

SUBMISSION FROM CAITHNESS PARENTS AUTISM SUPPORT GROUP

Introduction

1. A meeting was held to enable the local Caithness community to positively engage and feedback on the ongoing Autism (Scotland) Bill consultation. This event was organised by Mark W. Norton on behalf of the Caithness Parents' Autism Support Group. Robert MacBean, Parliamentary and Policy Officer of the NAS (Scotland), attended as the invited guest speaker. Around 30 people attended this event from all over Caithness.

Strategy direction and consultation questions

2. It should be made clear that the focus of this meeting was to produce a collective response by the people of Caithness to the Autism (Scotland) Bill consultation. This Bill will enable the imposition of obligations on both the Scottish Government and local authorities and councils to formulate and define a national autism strategy. It would also oblige local authorities to provide a diagnostic service for children and adults with autism, needs assessment, planning of services, training of staff and leadership at local level.
3. Robert MacBean gave a detailed and effective presentation on the Bill itself, the process and procedures for its passage to law and subsequent implementation. On conclusion of this presentation, the meeting then split up into two groups to discuss consultation questions, with one chaired by Robert and the other chaired by Mark.

Feedback from discussion group – Mark W. Norton

Would people with autism in Scotland benefit from a national strategic approach?

- The group felt strongly that such an approach was needed indeed;
- Recognition was given that the rural nature of the Highlands in general would make such legislation difficult to implement. The point was nonetheless made that Caithness is more densely populated than other parts of the Highlands;
- The suggestion was made that there could be a base for such a service on this basis in Caithness and possibly in Sutherland, although it was thought that it would be more likely be a service combined for both.

Is autism strategy legislation needed to make a national autism spectrum disorder (ASD) strategy effective?

- The Group again felt that a nationally recognised and enforced strategy was indeed needed to implement a national autism spectrum (AS) strategy;

- Emphasis was put on the necessity for such a strategy to be legally enforceable, otherwise funding for continued services would be put at risk;
- Autism was now recognised as a newsworthy item and it is important to ensure that this is continued;
- Raising of the profile was recognised as important, but this needs to be done in conjunction with the national strategy implementation to ensure some guarantee of service and funding;
- Such an Act is also considered necessary to ensure effective diagnosis at an early stage to ensure treatment.

Are the duties proposed appropriate to enabling a national ASD strategy for Scotland?

- This elicited some discussion, with the feeling that assessment for children with AS needs to be guaranteed by such an act;
- Serious concern was expressed at the perceived “wooliness” of the proposal for a Autism (Scotland) Bill, with particular worry at the use of the term “issue statutory **guidance** to local authorities and health boards...”;
- The word “guidance” was felt to allow an “escape clause” for local authorities or councils to avoid committing to provide a service. This should be replaced with “duty” or “obligation” to enforce the support and service provision;
- The general conclusion was felt that, while the duties went some way towards a national strategy implementation, firmer wording emphasising duty and obligation was required.

Are the duties proposed appropriate to guide local agencies to take a strategic approach to autism services in their area?

- The group again expressed concern at the usage of the words “guidance” in the proposal for an Act, which is taken to mean “should” rather than “must”. The term “guide” in the question should read “require”;
- Some thought was given as to whether this wording was deliberately chosen to ease the Bill’s passage through Holyrood;
- Much firmer wording is therefore felt to be required. The further fear was expressed, by more than one person in the group, that ineffective and wrong formulation and implementation of a national AS strategy could be used as an excuse to cut back on the funding of AS services in Caithness;
- It is critically important that this Bill is used to maintain and improve AS services in Caithness.

Are there any other comments you wish to make about this proposal?

- This elicited further discussion in the group, with a number of constructive suggestions made. One strongly made point was that this proposed strategy should focus on support and assessment for families and carers of people with AS, as well as such people themselves;
- Joint co-operation and pooling of resources should be enforced between all local agencies involved in providing care for people with AS. This would include the NHS, local authority/ council, education and social services, with a view to enforcing a common sense approach;
- Serious and vocal support was given to the idea of a local leader/ co-ordinator, with the power and authority to enforce a co-ordinated and professional approach to providing services for AS support on the lines suggested in the Bill;
- Some discussion about how “local” a co-ordinator would need to be. It was felt that the ideal person would be located in Caithness, although it was recognised that a more realistic location would be to cover Caithness and Sutherland. Such a co-ordinator must be as locally based as possible;
- The additional strong point was made that such a strategy should give national backing to the provision of contingencies for children and adults with AS who may be at risk of harm;
- A proposal was made that some benchmarking should be made against rural areas of England to see how they have fared after the English strategy was implemented in 2009. The point was later made that this strategy had only been in place for a few months, so it was too early to make an informed judgement.

Feedback from discussion group – Robert MacBean

Would people with autism in Scotland benefit from a national strategic approach?

- Scotland is not a uniform country and in rural areas it is much more of a challenge to guarantee access to services. The postcode lottery of autism services does need to be tackled. Too many professionals and service managers appear to be working without effective guidance.
- People with autism need to be integrated within their communities and unfortunately too many have to leave their area to get support.
- An Act would need to establish the need that exists and isn't being identified, especially for adults who have not been diagnosed. The capacity and ability of staff who need to work with people with autism is significantly lacking across services.
- A strategy would help address the shortcomings in identifying planning appropriate support but it must also have regard to the difficulties faced in smaller, rural communities.

Is autism strategy legislation needed to make a national ASD strategy effective?

- Too many people don't know their rights when trying to get support services. Without a clear legal framework for autism the result is effectively that no services are being provided.
- A law is definitely needed. We would ask how successful the strategy for Wales has been without legal backing?

Are the duties proposed appropriate to enabling a national ASD strategy for Scotland?

- The proposed duty to produce a strategy is appropriate and should be supported by requiring Scottish Ministers to consult, produce appropriate guidance, ensuring resources are properly targeted and that the strategy is reviewed after an appropriate period.

Are the duties proposed appropriate to guide local agencies to take a strategic approach to autism services in their area?

- Training and local plans are very essential measures if a national strategy is to be effective. The group also supports the formation of local autism teams to take these forward.

Conclusion

4. The meeting concluded with a discussion about the consultation. The following points were made in conclusion:

- The precise wording of the Autism (Scotland) Bill would have to be very carefully chosen to ensure its passage through Parliament;
- Provision of services in rural areas and staff training for an effective range of services would have to be ensured;
- NAS would be monitoring every local authority to ensure their effective co-operation in the implementation of this Bill should it become law;
- It was agreed that the minutes of this meeting, and the records of the discussion of both groups, would be forwarded to the Caithness Parents' Autism Support Group, and their wider membership. Mark and Robert would work together on this;
- The author of this report would like to express his gratitude and appreciation to Robert MacBean of the NAS and the attendees of the meeting for making this a productive and successful meeting. The Press coverage of this event bears testimony to the success of this event.

Mark Norton
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