

Learning Disability Services for the Future - Consultation Responses

1. Purpose of this paper

- 1.1 The purpose of this paper is to report themes from the recent public consultation on the future of Learning Disability Services in Milton Keynes.

2. Background

- 2.1 A strategic review of learning disability services was completed in 2012, however at the time recommendations were not taken forward. In 2014 the Joint Commissioning Team, in partnership with the Institute for Public Care (IPC), refreshed the review and recommendations. The Joint Commissioning Team commenced a consultation with people using services, their carers and families, and broader stakeholders to shape services for the future.
- 2.2 The consultation was held through a series of public meetings and workshops. Talkback, a local advocacy group specialising in working with people with a learning disability, were commissioned to facilitate the process and document themes from the meetings. The consultation took place over:
- Four Public meetings held across Milton Keynes, including the Health and Social Care Select Committee. A presentation was delivered at each event with a question and answer session.
 - A presentation was delivered and question and answer session held at two Learning Disability Partnership Board meetings.
 - Talkback facilitated five additional supported sessions in day centres at Tower Drive, Surrey Road and Whaddon Way to discuss the issues in the consultation.
 - The consultation was also hosted on the Council's website and people were encouraged to contact the council via email or letter.

3. Consultation Responses

- 3.1 Themes used in this report are from the responses to the consultation received by email and from the work completed by Talkback. Broad themes have been used along with direct quotes of those who participated. These have been divided into comments of adults with a learning disability and parents and carers.
- 3.2 The meeting attendances are detailed in the table overleaf:

| Venue and Date | No. People with a Learning Disability | No. of 'Others' (Parents, Carers & Staff) | Total |
|--|---------------------------------------|---|-------|
| Civic Offices - 30th July | 4 | 18 | 22 |
| LD Partnership Board - 1st September | 29 | 90 | 119 |
| Bletchley Leisure Centre - 7th September | 0 | 30 | 30 |
| Tower Drive Day Service - 14th September | 9 | 4 | 13 |
| Tower Drive day Service - 15th September | 8 | 4 | 12 |
| Whaddon Way Day Service - 23rd September | 10 | 5 | 15 |
| Whaddon Way Day Service - 28th September | 9 | 5 | 14 |
| Newport Pagnell (Lovat Hall) - 29th September | 6 | 15 | 21 |
| Surrey Road Day Service - 1st October | 14 | 0 | 14 |
| Health and Social Care Committee - 6th October | 3 | N/K | N/K |
| LD Partnership Board - 31st October | 8 | 23 | 31 |
| Total | 100 | 194 | 294 |

3.3 In addition 12 written responses were also received via email to the Council. All were from the parents of adults with a Learning Disability. A response from the parents of someone whose current support is not covered by this consultation was also received and responded to separately from this report.

4. Themes from people with a Learning Disability included:

- The importance of buildings such as day centres for making and maintaining relationships, and the organisation of group activities.
- People spoke highly of the staff and the trusting relationships that existed.
- The importance of community and how services had helped with a feeling of belonging.
- Worries about being isolated.
- Worries about finding a Personal Assistant (PA), only being supported by one person and not a team of people.
- People wanted to know if they would get the same amount of support (hours) if they were supported by a PA and paid by a direct payment.
- People wanted to know more about direct payments and what this meant.
- People wanted to know how group activities could be organised if they received support via a direct payment.
- People with a learning disability said they have gone through changes they didn't want, or didn't know were going to happen in the past (such as the closure of large residential care settings). There were things they missed about the past and this made them worried about change in the future.

4.1 Quotes of people with a learning disability:

- *"We want to be part of a real community"*
- *"(we)...build networks somewhere and then we have to leave"*
- *"I like my staff"*
- *"It's good being with all your friends (at the day centre)".*

- *“I have made good friends here, I wouldn’t see them if I didn’t come here...”*
- *“If Surrey Road closes I’d have to stay at home and do jigsaw puzzles”.*
- *“I’d like to go out more with my staff”.*
- *“I don’t want things to change”.*

5. Themes from Parents and Carers:

5.1 Many of the Parents and Carers that responded to the consultation were the carers of people with higher, complex or profound needs. There was much concern voiced about the needs of these individuals and how changed services could meet these needs, along with strong views that these needs are currently being met well by services delivered by the Council. It must be noted however that this group are the least likely to be affected by proposals, with the majority of these needs still being met directly by the Council.

- *“Who decides what constitutes profound?”*
- *“trepidation over this consultation”*
- *“very emotive subject”*
- *“I have concerns about the monitoring of quality of staff (of new services, particularly shared lives)”*
- *“Is the money that is going to be saved going to be enough for all these new ideas?”*

5.2 Safety and security were recurring issues of concern. Parents and carers think highly of both the internally provided Short Breaks Service and Day Centres. Respondents also spoke of the trust held, and that they needed to have, in the people who were supporting their loved ones.

- *“Milton Keynes has done so much for us, and we don’t want it to change”.*
- *“We accept there have to be changes but we want the same, reliable and safe services we receive now”.*
- *“this is a moral issue, we have to protect the most vulnerable*

5.3 Many stressed the importance of consistency and routine for meeting some people’s needs, and for parents and carers to be able to manage their caring responsibilities. Some of the ideas in the consultation were viewed as a threat to this. With carers worrying about how this could be maintained if day centres and short breaks services were closed or people were forced to use direct payments.

- *“If my son’s routine is knocked out, it’s us that have to pick up the pieces not you”.*
- *“I can drop him there (day centre) and I know he is happy and safe and I can get on and go to work”.*

5.4 Some people felt that although there had been improvements in the lives of people with a learning disability in Milton Keynes, there still needs to be a drive for much better access to universal services such as GP’s, Dentists and other health services in order to have all of their needs met.

- 5.5 There were differences in experiences of people from different age groups reported. For many whom care for older people, there is a feeling of a constant changing agenda. There are feelings that rights have been hard won and, although changes over the years have brought many positive improvements and outcomes, these have also brought many challenges. For some, further changes are perceived as posing yet another threat to the stability and security of the people they care for.
- *“It’s taken us a long time to get to where we are (disability rights and the standard of LD services)”*
 - *“Over the years (the service) has moved on from `no service to the high quality reliable and reassuring service which people ... with Profound and Multiple Learning Disabilities enjoy.”*
 - *“(these services) are the jewel in the crown”*
 - *“It is good things are changing for the kids coming through, they already have these choices, but it wasn’t the same for my brother”.*
- 5.6 Some of those who cared for younger people spoke highly of the support they had received through transition and were more optimistic about more flexible ways of providing support, such as direct payments and short breaks via shared lives. Some however still voiced concerns about changes to the current mix of services, as these were of importance to their loved ones and important in supporting their role as a Carer.
- 5.7 A number of people contributed very personal accounts of their experiences of supporting the people they care for. The importance placed on the wellbeing of the cared for person was clear and was a consistent driver of the concerns raised in the responses.
- 5.8 A number of people recognised the pressure the Council is under, and the need for the Council to manage resources more effectively. However this also caused concern about the role of resources as a driver for proposed changes.
- *“our most vulnerable are being sold off to the lowest bidder”*
 - *“reduce all three BUILDINGS, MONEY and PEOPLE”*
 - *“if your system works and the participants benefit from it why change it for changes’ sake?”*
 - *“I understand that saving has to be made, however for us we have a service that works so well that we can only see the changes being detrimental for XXXXX”*
 - *“WHY FIX WHAT IS NOT BROKEN! Other than to save money!!”*

6. Short Breaks:

- 6.1 People with a Learning Disability commented on enjoying and valuing the services provided by the Council and the importance of the relationships and activities accessed whilst receiving short breaks. People look forward to the time away from home and it was clear the break was of value for both the carer and the person with a learning disability.

- 6.2 Parents and Carers spoke highly of short breaks and stressed the vital role it played in maintaining their quality of life as a family, and sustaining them and their families in their caring role. People also spoke of the importance of the trust held in the staff and the services the Council delivers.
- *“I wouldn’t be here today if it wasn’t for short breaks”.*
 - *“Respite is a lifeline for some people”.*
 - *“If families aren’t supported to continue in their caring roles then the Council will see the true cost of supporting people”.*
 - *“I would be willing to contribute more towards the Short Breaks Service in order to save it.”*
 - *“Carers health and sanity will be compromised”*
 - *“...trained, competent and caring staff who know XXXXX and also know us which makes it easier for us to leave XXXXX for a few days (to rest).”*
 - *“My definition of stress is ... a situation you cannot walk away from. If you have a stressful job or you can ultimately walk away if it all gets too much. We can’t walk away. These are our children.”*

6.3 However, some people spoke of the inflexibility of current arrangements and that their lives were governed by when respite was available. Flexibility, and not just the amount of respite resource available, seems to increase value for carers and provide a real benefit. A lack of flexibility means the resulting break from their caring role was felt to be less useful and therefore effective than it could be if available in a more flexible and predictable way.

6.4 Short breaks overlaps with Shared Lives in the consultation which is addressed in Section 10.

7. Supported Living:

7.1 One person with a learning disability spoke at a public meeting about the importance of the Community Support Team and Equality Works in their life. This respondent also touched on the importance of enough suitable housing for people’s needs, an area that requires investment and development locally.

7.2 Other respondents were sceptical about the use of technology in supporting people in supported living, particularly the use of social media which increased fears about safety and security.

- *“... suggest that someone in supported Living could be check on by using Telecare, Facetime or any other social media I could not believe my ears”*

7.3 The consultation received one written responses in relation to changes to the Supported Living Services run by the Council. This was in relation to perception that this support would have to be provided via a Shared Lives carer in future. There is however other providers who provide supported living services in Milton Keynes. Shared Lives would be an additional option to these services and responses in relation to Shared Lives are outlined in Section 10.

8. Day Services:

8.1 Day Centres were also highly thought of by both people with a learning disability and carers. Themes included the value of structured day activities and the routine this gives people, centres as places for skills to be developed, and relationships to be formed and maintained. In addition carers spoke of the role of day services in enabling them to continue to maintain employment.

- *“my son going to the day centre, means that I can go to work”.*
- *“XXXXX learned to socialise at... (the day centre)”*
- *“the group between special needs and school leavers are the ones to whom day centres have been the life blood to both service users and carers”*
- *“If these centres close it will not only affect the users but their whole families-who may find that this may be the last straw”*
- *“if all those affected suddenly needed full time care because the families couldn't cope- then MK council will see what the true cost would be”*
- *“XXXXXXXX loved his 2 days in a different, controlled setting, being BUSY, ACTIVE and above all MOTIVATED”*
- *“Buildings are good - buildings are needed ... you should visit the day centre to see what happy places they are”*

8.2 Some were concerned that if day centres are only used by people with profound needs, both they and people with lower needs, would miss out on the social interactions that currently happen within centres.

8.3 Specifically there was concern voiced about the current use of the Beanhill Day Centre and a feeling that this had already been closed with little or no warning to users.

9. Direct Payments:

9.1 There were many concerns raised that people needed more information about direct payments and how this would work in practice, raising questions such as:

- What support would be given to understand and manage direct payments?
- How would people maintain the organisation and communication necessary to maintain group activities?
- How will people be able to access the therapies and other support that building based services facilitate?
- Won't it be more expensive for people to access universal services with 1:1 support?
- Won't people be more isolated?
- Will people be able to access the same amount of support (hours& days) with a direct payment?

9.2 Questions were raised about people with a learning disability needing to become employers and how this can be supported. Some carers voiced the opinion that for them to support people to manage their direct payments would add further to their responsibilities and stresses as carers.

- *“... I am not an Accountant and do not have the time to sort out payments and arrange Day/Respite Care when looking after 2 Adults with learning Disabilities and an 81yr old Mother”*
- *“Direct Payment is not suitable for all families... we have too much to do as it is. We need help to get through each day, not have our workload increased even more”*

9.3 Concerns were raised about how people will be supported to find and engage with personal assistants, organise group activities and maintain existing relationships built around building based services.

- *“I have no confidence we will be able to find enough carers (in reference to direct payments and shared lives)”*

10. Shared Lives:

10.1 The idea of shared lives felt far removed to a lot of people’s experiences of accessing support. Most of those engaged in the consultation could not see how this would work in practice. Many wanted more information and to be able to see it working in other areas.

Themes included:

- Concerns about how this would be monitored and how safety could be ensured.
- The need for a clearer understanding of how different needs could be met in a shared lives scheme.
- Uncertainties if there is enough people who want to become this type of carer.
- Concerns about how carers would people be recruited.
- Concerns about Shared Lives decreasing group activities (in respite) and therefore increasing isolation.
- Questions about the costs of installing specialised equipment in shared lives carers homes to support people

10.2 Quotes from respondents included:

- *“we need evidence of shared lives working somewhere else”.*
- *“Does the Council feel there are enough people who want to be involved in such a scheme?”*
- *“Abuse of the service-user... .. who will be there to monitor ...that the person is treated properly?”*
- *“Carers health and sanity will be compromised”*
- *“we believe(Shared Lives) would be totally inappropriate ... (for)... high levels of need and high use of specialist equipment”*