

# Brighton and Hove City Council Learning Disability Accommodation Strategy 2018-2022 Consultation with parent carers, January 2018

## Introduction

Brighton and Hove City Council have drafted their 2018-2022 accommodation strategy for adults with a learning disability (LD). Amaze and PaCC were asked to consult parent carers of young adults with LDs on the strategy and how it addresses the current and future needs of their young people as they reach adulthood. The Strategy proposes an increase in Supported Living and Shared Lives placements with decreasing use of residential care. This reflects a vision of people with LDs having more independence and choice, living in their home city and local community.

## Methodology

Early discussion with parent carers made it clear that they were often unfamiliar with the accommodation options mentioned in the strategy and so not well placed to respond. We therefore organised a focus group that combined an information session for parent carers on post-18 accommodation, particularly Supported Living and Shared Lives, with gathering views and concerns relevant to the strategy. The session included parents of older young people able to talk about their experience of choosing and using Shared Lives, Supported living and residential care. Eleven parent carers attended the focus group and another four were unable to come but contributed separately.

## Demographics

**15 parent carers** including one long term foster carer and one grandparent, all living in Brighton and Hove. Two of the parent carers have two children with LDs in the relevant age group.

**17 young adults** across the transition age range and with variety of needs, all either under adult LD services or likely to meet the criteria at 18

Ages: 15 x2, 16, 17 x3, 18, 19, 20 x4, 21, 22 x2, 23, 24

Needs/disabilities: all have LDs, most would be described as severe, four as profound and multiple. Several also have ASC. Two young people had more moderate learning disabilities but additional factors such as ASC. Five are full or part time wheelchair users and have medical needs, particularly complex for a couple who get continuing health care funding.

## Existing living arrangements

Under 18: 4 living at home with family, one in foster home, one in 52 week residential school. Mix of respite arrangements including Barnardo's link family, Drove Road, Tudor House and PAs via direct payments.

18 and over: One in supported living. 10 living in family home, of which three use Shared Lives part time, one Beach House and several also have DPs and/or get day services e.g. from Grace Eyre. One of the 10 is moving shortly to residential care.

## Response to strategy

The overall vision and strategic direction of the draft strategy were not contentious with parent carers. Once they understood what Supported Living and Shared Lives meant in practice, they were positive about a move towards increased use of both in the future. This was mixed with a concern whether these options would meet the needs of all young people and particularly those with more complex needs around health or behaviour.

There was also recognition of the particular challenges presented by the nature of the housing stock in the city and the inflated housing market.

Some parents queried how the figures about future need/demand had been calculated, specifically those about number of young people projected to require fulltime accommodation. They wondered if their young person was included in the figures and some said that they and their son or daughter had not been asked in any detail about their future plans and aspirations. They were clear that what they want will change in the years beyond 18.

*We didn't want her to move out at 18 but how would they know what we want next as no-one has asked in the last couple of years.*

- Vision is good but does it cover ALL young people with LDs?
- Are the demand projections accurate?
- Needs and aspirations change over time especially between 16 and 25

A number of themes emerged from the consultation which we expand on below.

## Moving towards moving out

Some parents are clear that moving out of the family home at 18 or soon after is the best choice for their son or daughter and the family.

*She is so active that being at home with just older parents once her sister had left was wrong for her. We knew we had to press for a busy, youthful environment for her.*

But the majority of families are looking for a later or more gradual move from home.

*I am happy to have her living with me. I'm not in any rush to change that. But I also know I won't be around forever. I need a route ahead.*

*She is 17 but cognitively around 4-6 months and our parenting is very tactile. She feels emotionally too young for full time care. I think 25 feels like the transition point for this rather than 18, which indeed mirrors changes in legislation.*

They want the accommodation strategy to take this into account more clearly, with transitional steps if possible and advice about what the options are for their individual young person.

For some families, Shared Lives is a good way to achieve this more gradual shift as it can be part time. Parents feel it gives the young person valuable experience of living away from their family.

*I am not sure he has a concept of moving out, but Shared Lives means he has an experience of living elsewhere and not being 100% with us.*

*His Shared Lives family have someone fulltime as well. He thinks he will leave home one day. Full time Shared Lives might not be the right choice but it is a stepping stone now.*

Shared Lives carers can help young adults with learning life and independence skills. Using Shared Lives also allowed parents to adjust to new ways of seeing their adult child and their future.

*Emotionally I need to get to the place where I can push him on.*

*She goes to Shared Lives twice every six weeks. We never ever thought she would do this. I want to know more about what could be next.*

Some parents feel that what they are looking for is appropriate respite so their young person does not need to move out of the family home for many years to come. They might like Shared Lives but suspect that it is not an option because their young person has higher care needs, due to behaviour that needs support or physical care and medical needs. The parent whose young person uses Beach House said they were told to consider Shared Lives but then were told they could not place him with his needs. She doesn't want him to leave home yet and feels Beach House is only just good enough.

*I am happy that he is safe there but I don't feel that they really 'get' him. He often doesn't eat well there and they have trouble getting ready in time for college and to take his meds. There is no other provision as far as I am aware.*

Parents said that options other than full time care or accommodation for these more complex young people are very limited or non-existent. What they would like is an adult version of Drove Road or Tudor House.

*Basically we are looking for a large respite package but not full time care. There is an expectation that we would want full time care as she is so complex. There are no local respite homes that are appropriate. Beech House is for smaller packages and generally young people with less complexity and is 18 to 80. Chailey is ideal but is £900 a night which is double Tudor and Drove Road. There is no transition so literally the day she turns 18 she leaves Tudor house. It's very stressful!*

Parents explained that with young people who are pre-verbal and have complex communication challenges, good care for them depends on knowing them really well and being able to spot subtle changes in their demeanour. So a pathway from living at home to moving out is not just about them having experience of staying elsewhere, but also about their future carers getting to know them. A safe move into full time care should involve a long handover period so staff can learn these clues, but existing models do not allow for this. There would need to be an extended period of double funding or a provider commissioned to run respite and supported living side by side so a young person would already be known well by carers when they move to fulltime.

- Need a gradual pathway towards young people moving on from the family home
- Parents don't want harsh dividing lines between respite and accommodation
- Are there different and better models for young people with higher needs?

## Understanding the options

Parents at the focus group had misconceptions about both Shared Lives and Supported Living; for example assuming that an adult would need to be very independent in terms of personal care skills to use Shared Lives. Only those already using Shared Lives understood that the Shared Lives carers got training, support and breaks. It was understood that the carers would include the person in family life but not the extent to which they would help them pursue activities in the community too. Also that they could help the person they cared for with looking after themselves, support them with health appointments, budgeting, learning life skills etc. More information should be made available.

Parents were also unclear about what constituted Supported Living, the variety of Supported Living models and the differences between Supported Living and residential care. At the focus group we had two parents of adults with LDs speaking about Supported Living as used by their adult children, and parents were surprised that one was a shared house model, like a group of flatmates but with staff around day and night, whilst the other had a self-contained flat with her own front door but 1:1 support all day and a sensor to pick up if she needed support at night. Parents wondered if young people in Supported Living would have to conform to a group activity schedule and were surprised to hear experiences of flexible choices. More information on the varied nature of Supported Living would be useful.

Parents were also unsure how and when to start asking about their young person moving from the family home, and how decisions are made and reviewed.

*I have no idea how long it takes and when I need to start pushing about it.*

*I was shocked when he moved from DVLC to Plumpton and the social worker asked if we'd still want shared lives to continue. I didn't know it was at risk.*

- Better information needed about range and character of options
- More advice and information about processes and timescales.

## Financial arrangements

Parents found the differing financial arrangements for accommodation options confusing. They do not feel this is always explained properly.

*The information I found seemed to be aimed at older people moving from their own home, not a young person starting out.*

Parents liked the idea that both Shared Lives and Supported Living allowed for the individual to retain more responsibility for their own money and choice about how to use it once they had paid their share of bills etc, compared to the inflexibility of residential care. But they also heard that it could leave families having to pay for things for their adult children as the financial assessment

might not recognise all their necessary expenses and leave the individual with not enough to replace things like clothing and furniture over time. One parent had not been told about grants for the cost of moving in and setting up home. Parents of young people with higher needs were concerned they would not be able to have them home to visit as they would no longer be able to fund PA support for two-handed care.

Parents would like more detailed guidance about how the financial side works to be sure they are making good choices with or for their young people.

- Clear and transparent information about financial arrangements

### **Meeting the most complex needs**

Parents of the young people with more complex needs felt the accommodation strategy did not seem to address them and their sons and daughters. This was the case for young people with physical disabilities and health needs as well as a learning disability or those with a combination of LDs, ASC and behaviour issues that mean they require intensive support. The strategy mentions as a challenge in section 7 that “the city lacks certain types of models of accommodation that many people with higher needs require. In particular there is a lack of annexes, services for young people with Profound and Multiple Learning Disabilities (PMLD) who often require wheelchair access and specialist equipment and capable environments for people with behaviours that challenge.” But parents could not see how the Strategic Commissioning Intentions address this.

Some would have liked to consider Shared Lives but the strategy does not make it clear if there is an intention to seek out Shared Lives carers who can offer higher levels of care or would be willing to have additional carers come in to their home at times as happens in the family home. Can adaptations be carried out in Shared Lives accommodation? One parent was aware of this happening in another local authority, but parents felt the nature of much of the housing in Brighton could be a barrier without major investment.

*If we asked for Shared Lives for our son, the house would need adapting, hoists fitted and more. If he said this was what he wanted would they try to make it happen?*

Parents asked similar questions about Supported Living. Parents would like supported living to be an option but were not clear if there was a level of need beyond which it would not be possible. The strategy mentions increasing the range of accommodation models but not who this would be for, other than a reference to lower support needs with sleep in support. Parents asked if the local authority was planning for the increasing level of complex needs there is amongst the young people approaching adulthood. And if they did commission Supported Living accommodation suitable for these young people would that mean they would have to live together.

*Will all the physically disabled young people be stuck with each other just because that is how the accommodation is organised?*

*My son cannot communicate without direct help. If he is in an environment with other people who also need this level of help to communicate the only way they can interact is via their carers. This would be so limiting.*

- More clarity in strategy about planning for young people with higher needs
- Realistic information about who can ask for Shared Lives or Supported Living

## Choice and control

Parents value choice for themselves and their young people. They want their young people to have as much control over their own lives as they can in their adult life. They welcome this in the vision of the draft strategy and want to be sure this will be the reality.

Parents who use Shared Lives identify it as offering significant levels of choice and flexibility. They exercised choice in setting up Shared Lives arrangements.

*The team were good. They matched us with a single man and we felt this wasn't right for our son.*

*They would have looked for another match but we found one via his special school.*

*His Barnardo's link family carer decided to switch to Shared Lives so he could carry on there.*

They reported that their young person was able to do varied activities as well as being included in day to day life of the carer and mixing with other people they care for. They even reported being able to swap dates around at times. They appreciated that they did not have to be the employer as with PAs via direct payments and that there was a level of quality assurance. They did not necessarily expect to go with Shared Lives when it was time for their young person to move out fulltime and were aware that the Shared Lives carer would grow older as they did, so change was inevitable.

Parents felt that Supported Living offered great potential for choice, a home not an institution, but were also aware that this would be counterbalanced by issues around availability locally. There might not be space in a suitable property with the right level of care at the right time. The parents using Supported Living spoke about the significance of the dynamics among the group if it was a shared house and this could change as people come and go. Staff turnover is also a worry. Parents had to make multiple visits before making a decision, accept compromises and keep an eye on things.

*We didn't want her to be the only young woman in the house but otherwise it felt like the right place for her. And it has worked out fine. They are almost like brothers to her now.*

*I want to get her back to this area but if I prioritise that what will we have to accept, will it be what she needs?*

They wanted their young people to have more part in decision-making but opportunities were limited. Parents would like commissioners to encourage providers to use models like house meetings and seek to involve residents in staff recruitment. And they want to know there will be advocacy for them in the future so they always have a voice.

*She has a lot of choice about what she does with her time and the activities outside college time. But she doesn't get a say in who she lives with and who cares for her.*

*I'd love my son to have a say in this. And will there be an advocate for him when I am not around?*

Some parent carers would like to be able to be involved in recruitment of care staff themselves.

*I know him best and I've been doing it with PAs for years so they could use this.*

Issues around a lack of choice are most acute for families with a young person with higher and more complex needs. They can amount to an all or nothing decision to take full time care.

*He is leaving home earlier than I wanted. I wanted respite and not full time, but it was difficult to find other than inappropriate residential homes. I was told that he has to move as soon as the bungalow is ready.*

*As she is NHS funded they are looking at possibly setting something up with a provider in Worthing. We may be able to share a bed but she needs a safe bed, which is specialist and expensive equipment. Her condition is life-threatening. It is hard to hand over responsibility for this to others. It has been suggested she lives at home with a full wraparound care package but her seizures are such that we (including her siblings) would still live with this severe stress in our home all the time. We weren't offered any alternatives for him and I know of one family whose son turned 18 last year who wanted to carry on with short respite breaks and feel that they have no choice but for him to go into residential as there is nowhere suitable.*

- Need to focus on maximising choice as things can easily reduce it despite intentions
- Both Supported Living and Shared Lives have strengths in terms of choice
- Lack of choice and control is still a reality for those with complex needs
- Young people with LDs should be consulted about the strategy

## **Conclusion**

Parent carers saw positives in the strategy, but questioned if all young people with LDs were considered in it.

- They would like the strategy to recognise that many young people need a gradual move from home to full time life elsewhere
- They want more information on what the options look like, the process and timescales involved, and the financial implications.
- They want choice and control for their family and for their young person as an adult.
- There are particular issues for those with higher and more complex needs.