

Department of Health, Social Services and Public Safety

Introduction

1. The purpose of this paper is to update members of the Health and Social Care Committee on the Departmental view on the Private Member's Autism Bill, in advance of the oral evidence session scheduled for 20 January 2011. The key points remain those outlined in our paper of 29 November 2010 and covered in the oral evidence presented to the Committee on 2 December. For ease of reference, the previous Health Committee submission (**Appendix A**) is appended.
2. The Department has significant concerns regarding the content and quality of the Bill and remains of the view that legislation is not required to drive forward service improvement; the focus should be on the application of all available resources to the enhancement of front line services rather than on legislation and the bureaucracy which will inevitably come with it.
3. This paper concentrates on issues relating to:-
 - **Amendments to DDA;**
 - **Competence of the Bill, and clarity of intent;**
 - **Cost; and**
 - **Bureaucracy arising from the Bill.**

Amendment to DDA

4. **Clause 1** of the Bill includes amendments to the Disability Discrimination Act 1995 to include the words – “social (including communication)” and amendment to Schedule 1 to include “taking part in normal social relationships” and “forming social relationships”.
5. You will be aware that responsibility for anti-discrimination legislation, including for those with disabilities, rests with OFMDFM. In such

circumstances, the Committee might wish to seek the advice of the relevant department regarding any proposed changes to the DDA.

6. It remains this Department's view, as stated previously, that autism is already embraced by the DDA, as evidenced in practice by case law. In addition, the proposed non specific changes could have far reaching negative effects on individuals and society which may not have been intended by the proposer of the Bill.
7. It is also of note that proposed changes to the DDA, in our view, will not have the desired effect of increasing access to Social Security Benefits (as suggested); for example, Disability Living Allowance is based on the impact/disability arising from a condition and not the condition itself.
8. However, legislation and regulations on access to social security benefits fall within the remit of the Department of Social Development (DSD). Any further detailed information should be sought from that Department.

Competence and Clarity of Intent of the Bill

9. **Clauses 2 and 3** provide for the formation and content of the autism strategy. From a policy perspective, it remains uncertain what the proposed strategy (as outlined in the Bill) is designed to do. This is especially so as there is already in place an ASD strategic action plan and an infrastructure to deliver it.
10. The Bill is stated as having no significant cost, yet it might be argued that the Bill's intent is to improve the rights of individuals and their carers to have needs met. This could not be achieved without significant cost. Hence, the intention is not clear. It should be noted that the approach taken in this Bill is somewhat different to that of the Autism Act 2009 which clearly defines duties and responsibilities within the Autism Strategy.

11. In addition, Health Committee members will be aware that, in December 2010, the Committee for Education, Lifelong Learning and Culture in Scotland (the Committee to which the lead on the Autism (Scotland) Bill was allocated) rejected the Bill - expressing concern that the bill may not deliver the required improvements. It stated:-

“... the committee is not convinced the proposed Scottish Government strategy on autism would be improved by passing of autism specific legislation”

“ we are also concerned this bill could create a perception of two- tier disabilities, with some strategies thought of as more worthy of legislation and therefore seen as having more weight.

12. The Bill was debated at Stage 1 in the Scottish Parliament on Wednesday 12 January 2011 and was rejected by 109 votes to 5 with 2 abstentions.

13. In respect of the Autism Bill (NI), the Department has no policy rationale to underpin the development of this piece of legislation. Indeed, some concern has been expressed that such a Bill might possibly be subject to challenge under the European Convention on Human Rights, particularly in relation to individuals and families living with other significant disabling conditions.

14. Given the above paragraphs, the Health Committee may wish to consider the legislative competence of the Assembly in relation to the provisions of this Bill.

Cost

15. Unlike the Autism Bill in England, this Bill indicates that there is little cost attached. In Scotland, a Financial Memorandum was attached to the autism legislation, and included costings but chose not to include costs for the implementation of the Bill.

16. It is difficult to understand how '*no significant costs*' have been assessed. For example, the inclusion of such non-specific terminology within the amendment to the DDA such as "social (including communication)" and "taking part in social normal social relationships and forming social relationships" may bring individuals (without autism) within the scope of the Disability Discrimination Act. Such an approach could have significant human cost for individuals and families and could have significant financial costs for organisations that would be required to take account of such non-specific "disabilities".
17. In addition, each government department would need to make an assessment of the impact of the change to the Disability Discrimination Act, and the placement of the definition of autism (Clause 4) on the face of the legislation.

Cost of the strategy

18. The cost of formulation of a rolling and indefinite autism strategy is not specified nor is the need to establish extensive monitoring arrangements. This could be extensive.

Cost of Training

19. In addition, whilst no costings have been done by the Bill sponsors for the required public awareness raising or training of front line civil servants the Department has attempted to develop indicative costs for both requirements. Training for civil servants brings a potential cost of some £1.8m (based on circa 25,500 civil servants at £65 per head).
20. Whilst that is the requirement of the legislation we would contend that such training would not actually encompass the key target staff i.e those in the public sector employed in providing front line services in education, health and social care, housing and many other areas.

Awareness

21. It is difficult to calculate the potential cost of public awareness-raising without some parameters to define the extent of the campaign. However, advice from the Government Advertising Unit suggests that awareness campaigns are largely designed to fit the allocated budget. For example a budget of £25k will provide a small advertising campaign (largely using existing print and radio material); £235k can provide development of new material for all media, limited TV, press online and radio adverts, modest outdoor advertising e.g. on buses and bus shelters and some benchmarking and tracking research.

Increased Bureaucracy arising from Autism Bill

22. Through the current Regional ASD Network Group, work has been undertaken with minimal bureaucracy and without the need for legislation. This highlights the commitment of the DHSSPS to enhance ASD provision.

23. The Department continues to have concerns that the introduction of specific autism legislation, at this time, could be disruptive to the ongoing work of the Regional Group, could delay the implementation of the current ASD Strategic Action Plan, and would create a bureaucratic and costly approach to the development and monitoring of a new ASD Strategy.

24. The following paragraphs highlight the work of the Regional ASD Network Group which leads on the implementation of the DHSSPS ASD Strategic Action Plan 2009.

25. The ASD Strategic Action Plan is underpinned by an additional £1.5 m specifically for autism services. This will rise to £1.6 million (recurrent) from April 2011 following the Minister's announcement in November 2010 of an additional £100k towards developing specialist adult autism diagnostic services.

26. Significant improvements in autism services, led by the Network Group, include the reduction in waiting times for ASD assessment and diagnosis in children, despite increasing demand.

27. In addition, in November 2010, the Minister announced the development of a regional Diagnostic Pathway for Children and Young People for implementation from December 2010 and the development and commencement in 2011 of a diagnostic service for adults with autism.

Conclusion

28. The DHSSPS does not need an Autism Bill to facilitate change. It wants to assure the Committee of its intention to continue to improve autism services for both children and adults, within the resources available to it.

29. The potential costs arising from the Bill are substantial. It will bring significant additional costs in bureaucracy, infrastructure, poorly targeted training and impose an onerous requirement on this Department to monitor and report performance across other Departments.

30. The DHSSPS does not wish to spend resources on bureaucracy but rather concentrate on agreed priorities, which are directed towards frontline services.

31. The impact of this Bill has also the potential to be significant for other Departments' policies and legislation. The Committee will wish to consider whether specific advice on issues relevant to other Departments should be secured.

32. Having taken legal advice, it is the Department's view that there are potential significant and far reaching implications arising from this Bill, with particular reference to Clauses 1, 2 and 3. The Committee will

wish to consider the impact of ECHR and whether Clauses 2 and 3 might call in to question the legislative competence of the Assembly in relation to the provisions of this Bill.

January 2011 - DHSSPS

**AUTISM BILL (PRIVATE MEMBER'S) - DHSSPS PERSPECTIVE
(SUBMITTED TO COMMITTEE IN NOVEMBER 2010)**

Introduction

1. The purpose of this paper is to provide an up to date Departmental view on the detail of the Private Member's Autism Bill which was introduced in the Assembly on 8 November 2010. In doing so, it is recognised that an Executive view of the Bill is being sought by Minister McGimpsey to inform the debate on the second stage of the Bill which is scheduled for the 7 December 2010. Therefore, this paper confines itself to the impact of the Bill on DHSSPS policy responsibilities.

Background

2. This Autism Bill is a Private Member's Bill which has been developed by the All Party Group on Autism supported by Autism NI which provides the secretariat to this Group. The Department's view on the need for legislation on autism has already been submitted to the Committee on 28 September 2009.
3. Whilst recognising that the content of the proposed Bill has changed since it was last discussed with the Health Committee on 1 October 2009, the Department remains of the view that legislation is not required, at this time, to drive forward service improvement; the focus should be on enhancement of front line services not on legislation. This view is complemented by the Independent Review of Autism Services (2008), which did not support legislation but highlighted the need for significant service developments to meet the needs of those living with autism. As a consequence, the DHSSPS published an ASD Strategic Action Plan in 2009. As part of this Plan, a Regional ASD Network Group was established and is now operational and includes

involvement of 30 parents, service users and carers, together with 10 key voluntary organisations in decision-making.

4. The ASD Strategic Action Plan is underpinned by an additional £1.5 m specifically for autism services. This will rise to £1.6 million (recurrent) from April 2011. The Regional Network, with significant involvement from the Reference Group, is responsible for the coordination of the regional approach to service development and investment.
5. Significant improvements in autism services include the reduction in waiting times for ASD assessment and diagnosis in children despite increasing demand, the development of a regional Diagnostic Pathway for Children and Young People for implementation from December 2010 and the development and commencement in 2011 of a diagnostic service for adults with autism. All of this work has been undertaken without the need for legislation and highlights the commitment of the DHSSPS to ASD provision.

Detail of the Autism Bill

6. The Department has significant concerns that the introduction of an Autism Bill, at this time, could be disruptive to the ongoing work of the Regional Group, could delay the implementation of the current ASD Strategic Action Plan, and would create a bureaucratic and costly approach to the development and monitoring of a new ASD Strategy.
7. More specifically, the Department has significant concerns regarding:-
 - the unilateral change in definition to the **Disability Discrimination Act**, which has not been done in other UK jurisdictions;
 - the insertion of a **wide definition of autism in legislation**, which has not been done in other jurisdictions of the UK (and its impact on individuals and society);

- **Cost** – it is stated that the Bill will not have significant cost implications – the Department disagrees with this statement;
- **Autism Strategy** – the necessity for legislation to do this is not proven – particularly when infrastructure is already in place.
- **Data collection** – legislation is not needed to collect prevalence data (see also below).

Amendment to Disability Discrimination Act 1995 (DDA)

8. The Bill includes amendments to the Disability Discrimination Act 1995 to include the words – “social (including communication)” and amendment to Schedule 1 to include “taking part in normal social relationships” and “forming social relationships”;
9. The changes to the DDA are significant, as the inclusion of wording such as “social (including communication)” as a disability could be open to wide interpretation and might have the potential for challenges to be taken by others in society/workplace that do not have autism. In addition, it should be noted that in England, the Autism Act 2009 does not have such amendments to the DDA. Nor does the recently proposed Autism Bill in Scotland. Given that existing case law appears favourable to the inclusion of the symptoms of autistic spectrum disorders, the Department cannot see the benefit of the proposed new definition – further, the proposal may actually be harmful if it were to cast doubt on the DDA definition as it would continue to apply in GB, as the DDA is a Westminster enacted, UK wide act, and the Assembly has no power to amend it as it applies to England, Scotland and Wales. It should also be noted that guidance issued here from OFMDFM – *Guidance on matters to be taken into account in determining questions relating to the definition of disability* - already recognises that that a disability can give rise to a wide range of impairments which may not be immediately obvious. A number of specific examples are given in this document including autistic spectrum disorders.

Inclusion of Definition of Autism in the Legislation

10. The Bill also introduces a wide definition of autism to include several established syndromes in addition to adding "*any pervasive developmental disorder not otherwise specified*" - all within the definition of "autism". Such a definition is outside of the meaning of autism as used in standard clinical practice guidance - as defined within the International Classification of Diseases (ICD 10). Within this context, there is an established definition of *pervasive development disorder*. It includes childhood autism, atypical autism, Asperger's Syndrome, but also other coded categories. It should be noted that the recent proposed Scottish legislation does not include a definition of Autism on the face of the legislation - it explains that to do this is not advantageous "*as research and experience refines the understanding of autism, so the range and characteristics will change. It is because of this that no definition of the autistic spectrum condition has been included*".

11. Clearly a unilateral approach to the definition of autism to be included on the face of NI legislation is not advantageous and could adversely impact on the labeling of individuals. In addition, this also has the potential to adversely impact on data collection on the prevalence of "autism".

12. The objective of current health and social care services is to provide appropriate care and support based on individual patient needs rather than a specific diagnostic label. This allows greater efficiency in delivering services within a programme of care rather than dividing efforts according to diagnosis. Trusts also have the appropriate level of flexibility to meet priorities, particularly important with a condition covering a spectrum of abilities.

Cost

13. Unlike the Autism Bill in England, this Bill has no finance clause; hence, it erroneously implies that this Bill has little cost attached. In Scotland, a Financial Memorandum was attached to the autism legislation, and included costings but chose not to include costs for the implementation of the Bill.

14. The NI Autism Bill is more extensive than either England (which is adults only) or Scotland which primarily relates to development of an autism strategy. As no financial memorandum has been attached to the NI Bill, it is difficult to understand how no significant costs have been assessed. For example, the inclusion of such non-specific terminology within the amendment to the DDA such as “social (including communication)” and “taking part in social normal social relationships and forming social relationships” may bring individuals (without autism) within the scope of the Disability Discrimination Act. Such an approach could have significant human cost for individuals and families and could have significant financial costs for organisations that would be required to take account of such non-specific “disabilities”.

15. The cost of formulation of a rolling and indefinite autism strategy is not specified nor is the need to establish extensive monitoring arrangements. In addition, no costs have been attributed to public awareness raising, or training of front line civil servants. It also gives a mandate to DHSSPS for this strategy and its monitoring, without necessarily having the power to facilitate change outside of a health and social care environment.

Autism strategy

16. Legislation is not needed to effect service change or to develop an autism strategy – DHSSPS consulted upon and issued a Strategic Action Plan in June 2009, and DE is well advanced in producing a detailed autism strategy which will be published for consultation in

17.2011. The Regional ASD Network Group, which is part of the DHSSPS Action Plan, is already in place and provides an annual written report on its actions. It has considerable voluntary sector, parental and service user involvement through its Reference Group. Good progress is being made to enhance service provision especially to reduce waiting times for diagnostic assessment and to develop a diagnostic pathway for children and young people. This regional Diagnostic Pathway has been agreed for implementation from December 2010. In addition, further investment has been secured in November 2010 to commence development of adult diagnostic assessment and treatment services in each Trust in 2011.

18. Through the Regional Network, the Department's focus has been to involve parents, carers and the voluntary sector organizations in commissioning and development of autism services. In doing this, there is a focus on reduction of administration and diverting all available resources towards improving and creating front line services. This Bill, if enacted, does not sit well with this policy as further resources will have to be diverted towards development of a strategy, thus cutting across existing strategies. In addition, the Bill implies a cost neutral environment for all government departments; clearly this could not be the case and even the production of a cross departmental equality impact assessment and monitoring arrangements for the strategy would require investment. In addition, an autism public awareness campaign and steps to train NI Civil Service staff in direct contact with the public would require investment.

Prevalence Data

19. It is recognised that data collection is important and that more information is needed in regard to the prevalence of autism (children and adults). Legislation is not needed to improve prevalence data. As part of the ASD Strategic Action Plan, HSC Trusts are currently working on improvements to their data collection on ASD as part of

their service improvements and it is anticipated that this will be quality assured across Education Databases to ensure consistency.

Conflict with existing legislation

20. As noted above, unilateral changes to the DDA may cause some difficulties on a UK wide basis. In addition, Members will wish to note that Section 75 of the Northern Ireland Act 1998 does not apply to this Bill since it is a private member's Bill and is not being introduced by a public authority. The sponsor is, therefore, not required to carry out an Equality Impact Assessment on the Bill. However, any autism strategy, developed by the DHSSPS, with the involvement of other Government Departments would be subject to Section 75 of the NI Act.

21. Each government department would need to make an assessment of the impact of the unilateral change to the Disability Discrimination Act, and the definition of autism – given their broad nature.

Conclusion

22. Good progress is already being made to enhance service provision for those living with autism. No legislation is required to produce an autism strategy; indeed the introduction of an indefinite autism strategy underpinned by legislation may have the potential to do harm as it could dismantle the progress that has been made to date.

23. The focus should be on improvement of frontline services for those living with autism rather than the diversion of resources to the proposals in this Bill. Therefore, on the basis of current autism policy developments, cost and potential significant implications for the Disability Discrimination Act, and the potential negative impact of putting a circumscribed definition of autism in legislation, this Bill is not supported by the DHSSPS.

24. No comment is made on the legislative competence of this Private Member's Bill. This is a matter for the member.

