

SUBMISSION FROM CAPABILITY SCOTLAND

Background

- Capability Scotland works with disabled people of all ages and their families and carers throughout Scotland to provide a broad range of flexible, personalised care services. We are also a campaigning organisation, committed to using the influence we have to ensure disabled people achieve the same human and civil rights as the rest of society.
- Capability Scotland welcomes the opportunity to respond to the public consultation on this proposal for a Autism (Scotland) Bill put forward by Hugh O' Donnell MSP.
- Capability offers direct support to young people and adults on the autism spectrum in a range of services that includes day centres, community living services and residential care settings.
- We also have two dedicated transitions co-ordinators working for Angus Council and East Lothian Council, one of whom specialises in transitions involving younger people who are on the autism spectrum.
- This work is aimed at achieving improved outcomes for individuals whilst identifying gaps in provision so as to be a catalyst for service change and development. These post-holders have fed into the general and specific comments on this proposal.

General Principle of the Bill

1. Capability welcomes the Autism (Scotland) Bill put forward by Hugh O'Donnell MSP. We strongly agree that there is a need for a strategic approach to supporting people with autistic spectrum disorder (ASD) in Scotland. Giving legislative backing to a Scottish autism strategy will help to ensure equitable access to diagnosis, assessment and services and will improve consistency in the planning and commissioning of services.
2. Currently, services and support for those with ASD are offered in a piecemeal and inconsistent fashion throughout Scotland. The existence, quality and nature of services and their accessibility to those with ASD can vary significantly from one area to the next. While some areas have a specific individual, such as an ASD co-ordinator, who has responsibility for providing services to those with ASD, others have no specific post. Even in those areas with a coordinator, the remit of this role doesn't always have a strategic element to it and rarely addresses national co-ordination.
3. In order to ensure local and national consistency and an improvement in services to people with ASD it is important that the strategy has

legislative effect. We believe that there needs to be legislation which puts a duty at a national level to set strategic direction, and legal obligations at a local level to meet and implement strategic objectives. This will help to ensure the provision of appropriate and effective services for people with autism across Scotland.

4. There are examples of very good practice throughout Scotland, but services are often not delivered in a consistent or planned way and there are particular difficulties for people at key points in their lives eg major life transitions. The overall need to have a coherent, planned strategy to meet the significant needs of this group of people is vital. Differing priorities between local authorities mean legislation is the best way to ensure consistent results. Local authorities and health boards will be obliged to plan and prioritise the improvement of services for those with ASD despite the difficult economic climate. Without legislation coordinated action of this kind can be difficult, particularly given the Scottish government's inability to ring fence local authority funding.
5. Examples of inconsistencies include the difference in provision for young people in East Lothian compared to those based in Edinburgh. Edinburgh operates a supported employment service, Intowork, which has specific experience of working with people on the autistic spectrum, whereas only generic disability employment agencies are accessible within East Lothian.
6. Furthermore, young people with ASD in East Lothian have to travel to Edinburgh to access ASD-specific social groups, and the main hub for ASD resources, No.6 (with whom East Lothian Council have a service-level agreement), is also based in Edinburgh. East Lothian extends as far as Dunbar; to access a service within Edinburgh would mean a one-way 30 mile trip, or a bus journey of an hour and a half. As a rural community, these Edinburgh-based services are simply not accessible to the whole of East Lothian.
7. We believe that work around the preparation of a national strategy should involve a mapping of currently provision to allow gaps and inequalities to be identified.
8. Susan Ashton, a parent of a child with autism who uses Capability's Family Support Service told us,

"Autism services need standards and consistency throughout the UK. I am conscious that as a Mum of a 13 year old with classic autism I am constantly anxious about his future both in school and after. As my son gets older I do see how help is available. However you really do feel like you are jumping into a black hole at every decision. The future is far from clear. It is very wearing and can make you feel quite desperate."

Diagnosis

9. The Bill specifies improvement in diagnosis as an area to be addressed in the Scottish autism strategy. Capability's transitions co-ordinators feel that it is essential to have a clear pathway to diagnosis for children and young people with ASD, understood by health and education professionals in order to advise families. A clear indication of the numbers of young people on the autism spectrum is felt to be vital for services to be commissioned appropriately and be better prepared in terms of responding to upcoming need. Improvement in diagnosis could, over time, help to address the shortfall in services by giving authorities a more accurate understanding of demand. This could lead to earlier low level intervention and commissioning of more appropriate services. This in turn can help to prevent needs escalating to crisis-level and save the local authority the associated increased cost.
10. Inconsistencies in definitions and classifications of ASD between agencies can also lead to a failure to provide appropriate support. Under the *'Same As You?' review of services for people with learning disabilities* (2000), a learning disability is classified in such a way that high-functioning autism and asperger's syndrome are included, and yet in practice statutory agencies such as health still work to a medical model of an IQ of 70 and under. This means that on entering adulthood a young person with autism may not be considered for learning disability services, and if they do not qualify on mental health grounds, may be left without support. Legislation could ensure that local areas have a legal obligation to establish cross-agency leadership arrangements, to develop joint working, which will in turn minimise the risk of this type of unmet need or "service gap".
11. A more consistent definition, unified approach and consequent development of accessible services must be instigated, and the strategy could ensure that this process is initiated similarly across all the local authorities.

The identification of children and adults locally

12. Improved identification of children and adults is vital to ensure they are able to access the support they need. However, our concern lies with the need for extra resources and spending to provide "reshaped" and new services in the context of local authority spending cuts and cost-efficiency savings. In the current financial climate meeting this "extra" demand may prove almost impossible without significant funding from central government.
13. We are concerned that the Financial Memorandum for the Bill states that the only costs to local authorities in relation to the Bill will be those resulting from the consultation process. This is not realistic if better diagnosis and identification are to lead to increased demand for a higher quality of service. There is a concern that failure to attach funds to the

legislation will lead to failure to implement the guidance or to other groups being denied essential services.

14. It is probable that in the longer term any initial cost will be recouped through better organised and more effective services for people with ASD. This will not only lead to savings as a result of greater efficiency, but also through the improved prospects of service users. Improved educational, employment and health prospects will lead to reduced costs relating to welfare benefits, mental health care, crisis interventions and lost tax revenues. However, this does not negate the need for the Scottish Government to make initial investment to implement the guidance.

The planning and provision of services

15. Any national autism strategy must encourage longer term planning of services and better consideration of transitions between services. Autism is a life-long condition, and support for individuals must reflect this, developing and changing throughout the different phases of a person's life. ASD by its very definition covers a diverse range of people with widely differing support needs. Resources must be utilised in a manner that ensures services can be delivered that are appropriate for each person. This must be done in a strategic and long term manner. For example people with high functioning autism or asperger's syndrome may greatly benefit from support which could be termed as "preventative", this could be achieved through planned early-interventions, such as life skills coaching, which can promote independence and prevent a service user from possibly reaching a crisis point (and then requiring expensive interventions) at some point later in life.
16. In order to be effective, an informed and strategic multi-agency approach must be taken to planning services. Failure to do this is often exemplified in relation to young people's services. There may be well planned services for children and those at school, but inappropriate or scarce provision post-school. Within East Lothian, for example, children with high functioning autism and asperger's syndrome do not meet the assessment criteria for children's services, but may qualify for support within adult social care (ASC). As ASC support does not usually begin before a young person is 16, this can lead to inadequate preparation for the transition from school to adult life, and as indicated in the Bill, this cohort of young people will need a much longer lead-in to ensure that anxiety is minimised and their transition successful.
17. Early low-level intervention through adequate planning and preparation will prevent needs escalating to crisis-level post-school – saving the local authority the associated increased cost, but more importantly, moving young people on to a positive experience post-school rather than the possibility of failure and subsequent mental health issues. It would be essential to identify within a national strategy with which authority the

duty lies to instigate and support transition planning, and that this is backed up by adequate training of staff involved.

Staff training

18. Specific training is vital for those working in this field, in order to effectively understand and support people with an ASD. The quality and standard of this training is very variable throughout Scotland. Setting and defining required standards for ASD training should be a key strategic objective. It is also essential that people with ASD and those who work with and support them have an opportunity to input into any training delivered.

Leadership on ASD at local level

19. Guidance should be given on how the local agencies interface with each other, to ensure effective collaborative working and to avoid possible service “gaps”. Presently there are gaps in the provision of services and this has to be addressed.
20. There is also a need for effective management and sharing of information at local level. The Bill should specify for strategy guidance to include multi agency information sharing as well as ownership and confidentiality of information. Too often families are forced to repeat their story to a multitude of professionals carrying out similar assessments. This information is then not shared, leading to inappropriate support and silos of knowledge about the needs of young people. ASD identification and assessment of need could usefully be linked in to the single-assessment ethos embodied by Getting it Right for Every Child (GIRFEC).

Additional points

21. The Bill specifies that in issuing or revising guidance, the Scottish Ministers should consult organisations representing persons with autistic spectrum conditions, professionals; those involved with relevant research, local authorities and NHS bodies. We would like to see this list extended to include a duty to consult people with an ASD and the organisations that support both them and their carers. It is essential to hear the voice of those with an ASD and those who support them as this will be the best indicator of what is working and what needs to be done to make services more effective. In a survey carried out by the National Autistic Society in 2009 almost 90% of respondents felt that if local authorities knew what service users and their supporters actually wanted in terms of support their everyday experiences of services would improve.
22. The Bill should also specify that guidance should include information on improving the involvement of people with ASD in relation to relevant policy and service decisions.

23. Section 3 obliges local authorities and NHS bodies, when providing relevant services to have regard to the guidance which the Scottish Ministers will produce. It would be preferable if the Bill were also to include a mechanism for monitoring the action of health boards and local authorities in relation to their progress in implementing the national strategy. This could be done through an obligation to provide annual reports or by using the guidance to encourage local authorities to include autism strategy related outcomes in single outcome agreements.

Parliamentary and Policy Officer
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