

# Parents with learning difficulties and their communities: A role for asset based support?



## Easy Read Research Report 2022



UNIVERSITY  
*of York*



FUNDED BY

**NIHR** | National Institute for  
Health and Care Research

This report describes research undertaken by the Parents and their Communities Team. They are:

*University of York*

Jenny Threlfall  
Hannah Jobling  
Katie Graham  
Sam Hinrichs  
Lyndsey Kramer

*York People First*

Becca Cooper  
Claire Dobson  
Andy Pollin  
Eileen Stroughair  
Michael Scott

*Independent Researcher*

Stephen Lee Hodgkins

With special thanks to everyone at the Elfrida Society Parents' Project.

If you have any questions about this project please email York People First: [speakingup@yorkpeoplefirst.co.uk](mailto:speakingup@yorkpeoplefirst.co.uk) or Katie Graham: [katie.graham@york.ac.uk](mailto:katie.graham@york.ac.uk).

This project is funded by the NIHR Research for Patient Benefit Programme (project reference NIHR200075).

The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

# Parents with Learning Difficulties and their Communities

What is their experience?



What is community life like for them?

Do 'asset based approaches' help?



## How we did the Research.

It was a collaboration between the University of York and York People First, who first came up with the idea.



We did interviews and focus groups, with 13 parents and 33 workers.



We then listened again to what people said and sorted this into themes.

## What is Community life like for Parents?

Parents told us about their experiences of ;

1. Relationships and Networks - Friends, family and formal support.



2. Places - Neighbours, local groups and things nearby.



3. Communities of Interest - Activities, parenting and faith groups, schools and peer support.

## How is it Difficult?

Parents said they face barriers to;

1. Accessing community places, both physically and because of fears.



2. Forming social relationships, because of stigma, trauma and isolation.



3. Connecting with communities of interest, because needs can't be met, and being frightened of services.



## Can Asset Based Approaches help?

We found Asset Based Approaches could help parents to;



Form strong community relationships.



Help communities be better at welcoming parents.



But we think Asset Based Approaches need also to integrate trauma focused practise and create more equitable resources.

## What we think will help Parents!

- ★ Help Parents find out about what's available and support them to join in.



- ★ Making sure information is in EASY READ formats.

- ★ Communicating clearly in conversations.



- ★ Support Self Advocacy Groups.



November 2022

# Introducing the project

Everybody needs support to be a parent



Often people with learning difficulties need some extra support to be parents.



Communities are important for support. But finding the support we need in the community can be difficult.



This project was created by York People First and the University of York to find out what parents think about their communities and the kinds of support they want.



# How can our communities be more welcoming for parents?

This project is about how our local communities can support parents.

Local councils are using 'asset-based approaches' as a way of developing more supportive communities.



We think asset based approaches are about:

Relationships with our friends and family.



Places we go like parks, libraries, cafes, cinemas, pubs, community centres, friends' houses.



Valuing what we can do instead of what we can't do and about being treated equally and with respect.



Opportunities to do what we want to do at our own speed and in our own way.



# What we did during the project

We interviewed 13 parents with learning difficulties.



We also interviewed 33 people who support parents in their communities.

We listened to what people said and this report shows what we learned.



**Parents** with  
**Learning Difficulties**  
and their **Communities**

What is their experience?

What is community life like for them?

Do 'asset based approaches' help?



# Why we wanted to do this project

We have been thinking about how parents are supported for many years.



In 2018 we organised a conference and invited people from the NHS, Mind the Gap, Social Workers and anyone who was interested in getting involved. At the conference we performed Claire's Story about being a parent.



This project came from what we learned at the Conference.



We want to make a difference.

We have really enjoyed working with The Elfrida Society in London. Together we have been making films which we hope will be helpful for parents.



The next pages share what we have learned from doing this project.

# What does community mean to parents?

Community means different things to different people.



The people involved in this project talked about the relationships that are important to them and the places they visit.



## Family and Friends

The relationships that were important to parents were family and friends.



Parents talked about the importance of having good relationships with their family and friends.



Family and friends offered practical and emotional support.





## Local Places

Parents talked about going to a range of places with and without their children.



People talked about going to the local park, local cafes, shopping centres, libraries and the beach.



Although many had local places they liked to go to, some felt that there were not enough options for them and their children.



Some parents worked or volunteered in their local area.



## Groups:

Parents talked about going to a range of groups regularly.

These included:

- Activity groups for example, sewing, art classes, knitting.
- Parenting groups including baby massage groups, walking groups and play groups.
- Peer support groups including men's groups, groups for women who have survived domestic abuse and self-advocacy groups for parents with learning difficulties.

They found going to groups enjoyable and for some people the groups have become an important part of their lives. Some groups were more welcoming than others.



Peer support groups were really important to many parents:

They said these groups are really important for these reasons:

**Making Friendships:** Parents talked about the important friendships they have made at peer support and self-advocacy groups.



**Helping each other:** In these groups parents were able to support each other. Parents share their experiences and talk about what is difficult and what is helpful for them as a parent.



**Parenting advice:** Parents in peer support groups got valuable parenting advice from the group.



**Learning skills and developing confidence:** Parents talked about learning new skills and gaining confidence in their parenting skills and in other aspects of their life.



# The challenges parents faced in their community

There were lots of things parents found helpful in their local communities.

However, life isn't always easy and some things were difficult.

## Family and Friends:

Although friends and family can offer important support, these relationships can also be difficult.

Some parents had experienced bullying at school and in adult life and some parents talked about making the 'wrong friends'.

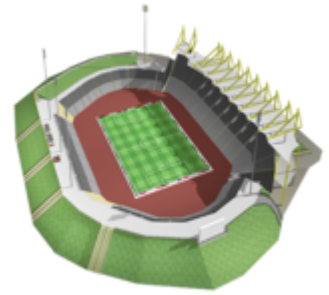
Parents needed to make sure they were safe in their neighbourhood and their friends were a positive influence on their family life.

This made some parents choose to 'keep themselves to themselves' to protect their children.



## Difficulties in the local area

**Getting around:** Some parents found getting to places Difficult.



One parent said:

*“So there’s a proper football team and he can’t go because we can’t get to the other places where they’re playing and nobody’s there to help.”*

**Unfriendly communities:** Some parents were discriminated against in the local area which made them anxious about leaving their homes.



**Professionals:** Some parents found professionals unhelpful. Some professionals struggled to communicate clearly.



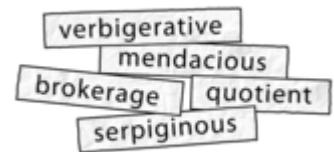
**Parent and child groups:** Parents felt that these groups were important for their children, however they were not always very welcoming and some parents were nervous about going to these groups. Some groups were not accessible to disabled children.



**It can be difficult to know what is available in the community:** It was not always easy for parents to know what was available in their local community to support them.



Information is not always accessible.



This might be because information is not presented in easy to understand language or because it is online.



Not all parents have access to the internet or mobile phones and computers.



One person who supports parents in their community said:

*“People just assume everybody’s got a phone with the internet, and not everybody does. So, some people don’t even have a camera phone. So there’s a big assumption that people have got these things but they haven’t at all; especially, if people are struggling to look after their kids, they’re not gonna have a laptop, they’re not gonna have the money to buy things like that either. “*



## What helps parents be involved in community groups?

1. Involving parents in the development of new groups. This is often called co-production.



2. Making sure the group is relevant and helpful to parents.



3. Sometimes an activity (for example knitting/games) can help parents to build relationships.



4. Groups need to be accessible. There are lots of ways to do this including:

- Accessible, easy read, information shared in different ways - not just online.



- The timing of activities - making sure parents can come using public transport.



- Parents seemed to like small groups.



- Parents and practitioners talked about how helpful it is to go to a group with a supporter for the first time to settle into a new group and develop relationships.



# How can asset based approaches help support parents in their communities?



Different areas of England and Scotland have different support in the community. We found three types of support developed to support parents with learning difficulties. These are:



- Local Area Coordination / Social Prescribing
- Shared Lives
- Peer Support Groups



These different types of support focused on:

1. Supporting parents to develop social networks.



2. What people could do, not what they cannot do. Many practitioners call this a strength-based Approach.

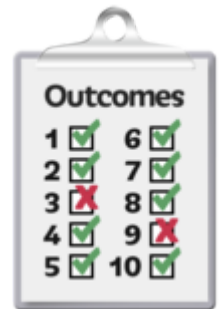


3. Involve parents in the development of resources.



## People talked about Asset Based Approaches being helpful in these ways:

They focus on what people can do and this helps people to live the life they want to live.



They are not too expensive and can help Local Authorities to save money.



But it is not all easy and people involved identified some difficulties.

It is difficult to know exactly what difference Asset Based Approaches make.



Funding cuts have had a big impact on community-based resources like community centres and support services



# Our ideas: Making the most of our communities

Here are some things that we think will make things better for parents with learning difficulties in their communities.



- 1. Accessibility:** Groups need to be welcoming and friendly.

Buildings need to be accessible to all including ramps and lifts in buildings.



- 2. Easy read information:** All information needs to be in easy read formats. Here are our tips for easy read documents:

- Pictures - we use photo symbols
- Big print - font size 14-16
- No jargon
- No fancy fonts
- It's about the person and their preference - audio / video versions would be helpful for some

- 3. Communicating clearly**

- Take it in turns to speak
- Respect what people say
- Give people time to answer
- Be open and honest
- Try not to be patronising
- Talk to me and not my support worker



## 4. Supporting self-advocacy groups

Self-advocacy groups were very important to many of the parents involved in the project.

We think that self-advocacy groups are a vital part of our communities

We think self-advocacy groups can be supported in these ways by:

- Recognising peer advocacy groups and their lived experience.
- Involving self-advocates in decisions that affect their lives.
- Promoting self-advocacy groups to people who might be interested in being involved.
- Local council's paying attention to the experiences of self-advocates in their communities.



**Involve**



# Parents with Learning Difficulties and their Communities

What is their experience?



What is community life like for them?

Do 'asset based approaches' help?



## How we did the Research.

It was a collaboration between the University of York and York People First, who first came up with the idea.



We did interviews and focus groups, with 13 parents and 33 workers.



We then listened again to what people said and sorted this into themes.

## What is Community life like for Parents?

Parents told us about their experiences of;

1. Relationships and Networks  
- Friends, family and formal support.



2. Places  
- Neighbours, local groups and things nearby.



3. Communities of Interest  
- Activities, parenting and faith groups, schools and peer support.

## How is it Difficult?

Parents said they face barriers to;

1. Accessing community places, both physically and because of fears.



2. Forming social relationships, because of stigma, trauma and isolation.



3. Connecting with communities of interest, because needs can't be met, and being frightened of services.



## Can Asset Based Approaches help?

We found Asset Based Approaches could help parents to;



Form strong community relationships.



Help communities be better at welcoming parents.



But we think Asset Based Approaches need also to integrate trauma focused practise and create more equitable resources.

## What we think will help Parents!

★ Help Parents find out about what's available and support them to join in.



★ Making sure information is in EASY READ formats.

★ Communicating clearly in conversations.



★ Support Self Advocacy Groups.



November 2022