

## **PE1704/R**

Petitioner submission of 17 December 2018

As the author of this petition and as the parent of a child with autism who has very high support needs and is non-verbal I was very disheartened at the poor response from other stakeholders. E.g. Only 12 of 32 local authorities bothered responding to the Scottish Parliament petitions committee request to comment on the petition seeking real and meaningful change and improvement in the support and services for autistic people in Scotland. In addition, many of the responses were short, vague and used inconsistent terminology.

Great disparity across Scotland in the nature and quality of autism support and services is reflected in the approximately one third of authorities that bothered to reply to the petition. Feedback across the wider autism community in Scotland would appear to indicate that this is the nature of autism support nationally.<sup>1</sup>

### **I would be concerned if the committee responded based largely on these responses.**

This disparity is clearly at odds with the goals of ensuring all autistic people in Scotland receive the support and services they need. This is the main premise on which I would appeal for autism specific legislation.

Autism is of course a wide ranging and complex life long condition. How it impacts on individual's lives varies widely. It must be acknowledged that simply because an autistic person is cognitively able to lead an independent life they may still have great challenges to face in everyday life. e.g. social difficulties at work, misinterpretation of behaviours, secondary mental health issues like anxiety. Autism in the context of the petition should be taken as wide ranging and encompass the range of co existing conditions identified in the Autism plus model<sup>2</sup> versus autism pure – NCBI.<sup>2</sup>

I was making the assumption that this would be clear to service providers and policy makers as it is accepted by professionals working in the area. In this context i.e. a recognition of the wide autistic spectrum and autism plus, the petitions request that within education there should be specific autism support is valid and is not simply promoting improvements for a narrow group over other types of disabilities. (As some responses have sought to suggest)

Some replies have sought to suggest that the petition is seeking to impose assessments and services on autistic people, where this is not sought. This is not the case and the caveat of the agreement of the autistic person is assumed. I felt this would be clear but the wording of the petition should have been more explicit in this regard perhaps.

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<sup>1</sup> [https://www.change.org/p/scottish-goverment-let-s-make-real-change-happen-for-autistic-people-and-families-in-scotland?recruiter=45827484&utm\\_source=share\\_petition&utm\\_medium=copylink&utm\\_campaign=share\\_petition](https://www.change.org/p/scottish-goverment-let-s-make-real-change-happen-for-autistic-people-and-families-in-scotland?recruiter=45827484&utm_source=share_petition&utm_medium=copylink&utm_campaign=share_petition)

<sup>2</sup> <https://www.ncbi.nlm.nih.gov>

Several contributors have acknowledged that there require to be real measurements of the impact of the Scottish Autism strategy.

NAS Scotland agrees as to the importance of early diagnosis for accessing supports and calls for the Scottish Government to follow the English Government in publishing waiting times for autism diagnosis.

With regard to statutory assessments the response correctly points to the relevant assessments provision under older legislation that remains on our statute eg Children Scotland Act (1995) Sections 22, 23 and Community Care Act (1990) for adult assessments but the fact is that these provisions are much less used nowadays. For children the use of the GIRFEC framework (C&YP Act 2014) has overshadowed the earlier provision but does not always lead to the statutory assessment of children with disabilities and affected others. This assessment is essential for accessing supports like respite, direct payments and adaptations to a home.

Similarly, the statutory provision for a meaningful assessment of carer needs has tended to rarely take place or is being replaced by the provision under the new Carers Act Scotland that allows the authority discretion as to what the criteria for support is.

This has been a subtle but highly significant change in supporting carers and families and has in my professional experience produced a reduction in support. The further barriers to statutory assessments from the priority system used by many local authorities has led to assessment and accessing supports only being a right IF the authority deems it a priority.

While I acknowledge that this is largely to do with a lack of resources it is also sadly at times due to poor understanding of the complexities of an individual's autism. In Argyll I have many cases where this is the situation. This could be due to the needs being less obvious for a young adult with AS, and can lead to isolation, exploitation and mental health difficulties for the person.

Another issue is the use of generic social workers and locum social workers who have no experience or understanding of autism. In many cases this means there is little or no engagement with the person or family unless there is substantial support needs around a pronounced learning disability for example. This is another reason in my opinion of why specific legislation is needed for autism because there are so many difficulties and barriers around the understanding of and engagement with autistic people. Many of the families I have supported at Inspired by Autism<sup>3</sup> have no idea that under the Children's Scotland Act (1995) there is a statutory right to assessment for a child with disabilities and affected others e.g. siblings.

Similarly, with the Carers assessment under the same act that specifically looks at the effect on parents, families and carers and what support might be appropriate. In many cases families have no awareness about respite options and with an autistic

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<sup>3</sup> <https://inspiredbyautism.org/>

child if such input is not introduced early and in a carefully planned fashion the chances of successful engagement is reduced.

Named Person's particularly in school settings have also often got little awareness of the availability of supports like respite or direct payments for example. In many cases this type of support is essential for the wellbeing and healthy functioning of families. The GIRFEC framework has in my opinion somewhat overemphasised concepts and ticking of boxes e.g. Shannari wheel, my life triangle, rather than addressing the acute needs of autistic children.

These problems of lack of support and engagement that should have been addressed through the statutory assessments under sections 22 and 23 of the Children's Scotland Act 1995, contribute to the difficulties when autistic people become young adults.

Having never had proper or adequate assessment of their needs and without prior engagement and knowledge of possible supports, while often facing the difficulties of looking for work or adjusting to student life or independence, this group can be very vulnerable indeed.

The provision of transitioning guidelines by ANS is simply not adequate to address these issues and it is my strong feeling that a statutory option of support up to the age of 25 for autistic young people should be on offer, if they wish to pursue this help.

There were rather defensive responses from some local authorities. A common theme in responses is references to assessment processes with promising titles but that are vague and unclear in what they actually mean or entail or indeed indication of their effectiveness e.g. Children in North Ayrshire with Autism do have their needs assessed through our staged intervention and Child's Plan process. This process acknowledges their autism and identifies the effect it has on their lives. A number of specific targets based on wellbeing are set in response to the child's individual needs and support is allocated from a core budget to support them.

In the context of adult services, North Ayrshire is an active partner in the delivery of a broad ranging pan-Ayrshire Autism strategy aimed at encouraging appropriate access to services for people with autism, including delivery of training at very various levels to complement relevant expertise where it already exists, and exploring means of addressing recognised issues in relation to assessment and diagnosis.

Essentially, Resources are allocated using a 'Prioritisation of Need Framework'. In common with many other Partnership's across Scotland, Argyll and Bute HSCP have put in place a prioritisation framework to guide the allocation of resources to those in the greatest need. The need for such a framework is a direct response to the increasing gap between assessed need and available resources. (Argyll & Bute Council)

**It must be acknowledged that views from service providers have a bias towards their own positive portrayal.**

With regard to the petition call 'that young adults with autism will have a statutory right to specialist support from their local authority up to the age of 25,' it is disappointing that several authorities e.g. South Lanark interpreted this as possibly forcing supports on autistic people, who did not want this. This interpretation was disingenuous and defensive in nature and I felt it was clear that this support would be a right IF the person wished to access it or if they lacked cognitive capacity, as it is with regards to care leavers. The reference to corporate parenting is very far removed from the intention and spirit of the petition.

Dundee recognises that Support should be available through out adulthood and this the petitioner would agree with. The 'up to age of 25 years' was aimed at ensuring the transition to adulthood was adequately supported but was not at the expense of ongoing help through out adult life.

There is and has been a lack of a voice from service users and autistic people, with only limited and very controlled attempts to do so. The samples referred to in the SG and ANS responses are based on very limited groups and those who have a history of involvement.

However, I would suggest that for many (the majority of those living with autism) many barriers both structural and practical prevent their involvement. E.g in Argyll the Autism Strategy and ANS events were scheduled in venues and at times that prohibited parents attending and required access to transport and child care, neither of which was available.

Unlike the professionals attending no travelling expenses were available to autistic people and their families and carers. These events were always top heavy with professionals. The events to inform the final phase of the SG's Strategy presented similar problems and were in limited capacity venues unfortunately. The events themselves were highly structured and based around the new goals, failing to ask if these were the most useful and relevant goals.

Although the SG presented this as based on responses from across the autism community it really has to be acknowledged that just over 600 responses were received from the online consultation and around the same number attended the very structured consultation events.

They conclude that the sample was therefore greater than 1000 but do not acknowledge that many of the same people were likely to have participated in both. In short it is fair to assume that the decisions about the last phase of their strategy was based on a very small percentage of those living with autism in Scotland and the methodology used certainly never maximised the participation of those living with autism.

For many the amended goals were simply not meaningful in a sense that they could promote real, measurable and desperately needed improvements. That concerted efforts have not been made to reach out to the wider community must be remembered when assessing the validity of both SG and ANS reported findings.

Anecdotal evidence gathered in the [comments section on my petition](#) and in similar petitions suggest a very high level of dissatisfaction with the current state of autism support services in Scotland today. It remains astonishing that so few resources and efforts have been aimed at establishing the true picture in Scotland.

### **Lack of timescales for delivery of autism services are acknowledged.**

Teaching unions appear very supportive of development and training opportunities for staff in schools. The EIS submission understandably focussed on the issue of assessment for classroom support, training and registration for ASL staff. They rightly expressed concerns over the nature and availability of assessment and highlighted the shortage of educational psychologists employed across our authorities, as well as a lack of courses to increase numbers.

This is clearly a huge problem and must contribute greatly to the under assessment and subsequent lack of support so many autistic children require to endure in mainstream settings.

The EIS submission also makes very valid points about the demands on and implications of the policy of mainstreaming. E.g. this cannot be presumed as appropriate for all autistic children

### **Charitable organisations with specific remit to autism seem more supportive of suggestions in the petition.**

Need for a specific autism Act is being questioned due to the raft of related legislation- Equalities Act, ASL Education Act, Social Work Scotland Act and yet these acts allow a wide disparity in how statutory obligations are interpreted and met by different service providers.

East Ayrshire response largely supportive on all points. Glasgow Council was supportive of an Autism Act. South Lanark information around diagnosis is rather unclear. They talk about the time taken to be seen and that the assessment process is an ongoing one.

If a child is for example in early primary school and no diagnosis can be arrived at conclusively for a number of years this prohibits accessing supports and to suggest otherwise is wrong in my opinion. E.g. DLA, respite, classroom support. This authority appears to support the need for specific autism legislation.

ANS reply I found very interesting. That it has differentiated (finally!) between underpinning support in the form of guidance that they and the SG autism strategy are largely concerned with, and my call for improvements in direct services is a step forward, albeit late in the day.

The practice of not differentiating clearly about 'underpinning supports' like local strategies, guidelines and advice versus (the reduction of) 'direct services' has in my opinion been highly misleading and has represented bad faith as well as considerable hardship and frustration for those living and working with autism.

I was personally involved in the 'relaunched' local autism strategy in Argyll, around the 5-year stage of the 10 year strategy, after the initial one had failed and disappeared. ANS supported this process. I was determined to press for improvements in direct services but the process sadly only produced more 'words on paper' and the further promotion of meaningless jargon. This relaunch in Argyll has once again failed and the forum has simply fizzled out and no longer meet.