



UNIVERSITY
of York

Parents with Learning Disabilities and their Communities

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What our research is about

Having good relationships in our communities is important for everyone, including parents with learning disabilities

We know from other research that parents with learning disabilities tend to find it more difficult to build social networks than other parents

We wanted to find out if *asset based approaches* can help parents with learning disabilities to form good relationships in their communities that can support their parenting

Asset based approaches

Asset based approaches are community led and strengths focused means of promoting health and well-being

Asset based approaches:

- Focus on social networks
- Are strengths based
- Are co-produced

The questions we asked

How do parents with learning disabilities experience their communities?

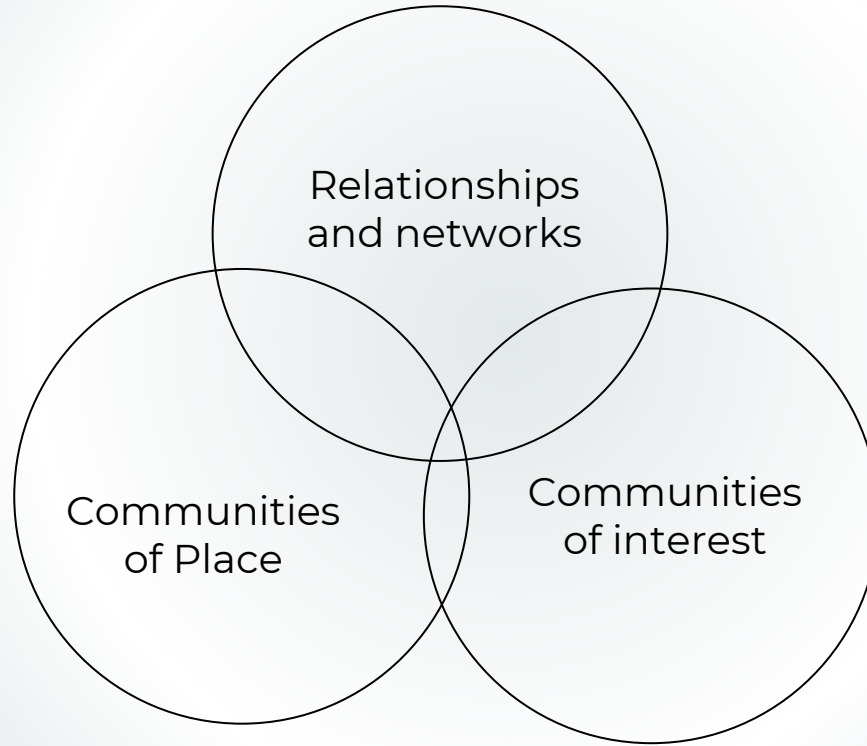
What might make it more difficult for parents with learning disabilities to be involved in their communities?

What is the potential for asset based approaches to support parents with learning disabilities to participate in their communities and to successfully parent their children?

How we did our research

- We used qualitative research methods and interviewed people from all over the UK
- We interviewed 33 professionals who know about asset based approaches or about parents with learning disabilities
- We interviewed 13 parents with learning disabilities (twice each)
- We held four focus groups with professionals

What is 'community' for parents?



Relationships and networks



"we're always there for each other, it's not like it ever goes away like if we; like my friend, he went through a bad period for a bit there so I, I helped him with stuff, so yeah. ...[...]. And then one of my other friends, her mum and dad wasn't well, so I was there for her as well."

- Parent 13

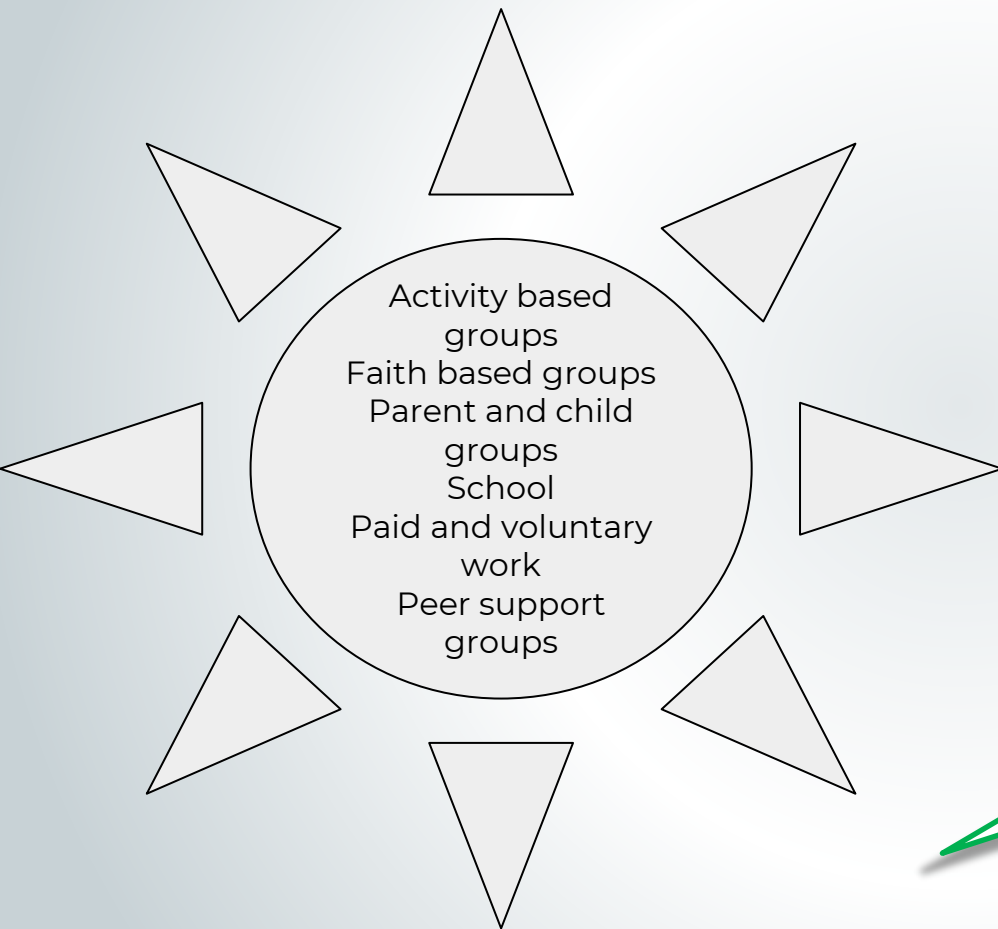
Communities of Place

"I couldn't have moved to [a] better place because the neighbours I've got now, they're just brilliant; they, they know about me mental health, they know we've got learning difficulties, the three of us, they help us massively, like they're the best, like I'm closer to them than I am to any of me friends that I grew up with and stuff, they're there for us more than them..."

- Parent 4



Communities of interest



"Yeah, just having similar issues or exactly the same and just being able to like load off and listen to their problems and try and help them and support them; we just support each other, we just try and support each other the best way what we can and we help each other with that as well. So we're all like really supportive of each other, we're just like a, yeah, like a happy family, one big happy family (...)."

- Parent 3

Why might community be difficult?

Barriers to communities of place

Transportation
Accessibility
Traumatic experiences
Perceptions of danger

Barriers to social relationships

Previous trauma
Stigma and exclusion
Long term social isolation

Barriers to communities of interest

Resources not available
Resources not accessible
Children's needs not catered for
Fear of services
Groups don't fit

Barrier: Stigma and exclusion

Stigma due to learning disability

[I tried] to be friends with people from other [places] but I guess when you tell them about you having this learning difficulty then they said, they are sorry, we don't want to be friends with people like you; and for me it's quite heartbreaking, heartbreaking. It's, kind of they just push you away, they don't want to get to know you.

- Parent 6

Stigma because of child protection involvement

It's that lacking the opportunity to make connections and get to know people, because you're carrying the stigma. It's a taboo thing to have, you know, your children at risk from you and to be on a child protection plan, or to have them removed, it's huge, you cannot imagine what that's like.

- Professional 5

Barrier: Previous trauma

Effect of trauma on mental health

I'm always like looking round just in case; like if there's a male like say walking behind me I tend to cross the road or I tend to just stop and just like face like the roads until the male gets by, then I'll just stand against the fence until he gets by, cos I don't want any males walking behind me cos it just, it, it just frightens me. I don't want to be feeling like all tight inside and anxious. But it's just, I think the reason is because of the experience I had and I've just never got over it.

- Parent 3

Effect of trauma on relationships

I got abused pretty bad, hit every day. I never got the experience to have a childhood myself ... I just, like, keep myself to myself, like not getting involved with people. I'm a very lonely person. I suppose I've got some trust issues with like, maybe male and some female, because, like, growing up I've always been bullied by other women, and children as well.

- Parent 3

Barrier: Long term social isolation

Current social isolation

I think I've a bit of a, I'm just gonna say it, a boring life, I really do, cos unless, if say, if me mam and me sisters didn't live local and they're quite far away I'd be in the house twenty-four/seven most likely, unless I was going to the shops, going to the doctors, things like that.

- Parent 4

Past isolation makes it difficult to fit in now

I don't think they can really identify in that community sense. So even if, you know, from their childhood they've lived in the same area and obviously their parents are there, it's that fitting in, isn't it, you know, they don't have a sense of belonging with their group.

- Professional 21

The promise of asset based approaches

Types of ABA working with parents with learning disabilities

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

How are ABA supporting parents with learning disabilities with the following?

- Building social networks
- Having confidence in their own strengths
- Working together to create better communities

ABA and building social networks

Connecting parents with shared experiences

He went and supported another dad and he saw the impact of that straightaway; just that whole wellbeing, you know, the whole self of that dad changed and felt more positive, because he'd identified with somebody else who was like him and he thought he was alone, he was the only dad who had become known to child protection and he was the only single dad that had happened to, but actually he wasn't. And very quickly, within his own physical community, we'd connected him to a dad.

- Professional 19

Building long lasting relationships

I mean I could delete their numbers and never speak to them again when they leave, but, you know, if you feel empathy for people, and you've built those sort of friendships and bonds while they've been here, and bonds with their children, certainly for me I couldn't just write them off. If you made those sorts of bonds and friendships with people and then dropped them afterwards I think that would just, you know, wouldn't be good for the person.

- Professional 18

Making communities more welcoming

The other side is to develop, increase the capacity of communities to be welcoming, inclusive places. As communities become more welcoming, inclusive places so there are more opportunities for people with learning disabilities to develop to find their place, to belong, to contribute in mainstream places, mainstream community life.

- Professional 3

The benefits of ABA and social networks

Advice and support from social networks

I think those informal supports where other mums, and other dads, who can pass on their collective wisdom about, you know, what you do when your baby won't sleep or when, they won't feed or when they start to press the boundaries; all those things. There's all the other stuff as well, there's the practical support that people need, the practical advice, navigating systems. So having a network of people you can go to, I think that's really important.

- Professional 19

Mutually beneficial relationships

People with rights in a real sense also have responsibilities, and they have rights to relationships and then the responsibilities that go with those relationships, which then suggest some more kind of whole household, whole community approach to thinking about working with people with learning disabilities ... It's about seeing the whole person, it's about recognising the value of relationships and seeing people as having something to contribute to relationships, to be a full part of households and communities and wanting to live socially, not just wanting to be supported.

- Professional 1

Challenges to asset based approaches

Challenges to community life

Barriers to communities of place

- Transportation
- Accessibility
- Traumatic experiences
- Perceptions of danger

Barriers to social relationships

- Previous trauma
- Stigma and exclusion
- Long term social isolation

Barriers to communities of interest

- Resources not available
- Resources not accessible
- Children's needs not catered for
- Fear of services
- Groups don't fit

More challenges to ABA

- Focus on risk in statutory services
- Difficulty of co-production
- Parents' distrust
- Lack of real power sharing

What do our findings mean in practice?

Using asset based approaches with parents with learning disabilities

Supporting parents to form stronger relationships in their communities

Supporting communities to become more welcoming of parents with learning disabilities

What else might be needed alongside asset based approaches?

In order to overcome barriers to community, asset based approaches may need to be adapted or added to:

- Integration of trauma focused practice
- Advocacy services provided alongside asset based approaches
- Focus on creating more equitable communities and services for parents - systemic approach