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Thinking about how people with learning disabilities can lead good lives

Plain English Summary



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Background

People with learning disabilities often lead poorer lives than people who are not disabled.

Support staff may not treat people with learning disabilities well and may stop them doing things other people do.

In this research we focused on the opportunities people with learning disabilities have to do things they love doing.

This is called a 'Capability Approach'.

'Capability' is a complicated word, so we call it the Freedom Approach.

The Freedom Approach

Someone called Amartya Sen came up with the Freedom Approach.

Key to this approach is everyone should be treated with respect.

Sen says there is a difference between what we do and what we would love to do.

He says having opportunities to do what we love to do is key to a good life.

It is important that we know what people love to do.

The Freedom Approach has not been used much in social care research.

One study found people with learning disabilities did not have a choice about what to do in their spare time and were lonely, bored and anxious.

Another study about people who lived in a care home found staff support and pocket money were key aspects for people to do things they loved.

Sen said disabled people may sometimes not expect to do things they love doing.

This makes it even more important to ask them and find out what those things are.

What did we do?

In this summary we focus on part one of the Flourishing Lives project.

The research team included people with learning disabilities and family carers.

50 people with learning disabilities and 28 family carers took part in 20 interviews and 13 focus groups.

These were held online because of the pandemic.

We asked people what made them happy and what helped them do things they love doing.

We made a list of things we found from other research to help people think about our questions.

This list was about good care and included relationships, money and leisure activities.

Everything people told us was recorded and typed into word documents.

We read it all and divided it up into sections relevant to the Freedom Approach.

The sections included headings like 'resources' which is things like money, and 'empowerment' which is feeling confident to do things.

We then looked at what was in the sections and thought hard about what they included.

What did we find out?

We found one main area we called 'Doing what you love and growing'.

We found three small areas we called 'Choice, opportunity and empowerment', 'Being out in the World' and 'Lowered expectations and stuck lives'.

We talk about these themes in order.

Doing what you love and growing

People told us they love being outside, gaming, spending time with family, friends and pets, helping others, working or volunteering and looking at family photos.

Some family members were able to arrange activities to help their relative 'grow'.

These families had a lot of resources to do this.

Joan's son loves music and has a packed week of activities.

It was not clear if these were activities Joan's son loves doing.

Joan said her son gets anxious if he does not have things to do.

We think this may be partly to do with uncertainty about the future.

People with learning disabilities told us they like to keep busy.

Matt told us:

You need a reason every day to keep going. If I'm not kept busy, that's when I start to panic because I have no idea what I'm going to do.

Families with a lot of resources could arrange direct payments to employ staff and had money to add to support their relatives.

Sian told us there can be extra costs like paying for the support staff to have a meal if her son goes out to eat.

Parents told us they were growing older and would not always be able to help.

Mary was thinking about what might happen if she was not around to look after her son. She has been organising things, so her husband and son know how to look after her son in the future.

Some people with learning disabilities did not like the support they were offered and looked after themselves.

These people did not have the resources some families had.

Some parents without a lot of money struggled and seemed to be more accepting of the services offered.

They said they had little freedom to plan activities their relatives would enjoy.

Choice, confidence and employment

In social care, there is a lot of talk about choice.

Some parents talked about trying to make sure their daughter or son could make choices.

Some parents said it was important the person did certain things, like sport.

We wonder who these things are important to.

Self-confidence was very important to people with learning disabilities.

Some people told us they loved the opportunity to do new things like travelling alone on public transport.

Doing something new helped people grow more confident.

Joe's sister, Maria, told us:

I thought, 'This is him blossoming'. He had a part-time job where he was delivering leaflets, with support... to give him that kind of confidence of "I can do this." And he was going door-to-door, getting out in the community, being confident in where he is going.



Addy told us:

Since leaving home, I've done so much. I've managed through joining the chorus, through competitions they've had, I've travelled to [city in the US], against my mother's wishes. I've grown in confidence. Confidence, I think, means a great deal. Growing in confidence, growing from one person into another person, is extremely important.

Relationships with staff are important for building confidence.

People with learning disabilities were empowered by staff to do things they loved.

Staff helped people take the steps necessary to do things or achieve things.

Some people with learning disabilities said their families were too protective so they were not able to develop confidence.

They had no opportunities to learn to cook, clean or look after their own money.

Confidence could also be lost through bullying, missing out on education opportunities and when activities stopped during the pandemic.

Some parents talked about 'guiding' choice and encouraging the person to do something that is good for their health.

Ralph told us his son:

often needs encouraging to do something that he enjoys doing...If you say to him 'Would you like to go for a walk?'. "No!". Well, if they call that the freedom of choice and take that first answer as 'no', you know, it's not good for him and he does enjoy going for a walk. So, I think that there has to be a certain sort of guided choices really.

Guiding choices included encouraging people to think about the future.

Some people with learning disabilities did not want to think about the future.

Some people found it too worrying to think ahead and younger people said they would wait until they were older, perhaps in their thirties.

Kane said:

I need to find out with my parents...or my brother, to think about how to be safe outside and to look forward (and) work with me by supporting me with my own house...They can help me by supporting that.

Some family members told us they were frustrated and did not know what options there would be in the future.

Relationships, being out in the world and belonging

People with learning disabilities told us how they gave back to others by being loving, offering kindness, help and support.

Jen said:

I just love being there for people. The amount of people I've cheered up on Zoom, haven't I Rob? I've cheered people up when they've been down, and they've picked me up when I've been down. We've all been there for each other.

This giving helped people feel they belonged.

Some people also did housework, some worked, Jim was involved in charity fundraising and some people were involved in sports coaching.

Day centres, charities and other organisations had an important role in supporting people to develop relationships.

People with learning disabilities said the friends they made through these activities offered them support and opportunities to be themselves.

Some parents did not think these friendships were important.

Some people with learning disabilities wanted a partner and to have sex.

Some parents told us they wanted the person to have someone to cuddle.

Other parents said they worried about relationships.

Some people with learning disabilities who lived at home said they did not have the opportunities to meet people their own age.

Mary said her son's carers are brilliant though they are in their late 60s and 70s.

Some parents said the person did not have relationships because they did not understand social rules or have social skills.

Some people with learning disabilities loved being out in the world.

Cath said this about her son:

He just likes being with people and he does like being out...He's got his freedom pass and he'll just go all the way to the other side of London on the bus. He just likes being out and about and travelling around and talking to people. He will talk to anybody.



We found some sadness in what people told us.

People with learning disabilities said they did not feel they fitted in.

Colin told us:

I pretty much keep myself to myself. I've extremely very few friends. I'm not even sure I could do a handful in digits, you know...It's just that's the way I am... A normal day to me is the solitude. I feel like I'm an oddball and I've got not much chance of having any sort of relationship. So, if that means help with how to be in a relationship, be it a friend or a lover, whatever. Then, that probably would be handy for me because I'm bloody clueless.

People with learning disabilities told us about things that they felt were off limits to them, like getting married or having children.

Stella told us it was hard when her son asked her if he would be able to drive a car or ride a motorbike.

We think from what people told us they felt shut away from the world.

Parents of people with profound learning disabilities said they wanted the person to be happy and connected to the world.

Lowered expectations and stuck lives

We found staff could be reluctant to find out what was important to people they support.

What people wanted to do, or family suggestions about what they liked, could be overridden by rules, a lack of staff or resources.

Georgie's mum said:

She doesn't have a choice, she can't do things what she wants when she wants, so she has to do (activities she enjoys) according to the staff, when they're available.

We found an acceptance of supporting people to do the minimum.

People's routines were based on food, shelter and safety with little curiosity about supporting people to have a good life.

Maria said:

He's got a lot to give, and he wasn't really being thought about. It was more, "How can we get through shifts? What can we do to sort of fill the time up until it's time for him to go to bed and have his bath and clean him?" That's not good enough for my brother.

Filling up time is the opposite to leading a good life.

Some people with learning disabilities have time filled for them for weeks, months or years.

What does this mean?

We wanted to see if a Freedom Approach would help us learn new things about the lives of people with learning disabilities.

We found a mix of things including relationships between people, family and support staff, resources and social care rules influence the opportunities people with learning disabilities have to do things they love.

It is vital that staff and family members understand what these things are to ensure people have opportunities to do them.

The effects of cuts to social care services can be worsened by lowered expectations of what is acceptable.

We found people were living life without access to opportunities to do things important to them.

We found some people were lonely or sad and wanted relationships or work.

Some families had resources to provide the person with a full life of activities.

This involved a lot of work which was often done by mothers.

People with less money tried to balance their own needs with those of their family members.

We could not decide if the activity rich lives were full of things the person loved doing.

It was not clear how much influence they had in designing their lives.

It was not clear if they were attempts by families to provide opportunities to do things they love or to stop feelings of anxiety or uncertainty.

People may not be allowed to take risks necessary for leading a good life.

The work undertaken by family members can be critical, particularly because of social care cuts.

Family carers will grow too old to provide this work.

We found parents did not always value the person's friendships or activities.

We wonder if family members are reluctant or unable to fully explore what the person wants to do.

Families may override the person's wishes to encourage them to do things they feel are important or good for the person.

It is difficult to know whether 'guiding choices' is a good thing.

Support staff play a key role in helping people learn new skills and develop confidence.

We need to find better ways of finding out what is important to people that move beyond thinking about choice.

It is hard for people to think about what it is they value if they have not had the opportunity to do this and be able to talk about or communicate it.

Supporting people to communicate this in research is also important.

It is hard to think about and talk about opportunities.

It is much easier to talk about what it is people do.

Final thoughts

The lives of people with learning disabilities are often presented through other people rather than an understanding of what is important to them.

We could see how families with resources can create full lives for family members.

We did not know if these lives involved opportunities for the person to do things they love doing.

People with learning disabilities may be asked what is important to them but are not always supported to explore what it is they love doing.

The focus on what people do rather than what they would love to do means people can lead poor lives.

We argue social care support needs to change to include the development of opportunities for people to do activities they love and be fully out in the world.

Part of this change needs to involve new research methods to understand what people with learning disabilities love doing and what is needed to achieve this.



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