

Executive Response to the Report of the Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions

The Responses to the Adult Autism Overview & Scrutiny Panel Recommendations have, where relevant, been informed by:

- The Autism Act 2009
- *'Fulfilling and rewarding lives'* The strategy for adults with autism in England (2010)
- *'Fulfilling and rewarding lives'* The first year delivery plan for adults with autism in England
- *'Fulfilling and rewarding lives'* Statutory Guidance for local authorities and NHS organisations to support implementation of the autism strategy
- Adult Autism Joint Strategic Needs Assessment (JSNA) (DRAFT)
- Potential implications for 4 key areas (Finance and resources; internal systems and processes; stakeholders; learning and development)
- Current resource constraints

1. **RECOMMENDATION:** with the permission of the person with ASC, parents and carers should be included in discussions and decisions as much as possible.

RESPONSE: AGREEMENT IN PRINCIPLE:

- a) It is important that parents/carers have access to a range of good quality information about autism as early as possible in the identification and diagnostic phase and throughout the care pathway process supporting them to fully participate in discussions and to make fully-informed decisions on behalf of, or with, the person for whom they care.
 - b) The rights of the person with autism *not* to have parents/carers involved in discussions and decisions about them should also be taken into account, unless this presents a risk to themselves and/or to others
2. **RECOMMENDATION:** - the panel recommend that training on ASC awareness should be widened and delivered to as many council staff as possible in frontline services to educate them in ASC. As part of this training, the Learning and Development team should look to involve people who have ASC in the delivery programmes for frontline staff

RESPONSE: AGREEMENT IN PRINCIPLE, with details regarding the provision of training to be developed as part of the strategy

'Fulfilling and rewarding lives', the strategy for adults with autism in England (2010), recommends increasing awareness and understanding of autism (Strand 1), particularly for staff who provide services to adults with autism.

- a) A phased process of training and development to be considered to ensure that priority areas of need are addressed as early as possible. For example, staff that are most likely to have contact with adults with autism should be the priority groups for training.
 - b) Provision of general autism awareness training, (which should ultimately be available for everyone working in health and social care). Core aims of the training should be that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis of autism or who display these characteristics
 - c) Autism awareness training included within general equality and diversity training programmes
 - d) Where appropriate, to consider shared training and development across sectors and/or regions to increase efficiency and effectiveness and to support sharing of knowledge and good practice, collaborative working and development of networks
 - e) Where relevant, adults with autism and family/carer representatives to be involved in the delivery of training to identified target groups and supported to do this appropriately (e.g. reimbursement of travel costs; relevant information/preparation for both trainees and trainer)
 - f) Decisions on training (and associated resource issues), would be the responsibility of those organisations/agencies that interface with or are involved in the care of adults with autism
3. **RECOMMENDATION:** - GPs are surveyed to identify the most urgent ASC training needs and gaps in their knowledge. Specialised autism awareness training to address this should be incorporated into the annual training programmes for GPs in the city as part of their continuous professional development (CPD). This could take place in a number of ways, including the annual GP appraisal and revalidation scheme or through on-line dedicated computer-based training modules.

RESPONSE: AGREED TO CONSIDER THIS AS PART OF THE DEVELOPMENT OF THE LOCAL JOINT AUTISM STRATEGY WITH THE PCT

- a) A simple survey could identify learning needs and specific autism modules could be incorporated into the 'protected Learning Scheme' and the local GP refresher courses
- b) The GP Tutor & the local paediatric department provided a lecture on 'The Autistic Spectrum' in October 2010 for local GPs.

- c) Specialised training for staff working in key roles (e.g. those conducting community care assessments), should also be considered as part of the CPD process so that there are some staff who have clear expertise in autism
4. **RECOMMENDATION:** - that key frontline police officers such as custody officers and others should receive more enhanced ASC awareness training, possibly on an annual basis. This should be extended to include criminal justice colleagues such as magistrates, probation officers and lay visitors.

RESPONSE: AGREED TO APPROACH CRIMINAL JUSTICE SYSTEM TO SEEK AGREEMENT FOR THIS RECOMMENDATION

- a) Specialist autism awareness training for police officers and criminal justice colleagues would potentially enable earlier identification and diagnosis of people with autism and facilitate appropriate communication and behaviours
 - b) Enhanced and/or additional training would benefit frontline officers who are more likely to be in regular contact with adults with autism
 - c) Consideration should be given to including autism awareness training within current equality and diversity training programmes
 - d) Responsibility for the development, implementation and associated resource issues would lie with the relevant police and criminal justice authorities. It is further recommended that any training that is delivered is at an appropriate level and developed by suitably qualified professionals.
5. **RECOMMENDATION:** - It is imperative that the numbers of families caring for adults with ASC must be identified. If these families are appropriately supported now, this will help to minimise the need for potentially resource intensive support at a time when the main carers are no longer able to care for them.

As part of this, the Panel recommends exploring the options of extra respite care, both in provision and variety, for parents of adults with ASC.

RESPONSE: AGREED TO EXPLORE OPTIONS TO SUPPORT FAMILY CARERS AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Autism awareness training will play a key part in earlier identification of autism across a range of sectors (e.g. schools; further and higher education; social care; primary health care; secondary health care; police; judiciary system; employers), and lead to earlier identification, diagnosis and assessment of need for the person with autism. Post-diagnostic support for families/carers

through signposting to relevant agencies could minimise future support needs

6. **RECOMMENDATION** – GPs must have the best available tools to aid diagnosis. As part of this, the panel recommends that health partners amend and clarify the existing ‘Map of Medicine’ used as a diagnostic tool, to ensure that it is easier for GPs to diagnose ASC in adults.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Where appropriate and possible, consideration to be given to adaptation of existing diagnostic tools to enable health care professionals to identify possible existence of autism and to refer on along the care pathway as appropriate

7. **RECOMMENDATION** - The panel heard that there were currently two pathways to diagnosis, through Mental Health services and through Learning Disabilities. However, they were not always as well linked as they might be. The panel recommends that there are clear accessible pathways both for diagnosis and for support services for those with ASC, no matter how the ASC is affecting an adult. These pathways must work in conjunction where appropriate

RESPONSE: AGREED TO REVIEW CARE PATHWAYS AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

8. **RECOMMENDATION** – The panel feels it is imperative that families and carers are kept more informed of what is happening or what is planned in terms of transition. Joint working and information sharing between children’s and adults services is crucial to ensure the service is managed as smoothly as possible.

Transition planning must include statutory and third sector agencies in a joint working approach. A strong role for the voluntary sector, recognising their commitment and good work done in supporting adults and their families, and including the good practice already built up, would improve the service and support for families.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Key information/data shared between children’s and adult services and relevant voluntary sector organisations throughout the care pathway would help to improve information flow linked to numbers, level/type of need, resource and capacity issues. Information needs to be shared without out any risk to confidentiality.

- b) Build on existing collaboration between social, health and voluntary sectors to improve service planning, implementation and delivery and building on good practice where this is evidenced to be effective in the support of families/carers

9. **RECOMMENDATION** – The panel understands that the eligibility criteria for accessing Adults Services is set at a higher need level than accessing Children’s Services; it recognises that there are limited resources. The Panel is concerned for those young people and their families who have had services up to the age of 18/19 and are then left unsupported. The Panel urges further exploration of less formal support mechanisms, such as buddying and advocacy. This will be particularly important if some of the current support services for children with special educational needs are removed.

RESPONSE: AGREED TO EXPLORE HOW ACCESS TO UNIVERSAL SERVICES CAN BE IMPROVED AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Consideration given to exploration and links with alternative, less ‘formal’ mechanisms to support post-18/19 adults (e.g. FE and HE student support services; ‘buddy’ systems)

10. **RECOMMENDATION** – the panel recognises the importance of life long learning and development for some people with ASC, post the age of 19, due to the difference in their developmental and their physical age. The panel recommends that further consideration is given to how to offer further adult learning opportunities to people with ASC where appropriate to continue with their overall development.

RECOMMENDATION: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Consideration given during the curriculum planning process to extend opportunities for life long learning to adults with autism
- b) Strengthening employer links and exploring the opportunities for life long learning provided in the context of employment, whether paid or voluntary

11. **RECOMMENDATION** –that the council publishes a simple, practical guide for employers to give some guidance and support for employing and working with people with ASC, based on the guidance given by Assert. This could be used to encourage employers’ organisations in the city to employ people with ASC.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) This will be considered within the context of the work currently being done on information and advice services across the city to ensure that information is of good quality and 'fit for purpose'
- b) Encouragement of further employer representation on relevant stakeholder groups to be explored to support information and knowledge exchange, mutual support systems and increase in employment opportunities

12. **RECOMMENDATION** - the panel heard that West Sussex operated a triage service model for diagnosing ASC; it was able to see people more quickly than the Brighton and Hove model, but offered a less intensive service. The Panel would like to encourage health colleagues to explore this as an option for service provision in the city. This might reduce the waiting time for diagnosis.

RESPONSE: AGREED TO EXPLORE THIS AS PART OF THE DEVELOPMENT OF THE LOCAL STRATEGY

13. **RECOMMENDATION** - The Council and its partners should work together to set up a dedicated team of professionals to act as lynchpin and first point of contact for adults with ASC. This might involve a virtual team rather than necessarily a relocated physical team.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) This would need extensive discussion and the agreement of all key stakeholders/organisations and careful consideration given to the potential impact on caseloads, capacity, and existing services to users

14. **RECOMMENDATION** - the panel recommends that there is an inter-operable database of people with ASC, perhaps overseen by the integrated team previously recommended in order that all of the service providers could access and use it with the necessary security precautions.

RESPONSE: AGREED TO EXPLORE RECOMMENDATIONS TO IMPROVE INFORMATION SHARING AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Further clarity around collection, analysis, use and accessibility of data and ensuring that this supports all-round, short- and long-term effective decision making.

15. **RECOMMENDATION:** - the panel recognises the excellent work carried out by third sector colleagues supporting people in the city with ASC. The Panel recommends that the Council looks at the ASC services that third sector providers deliver on behalf of the council and undertake a review as how to provide appropriate funding accordingly to make the best use of their expertise.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY