

SUBMISSION FROM NORMAN GRAY

Rational for the submission

I am a parent of a 31 year old adult who has Aspergers Syndrome. From the age of four professionals knew there was "something wrong" with him but it was not until he was nineteen that he received a diagnosis. We have struggled throughout his life to receive the support he requires and deserves but often to no avail as he moved from school to further education, then on to employment and eventually into independent living.

One of the factors influencing provision has been the fact that he has been just ahead of the developments into recognising and managing the condition and this was particularly true in education. Since so much has changed there since he left I feel I am incompetent to speak about educational provision but would like to address other issues which have affected him to date.

Diagnosis

Diagnosis was a problem and from discussions with parents of younger children still seems to be an issue. During our son's 15 years of attending psychiatry prior to his diagnosis we were told there was "traces of something there like autism" but no professional was willing to commit themselves or take the issue further. When it seemed as if progress was being made we reached a divide as he moved from paediatric psychiatry into family then into adolescent and finally adult. At each stage we had to rebuild trust and seemed to start all over again. When we expressed our concerns about the lack of a definitive answer the psychiatrist did refer us to a clinical psychologist who diagnosed Aspergers Syndrome. The attitude of the psychiatrist was "you have a label but nothing has changed".

What is required is a system which is uniform across all health boards with a central team dedicated to receiving referrals, carrying out diagnosis and setting wheels in motion to address the situation irrespective of the age of the patient.

Transition from education

Leaving school is a bewildering time. As parents we were not fully informed of the options open to him despite a transition case conference. There was a marked lack of social work input which would have smoothed the way ahead. There was a careers officer present but there seemed to be a lack of real understanding of our son's needs and how best to address them. By luck more than good guidance he went into further education and took a hospitality management course which has given him a career pathway which has been his salvation.

On leaving education, the Employment Disability Unit was helpful to a degree but again his needs were not fully understood. It was a chance observation of our son working at a function when a student by a hotel head waiter that

secured him a placement at his hotel where he has been ever since. I was instrumental in getting the clinical psychologist who had diagnosed him to talk to the hotel management about his condition and how to manage him. One of the management took responsibility for managing him and this has been successful as his 12 years at the establishment as a part time function waiter demonstrates.

It would have been very valuable to have had a care manager appointed as part of the transition process. It takes time for an autistic spectrum disorder (ASD) sufferer to get to know and trust a person and equally time for a carer to get to know the individual traits of the sufferer. A care manager would be able to follow through all the stages post education and ensure that informed choices which suited the sufferer were being made at all stages.

Provision of services

This has been the most disappointing aspect of all. Throughout his attempts to gain help from services there has been the lack of understanding of his needs brought about by the fact that Aspergers is a developmental disability and not a learning one. Because of this, services are geared to provide inappropriate help for him. I can illustrate this by referring to his request for help in finding a house and managing it once he had decided to move to independent living in preparation for our being unable to support him.

Our first difficulty was in gaining a referral to a social work housing manager. Once established he was assessed and deemed low priority since he could manage himself in the practical aspects but no account was taken of the difficulties faced in the social or management aspects of a home. Medically he was assessed as low housing priority because there was nothing physically wrong with him. We were informed of the type of sheltered housing available to him and we could not have contemplated that due to the nature of the provision and its location. He would have been even more isolated there than he is at present.

When we were able to buy a house for him he asked for help in getting to grips with managing it. Services were willing to take him shopping and show him routines for dusting etc but he could do all that. They failed to realise his needs were in understanding the value of money and dealing with official letters, bills etc.

Here again there was a lack of a true understanding of his needs and a failure of the model ,based on learning difficulties, to address the needs of someone with a developmental disability who has quite high intelligence.

In an attempt to address the problem of isolation created by the syndrome a social group was formed locally. For some attending the group this is their only activity out with their own house where their carer does not go and stay with them. Under the auspices of the National Autistic Society, they meet and plan activities such as golf; ten pin bowling; theatre night; meal out etc. Local

services refused to fund this in any way claiming it was a social activity and not one related to their needs.

The basic problem with services is that the ASD needs are not fully understood and training in recognising them and acting on them appropriately is required to address the areas of deficiency. The fact that sufferers do not necessarily have a learning difficulty is the biggest hurdle to overcome.

Criminal justice

Our son has fallen foul of the justice system as a result of his condition. Like many ASD sufferers he reacts badly to unexpected touch and “lashes out” if touched unexpectedly, especially in a stressful situation. One such situation occurred when he fell foul of a door attendant at a nightclub when he tried follow our instructions and avoid being separated from his friends. The police intervened and grabbed his shoulder from behind whereupon he threw his arm back and caught the policeman. They would not listen to his telling them of his condition, looked at him and said he was “having them on” in claiming a disability. This case was referred to court but not proceeded with at considerable expense all round.

If police forces across the country adopted the *Autism Alert* card system which Strathclyde police have, the situation would have been dealt with at source since he could have shown them his card verifying his condition and their training would have allowed them to diffuse the situation on site.

Financial implications

The Bill will have some financial implications not least in establishing some new systems and meeting the training demands required to meet the needs of ASD sufferers. However this demand will not be uniform since some authorities already have resources in place while others do not, giving the “post code lottery” effect so evident in diagnosis and provision at present. The financial effect will be felt least in education where I feel authorities have addressed the problem in a variety of ways.

A more important financial issue is in the preventative side. If the needs of sufferers are properly met then their medical demands would be reduced especially in the psychiatric field where at least one friend of our son has had to receive treatment for a nervous breakdown caused in part by the poor management of his condition.

Proper management would also enable more sufferers to be in gainful employment thus reducing the demands on benefit but more importantly improving their mental wellbeing. We notice that our son changes and becomes difficult to manage at home if his hours of work drop. If this continues for any length of time he does become quite depressed and it is easy to see how this could spiral downwards over time.

Why a Bill

I feel a Bill is essential to ensure that the current inequalities of provision are removed giving all sufferers an equal opportunity to progress and families the reassurance that they did not have to move home or school to obtain the services their child requires. Equally it removes the additional strain of re-establishing provision which may or may not be present in a new location if you have to move.

In times of financial constraint it is very tempting for local authorities to remove specialist help especially in education where it may be thought that general support services could meet their needs. The provision of the Bill would ensure that these needs are still being met as required. A strategy seems to be the favoured way ahead for most of the local authority respondents to date and I cannot help feeling that this is because they are not bound by a Bill to meet the recognised provision.

Why an autism specific bill.

Our experience, some of which is highlighted here, indicates that it is not feasible to meet the needs of ASD sufferers through learning difficulty provision. While there are overlaps, the distinguishing feature of ASD sufferers is their level of intelligence and the uniqueness of each one in the traits they show and how they react. It is as my son says "its like trying to fit a square peg in a round hole and it just gets blocked or trying to fit a round peg in a square hole and it just falls through "

Consultation to date

I feel the level of consultation to date has been quite comprehensive and been reflected in the quality and extent of the replies. It should be able to give those involved in the bill a fair reflection of the nature and depth of feeling regarding it.

Norman Gray
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