Down Syndrome Act 2022 guidance: call for evidence

Healthwatch Birmingham welcomes the opportunity to respond to the Department of Health and Social Care's Down Syndrome Act 2022 guidance: call for evidence. Our key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care. In line with our role, we have focused our comments on:

- Patient and Public Involvement and engagement
- The views and experiences of the people of Birmingham

Healthwatch Birmingham welcomes that the opportunity to respond to the call for evidence has been available since July. This long period to allow responses helps ensure everyone has the opportunity to share their views.

We note that an email address and postal address have been made available for members of the public, such as those without digital access, to share their views more widely just than the survey.

Healthwatch Birmingham are pleased to see the inclusion of easy read documentation, and BSL versions of each set of questions. This allows more people to be empowered to respond to the call for evidence. However we note that the BSL questions were only added late in the response period, which will have limited their use.

We note that specific questions have been asked of relevant stakeholders to the call to evidence prompting wider involvement in the topics for discussion.

Call for evidence

Healthwatch Birmingham welcomes the focus on all areas that affect the lives of those with Down's syndrome and their relatives. People in Birmingham tell us about the many different ways their lives are affected when dealing with health and social care services.

Our comments focus on day opportunity services, direct payments, mental health, housing, pandemic experiences and positive experiences.

Day opportunity services

Our recent report *Experiences of day opportunity services in Birmingham* highlighted the importance of day opportunity services to service users, their carers and families.

Our research indicates that service users and their carers/families value the role of day opportunity services in their life. We found that:

- The main reasons people use day opportunity services are due to personal loss, isolation, poor health and wellbeing, to maintain health and wellbeing and to support carers.
- Day opportunity services have an impact on social and preventive outcomes by supporting continued independence of service users, supporting their health and daily living needs, and enabling family carers to have a break and/or continue with employment.
- Attending and participating in activities at day centres has a positive impact on people's mental health, social contacts, physical function and quality of life.
- The challenges faced by carers/families and service users during the pandemic, when day opportunity services were closed, further highlights the important role that day opportunity services play in supporting emotional and physical health. The pandemic has left many carers/families exhausted and emotionally drained.
- It is important that people have the choice to access services they want, including day opportunity services.
- Use of personal budgets and direct payments might be useful for enabling people to access varied services but are not appropriate for everyone.
- There is a perception amongst the people we spoke to that personal budgets and direct payments are being used to mask cuts to day service provision.
- There are inadequate services in the community that day opportunity service users can choose from, meaning limited 'choice and flexibility'.
- There is inadequate information made available on the services which are accessible to day opportunity service users in the community.
- Day centres need to be better regulated for the quality of care they provide

Direct payments

We published a report *Direct Payments in Birmingham: Choice, control and flexibility* which looked at whether service users, carers and families feel supported in the use of direct payments by local authorities.

Our key findings were:

- People need clearer information from Birmingham City Council about their entitlements to Direct Payments. This is needed to increase their uptake.
- People need diversified ways to learn about Direct Payments. Well above two-thirds of people who shared their experiences had received the information from social care workers, with the remainder citing a third-sector organisation or word of mouth. Direct Payment users need freedom to plan flexible and innovative ways to meet their care and support needs.

- Service users and carers need to know what they should expect when they try to access, and then use, Direct Payments. This includes how service users and carers can feedback to Birmingham City Council about their experience of trying to access and use Direct Payments.
- People need to be supported through the process by being given the necessary information and advice, control of the Direct Payment and how it is spent, and support without undue constraints and bureaucracy.
- Frontline council staff need a clear understanding of Direct Payments, the support offered by services, targeted training and support to ensure that Direct Payment users receive consistent information and support.
- Direct Payment users need to be supported to build their capacity to manage their payment including guidance and training.
- Assessments and reviews need to be genuinely person-centred, timely and accurate.
- The constraints of the system, which lead to an inconsistent and/or lack of support from social care workers, needs to be addressed.
- There has to be real collaboration with Direct Payment users to make a difference to how they lead their lives.

It is clear that if the use of direct payments it to be extended, better guidance is needed for local authorities to best support service users, carers and families in their use.

Mental Health

Our recent report *Access to mental health services for children and young people in Birmingham: what needs to change?* found that *"Mental health support for CYP (children and young people with other conditions needs to be reviewed and improved in order to address the specific needs of this group –i.e., autistic, Asperger's, learning disability etc."* People have frequently told us at their frustrations finding professionals who are willing to treat them for mental health problems when they have existing conditions.

Housing

People have contacted us for help and information about housing situations for their relatives. It is clear that further information and support needs to be shared with service users, families and carers when making decisions about housing. This needs to include how to raise concerns about decisions made and care received.

> *The caller's brother had Down's Syndrome and was previously cared for at home. He later had to go into hospital, where the caller was later told he would be allowed to return home… was later told that he wouldn't actually be allowed to return home - instead he would have to be cared for in a care home… her brother also passed away in the care home. She has made a*

> *formal complaint to the hospital [about his discharge] and received a 14-page document, parts of which she doesn't understand.*

> *The caller is ringing about his sister, who has downs syndrome and other learning disabilities. She lives in a small care home. She has been there for 3 years, previously lived with their parents, but both have sadly died in the last two years. Prior to Covid, she was attending a centre, where the manager has shared concerns with the caller about the care she is getting from the home. She has had long infected toenails that weren't noticed, and has not had her glass eye cleaned, as is needed regularly. She hasn't been taken to church or involved in her religion. The caller has raised all these concerns with his sister's social workers… The caller does not get on with the current social worker, who has left her at this home, and doesn't seem to have addressed his concerns. […] the social worker has even said that his sister is probably now used to no contact with the family.* (A safeguarding concern was raising with the local authority following this feedback)

Pandemic experiences

During the national lockdowns for the recent pandemic, we heard from people who felt that the needs of people with down's syndrome were not prioritised as they should have been.

> *Caller is an advocate. His concern is regarding people with Down's Syndrome not being contacted by GP surgeries in regards to their extremely clinically vulnerable classification. He has contacted multiple organisations regarding this. He feels as though nobody is acknowledging his concerns.*

People told us about problems getting vaccinations at the right time during the roll out as their relatives had not been invited at the right time. We also heard how the information about vaccinations was not available in easy read and other formats.

> *The individual is concerned about his adult daughter with down syndrome has not received a letter from NHS England when it was announced in early November that all adults with down syndrome will be in the 'extremely clinically vulnerable' group. The individual wrote an email to the GP in early December when the rollout of the vaccine was announced. Their reply was very disturbing. They replied saying that he has nothing to be concerned for as his daughter was still a child and that she did not fall into the 'extremely clinical vulnerable' group. Whereas she is 23 years old. The individual wants that GP's must ensure that all adults with down syndrome should be appropriately registered on their NHS data base for the Covid 19 vaccine Rollout. He is concerned as the directive is that people should be sent a letter and then contacted via phone. He also wanted assurance that this information would be given in multiple languages, and in an easily understandable manner.*

As discussed earlier when hearing about day services, we heard how a lack of access to the usual support services caused problems for people.

> *We were hoping that our son would attend a day centre, but this has not happened because day centres are closed. Son is happy and well, but I am caring for him while working from home and we have had no support.*
>
> *Due to day services, clubs, 1 to 1 support not happening I am now caring for an adult with autism and a learning disability, who is naturally anxious due to so much change … without help – 24 hours a day, 7 days a week. I am exhausted*
>
> *It's taken her a while to get back into the swing of things. It was very difficult during the lockdown - she deteriorated.*

Positive experiences

We have also heard about positive experiences people have had of services in Birmingham.

> *Excellent help and provision by dieticians they do a check up for my child every 6 months for my child who has Down's Syndrome. I have no doubt that this service is helping with my child's quality of life.*

Healthwatch Birmingham are keen to see how people's evidence has been used to shape the final published guidance.

Yours Sincerely,

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