

# What Matters to Me

## Easy Read Summary



What Matters to Me is a project that was led by the Challenging Behaviour Foundation.



The project was about working with young people who have severe or profound and multiple learning disabilities.



We spoke to the young people's families and other important people in their life, because they know them best.



People with severe or profound and multiple learning disabilities often communicate in other ways. They don't always use spoken words.



This means people may not always try to find out what is important to them. They are not always included in decisions about their lives.



11 young people were involved in the What Matters to Me project.



They took part in different activities including arts and crafts, sensory and music sessions.



Their own individual ways of communicating were used to understand things that are important to them.



We talked about 'transition.' We wanted to find out what they needed when they moved into adulthood.



Our learning also found 6 important things that people need to think about when they work with people with severe or profound and multiple learning disabilities.



We call these the “**principles of engagement**”:



- Include a person's family and other important people in their lives



- Have enough time to get to know the person



- Build relationships and learn to understand the person's needs



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



- Think about the place:  
Does the place meet the person's sensory needs?  
Is the place accessible?  
Does the person know the place?



- Be flexible, and suit the way you work to the person



We found 8 things that are important to young people when they move into adulthood.



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



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



- To communicate in lots of ways and to have staff that support them to communicate



- To make choices and be part of decisions



- To meet friends and do things together



- To work with staff who know them well



- To get advocacy from family and other important people



- To get good healthcare with reasonable adjustments



We put all the things we found on a website so that more people can learn from what we have done and work with more young people to find out what is important to them.



We have also used what we learned from working with young people to tell the government how to change the law.



We have also told support services how they can use what we've learnt to change how they work.



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