

A Parent's Guide:

Improving the well-being of young children with learning disabilities



A collaboration between the University of Warwick, Cerebra, Mencap, the Challenging Behaviour Foundation, and parents of children with learning disabilities

The idea for this booklet was motivated by parents' concerns about the lack of accessible guidance on how families can help promote the well-being of their child with a learning disability. We would like to thank all of the parents who contributed their stories in this booklet, all the parents who participated in research studies over the years, and the parents who gave us their feedback on this booklet.

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Introduction: The well-being of children with learning disabilities

What is this booklet about?

This booklet has been created to help parents support the well-being of their young child with a learning disability (aged 0 to 5).

The information in the booklet comes from research by a team at the University of Warwick (Samantha, Vaso and Richard). With our colleagues, we have been studying the well-being of families of children with a learning disability for over 20 years. This booklet draws on our research, and has a specific focus on child well-being. The family activities that are described in the booklet have been shown to be important for improving well-being for children with a learning disability.

We also asked parents of children with a learning disability to describe how they actually do these family activities. We have included some of their stories in this booklet. Some of the parents who contributed their stories have children who are young (between the ages of 0 and 5), just like the parents for whom this book has been developed. Their stories illustrate how parents nowadays handle some of the stuff that research evidence has shown to support child well-being. Some parents we spoke to have children who are a lot older, but they reflected back to the days when their children were younger. These parents have the benefit of hindsight: they are able to reflect on what was important and what less so, and share some of their reflections with parents who are now raising their young child with a learning disability.

What are learning disabilities?

We sometimes use different terms to describe a learning disability, such as "special educational needs", "developmental disability" or "developmental delay".

A child with a learning disability can find it hard to understand what is happening, to learn new things, and to be involved in everyday activities.

Children who have a learning disability need more help doing things, for example washing, dressing or looking after themselves. They might need help with communication.

There are different levels of learning disabilities, including mild, moderate, severe and profound/multiple learning disabilities. Children with different levels of learning disability might have different strengths and difficulties.

What is child well-being?

There are lots of different ways to describe well-being, and it can be different for different groups of people (e.g., children, adults, older adults).

In this booklet, we are going to be guided by the United Nations International Children's Emergency Fund (UNICEF) definition.

Child well-being is made up of different things, and is not just about emotions:

- Physical health, development, and safety
- Cognitive development and education
- Psychological/emotional development
- Social development and behaviour
- Relationships with family
- Relationships with peers
- Relationships at school
- Relationships in the community

We know from research that children with a learning disability are more likely to have problems with their well-being than children without a learning disability.

We also know that there are things that can be done to improve the well-being of children with a learning disability.

What do we mean by 'family'?

We know that families are made up of lots of different people, and that some of these people may not be biologically related to each other.

We will be using the word 'parent' in this book to describe a lot of different people who look after children, including family carers, step-parents, grandparents. We consider a 'parent' to be any adult who helps raise and look after the child (i.e., carries out some of the tasks a parent would usually do).

A message from Parents to Parents:

The parents we spoke to said that raising a child with a learning disability is a learning curve, and that it is OK to not know everything. A few of the parents said that their lives stopped for a year or so while they adjusted to their new way of life, but that now (a year or two later) their new life feels normal. They thought that it was really important to let other parents know that they shouldn't feel guilty for finding things difficult, and that it won't be this way forever.

This booklet was written with young children (0-5) in mind, but parents of older children might also find it useful.

We have divided the rest of this booklet into four chapters:

Chapter 1: How to look after yourself (Parental well-being)

Chapter 2: Organising family life

Chapter 3: Spending time together

Chapter 4: Activities to do with my child with a learning disability at home and outside

You do not have to follow the order of the booklet, and can use it flexibly depending on what information you would like to know at the time.

Having said that, please do read Chapter 1. We know that parents generally put themselves last, focussing their energy on their children, but our research shows that sometimes the best thing you can do for your child is to look after yourself.

Chapter 1: How to look after yourself

What is parental well-being and why is it important?

We have research evidence that looking after your own well-being increases the well-being of your child with a learning disability. For example, mothers who have a more positive outlook on life have children who show more positive social behaviours.

We know that, sometimes, the number of challenges you face can make looking after yourself feel like an impossible task. Research shows that these challenges can pose risks to your physical and mental health.

We know from research that parents of children with a learning disability can be twice as likely to experience high stress levels as do other parents. High levels of stress can have a negative impact on your well-being.

Our research also shows that the distress and physical health problems experienced by mothers can contribute to behaviour problems later on in their child's life. If parents are stressed, they can find it hard to effectively deal with their child's problem behaviours.

None of this is your fault. Families of children with a learning disability have a lot to cope with, and a lot of the stress that parents feel can come from a lack of support or difficulties that are not related to the particular needs of your child. You can't necessarily remove all of these challenges, but you can make little changes to help you to cope with them better. We know that making these little changes are good for parents and their children.

Research shows that even though parents of children with a learning disability might have high stress levels, they still experience positive well-being, the same as parents who do not have a child with a learning disability. This was a very significant finding in our work; one that we believe is worth remembering: parents can and do have positive experiences even when they are experiencing stressful situations at the same time.

You can try to boost the positive aspects of your well-being (for example how happy you are with life in general). This is important to do even if there is still significant stress in your family life.

We also know that increased children's positive social behaviour can contribute towards improved mothers' psychological well-being, including increased life satisfaction.

Overall, there are two aspects of well-being: one is positive well-being and positive mental health, and the second one is psychological distress or mental health problems. For parents of children with learning disabilities both aspects of well-being are important. We review below ways to boost the positive stuff and also ways to reduce the negative stuff.

What will life look like in the future?

Parents of young children with a learning disability often wonder what life will look like in the future. We know from research that the quality of life of people who care for someone with a learning disability is similar to the quality of life of other carers.

There are some ways that carers of someone with a learning disability are different to other carers. Carers of people with a learning disability may have less time to spend with other members of their family, and less free time to pursue their own hobbies and interests. Research suggests that this impact comes about because of the long hours needed to care for a person with a learning disability. We also found that caring for people with a learning disability is more physically demanding, and can be more financially difficult, than caring for other people.

When caring for children, we know that children with learning disabilities are more likely to display behaviours that can be challenging; this can be particularly difficult, especially without information and support. All of these effects can impact on the well-being of the carer. [The Challenging Behaviour Foundation](#) offer information and support for parents of children with severe learning disabilities and challenging behaviours.

Our research has shown that raising a child with a learning disability has positive effects on the family. Some of these positive experiences may be unique to families of children with a learning disability.

Parents of children with a learning disability can feel that, since having their child, they have:

- Grown as a person
- Learned new things or skills
- Been able to put life into perspective
- Grown closer with their family
- Become more tolerant and accepting
- Become more determined to face up to challenges
- A greater understanding of other people.

It is important to take time to see the positive aspects of raising a child with a learning disability, even though sometimes it can feel difficult.

How to support your well-being

There are many ways that you can look after your own well-being. Not all of these will work for everyone, and there could be some trial and error involved while you find what works best for you.

We know that the simplest things, like eating healthily, getting enough rest, and exercising regularly can be the most difficult when caring for a child with a learning disability. But it is important to do these things to look after yourself. Most parents we spoke to said that sleep was the most difficult thing for them to do. Addressing your child's sleep issues will help you get a better night's sleep. You might need some help from others when you try to deal with your child's sleep difficulties. [Cerebra](#) have a team of sleep practitioners who can offer help and advice about children's sleep problems.

You could try to make some small changes that can benefit your own and your child's well-being. Parents and practitioners advised that some examples of small changes are:

- Putting on some music that you enjoy and sing or dance to it
- Thinking about short journeys that you can walk, instead of driving
- Thinking back to the things that you most enjoyed before you had children (e.g., playing sports, going out with friends, reading), and trying to think of a creative way to fit some of them back into your life.
- Trying something new that you've wanted to do for a while. The parents we spoke to said that this could be a good way to meet new people as well.
- Find someone who can support you to have short and regular breaks to do something you enjoy (e.g., having a quiet cup of tea, going for a walk).



It might help to talk to other parents who are going through a similar experience to you. You could join a support group for parents of children with disabilities. Some of the parents we spoke to said that they were members of online support groups and parent groups on social media; they said that these were really good to get support from people who are similar to them.

We know from research that using mindfulness and meditation, can help to improve parental well-being. Mindfulness might also help us to make practical changes after practising it for some time as we are less likely to be reactive in stressful situations. There are courses available on mindfulness and these might help to get you started. Some of the parents we spoke to said that parents could use mindfulness or meditation apps on their phones, and this might be easier to do than going on a course.

Parents tell us that trying to take regular breaks from your caring responsibilities to look after your own health and well-being is also very

important. You could ask family and friends to help out, or ask your [Local Council](#) for guidance about respite support. Parents we spoke to said that help is out there, and taking some time to find it can give you the time in future that you need to look after yourself. All parents said that time was the best resource when they are trying to look after themselves.

Trying to make time for yourself might feel impossible, especially when your child is young or has complex needs. But looking after yourself is not time out from caring for your child. It is an investment that supports you, your child, and your unique relationship.

Some parents that we spoke to said that even really short breaks can help them to look after themselves. This might be more manageable for some families.

We spoke to parents of children with a learning disability about some other ways that they look after their own well-being:

“I try to see a friend one evening a week, and get caught up with them. There are nights where I sit down and I am too tired, and don’t want to go, but it is worth it for that bit of sanity and get out and be with my friends and catch up.”

A mother of a two and a half year old boy with Down’s syndrome

“I enjoy playing football, and that’s my own time a few nights a week if I’m not working. I find it hard to find time sometimes, because I work full-time.”

A father of a three year old boy with a learning disability

“It’s not easy to fit everything in. We have to roll with it, and take time for ourselves whenever we can. We usually take time when we have dropped our daughter off at nursery to get a bite to eat, or spend some time with the other parents [of children with learning disabilities].”

A mother of a three year old girl with a learning disability

Our partner, Cerebra, recently put together a guide for parents on their emotional well-being. We collaborated with Cerebra on this guide to support the research evidence. The guide also provides further information and advice on how you could support your well-being. The guide can be found here: <http://www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-emotional-well/>

Another of our partners, the Challenging Behaviour Foundation, has developed an information sheet on the impact of caring for a relative with a severe learning disability and behaviours described as challenging. The information sheet can be found here: <http://www.challengingbehaviour.org.uk/learning-disability-assets/12impactofcaringonfamilies1.pdf>

Reflection activity: Parents felt that there should be some space for reflection. Below we added a few questions to guide your reflection if you wanted to take the opportunity to think about ways forward.

Take some time to read through the following questions and note down some ideas about what you could do after reading the last chapter.

1. What would I really love to do, just for myself?

2. What can I practically do to carve out a little bit of time to do something for me?

3. When will I do this (what day of the week, what time of day)?

4. Do I need to ask for support from someone else?

5. When will I start?

One month review

1. How is it going?

2. Do I want to carry on?

3. Do I need to make any changes so that I can take time to myself?

4. Has it made any difference to my well-being?

5. What will I do from now on?

Chapter 2: Organising family life

Social Activities

One of the most important aspects of families' social lives is having friends and meeting with them. Our research shows that children spending time with their friends when they are young can improve their positive social skills and behaviours.



Our research has shown that it is important to make time to meet with friends to play outside of school or the immediate family. Social relationships are important for everyone, and the same goes for children with a learning disability. Apart from having fun, it is time spent with peers, where a lot of learning takes place: how to take turns, how to share, how to ask nicely, how to negotiate. So instead of thinking of this as just fun time, we know now that playing with other children has a long lasting benefit on the social skills of children with a learning disability.

It isn't always easy to fit in playdates in a busy life. Here is how other parents have told us about the sorts of social activities they plan for their children:

"He loves going to his Nanny's house and spending time with his cousins there. One of his cousins is around the same age as him, and his cousin will give him toys to play with. It took a bit of time, but he is developing social skills of giving and taking toys from his cousin."

A father of a three year old boy with a learning disability

"She had so much interaction with people who were not disabled. This can only be good for her, it helped her communication skills. She was able to speak and play with other people, even though her speech was a little bit delayed."

A father of a 24 year old woman with Down's syndrome

Family Home Life Routines

As parents, we have heard time and time again about the importance of family life routine. Getting our family's life into a routine is something health professionals advise us to do shortly after our child is born. This usually means to try and have regular sleep and wake up patterns. In older children, it means having regular meal and bedtime routines.

Some of the parents we spoke to said that they weren't able to get into a routine until their child was a bit older, so they said that it is possible to start a new routine at any time.

Having some home life routines can make running family life easier. It means that parents and children know what's coming up and feel that they have some sense of control over their daily lives.

It helps with planning for everyday tasks (e.g., when to do out-of-home chores and when to avoid them), and planning for extraordinary tasks (for example, whether the family can go on a holiday, and what time of the day it is better to set off on a journey).

As researchers, we looked into whether family home life routines at the ages of 3 and 5 years had any longer-term benefits for children with learning disabilities at the age of 7 years. We looked at two dimensions of

family routines: living in a calm and organised household, and having regular meal and bedtimes. Neither of these appeared to be having a longer-term effect on children's behaviour, social skills, or independence. Instead, we found that for young children a close and warm relationship with their parents is more important.

Does this mean that routines are never important? Of course not. For example, a regular bedtime routine, helps to achieve better sleep in both children and adults with a learning disability.

Some children with a learning disability, including those who also have autism, might also really like routines. Routines can help children to feel that life is more predictable and so it can help them with their anxiety.

Having home routines makes it easy to run family life on a daily basis. However, if you sometimes slip out of these routines, there is no evidence that this will have a negative longer-term impact on your child's behaviour or social skills.

Some of the parents we spoke to said that their routines are flexible, and will change depending on the time of year (e.g., less strict routines in the Summer holidays).

Parents of children with a learning disability have told us about some of the ways that they try to have good routines for their children.

"We try to keep everything structured so that he is used to what happens every day. We keep the same routine so that he doesn't get out of sorts."

A mother of a two and a half year old boy with a learning disability

Reflection activity

Take some time to read through the following questions and note down some ideas about what you could do after reading the last chapter.

1. What have I learnt from this chapter that is relevant to my situation?

2. How can I use this information to help organise family life in relation to social relationships and family routines?

3. Do I need any support from anyone to make this happen?

4. When will I do this (what day of the week, what time of day)?

One month review

1. How is it going?

2. Do I need to make any changes?

3. Has it made any difference?

4. What will I do from now on?

Chapter 3: Spending time together

In any family context, we can make a distinction between two dimensions: what we actually do (e.g., parenting) and our relationship with the other person. This chapter is about relationships. In families, there are parent-child relationships, parent-parent relationships, parent-sibling relationships, and sibling-sibling relationships.

Through our research, we know that positive relationships improve the well-being of children with a learning disability.

Positive relationships are helped if people just make time to spend with each other, just to enjoy each other's company, when there is no need to achieve anything or get somewhere. This can be by:

- spending time with the other person
- just having a chat
- being physically close
- doing an activity that the other person is good at.
- doing something fun together

Spending time having fun or seeing the other person's strengths improves our relationships. If you decide to identify an activity to do together, it might be worth spending a bit of time thinking about the strengths of the other person in advance: What do they enjoy doing? What are they good at? This will allow them to show their strengths.

Seeing others in a positive light is good for relationships. The daily grind of everyday life doesn't always allow us to do this. So, it is important to make some time to either do nothing – just be with the other person – or share an activity they are good at.

These activities don't need to be very long, they could be as short as 5-10 minutes.

In this section, we will give some examples about why it is important to have positive relationships, and ways to build more positive relationships with your partner, your child with a learning disability, your other children, and how your children can build positive relationships together with their brothers and sisters.

Relationship with your partner

We know that not all families will have two parents in the house, but where there are two adults it helps to try and build in things which maintain a positive relationship. Positive relationships between a parent and their partner can help to reduce parents' negative feelings (such as depression). Positive relationships between the two parents also help the child: they can help parents work better together to reduce behaviour problems in children with a learning disability.

Parents of children with a learning disability have told us about some of the things they do to build positive relationships with their partner:

"We are at the stage that now he is sitting upright and he can stay with his older sister on his own so that we can get a cuppa together in the kitchen."

A father of a three year old boy with a learning disability



“Me and my husband go out on date nights and do things together that is adult time, without talking about kids or laundry. We go somewhere and have a little bit of adult conversation. When we go out on our own, we usually go for a nice meal or a few drinks, or go to see something we want to watch the cinema.”

A mother of a three year old girl with a learning disability

“It is important to make time for yourselves as adults, and as a couple. When our daughter was younger, we would set aside an hour a day for ourselves, whether it was to have a chat or watch something that we wanted to watch on the television.”

A father of a 24 year old woman with Down’s syndrome

“We also find time to talk on our commute to work in the morning in the car on the `phone, so every day we speak to each other in the car for at least 20 minutes and can get caught up on what’s been happening, what we need to do and plan things such as date nights, days away, etc. during this time. This is just a little bit of time that we find where we can actually have an uninterrupted conversation when there are no children involved.”

A mother of a two and a half year old boy with Down’s syndrome

Relationship with your child

Research has shown that having a close relationship with your child while they are younger helps with behaviour problems both now and in the future.

Parents want to build healthy and happy relationships with their child who has a learning disability. As well as being important in its own right, these firm foundations will have benefits in the longer term. A positive relationship is one where people feel warmth for each other, affection, and where they can communicate openly.



Of course, relationships can at times become strained and conflict often arises. This cannot be avoided altogether. Making an effort to nourish a close, warm relationship with your child with a learning disability (despite moments of conflict and difficulties) is an investment that supports your child's well-being.

We know that you will probably spend a lot of time with your child, and this is good because one of the ways a close relationship can be nourished is by spending quality time together with your child. This should be time just being; enjoying each other's company, without needing to achieve anything or get somewhere. It could be just having a chat, sharing a cake, having a laugh. Or it could be time doing things that your child, or you both, enjoy.

Children with a learning disability have told us about some of the things that they enjoy doing:

- Playing in the garden (e.g., on their bike, on the swings)
- Reading books
- Listening to music
- Playing games
- Going to the park
- Playing with their pets
- Drawing and painting
- Pretend play
- Sensory activities

Not all children will want to or be able to do all of these things, these are some suggestions from other children with learning disabilities. Whatever it is, let your child lead this quality time together. You just need to make sure that you make time and space for this to happen, and for your child to explore what they enjoy doing.

Spending time together just enjoying each other's company might happen naturally during the day. Family life is busy especially when you have a child with a learning disability and perhaps other children with disabilities too. If it doesn't happen naturally, you could plan for it to happen. It doesn't have to take long, and it doesn't have to be every day. We don't really know how much quality time is needed from our research with families. But we know from other research that 'little and often' is more likely to happen, and parents are more likely to keep 'little and often' going.

It may be more practical for families to build 10 or 15 minutes of "fun time" together into their routine most days, rather than trying to set aside a whole day free of other demands and distractions. Although of course both would be even better! Don't worry if the time is not "fun" at first, if you feel bored with no specific goal in mind or if your child is in a bad mood. Over time, devoting time each day to just being together or doing something your child enjoys and giving them your full attention, will strengthen your relationship.

Some parents of children with a learning disability have told us about some of the things they do to spend quality time with their child:

“He loves music, and I’ve always loved music. I always sing around the house and I always find that music helps in many ways, whether as a distraction or as a game or a learning tool. I sing things in a funny voice or slow things down and he just laughs his head off and it is a lovely rewarding moment. We mess around together like that a lot.”

A mother of a two and a half year old boy with Down’s syndrome

“We play a lot of games together, as a family, and the games are always on his level. We also act silly for him, to make him smile.”

A father of a three year old boy with a learning disability

Relationships between siblings

Research about sibling relationships tells us that warm and close relationships between brothers and sisters, with low amounts of sibling conflict, can lead to better outcomes for all children. Although there is less research about sibling relationships and later outcomes for children with a learning disability, there is no reason to suppose this would be any different for them.



So, having more positive relationships between children with a learning disability and their brothers and sisters is likely to be a good thing for the child and their siblings.

Here are just a couple of examples from parents about how they support their children to have a positive relationship with their siblings:

“We always try to include our youngest son [who has Down’s syndrome] in everything even when we think he may not be interested in it or ‘get it’, so for example, I was racing cars around the bedroom with his older brother and we asked him to join in and he played for a little bit and he was laughing and enjoyed it. He thinks that his older brother is great and funny.”

A mother of a two and a half year old boy with Down’s syndrome

“The interaction with her siblings was great for her. They would take her everywhere, play with her and take her out with their friends. Her older sister, who was two years older, would do everything with her, they would do everything together.”

A father of a 26 year old woman with Down’s syndrome

If positive relationships are a good thing, it is also important to think about what might get in the way of these positive relationships. For children generally, and for children with a learning disability, research shows that high levels of behaviour problems can disrupt sibling relationships. If either the child with a learning disability or their brother/sister has high levels of behaviour problems, working to address these behaviour problems should help their sibling relationship (and ensure that this relationship can contribute positively to both children’s development).

[The Challenging Behaviour Foundation](#) offers information and support for parents of children with severe learning disabilities and challenging behaviours. [Paving the Way](#) is another source of information for parents whose children with a learning disability present behaviour that challenges.

Some of the parents we spoke to said that it was important for them to talk about their child’s learning disability with the child’s siblings:

“Our older daughter is learning Makaton to be able to communicate with her sister. Being involved makes her feel really special. We made a decision when our younger daughter was born that our oldest daughter would not feel pushed aside because her sister is disabled. We have started to include our oldest daughter in conversations about her sister’s abilities, and she can now understand why her sister does things and how she can play and interact with her.”

A mother of a three year old girl with a learning disability

Reflection activity

Take some time to read through the following questions and note down some ideas about what you could do after reading the last chapter.

1. What have I learnt from this chapter that is relevant to my situation?

2. What changes can I make to my life to allow me to spend time with other members of my family?

3. When will I do this (what day of the week, what time of day)?

4. When will I start?

One month review

1. How is it going?

2. Do I need to make any changes?

3. Has it made any difference?

4. What will I do from now on?

Chapter 4: Activities to do with my child with a learning disability at home

So far, we have been talking about activities that support warm, positive relationships. We will now zoom in on other activities: activities that you could do with your young child with a learning disability at home to support your child's development.

What sorts of activities can I do with my child at home?



Some parents do activities with their young children to improve what the child can do; to improve their development. Activities that you could do with your child include:

- Reading a book or sharing a story with your child. These could be books with or without words (e.g., [Books Beyond Words](#))
- Singing or rhyming with your child
- Trying to teach them letters of the alphabet, or help them with their reading
- Trying to teach them numbers, or help them with maths
- Painting or drawing with your child
- Learning to sign together (e.g., Makaton)

These are activities parents do with their young children (from 0 to 5 years). Some of the activities above can be done at any age; others only make sense when the children are a bit older (for example, learning to count after 2 or 3).

Parents of children with a learning disability have given us some examples of the types of activities they do with their child at home:

“As part of his bedtime routine we read him a story, and I usually pick books that have flaps in them so we can lift them and see what’s under them. Now that he is a bit older I offer him two bedtime books and he chooses the book that he wants me to read to him. Making a choice is good for his communication skills.”

A mother of a two and a half year old boy with Down’s syndrome

“We are also trying to teach her to do things with a pen. Her sister and I got some pens out a few weeks ago and just started doodling. We started off by trying to get her to grasp a pen, and now that she can do this we are putting the pen to the page so she can draw lines. We do everything in little steps, so that she can learn one thing before we move on to the next step.”

A mother of a three year old girl with a learning disability

“We also got her jigsaws from a very young age, ones with bigger pieces that she could pick up, and that was to encourage her fine motor skills.”

A father of a 26 year old woman with Down’s syndrome

“We try not to limit what he can do with Makaton by only using a few of the same signs all the time, because if we keep learning new signs then he will start to use them too.”

A mother of a two and a half year old boy with Down’s syndrome

“Our daughter will be sitting in the living room and you can go down and sit with her and teach her another song. We are teaching her all the body parts this way. We start by doing the actions on our own bodies and then we move on to her so that she can be more aware of her own body.”

A mother of a three year old girl with a learning disability

“A lot of the nursery rhymes are geared to teach children things, like counting backwards or parts of the body, so it is really good from that perspective as well that they are learning but they are also having fun.”

A mother of a two and a half year old boy with Down’s syndrome

Some of the activities mentioned already are relevant to all children, no matter how severe their disability is. Some might need a bit of adjusting for your child:

“It’s all about making adaptations for him to do the same things as his brother. I usually do what I would have done with his brother, but a lot of the stuff I have to repeat and take things slower. We can do the same things with him, but we just have to break them down a bit differently.”

A mother of a two and a half year old boy with Down’s syndrome

What benefits will these activities have for my child?

Research into the benefits of the activities described above (the ones parents do with their children at home) started a long time ago with children who do not have a learning disability.

Research initially looked at how these activities (known as the home learning environment) when children are toddlers can actually support their academic skills and how well they do at school. Activities such as reading to your child, singing, teaching them letters and numbers were shown to make a large difference to how well children do later at school in English and Maths.

Our research looked at another type of benefit these activities have. Our research showed that doing these activities at home when children are young improves their positive social skills later in childhood. Positive social skills include things like helping, sharing, co-operating, understanding how other people feel (empathy), and being independent.

Really importantly, children (with learning disabilities) whose parents said they have done these activities with them when they were young (3 years old), later said that the children were happier (when they were 7 years old).

We believe that these activities benefit many aspects of children's well-being for several different reasons: it is time that the parent puts aside to do something with the child; time where the adult 'shows' the child how to communicate in social situations, and time doing something fun that also supports the child's learning.

Reflection activity

Take some time to read through the following questions and note down some ideas about what you could do after reading the last chapter.

1. What have I learnt from this chapter that is relevant to my situation?

2. How can I do some of these activities with my child?

3. When will I do this (what day of the week, what time of day)?

4. When will I start?

One month review

1. How is it going?

2. Do I need to make any changes?

3. Has it made any difference?

4. What will I do from now on?

Conclusion

With this booklet we wanted to share with parents some of the most interesting things we have found about the well-being of children with learning disabilities and their families' well-being during the course of our research.

This is not the end of the story, as research continues and our research will continue to explore ways to support the well-being of families such as yours.

We hope that you found this guide interesting and useful. Parents of children with learning disabilities worked closely with us and our partners to provide a meaningful context to the research, and share their wisdom through examples from their own lives. For us, this is where research and practice really come together in a way that is meaningful both for researchers and families.

If you found any of the suggestions interesting, we would encourage you to spend some time reflecting on these and maybe even trying some things out. You are already doing an amazing job supporting your child with a learning disability, some of the suggestions here might support you further in your role as parents.

The parents we spoke to and our colleagues in the Challenging Behaviour Foundation, Cerebra and Mencap wanted to remind you that you are not alone on this wonderful journey. Try something new or keep on trying even when things are difficult. Engage the help of others. Research has repeatedly shown us that good stuff can happen at the same time as the difficult stuff. When he talks about the resilience of families with a child with learning disabilities, our friend and colleague Steve Noone often reminds us of Jon Kabat-Zinn's saying 'You can't stop the wave, but you can learn to surf!' On our part, we will continue researching how best to surf when you are a parent of a child with a learning disability.

Contributor biographies:

Samantha Flynn is a Research Assistant within CEDAR at the University of Warwick, where she has worked since 2016. Her research relates to the health and well-being of people with learning disabilities and their parents. Before working at the University of Warwick, she worked for the National Autistic Society where she co-ordinated a peer mentoring scheme aiming to improve the social and psychological well-being of children and young people (10-18) with autism.

Vaso Totsika researches developmental disabilities. She is particularly interested in families of children with learning disabilities, researching the well-being of children with learning disabilities in relation to their parents' well-being and everything else that happens in families. Learning disabilities don't stop at childhood though, and Vaso's research is also concerned with the quality of life of adults with learning disabilities and their carers, whether family carers or support staff. She is currently an Associate Professor at the University of Warwick where she does research and teaching. She is also an adjunct Senior Research Fellow at Monash University (Centre for Developmental Psychology and Psychiatry).

Richard Hastings carries out research focused on the needs of children and adults with learning disabilities and/or autism and their families and carers. Much of this research is done in collaboration with people with disabilities, family members, and with charities. Richard is a Professor at the University of Warwick and is the Cerebra Chair of Family Research there. He is also a Monash Warwick Professor in the Centre for Developmental Psychiatry and Psychology at Monash University in Australia. Richard has four children.

Viv Cooper is the parent of a young man with severe learning disabilities who displays a range of behaviours described as challenging. Her experience of trying to access information and support when he was a child was very difficult. After living 275 miles away from home as a child, because no local service could meet his needs, her son now lives locally in a supported living service. She founded the Challenging Behaviour Foundation (CBF) in 1997, and in 2012 Viv was awarded an OBE for services to families and people with severe learning disabilities. In 2015, she was awarded an Honorary Doctorate from the University of Kent.

Jacqui Shurlock is the Children and Young People Lead at the Challenging Behaviour Foundation. She led the Early Intervention Project: a three year national project, funded by the Department of Health, which gathered evidence and identified best practice on early intervention for children with learning disabilities whose behaviours challenge. Previously Jacqui led a number of policy teams at the Department for Education, including disabled children policy and Every Child Matters and before that

she supported young people with learning disabilities whose behaviours were described as challenging.

Margaret Kelly has been Director of Mencap in Northern Ireland since September 2015. She has over 25 years' experience in the voluntary and community sector, working primarily with families and children's charities. Margaret has previously held leading roles in Barnardo's NI and The Fostering Network. She has worked with the NI Assembly and a range of government departments on the development and improvement of policy and practice for families. Margaret has extensive experience in commissioning, managing and publishing research, as well as ensuring that both policy and practice are underpinned by an evidence base.

Joanne Sweeney is the Family Support Manager with Mencap NI working with parents and carers of children with a learning disability aged 0 to 7 years. Since taking up post in December 2016 she has worked with a range of partners to develop an early intervention programme for families in Northern Ireland. Joanne has a background in youth work, community development and family support and in her previous post developing a school-based family support programme for parents and nursery-aged children.

Tracy Elliott is Head of Research and Information for Cerebra and has been with the charity since 2010. Prior to joining Cerebra she worked for the charity Home-Start and in the University Sector. She has two children, a son and a daughter, her daughter is autistic and has severe and enduring mental health problems. Her family experience drives her ambition to promote understanding of difference so young people, like her daughter, can live life to the full without stigma, prejudice and barriers and families get the support they need to raise their children in a positive environment.

Claire Flynn is a Coventry based artist who specializes in drawing and portraiture. Currently, her artistic practice comprises of portrait commissions, religious statue restoration and teaching in schools. In addition to private commissions, some of Claire's recent clients include churches within the Catholic Archdiocese of Birmingham, schools in Coventry, and the University of Warwick.

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