

<b>DEPARTMENT: Western Health &amp; Social Care Trust</b>		<b>COMPLETED BY: Dr Mary McDaid, Dr Thomas McCarthy &amp; Margaret Ferris</b>
<b>PRIVATE MEMBERS BILL – Autism (Amendment) Bill</b>		<b>DATE: 14<sup>th</sup> October 2021</b> <b>Sponsor – Pam Cameron MLA (DUP)</b>
<b>Additional components of strategy</b>		
<b>Section</b>	<b>Objective</b>	<b>Where applicable or relevant, please state how this will impact on your Department, including potential costs.</b>
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"> <li>(a) People with autism, and</li> <li>(b) The families and persons with autism.</li> </ul>	<p>Within HSCT's the training component of the bill will impact in a number of different ways.</p> <p>Consideration needs to be given to the following; - training for HSC staff – Level/Frequency</p> <ul style="list-style-type: none"> <li>- level of training to be provided – accredited/non-accredited. Are there accredited courses available or do these need to be developed?</li> <li>- facilitation of such training <ul style="list-style-type: none"> <li>- Training within HSC it will require specialist clinical staff from Autism Services to be released to facilitate same. This will have financial and time associated costs. This will also impact upon service delivery and timely access to autism services within the Trust. Current capacity already outstrips demand resulting in lengthy waiting lists to access services.</li> <li>- Costs associated with releasing staff to facilitate and attend relevant training.</li> <li>- Consideration should be given to development of an Autism Training Framework with different levels of training</li> </ul> </li> </ul>

		<p>available based on staff's roles and responsibilities, for example,  Level 1 – Autism Awareness  Level 2 – Understanding Autism  Level 3 – Enhanced skills in Autism  Level 4 - Autism Expertise</p> <p>Clinical staff from across Children and Adult services continue to facilitate autism training for staff across the Trust and also external professional staff within the GP Federation and Surestart.</p> <p>Consideration in this clause should also be given to provision of training to those who are/will be working with individuals with ASD.</p>
(4B)	<p>The autism strategy must set out how the Department is to make provision for an autism early intervention service.</p>	<p>In order for HSC to deliver on this objective significant investment will be required to ensure timely early intervention following confirmation of diagnosis. The current resource does not meet the current level of demand and this demand continues to increase year to year and the complexities presenting are also increasing in nature.</p> <p>Effective early intervention to each individual with autism requires specialist clinical staff to assess and design the appropriate interventions.</p> <p>Early intervention will assist persons in attaining their best outcome throughout their lives.</p> <p>Work is ongoing within the WHSCT to take the principles of the Draft Regional EHWP Framework which has focus on early intervention based upon need rather than diagnosis,</p>
(4C)	<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>	<p>Consideration should be given to developing an interdepartmental autism information resource</p>

	<p>(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>	<p>which is managed on a regional basis with links to community and voluntary sector organisations similar to what ASDWales has established. From HSCT's perspective time to develop resources from a health perspective will impact upon the Trust or will this be managed centrally by PHA?</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"> <li>• lifelong learning</li> <li>• employment support</li> <li>• recreation</li> <li>• emotional and mental wellbeing, and</li> <li>• supported living</li> </ul>	<p>This is an important issue. The numbers of adults with a diagnosis of ASD is increasing and all those who are diagnosed with ASD as children will spend the majority of their life eligible for adult services.</p> <p>There are a number of elements of ASD that are linked to services other than health. There is a need for the Department of Health to consider what elements of health and social care they will provide and how this will be stratified and administered.</p> <p>Depending on the plans and how these are administered there will be implications for health and social care.</p> <p>For HSCTs to support delivery of this objective significant investment is required to establish an adequate adult autism service provision in terms of diagnostic assessment and lifelong support and intervention within Trust areas. Currently there is a very limited resource for adult autism provision which has resulted in lengthy waiting lists, unfunded pressures through provision of self-directed support and many areas of unmet need have been identified. The demand continues to increase year on year.</p>
Section 3 (A) (1)	<p>The Department will take into account best international practice on autism.</p>	<p>A regional clinical group could be established to support the provision of best international clinical practice across the region and provide advice to</p>

		<p>the Department. This will have financial and service delivery implications for Trusts as staff are released from day to day duties to support this group.</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>There is a need to develop clear and functioning pathways to ensure collaborative working where all relevant services work together to meet the needs of people with autism, their families and carers. Ensuring the needs of people with autism are met by all providers, including those where ASD is not a 'specialism,' or prime statement of purpose.</p> <p>Within HSCTS there is a focus on individualised care and support to meet the needs of people with autism, their families and carers allowing for choice and flexibility in the way these are accessed and provided using the self-directed support model. However no additional funding resource has been provided to Trusts to support the self-directed support model for Autism and as a result Trusts have an unfunded pressure relating to this provision which is continuing to increase due to the demand and the assessed need for this support for people with autism.</p> <p>3(A)(3) – Within Trusts autism services have adopted a multi-disciplinary approach. Given that the autism strategy straddles a number of Government Departments it is important to identify that the autism strategy takes a multi-agency approach as well as multi-disciplinary. Additional staff will be required to enhance multi-disciplinary teams to meet the demand for diagnostic assessments and clinical support and interventions.</p>

		<p>3(A)(4) – Clarification in terms of what areas consistency of practice is required. Autism does not have a designated programme of care therefore it sits within different directorates across HSCTs.</p> <p>The WHSCT is working alongside its Paediatric colleagues across the region, the PHA and HSCB to create consistency of practice.</p>
3 (A) (5)	The Department must set out measurable targets against which its effectiveness may be assess.	It will be important that the targets set are meaningful and measurable and that there is consistency in reporting of data across the region.
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.	<p>It will also be important to consult with those providing clinical services/service users/carers to agree the targets to ensure what is being required can be measured.</p> <p>Funding to support information services in reporting on such targets will be required.</p>
4	<p>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> <ul style="list-style-type: none"> <li>• the autism strategy,</li> <li>• the prevalence of autism in children and adults,</li> <li>• the needs of persons with autism.</li> <li>• the needs of families and carers of persons with autism, and</li> <li>• the potential for collaboration with bodies with an interest in promoting the rights of persons with autism</li> </ul> <p>in this section 'funding for autism' means:</p> <p>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;</p>	<p><b>Please also state how, and if, this can be managed within your Department.</b></p> <p>This will be difficult to report on from a Trust perspective. All autism funding does not sit neatly in one place and as eluded to earlier Autism does not have a dedicated programme of care and can straddle a number of programmes within Trusts. Many people with autism have co-occurring mental health and/or intellectual disabilities therefore the support provided may be funded from a range of funding areas within Trusts.</p> <p>Additional resource to support the finance department to report on this clause will be required.</p>

	<p>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>	
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>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"> <li>• to monitor the implementation and effectiveness of the autism strategy;</li> <li>• to assess the efficacy of the funding arrangements in respect of autism;</li> <li>• to keep under review the adequacy and effectiveness of the law and practice relating to autism;</li> <li>• to keep under review the adequacy and effectiveness of services provided for persons with autism, their families and carers;</li> <li>• to commission independent research on best international practice on autism;</li> <li>• to advise the Assembly, if requested, on matters relating to autism; and</li> <li>• any other function which the Department may confer upon the reviewer.</li> </ul>	<p>Consideration could be given to this function being facilitated within existing structures and lines of accountability.</p> <p>If this role is established, this will lead to the need for staff within Trusts and other departments to spend considerable time developing and providing information for such a reviewer. This will have cost and time implications.</p>
Further clause (presented in Explanatory and Financial Memorandum NIA Bill 31/17-	<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><u><a href="#">Autism Strategy 2023-2028   Department of Health (health-ni.gov.uk)</a></u></p>

22 EFM but not  
in Bill)