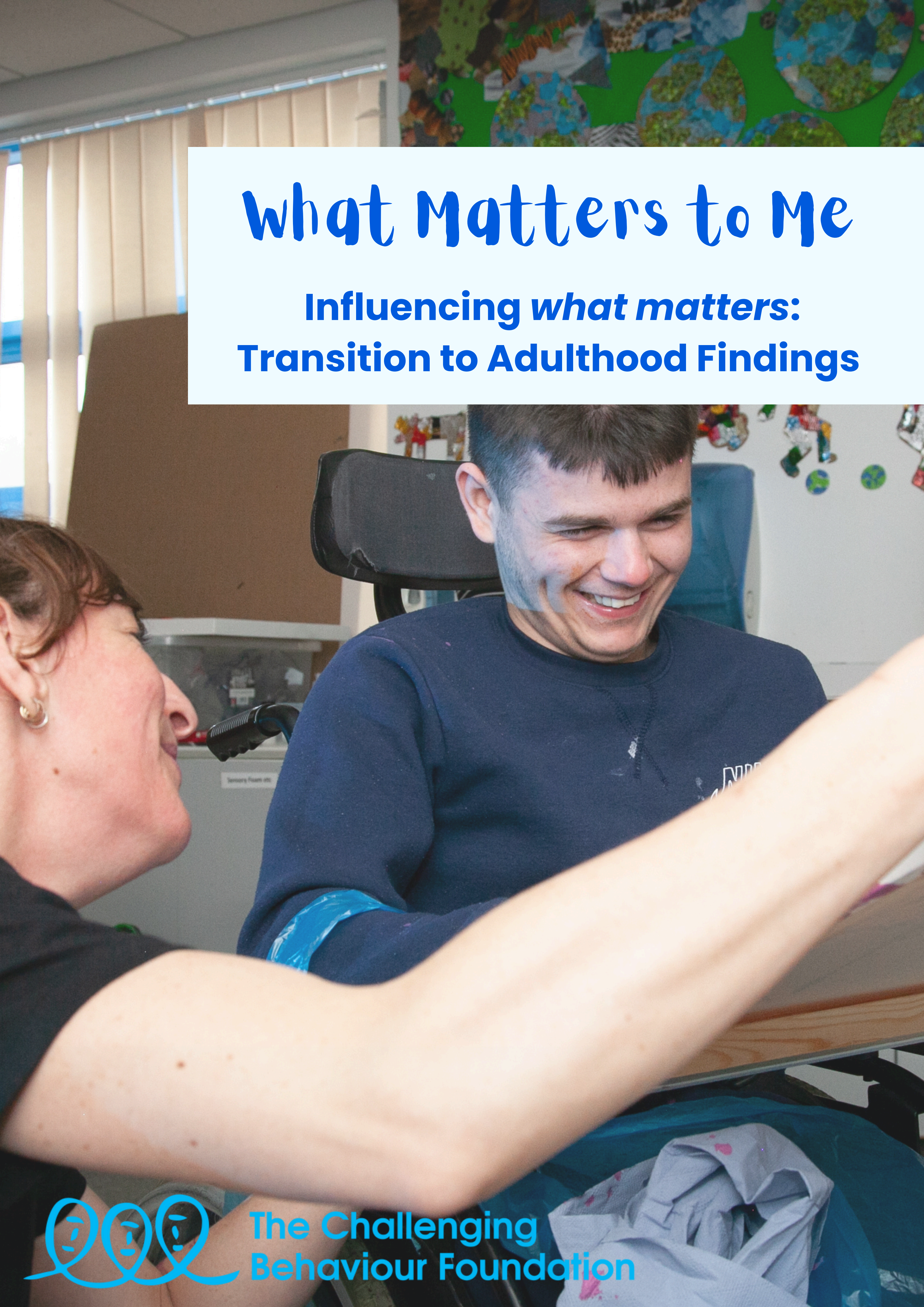
What Matters to Me

Influencing *what matters*: Transition to Adulthood Findings



The Challenging
Behaviour Foundation

Contents

Executive Summary

This report outlines the findings of a project led by The Challenging Behaviour Foundation (The CBF) from 2022 to 2025 called What Matters to Me, and accompanies a film resource which can be found on the What Matters to Me webpage.

The project engaged young people with severe or profound and multiple learning disabilities, alongside their families and others who support them, to influence policies and improve services and support. It had a specific focus on the transition from childhood to adulthood. The project identified **eight key thematic findings** of things that are important to and for young people as they transition to adulthood.

The project provided insight into the experiences of young people and their families as they navigated the system during transition from childhood to adulthood and the impact this had. Our findings touched upon health, education and social care systems. As well as exploring some of the challenges, we also heard from families about positive experiences and what worked well.

Through our direct engagement we observed elements that are vital in order for young people to get their needs met, their rights upheld and to live good, happy lives.

All the things that needed to be in place can at times be difficult to access in adult services. The findings in this report provide evidence for what is important to and for young people with severe or profound and multiple learning disabilities, and why, and how we aim to use our evidence to drive positive change.

It is possible to find out what matters to people with severe or profound and multiple learning disabilities!

It is possible to use what matters to make a difference!

Support young people:

- To be ambitious – have meaningful opportunities to achieve, learn and change
- To live in safe accessible places – at home and in the community
- To communicate – understand individual communication and provide a range of methods, and staff to support this
- To make choices and influence decisions
- To meet friends and do things together
- With staff who know them well
- With advocacy from family and other important people
- To access healthcare with reasonable adjustments

Our findings emphasise the importance of early planning, coordination amongst professionals and a strong theme of person-centred practice. We have linked our findings to the recommendations in The CBF's co-produced action plan, and includes things such as:

- Improving community support
- Person-centred decision making
- Promoting advocacy and involvement of families in decision-making processes

Explanations of the words highlighted in bold can be found in the What Matters to Me glossary.

Family Carer Experiences

> No one's willing to take accountability. And Aimee's just kind of there, and no one's talking to her, and no one's preparing her for the big wide world. And it's really hard as a mum to kind of sit back and watch this happen, knowing that it's likely to be an absolute disaster, but there's nothing I can do about that
>
> Family Carer - What Matters to Me

“We're in the process of Aimee transitioning from pediatrics to adult care. And it's all happening in different stages. It's all really fragmented and really difficult to keep track of. So, epilepsy and neurology services in London, we literally transitioned to the day after her 18th birthday, and we had a really good joint clinic with her pediatric neurologist and her now new adult neurologists and both epilepsy nurses. And that was really, really positive. Aimee was there, the whole family was there, and it did feel like a really positive family transition session.

Everything else to do with transition has been just a nightmare, in some services we're still in pediatrics, mainly because no one has the time or the resource to do the paperwork necessary and to do the transition process. So we're just kind of loitering in children's services still. With regards to social care, we're finishing education next year, and it's really hard to find somewhere that is suitable for a young person with very complex needs. We don't want her to go into residential supported living, so it's got to be some kind of day service.

The day centers that are local to us just aren't appropriate. One of them is likely to close, and there's a consultation on that at the moment. So, we found something that we think would be appropriate, its very community based, but it is more expensive than the local authority run day centre. And it feels like a real fight to get this in place, and we still haven't got it in place. We were told the funding needed to be agreed by January, and we're nowhere near that. We're still transitioning from a social care package to a continuing health care package. Everyone seems to want to pass the buck with regards to who does the funding. There are enough staff within continuing health care to effectively manage what we need, so we're just in limbo.

I know how services run, and I'm really worried that we'll get to July and Aimee won't have an adult package in place. She'll have no placement, nowhere to go. And she needs a long lead in time. She needs the transition time and the package that's needed we would have to employ a team of carers and that takes time. And it feels like every day is passing. No one's willing to do anything. No one's willing to take accountability. And Aimee's just kind of there, and no one's talking to her, and no one's preparing her for the big wide world. And it's really hard as a mum to kind of sit back and watch this happen, knowing that it's likely to be an absolute disaster, but there's nothing I can do about that.”

Family Carer from What Matters to Me

Introduction

What Matters to Me was a 3-year project (2022 – 2025) led by The Challenging Behaviour Foundation that involved engaging directly with 11 young people aged 16-21 years who are described as having a severe or profound and multiple learning disabilities. The engagement took place geographically across the Southeast of England and included consulting with young people's family carers and **support circles**. The purpose of the project was to explore creative ways to seek the experiences, preferences and views of young people who are often not involved in consultations or decision-making processes with a focus on finding out things that are important to and for this group as they transition into adulthood.

The What Matters to Me project uses the term **'transition'** when referring to the transition from childhood to adulthood and the change in the support and services young people access. It is a significant milestone in any young person's life, and the findings from the What Matters to Me project may reflect the needs and wants of many young people. However, the difference is, in order for people with severe or profound and multiple learning disabilities to get their needs met, they rely heavily on statutory services with the associated funding and resources available to achieve this. There are many things that should be in place when a young person transitions into adulthood, but services and support available can often be fragmented and fall short of meeting the needs of the young person.

Early in the project, we had initial discussions with families and key people involved in the project, to consider some of the main issues and challenges affecting young people with **severe** or **profound and multiple learning disabilities**, and to think about a focus for the project. The What Matters to Me project found that families of people with severe or profound and multiple learning disabilities often describe the transition to adulthood as a 'cliff-edge' experience, a period of great uncertainty and having to navigate through a disjointed system.

The transition to adult services involves moving from paediatric care and educational settings to adult healthcare, social services, and community support systems. It is a time when young people with severe or profound and multiple learning disabilities must adapt to new environments, routines, and relationships. A successful transition requires careful planning, collaboration between services, and a solid understanding of a person's wants and needs.

The aim of having a ‘topic’ for the project was to provide us with a focus for the direct engagement. By identifying what matters through directly engaging with this group of young people, their families and their support circles, we can ensure their own experiences, preferences and views can influence the support and services they can access.

The purpose of sharing the transition findings from the What Matters to Me project in the film and in this report is to disseminate what we found to be important to and for the young people who were involved in the project. These transition findings are also reported in the short film developed as part of the What Matters to Me manifesto, you can watch this here:

Resources available from The Challenging Behaviour Foundation and other organisations about transition:

- The Challenging Behaviour Foundation's Transition Webpage [Transition to Adulthood]
- Kids Transitions [Report]

Transition is a subgroup of our Challenging Behaviour-National Strategy Group, and part of the co-produced action plan is focused on this important stage. The co-produced action plan includes actions that need to be taken by policymakers and key stakeholders to improve the way this is experienced by young people and their families. You can read more about these here:

- [Transition to Adulthood - Actions for Policy Makers]

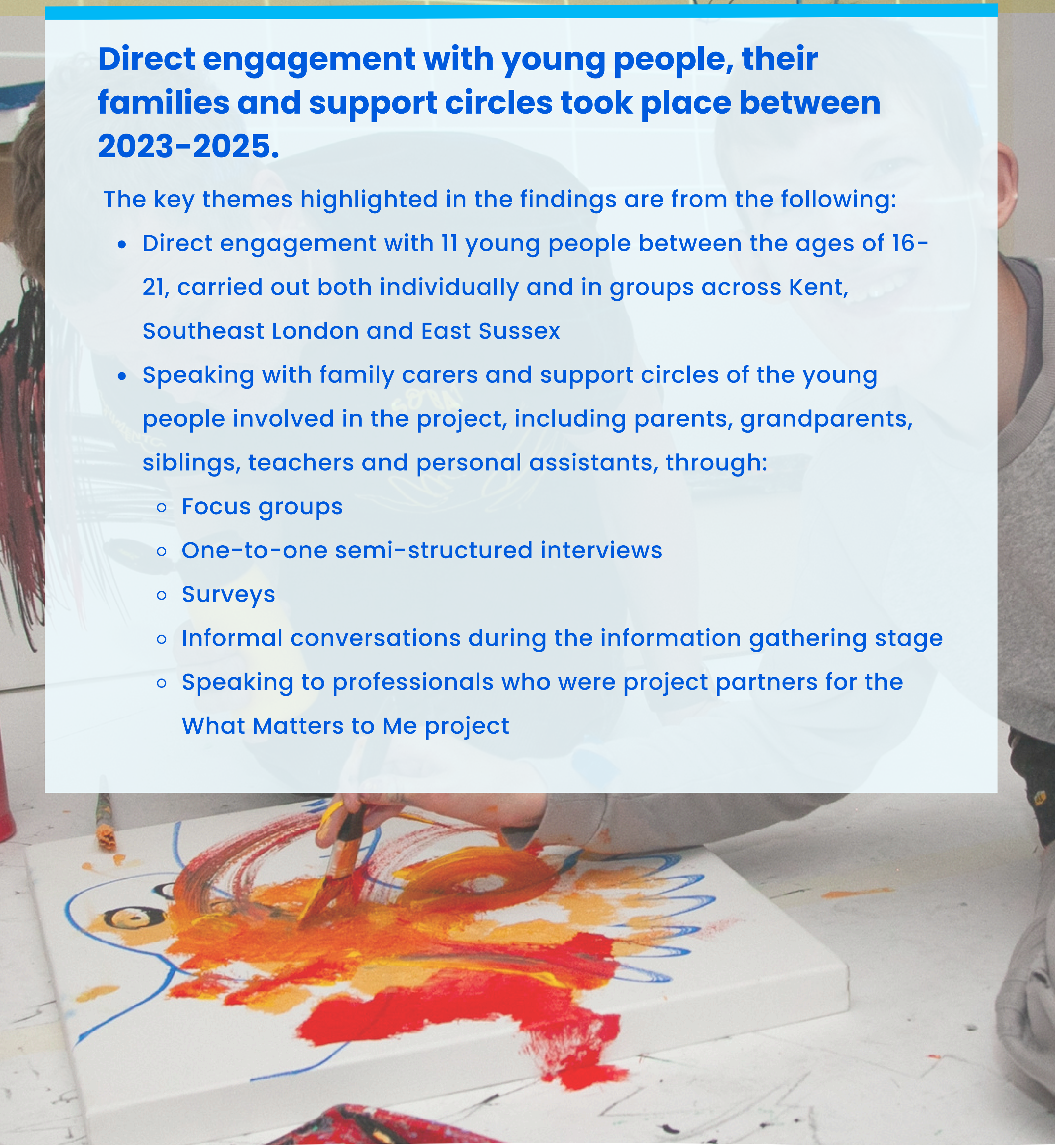
Engagement

The findings of our project are based on insights gained through observing and interacting with young people, speaking to families and individuals who know them well, and presenting this information in a manner that reflects a consensus of our interpreted learning, highlighting key themes.

The engagement was supported by two project partners:

- Ifield Post-16 - A specialist sixth-form provision
- Demelza Transition Team – A children's hospice

We also worked individually with one young person and their family



Direct engagement with young people, their families and support circles took place between 2023-2025.

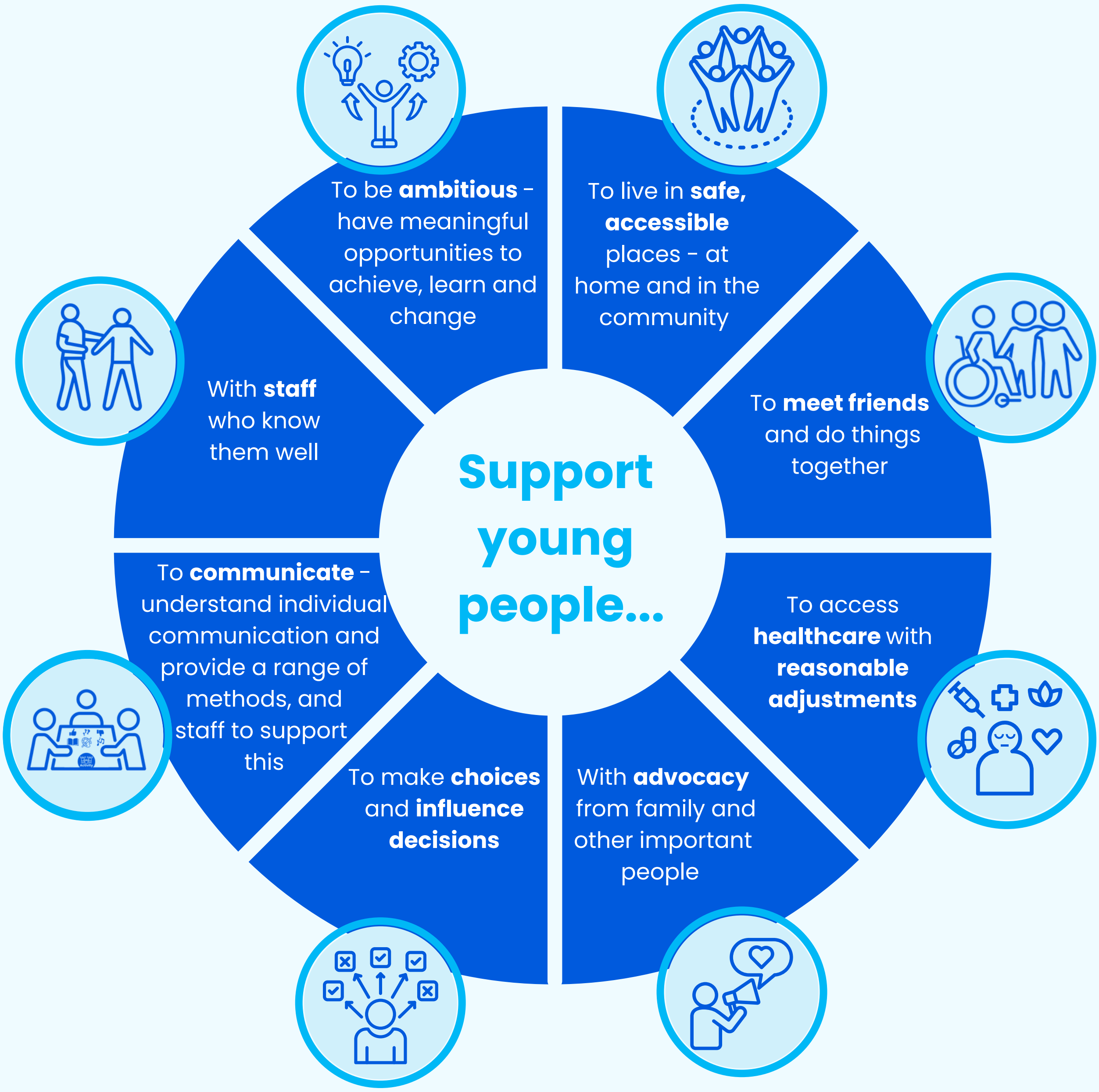
The key themes highlighted in the findings are from the following:

- Direct engagement with 11 young people between the ages of 16-21, carried out both individually and in groups across Kent, Southeast London and East Sussex
- Speaking with family carers and support circles of the young people involved in the project, including parents, grandparents, siblings, teachers and personal assistants, through:
    - Focus groups
    - One-to-one semi-structured interviews
    - Surveys
    - Informal conversations during the information gathering stage
    - Speaking to professionals who were project partners for the What Matters to Me project

You can find out more about the methodology of our engagement in the resource on our website - What Matters to Me Methodology Using a Mixed Method Approach

Thematic Findings

We identified 8 key themes of things important to and for young people as they transition into adulthood. In this resource we expand on each of these themes and share project evidence and case studies supporting these findings:



Support young people...

To be **ambitious** - have meaningful opportunities to achieve, learn and change

To live in **safe, accessible** places - at home and in the community

To **meet friends** and do things together

To access **healthcare** with **reasonable adjustments**

With **advocacy** from family and other important people

To make **choices** and **influence decisions**

To **communicate** - understand individual communication and provide a range of methods, and staff to support this

With **staff** who know them well

The findings we identified through the project are not reflective of everything that needs to be in place to support a young person well into adulthood, they are key things that we were able to identify as being important to and for young people we engaged with as they transition into adulthood.

Support young people to be ambitious – have meaningful opportunities to achieve, learn and change

We should all be supporting people with severe or profound and multiple learning disabilities to be ambitious and ensuring they are provided with meaningful opportunities which lead to a fulfilling life.

People with severe or profound and multiple learning disabilities rely on those who support them to provide access to things that can enhance their lives. Too often this group of young people are denied opportunities as it can be seen as being too difficult to do, not worthwhile, or there are barriers such as a lack of resources or funding to provide such opportunities. A strong theme that came from the project was the importance of trying new things and providing ambitious opportunities for young people as they navigate the journey to becoming young adults.

> *“That’s a key word, trying it, but quite often our children aren’t even given the opportunity to try it, or see if it could be worked or adapted to include them”*
>
> Family Carer - What Matters to Me

Throughout this project, we provided some new opportunities for the young people to explore during the engagement sessions. These were carefully thought out and consultations took place beforehand with those who knew the young people well. By doing this it has given them ideas or provided them with the confidence to try new things or consider other ways to do things; things that may have felt ‘out of reach’ for someone with a severe or profound learning disability.

Opportunities to learn and achieve through art:

We ran a 2-day workshop at Ifield with Project Artworks, during which, one of the young people was given the environment to express himself in more creative ways:

Christopher working with an artist from Project Artworks drawing characters on the wall

> “*Christopher generally does mark making...single lines and very kind of quite broad strokes. But what he did in the project was he was creating figures that were characters, and he named the characters. One of them was Christopher and he was talking briefly. He has quite limited language and can be very echolalic, but he was able to express himself through the art to share the things he enjoyed. And then he was so proud of the work he produced. He was holding his canvas up, really smiling and showing everybody that this was what he'd done. So, it was really wonderful to see that.*”
>
> Head of Post-16 Specialist Sixth From

Being ambitious about what a young person can do, achieve or might enjoy, doesn't have to mean making large changes, it can be about giving them opportunities to explore other things in their day to day lives that might not initially be considered.

> “*She started to like being read to. For years and years, we thought she liked stories like Gruffalo and that sort of level picture book. And then one day, she was having a bit of a difficult day at college, and one of the teachers in the sensory room just picked up a book on the side and which was a Enid Blyton magic faraway tree and started reading it to her and she reacted really positively, and that's something that she's really enjoying lately, being read these type of books.*”
>
> Family Carer - What Matters to Me

Sometimes, for a person with severe or profound and multiple learning disabilities to be ambitious, it takes a lot of time and planning, but it doesn’t mean that it can’t be done or at least tried!

> “*I would like for Cerys’ future, for her to be able to access as much as she can. For her to be given as many opportunities as possible. She deserves, as well as every young person with special needs, to have a good quality of life. And we really need to listen to our young people about what they want and what they need to be able to do that. And we need to provide them with the appropriate support to be able to do that, at the end of the day. She is a human being like anybody else. Why should she not be entitled to a good quality of life?*”
>
> Family Carer - What Matters to Me

> “*In transition, too often opportunities for our young people are limited. They have ambitions, they need to be able to access the world around them, to be able to share their passions and interests. So, I think it's really important that we provide those for young people.*
>
> Head of Post-16 Specialist Sixth From

Support young people to live in safe, accessible places - at home and in the community

Living in a safe and accessible home and community is paramount to a person's wellbeing. A person’s home, and the community they live in, should cater to their individual needs. Decisions about this should be made first and foremost through considering the needs of the individual, not for funding or budgetary reasons.

We heard from families about the lack of options presented to young people after leaving an educational setting, when it comes to where they might live or what their day-to-day lives might look like and access to their local community. We know from years of experience working with people with learning disabilities and their families how important good community support is, and the serious implications that it can have on a person when they can't get their needs met locally. This risk is increased when a young person is trying to find suitable provision during the transition from an educational setting.

> “*When I have those conversations with families, preparing for adulthood includes thinking about where they are going to live. Having a safe, accessible home and a community around them to enable them to access the world is vital. There are just not enough provisions, there isn't the funding, there is not enough around. For our young people and their families, accessing them is really complicated and we need to do better with that*”
>
> Head of Post-16 Specialist Provision

A sense of belonging and safety in the community:

Throughout the project we spent time with some of the young people at home, at their educational settings and within their local community. It was clear from these interactions and observations how important it is for young people to have access to familiar environments where they feel safe and familiar people who know them well.

We observed Cerys attending an Art Breaks session at Project Artworks; a collective of neurodiverse artists and activists working from a studio based in Hastings.

The Art Breaks workshop sessions run across school holidays and at weekends and provide a safe space facilitated by skilled professional artists for people with complex needs to experience art as a tool for exploration, communication and self-expression. Cerys has been attending Project Artworks for around 15 years since she was a child. It is a place she is familiar with and she has built strong relationships with the artists during these sessions.


Cerys participating in a session at Project Artworks. The artist is interacting with Cerys using Intensive Interaction.

Having the opportunity to attend sessions like this within her local community provides Cerys with meaningful opportunities to be a part of her community and to express herself in a safe environment tailored to her needs. During the sessions we observed, it was clear Cerys was in an environment she felt safe and secure in, she ran straight through the door, vocalising positively in anticipation of the activity she was about to engage in. She carried out her usual initial response of removing the lids from every paint bottle she could see before then settling in a specific area of the workspace, freely expressing herself. Mum shared with us that this was the highlight of her school holidays, and they felt really lucky to be able to access this activity in their local area.

> *“For many years now, Cerys has been going to Project Artworks, and their art break sessions. She absolutely loves it. She goes into an environment that she's familiar with. The staff that are there know her really very well, and they have her space all set up ready for her. It's very safe. She can completely be herself, and she goes in, and they have paint bottles lined up, and she starts working with the paint. Working with the brushes, she makes some amazing pieces of artwork, which we're really proud of. But what is really lovely to see is her interacting with the staff, and she becomes very calm. Her anxiety seems to melt away. And she can be herself; there's no restrictions. She can do what she likes, and she absolutely loves it. She gets so much from it, and it's just such a valuable resource, run by a wonderful charity.”*
>
> Family Carer - What Matters to Me

We worked with two young people and families from East Sussex on the What Matters to Me project. These families shared with us concerns that community support was actually decreasing in their local area, with the upcoming consultation on closure of a day care centre used widely by young adults with learning disabilities. This was having a huge impact on the local community, the people with learning disabilities and their families in the area. For young people with severe or profound and multiple learning disabilities this would mean having to travel to neighboring towns to access services that should be available to them in their own communities. We know from our work with families that these huge changes can impact not only the young person, potentially causing increased anxiety and as a result an increase in challenging behaviour, but also the worry for families as well as the added financial strain.

> *"It's really frustrating because there is probably one place for Cerys to go to in terms of a daycare center when she finishes her current college placement. And sadly, that is looking to be cut by the local authority and closed down. And it will mean that children like Cerys and lots of children from within a wider area are going to all have to go into one placement, which seems to suit the local authority, but does it so our children and our young people, are we thinking about what they want and what they need?"*
>
> Family Carer - What Matters to Me

Accessibility

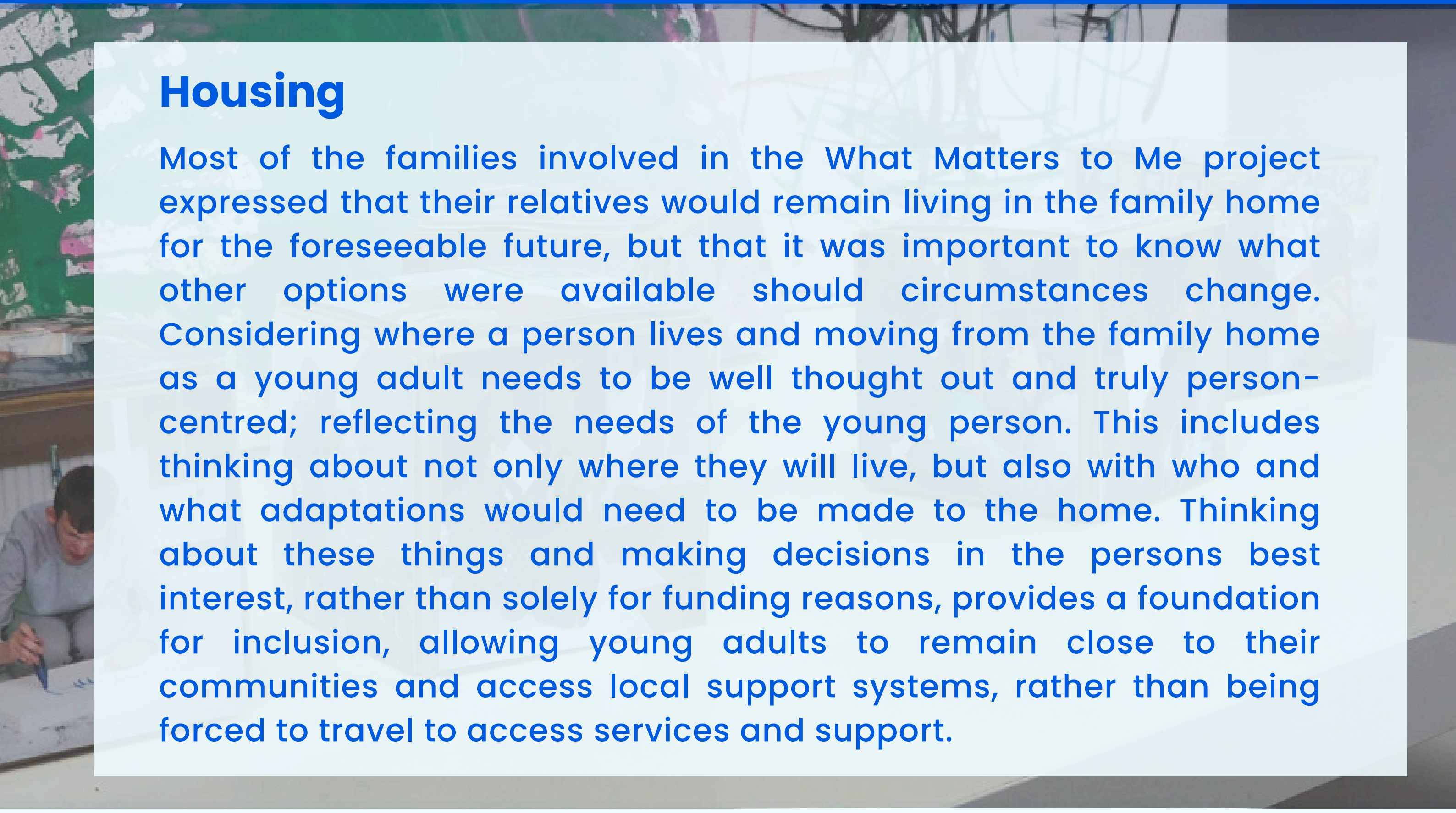
Ensuring accessibility in homes and community areas goes beyond having wide doors and ramps. It involves thoughtful planning and considerations of layouts that accommodate various needs such as sensory needs, including primarily that the environment keeps the person safe. It's important that we see these things factored in, not only to a person's home, but to the places they access in their communities.

There needs to be opportunities within communities which people with severe or profound and multiple learning disabilities can access, this doesn't mean having one day centre that everyone with this level of needs can go to. It's about consideration being taken in the planning, development and designs of community based support, to ensure that it considers the needs of people with the most complex needs, so that it is truly inclusive and accessible for all.

> *The government said, everyone needs wider doors and ramps so that people can get in. That's brilliant, but if once I'm through the door, I can't get through all the tables to sit down and have a meal with my son or I can't change him, there's no point in you having wide doors. It's almost like the process was started, but I don't think some people still nowadays get the real gist of disabilities.*
>
> Family Carer - What Matters to Me

During the project, we had planned to carry out some engagement activities in the local community instead of in the usual setting. We were planning to do an activity with a group of 4 young people and their families, however it proved to be really challenging to find a suitable location to bring these young people together due to a lack of suitable facilities being available. Finding an activity or place to go that was age appropriate, with facilities such as a changing places toilet which was required for the young people, was really difficult and families are met with these challenges day in and day out.

> *In terms of further education or day centres, unfortunately options I have been presented with are extremely limited i.e. just one option, which means there aren't any choices! Previously I have had to research and investigate myself to find further options. Services seem to be very reluctant to present these to you, unfortunately I feel, for financial reasons. They seem to push educational placements/day centres that are already funded by the local authority, rather than those that perhaps suit the best interests of the young person.*
>
> Family Carer - What Matters to Me



Housing

Most of the families involved in the What Matters to Me project expressed that their relatives would remain living in the family home for the foreseeable future, but that it was important to know what other options were available should circumstances change. Considering where a person lives and moving from the family home as a young adult needs to be well thought out and truly person-centred; reflecting the needs of the young person. This includes thinking about not only where they will live, but also with who and what adaptations would need to be made to the home. Thinking about these things and making decisions in the persons best interest, rather than solely for funding reasons, provides a foundation for inclusion, allowing young adults to remain close to their communities and access local support systems, rather than being forced to travel to access services and support.

Support young people to communicate – understand individual communication and provide a range of methods, and staff to support this

Every one of us has a need to communicate, it is a fundamental right we all share. People with severe or profound and multiple learning disabilities might communicate differently, for example through facial expressions or movements, vocalisations, signs or using objects of reference.

Ensuring that young people have the tools and support they need to express themselves is essential, and whilst this may be well embedded in some educational settings, it is vital that it continues to be in place in post-educational settings.

> ***"Communication shouldn't be a privilege; it is a right"***
>
> Family Carer - What Matters to Me

Aimee is choosing between two pictures to add to her 'all about me' poster during one of the engagement sessions.

Tyler is using his VOCA to choose what colour he wanted to paint with during the Project Artworks session.

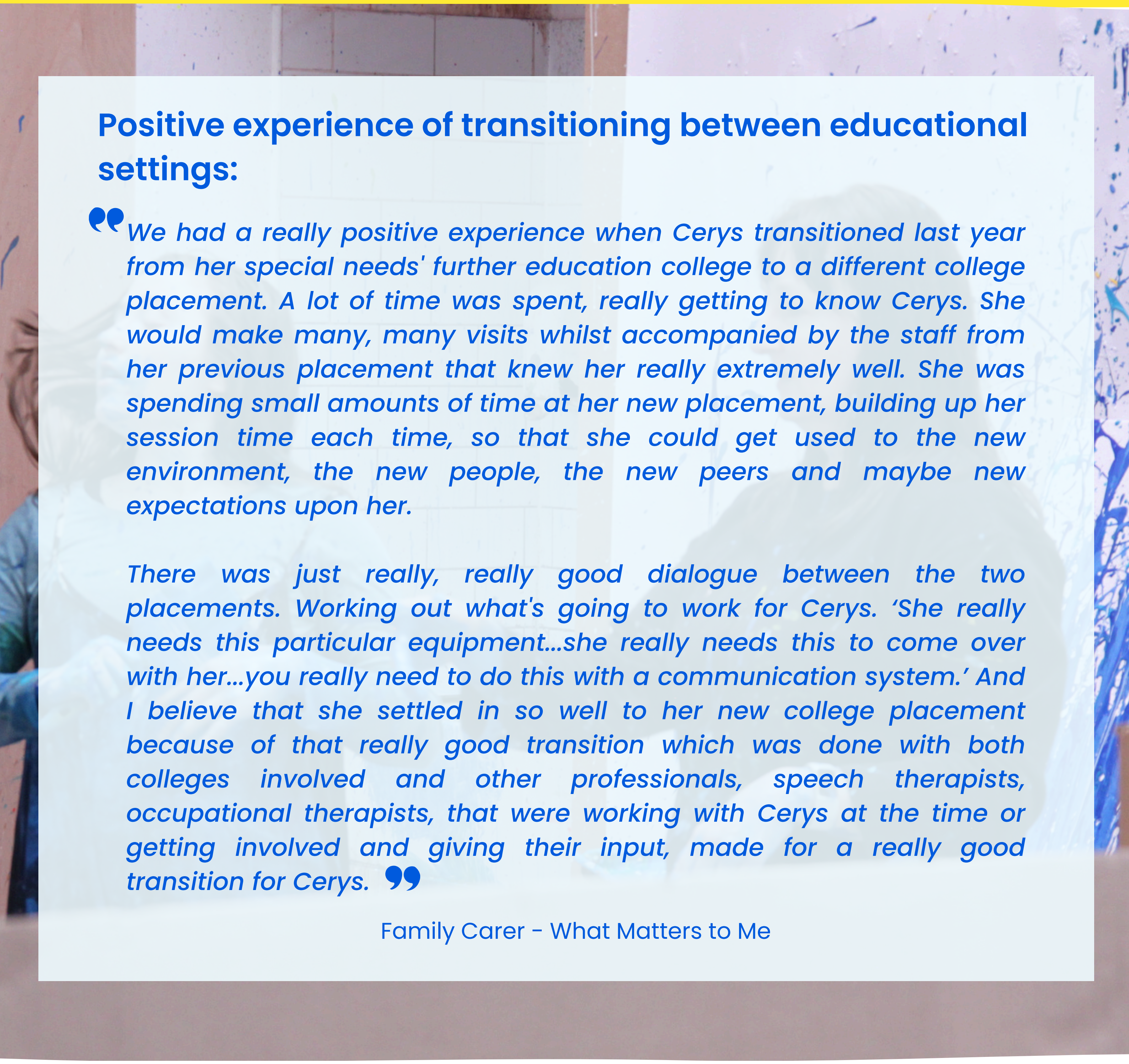
> *“Going through school, I really felt that it was like there's one method. It's PECs and everybody's going to use it. We're going to push this square peg in this round hole. I just think back now, and I think of the years that we've spent really trying to push, push, push one method of communication because that's what everybody else did and that's what's used in that school.”*
>
> Family Carer - What Matters to Me

It is important in both children’s and adult’s services that communication methods are individualised and tailored to what works best for the person. Communication support should be consistent and young people transition from one service to the next.

At Ifield we observed and actively used a range of communication methods with the young people we were engaging with, including the use of Voice Output Communication Aids (VOCAs), Picture Exchange Communication System (PECS) symbols, Intensive Interaction and Makaton signs. The use of Makaton was a part of every communication between staff and young people, even for young people who perhaps did not use signs themselves, as this often aided their understanding.

The daily activities were all communicated not only verbally but visually with symbols and photographs. It was clear how important this total communication approach is in aiding understanding and supporting communication for young people. It's vital that this emphasis on communication continues outside of the education setting as these young people move on to accessing adult services.

During our engagement we also observed and included other approaches including Intensive Interaction, which was used not only throughout the educational setting, but also by facilitators at the Project Artworks workshop. It is vital that staff supporting young people in adult-based settings have the training and skills to be able to provide this.



Positive experience of transitioning between educational settings:

> *"We had a really positive experience when Cerys transitioned last year from her special needs' further education college to a different college placement. A lot of time was spent, really getting to know Cerys. She would make many, many visits whilst accompanied by the staff from her previous placement that knew her really extremely well. She was spending small amounts of time at her new placement, building up her session time each time, so that she could get used to the new environment, the new people, the new peers and maybe new expectations upon her.*
>
> *There was just really, really good dialogue between the two placements. Working out what's going to work for Cerys. 'She really needs this particular equipment...she really needs this to come over with her...you really need to do this with a communication system.' And I believe that she settled in so well to her new college placement because of that really good transition which was done with both colleges involved and other professionals, speech therapists, occupational therapists, that were working with Cerys at the time or getting involved and giving their input, made for a really good transition for Cerys."*

Family Carer - What Matters to Me

Support young people to make choices and influence decisions

Empowering individuals to make their own choices and influence how they live their lives provides a sense of autonomy, something that is too often overlooked for individuals with severe or profound and multiple learning disabilities. Even if someone has a severe disability and lacks the capacity to make an informed decision on a particular issue, they can and should still be included in the decision-making processes. Supporting an individual's communication methods is crucial, and understanding and responding to their cues allows them to have an impact on what is going on around them.

Communication plans developed in educational settings can capture really well how to ensure a young person is included in making choices. It's important that this information is carried over to any post-education settings, as the importance of making choices and having an influence is just as important in adulthood as it is in school or college.

There is also a huge gap in engagement at a strategic level. People with severe or profound and multiple learning disabilities need to access and rely on statutory services, and yet their experiences, preferences and views are not sought to feed into service planning and delivery. If we can engage well and get it right for people with the most complex needs, it's almost certainly going to be accessible and successful for everyone else.

> *College has been really good with starting to talk to Aimee about transitioning, they're very good at this. She has symbols for everything; 'I don't like' and 'I like' symbols and everything she does, she then has to point to whether she likes it or not. And she's really taken to that and she's really consistent with it. So, they are constantly engaging with her and getting her views, it's been really, really positive.*
>
> Family Carer - What Matters to Me

> *Just thinking about good transition and what I would like for her in an ideal world, it would put her right in the centre and every meeting and every appointment and every assessment would involve her.*
>
> Family Carer - What Matters to Me

> *I find that schools and colleges, because they know her so well, they can engage with her to find out what she wants and what she needs. But sadly, organisations like local authorities don't tend to spend that time with our children and young people, and don't go in depth into what they want and need.*
>
> *It's their decisions that influence really important things, like future decisions for their lives. And unfortunately, there's times when you feel like you're not being listened to, that Cerys isn't being listened to. Myself as a parent isn't really being listened to.*

Support young people to meet friends and do things together

Opportunities for social interaction can be difficult and limited for people with severe or profound and multiple learning disabilities outside of the education provision which they stop accessing as they become young adults.

We heard from families how often social sessions designed for people with **SEND** are still not accessible for this group, with sessions being run at inappropriate times or without the proper facilities for them to be able to attend, and very often aimed at younger children.

The first full engagement day at Demelza was an ‘exploring experiences’ day. We had planned to bring 4 young people and their families together to take part in a range of activities, this included observing activities, getting involved when appropriate, and observing interactions between the young people and their family carers and people who knew them well. This first day involved group hydrotherapy, individual music sessions, and exploring some sensory activities.

We wanted to trial a group hydrotherapy session, to observe reactions between the young people if they were able to interact in a different environment together. The reactions between the young people were overwhelmingly positive. We had gathered background knowledge of what **observable indicators** were positive so we were able to see the positive facial expressions, laughing and vocalisations from the young people as they played together in the pool.

The interactions between the young people in the pool showed the importance of young people being able to meet friends and do things together. In order to do this, they need to live in an accessible community, where they can go and participate in an activity such as swimming together.

As a result of these sessions which we ran just for the project, Demelza have now gone on to hold regular group transition hydrotherapy sessions as part of their service delivery, so that more young people can socialise together. You can find out more about this in the circles of influence case study film: Using What Matters: The Circles of Influence

For one young person, swimming made them tired, and they were able to communicate – through using their own personal signs, that they wanted to go home because they were tired rather than stay for lunch. This showed the importance of communication and having people who know the young person and their individual styles of communication well.

> *"For our young people to be able to socialise and interact at their own time and in their own safe space is so wonderful, for them all to be able to meet and interact in their own ways without being rushed or interrupted. Swimming together, just them, was so special."*
>
> Family Carer - What Matters to Me

Ivy, Fenton and Ewan enjoy a pool session together, playing ball games during a project engagement day.

Rilee and Christopher are throwing the ball to each other during a story sharing session, thinking about how the outside space at Ifield could be improved.

Accessing an activity such as swimming is often primarily with a person's care giver, so there needs to be increased opportunities for social interactions with friends. This is something important to all young people, but for this group there are often so many barriers and restrictions and there is not enough available outside of educational settings for young people to spend time with friends participating in activities together, this can lead to feelings of loneliness and isolation.

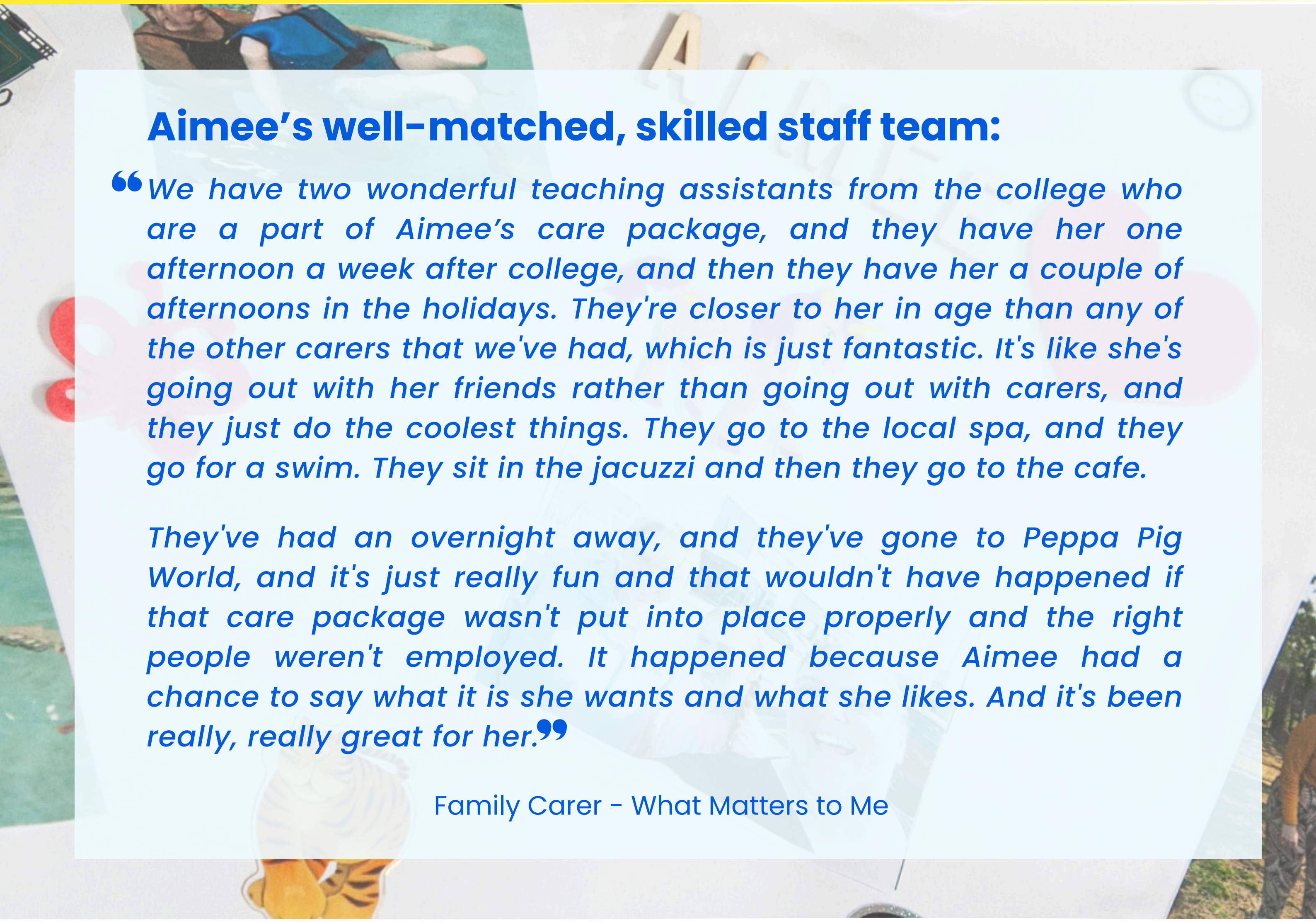
An individual having a severe learning disability does not mean they do not need or should not have opportunities to create and develop friendships, and the reactions we have seen from the young people throughout the project strongly evidences the importance of this.

> *“There is nowhere for Fenton to go to socialise with his peers.”*
>
> Family Carer - What Matters to Me

Support young people with staff who know them well

Skilled staff who are familiar with an individual's needs are fundamental to ensuring effective support. Staff involved in a young person's care need to know the person well in order to support them to access community activities and experiences, and to ensure their needs are being met. Young people need staff who know their likes and dislikes, who will know what to look out for to ensure the person is feeling happy and safe, and who can identify any potential triggers or things that the person may find difficult or uncomfortable.

For individuals with severe learning disabilities, this understanding is really important as young people may rely on non-verbal cues or specific methods to express their feelings and needs. Staff must be trained to recognise and interpret these cues accurately. Staff retention is also important for building trust and routine, having a consistent and dedicated team of caregivers can provide a stable and reassuring environment, promoting a sense of security and well-being.



Aimee’s well-matched, skilled staff team:

> *“We have two wonderful teaching assistants from the college who are a part of Aimee’s care package, and they have her one afternoon a week after college, and then they have her a couple of afternoons in the holidays. They're closer to her in age than any of the other carers that we've had, which is just fantastic. It's like she's going out with her friends rather than going out with carers, and they just do the coolest things. They go to the local spa, and they go for a swim. They sit in the jacuzzi and then they go to the cafe.*
>
> *They've had an overnight away, and they've gone to Peppa Pig World, and it's just really fun and that wouldn't have happened if that care package wasn't put into place properly and the right people weren't employed. It happened because Aimee had a chance to say what it is she wants and what she likes. And it's been really, really great for her.”*
>
> Family Carer - What Matters to Me

At Ifield, we observed clear strong relationships between young people and the staff supporting them. Whilst even in educational settings staff retention can be a challenge, it is often significantly more difficult to retain staff in adult settings and a lack of consistency for young people with severe or profound and multiple learning disabilities can be really detrimental to getting their needs understood and met. Often a young person will transition into adult community care and be faced with a high turnover of support staff across potentially differing settings, and this can be really unsettling for a young person. At times during the project, we heard how some families had experiences of not being able to find adequate staff cover to cover care packages that have been put in place, with one family telling us that in principle they have a care package for 7 nights of care but it has not been put in place as there are no staff available.

> *“My social worker up until Ewan was 16 was phenomenal and now, I don’t even have a social worker. The system is broken. They haven’t got capacity and that’s all there is to it. We transitioned just over a year ago and we’ve had one contact.”*
>
> Family Carer - What Matters to Me

Support young people with advocacy from family and other important people

Families are important in a child's life, but they're also important in an individual's life as they move into adulthood. Families told us that in children's services, there is much more of a culture of listening to families and engaging with them as part of the process, but this is equally important as young people move into adulthood.

If you are not able to **self-advocate**, if people are unaware of what matters to you, an **independent advocate** can also play a vital role in ensuring that your views and preferences are not ignored.

> *❝ Being allowed to make decisions around his life, is almost impossible. You have to jump through so many hoops and get these people to agree it, but these are people that are making decisions about my child that don't even know him. They've never even spent 5 minutes in a room with him. They don't know what it's like when he has a seizure or when you want to go out for a few hours and he opens his bowels. They do not have a clue, yet they're the ones that can do the yes or no about someone they don't know. ❞*
>
> Family Carer - What Matters to Me

Families know their relatives well. In the vast majority of cases, they provide lifelong love, care, support and advocacy for their relatives and this role can also be enhanced by and in partnership with a skilled **non-instructed advocate.**

> *❝ I'm tired of fighting for what should automatically be her right. I'm tired and I'm bored of the same fights all the time. It is clear they are desperately under resourced, which has a huge impact on the service young people receive. ❞*
>
> Family Carer - What Matters to Me

> *“I wish that some professionals would realise and take on board that as parents and carers live and care for their child 24/7, and have done all their lives, they do know them best and their views and opinions should not be dismissed. I also hate it when it feels like a decision has been made by a professional or organisation about your child without any consultation with the parent or young person, often without even meeting them and knowing very little about us.”*

Family Carer - What Matters to Me

Support young people to access healthcare with reasonable adjustments

Accessing health services can be a challenge for individuals with severe or profound and multiple learning disabilities because services are not designed around their needs. Appointment times can be too short, environments too busy and noisy or health staff unaware of how best to communicate with individuals.

> *“I've been in situations when we've had hospital appointments, where we've had to wait in really busy, loud waiting rooms before the appointment, which is really when my daughter gets worked up, gets very anxious, we've had medical appointments where we've gone into buildings with narrow corridors, you can't get a wheelchair down very easily. And things like that can be really, really difficult, it can either make or break an appointment.”*
>
> Family Carer - What Matters to Me

Making **reasonable adjustments** is important because unmet health needs have a high human cost and significant consequences which can result in unnecessary pain and suffering. Physical pain can be debilitating and can result in behaviour that is challenging, which in turn can lead to restrictive practices, overmedication and exclusion. Using tools such as individual **hospital passports**, the support of skilled **learning disability nurses** and combining health procedures or appointments where possible can have a really positive impact and ensure good outcomes for all.

Under the **Equality Act 2010**, healthcare providers are required to make reasonable adjustments to ensure that individuals with disabilities are not at a substantial disadvantage compared to those without disabilities. This Act mandates that adjustments should be made to physical features, policies, and procedures. Reasonable adjustments should be in place to ensure that there is an environment where everyone can receive the necessary care without barriers, and that the care received is dignified, respectful and effective.

Accident & Emergency Experience

At the story sharing session, one young person who attended had broken their leg a few weeks before, this prompted a discussion with families about healthcare and the difference it makes when reasonable adjustments are in place, as well as all the families' experiences of accessing adult health services from paediatric care.

> *"We checked her in, and we were told it was a 9 hour wait. I asked for the learning disability liaison nurse and the receptionist didn't know what I was talking about. I explained that she wouldn't be able to wait nine hours and was told, 'Oh well, if you have to leave, just leave.' We couldn't leave, her foot needed to be X-rayed, and there was nothing I could do. So then when we went to see the triage nurse again, we asked about the learning disability liaison nurse and again they didn't know what I was talking about. There's just a complete lack of understanding and a lack of education which, when you're in the most front facing part of a hospital, was really really difficult - there was just no support."*
>
> Family Carer - What Matters to Me

People with severe or profound and multiple learning disabilities will very likely need to access health services more frequently than non-disabled people. The transition from paediatric to adult healthcare in both primary and secondary care settings can be significant for young people and their families. In paediatric care, a child may be under the same consultant for much of their childhood, and transferring care to a new adult team can be challenging due to differences in capacity and service provision. Families reported that adult services appear more generic compared to the specialised care provided in children's services. Accessing hospital services can be stressful for families due to different rules or policies on adult wards, which can add difficulties to the situation, including concerns about staying with their relative or how their relative will adapt to the environment.

> *"I have in the back of my head constantly the worrying that if I need to take him to the hospital, I'm going to do everything in my power to fix him at home. Because if I take him to the hospital, I'm not going to be able to stay with him. And that fear should not be there. I would never put Ewan's health at risk, but the fear of that puts you in a situation where it creates more stress. That when you get there, you're not going to be able to control or support your child in the way that only you as the parent or carer, knows how to do."*
>
> Family Carer - What Matters to Me

Recommendations

The Challenging Behaviour Foundation has worked with families, people with learning disabilities and a wide range of experts to co-produce an action plan covering all areas of life for people with learning disabilities. It includes recommendations for policy makers and stakeholders and has been informed by the findings from the What Matters to Me project.

The recommendations below are formed from existing action-plan recommendations that would help to deliver the elements of support that this project has found to be key for young people with severe or profound and multiple learning disabilities as they transition to adulthood. The recommendations also link with important recommendations from other charities reports and directly through the influencing and strategic work that has developed during the What Matters to Me project.

Findings - support young people:	**Recommendations for policy makers and commissioners**
1 To be ambitious – have meaningful opportunities to achieve, learn and change	**1a** - **Department for Education** to consider the What Matters to Me findings as part of the SEND reforms and consultations. **1b** - **Department for Education** to consider how to directly hear the views of children and young people with severe or profound and multiple learning disabilities in consultations. What Matters to Me
2 To live in safe, accessible places – at home and in the community	**2a** - The **Government** to increase the availability of capital funding to develop housing for people with a learning disability and autistic people. **2b** - The **Ministry of Housing, Communities and Local Government** and the **Department of Health and Social Care** need to: • Work with local authorities to support them to conduct research and analysis of their local population, and to use this to develop housing that will meet these needs • Work with local authorities to support them to join up housing, health and social care • Promote the involvement of housing professionals in transition planning for young people with learning disabilities

	2c – **Local authorities** to have a policy for contacting people with a learning disability and their families to create plans for the future. Co-Producing a Lifelong Action Plan - housing
3 To communicate – understand individual communication and provide a range of methods, and staff to support this	**3a** - **NHS England** to support the communication needs of everyone with severe or profound and multiple learning disabilities throughout their life. This means Speech and Language Therapy (SALT) services working directly with every individual and providing ongoing and appropriate training and advice to everyone caring for or supporting each individual (e.g. families, social care and school staff). What Matters to Me
4 To make choices and influence decisions	**4a** - The **Department for Education** and the **Department of Health and Social Care** need to: • Introduce a Transition Coordinator who is trained in augmentative and alternative communication to help explain people's options, entitlements and rights, focusing on what is possible, not just available (e.g. bespoke packages of care and support) • Facilitate a transition community of practice including sharing examples of good practice and high-quality training Co-Producing a Lifelong Action Plan – Transition
5 To meet friends and do things together	**5a** - The **Department for Culture, Media and Sport** to consider the perspectives and experiences of young people with severe or profound and multiple learning disabilities in the National Youth Strategy. What Matters to Me **5b** - A new, cross-departmental National Play Strategy for England which: • Prioritises accessibility, equity, and inclusion, ensuring that all children and families have the time, space, and opportunities to play which reflect their needs, interests, and identities

	- Aligns with the Government's Young Futures programme, Family Hubs, and youth club plans to embed accessible, equitable, and inclusive age-appropriate play spaces and support for families to play through hubs Centre for Young Lives – Play Commission **5c** – The **Government** should introduce a Play Sufficiency Duty for England: - The duty should require local authorities to regularly and periodically assess the sufficiency of opportunities to play in their areas and require them to secure further opportunities where they are found to be lacking. Assessments should be grounded in a focus on ensuring all children have opportunities to play and that spaces are inclusive and accessible Centre for Young Lives – Play Commission
6 - With staff who know them well	**6a** - The **Government** needs to: - Introduce a strong duty on commissioners to develop community support for people with a learning disability within their local area, and back this with resources Co-Producing a Lifelong Action Plan – Workforce - Amend the Care Act 2014 to introduce a statutory age to start transition planning (aged 14 years) and ensure that there is a named social worker to lead the assessment and planning process and co-ordinate with other agencies Co-Producing a Lifelong Action Plan – Transition - Amend the Care Act 2014 to introduce a statutory age to start transition planning (aged 14 years) and ensure that there is a named social worker to lead the assessment and planning process and co-ordinate with other agencies Co-Producing a Lifelong Action Plan – Transition

7 - With advocacy from family and other important people	**7a –** Ensure that all children and adults with a learning disability have access to skilled, high-quality, independent advocacy that is long term, not issue based – including non-instructed advocacy. Co-Producing a Lifelong Action Plan – Advocacy **7b –** All children with disabilities and complex health needs should have access to independently commissioned, non-instructed advocacy from advocates with specialist training to actively safeguard children and respond to their communication and other needs. Child Safeguarding Practice Review. Phase 2 report **7c** - A minimum qualification standard for non-instructed advocates should be established. As well as teaching advocates about the legal framework for children's rights, non-instructed advocates should be trained in how to support children with complex needs and disabilities. Moreover, non-instructed advocates should be required to have prior experience in working with children with complex needs and disabilities. Children's Commissioners Office – the state of advocacy **7d** – Front line health and social care staff to work in partnership with family carers and communication partners (who may also be staff or advocates who know the individual well) to make any general changes likely to improve support for, and communication with, people with severe or profound and multiple learning disabilities. What Matters to Me **7e** - **Department of Health and Social Care** and **Department for Education** need to implement that approaches and guidance in this area is developed to ensure that unless the person drawing on advocacy doesn't want the advocate to speak to or work with their family members, or

	there is clear documented evidence that it is not in the person's best interest (where the person lacks capacity), advocates should work together with and alongside family carers. This guidance should recognise that families are often a vital resource to understanding a person's communication, and therefore their wishes, aspirations, and needs as well as being central in a person's support network and life. Any guidance that is developed should be co-produced with family carer groups. A review of advocacy for people with a learning disability and autistic people who are inpatients in mental health, learning disability or autism specialist hospitals
8 - To access healthcare with reasonable adjustments	**8a** - The **Department of Health and Social Care** need to: • Ensure that all people with a learning disability aged 14+ are on the Learning Disability Register. • Ensure all people on the Learning Disability Register are receiving Annual Health Checks. Co-Producing a Lifelong Action Plan – Health **8b** - **General Practitioners** to provide annual health checks to people on the learning disability register aged 14+ ensuring reasonable adjustments are made. What Matters to Me **8c - The Department of Health and Social Care** need to: • Recruit and train additional Learning Disability Liaison Nurses. • Increase awareness of the role of Learning Disability Liaison Nurses. Co-Producing a Lifelong Action Plan – Health

Conclusion

At 18, most young people are embarking on an exciting stage of life, becoming independent, considering future goals and relationships.

Young people with severe or profound and multiple learning disabilities have the same rights; but for them life often starts to get worse: decisions are made for them, often without consideration or finding out what they need or want, the options for what services and support can be accessed becomes more limited than in children's services, and it can become a worrying time of not knowing what the future might look like. So instead of feelings of excitement, it can cause feelings of isolation and loneliness.

The projects findings of what is important to and for people with a severe or profound and multiple learning disability, requires a system to be in place that works collaboratively across all teams, involves truly person-centred planning and decision-making, and starts early from the age of 14 years. This provides young people and their families with the trust and reassurance that services and support will be in place to properly meet people's needs as they move into adulthood.

> *“There are so many barriers for our young people. And if we don't ensure that provisions are there and services are there for young people and their families, we're failing them.”*
>
> Head of Post-16 Specialist Provision

The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

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