

Moving on - the Final Transition

“What happens when - a carer can no longer care?”



Two thirds of adults with a learning disability live with their families, the majority with their parents. Of these, 40% live with a parent over 60 and 33% live with a parent over 70 years old (Emerson and Hatton 2008).

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Twenty-five per cent of people with learning disabilities living at home with family carers over the age of 70 are unknown to services until there is a crisis (Department of Health, 2001b).

Introduction

Moving on - the final Transition

"What happens when a carer can no longer care"

Acknowledgements

We would like to thank all parent/family carers who gave up their time and were so open with their views and experiences. We would also like to thank the West Berkshire Learning Disability Partnership Board (LDPB), West Berkshire Mencap and the staff at the Slater Centre for arranging the session.

Disclaimer

Please note this report represents the views of a random group of parent/family carers of adults with a learning disability (LD) living in West Berkshire and is not meant to be representative of all parent/family carers with LD children in West Berkshire.

An estimated 29,000 people in England with severe and profound learning disabilities live with parents aged 70 or over. Every year, people with a learning disability have their lives thrown into crisis when they and their parents are no longer able to cope. This report presents a picture of older parents living with the constant fear of where their son or daughter will live when they are unable to care for them or after they die. It estimates that only one in four local authorities are planning to meet their future needs

(The housing timebomb: the housing crisis facing people with a learning disability and their older parents: Mencap 2002)

Methodology and Findings

Methodology

Healthwatch West Berkshire (HWWB) was asked to join the West Berkshire Learning Disability Partnership Board (LDPB) in finding out from parent/family carers of those with a son or daughter with a learning disability (LD) what their thoughts were on what would happen when they either couldn't care anymore or if they died, and what they hoped would happen. This document should be seen as an opening discussion document with a view to improving outcomes for families with LD children.

This issue was raised at the 'Big Meeting' of the LDPB on 26th January 2016 after the Head of Adult Social Care West Berkshire Council (WBC), had presented 'A New Way of Delivering Adult and Social Care'. Though a Service Manager for LD at WBC, offered to attend the subsequently arranged meeting, the parents felt happier discussing it with organisations independent of their dependents care i.e. HWWB, LDPB and West Berkshire Mencap (WBMencap).

Two sessions were arranged at the Slater Centre by WBMencap on March 24th so more parent/family carers of adults with LD could attend. It was attended by approximately 11 parent/family carers.

Summary

Nearly all the parent/family carers were over 60 and their dependents all over 19 years old with some in their 40s and 50s. The time for planning steps into 'independent living' with a pathway approach and support from the family has largely been missed. It also appears a new generation of families with younger dependents may equally risk missing out on a planned transition from care at home, to a more fulfilling and independent life with the appropriate care available.

It is clear that all parents share the same concern - that there is no long term plan for those they care for once they can no longer cope or pass away. With the Care Act 2014 making carers as important as those they care for, this lack of planning needs to be looked at urgently. An up to date assessment of the scale of the issue in West

Berkshire should be made and a strategy written to clearly state how the Council will involve parent/family carers in a long-term plan of what will happen once they can no longer care.

It is apparent that this will also need to involve a multi-disciplinary approach including Housing, GP's, Social Housing Providers etc.

Key Issues, Questions Raised and Direct Quotes

- Crisis can be temporary (e.g. carer unwell) or permanent (just cannot do it any longer, or bereavement) - initial crisis might be the same, but then what? **Is there a 'plan' the Council have to follow? Can we see it?**
- If the Council know that they will place someone temporarily (in a crisis) into Bailey Thomas - **What if Bailey Thomas is full? Where would they then look to place them?**
- All carers were saying the same thing - i.e. that they are scared what will happen to the cared-for. Having a plan in place takes some of the anxiety away. **Does this not being done potentially breach the Care Act which considers Carers as equally important?**
- Even parents whose cared-for are already in adult placements (Supported Lives for example) feel anxious and wish to know what the plan would be for when they die and when/if the current placement cannot be sustained - although this is probably more straightforward than those living at home or with unpaid carers.
- **If the New Way of Working is to keep people in the community, then will the Council look to place the cared-for with other family members/relatives?** This may not be practical at all, or in some cases perhaps only for a maximum number of weeks. This needs to be incorporated into any care plan. GP's etc. also need to know what has been agreed.
- **What happens to those living independently (married couple) as they age? Is there an elderly specialist home for adults for LD?** If possible, there should be something available for say over 45's/50's with LD, with warden/resident support. Much the same as retirement homes with 24/7 office support. Especially in the light of statistics* showing dementia occurring earlier in those with LD (*see Appendix A). **Is there a plan for this sort of facility and if not what are the suggested solutions?**
- **Does West Berkshire Council hold the list for everyone who wants to live independently and how many are on the list and how old are they? Does this match the 'Market Position Statement'?**

<http://info.westberks.gov.uk/CHttpHandler.ashx?id=39300&p=0>

- Do the Council know how many cared-for with LD are living at home, how old they are and how old their parents/carers are? (A survey of this was undertaken some years ago does the council have access to it?)
- Is there an 'End of Life Care Plan' for those with LD?
- Surely an assessment of housing needs is carried out prior to 18-25 years so that the Council know what provision will be needed and with what support packages. Has this been done or are there plans to do one and by when?

"Phoenix Centre plan would have been excellent",

"Why can't council look at groups of people?"

- Parents were told to put their cared-for on the common housing register, but is this not only for those with social needs? Can the Council confirm which list should be applied for?
- Do the Housing Officers have to consider LD in their decisions?
- Do annual reviews help guide long term planning and why are they not always done annually?
- Are GP's helping?

"No actual input looking forward, just a health check"

- There are college courses for those with LD to help prepare them for independent living, however there isn't anywhere for them to live independently. Once they have completed the courses they just return home!

Miscellaneous Comments of Parents/Carers

"What about those who haven't ever used a service!"

"If you evict the cared-for, parents lose control of care"

"No one at the council will help"

"Do they [the Council] have any understanding of the worries and concerns?"

"[The] worst housing block was for those with LD & best for those to be sold"

"Care plan accuracy is questionable & temporary staff is a problem"

"Pelham House has beds for those with LD, but they went to others and were taken by those from outside West Berkshire"

"How do you bid for a place?"

Recommendations - Accepted by West Berkshire Council Adult Social Care

- A follow up meeting with the parent/family carers
- Meeting to be arranged with West Berkshire Council Service Heads to discuss the findings with HWWB, LDPB, WBMencap and parent/family carers
- Report circulated to relevant stakeholders and policy makers e.g. CCG, Health and Wellbeing Board, Elected Officials, Voluntary Sector, local MP
- HWWB/LDPB to research 'best practice' solutions from other areas and report back (this may require commissioning)
- Possible adjustments to both the 'Market Position Statement' and the JSNA
- Creation of a collaborative Action Group to deliver real change to current position and managing 'One crisis at a time' methodology

Appendices

Appendix A

Tandra Forster, Head of Adult Social Care, West Berkshire Council's response, received 16th September 2016

1. Is there a 'plan' the Council have to follow? Can we see it?

We place a high value on the contribution that carers make, recognising that for many families the ability to have loved ones remain living at home for as long as possible is the most desirable outcome. In agreeing how support will work we talk to carers about their needs and consider with them what is needed both in the short and long term. As part of this planning together we identify what support may be needed throughout the year to enable the caring arrangement to continue and gain an understanding of what plans will be for the future.

We agree that planning in a crisis is uncomfortable but circumstances can change and that this may lead to a breakdown in caring arrangements. The Care Act (2014) has created an opportunity for the Council to think again about how we work with people and their families, and we feel that the introduction of a strengths-based approach will really help to deliver better outcomes. Our focus is that where support arrangements become untenable we will work quickly to stabilise the situation before agreeing with them what new arrangements will be.

2. What if Bailey Thomas is full? Where would they then look to place them?

Bailey Thomas House is a popular resource with many people and wherever possible we will seek to help them receive support at the service through careful scheduling. It isn't considered a suitable option by all people and their families and in those instances we will look at finding different solutions to enable respite. This will be worked through with them on an individual basis.

3. Does this not being done potentially breach the Care Act which considers Carers as equally important?

The Care Act (2014) introduced a new duty to carers in recognition of the valuable contribution they make to Adult Social Care. All Councils are required to provide a range of information, advice and guidance and to offer an assessment to look at the caring role and what they might need. The new law also expects us to start to offer support to transition young people from age 14 in to adult services to try and minimise the impact the change will have on people at their families. We have already made changes to the way we work to ensure that we comply with these

requirements and have appointed to a new Transitions Team Leader role. The post-holder will be responsible for co-ordinating all work with people who need to transition; this will include ensuring annual reviews look closely at current support arrangements to understand if they will need to move on and what type of support will be required ongoing.

4. If the New Way of Working is to keep people in the community, then will the Council look to place the cared-for with other family members/relatives?

The council has always been committed to help as many people as possible achieve independent living in the community and only using more formalised services where there is no other option. This could include consideration of a whole range of support arrangements, including living with other relatives if that is what they would like, but it will be dependent on what is agreed with the person and their family.

5. What happens to those living independently (married couple) as they age?

All adults who are being supported by adult social care are entitled to annual review where any changes will be looked at to see what changes need to be put in place so they receive the appropriate support.

6. Is there an elderly specialist home for adults for LD?

We don't have specialist housing for older adults with a learning disability, however we take account of a range of factors when working with an individual including their age. For many adults with a learning disability we have found they can be appropriately supported in sheltered accommodation or extra care housing. For some, more specialist care is needed and so only a residential setting would be appropriate. When seeking a placement we will take account of a range of factors including age to ensure compatibility.

7. Is there are plan for this sort of facility?

We are currently developing plans to increase the range of supported living options in West Berkshire. We would always work with people and families to think about appropriate settings and who they may wish to live with as we recognise this has a positive impact. As highlighted in the response to question 6, there are already adults with learning disabilities supported in specialist housing for older people and we are committed to maintaining this.

8. Does West Berkshire hold the list for everyone who wants to live independently and how many are on the list, how old are they? Does this match the 'Market Position'?

We have information about people with learning disabilities and the type of support they need, this will include living arrangements. The Market Position Statement includes information from a wider range of sources e.g. the Joint Strategic Needs Assessment.

9. Do the Council know how many cared for with LD are living at home? How old they are and how old their parents/carers are?

We hold a range of information about the people we support, their families and carers on their individual records. This will include age, family networks, needs and current circumstances.

10. Is there an end of life care plan for those with LD?

Where appropriate an end of life plan will be in place.

11. Do we have an assessment of housing need prior to 18 to 25? Do we plan another one?

This is dealt with as part of our Housing Strategy. We are about to go out to consultation on a new draft and I would encourage you to comment once the details are shared.

12. Parents were told to put their cared-for on the common housing register, but is this not only for those with social needs? Can the Council confirm which list should be applied for?

The Common Housing Register is open to all adults in need of social housing. Priority is given on the basis of housing need following a discussion with a Housing Options Officer, see attached Choice Based Lettings Policy to see how points are determined. For adults with a learning disability who will need support to live independently then they and their family should talk to Adult Social Care to agree what care is needed.

The council also has some specialist supported housing for adults with learning disabilities. Where there are vacancies this can be discussed with adult social care to consider if it would be a suitable place for the person to move to, this will include both consideration of the environment and compatibility with other people already living there.

13. Do housing officers have to consider LD in their decisions?

Housing officers will focus on the housing needs of the individual; if their learning disability means some accommodation types or locations are not suitable then that will be taken into account when advising on which properties to bid for.

14. Do annual reviews help guide long term planning and why are they not always done annually?

Firstly, yes annual reviews do help with long term planning. Secondly, the Council are committed to ensuring all adults in receipt of support have an annual review. This can prove challenging as some people may need a review within the year because their circumstances have changed and this impacts how quickly we can work. Last year we completed 95% of reviews within the year. As part of our re-

organisation we have established a team that focuses solely on planned review work.

15. Are GPs helping?

We are working to improve our links with GP surgeries and we would hope that this will help all of the people with care and support needs in the community. We recognise that General Practice is a challenging environment and it is not easy to meet the needs of all patients equally well.

Appendix B

Dementia Statistics

(source: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103)

People with learning disabilities are at increased risk of developing dementia as they age, compared with others without a learning disability, although the figures vary according to how the diagnosis is made. About 1 in 5 people with a learning disability who are over the age of 65 will develop dementia. People with learning disabilities who develop dementia generally do so at a younger age. This is particularly the case for people with Down's syndrome: a third of people with Down's syndrome develop dementia in their 50s.

Down's syndrome and dementia

When people with Down's syndrome develop dementia, it is usually due to Alzheimer's disease. Studies have estimated that 1 in 50 people with Down's syndrome develop dementia in their 30s, rising sharply to more than half of those who live to 60 or over. By comparison, the number of people among the population without learning disability aged 60-69 years who develop dementia is about 1 in 75. These studies, therefore, show a greatly increased risk of developing dementia among people with Down's syndrome, compared with the general population without a learning disability.

Studies have also shown that by the age of about 40, almost all people with Down's syndrome develop changes in the brain associated with Alzheimer's disease. However, not all go on to develop clinical symptoms of dementia. The reason for this increased risk has not been fully identified, however it is thought to be linked to the extra copy of chromosome 21 which most people with Down's syndrome have. This chromosome carries the amyloid gene thought to play a role in Alzheimer's disease.

Other learning disabilities and dementia

Studies suggest that approximately 1 in 10 people aged 50 to 65 with learning disabilities other than Down's syndrome have dementia. This rises to more than half of those aged 85 or over. This suggests the risk is less than for people with Down's syndrome but still between two and three times greater than for the general population.

Key reading

Mencap (2002) *The Housing Timebomb*, *The housing crisis facing people with a learning disability and their older parent* <https://www.mencap.org.uk/sites/default/files/documents/Housing%20Timebomb.pdf>

Bigby C (2000) *Moving On Without Parents: Planning, Transitions And Sources Of Support For Middle Ages And Older Adults With Learning Disabilities*. NSW/Baltimore: McLennan and Petty Brookes

Cairns, D et al (2013) The need for future alternatives: an investigation of the experiences and future of older parents caring for offspring with learning disabilities over a prolonged period of time. *British Journal of Learning Disabilities*, Volume 41, 1, 73-82

Key reading(cont)

Cowen, A and Hanson, J (2013) *Partnership Working with Family Carers of People with a Learning Disability and People with Autism*. Birmingham: BILD

Dillenburger, K and McKerr, L (2011) 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities*, Volume 39, 1, 29-38

Dillenburger, K and McKerr, L (2009) '40 years is an awful long time': parents caring for adult sons and daughters with disabilities. *Behavior and Social Issues*, 18, 155-174

Magrill, D (2007) *Supporting Older Families: Making a real difference*. London: Mental Health Foundation
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Walker, C and Walker, A (1998) *Uncertain Futures: People with Learning Difficulties and their Ageing Family Carers*. Pavilion Press. Joseph Rowntree Fund www.jrf.org.uk

Walker, C and Ward, C (2013) Growing older together: ageing and people with learning disabilities and their family carers. *Tizard Learning Disability Review*, Vol 18(3), pp112-119