

Personalisation in research and practice:

Methods and early findings from a study into good practice in social care for people with complex and severe needs

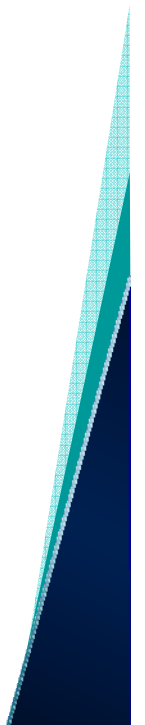
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University of York**



Background


- ◆ Growing numbers of people with complex and severe disabilities
- ◆ Henwood and Hudson (2009) for CSCI: are the processes of implementing personalisation appropriate for these groups?
 - ◆ Assessment
 - ◆ Resource allocation/budget size
 - ◆ Flexibility as needs change
 - ◆ Co-ordination with other services/funders
 - ◆ Mental capacity



Aims of the study

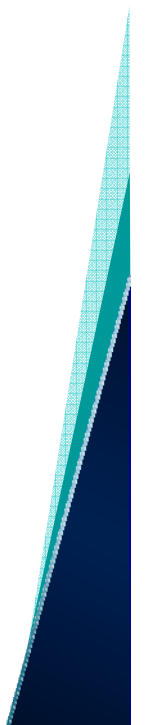
- ◆ Identify features of services desired by people with complex and severe disabilities
- ◆ Identify examples of good practice, especially where evidence available
 - ◆ Include commissioning, operational arrangements, front-line delivery

‘Exemplar’ groups:

- ◆ Young adults with complex/life-limiting health problems
 - ◆ Adults surviving major accidents/trauma
 - ◆ Older people with dementia plus physical/sensory impairments
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Study design

- ◆ Consultation with key stakeholders
 - ◆ Professionals/providers/voluntary organisations
 - ◆ People with complex and severe disabilities and their carers
- ◆ Literature review
 - ◆ Search terms/strategy informed by consultation
 - ◆ Specialist partner
- ◆ Case studies of good practice
 - ◆ Identified from consultation and literature review
 - ◆ Descriptive accounts, multiple perspectives

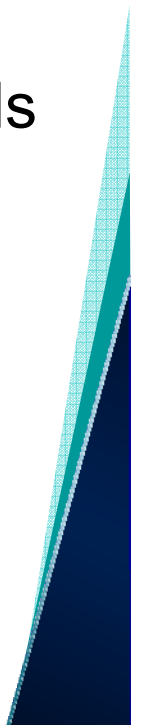


Consultation with people with complex needs

Documents and approach

Consultation methods

- ◆ People may have cognitive or communication impairments
- ◆ How to make the consultation meaningful for everyone?
- ◆ Sought advice from:
 - ◆ National charities of and for people with complex needs
 - ◆ Networks for people with communication impairment
 - ◆ Networks specialising in facilitating participation
 - ◆ Key practitioners
 - ◆ Other researchers
 - ◆ People with communication impairment and their carers



If I say yes, what will happen?



Kate or Jenni will meet you to talk about the project.



They could come to your home or to another place if you prefer.



We will pay any costs, including your travel. We will give you a £10 voucher to say thank.



If you need help to speak, or would like someone to help you, this is ok. Please tell us on your Response Form or ask someone else to tell us.



You can send us an email if you want.



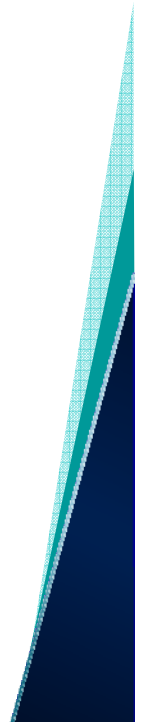
If you agree, we will tape record the meeting. This is so we can listen to it later.



Kate or Jenni may also take notes.



You can stop or take a break at any time.





Good practice in social care

Consent form (carers)

Thank you for thinking about taking part in this research. If you have any questions please talk to Kate or Jenni before you agree to take part. They will keep a copy of this form, and give you a copy to keep.

Please tick the boxes.

	 Yes	 No
I have read the information sheet		
I have had time to think about taking part		
I have asked questions if I wanted to		
I know I do not have to take part		
I know I can stop taking part if I want to		
I agree that you can record our conversation		
I agree to take part in the research		

Participant name Date Signature

Researcher name Date Signature

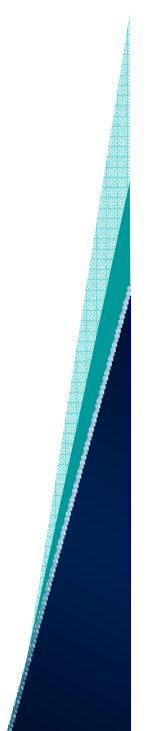
Consultation methods

During the consultation:

- ◆ Check people feel fully informed
- ◆ Allow enough time
- ◆ Be aware of fatigue
- ◆ Use of visual aids
- ◆ Have someone else present?

After the consultation:

- ◆ Send transcripts or summaries
- ◆ Be clear about what we understood



Outcomes of consultation with professionals:

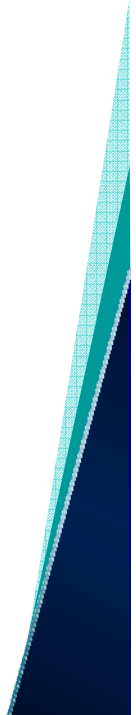
Personalisation and complex needs

Personalisation and complex needs

- ◆ Support for personalisation *in principal*
- ◆ Particularly important for people with complex needs

*the more complex the needs the
more unique they are*

[SY5]



Personalisation and complex needs

Some key distinctions:

1. Personalisation ≠ Personal Budgets (PBs)

I think you can deliver personalised services without Personal Budgets and I think you can have Personal Budgets without really personalising services

[SD8]

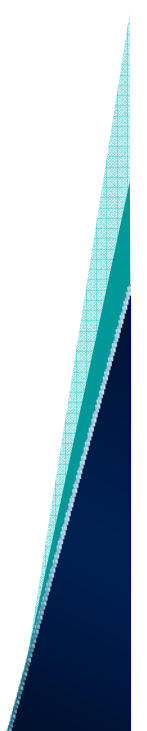
Personalisation and complex needs

Personalisation:

- ◆ People treated as individuals
- ◆ Care and support tailored to meet their individual needs
- ◆ Choice and control at all stages/in all settings (including residential care)

Personal budgets:

- ◆ One way of achieving (but not guaranteeing) personalisation



Personalisation and complex needs

Some key distinctions:

2. PBs in practice \neq PBs in principal

- ◆ Support for PBs for people with complex needs *in principal* (as well as some concerns – see next slide)
- ◆ But to work *in practice* there needs to be:
 - ◆ More support for people with complex needs
 - ◆ More flexibility
 - ◆ Greater awareness of needs (including higher order needs)
 - ◆ Increased range and quality of providers

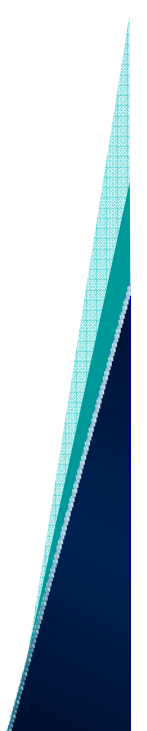


Personalisation and complex needs

Some key distinctions:

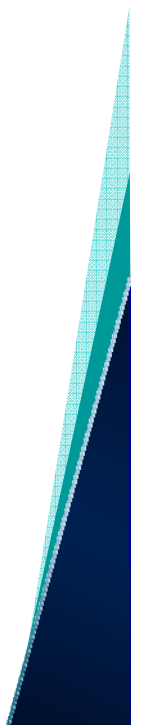
3. Personal Budgets \neq Direct Payments

- ◆ Seen as interchangeable
- ◆ Concern that people with complex and severe needs may not have the capacity to manage DPs themselves
- ◆ Problems around family carers managing DPs for them
 - ◆ adds stress at difficult time
 - ◆ choice and control for who?
 - ◆ Little awareness of alternatives



Next Steps

- ◆ Analyse responses from people with complex needs and carers
- ◆ Identify key features of good practice
- ◆ Complete scoping review
- ◆ Examine up to 6 examples in more details



More information

php.york.ac.uk/inst/spru/research/summs/complex.php

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