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

Research Report 2022

UNIVERSITY of York

YORK PEOPLE FIRST 2000
PEOPLE SPEAKING UP FOR THEMSELVES

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An easy read version of this report is available.

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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 cant 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

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Chapter One
Introducing the Parents and their Communities project

Every parent needs support, whether from family, friends, neighbours, or elsewhere. Being part of a reliable and interconnected community can be invaluable in ensuring that children are able to thrive in a safe and nurturing environment. For parents with learning difficulties, supportive social networks can make the difference in enabling them to care for their children in their own homes[1]. They are sources of emotional support, of parenting advice, and of material support[2,3]. However, many parents with learning difficulties have few social connections; they experience stigmatisation and exclusion in their communities[4]. They do not have access to the extensive benefits that come with being integrated into a community.

Asset based approaches are a family of methods of fostering community inclusion that focus on individual and community strengths[5]. They have become an increasingly popular form of service provision in the UK over recent years and people with learning difficulties have been thought to benefit particularly from the introduction of asset based approaches[6]. This report describes research undertaken to understand the fit of asset based approaches for supporting parents with learning difficulties. We report on a series of interviews that we conducted with professionals and with parents from across the UK in which we explored ideas about community for parents with learning difficulties, what might make it difficult (or less difficult) to become part of a community, and the potential of asset based approaches to support parents with learning difficulties to participate in their communities.

This project was developed by York People First - a self-advocacy group in York - in collaboration with researchers at the University of York. The idea for the project emerged following many years of discussion and concern about how parents with learning difficulties are supported in their parenting. Language and terminology are often the site of contest and challenge and this is very much the case for people with

learning difficulties. This project uses the term 'parents with learning difficulties' to reflect York People First's analysis that the social model has historically failed to reflect the life experiences of people with learning difficulties and to emphasise the capacity for people with learning difficulties to learn and develop like people without the label of learning difficulties. Research, policy and practice tend towards the use of a range of language including learning disabled and intellectual disabilities amongst others. This project uses the term people/parents with learning difficulties, reflecting the views of York People First.

Who are parents with learning difficulties?

There are as yet no definitive figures of the number of parents who have a learning difficulty. Estimates suggest that around 1-2% of births in England are to parents with a learning difficulty[7]. This may equate to around 53,000 individuals currently parenting with a learning difficulty[8]. One of the reasons why determining the overall population of parents with learning difficulties may be problematic is that many - if not most - of the parents are likely to have mild disabilities and therefore not meet the eligibility criteria for formal intervention. They may not be counted because they are unknown to either childrens or adults services[9]. There also remains considerable uncertainty about the well-being of parents with learning difficulties when compared to that of parents in the general population. While the general physical and mental health of parents with learning difficulties is poorer than that of other parents[9], there is less clarity about outcomes for their children. Although some studies have indicated that having a parent with a learning difficulty places children at higher risk behaviourally and developmentally, another body of research suggests that their outcomes are similar to population norms[10]. There is additional ambiguity about whether children of parents with learning difficulties are more likely to experience maltreatment than other children. Research from the US found that children of parents with learning difficulties who are involved in the child protection system are at higher risk for emotional or psychological abuse, but are less likely to have experienced physical or sexual abuse, or neglect[11].

In order to understand the possible comparatively negative outcomes for parents with learning difficulties and their children, it is important to consider the broader context in which parenting takes place. Parents with learning difficulties tend to experience multiple disadvantages. For example, they are more likely to experience poverty and environmental adversity than other families[9]. Parents with learning difficulties also tend to have access to fewer social resources and they may also experience stigma and discrimination related to their disability[9,11,12]. These contextual factors inevitably make parenting a more difficult task and may provide a

partial if not primary explanation for the disparities described above. We cannot support parents with learning difficulties to care for their children without understanding the contexts in which they live.

Community life for parents with learning difficulties

The communities in which parents with learning difficulties interact are diverse. They are composed of family and friends, of neighbours and casual acquaintances, of other parents with learning difficulties or parents with no evident disabilities at all. Many of their interactions are likely to be with professionals. In order to understand how parents with learning difficulties experience community, it is important to first think about what we mean by the term.

Community is a complicated concept that most of us have an instinctive understanding of, but probably find difficult to define. One way of understanding it is to think about the different types of community that we might belong to. A community might, for example, be defined around a geographical boundary such as a city or a neighbourhood (a community of place); a group of people who share a common identity because they live in the same place. Alternatively, a community could be united around a common set of values, heritage, or sense of belonging such as religious groups, or sports clubs (a community of interest). Others have pointed towards communities that are based on social networks or relationships such as families or close friends.

Table 1.1: Types of communities

Social and family networks
This describes the social and family networks we are connected with.
Communities of Place
Communities of place describes geographically based communities. These might be via local spaces like parks, cafes, community centres and libraries. Communities of place may also include the people we know through happenstance - the people and places we encounter regularly in our communities.
Communities of Interest
Communities of interest describes the communities that are formed through a shared interest. In this project important communities of interest include parenting groups and self-advocacy groups.

No matter the type of community that a parent with learning difficulties belongs to, any positive impact that it might have will depend on the nature of the parent's interaction within it. Here it is useful to think about two ways in which parents interact with their communities. First, parents interact as part of their individual social networks. We have used ideas about social capital to help us to understand these relationships. Second, parents participate in their communities as citizens.

Social networks and social capital

At its most basic, social capital can be thought of as the ability of a person "to secure benefits through memberships in networks and other social structures"[13]. In other words, social capital consists of the social networks that parents are part of as well as that which they gain through those relationships. Parents who have plentiful social capital can secure for their children benefits such as material goods, and access to social and educational opportunities.

This doesn't mean that parents who have more social connections always do better or that their children always experience better outcomes. The social capital framework also leads us to consider the types of relationships that parents have. Not all relationships are beneficial. In order for social capital to be built within a relationship, both trust and reciprocity should be present[14]. In a relationship defined by trust, each person can rely on the other; they are predictable and follow certain social rules that are understood by all involved. In order for relationships to be reciprocal they must have a two-way element; there is a sense of obligation between the individuals involved. Parents who build and maintain these types of relationships with others in their community have access to resources such as advice, information, and other social supports that can enhance their parenting and bolster their children's well-being.

Within a parent's social network there will also inevitably be some relationships that are stronger than others. Close relationships between people who know each other well and share aspects of their lives with each other are referred to as 'strong ties.' When parents within a community are well connected with each other and share strong bonds, they are also likely to share beliefs and expectations about parenting and have a strong sense of obligation to each other. They behave in a way that reinforces each others' parenting and supports the development of all their children[15].

This is not to say that less close relationships, or those with 'weak ties' are unimportant for parents and their children[16]. Parents may gain access to additional support, information, and advice when they get to know people who are outside of their immediate circles. In particular, relationships that are formed with people across social divides such as class or disability status are likely to bring in benefits that are not possible through connections with people who are exactly the same.

Communities, Participation, and Citizenship

Policy across the United Kingdom makes it clear that people with learning difficulties should live and be involved in their communities. For example, the guidance from NHS England *Building the Right Support,* states, "We need to see people with a learning disability and/or autism as

citizens with rights, who should expect to lead active lives in the community and live in their own homes just as other citizens expect to"[17]. As this, and other similar documents imply, people with learning difficulties should not be limited to passive or tokenistic involvement in their communities; instead the conditions should be created where active and substantive participation is possible. More specifically, people should be able to receive information about decisions that affect their lives in a format that they can understand, and they should be able to participate in those decisions. Being a citizen is not just about having rights; it is about being able to join in the process that brings those rights into being.

Benefits of community for parents with learning difficulties

There is a growing body of research evidence that highlights the importance of community involvement in the lives of parents with learning difficulties[18]. Studies have demonstrated that informal social networks can provide practical and emotional support for parents with learning difficulties[2,3]. They may also learn important skills to assist them in their parenting and other aspects of life from their social connections[19]. Parents with learning difficulties who have greater levels of social support are also more likely to have better mental health, to experience less stress associated with their parenting, and to engage in more positive parenting practices. These benefits are in turn associated with greater child well-being[20].

Fewer studies have investigated the benefits of community participation in the sense of citizenship for parents with learning difficulties, though the emerging evidence is positive. A small study of five Australian parents sought to explore how they experienced and participated in community life[21]. The authors found that the parents they interviewed, like most non-disabled parents, demonstrated "instances of inclusion in everyday community life." An important conclusion from the study was that the parents were active agents in their own lives, taking the initiative to create their own social belonging by being out and about in their neighbourhoods. They held valued social roles, the most important of which was 'parent'. A second qualitative study of twenty-one parents with 'intellectual disabilities' in New Zealand concluded that community participation and citizenship were important factors in promoting "good enough" parenting[22].

In view of these benefits derived from social support, it is concerning that parents with learning difficulties tend to be socially isolated when compared to other parents[23]. Parents with learning difficulties tend to have fewer supports than other parents, to be less likely to have relationships with other parents that they could talk to about their experiences or to have someone to share their feelings with[24]. Further research has indicated that in comparison to other parents,

parents with learning difficulties receive less support from their families and have lower levels of social capital derived from relationships with others in their neighbourhoods[9].

Supporting parents with learning difficulties

Parents with learning difficulties often rely on professional support, such as that from a social worker, a nurse, or a project worker, to help them with their parenting. However, getting access to support and getting the right sort of support can be challenging. Parents with learning difficulties may experience professional intervention as unnecessarily intrusive and punitive[25], and face presumptions of incompetence from professionals about their ability to effectively care for their children[12,26]. A recent systematic review of the literature about parental support found evidence for a mismatch between the support needs that parents expressed and that which was offered through the services available to them. Whereas parents focused on their need to be accepted as 'full' parents and offered support with a broad range of activities, professionals centred their assessment and intervention around the perceived limitations associated with the parents' disability[27].

The Working Together with Parents Network has produced good practice guidance for professionals working with parents with learning difficulties[28]. The document covers the range of professional support that parents should be able to expect from local authorities. Importantly, the guidance indicates that parents should be supported to be fully included in their communities.

Exploring how parents interact with their communities and approaches to developing more inclusive and welcoming communities for parents with learning difficulties is an important area for research and practice. The need for active and well resourced communities has been recognised and different approaches to community development have been adopted locally throughout the UK. In particular asset based approaches have become increasingly common. However we do not have a clear idea about how these approaches can support parents with learning difficulties.

Asset based approaches

Asset based approaches are community led and strengths focused means of promoting health and well-being[5]. Whereas deficit approaches foreground what is not working, asset based approaches seek out and put to use the resources - or assets - already present in a community. Included among potential assets might be individual interests, skills or knowledge; relational assets such as friendships and social networks; community organisations such as business or voluntary agencies; and physical resources such as buildings and

other places people can meet. It is by drawing on these disparate resources that asset based approaches seek to promote healthier and stronger communities.

The concept of social capital is an important underlying feature of asset based approaches. By building relationships between people and groups, services working from an asset based perspective also seek to build social capital within a community. We can expect that when social capital increases, it will be followed by increases in other desirable outcomes such as health, well-being, and resilience[5].

For the purpose of this research, we have identified three core principles of asset based approaches:

- *Asset based approaches focus on social networks*. They encourage people to build mutually beneficial social relationships.
- *Asset based approaches are strengths based*. They help people to identify and build on the strengths and resources that already exist within themselves and their communities.
- *Asset based approaches are co-produced*. They work with people to co-design and co-deliver services and to create new resources within their communities.

It is important to note that while asset based approaches share these common principles, they are not a defined method. Services that claim the label 'asset based' do not follow a particular manual and may vary considerably in their focus and practice. Many examples of asset based approaches are centred on a neighbourhood or other place based community. Asset Based Community Development (ABCD)[29] provides a well known example of this geographically boundaried approach. Other asset based approaches focus on communities of interest, such as children and young people, people with mental health needs, and people with disabilities.

Fit of asset based approaches with policy for people with learning difficulties

An intention to build more inclusive communities has been on the policy agenda since the publication of Valuing People[30]. Valuing People sought to respond to the discrimination people with learning difficulties face. The core ideas throughout the Valuing People papers were independence, choice, rights and inclusion[30,31]. In combination these were put into practice via the personalisation agenda which advocated a citizenship and strength based approach. Strength based approaches have also been legislated in the form of the Care Act (2014) which also connects 'wellbeing' with outcomes in relation to different domains of life - most notably for parents with learning difficulties:

- Participation in work, education, training or recreation
- Domestic, family and personal
- The individual's contribution to society.

The Care Act (2014) places a responsibility upon local authorities to promote wellbeing including the support of family life. As such, local initiatives which seek to promote community development and inclusion via strength based outlook need to be open, accessible and responsive to the needs of people and parents with learning difficulties. Initiatives utilising asset based thinking have therefore been promoted by local authorities to help them to meet their responsibilities - beyond assessment, funding and service commissioning - to develop opportunities in our communities.

Fit of asset based approaches with models of support for people with learning difficulties

Given the aforementioned policy developments, it is perhaps unsurprising that asset based approaches also have a natural synergy with some of the key models of service that have been used by local authorities and other organisations to support people with learning difficulties. Although not all of the following models use the formal language of asset based approaches, they share its core principles.

Local Area Coordination: Local area coordinators use a strengths based approach to offer direct support to families and to connect them with other people and resources in their communities. The approach was originally developed in Australia to support people with learning difficulties and has been adopted by several local authorities throughout the UK[32,33].

Social Prescribing: Whereas local area coordinators work within a specific geographical area, social prescribers are typically located in health care settings. Their role is to offer a form of non-medical intervention in order to increase patients' health and wellbeing. They achieve this through offering a range of practical advice and information and through linking patients with opportunities for physical and social activity in their communities[34].

Shared Lives: Shared Lives matches people who require support to live independently with a carer in their community. Under the scheme, people live with or spend significant time with the Shared Lives carer, becoming part of their family and community life. The majority of Shared Lives participants are people with learning difficulties. Some placements may also be offered to parents with learning difficulties and their children. Shared Lives is most often offered through local authorities[35].

Peer support: While peer support groups are not necessarily run using an asset based approach, many take

a deliberately strengths-based perspective and offer participants opportunities to build their social networks through various social activities. Peer support groups may also be organised around a self-advocacy agenda. The self-advocacy movement is a well-established avenue through which people with learning difficulties have campaigned for their right to citizenship in their communities[36].

Research about asset based approaches and people with learning difficulties

Although asset based approaches are becoming increasingly influential in services that support people with learning difficulties, there is not as yet a wide literature that evaluates their effectiveness. The majority of the evidence that exists is anecdotal, but does suggest the potential for asset based approaches to have a positive impact for the population. A 2016 review of the literature pertaining to asset based approaches for people with learning difficulties uncovered no peer reviewed articles on the topic[37]. Research published in the 'grey' policy and practice literature indicated that asset based projects are valued by their participants and may serve to expand their social networks. Similarly, a more recent report suggests that the adoption of the ABCD model by Leeds City Council has had a positive impact on the well-being of people with learning difficulties. The report describes how the approach as a whole has "improved health and well-being outcomes, supported active lifestyles and reduced loneliness and social isolation", noting in particular the gains that have been experienced by people with learning disabilities[38].

Despite the widespread adoption of asset based approaches by local authorities and possible indicators of their usefulness in promoting social connectedness and well-being, it would be unwise to suggest that they offer a foolproof or unproblematic means of supporting people with learning difficulties. Two particular criticisms of asset based approaches have been offered in the literature that are relevant here[39].

First, there is an implicit assumption that communities are somewhat cohesive and that they share common values and goals. In reality, even within a community that is defined by interest rather than by place, its members will almost certainly differ in their other identities. Communities are made up of people who have different interests and priorities and who may often disagree with each other. Asset based approaches have little to say about conflict or about the challenges of forming relationships between people who may share very little in common. The reality is that while many people with learning difficulties have benefitted from supportive social networks, most have also learned to cope with the more difficult aspects of community. They face stigma, discrimination,

exclusion, and violence as a result of disablism in our society[4,40].

A further criticism of asset based approaches is that in their focus on what is good, they ignore issues of power, privilege, and the economic realities that shape people's lives. The disparities in psychosocial and health outcomes that people with learning difficulties experience are rooted in social inequities such as discrimination and poverty[41]. Interventions that harness individual or even communal strengths cannot overcome systemic injustice. Furthermore, people with learning difficulties may live in whole communities where resources are scarce. Asset based approaches may work better in communities that are already more adequately resourced.

Asset based approaches and parents with learning difficulties

With that in mind, the potential benefits of asset based approaches for parents with learning difficulties are clear. Many parents are isolated from their communities and do not have the opportunity to benefit from strong social networks. Support that they might receive from professionals is diminished due to an overwhelming focus on risk to their children. Accordingly, research that has sought to identify good practice in supporting parents with learning difficulties has pointed to the need for services that work in partnership with parents and are strengths based[42]. Asset based approaches, in their central focus on fostering social networks, building on individual and community strengths, and co-production of services, appear to provide a natural fit. Furthermore, they provide a means of preventative support that may allow for more parents with learning difficulties to care for their children in their own homes, thereby retaining their right to family life.

The lack of an established evidence base for the use of asset based approaches with people with learning difficulties is even more apparent when we turn to consider their appropriateness for parents with learning difficulties. In our preparation for this project, we were only able to find one report that described an intervention aligned with asset based approaches. In a cost-benefit analysis of preventative interventions with parents with learning disabilities, Bauer describes a case study of an asset based project in which parents with learning disabilities accessed services and support in their communities[43]. The author concludes that asset based approaches may offer a potentially valuable and cost effective way of working with parents with learning disabilities, and that this requires further investigation.

It is within this context that this project was developed. We designed the project in 2019 without any anticipation of the changes we were to experience during the global pandemic. Our original plans of using creative and place-based research methods with parents became impossible, however the focus of the

project remained the same. Table 1.2 details the research questions addressed in this report.

Table 1.2 Research Questions

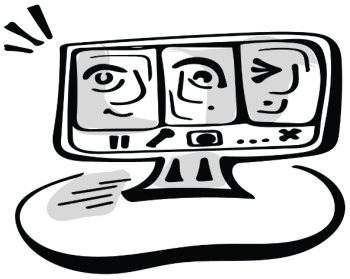
1. How do parents with learning difficulties experience their communities?

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

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

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.

Chapter Two
Research methods

Research design

In order to answer the research questions described at the end of the last chapter we needed to gain an in-depth perspective of how parents and professionals understood a range of issues relating to community in the lives of parents with learning difficulties. We therefore chose to use qualitative methods (long form interviews and focus groups) which would allow us to describe parents' lives in detail, to explore the meaning of 'community' for parents, and to interpret our findings with reference to asset based approaches.

Research partnership

Our research was conducted in collaboration with York People First (YPF). YPF is a self-advocacy group, run and controlled by people with learning difficulties. Members of YPF have been involved in all stages of the research. The idea for the project came from the group. We worked together to come up with our research questions, to design the research, to collect the data, and to think about our findings. The illustrations that you will see throughout the report were drawn by our colleague, Stephen Hodgkins, and represent the conversations of YPF about the findings of the project.

Context of the research

It is important to note that the methods used to conduct the research were shaped by the time at which the project took place. We started to interview participants in June 2020 near the beginning of the global pandemic. Lockdown and subsequent social distancing regulations meant that the substantial majority of our interviews were conducted via online video conferencing platforms such as Zoom. The advantage of this method was that we were able to interview participants all over the UK with relative ease. The adjustment to an online world was, however, difficult for everyone, and may have been especially so for people with learning difficulties. We worked carefully to ensure that the parents we interviewed using online methods had the equipment and technological support they needed to take part. Once restrictions were relaxed, we offered the option for face-to-face interviews and conducted a handful of sessions in this format.

Ethical approval

Before we began our research, our plans were reviewed and approved by the NHS Health Research Authority's Social Care Ethics Committee. All participants were given written information about the research and an easy read version was prepared for the parents who took part. Each person gave written or verbal consent to participate before their interview or focus group began.

Interviews with professionals

Recruitment

We recruited professionals to be involved in our research if they had expertise either in working with parents with learning difficulties or in asset based approaches with people with learning difficulties. Our sample was formed through contacts that we had encountered through our previous research, professional networks such as the Working Together with Parents Network, and recommendations from previous interviewees. We sought to interview people from a variety of statutory and voluntary sector settings, across health and social care, from different regions across the UK, and representing rural and urban areas.

Conducting the interviews

We created two different versions of our interview guide for professional participants. We used the first version of the guide with professionals who had expertise in working with parents with learning difficulties. These guides covered themes including challenges to parenting for people with learning difficulties, formal and informal support for parents, and parental community involvement. We used the second version of the interview guide in our interviews with professionals who were experts in asset based approaches. These guides contained questions about the nature of asset based approaches and their use locally to the interviewee and in the UK as a whole. The interviews also addressed the actual or potential use of asset based approaches with parents with learning difficulties.

We designed our interviews to be semi-structured, meaning that they provided a basic guide of principal questions and follow-up prompts, but interviewers did not necessarily maintain the same order of questioning or explore the same subjects in depth in each encounter. Interviews were conducted online and typically lasted for about an hour. They were recorded and subsequently transcribed.

Sample characteristics

The professionals were split evenly as to whether their primary expertise was in asset based approaches (17 of 33 participants) or parents with learning difficulties, although a minority of participants were experienced in using asset based approaches with parents with learning difficulties (see Chapter Five). Experts in asset based approaches worked in a number of different settings, including Local

Area Coordination, Social Prescribing, Shared Lives, and Peer Support. Experts in parents with learning difficulties included social workers, nurses, advocates, and support workers. The majority of professionals we interviewed were from the Yorkshire and Humber region (21 participants), reflecting the location of the research team. Three were from the South West of England, one from the East Midlands, and one from the North East. Four were from Scotland and a further four represented national organisations.

Interviews with parents

Recruitment

We sought a sample of parents who represented different areas of the country and lived in different types of geographical communities (i.e., rural and urban). Most parents that we spoke with were recruited through organisations that worked specifically with parents with learning difficulties. In order to be included in the project parents had to self-identify as having a learning difficulty/disability (see note on language in Introduction), and have at least one child under the age of eighteen. Although they did not need to live with their child, they did need to have contact with them on a regular basis.

Conducting the interviews

Each parent was interviewed twice. The guide for the first interviews focused on narratives of parenting and the support that parents relied on in bringing up their children. They were asked about internal resources, individual relationships, groups, and community resources that they had drawn on from pregnancy up until the current day. The guide for the second parent interviews focused on parents' interactions with their communities. For example, we asked parents about use of and feelings about their community and about things they would like to see change.

Eleven parents were interviewed online and two face-to-face. In person interviews took place at the agency through which the parent was recruited. Each interview lasted for up to an hour, was audio recorded, and later transcribed.

Sample characteristics

In common with the majority of research concerning parents with learning difficulties, most of the sample was made up of mothers; we only interviewed one father. Most parents were also White. Parents had between one and four children and a small majority were single parents, although we interviewed five parents who were married or lived with their partner. We interviewed two parents who did not live with their children but had regular contact with them. More detailed information about the parents who participated in the interviews can be found in Table 2.1.

Table 2.1 Characteristics of parents interviewed

Characteristic		Frequency	Percent
Age	20-30	2	15.4
	30-40	5	38.5
	40-50	6	46.2
Gender	Female	12	92.3
	Male	1	7.7
Ethnicity	White British	12	92.3
	Black British	1	7.7
Relationship status	Single	8	61.5
	Living with partner/ married	5	38.5
Number of children	1	3	23.1
	2	6	46.2
	3	3	23.1
	4	1	7.7
Residence of children	Home	11	84.6
	In care	2	15.4

Focus Groups

Once we had completed all of the individual interviews with parents and with professionals we conducted four focus groups with professional experts in the field. The purpose of the focus groups was to explore further professionals' conceptualisation of asset based approaches and their usefulness for supporting parents with learning difficulties.

We recruited participants through the networks that we had established in previous stages of the project. Five professionals who took part in the focus groups had also participated in an individual interview; thirteen additional professionals also took part. We ran four focus groups in total. Two groups had four people in them and two had five members. Expertise of the participants was in family and parenting (seven participants), learning disabilities/difficulties (six participants), and advocacy or asset based approaches (five participants). Five of the professionals were from

the Yorkshire and Humber region and four from the South West. The others were from London (three participants), Wales (three participants), and Scotland (one participant). Two represented national organisations. The groups were jointly led by members of the academic research team and representatives of York People First.

The guide for the focus groups centred principally on parents' interactions with and contributions to their communities and on the broader social networks of parents. We decided to conduct the groups online in order that participants could more easily attend as part of their working day and to allow an exchange of ideas between professionals from different disciplines from across the UK. Each group lasted for an hour, was audio recorded and subsequently transcribed.

Analysis

We used the qualitative technique of thematic analysis to understand the data that we had collected during the interviews and focus groups[44]. Researchers use thematic analysis to find and interpret patterns in their data. It is a widely used technique that is suitable for the interview and focus group data that we had produced through our research.

We followed a defined process of familiarising ourselves with our data by re-reading the transcripts and listening to the audio recordings, coding the data by applying labels to short segments of text, and searching for wider themes suggested by patterns that emerged through the codes. The analysis was a team process, with meaning being sought and solidified through discussion. As mentioned above, we also maintained an open dialogue with our partners from YPF, who listened to portions of interviews, identified meaningful data, and discussed emerging findings.

In the following three chapters we present the principal findings of the research.

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.

Chapter Three
Community life for parents with learning difficulties

This project was designed to amplify the voices of parents and how parents feel part of their communities. This first chapter shares some of the things parents value in their communities. The parents involved in this project live in different places throughout England and Scotland and live in urban areas and very small rural communities. Community means different things to different people and its meaning shifts and changes over time. Developing 'community' and 'community assets' is the site of policy interest and therefore understanding parents' views and experiences of their communities is an important starting point.

This chapter describes the various communities parents are involved in and how they positively shape their lives. Community was spoken about in different ways by different parents including social and family networks, groups and community based activities and their local area. This chapter brings together our learning about what community means for parents and their children with a focus on:

i) Relationships and Networks
ii) Communities of Place, and
iii) Communities of Interest.

This chapter draws primarily on the lived experience of parents alongside reflections from the practitioners interviewed about the aspects of their communities particularly valued by parents.

Relationships and networks

In the Introduction we set out the importance of social networks to all parents and parents with learning difficulties in particular. However, it is not just the existence or size of social networks that is important, but the quality of those networks. This section highlights the value parents attached to relationships and networks, the support they received from these relationships and how they maintained these relationships.

Family support

Some parents spoke of supportive family networks involving regular contact with parents (grandparents), siblings and other extended family members. Many parents talked about calling on family members for practical as well as emotional assistance. A parent described the importance of her close knit family and their support for her and her children:

"My twenty year old is with my mum and I've got a very supportive family, they're there for me whenever I need help. My dad, I see my dad every Tuesday and Fridays, he comes to see me and the kids and, yeah, just got a very close family, and my daughter, she's got autism, my twenty year old's got autism, just been diagnosed, so it's been, bit hard with her, bit ups and downs, but [I've] just got a very close connect family, so yeah, they're, they're brilliant."
- Parent 12

"Definitely a support structure around them, really supportive parents; that just helps so much and, the obvious thing for me really has been that support, whether or not they've been with the father of the baby … the main thing's been the support structure round them, it's just so important."
- Practitioner 17

Friendship networks

In addition to family networks, networks of friends, both old and more newly formed relationships based on becoming a parent were important parts of parents' community life. The importance of friendships were evident in our conversations and some parents described the significance of long standing friendships in supporting them as a parent, but also enabling them to continue to pursue their interests in life.

"I've got a couple of friends, I've got one in [local town] who was at school with me. and I've got another one as well, then I've got one that I was in a group with; I see her once every month as well; and I can really say one of my friends is a wee bit supportive with me, I could go and talk to her, do you know what I mean?"
- Parent 7

Friendship is reciprocal and parents also spoke about the importance of two-way relationships.

"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

Keeping in touch with friends can be difficult when life is very busy. The challenges of maintaining friendships were exacerbated by the periods of lockdown, so parents used technology to keep in contact with friends they are not able to see regularly.

"I don't spend time with them but I do now and again chat to them on WhatsApp, me friends from school, that I had from school, and I do like chat to them online, but I don't get to see them. One of me friends were on about like maybes doing a reunion just for to have a catch up with each other again."
- Parent 3

Formal support networks

In addition to friends and family all the parents involved had some form of more formal support from community based organisations and local authorities. Although the research suggests (as highlighted in the Introduction) relationships with professionals can be challenging, some of the people interviewed shared some very positive experiences of working with professionals. The majority of these organisations had a specific aim to support parents to build and maintain their social networks to help them to be a parent. Support varied from a school recognising the need to adapt their parents evenings to become more accessible for a parent with learning difficulties and a visual impairment, to specific parenting support, specialist midwives who had experience of working with people with learning difficulties, and advocacy support. A common theme in professional support was knowledge of the local area and recognition of the specific needs of the individual parent. One parent spoke of the importance of her 'coach worker' in supporting her to connect to local groups to help her manage her mental health and be there for her children:

"Well I've been going to this group for over a year now, and she's really a coach worker but I just call her a support worker, she's just try[ing to] get me going out again a bit more, cos I was just keeping meself locked up, I didn't want to go out. … she's been working with me for, I think it's nearly a year, and we do gardening and sewing. So I'm looking forward to them."
- Parent 3

Another parent spoke about how her advocate supported her to overcome her fear of joining new groups:

"For some reason I just couldn't get it out me head and I just kept talking about it to me mam "What should I do? Should I go along? I'm frightened." I decided to go, and for a while [support worker] would come with us, and then [advocate]. She would sit in the group along with us as well; and now I couldn't be without it, couldn't be without it now. I'd be devastated if it ended, completely, literally."
- Parent 4

There were positive experiences of professionals offering specific parenting support or social work support and this was linked to an understanding of the communication needs of parents and tailoring their approach to the parent.

"The last one that I have to say that it went to a child social worker and, and he was brilliant, he was really

good with this family, he'd done visual timetables; I mean I think the baby's gone home and you can't see the wallpaper for visual timetables, he's really been really creative, but he's very experienced and he's had other parents with learning disabilities. So that also makes a difference. I think if they'd have had a different child social worker it might have gone into a Court process, cos there were alarm bells, if you like, but he's been very good and he's put additional support hours in as well. So there's a lot of support going into that family to keep that baby at home."
- Practitioner 2

Table 3.1 Relationships and Networks

Relationships and networks	What parents value about their relationships
Family	Advice Emotional support Practical support
Friends	Emotional support Practical support Reciprocity
Formal support	Understanding unique needs Professionals being creative with reasonable adjustments Knowledge of local resources

Communities of Place

Neighbours

We encounter our neighbours on a regular basis, although we have little to no control over the people in our surrounding area. The parents involved in the project had a range of experiences both positive and negative of their local area. Some parents were fortunate to have positive relationships with the people who lived around them. Neighbours were described by some parents as friendly and supportive. One parent described an important friendship with a neighbour when she was new to the area who introduced her to her local church.

"There's a lot of people running around. There's Tesco's and all that. I've got a neighbour who lives right next door to me; she's a lovely

neighbour. Everyone knows me and my family so we get looked after.
- Parent 5

Another parent spoke about the difference it has made moving into a new area:

"I just could not wait to get out of there. It was so stressful, cos moving is stressful anyways, isn't it, but [it is] the best thing; and now I couldn't have moved to [a] better place because the neighbours I've got now, they're just brilliant; 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

Local resources

Beyond the immediate environment of their neighbours, parents spoke about the range of places they like to visit with their children. These included parks, football pitches, cafes, cinemas, shops, beaches, libraries, museums, and churches. However, several parents expressed concerns about the lack of resources available in their local community.

Our local outside spaces became more important than ever during lockdown and this parent described the pleasure he got from walking in his local area:

"It's like a really nice area and we've got, at the beach and that there's loads of places to go. It's quite a lovely place to live, cos where I used to live there wasn't really much to do, where I used to live there wasn't places to walk to, cos we've got a big hill as well, it's nice for walking round, and it's got a big lake and all that so it's quite nice"
- Parent 13

Another parent, when describing what it is about being a mum that makes her really happy said:

" I like taking him for walks and meeting his friends... sometimes we walk from the hall to the school and back with the parents."
- Parent 8

The sense of being part of a community was talked about by parents in relation to local parks, soft play centres, cinemas, theatres, swimming pools, and football matches alongside having friendly and supportive neighbours and friends locally.

Local organisations

Local organisations were important connections for many of the parents. While reaching out could be difficult, we heard frequently about how parents were supported by practitioners to make the first step. One practitioner described the process:

"I introduced her to a lady who is trained in the Christians Against Poverty and introduced them to each other - cos there's several organisations that work with

budgeting and stuff. So I saw her again the other week and she was absolutely full of it, all her finances are sorted out, everything's sort of like where it should be, she's even got spare money amongst that they're saving towards a holiday, which is absolutely brilliant"
- Practitioner 21

And parents spoke of the importance of local neighbourhood groups. One interviewee described the opportunities a local group offered to her as a parent in terms of developing friendships with other parents and the activities available to her children:

"First it was just like the after school club but then they had their own like family group. So for basically all the families, I think there was about ten of us, like ten different families all doing like weekly groups and playing games, getting to know other families in the community like, that's how that sort of started, and then some of the trips, like we went to [a] festival, but we had already moved to [a nearby town] but we were still able to go. So I still keep in contact with the families and stuff."
- Parent 7

Table 3.2 Communities of Place

Communities of place	**What parents value about their communities of place**
Neighbours	Friendly Welcoming Understanding
Local Resources Parks / local green spaces Cafes Local shops	Opportunities to walk Easily accessible on foot / via public transport Meeting friends locally Free activities Eating out
Local Organisations	Advice Developing friendships (both parent and child) Activities for children

Communities of Interest

Parents and practitioners spoke about a range of resources in their local areas. The previous section explored communities of place - the local places parents interact with on a daily basis due to where they live. This section sketches out the other places and groups parents and practitioners discussed in our conversations related to their interests and faith as well as their parenting.

Activity based groups

Parents were frequently involved in community groups, not necessarily directly related to their parenting or learning difficulty. These groups included art classes, sewing groups, gardening groups, choirs, and attending a women's centre.

"I go to [a sewing group] and I'm learning how to use a sewing machine. I've never used a sewing machine before but she says that it was excellent how I could get the lines so straight. And then on a Wednesday we do cookery and we get to bring one of the kits home of what we've made that day; and I can't remember, I think it's Hawaiian or something, made in Hawaii or something that we're making today, chicken something, and then I'm gonna be going to me gardening group but we're going to [...] Farm; we're just going round there to have a look at their plants and have a look at the animals."
- Parent 3

Activity groups offer opportunities for some structure in the week and to meet friends. They also create the possibility to learn new skills. Practitioners also highlighted the importance of activity groups as a source of informal support in a welcoming and non judgmental atmosphere. This practitioner outlined the range of activities they were aware of and the potential benefits:

"[W]e had a Men's Shed project, for example, at one point where men would meet together in a shed and they would just do bits and bobs together, and they did different activities in the community like gardening and a bit of cooking; so we know parents want to build up their skills around cooking and cooking on a budget. So I think they draw on, they draw on informal support I think as a priority, just to meet up and have a cup of tea and get to know other people."
- Practitioner 19

Faith based groups

Faith based groups were an important part of the lives of some of the parents involved in the project. Faith based groups offered bible study groups, advice, and in most cases a sense of being part of something important. One parent talked about how she was introduced to her local church by her neighbour when she first moved into the area:

"I was born a Roman Catholic but when I moved to [town] I couldn't

find a Roman Catholic church; so my neighbour kept knocking on my back door saying "Do you want to go to church?" And I said "Well I've got a load of boxes that I need to unpack." So in the end I said "Yes, fine, I'll go to church." I go there every Sunday with [Son]. So yeah...it's like a big family really. "
- Parent 5

Parenting and child related groups

Parenting specific groups such as play groups held in children's centres, libraries and community centres were attended by some of the participants. Parents talked about the benefit of these groups for their children, giving them the opportunity to play and get advice from other parents. One parent reflected on the opportunity to meet with other parents and chances for their child to play:

Well it's actually good cos like I don't feel like the, other parents are talking to other people and all that stuff, like you don't want to talk over them and all that stuff, it's nice to just sit there and just play and get to meet other children and all that stuff, just while your child is there and playing.
- Parent 10

A practitioner gave an example of a successful group for fathers:

"Can I just say one positive group?... it was a dads' group, not targeted at [people with] learning difficulties, but anybody welcome and, and the thing that drew the parents in that I was working for, it was bacon sandwiches, on a Saturday, and it really embraced the fathers that went there actually, and the mix of learning difficulties and non-learning difficulties worked really well together, because they were almost looking at them as role models, father figures, but it was the bacon sandwiches that drew them in."
- Focus Group 1a

Schools

Practitioners also pointed to the close relationships that many schools had with parents with learning difficulties in their communities:

"So in every community you're gonna have a school, do you know, there's lots of wonderful work going on with community hubs and the schools' hubs areas that are working together as a school. So there's, there's a fantastic opportunity there, they're out there, they're already doing good work; so to link in with something like that rather than reinventing some, some form of a support building or agency, do you know, just being able to work closely with schools; I mean they, they'll, they'll deal with the parents a lot as well so there's a lot of knowledge there and a lot of community knowledge, as well as knowledge of the parents."
- Practitioner 17

Paid and voluntary work

Work was an important part of the lives of many of the parents involved.

Some parents were in paid work, others worked on a more casual basis for self advocacy groups leading training sessions. Others volunteered in a variety of settings including childcare nurseries, charity shops, and a day centre for older people. Work, in whatever form, offered structure and, when talking about self-advocacy roles, the possibility of making a difference:

"I've been on my feet for the last two weeks; I've been doing work for People First, I've done two presentations; one for the University of [local city] for social work, and I've also done another on day services for people with learning disabilities. The point of them is to get the message over that a lot of people are not getting their services back at the moment."
- Parent 7

Work was not straightforward and could create challenges for parents, particularly in the current economic climate where employment could not be relied upon. One parent spoke about the importance of the support they received from a support worker:

"[T]hey give me help to look [at] further education and help me with more stuff when I worked at [a shop]; .... So yeah, so they're really good.. They help me, they help me with like disciplinaries and like other stuff, if I've struggled in my work"
- Parent 7

Peer support groups

Discussion of peer support groups was a common theme across many of the parent interviews. Some of these groups were primarily focused on being a parent and the specific challenges of parenting with a learning difficulty, other groups had a broader focus on self-advocacy and rights and others were related to other experiences shared by the group, for example groups with a focus on surviving domestic abuse.

Parents and practitioners highlighted the importance of peer support in general but also most specifically to support them in their parenting and mutuality of that support. The positive experiences for parents included:

Being accepted and welcomed.
One parent spoke about the importance of acceptance and a non judgemental culture in the peer support group they were a member of:

"Just being able to come along and talk and they listen and they don't judge yer and if you do say something, not something wrong but if you do say, like if it's a subject that's brought up or something and you say something but it's not the correct thing, they don't sit and sorta laugh at you and things like that, unless it's something funny, whereas I've been in situations like that before when I've said something and it's not been the correct thing and people have just took the mick and, yeah"
- Parent 4

The creation of groups where parents feel safe to speak is the foundation of a supportive group. The importance of these groups was emphasised by an advocate who highlighted the very particular experiences of parents with learning difficulties who have social services involvement throughout their pregnancy and in their children's lives:

"The beginnings of the group was trying to create a safe space where people going through such difficult times, facing care proceedings had somewhere to go, because they didn't know who to speak to about what they were going through. They were sworn to silence because they're going through court hearings. The social workers are on 'em like a ton of bricks if they even utter a word or mention their child's name to somebody outside of the immediate care proceedings, and it was really difficult for them to, you know, kind of go through a process without having support from anyone; sometimes not even family members were allowed to know what was going on. They do things like viability assessments on their own parents, you know, people who have cared for them their whole lives, and so this real kind of intrusion into every aspect of their private family life meant that they couldn't go anywhere, they couldn't talk to anyone. And so the beginnings of the peer support group was literally having a coffee morning with people who had no-one else to talk to and I think offering that space."
- Focus group 2b

Forming Friendships.
Strong and enduring friendships were made by parents regularly attending peer support groups. Involvement in the group could develop a sense of belonging and being part of something:

"So getting to know the other mums, I just feel like I'm part of, like two different families, I'm part of the family of [support organisation] and, [peer support group], I feel like I'm part of their family, and then I'm part of the family of [another support organisation] and then obviously I've got me family here. So I feel like I've got three families but just two of them are just a family of friends and support."
- Parent 3

Mutual aid.
Sharing experiences within peer support groups offered parents the opportunity to exchange their learning and support each other.

"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

Parenting advice.
The challenges parents face when raising their children shift - one week

can be very different to the next - and membership of a peer support group with others who have and are going through it can be very important. One parent reflected on the specific experience of having social services involvement and how the group offered support - not only in relation to parenting - but also the experience of support from social services:

"I'd like to have more support than I did with my other one, I'd like to have more help with Social Services, like get people that can help us with this one, like go to places and people that have got learning difficulties and they still have their babies; I can talk to people now and go to places with a load of people now, like go to people that have learning difficulties that have children that, have their support and stuff, like to go to more groups and understand more to being a parent than doing it on my own, basically. I'd like more help than I did before with [first child]."
- Parent 2

Others spoke about how their peer support group had helped them to learn how to better understand their children's feelings and offered them ways to support their children through the challenges of life.

Learning skills and developing confidence.
The benefits of peer support groups extended beyond specific parenting advice and offered parents the opportunity to develop their self confidence, to practice new skills, and to learn how to manage their own emotions.

"Yeah, I did not have a lot of confidence and I don't know why that was, but since I've been going to the group [advocate] and [advocate] helped me to get my confidence back. So since then I've been going to the group. [Name] was my advocate and she invited me to the [group]. The group is like a family and whatever's talked about in the group stays in the group, which I love.
- Parent 5

Table 3.3 Communities of Interest

Communities of interest	**What parents value about these communities of interest**
Activity based groups - Men's group - Sewing - Cooking - Art class	Daily structure Fun Make friends Learn skills Free / affordable
Faith-based groups	Social connections Support Advice
Parenting based groups (general) - Walking group - Play groups - Baby massage - Dad's group	Shared experiences Opportunities for children to meet and play with other children
School	Support resource Friendship - both parent and child
Peer support groups - Self advocacy / speaking up groups - Parenting groups	Friendship Mutual aid Parenting advice Learning new skills and developing confidence

This chapter has discussed how the parents and practitioners involved in the project viewed the opportunities in their communities. Although we have sought to highlight the many things parents value in their communities and the positive aspects of where they live and the people in their networks, it is clear that there are many challenges. Whereas some parents have spoken warmly of their friends, neighbours, and the resources available to them in their local areas, this is very much a partial picture. The next chapter starts to reflect on some of the challenges parents face in their communities.

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 cant be met, and being frightened of services.

Chapter Four
Why might community be difficult?

In the previous chapter we discussed how communities of various types were important for parents with learning difficulties. Many parents were embedded in their social networks and relied on them for personal and parenting support. However, we know that finding and maintaining community is not always easy. Some of the parents we spoke to did not have many family members, friends, or other people that they could call on. They were like many other parents with learning difficulties, who as a population, tend to be more socially isolated than other parents[9].

In this chapter, we focus on some of the factors that might stop parents from building social networks or cause them to disconnect from their communities around them. We focus on explanations that both parents and professionals gave in their interviews and focus groups for why community might be a difficult thing to build. In doing this, we also offer a few ideas about what can be done to overcome these barriers and dig a little deeper into two barriers that run as undercurrents through many of our conversations, that is the experiences of trauma and stigma that parents bring with them to their social relationships.

We summarise the themes we found in our data about barriers to community in Table 4.1. We have grouped the barriers under those that have particular relevance for accessing communities of place, to forming social relationships, and to accessing communities of interest. Of course, no classification scheme is perfect, and many of the themes have relevance for two or more of the different types of community. Following the Table we provide a brief overview of each theme and examples of what parents and professionals said in the interviews.

Table 4.1 Barriers to community for parents with learning difficulties

Barriers to accessing communities of place
Physical barriers Lack of transportation Lack of accessibility due to multiple disabilities *Psychological and social barriers* Traumatic experiences in the community Perceptions of danger in the community
Barriers to forming social relationships
Psychological and social barriers Previous trauma Stigma and exclusion Long term social isolation
Barriers to accessing communities of interest
Physical barriers Resources not available or not known Resources not accessible Children's needs not catered for *Psychological and social barriers* Fear of formal and informal service providers Lack of fit of mainstream service provision

Barriers to accessing communities of place

Lack of transportation

Parents were reliant on public transportation or the goodwill of their social networks to access services or activities for themselves and their children. Both sources of transportation were experienced to be unreliable and a source of frustration for some parents, especially those living in rural areas where fewer options were available.

"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."
- Parent 1

Lack of accessibility due to multiple disabilities

Many of the parents in our study experienced physical disabilities in addition to their learning difficulties. Parents described places and events in their communities as being physically inaccessible for a variety of reasons, including blocked streets and pavements, lack of resources for people with hearing or sight impairments, and the need for personal assistance. Other parents talked about their inability to engage in community activities such as volunteering because of inaccessible environments.

"I'm fine during the day if somebody's with me, see at night I've got to have somebody with me cos I can't see. I can't even go to church events at night either, if there's like bible studying at night or something like that."
- Parent 7

Traumatic experiences in the community

Some of the parents we interviewed had experienced significant incidents of verbal or physical victimisation while out in their communities. Professionals had also observed similar and often ongoing abuse. Parents who had experienced violence in their communities often reported associated mental health symptoms and a reluctance to leave their homes or engage in social contact. (See *Spotlight on Trauma*).

"A number of people I've worked with have been very severely persecuted in the local community and I think until I offered to do a bus ride with a mum going off to family contact, I didn't realise how bad that was. The amount of abuse in a sort of twenty minute journey she experienced, the name calling, horrendous things."
- Professional, Focus Group 3

Perceptions of danger in the community

Some parents reported a general perception that the communities they lived in were not safe. They referred to examples such as gang activity, theft, and assault to make their case. These parents explained that people in their communities did not care for each other but only looked out for themselves. A minority of these parents had chosen to move

house to find a neighbourhood where their family could feel safer.

Q: "How do you feel when you're out and about around where you live?" A: "Safer, safer than when I lived over there. Not so much watching over my back. Not that I did anything wrong over there, it was just the type of people that lived over there; you half expected things to happen, so yeah."
- Parent 4

Barriers to forming social relationships

Previous trauma in relationships

Several parents reported experiences such as bullying victimisation during childhood or domestic violence in adulthood. Some of the parents described how their learning difficulty had made them more vulnerable to such abuse throughout their lives. Many of these parents reported ongoing mental health problems associated with their traumatic experiences. They found it difficult to trust other people and deliberately maintained a level of social isolation. (See also *Spotlight on Trauma*).

"When you're working with people that experience kinda high levels of anxiety; we've no concept of it. I work with a mum myself who's got really high levels of anxiety and she's got bipolar, she's got a learning disability, she's got bipolar and chronic PTSD and, you know, I walk down the street with her and it's such a different experience cos I say to her "Tell me what you're thinking now, tell me." And she thinks people are gonna be staring at her and laughing at her, and she thinks that because they were a bully at school. And this person's nearly forty, you know; to carry that all of your life."
- Professional 19

Stigma and exclusion

Parents' exclusion from hoped for social connections was related to their stigmatisation on two counts. They were discriminated against first because of their disability, and second, for some parents, because of their involvement with the child protection system. Professionals we interviewed noted that parents with learning difficulties experienced marginalisation in all areas of their lives. They were stigmatised in informal settings such as picking their children up from school as well as in more formal settings such as in contact with social workers. (See also *Spotlight on Stigma*).

"I think parents with a learning disability can feel judged and stigmatised and have had negative experiences throughout their life, whether it was their own schooling or their own early parenting. And it's tricky because not all elements of the community are caring, you know, and they are judged and stigmatised, you know, in the school playground, at school, parents evening, by social work, by housing services, and so we have to resource them for that."
- Professional 17

Long term social isolation

Many parents spoke about how they preferred to keep themselves to themselves. Professionals observed that the parents they knew had often been isolated from their communities since childhood, especially if they were educated in a non-mainstream school. They therefore possessed few tools to fit in with their peers in the present day. Other professionals discussed the "spiral of isolation" that parents could encounter if they don't engage in mainstream community organisations and had no opportunities to form further connections.

"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 16

Barriers to accessing communities of interest

Fear of formal and informal service providers

Professionals discussed that parents they worked with often lacked confidence to engage with informal groups in their communities or with formal services. They speculated that this was because experiences of powerlessness throughout their lives had caused them to fear interactions with anyone who appeared to be in a position of authority.

"What I generally find is that when you go in, they're very, very frightened, they're frightened of services and they're frightened of professionals because of the power bases and how they've been treated as they've come up in life, and they've devised their own ways of coping. So when you first go in, they don't want to admit that they don't understand. … I think these are the big issues because I don't think you can just say, take people and put them into able-bodied situations; it's just not as easy as that."

- Professional, Focus Group 2

Lack of fit of mainstream service provision

Professionals noted that participation in mainstream services or community groups was often very difficult for parents with learning difficulties. Parents' anxieties about attending a group such as 'mothers and toddlers' for the first time were frequently realised because other attendees did not understand their disability or include them in conversation. Professionals noted that the parenting experiences of parents with learning difficulties were often different to those of other parents and that mainstream programmes might not meet their needs. Others discussed the need for parents with learning difficulties to be with others with similar experiences so that they could support each other and feel at ease together.

"I've certainly heard comments from parents saying they've walked in and not felt accepted and not felt welcomed and so they go once and then they don't return. So I think the initial walking in is a very brave thing for them to do and then they don't feel, rightly or wrongly, but they don't feel accepted or they say it's very cliquey and nobody spoke to me, and then they don't go back, they don't return."
- Professional, Focus Group 1

Resources not available or not known

Many of the professionals that we interviewed felt that there were too few resources in their communities that could support parents with learning difficulties with their parenting. It was often pointed out that some groups or services that parents had used had been defunded and no longer existed. Furthermore, professionals observed that parents were frequently unaware of resources that did exist within their communities, which were seldom advertised in an accessible manner.

"[They don't know] what services are out there. I kind of know about things because I sign up to loads of e-newsletters and I'm keeping an eye on events in [city] or things that are coming up, but if you're not using technologies, if you're not online as much, then you're not gonna be aware of, of things that might be really beneficial to you or things that you might really enjoy."
- Professional 27

Resources not accessible

A frequently reported barrier to parents participating in mainstream services in their communities was the accessibility of publicity materials and resources used during groups or meetings. Participants described how resources, for example for parenting programmes, typically relied heavily on the written word and were not designed with people with learning difficulties in mind. Similarly, a substantial barrier was presented by the extent to which community groups and services relied on technology to interact - especially since the pandemic. Participants explained that many people with learning difficulties do not have access to the necessary technology or do not feel comfortable using it.

"People just assume everybody's got a phone with the internet, don't they, and not everybody does, do they? So, you know, some people don't even have a camera phone do they? So it, it's really, there's a big assumption that people have got these things but they haven't at all; especially, you know, 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. "
- Professional, Focus Group 4

Children's needs not catered for

Parents struggled to engage with services or groups that did not provide child care. Because most parents did not have an extensive social network that could look after

their children regularly, most had to rely on one or two family members who were not always available at the necessary times. Other parents spoke about how difficult it was to participate in parent/child activities in the community when their children themselves had learning difficulties that were not catered for.

"I liked going to the group with them, like the boys were able to meet other children their age, meet other parents, but it was just the fact that my old, my oldest son was in playgroup and when I went to pick him up he was just sitting in the corner on his own just crying, just sitting crying on his own in the corner, yeah, so. And I mean he wasn't like speaking till like about five, so I found that difficult."
- Parent 3

Facilitating parents' involvement in community groups

While professionals had plenty to say about what made it difficult for parents to access groups, services, and other resources in their communities, they also had a variety of ideas about what would make it easier for parents to get involved. Table 4.2 presents a summary of their ideas; these are expanded on below.

Table 4.2 Facilitating parent' involvement in community groups

Co-production
Purposeful and relevant activity
Logistics and accessibility
Welcoming and non-judgemental
Introducing parents to groups

Co-production

Professionals talked about how when designing new groups or resources it was important to include the input of parents themselves. This ranged from including parents in the development of content and design of programme materials to a central role in the conceptualisation of the activity itself. (We write more about co-production, including some of its inherent challenges, in the next chapter).

"It's making sure the group's small enough that everybody gets a voice; and it's about asking the person with the learning disability what they want, because I don't think they've ever been given the full control of, well what do you want? How do you want it? Where do you want it? You know, and doing it in a co-productive way that they have control, they have the power to decide, because otherwise we're doing to or for rather than with."

- Professional, Focus Group 3

Purposeful and relevant activity

Groups that were more successful focused around teaching skills that parents wanted to learn. Professionals noted that these skills could be wide ranging; the concurrent and perhaps more meaningful goal was that parents formed relationships with others in their communities.

"I think that's really helpful, if you sometimes have a bit of a hook like knitting and there isn't much knitting that goes on actually in the end, but it gives people a kind of way in, doesn't it, to meeting up with people, and really what people want to do is that. So I think that's quite a useful thing. You need to have a little bit of a hook, and in the end, in the long run, it's not even that important but it gets you in there."

- Professional, Focus Group 3

Logistics and accessibility

Professionals we spoke with mentioned a number of practical issues that needed to be considered by anyone creating or running groups for parents with learning difficulties. Among the issues raised were the appropriate use of technology when agreed by the members, communication using the preferred method of individual parents, support to use transportation, and running events at times when parents can be supported to attend. Another important issue was ensuring that all groups (including the materials and publicity they used) were accessible for parents with learning difficulties and other disabilities.

"And just being very mindful about the parents' sort of literacy skills and also being very mindful if there are any other issues, for example, you know, Braille or signing or things in big print. Yeah, so we try to make it as inclusive as possible."

- Professional, Focus Group 4

Welcoming and non-judgemental

As discussed above, walking into a group for the first time can be very

intimidating for parents. Professionals therefore emphasised that groups should be designed to be welcoming and non-judgemental. Groups that achieved this ethos were often small and took the time to allow their members to become comfortable with each other before expanding.

"I think the facilitators just were very much, oh come in, sit down, let's give it a try, see how you get on; and very gradually the other parents started to include the mum that I'd gone with; and she'd always found it very difficult to be included in community type activities, she was always worried about, you know, her use of language and her behaviour. But I understand that after going a few times; there were quite a lot of adaptations and she started to model some quite positive behaviours and interactions based on what the other parents were doing. It was just very friendly is the only way I can describe the atmosphere there."
- Professional, Focus Group 3

Introducing parents to groups

A recommendation that was made frequently by professionals was that somebody accompany parents when they first go to groups that are already established in their communities. This person could be a professional, but could also be a family member, a friend, or another parent. The role of the person accompanying the parent would be primarily to give them confidence to enter an unknown environment and to help them to make the first steps to develop relationships there.

"The parent support worker comes along with the person and introduces them, gets them embedded into the group. Really our job is the introductions, get across a lot of information that the person wouldn't necessarily say themselves ... to make that connection and, and just make everyone feel, hopefully feel welcome and involved."
- Professional, Focus Group 4

Spotlight on Trauma

In analysing our data we noticed that many of the parents we interviewed had experienced traumatic events over the course of their lives. They had been abused as children, they had been bullied in school, and they had experienced violence in their homes and communities as adults. These experiences provided an important part of understanding why some parents may have struggled to form relationships with other people in their communities.

An example was provided by a mother we spoke to who described that as a child she was physically abused by her biological mother and then in care settings. She said, "I got abused pretty bad, hit every day. I never got the experience to have a childhood myself." At the same time she was being bullied by a group of children at her school who punched her and hit her. As might be expected, this ongoing victimisation had a profound impact on her life. In addition to coping with depression and anxiety in her adult life, the mother also explained the effect it had had on her ability to trust:

> 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.

The mother went on to tell us about an incident in her young adulthood in which she was physically assaulted while out in the community. Describing the effect the event had on her current life she said:

> 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. I mean I've got like a scar somewhere on me head.

We heard similar stories from the professionals that we spoke with, who also described the long term impacts of parents' victimisation, including depression, low self-esteem, and anxiety about being in groups or meeting new people.

These narratives are not unusual; we know from previous research that people with learning difficultiesare more likely than others to experience traumatic events such as child abuse and domestic and community violence[45,46]. They are also more likely to be living with post traumatic stress symptoms[47]. These

symptoms, including avoidance, hyperarousal, and negative changes in cognition and mood, are similar to some of the struggles that parents and professionals talked about in our study. Post traumatic stress is also closely associated with mental health problems such as depression and anxiety that may make it difficult for parents to maintain their existing relationships or to form new ones[47].

As we look for ways to support parents with learning difficulties to get involved in their communities and to build social networks, it is important that we pay attention to the potential effects of trauma in their lives. Of course, many parents with learning difficulties thrive in their relationships and communities despite the traumas they have experienced. Others may need some help. It is important that people working with parents in health and social care settings as well as in informal community settings are aware of what trauma symptoms look like, including those that might manifest as avoidance of or discomfort in social settings. We should also be aware that parents may need specialist trauma focused intervention before they are able to fully engage in their wider communities.

Spotlight on Stigma

Stigma was a recurrent theme across all of the interviews and focus groups that we conducted. The parents we interviewed talked about feeling judged by professionals they encountered who seemed to apply undue scrutiny to all aspects of their parenting, based on no other concern than their disability. Some described how they felt ostracised from others in their communities who they observed to be treating them differently because of their learning difficulties. We heard similar accounts from practitioners in interviews and focus groups. The findings from our study are consistent with previous research which has documented the stigmatisation of people with learning difficulties in general[48] and more specifically parents with learning difficulties[12].

Stigmatisation occurs when people are labelled negatively because of their identity, resulting in loss of status and discrimination. Because people with learning difficulties have less power within their communities than people without disabilities, they are especially vulnerable to this process[49].

Parents with learning difficulties who have had their children removed from their care face a double jeopardy of stigmatisation that can lead to isolation. They are liable to be judged upon meeting new people both because of their involvement with the child protection system and because of their disability. A practitioner described her observation of the former:

> 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.

A parent we interviewed told us about how difficult it was for her to make friends because of the stigma that came attached to her learning difficulty. She described evocatively the hurt that resulted from being rejected when she tried to form relationships in her community.

> [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.

Knowledge that they were being stigmatised had a profound psychological impact on many parents who took part in our study or who were known to practitioners who we interviewed. Several practitioners described the low self-esteem that they observed in the parents they worked with.

> They don't want to go out because there's the stigma and they feel like there's a stigma around them. Most of the families that I work with learning difficulties have got very, very low confidence and that's all, I think, down to the stigma and down to the fact that they're not getting out and about and they are very isolated and they don't feel like they fit into the community like maybe other people do.

The idea that stigma, low self-esteem, and self-isolation were behaviourally reinforcing was a common theme among our participants. Parents struggled with their identity because of societal perceptions about learning difficulties and parenting. Expectations of being judged, together with actual experiences of being discriminated against when out in the community, resulted in social isolation and further reductions in self-confidence. Previous studies have described how similar processes can disrupt the formation of social networks for people with learning difficulties[48].

This focus on stigma is not to suggest that parents with learning difficulties have no agency in creating their own positive identities as parents and community members (see Chapter Two). It does instead indicate that there are unique barriers that parents with learning difficulties face in looking for community that might not be encountered by other populations. Practitioners looking to support parents in building social networks should be aware of strategies to help combat stigma and its effects. For example, in a recent study of the experiences of stigma of parents with learning difficulties, the authors found that parents who were members of a self-advocacy group appeared to have a strong sense of social belonging and an ability to reject an unwanted stigmatised identity[12]. In the next chapter of this report we also highlight the role that professional advocacy has played alongside asset-based approaches in combating discriminatory practices targeting parents with learning difficulties.

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.

Chapter Five
The promise of asset based approaches for parents with learning difficulties

In Chapter Four we examined the barriers that parents with learning difficulties face when forming social networks and accessing different types of community. At this point we are presented with the question:

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

This chapter presents evidence on this topic from our interviews with professionals who were experienced in working with parents with learning difficulties and/or in asset based approaches. In particular, we focus on what we learned from professionals who had experience using asset based approaches with parents with learning difficulties.

Through the course of our interviews, we identified a small number of asset based approaches that were being used to support parents with learning difficulties and their children throughout the United Kingdom. Determining what was and what was not an asset based approach was not straightforward. Some programmes or services made it easy; they labelled themselves, and we agreed. Others had all the hallmarks of an asset based service, but did not use that language to describe themselves. We also found that multiple organisations used the term 'asset based' without appearing to adhere to any of the core principles of asset based approaches we described in the Introduction. The organisations that we identified that appeared to broadly aspire to asset based principles and to include parents with learning difficulties in their programmes fell into three principal categories:

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

We have written more about each of these models of asset based approaches in the Introduction. In

the chapter that follows, we have, where pertinent, identified the model of asset based approach that the interviewee we quote works with. We do not, however, identify any individual organisation or locale in order to preserve the confidentiality of our participants.

Searching for the core principles of asset based approaches

In order to understand the 'fit' of asset based approaches for parents with learning difficulties we asked our participants about the three hallmarks of asset based approaches we outline in the Introduction. We talked with them about how asset based approaches build *social networks* for parents with learning difficulties, how they operated from a *strengths based perspective*, and how they incorporated *co-production*. For each of these topics, we were interested in 1) how they were conceptualised (thought about), 2) how they were put into practice, and 3) what challenges might arise in using asset based principles with parents with learning difficulties.

Social networks

Conceptualisation of social networks

Participants who had expertise in providing asset based approaches to people with learning difficulties all spoke about the importance of social networks for parents' personal lives and for their parenting. We detailed the benefits that they understood to derive from the networks that parents built within their communities in Chapter Three. However, it is worth noting here a couple of ways in which participants thought about social networks which were particularly associated with asset based principles. First, participants noted that parents benefited from the relationships that they formed through asset based services that they took part in. The networks they formed had a positive impact on their parenting and on their children.

"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

Participants also emphasised the asset based principle that social networks should lead to mutually beneficial relationships. To be truly part of a community, parents should not be solely recipients of care or services, but they should also contribute towards the relationships that they are part of.

"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

Social networks in practice

The professionals we interviewed described a variety of methods of supporting parents to build mutually beneficial social relationships in their practice. These methods varied widely, according to the model of asset based approaches that the participant adhered to. For example, participants we interviewed who facilitated peer support groups as part of their services spoke about the importance of giving parents the opportunity to form relationships with people other than the professionals who were ever present in their lives. They also emphasised the mutuality of relationships formed in peer support settings, and the multiple benefits that could come from connecting similar parents together. One participant described the experience of a dad who became a peer supporter:

"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

Some participants mentioned helping parents to form and strengthen relationships through the use of a manualised programme such as Mellow Futures, a parent training intervention, which has been adapted for use with parents with learning difficulties. Other professionals relied on long-term strategies to help parents work towards independence and the lives that they want for themselves. A participant who had experience with Shared Lives explained the longevity of relationships that she had formed with parents and children who had lived in her home:

"I mean I could delete their numbers and never speak to them again when they leave, but, 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 that wouldn't be good for the person."
- Professional 18

Participants we interviewed who worked in Local Area Coordination or Social Prescribing described how they would work alongside parents to help them to connect to "likeminded" people in their communities. They talked about how they worked to connect parents to groups in their communities, such as social clubs or life skills classes, where they would be likely to build friendships. One interviewee made the important point that their work was not only about helping parents with learning difficulties to connect with their communities, but also to work with communities to become more accepting of parents with learning difficulties.

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

Social network challenges

The formation of social networks was integral to every example of asset based approaches that we came across, and examples of the difference that positive relationships made in the lives of parents with learning difficulties and their children were abundant. However, as we wrote about extensively in the last chapter, communities almost always have a 'dark side'; they can be hostile and discriminatory. While we have not repeated that data here, it represents a clear challenge to the easy 'fit' of asset based approaches with parents with learning difficulties.

Strengths Based

Conceptualisation of strengths based

Experts in asset based provision that we interviewed each emphasised the importance of a strengths based perspective to their work. Applying asset based principles to supporting parents with learning difficulties meant recognising their capabilities as parents as well as the resources available in the community that could support their family life. The approach was contrasted with the deficit based approach that parents often experienced in their encounters with other health and social care services. A professional who worked in the Local Area Coordination/ Social Prescribing model of asset based approaches explained:

"How we see it is that an asset based approach is about seeing the value in the individual and what they can do for themselves alongside seeing the assets within a community as well and how a community can look after and take responsibility for those within it. Our focus is around the individual and looking at their abilities of what they can do and not what they can't. It's being allowed to give people that time and space to trust us and supporting that person to feel empowered, not disempowered by another service

doing to them rather than them being empowered to help themselves and advocate on their own behalf with us there behind them."
- Professional 8

Strengths based in practice

In practice, working from a strengths based perspective looked similar for professionals across different models of asset based approaches. In particular, they acknowledged and reassured parents of their capabilities as parents and as community members. Our participants noted the positive psychological impact that this could have on the parents that they worked with, many of whom only heard their parenting spoken about in negative terms by professionals that they encountered:

"When we give somebody that kind of positive affirmation and acknowledge their strengths, acknowledge what they are doing rather than what they're not doing - because we know a lot of services will do that for them - then they feel included, and they feel part of a community already, and through doing that we know that we can, you know, end up with a group of community members who have got a great life experience, great empathy and ability and great compassion to understand other vulnerable groups in the community."
- Professional 19

The same participant continued to express the impact that acknowledging parents' strengths could have on their community participation, emphasising that it is also key to helping parents overcome the stigma they face due to their disability.

"Not all elements of the community are caring and [parents with learning difficulties] are judged and stigmatised in the school playground, at school, parents evening, by social work, by any housing services, and so they need to be resourced to combat that, and that's that bit again about being strengths-based that you can give, you know, it's not only about making sure they feel included and special within a community, but it's about them feeling resilient within communities as well."
- Professional 19

Some professionals also spoke about using their strengths based work to try to influence parents' encounters with statutory services. For example, one participant explained how they worked with a parent to recognise their achievements and to challenge the current narrative of them as an inadequate parent:

There's all these things that social work and other services say where parents aren't achieving the outcome they want them to be achieving. I'm like "Well, you know, they haven't had a drink for two months. They've home cooked three meals this week and they've had two pizzas." And I'm like "That's like me." We try and make them [the parents] literally write down and record their

positive thoughts and positive actions. We tell them that they're good and give them examples of what they've done really well."
- Professional 19

Strengths based challenges

Despite the positive rhetoric, the lack of fit with the values and assumptions often made within statutory services about parents with learning difficulties made working from a strengths based perspective challenging. Both practitioners and parents in the study reported that learning difficulties were seen as deficits that disqualified parents from caring for their children. One practitioner who was engaged in asset based work with parents with learning difficulties described their experience:

"We very quickly come into conflict with our colleagues [in children's services] about the parent's right to parent, you know, as soon as someone has a label of a learning disability, that unfortunately seems to throw up an instant barrier to the person's ability, with support, to keep the family together and to parent."
- Focus Group 2

Professionals who worked in asset based settings with parents noted that they tended to focus more on parents' strengths, even when the situation the children are living in "might not be perfect". In contrast, they believed that social workers tended to be overly alert to risk in their decisions, and prematurely remove children from their parents' care:

"The social workers that then go into these roles are risk averse; and we're not asking people to take huge risks, we're asking people to work alongside the parents and manage any risks … I had one social worker tell me from children and families, "I don't want to end up on the front page of a national newspaper," and I get that."
- Focus Group 2

Advocacy as an additional role

Practitioners who worked from an asset based perspective described how their different approach to working with parents with learning difficulties from that of risk focused statutory services often led them to engage in advocacy on parents' behalf. In fact, advocacy appeared to form a major part of the role of many practitioners engaging in some forms of asset based approaches, such as Local Area Coordination.

"There's more of a role of advocator, I think, for people who are introduced to me who have extra needs. I'm just thinking of parents that I'm currently walking alongside and it is about that advocacy. There's another chap that I'm supporting who's, two of his children are on child protection plan, he's with a new partner who is expecting really soon, he has ADHD and some sort of other condition, it's about managing his, that his processes thoughts, funnily enough, and he struggles in meetings. So his mum asked if I would be involved

with him to support him in child protection conferences and, and stuff like that. So again that support, that extra support, that extra advocacy has helped and works really."
- Professional 21

"I've stopped short of using the word 'advocacy' because there are advocacy, specialist advocacy agencies out there, but we are almost advocating for the person we're kinda promoting their rights."
- Professional 33

Co-production

Conceptualisation of co-production

As we outlined in Chapter One, co-production is key to asset based approaches. It is embedded as a principle in many of the models of support that people with learning difficulties rely on, including the self-advocacy movement. In line with this, practices such as including parents with learning difficulties in the design of services and in decision making were mentioned in our interviews as at the heart of an authentic asset based approach.

"I don't think you can take an asset based approach to, say, supporting somebody with a learning disability without seeing them as fully human and therefore recognising their agency and that the more that you hoard power for yourself and refuse to share it with that person, that you're actually harming them as well. So you can't be genuinely developing an asset based approach, working in an asset based way if actually you take all the decisions and hold all the power. "
- Professional 1

Co-production in practice

We spoke with some providers of asset based services where it was clear that these principles were successfully put into practice. For example, participants spoke about how their organisations worked from the "bottom up," organising around members or their community rather than around an agenda imposed on them from above. This practice appeared to be particularly central to the peer support models of asset based approaches that we encountered.

Challenges to co-production

However, it was less clear where principles of co-production fit into other programmes or services that we encountered. In fact, a number of participants talked about the difficulties of co-production. The ideal of people with different viewpoints and levels of power working harmoniously together was not always realised. Participants in the focus groups discussed some of the difficulties inherent in co-production. For example, they pointed out that shifting to a collaborative way of working was not easy for parents with learning difficulties when the majority of past interactions with service providers had been hostile. A participant who worked with a group of child protection involved parents explained:

It can come across as quite aggressive when frustrations get there, you know, and you've got to understand a person who's like, you know, dealt with lots and lots of professionals and then they're trying to sort of like have their say and they're not normally listened to or understood.
- Focus Group 2

The practitioners also believed that when parents were involved in decisions about service design or delivery, it was more for show than with any realistic expectation that their ideas would be incorporated into official plans. Another participant recounted the process that they had observed, saying:

"I think that this whole experts by experience idea is fantastic, but … it's used in the wrong way; it's like we've got this idea, this is what we're gonna do, we'll get a few people in who are experts by experience, we'll hear what they have to say, but they don't go with their idea, they've already made their mind up about how this was gonna look and what's gonna happen. It's just tokenistic to hear from these experts by experience and it's a transaction. Why would you ask somebody for their opinion if they're not gonna influence change? It's, it's not right, you know, it's kind of like, what's the point in doing it?"
- Focus Group 2

Another participant summed up the current situation by pointing out that while much progress had been made for parents with learning difficulties and for people with learning difficulties in general, there was still a long way to go if the full ideals of asset based approaches were to be realised. Specifically, non-disabled people would need to surrender resources and decision making power to disabled people.

"I would argue that there's still a massive distance to go. I think a genuinely asset based approach suggests transfers of knowledge, resources and employment towards people with lived experience and away from, you know, non-disabled people supporting disabled people, for instance."
- Professional 1

The 'fit' of asset based approaches at the systemic level

We have so far examined the 'fit' of asset based approaches for parents with learning difficulties according to three core principles of social networks, the strengths based perspective, and co-production. In our conversations with professionals, we also noted several recurring themes about the benefits and challenges of using asset based approaches to support parents with learning difficulties at a systemic level. We give an overview of these themes in the remainder of this chapter.

Systemic benefits of asset based approaches

More positive outcomes

Professionals who worked within asset based services used anecdotal evidence to demonstrate that this way of working was more effective in the long term than other methods of service provision that they observed or had experienced.

I do think it [using asset based approaches] is the best way to work personally. It's sometimes hard to get your mindset around it when you've worked in other ways. I was a health trainer and a community health educator and it hasn't worked, the same people are still in the system all these years. Whereas [through the asset based organisation] the people have moved on, you know what I mean? I've done it both ways now, and I believe that the asset based way is the right way.
- Professional 20

Interviewees noted that the support parents were offered through asset based approaches often enabled them to exceed the expectations that were placed on them by other professionals and societally. They were able not only to acquire parenting skills but to assume a positive role in their communities.

"And we, you know, we work with some parents who will never have a job but they're good, they're good community citizens, you know, and they're good parents, and I think that's amazing because with, you know, that wasn't their history, that wasn't what happened within their family and that's, they've, you know, we have broken a cycle there."
- Professional 19

Not all parents who participated in asset based services lived with their children. We did hear some stories though where parents were able to keep their children in their care or had them returned to their care with the support of a professional using an asset based approach.

"So I suppose through recognising [the mum's] strengths and skills and capacity, capabilities, they turned it around and it went from being a permanence planning meeting to let's get her daughter home; and what's really wonderful now is her daughter started school last year and is absolutely thriving, and [the mum] she, you know, she has got a learning disability and has got poor mental health but she's an absolutely amazing mum, she's a great contributor to community life and, I really believe in her."
- Professional 19

Makes economic sense

Professionals who worked from an asset based perspective argued that because their work was primarily preventative, it relieved pressure from frontline health and social care services. Early intervention saved individuals presenting with more acute problems further down the line.

"We should be investing in this because this is actually often what's

decreasing our spend on frontline services, you know, our acute A & E, our, you know, our interventions that has got to such a stage that a drastic intervention needs to, needs to happen. We're all about avoiding that and about keeping the people functioning within their communities and happy and healthy and safe."
- Professional 33

Several professionals made the argument for the superiority of the asset based approach based on its potential to save money in contrast to more traditional services. As above, this observation was tied to the focus of asset based approaches on parents' strengths and keeping families together in their communities as a preventative intervention.

"I remember being in a meeting where a social worker said that they would rather have this young person accommodated and taken away from the, the family to avoid any potential risk, and she disclosed the cost of that, and I was absolutely horrified, you know, and I was saying "But even, you know, twice as much support as we're suggesting would be a fraction of this cost." Do you know what I mean?"
- Professional 33

Systemic challenges to asset based approaches

Lack of clarity about concepts and outcomes

An important challenge to the implementation of asset based approaches stems from the fact that their effectiveness is hard to measure. Despite the positive anecdotal evidence, it is difficult to actually determine the difference that asset based approaches might make to outcomes for parents with learning difficulties and their children.

"Asset based approaches are not services that you can monitor and regulate and there's not a defined workforce that you've got control over that you can train and improve; I mean you can offer but you can't put the workers who are facilitating community groups and community resources through a programme of awareness raising; it's far too nebulous. So it's hard to control the environment because it's the whole community and it's hard to monitor and evaluate what difference you're making and whether the community is becoming more inclusive."
- Professional 3

As the professional in the previous quotation alluded to, asset based approaches do not typically mandate a specific programme that can be administered, monitored, and evaluated. A related problem is that it can be hard to judge when a service is actually being run from an asset based perspective, or when the language is just being appropriated, further confusing attempts to evaluate effectiveness. Participants in our study identified a gap between the rhetoric of asset based approaches and their actual practice in some cases.

"I think if you look in the public sector, for example, people talk about asset based approaches all the time and I think what they mean by that is focusing on people's assets rather than their deficits, you know, and that's difficult to assess what they're really doing there. It's become one of those phrases that's almost meaningless. People carry on doing the same thing but they just say, oh this is an asset based approach now, you know; well maybe it is, maybe it's not, but they haven't started doing anything differently just by giving it a label."
- Professional 3

Vulnerability to funding cuts

Professionals additionally discussed the vulnerability of asset based approaches to funding cuts as a major challenge to their use with parents with learning difficulties. Participants linked this issue directly to the difficulty in evaluating the effectiveness of asset based approaches and ignorance about learning difficulties/disabilities among people with power to commission services.

"[asset based approaches are] often under scrutiny for where the council's always making cuts and it's not unusual to find someone in a department that's tasked with making these cuts that suddenly appears on the horizon, goes, I need you to quantify why it's cost effective or why we're doing this; and possibly people with little or no knowledge about learning disability parents."
- Professional 33

Another participant pointed out the susceptibility of asset based approaches to funding cuts due to their status as non-statutory services. The practitioner quoted below believed that her service was particularly vulnerable in an unfavourable political and economic climate.

"So anything, anything at the moment that isn't statutory is at risk; I don't care what it produces, what outcomes it achieves for people, and it don't matter how foolish it would be to cut it, which it would be because it does work for people, it creates an amazing environment and the things that it can open up for people, and the freedom it gives to other services is massive, but there's still no getting away from the fact it's not statutory. So I could sit here and tell you that without a shadow of a doubt it is sustainable, it works, the figures speak for itself, the stories that we have shows all of that, but reality is we're a local government funded by central government and the economy is, is stuffed and we aren't a statutory service."
- Professional 21

In the next chapter we weigh the evidence from the previous three chapters to draw conclusions about the use of asset based approaches to support parents with learning difficulties.

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.

Chapter Six
In conclusion

In this final chapter we take a step back to think about what conclusions we can draw about the use of asset based approaches with parents with learning difficulties based on the findings we have presented. We offer suggestions about what the findings mean for policy and practice from both the academic research team and from our partners from York People First.

Community ties

Our research demonstrates that many parents with learning difficulties have important ties to the communities that they live in and interact with. This finding provides a counter narrative to the dominant story of social isolation that most research about the networks of parents with learning difficulties has focused on. The parents we spoke to in our study discussed how they were involved in relationships with family and friends, in the geographical communities in which they lived, and in other social groups and organisations depending on their interests.

Within parents' communities, they unsurprisingly had some relationships that were of more significance than others. To use the language of social capital, they had both strong ties and weak ties. Parents valued different aspects of these various types of relationships; that is, they secured different benefits from them. From the strong ties they had with families and friends and sometimes with formal service providers, they gleaned substantial support that appeared to directly impact their parenting. They received emotional support, material assistance, and practical advice. Parents' interactions with people in their communities of place or their communities of interest mostly produced relationships that could be considered as weak ties. These social connections were nonetheless meaningful, yielding benefits such as the opportunity to engage in enjoyable activities with their children and the exchange of parenting advice in peer support groups. Research suggests that having a variety of weak and strong ties is associated with well-being[50]. If we disregard relationships that appear to be less important we may be missing a crucial part of the social

environment that can contribute towards positive outcomes for parents with learning difficulties and their children.

Barriers to community

Despite this evidence of the value that parents placed on their various social relationships, a substantial proportion of parents we talked to found community to be difficult to find or maintain. We found that parents experienced different interrelated barriers when trying to connect with various types of community. It is worth noting that while many communities might be difficult for all different sorts of people to participate in - they might, for example, be insular and unwelcoming or remote and not well connected - we identified a number of barriers in our research that were particularly pertinent to parents with learning difficulties. Some of these barriers fell broadly under what might be called accessibility issues. Community groups did not provide materials in suitable formats or made technology use unavoidable. Some community resources were not easily reachable by public transportation and no provision was made for parents' additional physical disabilities. Other barriers were social or psychological in nature: parents contended with the stigmatisation of their identity and status by professionals and potential community members. Although trauma is not unique to parents with learning difficulties, they experience victimisation at a higher rate than other parents[45,46], and it also emerged in our research as a significant barrier to community participation.

Our findings indicate that the reasons parents with learning difficulties may be isolated are multifaceted. To understand an individual's relationship to community, we must think about the physical and social geography in which they live and their own personal biography in the context of historical, societal and professional expectations of parents with learning difficulties. Supporting parents to overcome these barriers and gain the advantages of community participation is a necessarily complex endeavour. We now turn to consider our findings relating to asset based approaches in the light of our understanding of the complexity of community for parents with learning difficulties.

Asset based approaches

The value of asset based approaches

Our findings indicate the potential for asset based approaches to support parents with learning difficulties to gain many of the benefits associated with community participation as discussed above. Throughout our interviews with professionals we encountered diverse examples of good practice in which the principles of asset based approaches were successfully worked out. In particular, practitioners seemed to have made headway in helping parents to widen their social networks and were fruitfully building on individual and

communal strengths in their work. Anecdotal evidence of positive parent and child outcomes were used to support professionals' descriptions of successful practice using asset based approaches. These findings add to the small, but slowly growing qualitative evidence suggesting the value of asset based approaches for supporting people with learning difficulties[37].

Adapting asset based approaches

However, our findings also imply the need for some caution in the use of asset based approaches with parents with learning difficulties. While asset based principles undoubtedly can be harnessed to support parents and their children, we suggest that the approach is not sufficient to meet all the needs of the population. We have already outlined in this report how in order for many parents to participate fully in their communities and to gain the full advantages of citizenship for themselves and their children, multifarious and seemingly insurmountable obstacles must be overcome. Asset based approaches may therefore need to be adapted or added to in order to meet the complex needs of parents with learning difficulties.

First, asset based approaches may need to be adapted in view of the complexity of experiences that parents with learning difficulties bring to their parenting. For example, we emphasised earlier in the report the effect that traumatic experiences could have on parents' mental health and on their ability to form trusting relationships within their social networks. Asset based approaches that target parents with learning difficulties may therefore need to be adapted to reflect a trauma-informed model of practice. The core values of trauma informed practice (choice, collaboration, empowerment, safety, and trust) integrate well with those of asset based approaches as they put an emphasis on the strengths of the person seeking services and on the need for collaborative relationships[51].

Second, asset based approaches may need to be used alongside other methods to support parents with learning difficulties. The challenges that parents with learning difficulties face in assuming the role of 'parent' are significant. Although asset based principles are clearly beneficial in providing parents with the social relationships that can boost their confidence and support their parenting, parents must also navigate complex and sometimes discriminatory systems to maintain their family lives. The majority of the practitioners that we spoke to during our research that took an asset based approach also assumed the role of advocate, whether formally or informally.

The purpose of advocacy is to support people to speak for themselves, to secure their rights, and to access needed services[52]. Advocacy has long been seen as an important component of good practice in supporting parents with learning difficulties[42]. Previous research has found that advocacy is valued by parents with learning difficulties. The benefits are especially

clear when advocates support parents in their contact with the child protection system, enabling them to understand and challenge the proceedings[53]. Our own research suggests that it may not only be beneficial, but also necessary for services provided with an asset based focus to incorporate an advocacy component. Asset based approaches do not easily address the power imbalances or systemic dysfunctions that parents with learning difficulties encounter in their communities or in parenting their children. Advocacy is a proven method of countering some of these problems.

Third, we have highlighted the role that stigma and discriminatory systems played in the lives of the parents involved. It is unlikely that parents with learning difficulties will be able to participate as full citizens in their communities until systemic change is achieved in some important areas. Even if parents possess a variety of both strong and weak ties in their communities, they will almost certainly still face experiences of disability discrimination. We saw examples of this through bullying at school, financial challenges, and housing concerns - several parents spoke of moving house to avoid anti-social behaviour in their local area.

Thinking about the range of these experiences encourages a more inclusive and expansive approach to support for parents with learning difficulties - as one participant advocated - a whole community approach - which includes statutory support from local authorities. This means that a systemic perspective needs to be embedded within asset based approaches. Understanding how parents with learning difficulties experience intervention and community at a systemic level and how they may be best supported from this perspective is an area that requires further research, as detailed below.

Recommendations for Practice and Policy

Based on the findings of our study, we present the following recommendations for those interested in the use of asset based approaches to support parents with learning difficulties.

Using asset based approaches with parents with learning difficulties

Asset based approaches are a potentially valuable means of supporting parents with learning difficulties to successfully maintain a family life within their communities. Here we provide some suggestions about ways in which the core principles of asset based approaches may be successfully implemented with this population.

Social Networks

Asset based approaches may be used to support parents to develop social relationships within their communities. Parents with learning difficulties may face substantial

barriers in their quest to form social networks, as outlined in Chapter Four. Our findings suggest a role for practitioners in both supporting parents directly and in working with communities to make them more welcoming to parents.

Strategies to support parents directly:

- Connecting parents to community groups, services, and activities is at the heart of an asset based approach and of immense value to parents with learning difficulties. Practitioners should be prepared to provide accompaniment for parents entering new places in their communities in order to ensure accessibility and to ease fears of othering and rejection.
- Support parents to access community resources in ways that acknowledge their whole person. Parents with learning difficulties may struggle to express their needs relating to multiple parts of their identity, in addition to their learning difficulty. In the appendix to this report we outline an additional project that we undertook, looking at ways for parents from diverse cultures to introduce important aspects of their identities and needs to new people that they meet.
- Peer support plays a particularly important role in providing parents with emotional and practical support from others who understand their experiences. Asset based services can play an important role by facilitating the creation and development of peer support groups. Practitioners should also explore digital accessibility for parents who live in areas where there are fewer other parents with learning difficulties and who may want to connect with others outside of their geographical area.
- Create services that provide long lasting support and relationships. Although not all asset based models are positioned to support parents for long periods of time, our research suggests that there are important benefits to supportive relationships that last over years rather than months.

Creating welcoming community resources:

- Involve parents in the creation of new groups, activities, and services, including in the development of content and design of materials to be used in them.
- Provide activities that have a purpose that parents (and other community members) will be drawn to and focus on. Relationships are often formed within the context of other activities.
- Focus on creating resources that are welcoming and non-judgemental rather than

activities that will reach the maximum number of people.

- Resources should be accessible to parents both in terms of their learning difficulty and in terms of their social and physical needs. All materials used within or to advertise activities should be created in accessible versions. Support should be provided with transportation. Groups should also take place at times when parents can be supported to attend and child care can be provided or arranged.

Strengths based approaches

In contrast to many health and social care services provided to parents with learning difficulties, asset based approaches operate from a strengths rather than a deficit perspective. Our research suggests that the strengths perspective can play an important role in supporting parents to counter the stigma they experience and to more successfully navigate difficult statutory systems. Practitioners working from a strengths perspective will acknowledge and reassure parents of their capabilities especially in relation to caring for their children. They will also emphasise what parents are achieving as taking precedence over what they are not achieving in their conversations with parents and with other professionals.

Co-production

Co-production is a core value of asset based approaches. It is important that parents with learning difficulties are seen as partners in the quest to promote their own well-being and that of their communities. They should be involved in decisions that affect their lives and those of their children. Co-production was, however, perhaps the asset based approaches principle that appeared to be least realised in practice. While we noticed some examples of meaningful parent involvement, the barriers to working in true partnership often seemed to prove too difficult to surmount. While there is much to be learned as yet about how co-production might best be achieved with parents with learning difficulties in the context of asset based approaches, there is a long history of activism among people with learning difficulties that may be drawn on. Advice about how to more fully involve parents in the development and ongoing management of community resources may be sought from experts such as people involved in the self-advocacy movement.

Adapting asset based approaches for parents with learning difficulties

Asset based approaches as they are may be ill-equipped to meet the needs of parents with learning difficulties. In the remainder of this section we offer some suggestions about how they might be adapted or added to accordingly.

Ensure service provision is trauma informed

Practitioners working in asset based settings with parents with learning

difficulties should have training in the principles of trauma informed practice and operatie within its core values.

Furthermore, practitioners should ensure that they are informed about:

- what trauma symptoms look like, including those that might manifest as avoidance or discomfort in social settings.
- when parents may need specialist trauma focused intervention before they are able to fully engage in their wider communities and how to access these.

Engage in advocacy

Services provided with an asset based approach should acknowledge that advocacy is an important component of helping parents with learning difficulties to maintain a family life within their communities. Depending on the model of asset based approach used, this may be provided as a central part of the service, or practitioners may instead be prepared to refer parents to specialist advocacy services. Parents with learning difficulties may require advocacy for issues that allow them to live as full members of their communities, for example pertaining to housing, transportation, access to services and to information. Others may require advocacy to support their interaction with professionals, including those concerned with child protection.

Thinking systemically in research and practice approaches

The core values of asset based approaches relating to social networks, working with people's strengths, and co-production lend themselves to more innovative work in this area. The direction of policy and practice in statutory social care and community based support is aligned to these values, however in practice working in these ways is challenging.

This research has focused on community settings. Other longstanding and influential work by the Working Together with Parents Network[28] at the University of Bristol has focused on the rights of children and parents and good practice guidance for local authorities, community organisations and the courts and there is increasing interest in understanding the role of adult social care in supporting parents with learning difficulties.

Each of these research and practice agendas are vitally important in shedding light on the experiences of parents with learning difficulties.

It is clear that the life of a parent is complex for many different reasons stemming from personal biographies involving experiences of discrimination, inequality, intervention by professionals (who may only rarely work with parents with learning difficulties), and inaccessible community resources. Making connections between legal and professional interventions with a

recognition of the challenges of community life seems to be crucial in understanding the experiences of parents and their families and therefore identifying opportunities to develop support.

Taking inspiration from systemic perspectives, as advocated by some asset based approaches such as Local Area Coordination, responding to this complexity requires a systemic view which could help us to see the connections, opportunities and challenges in the systems which parents have to navigate. Significant areas of life were raised by parents and practitioners which we were unable to explore due to the scope of this project including relationship education in young life for people with learning difficulties, the assessment criteria in children's social care, the education system and its support for both children with and without learning difficulties who have parents with learning difficulties, how far the Care Act has provision for parents with learning difficulties, housing, and local responses to anti-social behaviour amongst others.

Seeing the whole system is never possible[54], but thinking systemically and attempting to engage locally with the multiple and complex systems parents interact with could help us to connect up and interrogate the challenges parents face when becoming a parent and identify the opportunities to better support parents with learning difficulties in future.

York People First: Making the most of our communities

The following table presents York People First members' discussions about how communities can be welcoming to parents with learning difficulties, based on a discussion of the study's findings.

Table 6.1 YPF suggestions for making communities welcoming

Accessibility
Places should be welcoming Physical accessibility - ramps/ lifts in the building
Easy read
Include pictures Big print - minimum 18 No jargon No fancy fonts - as clear as possible Different formats - audio and/ or video/ braille
Communicating clearly
Take it in turns to speak Respect what people say Give me time to answer Be open and honest Try not to be patronising Try not to rush people Talk to me and not my support worker Some people prefer face to face conversations Some people prefer using phones.
Supporting self-advocacy groups
We think that self-advocacy groups are a vital part of our communities. We think they can be supported in these ways: Recognise peer advocacy groups and their lived experience Involve self-advocates in decisions that affect their lives Promote self-advocacy groups to more people Local council's need to listen to the experiences of self advocates in their communities

Appendix
Making videos to support community interactions

Going into a new group or a new environment can be intimidating. Many parents with learning difficulties get anxious when meeting new people in their communities (see Chapter Four). The task of explaining their needs and preferences can be even more challenging for parents who have different cultural backgrounds. We know from previous research that accessing services is more difficult for people with learning difficulties who belong to minority ethnic communities than it is for people from the majority population [55].

An additional project

As an additional part of our project, we decided to see if we could find a way to make it easier for parents to introduce themselves and tell others about what they need. For this extended work, we partnered with the Elfrida Society Parents' Project, a London-based organisation that advocates for parents with learning disabilities and/or learning difficulties in all matters related to child in need and child protection processes.

We began by meeting to talk about what it was like to go into a new place as a parent with a learning difficulty, or to talk to a new person, for example in a school, children's centre, or doctor's office. Our group was made up of parents and staff from the Elfrida Society, members of York People First, and researchers from the University of York. Parents shared their personal experiences and thoughts about what would have made it easier for them. We talked about how people make assumptions about parents' backgrounds and abilities. We talked about how difficult it can be to explain things that are important when already feeling anxious and how frustrating it is to be asked the same thing over and over again.

Telling parents' stories through video

One idea that emerged through our conversations was to create short videos in which the parents could effectively tell their stories. The videos would allow parents to give a short account of things that they wanted people they met in their community or when accessing services to know. For example, they could explain their learning difficulty, their cultural background, their children's needs, and anything else that was important to them. These videos would be the property of the parent and could be attached to emails or messaged via

WhatsApp or any other method the parent chose to communicate it by.

Eight parents who were connected with either the Elfrida Society Parents Project or with York People First made videos. They began by creating storyboards of content that they would like to include in their videos. Parents included information on their storyboards about their family and cultural backgrounds, their children, their learning difficulties/disabilities, and the things that they enjoyed doing (such as the football team they supported). They also wrote about things that were important to them personally; for many this included the way people treated them compared to non-disabled people. Creating the storyboards was a collaborative process. Researchers, staff, and other parents all helped each other out where they could.

The next step was to create the videos. Parents used their storyboards as guides to tell their stories while a member of the research team filmed them. Members of the York based research team then edited the videos to reflect the stories that the parents wanted to tell.

Reflecting on the experience

Once all the videos were completed, we all gathered at the Elfrida Society to watch each other's videos, to discuss the process of making them, and to think about how they could be used in the community. Videos ranged from a couple of minutes in length to almost 15 minutes depending on the purpose that the parent intended to put the video to. Shorter films often provided brief overviews of the participant's individual and family circumstances, concluding with instructions about how they would like to be interacted with. Longer videos told a more complete story about the parents' experiences over the course of their lives. Many made reference to the discrimination or racism that they had experienced in various community contexts.

As a group we concluded that the films would provide valuable assistance in helping parents to inform new people that they meet about what is important to them, as well as in giving instructions about the way that the parent would like to be treated in the service or community resource they were accessing. While the intention of the project was to focus on minority ethnic parents, the group concluded that the videos could be useful for all parents who want to express their multifaceted identities in new venues and relationships. More research is needed to understand the experiences of parents using the videos and the effect that they have on their community interactions

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