Area Board Update November 2023

healthwatch Wiltshire

Autistic people tell of their struggles to find mental health support

Autistic people, and their families and carers, have told us of their desperation and frustration at not being able to get support they need for their mental health.

People said they felt isolated and misunderstood, falling between the gaps in services which aren't designed to meet their needs and where staff lack training and awareness to support them.

These are the stark findings of our work hearing the experiences of autistic people, and their carers, who have accessed mental health services in Wiltshire in the last three years.

In a joint project with Wiltshire Service Users' Network (WSUN), which runs the Wiltshire Autism Hub, we listened to feedback from more than 50 people to understand what is good and what could be better about local mental health services.

What did people tell us?

- Most people went to their GPs first to get help, but faced a long wait to be referred on to other services. Some said they could not get any support at all.
- Autistic people did not find services helpful. They didn't think talking therapies were suitable for them and sometimes made symptoms worse.
- Mental health staff lack training, awareness and understanding of autism. Sometimes this has resulted in misdiagnosis and inappropriate treatment, or no support.
- Thresholds for getting mental health help are very high or inappropriate for autistic people.
- Some people said they had used expensive private consultants or therapists in an attempt to get help.
- Carers said the Child and Adolescent Mental Loc

Health Service (CAMHS) was overwhelmed and the waiting times very long.

- Waiting times for an autism diagnosis were seen as unacceptable, with little support or guidance post diagnosis.
- Communication difficulties, coupled with a lack of flexibility from services – such as only offering phone calls rather than face to face appointments – creates a barrier for autistic people to be able to access help.

Stacey Sims, Healthwatch Wiltshire Manager, said: "It is clear that autistic people and their carers have struggled to access support for their mental health in Wiltshire, and this has had a serious impact on them and their families.

"I want to thank everyone who took part for the experiences they've shared with us, and for suggesting ways to improve local services. We'll be monitoring how these services are developed in the future so they can better support autistic people, and those who care for them."

Louise Rendle, CEO of WSUN, said: "Research has shown that autistic people are much more likely to have anxiety, depression, Obsessive Compulsive Disorder (OCD) and eating disorders than non-autistic people. This report highlights how important it is that mental health services have specially trained staff with awareness in autism.

"Adaptable services that provide reasonable adjustments will help ensure that autistic people and their families have equal access to high quality mental health provision. Too many autistic people still struggle to get appropriate support and we see through the Autism Hub the impact this has on people's lives and that of their families."

Look out for the report on our website.