

Words matter: personal assistants need to support decisions by people with learning disabilities

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Getting Things Changed

This research analyses the detail of communication between personal assistants and people with learning disabilities.



About the research

Disabled people have the right to support to achieve autonomy. This principle is enshrined in the 2007 UN Convention on the Rights of Persons with Disabilities and also in the Mental Capacity Act 2005 in England and Wales. But how is decision making supported in practice, in daily interactions between people with learning disabilities, their personal assistants (PAs) and other support workers?

In this research, we wanted to understand the detail of how conversations with support workers and PAs help people with learning disabilities to make decisions. Nine people with learning disabilities took part, five with the PAs they employed, and four with members of staff in their pottery workshop. We collected nine hours of video data of real life interactions that happened in settings including people's own homes, shops, cafes, leisure

activities and workshops. Using a Conversation Analysis approach, we were able to see how the fine detail of each interaction could undermine, or support, the person with learning disabilities to make good decisions.

The Misfits Theatre Company, a theatre group of actors with learning disabilities, helped us to think about our data by talking about extracts, and by re-enacting some of the scenes from our findings. They have made a film to assist other people with learning disabilities to take more control of their lives (see 'further information, overleaf).

This research reveals how the fine details of interactions are crucial to supporting decision making and enabling equality in conversations.

Policy implications

- The Department of Health and Social Care should provide examples in statutory guidance of how the principles of ‘personal dignity’ and ‘control by the individual over day-to-day life’ are enacted in practice, balancing the need to advise a person with learning disabilities with the need to support choice and control.
- Councils need to ensure that positive risk-taking is given equal consideration with safeguarding, via person-centred reviews, involving all stakeholders.
- Councils should consider how to support and consult with local arts-based organisations and social enterprises for people with learning disabilities.
- Service providers and personal assistants need better training to ensure that they interact in respectful ways, and devote time to talking. This training could be delivered jointly with people with learning disabilities themselves.
- Social care practitioners need to understand how the precise details of conversation can support decision making, in line with the Mental Capacity Act (MCA).
- Disabled people’s organisations need to be funded to work with schools, colleges and social care providers to prepare people with learning disabilities prior to having a PA in their lives, so that they can gain understanding of how to manage the interactions and the relationship.

Key findings

- People with learning disabilities were active in seeking out support for their decisions. This happened when their supporter or PA paused from their activities. Time for those conversations was vital.
- When someone makes an unwise decision, despite the principles of the Mental Capacity Act, we have seen how the PA sometimes stepped in saying: ‘This one is cheaper’ or ‘This may be better for you’. Where the person with learning disabilities needed advice to inform their decisions, they generally asked for it directly or indirectly.
- The relationship with a PA or supporter is the key factor in making things work well; one person in our research had a PA who was a friend, and who became a good role-model for her in her family life. However, PAs may have a difficulty in straddling contradictory roles in that relationship.
- People with learning disabilities sometimes asked their PA to do a job for them, but it was often harder to have control over smaller decisions during joint activities with their PA.
- Good conversations depended on the two partners matching body postures, sensitive timing and giving feedback to show listening.

Further information

This research was part of a large grant, 'Tackling Disabling Practices: co-production and change', funded by the Economic and Social Research Council (ESRC) ES/M008339/1, led by Val Williams. For more information about the project: <http://www.bristol.ac.uk/sps/gettingthingschanged/about-the-project/>

Email: gtc-sps@bristol.ac.uk

The Misfits Theatre Company is based in Bristol (<https://misfitstheatre.com/>) and has produced a film for this research, which is available for free download by following the 'videos' link on our project website. The film called 'A Good Match' can be used by people with learning disabilities and their friends, who would like to find out more about how to work with a personal assistant.

Mental Capacity Act 2005 c9: <https://www.legislation.gov.uk>

Care Act 2014 c23: <https://www.legislation.gov.uk>

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PA's can support people's plans, without taking over, as this recorded dialogue shows:

PA: I could do Thursday evening. So we could go to the disco together, if you wanted to go.

Anna: Oh, it's next week.

PA: Yeah.

Anna: Wow, that's quick.

PA: Shall I put a little thing so you can remember (.) so it's in the evening, so if I just put 'disco question mark', then you can remember to think about it.

(Person with learning disabilities and PA)

