



BHSCT AUTISM SERVICES

BHSCT provides diagnostic and intervention services for children & young people (Childrens’ Autism Assessment & Intervention Service CAAIS) and Adults and their carers and families.

The majority of the resource is within children’s service, with a small team in adults mainly providing diagnosis alongside some intervention work in partnership with contract with Cedar Foundation.

Autism services across the lifespan need close collaboration with other Trust services including children’s services, mental health services and disability services; alongside wider collaboration with other departments outside of Health & Social Care including Education, Depts of Communities and Justice as examples.

BHSCT also provides an Advice service (BAAS Belfast Autism Advice Service) for 16+years and their families/carers which is supported by a multi-agency approach and is delivered in partnership with Cedar Foundation, DEL Careers Advice Service, DES Disability Employment Service, NISSA, NAS, AI, Carers NI and the Belfast Metropolitan College.

Supporting the Autism Act and the Autism strategy BHSCT has a quarterly Autism multiagency stakeholder forum which is chaired by the BHSCT and includes Dept Education, Dept Communities, Youth Justice Agency, 3rd Sector Autism organisations and service user representation.

The services across all ages have been under pressure since their establishment with significant demand outstripping capacity. This gap continues to grow as noted below. Whilst we have been grateful for the support and additional commissioning over the years, it has never been at a level to sufficiently address the demand and long backlog tails continue to grow. The challenges posed by COVID-19 have significantly added to the difficulties. An inability to provide face-face appointments for a portion of time, combined with an inability to use the standardised observation scale with a face mask have all contributed to the increase in waiting lists. The number of patients waiting first appointment for each service is noted below0.

Number on the Adult ASD assessment WL.

Month Ending	> 52 weeks (365+ days)	Total Waiters	Longest Wait (in Days)
Sep-21	394	494	1919

Number on the Adult ASD intervention WL

Month Ending :	> 52 weeks (365+ days)	Total Waiters	Longest Wait (in Days)
Sep-21	6	31	603

Number on the CYP ASD assessment WL

Month Ending :	> 52 weeks (365+ days)	Total Waiters	Longest Wait (in Days)
Sep-21	1079	2020	1056

Number on the CYP ASD Intervention WL*

Month Ending :	> 52 weeks (365+ days)	Total Waiters	Longest Wait (in Days)
Sep-21	0	132	64

*The CYP ASD WL is significantly reduced from pre-COVID19 levels as we redirected resources to this part of the service from assessment when we couldn't carry out assessments due to measures to mitigate covid19 restrictions.

Recent submission to the DOH noted that the BHSCCT capacity to conduct new assessments (approx 600 per year for children and 40 per year for adults) has never been able to match the number of referrals accepted each month. In some years where additional non-recurrent funding was available, the Trust increased capacity through IS contracts. However, the increasing and significant backlog has meant that waiting times have continued to increase. Please see illustrative figures below in Table 1. This cumulative effect combined with significant loss of capacity from March 2020 related to measures to mitigate COVID-19 have increased the number of families waiting and their waiting time. In addition, there is a significant, growing intervention demand as a result of the number of confirmed ASD diagnosis.

This deficit has been highlighted to DoH, HSCB and PHA colleagues for a number of years. Information with regards to waiting lists across children and adult services and with respect to diagnostic assessment and intervention is sent to HSCB monthly.

BHSCCT took the decision to accept private diagnosis which were evidenced to be in line with NICE guidelines in 2016/17. As the BHSCCT did not have commissioned capacity to ensure that diagnosis were delivered in a timely manner and it would not be appropriate to make families undertake a repeat assessment without a sound clinical rationale, it did not seem a sustainable position that appropriate private reports were not accepted. Criteria for acceptance are clearly noted and were sent to all known providers and are openly discussed with parents.

Table 1: Cumulative challenges for BHSCT ASD D referrals for CYP in relation to referrals and numbers waiting

	Total Number	Percentage change from 16/17 baseline
Current capacity following 2016 investment N=600		
16/17 No. of referrals accepted	523	-
No. on WL	878	-
17/18 No. of referrals accepted	910	+74%
No. on W/L	696	-20%
18/19 No. of referrals accepted	1059	+100%
No. on W/L	725	+23%
19/20 No. of referrals accepted	843	+61%
No. on W/L	1236	+40%
20/21 No. of referrals accepted	765	+46%
No. on W/L	1866	+112%

Table 2: Cumulative challenges for BHSCT Adult Diagnostic service in relation to referrals

	Total Number
Current capacity n=40	
17/18 No. of referrals	194
18/19 No. of referrals	179
19/20 No. of referrals	186

20/21 No. of referrals	111
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Significant work was done over Covid to support families who have a diagnosis but also for those waiting on assessment including development of online workshops and resources and a focus on intervention and support. We have recently released our [Help for Parents & Carers](#) as we are very mindful of the challenges faced by families as they await diagnostic assessment in the current challenges.

The BHSC has submitted a response to the Autism Amendment Bill with respect to potential impacts on the trust. This is enclosed.

Ongoing issues/ challenges

1. Demand for Autism diagnosis and subsequent intervention continues to rise. The current systems are not commissioned to meet this level of demand. There is a need for recurrent investment to meet the recurrent demand and also non-recurrent investment to manage the tails due to the capacity-demand gap that has been building over many years and was exacerbated by COVID-19. Without this input, waiting lists will continue to grow. There is a specific need to consider funding needs within adult services. It is currently funded for approximately only 21% of the total demand based on referrals prior to this year.
2. The growth and presentation of autism in NI is poorly understood and research into this area is needed to understand population prevalence and need in the coming years. Narratives around increasing rates of referral and diagnosis often feel targeted at clinicians and Trusts and this presents challenges and confusion of messages around accessibility and considering autism as part of assessment and presentation. Differences in Trusts' systems and referral mechanisms perpetuate these perceived variations.
3. Whilst training with regards to Autism is important (as noted in the Amendment Bill), consideration needs to be given to the spectrum of need and to consider carefully that training does not perpetuate certain presentations and needs and potentially continue to stigmatise and narrow perceptions of those who have a diagnosis of autism. Involvement of those with a diagnosis needs to reflect the breadth of need and ensure this is reflected in any training. Potentially more work needs to be done to increase a culture of tolerance of difference and acceptance rather than training around 'disability'.
4. Better clarity around "early intervention in autism" is required. The Children's Emotional Health & Wellbeing Framework has been launched to provide early intervention for children presenting with delays or differences in development. Early intervention is key and it is here that the evidence base is seen, rather than in concepts of early diagnosis. Autism-aware interventions are appropriately developed and delivered within this framework. Investment in early intervention should be focused into this Framework, where a consideration of autism should form part of the clinical discussion.
Timely intervention for Autism specifically will require additional investment in Autism Assessment and Intervention services to allow quicker access to children, young people and adults to both diagnosis and subsequent autism-specific interventions.

5. Leadership of the Autism Act has sat within Health & Social Care and this has resulted in services being overly focused into this area. In reality most parents seek a diagnosis due to concerns that their children are not accessing sufficient support within educational environments. Young people and adults require support with employment, living arrangements, finances and a diagnostic process remains a pathway to accessing these supports. There needs to be more engagement and accountability across all Departments and all areas of expected life goals to support individuals struggling with difference and make our systems and supports more accessible to all.
6. Any development of an Autism reviewer needs to be seen as independent, from the third sector as well as statutory services. The 3rd sector are significant partners in the delivery of support and services to families supporting children, young people and adults with autism and need to be include in any accountability reviews.
7. A wider and more comprehensive piece of work needs done to consider outcomes for individuals and their families with autism. Their needs vary along a wide continuum, and better understanding of their desired outcomes may change the delivery of services and funding significantly. Currently outcomes are based on waiting lists, but this in no way reflects improvements to life plans, goals or expectations.

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18/10/21

BELFAST HEALTH AND SOCIAL CARE TRUST		COMPLETED BY: BHSCT
		DATE: October 2021
PRIVATE MEMBERS BILL – Autism (Amendment) Bill		Sponsor – Pam Cameron MLA (DUP)
Additional components of strategy		
Section	Objective	Where <u>applicable or relevant</u>, please state how this will impact on your Department, including potential costs.
Section 2 (4A)	<p>The autism strategy must set out how training (including accredited training) is to be provided to the staff of Northern Ireland Departments and other public bodies to best address the needs of:</p> <ul style="list-style-type: none"> (a) People with autism, and (b) The families and persons with autism. 	<p>The BHSCT currently offers staff, family and carer training but if this is to be rolled further then there will be some ongoing cost for the staff time and ICT required to deliver this.</p> <p>In particular, there is a growing demand for individual training from staff across HSC services where a service user has a diagnosis of ASD or is awaiting ASD assessment.</p> <p>From a population perspective, this is not unexpected as raising awareness of ASD has been one of the Act's core objectives. In addition, over the last 5 years each of the Trust's CYP ASD assessment services have been providing more assessments and this has naturally led to more positive diagnosis than ever before.</p> <p>There is no sign that this trend will reverse as referrals for ASD assessment increase year on year (please see summary update).</p>

<p>(4B)</p>	<p>The autism strategy must set out how the Department is to make provision for an autism early intervention service.</p>	<p>Better clarity around “early intervention in autism” is required. The Children’s Emotional Health & Wellbeing Framework has been launched to provide early intervention for children presenting with delays or differences in development. Early intervention is key and it is here that the evidence base is seen, rather than in concepts of early diagnosis. Autism-aware interventions are appropriately developed and delivered within this framework.</p> <p>Investment in early intervention should be focused into this Framework, where a consideration of autism should form part of the clinical discussion. Timely intervention for Autism specifically will require additional investment in Autism Assessment and Intervention services to allow quicker access to children, young people and adults to both diagnosis and subsequent autism-specific interventions.</p>
<p>(4C)</p>	<p>The autism strategy must set out how the Department is to make provision for an autism information service which is accessible (both in person and remotely) by –</p> <ul style="list-style-type: none"> (a) persons with autism, (b) the families and carers of persons with autism, and (c) professionals working with persons with autism, and their families and carers. 	<p>There should be a regional approach to this that offers a menu of options for accessing information. Whichever organisation manages this will need funding for staff and overheads including ICT.</p>

(4D)	<p>The autism strategy must set out how the needs of adults with autism will be addressed, including their needs in respect of:</p> <ul style="list-style-type: none"> • lifelong learning • employment support • recreation • emotional and mental wellbeing, and • supported living 	<p>Leadership of the Autism Act has sat within Health & Social Care and this has resulted in services being overly focused into this area. In reality most parents seek a diagnosis due to concerns that their children are not accessing sufficient support within educational environments. Young people and adults require support with employment, living arrangements, finances and a diagnostic process remains a pathway to accessing these supports. There needs to be more engagement and accountability across all Departments and all areas of expected life goals to support individuals struggling with difference and make our systems and supports more accessible to all.</p> <p>Should the diagnostic process remain a pathway to wider services, it should be noted that there is currently an approximate 5 year wait for an Adult ASD assessment in BHSCT. The service is currently funded for only 21% of the demand it experiences (based on last the 3 years of referrals for assessments prior to this year - please see summary update).</p> <p>This has obvious negative consequences if services, essential for living a full life, are provided based on the definition of 'adult with autism' yet adults cannot access that assessment and possible diagnosis easily.</p>
Section 3 (A) (1)	The Department will take into account best international practice on autism.	The BHSCT would support this proposal.

(2)	3 (A) The autism strategy must take into account that persons with autism, and their families and carers, have individualised needs.	Unable to provide assessment without more detail of impact as the service is already multidisciplinary in nature.
(3)	3 (A) The autism strategy must take a multidisciplinary approach.	
(4)	3 (A) The autism strategy must aim to ensure consistency of practice across all HSC trusts.	
(5)	3 (A) The Department must set out measurable targets against which its effectiveness may be assess.	A wider and more comprehensive piece of work needs to be completed to consider outcomes for individuals and their families with autism. Their needs vary along a wide continuum, and better understanding of their desired outcomes may change the delivery of services and funding significantly. Currently outcomes are based on waiting lists, but this in no way reflects improvements to life plans, goals or expectations.
(6)	3 (A) Without limiting generality of consultations required under section 2 (2) those measurable targets must be developed in consultation with bodies with an interest in promoting the rights of persons with autism.	
4	The Minister must lay before the Assembly, for each financial year, a report setting out how the funding for autism in respect of that year, to account of:	Please also state how, and if, this can be managed within your Department.

	<ul style="list-style-type: none"> • the autism strategy, • the prevalence of autism in children and adults, • the needs of persons with autism. • the needs of families and carers of persons with autism, and • the potential for collaboration with bodies with an interest in promoting the rights of persons with autism <p>in this section 'funding for autism' means:</p> <ol style="list-style-type: none"> a) in respect of the Department, the allocation of funding for health and social care, in so far as it relates to the autism strategy; b) in respect of other Northern Ireland departments, the allocation of funding for that part of the autism strategy which falls within their responsibilities. 	<p>The budget for working with CYP and adults with ASD is contained across many different services and budgets within BHSCT. Services are normally needs led rather than diagnostic label led. It will be very challenging to extract this accurately as many may not be labelled 'ASD funding' or only for those with ASD.</p> <p>Budgets for those services that are clearly designated solely for ASD assessment and intervention are also located across various services within BHSCT. In order to report on this it will be helpful streamline these into a single budget each for CYP and adults.</p>
5	<p>The Department must appoint a person as an autism reviewer.</p> <p>The reviewer must issue a report annually on the exercise of their functions and may issue additional reports.</p> <p>The reviewer must send a report annually on the exercise of their functions, and may issue additional reports.</p>	<p>Any development of an Autism reviewer needs to be seen as independent, from the third sector as well as statutory services. The 3rd sector are significant partners in the delivery of support and services to families supporting children, young people and adults with autism and need to be included in any accountability reviews.</p> <p>Also, if this function is required, a balanced review process with a panel rather than an individual may be more helpful. An individual may have increased risk of actual or perceived bias.</p>

The reviewer must send any report to the Department.

On receiving the report, the Department must it before the Assembly.

The Department must pay the reviewer expenses and allowances which are reasonably necessary in order to allow the reviewer to carry out their functions.

The functions of the reviewer are:

- to monitor the implementation and effectiveness of the autism strategy;
- to assess the efficacy of the funding arrangements in respect of autism;
- to keep under review the adequacy and effectiveness of the law and practice relating to autism;
- to keep under review the adequacy and effectiveness of services provided for persons with autism, their families and carers;
- to commission independent research on best international practice on autism;
- to advise the Assembly, if requested, on matters relating to autism; and
- any other function which the Department may confer upon the reviewer.

<p>Further clause (presented in Explanatory and Financial Memorandum NIA Bill 31/17-22 EFM but not in Bill)</p>	<p>As well as an obligation to consult other Northern Ireland departments before preparing the strategy, the Department is now obliged to consult other persons.</p>	<p>A consultative questionnaire to request call for evidence launched on 23 August and will close on 8 October.</p> <p>Autism Strategy 2023-2028 Department of Health (health-ni.gov.uk)</p>
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