

Mental Health Partnership Board:

Autism Task and Finish Group report



Published April 2022

Contents

1	Mental Health and People with Autism Spectrum Conditions.....	3
1.1	Aims of the Task and Finish Group.....	3
1.2	Why?.....	3
1.3	What we did	3
2	What was learned.....	4
3	What was not covered.....	6
4	Recommendations	7
5	Appendix 1.....	8
6	Appendix 2.....	14

1 Mental Health and People with Autism Spectrum Conditions

1.1 Aims of the Task and Finish Group

The Task and Finish Group was organised to understand more about the gaps, opportunities, good practice, and need further for further research across Milton Keynes (MK) and its relationship with the Integrated Care System (ICS).

1.2 Why?

Because information and feedback to the MK Mental Health Partnership Board over many years suggests a high level of confusion, frustration, and a need for more knowledge among service users and their families/ carers and within all public services in MK, about services for those with an Autism Spectrum Condition (ASC).

ASD is the medical name for autism however autistic spectrum condition (ASC) is also used instead of ASD to highlight the broad spectrum of autism and avoids the label of having a 'disorder.' This report will use the term autistic spectrum condition.

Feedback from people with autism suggest that anxiety, depression, OCD, and self-harm (possibly, in particular, eating disorders) are conditions which affect many autistic people's mental wellbeing. The experience of each autistic person of their condition is of course individual but there is evidence that females may 'mask' the condition more effectively than males, and that for many, getting a diagnosis and some low-level support and signposting make a massive difference to their sense of wellbeing and could prevent the later presentation of more serious mental health issues.¹

1.3 What we did

The group was made up of Health and Social Care professionals, Service providers, and family members and carers of people with lived experience. The group met four times to exchange information, ideas, and intelligence.

¹ <https://www.theguardian.com/society/2021/nov/19/melanie-sykes-highlights-rapidly-growing-awareness-of-autism-in-women>, accessed 14/02/2022

Sections of the National Autism Strategy (2021)² were used as a springboard for initial conversations. The comments, suggestions, and discussions were compiled into a draft report to be approved by the group for wider sharing and publication. The TaF meeting notes have been attached at Appendix 2.

2 What was learned

It was felt to be very important that professionals as well as the wider community had a greater understanding of ASC as a neurological condition. People with an ASC may have mental health concerns or have learning difficulties but, equally, they may not. These mental health issues or learning difficulties should be appropriately assessed and support provided as they would in any other person. The move by the Mental Health provider in Milton Keynes to a needs, not diagnosis, led service is a very welcome progression.

Because of this, members of the Task and Finish group were pleased that Autism has been separated from the Mental Health portfolio, although disappointed that it is now being associated with Learning Disabilities in commissioning documents and roles. It was felt that this association will give rise to further misconceptions about Autism Spectrum Conditions.

The discussions highlighted the need for appropriate and timely support for adults with an ASC diagnosis. The Integrated Autism Service (IAS) provides a short-term support around what a diagnosis may mean for a person. However, because this support and signposting is limited to those adults who are newly diagnosed by that service, there is no provision for even this limited clinical support for those who were diagnosed prior to the creation of the IAS.

It was felt that the awareness and referral pathway for children in Milton Keynes is becoming more embedded, there also needs to be a simple and accessible assessment pathway for adults. This is of particular concern to individuals and families of people who have always known that there was something 'different' about the way they interacted with the world. Many adults who have received a diagnosis of an ASC later in their lives have

² <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>,

been diagnosed with anxiety, depression, or a personality disorder. The interventions they have received for these conditions have not been always successful as treatment was not offered through an ASC lens. Diagnosis should be a gateway into high quality support, from a truly integrated team of mental health and other appropriate professionals, available on need, not date of diagnosis³

Family members / carers sometimes feel frustrated and shut out by what they see as unhelpful interpretation of GDPR. It was felt that the lack of shared pertinent knowledge and decision-making has been a barrier to timely and robust care / treatment.

There were concerns raised across a number of contributors around patchy knowledge within General Practice and the paucity of signposting to services and support available in the wider health services and the VCSE.

Much time and good intention is spent in some settings to improve communications around individual need and to increase understanding of the autism lens by all the staff. This is often led by individuals without a strong system in place in a setting to enable structural and long-lasting good practice. “Enabling not Labelling” should be inherent and visible in every setting.

We were challenged by some members to reflect on the growth of wider MK and the associated increase in population of autistic people. That Planners, Politicians and Strategists across all sectors (business, public sector, VCSE and Education) should always be considering how to support and capitalise on the skills base of this section of the population. This is particularly relevant as MK promotes itself as the place for IT and Social Entrepreneurs.

³ See Appendix 1 - Lived Experience of Autism in MK

3 What was not covered

- **Ideas about promoting Milton Keynes as an Autism-aware city.**
There may be scope to research further through the National Autistic Society, especially around the criteria for the Autism Friendly Awards. There is also an opportunity to understand the positive effects that Milton Keynes becoming a Dementia Friendly city may have on all residents, including those with Autism.
- **Statutory Education establishments** and the links and opportunities to work differently with Children's and Adolescents Mental Health Services (CAMHS), or indeed, promote and celebrate good practice. Recent research undertaken by Healthwatch Milton Keynes, YiS Counselling Service, and the Parent and Carers Alliance (PACA), suggests this would be a fruitful area to explore more fully. An evaluation of the Keyworker initiative operating across Bedford, Luton and Milton Keynes (BLMK) would also be useful.
- **Direct experiences with Police, Probation and Courts.** The National Autism Strategy Implementation Plan (pp 21 ff) contains a number of objectives to improve the experience of people with Autism who come in to contact with the Criminal Justice System (CJS). Reading this in tandem with recent National research by the Justice Inspectorate⁴ suggests that there is scope at a local level to improve the experience of those with neurodivergent needs. The case studies in the CJS report are particularly useful and could be used as a stimulus for debate across a number of public sector services.
- A review of feedback on Community Mental Health Services in Milton Keynes compared with the recent Care Quality Commission report.⁵ Time to reflect on this report and local feedback could be well-spent by all sectors involved in improving and supporting people's mental wellbeing.

⁴ <https://www.justiceinspectorates.gov.uk/cjji/wp-content/uploads/sites/2/2021/07/Neurodiversity-evidence-review-web-2021.pdf>, accessed 22 February 2022

⁵ <https://www.cqc.org.uk/publications/surveys/community-mental-health-survey-2021>, accessed 22 February 2022

4 Recommendations

- Expand opportunities for joint learning with the voices of people with ASC at the centre. Continue to gather and collate information and knowledge through regular events managed by TalkBack. It may be useful initially to focus on the themes within the National Autism Strategy (2021).
- 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, Making Tracks (providing pathways to work for adults with Autism,⁶ MK Gallery's approaches to working with, and considering the needs of, neurodivergent people and their families, and the developer aiming to provide a high level of acoustic-proofing across the Love Wolverton redevelopment of the Agora site.
- Improve communications on research (national and local), data gathering, good practice, and support (including peer) services across all Milton Keynes public sector organisations which directly, and often, interface with people with Autism.
- Seek funding to coordinate and expand training opportunities across all public sectors, including Probation and Prison, and promote training to the private sector starting with retail, hospitality, transport and IT (services/ manufacturers/ software developers). Use the recommendations of neurodivergent people and experienced service providers to seek trainers who 'know' BLMK.
- Make use of the knowledge of local and respected Trainers and Learning Resources. Our contributors had recommendations to make.
- Unified and efficient Communications across the ICS; use service users and carers as well as practitioners across many fields to share their Journeys and their Learning

⁶ <https://oldschoolwolverton.org/making-tracks/>, accessed 22 February 2022

5 Appendix 1

Lived experience of autism diagnosis, mental health support and services in Milton Keynes.

A project devised by Talent Unlimited MK (TUMK) and TalkBack MK. The lead was Jane Lynds (TUMK). Ten participants, all adults with autism living in Milton Keynes shared their personal experiences.

Significant findings

1. Of the 8 participants who were diagnosed as adults **none** had been advised by any **medical professional** that they may be autistic although many had years of various interventions/services.
6 out of the 8 adult diagnosis group had spent many years under CAMHS and or their school's SENDIS teams without any mention of any underlying autism.
2. 2 participants who had previously been diagnosed as having a personality disorder had that diagnosis withdrawn when they were later diagnosed as having autism.
3. 7 out of 8 participants felt that getting a diagnosis was positive (the other felt it was mixed)
4. There was general dissatisfaction with most services pre and post diagnosis, either lack of or unsuitability of support offered. Most participants (6 out of 8) had to wait over 2 years for a referral for diagnosis from medical professionals.

Recommendations from findings

1. It is vital that all health professionals including, GP's, and all members of mental health teams are trained in autism awareness.
If someone presents with anxiety, trauma, depression or any form of self-harm. A simple internal check list, suggested below, would help to filter for those who maybe autistic.
 - **Does this person give unusual eye contact?**
 - **Is their expression fixed or of a limited range?**
 - **Have they had issues since childhood?**
 - **Are their personal explanations of why they are anxious / in trauma / depressed / self-harming, linked to difficulties with socializing and relationships?**

If a patient answers yes to at least 3 out of 4 of these bullet points, a formal autism screening is strongly recommended, followed by an appropriate referral.

2. Diagnosis should be a gateway into high quality support, **from a truly integrated team** of mental health and other appropriate professionals, available on need, not date of diagnosis.
3. GPs and other medical professionals should listen to their patients/clients if they mention autism and offer a screening and refer as appropriate.

4. SENDIS and CAMHS teams should be trained in autism awareness and be proactive in getting appropriate diagnosis for children and young people. Anecdotally MK appears to have a significant number of undiagnosed adults with autism who should have been diagnosed when at school.

5. Further research is urgently needed to check if the issues raised in this project are reflected across a wider adult autistic population. This would include variations across England. The initial check list for professionals requires further input and research.

Overview of project

The project asked 10 autistic people a set of questions about their lived experience of mental health services in MK. The interviews were conducted largely via zoom, with a minority of forms completed in writing via email. They were delivered by Jane Lynds who has extensive knowledge of adults with a diagnosis of autism and was familiar and trusted by those taking part.

The purpose of the questions was to discover information about individual experiences of diagnosis, services and life in general, so an emerging idea of issues/concerns in MK could be formulated. The questions were devised with input from members of TUMK (all members are adults with Autism from MK), who fully approved and supported the project and gave invaluable insights from the beginning in late summer 2020 until its completion April 2021.

The 10 participants were all adults with a diagnosis of autism who are members / users of TUMK, Talkback and or MK AS meet up.

Although this was a small sample, the matters raised were important to those taking part. Anecdotally, the findings seem to reflect the wider experiences of adults with autism in MK.

All participants were made fully aware of the purpose and process of the questions. Participant's personal details were not shared with any third parties and stored securely

Results from questions

Q.1 Age: 20 – 29: 3 participants

30 – 39: 4 participants

40 – 49: 4 participants

Q.2 Gender: 6 males 4 females

Q.3 Age of diagnosis: under 10, 2 participants

20 – 29, 5 participants

30 – 39, 2 participants

40 – 49, 1 participant

Q.4 Co morbid diagnosis

OCD – 1

Learning Difficulty – 2

Hearing loss – 1

Fibromyalgia – 1

Depression – 5

Personality disorder – 2

Dyslexia – 4

Dyspraxia – 1

Anxiety – 4

CPS (Chronic Fatigue Syndrome) – 1

PTSD (Post Traumatic Stress Disorder) – 1

Panic disorder – 1

Dysexecutive Syndrome – 1

Agoraphobia – 1

2 diagnosis had been withdrawn both for Personality disorder

Q.5 Diagnosis were from:

Private practitioners – 5

Early years team – 2

NHS – 2

Unsure – 1

Q. 6 Who first suggested you may have autism:

Personal research – 3

Family – 4

Friends – 2

Tutor – 1

Q. 7 Time taken from initial thought that you may have autism to requesting a diagnosis:

A few months – 1

6/12 months – 1

2 years – 1

3 / 4 years – 1

7 / 10 years – 1

10 years + 1

17 years + -2

Q. 8 Time taken from initial request for diagnosis till actual diagnosis

Few months – 3

6 / 12 months – 3

17+ years – 2

"I was taken to GP by mum as a child he said I was attention seeking."

Q. 9 Services from Mental Health professionals before diagnosis

Yes – 6

No – 2

N/A – 2 (early diagnosis)

"CBT didn't work " "Was on list for high intensity for over a year, when I finally got appointment it was pointless" "CBT was actually harmful and incompetently done, the guy was reading from a textbook."

Before diagnosis did any member of any mental health team suggest that you maybe autistic

No – 8

Yes – 0

N/A – 2

Q. 10 Services from teams since diagnosis

Mental health team – 6

Social services – 5

Voluntary sector – 10

“Mental health team were not interested after diagnosis.” “My GP has never contacted me over the report.” “Supported living very helpful” “I needed not group sessions, needed to be longer and more targeted.” “Carers mixed don’t really understand Autism.”

Q. 11 Childhood support from CAMHS / SENDIS teams

Yes – 6

No – 3

Unsure – 1

Q. 12 Childhood diagnosis – both were unsure of whether childhood diagnosis was helpful

Q. 13 Has diagnosis as an adult helped or hindered you

Yes – 7 Both – 1

“ Diagnosis resulted in social stigma at home”

When asked about what improvements could improve their current life experience, their answers included:

- More information about autism
- Need to know things in advance and reason for any changes, need really clear instructions at work
- No good professionals saying go and research help as I don’t know how to start!
- There needs to be a professional and well organised Autism team
 - Help with experienced symptoms, sensory processing and executive dysfunction
- More in depth mental health support which includes social support (two people mentioned this)
- Would like to live with others with autism not on my own I feel very lonely on my own
- Be able to help others with autism who may be embarrassed in work place
- Have a job again

Other comments included:

- Angry my autism wasn't picked up earlier, would have been able to understand myself.
- My special school was good with autism but not Dyslexia
- **Its 2021 and still there really is no help for adults with autism this needs to change**
- Group mental health support is not always appropriate, it takes too long to get to know and trust the group
- What would my results been like if school or college had known about my autism?
- Be good to do new social things including sports, have been going to same clubs for years.
- Don't think integrated service is fair it should serve all adults with autism if they need help (two people mentioned this point)

6 Appendix 2

October 19 2021

Talkback

- Talkback are holding one of their quarterly engagement events in November (this event replaces the former Partnership Board meetings)
- Talkback holding a small-ish focussed forum. MKC/ CNWL will be able to hear personal experiences of people with Autism trying to access MH support. TalkBack and Talent Unlimited will present some 'thematic' experiences and will be supporting people with Autism to present their own stories, in their own words.
- The event will provide some education about what reasonable adjustments could/ should be made by Mental Health services as well as about what services are actually available.
- CNWL have offered Talkback the opportunity to feed into the new Sensory Pods and garden at the Campbell Centre
- Talkback/ Talent Unlimited are going to be 'listening' for a month and then providing the feedback to CNWL two weeks prior to the focussed forum so that they can come with solutions/ answers.
- The focussed forum has limited numbers but there will be two engagement events as well; there is a window of about 10 days to feed in ahead of the event
- Healthwatch to put call out to providers and families and carers to gain their thoughts for a later engagement event with a focus on family / carers

Autism Strategy discussion, focussing on 'Tackling Health & Care Inequalities for Autistic People

- The 'dual diagnosis is the hardest part for people trying to access services - it becomes a barrier.
- Need to ensure that the system are not 'labelling' but 'enabling'
- Anyone looking at mental health or other needs, need to ensure they are looking through the Autism 'lens'
- Eating Disorder: Talent Unlimited mentioned ASD/ Disordered Eating correlation. **Action for Healthwatch and MHPB Chair - ensure Eating Disorders workstream (MH Transformation Board) are aware and are embedding Autism appropriate practice/ training in to workstream from outset.
- Autism Annual Physical Health Check - is this happening - Pilot completed at national level - question for ICS.
- Over prescribing vs appropriate prescribing - data needed
- Diagnostic services in MK - what/ where are they?

- Where is the seamless joined up support service following diagnosis?
- Where is the data?
 - Waiting list for diagnosis
 - Correct diagnosis/ what does diagnosis mean for individual
 - What post diagnostic support is available?
 - What is the waiting list for this?
 - What does it address?
 - How successful has this been?
 - What signposting is there - to where?
- What is the ICS doing regards Autism
 - Has there been an ICS champion recruited?
 - Who will it be?
 - How is it going to work across the system and how is the expertise going to be retained?

Autism Strategy discussion, focussing on 'Building the Right Support in the Community and Supporting People in Inpatient Care

- Hospital need to be able to see diagnosis - patients shouldn't have to go through this with every contact/ department - Trans Status manages to make it on to all referrals - why not ASD needs?
- Easy read letters must be made available
- MH Transformation have Bridge and Crown PCNs - could the Autism support/ Strategy actions be trialled here?
- Need to include Housing and Planning departments because of the Housing issues autistic people often face and the fact that new homes are being built all the time in MK
- Could Wolverton Agora site be a case study? (The Value / Benefits circle)

General discussion points

- Prevention is the key to everything - if we get this right, a lot of the crisis issues will be avoided
- The strategy, as often the case, on occasions refers to autism as if it were a Learning Disability
- Book Recommendation: *Been there, Done that, Try this* by Tony Atwood
- Author recommendation: https://en.wikipedia.org/wiki/Temple_Grandin
- People on the call made recommendation regarding trainers who 'know' MK & Bucks.

Discussion around ADHD/ ASD and MH and ASD. Also discussed the use of terminology around ASC (conditions) rather than ASD (disorders).

Thursday 18th November Talkback event.

TalkBack have contract with Council to run engagement events to replace the Partnership Board. [CNWL Psychiatrist] coming to the meeting. TalkBack and Talent Unlimited providing Case studies and personal stories. Questions to be sent to Psychiatrist in advance so that any answers can be provided at the event. Service users (2 or 3) experiences will be given in person

Talent Unlimited providing information about what service should look like - document will be circulated once finalised.

The stories from Service users seem to suggest that they feel there is not a lot of support for people with an existing diagnosis. Short post-diagnostic support through the Integrated Autism Service but only for 'new' diagnosis.

ICS -

Doing Annual Health checks - have seen a large increase in number of checks recorded. Is this the actual case? What is the situation in MK? Commissioner asked What data do we want? Need some clarity on what would be useful.

LeDER Strategy Learning from lives and deaths - People with a learning disability and autistic people (LeDeR) policy 2021, March 2021. The LeDER work reports to the ICS Transformation Board.

ICS Champion (National Autism Strategy) - Commissioner advised Priorities are being set (especially around health inequalities) and thinks Autism will be one of these areas. As Commissioner, not sure but maybe she is also 'Champion' in NAS sense of term. Will look at this and see how this is to be embedded.

Discussion on wider issues -

Housing (planning communities rather than just 'houses'). Commissioner talked of recent work with Bedford Council around building specifications and planning. MKC has a market position statement (see attached) 2019 - 2022. Need to familiarise ourselves with this.

Communication between Health/ Social Care/ Community. Healthwatch to send Commissioner the Director of Adult Social Care details to ensure inclusion in any plans.

Commissioning conversation around how system can involve VCSE in service delivery. Suggestion that, with MH Transformation moving towards a needs not diagnosis led service, LD&A Commissioning talk with MH Commissioning to see if LD&A workforce funding could be applied to training MH staff to work effectively with people who have Autism.