

29 October 2021

VIA EMAIL ONLY: committee.health@niassembly.gov.uk

Committee for Health
Parliament Buildings
Stormont
Belfast
BT4 3XX

RE South Eastern Health and Social Care Trust (SEHSCT) response to the (Autism Amendment) Bill - Impact on Services provided by Trust.

Children's Autism Service.

The SEHSCT welcomes the Autism (Amendment) Bill and the opportunity to comment on the potential impact on services provided.

Section 2 (4A) Training: the Children's Autism Team currently provide training to Trust staff, both generally in relation to adapting practice to support people with autism and their families and in response to more specific situations if required. The Trust would welcome a regional approach to training for staff across Departments and other public bodies to ensure consistency of accessibility and quality and to avoid duplication across Trusts. We suggest that training should be co-produced. There would also be a requirement for regional agreement on what constitutes accredited training. Service delivery in response to Covid has evidenced the benefits of virtual delivery of training and this approach to delivering training would require technical and IT support to maintain it and also Clinical Support to quality assure. This would have funding implications at Trust level.

(4B) Autism Early Intervention Service: The provision of an Autism Early Intervention Service is in keeping with the Emotional Health and Well-being Framework, which advocates an early intervention approach for children presenting with neurodevelopmental, behavioural and emotional well-being needs. The appointment of a Coordinator at HSCB/PHA will support the implementation of this framework. We would suggest that an early intervention service should be available pre-diagnosis. There would be significant funding required at Trust level to fully develop this service.

(4C) Autism Information Service: The ASD Coordinators are already working collaboratively to share information and resources which are delivered locally, with the aim of sharing good practice and reducing duplication. A regionally led approach to this and the inclusion of 3rd sector organisations would be welcomed. Again, lessons learnt from service delivery during the Covid situation and feedback from families would indicate that the ability to access information remotely is beneficial to families. A regional virtual repository for the sharing of information, resources and

psychoeducational training would be welcomed. This would also require IT and clinical support. If a centralised Autism Information Service was available this could then be accessed locally.

Section 3 (A) (1) Best International Practice: The availability, quality assurance and dissemination of this information would have a positive impact on service delivery and governance. Again a regional approach to this would be welcomed.

3 (A) (2), (3), (4) Individualised Needs / Multidisciplinary Approach / regional consistency. An individualised approach is already embedded in practice; however, the provision of additional funding for intervention would enable this to be further developed at Trust level. The ability to increase capacity for intervention would support delivery of a more coordinated, comprehensive needs assessment and intervention plan for children and families.

In meeting the individualised needs of children with autism it is recognised that they may have comorbid conditions which require collaboration across a range of services. These services also need to be appropriately funded to ensure they are accessible in a timely manner for all children eg; CAMHS, ADHD, Occupational Therapy, Speech & Language Therapy

ASD Coordinators and Clinical Leads meet regularly to work collaboratively towards regional consistency. An example of this was in response to Covid and its impact on service delivery, particularly Autism Assessments. A Task and Finish Group was set up to agree a regional approach to adapted assessments which was issued to clinicians regionally and enabled the continuation of assessment activity during lockdowns. The appointment of a Coordinator at HSCB/PHA will further assist with this on-going work.

3 (A) (5) Measurable Targets These should be agreed with a range of stakeholders, including clinicians within the Trusts as well as the autistic community. The funding requirements of any new targets should be considered from the outset and plans put in place to provide adequate funding to enable targets to be monitored and met.

Section 4 (3B) Annual Autism Funding Reports: The Trust acknowledges the importance of annual reporting associated with funding. A regional approach to gathering data will assist this process whilst recognising there will be a financial burden to the collection and collating of data.

While the Trust appreciates the focus through the Autism Act, Autism Strategy and this Autism Amendment Bill on Autism, we are very aware that children present a range of other neurodevelopmental, emotional health and well-being condition which also need to be addressed through the provision of additional service and associated funding.

Yours sincerely



ROISIN COULTER
Chief Executive

DEPARTMENT:		COMPLETED BY:
SEHSCT		DATE:
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> <p>(a) People with autism, and (b) The families and persons with autism.</p>	<p>Section 2 (4A)Training: the Children’s Autism Team currently provide training to Trust staff, both generally in relation to adapting practice to support people with autism and their families and in response to more specific situations if required. The Trust would welcome a regional approach to training for staff across Departments and other public bodies to ensure consistency of accessibility and quality and to avoid duplication across Trusts. We suggest that training should be co-produced. There would also need to be regional agreement on what constitutes accredited training. Service delivery in response to Covid has evidenced the benefits of virtual delivery of training and this approach to delivering training would require technical and IT support to maintain it and also Clinical Support to quality assure. This would</p>

		have funding implications at Trust level.
(4B)	The autism strategy must set out how the Department is to make provision for an autism early intervention service.	(4B) Autism Early Intervention Service: The provision of an autism early intervention service is in keeping with the Emotional Health and Well-being Framework, which advocates an early intervention approach for children presenting with neurodevelopmental, behavioural and emotional well-being needs. The appointment of a Coordinator at HSCB/PHA will support the implementation of this framework. We would suggest that an early intervention service should be available pre-diagnosis. There would be significant funding required at Trust level to fully develop this service.
(4C)	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 – <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. 	(4C) Autism Information Service: The ASD Coordinators are already working collaboratively to share information and resources which are delivered locally, with the aim of sharing good practice and reducing duplication. A regionally led approach to this and the inclusion of 3 rd sector organisations would be welcomed. Again, lessons learnt from service delivery during the Covid situation and feedback from families would indicate that the ability to access information remotely is beneficial to families. A

		<p>regional virtual repository for the sharing of information, resources and psychoeducational training would be welcomed. This would also require IT and clinical support. If a centralised Autism Information Service was available this could then be accessed locally.</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>4(D) The Trust welcomes the commitment for the Strategy to address the needs of adults with autism. The development of Strategy and Services for adults with autism lag significantly behind the focus which has been afforded for children with autism. This fails to acknowledge:</p> <ul style="list-style-type: none"> - the increasing number of adults who have received a diagnosis of autism in adulthood, and - that young people will transition to adulthood at age 18 years, and that their needs can intensify at that time, rather than reduce. <p>There is a consistent body of research that evidences adults with autism have significant rates of unemployment, poverty and social disadvantage. They also have higher prevalence rates of physical and mental health difficulties, including premature death as a result of</p>

		<p>suicide and untreated health conditions. We welcome the intention for the Strategy to address these areas of unmet need for adults with autism.</p>
Section 3 (A) (1)	The Department will take into account best international practice on autism.	<p>Section 3 (A) (1) Best International Practice: The availability, quality assurance and dissemination of this information would have a positive impact on service delivery and governance. Again a regional approach to this would be welcomed.</p>
<p>3 (A) (2)</p> <p>3 (A) (3)</p> <p>3 (A) (4)</p>	<p>The autism strategy must take into account that persons with autism, and their families and carers, have individualised needs.</p> <p>The autism strategy must take a multidisciplinary approach.</p> <p>The autism strategy must aim to ensure consistency of practice across all HSC trusts.</p>	<p>3 (A) (2), (3), (4) Individualised Needs / Multidisciplinary Approach / regional consistency. An individualised approach is already embedded in practice; however, the provision of additional funding for intervention would enable this to be further developed at Trust level. The ability to increase capacity for intervention would support delivery of a more coordinated, comprehensive needs assessment and intervention plan for children and families. In meeting the individualised needs of children with autism it is recognised that they may have comorbid conditions which require collaboration across a range of services. These services also need to be appropriately funded to</p>

		<p>ensure they are accessible in a timely manner for all children eg; CAMHS, ADHD, Occupational Therapy, Speech & Language Therapy</p> <p>ASD Coordinators and Clinical Leads meet regularly to work collaboratively towards regional consistency. An example of this was in response to Covid and its impact on service delivery, particularly autism assessments. A Task and Finish Group was set up agree a regional approach to adapted assessments which was issued to clinicians regionally and enabled the continuation of assessment activity during lockdowns. The appointment of a Coordinator at HSCB/PHA will further assist with this on-going work.</p>
3 (A) (5)	The Department must set out measurable targets against which its effectiveness may be assess.	<p>3 (A) (5) Measurable Targets These should be agreed with a range of stakeholders, including clinicians within the Trusts as well as the autistic community. The funding requirements of any new targets should be considered from the outset and plans put in place to provide adequate funding to enable targets to be monitored and met.</p>
3 (A) (6)	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:	<p>Please also state how, and if, this can be managed within your Department.</p>

	<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> <ul 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>Section 4 (3B) Annual Autism Funding Reports: The Trust acknowledges the importance of annual report associated with funding. A regional approach to gathering data will assist this process whilst recognising there will be a financial burden to the collection and collating of data.</p>
<p>5</p>	<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>The reviewer must send any report to the Department.</p> <p>On receiving the report, the Department must it before the Assembly.</p> <p>The Department must pay the reviewer expenses and allowances which are reasonably necessary in order to allow the reviewer to carry out their functions.</p> <p>The functions of the reviewer are:</p> <ul style="list-style-type: none"> • 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 	

	<ul style="list-style-type: none"> 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>While the Trust appreciates the focus through the Autism Act, Autism Strategy and this Autism Amendment Bill on Autism we are very aware that children present with a range of other neurodevelopmental, emotional health and well-being conditions which also need to be addressed through the provision of additional service and associated funding.</p>
<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>

SOUTH EASTERN HEALTH AND SOCIAL CARE TRUST

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