

Desktop Review of Autism Research

My Voice Matters

A Young Healthwatch Volunteer Desktop Review.

My Voice Matters is ensuring the voice of people with diverse lived experiences and backgrounds are heard.

We are proud to be able to give the opportunity for seldom heard voices to be heard by providers and wider organisations in their own words.

This desktop review has been researched and written by Flavio Fernandes De Oliveira; a Young Healthwatch volunteer.

Introduction

A Young Healthwatch Volunteer reviewed the reports produced to understand the common themes and issues affecting people who are diagnosed with Autism.

The desktop review pulls together the common themes and issues found.

Common themes/findings

A number of key issues/themes have been identified across all the reports these are:

- Lack of effective communication from GP Practices and/or professionals.
- People with autism feel they are not being listened to.
- Differentiating the information for people with autism to the other patients.
- The increase in knowledge and understanding of autism within the staff of the GP Practices.
- Tailoring the communication to people diagnosed with autism to make it more accessible.
- Spreading awareness for those surrounding the individual with autism.
- Developing a comfortable environment in the GP Practices, so that the individuals with autism feel more comfortable when visiting said GP Practice.
- Support people awaiting a diagnosis.
- Ensure people are aware of the annual health check.
- Ensure professionals are properly trained.

Healthwatch Reports

Autism children and young people in Croydon

The information provided from this report indicates that an issue in which children with autism face is that the lack of effective communication from their GP Practice, leaving them feeling as if they are not even in the room. The implication being that the GP Practice is not directly communicating with them, but with the parent or guardian accompanying them. Therefore, a more personal one-to-one approach, with a more accessible and welcoming environment would improve attendance rates. Moreover, a consistently answered 'calling in' option that is more person-centred would also be an improvement on the current options.

A major issue that appears in this report and many others, is the lack of relevant information being given to the patients. For example, having a GP with a clear understanding of all the relevant pathways and organizations to refer to, whilst also providing a single link that gives a comprehensive list of informative services instead giving multiple links, as having multiple links could cause confusion. Moreover, this comprehensive list should be advertised all over local GP Practices and schools, thus, making it easy to find this information when needed. It would also be useful to differentiate the patients whom have been diagnosed with autism to other patients in a systemic way, namely, the use of a recognizable symbol that would indicate to the staff that the patient has autism.

https://www.healthwatchcroydon.co.uk/wp-content/uploads/2017/10/autism_-_children_young_people_in_croydon.pdf

What people think with autism spectrum conditions and their carers think of services

As per the previous report, a major issue that is presented in this report is the lack of effective communication of the relevant information given to individuals in the autism spectrum. Introducing an initiative and training to improve awareness of autism amongst the staff working in the GP Practice and hospitals would greatly improve the lack of effective communication. GP Practices and hospitals should establish a system of recording a patient's preferences and/or needs for face to face, phone or video appointments also taking into consideration how these needs should be met. People

with autism should also be given a written summary of what was discussed during their appointment, this would eliminate any confusion caused during the appointment.

Instead of handing out an overwhelming amount of mostly irrelevant information to the individual with autism, consider a reduction in the volume of general information and hand out a more individually tailored pack.

https://www.healthwatchwiltshire.co.uk/sites/healthwatchwiltshire.co.uk/files/What_people_with_autism_spectrum_conditions_think_of_services.pdf

The reality of autism for young people and their families in Kent – Summary

For young people and/or children on the autism spectrum there should be more information about getting a diagnosis, what therapies are available or what treatments, and management must be provided to young people at this critical stage. As stated previously a comprehensive list of support available would tremendously help with this. Furthermore, as stated in the report, there should be a clear offer of CBT or alternative age-appropriate support therapy following a diagnosis. Once the process of diagnosing an individual is done, there should be a clear process to follow up with a young person; including CBT, referral to local support groups and return appointments.

For parents and carers of young people with autism, information and support must be made available for parents and carers when the child is referred for an assessment and not have to wait until the diagnosis itself. Currently, there are training courses available to parents such as Cygnet and Early Bird, however, these are only available post-diagnosis, and there should be early access to these courses if an early screening indicates that the young person has a high likelihood of having ASD. Furthermore, parents of young people on the autism spectrum have told us that they want more support. Moreover, the crisis line currently in operation should have a dedicated staff available, who are experienced in supporting parents, carers and young people who are struggling.

To prevent families from feeling “lost” within the system, health care professionals who have received a referral from CYMPHS services should acknowledge in writing and sent to the family, the GP Practice and the SENCO, with a named contact person whom can advise on referral progress. To prevent any emotional isolation of children with high

functioning autism, the child and families should have a named member of staff, specializing in supporting the emotional needs of young people in the school setting.

<https://www.healthwatchkent.co.uk/sites/healthwatchkent.co.uk/files/Healthwatch%20Kent%20Report%20-%20the%20reality%20of%20autism%20%281%29.pdf>

Mental health partnership board, autism task and finish group report

To summarize this report, three main points are given. The first point being, the expansion of opportunities for joint learning with the voices of people with ASC at the center, whilst continuing to gather and collate information and knowledge through regular events managed by Talkback.

The second point given by the report is the design and embed celebrations of the many achievements and contributions which neurodivergent people make to Milton Keynes, and disseminate local examples of good practice, e.g. the work of occupational therapists.

The third point being the improvement of communications on research (national and local), data gathering, good practice, and support (including peer) services across all Milton Keynes public sector organizations which directly, and often, interface with people with autism. One more point to bring up would be to make use of the knowledge of local and respected trainers and learning resources.

<https://www.healthwatchmiltonkeynes.co.uk/sites/healthwatchmiltonkeynes.co.uk/file/s/Autism%20Strategy%20HWMK%20MHPB%202022.pdf>

Progressing Autism Assessments for Adults

To summarize, the report named above indicates the investment in new staff to “make the current situation safer”. Moreover, letters co-written with autistic people have been sent to people waiting for assessments, letting them know that waiting estimates have been changed; this has received positive feedback. In addition, they are making videos to give people further information.

<https://www.healthwatchmiddlesbrough.co.uk/sites/healthwatchmiddlesbrough.co.uk/files/A%20Parent%20Carer%20Perspective%20-%20Replacing%20the%20Autism%20Pathway%20-%20TVCCG%20Response.pdf>

A parent perspective – Replacing the autism pathway, for 5 – 18-year-olds, across South Tees, Summary Report

In summary, this report states that some support provisions are already in place. However, parents and carers want increased accountability for the quality of delivery. The emphasis on training and awareness, indicates the need to avoid misinterpretation of masking and troubling behaviours.

Highlighted in the report is the concern that parents and carers of autistic children have for the lack of skill and knowledge (specific to this topic) to properly recognise other neurodevelopmental conditions. Therefore, parents and carers fear that if their child does not fit the autism/ADHD criteria, they will not be properly assessed with far reaching consequences.

<https://www.healthwatchkent.co.uk/sites/healthwatchkent.co.uk/files/Healthwatch%20Kent%20update%20on%20Autism%20services%20April%202020.pdf>

‘Champions and challenges’ – An in depth look at the look at the health and social care experiences of those who have a learning disability and/or autism within Luton

The information provided in this report indicates that the spreading of awareness of the annual health check will improve the translation to the EHCPs. Moreover, the report describes the good practice within the IST in mental health services that should be shared with the wider health system. Furthermore, staff noted that training of learning disabilities would be beneficial for all staff to have.

Moreover, the promotion of annual health checks is a necessity, whilst also teaching the individual the importance of these annual check-up. Having access to the GP and the same health care promotion would maintain a better relationship with the professional, making it easier for the person with autism to attend these annual meetings.

<https://www.healthwatchbromley.co.uk/sites/healthwatchbromley.co.uk/files/Autism-Care-Pathway-in-Bromley-18-PDF.pdf>

'Right to be heard', the government's response to the consultation on learning disability and autism training for health and care staff

To summarize the report linked below, the writer of the report received strong positive responses to the consultation, with clear recognition that health and social care staff must have a better understanding of how to support people with learning disabilities and autistic people more effectively. Furthermore, the report indicates that all training and development undertaken to be consistent with the framework. Moreover, this implies that all staff undertake training and development and it must be proportionate to their role and the level of interaction they have with people with a learning disability.

<https://www.healthwatchkent.co.uk/sites/healthwatchkent.co.uk/files/Healthwatch%20Kent%20Report%20-%20the%20reality%20of%20autism%20%281%29.pdf>

NHS Reports

Five-year NHS autism research strategy for England

This in-depth report indicates that there are five main points of improvement to be made within the NHS in terms of help people with autism. The first states that the NHS autism services require the building of an evidence-based culture. Further breaking this point down, people with autism and their advocates should be supported in asking for their evidence supporting their clinical diagnosis. Furthermore, the report indicates that the NHS requires appropriate funding for autism research in England.

The third main point given in this report is for the better answering of relevant research questions. For example, communicate NHS autism gaps to the research community or support longitudinal cohort studies. Moreover, ensuring a higher quality of relevant research would vastly improve the quality of available support for people with autism.

<https://www.england.nhs.uk/wp-content/uploads/2022/03/B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf>

A parent/ carer perspective – replacing the autism pathway report, NHS Tees Valley CCG report

The information provided by this report indicate to several points. The first point being the elimination of discrimination and for the health care professionals maintain the provision of a fair system with equal access based on needs not on poor parenting or socio-economic factors. Moreover, the information the parent or carer provides should be taken seriously, whilst also being respectful and maintaining professionalism. These points given in the report make up the “culture” sub-section.

In the sub-section called “the new pathway”, it is suggested that clear and super-friendly information is to be given to the parents or carers to better let them understand this new pathway, whilst considering the parents or carers concern about the new pathway. Furthermore, the new pathway should be monitored and regularly evaluated as to keep it as up to date as possible.

The sub-section “support in school” indicates that we should improve the wellbeing of children by increasing their knowledge and understanding of neurodevelopmental conditions and the role of education on referring onto the pathway. Moreover, the

report suggests, as to improve the children's wellbeing, the mainstream and specialist schools should aim to work effectively together.

In my opinion, the most important sub-section is the "training and awareness" subsection. The report suggests promoting and providing appropriate training and awareness to all front-line professionals. Moreover, promoting a public awareness of neurodevelopment conditions and how they may present.

<https://www.healthwatchmiddlesbrough.co.uk/sites/healthwatchmiddlesbrough.co.uk/files/A%20Parent%20Carer%20Perspective%20-%20Replacing%20the%20Autism%20Pathway%20-%20TVCCG%20Response.pdf>



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