A Life Course Approach to supporting People with Autism in Barnet

Children and Young People's Partnership Board

3rd February 2020

What can this Deep Dive help us do?

- There is already an Adults Autism Strategy and Action Plan for Barnet which needs to be refreshed
- To make this an all ages strategy for Barnet, a Children and Young People's part of the strategy is being developed, which will be signed off by the Children's Partnership Board
- Both strategies will be underpinned by an updated Action Plan, which will detail what we will deliver over the next 2-3 years
- Your role today:
  - Look at the trends and what users say about services
  - Review the strengths, solutions and what is needed to get us there - help us road test them
  - Think about how your organisation can help us move forward

What is Autism?

- It is rooted in **biology** - '**nature**' rather than 'nurture' - it cannot be 'unlearnt' or 'cured'
- It can be described as **global difference** - it has a wide-ranging impact on how someone makes sense/interacts with the world around them
- It is characterised by **difficulty in social interaction**, **communication** and by **restricted or repetitive patterns of thought and behaviour**
- Not everyone with Autism has a Learning Difficulty, but 44% of people with a Learning Disability have Autism[1]

COMMON MYTHS

People with Autism…

"…always have exceptional talents"

"…are always good with numbers"

"…always have a keen eye for detail"

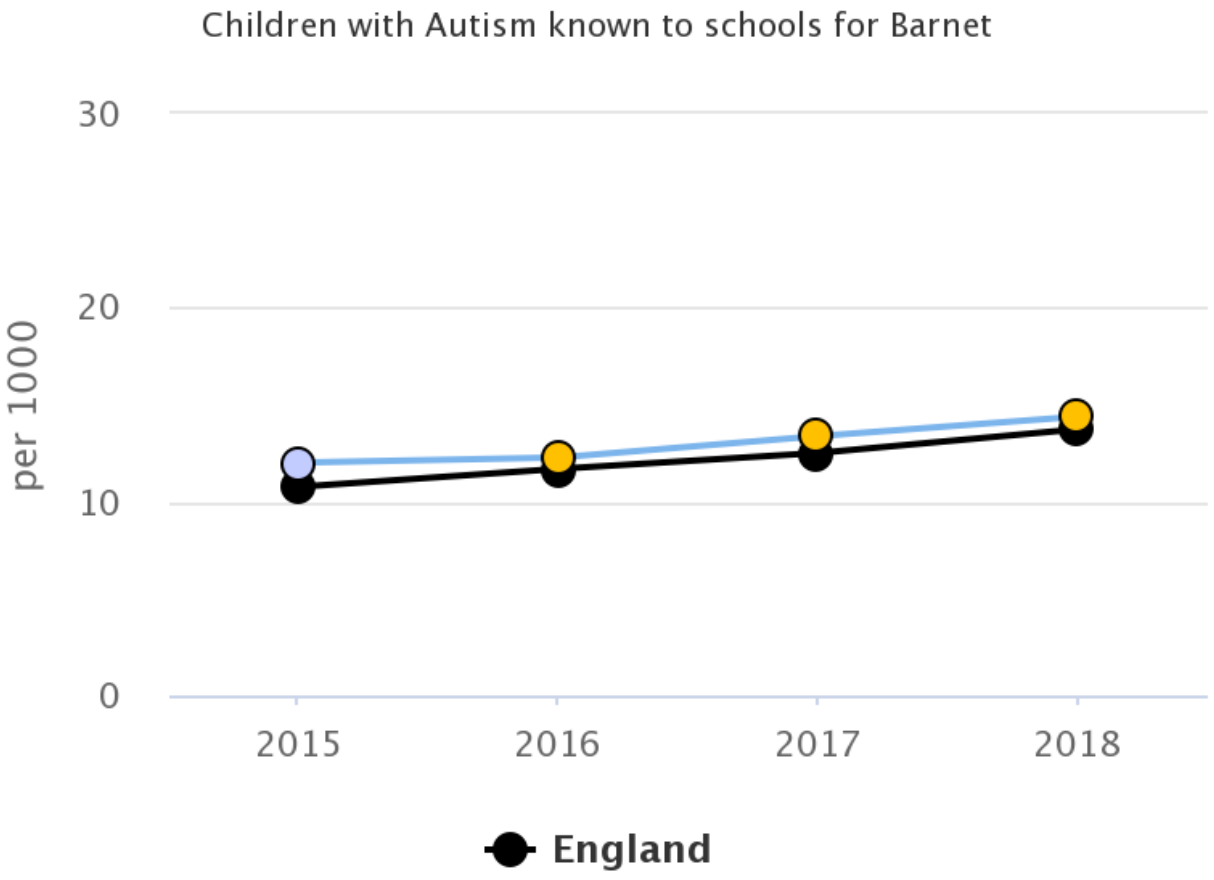
"…are always the quiet, geeky types"

The view from people with Autism (courtesy of Barnet Mencap)

The Trends

Prevalence of Autism is growing nationally

- NHS Information Centre for Health and Social Care suggests that around 700,000 people are on the autism spectrum in the UK, more than 1 in a 100 people[2]
- Numbers have been increasing nationally, research has indicated that this is driven by:
  - Better understanding of autism in the community and among professionals[3]
  - Changes in the diagnostic criteria, and its application[3]
- People with Autism are **more likely** than the non Autistic population:
  - to have **difficulty at school**, [4]
  - be **at risk of poor mental health**, [4] and
  - **not to be in employment** as they get older[4]



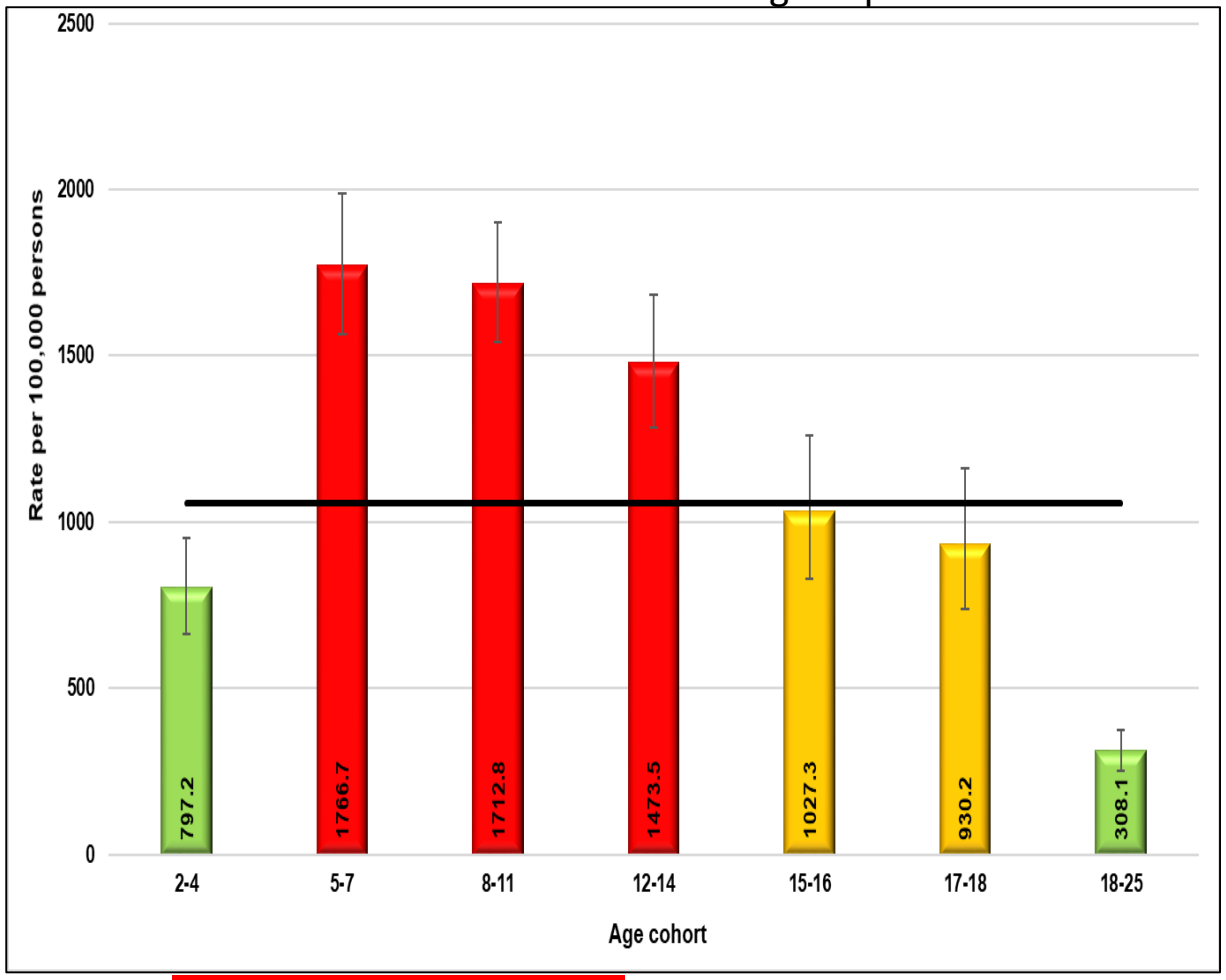
Source: Public Health England, 2018

Autism in under 18s in Barnet is also increasing…

Looking at our current school population:

- 1,213 children and young people in Barnet aged 2-25 known to have Autism in Barnet (1.06% of the population)
- Within this cohort, there were 195 females (16%) and 1,018 males (84%)
- The ratio of **males: females** diagnosed with Autism ranged from **3.7:1** for the 2-4 years age cohort to **6.3:1** for the 12-14 age cohort
- Proportion of children diagnosed with Autism in Barnet was **higher than average for 5-14 year olds** (1.8% of the population), **compared to an overall prevalence rate of 1.1% for 2-25 year olds**
- The number of children diagnosed with ASD in Barnet is lower than the North Central London average in school pupils in school years 10-13
- Over a **third (38.5%) had English as an additional language**

Prevalence of Autism in Children and Young People in Barnet



Significantly higher than average prevalence rate
Similar to average prevalence rate
Significantly lower than average prevalence rate
Average prevalence rate of ASD for cohort aged 2-25 years

…and can present with other issues…

Looking at young people with Education, Health and Care Plans:

- **57.8%** of children and young people with Autism have at least one secondary need
- The highest proportions of secondary needs are:
  - Social, Language and Communication need (SLCN),
  - a Severe Learning Difficulty (SLD), or
  - Social, Emotional and Mental Health (SEMH)

		Secondary need														
		ASD	HI	MLD	MSI	OTH	PD	PMLD	SEMH	SLCN	SLD	SPLD	VI	No secondary need	Total	% of pupils with no secondary need
Primary need	ASD	<5	<5	32	<5	15	<5	<5	39	154	81	8		468	809	57.8%
	HI			<5		<5		<5	<5				<5	30	37	81.1%
	MLD	<5	<5	15	<5	8	6		<5	44		<5	<5	52	143	36.4%
	MSI			<5						2				<5	6	50.0%
	OTH		<5	<5		<5	<5		<5	11	<5	<5		36	59	61.0%
	PD	<5	<5	14	<5	<5		<5	<5	10	5	<5	<5	53	95	55.8%
	PMLD	<5			<5	<5	<5				6		6	50	75	66.7%
	SEMH	<5	<5	13	<5		<5	<5	<5	16	<5	6		118	163	72.4%
	SLCN	8	6	30		7	10	<5	25		<5	19	5	132	248	53.2%
	SLD	6	<5			7	15		11	24	<5		<5	37	106	34.9%
	SPLD	<5	<5	<5		<5	<5	<5	6	11	<5			43	70	61.4%
	VI		<5	<5		<5	<5			<5				12	21	57.1%
	Grand To	30	20	114	8	47	45	9	94	274	100	41	16	1034	1832	56.4%

… Plus Children with Autism Become Adults with Autism

In Barnet in 2019, there were an estimated:

- **2,488 younger adults** (aged 18-64) known to be living with Autism in Barnet, which is the **2nd highest number of all the London boroughs**. Forecasts indicate that the number of young adults with autism will increase by 3.6%, by 2023
- 524 older people (aged 65+) with Autism in Barnet, which is the 2nd highest number of all the London boroughs. This is predicted to increase by 11.5% by 2023.

In 2018,

- There were 122 autistic people who were social care eligible.
- 87.7% of known autistic people with learning disabilities were eligible for social care.
- As parents / carers / family members in their caring role continue to age, their ability to provide care and support for relatives with support needs is reduced. Therefore, there is a need to ensure that we build resilience, so people can live as independently as possible.

How do we ensure that people with Autism thrive as a child and as an adult?

What do Autistic people say about our services?

Focus groups with young people, and our working groups have said…

- Chances to be listened to – student voice groups, and adults autism working group
- Therapeutic services – speech and language, mental health
- Support at school or college
- (Therapeutic) leisure activities and the chances to make friends
- Help at home
- Positive about the proposals for a North Central London diagnostic service (Autism and ADHD)
- They value voluntary sector services

- There is still a lack of understanding about Autism and how they can be supported, in school, from peers and in the community
- Young people with Autism are more likely to get anxiety or stressed
- Lack of advice about accessing a career
- Worried about making friends in future
- Lack of advice on what is available as they grow up
- Diagnosis should be quicker
- Need for navigation of system and services

What do their families and carers say about our services?

72 people responded to our questionnaire aimed at parents and carers of people with Autism…

- Support from their school, or education – generally based on a key point of contact
- Peer support
- Holiday and weekend groups
- Triple P parenting courses have helped
- Voluntary provision
- Therapies such as CAMHS and Speech and Language (when accessed, see below)
- SENDIASS

- Being able to access the right services at the right time for their child – marginally more parent-carers felt that they were able to access the right services, than accessing services at the right time
- Comments about having to wait for services, and needing to push for decisions
- Offer is not clear – parents/families feel confused about what good provision should be, and how to access it
- Services tend to be generic SEND services, rather than specialist Autism ones
- More holiday and weekend clubs
- More awareness more generally
- More specific approaches to Mental Health and autism in girls

A person's journey now…

PRE SCHOOL

2004 (Birth)	Child C born. Diagnosed with Epilepsy and Global Development Delay and under review at hospital. Has two older siblings

AT PRIMARY SCHOOL

2010 (age 6)	Child C at Primary School in Barnet Statement of SEN developed
2012 (age 8)	Child C is added to Disabled Children's Register, and is not accessing any other support other than SLT, OT and Physiotherapy
2013 (age 9)	Child C has support from Family Support Team
2014 (age 10)	Child C referred by primary school to Social Care. Parents say they are unable to manage their child's behaviour

AT SECONDARY SCHOOL

2015 (age 11)	Child C is at secondary school and referred to Social Care, as report of harm due to physical restraint. CAMHS are now part of team around the child. Parents say they are unable to cope. Family Support and Short Breaks provided.
2016 (age 12)	Child C formally diagnosed with Autism and Attention Deficit Hyperactivity Disorder. Medication trialled for ADHD.
2017 (age 13)	Child C referred to Social Care again, following violent incident. Section 47 visit with Police. CAMHS develop Positive Behaviour Support Plan with family
2018 (age 14)	EHCP developed Specialist Family Support delivered, CAMHS continue to be involved
2019 (age 15)	Police call due to violent incident by Child C at home. Parents say they are unable to cope and ask for Child C to be accommodated elsewhere. Child C is currently living at home, under an court agreed Interim Supervision Order

…What could we have done differently?

What do people with Autism want for their future?

11 – 17 year olds with Autism were also asked about what support they want for the future. This is what they said…

A lot of support preparing for independent life, making and maintaining friendships and finding a suitable job for individuals with autism.

Help to fulfil my dreams to become a racehorse trainer, and therefor get funds in order to go to a college supporting that eg. Capel Manor, Oaklands ect.

Help in gaining access to a university/college

as much support as I can from teachers and family members for exams and also my personal problems from out of school and also teachers need to understand things that make you angry and why and help you with it.

The importance of getting it right – for services

Not being able to provide appropriate support locally has meant that young people are placed in residential schools, often out of borough

We currently have **22 young people (up to the age of 25)** in these settings with a total annual cost of **£3.9m** across education, health and social care

In addition to this, since April 2019, **six people** with Autism and a Learning Difficulty have been admitted to a **mental health inpatient bed** funded by health.

Once in residential provision, a person is likely to stay in residential care as they get older

The importance of getting it right – for children

Distress being fed by failed placements and negative experiences

A national review by Lenehan and Geraghty of people in residential special schools and colleges found that:

- **70%** of children were in residential special schools because of **challenging behaviour**[5]
- Young people have had a **number of failed school placements** and **negative experiences** before they got to a residential school.[5]
- These failed placements and experiences unsettles people further, leading to **more distress** in that young person, shown as **challenging behaviour and/or mental health issues**.[5]

Breakdown of the carer relationship

A US study looked at protective factors against distress for caregivers of young people with Autism. It found that the following factors positively correlated with increased distress in the caregiver:

- the **child's externalising behaviours**, e.g. displaying challenging behaviour
- Lack of perceived **social support** and **family resources**
- Low **parenting efficacy**

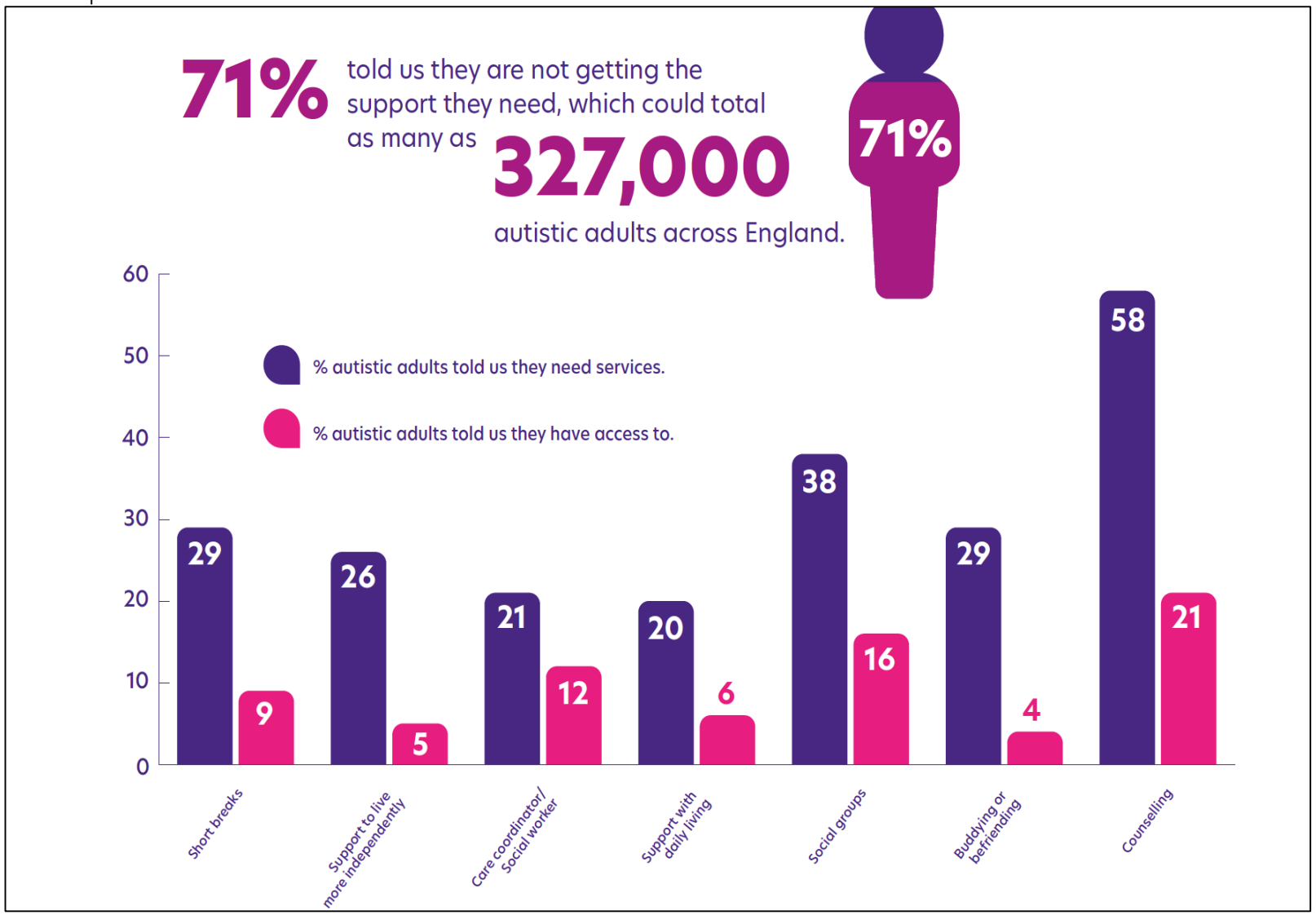
High levels of caregiver distress were linked with poorer child wellbeing, and a worse relationship between caregivers and children

Poorer outcomes for people with autism

The importance of getting it right – for adults

Unmet care needs of adults with autism in England, 2019

Source: "The Autism Act, 10 Years On" report.



What’s going well, and what can we do even better?

Identification, Diagnosis and Awareness

What we are already doing:

- **Improved identification: Girls being identified, diagnosed and supported earlier**
- **Invested in our autism assessment pathway to reduce waiting times for children and young people**
- **Established an integrated (Senior Care Coordinator) post in Barnet Enfield and Haringey Mental Health Trust (BEHMHT), with delegated responsibility from the CCG, to oversee ASC / LD cohort to support admission avoidance across the partnership**
- **Improved assessment timeframes for EHCPs so that the needs of CYP are fully represented**
- **BEHMHT has co-produced a redesign of services to improve access to treatment waiting times**
- **Autism Education Trust materials are available to support schools**

We can do even better:

Different partners use different approaches to supporting people with autism – let's move towards a **common approach(es), language and practice**

Ensure that **training** to support practitioner and community understanding **reaches every area of the workforce and community**

Explore the interplay between **autism, conditions such as trauma, self harm, eating disorders and gender dysmorphia**

Continue to work with providers, education, social care and families through our Autism Strategic Group **to redesign the diagnostic pathway to reduce waits and improve access to services**

Review **current advice and support regarding sleep**

Continue to **monitor and improve community provision including waiting times and availability of therapies** (speech and language, occupational therapy and physiotherapy)

Developing training/support materials for schools which aim to bring greater **consistency of approach across schools** in the areas of identification of need, and meeting needs of children and young people with ASD.

Information, Advice and Guidance

What we are already doing:

- **Local Offer in place online - https://www.barnetlocaloffer.org.uk/**
- **Support from SENDIASS, and advice from schools, education or the voluntary sector is valued by people with autism and their carers**
- **Services commissioned via Barnet Mencap**
- **Specific parent-carer focussed approaches such as Triple P and Cygnets are welcomed by parent-carers**
- **Informal peer to peer relationships via the Parent-Carer Network**

We can do even better:

More creative use of the Local Offer, and how we publicise and update it with new materials

More post diagnostic workshops and materials to be produced to help people understand what Autism is, and what is available to help

Some parent carers and professionals have identified a **positive campaign**, **promoting Autistic people and their positive role in the community**, could be of value

Could we look at **expanding buddying and peer to peer support networks** to help support individuals and carers?

Support – Early Intervention and Prevention

What we are already doing:

- Users and their parent-carers value leisure activities, and weekend and holiday short breaks provision
- Barnet, Enfield and Haringey Mental Health Trust (BEHMHT) are developing a psycho-education offer for children and young people and their families

We can do even better:

Earlier identification will help intervention to be delivered earlier

More provision of weekend and holiday leisure activities, including overnight respite

More **home based intervention** – the Ealing model? A multi-disciplinary centre which puts all services in one place?

Support – Early Intervention and Prevention

A solution? Intensive Therapeutic Short Breaks Service - Ealing

- Service targeted at under 18s at imminent risk of family breakdown due to severe Challenging Behaviour, where there is a high level of distress, and the family feels unable to look after the young person
- Uses a three pronged approach, led by 2 FTE clinical psychologists, and supported by the multi agency network, focussed on:
  - Regular short breaks, delivered primarily by carers at home, to help give the family unit space
  - Therapeutic interventions to help repair relationships
  - Positive Behaviour approaches – delivered using the PBS framework, and developed by the young person's family network
- Investment of around £190k per year, but also pulls on existing multidisciplinary team for children with learning disabilities

Support – Early Intervention and Prevention

Impact of service:

- Of the 43 children seen, 36 avoided residential placement and continue to live in the community.
- The remaining 7 of these children are currently in residential placements (3 of these are now adults). A further 3 went to residential school but then returned home.
- No children accessing the ITSBS admitted to Tier 4 inpatient in last 3 years.
- Tizard Centre has measures improvements in challenging behaviour and parental concerns

Source: LB Ealing presentation to NHS England, November 2019

Can we do this here?

Support – Early Intervention and Prevention

A one stop shop?

Kaleidoscope, Lewisham

Support – Crisis

What we are already doing:

- **Improved identification: Robust MDT admissions avoidance monitoring process – no LD admissions**
- **Establishing new NCL diagnostic and support services to improve waiting times and meet need for local provision**
- **Worked with NCL TCP to establish PBS training and support and NHSE commissioned Community Forensic Services provided by Barnet, Enfield and Haringey Mental Health Trust**
- **Updating our needs assessment and action plan**
- **Supporting GP practices to increase the number of annual health checks for people with learning disabilities including those with autism**
- **Focus on improving access to mainstream services for people with learning disabilities and autism, reducing health inequalities**
- **NHSE roll out of Autism and Learning Disabilities training for all NHS staff**

We can do even better:

Formalise crisis pathways and identify gaps. Identify people with Autism with mental health and complex needs supported through MDT working (admissions avoidance) and joint working with mental health commissioners and services

Work with providers, social care and people with Autism and their families and carers to **establish the new diagnostic and support service for adults in NCL** - to establish a local service reduce waits and improve links and access to services.

Strengthen **partnership working to support early Intervention for young people with LD / ASC**; building on the successes of transforming care and in line with the NHS Long Term Plan

Continue to **monitor and improve community provision** including
waiting times and availability of therapies (speech and language, occupational therapy and physiotherapy)

Consider implications for New **Care Models (CYP inpatient);** work with specialist providers to ensure appropriate inpatient provision for this cohort

Housing and Employment

What we are already doing:

- **There is a good range of providers of supported accommodation appointed to our Approved Provider List - supporting people to progress towards independent living through integrated support plans and clear move-on pathways.**
- **Growing expertise in the market to provide specialist services**
- **We have bespoke accommodation and support services for people with complex needs including innovative, flexible short term support to support people in a crisis and a new Shared Lives option.**
- **We are working more closely with mental health services to develop crisis pathways.**
- **We have pro-active family and carer support in the borough and we continue to develop and invest in services which helps people maintain their caring role.**
- **There is a range of social and community support services including specialist day services which support to progress peoples independence and employment.**
- **There is a range of approved employment support providers.**

We can do even better:

We want to **develop our innovative Home-Instead (CrashPad) model** and to improve how the service can be improved to respond more quickly and effectively. This includes 'in-reach' and close working with existing services.

We have **few providers delivering employment support and day opportunities** and need **more providers of supported living where clients require between 4 and 21 hours per week** (low support).

More opportunities for job roles, supported internships and work experience

Better **joined up identification process of suitable clients for housing** suited to the broad range of service user needs.

We are **reviewing our commissioning arrangements for employment and day opportunities** in 2020. This will include a review of our Approved Provider contract and specification.

We want to work with **independent leisure providers as well as improving and modernising existing respite provision**

Parent-carers are clear about what they think is important to improve

Rank	Suggestion	Percentage of Vote
1	Early intervention and prevention team to support 5-18 year olds. Based on Pre-School Teaching Team and/or BEAM, with home visits and working with education and health services.	17.9%
2	Improve professionals' understanding about Autism, how it presents, and how to support children, young people and adults who are Autistic	16.2%
3	Rapid Response team to respond if a child or young person is in crisis, and is at risk of going into hospital or a secure unit	13.3%
4	Resources and training for parents to understand Autism and Adolescence, and what they can do	12.7%
5	Increasing the options for employment, training and housing for young people with Autism as they move towards adulthood	12.1%

Recap on recommendations

	GAP	RECOMMENDATION
THEME 1 **Identification, Diagnosis and Assessment**	▪ Different partners use different approaches ▪ Although this has been improving, there is still late diagnosis and identification ▪ Lack of understanding in the community and among professionals about Autism	▪ Partners sign up to a common approach and set of interventions ▪ Comprehensive training plan for the workforce, including schools and settings and community groups based on the common approach ▪ Continue to redesign diagnostic pathway, reducing waiting times and increasing availability
THEME 2 **Information, Advice and Guidance**	▪ Local Offer known about, but could be used more creatively ▪ Parent training well received, but there is a desire for more face to face information, particularly post diagnosis	▪ More active and creative use/promotion of Local Offer ▪ Post diagnostic workshops and increase delivery of parent training ▪ Develop more formal buddying and peer-to-peer networks for people with Autism and Parent Carers

Recap on recommendations

	GAP	RECOMMENDATION
THEME 3 **Support – Early Intervention and Prevention**	▪ Identification comes too late for good early intervention work to take place ▪ We have some multi-disciplinary working, but can we do more? ▪ Short Breaks and Leisure activities are popular, but there is a limited supply	▪ Explore how multi-disciplinary working can be strengthened (a centre of excellence like Kaleidoscope?) ▪ Expectation that all schools and settings are "Autism friendly" ▪ Stronger home based support models to prevent issues moving to crisis point ▪ More provision of weekend and holiday leisure activities, including overnight respite
THEME 4 **Support - Crisis**	▪ Options for crisis interventions increasing, but still in its infancy ▪ Waiting times for services, including diagnosis	▪ Formalise crisis pathways, and build on our Transforming Care approach ▪ Develop our innovative Home-Instead (CrashPad) model ▪ Establish the new Autism and ADHD diagnostic and support service for adults in North Central London

Recap on recommendations

	GAP	RECOMMENDATION
THEME 5 **Housing and Employment**	▪ People need to be matched earlier with housing options that suit their needs ▪ We don't have enough Supported Living providers where people require a low level of support ▪ A lack of opportunities for supported internships, work experience and job roles	▪ Joined up identification process of suitable clients for housing ▪ Develop the market to provide a greater supply of supported living for people requiring a low level of support ▪ Review our commissioning arrangements for employment and day opportunities, to ensure that support is maximised ▪ Increase the supply of varied job opportunities for people with Autism

QUESTIONS FOR THE BOARD

? Are these the right gaps and the right recommendations?

? How can you help us to achieve them?

Keeping the momentum going

Following development of the strategy and action plan, the challenge will be to implement the strategy and action plan. There is currently an Autism Lead for Adults (which has been absorbed into an existing role), but not for Child orientated services.

To lead the delivery of the Strategy and Action Plan, does the Board want to consider:

- A single dedicated Autism lead for Barnet to work across the partnership?
- Nominate a range of existing staff as leads?

Next Steps

- Children’s Autism Strategy is being drafted – consultation on this and development of a draft Action Plan will be over the next few months
- Adults Action Plan development process is starting in January 2020
- Both the Children’s Autism Strategy and Children’s/Adults Action Plan will be signed off by May 2020 (Children’s Strategy/Action Plan by the Barnet Children’s Partnership Board, the Adult Action Plan by the Health and Wellbeing Board)

Citations and Sources

[1] National Prevalence Data

[2] The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care

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