



What Matters to Me

**Methodology: Using a Mixed
Method Approach**

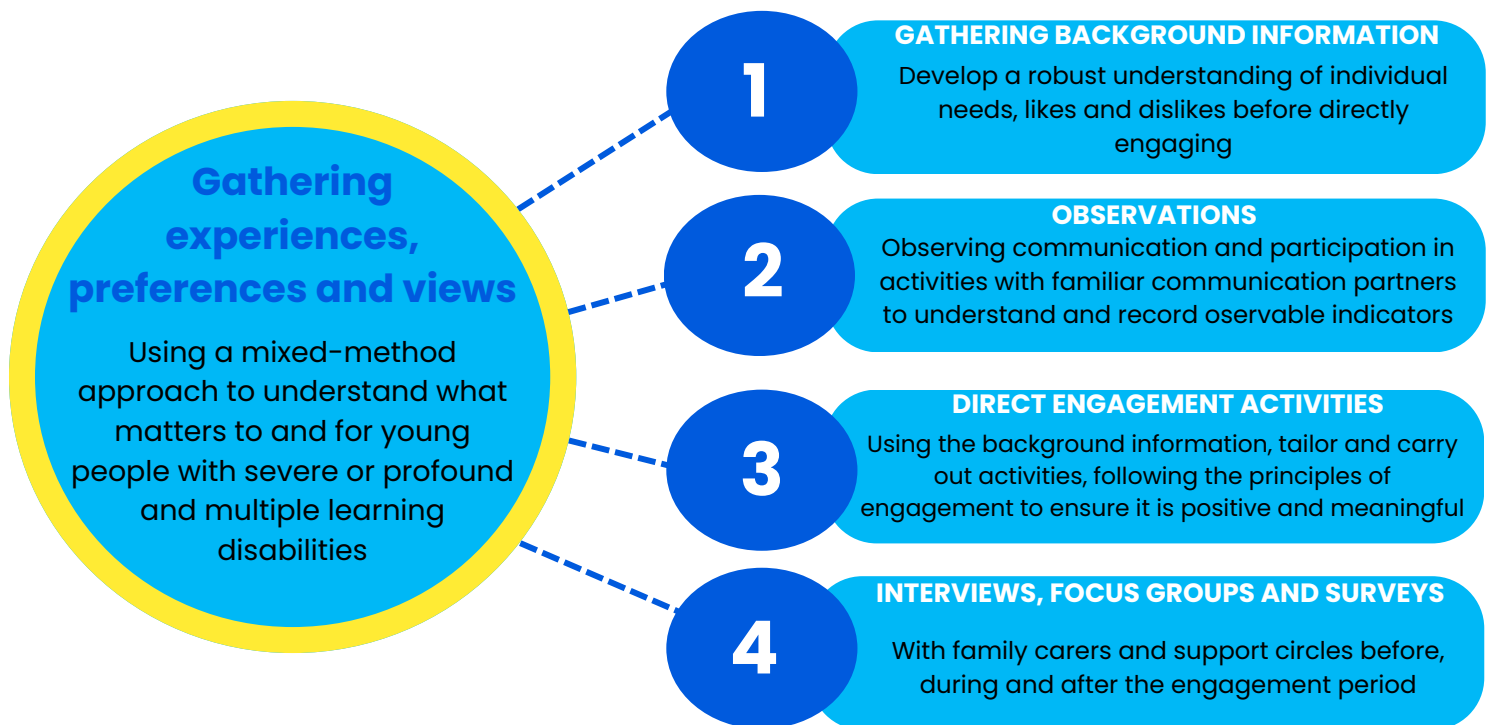


**The Challenging
Behaviour Foundation**

Using a Mixed Method Approach

The What Matters to Me project used a mixed method approach, as developed in preceding projects, to ensure our engagement was meaningful, and our learning was accurately reported.

The inclusion of various perspectives; from the individuals themselves, their families, and their support networks, helped to create a more complete and accurate picture of their experiences, preferences and views.



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!

An important first step was the gathering of information about the young people we were working with, including their needs, ways they communicated, likes, and dislikes. This involved finding out information from those who know them well. Part of this step included gaining consent, or following a best interest process, which also provided valuable insight into the individuals' views, feelings or wishes and how they might communicate this. We followed a robust **consent** and **best interest** process assessing capacity in line with the **Mental Capacity Act (2005)** and completing a stringent best interest assessment with each individual who took part. See our [consent and best interest guide](#) for more information on this!

Here are some ideas of what you might want to find out about an individual when planning to involve them in engagement activities:

- How does Louie generally communicate their wants, needs and feelings? (getting a general idea about whether he can communicate through signs, symbols, body language, facial expressions)
- How do you know when Louie is happy or enjoying an activity? (what **observable indicators** are we looking out for to know that he is responding positively to an activity)
- How do you know when Louie is unhappy?
- How do you know when he is distressed?
- What activities does he seem to enjoy?
- What activities does he dislike?
- What things do we need to think about when communicating with Louie? (processing time, visual aids, environment factors)
- Do we need to be aware of any health or medical background when including Louie in activities? (**pica**, epilepsy, allergies)

Who might you want to speak to, to get some background information about an individual?

- Family members – parents, carers, siblings, grandparents
- Support Staff – teachers, support staff, **PA's**
- People who know the individual well (their **support circle**)

As part of the What Matters to Me toolkit, there is a handy tool that can be completed by people who know an individual well to provide background information to support positive engagement.

Fenton

Fenton was the first young person that was involved in the project, through visits at his home and during a respite stay at Demelza we learnt about how Fenton usually communicates.

Fenton's communication is very subtle, primarily through facial expressions and eye movements. We also learnt about some activities that Fenton enjoys doing, and how we might be able to tell this – what his positive observable indicators are.



Fenton's Mum shared with us that whilst in a hydrotherapy pool, his body relaxes, and he becomes significantly more engaged than he does outside of the pool, this might be visible through relaxed facial expressions and smiling. Given that this was felt to be an environment that Fenton would be most comfortable interacting in, we were fortunate to have access to use the facilities at Demelza, so we factored in a group hydrotherapy session during our first 'exploring experiences' engagement day.

Whilst in the pool, Fenton was able to communicate his enjoyment for the activity through smiles and using eye movements with his Mum who was supporting him in the pool (communication partner). Through eye movement during a game of 'sharks' he was able to express yes when asked by his Mum if he wanted 'more' (i.e. to continue participating in the game with another young person).

Finding out at the initial stages what Fenton liked and what would help him communicate and actively engage during the sessions, allowed us to plan and carry out a meaningful engagement session.

“Most people sort of say, oh, I've never seen him smile like that before – it's because you haven't given him a reason to”

Fenton's Mum on speaking about his reactions in the pool

After finding out important information about an individual, we used this when spending time with them to develop a deeper understanding of how we could best engage with them. Within the project we spent time observing communication and participation in activities between the young person and someone who knows them well, such as family or support staff in different environments – at home, at college or out and about in their local communities. This step was crucial in understanding the dynamics and nuances of their interactions.



Aimee

During a visit to Aimee at her college, we were shown the communication aids she uses by her support staff and had the opportunity to observe how much of a vital part these play in Aimee communicating her wants and needs in her daily life.

Through seeing the visual support aids that she used and how she used them, we were able to replicate using similar aids for the engagement sessions we planned, keeping this familiar for Aimee and providing methods for her to engage with.



“Aimee has no speech. She is vocal but not verbal. She has likes, dislikes, interests and views just like all of us, but for Aimee it is incredibly hard to get these understood. What has been really wonderful about this project is that Aimee has been the very centre of it right from the beginning. Taylor has been to visit Aimee at home and at college to get to know her and learn how she can best engage with her”

Family Carer

3 Doing activities together

Direct engagement

Using what we learnt about the individuals through gathering information and observations, we were able to plan meaningful engagement activities. It was important that we used a person-centred approach, and we continued to consult support circles in the planning of the activities. It was equally as important that throughout these activities, we were aware of and responding to, the **observable indicators** to enhance the engagement, or if we were seeing signs of unhappiness or distress, then we immediately stopped the activity. The **support circles** played a key role throughout all of this. When carrying out direct engagement, we followed the principles of engagement, a set of key considerations identified through this project. You can find out more about some of the activities carried out with the young people in the [Principles of Engagement film](#) and written report.



4 Review and check

With family carers and support circles

Finally, we engaged with family carers and **support circles** through more formal approaches such as interviews, focus groups, or surveys. This ensured that the direct engagement learning was being interpreted correctly and comprehensively. For the What Matters to Me project, it was really important that those who knew the young people best were included in all these steps, but we needed to facilitate a more formal way of checking with them, that we were interpreting things correctly. Throughout the project we held various focus groups, both online and in person. We also carried out short surveys and ensured the families were involved in the development of the manifesto, the key learning themes and that the findings accurately reflect the engagement.

This didn't always have to be a complex or formal process, it could just be checking in more informally such as asking, 'we noticed this, which we think means this, would you agree?' By combining observations with direct engagement and formal consultations, we not only validated our findings through multiple sources, but also ensured that the experiences, views and preferences of those who may not be able to articulate their needs directly were considered. This approach leads to more effective and empathetic support strategies that can significantly improve the quality of life for the individuals involved.



1

GATHERING BACKGROUND INFORMATION

Develop a robust understanding of individual needs, likes and dislikes before directly engaging



2

OBSERVATIONS

Observing communication and participation in activities with familiar communication partners to understand and record observable indicators



3

DIRECT ENGAGEMENT ACTIVITIES

Using the background information, tailor and carry out activities, following the principles of engagement to ensure it is positive and meaningful



4

INTERVIEWS, FOCUS GROUPS AND SURVEYS

With family carers and support circles before, during and after the engagement period

Gathering experiences, preferences and views

Using a mixed-method approach to understand what matters to and for young people with severe or profound and multiple learning disabilities



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