



What Matters to Me

Guide to Consent and Best Interest Process

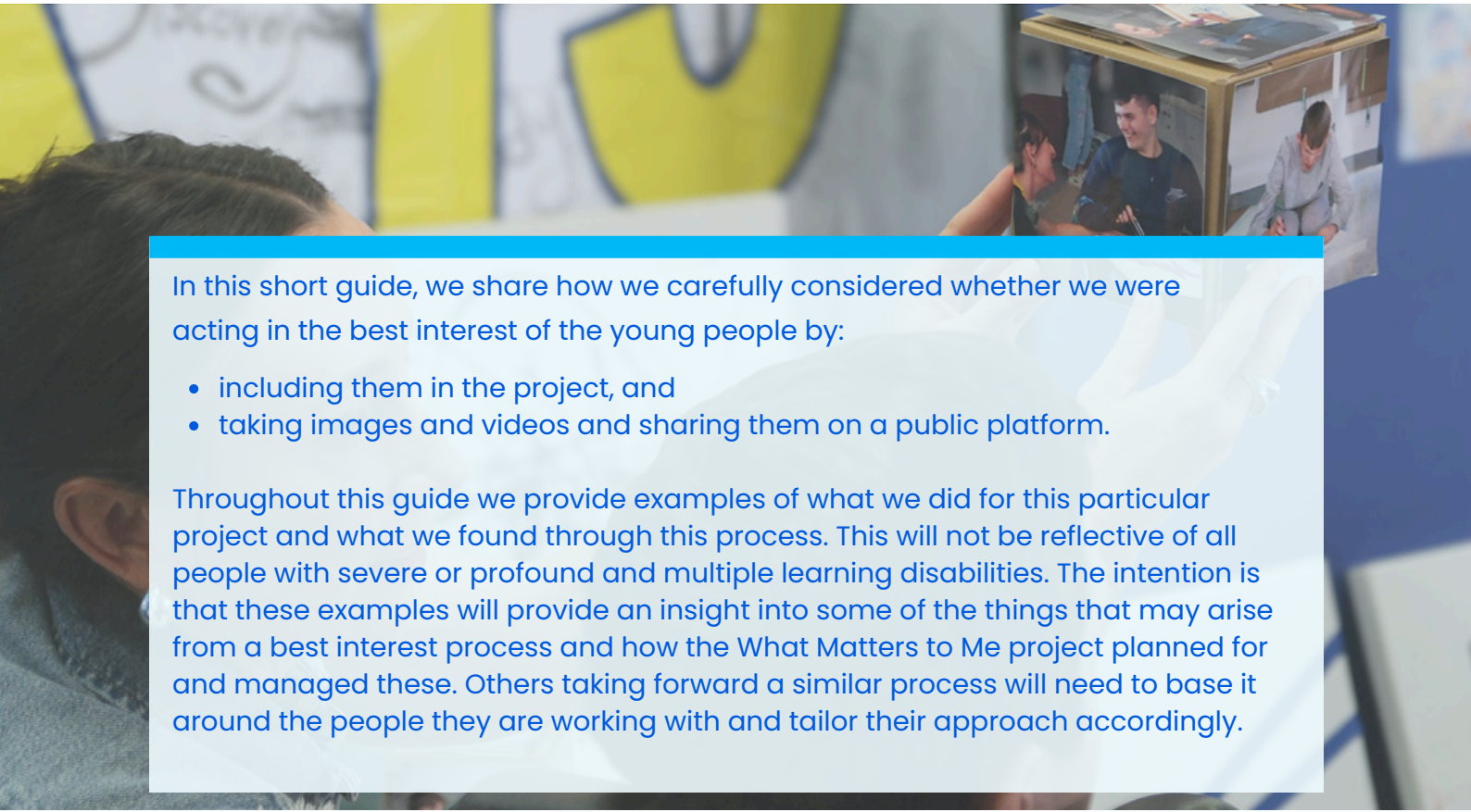


The Challenging
Behaviour Foundation

Introduction

Obtaining consent for people who lack the capacity to consent themselves, and adhering to a comprehensive best interest process is an essential aspect of direct engagement. This guide examines the complexities involved and outlines the process and considerations followed by the project to ensure compliance with best practice. We understand that this process can take time and resources, and can seem quite daunting, however it should not be a barrier to including people with severe or profound and multiple learning disabilities in engagement.

Building on learning from previous engagement work, we wanted this project to have a more creative output than a written report, and so it was felt that the key learning would be more powerfully received through using multi-media to convey our messages. By using images and film of our engagement with the young people and their families, it added an additional layer of ethical considerations regarding gathering consent and acting upon best interest of sharing such materials of young people who would not have the capacity to consent themselves.



In this short guide, we share how we carefully considered whether we were acting in the best interest of the young people by:

- including them in the project, and
- taking images and videos and sharing them on a public platform.

Throughout this guide we provide examples of what we did for this particular project and what we found through this process. This will not be reflective of all people with severe or profound and multiple learning disabilities. The intention is that these examples will provide an insight into some of the things that may arise from a best interest process and how the What Matters to Me project planned for and managed these. Others taking forward a similar process will need to base it around the people they are working with and tailor their approach accordingly.

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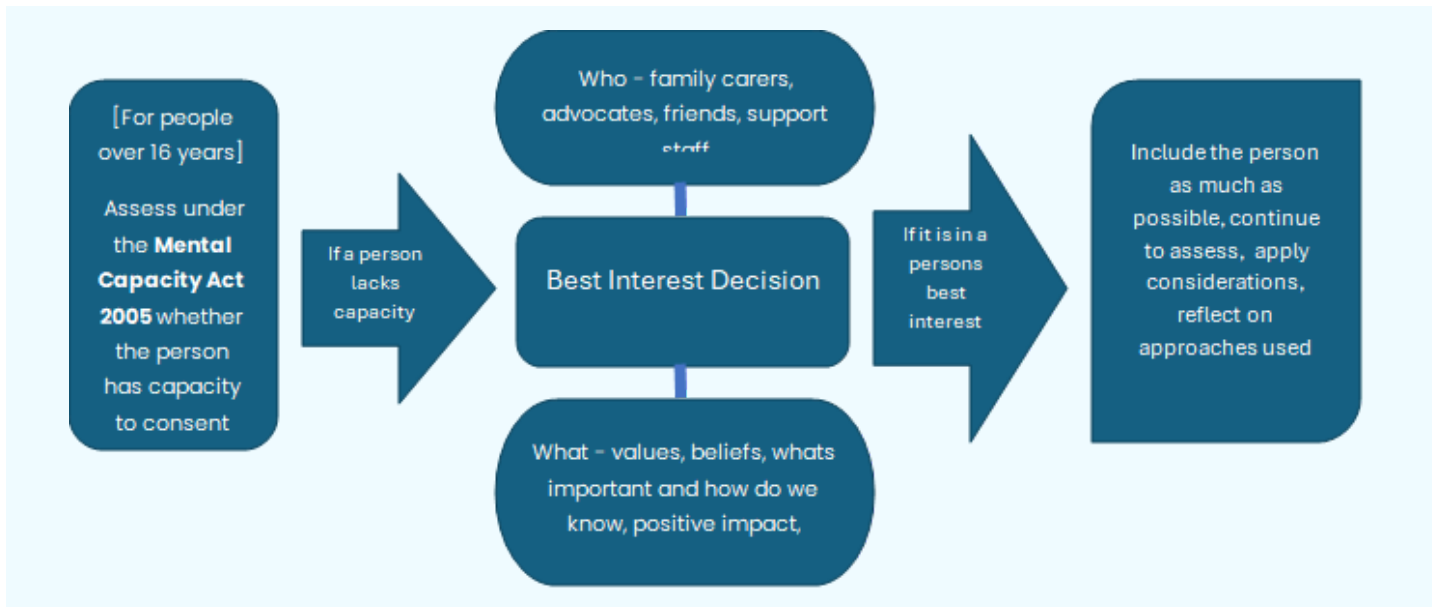
Top Tips!

When engaging directly with individuals who have severe or profound and multiple learning disabilities, one of the initial steps is to obtain consent or go through a best interest decision process. This step ensures compliance with legal requirements and should not be perceived as intimidating or a hindrance to engagement with this group.

This process gives professionals valuable insights to improve engagement, creating a positive experience for the individual and greater success for the professional. Here are some of the top tips we learnt through the consent and best interest process for the What Matters to Me project:

- Use the process to learn key things about the person
- Learn the young person's observable indicators and be aware of these throughout
- If the person does not seem happy – stop!
- Best interest is not static – it needs to be continually assessed
- Evaluate risk and benefit
- Use knowledge from those who know the person best!
- Be ambitious to try things, so long as the person is happy and safe
- Be flexible and creative
- Document decisions
- Review and reflect – together!

A simple flow-chart to demonstrate the consent and best interest process we used in What Matters to Me:



What is Consent?



To a) take part in a project or to b) share images or photos after, it is important to gain the consent of all participants. For children and young people under 16, parents can give consent, but best practice would be to ensure that young people themselves consent too.

People with severe or profound and multiple learning disabilities may lack the capacity to consent due to significant cognitive impairments that affect their ability to understand and process information. These impairments can hinder the capacity to weigh options and communicate choices effectively.

This project was aimed at young people aged 16-25. Because all the young people taking part were over 16 at the start of the project, in line with the Mental Capacity Act 2005, we had to firstly assess capacity. Our project was specifically aimed at engaging directly with young people who would be described as having severe or profound and multiple learning disabilities.1

What is Capacity?

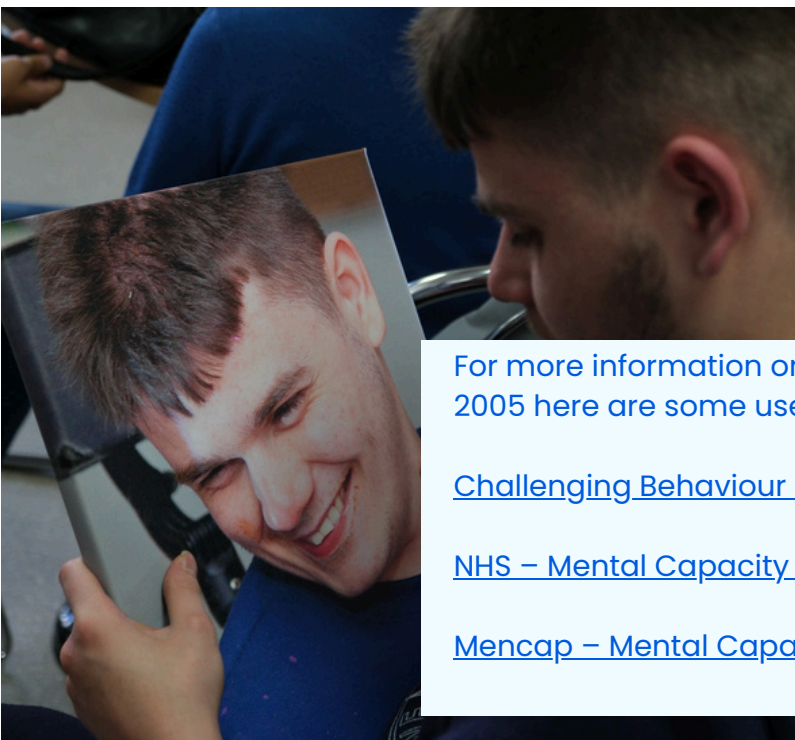
Capacity refers to the ability of a person to make their own decisions. It involves an individual understanding information relevant to a decision, retaining that information, using or weighing that information as part of the process of making the decision, and communicating their decision (whether by talking, using sign language, or any other means).

The Mental Capacity Act (MCA) 2005 provides a framework designed to protect and empower people who may lack the capacity to make their own decisions. It applies to individuals aged 16 and above and requires that capacity assessments be conducted without presumption of capacity.

The MCA says:

- assume a person has the capacity to make a decision themselves, unless it's proved otherwise
- wherever possible, help people to make their own decisions
- do not treat a person as lacking the capacity to make a decision just because they make an unwise decision
- if you make a decision for someone who does not have capacity, it must be in their best interests
- treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms

If a person lacks capacity, decisions must be made in their best interests.

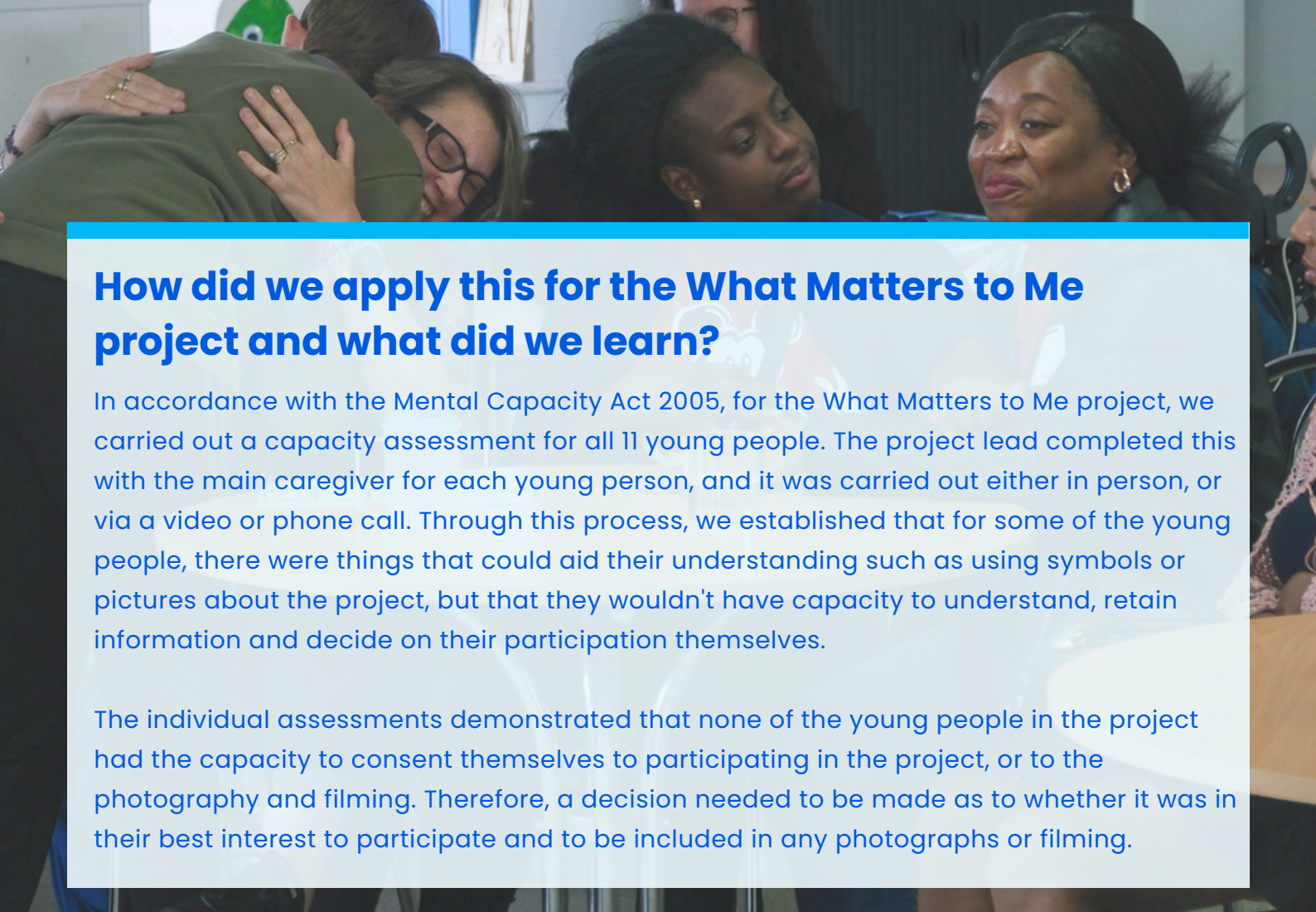


For more information on capacity and the Mental Capacity Act 2005 here are some useful links and resources:

[Challenging Behaviour Foundation – Mental Capacity Act 2005](#)

[NHS – Mental Capacity Act](#)

[Mencap – Mental Capacity Act resource pack](#)



How did we apply this for the What Matters to Me project and what did we learn?

In accordance with the Mental Capacity Act 2005, for the What Matters to Me project, we carried out a capacity assessment for all 11 young people. The project lead completed this with the main caregiver for each young person, and it was carried out either in person, or via a video or phone call. Through this process, we established that for some of the young people, there were things that could aid their understanding such as using symbols or pictures about the project, but that they wouldn't have capacity to understand, retain information and decide on their participation themselves.

The individual assessments demonstrated that none of the young people in the project had the capacity to consent themselves to participating in the project, or to the photography and filming. Therefore, a decision needed to be made as to whether it was in their best interest to participate and to be included in any photographs or filming.

What is a Best Interest Decision?

The Mental Capacity Act 2005, states that when a person lacks capacity to consent themselves, a decision must be made in their best interest. An assessment will take place to ensure their involvement aligns with what is felt to be in their best interest.

The MCA sets out a checklist to consider when deciding what's in a person's best interests.

It says you should:

- encourage participation – do whatever's possible to permit or encourage the person to take part
- identify all relevant circumstances – try to identify the things the person lacking capacity would take into account if they were making the decision themselves
- find out the person's views – including their past and present wishes and feelings, and any beliefs or values
- avoid discrimination – do not make assumptions on the basis of age, appearance, condition or behaviour
- assess whether the person might regain capacity – if they might, could the decision be postponed?

For more information on best interest decisions, check out these helpful resources:

[The Challenging Behaviour Foundation – Making Decisions](#)

[Paradigm – A Practical Guide to Supportive Decision Making](#)

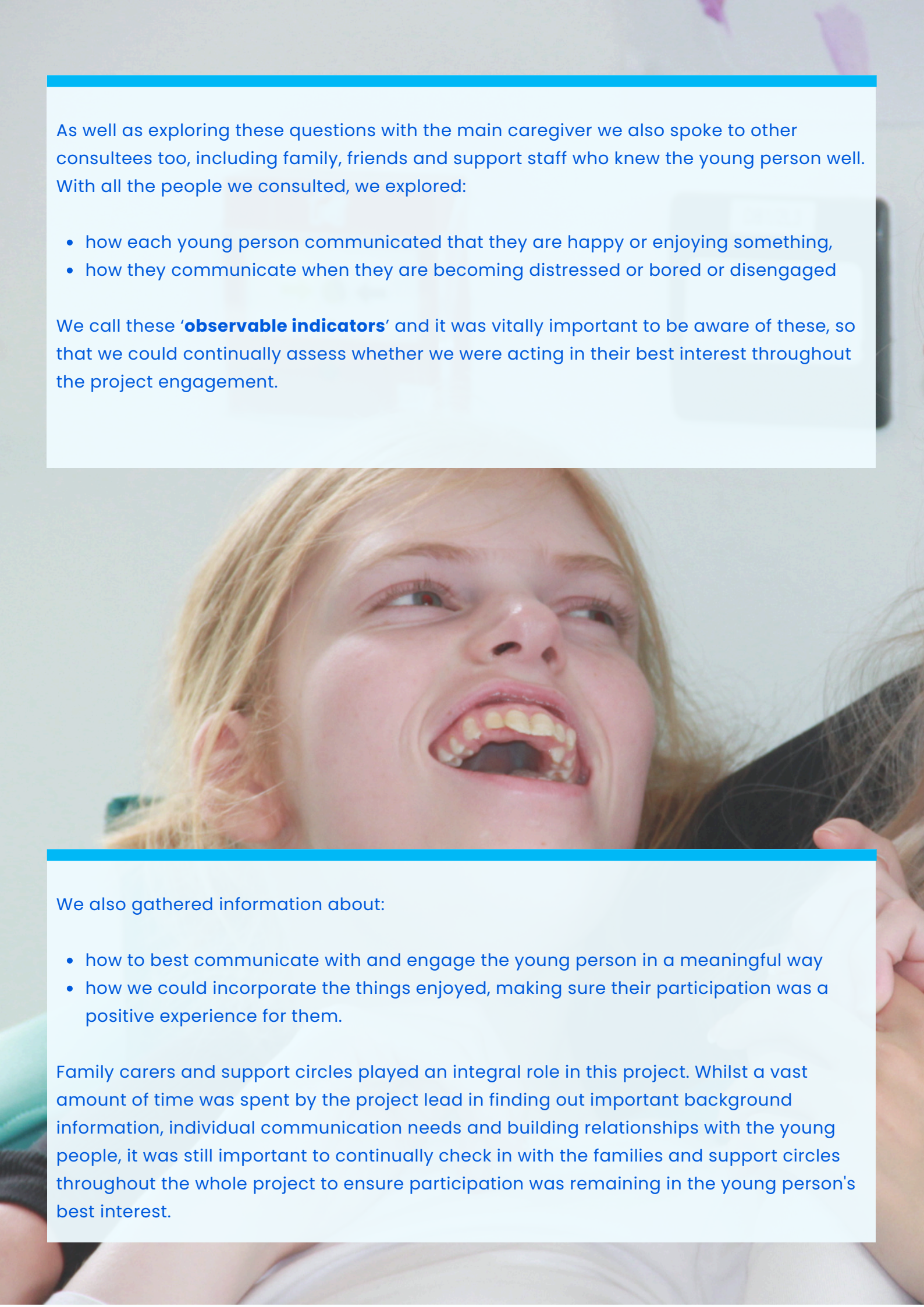
[Cerebra – Decision Making, Confidentiality and Sharing Information](#)

After assessing the capacity of each young person with their main caregiver and concluding that a decision on project participation needed to be made in their best interest, we followed our robust best interest process.

For the What Matters to Me project, we followed processes developed in previous projects (see [What Matters to Me – Project Background](#)). We asked a range of questions about the young person to gather important background information - things that are important to and for them and considerations that needed to be taken into account. The overarching best interest assessment was carried out with the young person's main care giver and involved weighing up:

- the benefits of participating (and of taking photographs)
- the possible negative consequences of participating
- how we would mitigate and reduce the chances of any negative consequences





As well as exploring these questions with the main caregiver we also spoke to other consultees too, including family, friends and support staff who knew the young person well. With all the people we consulted, we explored:

- how each young person communicated that they are happy or enjoying something,
- how they communicate when they are becoming distressed or bored or disengaged

We call these '**observable indicators**' and it was vitally important to be aware of these, so that we could continually assess whether we were acting in their best interest throughout the project engagement.

We also gathered information about:

- how to best communicate with and engage the young person in a meaningful way
- how we could incorporate the things enjoyed, making sure their participation was a positive experience for them.

Family carers and support circles played an integral role in this project. Whilst a vast amount of time was spent by the project lead in finding out important background information, individual communication needs and building relationships with the young people, it was still important to continually check in with the families and support circles throughout the whole project to ensure participation was remaining in the young person's best interest.



Some examples of possible negative consequences we identified and proposed mitigations included:

<p>New people and new experiences being overwhelming and leading to the person showing signs of distress:</p>	<p>Gathering background information including knowing the signs of when a person is starting to become distressed and stopping the activity straight away.</p> <p>Using the background information to carefully plan suitable activities that the young person usually enjoys and avoiding activities or triggers for distress.</p> <p>Engaging in familiar environment with familiar people also involved (families and/or support staff would be present during all engagement)</p> <p>Listening to, and being led by family and support circle as to when engagement needs to stop or be changed.</p> <p>Using communication support tools where appropriate such as symbols and pictures to aid understanding of the project activities and the people involved.</p>
<p>Changes to routine</p>	<p>Incorporating, in as much as possible, engagement within usual familiar activities and routines.</p>
<p>Frustration at not having communication understood and needs met</p>	<p>Spending time gathering important background information to understand individual communication needs and ensuring we have the skills and materials to best support effective communication.</p> <p>Utilising the invaluable skills of family and support circles who know the young person well, to be key communication partners and support the project lead in the engagement.</p>

Some of the key positive impacts for the young people established through the best interest process included:

- Providing opportunities for the young people to take part in activities they enjoy
- Providing opportunities to engage in new activities which may lead to finding new ways to improve engagement and/or communication
- Supporting their ability to express their experiences, preferences and views without undue restrictions or burdens
- Providing a platform for sharing their experiences, preferences and views with the purpose of influencing and shaping support and services
- The learning from the direct engagement could result in changes that has a positive impact on other people who have severe or profound and multiple learning disabilities
- Providing information to others about how to best engage with people with severe or profound and multiple learning disabilities
- Providing a 'voice' for people who are often overlooked or 'missed out'
- Raising awareness of the value of directly engaging with people with lived experience and the issues faced by people with severe or profound and multiple learning disabilities

A huge amount of the project learning was established just through gathering the relevant information through the best interest process. It allowed us to shape how we would best engage with this group of young people and provided the foundations for the principles of engagement we established as one of our key learning strands.

[Film: Finding out what Matters: Principles of Meaningful Engagement](#)



Taking and using images and film

Our approach to capturing our engagement through images and film meant we had an additional layer of consent and some ethical implications to consider.

Sharing images and film can be a powerful way to convey messages and demonstrate visually something that might be difficult to explain in a written report, especially when we are engaging with people who may communicate very subtly or use individual communication that may not be familiar to others.

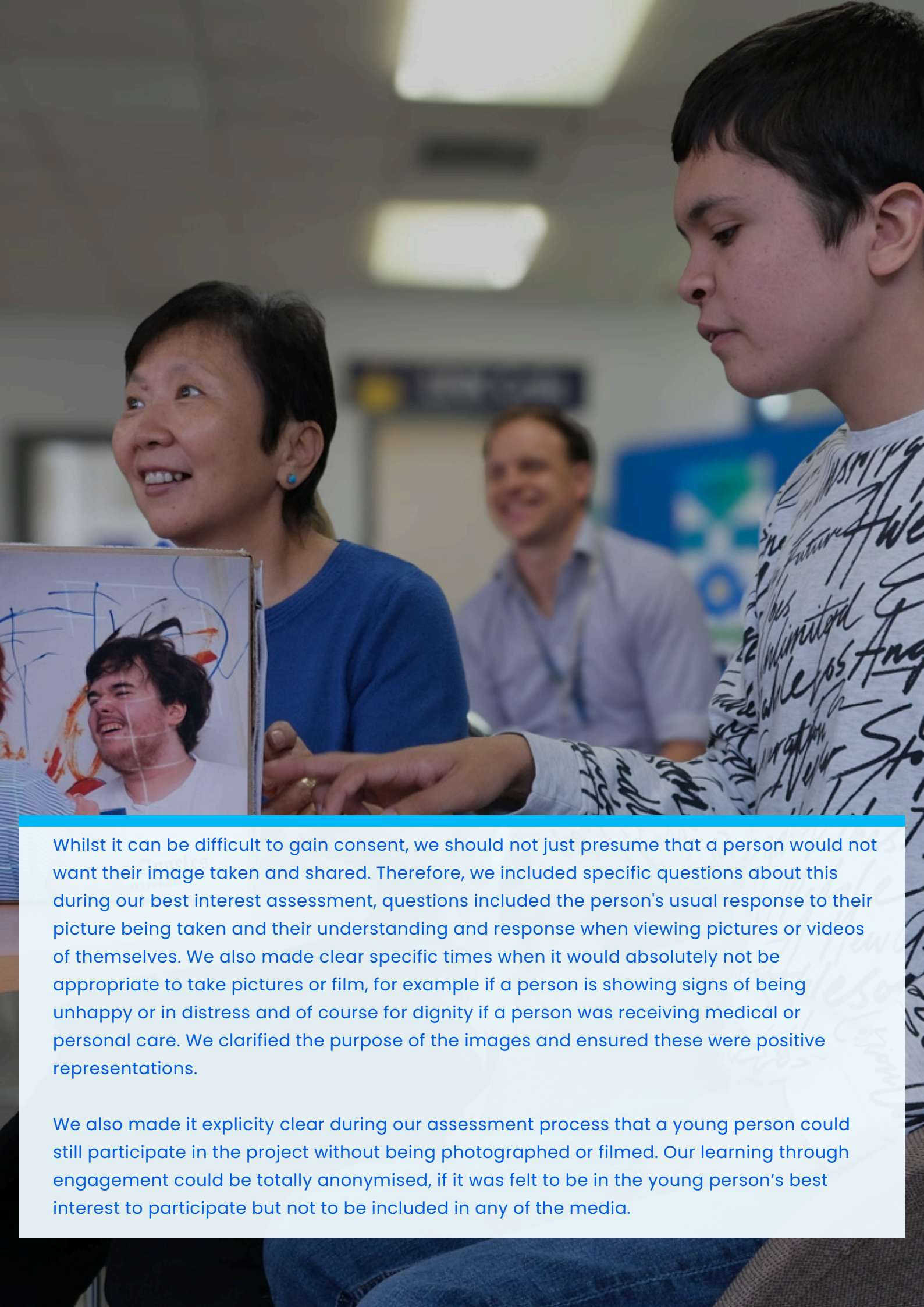
The project aims were to influence policy and shape support and services, so we wanted to adopt the most impactful way to show the importance and value of engaging directly with people with severe or profound and multiple learning disabilities. This meant we had to think very carefully about whether it was in each individual's best interest to have their images taken and shared on a public platform.



For more information:

[PMLD Link/Mencap - Consent for Videos and Photos of People with PMLD](#)

[RIX Webinar – In February 2025, we shared our practices and approaches to using images and videos at a webinar hosted by RIX Inclusive Research on ethical issues on sharing online images of people with PMLD. Here we were able to share our formal approaches as well as our practical approaches to this complex but important topic. Follow RIX Inclusive Research for updates on their review of practice.\]](#)



Whilst it can be difficult to gain consent, we should not just presume that a person would not want their image taken and shared. Therefore, we included specific questions about this during our best interest assessment, questions included the person's usual response to their picture being taken and their understanding and response when viewing pictures or videos of themselves. We also made clear specific times when it would absolutely not be appropriate to take pictures or film, for example if a person is showing signs of being unhappy or in distress and of course for dignity if a person was receiving medical or personal care. We clarified the purpose of the images and ensured these were positive representations.

We also made it explicit clear during our assessment process that a young person could still participate in the project without being photographed or filmed. Our learning through engagement could be totally anonymised, if it was felt to be in the young person's best interest to participate but not to be included in any of the media.

How did this apply to practice during the project?

Issues around consent, assent and ensuring that we were acting in the best interest of the young person were continually assessed throughout the project.

Here are some approaches we used to ensure we respected young people's responses to confirm that we were acting in their best interest throughout, especially when it came to taking and sharing images and films.

What we did:

- Shared the images and video clips with the young person as well as their family carers and support circles to make sure that all were comfortable with the images;
- Developed an understanding of positive and negative observable indicators. We monitored young people's responses to seeing their images/video clips and using this information to think about how the young person might feel;
- Gauged reactions and used such reactions, alongside speaking to family carers and support circles to determine how we use materials.
- Got the young people involved in sharing their images/video clips - pressing buttons/ showing physical copies of their images (and using our knowledge to interpret the responses of the young person).





How we did it:

- Showed the young people their pictures on canvas' (as a present to keep);
- Made photo cubes for young people to physically hold, with the option to be able to take off the pictures, as they were velcro'd on;
- Watched the video clips from previous engagement activity as groups and individually (this also reinforced the memory of the previous engagement);
- Showed posters where images of the young people were featured - their reactions were clearly positive, with some young people physically pulling peers and adults to the place where their picture was displayed to show them.

By taking on board young people's responses, family carers thoughts and feelings, and working with professionals with extensive experience, we had some concrete ways we could demonstrate that we were involving the young people as much as possible and responding to their reactions in how we were using the materials.

Adherence to the Mental Capacity Act (2005) and the rigorous consent and best interest processes is about more than just compliance with the law, it also instill confidence that the young peoples' autonomy and rights are respected and upheld. It ensures that any actions taken are in the best interest of those who may lack the capacity to make certain decisions independently.



1 – Someone with a severe learning disability will likely use little to no speech and will need lifelong support with daily activities like dressing, washing, eating and keeping safe. A severe learning disability will be identified at birth or during someone's early childhood. Someone with profound or multiple learning disabilities (PMLD) will have more than one disability and will have difficulty communicating verbally. Many people with PMLD may have additional sensory, physical or health needs or mental health difficulties. (Mencap and PMLD Network)

