



Some groups of disabled people may need support or care services. But how can the interactions with those personnel best be managed, so that the disabled person is in control?

Summary

- In everyday life people get their personal business done, by talking with each other in lots of different situations.
- People should be treated with respect in these conversations, and have control and choices in their lives.
- But disabled people often get treated as less-than-competent conversational partners, losing their turn in a conversation, or finding their response taken as inadequate. That happens routinely during interactions within social care and support¹.
- Policy in the UK such as the 2014 Care Act² wants people who use social care to be in control, and to experience ‘wellbeing’.
- We can find out more about how things can be done better by recording conversations as they happen, and looking at how people communicate. Conversation Analysis³ has revealed a lot about how social interaction in general works, and we can use that knowledge to think about what happens with disabled people.
- Disabled people themselves are not passive. They can help to look at what happens in conversations, and can lead the way in making changes.
- We want to see if these ideas can help us have an impact on the types of interactional practices available to disabled people and their conversational partners. There have been some attempts to do this, already, in ‘applied Conversation Analysis’⁴. We want to see what else might help to make it all more practical, so that we can help make a real difference to disabled people’s lives.

¹ Williams, V. (2011) *Disability and Discourse: inclusive conversation analysis with people with intellectual disabilities*. Chichester: Wiley-Blackwell.

² *The Care Act* <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>

³ Sidnell, J. & Stivers, T. (2012) *The Handbook of Conversation Analysis*. Chichester: Wiley-Blackwell.

⁴ Antaki, C. (ed) (2011) *Applied Conversation Analysis: intervention and change in institutional talk*. Palgrave-Macmillan.

What is the problem?

In theory, welfare and social services are provided by our society to enable all citizens to live a full life. That includes social care, health services and education. But in gaining access to services, disabled people are often at a disadvantage. We know that people with learning disabilities have problems because of the way health professionals communicate with them⁵, and people with dementia are often expected to use services that do not meet their needs⁶. For example a woman with dementia told us that she was sent to a large day centre, where there were far too many people; she needed to communicate in quiet spaces, with just one other person at a time. However, even in that situation, there may well be power differentials, enacted through the way professionals set agendas or ask questions⁷. Beyond that, there can also be problems for disabled people in social and health care settings which amount to abuse⁸.

What are the policies?

The 2014 Care Act sets the broad goal of ‘wellbeing’ for all people using social care, and the service model vision statement⁹ expects that young people and adults with a learning disability and autism have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. The Winterbourne View Enquiry concluded that people with the most complex needs should have personalised services in the community, with support staff who listen and actively engage with the individual. The government’s Dementia Challenge 2020¹⁰ wants greater recognition that everyone with dementia is an individual with specific needs and that people with dementia and their carers should be fully involved in decisions, not only about their own care, but also in the commissioning and development of services. ‘Living well with Dementia’¹¹ set the standard that people with dementia should equally be ‘treated with dignity and respect’, and the Dementia Challenge 2020 promotes innovative care at home, with personalised and appropriate care for each individual. These policies emphasise the importance of a personalised approach; but practice may be very different.

How can we look more closely at these issues?

Disabled people tell us that it matters a good deal how people communicate with them. They want good relationships with practitioners, and particularly with front-line care and support staff, who often have to come into their own home. There is a good deal known about how communication

⁵ See MENCAP’s basic advice at: <https://www.mencap.org.uk/about-learning-disability/information-professionals/communication/communicating-people-learning-disability>

⁶ Boyle., G. (2010) Social policy for people with dementia in England: promoting human rights?, *Health and Social Care*, Vol. 18, No. 5, pp. 511-519

⁷ Antaki, C, Finlay, WML, and Walton, C. (2009) Choice for people with an intellectual impairment in official discourse and in practice. *Journal of Policy and Practice in Intellectual Disabilities*, 6(4) 260-266

⁸ Bubb, S. (2014) *Winterbourne View – Time for Change*. <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>

⁹ P. 4: Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

¹⁰ Department of Health (2015) The Prime Minister’s Challenge on Dementia 2020.

<https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

¹¹ Department of Health (2009) Living well with dementia: a national dementia strategy

works in general, through Conversation Analysis (CA). One branch of CA for instance looks particularly at the conversations that happen in institutional contexts, such as classrooms, services or health settings. The findings are very relevant here, since they help us to understand the way power imbalances are built into the structure of conversations, and the precise ways in which practitioners might take control of the agenda of a service-led conversation. These interactional matters have real impact on people's lives; for instance, people with intellectual disabilities may consider that they have to 'do better' or to please others¹², and others may become known as people with challenging behaviour.¹³

Practices at micro-level

Social care and health practitioners, as well as educationalists, generally enter their professions because they want to make a difference to people's lives. They may care a lot about the work that they do. But they can easily get caught up in practices that are unhelpful or controlling. A micro-analysis of conversation can pinpoint some of the strategies that are routinely used¹⁴, and can sometimes suggest ways of altering the structures of a conversation in order to make for a more successful exchange. We build on other examples of CA research¹⁵, which described some of the methods by which a non-fluent aphasic man whose lexical output was limited to 'yes', 'no' and 'and' was able to take an active part in conversations in the family home because of the question design of his interlocutors. People with dementia or traumatic brain injury (TBI) have been shown to display particular patterns of behavior in talk-in-interaction which have been hypothesized to be linked to their cognitive and communicative/linguistic deficits. For instance, there may be long silences before their uptake of a turn in the conversation. However there has been research¹⁶ focusing on the co-construction of conversations with people with dementia, showing that the willingness of conversation partners to tolerate those silences was important.

But we know this is not the whole story: it may be that we need a wider understanding of power within institutional settings, in order to really shift the systemic practices in which organisations are caught. Individual support or care workers can only change their own practices in that wider context, and we need to know how a more personalised approach to care can be disseminated throughout an organization. We also know that it takes at least two people to make a conversation. Therefore, the changes that may happen at micro-level are not just about one party (the practitioner), but also about the way disabled people take action for themselves.

What do we plan to do?

We aim to video record conversations between disabled people and their support staff, during the course of their everyday interactions in the home. We plan to work with two main groups – young people with learning disabilities, and older people with dementia, both of whom are in situations where they are having to learn how to exercise control over their relationship with support and care

¹² Williams, V. & Porter, S. (2015) The meaning of choice and control for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities*, 10.1111/jar.12222

¹³ Ponting, L., Ford, K. et al. (2010) *Training Personal Assistants*. Brighton: Pavilion Publishing.

¹⁴ Antaki, C, Finlay, W.M.L., Jingree, T and Walton, C.(2007) "The staff are your friends": conflicts between institutional discourse and practice. *British Journal of Social Psychology*, 46, 1-18

¹⁵ Goodwin, C. (1995) "Co-Constructing Meaning in Conversations with an Aphasic Man." *Research on Language in Social Interaction* 28(3): 233-60.

¹⁶ Perkins, L., Whitworth, A., and Lesser, R. (1998) Conversing in Dementia: a conversation analytic approach. *J. Neurolinguistics*. Vol. 11, Nos 1-2, p. 33-53.

staff. We will spend time with each 'pair' (disabled person + support worker) and make videos with them of the activities and talk they engage in together. Using the techniques of CA, we will transcribe and analyse the moments of talk to uncover interactional structures which support the disabled person, and to explore interactional practices which could be altered.

We plan to take our video data back to the people who have played a part in the interactions, so that we can share it with them. We envisage that they will have ideas about aspects that could be altered, and we will also be able to point out both the successful and less successful practices. We hope in this way to be able to make changes, and to explore how far this type of detailed analysis can make a difference.

How will this research help to get things changed?

We plan to work with two groups of advisors, who have direct lived experience of receiving support services, and can help us interpret and think creatively about the data. One of those is a drama group of people with intellectual disabilities, who have a practised sensitivity towards words and how they are used. We are also planning to engage people who experience dementia in this work, in order to enable them to take an active role in guiding the research. We will seek to understand the things that are going wrong, from the perspective of the disabled person, as well as the things that are helpful in these conversations. We will then return to the disabled person and their support or care worker, to see if these insights can help them to decide on how to shape their interactions more successfully, and finally we plan to organise workshops to bring participants together and reflect on the changes to interactional practices that they can develop.

Key questions

- Can conversation analysis help us to understand the problems faced by disabled people in accessing respectful care and support?
- Is a micro approach to interaction sufficient, if we want to change the way disabled people are seen by support services, and consequently the way they are treated?
- Are there links with social practice theories, which have a wider understanding of how practices are constituted?
- Can this type of analysis be illuminated by working with disabled people themselves, as co-producers of knowledge and change?



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