

Meaningful involvement in organising our own support – ethical issues

*Yo Dunn PhD, Director, Autism Advocacy Consultancy and Training
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Background

The 'personalisation agenda' - opportunities for participation in the organisation of our own formal support services in education, social care and health

Tension between personalisation and cost cutting

Main Questions

What barriers do autistic people encounter to meaningful involvement in the organisation of our own support when accessing formal support services?

How can approaches to 'involvement', 'inclusion' or 'personalisation' be made more accessible to autistic people?

Barriers to meaningful involvement

1. Initiative/organisation

- A lot of executive function, organisational ability and initiative is required to get assessed, push the system to carry through the process, obtain and administer the support
- Either the autistic person must somehow manage this themselves (somewhere between utterly impossible and a minor miracle for most autistics) or else they must depend on someone else (often a parent) to do it for them and lose some autonomy
- Most opportunities for involvement simply assume that failure to initiate on the part of the service user means that they do not want/need to participate

2. Assumptions

- Facial expressions, body language and verbal statements mean what a neurotypical person (NT) would mean by them
- He/she is intelligent and/or verbal so they must be able to ...
- He/she is non-verbal and/or struggles with abstract concepts so can't possibly ...
- Models of personalised support tend to assume (and promote) the existence of a social circle around the service user and the availability of informal support systems (friends, neighbours, acquaintances)
- All social interaction is good. More social interaction is better.
- Autistics (and disabled people generally) are single people with no dependants
- An expert/professional is an NT with a formal qualification

3. Communication

- Lack of useful autism knowledge and real comprehension of autistic perception (the "double empathy" problem – Milton, 2012)
- Emphasis on oral communication at meetings with multiple people
- Participation by the service user is often only actually effective (and sometimes only acceptable at all) if it is expressed using high level

communication and social skills (e.g. tact, diplomacy, ability to see the service user from the point of view of others and express needs in terms that 'fit' criteria etc.)

- Vast amounts of implied information
- Vagueness and lack of precision
- Lying (autistic definition = saying things which are not literally true) e.g. 'you don't need that' rather than 'we don't have the money to pay for that service' e.g. 'I'll get back to you about that' rather than 'There isn't actually anything I can do about that'

How can approaches to 'involvement', 'inclusion' or 'personalisation' be made more accessible to autistic people?

What is the goal of 'involvement'?

If it is to be more than tokenism, then **involvement is not enough.**

All too often NT professionals design and organise a service/event/initiative/care package/life and then ask an autistic person to 'participate' in it

*A more ethical goal: **Autonomy*** – real control over our own lives including the support we need to live full and fulfilling lives.

How can this be achieved?

- Recognising and openly acknowledging the reality that progress is slow and the current shrinking of the welfare state makes increasing real autonomy in the real lives of autistic people very difficult.
- Working to provide opportunities for real choice and control which accommodate weak initiative and organisational difficulty and provide essential support with the goal of promoting full autonomy
- Making assumptions explicit and questioning them – this requires really listening to autistic perspectives to identify and challenge assumptions
- Working to communicate in autistic accessible ways which recognise the double empathy problem – so autistics must be fully involved in training at the design level and in the production of autistic accessible communication
- Embedding autistic involvement and real power and control from the top down and in the early design and implementation of services.

References

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