

Family Voice overview of Peterborough Autism Strategy 2016-20

1. Purpose

The aim of this report from Family Voice Peterborough (FVP) is to raise concerns regarding the Autism Strategy for 2016-2020 for Peterborough as it came to our attention that the scope of which only contemplates people with autism from 16 and over therefore only including those in transition to adulthood and adults. Autism is a lifelong condition that requires a lifelong support through all areas of living from early year's education passing by employment, but also by offering opportunities for emotional growth and community inclusion.

3. INCONSISTENCY ANALYSIS AND BREAKDOWN OF AGENCY SERVICES

3.1 One of the aims of this Strategy is to encourage all services and organisations to “think autism”, maximising the opportunities to better support autistic people in Peterborough this need is felt by parents and people with autism of every age, therefore a range of partners across the public sector (including health services), private sector (such as providers of care and support) and the voluntary, community already work together to support children and adults with autism and their families and carers to feel part of the society.

At a time of reducing budgets across public services, we need to strengthen the above partnership working even further, but also by having children and adult services working together and so the focus on actions that can make the most effective use of existing resources. This might mean reshaping current provision both on children and adult services and taking creative approaches towards the use of resources across partners to continue to develop services. Autistic people and their families and carers are central to this service development, and their involvement is key in shaping and delivering services, such as informal or peer support.

3.2 NICE has made recommendations about the delivery of care to children and young people on the autism spectrum. This includes a recommendation that local services should work with and support the families of children and young people on the autism spectrum. It also recommends that local services should be coordinated by a local autism multi-agency strategy group.

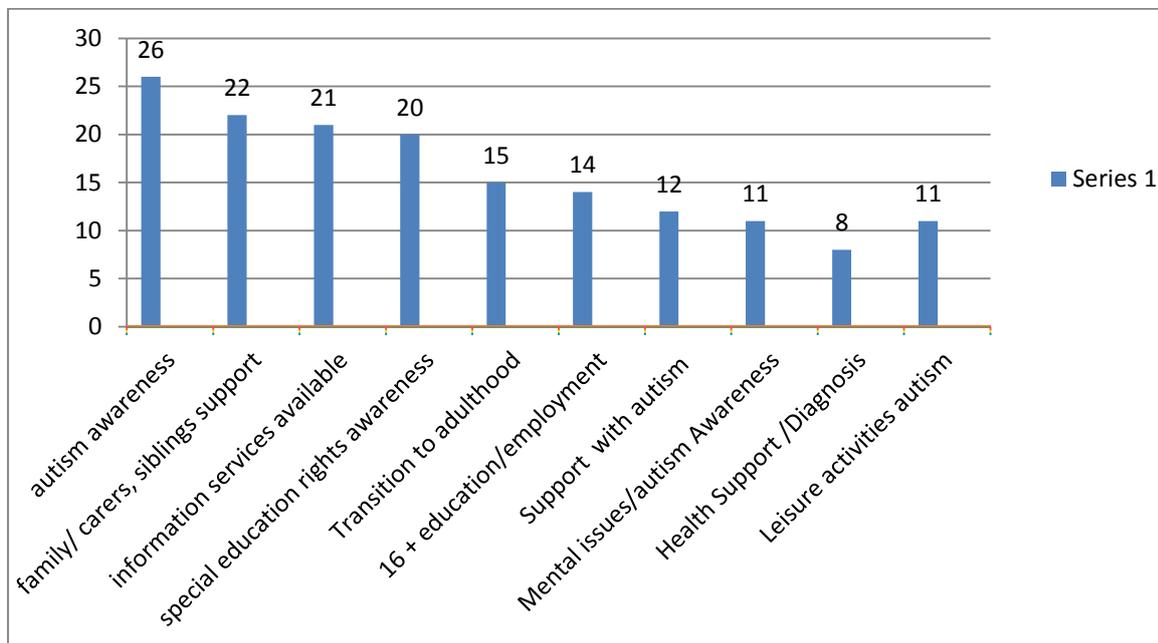
Autism is a lifelong condition and on the first autism board (15-Jun-2016) concerns were raised by FVP of a need to bridge the gap between children and adult services and support to the individuals and family, the base of this concerns is that a long term support is proven to lead into higher degree of independent living and able adults.

3.3 An informal Facebook Poll by FVP revealed concern from parents across all ages and not just transition to adulthood. The poll highlighted some important areas that the efficiency of the services needs to be addressed as a priority:

- 1. Increasing awareness and understanding of autism
- 2. Supporting families and carers of people with autism
- 3. Supporting better life outcomes for people with autism

- 4. Supporting people with autism to live safely and as independently as possible
- 5. Improving access to diagnosis & beyond

Areas for improvement in children services or transition services to adulthood



Out of 125 who saw the Poll a total of 31 individuals answered the questions spreading their answer on several options available according to what autism areas needed improvements.

Autism Awareness, family support including sibling, followed by services and SEN education information areas the main areas of concern in Peterborough. This are areas show the huge impact that autism has in the quality of life not only of the child /young adult but families and their capacity to care for the child in need, but also a gap that needs to be addressed by the Peterborough city council as part of the improvement in services.

3.4 Some samples of the qualitative data gathered:

“Our biggest concern at the moment is the lack of knowledge and support in school” said Hattie Hodkin.

“There is no health provision for people with ASD once they leave Paediatrics. We were told there were no resources and adults are only seen to be diagnosed.” stated Catherine Stone.

“Lack of training or support helping parents cope with behaviours if your child is diagnosed after nursery but before age 7 there is nothing other than cygnets when they are 7.” was affirmed by Helen Farrell.

“For schools to not try to 'diagnose' a child but work with family who is either looking for a diagnosis or received a diagnosis. Too many people especially at schools /gp's have limited knowledge and still go for standard knowledge which can be outdated or wrong. I.e. my friend struggled till son was 12 to get a diagnosis, as the child was sociable and had eye contact. Professional realised straight away that these were learned behaviours not natural behaviour and he was finally given diagnosis. For those

parents were it is not a clear cut case to support them in the areas where the difficulties/concerns are and if ASD strategies can support this child to give them access to this.” Stated Dafne Stoelhorst.

“The attitude of school management team not wanting to know and trying to pass the buck on the health and wellbeing of a child and that it took a year to complete an early help assessment form.” was Darren Bisby-Boyd comment.

“I would have liked once I had a diagnosis some info given if it was couple of months later and through the post (like what support you could access,caf, ehcp plans etc) Also when you do courses like cygnets etc would be nice if a parent (with a child with autism) as well as professionals did it as it would be nice to be able to connect with someone on the same wavelength as you . Also someone probably not teachers (as I feel not a lot really understand autism, that just my opinion) should go into assembly and explain to children what autism is about.” comment made by Andy Wallman.

3.5 Therefore FVP concludes as a high priority the importance of Peterborough Autism Strategy to include children services and support on the following points among others, the list below is not exclusive but mere suggestive of future improvements. The list is as follows:

- Primary health care trust may provide health and therapeutic services — such as speech and language therapy, occupational therapy, physiotherapy etc.
- The Local Education Authority may provide a range of services — such as a placement in a specialist nursery or school or support from a Special Education Needs Coordinator (SENCO) in a mainstream nursery or school
- The Local Authority may offer home-based social services — such as home adaptations, access to recreational and educational facilities, respite care etc.
- Central government may provide financial benefits — such as universal credit
- Other organisations may provide a range of other services and forms of support — such as advocacy, legal advice, online support, parent training, residential care, services training, etc.

Health waiting lists for services like CAMHS, Speech and Language, Occupational Therapy, etc., is well known by the population but despite this delay services are also registering a shorter percentage of time wasters which means that the referral process has become more accurate and the people seen actually are in need of help and it is of higher priority to support families in a critical situation to avoid escalation and families reaching crisis point. Below I leave a brief description of the services offered by Peterborough City Council but also a snap shot of services that are overrun need to be restructured and improved according to parental views, but this are also the services that due to demand are unable to deliver services to everyone in need and that will make the different between a dependent and relatively independent adult with autism, between a big budget to ensure adult living or minimal support.

3.6 Children and Young People

3.6.1 Universal support

Services that support all children and young people – children’s centres, schools, youth services, GPs and other health services, and voluntary and community organisations and activities – all play their part in helping families to identify the signs of autism and access diagnosis, as well as with developing strategies to support their child and ensuring that children with autism can

access support and opportunities.

3.6.2 Additional support

Cambridge and Peterborough NHS Foundation Trust provides a single diagnostic pathway for any child aged 0-18 years through the Autism Spectrum Disorder Pathway. The team includes a Community Paediatrician, a Clinical Psychologist and a specialist Speech and Language Therapist and Occupational therapist. Depending on a child or young person's need, they may be referred for further support – including Speech & Language Therapy, Occupational Therapy, Physiotherapy, and Specialist Dietetics services - or Children and Adolescent Mental Health Services (CAMHS).

CPFT in conjunction with the Local Authority also provides support post-diagnosis including a home visit, a free Introduction to Autism Course, and acts as an ongoing point of contact. For families who need additional help, Peterborough Council's Children's Teams provide help, guidance and support. The multidisciplinary teams include Family Workers, Educational Psychologists, Education Welfare Officers, Primary Mental Health Workers and Youth Workers who can help with managing behaviour and children's attendance and attainment at school.

Families can also access parenting programmes including the Webber Stratton, Triple P, Magic 1,2,3, early bird through different services within the Council and that are run by voluntary sector organisations.

Most children with autism in Peterborough are in mainstream education. Schools can access support from Educational Psychologists, Speech and Language and Occupational Therapy for pupils who need this. Pre-school children including those attending nursery provisions with a diagnosis of autism can be supported by the Early Years Team as well as the Portage workers.

In primary schools, two ASD advisory/ outreach teachers give advice on individual children and provide staff training.

Peterborough Parent Partnership provides confidential, impartial advice and support to parents and carers of children with special educational needs and/or disability, including autism, offering practical help, attending meetings at school and explaining the legal rights.

A range of voluntary groups and organisations supports children with autism and their families. National Autistic Society and Contact a Family and other Non-autism specific provide post diagnosis support. Peterborough Family Voice is a parent forum offering guidance as well as courses like parent expert to help parent's navigate the services in more efficient way.

Peterborough offers a range of supported activities and short breaks for children, but none Autism specific activities.

3.6.3 Specialist support

Peterborough City Council's Children and Young People's Disability Team provides assessment and care management to children and young people up to the age of 21 who are eligible for

social care support. This can be defined as a level and type of support that cannot be gained from universal services, and where children are at risk of significant harm and statutory processes need to be followed. This includes support in the community such as accessing short breaks provision. Children with complex needs can access overnight and daytime respite.

Peterborough has a range of specialist education provision across all school years, including the City of Peterborough Special School where the primary need is autism, but also Heltwate and Phoenix School which currently supports children with a statement of special educational needs with a diagnosis of autism and learning disabilities. There are specialist resource units at Welbourne Primary School, Nene Park Academy Secondary School and Peterborough Regional College that support pupils with autism alongside the mainstream education provision.

4. Priorities further Development

4.1 Priority 1-Increasing Awareness and Understanding of Autism

Our research has highlighted the importance of raising awareness of autism as much as possible among everyone who has contact with people with autism in a professional capacity. Understanding among GPs is critical as they are often the gateway to diagnosis. Increasing access to training and ensuring that existing training is accessed by the right people and across a broad range of organisations and services is key to widening awareness. Autistic people and their families should be involved in planning and delivering this training as much as possible. Taking opportunities to raise public awareness of autism through local events and information sources is also important.

People with significant contact with people with autism such as teachers, social care and health staff should be supported to deepen their understanding of autism. This should include building confidence to respond to autistic traits and behaviour and provide appropriate support, even before or without a diagnosis. Specific training may also be needed for those who support young autistic people transitioning to adult services, or for those supporting older people with autism.

The Council will continue to develop its information and advice offer to support people, by keeping the Local Offer information clear, accountable, transparent and up to date.

4.2 Priority 2- Supporting Families and Carers of People with Autism

Parents, families and other carers often provide valuable ongoing support to autistic people, both as children and through adulthood. The demand on carers will vary depending on the individual needs of the person being cared for; common complaints are to never get a break from caring, and suffering from depression and physical problems such as difficulty sleeping.

The Care Act introduces new rights for carers of adults, so that they are entitled to an assessment of their needs and support if they are eligible. Adult carers of disabled children get similar rights from the Children and Families Act.

Support for siblings of children diagnosed with autism; as part of our whole-family approach, it is important to make sure that siblings are referred to services for young carers and know about

other opportunities that will support them. Opportunities for short breaks were highly popular with parents.

4.3 Priority 3 - Supporting Better Life Outcomes for People with Autism

Strategy should set out how the Council will meet the requirements in the Children & Families Act, including the move to single Education Health Care Plans (EHCPs). EHCPs cover provision 0-25, to support improved transitions, and include all partners in an integrated process. The child or young person and their family are an essential part of this, to ensure the plan is personal to meet the individual needs identified. Many parents stressed the importance of getting the right support for their autistic children in school, to improve outcomes for pupils with autism, supporting their learning and attainment, and their development of social and communication skills. Using routes such as the Pre-School SENCO network supported by the Educational Psychologists to share learning and build knowledge that can be taken back to settings are important ways that this can be further developed. Continue to develop strategies to avoid exclusions or have low attendance.

Moving on to further education, training or work is an important time for people with autism. It is of high priority to develop a variety of options that caters to everyone's needs and levels of intellectual/ manual work as well as interests and areas of expertise by tapping into autism strengths.

Ensuring people with autism can access universal services should be the starting point to support people to stay healthy, live fulfilling lives and develop social skills. The Council should continue to work with a range of local services such as leisure facilities to support them to make reasonable adjustments that enable autistic people to access their services. Specific activities for children, young people and adults with autism are also important, and the Council also should work with a mix of voluntary organisations to offer a range of social and leisure opportunities, including support groups, specially community-based services – particularly for those who are not eligible for social care services and often rely on these services for support and advice.

4.4 Priority 4 - Supporting People with Autism to Live Safely and as Independently as Possible

Moving from children's to adult's service can be a challenging time for young autistic people and their families. Schools, colleges and other education providers have a critical role to ensure that young people can access the right support at this point in their lives. Voluntary sector organisations and peer support opportunities can also be important support to people through this period.

4.5 Priority 5 - Improving Access to Diagnosis & Beyond

Raising awareness of autism is especially important for getting a diagnosis of autism, as universal services such as schools and GPs are often the starting point for someone to discuss concerns. Helping people to understand autism and access services for assessment can be particularly important for adults who may have never had a formal diagnosis. Not everyone will want a diagnosis, but for some it is important to be able to understand their condition and explain their

behaviour to others.

There are diagnosis pathways in place for children and young people and, separately, for adults. There are currently waiting lists for both services. In the research parents said it was hard to get their child diagnosed, with the most common reason being the wait for an appointment. Diagnosis services are the responsibilities of the Clinical Commissioning Groups. Reviews of the current pathways are needed to ensure that capacity is available to see people within the timescales recommended by the National Institute for Health and Care Excellence (NICE) clinical guidelines.

After a diagnosis of autism, children and young people can access support from a range of places, depending on the level of need identified, but gaps were identified it is important to address them and to work to ensure that :

- Align with work through the Special Educational Needs & Disability to better co-ordinate support for children with autism
- Work with partners to ensure that people receiving a diagnosis can access appropriate support such as training, peer support, and resources to support self-management

5. Possible future Actions

5.1 Children and young people with autism promise of Future Outcomes Pledge

- Better educational outcomes – narrowing the gap in attainment, ensuring good attendance and reducing exclusions (linked to the objectives of Reading's Special Educational Needs & Disabilities Strategy)
- Being safer – improving parenting skills and confidence to manage behaviour related to autism
- Being included and able to participate
- Improving access to universal services and use of these services
- Improving access to and use of information and advice
- Being independent – reducing the number of young people not in education, employment or training

Family Voice Peterborough hopes that with this exposition of the points of concern on Children Autism Services and strongly recommends the discussion of the point among the interested, in order to assist all the agencies delivering a service to everyone in need of help.

Written By Claudia Dias (FVP Parent Representative)