

Better commissioning for better lives: top tips for commissioners

These top tips for commissioners are based on roundtable discussions between people with learning disabilities and commissioners in March 2022. They are part of our call to action to move beyond the years of policies and good intentions to now focus on making equality and inclusion for people with learning disabilities a reality.

1. Challenge discrimination – understand the barriers and impacts

Commissioners should be champions for equality, diversity and intersectionality. People with learning disabilities face discrimination and have poorer outcomes across multiple life chances. Professionals' attitudes can result in discrimination too, such as during the early stages of the pandemic, where there were instances of Do Not Resuscitate notices being inappropriately added to people with learning disabilities' medical notes.

Poor access to leisure and work limit chances to meet new friends or a partner – this adds to loneliness and can impact on mental health. People may also face compound discrimination due to gender, ethnicity, religion or sexuality, in addition to other social determinants which prevent people leading good lives.

We need to break this cycle. Inequalities are not inevitable. They are not all accounted for by health conditions. Many issues are interrelated. Understanding these issues is important so we can challenge and start finding solutions.

“Loneliness is made worse by the lack of public transport where I live. The buses stop at 6pm. I live on my own, I don't drive, my friends don't drive, so evenings are hard.”

2. Challenge and support the wider system to make reasonable adjustments

Societal barriers limit access to housing, public transport, mainstream health services and the community and so reduce people's rights and choices. A lack of reasonable adjustments often mean that mainstream services aren't inclusive, so people end up further marginalised. It's bigger than health and social care, but this cannot stop us. We need to highlight the issues and help mainstream services gain the right understanding so they can properly serve the whole community and discharge their duties under equality laws as effectively as possible.

Education is key. There must be a push for co-delivered training for healthcare staff so they can improve access and properly understand co-morbidities to move beyond assumptions about people's abilities and lifestyles. The Oliver McGowan Mandatory Training is a great start.

"I was sent to a mainstream group for mental health support. I found this really hard and uncomfortable. It was tough to hear people's experiences and I was not allowed to take my support worker. The information I was sent was not in easy read so I couldn't understand it."

"Really hard to access the dentist. I went to one that worked in a set way which I found terrifying. I went to the hospital and had fantastic treatment there."

3. Find out what's important to people (but assume basic rights)

Our starting point must be what is important to people with learning disabilities. Not everyone wants the same thing, but there are some givens such as basic rights, freedom, inclusion, equality, choice, the chance to have ordinary things such as a love, friendship, money, a job and contributing to the community. With this foundation we can then find out what matters to people one by one and work out what good looks like. Importantly, we must listen to people's real-life experiences, concerns and ambitions to inform strategic plans as well as their own "assessments".

"I care and worry about my family – help me to do this well."

4. Co-production – nothing about us without us

Decisions must be made with the people they affect – so people must be central to designing and reviewing services. We must learn how to properly co-produce as we'll get better results together. Co-production needs to be inclusive of people with a range of backgrounds, needs and circumstances so transformation isn't driven by a small number of people.

We need to share power and respect each other as equals. People need to feel trusted and listened to so they can make the right decisions. Ask people how they would like to be involved and what works for them. This needs to be the case for individual decision-making too. Build capacity, including peer support, to help citizens and workers (practitioners, commissioners and senior managers) to gain the skills, confidence and resources to come together to co-produce.

5. Be brave – stop being so risk averse

We need to challenge risk averse systems and risk averse decision-making. There is too much focus on what can't happen. We use labels as excuses rather than finding solutions. This happens in assessments too, rather than looking at aspirations and how to make things work. We think about safety rather than quality of life and often we are frightened to recognise the ordinary things that matters to us all, like love and dreams.

We must be brave enough to change the system rather than tinker around the edges. We need to back people, including social workers and providers, to make braver decisions.

“We weren’t supported to have a family – no help through pregnancy and having the child. We felt judged and emotionally drained. No one took responsibility to help us. Had a court hearing and we weren’t allowed to have an advocate.”

6. Empower people with information and with time

Empower people with proper information – what can they expect; what are services meant to do; what are ‘eligibility’ criteria; why do you pay for some services and not others? We must ensure workers have time for a proper conversation to connect on a human level. Get it right first time more of the time so people can access the services and support they need, when they first need it. Often we don’t get things right in childhood and we don’t give people the skills to help address issues and challenges later. People and their families need to be supported early so they remain empowered and supported to live an ordinary life in the community.

“It’s exhausting jumping through hoops to get support.”

7. Develop a shared vision and expectations

Co-produce a clear vision to galvanise action and focus on outcomes that are based on what’s important to people. Think about the focus of support – is it on what matters to the person and what will improve their life? Test out if the system has perverse incentives that work against some outcomes and independence. Make this vision part of the equalities agenda and ensure senior accountability for promoting inclusion and reasonable adjustments. It’s about doing the right thing, plus better outcomes mean better use of resources too.

8. More action – get better at making change happen

We know what people want – they have been telling us for a long time. There are lots of great ideas and good practice examples, but they need to be implemented at scale. Most specifications are aspirational but the delivery does not always match. We must move our energies and resources to supporting people to have good inclusive lives in the community based on rights and equality. Without this, people will always be Service Users rather than citizens with a home of their own with people they choose.

Good planning takes time and trust. Model good practice – employ people, invest in what works. Follow through and check things are working in the right way. Commissioning is about quality and outcomes – not just moving on to the next procurement. Be ‘can do’, start your own local conversation about Commissioning for Better Lives and start making the right change happen.

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