



What does good information on social care and positive practice look like for people with learning disabilities and their families?

Summary report



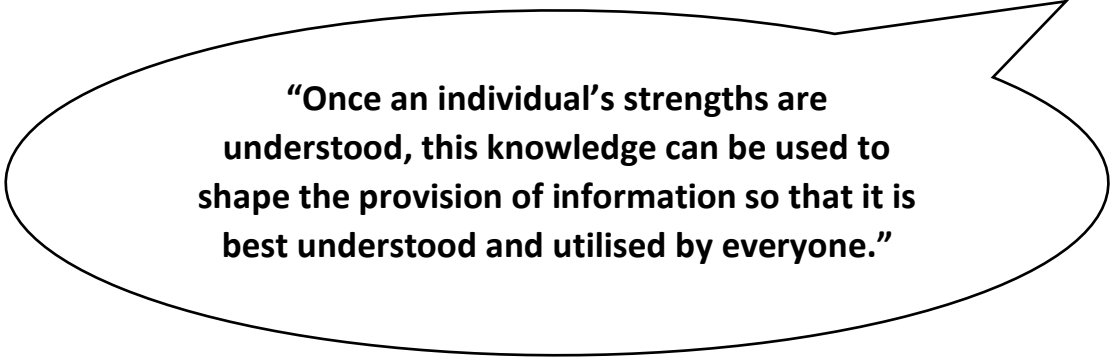
What this is about and who is it for?

Learning Disability England have worked on this report as a member of [The Valuing People Alliance \(VPA\)](#). We wanted to work together with people with learning disabilities, autistic people and their families to find out what needs to happen for them to get good information about social care and for them to be able to understand and use that information.

We are sharing this report summary to support anyone designing, commissioning or delivering a service to understand what people with learning disabilities and autistic people say helps them get, understand and use information on social care.

Learning Disability England and everyone who has contributed towards this project hope this can be used to make sure people with learning disabilities, autistic people and their families can not only find accessible information but that this information is shared in the right way, is easy to use and is effective in making a difference.

Key messages



“Once an individual’s strengths are understood, this knowledge can be used to shape the provision of information so that it is best understood and utilised by everyone.”

Information must be person-centred and varied

- No one size fits all, a variety of accessible formats is needed.
- Reasonable adjustments might include a follow-on video call as well as accessible formats.
- Digital information should be designed to be accessible – there are resources to help with that.
- Build in a variety of face-to-face options in your information delivery.
- The websites flagged by those contributing to the project can be used as examples of good practice and to help shape the design of future information provision.

Humanising and helping to develop trust for services is key

- There should always be an option for support from ‘real people’ to understand and use information.
- Examples of methods that help humanise support includes the use of one-page profiles, an individual’s photograph in their signature and good interpersonal skills.

- Information should come from sources seen as trusted – this can be achieved by communicating in ways that help people feel they are equal and listened to as well as there being a variety of sources or roots to get and understand the same, consistent information.
- Trust works both ways – people need to feel trusted to make decisions that are right for them.
- An example is - Be-Human.org.uk – [Be Human](http://Be-Human.org.uk), which provides guidance to organisations for how they can be ‘more human’.

Information Service design and delivery needs to consider and remove the barriers for people with learning disabilities, autistic people and their families

- One barrier is the extent of information out there and a lack of knowledge as to where to go for the right information. Trusted community or peer led services was 1 solution offered.
- Another barrier and eventual solution – allowing for councils to share specific information about suitable social care providers.
- People felt they had less people to go to for information or support than previously, they acknowledged the limitations that exist in providing a solution but a deeper consideration for the allocation of funding in this area and increasing awareness of the services that are out there could be effective smaller actions.

More opportunities for feedback are needed and in accessible ways

- Most people found little chance to give feedback about information services or experiences but valued being able to do so.
- People require more direction around opportunities to give feedback can be found.
- People need to feel listened to and their concerns acknowledged.
- There need to be different ways to provide feedback that meet all accessibility needs.
- Coherent reviews coproduced with people who draw on support seem to have more impact on service design and delivery than 1 off feedback

Support is needed to find, consider and use social care information

- Support must be provided at all three stages of the process.
- It shouldn't be assumed that information is clear, in the delivery of information opportunities for clarification and alternative accessible formats should be given.
- Family members are vital in maintaining this system of support – more support for family members will benefit everyone.

The voice of people with learning disabilities and families should always be respected

- When people felt respected, they were more likely to trust services and turn to them, particularly in times of uncertainty.

- People need to be listened to and allowed to lead decision-making based on having information they can understand and use to make informed choices.
- Education that all people with learning disabilities communicate and understand differently so an individualised approach allows people to communicate with people in ways that make them feel understood.

How we did this project

We designed this small project in partnership with the Valuing People Lived Experience group and people working in policy development. After design, the next step was to send out a call for evidence. Through [Health and Wellbeing Alliance networks](#) of family/carer organisations, self-advocacy groups, community groups and social care providers were asked how they get good information about social care and examples of positive practice.

The call for evidence was open for seven weeks. Thirty-eight people or organisations responded to the online surveys. Five people also contacted us via email responding to the questions or linking us to resources.

There was then a focus group meeting held with people with learning disabilities and family members to discuss experiences of finding information, what constituted 'good information' and some of the ways this information was used.

The Valuing People Alliance lived experience group reviewed all the information and decided on these final key messages.

Learning Disability England on behalf of the Valuing People Alliance



[Find out more about the Valuing People Alliance here](#)

The Valuing People Alliance is part of the VCSE Health and Wellbeing Alliance (HWA). This work has been funded through the HWA, jointly managed and funded by Department of Health and Social Care, NHS England and UK Health Security Agency. For more information, please visit:

<https://www.england.nhs.uk/hwalliance/>

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