personality disorders.

The most common problems reported by the young people in our study were:

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

However, in every single person these issues had escalated at the time of transition, or indeed new problems had emerged. In one case, this had resulted in an attempted suicide. Other less extreme manifestations had notably included aggression. This was true both of the people with high support needs, and those with moderate learning disabilities. 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. ”*

## What can lead to mental health problems in young people with learning disabilities?

### MAIN MESSAGE

Young people with learning disabilities experience the same range of life factors that can trigger mental health problems as any other young person. However, there may be even more risk points for them.

These were some of the common factors that had led to emotional problems for young people with learning disabilities in our study:

- moving on from school or college, especially when that was a sudden and unplanned event (several young people we met had been excluded from their schools)
- the death of someone who was close to them (eg a grandparent, or another family member)
- losing friendships and contact with people they knew well
- moving into large systems (eg colleges) where people did not understand their problems
- bullying and other forms of abuse.

In retrospect, one parent knew very clearly what the problems for her child had been on leaving school. They were:

- never feeling that anyone took his needs seriously
- anxiety and fear that he wouldn't cope
- total lack of confidence, and no time given to him to opt out and have time to 'grow up'.

Transitions personal advisors in Somerset (see **Section 4**) listed the following reasons for emotional distress in young people with learning disabilities:

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

This is what one transition personal adviser said:

*“ Young people are asserting themselves at this stage. At school, nowadays, there is a lot less asking them about what they want. So when they leave school, they need to assert themselves. On the other hand, people feel they have lost control over their lives, and they do things to gain control over one area of their lives at least. ”*

The particular triggers that had caused problems all related to change, or frustration caused by bad management of a changeover period. One parent said:

*“ There was a lot going on in his head, and he couldn't cope with the changes at all. ”*

## What young people feel

### MAIN MESSAGE

It is important to listen to young people themselves. They can often tell us about their feelings, especially if we take time to learn to communicate with them.

All the personal advisors who spoke with the *Mind the gap* project emphasised how long it takes to get to know well a young person with learning disabilities. That is really important, as young people will only open up if they feel they are in a relationship of trust.

Personal advisors said they needed to:

- take time to get to know young people
- go out to places with them, and be friends
- meet up with young people in different places - at school, at youth clubs, with friends, with family
- talk with young people at home, but also on their own.

It is hard to talk about feelings, but there are some books and leaflets that might help with this. These are listed at the end of this guide in the **Resources** section.

## Young people showing us how they feel

### MAIN MESSAGE

Not everyone can talk about their symptoms. But they can often show through their behaviour and reactions how they are feeling.

Some young people will show others how they feel by changes in their behaviour, their 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.

These are some of the things that might happen:

- changes in eating habits
- shouting, crying or throwing things
- staying in bed, and not wanting to get up and do the usual things
- refusing to go to the usual places, like school or college
- going back to ways of behaving that were typical of the person when younger (eg bed-wetting).

These are the common ways in which emotional distress can show itself:

### **Depression**

- loss of interest in usual activities
- feeling irritable and impatient
- lack of energy
- consistently feeling 'low'
- changes in sleep pattern
- not wanting to communicate with others

### **Anxiety**

- needing extra reassurance
- being clingy to people they feel safe with
- having pain or discomfort - often caused by muscular tension
- feeling sick or having an upset stomach
- being restless
- difficulty in concentrating
- sleep disturbance

**These are some of the more common symptoms if a person is experiencing a severe mental health problem such as schizophrenia (also referred to as psychosis)**

- Experiencing something through one of your senses that is not really happening, and that no-one else experiences. This can be hearing voices, seeing things that are not there, feeling things on your skin when nothing is there.
- Believing things that are not true, and not being able to change your mind about them. The beliefs tend to be quite bizarre and strange - eg believing that spies are following you, or that you have super powers.

# SECTION 3

## Alleviating mental health problems

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### The label ‘mental health need’

#### MAIN MESSAGE

Many people do not like the label of ‘mental health’. It often implies a medical approach. Such an approach locates the problem in the person and assumes that the person can be ‘fixed’.

We know that many young people with learning disabilities have emotional problems. But the very fact that these issues are not diagnosed means that professionals, families and young people are not used to discussing young people’s needs for mental health support. The people in our study did not generally use the term mental health need.

We also found lots of other people who did not like the words mental health. People who work in learning disability services said they only used the words mental health for people who moved from learning disability into mental health services.

The words people said they preferred were

- stress
- emotional distress.

This is what we found worked well.

- If we were unsure what words to use, we started off with stress or emotional distress. Then people could move on to using whatever words they wanted.
- Some people with learning disabilities do use mental health services. When using the words mental health, we said mental health support need.



- When talking with professionals outside mental health services, we generally talked about positive emotional support.

## The words used by young people themselves

### MAIN MESSAGE

Young people themselves use different words to describe how they feel.

We asked young people what words they preferred. These were the words they used:

- stressed
- depressed
- distressed
- sad
- angry.

They also used phrases like: 'I've lost the plot' or 'I've lost it'.

*“ I feel sad, upset and depressed when I keep things in. ”*

## Models of mental health distress

### MAIN MESSAGE

A social model of emotional distress recognises that the symptoms people have can be a natural way of reacting to life circumstances.

### The medical model

Some of the Connexions personal advisors felt that mental health meant a medical model. That is often true.

A medical model:

- involves a diagnosis (many people feel this is stigmatising and sticks with them for life)
- sees the problem as an illness in the individual
- seeks a cure, often by traditional medical means such as medication
- tends to focus on people with severe mental health problems.

## Treatments

### **Medication**

There are many different types of medication that can be used for mental health problems. They are usually called psychotropic medications. If the problems are of a severe nature it could involve a hospital admission.

Depending upon the diagnosis the drugs prescribed include anti-depressants, anti-psychotics and mood stabilisers. When a person is prescribed medications such as these, they and their carers should always weigh up the benefits of taking the medication against the possible drawbacks. To do this, you and they will need to know:

- what it is prescribed for
- why the doctor thinks it might be useful
- what the possible side effects are and how you might recognise them
- what you should do if side effects do occur
- who to ask for more information or to answer any questions you have about the medication
- how frequently the medication will be reviewed.

### **Therapies**

There are other ways that the health profession can support people, besides medication.

**Talking therapies:** where people get one-to-one help to talk through and understand themselves better.

**Creative therapies:** like art or music therapy.

**Cognitive therapies:** where people work out ways of dealing with their problems.

All of these are about listening and giving people time.

## The social model

The social model may be most relevant for people whose problems are grounded in social and environmental factors. Emotional distress is a natural way of reacting to very difficult life circumstances. It does not deny that people may have very painful feelings, but a social model means that:

- you help someone understand and get over the pain they are feeling
- you also help them get over the social barriers and difficulties they are facing in their lives
- you help the person live with the difficulties they face.

This is how one of the Connexions personal advisors put it:

*“ What young people need is time, and a human face and loads and bags of reassurance. ”*

One transition personal adviser (see **Section 4**) described a young man who had consistently sought help, and had a number of severe symptoms of distress, including self-harm. The approach to this young person was:

*“ to try and get a boost going in him, rather than to treat him as ill. ”*

The causes of his emotional distress were:

- lack of social opportunities
- family issues
- failure in work-related activities.

The advisor felt that the most important thing was to tackle these issues, and to create opportunities with the young person to enrich his life. This was a very clear endorsement of a social approach to mental health distress.

## The bio-psycho-social model

The bio-psycho-social model is well known within mental health services, although arguably the medical model still dominates. By combining the use of medication, social interventions and psychological approaches, people can be supported to overcome their mental health problems. For example, a depressed person who was living alone in a flat could be treated with medication and cognitive behaviour

techniques to overcome the depression, and be given support to find more suitable accommodation. This model can be used with people with mild or severe mental health problems.

## When learning disability meets mental health services

### MAIN MESSAGE

Learning disability and mental health services need to find better ways of working together.

Many of the families in our *Mind the gap* research, as well as the professionals, said that mental health services were overstretched.

“ *You get to breaking point before you are referred, and then you have got an 18-month waiting list.* ”

Learning disability services are a service for life. They accept that people will always need support. But mental health services are there to help people recover and move on. There are lots of cultural differences between the two sets of services, and sometimes between the needs of different people. The result is that some people with learning disabilities and mental health support needs get lost in the system. They literally fall down the gap.

James is a 17-year-old with Asperger's Syndrome. He went to mainstream school at the primary stage, but has been out of school since the age of 11. He had apparently been told that he 'wouldn't get a service from mental health'. However, learning disability services do not consider that he meets their criteria. As the transition personal adviser says, 'they are batting him back and forwards'. The adviser has managed to do a carer's assessment, and a psychologist is assessing James' IQ. There is a consideration of joint funding from health and social services for him. However, the transition personal adviser is finding that it is an 'uphill battle just to contact his childhood social worker'. The only appropriate service is a specific support service for autism, which he is now receiving, but this is not proving totally successful. The transition personal adviser feels that they 'may need to go back to the drawing board'.

Connexions cannot actually provide an appropriate service, but it is good to try to act as a catalyst, and get people working together. Two ways that joint working could really help to move things forward are by:

- developing a programme of joint training
- building more substantive links between the two services at the local level, for instance by use of joint appointments and joint membership of teams.

## Helping someone through their mental health problems

### MAIN MESSAGE

Sometimes it is necessary to make sure someone with learning disabilities gets good and swift support for a mental health problem.

#### An example from Somerset

Mark was a young man who was identified by his transitions personal adviser as experiencing mental health problems. She noted his mood changes, tiredness, and lack of motivation as signs that he was probably depressed. However, she said 'it's very difficult to put your finger on that one'. Her response to this situation was to talk with Mark and his family. With Mark's permission, she put in a referral to a psychologist, but also insisted that he go back to his GP. She explained that people like Mark may have many professionals who are worried about what to do for him, but the GP is often the central link.

The above example illustrates how Connexions personal advisors can help by noticing a problem, and encouraging someone to go through the appropriate referral route to get psychiatric support.

Personal advisors in Somerset who worked with young people with learning disabilities felt that:

- a referral to mental health services would only be made when the multi-disciplinary learning disability team could not cope
- if mental health services were needed, the best route for the individual was to go to their own GP as a first port of call, just as anyone else would.

Sometimes, however, there were other local routes to obtaining good support. In Somerset these included:

- liaison social workers, whose job was to provide a link between learning disability and mental health services
- community nurses who similarly spanned the two sets of needs.

## Providing for young people with complex needs

### MAIN MESSAGE

Some young people will need specialist services that go beyond what either learning disability or mental health can provide.

There is an urgent unmet need that still exists for certain young people who have both complex and challenging high support needs. These young people often face transition without any choice of appropriate support.

Marie was a young woman who had complex needs, and did not express herself in words. She had become very anxious. She had been permanently excluded from school, and this led to her beginning to self-harm. Her parents were not coping. The transition personal adviser (TPA) found herself faced with a crisis situation, with a young person who clearly needed alternative living arrangements very urgently. Marie's transition to her new home took about four months, and, as the TPA put it, 'this delay was really dire'. However, what the TPA was able to put in place was a transition process that gave Marie a slow induction to her new situation. This was done through multi-disciplinary input. For instance, one of Marie's main problems was that she could not express her feelings clearly, and so a speech and language therapist went to see Marie regularly, and to advise other members of the team. The psychologist who was also part of the social services team was on hand to assess and support Marie's behaviour with very clear guidelines. As the TPA put it: 'I thought this home may not cope, that her needs might be above the level of what they could do, but that hasn't in fact happened.' In Marie's case, there has been no input from mental health professionals, despite her clear signs of mental health distress. The TPA felt that a referral to mental health services would only have happened for Marie if there had been problems that the existing multi-disciplinary team could not handle.

- We all need to get better at helping people like Marie, and this can often happen in the community.
- Some people like Marie are living in their own homes, with supported living arrangements and 24-hour support.
- Don't just think that someone like Marie needs 'specialist' provision, especially if it is far away and out of the local area.
- Do consider referring someone like Marie to mental health professionals.
- The National Standards Framework for Children and Young People (Mental Health) is calling for all child and adolescent mental health services to improve access for children and young people with learning disabilities.
- In some areas, a specialist team for learning disability and mental health may be able to help Marie.

## Emotional support from all services

### MAIN MESSAGE

All services need to get better at recognising and supporting young people with learning disabilities who have emotional needs.

There is a strong argument that by getting the whole transition process working more smoothly, mental health problems can be alleviated, or even avoided. Certainly, this is how one of the transitions personal advisors (see **Section 4**) framed the issue:

*“ I would say one of the main stresses is not knowing what is going to happen to them. I think if we could get in earlier and sort things out earlier then some of it might be avoided. ”*

We asked young people what makes 'good support' for them, and this is what they told us.

- Young people want to know that their key support person is going to stick by them.

*“ I think it is because I know that no matter what happens she will be there for me. ”*

- They wanted supporters who:
  - cared about them
  - knew them well
  - 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. People spoke of 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. ”*



# SECTION 4

## The Somerset model

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### Transition personal advisors

#### MAIN MESSAGE

Connexions Somerset has employed full-time personal advisors who are dedicated to young people with learning disabilities who are likely to be in receipt of social services support as adults. They are attached to social services community teams for adults with learning disabilities.

The Connexions service in Somerset has taken an important step. From the joint funding with social services, they have appointed dedicated personal advisors for young people with learning disabilities.

Since Somerset is a large county, four of these new posts were created. The post-holders are called transition personal advisors (TPAs).

- Although employed by Connexions, each of the post-holders is based partly at the local Connexions office, and partly within the community team for adults with learning disabilities (multi-disciplinary social services teams). They have one foot within Connexions, and one foot within social services provision.
- The transition personal advisors aim to meet with young people from the age of 14. For two years, until the young person reaches 16, there is joint work between the Connexions individual support personal adviser, and the TPA.
- Planning for future needs and service provision for transition is undertaken by a steering group that meets quarterly.

Because each of the TPA posts in Somerset is based within a multi-disciplinary team for adults with learning disabilities, 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.

This is what transition personal advisors said:

*“ Like anyone else going in, you are advocating for the young person, and how best to get the resource for that young person. ”*

*“ I work for Connexions but ... I am very closely allied to social services... my job is to help and guide young people and their families through the move from child services into adult services. ”*

## Making sure young people don't fall down the gap

### MAIN MESSAGE

The TPAs keep in close contact with the individual support personal advisor, so there should be few surprises in terms of caseload at the age of 16.

- It is the individual support personal advisor who is the first to meet the young person at school. They carry out a baseline assessment report with them at the age of 14.
- They 'pass on' young people with learning disabilities to the TPA at the age of 16.
- The TPA can carry on working with a young person until the age of 25.
- Many young people whose primary need is for emotional support, but who also have a mild learning disability, will be seen by a specialist individual support personal adviser.
- There is cross-over between all the personal advisers in the Somerset team - the TPAs work jointly with the Connexions individual supporter between the ages of 14 and 16. A team approach ensures that each young person is treated as a unique individual.

Throughout this process there is also a need to 'pick up' those who may have attended mainstream school, those whose needs may be changing, or those who have simply fallen through the net. For instance, one of the TPAs mentioned that she had been

sending letters out to all the mainstream schools in the area, to ensure that they also knew about the referral process. As she said:

*“ It’s taking time to know where each building block goes, and to make the whole wall. ”*

However, early findings indicate that, in general, the TPA strategy has been successful in its first two years of operation. What the TPAs can provide is intensive and detailed support, which would not have been possible without the joint funding between Connexions and social services.

An evaluation showed that families and young people all appreciated the new strategy. All of them knew who their own TPA was, and appeared to value the support offered.

*“ We have been most impressed by the personal advisor concept. It appears to work particularly well for our son. ”*

*“ She (the TPA) has been a lifeline to us over the past 12 months. She has assisted and supported us in every way...her approach is always positive. ”*

# SECTION 5

## Person-centred approaches and how they work

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### What does person-centred planning mean?

Person-centred planning means putting the person at the centre of planning for their lives.

Person-centred planning is about:

- listening to, and learning about, what people want from their lives
- helping people to think about what they want now and in the future
- family, friends, professionals and services working together with the person to make this happen.

### Helping a young person to get back in control their life

#### MAIN MESSAGE

One of the main reasons for emotional problems at the transition stage is that young people with learning disabilities feel out of control. Therefore a Connexions personal advisor can be a key person to help them.

The personal advisors in Connexions Somerset felt that their own role was to seek more opportunities for people rather than just seeking medical help.

How can person-centred approaches help people regain this control of their lives? This is what one of the transitions personal advisors in Somerset said about person-centred planning:

“ *It’s about the person being in control, and in the centre of what has been agreed. It is an approach, not a plan. It’s not what you’ve got, it’s how you do it.* ”

There are many sources to learn about person-centred planning. In the resources section, you will find many websites and other information. There are also training opportunities offered by the British Institute of Learning Disabilities ([www.bild.org.uk](http://www.bild.org.uk)), the Foundation for People with Learning Disabilities ([www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)) and Paradigm ([www.paradigm-uk.org](http://www.paradigm-uk.org)), amongst others.

These are the main points to remember:

- the aim of person-centred planning is to listen to the individual person with learning disabilities, and to make sure they are in control
- the tools of person-centred planning include PATH (Planning Alternative Tomorrows with Hope), Essential Lifestyle Plans, MAPS (Making Action Plans) and Personal Futures Planning
- all these tools are ways for people to talk with someone about their own life, and to help them dream and plan for the future. They all involve people in thinking creatively, and they are not meant to be rigid blueprints for success. They are simply ideas and suggestions that can be adapted to the circumstances of the person you are working with
- if you can get familiar with any of the tools, it is useful. You will be able to pick and mix what is right for the young person you are helping.

For further guidance see the *Valuing people* guidance on person-centred planning at [www.valuingpeople.gov.uk/PCPGuidance.htm](http://www.valuingpeople.gov.uk/PCPGuidance.htm).

**Remember:** person-centred planning is about a person’s whole life, their dreams and goals. It is not just about services, so don’t let your thinking be restricted by the services that are on offer.

Here is an example of person-centred planning in action. It is taken from a pack called *Families leading planning* (see **Resources**).

Martin is 13-years-old, and has severe complex learning and speech difficulties, epilepsy and many other labels. Martin is growing up into an endearing young man, who is full of confidence and determination. With the support of his mother, he was introduced to friends who could help him develop an essential lifestyle plan. These were the things that came out of his plan:

- he wanted to be with his peer group in the community. He was able to visit a school, and show them a five-minute video of himself, to help students there understand him
- he now attends his local mainstream school part-time
- he wanted to travel, and was able to go on holiday with a supporter
- Martin now has a mixed support package, using direct payments
- he also goes to a local scout group on a regular basis.

## Working with families

### MAIN MESSAGE

Families and friends are important to young people with learning disabilities. They can be strong allies in helping the young person to get it right. They should be listened to, and treated as experts about their children's needs.

In Somerset, we have found that parents and families have an important role to play. Connexions personal advisors are clear that they have to spend a lot of time with parents, as well as young people.

Parents also have needs. If they are to be good allies, they need:

- good, clear information
- to be listened to
- emotional support for themselves.

Connexions in Somerset is working on a new information strategy to ensure these information needs are met. An accessible website is also planned, led by a group of young disabled people. They felt that information could empower people to find things out and make choices for themselves.

Person-centred approaches also bring together family members and friends, to support the young person in informal as well as formal ways. Parents often get involved in:

- circles of friends to support a young person
- voluntary support groups
- peer support groups for parents as well as young people.

Connexions personal advisors can help parents by giving them information about these initiatives and about ways in which they can get support.

## A person-centred approach for parents

### MAIN MESSAGE

In Somerset, parents felt that they too needed emotional support. By becoming stronger in themselves, they can help their son or daughter more effectively.

This is what one parent in Somerset said:

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

In Somerset, as part of the action research project, we ran a parent-facilitated support course. This gave parents the opportunity to:

- express their emotions
- share personal feelings with each other
- plan for their own lives and their future
- find their own interests and identities again.

This is what one parent said after the course:

*“ It's given us the confidence to go and ask people - professional people. We are not going to accept not getting help this time. ”*

Parents on the course said that they had found their own identity again: they felt stronger in themselves, and more prepared to express their emotions openly and seek support for themselves.

Connexions personal advisors, working with parents of young people with learning disabilities, need to:

- remember that parents are people too, and encourage them to take time for themselves
- give them advice about seeking counselling for themselves when they need it
- inform parents about their rights to an assessment of their own needs for a life beyond caring, under the Carers (equal opportunities) Act 2004. They can seek this through the social services team that supports their son or daughter
- put parents in touch with carers' centres, carer support officers, and support groups.



# SECTION 6

## Young people supporting each other

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### Friendships

#### MAIN MESSAGE

Young people in the *Mind the gap* research told us that the most important people of all were their friends.

“ *You can share a secret with your friend, something you wouldn't tell anyone else.* ”

In *Mind the gap* we worked with young people to help them to support each other. A group of young people ran their own course for other young people about emotional support. The group was called *The strongest link* and they called the course *We are the strongest link*. These were the sessions in their course.

1. Friends and social life.
2. Feelings.
3. Growing up and relationships.
4. Getting support.
5. Helping yourself.

We produced a pack about the course, which you can download free from the Foundation for People with Learning Disabilities website at [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk).

This is what young people said about the course:

“ *I've kept things in for two years. I felt very happy when I let it out, and shared this with someone.* ”

“ *It's given me a lot more confidence.* ”

“ *Now I feel part of a team, before I was a bit of a loner.* ”

## Helping young people to get the skills to speak up

### MAIN MESSAGE

Connexions personal advisors and others who work with young people could help them to run groups like *The strongest link*. Young people can support each other for a better life.

You may be supporting young people who have difficulty in speaking up for themselves, and who do not have the confidence to take part in group activities. On the *We are the strongest link* course, we explored some ways of helping young people to be in control of things. Some of the main points were:

- we used a facilitation style that encourages young people to run the sessions for themselves
- we nurtured self-confidence and team work amongst the young people
- good preparation was key
- we had a fun atmosphere
- young people were allowed to take responsibility, even when things went wrong.

One young person said how nervous he had been at first:

“ *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.* ”

In *We are the strongest link*, we found it was essential to build in good and structured preparation time, but equally the course was built around fun and flexibility. Young

people had many good ideas about how to ensure the right atmosphere was maintained. 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.

# SECTION 7

## Mapping the services in your area

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### Sharing experience and working together

#### MAIN MESSAGE

It is important to work together with other professionals, to share knowledge.

It's impossible to be the expert on everything. Connexions personal advisors have a hard job, and you may be faced with a young person with learning disabilities who has needs for services that you know nothing about.

If you have mapped the services in your area, you will find it much easier to find the right support. Mapping is simply a way of keeping a record of referral routes that have worked for young people. The map will need constant updating, and is a way of sharing ideas and information among colleagues.

Here are some ways of making the links with those services, and finding out more.

- Connexions personal advisors themselves can have regular meetings to share their knowledge of referral routes. This can best be done by talking through real situations and referrals.
- Joint training with other professionals can help. This can include social services and mental health services.
- Your area representative from the *Valuing people* support team could help you to find out about training opportunities locally. Have a look at their website at [www.valuingpeople.org.uk](http://www.valuingpeople.org.uk).

## Working out your own map

### MAIN MESSAGE

Every area is different, and provides different opportunities. These will change with time. So a practical and useful map has to develop with the services.

In Somerset, a mapping exercise has been started to help Connexions personal advisors follow referral routes that work for the particular young person they are working with. The points made by Connexions advisors there were:

- referral routes are only any good if the expected time delay for waiting lists is attached to each service listed
- referral routes should not be prescriptive - people should have a choice about the kind of support they want
- it should not be assumed that people with learning disabilities need medical support, or medication, when they experience mental health problems
- creative solutions that defy conventional referral routes can often be found.

## A brief training exercise

Connexions personal advisors may find it helpful to do this training exercise together, to share with each other the routes that you have found.

The aim is to explore together:

**Who can help a young person with learning difficulties who also has emotional support needs?**

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 you, as a team, to think about the referral routes that people can follow.

As a team or in pairs review the following four scenarios. For each scenario write down your ideas of who might get involved with each of these young people. Use a separate piece of card or paper for each person/service who might get involved.

Then, take one person at a time and talk through the path that the young person might follow. Use your cards to graphically map out the route, placing them on a

table, floor or wall with arrows in between. Remember that there are probably many routes, and many outcomes. However, the rules are to:

- listen to each person
- 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.

Jack has a moderate learning disability, and displayed challenging behaviour in the form of aggression during adolescence. Perhaps he had a rough deal, with 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, she started to show signs of anxiety and depression (or maybe even psychosis).

Srikant had episodes of depression or anxiety throughout his childhood. He has a learning disability, but attended mainstream school. He has received services from child and adolescent mental health services.

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.

## A final word

If all services were actually co-ordinated, and young people could move smoothly into their options for adulthood, then Connexions personal advisors would be able to work themselves out of a job.

As one personal advisor in Somerset put it:

*“Transition is a concept that has been inserted into young people’s lives, in order to fill a gap.”*

But the main thing to remember is that young people with learning disabilities have emotions, and that these need to be recognised. The final word should go to a young person who was part of the *Mind the gap* research group. Here he is describing what it feels like to have an emotional problem:

*“ It’s like going into prison - you come out different. You’re not speaking to anyone are you? So when you come out, you think - I’ve been quiet for so long, that it’s time to go and catch up with other friends. ”*

It is likely that good guidance and support will be needed for some time to come, and it is important that Connexions nationally learns from the example in Somerset, so that they work towards getting it right for young people with learning disabilities and mental health support needs.

## References

Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st Century*. London: Department of Health.

Department for Education and Skills and Department of Health (2004) *National service framework for children, young people and maternity services: mental health and psychological well-being of children and young people*. London: Department of Health.

Foundation for People with Learning Disabilities (2002) *Count us in: the report of the committee of inquiry into meeting the mental health needs of young people with learning disabilities*. London: Mental Health Foundation.

Simons, K. and Russell, O. (2003) *Lines in the sand: final report from Crossing the Line research project on the interface between mental health and learning disability services*. Bristol: Norah Fry Research Centre.



## Resources and further information

### *Accessible information about mental health medication*

A series of leaflets using pictures and easy English to describe 18 different types of psychotropic medications. Available from The Elfrida Society.

[www.elfrida.com/publications.htm](http://www.elfrida.com/publications.htm)

### *All about feeling down: a booklet for young people with learning disabilities*

London: Foundation for People with Learning Disabilities, 2003.

This is a guide for young people themselves, written and illustrated in a clear and easy way so that young people with learning disabilities can use it themselves, or with support.

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

### *Depression in people with learning disabilities*

This leaflet is well worth looking at. It is practical and has many examples and case studies. It also has lists of symptoms and signs of depression, and could be used for training purposes or as a basis for discussion.

[www.rcpsych.ac.uk/info/help/depld/index.asp](http://www.rcpsych.ac.uk/info/help/depld/index.asp)

### *Families leading planning: looking to the future*

A. Short, H. Sanderson and M. Cook. York: Helen Sanderson Associates, 2004.

A practical resource-based pack for parents and other family members of young people with learning disabilities. It introduces and explains person-centred planning, and explains how families can become involved in leading a plan for their own son or daughter. It is full of illustrations, stories and contributions from families, and tools which can be used by families.

### *Guide to mental health for families and carers of people with intellectual disabilities* Geraldine Holt et al. London: Jessica Kingsley Publishers, 2004.

This book outlines a range of signs and symptoms of mental distress that can affect people with learning difficulties. It explains why mental health problems might arise and advises what can be done to help people with learning disabilities and their carers.

## Resources and further information

*Meeting the emotional needs of young people with learning disabilities: a booklet for parents and carers*

London: Foundation for People with Learning Disabilities, 2003.

This booklet is not only useful for parents and families, it is also essential reading for supporters and Connexions staff. It takes a positive approach to emotional wellbeing, and gives information about how to seek specialist help.

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

*Mental health problems and learning disabilities*

This short leaflet from Mind provides a general overview, as well as some specific advice. It is targeted mainly towards students and mental health professionals.

It has many useful references and addresses.

[www.mind.org.uk/Information/Factsheets/Learning+disabilities/](http://www.mind.org.uk/Information/Factsheets/Learning+disabilities/)

**The following websites may be useful. They all give links to many other sources of information.**

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

The British Psychological Society. One of the aims of the BPS is to raise public awareness of psychology and increase the influence of psychological practice in society.

[www.estiacentre.org](http://www.estiacentre.org)

The Estia Centre is a training, research and development resource for those who support adults with learning disabilities and additional mental health and/or challenging needs.

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

The aim of this site is to provide access to best current knowledge in relation to the development and delivery of services for people with a learning disability. There is information about training and courses in mental health support for people with learning disabilities.

[www.thenadd.org](http://www.thenadd.org)

National Association for the Dually Diagnosed (NADD) is the leading North American expert in providing professionals, educators, policy makers, and families with education, training, and information on mental health issues relating to people with intellectual or developmental disabilities.

## The Foundation for People with Learning Disabilities

We use 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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