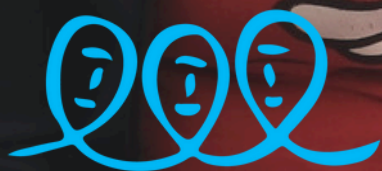


# What Matters to Me

**Finding out what matters: The  
Principles of Meaningful  
Engagement**



**The Challenging  
Behaviour Foundation**

# Introduction

Communication is a basic human right; it is how people express their needs and feelings, participate in decisions, and engage with their community. Children, young people and adults with **severe** or **profound and multiple learning disabilities** often face barriers in communication due to the unique ways they express themselves, such as by using body language, facial expressions, signs, or symbols. This can sometimes mean it is difficult for others to understand a person's wants and needs, and steps are not always taken to adapt engagement in important activities such as decision making and consultations processes.

The What Matters to Me Project identified six key principles of engagement to facilitate opportunities for people with severe or profound and multiple learning disabilities to influence the support and the services they receive, and the world around them. Whilst this should be the right of all young people, unfortunately this sort of engagement just doesn't happen often enough. Engagement with this group is frequently overlooked at all levels. Whether it's in an assessment for a social care package, in **EHCP** planning or perhaps an Integrated Care Board (ICB), or local authority not consulting with this group when making changes to their policy or practice. We see many consultations about policy and practice which affects people with severe or profound and multiple learning disabilities but they rarely seek the perspectives of those individuals.



***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!***



# The importance of meaningful engagement

People with severe or profound and multiple learning disabilities are likely to rely heavily on accessing statutory services, and so it is important to make sure there are steps in place to involve them in decision-making and consultations, to ensure their rights are respected and their voices are heard. Putting these steps in place not only enables individuals to influence the services and support they receive, but it also ensures that care is person-centered and tailored to meet individuals' specific needs.

True engagement not only enhances a person's quality of life, but also embeds a culture of co-production within organisations, improving trust and relationship-building. Wider public consultations need to consider creative, alternative engagement methods that do not rely on respondents to be able to read or write to articulate their views so that services can better reflect the realities and preferences of those who rely on statutory care, ultimately leading to more effective and compassionate outcomes.

*“It's so important for young people like Fenton to be supported and listened to. It's their right. They deserve it.*

*They just need to be listened to, and time taken out to hear what they've got to say, because they all have something to say and give.”*

Family Carer – What Matters to Me



Not only is it important to ensure everyone can influence the services and support they access to ensure it works as well as possible for the people who draw on support, it is also the law.

The **Children and Families Act 2014** states that local authorities should ensure that children, their parents and young people are involved in discussions and decisions about their individual support and local provision. The **Equality Act 2010** ensures that disabled children and young people are not discriminated against and have equal opportunities to participate in all aspects of life.



*“Every person, every child, every young person is entitled to be able to give their views and their opinions, to be able to tell us what they like, what they dislike, what they want, what they need. And just because it can be difficult to obtain these from children and young people, doesn't mean that we really shouldn't try.”*

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*“This kind of direct engagement with our young people is important because it impacts their lives. This project has enabled us to share with policymakers at local and national level exactly what our young people need, because it's about their future and they're entitled to this. And unless you get to know these young people, you're making decisions based on no evidence. You need to ask them what they need.”*

Head of Post-16 Special Education Provision



# Engagement and Influencing:

“In our experience it has differed how services have engaged with Cerys in order to try and find out what she needs, what she wants, and what her opinions are. Education; the schools and the colleges that she's attended have always been very good at obtaining her opinions and views, because they know her so well, because they work with her on a daily basis. They get to know her very well. They know her likes and dislikes. They know things that can trigger anxieties, things like that.



But unfortunately, in some other services where they don't have the opportunities or don't go to the lengths to get to know Cerys very well, sadly they don't tend to try and get her views, ideas and opinions.

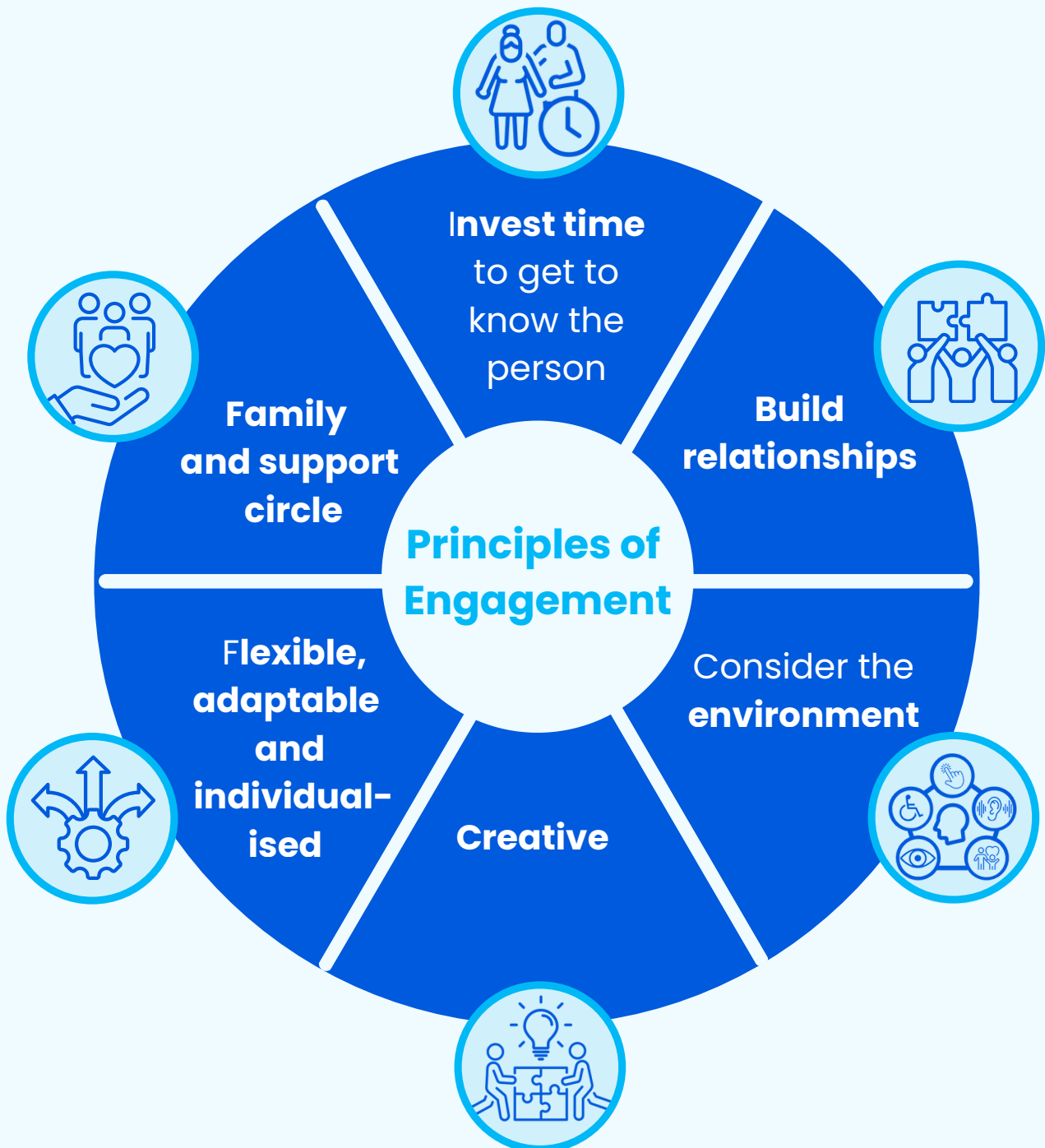
We've had situations where in **EHCP** annual reviews, schools and colleges will work really hard to try and compile a report with Cerys' views and opinions of what she likes about school, what she doesn't like, what she needs. But sadly, when it comes to writing the **EHCP**, local authorities tend to ignore that information.

They don't get to know the child or the young person and sadly make decisions based on budgetary reasons rather than what we and what Cerys may feel she really needs, as I have.”

Family Carer from What Matters to Me

# Principles of Meaningful Engagement:

Whilst gathering the background information, observing and planning the activities and indeed carrying them out, the project started to identify some key principles that should be followed to ensure that the engagement was a positive experience for the young people and that we were able to gather information for the purpose of the project.



# Engage a person's family and support circle

Families are often key advocates for their relatives and involving families and support circles ensures that the individual's preferences and needs are known and respected during engagement and in decision-making. Family carers and key people involved in an individual's life will know them best. This might be parents, siblings, carers, paid support staff such as PAs, teachers or service providers. When engaging with a person who doesn't communicate verbally, we need to rely heavily on the information that can be gathered from families and support circles. This can help with knowing how best to engage, what things the person might like or not like, and what things we need to know to make sure the person is safe and happy during engagement. They are often experts in knowing their relatives and it is important to ensure this is respected.

“ Taylor hadn't really met us, but she was messaging saying, do you think they'd like this? Do you think they'd like that? I was thinking about this, do you think it would work? And we were going either yes or no or no idea, we'll try it, but I'll be honest, she's probably the only person I've ever come across that's done that. ”

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“ I think good engagement, just thinking about how it would look like – it would involve Aimee right in the very centre but also involve her close family. We know her; we've been alongside her for the last 19 years doing this journey with her. We know what she likes, what she doesn't like. ”

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# Invest time to get to know the person

Investing quality time to understand an individual's needs including how they communicate, as well as their likes or dislikes is crucial. Everyone is unique and has different wants and needs, and people with severe or profound and multiple learning disabilities also need people to spend time with them and alongside them, to learn the nuances of their communication and build trust. Families and support circles can help with key background information and can share how an individual communicates. Then, to engage in a meaningful way, the time must be spent to really get to know the individuals.

*“It's for young people like Fenton who just needs to have time allocated for people to get to know him, rather than coming straight to me. They are quite discrete, his yeses and noes and what he does and doesn't like. But if people actually take the time to talk to him at an eye level, rather than sort of talking over him or at him and just spend that small amount of time, just to talk to him and see how his reactions are, and he will give a yes or no of what he likes or not. But people just have to take the time, rather than just going straight to asking me what he does or doesn't like or just assuming oh he's in a wheelchair, he's severely disabled, so he's not going to want to or need to do that anyway.”*

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*“I think engaging with us is really, really important. But with Amiee at the center and making time to engage with her. It does take longer for Amiee to communicate; it takes longer for her to process things. Whoever's engaging with her needs to allow themselves time to get to know her, for her to get to know them and come to trust them, like them and want to work with them. But for them to take the time out, to use the resources that she needs, whether that's a now-next board or symbols. But just to learn from us and to learn from her and to spend that time with her.”*

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# Build relationships and develop an understanding of people's needs

Building trust through consistent interaction helps professionals understand an individual's needs better. People with severe or profound and multiple learning disabilities will need a longer time to process information, no matter how small, and to recognise and respond to others. By building relationships, it increases familiarity for the person, and they will be more likely to engage and interact. Many of these principles are interlinked, but it fosters a sense of trust with the person and gives the person carrying out the engagement more knowledge of how to make the engagement as effective as possible.

## Importance of building trust and relationships for engagement:

To understand an individual's experiences, preferences, and views, building relationships can make a huge difference. In one of our sessions, thanks to Pete's effort to build that relationship, we saw Fenton share his joy for music, although he hadn't enjoyed music therapy before.

*“I was quite sceptical about it. Being a 17-year-old young lad, I thought Fenton would be into drums and loud sounds and symbols and all of that.*

*Pete found that if he used the iPad and put the instruments into the iPad to make the sounds, Fenton was starting to move his hand to strum the instrument on the iPad, and that was just literally by Pete sitting back, watching how Fenton reacted to the sounds and the noises, what worked, what didn't work, and opening up a huge window for Fenton, which honestly, I didn't know whether it was going to work, but it really did.*

*Pete quite quickly found out that actually Fenton likes string instruments, and he seemed to love the harp and the harpsichord, and they were what really activated Fenton's brain and got him looking at Pete, moving his hand.”*

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# Get to know a person's likes and dislikes and be creative

Respecting and incorporating a person's preferences into their daily activities enhances engagement. Creative approaches should be encouraged, and funding made available for this to happen, to gather views such as in consultations. To get a real insight from the person we are engaging with, we need to have an understanding of their likes and dislikes and use this in the planning and delivery of engagement activities. Through this project, we have observed increased interaction with young people, when we have found creative ways to use the things we know they like during the sessions.



“We decided to run our first engagement session at Demelza with a session in the hydrotherapy pool. Whilst gathering the background information for the young people due to attend, we repeatedly heard how much more animated the young people would usually be in the pool environment.

One family member said they think this is down to being able to concentrate more on being ‘in the moment’ and in the environment, rather than possibly being uncomfortable in a wheelchair without the ability to move his body.

We observed this so clearly in the session, when one young person showed very clear facial expressions of happiness which was only ever really shown at that level when he was in the pool.”

What Matters to Me Project Lead



# Consider the environment such as sensory needs, accessibility and familiarity

Engaging with an individual in familiar environments, considering things such as sensory needs and accessibility, is essential. It may be important for a person with severe or profound and multiple learning disabilities to ensure normal routines are not disrupted, or changes are made carefully with as much planning as possible. This can be helped by considering where or when engagement will take place. Being led by family carers and support circles, considerations need to be taken to ensure the person feels comfortable, safe and happy in the place the engagement is taking place. Steps also need to be taken to make sure the environment is physically accessible and safe for the person you are engaging with, thinking about needs such as mobility, **PICA** behaviour and allergies.

“The decision to go into the community with the young person we worked with individually was because our visits usually took place at home during their day off from college in the week.

This meant that this was really changing their routine, their day off usually meant they could chill out and enjoyed doing things in their bedroom. So, whilst they did engage well during the visit, they were keen to continue their normal routine as opposed to doing activities with me in the living area.

And so, for the next session instead of meeting with her at home, I met her and her family out and about in the community, where I could observe and get involved in some of the things they liked. One of these included playing the 2p machines at the arcades, I was able to see and join in playing with the young person.”

What Matters to Me Project Lead



“In order to engage better with young people, we [need to] consider the environment that they're in at the time when we're trying to engage with them. I've been in situations where 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 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. We've walked into a room

where there's been markers and pens left around which my daughter, for her sensory needs, just grabbed hold of the pen and chewed it dry. And things like that can be really, really difficult. It can either make or break an appointment.”

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# Be flexible, adaptable and use individualised approaches

Flexibility in adjusting schedules, routines, and communication methods to fit individual needs is key. It's really important to be flexible in your approach when working with people with severe or profound and multiple learning disabilities. We must be flexible not only with things such as timings and environment, but also in the methods we use. We need to be responsive in real time to changing things up to best suit the people we are working with, even if that doesn't quite fit the original plans!

Due to the complex health needs of some of the young people, we had to be really flexible with timings, not too early and factor in plenty of time during sessions for personal care, feeding routines, being mindful of triggers for seizures, or upset.

*“As well as being flexible, we have to be able to adapt quickly. One of our earlier sessions at Ifield we trialled a whole day plan of activities (it had previously worked well at Demelza) – but for the dynamics of this group, the morning worked well, but by the afternoon their routine was too disrupted and some young people started to show signs of wanting to stop – so of course we did!”*

What Matters to Me Project Lead



*“It's not easy to get these young people up, ready and out the house. The timings of things that are being run need to take this into consideration.”*

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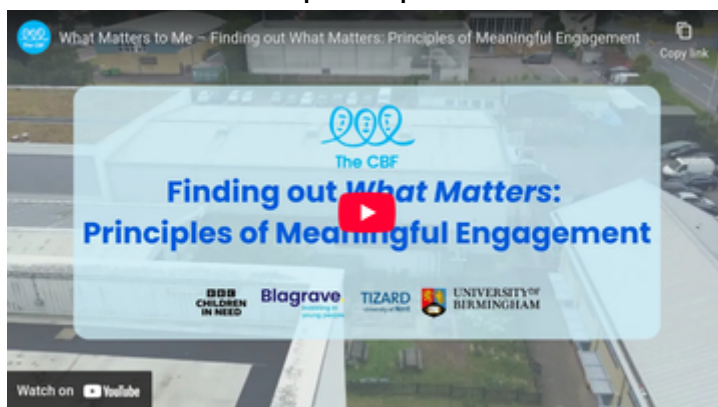
*“That's the biggest thing is most places and people, companies, whatever, don't have flexibility. If he has a seizure, they haven't got that 10 minutes to wait for him to sort of sort himself out and come to they're like, oh, well, we'll finish there.”*

Family Carer – What Matters to Me



# Conclusion:

By building in some time to reflect after an engagement session, whether that was individually or in a group, we were able to see the principles that started to emerge about what needed to be considered in the planning and delivery of our engagement sessions. This was identified as a key learning element of the What Matters to Me project and as such we presented this learning in the manifesto film and write-up.



**The principles of engagement film** can be found [here](#).

Embedded within the What Matters to Me project is the approach of ensuring engagement translates to influence and change. We share in the circles of

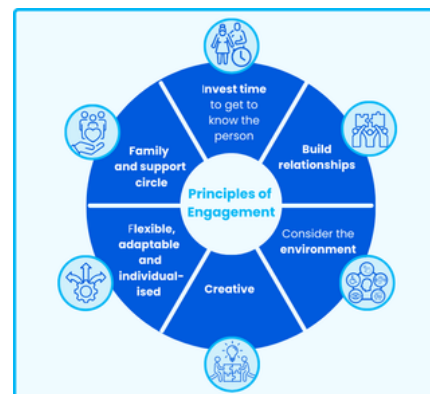


influence film and write up, the importance of people with severe or profound and multiple learning disabilities being given opportunities to be included in engagement so that their experiences, preferences and views can shape the support and services they access.

**The circles of influence film** and write-up can be found [here](#).

As part of the manifesto, there is also a practical toolkit, which includes a resource based on the principles of engagement and can be used by family carers and support circles to document and share information about how to best engage with an individual.

The **resources from the toolkit** can be found [here](#).







**The Challenging  
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