GROWING UP IN BARNET

AN ETHNOGRAPHIC STUDY INTO THE LIVES OF DISABLED CHILDREN AND ADOLESCENTS

BARNET
LONDON BOROUGH

HABITUS
Collective

ACKNOWLEDGEMENTS

We would like to express our gratitude to the children, young people and parents who took part in this research study. Thank you for your time and willingness to share your stories, and for allowing us to draw on your experiences.

A heartfelt thank you to the educational settings, community and voluntary sector organisations for facilitating access to disabled children and young people. A special thanks to the 0-25 Disabilities Service team for supporting the recruitment process, and linking us to educational settings and participants. Your collaboration enabled wide participation and helped us engage with a range of children and young people across the borough.

For the purposes of this report, we adhere to the principles and values of the Social Model of Disability, meaning that we acknowledge that disability is created by society, and disabled people face structural and social barriers that cause disabling conditions (Inclusion London, 2023). Throughout this report, we use the term disabled but recognise that not all children and young people who took part identify as disabled. Language around disability is fluid, and we recognise that disabled children and young people play an important role in feeding into and shaping the use of language in line with the principles of the Social Model of Disability.
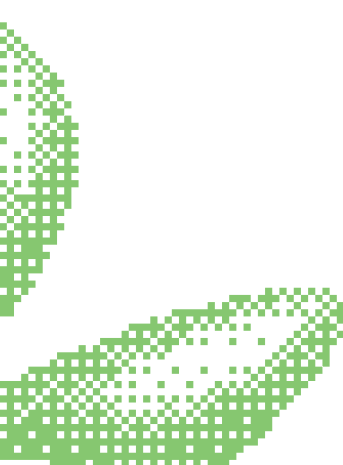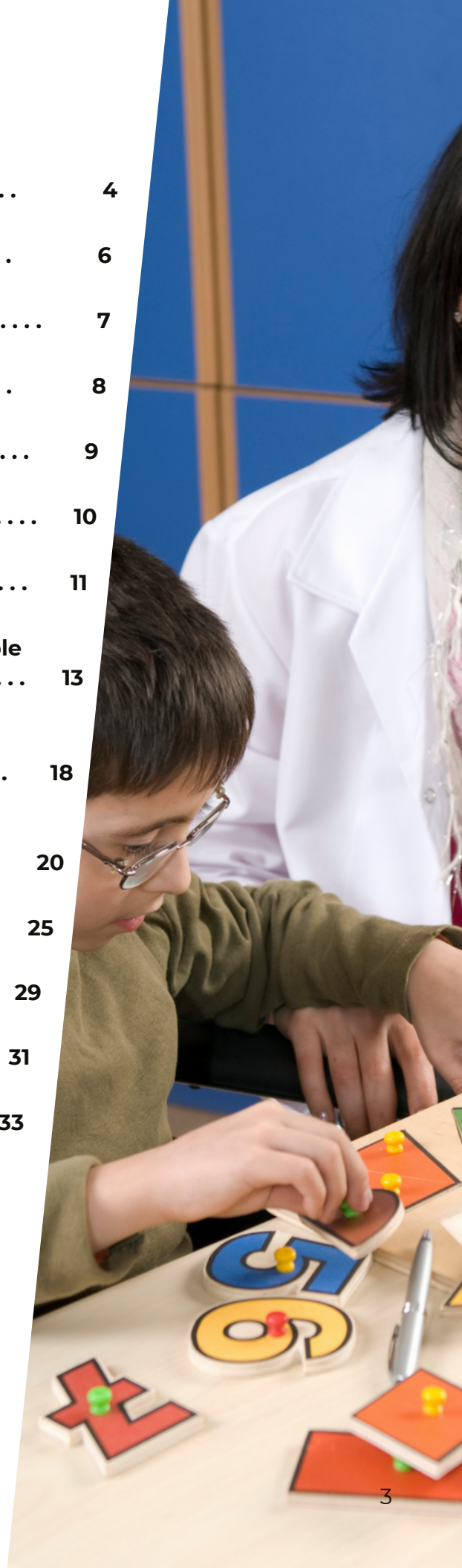
A note on the report

This report has been structured to present key findings across the main themes to concentrate on the experiences of the children, adolescents and young adults who took part. We define children as those between 5-10 years of age; adolescents as being between 11-15 years of age; and young adults as being between the ages of 18-23.

We have separated the report to reflect overall findings, as well as those that speak to each specific age group to take into account differences in experiences. Each section draws on a set of personas, case studies and stories to bring to life the experiences collected.

CONTENTS

KEY MESSAGES

Inclusive spaces allow children and young people to be their authentic selves.

For children and young people to feel they can be their authentic selves, they need to feel safe, seen and heard. Not all children and young people feel confident in being themselves in public, and some may require specific conditions to help them feel safe and able to be themselves.

Disabled children and young people share intersecting identities, which include their gender identity, ethnicity, religious beliefs as well as their disability. Understanding how children identify, and their experiences of navigating the world around them is key to creating inclusive spaces. This also acknowledges that some children or young adults identify as disabled, whilst others do not. Creating opportunities where young people are able to identify openly becomes important for them to feel seen, as well as providing them with ways to explore and express their identity.

Integrated and intergenerational activities fulfil a need and are important in creating inclusive spaces for children and young people. In some instances, having mixed groups to include non-disabled and disabled children and young people can create opportunities for socialisation which may be otherwise limited. This can bridge experiences and help cultivate a sense of belonging.

We have a lot of aspirations... a lot of things we've planned for ourselves. So we hope that we get the necessary support to push them forward.

Trusted relationships and relational approaches can make a lasting difference to children and young people.

Person-centred and highly relational approaches to supporting children and young people can result in transformative outcomes. Trusted relationships with professionals such as social workers, community or key workers can lead to children and young people achieving positive outcomes. It can be transformational when children and young people's physical and emotional needs are recognised and responded to in a holistic way that also includes the whole family.

How professionals at educational and play settings interact with children and young people can also have a lasting impact and support them in feeling more confident to socialise and interact with people. Play, physical touch and personal connection can present opportunities for children and young people to develop trust. Finding ways of engaging and interacting with disabled children and young people in a way that speaks to their lived experience can present opportunities to better support them. In the long term, this can ensure that young people grow up to have positive experiences and perceptions of statutory services and professionals.

Considering how children and young people experience transitional stages and providing the right support at the right time is key.

Each child and young person experiences transitions in different ways. Some find transitions (however big or small) stressful, which can lead them to withdraw or disengage, whilst others see it as an adventure. Oftentimes, transitionary phases can be highly stressful and lead to changes in behaviours. Allowing children and young people to share their experiences is key, and creating space for this to happen can be highly valuable, particularly if a young person is experiencing difficulties.

In creating positive transitional experiences, children and young people may require specific support. This can prevent a small issue from compounding and can be an effective early intervention approach. In cases where young people have not received adequate support, this has led to dropping out of school or isolating from family and friends. Creating opportunities where children can access the right support at the right time can minimise tension points over time.

Connected parents lead to connected children.

Children and young people are not separate from their families. Being aware of the context and circumstances of each family, such as immigration status, housing, as well as financial stability is important in finding ways of supporting children and young people. Acknowledging the barriers families face can in turn minimise challenges that children and young people are likely to experience. This also promotes a holistic and equitable way of ensuring all children are able to access the support they need.

Barriers around lack of information or know-how can hinder opportunities for social interaction and informal support mechanisms. This was expressed by parents, adolescents and young adults who rely on word of mouth to find out what's available and what they are eligible for. There is an appetite for adolescents and young adults to be part of a community, however, opportunities aren't always clear. This results in some young residents missing out on social connection, skills and training as well as civic engagement.

INTRODUCTION

Barnet's Area SEND Inspection in January 2022 found that 'Children and young people with SEND enjoy their time in education and in their social lives. They like living in Barnet. They feel well supported by the professionals who help them. The support they receive helps them to access learning at school and college more easily' (London Borough of Barnet, 2022).

Barnet Council's Children and Young People's Plan 2023-2027 sets out how the council will support children and young people to ensure they are at the heart of all decisions that affect them. The vision for the council is to ensure that all children who live and study in the borough have the best start in life, and for every child and young person to achieve positive outcomes. This vision aligns with the council's commitment to tackling the gap and fighting inequalities.

Aim and objectives

The council's action plan highlights important steps to support children and young people with SEND. Insights from the Young People's Resident Survey (YPS) revealed that children and young people with a disability are less likely to say they are happy with their local area as a place to live and would like support to help them live happy and fulfilled lives. To support the council in responding to the needs of disabled children and young people, Habitus Collective were commissioned to conduct a short in-depth study to capture the voices and experiences of disabled children and young people who live and study in Barnet.

This research project is part of a wider ethnographic study which examined disabled resident's experiences of living in the borough. Through in-depth interactions with a set of disabled adult residents who live and work in the borough, Habitus collected insights into what everyday life looks like, including barriers that residents experience when engaging with community life. What was missing from the study was the voices of children and young people themselves. We wanted to understand how children and young people see themselves, how they form friendships and take part in social life, including services and social activities they engage with.

Insights and stories collected by Habitus Collective will help Barnet Council gain a deep understanding of the lives of a small cohort of disabled children and young people, and shape their Children and Young People strategy.

The research questions explored as part of this study were:

1. How do disabled children and young people identify, and how does this vary depending on their age group, disability experience, gender identity and ethnic heritage?
2. How do disabled children and young people form friendships and connections?
3. Where do disabled children and young people have opportunities to be their authentic selves?

THE CONTEXT: DISABLED CHILDREN AND YOUNG PEOPLE IN BARNET

5,912
children and young people with Special Educational Needs are estimated to live in Barnet

14%
of pupils have a statement or EHC plan or are receiving SEN support *

4%
of pupils in Barnet have an education, health and care (EHC)

[Barnet Children and Young People's Plan 2023 – 2027](#)

[Young People's Perception Survey (2022)](#)

77%
of disabled youth who live in Barnet are satisfied in local area compared to 94% of all young people

50%
of disabled youth want support with long-term health problems or disabilities

43%
of disabled youth want support with emotional and mental health problems

It is well evidenced that disabled children and young people face numerous barriers to everyday life, which cause restrictions on their lives. Studies have shown that disabled youth may experience isolation and have fewer opportunities to take part in social activities and to form friendships and relationships ([Parsons and Platt, 2013](#)). Parents can also be more protective of disabled children ([Martin et. al, 2011](#)).

Studies have also shown the differences in how young people identify and view their disability, and how in some cases their disability is perceived as the dominant status which means that other aspects of their identities are side-lined ([Watson et al., 2011](#)). There is much to be said about how disabled children and young people navigate barriers, form friendships and identify. Finding ways of engaging disabled children and young people in meaningful ways can unlock deep insights that can help address some of the ongoing barriers.
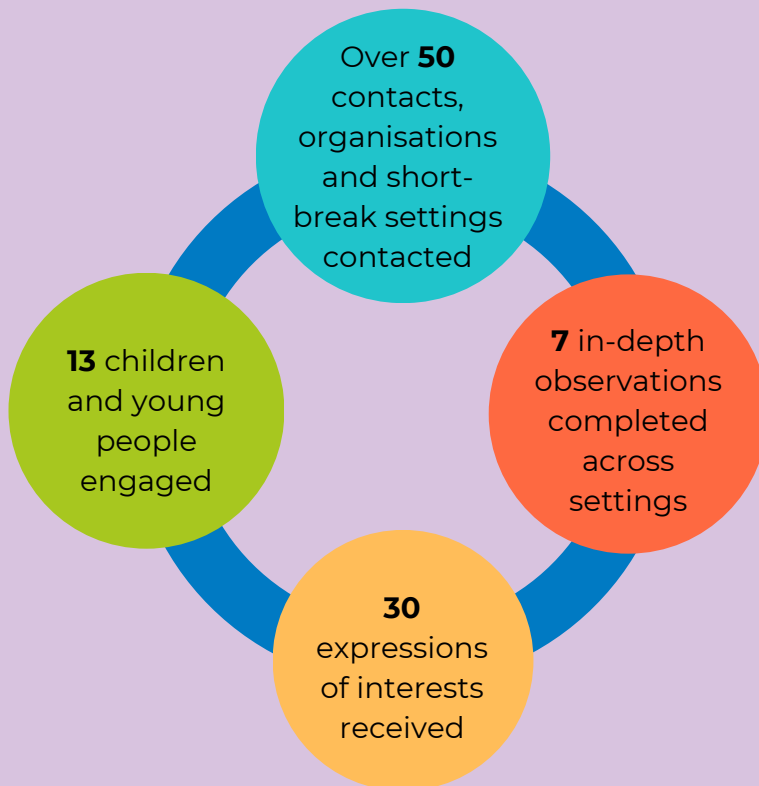
METHODOLOGY

Drawing on the principles of rapid ethnography (RE), Habitus conducted observations and visits at specific community settings and spaces and spent time with children, young people and families.

Our approach was shaped by how children, young people and families wanted to engage in the study, and before visits and interactions, researchers asked participants how they wanted to engage with the study. Habitus offered a range of ways which shaped the observational interactions, which will be discussed in the subsequent section.

Below is an illustration of our approach which was co-developed with children, young people and parents.

Phase 1: Community observations and engagement

Over **50** contacts, organisations and short-break settings contacted

13 children and young people engaged

7 in-depth observations completed across settings

30 expressions of interests received

Figure 1: Engagement Phases

Phase 2: Observations and interactions with Children and Young People

This involved in-depth fieldwork with a cohort of children and young people and their families in the home, at local libraries and online.

7 Home visits incl in-depth observations of routines and speaking to children and young people

2 Observations and interactions at a library setting

4 Online interactions and conversations

TOOLS AND DATA COLLECTION

Drawing on participatory tools, the research team designed a set of 'Activity Packs' to interact with children and young people with varying needs. These included sheets where participants were able to draw or write about themselves, their schooling life, some of their favourite things as well as their dreams and aspirations (see Appendix A for an overview of tools). Participants were also invited to take part in a photo collage project, and Habitus offered disposable cameras as well as the option to take pictures on their smartphones. [1]

The research team also interacted with younger and non-verbal children through play and the use of cue cards. Using a range of tools allowed the research team to meaningfully engage and build connections with participants.
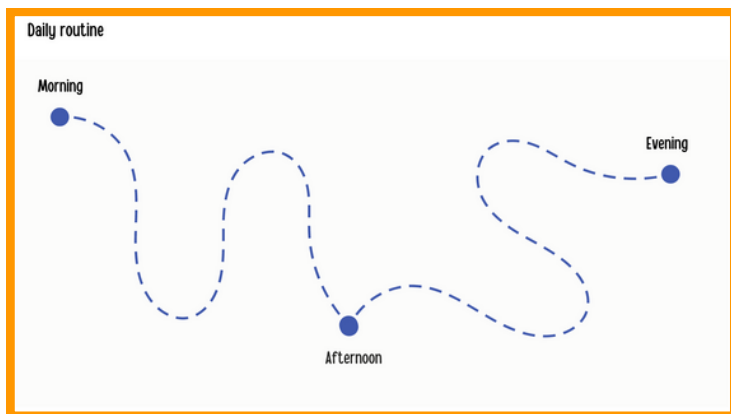
'All About Me' Activity Packs to capture young people's ideas and views relating to their family, school, and things they enjoy.

'About Me' Drawing Sheets for younger children and children who may have learning needs.

'Photo Project': for children and young people to capture pictures that describe their day to day life, things that inspure them ir they enhoy taking part in.

Jamboard conversation starter: for young adults who prefer to interact online. This included a set of prompts as well as creative tools
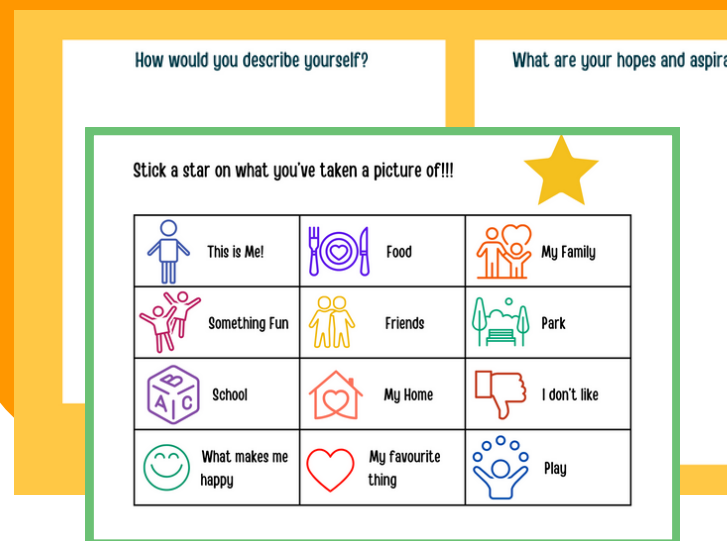
Figure 2: Fieldwork tools

[1] The majority of participants preferred this option; however, it was difficult to collate pictures as many children and young people not sending these through.

PARTICIPATORY TECHNIQUES

Below are some considerations for future engagement activities with disabled children and young people:

- Not all disabled children and young people want to engage in the way that we thought. Allowing for flexible approaches and being led by the child/young person was incredibly important.
  - Providing participants with options as to how to engage can lead to meaningful, inclusive and equitable participation. This can be using cue cards, or creative activities like drawing, taking pictures or using smart devices to initiate conversations.
  - For children, having a parent/caregiver present meant that we were able to forge connections more easily, and observing/interacting with the family unit rather than the child alone provided much insight into the family's context and dynamics.
- Allow enough time for interactions – whether this is around the completion of activities or responding to questions. We realised we needed to hold space and allow time for participants to respond to questions. This also meant deviating from our plan and following the child or young person's cue.
- Using objects that children are familiar with can be key to meaningful engagement – we found that children liked to use their mobile phones or tablets to show us pictures or watch TV shows or clips. This was a good way of understanding their preferences, routines and likes.
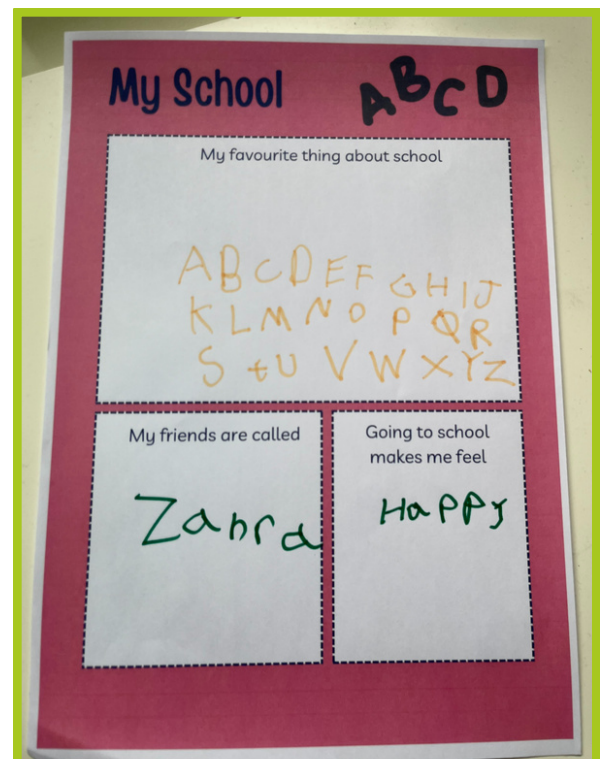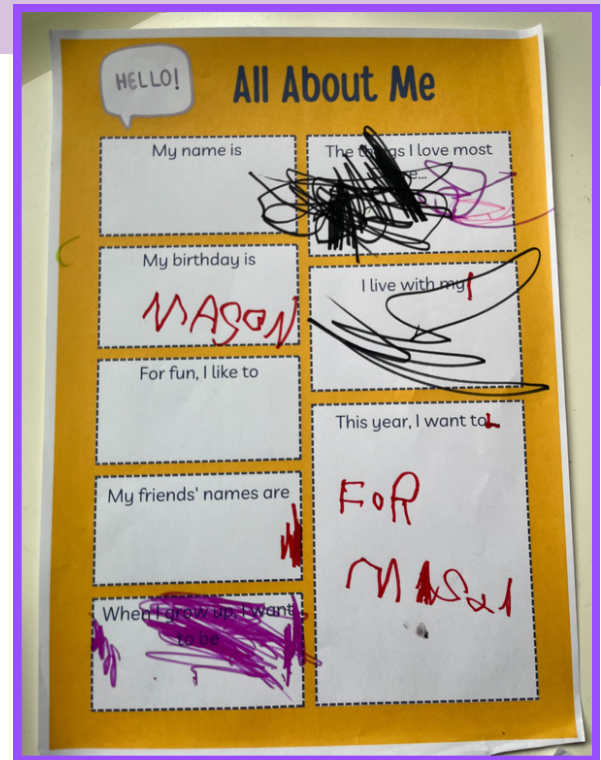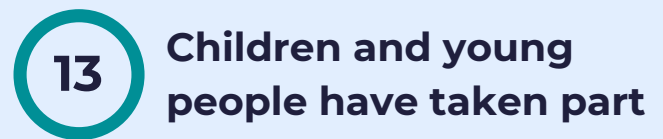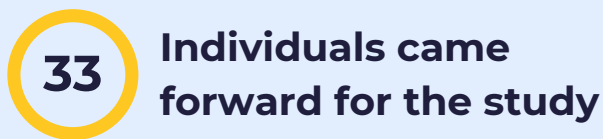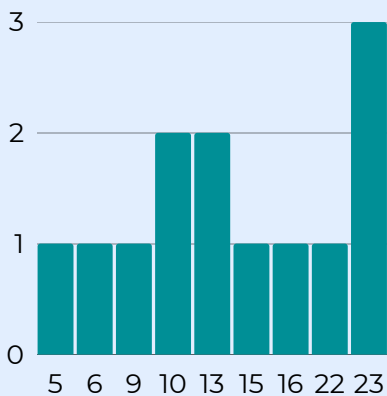
ENGAGEMENT AND REACH

In total, 33 expressions of interest were received, though some participants were not eligible, whilst others 'dropped off' after the initial contact.

Owing to the scope of this study, Habitus had a relatively small sample size of 13 disabled children and young people. 5 of these were in-depth observational interactions in the home and at a library setting. The demographic data presented in the dashboard below is of the children, adolescents and young who took part.

ENGAGEMENT DASHBOARD

33 Individuals came forward for the study

13 Children and young people have taken part

Age

3
2
1
0

5 6 9 10 13 15 16 22 23

Gender

Female
5
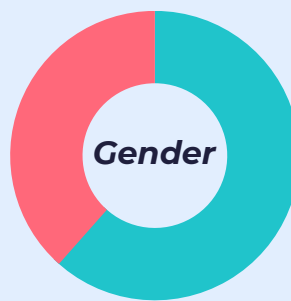
Male
8

Category of Impairment*

Autism
Hearing Impairment
Physical Disability
Visual Impairment
Learning Disability

0   5   10   15
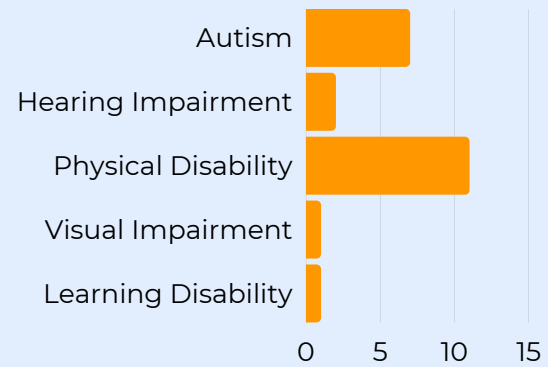
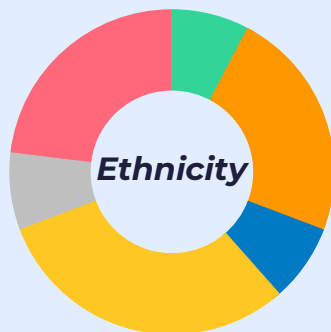*some young people experience multiple impairments

Ethnicity

White Jewish

White British & European
1

Arabic
1

Did not disclose
4

South Asian
3

Black British/Caribbean/African
1

Education / Employment Status

Student - Specialist School

In Work

Student - Mainstream School

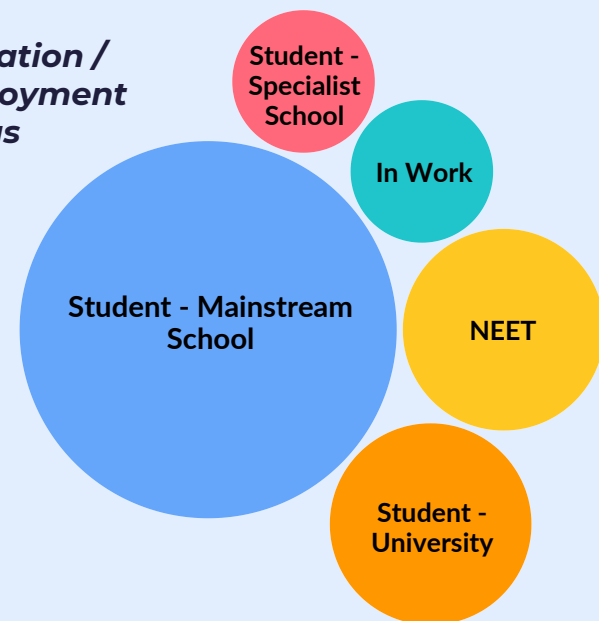NEET

Student - University

Figure 3: Participant demographics

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Some areas of consideration are listed below:

- There is a greater representation of children and young people who identified as male (n=8) compared to female (n=5). This suggests that outreach and engagement activities have been successful in engaging typically 'difficult' population groups, including adolescents, male participants as well as individuals from minoritised ethnic communities.
- Disability experiences vary; however, we noted a higher representation of children and young people specifically those who are neurodivergent.
- The majority of participants attended mainstream schooling, with the exception of two participants who completed/are in special schools.

It's also worth noting that engaging adolescents between the ages of 15-18 was difficult. One young person withdrew their participation on the day of the visit, and another did not want to interact with the research team when in the home. Both were between the ages of 15-17 years of age. Despite extensive outreach and engagement to specifically encourage uptake from this cohort, our experience tells us that young people between this age group may be less likely to want to take part in engagement and research activities.

Research Ethics

Habitus developed a robust ethical process and framework which was implemented throughout this project and worked with Barnet council's project steering group to oversee ethical responsibilities. Given the project took place during the summer holidays, and involved observations at a range of community and Short-Break settings, the research team ensured minimal interruption to children and young people's routines or schedules. The research team undertook active observations, ensuring they immersed themselves in the setting.

With respect to consent, Habitus provided parents and caregivers, setting providers and children and young people with information sheets during observations and ahead of in-person visits. Consent (verbal and written) was sought by children and young people throughout, with opportunities for participants to withdraw at any time. Parents and caregivers were also asked to sign consent forms. Consent from non-verbal children was obtained both through the parent or caregiver, and the children were allowed to refuse interaction with Habitus at any point during the team's visit.

Participants received a gift voucher of £30 for taking part.

Limitations

When considering the findings of this study, the following limitations should be taken into account:

1. Whilst the cohort was diverse in the range of disabilities and ethnicities of participants, there was an under-representation of female participants, as well as participants aged 17-19.
2. All of the participants, including parents and caregivers who engaged in the study self-selected to take part. The sample of the participants who engaged also do not serve to speak to the various experiences of disabled children and young people. As such, findings from this study serve to provide nuanced insight into the lives of a select number of participants.
3. Fieldwork period was short and spanned the latter part of the summer holiday. Whilst this was sufficient to observe specific settings and interact with a small cohort of children and young people, many participants were not available to take part owing to summer holiday plans. A longer data collection period, and access to educational settings would have allowed for broader sample of children and young people.

CREATING INCLUSIVE SPACES TO ALLOW CHILDREN AND YOUNG PEOPLE BE THEIR AUTHENTIC SELVES

For children and young people to be their authentic selves, they need to feel safe, seen and heard. Understanding how children identify, and their experiences of navigating the world around them is key to being able to create inclusive spaces. This is also acknowledging that some children or young adults identify as disabled, whilst others do not. Children and young people also share multiple and intersecting disabilities as illustrated in the Engagement Dashboard. Creating opportunities where young people and young adults can identify openly becomes important in feeling seen and creating opportunities to explore and express their identity.

Identity and ways of identifying differ and these can shape how children and young people navigate the world around them.

How children and young people identify, and in turn, how they engage with their social and community support varies depending on age, their disability as well as who they are. We found that exploring and pinning down concepts of identity and ways of identifying can be difficult, especially for younger children and those with learning needs.

We found that participants share multiple and intersecting identities – whether that is ethnic heritage or disability experiences.

There is a marked difference in how children and young people talk about themselves (see Figure 4). Therefore it is important to take an intersectional approach by recognising how intersecting identities influence lived experience, particularly for children and young people from multiple minoritised groups.

Firm sense of identity and confident to express themselves

Self-expression and identity is beginning to develop

Interactions mostly centred around themselves - conversation are around "me", mentions of others are centred around their role in their lives.

Understanding of their condition and what it means develops

Aware of their disability and how it shapes their needs

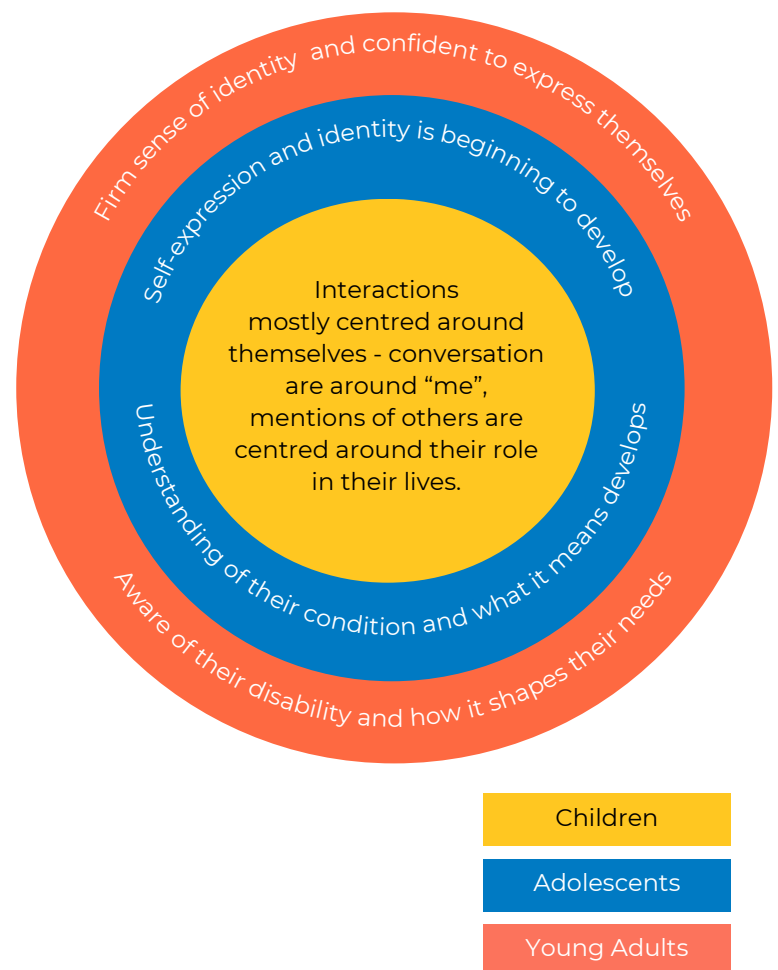Children

Adolescents

Young Adults

Figure 4: Stages of Awareness

Below are three stories which reflect the experiences of disabled children and young people. These highlight the different ways in which children and young people think about their identity and who they are. These stories tell us that understanding lived experience and a young person's context is important in creating opportunities for them to be able to identify in different ways.

Kwame and Imani

Kwame (6 years old) and Imani (9 years old) come from a large family who have been settled in the London area for 20 years. They live at home with their mum and three brothers. Although both Kwame and Imani are both Autistic and non-verbal, they communicate and interact with people and places in very different ways. Kwame is more open to interacting with people and likes to use gestures and expressions to help him communicate. Imani prefers to not make eye contact and will reach out by touching someone's hand if she needs something. Both siblings also share very different characters, with Imani preferring to spend time by herself watching videos. Kwame loves to play with car toys, and this can be a great way to interact with him.
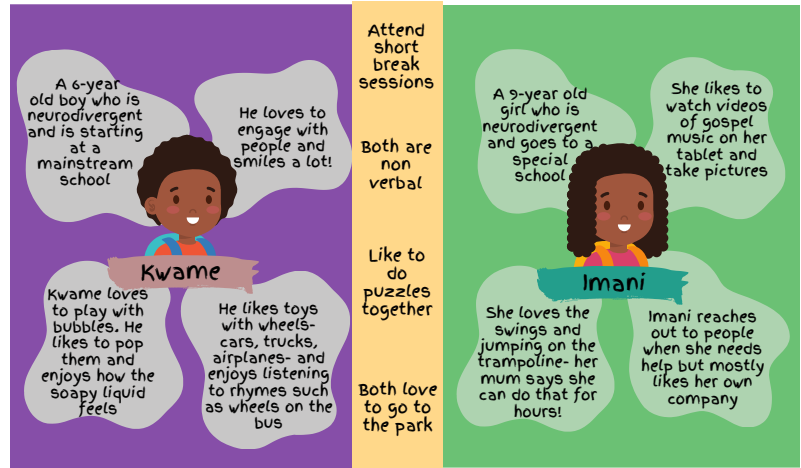
Figure 5: The lives of Kwame and Imani

Taylor

Taylor is 13 years old and is neurodivergent. She goes to a mainstream school which she enjoys and spends her evenings and weekends either at home or at her grandparents. She is aware that she is Neurodivergent, but this doesn't stop her from doing things she loves. Taylor loves musical theatre, writing songs and reading about politics and history. She is confident and sure of herself and what she likes and doesn't like. She uses how she dresses or what she listens to as forms of self-expression.

Taylor spends her free time taking part in a range of activities – from rock climbing to spending time alone to drawing in her colouring book, which she finds therapeutic. Apart from her family, Taylor does not really hang out with people her age, and prefers the company of her SEN support worker or her teachers. She prefers to spend time alone, do the things she enjoys, and finds being in crowds quite difficult. Taylor has very strong beliefs, particularly relating to feminism and gender equality, and she expresses these confidently.
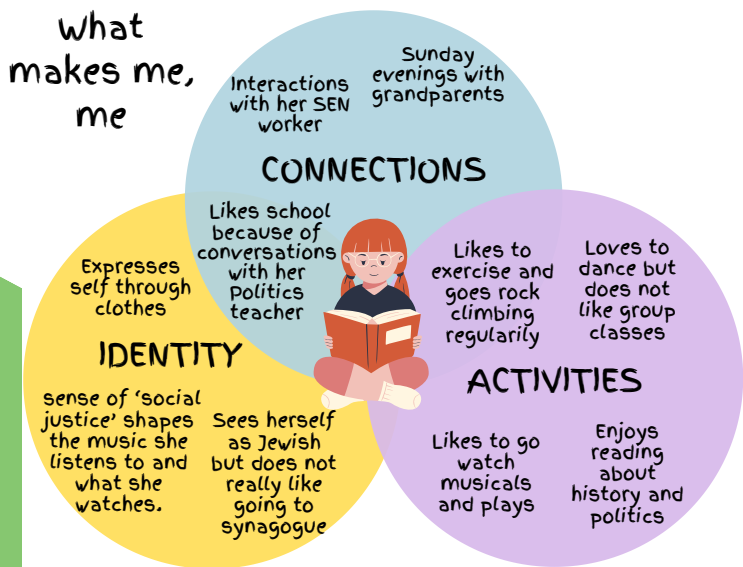
Figure 6: Different aspects of Taylor's identity

Samuel

Samuel is in his early 20s and has grown up in Barnet for the most part of his life. He identifies as Black British, but in respect to his disability, Samuel prefers to identify as 'partially blind' or as 'having poor vision' rather than as disabled. Although Samuel sees his disability as part of who he is, he doesn't feel like he's always given the opportunity to identify in the way that he wants to. He's found this to be the case especially when trying to access support, for instance for benefits or work, where eligibility assessments are based on his disability rather than need. This makes Samuel hyper-aware of his disability. He feels that he is made to choose how he can identify, even though this may not speak to his experience. How Samuel discusses his identity is shaped by his social surroundings. He uses the word "being allowed" when speaking about how he is able to identify in a way that speaks to him.

It depends on the space where I am at. In some spaces, probably for some applications you have to put in. You don't see things like partially blind. It just asks you, are you disabled or not? And you just have a yes or no answer. So in those spaces, I don't have any option to identify as disabled, or physically disabled. If I'm in spaces where I'm allowed to give details and allowed to talk more about the specific condition, I'll prefer to identify as being partially blind.

Samuel lives a 'normal' life by working as a freelancer whilst pursuing his studies. He sees himself as a normal young adult and wants to challenge perceptions about how people perceive him. Samuel is highly motivated to challenge the perceptions of disabled people and has aspirations for setting up his own marketing agency.
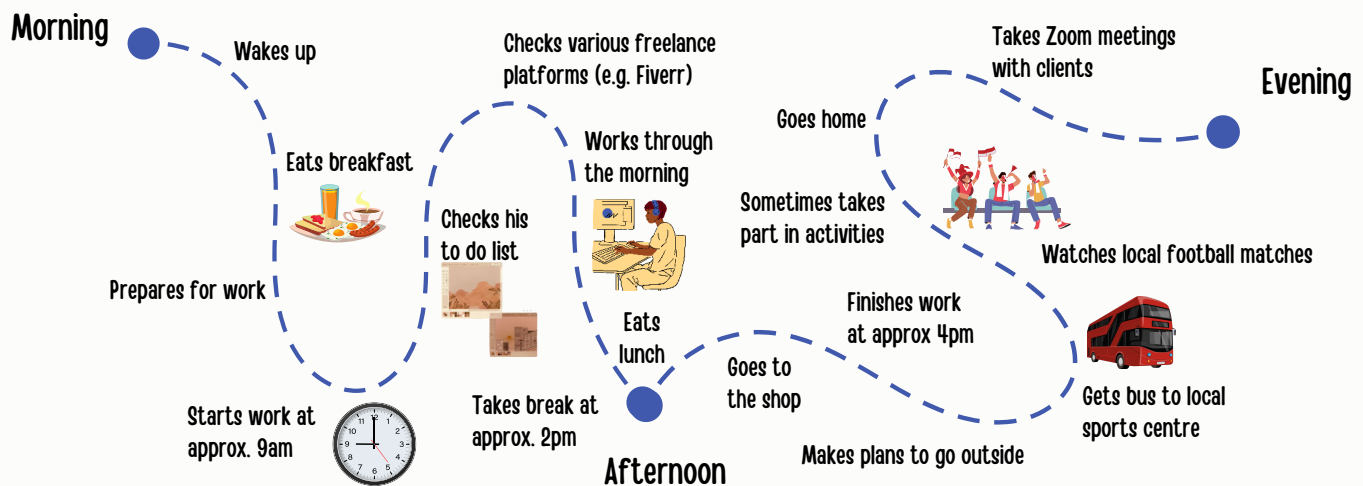
Figure 7: Samuel's daily routine

Hassan

Hassan, also in his 20's, has lived in Whetstone for much of his life. He went to a mainstream school and is an active member of his community. For Hassan, his disability is part of who is he, and finds that it is other's perception of his disability that becomes a barrier.

I wouldn't say I identify as disabled even though people can have different opinions about it. I just know when people are talking about disability, they're talking about the 'lack of'... I don't allow it to stop me from doing whatever I want. I have second thoughts on what I could do or couldn't do. But then I really don't allow that to determine a lot about my life.

Integrated and intergenerational services fulfil a need and are important in creating inclusive spaces for children and young people.

Educational and community settings become highly important in creating opportunities for friendship and connections and preparing children and young people for key stages of transition. Some children we spent time with preferred to play on their own, whilst others struggled with interacting with their peers. This was raised as a concern for parents who worried their children would become isolated. For some children like Rosie, short-Breaks were their first introduction to educational or community-based settings outside of the home. These spaces are important in supporting transition into primary school by providing children with structured routines, and opportunities to develop social skills to feel confident and comfortable in new spaces and settings.

Rosie

Rosie is 5 years old, and she attended her first Short-Break at a special school in Barnet. Rosie is new to a class setting, her parents enrolled her for the summer to get her ready for primary school starting in September. Her parents could set some learning goals for Rosie to meet during this time, and it has given her the opportunity to socialise with peers and provide a structured schooling routine. She enjoys coming to the setting and has learnt how to eat by herself and communicate using cues. She is now more confident and better able to express her needs more openly.

Ensuring that children and young people from different backgrounds and experiences have opportunities to mix and socialise is also incredibly important. Despite there being an appetite for opportunities to spend time with peers who go to mainstream schools, these spaces aren't always available.

This can result in disabled children and young people being siloed, which in some cases can lead them to feel 'othered'.

Alicja

Alicja attended a drama school this summer delivered by a large theatre company in Barnet. This was Alicja's first time going to a setting that had children from mainstream schools as well as disabled children. For Alicija, this was an opportunity to meet young people of similar ages but of different backgrounds and experiences. She initially found the space to be overstimulating and it took her some time to settle and become accustomed to it. This was facilitated by the support worker who helped Alicja when she was feeling overwhelmed or stressed. Over the coming weeks, Alicja began interacting with new people, something she had previously struggled with. Since then, she has taken up more drama classes and is looking forward to the next summer camp. For Alicja's mum, this setting has helped her realise that her daughter can and wants to take part in more inclusive and open activities.

It is important to recognise that specialist settings have trained staff and resources to support disabled children and young people in a way that many public spaces do not. For instance, trained support staff, accessible toilets, hoists and 'quiet rooms' are not always available, which can be a key barrier to disabled children and young people accessing mainstream settings.

Recognising these barriers and finding ways of bridging siloed ways in which services operate can be an important element in creating a truly inclusive borough that celebrates difference in all forms.

CONSIDERATIONS!

- Professionals, or those working with disabled children and young people, need to adopt a range of approaches when engaging with them. Play becomes important when interacting with younger children, whereas older adolescents may prefer to interact through conversations. Leaving enough time for them to respond and being led by what children and young people want to talk about is key.

- Young adults have a stronger grasp of who they are and how they want to identify. Some identify as disabled whilst others do not. What impacts this is the spaces and places that allow them to identify in ways they want to, including who they are interacting with.

- Looking at how community settings and services can be designed to bring together disabled children and peers can transform how the borough embeds Equity, Diversity and Inclusion. This means also looking at how offers and services can be integrated to allow for an exchange of experiences and create a sense of belonging and connection.

- Recognise that making friends can be difficult for some children and young people who prefer their own company. Finding ways of supporting them to interact and play with peers in a way that feels comfortable can be important in building their confidence and socialisation skills.

SUPPORTING CHILDREN AND YOUNG PEOPLE THOUGH RELATIONAL AND TRAUMA-INFORMED APPROACHES IS VITAL

Person-centred and highly relational approaches to supporting children and young people can result in transformative outcomes. How professionals in educational and play settings interact with non-verbal children through touch, play and personal connection can instigate meaningful connections. In turn, this can facilitate trust and create a sense of safety that allows children to engage meaningfully. Observations conducted in a range of settings revealed the varying ways in which staff embed relational and trauma-informed approaches.

Finding ways of engaging and interacting with children and young people in a way that speaks to their lived experiences can present opportunities to better support them. In the long term, this can also ensure that young people grow up to have positive experiences and perceptions of statutory services and professionals. For instance, regular and consistent communication and familiarity with a professional can be highly important for children and young people to build trust. The Barnet disability study on disabled adult residents found that a lack of consistency, poor communication from professionals and negative experiences early on can result in individuals disengaging with council and community services (Habitus Collective, 2023).

The children in Blossom Class love coming to class during the summer holidays. Their favourite part is sensory story time where they get to sing and have a massage whilst Miss Vanja tells them stories. Miss Vanja and the team let the children in class hold hands or give hugs when they want to. This is especially nice for children like Oscar who sometimes struggles to settle down. When he needs some quiet time, he can make eye contact with Miss Vanja who will pick him up and cuddle him before settling him on the comfy chair. Miss Tina and Esme are also great with Raza and Savannah who need a bit of help sitting up. They tell Raza and Savannah what they're going to do so they can both prepare and know what's happening next. This is important because it gives the children in Blossom Class an opportunity to respond to what is happening around them. These small but very important approaches help children like Oscar, Raza and Savannah communicate, but also provide them with opportunities to make decisions for themselves.

Conversations with young people who had experiences engaging with a range of professionals highlighted the importance of person-centred and trauma-informed approaches. Having a professional who listens, can relate to, understands the young person's circumstances, and supports them holistically can instigate a wave of change, as highlighted by Hassan's story below.

Hassan describes himself as being passionate about helping people. One of his aspirations in life is to "give back to the community" the support he received while growing up. He is currently studying for a diploma in Social Work and was inspired to pursue this field after interacting with a charity programme coordinator who was also a wheelchair user. Hassan spoke fondly of this person and explained "*I think he was such a lovable person. He was also a disabled person and for me that helped because I saw someone like me. He had so much positive energy, and he was able to help me a lot because of the work he did I felt like there is a lot that I can do for myself, and I think all of the things that drives me. So he was like more like a mentor or like somebody that inspired me.*"

Hassan's story shows how relational approaches can lead to young people feeling inspired and hopeful. These can be powerful mechanisms that can create the conditions for children and young people to thrive.

CONSIDERATIONS!

- Building a rapport with parents and caregivers is important when engaging with disabled children and young people. It is necessary to consider the role these adults play in a young person's life and engaging with them is a key part of taking a relational approach.

- Positive role models are integral while growing up. Young disabled adults described how interactions with the adults around them during their childhood shaped their hopes and aspirations for the future.

EXPERIENCES OF TRANSITIONAL STAGES: PROVIDING THE RIGHT SUPPORT AT THE RIGHT TIME IS CRUCIAL

Interactions and conversations with young people and parents revealed that having a range of informal and formal support mechanisms, and access to the right support at the right time can make a huge difference during periods of transition. Not all young people, parents or families know about the types of support that exist to help during challenging periods, which in some instances can lead to heightened barriers and difficulties.

Findings from conversations, reflections and observations reveal that having access to the right information and support in accessible ways can lead to difficulties being addressed and prevent these from becoming larger issues leading to negative outcomes.

Transitions can be stressful and lead to children and young people experiencing difficulties and stress.

Children and young people experience transitions in different ways. Some find changes to their daily routine or structure (however big or small) stressful, which can lead them to withdraw or disengage. For some youth, like Zain (see below), these can be exciting moments, which allow them the opportunity to try new things or 'push themselves' in a different way. Without the right support, transitionary phases can be highly stressful and lead to negative changes in behaviours. What emerged from conversations with young people and parents was the importance of allowing them to share their experience.

Creating space for this to happen can be highly valuable. Educational and community settings become highly important in creating opportunities for friendship and connections and preparing disabled children and young people for key stages of transition. For some children, accessing Short-Break settings helped them transition into primary school. These settings can help children prepare for structured routines, whilst also developing social skills to feel confident and comfortable during transition stages.

Holly is a 13 year old Autistic girl who loves academic work but has had a difficult time adjusting at school. She previously attended a mainstream primary school, which she enjoyed and her mother felt was 'a good fit'. As she got older, she had less in common with other students in terms of accessibility and interests and could not connect with them. She attended a special school for secondary, which Holly describes as 'okay for the first year but afterwards it was all downhill'. While her physical needs were supported- toileting and accessible spaces- her mental and emotional needs were overlooked. It is difficult for Holly to reach out and express these needs, with staff reporting her as 'being absolutely fine at school' and that she should 'just tell us what she needs'. These experiences led to her leaving school. Currently Holly is waiting for the result of her educational assessment and hopes to continue learning at home.

There are many different transitions that children and young people experience. This can be from a play setting to school, school to higher education or from living at home to independent living. These periods can be highly stressful for children and young people – they can disrupt routines and, a sense of familiarity and cause changes in behaviours. It can also make young people feel vulnerable, particularly if this is their first experience of doing something on their own. Conversations with young adults revealed that transitioning from primary to secondary school required adjustment – and many found mainstream schools to be challenging because of the attitudes of peers.

Making friends was raised as being difficult because of the pressures around fitting in, or lacking the skills to build relationships, particularly with others who also find this challenging. As such, professionals such as teachers and SEN support workers were considered as 'friends' for a number of children in this study.

Though transition periods are part of growing up, they can impact disabled children and young people over time. Parents, extended family, and friendship groups can be important in supporting youth during change periods. Friendships in particular can easily get lost in this transition. There may be instances where professionals can support children and young people to navigate new experiences. Stories from young people reveal that having support and being able to share their concerns or experiences can be important in not feeling alone.

Zain

Zain is a 16-year-old wheelchair user. He moved to Barnet from Lebanon 3 years ago with his mum and twin sisters. This was a tricky time for Zain because he had to adjust to a whole new way of life. It was made harder because Zain started school - something new to him as he'd been home-schooled in the past. Zain describes his first few days at school as scary, but he had a support worker who helped him settle. He knew that "trying new things is always scary" but having someone to support helped him settle and be confident in going to school. He has now made friends and enjoys going to school. For Zain, school is the only place where he can socialise with his friends and engage in activities that he likes such as swimming and art classes. While he wishes he was able to do these things outside of school, it is difficult as his mother (his primary caretaker) would have to be there to support him. He has explored going to local activities, but found that these are usually catered to younger children.
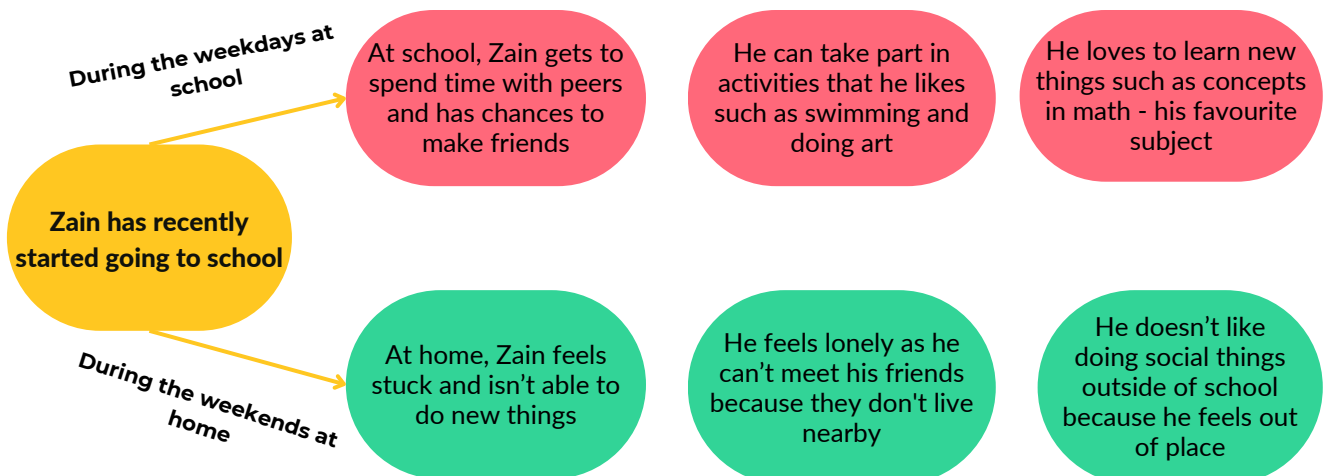

Figure 8: Zain's experiences

Access to the right support at the right time can be key in creating conditions for disabled children and young people to thrive.

We found that like adult disabled residents in Barnet, children, young people and families rely on the council to have their basic needs met. This is particularly important if families are isolated, or do not have strong community connections. For disabled children and young people who share multiple and, in some cases, complex needs, knowing where to go for support can be transformational. This combined with access to person-centred holistic support, and accessible information relating to benefits, education, employment and eligibility can help ensure children and young people achieve the best possible outcomes.

Conversations and observations revealed that Short-Break settings and community groups are important and can be key sources of information and support. Parents discussed drawing on each other's experiences to find out about different providers, or information about sessions in and around the borough. Accessing information through formal routes appears to be a barrier for many. Young adults especially said they wanted to know more about what they could be eligible for, particularly around housing, training, and employment. Providing information about these areas in ways that reach young people is important in ensuring information is made available inclusively and equitably. Suggestions from young adults included the use of social media, whilst others suggested posters at libraries, cafes as well as in educational settings like colleges. Hosting information sessions in assemblies or 'seminars' at educational settings on services available to disabled youth can also be powerful in ensuring young people have access to information and support when they need it.

A standout barrier is access to different services. I was only lucky to be aware of these services through some of my friends... there's not so much information around this about the services. I know where to look out for information, but even then there is still information that I miss. And I'm not aware of why. I feel like having all this information coordinated and, in a space, makes it easier for different people to know and be aware of the different services and support that is available for them. (Adan, 23).

What emerged from conversations with participants is the importance of equalising opportunities, particularly for disabled children and young people. There are instances where the support received by the council and educational settings led to young people gaining independence and opportunities to thrive.

When reaching out to young people, it's important to reach out with a message about why it's important to them. So like training or employment – this is to get their attention and work with the right channels to reach them. (Hassan, 21).

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Andre moved out of his family home soon after he finished school. Now in his early 20s, Andre lives independently and shares a flat with two friends. Before moving out of home, Andre explained that he had no idea about how to go about finding an accessible flat, sorting out benefit entitlements and accessing the support that would allow him to thrive. He explains that this was because "*my dad was concerned with all of those things when I was at home. I didn't know anything. When I was young, I used to think it would be easy to get my first house on my own. The reality was that I knew very little.*" Andre approached Barnet council and was provided with support from a Housing Officer. The Officer helped Andre find an accessible apartment that had enough space and was in good condition. He was able to get support with budgeting, filling application forms and information about how to sign a contract and maintain a tenancy agreement. Because of this, Andre has been living independently which he says is important to him as a young disabled resident. Andre is now settled and pursuing higher education in Public Administration at Middlesex University. He has also established himself in the community and loves living in Barnet.

In contrast, in cases where focus has been placed on one aspect of a young person's life, this can lead to negative outcomes. Acknowledging and responding to disabled children and young people's physical and emotional needs becomes an important part of upholding the Social Model of Disability. This includes opportunities for children and young people to be able to express themselves and the difficulties being experienced. Often, stigma relating to poor mental health and disability can result in young people disengaging from services, which in the long term impacts the outcomes they can achieve. Having a range of services to support multiple needs also can minimise the reliance that families have on council services, and in turn, offer a more holistic approach to support young people. Continued funding for community-based and specialist services can be important in being able to adequately support young people, particularly during transition phases.

The two examples highlight the importance of taking into consideration both mental and physical well-being when supporting disabled youth and young adults. As many young people explained, their disability is part of who they are, and though they may require support relating to accessibility or accessing specific support, they also require access to services for their mental well-being.

Sally is 13 years old and enjoys learning. She is verbal, neurodivergent, uses a wheelchair and is confident in getting out and about. She attends a specialist secondary school as she found it very difficult to connect with her peers and make friends as she got older. Holly recently had a bereavement in her close family, which has left her needing emotional support. Both she and her parents feel like her emotional support needs went unnoticed at school as Sally finds it challenging to let others know how she is feeling and ask for support. This has led to Sally feeling like school is a negative space for her now.

CONSIDERATIONS!

- Transitional periods can be difficult for young people but also affect their caregivers. As caregivers are spending time engaging with professionals to access services, it takes away time to support the young people.

- It's important to take a 'whole self' approach when supporting disabled children and young people. This means recognising and responding to physical as well as emotional and psychological needs.

- While feeling connected and able to interact with peers when younger, transitional periods have been identified to highlight differences. Recognising that change can bring uncertainty and be a period of anxiety requires focused support to help children and young people manage periods of transition.

CONNECTED PARENTS LEAD TO CONNECTED CHILDREN

Children and young people are not separate from their families, and taking the familial context, including immigration status, housing, as well as financial stability is important in finding ways of supporting children and young people holistically. Embedding a Think Family approach to practices helps minimises the challenges that disabled children and young people are likely to experience by looking at familial circumstances. This can help promote an equitable practice by ensuring that the planning of care packages includes the whole family.

Understanding familial context

Children and young people take part in a range of activities within their community. This is often determined by the family's context. We found that some parents were well connected to their area, and had strong networks, which led to children and young people engaging in a range of activities - for instance, rock climbing classes or activities led by community organisations. Having links and connections also meant parents were able to find out about local services through word of mouth and broaden awareness around the type of activities and services they could access with their children.

In contrast, less connected parents have less awareness of activities and services available, which impacts how disabled children and young people engage in community life. How well a parent is connected can shape how a disabled child or young person is connected to their community and can either limit or enhance opportunities for socialisation.

Kwame and Imani's family arrived in the UK 20 years ago. Kwame and Imani's mother, grandparents and their mother's brothers and sisters all moved over together.

They don't get to see their grandparents much as they'd like to because their grandparents are caregivers to a relative who is disabled. They still speak over the phone every week.

They see their uncle very often, and he looks after them when Mum needs some time for herself. Kwame, Imani and their brothers love spending time with their uncle. They get to go to the park and leisure centres all the time.

They also have family friends nearby who have children around Kwame and Imani's age. Their mother says they love coming to play with Kwame and Imani. Mum also finds out about new activities through her friends which means Kwami and Imani get to try new activities.

Figure 9: Kwame and Imani's social networks

Dami is 5 years old, and lives with Mum, Dad and his little sister

Dami's mum arrived in the UK alone, and had to leave her family behind

Dami loves to do play with his train set and draw.

Dami was diagnosed with Autism in early 2023

Mum has struggled to get support for Dami, because he was only recently assessed

He has a picture of his graduation from nursery which he likes to show people

Because Mum doesn't know about services she can access, Dami doesn't tend to take part in activities very much

Dami attended his first short-break setting this summer, and enjoyed it very much

He doesn't like winter because he doesn't get to go out and play

Dami will be starting school in September

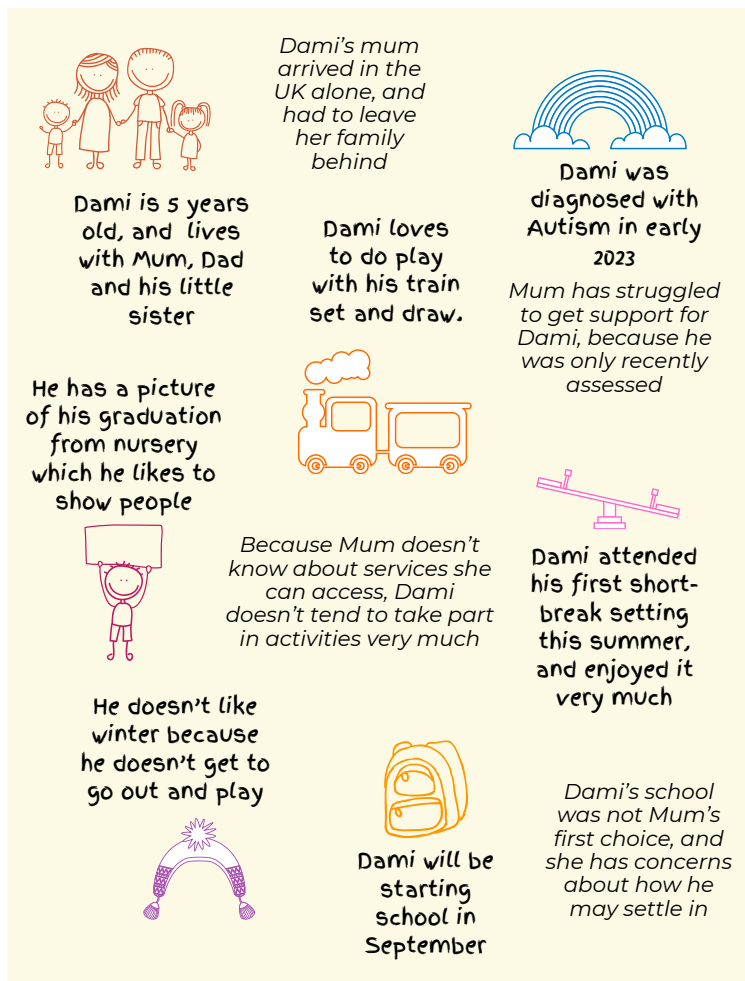Dami's school was not Mum's first choice, and she has concerns about how he may settle in

Figure 10: Dami's context

Dami is five years old and arrived with his mum and sister a few years ago from Albania. They are a migrant family, and Dami's mum does not have any family or connections in Barnet. Dami was only recently diagnosed with Autism, and his mum has not been receiving support until very recently. Figure 10 shows Dami's family's context and provides a glimpse into the wider familial context. It shows that Dami's experiences are not formed in isolation.

Dami's mum has been trying to access support since arriving and has been in contact with a range of professionals and organisations. She is worried that Dami may struggle without the right support, but because she is new to Barnet, she does not know what she can access or what they are entitled to. Despite Dami being diagnosed with Autism earlier this year, Mum does not feel like he is getting the right support at the right time, which she fears will impact his educational and well-being outcomes in the long term.
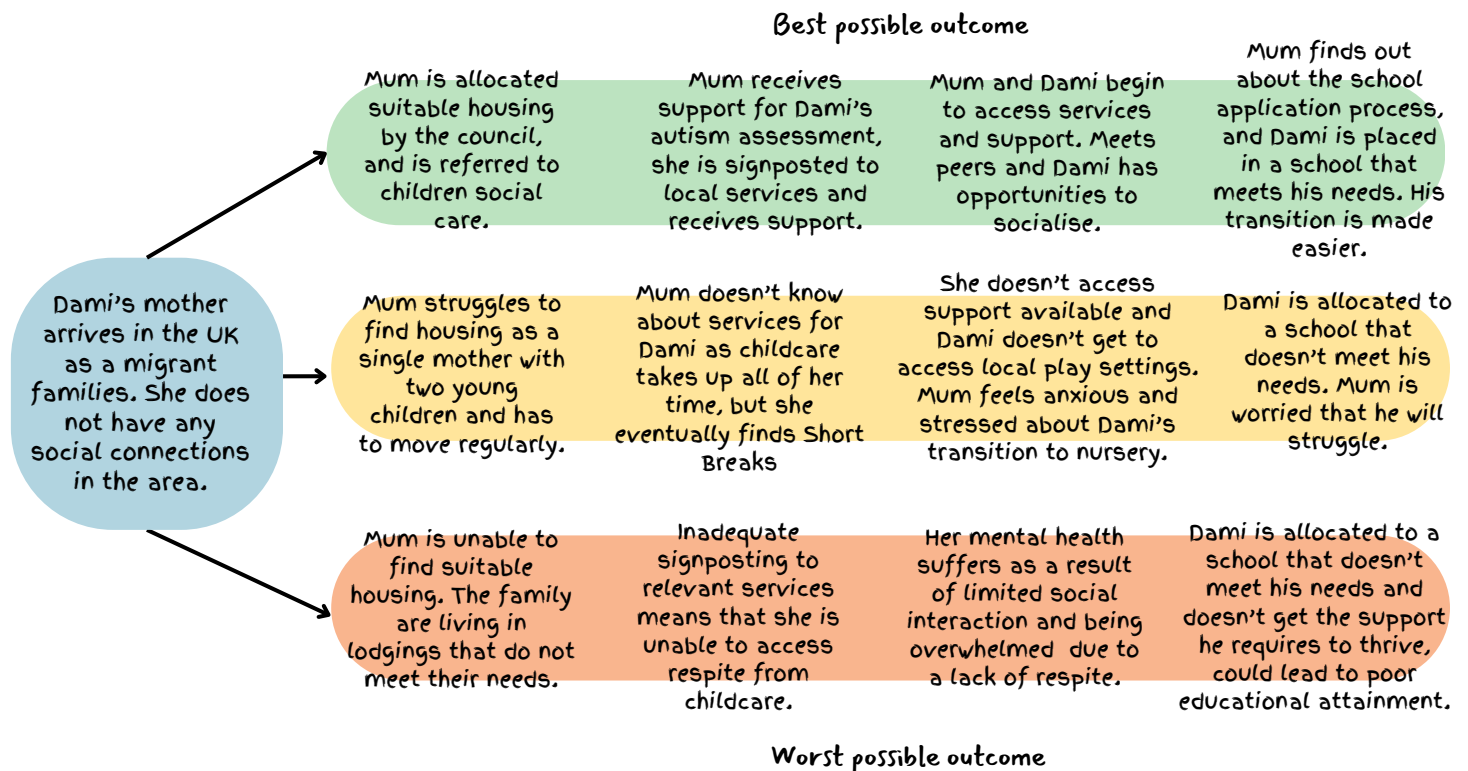

Best possible outcome

Dami's mother arrives in the UK as a migrant families. She does not have any social connections in the area.

Mum is allocated suitable housing by the council, and is referred to children social care.

Mum receives support for Dami's autism assessment, she is signposted to local services and receives support.

Mum and Dami begin to access services and support. Meets peers and Dami has opportunities to socialise.

Mum finds out about the school application process, and Dami is placed in a school that meets his needs. His transition is made easier.

Mum struggles to find housing as a single mother with two young children and has to move regularly.

Mum doesn't know about services for Dami as childcare takes up all of her time, but she eventually finds Short Breaks

She doesn't access support available and Dami doesn't get to access local play settings. Mum feels anxious and stressed about Dami's transition to nursery.

Dami is allocated to a school that doesn't meet his needs. Mum is worried that he will struggle.

Mum is unable to find suitable housing. The family are living in lodgings that do not meet their needs.

Inadequate signposting to relevant services means that she is unable to access respite from childcare.

Her mental health suffers as a result of limited social interaction and being overwhelmed due to a lack of respite.

Dami is allocated to a school that doesn't meet his needs and doesn't get the support he requires to thrive, could lead to poor educational attainment.

Worst possible outcome

Figure 11: Outcomes for Dami's mother

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Finding belonging and community – what young people want

All the disabled children and youth who took part in this study spend the majority of their time in Barnet. This included accessing educational settings as well as Short-Break and community activities. Six of the thirteen participants accessed Short-Break settings, and an additional three are currently being supported by the council's 0-25 Disabilities Services. Of the four young adults, only one engaged with a community-based voluntary organisation which they had done since they were adolescents.

Many of the parents who have lived in Barnet for some time had a good understanding of the services available and used their social networks to find out information and keep up to date. There were a handful, like Dami's mum who were new to Barnet and were still finding their feet. Some parents like Alicja's mum noted not being aware of Short-Break providers and community sessions close by to them and instead travelled across the borough to take their children to classes which met their interests and individual needs. When told about local activities, parents expressed willingness to sign up for these. What this suggests is an appetite for parents and disabled young people to engage in a range of community-based activities, as Alicja's mum explained:

> **I want the best for her (Alicja), she is very sure of what she likes and it's sometimes difficult to find activities that will interest her. We try and find drama and arts-based classes, but apart from the one in North Finchley, I don't know of many nearby.**

The young adults who took part had a strong sense of belonging to Barnet and their community. Almost all explained that they didn't feel a 'need' to venture outside of the borough because they had 'everything they needed' in Barnet. As Samuel explained:

> **If there's a serious need for it I'll go out of Barnet, but there's not so much of a need for me to go outside the valley. On weekends I visit the cinema or parks with friends, but that's all in Barnet.**

What young people want is more spaces and opportunities to socialise with friends, including peer-led spaces where they can share stories, advice, information and importantly find meaningful connections with others. Having spaces where disabled youth can feel empowered, and find out about initiatives and support offers available to them is important in helping them feel part of a diverse and equitable borough. Many young adults want to become disability advocates and work closely with the council and community services to improve barriers for all disabled people across the borough. The willingness of young people and adults to be involved in decision-making processes is a testament to them already feeling like they belong in Barnet.

> **I love living in Barnet, you have different kinds of people - you have people from the upper-class middle-class and lower-class all living in Barnet, and I like the fact that it's also a sound environment. I think there is so much less of the city noise. In Barnet, I enjoy the trees and parks. (Adan, 23).**

CONSIDERATIONS!

- Parents of disabled children and young people need respite. While Short-Breaks and local activities have been useful in providing space and time for caregivers, many parents do not have the time to connect with their community as much of their day goes to supporting their children. Providing opportunities for parents to engage with their community allows children and young people to go out and engage as well.

- Disabled young people are eager to participate in activities, but they lack information about access to events and services nearby. It is important to reach out and connect with young people in places that they frequent as well as using ways that work for them- going to them instead of waiting for them to come to us.

- Considering how disabled youth access information or keep up to date is important, especially in making them feel part of Barnet and within their community. Using social media or creative means to circulate what's happening can be an important way of getting them to participate in council and community life.

RECOMMENDATIONS

The recommendations outlined below mirror those of the Barnet Adult Disability study as there are overlapping themes in the findings from both.

1 **Understanding how disabled children and young people identify and want to be identified is key to meaningfully engaging them.**

- Minimising barriers to how children and young people can identify is important – for instance, having forms which ask whether individuals have a disability or not can remove opportunities for youth to identify in a way that speaks to them. It may also lead to children and young people feeling 'othered'.

- Embedding a 'whole self' approach when supporting disabled children and young people, including responding to physical as well as emotional and psychological needs and involving them in decision-making processes is central to equitable practice.

- Using play or creative methods can facilitate conversations with disabled children and young people, and allow them to engage in ways that help them connect.

2 **Consider how disabled children, young people and their families access information and find different modes of making this accessible.**

- Considering how disabled youth access information or keep up to date is important, especially in making them feel part of Barnet and within their community. Using social media or creative means to circulate what is happening can be an important way of getting them to participate in council and community life.

- Using community networks and links to share information about services and local activities using simple and accessible language can help families and disabled children find out about what is available across Barnet.

I think what we need is for the council to bring out empowerment initiatives, to help disabled people feel empowered. I think this will strengthen the local community and help disabled people like me feel like there are things for us in our area.

3
Community matters – working with voluntary sector organisations can help disabled children, young people and their families engage meaningfully in community life.

- Building a rapport with parents and caregivers is important when engaging with children and young people. Taking a 'Family First' approach is necessary to ensure children, young people and families are supported in the right way.

- Linking and collaborating with community organisations that offer a range of offers can help disabled children and young people feel part of a community. This includes broadening peer spaces so that children and young people can develop a sense of belonging.

4
Create opportunities to enable disabled youth and their families to engage in community life and civic participation in different ways.

- Looking at how community settings and services can be designed to bring together disabled children and peers can transform how the borough embeds Equity, Diversity and Inclusion. This is also looking at how offers and services can be integrated to allow disabled children and young people to take part in mainstream activities and vice versa.

- Broadening opportunities for engagement in consultations, and council and community meetings can help disabled children and young people feel part of a dynamic borough. Using social media platforms and word of mouth can be useful ways of sharing opportunities.

I wanted to get involved in this study because I want to improve and contribute to improving services. I want to feel like making changes to better the situation for disabled young people in Barnet.

CONCLUSION

This study is part of a larger research project to develop an understanding of the experiences of disabled residents in the borough of Barnet, to centre disabled children and young people. Key findings from the study include:

1. **Diverse and inclusive spaces allow disabled children to be their authentic selves.**
2. **The importance of creating environments where trusted and peer relationships can flourish.**
3. **Taking a whole-person approach during transitional stages is crucial to disabled children and young people having the right support at the right time.**
4. **Connected parents lead to connected children.**
5. **Young people want to be included in decision making and creating solutions.**

While findings from the adult study emerged here and remain important - lack of awareness of services, intersecting identities, and the need for community - for the disabled children and young people that participated in the study highlighted different aspects of these broader findings. Growing up in Barnet presents disabled children and young people with a range of opportunities to achieve key milestones. However, barriers faced echo those experienced by disabled adult residents.

For the disabled children and young people who took part, how they identify can be tricky. We found differences between ages, disability experiences and protected characteristics. What is clear though is that their perspectives of identity are constantly changing. How disabled children and young people are able to identify is also contingent on the spaces and people they interact with. In some instances, disabled youth feel like they are not given opportunities to identify in the way they want to. Taking an intersectional lens, and understanding that children share multiple and intersecting identities which shape their experience is key to being able to support them. This also means embedding new ways that allow young people to identify in ways that speak to them.

This also requires considering how processes can be adapted to allow children and young people to express themselves in ways that they see fit, rather than what we expect expressions of identity to look like.

Meeting young people where they are and in ways that they want to be approached is essential in creating trust and hearing from them about their experiences. Relational approaches are integral here as familiarity and trust make it possible for young people to reach out and seek help. Role models, as illustrated through Hassan's example can be incredibly important for disabled youth to feel seen. This can also influence their aspirations for the future.

Much like findings from the adult study, the familial context becomes extremely important. Disabled children and young people cannot be viewed in isolation as much of their lives involve their parents and caregivers. It is necessary to consider the support that families of disabled children have to adequately address the needs of children and young people. A Think Family approach, as outlined can be an important practice-based way of supporting families in the borough.

Growing up in Barnet can be exciting – the borough offers diverse and inclusive opportunities for disabled children and young people to socialise, access support and have their needs met. Despite this, the needs of disabled children, young people and families are growing. The stories and case studies presented in this study highlight some of the barriers and challenges faced. It seeks to bring to light to their lived experiences and nuanced insights into the day-to-day life of a small cohort of disabled children and young people. Many of the participants who took part want to have a say and have solutions to the barriers faced.

Continuing to create a range of opportunities for them to voice their experiences can instigate meaningful changes and help them feel part of a strong, more inclusive and equitable borough.

These photos are a collection of pictures taken by children who took part in the study. They took pictures of the things that make them happy.

APPENDICES

Appendix A: 'Activity Packs'- various tools used to engage with children and young people

My School
ABCD

My favourite thing about school

My friends are called

Going to school makes me feel

HELLO! All About Me

My name is

My birthday is

For fun, I like to

My friends' names are

When I grow up, I want to be

The things I love most are...

I live with my

This year, I want to....

My Family

The people in my family are

Together, we like to

My family is special because

Things I Love

These are a few of my favorite things:

Food:

Movie:

Book:

Animal:

Game:

Song:
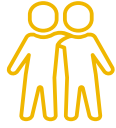
Dessert:

Interesting Things About Me

What makes me smile?

Stick a star on what you've taken a picture of!!!

This is Me!	Food	My Family
Something Fun	Friends	Park
School	My Home	I don't like
What makes me happy	My favourite thing	Play

We're inviting Disabled young people who live in Barnet to capture their day-to-day lives through photos. We've included some prompts below:

Want to share your daily routine? This can include what your day looks like and what you tend to do.

Any barriers or difficulties that you wanted to capture?

Have you seen something that has inspured you, or made you feel a certain way?

Have you taken part in any activities, events or outings? This could be something new you've tried or you've wanted to do for ages.

How to take part:

1. Take a picture or a set of pictures that inspire you, make you feel a certain way, or capture your experiences as a young person.
2. Send these to us via WhatsApp or message to 0777 819 2139 or email at Khushi@habituscollective.co.uk

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