



## **Recommissioning housing and support in Cornwall: feedback from adults with learning disabilities and autism in October 2023**

### **Introduction**

Cornwall Council is in the process of recommissioning housing and support services. Having established their key lines of enquiry, they have identified the Reach Standards as the framework that best fits their requirements for qualitative engagement.

As part of their stakeholder consultation, they asked Cornwall People First (CPF) to provide opportunities for people with learning disabilities and autism (LD/A) who either use these services, or may use them in the future, to talk about their experiences and aspirations, with a view to informing the planning process.

CPF talked to people across the county. Some lived independently, others with family or in supported living settings. Some had formal support, others did not. Our goal was to capture a snapshot of 'ordinary lives' (Practical Guide to Reach Standard p 21) in Cornwall in 2023.

This report outlines what we did and what we found.

### **Method**

We set up four dedicated Speak Up groups across the county (Helston, Camborne, St. Austell and Saltash). Two of the groups were community groups and two were service based. We also conducted 3 individual informal interviews.

Each group was facilitated by two members of the CPF staff team. Each interview consisted of one interviewee and one interviewer.

Groups were divided into two to make it easier for participants to have the opportunity to contribute.

We created an Easy Read presentation (see references) to explain the purpose of the group, and to support understanding. The presentation was based on the Reach Standards and a list of supplementary questions were used as a basis for discussions.

In line with the CPF research policy, participants were assured their contributions would be treated as anonymous, (unless explicitly agreed otherwise), but we asked permission to make notes, and to share anonymised comments and quotations.

Participants were encouraged to discuss and contribute to a group agreement at the start of a meeting, to establish and make explicit 'ground rules' such as listening to each other, treating each other with respect, honouring difference etc.



Participants were given opportunities to take breaks, or 'time out' as desired, to ask questions at any time and to query anything they didn't understand.

At the end of each session, participants were thanked, and asked if they had any questions.

Again, in line with the CPF research policy, we offered to keep people informed of the progress of the consultation and eventual outcomes.

We have collated our findings and present the results in this report along with a discussion about why some of those things we found may be so.

## Results

The results highlight interesting themes. Where certain issues emerged that were especially salient to participants (e.g. support), we have elaborated on these in the hope that they will provide a more vivid picture of what matters most in the lives of the particular people we spoke to.

Conversely, where participants were less forthcoming or where issues were *seemingly* less pertinent, we have offered possible explanations.

Not every question was answered (or was answerable) by every participant. For example, not everyone gave a definitive answer about whether or not they feel safe in their community. Recorded percentages (54% and 13% respectively) are for *known* responses only.

## Demographics

**Gender:** Male 77%, Female 33%

**Age range:** 30 - 70

**Primary diagnosis:** Learning Disability (LD) 35, Autism (A) 9

**Total number of participants** = 44

## Care assessments

27% have had an assessment and receive support at home.

48% have had an assessment and receive day service support but not support at home.

11% have not had an assessment.

14% unknown



## 1. I choose who I live with

### Living with others

*'With mum and dad and the two dogs. I don't want to move out yet.'*

*'No, the others were already in there.'*

*'He doesn't talk to me'.*

*'They say ignore him, but it's not that easy.'*

50% of participants live with family members (including spouse). 36% is by choice, 27% is not by choice (37% not disclosed).

23% of participants (where known) live in supported living. 0% choose who they live with.

One woman said she was not happy as her housemate was a male who did not use verbal communication. She has asked to move but nothing has happened.

### Living alone

*'I like it quiet. I'm happy on my own'*

*'On my own – no one tells me what to do.'*

*'I hate it here. I'm so bloody lonely.'*

16% of participants live alone by choice

5% of participants live alone, not by choice

Of those who lived alone most were happy to do so. For those who did not live alone by choice, loneliness was the main negative factor.

Overall, most participants do not have a choice about who they live with, but report being happy with their living arrangements.

## 2. I choose where I live

*'Yes, it's good. Close to town and good for the buses'*

*'I love the cherry trees outside my window.'*

*'The house was damp, so I had to go. I'm in a new place, no friends though'.*



6% of participants say they had a choice about where they lived.

Overall, most participants were not given a choice about where to live but reported being happy with their living arrangements.

However, ancillary questions reveal not everyone is happy with all aspects of their living arrangements (see below). In these cases, there was little evidence of participants knowing how to make changes.

### **Support to move**

*'I don't like living near those kids. They are too noisy'*

14% of participants would like to move but do not know how they would go about it or how to get support to do it.

5% of participants would ask parents for support.

0% of participants would ask Adult Social Care (e.g. social worker) for help or support.

Overall, most participants did not know who they would ask for support to move.

### **Reasons for wanting to move**

*'Somewhere I could make my own meals'*

*'Nearer my brother.'*

*'The neighbours. They 'call' me when I go in and out'*

*'Better buses'*

*'I would like to have friends round more'*

Reasons include noise, to be nearer facilities, or friends and family, problems with neighbours and feeling unsafe (see later for more detail).

### **What makes a home?**

*'Having my boyfriend to stay'*

*'A comfy bed'*

*'My stuff -ornaments'*

Recurring themes included freedom to act autonomously, privacy, (especially having one's own room that others did not enter without permission), ability to make choices such as



having (and excluding) visitors, pets, and personalizing space by choosing décor and being able to have one's own possessions.

### **Autonomy at home**

*'He lets me watch the football if I do 3 hours work first'. (\*this being investigated)*

*'Don't want them in my home'.*

*'They come round every 6 months to check. Get really anxious cos it's never good enough and I don't get help anymore.'*

*'I could have someone to stay over but I don't want to'.*

7% of participants open their own post

43% of participants have a support worker or family to open their post

36% of participants open their own front door

7% of participants have others to open their front door

Overall, most participants do not open their post or their own front doors.

### **Neighbours**

*'V is good as gold. She checks up on me. I look after T(cat) when she goes away'*

*'Don't know 'em'.*

*'She bad mouths us and we want to be left alone.'*

*'They were ganging up on me.'*

*'He keeps trying to get me to drink but I am diabetic, and I don't want to.'*

*'I like to wear women's clothes sometimes and they think I am a creep'*

Some people knew and liked their neighbours, but more either didn't know them or thought they were 'just ok'.

Relationships with neighbours were often raised, mostly in terms of negative experiences. Among other things participants reported: being accused of poisoning a cat, banging car doors at night, staring through windows, being asked for money.

One participant expressed a desire to move because of bullying by neighbours but was told by his support worker that he would not find anywhere else.



Some participants had been accused of anti-social behaviour, such as playing loud music, having parties, or not putting rubbish out correctly. Participants as perpetrators of anti-social behaviour is considered later (see discussion)

Overall, where neighbours were significant it is more likely to be (but not always) for negative reasons.

### **3. I have my own home**

*'I want to get a 'home sweet home sign'*

*'I am having my own house done. I'm picking the colours and my nephews will do my house!'*

*'It took four and a half years on the waiting list to find it.'*

*'I'm keeping it clean and tidy.'*

#### **Tenure (where known)**

7% of participants are owner occupiers

25% of participants live in social housing

7% of participant in private rental housing

23% of participants live in supported living

Overall tenures were relatively long, varying from 5 to 19 years with many being at the upper end of the scale.

#### **Tenancy agreements**

*'It's too complicated'*

54% of participants are unaware of having any type of tenancy agreement.

4.5% of participants have signed but do not understand their tenancy agreement.

2% of participants have signed and understand their tenancy agreement.

Overall, most participants do not know about or understand their tenancy agreement, or the rights and responsibilities it gives rise to.

#### **Tenants' rights: quality of property**

*'I like it, but it needs a lot of repairs. Shabby.'*

*'My support stuck it down because H\*\*\*\*\* hadn't done it. Kept asking.'*



*'That window has been broken for years. It's got a bit of cardboard to keep the rain out'.*

Participants report it is difficult to get landlords to do repairs and that when they do the results can be poor. They said landlords could be difficult to contact and slow to act.

Mould, damp, and repairs such as broken light fittings or windows were often longstanding problems. One participant used the Cornwall Council Handy person service to fix a curtain rail, and said the service was very good.

Overall, participants were more likely to ask family members or support workers to fix repairs or to contact a landlord on their behalf.

### **Tenants' responsibilities**

Most participants have little or no understanding of their responsibilities or the consequences of breaches of their agreement.

Overall, beyond an understanding of the need to pay rent, most could not give examples of their responsibilities as tenants.

### **4. I choose who supports me**

*'If I wasn't happy, I could change.'*

*'No, it's who is on the rota'*

*'Gaw, I'm lucky I got J.'*

*'Not one who turns the TV over when he comes in. Is that allowed?'*

*'If I don't like staff, I'd call the office.'*

*'He comes 4 to 6 so can't help me with what I want - to get out at night'*

*'We are just given whoever is working'*

Many participants say they are happy with their support, even though they have not chosen the person, but when asked to explain what was good about their support, they found it difficult to elaborate.

One reason for dissatisfaction was lack of continuity of support personnel. Another was that support was not always at a time that was most useful or was cancelled at short notice. Others want more support with specific issues, particularly spending, saving, and budgeting.



Overall, very few participants report having a choice of support worker or being able to request someone with particular characteristics such as gender, although one said he had the chance to meet new staff during a shadowing shift and can say if he doesn't like them.

### **Support purchased through personal budgets**

*'I can call her any time'*

*'My support is good. She fits in round what I do'*

Some private arrangements seem to work well in terms of choice, continuity and flexibly. One person had been on the interview panel for his new support worker.

### **Informal support**

*'My brother helps me with everything I need.'*

*'I get support from my social circle.'*

*'I like coming to the CPF groups. I can ask if I don't know.'*

Family members (especially parents or siblings) are a main source of informal support and relationships are reported to be highly valued. Overall, familial support was likely to be practical rather than social or emotional.

### **Who would I choose if I could?**

*'Someone with a fun personality'*

*'Someone who gets me.'*

*'To fit round my life'*

*'Someone to do my paperwork'*

*'Someone to go shopping with.'*

Participants did not always find it easy to think about which characteristics they would choose if they could, but further conversations identified the following as being important: gender, similar age group, shared their interests, flexibility, willingness to support socialising, patience and trust.





## **Anomalies**

There was some variation in what support staff were able to offer. For example, some had help with painting and decorating, or had support to go on holidays while others did not.

Variations are bound to exist depending on individual care plans (some people knew what was in their plan, but more did not), but conversations did lead to confusion as to how much say a person had in terms of how their support hours were used.

For example, one participant was told it was 'not Adult Social Care policy' to support people to go to hospital appointments and that he would need to make his own way. Another was told support to go to hospital 'was not a good use of time' for the support worker. By contrast, another said he had been to hospital a few weeks previously, and that his PA had not only driven him but also gone down to the operating theatre with him.

## **5. I choose my friends and relationships**

*'A cup of tea with my family'.*

*'The bank called the fraud people for me. I was on -line dating and they asked me for money'.*

*(Go to) 'Barcelona with my girlfriend'*

13% of participants are in romantic relationships.

14% of participants would like to be in a romantic relationship.

One participant asked for help to plan what will happen when her partner dies.

Overall, most participants are not in a relationship with a partner.

### **Maintaining relationships**

*'Keep in touch by phone cos they are all far away'.*

*'Like living near Mum and Dad'.*

Geographical closeness, and opportunities to be together in person, helped maintain relationships.

59% of participants identify family as their most significant relationship.

11% of participants identify friends who are fellow day service members.



10% of participants identify support workers as significant friends.

Friendships and spending time with friends is important to participants. Time spent with friends tends to be in LD/A specific groups such as day services, CPF or similar LD/A groups.

Overall, most people socialise with family or service-based friends rather than developing friendships in the wider community. A recurring theme is a desire to make new friends and socialise more, especially in the evenings and at weekends, and the lack of support for socialising opportunities are sources of dissatisfaction, but we did not find examples of participants knowing how to make new friends.

## **6. I get help to make changes in my life**

*'Not really. I am bored doing the same thing all the time.'*

*'I would like help to get out in the evening.'*

*'I turned a job down cos I couldn't face it.'*

21% of participants would ask their family to help with change.

18% of participants would ask support staff to help with change.

2% of participants would ask a friend to help with change.

Areas where there is an expressed desire for change include wanting to spend more time with friends and family, wanting a romantic relationship, wanting more money or support, and wanting to get a job.

Overall, we did not find much evidence to suggest participants know who and how to ask for support to make changes. Since not everyone copes well with change, perhaps especially people with autism, they may not investigate choice and change without a high level of support.

## **7. I choose how to be healthy and safe**

### **Feeling safe at home**

*'Yep, my front door's got a double lock'*

*'I don't feel safe, it doesn't feel like home'*

*'My safest place is in my bedroom'.*

*'I like the cameras outside my house.'*



*'She owes me money. I avoid her cos she is dangerous. She came into my flat when I was asleep.'*

*'We didn't feel safe, so we fitted security cameras. The police said it was ok'*

Overall, most participants said they felt safe in their home.

### **Feeling safe in the community**

*'I don't want to go out. I was scared they would attack me again'* (following an assault)

*'I feel safe when I am local. On edge in places, I don't know'*

*'Not all the time. People sitting in the doorways worry me.'*

*'I never go out at night'*

*'Might get raped.'*

*'People drunk on the buses. So scared'*

54% of participants feel safe in their communities.

13% of participants do not feel safe in their community.

Street lighting and security cameras were the most often cited reasons for feeling safe.

Reasons for not feeling safe include neighbour smokes marijuana, no security cameras, drunk people, and being approached by strangers. Participants say they do not feel these are things they had a choice about.

Overall, while most participants say they feel safe in the community, most do not go out alone much, especially not at night. When asked how they choose to keep safe the main responses were by only going out with family or support staff, or by staying in. We did not find evidence of strategies for dealing with these situations other than this self-limiting behavior.

### **Physical health**

*'I go to Lidl and get the bargains. I cook healthy stuff every day.'*

*'Ride my bike on my own'*

*'Want to play basketball'*

*'I'd like to go swimming'*



*'I'd go to the park on my bike if someone could go with me.'*

16% of participants try to make healthy meals

Most get choices about what they eat and have support to cook. Some cook their own meals, and one participant is using a 'health plate' given to him by his diabetic nurse.

Three of the younger participants enjoy keeping physically fit and participating in sports such as cricket, football or running

Overall, most participants do not seem to prioritise physical fitness, though some say they would like to get fit if they had the support they needed to do so. Whether most participants are making healthy food choices is unclear.

### **Mental health**

*'I'm scared about when he dies. I can't stop thinking about it. It makes me anxious all the time and I think about it all the time. It worries me a lot. I need some help'*

Participants report having experienced stress, anxiety, unhappiness, anger and depression. Support has tended to be informal, such as family, friends or day service staff. We did not find examples of people accessing professional support services, (though a few with autism have tried).

Overall, most participants have experienced some mental health problems, but have not accessed professional support. Perhaps this reflects a paucity of support tailored to take account of emotional acuity differences for people with LD/A, and /or a lack of knowledge of where and how to ask for help.

### **8. I choose how I am part of my community**

*'All my friends are here'*

*'Go Costa twice a week and get a Mango Frappe.'*

*'Go to shops more with my friends.'*

*'I get about on my mobility scooter.'*

*'Do an exam in BSL. I do a bit but want to do more.'*

*'Get a blue badge to get out, but no-one will help me.'*

*'I would like support to chair a meeting.'*



Participants do not spend a lot of time out in their residential communities (see Standard 7) so do not tend to get to know many people well or to socialise there.

Key friendships and relationships were often formed in alternative communities, such as day services or extended family homes. Other communities tended to be specific to LD/A such as social or craft clubs, or in organisational groups such as CPF (see Standard 5.)

Two people regularly go out to a pub together, and a further 2 are supported to attend faith-based community groups. One person said his main hobby was dancing, and that he does this locally, however he has to be back by 9.30pm for medication and staff changeover.

Some participants would like to be more involved in their communities but do not know how to do it. In some cases, they have tried but felt rejected.

Overall, we did not find many examples of support to be part of a non-LD/A based community. Nor did we find much evidence of support to enjoy community-based hobbies, explore employment aspirations, or learn news skills as ways of scaffolding community integration.

This may be the price paid for support that has to prioritise practical issues such shopping and daily living (see Standard 4).

## **9. I have the same rights and responsibilities as other citizens**

### **Understanding politics and following the news**

*'I understand it myself and vote in the main election'.*

*'I vote. I get the post one.'*

*'Yes, but I'm not saying who!'*

*"B says they are all the same. I don't know about it.'*

*'The news is all doom and gloom'.*

*'I watch the news on my own in my bedroom'.*

*'I watch the news and I cry.'*

*'No, don't watch the news or vote – boring.'*

20% of participants vote



Overall few participants regularly watch the news, and most do not vote, but several said they would like more support to understand political choices and voting, especially in general elections.

### **Money matters**

*'I can spend up to £50 without asking permission.'*

*'I go shopping and I lose control of what I should be spending'*

*'What I need support with is PIP and benefits.'*

*'Yes – I want to earn some money.'*

25% of participants need support with money.

54% of participants have others who manage their money and are happy with this.

One participant has an appointee

Where known, support with finances was most often given by families, specifically fathers or brothers. Some participants said they would like a better understanding of money, paying bills and not getting into debt or owing money, and benefits.

Overall, less than half of all participants manage their own money but are happy with this.

### **The right to work.**

*'Be a games designer – I'm already good at it.'*

*'My dream job is to work in a bakery.'*

*'Clean the toilets'*

7% of participants are in paid work

11% of participants are in voluntary work

All paid work was part-time, and all those in voluntary work, are volunteering for more than six hours per week. Some said they are interested in volunteering but are worried about whether they would 'fit in'.

Overall, the majority of participants are neither in paid nor voluntary work, but where they expressed interest, they do not know how to find out more about their options. Some of the younger participants expressed a wish to be more involved in consultations such as this one and would like more opportunities to talk to the Council.



Some participants asked what would happen next. We explained that Cornwall Council would be running a series of workshops that we would be attending, and that we would track progress and report back to them in due course.

Some issues raised during the consultation are being followed up separately.

## **DISCUSSION**

Each group was about two hours long, and each interview about an hour.

As would be expected, there were some differences between participants attending the community-based groups and those attending service-based groups. In the main participants in the community-based groups had a higher level of independence and showed more engagement with issues arising from Standards 7, 8 and 9. Generally speaking, it was easier to establish themes for some standards than for others: even after explanations and supporting questions, some standards (e.g. Standards 6 and 9) were difficult for some participants to grasp.

While some participants know and like their neighbours this was not the norm. If disputes arose, people did not seem to have access to the right support to prevent escalation. Where participants were the targets of anti-social behaviour, they either tolerated it, or sometimes (eventually) reported it to the police. There was little evidence of intermediate action, or support to find solutions such as meditation.

Some participants have been perpetrators of what seems to be antisocial behaviour as well as being recipients of it. Most lacked knowledge of their responsibilities as tenants, and some disputes seem to have arisen out of issues such as participants not putting rubbish out at the right time or in the right place, or of them being excessively noisy. Timely intervention may have prevented escalation, but prior learning opportunities about how to be a good neighbour/tenant may be even better, especially for people moving on to independent living for the first time. The 7 Keys to Citizenship training supports people to learn about their civic rights and responsibilities and is likely to be helpful.

Many of the participants are happy with their support. More probing questions suggest they might like to be supported differently though (such as at different times), or to do things they aren't currently supported to do (such as going out in the evening). Group conversations revealed some confusion about support, suggesting participants are not aware of what is in their support plan.

Revisiting person-centred support plans with recipients, staff, and circles of support could iron out these discrepancies.



Many participants rely (often very happily) on parental support. As parents age, these arrangements will probably need to change. Change at short notice or due to an emergency can be especially difficult, and particularly so when it is caused by the death of a main carer. We found no evidence of participants being involved in conversations or making plans about their long-term future and the changes that could bring.

Contingency plans embedded in Person Centred Plans would increase the likelihood of appropriate, considered alternatives and so informed choice.

Similarly, of those participants reporting a lack of understanding of their finances the majority are happy to continue to rely on family members to manage their money for them.

These informal arrangements seem to work well, but there needs to be an eye to the future: aging parents will not always be there to lend a hand. Some form of money management education (see 7 Keys to Citizenship) could kickstart more self-reliance in some, while independent advocacy support may be more appropriate for others.

A recurring theme across the standards is a lack of opportunity to choose or change. Overall, we did not find much evidence of understanding, experience or action across key areas of housing and support, such as choosing who to live with, who to be supported by or how to make changes at home.

This is probably exacerbated by lack of familiarity with rights under tenancy agreements or entitlements under care plans. So, for example, participants who are not allowed to personalize accommodation or to choose support staff, are unlikely to challenge these situations.

We did not find many examples of changes of home either. Long-standing tenures were quite common. This could reflect genuine satisfaction levels or a lack of opportunity to move. It is likely that obstacles to moving such as the online bidding system, lack of independent advocacy support and poor housing stock may act as deterrents to change.

One key theme to emerge is an apparent contradiction between stated perceptions of community safety and behavior. While participants say they feel safe to go out in their community, in practice they do not necessarily do so. When they do, they are likely to be accompanied by a support worker or family member, and very few people go out on their own at night. Perhaps perceptions of safety arise from restrictive behaviour rather than feelings of safety per se.

While participants do report having choices, we did not find many examples of them being actively encouraged to find out about the range of choices open to them, whether in terms





of housing, support, or citizenship. This could hinder the expression of aspirations: if people don't know they have choices they are likely to be discouraged from further enquiry. As the Reach standards say, meaningful choices can only really be made if people can see how things can be done differently. They can only choose between those things they know to exist, and lack of knowledge is inherently limiting. 'Priming' sessions would help people explore what good housing and support provision could look like.

This consultation has provided useful and interesting feedback, but it is important to acknowledge and discuss limitations. Group work provides a good broad-brush approach for gathering baseline data, but the timescales were tight, and we did not have time to view the consultation documents in full before making arrangements. In practice, covering all 9 standards in one meeting was challenging, with participants showing signs of fatigue towards the end. Given the amount of information, with more time it would have been better to split each group over two sessions.

CPF only works with adults, and the youngest participants in this consultation were around 30 years of age. Gathering the views of people about to transition into adulthood, (and so into adult services for that first time), would present an ideal opportunity to find out about the issues that are important to young people, and to bear these in mind when designing housing and support services to suit their needs.

Our participants were predominantly male (77%). Reaching LD women, especially in the community is a perennial problem. It is likely that different approaches across the board are needed to reach women and to capture more of their experiences and opinions. For example, our results show a high degree of feelings of safety in the home, but we know from statistics (e.g. SARC) that women with LD are disproportionately at risk of sexual abuse at home. None of the women here spoke of this. Perhaps it has not happened to them or perhaps the public nature of group work inhibits disclosure. More individual interviews with more women might yield different results.

None of our participants lived in older people's sheltered accommodation or care homes. Knowledge of these people's housing and support needs would be interesting to investigate.

Our sessions in the main were with participants who use verbal communication. More and different ways of reaching people with different communication styles is needed to better represent their experiences. The provision of independent advocacy support might best ensure inclusion across the board.



Our sample of participants was 'ad hoc'. A stratified sample would be the safest way to extrapolate findings to Cornwall's wider LD/A population.

## **Conclusion**

We have listened to participants and summarised what they have told us about their experiences and what matters to them.

As the Reach Standards reflect, there is 'importance in continuity and moving forward even if it feels like we are taking small steps', and we hope the work we have done makes a small contribution in the recommissioning of housing and support services.

Reassuringly, many of our participants report happiness and contentment with aspects of their lives, but a critical issue is a seeming lack of clarity and autonomy in terms of choice and change. Put clumsily, if people don't know what they can choose, they don't know what they can choose.

Giving centre stage to real opportunities for choice and change in the direction and development of services will honour peoples 'right to an ordinary life' (Reach Standards, p14)

## **References**

Everyday Citizenship: Seven Keys to a Life Well Lived, Duffy and Perez

Cornwall People First Presentation (see separate attachment).

A Practical Guide to the Reach Standard 2019