

Croydon Council Health and Wellbeing Board

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Appendix 1

Let Autism Emerge from the Haystack

We must improve the lives of our autistic community

1. Recommendations:

Board members are invited to agree the following:

- 1.1 To note the content of this paper, and the accompanying Powerpoint presentation
- 1.2 To encourage organisations and agencies represented on the Health and Wellbeing Board to work together to improve our data and knowledge with regard to the health and wellbeing of our autistic residents
- 1.3 To encourage organisations and agencies represented on the Health and Wellbeing Board to agree, take shared ownership of, and implement those parts of the Croydon Autism Strategy and Action Plan which address issues of concern regarding the health and wellbeing of Croydon residents.
- 1.4 To encourage organisations and agencies represented on the Health and Wellbeing board to take up representation on the Autism Partnership Board, and the Autism Data Group, taking into account these bodies' dealings with issues relating to the health and wellbeing of Croydon residents.

- 1.5 To give consideration to the health and wellbeing needs of autistic Croydon residents in the evolution of any future refreshed Health and Wellbeing Strategy.

2. What is autism?

- 2.1 Autism, or Autistic Spectrum Condition (ASC), affects the way a person communicates, and experiences the world around them. Whilst autistic people often share common traits, they are all different from one another. Some people with autism can live almost entirely independent lives, whilst others have additional challenges, including learning disabilities or mental health conditions, which means their support needs are different.
- 2.2 Autism is often categorised alongside learning difficulties, or mental health conditions. However, it is not either of these things.
- 2.3 Most autistic adults can undertake at least some form of work, but only 14% are in paid employment.
- 2.4 Autism is sometimes seen as a condition which predominantly affects men. However, recent research and better understanding of autistic women suggests that this may well not be the case.
- 2.5 Autistic people – even those who present as independent and intellectually able - can feel and behave very differently from day to day. Appearing to be fine and not needing support one day, does not mean that the same will be true the next day. They may introduce a learned paper with confidence but suffer anxiety about routine daily interactions – such as buying a railway ticket - which neurotypical people perform very easily.
- 2.6 Autistic people commonly present as – and probably are – more straightforward and less prone to be manipulative than neurotypical people, but some may be vulnerable to manipulation themselves.

3. Challenges for autistic people in health settings

- 3.1 Health settings (as with many public places) can pose additional challenges for autistic residents. Many autistic individuals suffer as a result of too much sensory input.
- 3.2 Issues which may cause them problems can include:
 - Too much noise, or too many different sounds / noises
 - Bright electric lighting
 - Delays, particularly delays without a clear reason or likely timescale, can be very stressful for autistic people
 - Fear of the unknown when waiting to see medical professionals
- 3.3 **We need more data about this.** Are autistic people more likely to cancel or re-schedule appointments? We may be able to reduce this, help autistic people, and save money, if we can collect and use better data about autistic patients.

4. What does the autistic community say?

- 4.1 In January 2019, I launched (with the active support of a team of volunteers from the autistic community) a Hear Autism initiative. The team had a large number of detailed conversations with members of the autistic community in the ensuing months. In addition, I was informed by many other such conversations before and after Hear Autism. The narratives to which I listened set out rich personal experiences of local and national policies and practices.
- 4.2 Hear Autism showed me vividly and poignantly that – among other issues - the vulnerability of autistic adults who live independently or semi-independently is great. Many autistic individuals with the same potential as their neurotypical peers live stunted and withdrawn lives and suffer recurring episodes of mental ill-health. There is a pattern of a downward trajectory starting quite soon after the completion of full-time education or perhaps after a brief and unsuccessful period of full-time employment.

- 4.3 If the above is correct, it is a reminder that the route to good health and emotional wellbeing is through the meeting of the full range of prosocial human needs.
- 4.4 In order to mark the passage of the tenth anniversary of the Autism Act 2009, the National Autistic Society was commissioned by the All Party Parliamentary Group on Autism (APPGA) to prepare a report on progress made over the period. The report – which has detailed recommendations – deserves to be read in full. It contains a survey of the British autistic community. I have set out below some of the results.
- 4.5 8% of autistic adults and 5% of families stated that health and care services in their areas had improved between 2009 and 2019.
- 4.6 76% of autistic adults stated that they had reached out for mental health support in the last 5 years.
- 4.7 82% of autistic adults stated that the process of getting support from mental health services took too long.
- 4.8 14% of autistic people said there were enough mental health services in their area to meet their needs.
- 4.9 26% of autistic people said they were properly supported into adulthood.
- 4.10 The estimation of autistic adults regarding the “good understanding of autism” of various professionals was as follows: 10% for social workers, 19% for support workers, 22% for GPs, 13% for nurses, 11% for hospital doctors, 32% for mental health professionals, 4% for Jobcentre Plus staff, and 6% for police.
- 4.11 13% of autistic adults stated that the care and support they currently get helped them to find – or stay in – work.
- 4.12 What weight should our organisations give to these responses? If we are not prepared to give weight to them – why not? If we are going to give weight to them, what actions do we need to take?

5. The autistic population of Croydon

- 5.1 We cannot know the number of autistic people in Croydon. Autism is not recorded as a part of census data or in any other comprehensive way.
- 5.2 Studies from US Centers for Disease Control and Prevention, Northern Ireland and South Korea suggest prevalence of autism currently sits at **1.5 to 3 percent of children in the western world**. This is an increase from UK figures in 2006, which first suggested prevalence had reached 1 percent.
- 5.3 We do know that well over 2% of year 11 pupils in Croydon schools are autistic – the year group for which we are most likely to have accurate information.
- 5.4 According to very recent CAMHS data, 23% of all young people accessing CAMHS have a diagnosis of autism.
- 5.5 A new secondary special school will be opening in Croydon in September, specifically to cater for the significant rise in young people diagnosed with autism, and specialising in provision for those with more complex needs.
- 5.6 We also know that there is a strong body of expert opinion which holds that there is significant under-diagnosis of girls. Francesca Happé, Professor of Cognitive Neuroscience at King's College, London, stated in a 2015 interview:

"We think the social difficulties in some girls with autism may be less obvious [i.e. than that of boys – JF]. Some women with autism describe a strategy of copying somebody. They pick somebody in their class or workplace and they just copy everything about that person: how they dress, how they act, how they talk....."

"I think we know very, very little really about how autism presents in girls and women. There are some studies, but the main problem is that the studies start in a clinic. If we are missing women and girls with autism because we are not good at recognising them, then studying those we do spot isn't going to tell us very much about the ones we miss."

- 5.7 If it correct that there is under-diagnosis of autism in girls, it follows that the number of autistic people in our community may be closer to 3% than 2%. It is not in any way fanciful to postulate that the autistic population of Croydon is about 10,000, which is 2.6% of the total population.
- 5.8 A significant proportion of that autistic population is likely to be undiagnosed adults, who grew up at a time when knowledge and understanding of autism was less. Some of these individuals are aware that they may be autistic, but are unable to obtain a diagnosis, which may have a significantly deleterious effect on their mental health and emotional wellbeing. The absence of an adult diagnostic pathway for Croydon residents except for adults in crisis is not creditable.

6 Data

- 6.1 The Council is able to state with a high degree of accuracy the number of autistic children for whom it is providing schooling.
- 6.2 The Council database for adults only identifies those who have Educational Health and Care Plans and/or in receipt of social care/direct payments. The database does not include autistic people outside the aforementioned categories, and therefore it has no record of many adults with ASC who do not have learning difficulties.
- 6.3 At present, migration of data between Council departments is unsatisfactory, and data sharing between public bodies is extremely limited possibly due to data protection issues and/or incompatibility of respective software.
- 6.4 G.Ps are not expressly required currently to flag autism on a patient's medical records, although I understand that to do so would not be incompatible with data protection law. I have heard it said that to flag autism would not only be possible but easy. It would be a strong step forward if this were to come about.
- 6.5 The fact that ASC is not specifically a protected characteristic but is subsumed within the generic characteristic of learning disability (which is not a necessary attribute of autism) is probably disadvantageous to the autistic community as it prevents the

collation of comprehensive data. The amount of data about adults who do not have learning disabilities is negligible. Consequently, there is little hard evidence about the nature and extent of their episodes of mental ill-health, or about the nature and extent of their co-morbidities.

- 6.6 We do not know the number of autistic children who receive fixed term or permanent exclusions. Many attributes of excluded children are recorded, but not autism. From my conversations with parents, I am aware that many autistic children suffer recurring exclusions from a mainstream schools. The generic category of "SEND" is recorded but not the specific neurological condition.
- 6.7 There is also very limited data on autistic residents accessing health settings, or with additional health conditions/co-morbidities. Therefore, although we do know that during the pandemic there has been a significant increase in the number of deaths of adults with learning difficulties in care settings, we cannot identify how many of those who died were autistic. Thus far we have no data on how many autistic people have presented with mental health problems during the pandemic, and how the figures compare with non-pandemic years. I have asked about this data and not received a reply, and I am drawing the inference that such data is not gathered.
- 6.8 The stressful effect upon the mental health and emotional wellbeing of carers of looking after one or more autistic child or looking after one or more autistic child alongside non-autistic siblings during lockdown remains a matter merely of conjecture and anecdote.
- 6.9 The absence of detailed, granular information about the autistic community presents a formidable obstacle to the development of policies and practices which better meet the needs and aspirations of the community. As yet, we do not as a nation have a sufficiently conscientious desire to meet those needs and aspirations. If we did have a sufficiently conscientious desire, it would not be difficult to expand the necessary evidence base.

6.10 Government needs to consider the question of whether or not the collection and migration of autism data within and between agencies needs to be facilitated in order to improve the effectiveness of national and local autism strategies.

7. The physical and mental health of the autistic community

7.1 Autistic people die on average 16 years earlier than the general population and this increases if they also have learning disabilities.

7.2 Research from the USA has shown that adults with autism have significantly increased rates of all major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive compulsive disorder, schizophrenia, and suicide attempts. (Other research shows that 4 out of 5 young people with ASC experience mental health problems.)

7.3 The same research – which draws upon a study of the medical records of 1,507 autistic adults against the records of a control group of 15,070 neurotypical people shows that nearly all medical conditions were significantly more common in adults with autism, including immune conditions, GI and sleep disorders, seizure, obesity, dyslipidemia, hypertension, and diabetes. Rarer conditions, such as stroke and Parkinson’s disease, were also significantly more common among adults with autism.

7.4 The best known co-morbidities are as follows:

- Around 40% of autistic people have a learning disability.
- Autistic people are more likely to have Epilepsy, ADHD or ADD.
- Autistic women are considerably more likely to be anorexic than the general population.

7.5 We know anecdotally that Covid-19 has had a detrimental impact on autistic people. Many autistic individuals need or prefer a set daily routine, and find it hard to process or manage changes to their routine. The constant, unpredictable changing nature of day-to-day life has had a huge impact on autistic people and their families, in spite of the good work undertaken by many services to try to accommodate this.

7.6 It is concerning that in many health plans, autistic adults without learning difficulties are not specifically identified as a vulnerable group, and their needs by implication minimised.

7.7 The authors of the 2015 American research referred to above conclude:

“In this large, insured population, we see significantly increased rates of medical and psychiatric conditions among adults with ASD. These findings indicate an urgent need for the development of improved strategies for delivering effective health education and health care to this growing population (Nicolaidis, Kripke et al. 2014). A better understanding of the possible mechanisms leading to poorer health status will enable improved patient care and ultimately enhance the quality of life for adults on the autism spectrum.”

8. Addressing complex needs

8.1 The All Party Parliamentary Group on Complex Needs and Dual Diagnosis which was set up in 2007 has repeatedly criticised failure of policy-makers to address effectively the needs of patients with complex needs.

8.2 Anyone with two or more co-morbidities is described as having complex needs. A high proportion of autistic people have complex needs, therefore, the most usual needs being a mental health issue, one or more physical health condition, a learning disability, a physical disability, employment problems, housing issues, family or relationship difficulties, social isolation.

8.3 The All Party Parliamentary Group on Complex Needs and Dual Diagnosis stated in their 2014 report that:

“These needs are often severe, longstanding, difficult to diagnose and therefore to treat. Ongoing inequalities continue to exist and are only likely to increase as people live longer with a wider range of needs. Data on the complex needs people face is not generally recorded by government or shared between commissioners. This means that although there is much anecdotal evidence, much needed statistics are lacking. What we do know is that as well as thousands of individuals who would fall under our definition, there

are many groups within our communities that are more susceptible to having entrenched complex needs and experience staggering health inequalities. As a society we often fail to understand and coordinate the support people need, particularly when they find services difficult to engage with. As we have heard at every meeting of the APPG over the last 5 years, this lack of understanding, priority and support leads to people feeling helpless, facing discrimination and even premature death. Studies have been conducted which indicate that many people, from different backgrounds, across the country have complex needs and the majority of services are not being designed or delivered in a way that meets them. With increasing national focus on integration, wellbeing, giving patients a voice and reducing inequalities, people with complex needs - not just older people or those with long term conditions – must be considered when solutions are being sought.”

- 8.4 In 2014, the National Institute for Health and Care Excellence (NICE) published **Quality Standard 51 on Autism**. It recommends that people having a diagnostic assessment for autism are also assessed for coexisting physical conditions and mental health problems; that a personalised plan should be developed in partnership between them, their carers and the autism team: <https://www.nice.org.uk/guidance/QS51>
- 8.5 There has been little progress on the implementation of the NICE recommendation. The treatment of the many autistic people with co-morbidities is likely to be considerably sub-optimal until there is provision of multi-disciplinary teams which can take an overview of their needs and provide a satisfactory treatment plan.

9. Placements and discharge from placements

- 9.1 In November 2018, the Scottish Government published **“Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs”**, by Dr Anne MacDonald. This report is likely to be as relevant in an English context as in a Scottish.

- 9.2 The report identified 705 people with learning disabilities placed out of area, of whom 453 were out of area not through choice, and 109 were classed priority for return. Around **50% of the priority for return group had ASD**. The report's recommendations included the development of crisis services and flexible support responses, a more proactive report to planning and commissioning services, linked to local housing plans, and workforce development in Positive Behavioural Support.
- 9.3 Many of the recommendations of the Scottish report are similar to those contained in the Transforming Care report following the Winterbourne View scandal of 2011, most of which have still not been implemented universally.
- 9.4 Dr MacDonald argues for: minimising restraint; minimising use of psychotropic medications; MDTs working alongside generalist services; the provision of effective community services which enable people to be safely discharged from hospitals/ATUs; better post-diagnostic support, such support being particularly cost-effective.
- 9.5 Dr MacDonald identifies the following areas as being important for the wellbeing of autistic people, including those with complex needs:
- Physical health
 - Meaningful activity
 - Employment, Education and Volunteering
 - Transport
 - Finance /management of finance
 - Advocacy

10. Everybody supports a holistic approach

- 10.1 We know a lot now about what a good service for autistic people should look like. The challenge is to deliver it.
- 10.2 There is a long way to go. Some of the things the autistic community needs – in no particular order - are:

- Granular data
- Mainstream education which takes into account the attributes of those with ASC
- Effective diagnostic pathways
- More professionals at every level with greater knowledge of autism and sometimes with greater sensitivity to autistic people
- Multi-disciplinary teams
- More customised care planning including supported housing which enables the autistic resident to pursue their main interest
- Community provision of recreational and volunteering opportunities
- Jobs which are set up in such a way that the autistic employee is not doomed to failure
- Greater attentiveness to the needs of carers

10.3 It is a long list and not comprehensive.

11. Making a start

11.1 I sometimes reflect how vulnerable neurotypical people might be if society was organised through the prism of the neurodivergent.

11.2 So far, the autistic community has not been an effective political force. The fragmented nature of the community and the attributes of autism may hinder the development of that political voice. But a community should not need to shout to have its justified concerns placed more visibly on local and national agendas.

11.3 It is a significant step that the Council is evolving its first autism strategy and action plan. But there is such a long distance to travel, I suggest that joy needs to be suitably confined.

11.4 I invite the Council's partners – all of those to whom I have spoken have showed great goodwill – to share ownership of the strategy and action plan, and to regard it as a work in progress upon which we should resolve to build, and with a view to liberate the great talents which exist within our autistic community, and to

enable them to live stable, healthy and fulfilling lives in the manner to which they (like all of us) aspire.

11.5 With thanks to the many people who have contributed to this in a variety of ways, and most particularly Nicky Selwyn, Co-Chair of the Autism Partnership Board, and Kevin Oakhill, Croydon Council's Autism Inclusion lead officer.

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