

SUBMISSION FROM GABRIELE RICE-GRUNERT

1. Having married into a family with a diagnosed autistic spectrum disorder/condition (ASD/C) case in a child I came into a position of having dealings with service providers in two Scottish local authorities.
2. My view on the proposed Autism (Scotland) Bill is that it appears to me to be a necessity and the general principles very valid and well chosen to make the bill a powerful tool to finally get proper and evenly spread support to people on the autistic spectrum and at the high functioning end of the spectrum in particular. The dire straits of the financial situation the public bodies find themselves in cannot be a rational for not providing the help that is needed to the people of need. Below I lay out why I think so—
3. My observations over the past seven years, at least when it comes to the high functioning end of the spectrum, are that there appears to be a chasm between the claims and the reality of catering for the needs of people with ASD by the statutory service providers in some Scottish localities. Those personal negative experiences are the result of our dealings with the second local authority in this child's case (ie in our case the NHS and education department). I can't however comment on how more severe manifestations of ASD get treated in this same locality.
4. Despite all the recent and concerted efforts to provide well thought-out guidance and input and resources by Government bodies and private and professional interest groups and individuals, like the National Autistic Society (NAS) and the specialists in the field of ASD, it seems that there still exists an impermeable barrier of local policy and practice that does not allow for any of such help to trickle through to the people of need, ie the people with high functioning autism (at least (see above)) themselves and their families. Instead of help they actually experience an extra burden of added stress and hardship in dealing with the service providers when trying to access the help that is dangled in front of their noses in the official guidelines you can read anywhere on the internet.
5. Having gone and jumped through countless hoops to even be able to “feel” eligible to ask for specialised help by fighting for the necessary medical diagnosis - having reached that level of inner confidence to deal with a child's problems that are a result of the ASD triad of impairments - you are in the process actually liable to be attacked from members of the services for reaching for the diagnosis as if your desire would be to pigeon-hole your own child - while all you seek is help and advice to reach the best possible outcome for a young life challenged by an adversarial circumstance in their health/development.
6. The next hurdle then after the years it took to get to a diagnosis, and where we personally are still at presently, is to get the education services and in our case even the paediatric services of the NHS to fully appreciate the new situation beyond just filing the diagnosis somewhere and to fully integrate the parents in the (in our case sadly not really

existent) planning by those services for the needs of the child while in the care of the school system and beyond.

7. The crux seems to lie with the lack of (!) learning related intellectual impairment of the child with high functioning ASD, which is a bit surreal and perverse, while its deep reaching problems, eg in the social sphere as result of the ASD, are in practice being downgraded to mere minor hiccups that don't seem to need much support - contrary to all the scientific long-term evidence readily available showing the massive impact these problems actually have on a person throughout their whole life and which could be best helped through interventions at the earliest possible developmental stages.
8. Considering that in our case very early parental awareness could and should have started interventions from three years of age and now we are seven years later appears to me to be shameful.
9. That the development of social skills (and other affected areas of the child's abilities) actually also feature well in the written statements to the current curriculum, besides and on top of a child's capability to digest academic knowledge seems to get neglected. Maybe not for the normal range of issues for children NOT affected by ASD but very much so, in my experience, in the case of the child with high functioning ASD, at least in this particular Scottish locality.
10. This can, in my view, be demonstrated by the fact that in our case a speech delay, a very palpable and early symptom of the ASD, was dealt with in relative isolation after identification quite effectively by speech and language therapy (SALT), dealt with in detail, with parental involvement and in a multi-disciplinary fashion organised in the form of an individualised education programme (IEP) first initiated by the first local authority and then carried through by the second. Even without a medical diagnosis being present at first things were put into motion. That's how it should be in our view.
11. Yet, having overcome that specific problem, any special support for the child and any help and advice from the service providers to the parents and any interdisciplinary planning ceased after the age of seven (!) together with the IEP and hasn't been revisited since the diagnosis of high functioning childhood autism at exactly eight years old – that diagnosis acknowledging the more invisible, not so palpable symptoms. So people calling it the “hidden disability” are quite spot on when reflecting on the response of the local authority.
12. We are now two years after this - one would think - crucial step (and maybe even for some families traumatic step) of reaching a medical diagnosis and absolutely no specific or general help has reached us yet from the side of the local authority.
13. ALL efforts for any involvement and help whatsoever have come from us and have needed to be fought for, with little success. As an effected

family that wants to be active in helping and supporting their child one feels left alone and antagonized, again and again.

14. Maybe some of that almost institutionalised antagonism comes from the perceived need to preserve funding for the most adversely effected children by all the possible impairments that challenge peoples lives, which is, under the financial constraints, understandable from a public body's point of view, yet I doubt this is the main motivation. Whatever that motivation really might be, there is a statutory and human requirement not just for parents to look after their own child's best interests but also such a requirement of public service providers to strive for the best outcome for all minors and vulnerable people in their care, part of which is schooling.
15. It doesn't help when the local authority declares that by default all needs of the children in their care are catered for fully, when we know in our case nothing specific is done and instead it gets unambiguously declared that not even the new resource of the excellent Autism Toolbox (AT) provided to schools in spring of 2009 will be made use of - as they don't deem it's use would be appropriate in a "light" (sic) case of ASD - which is contrary to the content found in the accompanying written material to the AT itself. We got this statement of it being "inappropriate" as a reply to a request in the use of the AT in black and white!
16. We witness the depth and the effect of eg social impairment in normal, everyday human interactions and situations that will be a growing challenge for this child's future school years during adolescence and later in finding and building a fulfilling professional and personal life.
17. I think our family, but even more so the many other people in the same or much worse situation, deserve the support that's so far only being written and/or talked about to finally materialise, so that at least there is a chance that it can make a positive impact. Wasn't this the goal that all the people who devised those tools and guidelines lobbied and work for so hard over the years in the first place: That they be of help?
18. The current legislative situation clearly doesn't fulfil its purpose in providing help in our situation. The guidelines and legislation so far are seen by the local authorities as "general" and tools handed out as just some other (online) resource.
19. I have enough inside knowledge to see that there are many other people in a situation like ours in other localities. I also know there are people 'on the front-line' of public and private service provision, who support our view and commiserate with our suffering injustices and who know of many other people affected. But often support workers are held by local policies to reduce their input to the minimum and under the pressure of having to protect their working relationships do so.
20. There is no panacea for autism, no heal-all, the proposed Bill won't be one either and we as the affected people don't even seek that. We are

not fanciful dreamers - most live with the condition on a daily basis and try to make the best of it, even try harnessing it's upsides in specific skills. To suggest anything else is an unacceptable affront.

21. What we need is simply that best use is made of the current knowledge about how to best help children and adults with autism to learn to live with their impairments/otherness, so that those impairments/otherness have the least possible negative impact on their future and happiness and aspirations in life.
22. If there is a hope that the new Bill would change any bad aspects of the current situation to the better, I consider it worthwhile supporting against those who think all that's needed is already fulfilled in the current relevant legislation - as that is clearly not the case regarding high functioning ASD or something has gone very wrong in the implementation of the laws as they stand.
23. To start just another strategy that might go nowhere, as in the alternative suggestion to the Autism (Scotland) Bill as raised by Shona Robison MSP for the Scottish Government and as favoured by councils like Aberdeen, Angus and Fife, seems to me to be a weak choice compared to a new legislation if worded strongly enough - as a strong change to the better is what appears to be more than necessary in the current situation in Scotland. And why not take the chance and lead the way in the recognition and support for ASD/C in the UK and abroad? Ms Robison's submission seems to be a cost cutting exercise, certainly attractive in the current climate but of no substantial help to people on the spectrum and their families and carers.
24. Some are of the opinion an autism bill would single out one impairment over others and maybe they fear unfair allocation of funding. Looking at the reality of the situation of people with ASD/C in themselves or their family it appears they are singled out already by receiving too little support, understanding and help and often too late. Maybe then this Bill could counteract this apparent invisibility of ASD in the public eye which leads to institutionalised injustice and discrimination as matters stand.
25. I think a restriction of a Bill like this to those over a certain age, like 16, as elected for in other parts of the UK, would not be of the most help, but my understanding is that the Scottish Bill is different in this regard. Our situation certainly supports that it should cover all ages.
26. The provisions of the Bill to issue guidance by the Scottish Ministers to local authorities and to revisit the outcome of the guidance regularly and evenly across the land might be just what is needed to help overcome the severe, awkward and unusual problems for effected people that autism brings with it.
27. One comment I have regarding the wording of the Bill as it stands is that the named stakeholders do not include organisations of families and family carers of people on the spectrum, which seems to be an omission

as their high proportional presence in the consultation papers to the bill and also now in the replies to the call for evidence shows how they are also and very fundamentally effected by the issues addressed by the Bill.

28. We personally haven't reached the situation of being able to comment on how well the training of front-line support staff for ASD currently is in schools or outside thereof – as we haven't witnessed any such specialised support yet but are held up by unhelpful decision making on a higher tier of the local authority that means nothing but the general pupil monitoring via the class teacher is happening currently – so I haven't commented on that above. But reading what others have to say on this leaves me baffled and bewildered as to how all the schools and other agencies come by all their glorious awards for excellence in dealing with families with special support needs! I hope (irony alert !) this is all just a big misunderstanding and we will all live happily ever after...

Gabriele Rice-Grunert
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Ps. For good or bad, any decisions on the Autism(Scotland) Bill made now will long outlive the current difficult financial situation. It would, in my view, be extremely short sighted to base any decisions on that.