



Learning Disability Partnership Board consultation related to the Moving On project

Background to the consultation

The focus of this LDPB consultation overall is on people who are moving from one type of accommodation or living arrangement to another and more specifically those identified to be part of a “moving on “ project. Amaze was not able to identify any parent carers who had a son or daughter who part of the Moving On group. This was not unexpected given that this group are already in accommodation other than the family home and now wanting to move to an alternative. Instead we sought parent carers of young people with learning disabilities who were imminently in transition to or had recently moved into adult services. We asked parents to take part if they were either looking ahead to their son or daughter moving out of the family home or had recently been through the process of planning and making that move. Looking for parents for whom the planning process was current or recent and where this was not a “crisis” move limited the numbers significantly.

Who took part?

Six parents agreed to be interviewed individually and this covered 7 young people aged between 18 and 23. The interviews took place in the summer of 2016 as the original date for the LDPB was in the autumn of 2016. This was a limited sample and the experiences of the parents were quite diverse. Nevertheless some themes emerged and we have identified recommendations based on the feedback.

Experiences of planning for moving out of the family home

We found that where the parent had a transition review meeting with a worker from the transition team they recalled that they had been asked appropriately about their son or daughter moving out of the family home at some point. This was brought up sensitively with an awareness that the parent might not yet be at a point of contemplating this when the child was 17/18 and they were encouraged to think about whether it was something they would like to consider further in the future. Some has also had a brief introduction to what the range of options might be.

“The social worker did bring it up. We said we are happy to still have her at home. She’s only 18. It would feel much too soon for her to live anywhere else. The discussion pretty much stopped there.”

The one parent who had wanted to move swiftly towards setting up an arrangement for their child to move out reported a positive experience of joint planning with the social worker to achieve this.

“As parents we knew what we wanted for her – to leave home at 18 like her non-disabled sister. We were clear and assertive but this was matched by a real willingness to make it happen. I think we were lucky that despite having learning difficulties she is quite a straightforward girl who could fit with other disabled young adults.”

Less positively parents who were not contemplating a fairly immediate move out did not report having been given a clear idea about what the steps might be to act on this at a later stage. Nor did



they get a realistic impression of how long it might take between them deciding it was now the right time to look at their son or daughter moving to live independently of family and this becoming a reality. Parents whose child was still at home had little concept that there might be a long planning and procurement process to set up a placement in future.

“Other parents have told me I should be asking about it more, even before we are really ready to do it, because it could take a long time to get something sorted when we do think she is old enough.”

Parents who had said that they were not looking in the immediate future but would want this later assumed that someone would come back to them to review their needs. They did not necessarily understand that their child would not have a named social worker and that there was no fixed process for review. The parents whose child still has an EHCP noted that the annual review of the EHCP felt like a natural opportunity when moving on/out should be discussed but social care was not represented at the meetings as a rule so this did not occur.

“No one has come back to us to check what we want now. Is that meant to happen or are they waiting for us to push? Or are they waiting for a crisis? I know there isn’t enough money or enough staff so maybe that’s it. They let sleeping dogs lie, is that it?”

Most of the parents said that they assumed that their child was “known” to the system since early childhood and that there would automatically be a process of forward planning for them happening. Parents who had been through the process realised this had been a false assumption.

“We had mentioned since she started at DVLC that we would like her to move out whilst she was still at college so not everything in her life would change at the same time. We thought when we said it was now time to get on with this that they would be expecting that and ready with some ideas, able to say what the choices might be. It wasn’t like that at all.”

A couple of parents expressed a need for more planning with them about ways to ease their son or daughter towards living elsewhere.

“We need to take baby steps towards this. At the moment he comes everywhere with us and goes nowhere without us. I know we can’t care for him forever but we couldn’t just jump to him moving somewhere else full time. We need to learn and so does he.”

Others were worried about how they would adjust to life still as carers but no longer full-time, including what the benefits situation would be both for them as their son or daughter. Parents recognised that they would need to plan a new working life once they were no longer full time carers but felt they could not prepare for this now because they did not have the free time or head-space yet. One reported having another adult child living at home who also had learning difficulties but had been assessed as being too moderate to be entitled to help from the CLDT. Although she understood this she would have welcomed advice that recognised the complexity of the family situation.

Some had concerns about the options for adults that would be a barrier to good planning for an eventual move out of the home.



"I don't trust the providers out there. I see the students at St Johns who don't live at home and I feel they look less well cared for, I'm not saying neglected, just not the same as the ones that still live at home."

Parents find it worrying and unsatisfactory that they had a social worker they met and made some connection with at the transition planning stage, but that when they get back in touch they find the young person does not have this person or any named social worker and they are dealing with a duty system.

"I call it the taxi-rank system. It doesn't seem a good way of planning and working with us."

Some parents reported elements of good social work involvement, but not always looking beyond the immediate future.

"The person who did the RAS was good and they are sorting how to fund college days from adult social care next year, but they haven't talked about the future beyond that."

Parents of more complex young people expressed many difficulties and barriers in finding a suitable adult care arrangement. One parent described being stuck in a situation where the young person's needs are well understood and the need to find full time adult care to replace his existing children's services place had been agreed well in advance. But adult social care are struggling to set up a placement that meets his needs because there is a lack of specialist services locally that can deal with his challenging behaviour. He remains taking up a place in a children's provision. The parent is also worried that her son may be placed somewhere that does not have staff able to use PECS so he can communicate.

One parent who had been through the whole process of planning and setting up a place for their daughter to live away from the family home had found the experience very difficult and had trouble identifying any positives. She was aware that her daughter had highly complex needs but felt as this was well-known it should have triggered more proactive planning well ahead.

"We thought her transition worker had been working on it but this hadn't happened. We had said we wanted supported living and got the impression this might be possible but once things got seriously into the planning stage it quickly became obvious this was not an option and probably never had been."

She found it uncomfortable when her daughter's case was put up for tender to see if any providers could match her profile and even more painful when no one said they could. She found she was looking at things that weren't an option anyway. She did appreciate that the social worker at that point was honest in suggesting she look at some places not because they could meet her daughter's needs or had a vacancy, but more to get an idea of what residential and supported living arrangements looked like so she was not stumbling in the dark. One option was pursued although not ideal but then fell through. She agreed to another provider despite some misgivings and after various delays her daughter was able to move out. Since she was interviewed for this consultation she has let us know the placement has failed but as the funding had switched to Continuing Health Care this is outside the scope of this consultation.



Recommendations based on parent carer feedback:

- Moving on from the family home should be discussed at transition (as it is now) but if the family do not want to pursue it then there should be an agreed time to review this and a process that triggers this happening at that time
- More attention needs to be paid in the teenage years to issues that may make it more difficult to find a local placement for a young person, in particular challenging behaviour and disturbed sleep patterns or complex physical care requirements
- The duty system should be reviewed to ensure it does not prevent forward planning taking place for people with LDs and their carers
- EHCP annual reviews could be used more effectively to keep long term plans on the agenda
- Parent carers should be given information about the options to start thinking about what may suit the young person in future, including realistic advice if residential care is likely to be the only choice in practice
- Parents need information and advice to plan for the financial changes that follow from a child moving out e.g. changes to entitlement to benefits and the fact that your son or daughter living away from home will not be cost neutral i.e. parents carry on paying for things for them in practice
- There should be transparent information given about how long it typically will take to plan and set up a move
- Planning for the young person should include steps that prepare the family and the individual for moving out at a later stage, even if this is some way off. This needs to start from 16 or even earlier for the young person to experience spending time away from home other than in education
- Adult social care need to work more closely with providers to ensure that staff are able to use the augmentative communication systems that young people have learned to use so that skills young people have learnt at school are not lost and continue to be able to express their wishes.