

You are not alone

Caring for a son or daughter with a learning disability and emotional difficulties

About these guidelines

These guidelines have been written for parents and carers of young people with learning disabilities who want to know what help is available if their son or daughter develops an emotional health problem, and how they might go about getting that help. One of the authors has two teenage sons with autism and learning disabilities. They have been produced to accompany a suite of products from the *Making Us Count* research programme conducted by the Foundation for People with Learning Disabilities. The Foundation funded four research projects aimed at improving mental health support for young people with learning disabilities.

If you are worried about your child's mental health, you are probably the best person to recognise something is wrong. You know your son or daughter better than anyone.



Friends can offer helpful support

These guidelines will help you stay 'in control' and enable you to:

- focus on your son's or daughter's needs
- focus on your own needs
- improve your confidence to cope.

We hope they will also:

- give you some tools to help you work out your priorities
- give you some strategies to take things one at a time
- give you some basic information to get started
- support you with a way forward.

It is important to remember that you are not alone – there is a wide range of support, services and professionals available to help you and your son or daughter regain their mental wellbeing.

These guidelines aim to help you find the best and most appropriate services available in your area to meet your needs. They are organised into the following sections:

- **Identifying mental health issues**
- **Person centred planning – a useful approach**
- **Where to go for help**
- **Different types of support and treatment**
- **Support for parents**
- **Resources and information**
- **Person centred planning – an example**

Identifying mental health issues

The term 'poor mental health' covers a very wide range of conditions, from a lack of emotional wellbeing (emotional distress is a term some people prefer to use) to more serious conditions such as depression, anxiety or severe mental illness such as schizophrenia.

As a parent or carer you are not alone in facing the issue of poor mental health and what to do about it. It is now recognised that around 40% of children and young people with learning disabilities have a diagnosable mental health issue – so many carers share the same issues and problems as you are facing.

How you and other people respond to these behaviours will also have a direct effect on how your child copes with their problem, so it is important to try and understand what is happening through their eyes – to find the triggers for their loss of mental wellbeing.

To do this we need to look at and focus on your child in a person centred way, drawing a comprehensive picture of:

- who they are
- what is important to them
- what they want their life to be like now and in the future.



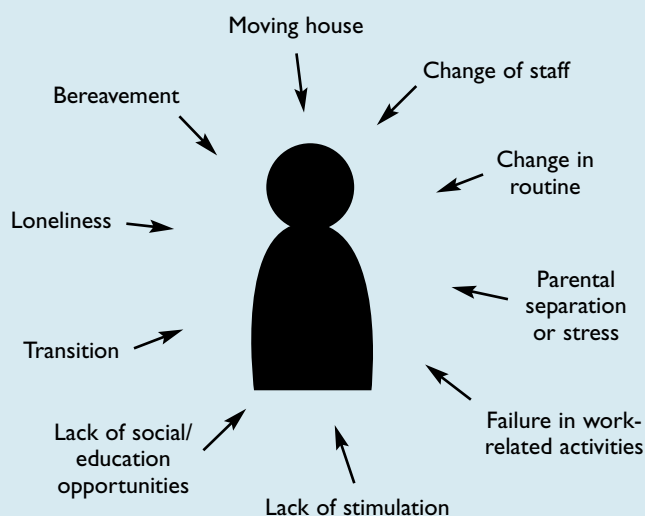
Try to understand what is happening through their eyes

This should help both you and your daughter or son to regain some perspective on the current situation and focus on how to address it.

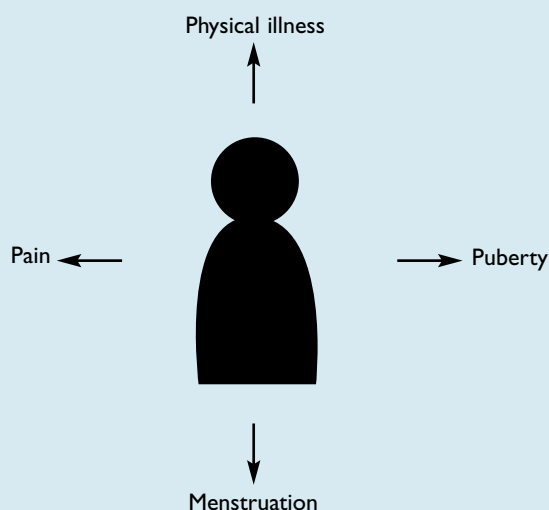
Young people with learning disabilities are faced with the same needs, hopes and fears as any other young people and the transition to adulthood is a particularly stressful time for any young person. In addition, people with learning disabilities may be vulnerable for a variety of reasons including physical ill health; a sudden or unplanned move from school or college; a lack of opportunities for work and leisure; bereavement; losing contact with people; moving into systems, such as a large college, where people do not understand their needs; bullying and isolation.

Some causes of changes in emotional and mental wellbeing

External causes



Internal causes



So how do you recognise if your son or daughter is affected by poor mental health or mental distress?

It can be difficult for anyone to identify or even admit they are feeling depressed or anxious. The young people who took part in the *Making Us Count* research projects found it particularly difficult to express their views and some resorted to aggression. Your son or daughter may tell you that they are unhappy or worried or that they feel that something 'isn't right'. You may notice changes in their behaviour, such as over- or under-sleeping or eating. If your son or daughter is unable to communicate verbally, then you will have to rely on spotting changes in behaviour. There are also particular life changes and events that are more likely to give rise to emotional distress.

Some effects on behaviour

- Anxiety about going out
- Obsessive behaviours
- Lack of concentration
- Being extremely withdrawn
- Aggression
- Loss of interest in activities
- Irritability
- Lack of energy
- Changes in sleep pattern
- Not wanting to communicate
- Restlessness
- Increased crying
- Changes in appetite

In addition, people with severe learning disability and/or those who do not speak may show the following behaviours:

- Changes in facial expression
- Biting (self and others)
- Grinding teeth
- Increase in repetitive hand movements
- Increase in sexual behaviour
- Increase in seizure activity
- Changes in posture
- Lack of responsiveness
- Increase or decrease in vocalisation
- Disruptive behaviour
- Thumb-biting
- Self-injurious behaviour

Joe's Story

Joe has high support needs and is unable to communicate through speech. He became withdrawn and started to hit his head when his grandmother died. However, his family were so trapped in their own grief they did not recognise how it affected Joe.

Joe's mum said:

'To my shame I had not noticed how Joe had withdrawn because he did not know exactly what was going on and was looking to his family to make sense of his loss.'

The family tried to help him by showing him photographs of happy times with Grandma and explained that she was tired and needed to go to sleep for a long time. Before her death Joe's grandmother recorded her voice to be included in a Christmas present and the family play this periodically to him. This has been hugely beneficial in contributing to Joe's understanding of his grandmother's death.

If a person is experiencing severe mental health problems they may:

- experience something through one of their 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 their skin when nothing is there.
- believe things that are not true, and not be able to change their 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.

Person centred planning – a useful approach

“ 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.



Person centred planning puts your son or daughter at the centre

Case study: Danny

Danny is a charming and bright young man who loves to talk, spend time with friends and have plenty to do. He has excellent computer skills and is particularly good at creating databases.

Danny is also a young man with a complex set of difficulties but with the overall label in social service terms of 'learning disability'.

Danny and his mum contacted an organisation that facilitated person centred approaches a while ago and explained Danny's frustration and depression at his lack of purposeful activity. The situation was deteriorating and leading to aggressive outbursts at home and difficulty in managing some of the other complexities of the syndrome Danny has.

Following a number of meetings and outings to get to know Danny better, the facilitator worked alongside Danny to identify people he could invite to join his circle of support. Those chosen were a mix of close and wider family, friends and social service professionals.

The circle met and Danny explained his situation. After discussion, it was decided that Danny would have a person centred plan with support from the circle. This process took some time, as Danny's concentration span is short. However, over the course of three months Danny's plan was completed and it was clear as this time progressed that Danny was feeling more contented. He said he felt like things were moving for him and that it was good to have so many people listening to him and what he wanted in life. Danny's mum said that things at home had calmed considerably.

With support and advice and practical help, many of Danny's goals have been realised over the past year. He has a paid job three days a week and volunteers to work with children on other days. He has accessed direct payments, has his own flat and a team of personal assistants to support him day and night. He goes home to mum and dad at weekends and their relationship is great.

Many people find person centred planning (PCP) an invaluable tool. It is a process of listening to and learning about an individual, who they are, what affects them, and what is important to them now and in the future. Don't be put off by the idea of yet another plan or task to carry out. A person centred plan can be a very simple and informal list. The method may vary but the principles underlying person centred planning are the same – focusing on how the person wants to live their life, the support they need to achieve that, and who can help, for example through a circle of support. An important part of planning is to find out about the person's gifts and talents and to support them to get more of the things that are important to them. It can also help focus on the future. Planning can then help to address obstacles (including health problems) and can be used to guide the compromises that we all make in life.

Using a PCP approach helps to highlight issues and bring them into focus.

- It makes steps more manageable and achievable.
- It can reveal 'real issues' hidden behind behaviours.
- It can show triggers more clearly and highlight motivation.
- It can show where communication is working and not working.
- It can show the most obscure activity as being a major success or disaster in your son's or daughter's daily life that may have gone totally unnoticed.

Case study: James

James had been excluded from his special school and had three Asbos. His family were at the end of their tether. James' mum contacted her local authority's learning disability services who referred her to the PCP co-ordinator.

The co-ordinator came to her home and met James and developed a way to find out the support he needed.

The co-ordinator helped James identify a circle of support. The circle of support met to figure out what James wanted for this future. Currently James is going to college to learn about computers and he is working as an administrator in a conference centre three days a week.



PCP can help young people achieve their dreams

A person centred plan (PCP) can also help your son or daughter or yourself focus on the questions you may want to ask professionals when you do seek help. It means you don't have to repeat yourself over and over again to different people because you can write down the key points of the plan for them and the main things you want them to know about your son or daughter. If you take this with you to any appointments, other people can quickly get a picture of your child as a whole.

If you think you may want to do a PCP but haven't got the energy or know-how to do it on your own, don't worry. There may be a co-ordinator in your area to help you and there are many voluntary organisations, advocacy groups and statutory services providing families with help in developing a PCP. Ask your social worker or Connexions service to find you a 'facilitator' (someone who can help you to bring a plan together). Other organisations that could help include local authorities, social services, local learning disability partnership boards or family carer groups.

An example of a person centred plan is included at the end of these guidelines.

If you would like to find out more about person centred approaches, this link will direct you to guidelines called *Linking up* which were written for Connexions and transition workers. Chapter 5 focuses on person centred planning. See www.learningdisabilities.org.uk. There is also a Personal Planning Book that can be downloaded from this site.

For further guidance see the *Valuing people guidance on person-centred planning* at www.valuingpeople.gov.uk/PCPGuidance.htm.

Connexions (in England) is a support service helping young people aged 13 to 19 with all areas of their lives from education, careers guidance and housing to problems with friends or health problems. Connexions will either help young people directly or put them in contact with someone who can. To find out more about Connexions near you call 080 8001 3219 or visit www.connexions-direct.com

Where to go for help

Having identified your daughter or son's poor mental health, your first thought will probably be: which service do I go to for help, and how? What should the first point of contact be?

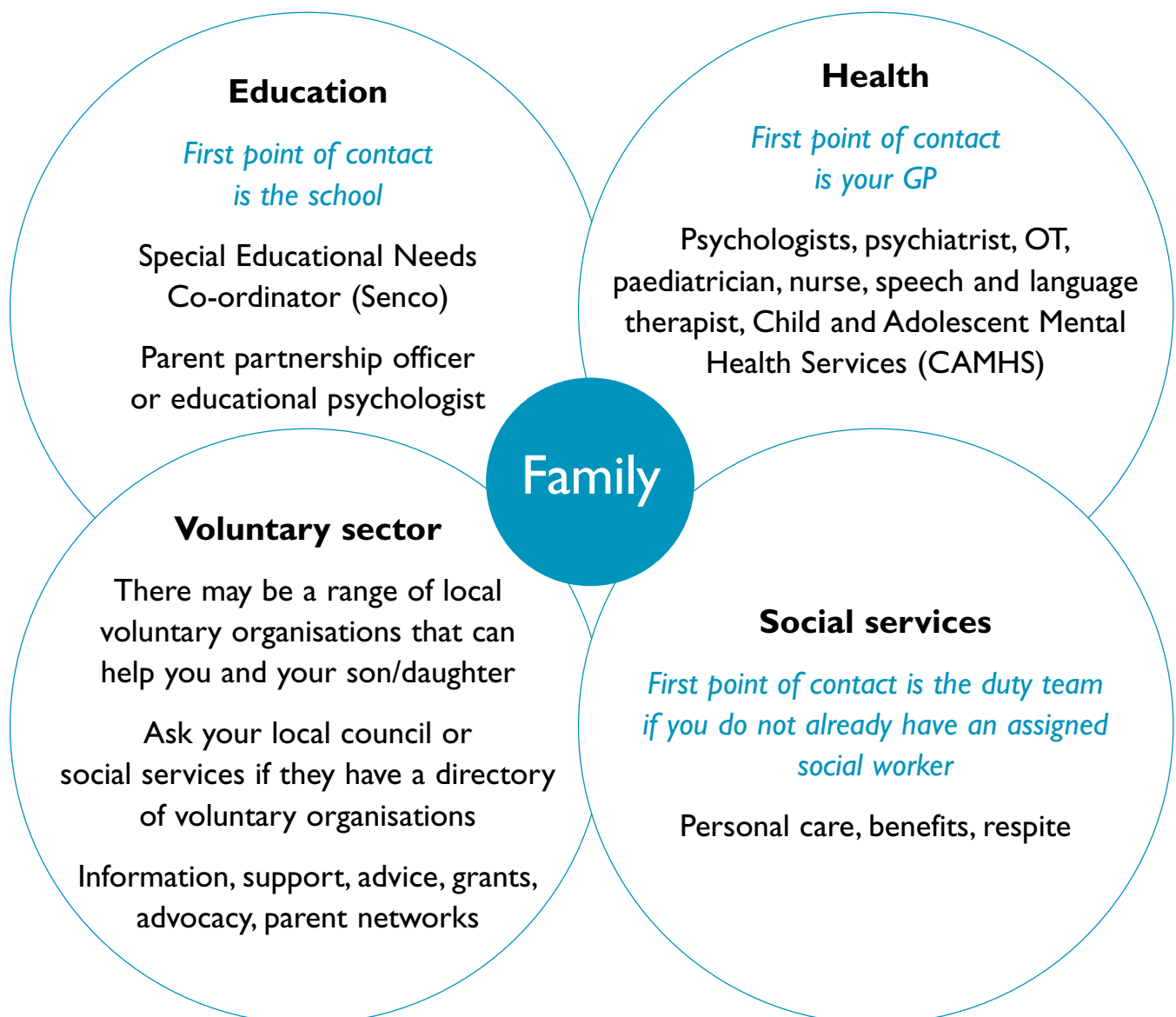
It is easier to find information and support if you begin by thinking about the kind of help you think you need. This may sound obvious, but when you are swamped with too much information you cannot use it effectively.

No one knows your child's needs or your needs better than you. Knowing their strengths and weaknesses is a big step towards coping and finding answers. It is important to see the positive as well as the negative aspects, as the positive aspects can sometimes be used to tackle and reduce the negative ones.

You don't have to know everything – it isn't your job to. Having access to people whose job is to know the answers is the key. The diagram below may help you think about who you may find it useful to speak to.



No-one knows your child's needs better than you



Case study: Mark

The Connexions service in Somerset has employed full-time transition personal advisors (TPAs) 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.

Mark is 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 said that he should 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.

Mark's case 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.

(Note: this is just one example and advisors may work differently in your area).

Your son or daughter should be registered with a local doctor (GP) and GPs now have a responsibility to be aware of any patients who have a learning disability. Your GP is the best starting point for dealing with any health issue, physical or mental. It is likely that they will refer you for more specialist help. There may also be a community paediatrician who can help.

Mental health provision for children and young people with learning disabilities is provided by a range of services and in a range of settings. Services and how they are organised also vary widely depending on where you live. For example, a 16-year-old young man with depression could be referred to the local Child and Adolescent Mental Health Service (CAMHS), the Community Team for Learning Disability (CTLTD) or Adult Mental Health Service, depending on where you live.

What are CAMHS?

If your son or daughter is aged 18 years or under they may be referred to the local Child and Adolescent Mental Health Service (CAMHS).

CAMHS is often used as a shorthand term to describe the range of services and professionals working in the field of child and adolescent mental health. Their services are generally organised into four levels of support.

- **Level 1** – CAMHS is provided by non-specialists that include GPs, health visitors, social services, schools, youth workers and voluntary agencies.
- **Level 2** – CAMHS is usually provided by individual specialist health workers such as psychologists, psychiatrists, paediatricians, nurses and educational psychologists who may be part of multi-disciplinary teams or networks through which work is co-ordinated.
- **Level 3** – CAMHS is a more specialist service for those with more severe and complex mental health problems usually involving a number of professionals.

- **Level 4** – CAMHS offers very specialist interventions usually through in-patient units or highly intensive outpatient teams.

The set-up of CAMHS is varied with some better equipped for working with children with learning disabilities than others. Some CAMHS teams will have a specialist learning disability team rooted within the service. Numerous government initiatives such as the *National Standards Framework for children and young people (2004)* are pushing for CAMHS to develop services to include the needs of this group, so in the next few months all CAMHS must be able to support children with learning disabilities.

The transition period between the ages of 16 and 18 may be problematic if neither adult nor children's services in your area are properly geared up to work with people of this age. Generally most CAMHS work with young people up to the age of 18, however this can vary on a local level.

Case study: Natalie

Natalie was a full-time student at a school for people with severe learning disabilities when, at the age of 16, she developed symptoms of mental illness. As her mother and maternal grandmother both had diagnoses of schizophrenia, which was well controlled in both cases, her GP was alert to the fact that she also might be suffering from a psychotic illness.

She suffered a serious adverse drug reaction to the medication prescribed and was admitted to a hospital. She was referred to the child and adolescent psychiatry service and received both out-patient and in-patient care. At the age of 18 she was transferred to the adult learning disability service. She was admitted to a specialist local in-patient unit for people with learning disabilities and mental health problems. Her care team involved both learning disability and mental health nurses, specialist learning disability psychiatrists, occupational therapy, speech and language therapy, psychologists and close working with her mother and her college.

Like other young women of her age, Natalie was interested in music, pop stars, make-up, hair care, cookery and various leisure activities – bowling and going to the cinema. Care plans

were developed with Natalie to enable full assessment of her mental health needs in relation to her learning disability, using these meaningful and valued activities as a means of assessment. While she was an in-patient she began to go to college again, which was a goal of hers.

By the time she was discharged she was attending college three days a week, had the additional support of a specialist community psychiatric nurse and had been prescribed medication that worked for her. She also had knowledge about her condition and what it meant.

The admission was successful for her because:

- the unit was small
- staff were trained in the needs of people with learning disabilities and mental health problems
- she was with her own peer group, who functioned at a similar level to her
- staff worked with *her* norms and goals, and not general norms and goals
- there was close co-ordination between services and her family
- she was given an accurate diagnosis and appropriate supportive drug treatment.

Services for those aged 18 and over

For those young people aged 18 years and over, it is likely they would be referred to the local Community Learning Disability Team (described opposite). Some of these teams do take referrals from a younger age range. However the person may be referred to the local mental health service for adults instead. Ideally both services will work together.

Community Learning Disability Teams

Your area will have a local community learning disability team (CLDT) that supports people with learning disabilities and their families. Teams consist of a range of professionals that include some or all of the following:

- social workers
- psychiatrists
- care managers
- psychologists
- community learning disability nurses

Some teams may have some of these additional professionals:

- dieticians
- physiotherapists
- speech and language therapists
- occupational therapists.

As a rule, you will be referred to your CAMHS or CLDT by a first point of contact such as your GP, a teacher, community nurse, paediatrician, social worker or voluntary agency. Most CDLTs accept self-referrals.

Support for people with learning disabilities around their mental health is not the exclusive responsibility of just one service. People may get support from primary care services (doctors and nurses at your local health centre), mental health services, learning disability services, voluntary sector services, and others. Generally speaking, people with learning disabilities with mental health problems should be treated by

mental health professionals within the mental health services rather than by learning disability specialists who may have limited knowledge of mental health issues. However, the focus of services today should be on the person, through person centred planning, and services are encouraged to work together.

Health action plans

You may or may not have heard about health action plans. It has been recommended by the Government that people with learning disabilities have a health action plan in order for them to be healthy and get the right help when needed. A plan can help address mental health issues and direct you to appropriate help and advice.

CDLTs can tell you about health action plans in your area. They can help you think about who will support you to develop a plan and make sure it happens.

Different types of support and treatment

Your son's or daughter's emotional difficulties may be caused by social or environmental factors, such as those mentioned earlier, like loneliness or problems related to work. Emotional distress is a natural way of reacting to very difficult life circumstances. In these circumstances the best way forward is to tackle the root causes and issues, thus improving the person's life and removing the causes of the emotional distress. This does not necessarily involve medical personnel but can involve other people such as teachers, social workers, Connexions workers (in England) and voluntary organisations. Ways of helping the person through this may include:

- helping them understand and get over the pain they are feeling
- helping them get over the social barriers and difficulties they are facing in their lives
- helping them to live with the difficulties they face.

If your child is suffering from severe or acute mental illness, it is more likely that medical personnel will need to be involved. In some cases this could include hospital admission within psychiatric or learning disability services depending on how your local services are organised. Although you may well seek advice from a social worker, teacher or indeed any support staff, a visit to your GP is usually needed for referral to mental health services.

Medical intervention can include various therapies.

- **Talking therapies** – where people get one-to-one help to talk through and understand themselves better.
- **Creative therapies** – such as 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.

It is also possible to combine types of treatment, for instance by using medication *and* tackling the root cause of any illness.

Support for parents

If your daughter or son is experiencing mental health problems, even of a mild nature, this is bound to put extra stress and strain on you, the carer. It is OK to acknowledge the emotions you have about the situation you are in. It is important you too are supported at this time. It is also important to recognise that it is not the person you are unhappy with, but the behaviour or circumstance you are in. Stress from the guilt of feeling emotions that you'd rather not admit to can cause you harm. If you feel unable to cope and out of control, then negative feelings are bound to build up.

However you are feeling, it is important to understand you are not alone – there are many families who are going through similar experiences and it is sometimes they who can offer support and understanding as only parents can.

The way you were told about your child's disability/ learning disability will have had a profound effect on your attitude and expectations in the future. The support you have been receiving so far may also colour your views on what help you seek now. If getting a diagnosis has been a long drawn-out process, you may be frustrated, but you can still ask for support.

If you are suffering from anxiety, stress, temper, anger, headaches, sleeplessness, irritable bowel... then these may be signs that you are in your 'danger zone' and could do with some help and support.



Parents can offer a lot of support to each other

There may well be voluntary organisations in your area that offer support to parents and carers and some people have set up their own local group. Ask your local social services about support groups or look for information in your local library. You could even get together with other carers and parents and set up a group. One carer group in Somerset put together their own course to provide them with social support and an opportunity to think about their own needs and goals. This course is described below.

A person centred approach for parents

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

A parent from Somerset.

Person centred approaches also work together with family members and friends, to support the young person in informal ways as well as formal ways. Some parents whose son or daughter have experienced mental health problems have been involved in:

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

This model was used by a research project in Somerset. In Somerset, parents felt that they too needed emotional support. By becoming stronger in themselves, they could help their son or daughter more effectively. A parent-facilitated support course was run by a local parent (one of the authors of these guidelines) and a facilitator. 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.

Aims and course content

The aim of the course, called *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: 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.



Parents benefit from talking to other parents

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 no 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.

Other support for parents

Parents are entitled to an assessment of their own needs, which may result in financial support to pay for a sitter or help in the house under the *Carers (Equal Opportunities) Act 2004*. They can seek this through the social services team that supports their son or daughter. If you do not have a social worker or care manager, contact your local social services department.

As already stated, many parents really benefit from talking to other parents. If you don't know of any groups in your local area, get in touch with carers' centres, local organisations such as Mencap or Contact a Family who can help you find a suitable group to be put in touch with.

These guidelines were written by Edwina Rowling, Rachel Mason and Jill Davies.

Resources and information

Booklets

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

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

Meeting the emotional needs of young people with learning disabilities: a booklet for parents and carers. Foundation for People with Learning Disabilities, 2003.

- Easy to read advice on supporting young people to be emotionally strong during the difficult time of adolescence.

Useful organisations

Circles Network

The Dunstan Centre
Pennywell Road
Easton
Bristol BS5 0TJ
Email: info@circlesnetwork.org.uk
www.circlesnetwork.org.uk

Contact a Family

209–211 City Road
London EC1V 1JN
Tel: 020 7608 8700
Fax: 020 7608 8701
Helpline 0808 808 3555 or Textphone 0808 808 3556
Freephone for parents and families (10am–4pm, Mon–Fri)
Email: info@cafamilly.org.uk

Foundation for People with Learning Disabilities

Sea Containers House
20 Upper Ground
London SE1 9QB
Email fpld@fpld.org.uk
www.learningdisabilities.org.uk

Transition Information Network

8 Wakley Street
London EC1V 7QE
Email tin@ncb.org.uk
www.myfuturechoices.org.uk

Young Minds

2nd Floor
102–108 Clerkenwell Road
London EC1M 5SA
Email enquiries@youngminds.org.uk
www.youngminds.org.uk

Websites

www.valuingpeople.gov.uk

- The site that supports the Government's plan for making the lives of people with learning disabilities and their families better.

www.mindbodysoul.gov.uk

- For young people aged 14–16. It has lots of information on how to keep healthy and feel good.

www.rethink.org/at-ease

- For young people who feel confused or worried about their feelings. It helps you to understand why they feel down and where to find help.

www.connexions-direct.com

- Connexions is a support service in England helping young people aged 13 to 19 with all areas of their lives from education, careers guidance and housing to problems with friends or health problems. Connexions will either help young people directly or put them in contact with someone who can.

www.learningdisabilities.org.uk

- Personal Planning Book. This book has been designed for people wanting their own personal plan. It is free to download from the website.

Person centred planning – an example

This is a real life example of what a person centred plan – here called a life plan – might look like. It doesn't have to look like this – every one will be slightly different and individual to suite each person's needs – but this could be used as a guide to get you started.

Sam – an essential life plan

Initial plan date

Subsequent revision dates

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Table of contents

- Purpose of this plan.....
- People in their life.....
- What people like and admire about them
- What people also say about them
- Characteristics of people who would be suited to supporting them best
- What is important to them.....
- What people need to know and do to support them
- How they communicate their needs and feelings.....

Purpose of this plan

This plan needs to be produced by yourself, drawing on information from the people that care about you and are involved in your life regularly.

It can be used to enable people to support your needs and be aware of your wishes.

People in my life

Mum

Dad

Simon

Buster

Puss

Tim

Jill

Jo

Mary

Green group

George Parsons

Mike

How do they know me

Autistic brother (15)

Family dog

Family cat

Carer (D/P's)

Carer for another ASD adult (21)

Older family friend

Friend from previous school

College peers

Tutor

Chapel youth club leader

What people like and admire about me

What do people like and admire about me?

Funny

Happy when I'm confident

Proud

Polite

Caring

What am I learning about myself?

I have a great sense of humour, but I need to learn when to STOP, as I get carried away and say silly things.

My persistence can ruin a good thing.

When I have a good day.

When I feel in control I can then try extra things.

When I make a meal or choose low-fat foods.

When I stop myself from sneaking food, or I own up to it.

I greet people by shaking their hand and ask them about the weather and their family.

I say excuse me most times, but will whinge like a baby if I think you aren't listening!

I am learning to be aware if you are sad or angry.

I will get you a cup of tea.

I will tell you to see the student union woman (counsellor!)

I love animals, and look after them well, in my care.

What is most important to me

Now

The area I live in

Somerset

What I live in

Semi detached in a quiet cul-de-sac with my family

Near bus route

Safe walk to shops

What surrounds me

My own bedroom – double bed with duvet

TV, video player, DVD, CD radio in my room

My own disco room... soundproofed

Own DJ equipment

A cat

In the future...

Somerset

*Detached house with friend maybe
My rules*

Near buses

Walking to shops

Same

No one touch my CDs or equipment

Disco equipment

Puss to come with me

My personal routines – daily

6.45am Get up
Shower
Dress

7.15am Fed the cat/mum feeds the dog

7.20am Get breakfast*

7.40am Check college bag for wallet/mobile and locker keys

7.45am Catch college bus

12.30pm Go to canteen for lunch*

3.45pm Recycling duty around the college

4.45pm Take bus home*

5.25pm Pop into shop* to buy treats!
Cross road, wait to catch another bus*

5.55pm Get home prepare a snack*

7.00pm Play music in Disco room

9.00pm Walk dog with mum/dad

10.00pm Go to bed – watch film

11.00pm TV off...perhaps!

Friday Eves

Go out with Tim to cinema, meal, bowling

Weekends

Chapel – getting less

Hire DVD

* unsupervised

Things I find difficult...

Things I need to work on

Independence

Personal skills

Responsibility

Decision making

Communication skills

Finances

Appropriate conduct

House keeping skills

How this can be achieved

Opportunities to gain experience in these areas.

With help from my circle of support and college.

Learning a healthy routine using symbols in the house.

Opportunities to take responsibility and be allowed to make mistakes... these need to be positively corrected.

Given limited choice, or coping strategies to stop anxiety when faced with too much choice.

Constant positive reinforcement/correction.

Always making me aware of 'draining' the bank.

And 'purpose/commitment' of some of the money.

Constant positive reinforcement/correction.

Giving me jobs around the house, ownership of decisions and their consequences.

Things that are important to me

What people need to know

Things I love...

...doing

Having fun with the dog

Training the dog

Eating food

Swimming/gym

Horticulture

...seeing

Watching Thunderbirds videos/DVDs

Films with girls in them!

Watching comedians, funny programmes

Watching the trains

Cinema

How this can be achieved

Daily dog walking –

*Being responsible for getting ready to walk
– lead/whistle/treats.*

*Encourage healthy eating. Awareness of
calories.*

Keep up my regular gym and swim.

*Give me an opportunity out of college to
work with plants/gardening.*

*These I love at full volume – I must learn
to turn the volume down*

Yes, I'm at that age! Nothing explicit yet.

*Remind me when they are on TV, one day
go to a theatre.*

*Go for regular walks to watch passing
trains.*

Things that are important to me

What people need to know

Things I dislike

Loud sudden noises

Being out of control

Being told what to do

Being rushed

Simon teasing me

Eating too much and getting fat

My feet hurting, long nails

My hair being washed

How this can be achieved

All I need is plenty of advance warning.

Give me options.

Ask me to COMPROMISE.

Remember to distinguish between what I must do for my well being and the choices I must be allowed to make... even if they are a mistake or a pain in the arse for others OR I WILL NEVER LEARN.

Be aware of others putting me under pressure.

Facilitate.

Educate others with discretion, but teach me how to handle them myself.

Keep me informed – but it's my choice – later remind me of consequences when I am concerned about my weight.

Regular inspection.

Encourage me to wash hair in the shower – rinsing well.

Things that are important to me continued

What people need to know

Things I love...

...hearing

Listening to music in the car or in the evening

Drumming – at college

Chapel music. Singing along/signing

...smelling

FOOD!

*Fresh air
'Vick' when I have a cold*

My cat

Shower gel

How this can be achieved

Having an opportunity to listen to the radio daily

Finding an out of college club

Encourage me back to chapel – for vibrant sermons

Encourage more hands on cooking at home

Access further courses at college, out of college

Dog walking

Give me opportunity to spend time with the cat

*Encourage me to shower regularly –
NOTICE I SMELL NICE!*

How I best communicate my needs and feelings

What is happening	I do this...	It means this...	You need to
<i>You are telling me what to do</i>	<i>I grunt, lower my head, ignore you</i>	<i>I feel out of control</i>	<i>Give me more notice Explain why you need me to do it</i>
<i>I am quiet and moving covertly in the kitchen</i>	<i>I act bright and cheerful to distract you</i>	<i>I am eating food or hiding it to eat later</i>	<i>Don't shout. Remind me what extra food does... it must be my choice to stop snacking</i>
<i>Everyone is occupied</i>	<i>I drive my imaginary car</i>	<i>I am bored</i>	<i>With a countdown first, distract me with something to do, be firm</i>
<i>Doing something for the first time</i>	<i>I hum and walk fast... talk a lot, about anything</i>	<i>I am nervous, people are watching</i>	<i>Give me lots of encouragement – do not help too much</i>
<i>Things aren't going right</i>	<i>I trash it, or call myself names</i>	<i>I think I'm a failure, I'm stupid</i>	<i>Tell me 'trying' is just as important as succeeding</i>

My additional weekly routines

Now

Mondays

Swim and gym with Dad (2 wkly)
Dad collects from college

Weekly eve shop at Sainsbury's
(Buy my own choices for me)

Draw out my weekly allowances for college,
shopping and spends

Tuesdays

Record a film for Wed eve

Wednesdays

Watch the above film

Thursdays

Hire a DVD

Fridays

Go out with Tim/Jill (D/Ps mthly)

Saturdays

Chill!

Sundays

Go to chapel (not regular)

How can it be improved

With Dad on shifts weekly lost. Look into
Tim/another to support every other week

Every other week go to Tesco with mum
and Simon when I get off bus

I can do this at cashpoint whilst I wait for
bus in town

Encourage me to alternate movie or DJ
music with interaction with others:

Going out a bit more – join a club

Games

Have visitors*

Stay over away from home

Looking on the internet*

Emailing/phoning/writing a letter

Find another person to go out every friday

Using D/Ps and benefits

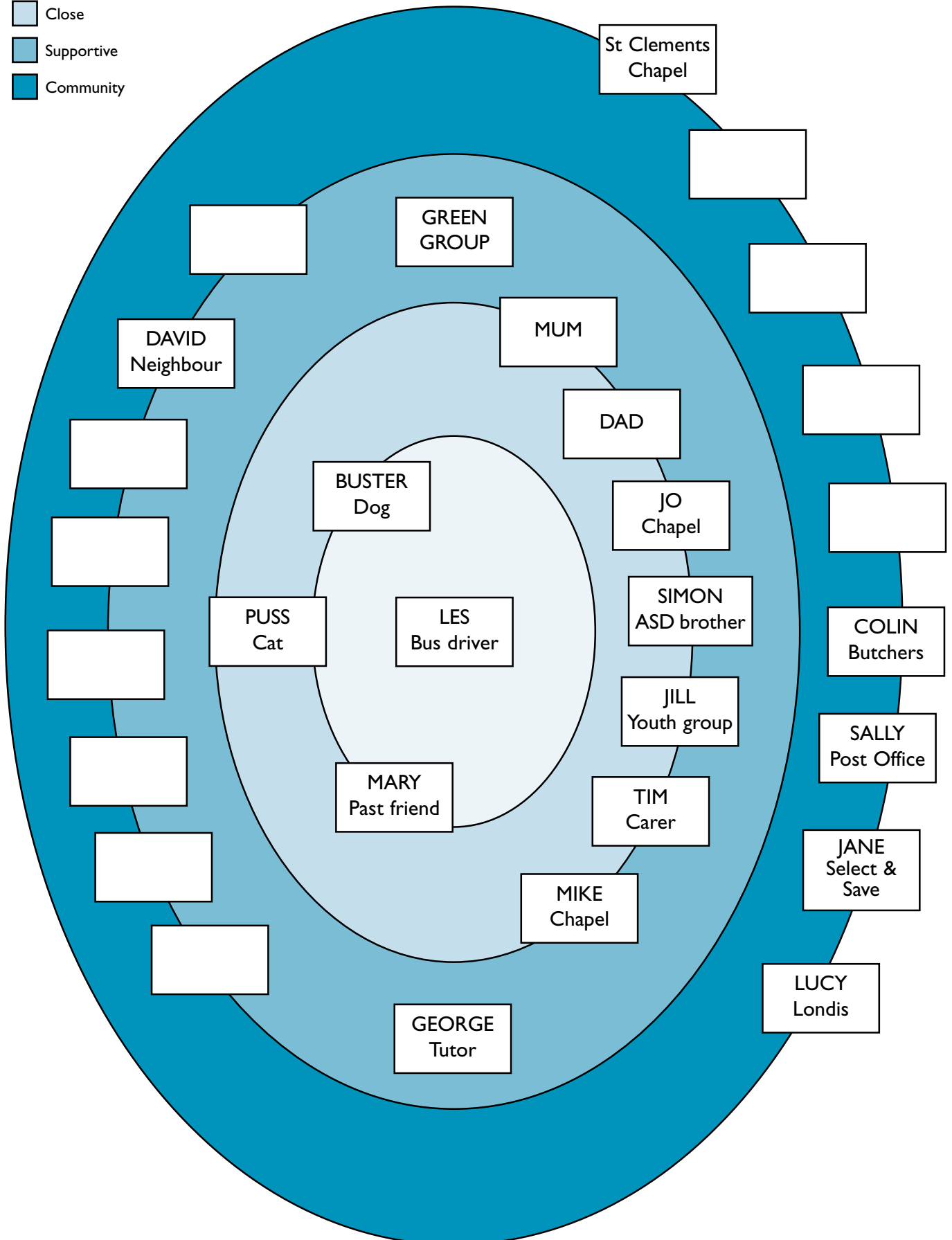
* already happening

My relationship map

My review date

30 March 2005

- Intimate
- Close
- Supportive
- Community



Summary of targets for transition: 16–20 years of age

Targets	Where we are now	Obstacles	How this can be achieved	Review stages
<p>House keeping</p> <ul style="list-style-type: none"> Cooking Cleaning Laundry Shopping Budgeting/bills Security Having guests Having a pet Garden Maintanance 			<ul style="list-style-type: none"> Work with college curriculum Work with Tim (DP) Has his own part of kitchen Separate shopping Supervises/org visitors Has own bank account Given responsibility reg 	
<p>Personal skills</p> <ul style="list-style-type: none"> Personal hygiene Personal appearance Punctuality Planning the day Keeping occupied Consideration for neighbours Arrange to meet someone Accepting invites at short notice Not pestering people Behaviour management 			<ul style="list-style-type: none"> Get added to college curriculum Work with Tim (DP) 	
<p>Communication skills</p> <ul style="list-style-type: none"> Mobile phone Texting Payphone Email Letter writing 			<ul style="list-style-type: none"> Get added to college curriculum Work with Tim (DP) 	

Summary of targets for transition: 18–20 years of age

Targets	Where we are now	Obstacles	How this can be achieved	Review stages
<p>Independence</p> <p>Awareness of consequences</p> <p>Voluntary activities</p> <p>Paid work</p> <p>Social activities/ membership</p> <p>Being left alone for 24hr period – at home</p> <p>Staying O/N away from home</p>	<p>Increasing daily</p> <p>Recycling in college</p> <p>DJ jobs</p> <p>Friday eves (irreg)</p> <p>2hrs to date</p> <p>College residential</p>	<p>Autism</p> <p>Carers</p> <p>His commitment</p> <p>Availability of carer</p> <p>Responsibility</p> <p>Opportunities</p>	<p>Talking through as many events as possible</p> <p>Find another person using his DPs</p> <p>Find him small pieces of work</p> <p>Tim cannot be replaced on Fridays</p> <p>Work with college links</p> <p>Find opportunity/training project?</p>	<p>Has he learnt from last experience?</p>
<p>Learn importance of</p> <p>Carrying wallet</p> <p>Being able to contact someone</p> <p>Personal safety</p> <p>Appropriate conduct</p>			<p>Add to college curriculum</p> <p>Work with Tim (DP)</p>	
<p>Knowledge of finances</p> <p>Income</p> <p>Outgoings</p> <p>Direct payments</p> <p>Saving</p> <p>Forms of money</p>			<p>Get added to college curriculum</p> <p>Work with Tim (DP)</p>	
<p>Community</p> <p>Independent travel</p> <p>Independent circle of support</p> <p>Walking out in the town</p> <p>Getting to know local shop staff</p>			<p>Get added to college curriculum</p> <p>Work with Tim (DP)</p>	