Obstacles to choice and control in residential services for people with learning disabilities

Magazine Component

What we learned

- In residential services for people with learning disabilities, there are many barriers to the promotion of choice and control.
- One major obstacle is that this policy is seen by many staff as conflicting with other policies, agendas and rules at play within services (e.g. health and safety, 'appropriateness', CSCI inspections).
- Some staff are also unsure how to promote choice when people have limited communicative abilities.
- A process of 'myth-busting' in individual services is useful to clarify how choice can be promoted in these situations, and to discuss possible conflicts with other policies and practices.

How we learned it

We recently carried out an intensive study of three NHS residential services (health and social care) for adults with learning disabilities, observing what happens from day-to-day in the lives of the residents. We video-recorded a range of everyday interactions between staff and residents, and collected ethnographic field notes. Some of the residents had little or no verbal communication. We carried out detailed analysis of incidents in which choices were offered to residents, and incidents when residents spontaneously tried to indicate their preference. At the end of the research we played some of the recordings back to the staff involved and discussed how practice might change.

Why it's important (100 words)

Government policy insists that organisations providing social care for people with learning disabilities should increase the levels of choice and control that service-users are able to exercise over their lives. However, despite a range of initiatives choice and control for people using services is still lacking in

many areas. This is particularly the case for those with multiple impairments and high support needs. This research highlights the ways, often barely-noticed, that people living in residential services can be routinely disempowered, and the dilemmas staff face when trying to carry out contradictory service agendas.

How it influences practice

- We recommend a process of 'myth-busting' in individual services.
- This would involve discussions with support staff about when it is appropriate for them to make decisions for particular residents, and what evidence can be used to establish a person's preference.
- It would also involve discussions about the other policies and practices that staff think conflict with the choice agenda. Decisions can be made regarding which policies take precedence in which situations.
- Such discussions can lead to concrete changes in everyday practice in residential services.

What else to read

Beamer, S. & Brookes, M. (2001) *Making decisions: best practice and new ideas for supporting people with high support needs to make decisions*. London: VIA

Grove, N., Bunning, K, Porter, J. & Morgan, M. (2000) *See what I mean: guidelines to aid understanding of communication by people with severe and profound learning disabilities*. Wolverhampton: BILD.

Harris, J. (2003) Time to make up your mind: why choosing is difficult. *British Journal of Learning Disabilities*, 31, 3-8.

Nind, M. & Hewett, D. (2001) *A practical guide to intensive interaction*. Kidderminster: BILD Publications

Values Into Action web-site: http://www.viauk.org/

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Web Component

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Government policy insists that organisations providing social care for people with learning disabilities should increase the levels of choice and control that service-users are able to exercise over their lives. However, despite a range of initiatives choice and control for people using services is still lacking in many areas[1,2]. We recently carried out an intensive study of three NHS residential services (health and social care) for adults with learning disabilities, observing what happens from day-to-day in the lives of the residents. Although a range of factors clearly limited the amount of control they could exercise over their lives (e.g. problems in communication/understanding), one major obstacle was that the choice and control agenda is seen by many staff as conflicting with other policies, agendas and rules at play within services.

Multiple agendas

In any residential service, there is a plethora of policies and agendas that govern what staff do in their interactions with the residents. Whatever their actual status, they are used by workers to explain why they do things the way they do. Examples include health and safety regulations, parental concerns, trust policies, CSCI inspections, and less explicit ideas of good practice which include notions such as ‘appropriateness’.

When we observed situations in which residents were denied the opportunity to participate in activities or to exercise choice or control over their lives, staff would often give these other values and agendas as reasons. Although sometimes policies were in conflict with the choice agenda, there was also a degree of misunderstanding of those policies or local regulations. In other cases, staff seemed to have become left behind after numerous organisational changes, and so continued to operate under the values of their

initial training or socialization into care work. A focus on cleanliness, safety and an orderly routine took precedence over the promotion of choice, empowerment, community inclusion and participation. We will give three examples of such problems, and then recommend a process of 'myth-busting' in individual services.

1) Choice

'Choice' may seem like a straightforward concept but what it means in practice can be a source of confusion. For example, these statements are from documents produced by the NHS Trust which hosted our research:

- Choice – The right of every young person living [here] to select either independently or with assistance a range of options, activities and choices specific to them.

- My plan (PCP) is facilitated with the person in finding out what is important to the person, not what others think is important for them.

Both of these statements locate responsibility for making 'choices' more or less with the individual with learning difficulties. However, some members of staff, particularly those who worked with individuals with severe communication difficulties, thought these statements meant that they were not supposed to make choices on behalf of someone else (e.g., though one resident could not indicate her choice of holiday destination staff felt they could not decide on her behalf). The result of this was often inertia: established routines would dominate the residents' lives because staff could not see how valid 'choices' could be offered or expressed. Clearly this represents a misunderstanding of person-centred approaches, which suggest that supporters make decisions based on their understanding of a person's preferences however these might be expressed[3,4].

2) Health and Safety

The government has called for a more open debate over how services balance risk against empowerment[5]. In two services in our study, food

hygiene and health and safety concerns were given by members of staff to justify the exclusion of service users from the kitchen, and from activities such as the preparation of drinks and food. In another service, a CSCI report noted that food packets were being stored in the fridge without their date of opening being properly recorded, something the residents could not do without help. This home for people with a range of cognitive impairments had no less than *five* chopping boards, of different colours, and all for the preparation of different kinds of foods. In all of these cases, rather than trying to provide a living environment which would enable the residents to exercise more independence and control over their lives, they are made dependent upon staff for access to household areas and activities that most readers would take for granted.

3) Physical contact

Our final example concerns physical contact between residents and staff. In one home, residents all displayed severe communication problems and many would approach staff for a hug or would want to sit holding hands. Given that they had little functional speech, this was one of the few ways they could sustain social interaction[6]. Although some staff saw no problem with this, others considered it inappropriate and believed it was contrary to guidelines relating to the protection of vulnerable adults or to notions of 'age-appropriateness' and professionalism. For the residents, it was deeply disempowering, since it made their most effective methods of participation ineffective.

Implications for practice

In some services there seems to be a high level of uncertainty about the intended functions of particular policies and an even higher level of uncertainty about which policies take precedence and under what circumstances they should do so. Of course, it isn't just uncertainty and misunderstanding, there is also wilful misinterpretation or misrepresentation which allows staff to continue their established ways of working. What we found surprising in all these cases was that they persisted with little management challenge.

For this reason we would recommend a process of ‘myth-busting’ in individual residential services, where managers identify where and when agendas and policies are being invoked to justify undesirable practices or as obstacles to change. This would involve discussion of which policies and agendas seem to be misunderstood or misrepresented among staff, and which have the effect of justifying the continuance of practices that disempower the residents. It is important that services understand not only the letter of the policy but its spirit. A concern with food hygiene and safety is laudable but it is not in the spirit of the policy to use it as an obstacle to the acquisition of skills and the development of independence. This process is best done ‘in house’, with a focus on what actually happens on a daily basis in each home. More debate with, and challenge to, inspectors is also needed so that the realities of empowerment within homes is understood. Without consistent and direct engagement with staff beliefs and practices regarding these issues, the goals of promoting choice and control in residential services will not be achieved.

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Abstract

Government policy requires organisations providing social care to promote choice and control. We recently carried out an intensive study observing what happens from day-to-day in the lives of people with learning disabilities in services. One major obstacle to the promotion of empowerment was that the choice and control agenda is seen by many staff as conflicting with other policies, agendas and rules at play within services. We recommend a process of ‘myth-busting’ in individual services.

References

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Further Information

1. Beamer, S. & Brookes, M. (2001) *Making decisions: best practice and new ideas for supporting people with high support needs to make decisions*. London: VIA

2. Dowson, S. (1997). Empowerment within services: a comfortable delusion. In P. Ramcharan, G. Roberts, G. Grant & J. Borland (eds) *Empowerment in everyday life: learning disability*. London: Jessica Kingsley

3. Edge, J. (2001) *Who's in control?: decision-making by people with learning difficulties who have high support needs*. London: Values Into Action.

4. Grove, N., Bunning, K, Porter, J. & Morgan, M. (2000) *See what I mean: guidelines to aid understanding of communication by people with severe and profound learning disabilities*. Wolverhampton: BILD.

5. Values Into Action (organisation which promotes best practice in the support of people with learning disabilities) web-site: http://www.viauk.org/

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