

SUBMISSION FROM EAST RENFREWSHIRE COMMUNITY HEALTH AND CARE PARTNERSHIP (CHCP)

SUBMISSION FROM CHIEF SOCIAL WORK OFFICER

1. Children's services professionals drawn from a wide range of agencies within East Renfrewshire met on three occasions to consider the implications of the proposed Autism (Scotland) Bill. After deliberations staff from education, social work, and health prepared their own service specific responses to the Bill and I have attached these for your information.
2. Overall there was a degree of consensus among the professional groups that met that legislation was unnecessary and could be counterproductive but that a national strategy would be welcomed.
3. A summary of key points raised within the three responses is outlined below—
 - There is ongoing lack of clarity about terminology across the country – the Bill doesn't address this but a strategy could.
 - In East Renfrewshire children and young people with and without diagnosis are assessed on their needs not assessed on a diagnostic label – as a consequence supports are put in place based on assessed need not a diagnostic label.
 - Many children and young people with autism spectrum disorder (ASD) have greater risk of co morbidities eg obsessive compulsive disorder (OCD), learning disability, complex physical disabilities, and in many cases the co morbidity is causing the greatest impairment, not the autism.
 - It is important that functional impairment is assessed as this varies hugely among the population that is diagnosed with autism.
 - Similarly there are many people assessed as being autistic who have no functional impairment and are fully functioning members of community/society.
 - Different diagnostic criteria are used to conduct the medical assessment to determine autism – debate exists nationally on the comparability of the tests, the Bill does not address this but a strategy could.
 - Concern has been raised that the weight of legislation will redirect resources to those with a diagnosis who may have no needs or very little functional impairment.
 - Legislation may increase numbers of those seeking a diagnosis, many of whom do not want a diagnosis but could be compelled to seek one in order to access services – this will also increase demand for second opinions.
 - The Bill fails to consider the financial implications of introducing legislation – the Bill if passed is very likely to have huge costs associated with it and these costs could be skewed away from those with high needs to those simply with a diagnosis or very low needs.

- Will other discrete conditions be offered the opportunity to pursue legislation? An Autism Act could set a precedent for those with other conditions to attempt to have legislation passed to meet their discrete needs.

Safaa Baxter

Chief Social Work Officer (Head of Children's Services & Criminal Justice)

8 October 2010

SUBMISSION FROM SOCIAL WORK DEPARTMENT

1. East Renfrewshire Council, Community Health and Care Partnership provide a range of support services to children and families. These services are not autism specific or indeed specific to any particular condition, but do take account of the assessed needs of children and young people with a range of different diagnosis, conditions and wide ranging needs. Services include a dedicated transition team supporting young people with the most complex needs from children's services to adult services.
2. Our support services specific to children and young people with additional needs, focus on offering opportunities to access and attend community based leisure & recreation activities, supporting friendships or contact with peers and others. Our support services specific to parents and families, are designed to enable parents in their parenting role. This can take the form of support in the family home or provision of short breaks outwith the family home.
3. Our aim in supporting children, young people and their families is to provide services which are of a high standard and competently meet the range of needs of the individual and the families we support. Recognising the range of specific needs of an individual includes taking account of those who have a diagnosis of autism and or an undiagnosed condition. Understanding how to best meet the needs of individuals with autism and providing support to families, requires a good understanding of the condition itself.
4. It also requires an investment by all agencies involved with the individual to work together to provide interagency child care planning, with collective responsibility to meet the holistic needs of the individual relating to their health, education and social welfare requirements and related support. This is outlined clearly in national policy direction of *For Scotland's Children, Scottish Executive 2001* and is a key principle of Getting it Right for Every Child.
5. However, it is critical that when considering any strategic planning in relation to individuals with autism, we do not create an unintended consequence of discriminating against those individuals with any other condition or diagnosis, or indeed those individuals with clearly recognised assessed need, but with no condition or diagnosis. Many of the young people and adults with complex health, learning, physical and

personal social care needs also have needs relating to ASD. In separating out the single condition of autism from other complex needs, we must not create a hierarchy of conditions or diagnoses in which to meet need or provide services.

6. Any necessary changes and improvements to our current arrangements will be best achieved by national strategic direction, and not as a result of statutory duties imposed by legislation as outlined in the Autism (Scotland) Bill. The Scottish Government has an existing ASD reference group working on a national strategy *Towards a National Strategy for Scotland* which is currently out for consultation. Membership of this Reference Group has been extended to include COSLA representation.
7. East Renfrewshire Council's, strategic planning arrangements for children services are undertaken through an integrated children services planning core group. This comprises of inter-department council representation, child health services and specialist health service representation as part of community health and care partnership arrangements. Therefore our current planning structures will allow for the development of an 'autism strategy' as highlighted within the Bill, with clear implementation arrangements to improve the provision of relevant services, which will be regularly monitored and reviewed.
8. An 'autism strategy' can also contain direction for inter-agency working, taking into account, up to date research relating to the development of 'relevant services' for individuals with a condition of autism. It can also highlight awareness raising issues for the local community and public service staff, together with the specifics of specialist staff training requirements for the range of key personnel working with individuals who have a condition of autism. Staff training can be single agency or inter agency, but should be delivered across all relevant agency departments. This can be achieved as a result of strategic planning with local authorities and NHS boards. Any subsequent development or re-design of services can be undertaken as part of this strategy, and can take account of local authority resource arrangements, specific integrated working arrangements and financial constraints.

Ann Marie Shields
Service Manager
7 October 2010

SUBMISSION FROM HEALTH DEPARTMENT

Section 1

1. We welcome the strategy if it is able to support and educate at a level of the universal provider in order that it would meet the needs of a wide population.

Section 2

2. We welcome the guidance to local authorities and NHS bodies to facilitate against “postcode lottery” and to encourage equity of services across local authorities and nation-wide. However, we are concerned that such guidance would mitigate against those who do not have a diagnosis; who do not seek a diagnosis, and this may impede clinical and professional autonomy and decision making.

Section 3

3. The section refers to the obligation of local authority and NHS bodies to provide relevant services. We would welcome clarification on what provisions to support these bodies would be afforded to them and what censors and penalties would be envisaged.
4. Autism spectrum diagnosis and asperger’s are a spectrum of conditions, which range from normal to those people with a significant functional impairment. As clinicians and professionals, we would be concerned that diagnostic labels would be seen by both lay and professionals as desirable and we are also concerned that medicalising variations in people presentations would stigmatise a section of the population who, by their differences, improve and enrich the fabric of society.
5. We would welcome clarity around the diagnosis and definition of autism, ASD and asperger’s. This is a clinical decision and the importance of a diagnosis is related to the impairment of function. Although ASD are lifelong conditions, the level of impairment varies from person to person and fluctuates depending on a number of factors including IQ and support services and family and social structure level and impact of impairment also varies throughout a person’s life. There are those with asperger’s syndrome who have a diagnosis but are fully functioning members of society.
6. The concern of an Autism (Scotland) Bill is that support and strategies would be diagnosis-led rather than needs-led. We feel very strongly that services should be on a needs basis.
7. In addition children, young people and adults with ASD have greater risk of co-morbidities and it may be that the co-morbidity is the condition causing greatest impairment.

8. In addition, if the Autism (Scotland) Bill is successful would this be a precursor for a number of other bills on discrete conditions? However, there are many children, young people and adults with functional impairments who do not fit any diagnostic category and could, therefore, be left less supported.
9. With regard to adult diagnosis, we would welcome clarity as to who would be expected to assess and provide a diagnosis.
10. There is a lack of clarity on how a local authority should respond to the guidance to promote and diagnose adults with a diagnosis of ASD. Again, we are concerned about the appropriateness of this, if there is not a functional impairment.
11. With regard to adult diagnosis, we feel that the current disability legislation could have implication for those applying for jobs, ie if the applicant does not disclose his disability, this could cause problems.
12. If autism is seen by families and as “the more important diagnosis”, there is a risk that co-morbidities are not adequately resourced. In addition, if the perception is that a diagnostic label would lead to resources, there is a possibility of more cases being presented for consideration of a diagnosis; and more requests for second opinions if the diagnostic label is not given. This will have a huge implication for services at a time when financial constraints are evident throughout the health service and local authorities.
13. We recognise, as outlined in the Autism (Scotland) Bill and accompanying documents, that people with autism have a greater instance of mental health disorders and offending behaviour. We agree that targeting supports into early intervention would reduce the risks for these people. However, although it would eventually save money, this is not a cost- free strategy, as to promote early intervention when resources are still required for co-morbidities; mental health concerns and forensic cases would incur additional funding.
14. We would welcome the bill as a vehicle to promote public and professional awareness, and to train and educate at a universal service level and specialist level.
15. We would advocate a greater focus and support for all at a universal level rather than targeting a particular group.

East Renfrewshire Council
Health Department
7 October 2010

SUBMISSION FROM EDUCATION DEPARTMENT

Introduction

1. We note that the consultation calls for written evidence on the general principles of the Bill.

Section 1: Autism strategy

2. Education services, including schools, in East Renfrewshire have developed over the years a greater understanding of the range and nature of impairment faced by children with core communication needs such as autism and aspergers syndrome.
3. However, a lack of clarity and consistency remains in the terminology used to describe the exact nature of children's difficulties. Inconsistencies and perhaps confusion exists over the terminology used to describe the range of ASD. For example, ASD is used by school staff to describe all children who present with core communication needs including aspergers and autism whereas in some services the "autism" would be the generic term used. Other terminology, such as "autistic spectrum condition" and "pervasive development disorder", is also being referred to by agencies and services. In this regard, it is important that the Bill and its associated strategy and guidance give clarity to the use of these terms both within and across services.
4. Any proposed strategy for the diagnosis of ASD should outline the ways in which subsequent services are accessed thereafter. In East Renfrewshire currently, children are supported by education services both in specialised provision and in mainstream schools without having to have a diagnosis of autism or ASD. For a diagnosis to be given, children have to undergo a medical assessment and currently two different criteria are used to make that diagnosis (ICD -10 and Gillberg's criteria). There is some debate over the reliability and validity of these as well as to what extent these criteria are comparable.
5. Possible benefits of a strategy—
 - Helps to achieve consistency across the country as to how children and adults access services and receive support
 - Helps to benchmark standards of provision across the country
 - Potential to promote the use of one set of criteria for the diagnosis of ASD which would be universally applied
 - The involvement and participation of stakeholders in the formulation of the strategy is a strength and due time should be taken to do this in as broad a sense as possible
 - Help to identify and support individuals not just with ASD difficulties but with associated mental health problems as well.

6. Possible drawbacks of a strategy—

- Singles out ASD and assumes that this is the main cause of impairment whilst in reality that is not necessarily the case even for children with a diagnosis of ASD
- Danger that services will shift resources and services towards those with low level needs given the statutory weight of the Bill
- The terminology of “strategy” gives the notion of a plan that it is foreseeable over a fixed term and that is achieved or not ie, would the strategy be to fully implement the guidance?
- A strategy which is overly prescriptive would not be welcomed but if too general it could be perceived as vague and consequently its impact weak and immeasurable.

Section 2: Guidance by Scottish Ministers

7. Any guidance associated with the strategy would be most welcomed if it were not prescriptive and allowed flexibility for services to take local decisions in the best interests of children and adults.
8. The guidance should specify the “gold standard” of provision from which services, independently and jointly, could produce action plans.
9. With regard to each of the points in the Bill under section 2:

The provision of relevant services for the purposes of diagnosing autistic spectrum disorders

10. Such guidance would be broadly welcomed although this is an area which may benefit from having legislation attached as opposed to guidance. Currently, as stated above, there is varied practice across the country as to how children and adults are diagnosed. This variance can lead to a vast number of people being diagnosed whilst at the same time having hugely different needs. It would be beneficial to have one nationally agreed standard through the provision of accepted criteria under which all those seeking a diagnosis would be assessed.

The identification of persons with such conditions

11. This is a vital point which has to be considered both within services and across services. Due to the issues raised previously with regard to the nature of ASD, persons with “such conditions” are identified differently across the country. In East Renfrewshire schools, it is children’s needs that are identified rather than the condition.
12. If the intention of the ministers is to track the numbers of children with “such conditions”, consideration will have to be given to how this can be done consistently within and across services.

The assessment of needs of persons with such conditions for relevant services

13. Assessment is a central aspect of determining appropriate support and intervention for children and adults with ASD. Even if a person is diagnosed with ASD, the label is so wide that it does not fully identify the needs of the individual. Persons with ASD can have associated co-morbidity such as learning difficulties, OCD, attention deficit disorder (ADD) and learned behaviours, which can often be the main barrier to accessing a suitable curriculum, employment or even to make the transition to independent living. The assessment of people with ASD needs to be holistic in order that services best understand the most pressing need of the individual in order that the most appropriate intervention can be sought. Suitable intervention would be assessed as that which will have the greatest impact in limiting barriers to learning and living. Services should not be restricted simply to individuals with a diagnosis of ASD for reasons previously stated.

Planning in relation to the provision of relevant services to person with autistic spectrum conditions as they move from being children to adults

14. The continuum of service is very important for persons with ASD, particularly at key points of transition. Currently education services in East Renfrewshire and transition planning for children and young people with ASD is a strength however, further work needs to be done with colleges, universities and employers in order that these services are equipped to engage with the transition process. Guidance which sets out clear expectations would help to clarify this need.

Other planning in relation to the provision of relevant services to persons with autistic spectrum conditions

15. Given the range of potential services involved and complex nature of ASD, clear guidance on how different agencies can work together to support people with ASD and clarification of the roles and responsibilities of key services and agencies would be welcomed. In particular, the transition from child to adult services in health, education and social work requires careful planning and guidance would be particularly helpful.

The training of staff who provide relevant services to persons with such conditions

16. East Renfrewshire's Education Department already has in place a training programme for staff working with children and young people with ASD. The Education Psychological Service, Speech and Language Therapy Services and specialist education staff are used to deliver training to staff in mainstream settings. This has helped to promote and sustain inclusion of children and young people with ASD. The department has encouraged and funded staff to undertake university post-graduate qualifications in autism however given current financial constraints, there is limited scope for this to continue on a large scale. The PG cert/diploma in Inclusive Education offered both at Glasgow and Strathclyde universities, is one which gives a more holistic view of

additional support needs, including ASD. The department is committed to supporting staff through this qualification.

17. Any guidance about the training of staff would have to be achievable in the current economic climate. Guidance would be most welcomed where it set out main outcomes for the training for staff but allowed for services to design their own programmes.

Local arrangements for leadership in relation to the provision of relevant services to persons with such conditions

18. Leadership in this area is crucial and is integral to all points above. In East Renfrewshire, there is a range of mechanisms within education to address the strategic direction for the provision for those with ASD, and these mainly pertain to children and young people.

Section 3: Local Authorities and NHS Boards

19. Agreed

Section 4 and 5: Interpretation, Short Title and Commencement

20. Agreed

Policy Memorandum and Financial Memorandum accompanying the Bill

21. The policy memorandum was helpful in setting out the objectives of the Bill and providing the legislative background for its introduction. In addition, it outlined the context which individuals with ASD live in Scotland and some of the key obstacles which they face.

East Renfrewshire Council
Education Department
8 October 2010

SUBMISSION FROM ADULT SERVICES

1. East Renfrewshire CHCP provides a range of services and supports to adults. None of these services are autism specific, however people with autism can and do access all adult services.
2. Up until recently individuals with autism who resided in the Greater Glasgow part of the CHCP, their families and local services had access to the Autism Resource Centre (ARC) in Glasgow. In early 2010 the service changed and some clinical staff who had worked in the ARC moved from the central base to provide input to four geographical areas within the Greater Glasgow and Clyde Board area. East Renfrewshire CHCP now has support from a designated Autism Clinical Co-ordinator who also works within two other CHCPs. The current role of the Clinical Co-ordinator is to work with local services to assess and diagnose individuals and to enable local services to provide autism specific support when required.

3. The development of an autism strategy is welcomed, however, it should ensure that there are not unintended consequences that could discriminate against those who have identified support needs but do not have a diagnosis of autism. The development of a strategy would be beneficial if it can help achieve local communities where people with autism are respected, included and participating citizens. The strategy should be a supportive one that enables the provision of the best and most effective support to be provided to people with autism without the need to divert significant resources from other vulnerable groups.
4. Any guidance associated with a strategy should not be too rigid and must allow for some local interpretation but without significant variation and should not mitigate against those individuals who do not have definitive diagnosis.
5. In East Renfrewshire, children's services take account of the assessed needs of children with a range of presenting issues and provide services that competently meet the specific needs of the individual and the family. Transition planning for young people moving from children's services works well and there is a dedicated Transition Team that support young people with the most complex needs, however specific guidance could assist in developing this further.
6. Improving training options for people who support individuals with ASD is a priority and staff can access a range of opportunities. It would be helpful if the strategy could provide guidance on the expected outcomes from training initiatives.
7. In summary, adult services in East Renfrewshire CHCP believe that changes and improvements for people with ASD will be best achieved by the development of a national strategy and not statutory duties imposed by legislation as outlined in the Autism (Scotland) Bill.

East Renfrewshire Community Health and Care Partnership (Adult Services)
8 October 2010