Education Autism Strategy Proposals

2016 - 2018

Prepared by Irish Autism Action with contributions from groups, members, parents & professionals.
Understanding Autism

Autism is a spectrum disorder that affects people in different ways. Each child with autism has their own additional support needs as well as having their own abilities that need to be enhanced. The shortfall in education and health services for children with ASD is something a proposed national autism strategy is intended to help highlight the clinical, health and social needs of those affected but would be of huge benefit in the research of effectiveness of interventions and medical treatments, and the exploration of possible environmental factors that interact with genetic profiles in causing autism.

There isn't the same pathway of care that there is for a typically developing child with no inpatient unit, no daycare programmes, no automatic access to therapies and interventions that are specific to autism to treat complex problems. People might think that a diagnosis of autism should be getting you services but, in a lot of cases, it is actually the opposite. People are handed a diagnosis and told to head for the internet. There is a high rate of mental health issues that exists along with autism and there is an increased risk of anxiety disorders, mood disorders and attention deficit disorders. These are all conditions for which there are certain treatments, but if you can’t access those treatments, they are no good to you. A lack of intervention compounds the situation you end up with people technically imprisoned in their own homes.

Our education system needs to change to prepare our children for adult life. The current education model focuses primarily on the academic side, but this is not enough as it does not prepare children for life. The social and emotional wellbeing of a child and their confidence and self-esteem is very important. Schools are judged as to how many students receive A’s in their exams, but how many of those students are happy about their lives, how many are confident and how many are actually feel they are actually socially and emotionally ready for the next steps in life.

Children with a diagnosis of ASD need to be supported better and we have to get a better understanding of autism nationally. As part of the next three year plan, our hope is for a more Autism aware and friendly society with the key focus working towards proper supports for families living with autism. Fundamentally, one important thing that has been completely ignored by the state is that autism doesn’t just affect the individual it also impacts on the family. For every person with a diagnosis a further 5 are impacted. Autism is a lifelong condition / disability. There are 276,000 people living with autism in Ireland.

The education current models across the three levels of schooling need review. From the special schools to ASD / Mild learning disability classes to the mainstream setting we need to change how we support children with autism under the following headings:

Considerations relevant to Special School settings

1. **Review of the current school calendar** - 183 days per year for a child with high support needs is not enough. The July provision is not mandatory and over the past few years we have seen a huge fall off in the amount of schools carrying out the July programme or even partial programmes. This leaves a long summer at home for the
children and for those aged 13 – 17 this can be exceptionally hard on families as the children regress due to the lack of structure and routine. The Home Tuition grant that is available where July provision is not been run is of little benefit for these families for a number of reasons. Finding the home tutor? The fact that it is only 40 hours over the month and the home environment in general is not ideal for this programme.

2. **More access to Specialist Services** - Across the special schools we need more support from behaviour management, Occupational Therapy, SLT and community programmes to prepare the child for life after 18.

3. **Greater accessibility to Special schools** – Undoubtedly, we need more special school places with a much greater emphasis on supporting the child and their family.

**Considerations relevant to ASD / Mild learning disability Classes**

1. **Increased training and better awareness** - In the ASD classes, the current models are working well in some schools but not so well in others. That lack of consistency leads to a poor understanding and schools and BOMs making decisions to leave children at home from school on Health and Safety grounds. While we will always advocate that Health and Safety is important we too must understand that Health & Safety is for everyone and not for a majority. Sending a child home from school without support is of no benefit to the child or the family. Equally it is just as hard to get the child to return to school and also for the family as their anxiety levels rise every time the phone rings, they are thinking it could be the teacher again. This has to stop.

2. **Increased access to Specialist Services** - We need more Behaviour specialists across the country to support these schools and an emergency funding model that can be accessed if need be to ensure that the child gets appropriate support and that no other child is impacted. Equally, this is better for the family too. We also need to focus on ability and ensure that children are given the opportunities to integrate to mainstream where possible with appropriate supports. At all levels it is very important that our teachers and educators have autism specific training and have a good understanding of ASD.

3. **Improved Standards and accountability** – The lack of standards results in an inequality of education provision.

**Considerations in Mainstream schools**

1. **Implementing Bullying policies** - In our mainstream schools, we are concerned that up to 34% and higher of ASD students are bullied. This has to change as being a victim of bullying can have a massive and much deeper impact on a child with ASD. Schools need to take bullying incidents much more serious than they are currently. Having a policy on their website is not enough. Quite often when families of children with ASD report bullying they are often ignored or brushed aside. In the same way we communicate headlice issues or other health issues in the schools we need to also raise awareness on the serious affects that bullying can have on a child and
publicise through the school’s website when a case has been reported / addressed. The details can remain confidential but it may prevent future bullying incidents.

2. **Explicit Social Skills instruction** - Resources and supports vary from county to county and this should not be the case. It should be the same across the board and the supports should be child centred. A compulsory social skills curriculum for children with autism in the school setting at every level, using video based learning and applying the content in practical scenarios is extremely important. The exemption from Irish also needs to be made easier.

3. **Better communication between school and home** - Families of children with ASD need to be respected more by educators and professionals by allowing their input into their child's Individual Education Plan (IEP). Families concerns are often dismissed by educators and lead to further problems down the line. It is important for educators to understand that children with autism spend up to 140 hours per week at home / in direct contact with their parents, so an overall approach to the education and wellbeing of a child needs to be recognised.

**Why as parents of a young man with additional needs do we feel we have to fight for everything for him, from therapy to equipment to service support, again and again and again?** Emotionally, mentally and physically it can be challenging for most carers in Ireland. When is this going to STOP and let Ireland help our less advantaged? View from a parent of a child with autism in Ireland.

*Contributions to this strategy were made by Irish Autism Action and the ACTivate club, a weekly support group run by parents of children with an Autism Spectrum Disorder and helped by volunteers and youth workers from CDYS Mallow.*

**We need to put a care plan in place from the time of diagnosis that provides life-long care to the individual including:**

a) Provide varying levels of support to the individual with an autism spectrum disorder initially equaling the level of support outlined in their diagnosis. This however should be monitored over time (by parents / school / HSE or care provider / social worker) adapting the support levels academically, socially and cognitively to enable increased independence for individuals on the autism spectrum to live as full a life as possible within their capacity.

b) Provide support to the families of individuals on the autism spectrum disorder including time out for parents and guardians, SIB shops for siblings adapted to the relative age groups and a dedicated person to support the family as a support line, on an ongoing basis.

c) Education both within the Department of Education at policy level and at ground level (teachers / SNA / administrative staff) and within the community about autism spectrum disorders and the impact it has on the child, the family and the community as a whole.

d) The goal is to promote positive mental health to the person with an autism spectrum disorder and their families enabling them to live and work in their community within a safe and happy environment.
**Provide services** – There is no one to rely on, no one to ring for backup. The services in the catchment areas currently can’t cover the amount of children on their waiting lists.

**Social skills curriculum for children with autism** – A compulsory social skills curriculum for children with autism in the school setting at every level, using video based learning and applying the content in practical scenarios.

**Educate the students** – Educate the other students about autism spectrum disorders and special needs in general using appropriate language and video based learning. Provide students with examples helping them to understand what is means to have autism / special needs and illustrate to them how they can help in simple ways. A greater understanding of diversity and respect for difference is needed in our schools especially for hidden conditions like autism, in order to reduce bullying and promote inclusion.

**Expectations are too high in gender related activities** – Not every child can do sport. Children with autism may or may not have various co-existing conditions that impact on their mobility. It is unfair to expect a “boy” for example to play hurling / football just because he is a boy. Teachers / school staff at ground level need to respect the child’s ability and provide alternative activities. Dialog between parents and teachers should be ongoing and together they should find alternatives suitable to the child’s ability following any recommendations provided in the child’s report. The Department of Education needs to build this into their policies and curriculum content.

**Teachers please read reports** – Many teachers never read reports and in unthinkable revelations by parents themselves, some teachers “pretend” they didn’t know a particular child has an autism spectrum disorder even though the parents would have given the report to the schools. Parents generally have to “fight” for services to even get a diagnosis, the least teachers and schools can do is to READ THE REPORTS and FOLLOW RECOMMENDATIONS.

**More Services** – In particular Speech and Language and Occupational Therapy, as lack of will have a detrimental effect on the child’s ability in school. Not addressing this in the early years will have an even greater negative impact on the child as they move up along the education system. It goes without saying that this has a knock on effect on the family and the community as a whole.

**More than ACCESS to an SNA** – Children in school settings need to know that their children have more than just access to an SNA. Access does not guarantee that their child will have an SNA when they need it, if there is another child “using” the SNA at the same time. Generally speaking, it is the child who is most at risk that gets the SNA, but risk however can be measured in various ways including physically, psychologically or otherwise. Some children will hide their anxieties and may present then as not needing the SNA as much as they may not have the skills to ask for help and may not even know what “state” they are in, however it’s the parents who will “pay the price” when the child comes home from school when then child has meltdowns and this then has a detrimental effect on the family. Unfortunately, when children get to the meltdown stage, they have lost control due to no fault of their own. A greater understanding of autism spectrum disorders is needed to avoid this happening or at the very least minimise the frequency of it happening.

**Teacher training compulsory** – Teachers should have compulsory autism specific training to give them the tools needed to deal with unpredictable events in the classroom and to minimise the risk of increasing anxieties during the school day.
A Special Education Needs coordinator – is needed in the school to coordinate the care and communication relative to each individual child, between the parents, HSE or service provider and the Department of Education including the Education Psychologist and the SENO.

Irish Autism Action are hoping to create a more Autism Friendly in 2016