

The State of Social Care in England 2007-08 - Part 2: Personalised support for people with multiple and complex needs – PMLD Network briefing

What the PMLD Network thinks

We welcome that there is a section of the report focusing on how personalisation is working for people with complex needs.

We know that many people with profound and multiple learning disabilities and their families face barriers and challenges when trying to get an individual budget and we welcome that this report identifies many of these.

It is only through identifying and acknowledging barriers that we can hope to work out solutions and ensure that personalisation can work for everyone including those with the most complex needs.

We welcome the focus on people with 'multiple and complex needs' however we think it is important to identify who has profound and multiple learning disabilities within this wider definition. This is because people with profound and multiple learning disabilities have the most complex needs and the particular challenges and barriers which they face could be missed if we are just talking about people with 'multiple and complex needs' – a term which could be used to describe someone with very different needs to someone with PMLD, for example someone with a mild learning disability who has a mental health problem and has entered the criminal justice system for a crime such as a sexual offence .

This part of the report follows up on the concerns raised in the 2005-06 report about how well social care services are meeting both the specialist and the ordinary needs of people who have 'multiple and complex' needs. Most importantly, it looks at what the personalisation agenda is offering people with multiple and complex needs.

CSCI notes the difficulty in defining 'multiple and complex needs' and says that as there is a lack of consensus about what the term means, there is a lack of numbers known.

CSCI highlight three factors affecting the scope of local authorities to respond in a flexible way to the needs of people with multiple and complex needs: poor strategic commissioning, lack of person-centred care and the marginalisation of human rights. CSCI quotes 'Death by Indifference' as evidence of people with multiple and complex needs not being respected. CSCI state this as the biggest problem.

CSCI found areas where local authorities have made progress including commissioning partnerships, health and social care and developing personalisation policies. Progress varies dramatically. CSCI also listed how local authorities need to improve.

Delivering Personalised Support for People with multiple and complex needs

The study revealed a general suspicion that the personalisation model has, as yet, been insufficiently developed for people with multiple and complex needs. CSCI highlight the following issues that need to be addressed in order to deliver personalised support:

Assessment and care management

Examples of good practice, but it varied a great deal around the UK. People with complex needs require intensive support for completion of self-assessment. CSCI found that trained staff was not using their skills to communicate with service users. They also found that there are problems with inappropriately categorising people once the assessment has been made and as a result people are receiving the wrong care.

Direct Payments/ Individual Budgets

Some local authorities showed reservations, led by local politicians, on giving direct payments and individual budgets to people with learning disabilities. Transparency of the RAS was highlighted as a concern.

Range of Services

CSCI found limited, traditional and insufficiently flexible services for people with multiple and complex needs. It also found a significant proportion of people with complex needs, and of their carers, were conservative in their service preferences and resisted attempts to reconfigure support – particularly day opportunities.

Safeguarding, Support and Advocacy

Many local authorities failed to have a clear 'risk strategy' for the implementation of choice and control. Support and advocacy was also a failure for many local authorities and needs to be improved. Successful stories of Individual budgets were found where there are high levels of support from the carers and local authority staff.

Flexibility and Accountability

CSCI reported that the balance between flexibility and accountability is continuing to evolve.

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