

## **SUBMISSION FROM ALLAN TUBB**

### **Provision of diagnostic services**

1. Currently adults with “autism and a learning disability” and adults with “autism and a mental illness” can receive services, although only if the mental illness matches discreet criteria. Adults with “autism and no learning disability”, such as people with asperger’s syndrome, have little or no service provision. Local authority social services and the NHS community mental health services, respectively, are generally unable to provide assistance, particularly for adults and older adults. If services are provided these are not consistent across Scotland. Any person who falls between the two end points of a range, or spectrum, of difficulties is forced to find coping and management strategies without assistance. Often these difficulties are hidden and are outwith the understanding and experience of most people.
2. The current attitude of NHS Highland, which is not unique among NHS Boards in Scotland, suggests it is willing to recognise autistic spectrum disorders (ASD) identified in children can be addressed but it is not willing to extend the same recognition to adults. Where these or similar problems exist the Bill would be greatly strengthened if legislation, rather than any accompanying statutory guidance, included the provision that—
  - A person should have the right to make a self-referral to an assessment and diagnosis service;
  - A person should have the right to access a professional advocate, accredited by the Scottish Society for Autism or the National Autistic Society Scotland, able to assist a person make a referral request or to seek an appropriate form of support;
  - Access to diagnostic services should be available to adults, who, because of age or circumstance, are unable to provide parental history;
  - Any diagnostic service must incorporate the skills required to include physical problems, often found in people on the autistic spectrum, in any assessment. For example: when symptoms of functional bowel disorder, which is commonly reported by people on the autistic spectrum, the diagnostic service requires the skills to assess the significance of this as part of the overall assessment rather than make a separate referral to another team.
3. The provision of diagnostic services has to be included in the performance targets set by the Scottish Government and made part of the reporting framework. In many ways these are blunt instruments but provide an effective means for implementing a national ASD strategy. Without such a requirement each local authority or NHS Board can

implement the strategy differently. In rural areas in particular there is not the same breadth and depth of provision in community mental health services that can be found in urban centres. Without legislation and mandatory reporting it is doubtful whether an ASD strategy by itself would be effective.

4. Any diagnostic service should be regarded as a service in its own right and not as part of another service. It is my understanding that staff attached to the autism diagnostic and assessment service proposed by NHS Highland will have other duties, which may have precedence. In principle this service is to be welcomed but to be effective it has to be recognised as a stand-alone service, rather than having to call on staff with other responsibilities.

### **Identification of children and adults with autism locally**

5. The purpose of this submission is with regard to adults, in particular adults who have coped with hidden difficulties for a considerable time and often without any understanding or explanation of those difficulties being provided. As retirement approaches the difficulties associated with an ASD become more difficult to manage as the support structure of a working environment is removed. The working environment is often the only form of social interaction and communication to a person with an ASD and its removal can lead to acute isolation, particularly in rural areas. It is difficult to know how any support service can mitigate this but it is essential that information from an appropriate assessment is available to ensure the correct care pathway is followed.
6. Too often the attitude of the gatekeepers is that people with hidden difficulties have evolved coping strategies over time and can be reasonably expected to continue to cope. As other problems associated with age also begin to impact, the coping strategies may begin to fail, leading to the need for any assessment to take account of and include the hidden difficulties.
7. NHS Education Scotland has compiled a set of guidelines covering (i) the patient with ASD; (ii) practical strategies; (iii) health issues; and (iv) identification and diagnosis (<http://www.nes.scot.nhs.uk/asd>). There are also Scottish Intercollegiate Guidelines Network (SIGN) guidelines, but this document is written for identifying good practice in service provision for children. Neither of these resources is particularly applicable to adults, particularly older adults. In many ways the NHS Education Scotland web pages appear to have been written without input from people who are recognised as having an ASD and, in parts, are seen to be rather misleading or offensive.

### **Assessment of their needs**

8. Although I am of the opinion that personal experience is appropriate and essential evidence to submit to the committee it is not included in the

current terms of reference, so I include it only to illustrate the current lack of understanding of service provision.

9. My own experience can be summarised as not being able to access a service that has the means to understand the problems and offer relevant advice. Instead I have been provided with inappropriate medication and therapy which were not beneficial, simply because the treatment was based on an incomplete diagnosis. More than 18 months after my GP made a referral to Highland Council social services, I am still waiting for an appointment. Various enquiries acknowledged that I remain on the list of referrals but, as there are more urgent priorities on the case list, no indication can be given of when it will be progressed. If I requested a care assessment this currently would not take into consideration the difficulties I have to cope with on a daily basis, as they are not related to a learning disability, a physical disability, or a mental illness.
10. It is a relief when I have spoken to an adviser working with one of the two national voluntary organisations on a few, brief occasions, simply because I find the way I explain my difficulties is understood. The same cannot be said for the many people I have had contact with in the NHS or social services, however well meaning. Recently a consultation with an NHS psychologist proved to be an exception to this otherwise dismal record. The only other person in an official capacity, who has been a rare and illuminating exception to this sequence, was a psychologist working for the Job Centre, who recognised the situation but had no remit to make a diagnosis or referral. In this respect I am of the opinion that if the recommendations in the subsequent DWP report had been available before I was given medical retirement and implemented by my ex-employer I might still be working today and making a useful contribution to society.
11. At the local level the development of diagnostic and advisory services for assessment and diagnosis must inform any referral to appropriate support services, including carer training. A multi disciplinary and/or multi agency team is required to implement this approach. Again the legislation must set out more clearly the obligation placed on local authorities and health boards for joint working and service provision. Wording in the consultation document implies this but was not sufficiently strong to ensure it would translate into practice.
12. Where there is a sparse population spread over a considerable area, which describes the greater part of the Highlands, the probability of social isolation is very real as families break down into ever-smaller groups. Currently the aim of many welfare services is to maintain people in their own homes for as long as possible. For many this is an outcome of choice, but for others it may only enforce the problems of isolation, particularly in later years. The same applies to urban areas but here the problem is easier to manage. Social isolation may not only be the result of mental illness, but it might also be the cause of that illness, particularly

long-term depression. It is recognised by some practitioners that people on the autistic spectrum do not thrive in isolation.

13. It is appropriate also to consider what many might consider to be an unacceptable solution. The issue of suicide is complex. Organisations and training opportunities exist to promote the recognition of suicidal tendencies and prevention of suicide. Whenever such an organisation is asked what after-care is provided the answer is often that this “is not what they do” or that “there are no resources available”. Where the person involved is potentially on the autistic spectrum agencies are almost certain not to have the skills or the knowledge to understand the factors affecting the crisis. If there is a family group the person contemplating suicide is often rejected for causing a number of problems over a period of time, often because of the lack of inter-personal skills. Particularly if a person has no means of social support it is difficult to know what care can be provided. There is a need for some form of post-crisis management but what is most appropriate usually is particular to the individual and often is beyond the gift of any help process. In many cases there is a need to increase the opportunity for people to make a meaningful contribution to society, which may not necessarily be paid employment or as part of a voluntary organisation – but simply being trusted to make a contribution to a community, recognised as part of that community, and allowed to be part of that community. Unfortunately human nature being what it is this is practically unachievable. It is also the reason for the campaigns run by the National Autistic Society, similar in concept to the anti-stigma campaigns run by mental health organisations. There may be a need for joint working between organisations and agencies in both fields of interest.

### **Planning and provision of services**

14. First I would like to recount a conversation with a GP at an unrelated meeting but which might illustrate certain aspects of planning and provision of services. Until recently NHS Highland permitted GPs to prescribe a schedule of directed exercise activities at Highland Council sports centres or gyms, sometimes referred to as “green gyms”. This facility has now been discontinued. In the opinion of the GP this provision was totally unnecessary as the locality provides any individual with an abundance of opportunity for walking and there is no need to provide alternative resources. Effectively he was making a value judgement based on his own abilities and perceptions, without understanding this would not be applicable to all, thereby excluding those people who might have hidden disabilities.
15. In this instance there are those who find it impossible to decide for themselves where to walk, plan the activity, or have the motivation to carry out the activity without an external stimulus.
16. Difficulties people on the autistic spectrum might have include decision-making, planning, motivation, and impulsivity. Taken together the first

three can be described as difficulty with organisation, leading to difficulties with all aspects of daily life. In this context impulsivity can also be seen as detracting from the ability to organise, causing an individual to act only on that stimulus which immediately presents itself. Any provision of service must be able to accommodate such difficulties, which often are the direct opposite to the natural reactions of the care provider.

17. Any care provision must make the best use of diminishing resources; it is therefore essential to have the flexibility to deliver the care people need rather than the care others think they need. As autism covers a spectrum of disabilities any service provision has to move away from rigid concepts and adapt to individual needs. It is essential that practitioners, who have a wide range of experience working with people on the autistic spectrum, are involved from the outset in any service design together with potential service users. Research to date suggests there may be a common core of difficulties experienced by people on the autistic spectrum with a range of other difficulties also present. To make any service effective it has to be flexible and meet individual needs.
18. Any attempts to have the issue of undiagnosed autism in adults discussed by any NHS Highland committee, particularly in respect of older adults, have been simply blocked or avoided. This is particularly critical for adults who may be wrongly diagnosed as suffering with dementia, where each care pathway is entirely different.
19. Any legislation should include the legal obligation for all Government departments and agencies to recognise any person with an autistic spectrum disorder has difficulties that can prevent normal participation within society. This will have implications for patterns of employment (such as part-time or flexible working hours), eligibility for benefit and recognition under the various equality laws.
20. As a layperson I have had great difficulty in responding to the consultation / evidence documents. The documents are very general and without detailed knowledge of the social care and health services it is difficult to determine what information is being sought. In some ways I find the boundary between social care and health care somewhat indistinct, particularly since the two are closely interdependent. Establishing a national care service would assist in the transparency of care provision and allow for effective use of resources, but the political environment today means this idea is most unlikely to be implemented. In the meantime improved joint working between Highland Council and NHS Highland is needed in respect of a future autism bill.

### **Training of staff**

21. Where the difficulties experienced by a person are largely hidden, referral depends on the understanding of the gatekeeper, usually a GP. In many instances this presents a barrier to accessing the appropriate

service and can be mitigated by a better understanding or allowing self-referral. Safeguards can be incorporated to prevent abuse of the system, such as allowing only a limited number of self-referrals over a given period.

22. From personal experience, both as a patient and as a committee member of NHS Highland, I have experienced institutional resistance to acknowledging the difficulties of people on the autistic spectrum and the provision of appropriate services. Staff at all levels must be aware that hidden difficulties mean that a person cannot be judged by the normally accepted standards of social communication.
23. Although not without flaws, the NHS Education Scotland website has much detailed information on the diagnosis and management strategies for ASDs. There has not been a single NHS practitioner or manager with whom I have discussed the issue of ASD that acknowledges the relevance of this material. To illustrate this: - one of the most senior managers in NHS Highland, when asked what provision was made for people with ASDs, responded that there are instances where a person should be told that the NHS is unable to provide assistance and autism was one such example.
24. A further example is the reaction of my GP when I asked to discuss the possibility of an ASD, particularly given the conclusions of the DWP report. The response was simple: "You are not autistic". There was no further discussion and I have been unable to discuss the various difficulties with anyone in the practice since. Although I can understand a GP not wanting to spend time discussing such issues with somebody who appears to have had a successful education and, until given medical retirement, a relatively successful career. On the other hand it should not have been rejected out of hand without a discussion of the issues giving rise to concern. There is a need for any GP, particularly as a gatekeeper to other services, to be fully aware of the hidden symptoms of autism.
25. Another problem often encountered is the number of different symptoms that can be associated with the spectrum. This presents a dilemma for health and social services. The current strategy appears to be to treat each symptom individually rather than as part of a spectrum of symptoms.
26. Where there is inappropriate treatment this leads to unnecessary cost to the health service and is of no benefit to the individual. Further, the administration of inappropriate medication can lead to lasting side effects. At the present time there is an indication that certain medications administered to people on the autistic spectrum elicit unexpected reactions; a great deal more work has to be done in this field before any substantive conclusions can be reached. This is particularly relevant to how the use of anti-depressants and other drugs associated with the

treatment of mental illness might affect people with an ASD. In the interim it makes the need for adequate and reliable diagnosis essential.

### **Autism leadership at local level**

Each NHS trust in Scotland that is responsible for primary care should be legally required to develop an assessment and diagnostic service. A diagnosis alone will not improve the quality of life of person with an ASD. In a similar way each local authority should be legally required to develop a means of providing assistance. Although local authority and NHS trust boundaries are not similar a means has to be found for effective joint working without the barrier of excessive administration costs through unnecessary duplication.

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7 October 2010