| REPORT TO: | HEALTH AND WELLBEING BOARD (CROYDON | | | | |
|----------------|------------------------------------------------------|--|--|--|--|
| | 21 October 2015 | | | | |
| AGENDA ITEM: | 8 | | | | |
| SUBJECT: | Local implementation of the national autism strategy | | | | |
| BOARD SPONSOR: | Paul Greenhalgh, Executive Director – People | | | | |
| | Croydon Council | | | | |

BOARD PRIORITY/POLICY CONTEXT:

The following report is written in the context of the following:

- Joint Health and Wellbeing Strategy priorities;
- National Strategy in relation to the Autism Act 2009;
- The Care Act 2014:
- Integrated Commissioning Unit (ICU) Commissioning intentions 2015-16.

FINANCIAL IMPACT:

The Financial context and impact of the local implementation of the national autism strategy is set out in sections 2 and 3 below.

1. RECOMMENDATIONS

This report is provided for information and recommends that the health and wellbeing board note the following:

- 1.1 Financial context in which the Act and national autism strategy is set;
- 1.2 The commissioning approach to local implementation of the national autism strategy;
- 1.3 The partnership approach to the local implementation of the national autism strategy.
- 1.4 To comment on further improvements to aid delivery of the strategy.
- 1.5 To receive a report with regard to services for children and young people with autism.

2. EXECUTIVE SUMMARY

2.1 The Adult Autism Act ("the Act") received Royal Assent on 12 November 2009. The Act placed a duty on the Secretary of State to prepare and publish by 1 April 2010 a strategy for meeting the needs of adults in England with autistic spectrum conditions, by improving the provision by local authorities and National Health Service bodies of health and social services to such adults. The Secretary of State is required to keep the autism strategy under review and may revise it.

- 2.2 The Act also required the Secretary of State to issue guidance, by 31 December 2010, to NHS bodies, NHS foundation trusts and local authorities on implementation of the strategy. The Secretary of State must keep the guidance under review, and consult with the NHS and local authorities both before issuing the guidance and before revising it in any way that would result in a substantial change. The Act puts on local authorities and NHS bodies a duty to act under this guidance.
- 2.3 Since the Act was introduced further guidance has been published which has, in fact strengthened the requirements of the Act.
- 2.4 In considering this report the Health and Well Being Board should bear in mind that autism is a "catch all" term and has a wide spectrum on which a person can be diagnosed. Ranging from classic autism at one end to Asperger's syndrome at the other the needs and abilities vary on an individual, case by case basis.

3. DETAIL

3.1 Introduction

- 3.1.1 Croydon Council has taken a pragmatic approach in the implementation of the Act enabling the council to improve and develop services and responses within the diminishing available resources. To this end, resources were focussed in specific areas of service provision, commissioning and procurement. A similar approach has been taken in relation to the commissioning of health services by joint commissioners and Croydon Clinical Commissioning Group (CCG).
- 3.1.2 The main focus on the Act is to improve service accessibility and response, increase awareness of autism amongst employees, volunteers and communities.
- 3.1.3 In delivering the national strategy at a local level the guidance gave clear direction as to how this should be done by placing a duty on all public bodies specifically local authorities and the NHS in their capacity as both commissioners and service providers. Through a simple approach of ensuring that all contracts and service speciation's contain clear expectations that services will meet the requirements of the Act regardless of which organisation is commissioning (local authority or NHS) a consistent approach can be achieved.
- 3.1.4 However, given the range and variety of services which are ranged under local authority and NHS more detailed focus is required in specific areas to ensure that the outcomes required within the Act are addressed.
- 3.1.5 To this end, the Act should (and is) viewed as a golden thread which runs through all strategic planning and service delivery. Simply autism should be seen as an additional "protected characteristic" and commissioners as well as providers apply the simple test of "does this service meet the needs of people with autism and their carers?" and "does this service meet the requirements of the Autism Act?"
- 3.1.6 This report gives focus to the provision of services for adults with autism given that the national strategy supports the Adult Autism Act. However, references

are made throughout the report to services for children and young people. Useful information on services and available support can be found on the Croydon Council website.

3.2 Prevalence

- 3.2.1 Estimates on the prevalence of autism amongst the population vary. The National Autistic Society estimates that approximately 1:100 of the population could be diagnosed as being on the spectrum (see 2.4) but in reality it could be as high as 1:50.
- 3.2.2 One factor which is likely to have impacted on the potentially increased prevalence could be greater awareness of the condition. Over recent years teachers, nursery workers and teaching support staff have benefited from greater awareness of autism. Where once a child may have been thought of as "fidgety" or "disruptive" staff have now been trained to look beyond the negative behaviour and consider other traits and other behaviours. In addition, greater understanding and awareness among parents has also contributed to this especially with the plethora of resources and information available on line. As such, the increase in awareness amongst early years staff and parents has resulted in an increase in referrals to specialist services for diagnosis.
- 3.2.3 Diagnosis amongst the adult population though remains low but steady. In many cases adults tend to be diagnosed only when a crisis has arisen possibly due to a later-life transition or involvement with the criminal justice service.
- 3.2.4 Improvements to referral and diagnostic pathways for adults are an area where development and improvements need to take place. However, due to the improved identification and diagnosis at an earlier age it is anticipated that the prevalence of undiagnosed autism in adults will diminish.
- 3.2.5 It should be noted that undiagnosed autism in adults generally occurs amongst those groups who later go on to be diagnosed with Asperger's Syndrome and by nature tend to be high functioning.
- 3.2.6 The table below provides an estimate of the prevalence of autism in the borough 2014-20 by age and gender.

Table 1
PANSI Data

| Data for: Croydon | | | | | |
|-------------------------------------------------------------------------|-----------|-------------|-----------|-------|-------|
| People aged 18-64 predicted to have autistic spectrum disorders, by age | and gende | r, projecte | d to 2020 | | |
| | 2012 | 2014 | 2016 | 2018 | 2020 |
| Males aged 18-24 predicted to have autistic spectrum disorders | 290 | 290 | 281 | 275 | 266 |
| Males aged 25-34 predicted to have autistic spectrum disorders | | 499 | 511 | 520 | 529 |
| Males aged 35-44 predicted to have autistic spectrum disorders | | 464 | 472 | 477 | 482 |
| Males aged 45-54 predicted to have autistic spectrum disorders | 464 | 477 | 475 | 470 | 461 |
| Males aged 55-64 predicted to have autistic spectrum disorders | 308 | 319 | 340 | 364 | 391 |
| Total males aged 18-64 predicted to have autistic spectrum disorders | 2,023 | 2,048 | 2,079 | 2,106 | 2,129 |
| Females aged 18-24 predicted to have autistic spectrum disorders | 32 | 30 | 29 | 28 | 27 |
| Females aged 25-34 predicted to have autistic spectrum disorders | | 59 | 59 | 59 | 59 |
| Females aged 35-44 predicted to have autistic spectrum disorders | | 56 | 57 | 58 | 59 |
| Females aged 45-54 predicted to have autistic spectrum disorders | | 56 | 57 | 57 | 56 |
| Females aged 55-64 predicted to have autistic spectrum disorders | 37 | 39 | 41 | 43 | 46 |
| Total females aged 18-64 predicted to have autistic spectrum disorders | | 240 | 243 | 246 | 248 |
| | | | | | |
| Figures may not sum due to rounding, Crown copyright 2012 | | | | | |

The information about ASD is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 was published by the Health and Social Care Information Centre in September 2009.

The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on The report Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special The National Autistic Society states that 'estimates of the proportion of people with autism spectrum disorders (ASD)

The prevalence rates have been applied to ONS population projections of the 18 to 64 population to give estimated numbers predicted to have autistic spectrum disorder to 2020.

3.3 Approach to commissioning and procurement

- 3.3.1 Croydon has taken two approaches to commissioning and procurement in regard to autism and can be categorized as commissioning for individual needs and commissioning for general need.
- 3.3.2 Commissioning for individual need refers specifically macro and micro commissioning of services to support an individual. This would take the form of commissioning a specialist placement provider who has demonstrable skills and track record in being able to deliver a range of accommodation or residential based services for a person with autism and a learning disability; alternatively, a provider may be commissioned to deliver a specific service to an adult with Asperger's syndrome who is experiencing mental ill-heath. It is Croydon's practice to commission on "need" rather than on "diagnosis", thereby providing services which respond to the individuals, needs and the required outcomes.
- 3.3.3 Commissioning for general need applies to how commissioners (including the work of the Integrated Commissioning Unit) have approached embedding good practice in services delivered by our partners and contractors. Consequently, guidance has been provided to commissioners to ensure that the Autism Act is referenced in service specifications and arrangements are put in place in order to monitor how contractors have implemented this requirement (e.g. of staff training, making reasonable adjustments, etc.).

3.4 Service for people with eligible assessed social care needs

- 3.4.1 As described in 3.1 above, Croydon's approach to commissioning and procurement is one based on need rather than diagnosis. However, there are a range of services which are commissioned to meet eligible need which are autism specific. This includes a range of residential services both in and out of borough as well as community based day opportunity services.
- 3.4.2 For many, the requirement for a residential care placement is often due to the comorbidity of autism and learning disability. Nationally the number of adults with a dual diagnosis of autism and learning disability accounts for around 30% of the total adult learning disabled population. Consequently, residential services for adults with a learning disability tend to be presupposed working with a customer group with multiple needs. Such services tend provide placements for people who are more likely to have "classic" autism as opposed to being high functioning (ie Asperger's Syndrome).
- 3.4.3 A similar profile can be found for supported living providers, it tends to be those offering services for adults with a learning disability that are more able to demonstrate their abilities in this area.
- 3.4.4 In terms of community based day opportunity services there is a slightly different picture. A number of agencies provide specific day opportunity services for adults with autism such as the National Autistic Society and Croydon Care Solutions. People in receipt of day opportunity services tend to be those who are higher functioning and have a degree of independent living (i.e. living with family or in supported living environments). Moreover, services tend to be skill development based ranging from activities of daily living to behaviour management.

3.5 Services for people who do not have assessed eligible needs

- 3.5.1 For many people who do not have assessed eligible needs the availability of information, advice and support is the cornerstone in their ability to remain independent in the community.
- 3.5.2 Our approach to commissioning and procurement is such that it is our expectation that services commissioned and funded are compliant with the Autism Act in terms of accessibility, reasonable adjustments and suitably trained staff.
- 3.5.3 Croydon has a rich and vibrant community and voluntary sector which continues to grow. Consequently, there are a number of organizations locally which offer support and services to people with autism, their carers and families.
- 3.5.4 Activities such as youth clubs, adult social clubs, drop in services and family support services are available. Some are free whilst some require a subscription but in the main, are comparable in cost to "main stream" activities such as cubs, scouts, brownies, guides, etc.

3.6 Service Demand – Current and Future

- 3.6.1 In the most recent guidance for the Adult Service Care Outcomes Framework (ASCOF) local authorities are now required to record the prevalence of autism amongst adults using and accessing services through the Short and Long Term Conditions (SALT) return. This requirement was introduced in 2014 with data being included in the 2015 return.
- 3.6.2 As this is the first year of recording in this manner it is expected that it will take some time before the prevalence data accurately reflects the population. The guidance states that recording can only take place where there is a formal diagnosis of autism or Asperger's Syndrome and does not report "self-diagnosis". Therefore, with this in mind it is not possible to give an estimate as the current demand for service based on diagnosis alone.
- 3.6.3 Using the data provided above it is estimated that in 2016 there will be approximately 2,250 people aged 18-64 with an autistic spectrum disorder living in the borough (ref 2.4 above). However, to give a sense of the proportion of this cohort who will be in receipt of some form of service we can use the estimate of 30% of adults with a learning disability being on the spectrum which would mean that in the region of 500 people would be in receipt of a service.

3.7 Outcomes

- 3.7.1 As in every area of health and social care outcomes are related to the individual but clearly link with those outcomes expressed in the independence strategy. There are a range of outcomes which both commissioners and providers seek to achieve through their respective areas and are broadly covered in 3.2 above. However, at an individual level listed below are some examples of outcomes which are being achieved:
 - Development of social communication skills to assist a person on the spectrum understand the world around them;
 - Development of general communication skills to enable a person on the spectrum to communicate effectively their needs and wishes;
 - Development of coping skills to assist a person on the spectrum manage situations which do not fit with "their plan";
 - Development of social networks to facilitate socialization and opportunities to meet with others who share similar "special interests";

3.8 Staff training 2011 to 2015

- 3.8.1 When the Act was introduced a clear area for service development was that of staff training. Whilst many staff within services such as learning disability and mental health had received some training it was by no means across the board for everyone. Training has been commissioned within the available resources and as stated above no additional resources were made available through central government to fund developments. A suitably qualified and accredited provider was commissioned to deliver training to council staff as follows:
- 3.8.1.1 Tier 1 training was aimed at social care staff and provided grounding on autism, what it is, how it affects people and strategies for communication. This was commissioned in recognition that autism is a condition that can

- affect anyone and is not just restricted to people with a learning disability for instance. It also paved the way for people attending the tier 2 training.
- 3.8.1.2 Tier 2 training was very much developed to support case management staff to enhance their assessment and support planning skills. Through providing greater understanding and awareness of the autistic spectrum and linking this with well-established methodologies such as person centered planning case managers have been able to develop better and more outcome based support plans.
- 3.8.1.3 In addition where the need for additional training had been identified by managers and supervisors this has been met through attendance at specialist training events, additional reading, on line training or job shadowing.

3.9 Staff training 2015 onwards

- 3.9.1 In commissioning training for 2015 onwards, consideration was given to the fact that the council needed to expand the skills for all customer-facing staff such as Access Croydon staff, housing staff, etc. Therefore, a programme has been commissioned to be delivered from 2015-16 onwards which will provide the two tier system as described above (but for all relevant staff) and an additional online e-learning module.
- 3.9.2 As well as meeting the learning objectives which have been set out, the provider must also demonstrate that the training has been coproduced by people on the spectrum and must be co-delivered by people on the spectrum.
- 3.9.3 In the winter of 2014, the Department of Health announced a one off capital grant of £18,500 for local authorities to apply for. Croydon elected to apply for funds to develop an e-learning module on autism which could be accessed by anyone who lives or works in the borough. The e-learning also has to be coproduced by people on the spectrum. The objectives of the e-learning module are to enable the Croydon community develop their awareness in autism and in time develop an autism friendly borough.

3.10 Key areas for development are:

- diagnostic pathways;
- information, advice and support;
- awareness and training;
- Accessibility of universal services.

4. CONSULTATION

- 4.1 Over the past 12 months there has been a significant change in the amount and type of community involvement. Perhaps one of the most visible methods of involving the community in autism agenda has been the development of a specific webpage on Croydon Council's website and the launch of a Facebook page.
- 4.2 The council Autism Champion supported by the Autism Lead has reconstituted the Autism Reference Group which has now been renamed the Autism Partnership Group. The Partnership Group meetings quarterly and includes representatives from statutory (health, social care, education) and voluntary sector organizations such as, parent support groups, carers and individuals on the spectrum and service providers. The agenda, minutes and related documents are available to the public on the autism webpages. Accountability and reporting mechanisms for the partnership group have yet to be fully embedded. This is in part due to a review of the current partnership arrangements within the council. However, it is envisaged that for practical purposes the Autism Partnership Group will in the interim report to the Learning disability Partnership Group.
- 4.3 In order to set the direction of travel and prioritise the areas of service development this is heavily influenced by the outcomes of the autism self-assessment undertaken approximately every 2 years. The self-assessment itself covers all the domains with the statutory guidance and the outcomes enable the partnership group consisting of all stakeholders (eg carers, service users representatives, providers and commissioners) to set out a clear work plan.

5. SERVICE INTEGRATION

- 5.1 Services are in the main already integrated with the health and social care sphere for those with eligible needs. Joint health and social care service delivery and commissioning within both mental health and learning disability services has been common place for many years in Croydon.
- 5.2 Taking a preventative, early intervention and whole family approach across all "people facing" services the needs of people with autism and their carers can be identified and addressed in a holistic way.
- 5.3 The Act clearly sets out the expectations in terms of not just service delivery being integrated but commissioning as well. To this end, the council and Croydon CCG through the ICU have clear commissioning intentions which further promote and embed the requirements of the Act in all service delivery. Consequently, the approach described in 3.3.3 above is one that has been adopted by Croydon CCG in the commissioning and procurement of NHS related services.
- 5.4 Whilst the Act relates specially to adults it does influence the commissioning and service delivery of services for children and young people. As such, the ICU through its procurement, commissioning and contracting functions applies the requirements of the Act across both children/young people and adult services.

6. FINANCIAL AND RISK ASSESSMENT CONSIDERATIONS

6.1 It is important to reiterate the point in 2.4 above in terms of funding. When the Act was introduced in 2010 it was done with no additional or identified separate funding from government to support it. Consequently, all developments and service improvements have had to be achieved within existing shrinking budgets.

7. EQUALITIES IMPACT

- 7.1 Although to date a Joint Strategic Needs Assessment (JSNA) has not been undertaken specifically on autism this is being addressed through the "golden thread" approach described in 3.1.5 above as and when services are undertaking Equality Impact Assessments.
- 7.2 Given the high demand and resources required to undertake JSNAs the Joint Strategic Needs Assailment steering Group have been asked to adopt the same "golden thread" approach described above in all forthcoming JSNAs.

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BACKGROUND DOCUMENTS: None