



2

Open Learning Materials

2a

Understanding why it is important to work with families

Michael is a man with learning disabilities...
He is also:

- a son,
- a brother,
- a cousin,
- an uncle,
- a grandson.



Aims of this section are to:

- Help you acknowledge your own attitudes to families.
- Understand why it is important to work with families.
- Understand the specific concerns of older family carers.
- Help you see people's lives in an historical context.
- Help you empathise with the family experience of having a learning disabled member.

Exercise 1

What is your experience of working with the family carers of people with learning disabilities?

Off the top of your head – are there some words or phrases that come to mind to describe your experience of working with families? Jot down your initial thoughts.

Make a note of them so you can look back later and compare them to your thoughts after you have worked your way through the material in this section.

Families needs are diverse and complex. Anyone can have a learning disabled child, so there can never be a *typical* family experience or a *single* family carer perspective. All families need to be respected for their unique qualities.

Having said this – families with a learning disabled member do share many experiences. There are many positive sides to caring for a learning disabled child, but research also shows us that families are disadvantaged compared to families where there is not a disabled child. These include:

- High levels of stress,
- Financial disadvantage through loss of earnings and the high cost of caring,
- Health problems,
- Isolation,
- Problems with finding suitable housing,
- Increased risk of marital breakdown.

(Quoted in *'Family Matters'*, DoH. 2001 – Beresford P. 1995.)

Research also shows us that whilst the situation is difficult for white family carers in the ways described above, the situation for families from minority ethnic and black communities is qualitatively worse in a number of ways. These include:

- High levels of unmet need – people are often completely unknown to services,
- Poverty,
- Poor housing,
- Social isolation,
- Lack of information,
- Culturally appropriate services.

(Baxter C. 1999 and Mir G. et al. 2001.)

What many families share in common is their relationship to and perceptions of services. As we will see below, many families feel frustrated by their encounters with services and the staff in them. 'Stress is caused more often by trying to deal with the service system than any particular characteristic of the person with learning disabilities', concluded a study of family carers in the Bristol area. (*In Their Own Right*, Norah Fry. 2000.)

Definition of 'family carer'

It is always useful to clarify who it is that we are talking about when we refer to 'family carers'. For the purpose of the Lifetime of Caring project, a family carer is defined as a person who has personal experience of caring for one or more persons with a learning disability who is a family member. A family carer has personal contact with a family member who has a learning disability; even though that individual may have chosen to have moved away from home, or been supported in moving away from the family home, or has needed to move away from home. A family carer is a person who is not paid to have a personal, continuous relationship with a person with a learning disability. (We recognise that not all carers will necessarily be related by blood, but that some people may choose to support a person with a learning disability in the way described above). Older carers are defined in the White Paper as aged 70 or older. In some projects the age is lower and can mean any family carer from the mid fifties onwards.

Exercise 2

What does 'family' mean to you?

Before we start thinking about the families of people with learning disabilities and their relationship with services, we need to think about our own attitudes to and experience of 'the family'. What does 'the family' mean to you?

This exercise gives you the chance to think about how complex family life is. How different it can be for different people. How we need to guard against making assumptions about people's experience, and recognise their experience might be different from our own!

- **Get three different pieces of paper.**
- **On one sheet list all the good things about family life – use your knowledge and personal experience.**
- **On the second sheet list all the negative or bad things about family life – again use your knowledge and your own experience.**
- **Finally on your last piece of paper write down all the different types of families we have in the UK today.**

When you have completed your lists go and ask two or three other people to answer the same questions and compare the results with your own.

When you start to list all the different types of families in the UK today you are struck by many different types of family structures there are. This exercise should hopefully alert you to the fact that there are really positive things about family life that we all value. People that know you well and love you. People who are there to support you if things go wrong or celebrate with you if you achieve something special. They can and do provide us with a sense of identity. On the other hand people can find their relationships within the family to be very stressful. We are most at risk of violence and abuse in our own homes at the hands of a family member. People write books about how to survive them! Families – with both their good and bad dimensions are part of the life experience of men and women with learning disabilities. For the most part, family relationships are for life.

Now that you have spent some time thinking about how families in general, it is time to think about the families of people with learning disabilities and why it is important that people in services engage with them in a more respectful way.

Why is it important to work with families?

A different way of seeing the world – professionals and families

Contrast the following quotes:

“What have families got to do with the national learning disability strategy? This is a strategy for people with learning disabilities not families.”

Comment from the head of a national organisation at the launch of the strategy in December 1999



“Families are the disabled person’s greatest resource.”

Mother describing her 24 hour role as carer for her learning disabled daughter

There is often a very big gap between how families perceive their role in relation to their learning disabled adult son or daughter and the way professionals perceive them. How do we account for the differences represented by these two quotes and the perspectives they represent? How can we change things? One way is for staff in services to develop a greater understanding of the valuable role families play in the lives of people with learning disabilities.

Exercise 3

List the reasons why you think it is important to work with families.

What do you think are some of the negative consequences for the person with learning disabilities if their families and services are in conflict?

Can you give any examples from your own work?

Family matters – why it is important to improve relationships with families!

- People with learning disabilities overwhelmingly value the support they get and the relationships they have with their families.
- Families have not always been recognised for the enormous contribution they make in relation to the care and support of people with learning disabilities. **The majority of people with learning disabilities have always been supported in the community by their families.** Research by Mencap suggests that the proportion of people with learning disabilities living at home with their families has not changed since 1969.
- **For the majority of people with learning disabilities, community care is actually family care.** It is estimated that over 60% of adults live with their families. We live in an ageing society and it is estimated that a third of all family carers are over 70. Many of them are caring alone.
- Since 1971 the only public policy that **specifically** focuses on people with learning disabilities (the last White Paper – Better Services for the Mentally Handicapped) was dominated by the move to close down the old ‘mental

handicap' hospitals. The process of deinstitutionalisation has been a very important one, but it has skewed the way the public perceives how the majority of people with learning disabilities are supported.

- **Not known to services.** Research here in the UK, in the US and Australia show that in any local area as many as 25% of people with learning disabilities are not known or in contact with learning disability services until their family carers become too frail, or ill to cope any longer.
- **Families are the only people with a continuous and lifelong commitment to the person with the learning disability.** Families are not paid to care. Some families have been caring in their home for 50 and 60 years. Paid staff might come and go, but your family does not, though relationships between family members will not remain the same as they move through life cycle, as we will discuss later.
- Parenting a child is very different from being the parent of an adult. As parents grow older, their adult children take on new roles in relation to them. This is true of people with learning disabilities. **Some people with learning difficulties become their carer's carer in later life. The majority of families are highly mutually interdependent. They come to depend on one another.**
- Even when someone leaves home it does not mean they leave the family. You can care *for* someone but you also care *about* them. The **caring relationship does not stop** when a person moves into service provision. Some services find this difficult to understand and feel some families are 'over involved' and 'over protective', rather than recognising that if someone has been caring for several decades they will continue to want to do so.
- Continued family involvement has been shown to provide vital protection against abuse for people living in services. (*Moving On Without Parents*, Bigby C. 2000.)
- **Families have a long and distinguished history of campaigning for better services and equality for people with learning disabilities.** Many older carers were bringing up their children at a time when there were barely any community based services and the stigma attached to having a 'handicapped' child was great. It is these parents who have helped shape the services we have today. Mencap was formed in 1946 because parents felt so angry that their disabled children were excluded from the right to go to school.

- Individual families have always **advocated vigorously** for the rights of their individual family member to receive quality services. How often have you heard staff talk about ‘pushy’ or over protective parents, but also comment that ‘those who shout the loudest get the best service?’. Perhaps it is true that for many people with learning disabilities, having a caring family is the greatest resource if you want to get a good service.
- As Professor Carol Walker has argued in the report ‘*Uncertain Futures*’ (Walker C. & Walker A. 1998.): **Families play a critical role in supporting people with learning disabilities to try new things and develop new skills.** If services want to work with the person with a learning disability and open up opportunities for them, then they have to engage the family. If they don’t, opportunities might be missed, just because the family has not been involved.

And yet – despite all these positive things about family carers the Family Matters consultation for the DoH found families:

- **Feel devalued and marginalised by professionals:**

“They never listen to us. They always judge us. No one ever bothers to ask us about what we think!”

- **Describe their relationships with services using the language and metaphors of war:**

“We are war weary. We are always battling. It’s like knocking your head against a brick wall. Stress is dealing with the services, not to do with our disabled son!”

- **Feel frustrated and angry:**

“They never listen to us. They make everything so difficult. I’m going to sue them.”

- **Feel they lack information and support:**

"If you are not looking, it certainly won't come and find you. No one tells you about anything you are entitled to. I've always found out from other parents. All I wanted was a couple of hours break to go shopping on my own, but this seemed too much to ask!"

- **Respond to service changes with great anxiety:**

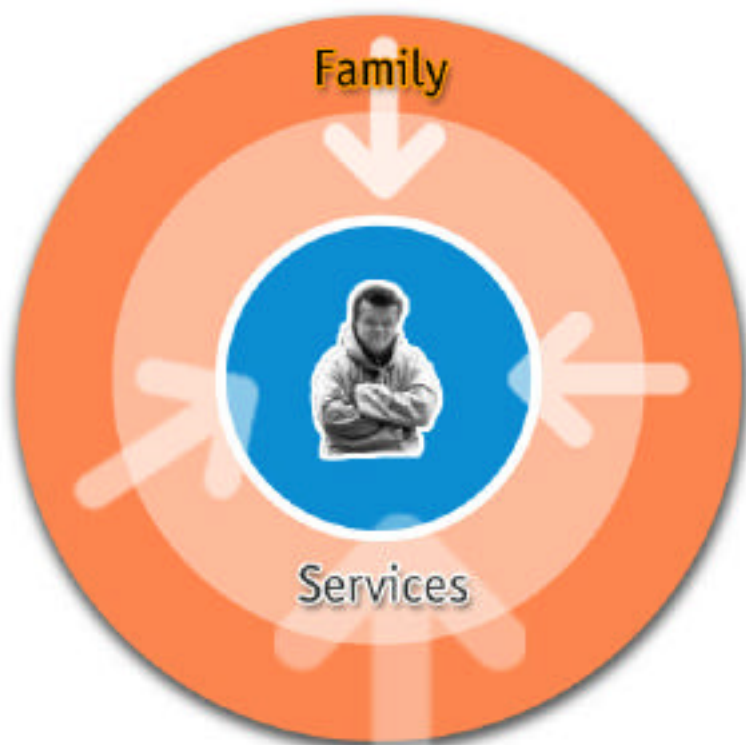
"They say they want to modernise day services, whatever that means. I reckon it's a way of cutting costs myself. I know we'll end up having him at home more, and he'll get bored! It's not fair - he loves his day centre, and we like a bit of a break."

Older carers

Many of the experiences of older family carers are similar to younger parents, but there are important differences, as we will discuss more fully in the next section. As the Walkers have argued, *"although older carers share many characteristics with their younger counterparts, there are also important differences, which have an impact on their need for services and support."*

These include:

- They are continuing to care and growing older at the same time.
- They are more likely to be caring alone.
- More likely to have a reduced networks as spouse, and have friends who have died.



- The relationship with their son or daughter is very important and this can develop into mutual dependency and very strong bonds.
- They have had a different experience of services than younger carers.
- They are less likely to ask for help, just at the time they might need more.
- Their sons and daughters are less likely to be receiving a service at all.

Developing empathy – seeing the world from the older carer’s point of view

Empathy: a dictionary definition

The power of projecting one’s personality into, and so fully understanding, the object of contemplation (in our case – older family carers)



developing your empathy gland!

The aim of this part of the material is to help develop some insight into the experience of being a family carer. You need to step inside the mind of the family carer and see the world from his or her vantage point!

To develop empathy you need to develop an appreciation of:

- People’s lives in a historical context,
- How family relationships change and develop over the course of the life cycle,
- Some of the feelings involved in the caring relationship.

The most useful and powerful way to do this is to talk to an older carer about their life.

Listening to people’s stories is always the best way of developing empathy. There is no better way of understanding the experience of older family carers than hearing their stories.

Enid and Mary's story

Enid and her learning disabled daughter Mary are inseparable. They have an active social life and love to go out and have fun. Enid is 83 and Mary is 54. Mary has always lived at home and, apart from an overnight stay in a hospital a couple of years ago, has never spent a night apart from her mother. Over the years, Mary has not received a great deal of support from local learning disability services. They did not know about her, and lost track of her somehow.

As a child Mary had a few years schooling at, what Enid describes as, a girl's special school run by nuns. At the age of 11 Mary was deemed 'Ineducable' and was asked to leave. A professional at this time told Enid, 'there's nothing more we can do for her, so you might as well take her home and make her happy'. So this is what Enid and her husband Brian did. 'We paid for her to have a private tutor for a while', Enid explains, 'but after that we bought a shop with the idea that at least Mary could work in it with us'. And this is what happened!

For 40 years Mary was unknown to learning disability services and wholly supported by her parents. But then Brian had a major stroke and life changed for the whole family. The shop was sold and Enid and Mary were more or less housebound as a consequence of having a severely disabled person at home to care for.

One day a District Nurse was visiting and noticed Mary. She wondered why Mary was not attending any form of day service and, after speaking to the family, made a referral to Social Services. As a result of this Mary started attending a community resource centre and now goes three times a week and loves it. Enid is very proud that Mary 'helps out' in the kitchen, making sandwiches and teas for the other people in the service.

Brian died four years ago and both Enid and Mary miss him a great deal. Though it 'frees them up' as they explain, to go out more and even take a holiday. Life is running very smoothly now, but Enid's (and Mary's), biggest worry is what will happen in the future. 'It would be reassuring,' says Enid, 'to know what was going to happen but no one will tell you anything. It is a great worry.'

No wonder people with learning disabilities prefer 'People First'. No wonder family carers get bemused by all these changes.

"Over the years different people come and say how he is a 'mongol', or now he's 'mentally retarded' or now he's 'mentally handicapped'. Now he's got 'a learning disability' and in a few years someone will come and tell me he's something else! To me, he's just John – my son – and nothing changes."

Exercise 4

Spend some time considering how the language we use to describe people has changed. Consider how these changes represent changes in the way people with learning disabilities are both perceived and how the language reflects the sorts of philosophy of care that underpinned the services designed to care and support them.

If you want to find out more speak to older people with learning disabilities or staff who have worked in services for a long time. You could also read about the history of people with learning disabilities in *'Forgotten Lives: Exploring The History Of Learning Disability'*, Atkinson et al. (BILD. 1997). For a personal account of growing up with a disabled sister read *'Caring For Kathleen'* (BILD. 2000.)

THINK ABOUT!

- What words are used in your service?
- What language do you feel comfortable with?
- Have you noticed families sometimes use different words – why do you think this is?
- How much should families be encouraged to use 'learning disability'?

Here are some more stories of people's lives, which illustrate how when you are born influences the sort of life that you have. This is true for all of us not just people with learning disabilities!

Maureen's Story

Maureen was born in 1949, the youngest child of six. Her mother was 45 years old when Maureen was born. Born without any discernible difficulties, problems developed after a bout of encephalitis when she was 18 months old. Maureen developed epilepsy and was obviously delayed in her development from this time.

This was confirmed when she was assessed as ineducable and therefore not eligible to attend school.

Maureen's parents became very active in the local parents campaigning group and helped set up a Junior Training Centre so that their children would have something to do during the day and be taught some skills, and have some company. Maureen's parents were actively involved as volunteers on a day to day basis in the centre and organised fundraising events to keep the venture afloat.

Despite the problems with managing Maureen's epilepsy and a constant fight to try and get her medication sorted out, her parents were determined that Maureen was never going to go into an institution. After she finished at the Junior Training Centre when she was eighteen Maureen moved over to the Local Authority run Adult Training Centre.

The rhythm of Maureen's life had remained fairly constant. Over the years her siblings moved out and started their own families and Maureen became an Auntie. The most traumatic events for both Maureen and her Mum were when her Dad died in 1971 at the age of 67. It took both her Mum and Maureen herself a long time to adjust to the death of her father, but the two women have been living together in harmonious companionship for the last 28 years. They are both socially active in the local church and the local Mencap group.

There has been very little involvement with Social Services over the years. Maureen's Mum said she was always a bit wary of them because she thought they would want to put Maureen in care. This reluctance to engage with the authorities became even more marked after the death of the father. Maureen's Mum always felt she had a good relationship with the day centre staff and if she had a problem she would often have a word with the Officer in Charge, who would sort things out for her.

There have been difficulties in recent years as Maureen's Mum has reached her 80's and her health and mobility began to decline. Maureen has come to do a lot more in the house and has virtually become her mothers' legs. Staff at the Day Centre were increasingly concerned and called in a Care Manager, but both Maureen and her Mum rebuffed him when he suggested that they make some plans for the future. All that Maureen's Mum would agree to was to have some help from the Home Help service. In all of Maureen's 50 years neither she nor her Mum have spent a night apart.

Peter's Story

Peter was born in 1971. He was his parent's first child and they were both in their early 20's. When the doctor told his parents that he was a 'Mongol' they advised them that they could have him put in a home the next day if they wanted. All the professionals that the family encountered were not very optimistic about the future. One doctor told them most mongol children died within the first year of life so advised them not to get too emotionally attached to their child.

A social worker from one of the newly formed Social Work departments visited them regularly to help them make the adjustment to having a mentally handicapped son and offered practical advice. At the age of two years old Peter went part time to a council run nursery that had just opened and which had a special needs room. The handicapped children were cared for in a different room than the other children, but they did have some playtime with the others on sunny days in the garden.

At five years old the doctor from the Special Needs clinic assessed Peter. She called his parents in to say that Peter was on the border between Severe Learning Disabilities and Moderate Learning Disabilities, according to her assessment tests. She told his parents the choice was theirs, but she would advise them to go for the SLD school because Peter would be a big fish in a little pool, where as at the MLD school he would be bottom of the pile and anyway, the other children could be very aggressive and disturbed.

Peter's parents opted for the SLD school and he started going to school on the big school bus at the age of five. He left at the age of nineteen. He was very happy at his school. He made great friends and his parents became very involved in the Teacher/Parent association. Attitudes were changing toward the end of Peter's school career and he was encouraged to be as independent as possible. He was travel trained to make his own way to and from school at the age of 14 years old. In his final years of school he worked hard to get his portfolio of Achievement and enjoyed a successful work placement at the local supermarket.

Peter's parents had always felt they managed well and had resisted the idea of respite care for many years. In his teenage years Peter did spend the occasional weekends with a Link Family. They all enjoyed the break, but felt it was an indulgence rather than a necessity.

His parents were keen to start planning for his future but found it hard to get Social Services interested in planning ahead. The social workers explained that they were under a lot of pressure and could only really help if the family said they couldn't cope anymore.

After leaving school the only two options that seemed available to Peter were to go to college or start to attend the local Social Education Centre. He choose to go to college. Again, when the college assessed him for a...

... suitable course they felt he was too able for the SLD course that they ran and suggested that he attended the programme for young people leaving the MLD school.

College was less successful than school in many ways. There was a much greater emphasis on promoting independence and personal responsibility and Peter found some of this hard. He had been used to quite a structured regime at school. One of the areas of difficulty was food. With all external restriction lifted Peter put on a lot of weight as he could eat what he liked, and as much as he liked in the college canteen. Many of his friends at the college enjoyed more freedom than he did in terms of restrictions in his life. At times this led to friction with his parents and Peter decided to leave home and live in a flat on his own or with some friends. His parents inquired at the local Social Services but were told that Peter would be very low priority.

After leaving college Peter was taken on by the local Supported Employment Service and was helped to get a job in the local supermarket where he had done his placement at school. The job had its ups and downs, but Peter continues to fill the freezers.

After several years of Peter nagging his parents, and his parents nagging the Social Services, Peter was offered a place in a house with three other men. It is owned by a local Housing Association and they all claim Housing Benefit. Social Services pay for the care and support element that is provided by an independent voluntary organisation. Peter moved out of his parent's home two years ago at the age of 26, but continues to see a lot of them.

Melissa's Story

Melissa was born in 1989 with Downs Syndrome. At the time of her birth her parents were given lots of positive advice about what she might achieve. They were given a lot of books to read and were introduced to another family who had an older Downs Syndrome child who gave them support and advice. The Specialist Health Visitor advised her parents on the ways that they could help her to develop. From 2 years old she attended a local playgroup in her village.

She is now ten years old and lives with her parents and her older brother in a small Somerset village. She attended her local primary school and is now attending mainstream junior school. She has a Special Needs Educational Statement and has a helper to support her in the classroom. Both Melissa's parents and the school think she is well placed at the school and doing well. It is not always easy. The other children are not unpleasant but she has no real 'best' friend and says that sometimes this makes her sad. She has an active social life in the village.

Melissa's family have never had any contact with the local Social Services department and say have never seen Melissa as a problem. They visit the local Child Development Team once a year to monitor Melissa's health, which is perfectly OK at the present time.

Melissa's parents try not to think about the future too much and are trying to get through day by day. They have seen some adults at the local day centre and feel very strongly that this would not be what they would choose for their daughter. Their long term aspirations are that she will be able to get a job and leave home to live with a couple of other people in a shared house, not too far from them. In the short term, the plans are that she will attend the local comprehensive school.

So, the lives of people with learning disabilities, and the opportunities available to them, are affected by when they were born in much the same way as it is for all of us. Just think about the world you live in, compared to your grandparents!



It is important to remember that family carers who are in their 70's, 80's and 90's inhabited a very different world to the one we live in today and should not be judged against standards set by today's services.

- They had their children at a time when there was a stigma involved in having a learning disabled child. Many parents were told that they should not expect their children to live very long. (In the 1930's the average life expectancy of a person with Downs Syndrome was 7 years old, today it is about 55 years.)
- Parents were actively encouraged to have their children put 'into care' or 'put away' so they could 'get on with their lives and forget about their disabled child'.

"I was told he was mentally handicapped and I could take him home or leave him at the hospital as he wouldn't reach the age of twenty. I chose to take him and I never thought I'd still be caring for him 50 years later."

- Their children were deemed ineducable and had no right to an education – and the battle for inclusion in education system has been a long one! Services in the community were minimal and many day training centres, for both children and adults, were run/set up by parental volunteers.

The older family carers of today were the families who resisted the pressure of professionals to send their sons and daughters away from home. Yet it is their sons and daughters, now in middle age, who receive less support than people with learning disabilities who went into institutions and subsequently came out into the community. In the report 'Fair Shares For All' people with learning disabilities living in the community with older family carers were: ('Fair Shares For All', Walker C. & Walker A. 1995.)

- less likely to be accessing or receiving support services,
- less likely to have an individual plan if they were getting some sort of service.

What we are really talking about here is **discrimination**. It is good that the White Paper – **Valuing People** is seeking to redress this with its determination promote the value of: – rights, inclusion, choice and independence for people with learning disabilities.

Developing empathy – getting inside the head of a parent of a child with a learning disability

In many ways this next exercise is at the heart of the trying to get you, as a person working in services, to develop a greater understanding of the point of view of the families you come into contact with. What does it feel like to have a learning disabled child or brother or sister? For the moment we are going to concentrate on parents. We are going to concentrate on trying to understand their feelings as parents.



developing your empathy gland!

Exercise 5

Imagine you have a learning disabled son or daughter!

Put yourself in the mind of a parent at different points in the life cycle:

- 1. Being told your child has a learning disability,**
- 2. During childhood,**
- 3. When your child reaches adolescence and young adulthood,**
- 4. When your adult son or daughter is in middle age – and you are getting older yourself.**

Taking each stage at a time fill in the following boxes. Think about what your feelings and emotions are first, then move on to worries and concerns. Finally, give some consideration to what actions by others might help alleviate some of your concerns. List things in the appropriate boxes.

List and describe the feelings and worries you would have if you were told your child has a learning disability.

Feelings and emotions	Worries and concerns	Actions by others that might help

List and describe the feelings and worries you would have during their childhood.

Feelings and emotions	Worries and concerns	Actions by others that might help

List and describe the feelings and worries you would have when the child reaches adolescence and young adulthood.

Feelings and emotions	Worries and concerns	Actions by others that might help

List and describe the feelings and worries you would have when your adult son or daughter is in middle age – and you are getting old yourself.

Feelings and emotions	Worries and concerns	Actions by others that might help

What sort of feelings emerged – what were your worst concerns? Could you identify what actions by others might help?

- How easy was it to "get inside" the parental role?
- Has it helped you feel more empathetic to the parental perspective?
- No one ever pretended family relationships are not complex.

Did you find that many of the feelings and worries were similar at different points in the lifecourse? Whatever stage the family is at, parents have similar concerns.

- Where will I get the information I need?
- How will I cope?
- Will my son/daughter get the right sort of support?
- Will services be able to support us?
- What will happen in the future?

By this point you should have come to some understanding of just how worried and concerned parents can be, and with some justification. You should now be able to see just how much emotion is involved in parenting a child with a learning disability.

"I cried and cried when the doctors told me. I don't know who I was crying for, me or the baby! I just felt so frightened, frightened of the future, frightened I wouldn't be able to cope."

"I worried about him leaving school. He'd been very happy there and he had plenty of friends. I just didn't know what was out there for him! The future scared me!"

"Of course I worry about what will happen to her when I'm gone. It's a horrible thought, but I've got to face it. It just seems so difficult to find anyone who can tell me with any certainty where she'll go. It is a terrible thing to say but I'd be happier if she went before me, to be really honest."

Siblings

So far we have talked about the impact on family life of having a learning disabled member from a parental perspective, but brothers and sisters are important too!

The siblings of a learning disabled child can experience a whole gamut of feelings and emotions from guilt, resentment, protectiveness, frustration, anger, love.

Many brothers and sisters, from the earliest of ages, play a crucial role in caring for and supporting their disabled sibling. As young carers they need support in their own right. For many this is a positive experience that influences their life. It is not surprising that many siblings of people with learning disabilities end up working in services or advocating on behalf of the rights of people with learning disabilities. For others the difficulties and emotions experienced in their youth can lead to a distancing from their relative in later life.

"I always felt my mother never had any time for me. She was so caught up with my sister's needs and her involvement with the local Mencap. I felt resentful."

As they grow older into adulthood this role can and does continue for many, as part of a life long commitment to the person with a learning disability. The importance of involving siblings in any planning for the future is discussed in more detail in the section **'Supporting People Through Transitions'**.

For an inspiring account of a sister's devotion and commitment to her disabled sister over half a century read Margaret Fray's account of *'Caring For Kathleen'*. (BILD. 2000) It is also a great historical record of attitudes and experiences.

"I loved my sister very dearly; to me she has always been the bravest person I shall ever meet, and she deserved nothing but the best this life has to offer."

So you need to remember!

Michael is a man with learning disabilities.

He is also:

- a son,
- a brother,
- a cousin,
- an uncle,
- a grandson.



Families are important in most people's lives. Families are important in the lives of people with learning disabilities. Go back to the first exercise. What words did you originally jot down? Do you feel differently towards families now?

In this section you have had the opportunity to reflect upon:

- Your *own* attitude to the families of people with learning disabilities.
- Why it is important to engage and work with families.
- The importance of seeing how history and the passing of time affects all of our experience.
- The specific situation of older family carers and their adult sons and daughters with learning disabilities.
- The need to develop empathy for the families that you work with or come into contact with in the course of your work.

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