

Profound and Multiple Learning Disabilities (PMLD) and Complex Challenging Behaviour/Behaviours that Cause Concern

1. Introduction

Following the 'Services for the Future' review and consultation in 2015, the Council agreed a number of changes to the services delivered by the Council to people with a learning disability. This means the Council is now changing the services it delivers directly to people in its Day Services and Short Breaks Service.

In future, the Council will only deliver services directly to people who have the highest and most complex needs and for whom either:

- **their needs cannot currently be supported in the community by other providers, or**
- **their needs are such that there are very few options for support in the community.**

Other providers do already support people with complex needs well in Milton Keynes, and the Council wishes to develop these services further to provide more choices and options for people with these needs.

Through the statutory assessment and review process, people with a learning disability and their carers, whose needs do not meet the definition of complex will be supported to access alternative services including community services that are available in their local community and used by members of that community.

The Council has a long history of close working and delivering services with a number of local providers. Many people already access a mix of services delivered by these providers as well as services delivered directly by the Council. The Council is working with these providers to increase the range of options available to people.

The Council will also provide support for people to manage their care and support in other ways, for example by using a Direct Payment. The Council is currently investing resources into the development of a new service to offer support to more people who wish to use a direct payment, making the process easier and more readily available for people.

The Council is also developing a new Shared Lives Service as an alternative for people who currently access the Short Breaks service and who need a break away from their home, but whom the Council doesn't consider to have complex needs.

'Complex needs' means people with 'Profound and Multiple Learning Disabilities' (PMLD) and/or 'complex challenging behaviour' we may also use the term 'behaviour that may cause concern'. More information about what is meant by this can be found in section 2 and 3 of this document, also some examples are included in Appendix 1.

2. What does MKC mean by Profound and Multiple Learning Disabilities (PMLD)?

As stated above, the Council is intending to provide services that support people with the most complex needs, often termed Profound and Multiple Learning Disabilities. In order to ensure that the right level of support is provided by the Council to this cohort of the population, we need to develop a definition of what is meant by this term.

By Profound and Multiple Learning Disabilities (PMLD) the Council is referring to:

- People with profound and multiple learning disabilities (PMLD) are among the people with the highest care and support needs in our community.
- They have a profound learning disability which means that they have severely limited understanding.
- In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other challenges such as epilepsy and autism.
- Most people in this group are unable to walk unaided and many people have complex physical health needs requiring extensive help and support to enable them to meet their daily living needs.
- Most people with profound and multiple learning disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols.
- Some people need support with behaviour that is seen as challenging, such as self injury.
- People with profound and multiple learning disabilities need high levels of support with most aspects of daily living: help to eat, to wash, to dress, to use the toilet, to move about and to participate in any aspect of everyday life, including identifying and managing everyday risks.

Despite such serious impairments it is very important to say that people with profound and multiple learning disabilities can form relationships, make choices and enjoy community activities, and should be supported to do this as often as possible.

(Adapted from 'Milton Keynes Council Learning Disability Strategic Review July 2015', The Institute of Public Care (p. 31, 2015), citing Mansell, (2010).)

The above definition is supported by examples given in Appendix 1. These examples are provided to illustrate the sort of care of and support needs that someone with PMLD may have.

3. What does MKC mean by complex challenging behaviour/s that cause concern?

The Council is working with all the organisations in Milton Keynes who support people with a learning disability to provide more effective support to those whose behaviours may cause concern. Following the Winterbourne View scandal, the Council has been working with Milton Keynes Clinical Commissioning Group on a programme to improve services for people with these needs called the Transforming Care Programme (TCP).

Through this programme, the Council is introducing a 'Positive Behaviour Support model' (PBS). PBS involves analysis of a person's behaviour, and then positive care planning and training for staff on the person's individual needs, to enable them to provide the support they need. This is so people can be supported in the least restrictive environment and experience better outcomes in their community.

By 'complex challenging behaviour'/'behaviours that cause concern' we mean the following:

- Behaviour can be described as causing concern when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the person or others.
- A variety of factors are likely to contribute towards the development, maintenance, and escalation of behaviours that cause concern. These include biological and genetic factors, communication, mental health, neurological, the quality of support, sensory difficulties and exposure to adversities.
- Behaviours that cause concern are generally considered as learned behaviour that serves important functions for the person who displays it (it helps the individual to cope better or exert some control over their immediate environment)

The above definition is adapted from 'Milton Keynes Council Learning Disability Strategic Review' (The Institute of Public Care, p.17 2015,) citing 'Challenging Behaviour: A Unified Approach' (The Royal College of Psychiatrists et al, (p14, 2007