Final Report

BLMK Adult Autism Pathway Project

Thriving not just surviving

February 2024

Commissioned by
NHS
Bedfordshire, Luton
and Milton Keynes
Integrated Care Board

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Foreword

I was 47 when I was referred for an autism diagnosis; two years after referral I was formally diagnosed by an NHS adult autism diagnostic team. My husband and three of my children are autistic. The lateness of my diagnosis was due to a number of reasons pertinent to the current position in understanding the complex and diverse identity of autism, especially in relation to having lived my life as my assigned gender- female. But also, due to my belief that my experience of the world was the same as everyone else. The resultant 'not knowing' has meant that for much of mine and my children's life, it has been without autonomy and agency. Being diagnosed opened doors of understanding, community and reflection. However, it also exposed traumas due to a lifetime of internalised ableism and masking. From the start of my diagnostic 'journey' I have been researching, listening and learning about autism in order to gain knowledge to be autonomous for myself and family. As a result, I have developed a passion for sharing the understanding and insights I've gained, as well as advocating for autistic people in less privileged positions than myself.

When we walk with people instead of leading or following them; we experience the unique sentience of others. We can see that there is not one single way to live, experience, perceive or express life. Definitions of 'normal' modify and constrain the diversity which is the very essence of humanity. As an adult nurse I have used my unerring curiosity and passion for diversity, reflexivity and learning in everything I do. In my 20 years of nursing, I have never met one single person who is the same, and I have never stopped learning from every experience of care I have been involved in.

Personal aspirations for the project:
My experience of diagnosis was not a negative one, but the lack of adequate provision and knowledge, especially during the wait time and post diagnosis, was. My aspirations for this project were to utilise my personal experience, as well as national and local evidence, legislation, guidance and experiences to inform recommendations in order to reduce health inequalities in BLMK.
I feel immensely grateful to have had the opportunity to undertake this project.

Lynette Morgan

"***Die welt verändertsich durch dein vordid, nicht durch deine meinung***."
[The world changes by your example not your opinion]
Paul Coelho

2. Glossary of terms, abbreviations and acronyms

Identity language

For the purpose of this report identity first language (Autistic person) has been used; it is acknowledged however, that there remains contention and confusion about terminology. In the absence of empirical consensus this report has gone on majority preference and reflects recommendations by National Health Service England (NHSE) *(A National framework to deliver improved outcomes in all age autism assessment pathways May 2023).* The use of this language is by no means meant to deny people the right to their preferred identifying language and it is essential that the individual's right to choose is respected.

Neurodivergent, neurodiverse, neurodiversity, neurotypical.

Neuro- Prefix used to create words related to the nervous system or nerves
Diversity- containing many elements that differ from each other
Neurodiversity- range of differences of neurology presenting within the human race
Neurodivergent- subset of minority of neurology differing from the majority neurotype
Neurotypical- people who are the majority neurotype who do not meet the criteria for autism or ADHD for eg.

The term neurodiversity was formed in the 1990's as a way to change the narrative and perspective about autism. From a broken medical appendage to an intrinsic part of an autistic person, an attempt to draw away from expected trajectories of 'normalcy' and suggest that there is no normal. In more recent years this concept has evolved by differentiating those who with same or similar traits differ from the majority. That is where neurodivergent(ce) has been born from.

This is included merely as a point of interest for those exploring better understanding of terminology and to remove any potential confusion. As in the main neurodiversity is most often used as an umbrella term for autism, ADHD, dyspraxia etc. There is no scope in this project to explore the definitive outcome of the use of this language.

Puzzle pieces

The puzzle piece is used in some areas locally, regardless of choices of individuals, professional teams need to be aware of the historical meaning and context of a 'puzzle piece'. Originally it was used to highlight 'missing pieces' ie that autistic people were not 'whole'. Furthermore, the inference still to this day is that by 'fixing' or 'replacing' the missing piece autistic people can be cured and made 'normal'. This remains a narrative for some major international organisations who dominate influence funding for research. Whilst this is slowly changing, it is important to acknowledge the context behind this and what the ethos of a service is built on and how that may be perceived by autistic people wanting/ needing to access services.

Medicalisation and social constructs

The Equality Act 2010 sanctions a duty to reduce inequity for disabled people by removing barriers where it is 'reasonable' and 'practicable' to do so. This endorses the concept that an individual may suffer inequity due to adjustable barriers in processes, environments, services and facilities. Not necessarily because of the diagnostic label they have. This shifts drivers for change, away from a deficit based medicalised approach to a social model of disability. Meaning that the onus is on everyone to embrace concepts of diversity, disability and equity. Thereby promoting social change that nurtures both a culture of acceptance and inclusion.

High and low functioning

Diagnostic statistical manual (DSM-5) updated terminology in reference to autism. In this; 3 functional levels are categorized. These are thought to enable the diagnostician to better define ‘support needs’ and degrees in which an individual may be impacted by particular areas of the diagnostic criteria. During the course of this project there were examples where risk and vulnerability were overlooked due to presumed functional levels. It is important therefore, that use of these definitions, particularly by those who do not understand the heterogeneity of autism, is with sincere caution.

Acronym	Full title
AADS	Adult Autism Diagnostic Service
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
BBC	British Broadcasting Corporation
BLMK	Bedfordshire Luton and Milton Keynes
CAMHS	Children and Adolescents Mental Health Service
CETR	Care education and treatment review
CHUMS	Childrens mental health and emotional wellbeing (charity)
CNWL	Central North West London (NHS trust)
CQC	Care Quality Commission
CTR	Care and treatment review
DHSC	Department of Health and Social Care
DSM	Diagnostic and statistical manual of Mental Disorders
EHCP	Educational, Health and Care Plan
ELFT	East London Foundation Trust
GP	General Practioner
HiQiP	Health inequalities Programme
IAPT	Improving Access to Psychological Therapies
ICP	Integrated Care Partnership
MHA	Mental Health Act
ICS	Integrated Care System
LD	Learning Disability
LeDeR	Learning from lives and deaths – people with a learning disability and autistic people
MCA	Mental Capacity Act
MDT	Multi Disciplinary Team
MCA	Mental Capacity Act
AADS	Adult Autism Diagnostic Service
NAS	National Autistic Society
NATP	National Autism Training Program
NDTi	National Development Team for Inclusion
NHS	National Health Service
NHSE	National Health Service England

ADHD	Attention Deficit Hyperactivity Disorder
OCD	Obsessive Compulsive Disorder
NATP	National Autism Training Program
ONS	Office for National Statistics
OT	Occupational Therapy
SEND	Special Education Needs and Disabilities
SLT	Speech and Language Therapy
SPACE	Sensory, Predictability, Acceptance, Communication, Empathy
STAMP	Supporting treatment and appropriate medication in paediatrics
STAMP	Supporting treatment and appropriate medication in paediatrics
BLMK	Bedfordshire Luton and Milton Keynes

3. Executive Summary/ Key messages

The BLMK adult autism pathway project reviewed and explored the current position for autistic adults across the area. Especially seeking to understand gaps in services and where these are reflected or experienced most by autistic people in BLMK.

A review of the evidence, legislation and guidance nationally and locally was incorporated with feedback from local systems, services, charities and voluntary sector. And most importantly from those people whose lives are at the heart of the project; local autistic adults.

3.1 Key themes identified in leading to inequity for autistic adults.

9X Autistic people are **9x** more likely to die by suicide

7-year reduced life expectancy

12-18% of homeless people are autistic

50% of people in criminal justice system are neurodivergent

Up to **80%** of autistic people have reported interpersonal abuse

Approximately **80%** of autistic people have a diagnosable mental illness

22% of autistic people are in employment

Over 2000 autistic people (and people with LD) in long term inpatients the average length of stay is **6 years**. In BLMK Jan 2024 there are 12 autistic people currently in an inpatient setting*

Approximately **75%** of those currently out of long term education in BLMK are autistic

71% of autistic people report dissatisfaction of social care support

These outline many of the national and local drivers of change for autistic people. Contributory factors to these iniquitous outcomes include barriers to accessing services due to some of the following elements:

- Stigma
- Lack of reasonable adjustments
- Misdiagnosis or delayed/ late diagnosis
- Inadequate understanding about autism from professionals and carers
- Lack of reasonable adjustments
- Trauma

* *These figures reflect national feedback that has not yet separated LD and autistic people however the local data is from Transforming care program and is in the tracker information from NHSE. It is not possible to say at point of writing why the figure is disproportionately high compared to other ICS footprints.*

3.2 Principal findings from local data.

1) Disparity in knowledge

All of people and teams spoken to fed back that at the heart of the problems they faced was due to limited knowledge and understanding of autism.

2) Gaps

Nearly every person and team spoken to spoke about ‘gaps’ which were as a result of exclusion by criteria.

3) Support

Many services and autistic people felt that a specialist team/ service similar to the principles of learning disability services would ensure oversight and access to services.

4) Convoluted systems

Concerns were raised by both professionals and people using services that accessing services was not in line with the Equality Act and were acting as a barrier to services.

5) Data

In order for data to provide a valid auditable baseline; electronic systems need to communicate with each other and record keeping needs to be accurate, reliable and up to date. This was an issue that not only impeded this project, but it has far wider implications when considering forward planning and governance.

6) Siloes

It was evident that siloes within services, between teams, and across different sectors and disciplines, accounts for a significant determinant of inequitable outcomes for autistic people. Examples of this include

- People did not know about what services offer
- Not knowing who to refer to for ongoing care
- Not knowing who to seek advice from
- Lack or ineffective collaborative working.
- Repeated inappropriate referrals

7) Language and communication

Language and communication differences are an integral aspect of autism. There is limited evidence consistently that this is understood when in practice. Examples of practice

- Services, teams, job titles amongst others have been given ambiguous names or acronyms which create barriers through confusion and anxiety
- Communication methods not made accessible for those with situational mutism or non speaking individuals
- Language used was often medicalised and in some cases offensive.

3.3 Themes

A joined up personalised approach is essential

After two years of comprehensively reviewing qualitative data from local people and services four key themes were identified.

1. **Joined up working**
2. **Early intervention/ prevention**
3. **Accountability**
4. **Training**

1. Joined up working

People across all sectors who provide and use services spoke of a need for a clear an easy point of access that will provide skills knowledge and expertise to both professionals and people using services. In addition, a way to close the gaps in communication and have a joined-up approach to care was evidently in dire need.

The prerequisite of the autism services is to provide diagnosis and consultancy for other services. This was included as service guidance before a) it became apparent that there are higher (almost 4x more) number of autistic people than previously thought. b) whilst demand has increased capacity has not and this creates critical concern in dealing with time sensitive acute situations where services need expert advice. The necessity for consultancy prevails whilst there is inconsistency of a robust knowledge base and understanding of autism across all sectors.

2. Early intervention/ prevention

Whilst not explicitly highlighted it is clear that services currently built to manage crisis particularly those under the transforming care agenda, can identify the points at which with the right support and early intervention crisis prevention can be facilitated.

Examples include:

- Those who are in desperate need of help which is not met by one single service but the safest place becomes inpatient or residential sites
- Those who spoke about attempting to access IAPT/ wellbeing/ talking therapies but were refused due to being autistic
- Those who’s physical health needs were overlooked or were told they ‘did not meet criteria’
- Those who support network is not robust or may harbour a source of harm
- Those who are transitioning between services (including childrens’ to adults’)

3. Accountability

Clinical oversight, governance and quality assurance.

People described being discharged or refused by services and there being no follow up or oversight to ensure that people do not fall between gaps in services particularly during transition points.

4. Training

Whilst training is currently being addressed through OMMT and NATP it is important to acknowledge that cultural changes needed will continue to take some years.

Issues relating to training, competence and consultancy was consistently raised as a significant concern from all areas. This was of particular concern as it was felt that this not only resulted in people literally falling between services it was an integral part in failures of care.

3.4 Recommendations

This project has gathered evidence from multiple sources so that robust recommendations could be formulated. A synthesis of the themes, background research and evidence, and feedback has indicated that addressing 'gaps' across the different providers would have a significant positive impact for autistic people in BLMK.

Solutions

Peer support

There are services set up in other localities across the country. Early indications shown from different models have shown that this has a positive impact on the outcomes for autistic people.

Website/ webpage information

There is an expectation in current culture that; what is not known can be found on the internet/ intranet. This is a valuable and, in many cases, the most accessible way to glean information. Systems should be investing more in digital platforms ensuring that their information is valid, reliable, accessible and useful for all. Indeed, virtual spaces can be, if well managed, a lifeline for many people.

Personalised care

As previously outlined, there is a critical need to address disparity in knowledge/ understanding of autism; especially as in some cases it means that autistic people have been refused care/ support. Personalised care research by Autistica is currently running a series of pilot projects which are reviewing a personalised profiling tool. This has the potential to address issues which arise where insufficient knowledge has previously created barriers. It also could be pivotal in ensuring the right care and support is provided at the right time.

Hub

Investment is needed in the 'pathway' from referral to diagnosis and post diagnostic support. There needs to be clear processes to access knowledge, skills, diagnosis and support. It is essential for those needing to access services as well as those providing it. Convoluted and inconsistent processes result in delays, oversight and risk. It is imperative that as a system BLMK consider the experience of those without 'inside knowledge' who need help that will not only mitigate current escalation but will consider long term planning. Especially considering those who's vulnerability and risk is increased. With this in mind this project recommends a single-point-of-access approach that is built on current infrastructure, but is focussed on linking together different services, providers and teams. A hub.

A hub that builds on diagnostic teams and offers a service that has clinical oversight and quality assurance. It would be the centre of expertise and ensure that local services provide a consistent approach that not just aims to keep autistic people alive and out of hospital, but its goal will be to provide neuroaffirming care and promote thriving. By connecting community with autistic people and autistic people with the community.

This project sought to identify <u>who</u> are the numbers, not just <u>what</u> are the numbers.

4. Introduction

The Bedfordshire, Luton and Milton Keynes adult autism pathway was a project commissioned by the BLMK Integrated care board. The project commenced in February 2022.

Demand for autism assessments has increased at an exponential rate. Current figures nationally show an 800% increase since March 2020 and just below 380% increase between 2011 and 2021 in BLMK. Despite this rapid growth capacity has not increased correspondingly. The direct result of this is wait times ranging between 18 months and 3 years from referral to assessment and approximately 1600 people are currently waiting for assessment across BLMK alone.

Recommended wait times between referral and assessment is 13 weeks (NICE), however as of September 2023 there were 157,809 people with an open referral and 85% of these (134,315) had been open at least 13 weeks. Additionally, the data from September 2023 showed a decrease in the number of completed diagnoses by approximately 25%. With increasing awareness and understanding there is little expectation that this demand on services is yet to plateau, let alone decline. For those who are at the point of transitioning to adult services, older adults, born female, or are from minority groups there is greater concern not only about the numbers of those waiting, those unaware, but also the barriers to services and additional risks associated with intersectional vulnerabilities. Statistics relating to incidence of those waiting or diagnosed from black and other ethnic minorities are shamefully insufficient.

Demographic scrutiny is important for services to understand any barriers or enablers which may be in place for those from minorities to access assessment. There remains, disparity in reliability of the demographic of autism assessment alone.

Wider implications of long term wait for diagnosis and access to support has been well documented in national reports, and research. Much of which have been reflected in the feedback and reviews from local people and services. These implications are exacerbated by additional risk factors and challenges such as access to adequate housing, co-occurring health conditions and disabilities, employment opportunities and health inequalities. Although there are many confounding factors, it is possible to link high incidence of mental illness to a sense of thwarted belongingness, a lifetime of being misunderstood, barriers to accessing services and opportunities, misdiagnosis, mistreatment, and social isolation. These in part can be challenged through an evidence-based understanding of autism, which is reflected in government papers and targets and was echoed as findings as part of this project.

Approximate costs of inpatient stay range between £300-£600 per person per day. The number of autistic people reported to be in inpatient settings has increased nationally. Average inpatient stay for autistic people is around 5.5 years[1]. A telling break down of the demographics reported in Building the Right Support for People with a Learning Disability and Autistic people (2022) is that there was a 70% increase in the number of autistic females in inpatient settings. This is possibly due to better reporting, better recognition and thus more likely demonstrating a truer picture of the extent of the problem. Given underdiagnosis of adults, especially older adults, we should consider that current figures may not reflect the true picture. O'Nions (2023) research suggests an incredible estimate of 250,000 to 500,000 people over the age of 50 who are undiagnosed.

1 Autistica ‘Breaking the cycle’ Campaign 2023

At the thin edge of the wedge, we are dealing with economic inefficiency. Whilst at the wider end is the devastating long-term impact for autistic people whose experience of care has, in multiple cases, left them with severe trauma and poor physical health. This iatrogenic harm along with that of missed diagnosis and misdiagnoses means that there are people across the country and locally who have avoidable long term serious disabilities and life limiting conditions. It is important that we consider the implications of long-term investment and system changes as this could produce profound tangible improvements across the board both from an economic and humane point of view.

The information that was explored and analysed during this project has emphasised knowns and identified nuances of local challenges and attributes. This report formulated recommendations through detailed analysis and will demonstrate an evidence base behind them. These recommendations form a cross system collaboration and commitment to change current working with the individuals as key partners in changes and developments going forward.

As a system we should be aspiring to achieve opportunities for a thriving autistic community, not hoping for surviving. To make key recommendations to ensure reasonable adjustments are considered to actively promote positive experiences for autistic people when accessing mainstream services, specialist health care, social care, and support from the independent and voluntary sector. Challenge systems and decisions that are oppressive or discriminatory and promote a person’s human rights as enshrined in law.

Learning from local and national serious case reviews, safeguarding reviews and near misses has been respectfully honoured as key drivers for this project and recommendations. With assurance that these weren’t statistics but people and that the systems locally have made a commitment in honour of those whose lives and care could and should have been better. This project is interested in who are the numbers not what are the numbers.

5. Background/ Context

Since the inception of the Autism Act 2009, the government was required to introduce an adult autism strategy. With increased scrutiny and guidance autistic people were in the public eye. In 2011 the BBC aired an investigation into Winterbourne View. This marked the start of a number of investigations into other hospitals who provided care for autistic people and people with a learning disability. In many cases the standard or care was comparable with the 19th century Workhouses, in that people's vulnerabilities were weaponised and used against them.

There have been a number of strategies produced the most recent strategy was; The national strategy for autistic children, young people and adults: 2021 to 2026. It focuses on improving understanding, access to education and transitions to adulthood, employment, health inequalities, reducing inpatient care, community support and the criminal justice system. In 2015 NHSE developed the Transforming Care Programme which provides guidance for local authorities, commissioners and provider collaboratives as an initiative to keep people at home and out of hospital. The NHS Long Term Plan (2019) set out improvements in accessing diagnosis, post diagnostic support and physical and mental health services. Mandatory training (Oliver McGowan Training) was made a legal requirement in The Health and Care Act 2022 for health and social care workers. In 2022 the DHSC updated Building the right support for people with a learning disability and autistic people: action plan. In this, several commitments were outlined across agencies. Importantly it defined commissioning for people's lives not just services. Alongside the guidance that has and will be published as part of these commitments, TCP's and CTR's will continue to work to keep people out of hospital by improving community support.
This includes resources for reasonable adjustments and sensory adapted wards. Autistica, funded by NHSE has been piloting coproduced tailored annual healthcare checks which is due to complete this year (2024). Further to this Autistica is running a series of pilots to ascertain the efficacy of personalised profile plans which can be used in a number of settings including mental health and employment. Much of this work has been developed from a seminal study in 2016 which demonstrated shameful iniquitous health outcomes and a reduced life expectancy for autistic people.

In 2019 the NHS England Long Term Plan included improving health provision for autistic people as a critical priority.

STOMP (stopping over medication of people with a learning disability, autism or both with psychotropic medicines) was launched in 2016 by NHS England along with Royal Colleges and other partners. In 2018 STAMP (supporting treatment and appropriate medication in paediatrics) was launched along with STOMP. This has allowed a robust framework and increased awareness in many mainstream settings. But it is clear that there are a number of people 'lost' in the system who have been historically prescribed medication, and have developed health complications as a result. The level of iatrogenic harm is not quantifiable as we have no idea of the total number of those missed or misdiagnosed.

The Green Light Toolkit (NDTi) first commissioned in 2004 was updated in 2022. It provides an audit framework for mental health services in order to benchmark services and develop improvements for autistic people and people with a learning disability especially in line with reasonable adjustments mandated by the Equality Act 2010 and the NHS Long Term Plan 2019.
In 2023 autistic people were named as one of the priority groups in the National

It’s Not Rocket Science was a report produced by autistic people within NDTi which outlines 10 recommendations for ward environments. As part of the NHS commitment to reducing health inequalities both resources to outline statutory responsibilities and a Health inequalities programme (HiQiP) was formed in 2021. As part of these commitments and the legal duty under the Equality Act (2010) is ‘anticipatory’. The duty therefore is upon the health service to know about the reasonable adjustments needed to enable equitable access services.

The NHS Spine means that information can be shared across different services. This includes patient health care records. A digital reasonable adjustment flag on health care records alerts services about specific reasonable adjustments that may be needed. This forms in part a response to the statutory duty under the Equality Act.

Suicide Prevention Strategy. This has tasked local ICB’s to improve access to assessment in line with NHSE national framework to address issues such as late diagnosis. Further to this it acknowledges training strategy set out in the Health and Care Act 2022.

Other recommendations of note from the National Strategies are to ‘raise awareness’. This encompasses a commitment across all sectors and is expected to be embedded within communities also. This will be greatly improved by training programmes such as OMMT and NATP. Other partners instrumental in raising awareness include charitable organisations and other services who promote co-produced training and study days, and support to families and carers.

6. Purpose and scope.

Purpose

To develop an evidence base of health inequalities and social determinants as per (National Strategy) for the local population.

Scope

To analyse a broad range of local and national materials and data.

Problem

Autistic people do not have equitable access to services

Challenges

a) heterogeneity of autism
b) disparity of how accessibility and equity is facilitated
c) Appreciating a true account of prevalence and impact is impeded by inconsistent data collection.

Goal

To address systemwide barriers to improve accessibility of services.

Rationale

This project covered a broad range of services over a diverse geographic and demographic footprint. There are multiple systems and services which have an integral role in improving autistic people’s quality of life. As such this project has not focused on one specific area, but instead has taken a holistic and dynamic approach. This enabled humanistic and experiential insight to identify inequalities experienced by autistic adults.

What this report will do and what it will not do

This report will outline recommendations and illustrate evidence of how these recommendations were formed. It will not attempt to fix systemwide problems or

Aim

The **first** aim of this project, therefore, was to explore how a ‘pathway’ might address the problems which cause inequity. **Second** was to ascertain what the problems (including gaps) and assets in service were locally. **Third** to compare these to the national picture.

cover every conceivable aspect of the systems within BLMK as this has not been possible.

7. Methodology

This has been an exploratory multimodal review using a reflexive thematic approach. To glean impartial authentic insights into the nuanced experiences of autistic people living locally with as much rigour as was plausible given the limited resources and extensive potential scope of the project. The different modes included ten phases some dependent, some independent and others consistent throughout the project:

1. Information gathering

National and local guidance and legislation was reviewed from the outset with due care and diligence to up to date publications and papers. This formed the benchmark from which the project grew. Along with this as previously stated this project has used the investment placed on it to consider the implications and learning from serious incidents and safeguarding reviews.

2. Research

As with information gathering concurrent research and evidence was monitored as key components of guiding principles and assurance of evidence base and relevance.

3. Scoping

Service scoping as far as practicably possible this project aimed to get a robust understanding of services and facilities available to local people. Further to this, scoping of national projects pertinent to local need were examined as a way to glean a broad range of recommendations pertinent to local nuance.

4.Data

Quantitative data would have added a powerful component of this project. However, confounding factors mean that figures may not be a true representation and therefore had limitations.

5. Interviews

A simple informal method of semi structured conversations and interviews were conducted online via Microsoft Teams©, telephone, Zoom, emails and in person.

6. Comparative analysis

In order to maintain ongoing prudent oversight of the sources and scope of this project. Information gathered was mapped out against the National autism strategy.
This allowed a benchmark audit process as well as a way to demonstrate specific areas of concern, acuity or where the information may have been wanting.

7. Thematic analysis

This was broken into two streams

Impact

Identified issues or problems experienced by autistic people and the outcomes.

Solutions

Solutions were from a range of feedback where work has been done and evidenced improvements were made. It also came from those who had lived experience or had professional experience meaning that they had a level of expertise and insight, which formed a basis of reasoned judgement.

8. Recommendations

Recommendations were then developed with the use of cross-referenced analysis
The areas of cross reference were:

- Local and National guidance, strategies and frameworks
- Legislation
- Evidence base and research
- Serious incidents and safeguarding reviews
- The themes formulated from this project.

This formed an evidence base for the recommendations.

9. Service implications

Commitment and investments are needed from services and the ICB. It is acknowledged that at a time of austerity measures and budget cuts, investment is likely to pose a challenge. However, the recommendations from this project are likely to lead to dividends in the quality of life for autistic people and longer-term

10. Ethical considerations

For the interest of maintaining confidentiality all information collected for this project from the interviews and group meetings has been anonymised.

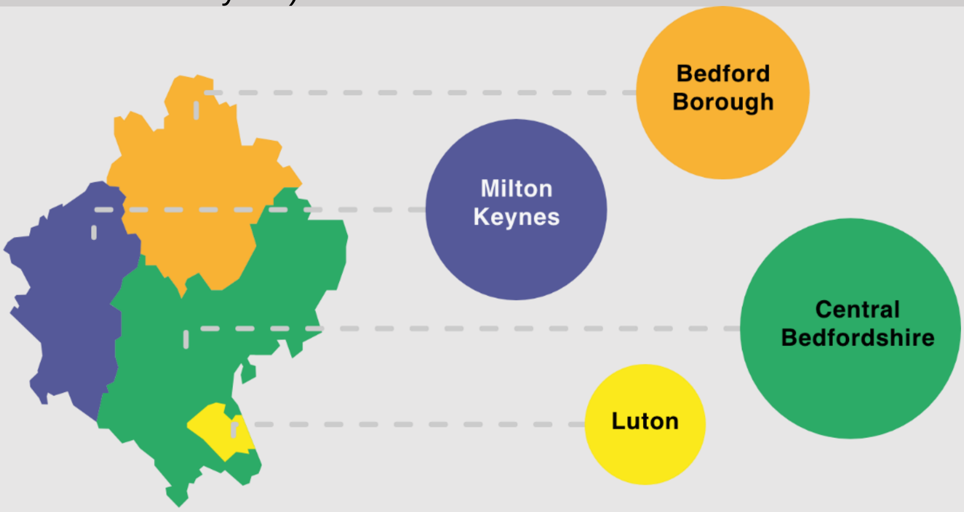
financial efficacy. Furthermore, investment to address electronic record inconsistencies and data collection is essential.

8. BLMK Context

Diversity of the population in BLMK is considerable with areas of significant deprivation and affluence as well as cultural and ethnic diversity. There are circa one million people living in BLMK. Prevalence of autistic people estimated at **12,016** in March 2022. This figure was provided by NHS Arden and gleaned from GP Snomed codes. It reflected **1.11%** of the population compared with national estimates of **1.04%** (Estimates dated 2020) from ONS.

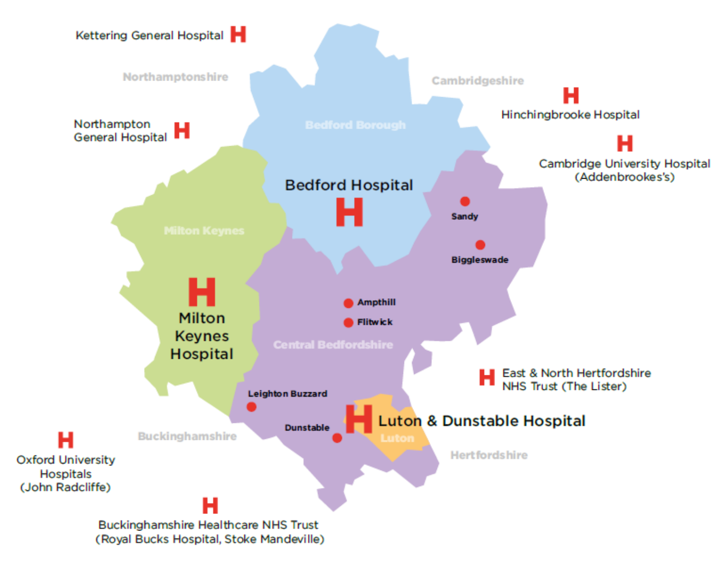
Infrastructure

Across BLMK there are three general hospitals, two mental health trusts (CNWL and ELFT). There are four local authorities and two adult autism diagnostic services (in Bedford and Milton Keynes).



BLMK ICS website 'our area' health and care partnership

There are currently 23 primary care networks and around 91 GP practices. Additional to these there are a number of further education sites, transport networks, national and local charities and other services. Although many services were contacted as part of this project limitation of resource and barriers to scoping has meant that these have less focus than other areas.



BLMK ELFT council of Governers. ICS website

Autistic adult population

This search was undertaken by NHS Arden using snomed codes. Snomed codes are the codes used in GP practices to record specific attributes.

Criteria: **BLMK Patients recorded as on the Autistic Spectrum**

Patients identified as on the Autistic Spectrum from Snomed codes:

35919005	Autism Spectrum Disorder
43614003	Autistic Disorder of Childhood Onset
231536004	Atypical Autism
373618009	Autism Spectrum Disorder with Isolated Skills

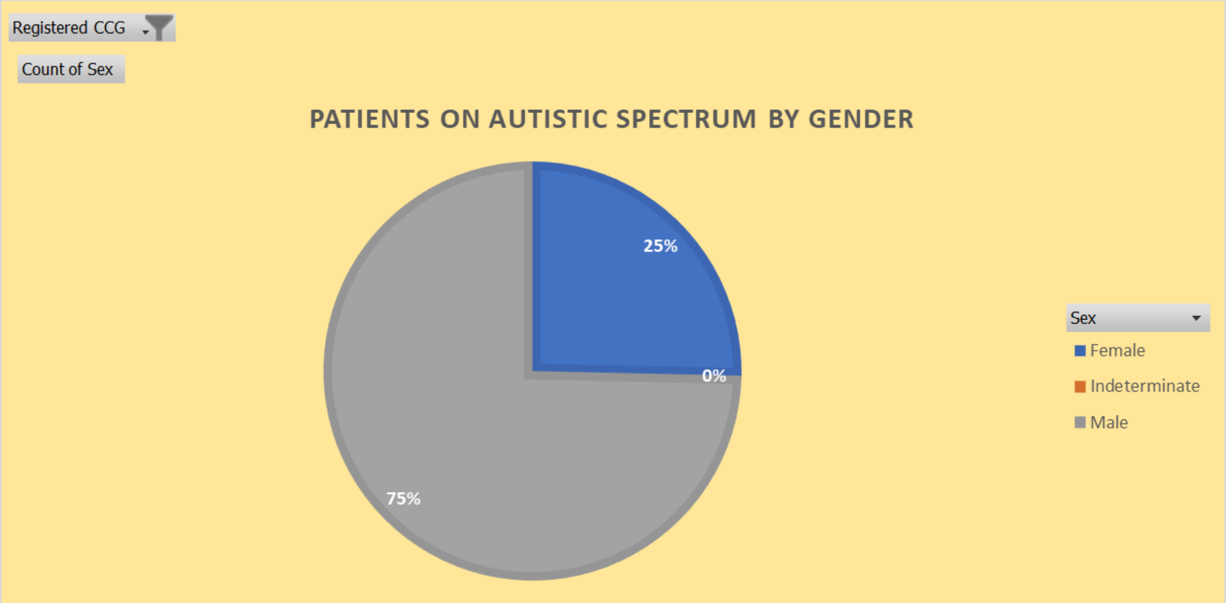
Of the above patients identification from Snomed codes:

44301001	Suicides
82313006	Attempted Suicides
248062006	Self-Injurous Behaviour
224927002	Medium Secure Unit
224928007	Regional Secure Unit
224929004	Secure Hospital
288562003	Secure Unit

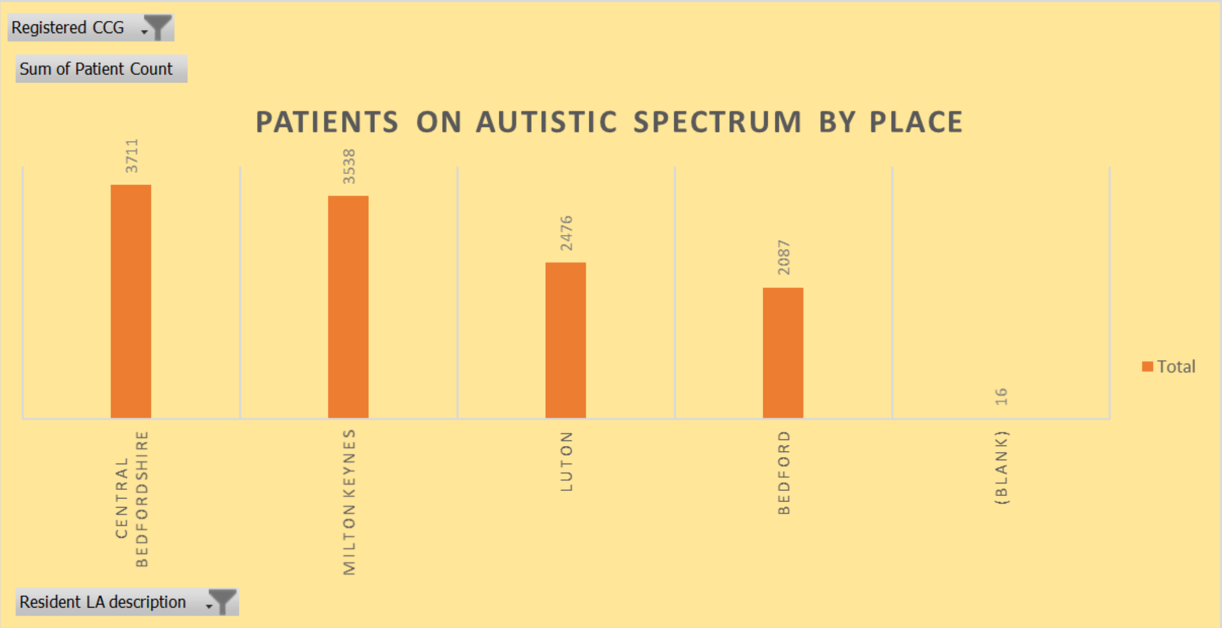
110359009	Learning Disability
408468001	Learning Disability -Speciality
416075005	On the Learning Disability Register
225343006	Assessment of Needs

Adult Mental Illness/Mental Health/Acute Services identified from referrals out.

SUMMARISATION OF FINDINGS	
Description	**Patients**
Patients on the Autistic Spectrum	12016
Patients with record of Suicide	10
Patients with record of Attempted Suicide	97
Patients with record of Self Harm	460
Patients with record of referral to Adult Mental Illness	98
Patients with record of referral to Mental Health Services	641
Patients with record of referral to Acute Services	13
Patients with record of time in Secure Units	13
Patients with record of Learning Disability	1668
Patients with record of Needs Assessment (excluding patients with Learning Disability)	1007



National studies suggest that boys are around 4 times more likely to be diagnosed autistic than girls. There is considerable evidence that women on average are diagnosed up to 6 years later than men (Autistic Girls Network 2022). There are two main theories explaining this disparity; That the diagnostic assessment and criteria was developed based on historical research of boys. And that women may be more likely to internalise or 'mask' due to different social constructs and expectations of female behaviour. Sex in itself offers somewhat of a red herring in this respect as for many years Autism was thought of as a male dominated 'condition' and thus that is where clinician expected to see it. Transgender and 'gender diverse' adults are thought to be 3-6 times more likely to be diagnosed autistic than cisgender *adults (Baron Cohen et al 2020). The many confounding issues around gender and sex therefore mean that data in this area gleaned from binary reports is possibly misrepresentative.*



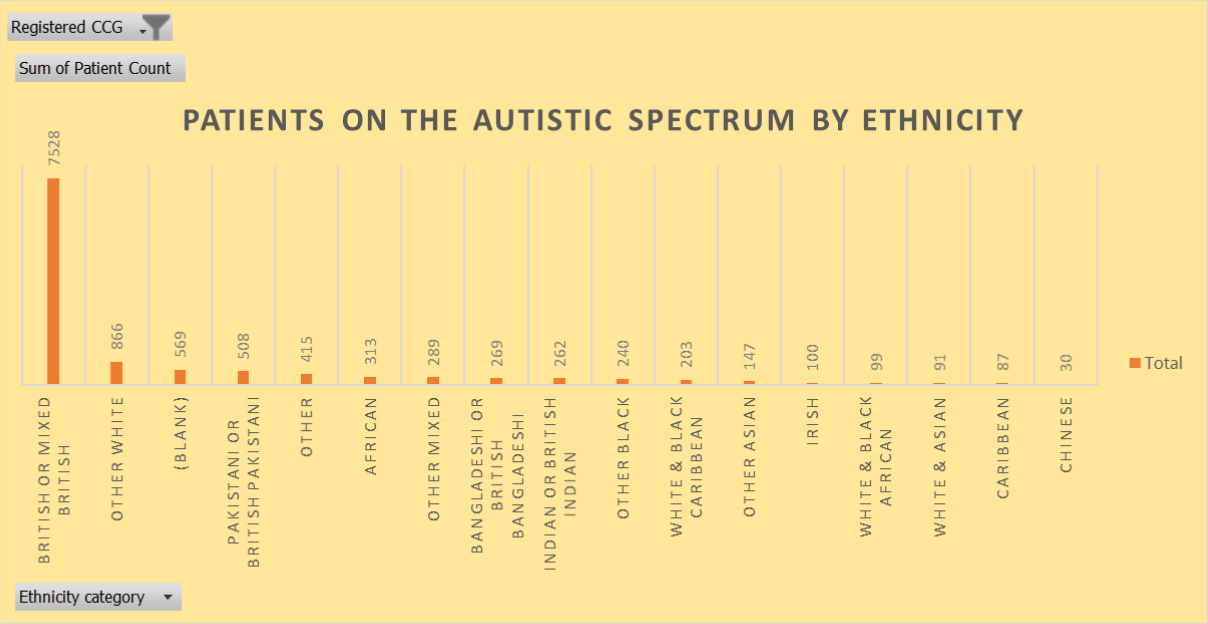
Total population

Central Bedfordshire (2019) – 295,541 (1.26% equivalent)

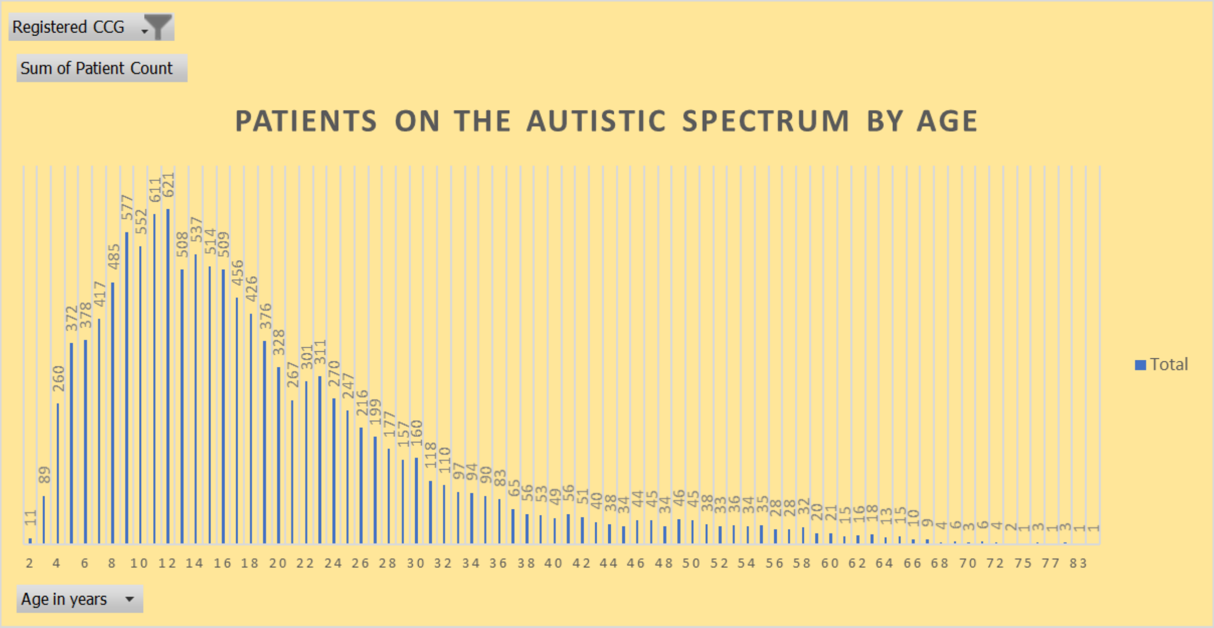
Bedford (2019) - 185,761 (1.12% equivalent)

Luton (2019) - 218,045 (1.13% equivalent)

Milton Keynes (2021) - 287060 (1.23% equivalent)



The Denny Review highlighted the upsetting inequalities and reduced life expectancy for people in BLMK. In this review those from Gypsy, Roma, Traveller and those from ethnic minorities were at a significant disadvantage. This disadvantage for many were challenges in accessing services. This may be particularly true for those who do not have English as their first language. Cultural sensitivity is needed especially in relation to health literacy. National data has demonstrated significant under reporting and diagnosis within some ethnic groups (O' Nions et al 2023).



Study by O' Nions et al (2023) covered on Page 14 highlights possible flaws in data in this area.

The data gleaned from NHS Arden compared with national statistics were unremarkable at the time of collation. Although there had been speculation 1.1% prevalence estimated from government surveys grossly underestimated the actual picture when taking into consideration

- Change in diagnostic categorisation
- Under reporting
- Non-disclosure
- Un diagnosed
- Mis diagnosed

Arguably the biggest influence on the exponential growth of autism rates in the population has been due to the global shift from the homogenous concept of autism to a greater understanding of the heterogeneity of autism. This has led to changes in diagnostic criteria, more people recognising it, increased acceptance and reduced stigma. Reliability in prevalence will remain affected by data collection, disclosure and record keeping.

The national strategy for autistic children, young people and adults: 2021 to 2026 (update July 2021)

"Improved data collection and reporting to drive system improvement"

Over the next 5 years, we want to improve the collection and quality of data on autism used across public services to better support the needs of autistic people and their families. Autistic people interact with a range of mainstream and specialist services across systems, such as health and social care, education and employment, and there are still gaps in data across these areas.

9. RESULTS/ OUTCOMES

Interviews were conducted in a semi structured format-

Staff members includes anyone who works in a professional capacity for an organisation providing services where autistic people access.

1. Everyone was asked to tell me about their experiences of working with autistic people
2. They were asked about examples exemplary work
3. They were asked to provide information about their role and the provision scope and area of the service they work for
4. They were asked whether they were able to identify gaps in service and to name them
5. They were asked about recommendations to improve services for autistic people
6. They were given opportunity to share further narrative about their view on how to meet autistic people's needs within their services

Autistic people, allies, parent, carers and representatives (anyone speaking as one of the afore mentioned not excluding those who were also staff members) were asked similar questions to those of the staff members.

1. Everyone was asked to tell me about their experiences of accessing services
2. They were asked about examples exemplary work
3. They were asked whether they were able to identify gaps in service and to name them
4. They were asked about recommendations to improve services for autistic people
5. They were given opportunity to share further narrative about their view on how to meet autistic people's needs

They were informed the scope of the project and that the information gleaned would be used to inform the project report and recommendations.

Feedback was split into categories by source (staff members category A and the second group category B). The feedback was anonymised by category letter and assigned a number. Then each of the themes were grouped together as below

	Broad themes 'Problems'	**Mapped to National strategy**	**recommendations**

1	Health inequalities and barriers to accessing services	Prevention/ early intervention. Improve access to healthcare. Improve links with community	1 Clear language 2 Diversity inclusion 3 Website 4 hub 5 social prescribers 6 training 7 data collection 8 reasonable adjustments 9 collaboration 10 coproduction
2	Data collection, records and reporting	Improve data reporting	1Digital flags 2Project to review GP records and pathway 3Low tolerance to incident reporting
3	Preparation for adulthood	Improve support for autistic people in their transitions into adulthood	1Transitions workers and peer support workers for those not eligible for key workers 2Training 3Advocacy
4	Care Act assessments	Support for meeting needs	1 Improve accessibility and support for application 2 training
5	Mental health services- eating disorders, crisis, psych liaison, community teams, Wellbeing, forensic services, perinatal	Prevention, early identification and intervention, community mental health support, housing and social care support	1Training (NATP) 2 Data collection of access 3Prevention and early intervention 4 Holistic care 5 Diagnosis 6 Needs led
6	Physical health- Primary care, secondary and tertiary care	Reduce health inequalities improve the life expectancy gap	1 Personalised care 2 Health passport 3 Care planning 4 Pilot project for autistic allocated time in surgeries. 5 SPACE 6 Reasonable adjustments training
7	Training	Improve understanding	1 Utilise NATP OMMT local coproduced training
8	Criminal justice	Justice report and evidence	1 Access to training programs run by local and national programs 2 Consider the barriers due to limited number of forensic psychologists 3 Liaison and diversion services and frontline to have SPELL training to reduce restraint, restriction and promote low arousal 4 Autism cards and system flags 5 RECONNECT service

9	Workforce capacity, demand recruitment and retention		1 Diversify roles and create opportunities for development and research
10	Dual diagnosis pathway		1 Consider how dual screening and/ or diagnostic ‘pathway’ may be plausible given co-occurrence (70%)
11	Housing		1Forward forecasting 2 investment in accessible housing
12	Diagnostic services	Diagnostic wait times, pathways, improving quality, post diagnostic support	1 Referral process 2 Expand service to meet demand 3 Waiting well 4 Pre and Post diagnostic support
13	Transport	Equality training, autism inclusive, ‘it’s everyone’s journey’	1 Communication passports 2 Training 3 Blue badge applications
14	Carers and families	Improve support for family members and carers of autistic people.	1Ensuring that carers and families are able to attain their own life goals 2 young people locally who are not in education or are in flexi education ensuring that they are coping and have adequate means to escalate and have resources to community 3 Aging carers 4 Autistic carers
15	Education	Improve accessibility and transitions to further education	1 Further education to work with young people to support them 2 Training 3 forward planning 4 SEND 5 EHCP
16	Employment	Support autistic people get into work or training, using reasonable adjustments where needed.	1 Build on programs led by local charities 2 IPS (individual placement support) 3 Fellowships 4 MK Dons disability work 5 Track NN 6 Clipper project 7 Employment support and advice in local authorities and charities
17	Co production		Promote the voice of local autistic people celebrate diversity and find ways to involve them in all new developments

The themes were extrapolated into reflexive analysis. The following two chapters outline the outcome of this analysis.

10. THEMES- Barriers to an equitable life

Principle findings were grouped together where there was clear overlap in order to create a strong thematic process, although there remains considerable overlap in some areas. The next section of this report is an overview of the qualitative thematic analysis.

	Themes	Sub themes	
1	Joined up working	Gaps/ siloes	Convoluted systems,
2	Support/ early intervention and prevention	Equal access to housing, social care, education, transport, employment, Welfare, health care	Convoluted systems,
3	Accountability	Clinical oversight, quality assurance, transitions	Convoluted systems, Data, Record keeping
4	Training	Language/ communication, disparity in knowledge.	Reasonable adjustments

Table 1. Themes of barriers to equitable life

10.1 Joined up working

> *"Services just don't talk to each other"*

There was grave concern from many about siloed working leading to risk for autistic people.

> *"Services work in Siloes, autistic people don't appear to be suitable for any silo.. results in ad-hoc care…single services end up holding risk which includes needs across other services - this is a safeguarding risk as no one is overseeing care".*

This concern was echoed across the board, in all sectors and services. With many commenting on the efficacy of LD services addressing gaps and negating siloes.

> *"There are gaps in services for autistic people without LD"*

People often commented on support before and after diagnosis.

> *"There is nowhere to refer autistic people to, who already have a diagnosis"*

> *Gap where people have a historical diagnosis. Post diagnostic support focuses on 'what your autism looks like' and they are requiring something more than that"*

> *"No groups or resources for autistic people as the diagnostic service only offers diagnosis"*

> *"There is a gap in follow on services"*

> *"The post diagnostic support is lacking"*

In this there was concern raised about those who were waiting or had waited for a protracted time but did not meet criteria for autism diagnosis. The 'topics' covered in recovery college had mixed feedback. Which reflects heterogenous needs and limitations of personalisation in group work. It was felt that more coproduction would be beneficial. It is acknowledged that pre diagnostic workshops have been commenced by Autism Bedfordshire.

There was a concern raised about those moving into the community from inpatient services. Joined up working with community and other teams. For people in specialist services or needing mental health care great strides have been made by the transforming care team across BLMK. Specialist OT and Community practitioners have been commissioned to work directly with autistic people under the transforming care program.

People spoke about being refused by teams because of their diagnosis, with this and other criteria exclusions; anxiety was expressed about autistic people ‘falling’ between gaps.

> *“..Many ..have suffered trauma after a very difficult upbringing- mental health need NOT autism. Family led trauma as well as school (ie bullying etc). They are vulnerable risks of being cuckooed, drug dealing- substance abuse, not because of being autistic- but due to vulnerability and isolation looking for connection with other ‘like-minded people’- but this is true of many young people who become very traumatised adults. Big gap in services here- complex care team have not been able to help. So they are sent to IAPT where they are considered to be too complex/ risky.”*

> *“...Depression, anxiety, OCD, eating disorders, under the mental health social work team section 117. Real challenges in getting mental health team to work with these adults, there seems to be an eagerness to learn and work with these adults, but we consistently go two steps forward and two back; they are referred back for post diagnostic support via the diagnostic team.”*

Not being accepted by teams for support and treatment was a repeated cause for concern. It is evident that there have been multiple cases where both professionals and autistic people have experienced being bounced back and forth.

There does not appear to be a time of greater risk, than for those young people moving from children’s to adult services. This has been demonstrated in multiple cases nationwide. Whilst it is not exclusive to autistic people, autism is definitely an added complexity.

> *“Biggest issue is that there isn’t an adult service which reflects CAMHS service…services are not compatible, there is a mismatch between criteria”*

A charity offering programs to support young people from 14- 25 in the Milton Keynes area, reported that a disproportionately represented percentage (26%) of those needing support were autistic. 64% of those completing the programs which focused on practicalities of independent living, such as; finances, cooking, further education, employment, housing etc were autistic. It would have been an interesting area to expand on, as much of the concerns in respect to care leavers and those historically under services do not always have the opportunity to develop these skills. Given the afore mentioned mismatch in offer between children's and adults' despite the virtues of developing independence skills, it can not replace the need for oversight.

This mismatch means that for some their support can include care ‘packages’ overseen by a care coordinator/ key worker. Receiving multiple contacts per week and tailored therapy under children’s services, but not meet criteria under adult mental health services.

The role of transitions workers within can be pivotal for the lives of the young people under mental health services during this precarious time. However, there are limited numbers of transitions workers, the criteria for allocation limits eligibility. Furthermore, it was reported by one team that out of a potential c.20 people in one area, only one person had been referred. There is a significant amount of focus locally in this area, with evidence of good collaborative early forecasting and planning. A local policy hub and training in areas such as mental capacity. These significant steps will help aid safeguard young people. However, it is important that this focus and attention is not stopped in momentum until there is more confidence in robust transition across the whole area.

For those who had social care involvement, had a care needs assessment or an EHCP it was possible that they had a proverbial safety net when other services 'drop off'. The role of transitions workers within mental health service According to data from NHS Arden (page 22), less than 1% of those recorded as autistic without a learning disability had a care needs assessment. The scope of this project precluded opportunity to robustly explore this data. However, there were two subthemes pertaining to care needs assessment raised universally and by both autistic people and professionals in the qualitative feedback:

10.2 Support/ early intervention and prevention

Along the assessment pathway there are key points (P41 Image 1) where support could prevent escalation or exacerbation of difficulties.

> *"pre diagnosis support via recovery college needs to take into account that some waiting*

> *"The application process is completely inaccessible"*

> *"Push back from teams about who's responsibility it is"*

On speaking about their difficulties, one autistic person shared how they had been asking for help for a long time and their situation had become desperate.

> *"I am afraid that I won't receive help until it is too late"*

Others spoke about delays whilst services 'argued' about where their care should 'sit'. Worryingly there were several autistic people who had 'given up' and accepted it as their fate.

> *"Older people are even less provided for"*

An area which was only raised on one occasion but considered by the author as a quintessential error of focus in contemporary society. Our aging population are frequently overlooked in many aspects of care and support. Care support for older people who may or may not be diagnosed, was raised by someone who described episodes of perceived antisocial or unusual behaviour resulting in exclusion from residential options.

Both local diagnostic teams have rejected referrals because they are incomplete or not completed properly. Reviews of issues relating to this, referral procedures including digital platforms are currently underway.

It was evident that there are significant demands on capacity, staff turnover is high and engagement challenging. The ward environments are not conducive to facilitate recovery. It is well documented that autistic people often experience traumatic experiences during inpatient stays. (Baroness Hollins 'My heart breaks' (2023), NDTi 'It's not rocket science' (2020), CQC 'Out of sight, who

> *may not get a diagnosis of autism, so focus should be on needs not diagnosis ie sensory processing, trauma etc."*

It was clear that for those waiting processing identity, being in limbo and unable to access support were challenging. Anecdotal reports from local and regional mental health, diagnostic and social care teams concur that there is a significant number of people who have been diagnosed whilst being supported with severe mental illness or other form of care crisis. The impact of this catalyst for diagnosis has serious implications for how diagnosis is made, the context of diagnosis for the person, support needs, trauma, recovery, as well as demands on service involvement.

> *"When autistic people present in crisis their mental health presentation overshadows the fact that they are autistic."*

> *"there is nowhere for 'them' to go in a crisis."*

A common area of concern were ward environments and understanding of autism with co occurring severe mental illnesses.

> *"staff aren't trained to use the sensory equipment"*

During the course of the project the author attended in patient areas in both Luton and Milton Keynes. The purpose of this was to glean some understanding of the challenges faced by staff and patients in the ward environments.

cares? restraint, seclusion and segregation' (2020).

> *"I remain affected in deep and devastating ways. Each day I wake up to the dull, enduring pain of isolation and aloneness. Emotional flatness, a difficulty in establishing meaningful contact with others, an oversensitivity to sensory and emotional stimuli, a distrust of people and regular flashbacks are but a few symptoms I still experience" Alexis Quinn Cited by Baroness Hollins[1]*

With all this in mind:

> *"Early intervention is key"*

This maybe best suited to children's services and in particular educational settings to set positive foundations. However, there is and will remain a number of adults still needing early support and intervention to prevent crisis.

Examples for this may be from addressing practical issues around housing and social support, or employment, education, welfare and transport. Specifically noted for BLMK were the challenges in both transport and housing across many areas, owing to the population density in some areas and broad range in environments there are areas of economic wealth and others of significant deprivation. Any future planning should consider the challenges this poses to those needing to access different services.

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1 Baroness Hollins' final report: My heart breaks- solitary confinement in hospital has no therapeutic benefit for people with a learning disability and autistic people. DHSC. (2023)

> *“Short term temporary housing works well.. but due to lack of available housing, there is a high number of homelessness, lots of people in temporary housing.. A project this year commenced to review housing for people… in need of supported living, eligibility will include autistic people also .”*

There was an example of an autistic person who had negotiated a robust care plan that outlined simple reasonable adjustments for an essential procedure. Instead of discussing this with the autistic person and forming a plan, it was decided that they were too anxious and were sent out of area for a different procedure, meaning that transport and care for their child had to be found.

> *“Mainstream services not sensitive to autistic people’s needs”*

This individual case, whilst exact in nature. It demonstrates a set of challenges in accessing support. Every barrier found of this nature marks another confinement and abandonment from services. It also raises additional issues around transport and added challenges for those who are autistic carers.

Transforming care program along with the key worker program locally works well in supporting people who sit within the parameters of this process. However, the majority fall somewhere outside of this level of acuity, this is in part what led to investigation into the efficacy of early intervention and prevention measures such as IAPT/ wellbeing, support groups and walk in/ online support.

BLMK have adopted early intervention and prevention transformational strategy to support vulnerable adults in the 2024-2025 forward planning. This joins up health, local authorities to reduce the impact of health inequalities.

There were many accounts of confusion about what was offered and to whom. For a number of autistic people, they felt that some charity’s main focus was for those with a learning disability. Whilst a representative of mental health charity suggested that they did not offer support for people with ‘really bad autism’. This seemed to equate to missed opportunities of early support for a proportion of people locally.

Examples of exemplary practice in respect of a proactive approach was evident but not consistent.

> *“We focus on needs and not diagnosis, we avoid the medical model and we have adapted therapies”*

> *“Supported employment intense support with job coach.”*

> *“Local offer includes information for employers on ASC (sic.) with difficulties and adjustments, and ‘rights’ Equality Act”*

The Future of primary care objectives focus on meeting demand and capacity by linking out access within communities. Improving access through expanding communication and booking digital platforms are all likely to improve general accessibility for all, including autistic people. A key an important time to watch how the changing primary care services improve health inequalities for autistic people who are known to struggle with access from this point in contact. Social prescribers in BLMK have been engaging with autistic people and helping them positively connect with community-based services to improve health (based on local example).

> *“There is no prevention work”.*

Early intervention and prevention should foster annual health checks and better understanding about under reporting and accessibility difficulties for physical and mental health problems.

10.3 Accountability

> *"Seems to be no accountability from professionals for those who do not meet criteria"*

Adult autism services have been relatively late in inception with many developing following the Autism Act (2009). Since the Act was published there have been phenomenal changes and developments both within the NHS, ICB's, local authorities and partners, coupled with the rapid and dynamic transformation in autism as a diagnostic category and identity (as discussed previously). It is imperative that the ICS and partners recognise this when considering this in future planning, service development and sustainability.

Transformation forms one part of the challenge for adult autism services which were developed for a fraction of the actual population of autistic people. And without the insight now available on risks, suicidality, homelessness, employment, education, co-occurring conditions and disabilities amongst several other complexities.

Adult autism services in this respect; designed and commissioned to offer diagnosis and consultancy only, are face with a proverbial tidal wave of diagnostic demand. Pressure to meet government targets mean that there is a danger of focussing on quantitative output. Given the current picture of complexities and risk, the concern is that the tidal wave may form a tsunami of devastating challenges for other services, and additional difficulties for autistic people

Furthermore recruitment, retention and staff turnover across health and social care pose real difficulties for some autistic people to achieve continuity of care.

> *"I've been discharged because staff have left, I've had to be re-*

> *"I was told that I was too 'high functioning' to receive help"*

> *"I had to pay for a private social worker in order to get help with housing"*

> *"I cannot get help with daily support so have to rely on elderly parents"*

> *"No forward planning from services.* Especially in relation to those cared for by aging relatives or who are carers"

Forward planning was echoed by many professionals and autistic people at different points in autistic life span. As with those who rely on aging parents for support and housing, autistic parents and carers also face real challenges in meeting the needs of dependants let alone their own.

A particular area of concern in relation to those who are transitioning from children's services to adult services.

> *"Young people are abandoned by services when they transition from childhood"*

> *"No receiving service in adult services from children's"*

> *"Forward planning/ strategies around...those not in school difficult to equate as schools are not obliged to let local authority know."*

> *"Sporadic support in further education. EHCP not always covered ≥18yrs support drops off"*

Perhaps most worryingly were those cases where no support was given, regardless of prior involvement and despite known risks or difficulties.

> *"Social care holding risk of those who aren't taken on by mental*

> *referred and it feels like you are starting all over again"*

Barriers to accessing services, apart from convoluted systems and processes, include those which may be seen as associated with autism- such as communication and language differences (ie situational mutism/ nonspeaking), sensory triggers, unpredictability/ changeability. It is significant then, that for those who do manage to get to the point of accessing services may be put in a position of refusal, discharge or frequent changes.

10.4 Disparity in knowledge/ Training requirements

There has been incredulity expressed locally about the efficacy and role of training in addressing difficulties face by autistic people. However, 100% of professionals and autistic people who discussed rejected referrals said that it was due to gaps in knowledge.

> *"We are not trained in autism"*

> *"They said they are unable to work with autistic people because they are not trained"*

Disparity in the quality of knowledge and understanding of autism, autistic identity and social disability was evident from the qualitative feedback. The variation was such that it would be difficult to pinpoint strengths and specific weaknesses to one area. Professionals who work in general areas of practice were open about their knowledge deficits. Whereas presumption about competence based on historical practice was evident in specialist areas. The extensive range in training, knowledge and understanding, corroborates the fundamental role of training in standardising practice and gaining quality assurance.

> *"Autism isn't a learning disability it's a mental disorder"* [1]

> *"We don't work with people who have really bad autism"*

> *health services and don't have a learning disability."*

> *"Social care sometimes hold the risk"*

The number of people who are in this position is a real concern. In the case of young people moving to adult services escalation procedures when there's no one accepting referral or referral not clear have been developed locally. Childrens and adult services are working together to create integrated support plans.

> *"Assumption that bad behaviour is because of being a bad person and they are presumed guilty"*

Training must be considered with compassion and understanding, as many professionals need to reflect and shift their perspective in line with the growth of autism understanding.

> *"The staff are scared ..of autistic people"*

It is a major piece of work, but without it regardless of new roles, services or teams, change will not happen- the problem will just be shifted to another area.

> *"Issues between autistic people being picked up due to 'this isn't mental health it is autism'"*

The importance of training is emphasized in the Health and Social Care Act 2022, and it underpins the priority in reducing premature deaths, poor outcomes and care failures.

> *"Staff need adequate training to meet the needs of autistic people and their families or carers."*

National reviews, strategies and guidance and reports into failures have repeatedly highlighted historical deficit in training for health and social care professionals. Whilst this is being addressed through NATP and OMMT.

Problems arise from deep-rooted paternalistic epistemic bias, coupled with the jaded origins of autism and autism ‘treatments’, they cast a disturbing contrast with contemporary autism theory.

“Assumptions are made about autistic people”

The time it will take to achieve consistent and sustainable change is dependent on; training availability, staff availability and for this training to make changes in attitudes and practice, not just to pay lip service to duty requirements.

“Teams just don’t get it”

1 Autism was defined as a ‘mental disorder’ in the Mental Health Act (1983). Long awaited reforms now scheduled 2024-2025 propose removal of learning disabilities and autism as a mental disorder detainable under section 3 of the Mental Health Act.

“Staff don’t feel confident and need a safe space to discuss anxieties and myth-busting”

Collaboration between local charities; Autism Bedfordshire and Talk Back, commissioners, both local adult autism diagnostic services and mental health teams has produced a number of study days, rolling training and conferences. To address gaps in knowledge in areas such as LeDeR program, sensory processing and other topics. Local SEND colleagues, parent carer groups and co production and engagement within local authorities offer regular training days on a range of subjects. The investment into training is evident and the engagement and dedication present. The real challenge is to create a cultural shift and engender systemic change.

“In society, we just don’t think about ‘it’ (sic.)”

“Cultural issues in mental health services”

Qualitative analysis of LeDeR reviews found issues relating to presumed functionality based on the absence of a learning disability. It highlighted risk relating to discriminative attitudes as a result of limited understanding. Not only offensive to those with a learning disability it has led to a bias in assessing capacity. Prejudice should never preclude assessment of safeguarding and mental capacity. The Mental Capacity Act (2005) guiding principles

The counterbalance of protection is empowerment, ensuring autonomy and community support is in place for the short fall which may arise due to changes in legislation do not leave autistic people even more stranded.

Not to be overlooked is the potential to create equitable access to mainstream services through reasonable adjustments. The Equality Act (2010) legislates that people are protected from discrimination and disadvantages are removed or reduced. ‘Reasonable adjustments’ was raised as a sub topic of training gaps. Where cases of inaccessibility, ‘non engagement’, exiguous care/ support, unmet needs and other failures were reported, it was repeatedly in conjunction with failures in making reasonable adjustments.

“not enough reasonable adjustments in mainstream services, across all services”

“In fact mental health do not understand what making a reasonable adjustment is in order for autistic adults to access support.”

“I have to explain at every appointment what my needs are and it is really difficult (pp)”

Challenges in meeting people's needs are multifaceted. In part due to digital systems and flagging, disclosure and care planning. However, it is crucial that are very clear to ensure that every practicable opportunity is given to a person to make their own decisions. With this in mind it is essential that training reflects the complex and nuanced nature of different practice settings. Especially, but not exclusively when guiding people working with autistic care leavers including long term residential, and others who may have fluctuating capacity, limited experience of independence and are potentially vulnerable to exploitative abuse such as cuckooing, coercion and other forms of abuse.

*S*ensory processing and sensory integration training has been offered across most mental health inpatient settings. This forms in part reasonable adjustments necessary for autistic people.

A positive step but there is some way to go not only in making this common place across other areas but also considering other elements of reasonable adjustments. Occupational therapy and speech & language therapy both have an important role in addressing training on areas such as; communication, executive functioning, neuro processing barriers to services.

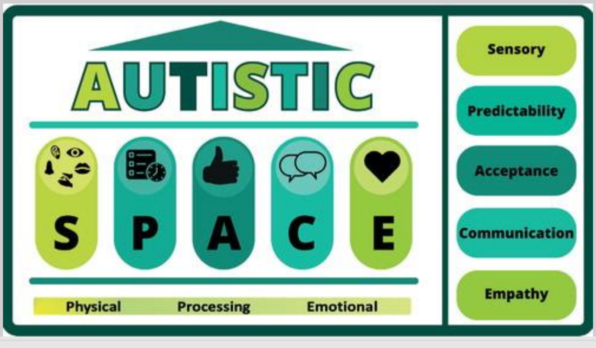
As the first step in referral for diagnosis in BLMK is via GP's it is not surprising that this was a topic that was a subject of feedback. In 2017 a report by Unigwe et al highlighted an urgent need to address training gaps and confidence for GPs. This has been echoed in the Health and Social Care Act and by the Royal College of GP's who have developed online training. Training however needs to be nuanced and focused on local drivers and culture. As well as addressing related problems such as reasonable adjustments and communication difficulties.

making adjustments for autistic people is personalised and sensitive to facets such as communication methods and sensory processing differences.

This has been one of the areas covered in local training days. However, it was evident from feedback from autistic people that their needs were not always taken seriously. One person shared their experience of not only being excluded from necessary health care but was subject to discrimination as a result of disclosure.

A primary care partnership in BLMK reported that there was a disproportionate amount of autistic people attending walk in centres due to being banned from surgeries for communication difficulties with receptionists. This is not an uncommon problem. Highlighted in research by Doherty et al (2023) difficulties in communication with Drs and reception staff was associated with all adverse healthcare outcomes in relation to barriers for autistic people accessing appointments. Three quarters of GP's do not feel confident in speaking with autistic people and only 40% have received any form of training. And 80% autistic people are reporting difficulties in accessing their GP. It is evident that collaborative and coproduced training is imperative in order to close the health inequalities of autistic people.

The SPACE framework offers a simple framework to building holistic physical, processing and emotional adjustments for: sensory, predictability, acceptance, communication and empathy. (Doherty et al 2023).



11. THEMES- Recommendations

	Themes	Sub themes	
1	Peer support	Continuity and consistency	
2	Websites/ webpage information	Continuity and consistency	
3	Personalised care	Continuity and consistency	
4	Hub	Continuity and consistency, Specialist expertise	

Table 2. Themes of recommendations

11.1 Peer Support

Peer support is not a new concept, developed in the 18th century in psychiatric care it has had mixed efficacy and models. In 2023 Autism Central commissioned by NHSE was a program designed to provide peer education to parents and carers of autistic people. In 2022 Health Education England published an autism peer support worker capability framework. Regardless of the underlying target of each program, the principles focus on mutual support of lived experience. The degree to which practical or therapeutic support is offered is dependent on need or basis of allocation. Similar to the principles of social prescribers and community connectors, peer support has the potential to create sustainable support for people by connecting them with their local community.

Peer support for autistic people has an added advantage in that it not only offers employment opportunities for local autistic people.

The SHAPE project a study led by B Beresford and S Mukherjee highlighted the impact specific aspects of post diagnostic support can have. They found that psychoeducation was particularly effective. A charity based in Berkshire has been running a training program of peer led psychoeducation support which has had positive results.

Peer support can be tailored for the individual and consider nuances like misdiagnosis and fluctuating functionality.

> *"We struggle in silence as we are too embarrassed. We need practical help, not support..just making a cup of tea, thinking what to eat..thinking this is stupid."*

Less intensive than key workers and transitions workers; peer support workers have the potential to hold a small caseload of people to offer holistic practical support. That builds on systems already in place which enable improved access for example transport or health (including social prescribing). Using social scaffolding to ensure autonomy by

> Workforce that reflects the diversity of local communities. (Fuller 2022)

It negates challenges sometimes arisen by communication barriers; such as the double empathy problem (Milton 2012[1]).

> *“Parents and carers need respite”*

establishing robust advocacy channels and utilising charitable organisations such as shared lives. Working to ensure that capabilities do not overshadow capacity and risk.

1 Damian Milton (2012) On the ontological status of autism: the double empathy problem. Disability & Society, 27 (6). Pp.883-887. ISSN 0968-7599.

11.2 Websites/ web pages

Reflecting issues that relate to training, consistency, and convoluted systems there is no one place to access consistent information about what is available and from where.

> *“No one place for information about what is available”*

The potential in opening access for those who are isolated, in creating a virtual safe space with reliable and useful information needs little explanation. Digital platforms have become common place in nearly every aspect of our lives. It is possible to draw on vast depths and breadths of expertise.

The number of short-term projects, programs, groups and activities found during this project up until its close was both equally encouraging and frankly disconcerting. There seem to be people, teams and services attempting to achieve the same goal which could be achieved with collaborative working or by using what has already been done. This is unsurprising given the nature of siloed working but could be remedied with a directory/ platform which includes an inventory of local and national work relevant to BLMK and autism.

Web platforms should be a base for transparency for people using the service. This is an essential approach in building trust for autistic people.

11.3 Personalised care

> *“Locally autism is a diagnosis of exclusion”*

As with the Beresford 2020 report and the SHAPE project; pre and post diagnostic support requires personalised care. Those who reported better outcomes were those who had a consistent allocated worker as opposed to group sessions. Whilst funding may not be available for allocated workers, personalised care is cost free. There are a number of examples of positive outcomes where such programs have been adopted. Autistica have been leading pilot projects which aim to glean data on the efficacy of personalised profiles. Where hospital passports and care planning has been less effective the

> *“they said ‘once you met one autistic person, you’ve met one autistic person’ and I realised then that they are all different.”*

Autism is an intrinsic part of neurodevelopment. Every other aspect of human existence; genetics, social, economic, culture, ethnic, race, gender, sexuality, age, etc has a role to play in creating the unique identity of every person. Being categorised by a single aspect of our identity is ludicrous and we should not be shocked by this concept. Intersectional identity is complex, people are complex, this is the principle of personalised care. Personalised care means that we are asking:

What matters to you right now?

real key task in this is for people to take necessary steps to move away from

> *“Labelling not enabling”*

to understanding individual needs by not treating a diagnosis.

Personalised care improves insight into co-occurring conditions, disabilities and challenges. It should be built into annual health checks using the determinants of health model.

Addressing what autistic people need in order to have an equitable life. It is needs led without overlooking the potential benefits of formal diagnosis. Personalised care can tackle some of the critical issues during the diagnostic wait times and ensure that people are waiting well and those who do not meet diagnostic criteria have a robust plan.

11.4 Hub

Universally echoed was the desire for a service that mirrors learning disability teams. The rationale for this was the efficacy in robust collaborative work with principles in personalised care and coproduction. It was felt that learning disability teams work holistically developing principles of health promotion and wellbeing.

> *“We need a dedicated service”*

There has been huge development in this area largely affected by the same legislation and reports as autism services. Locally the learning disability teams are well respected and felt to offer a robust and positive service.

> *“Take the work with autistic people out of mental health services, there have been successes with working with autistic people without LD under the LD team due to a robust MDT”*

Centralised unconvoluted service that has a single point of access has been an effective way to manage triaging and screening in mental and physical health services. Indeed, the principle of a single point of access can be seen across a number of systems with benefits from both users and providers perspectives.

> *“There are many inconsistencies”*

A hub would be the base for training, consultancy, diagnosis and multidisciplinary collaboration. It would hold oversight for peer support workers, website/ webpage information, working closely with transforming care, social care, housing, local authority, judiciary system, education and charity/ voluntary services.

Furthermore, with core principles of co production this service would evolve based on changes in local need. With the possibility of dynamic holistic working, research, service design and development. This would create an attractive recruitment incentive for professionals especially speech and language therapists, occupational therapists and psychologists.

> *“There are real challenges in recruitment, we are looking at recruitment initiatives and workforce dynamics”*

Services elsewhere have adopted an open door/ no wrong door model. This has worked for cancer screening services which facilitates expedited access to services within the local authority like social care and housing, as well as education etc promoting wellbeing. Whatever the ‘name’ of the model used it would be advantageous autism services to adopt similar principles for screening, early intervention and support to prevent crisis. Mirroring the key points of the Fuller

The benefit of a ‘hub’ model is that it enables a consistent approach which would be overseen by a robust governance structure within operational guidance. It builds on the integrated philosophy of the integrated care system. Joint problem solving, oversight- no one person left holding risk.

Continuity and consistency enable containment and helps foster positive relationships.

report (2022) a place-based neighbourhood team could offer holistic psychosocial personalised care and early intervention through a single point.

> More proactive personalised care with support from MDT of professionals to people with more complex needs, including, but not limited to, those with multiple long-term conditions. (Fuller 2022)

An excellent example of the hub (and spoke) model of care as described here was established in Leighton Buzzard (and expanded to Dunstable) early feedback of this ‘working together programme’ suggests positive outcomes for both people accessing services and those who are working collaboratively. Getting the right support from the right people and teams.

For those referred to the diagnostic services there are prediagnostic workshops offered by Autism Bedfordshire, recovery college workshops and support from Talkback is not limited to those formally diagnosed. However, for those who cannot access these workshops or whose needs are not met by them additional support may be required. Offering guidance and advocacy in part could address this, if given alongside personalised care.

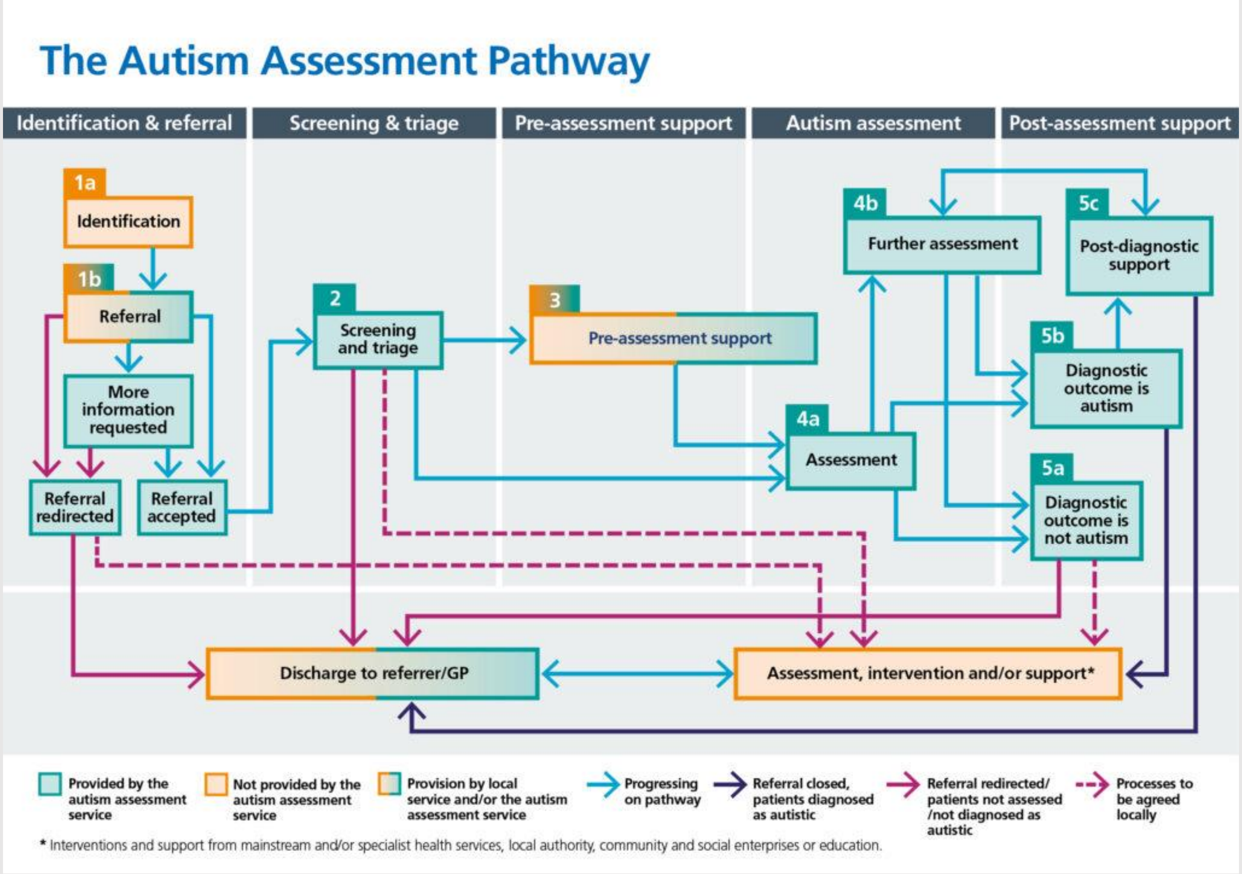


IMAGE 1 The NHSE national framework for autism assessment pathway 2023.

12. EARLY LEARNING

One of the benefits of this project has been the opportunity to network with local stakeholders and providers, developing a natural growth in information sharing. In addition, it has created a dialogue within and across services on how best to meet the needs of autistic people as well as considering how to address ‘gaps’. Further to this there have been a number of service developments, recommendations and improvements made as and when identified.

There are a number of individuals and teams who are dedicated and motivated to better the lives of autistic people. It was encouraging to experience this and nurture it. Indeed, at time of writing changes have already been put in place to address some of the issues identified here, independent of this project.

13. Afterword.

I'd like to acknowledge and share my sincerest gratitude to those who candidly shared their experiences and stories, without their input this report would not have been possible.

I could keep adding to this report from the streams of information from those who contributed and from the continued wealth of publications and reports. But a wise colleague once told me that I must learn to ‘draw a line’.

The nature of my enquiry has been from an autistic’s eye view, this has made it something of a personal journey of learning. Being in a virtual room of people who were unable to communicate because they couldn't quite fathom how to bridge the gap between talking ‘about’ autistic people, to talking ‘to’ an autistic person who wasn’t a ‘service user’ was fascinating. For once I was not the only one feeling uncomfortable and unable to speak. I hope that for those reading this report they may also find fascination and be able to use what I have collated here to their advantage. My ambition for this work is that I have faithfully translated the experiences in a way that guides positive practice and investments for change.

I have been purposefully honest and transparent about my experiences during this project, I felt it is an important illustration of experiencing local services. There is a power balance between the people who ‘know’ and the people who do not know. This immediately puts people at a disadvantage, and we should reflect on how as ‘caring professionals’ we tackle this in service developments and improvements. I’ve learnt beyond my comfort zone, I had to challenge my own confidence to overcome ambiguity and learn multiple terms, acronyms and colloquialisms of each different sector. I am not at all confident outside of the NHS still. It makes me intensely uncomfortable to admit this. So how do we expect people to feel if they need to access services and communication and language are a primary part of their disability, and they NEED this service for their welfare? We must do better; we must be curious, kind and compassionate. And not bamboozle people with our insider knowledge. We should never presume to know better. The only expert about a person is that person or the persons who know that person best.

I have the deepest respect for the work everyone provides, there has not been one person I have met during this work who has not made me feel humbled by their passion and dedication. Especially in light of our current work pressures. I am awe inspired at the talent and skills across all sectors.

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