

Appendix 3: Golden Threads

This document sets out key themes and aspirations which have been identified as part of the consultation work led by Disability Sheffield.

Day Opportunities

- People want to do work/volunteering/studying and meaningful activities with their days. They want to be supported by day services or supported living to do this. Either by having somewhere to go, or by having support in their workplace.
- On that note: people want to do jobs that are not just retail, charity shop etc. Some people really like this, but a lot of people want variety and to learn the skills to do so. People want to be paid or compensated for their work and contributions.
- It was asked at a meeting if people would want to do work in hospitals/healthcare. An opportunity came up to ask this at a BSF session. People would be interested in working in these settings, particularly when it comes to talking to their peers and advocating for them. A few of this group spoke about times they had unofficially advocated for others because they 'Know what it's like to not be listened to.'
- Assisted volunteering and more supported Internships which lead to meaningful work.
- People want to do meaningful things with their day. Art and craft can be fun but when that is all there is it is very limiting. In one person's words 'Don't want to be threading beads all day'
- People want more things to do in the evening. This could be activities set up just for adults with LD/Autistic adults- or places like nightclubs opening earlier. More accessible spaces need to be available.
- Easier access to information on what activities are in their area. People want more options and more choice.
- Lots of people report good day opportunities/clubs not restarting after Covid and not knowing about alternatives or what is out there.

Supported living

- Clearer complaints process for both residents and staff. People want to be able to change things in supported living in a timely manner, not having to jump through hoops.
- Family members report feeling steered towards supported living when children are still at home. It does not feel like a positive prospect for them.
- When supported living works well people feel supported to be independent. They have a say in the support hours and when they are. When it does not work, they feel unsupported, unsafe, and unable to talk to staff and change things.
- Young people need more support in transition period where they and their families decide what is best.
- Lots of worries when they are assessed as needing a certain amount of care/support and not having the funds to do this.
- The best supported living is where people have control over their decisions, and they are supported to do what they want when they want it. This includes going out late, not having to keep up with everyone else, choosing their own activities and not being told what to do.

- Lots of people want to be able to do things spontaneously. Feeling downhearted that they need a risk assessment to see family or friends when other people do not have to.
- People want to have some say about who they live with and decide bigger things as a group. E.g., going on day trips.
- Family members worry about costs of supported living and long-term care. Local Authority does not come close to expensive private provisions.
- People want a choice to get involved with the things they want, not have to jump through hoops and funding to go to different services. They want to see their friends and make new ones.
- A lot of people said they feel staff do not care. They do not understand different conditions, and they dismiss things when residents tell them what is important.
- People pointed out the above can be because people think badly of carers. People who need care know how invaluable it is and they want to make the job more attractive to attract the right people.
- People worry about who to contact when things go wrong as they do not always know or trust the people working for them or feel their worries go unanswered.
- Making venues and living spaces as accessible to all as possible. This still is not the case for so many spaces and houses.
- People want access to technology/phones so they can be more independent and contact people when needed. They want staff to be trained on how to support them to use tech.
- A good example of things working is when new staff shadow for a while when working with someone with complex needs so everyone feels comfortable before being left alone.
- People report being left out of decisions around staff. They want to know why their regular staff is changed, not just have to deal with it without being told in advance.
- Clearer communication needed around staff policies. E.g., Not being able to talk to my carers in public when they are with someone else, and never having this explained.
- Family/carers say people with higher needs not having enough support, and not having the same choices. If they communicate differently this is heightened.
- People want a named social worker who has been trained in LD and Autism. They feel that their wellbeing has decreased, and their needs are not being met since the teams became generic
- The idea of the local authority supporting families and groups of people to set up cooperatives to assist people to manage their own care, to live together with friends and to run businesses under this model which provides them with sustainable employment.
- Wanting to make informed choices about what supported living to go to, rather than being stuck in somewhere easiest/closest.

Respite

- People want creative choices around respite. Going to hotels, having a break at the seaside in a caravan with carers etc.
- People do not want to go to 'rubbish' respite centers where they have had bad experiences in the past.

- Some people get stuck in semi-respite services because their care is not getting permanent solutions put in place.
- Staff turnover in respite being hard to keep up with and not feeling supported by regular support or people they do not know is distressing.
- People with complex needs who go to respite regularly find it difficult being 'left' with staff they cannot properly communicate with.
- There is not much feedback on current respite because a lot of people who would go to respite either do not know what is available, haven't got the funding, or it doesn't meet their needs.
- People want respite in places that are not Sheffield. Examples being given are seaside places or places of interest.
- Another example is places like Burton Street having a respite center to go to in Anglesey, but they do not have the funds to make it wheelchair accessible.