

# Fostering access to education for autistic learners

**Recommendations and good practices** 



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## Introduction

In the European Union, it is estimated that 1% of the population is on the autism spectrum, which amounts to 5 million people. Autism forms a 'spectrum', which means that each person will experience autism differently. There is not one size fits all solution to accommodate the needs of autistic people. Autism is a lifelong disability, notably associated with difficulties in social communication and social interaction as well as sensory difficulties, such as increased or reduced sensitivity to light and sound. Enabling people on the autism spectrum to live long and fulfilling lives as autonomously and independently as possible, requires a change of mind-set in society to support their active participation and inclusion. It also entails to create and maintain the necessary support services and to foster accessibility for autism across all sectors, not least education.

Access to education is a key factor for inclusion which proposes quality education for every student. According to UNESCO, inclusive education is described as education systems that respect diversity, acknowledge and provide for different needs and characteristics of students with the aim to eliminate discrimination (UNESCO, 2009). A comprehensive inclusive education framework encourages equity in the school environment and embrace full participation of learners in both academic and social experiences. Multidisciplinary approaches are allowing school systems at all levels to support inclusion in the classroom focusing on both students' education and well-being.

People on the autism spectrum are more likely to face discrimination in accessing all levels of education across Europe which has a negative impact on their life outcomes. Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) provides that learners with disabilities should be supported to access education, notably through: reasonable accommodation, appropriate support, and effective individualized support measures.

Yet, the barriers to education that autistic learners face are plenty at all educational levels. Autistic learners present unique educational needs that are qualitatively different from other special needs and require specific understanding and approaches to meet them. However, they usually experience discrimination when it comes to reasonable adjustments that school environments shall undertake to support the needs of every student. The COVID-19 pandemic impacted students with disabilities who have lacked access to the IT equipment required to access online education. Online education also proved to be inaccessible for a majority of autistic children.

This report aims at summarizing the issues and difficulties faced by people with autism in relation to education across Europe and provide recommendations to overcome them. In the context of the United Nations Convention on the Rights of Persons with Disabilities, it outlines various forms of support that can be utilised to enable individuals in the autism spectrum to fully participate in education. Autism-Europe also ran a survey to identify examples of good practices at different levels of education to foster effective learning and inclusion of autistic learners. This report provides an insight in some successful educational practices for autistic learners in different education settings. Some of the examples of good practices in the field of education for people with autism have been provided on request by Autism-Europe's members and other relevant organisations.



## The right to education in the international, European and national contexts

The ratification of the UN Convention on the Rights of People with Disabilities (UNCRPD) by the European Union and all the EU member states has been a landmark. In relation to education, it provides that people with disabilities receive the support required, within the general education system, to facilitate their effective education; effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion (Art. 24).

In 2016, the General Comment No. 4 on Article 24- Right to inclusive education- of the Convention on the Rights of Persons with Disabilities was adopted. According to the General Comment, inclusive education is a fundamental right for every learner which 'encompasses a transformation in culture, policy and practice in all formal and informal educational environments to accommodate the differing requirements and identities of individual students, together with a commitment to remove the barriers that impede that possibility.'<sup>1</sup>

In the UN's Sustainable Development Goals, SDG 4 calls for countries to 'ensure inclusive and equitable quality education, and promote lifelong learning opportunities for all'. In 2022, the UN World Autism Awareness Day observance addressed inclusive education in the context of SDG 4. In this respect, inclusive education highlighted as "the key to the transformative promise of the Sustainable Development Goals, to leave no one behind"<sup>2</sup>.

At a European level, the European Pillar of Social Rights states that 'everyone has the right to quality and inclusive education, training and life-long learning in order to maintain and acquire skills that enable them to participate fully in society and manage successfully transitions in the labour market'.

In 2008 were also published the CM/Rec(2009)9 recommendation of the Committee of Ministers of the Council of Europe to member states on the education and social inclusion of children and young people with autism spectrum disorders that provides guidance for member states.

On 23 February 2022, the Council of Europe adopted the new Strategy for the Rights of the Child (2022-2027) highlighting the need for quality education to all levels of education and vocational training for persons with disabilities. Nevertheless, there is an absence of targeted actions in education of students with disabilities.

Further actions coming from the European Commission regarding inclusive education for all learners. The EU Strategy on the Rights of Person with Disabilities and the EU Strategy on the Rights of the Child both promote inclusive education within key actions. Additionally, a Toolkit for inclusion in early childhood education and care has been published in 2022. However, there is no comprehensive action plan to tackle existing inequalities in education across Member States.

The European Commission has also published the Implementation guidelines Erasmus+ and European Solidarity Corps Inclusion and Diversity Strategy Inclusion strategy aiming to address barriers in education, training and youth work. People with disabilities are describing as "people with fewer opportunities" in the area of education, mobility and youth opportunities<sup>3</sup>. Inclusive opportunities for autistic youth in education and exchange programs should become a reality across EU Member States, as it is an undeniable right for every student to engage in EU funded programs.

<sup>1</sup> CRPD\_General\_Comment\_4\_Inclusive\_Education\_2016\_En.pdf (right-to-education.org)

<sup>2</sup> World Autism Awareness Day - EN | United Nations

<sup>3</sup> implementation-inclusion-diversity\_apr21\_en.pdf



The EU adopted the Digital Education Action Plan (2021-2027) 'a renewed European Union (EU) policy initiative to support the sustainable and effective adaptation of the education and training systems of EU Member States to the digital age'. It is key that the digital transformation in the field of education is inclusive of learners with disabilities. Indeed, failure to provide access to reasonable accommodation in education to autistic people prevent them from acquiring job qualifications, thus also exclude them from the labour market at a later stage.

The EU has supporting competence in the field of education. In that context, it should encourage cooperation among Member States and support their actions. In particular, the EU can support its Member States by: - Promoting the coordination between Member States of relevant policies in the field of education in relation to autism

- Making recommendations to Member States to improve access to education for autistic learners, notably via the European Semester
- Adopting principles of best practices and fostering mutual learning between member states to respond to the needs of autistic people in the field of education
- Promoting training and common standards for professionals in autism across all relevant sectors
   Supporting research to improve the quality of life and inclusion of autistic learners
- Fighting prejudices and stereotypes as well as raising awareness
- Supporting and involving autistic people, their families and their representative NGOs through continuous structured dialogue

As the EU Agency for Special Needs and Inclusive Education states "flexible mechanisms for funding and resource allocation that support the on-going development of school communities"<sup>4</sup> are necessary together with monitoring frameworks aiming to review and evaluate the adequacy of the provisions for all learners.

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# Issues and difficulties faced by people with autism in relation to education and ensuing recommendations

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. Each autistic person is different, however they have impairments in three main areas: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour.<sup>5</sup> Anxiety and other mental health issues have been proven to influence in a negative way the learning activities of autistic people<sup>6</sup>. Moreover, autistic people can experience difficulties to engage with their peers or be victims of bullying<sup>7</sup> due to their difficulties with social interaction. The findings of multiple studies present that autistic students experience "significantly higher levels of behavioral and emotional difficulties at school than their typically developing peers". These behavioral and emotional difficulties can be expressed as attention difficulties and hyperactivity, anxiety, depression, and even aggression<sup>8</sup>.

Children and young people on the autism spectrum should enjoy equal opportunity for educational interventions that are appropriate to their needs and work towards social inclusion and irrespective of their age. However, autistic people are still discriminated against in the field of education across the EU, especially those in need of intense support are often excluded or do not have adequate access to education services.

Autism occurs in early childhood. In some children, the symptoms of autism, can be recognised in the first year of life. While, in other cases the first symptoms are noticeable at a later stage, usually when children are in elementary school. Diagnosing autism in early childhood is a crucial step to give access to adequate support in education for autistic persons.<sup>9</sup> Early detection of autism, when followed by appropriate diagnosis and assessment and by behavioural and educational intervention, can make a significant positive impact on long term outcomes for autistic people and their families. However, according to the conclusion of the EU funded project ASDEU released in 2018, diagnosis is still a key issue in Europe, and more resources are needed to facilitate early detection. Research showed that the average age first concerns about autism are identified is 25.3 months, while on average, diagnosis does not happen until 44.4 months – 19 months later. Most parents (68.8%) indicated delays of more than six months to access a diagnostic service. Only 44.8% of families reported that professionals informed them about their child's specific needs and 20% of families said they did not receive any information at the time of diagnosis. Families evaluated detection services negatively in terms of the attention professionals gave to parents' concerns. The delays in accessing early autism diagnosis deprives children on the autism spectrum of equal opportunities to access targeted inclusive education and to achieve social inclusion. Autistic children and their families are unable to access the right support at the right time due to lack of early diagnosis<sup>10</sup>.

<sup>Buescher AVS, Zuleyha C, Knapp M & Mandell SJ (2014) 'Costs of Autism Spectrum Disorders in the United Kingdom and the United States'.</sup> JAMA Pediatrics, 168(8), pp.721–728.
Ashburner, J., Ziviani, J., & Rodger, S. (2010). Surviving in the mainstream: Capacity of children with autism spectrum disorders to perform academically and regulate their emotions and behavior at school. Research in Autism Spectrum Disorders, 4(1), 18-27.
Marshall, D., & Goodall, C. (2015). The right to appropriate and meaningful education for children with ASD. Journal of Autism and Developmental Disorders, 45(10), 3159-3167.

<sup>8</sup> Ashburner, J., Ziviani, J., & Rodger, S. (2010). Surviving in the mainstream: Capacity of children with autism spectrum disorders to perform academically and regulate their emotions and behavior at school. Research in Autism Spectrum Disorders, 4(1), 18-27.

<sup>9</sup> European Parliament. Written Declaration on Autism [Internet]. 2015. Available: http://www.autismeurope.org/wp-content/uploads/2017/08/written-declaration-on-autism-to-the-ep.pdf

<sup>10</sup> Amin, T. (2015). Right to Education of the Autistic Children: An Overview. ASA University Review, 9(2)



The financial crisis has negatively influenced efforts towards inclusive education. Austerity measures in EU countries such as Greece and Portugal, found to have a negative impact on the inclusive education of autistic students<sup>11</sup>. Budget restrictions in education are likely to place persons who need more support and accommodations to learn, such as autistic people, at a disadvantage.

In some countries, Article 24 CRPD is used as a justification to cut funds to special schools without adopting adequate legislation, policies and without providing adequate funding to support the transition and to ensure appropriate support and accommodation for autistic pupils and students in mainstream schools.

Over the past years, education systems across the European Union have evolved, to move towards inclusive models. Therefore, education systems across the European Union have undergone systemic changes, to move towards inclusive models. Yet, many autistic learners still struggle in inclusive education, as they experience a lack of understanding of their individual needs and what is adapted support. Despite changes in the legislation of many countries, there is still room for improvement in education for autistic learners.

As mentioned thoroughly in the previous section, autistic people face a lack of flexibility of the education curriculum and infrastructure to use their strengths. There is a variety of support arrangements that can be implemented in education settings aiming to benefit the learning process of autistic learners.

In order to gain a better understanding of the lived experiences of autistic learners and their families in the various member states when it comes to including autistic people in the general school system, AE has carried out a EU-wide survey in 2019. It provided us with a regional overview of the opinion of autistic people and their families regarding available educational support and measures to promote access to education. AE member organisations and affiliates were contacted in order to find people to complete this educational survey. We received almost 2200 answers from 25 EU member states (the most answers from Germany, France, Spain, and Poland), and 12 third countries. The survey was made available for respondents in 8 languages: English, French, Italian, Spanish, Dutch, German, Polish, and Ukrainian.

For 14 EU countries (Belgium, Finland, France, Germany, Italy, Lithuania, Luxembourg, Latvia, Malta, Netherlands, Poland, Slovenia, Spain, United Kingdom) the kind of support for autistic learners on every educational level has been analysed, the results from 3 EU countries were omitted due to the lack of data to meet our standard for this report.

Next, a country by country analysis for each level of education of 17 EU countries of the 37 (including outside of the EU) from where we received a reasonable amount of responses is shown. The survey asks about inclusive education at preschool level, the primary level, the secondary level, the university level, vocational level and apprenticeships.

With the available data, recommendations have been formulated, following a life-long approach.





# 1-Access to individualised planning and adequate support for autistic learners in the education system

We looked at the picture across the EU and here are a few cases:

**In Germany** where less than a third (30%) knew of an individual educational plan in secondary education, one respondent said:

"Normally an educational plan is required when special educational needs have been identified. For very quiet students or pupils with Asperger's, this need is often identified very late, i.e. only when students fail in the school situation."

**In Netherlands** where only 1 out of 3 (36%) respondents knew of an individual educational plan at the secondary level, one respondent said:

"We have asked this question to several schools; the answer is no, giving different levels in one class is overburdening the teacher. Seriously this is the answer we got even though it is mentioned in all school brochures and laws as tailored education."

**In Spain** where around half (48%) knew of an individual educational plan at the secondary level, one respondent said:

[On knowing about IEPs] "Not generally. We are fortunate to be able to have a person-centred plan for our child, which encompasses their social and educational environment. It allows him to study at a public music conservatory. It is very costly for us, but the results are visible: He is in fifth grade and with a view to obtaining his degree (he doesn't have compulsory secondary education). [...] Education does not cure, what it does do is empower for life in society. We think that families encounter the belief that a student with autism, (unless it is Asperger's), is not capable of learning in a normalized environment, and that any resource that is not welfare, is a waste of time and money."

#### We recommend:

- Adopting a learner-centred approach. If such approach is already in force, then it must be reviewed regularly to ensure that its application is effective to ensure that autistic learners are supported to fulfil potential, enhance their well-being and quality of life.
- Establishing an individualised educational plan (IEP) for each autistic learner based on the assessment of their support needs and strengths as well as interests, with ability-appropriate learning objectives. It should be designed after careful consultation of autistic learners and their families using alternative and augmentative means of communications whenever needed. This consultation should take into consideration the desired outcomes of autistic learners for their adult life.

The objectives in the IEP must have an achievable timeframe and must positively affect a child's participation in education, the community, and family life.

- Providing better support for female autistic learners any learning support is more often than not tailored to a male autistic audience with less support for females.
- Adopting a multidisciplinary approach with regular coordination between educational and health and habilitation staff (such as speech and language therapists) to monitor autistic learners's experience in education and develop skills that fall outside of the regular curriculum (e.g. independent living skills, social and emotional understanding).
- Establishing a specialised learning support team that can assist autistic learners with any issues they may have, and to facilitate dialogue to resolve problems with the educational establishments.
- Ensuring adequate collaboration and communication between parents and professionals. Setting up effective and active parental forums from early education onwards to address problems and foster parental participation in the educational process. This will encourage



and empower parents to speak up and be adequately informed and involved. The close involvement of parents in the education of the learner is a determining success factor.

- Streamlining methods of communication between departments and between professionals, including at transition times, to keep parents continually informed on the progress of the autistic learner's development.
- Supporting parents via adequate community-based support services, resources and training to help maintain their children in the family.
- Supporting the development of accessible distance education programmes accessible to autistic learners who might benefit from them.
- Setting up community monitoring watchdogs to ensure support for all disabled learners is being adhered to as accessible community support must be available from appropriate, well-informed, multi-agency services. It would help all autistic learners address any inconsistencies in their education when their learning provider does not meet their obligations to autistic learners. The situation is different across the EU, but if a regulator already exists, it is not effective enough. Such a body must have power to conduct investigations and inquiries, act as a mediator and watchdog and also must have legal powers to suspend and dismiss educational staff that would not fulfil their professional obligations.

### The Individualized Education Plan (IEP)

The Individualized Education Plan (IEP) is a document which includes details on student's education. This education plan includes student's academic and social learning goals for the school year, teaching methods which will be used in order to achieve these goals as well as assessment tools for evaluating student's progress. IEP should be personalized in the particular needs and characteristic of the students taking into account their strengths and weaknesses. "The key word is individual. A program that is appropriate for one child with autism may not be right for another"<sup>12</sup>. School professionals, parents and other professionals working with the child should be collaboratively work to develop IEPs. In many Member States, there is a widespread use of IEPs (known as 'targeted action programmes' in Scandinavia)<sup>13</sup>.

Establishing an individualised educational plan (IEP) for each autistic learner based on the assessment of their support needs and strengths as well as interests, with abilityappropriate learning objectives should be encouraged in all education settings. It should be designed after careful consultation of autistic learners and their families using alternative and augmentative means of communications whenever needed. This consultation should take into consideration the desired outcomes of autistic learners for their adult life. The objectives in the IEP must have an achievable timeframe and must positively affect a child's participation in education, the community, and family life.

A well-developed IEP is core for adopting a multidisciplinary approach with regular coordination between educational and health and habilitation staff (such as speech and language therapists) to monitor autistic learners's experience in education and develop skills that fall outside of the regular curriculum (e.g. independent living skills, social and emotional understanding). Establishing a specialised learning support team that can assist autistic learners with any issues they may have, and to facilitate dialogue to resolve problems with the educational establishments is the most important step of adequate support for autistic students especially in primary and secondary schools.

<sup>12</sup> Individualized Education Plan (IEP) - Autism Society. (autism-society.org)

<sup>13</sup> eaf\_policy\_brief\_-\_sen\_children\_post\_copy\_edit\_15.10.13.pdf



# 2- Reasonable accommodation

We looked at the picture across the EU and here are a few cases:

When asked what the typical ratio of children with a disability to children without a disability in a mainstream class is, responses from **Poland** can be summarized in the following comment:

"Integration primary school 15-20 students, including 3-5 disabled, public primary school has no arrangements as to how many children with disabilities can be in the classroom."

When asked if trained assistants are working in the classroom, what is the ratio of trained assistants compared to the number of children with a disability, only a few respondents in **Malta** indicated one-to-one support. One respondent remarked:

"It depends on the disability and how lucky you are to get 1:1 for your child.... It may be shared by up to 3 children in the same or in different classes"

Only roughly 23% of respondents from **France** mentioned they had an assistant to support the child at pre-school level. Most of the respondents pointed out that assistants "lacked training".

Only roughly 12% of respondents from **Germany** know from their experience that schools in their area provide any form of reasonable accommodations for sensory needs of autistic people. In relation to this a respondent remarked:

"in very few individual cases material is made available (noise-protection headphones, seat in the back or at window, etc. as suitable; rarely empty room for retreat; (...); individual lighting is not known to me)."

1 in 5 (around 20%) of respondents from **Spain** indicated that alternative means of communication are used with the autistic children at pre-school school level. One respondent commented:

"There is support staff but not always with autism training, they tend to use pictograms but not properly."

When asked if schools support social communication of autistic children and their inclusion with neurotypical children during recreation and lunch times, trips, study visit, museum visit, sport activities, only 8% of respondents from the **Netherlands** knew of such support, with one respondents saying:

"This kind of support is at the discretion of the schools, so this differs greatly from one school to the other."

According to Article 2 of the UNCRPD, 'Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms'.

The accommodation of diverse learning needs and capacities in education settings is important for autistic learners. Nonetheless, national education systems are often found to be unable to accommodate the needs of autistic students and fully support them. A study based on a parent survey highlighted that schools had not made any specific adjustments 'relating to the physical, social and educational environment' to foster the education of autistic learners. More than half of the responders pointed that the only adjustment was to share information regarding the student's needs at school with the teachers. Follow autistic students' routines and avoid interruptions were also mentioned in the same study as reasonable adjustments. Thus the vast majority of respondents were dissatisfied about the accommodation provided for the needs of autistic learners<sup>14</sup>.

<sup>14</sup> 

Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2022). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people's experiences. Journal of Autism and Developmental Disorders, 52(3), 1131-1142.



Across Europe, the rates of students with disabilities acquiring university degrees and qualifications remain low, fact that prevents them from their right to access employment<sup>15</sup>. Moreover, there is a widespread lack of vocational training and higher education options that are suited to the needs of adults with autism in European Union. Autistic learners in higher education are facing unique challenges. While the number of autistic students enrolling academic institutions is raising, the dropout rates, the possibility to repeat courses or experience academic failure are remaining also in a high scale for autistic learners<sup>16</sup>. The effectiveness of reasonable accommodations in higher education for autistic learners is determined by multiple factors where individual and environmental aspects should be considered<sup>17</sup>.

Enrolment in adequate inclusive education settings from an early stage increases the probability of the students with disabilities to continue in higher education<sup>18</sup>. Reasonable accommodations such as built an autism friendly environment, including quiet, low-sensory spaces, specialist support for managing anxiety and stress need to be available for all autistic learners across the EU.

#### We recommend:

- Working towards a reduction in class sizes so that autistic learners' are afforded more individual attention.
- Making one-to-one time available for professionals and autistic learners to adequately assist autistic learners.
- Improving the built environment, and notably the lighting and soundproofing aspects, to help autistic learners participate in education. Classrooms and other part of schools should be designed to have a low echo or good acoustics as well as suitable lighting so that, the teaching space is able to accommodate autistic learners. It is important to provide access to quiet space and sensory room for autistic learners when needed so that they can avoid sensory overload.
- More investment in visual support and assistive technology in classrooms, paired with adequate training of teachers.
- Providing adequate support for learners during unstructured times, such as lunch breaks, nap times, etc.

- 16 White, Susan, Thomas Ollendick, and Bethany Bray. 2011. "College Students on the Autism Spectrum: Prevalence and Associated Problems." Autism 15 (6): 683–701. doi:10.1177/1362361310393363.
- 17 Dorien Jansen, Katja Petry, Eva Ceulemans, Ilse Noens & Dieter Baeyens (2017) Functioning and participation problems of students with ASD in higher education: which reasonable accommodations are effective?, European Journal of Special Needs Education, 32:1, 71-88, DOI: 10.1080/08856257.2016.1254962
- 18 European Agency for Special Needs and Inclusive Education (2018), Evidence of the Link Between Inclusive Education and Social Inclusion: A Review of the Literature

<sup>15</sup> European Commission (2018), Access to quality education for children with special education needs.



# **3- Flexible curriculum**

We looked at the picture across the EU and here are a few cases:

In all the EU countries we looked at there was hardly any possibility for a flexible curriculum for autistic learners.

A very small minority of respondents from **France** and **Poland** indicated that the education system in their area offers flexibility for autistic pupils and students to get their diploma. One respondent from **France** commented:

"It is impossible in France to miss a subject. If, for example, a child has difficulties in mathematics but is very good everywhere else, if he has a disability, the school will no longer want him and will try to guide him to a medical establishment or classes for disabled people, without trying to see if the problem would not come from them... "

On respondent from **Poland** commented:

"Unfortunately, it's not possible. A graduate who was humanistically talented had to pass his math exams, with which he had huge problems with. The letters to the Ministry of Education did not help. During their studies, they also have to obtain credits in the same way as other students (e.g. in writing, when they should orally or vice versa). The system is not flexible and there is a lack of knowledge about the specificity of the functioning of autistic pupils/students."

#### One other commented:

"The system of secondary school leaving exams should be made more flexible so that students with no mathematical skills can choose a different subject (the one from which they have rash abilities). And at the stage of studies, make the form of passing exams and obtaining credits more flexible (in accordance with the needs of students)."

9% the respondents from **Germany** and 15% from **Spain** indicated that the education system in their country does offer flexibility for autistic pupils and students to get their diploma despite areas where their autism might present particular difficulties. One respondents from **Germany** said:

"The school act now stipulates that simplifications, e.g. in examination situations, are required. Unfortunately, schools often don't know this and refuse to do it at the beginning and parents have to fight for it on behalf of their children. Then the question arises as to what such simplifications should look like, even if the school authority mentions many examples on its website. Nevertheless, it is difficult for each autistic person to define it individually, because teachers have no experience with it and have to provide a balanced level of difficulty, which means that they do not have any advantage over the autistic person."

#### One respondent from **Spain** said:

"In the Spanish education system there is a minimum evaluation, that is, you have to meet some minimum criteria if you don't meet the criteria you can't get the degree."

#### We recommend:

- Promoting a flexible curriculum in schools and establishment as autistic learners find the rigid structure of curricula challenging. Curriculum should be adapted according to individual strengths and interests. Situations should be assessed on an individual basis and learners should be allowed to opt out of some particular topics.
- Providing opportunities in the curriculum to develop social skills and life skills to enhance participation and independence in family, school, and community activities and foster inclusion.
- Offering support concerning organisational skills for autistic learners in schools or other educational establishments. The development of these skills will enhance academic learning and outcomes which are necessary to advance onto the next level of education.



# 4- Supporting adequate training and working conditions for education professionals

Autistic learners present unique educational needs that are qualitatively different from other special needs and require specific understanding and approaches to meet them. For autistic persons in need of intense educational support, the effectiveness of education is jeopardized by the lack of competences of teachers on educational strategies to respond to their major learning difficulties. OECD articulates in various publications that ongoing professional development is vital to equip school leaders and teachers with the required skills so they can successfully engage students with special education needs in the education process<sup>19</sup>. In 2018, the OECD Teaching and Learning International Survey (TALIS) revealed that teachers present "high level of need for training in advanced information and communication technology (ICT) skills and teaching methods for students with special needs". The need for training in both areas became particularly obvious in COVID-19 times. As illustrated by a recent study conducted in Croatia, the Republic of North Macedonia and Poland focused on experiences of teachers working directly with children with autism in both mainstream and special schools. More than 20% of the respondents had received no specific course in autism during their initial teacher education and an overwhelming majority – 93% of both mainstream and special school teachers identified a need to access further teacher education opportunities regarding autism, notably regarding theory, relevant practical strategies and mentorship/supervision<sup>20</sup>.

#### We looked at the picture across the EU and here are a few cases:

**In France,** respondents were asked if teachers had an adequate understanding of autism and the needs of autistic pupils. Almost half strongly disagreed that they had any understanding of autism, with one respondent remarking that:

"Great ignorance of neurodevelopmental disorders in general, including teachers. Too few incentives to revise their representations to really change the dominant culture within the national education system. A culture of academic excellence, of 'framing' children so that they are properly educated."

**In Germany,** respondents were asked if teachers had an adequate understanding of autism and the needs of autistic pupils. Around 1 in 3 strongly disagreed that they had any understanding, with one respondent remarking that:

"Unfortunately, there is a massive backlog in understanding for autistic children. Behavioural problems of learners with Asperger's were often attributed to naughtiness and bad upbringing by the parents or even psychological neglect of the child by the parents. It was completely overlooked that the behaviour of the child with disabilities was partly triggered by bullying by classmates, teachers, afternoon caregivers or even the school assistants themselves."

**In Poland,** respondents were asked if teachers had an adequate understanding of autism and the needs of autistic pupils. 13% strongly agreed and 16% strongly disagreed that they had an understanding, with one respondent remarking that:

"Depending on the educational centres, from "definitely yes": in specialist support centres, the best integrated schools, to "definitely NO": in most mainstream schools"

<sup>19</sup> OECD (2019), TALIS 2018 Results (Volume I).

<sup>20</sup> Natalija Lisak Šegota, I. Lessner Lištiaková, J. Stošić, J. Kossewska, J. Troshanska, A. Petkovska Nikolovska, T. Cierpiałowska & D. Preece (2022) Teacher education and confidence regarding autism of specialist primary school teachers, European Journal of Special Needs Education, 37:1, 14- 27, DOI: 10.1080/08856257.2020.1829865



#### We recommend:

#### **Develop autism standardised specific training**

- Mandatory autistic-specific training and neurodiversity training for teachers, supported by special needs teachers. This training must be applied to experienced practitioners to refresh their knowledge and for newly qualified teachers to equip them with the specific skills and knowledge needed for autistic learners. All teaching staff must know and feel confident in knowing what to do when faced with autistic learners.
- Mandatory autistic-specific training for all support staff working in educational environments, supported by special needs teachers. This list must include all staff involved in education, such as bus drivers, librarians, janitorial staff, office staff, cleaners, kitchen staff and other staff who would come into contact with autistic learners in educational spaces.
- Ensure closer management of newly qualified teachers enhancing support for junior teachers from senior teaching staff.
- Teacher training and continuous professional development should be free and accessible to professionals some teachers are paying for their own training and extra training to acquire skills that national teacher training did not supply them with.

# Ensure adequate working conditions to foster retention of qualified professionals

- Teachers' maximum class contact time must be respected as teachers are often so overworked that they cannot adequately assist their learners, least of all learners with additional support needs such as autistic learners.
- Provision of adequate salaries' for teachers and teaching support staff.
- Avoid temporary contracts for teachers, teaching assistants and support staff. Autistic learners are particularly sensitive to change and the same teacher throughout the whole year is essential. It is also essential to ensure that staff are appropriately trained and experienced.
- Provide on-going support for teachers and teaching assistants who must be able to adapt and understand autistic learners' needs, and therefore must be familiar with theory and research concerning best practices to support their learning.



# **5 - Facilitate better transitions**

We looked at the picture across the EU and here are a few cases:

In **Germany**, respondents were asked about support for autistic learners during the transition between different levels of education. Only 19% said they knew of any support with over half (53%) saying there was no support:

"No systematic support, only individual support within the care framework by the autism therapy centre."

In **Italy**, respondents were asked about support for autistic learners during the transition between different levels of education. Only 35% said they knew of any support with over half (52%) saying there was no support:

"There's a meeting between "old" and "new" teachers. But only if there is the good will of the teachers!"

In **Spain**, respondents were asked about support for autistic learners during the transition between different levels of education. Only 13% said they knew of any support with nearly two thirds (62%) saying there was no support:

"In the transition from pre- to primary school there was no special support from the school to make their adaptation easier and less stressful."

Only 5% of respondents from **Poland** knew of support offered to autistic learners during the transition between different levels of education.

Autistic people experience difficulties in social communication and interaction, and repetitive behaviours, as mentioned above. At school level, autistic students have specific needs at different educational stages since difficulties. The transition from primary to secondary school can induce more stress, depression and anxiety symptoms in autistic students. The transition from primary to secondary school is a major life event that can impact on children's educational and psychological development<sup>21</sup>.

It can affect their academic performance leading to school failure or even school dropout or absenteeism. Training addressed to teachers and classmates to improve the interaction with autistic students and develop more support, empathy and understanding of their needs at school has been identified as key. Students move from the top of the primary school hierarchy to the secondary one, and this frequently coincides with the onset of adolescence. It is a time of considerable change in social, structural, and academic terms and one to which young people are expected to adapt swiftly. This is not the case especially for young autistic person.

A long-term follow-up study on transitions revealed that adequate planning of transition from primary to secondary schools had successful results for autistic students. This adequate planning includes school staff planning for the transition, collaboration between teachers and support autistic students through the transition experience to a different educational setting<sup>22</sup>.

A good transition planning in schools to address the needs of autistic people should be foreseen in the national legislations and policies.

21 F. Rice, N. Frederickson, J. Seymour, Assessing pupil concerns about transition to secondary school

British Journal of Educational Psychology, 81 (2010), pp. 244-263, 10.1348/000709910X519333

<sup>22</sup> Keane, E., Aldridge, F. J., Costley, D., & Clark, T. (2012). Students with autism in regular classes: A long-term follow-up study of a satellite class transition model. Journal of Inclusive Education, 16(10), 1001–1017.

#### We recommend:

- Creating systematic "Round table" and efficient transition mechanisms, as successful transition requires coordinated, joint approach, which brings together all those involved in transition: the autistic learner, parents, representatives of the sending education centre/ school, representatives of the receiving educational centre/school/university and all professionals involved in the individual planning.
- Making sure that all necessary support system is in place by the start of the academic year. Any delay may jeopardise the transition and have long lasting impact.
- Helping learners to adapt, for example by giving the opportunity to visit the new classroom/ school/vocational training center/university outside of lesson time as well as meeting the new teacher(s). Providing adequate information document, for example with pictures of the staff involved. A change in classroom, teacher, teaching/learning support assistant or peer group can make autistic pupils anxious as it will mean a change to their routine.
- Foster support and raise awareness of peers, for example by establishing buddy programmes
- Developing the necessary support services and systems to support the transition to employment to avoid that people fall in gap after they complete their studies.



# 6 - Ensure access to lifelong learning education

#### We looked at the picture across the EU and here are a few cases:

To ensure their access to lifelong learning autistic people need to be able to attend vocational training, apprenticeship or higher education. Only 22% of all respondents **across the EU** know of any support for autistic learners for vocational trainings and apprenticeships. A third (31%) say there is no support available while almost half (47%) do not know of any support. Any support given to autistic learners was extremely limited, if in existence at all. A very limited number of companies accept autistic people in apprenticeships without having any sort of strategy on disabled recruitment.

One respondent from **France** noted that there was only one specialist autistic high school for autism which covered an urban area with a population of greater than 1 million people.

#### On respondent from the Netherlands pointed out that

"Efforts are being made but too individual and too little. Depending on the employer's commitment."

#### One respondent from Spain said

"The response of the educational administration is that support must be provided in compulsory education, and do not include support for the post-obligatory stages."

#### We recommend:

- Ensuring access to vocational training and run pilot programmes for apprenticeships to foster gold standards
- Encouraging employers to develop apprenticeship programmes for autistic learners by offering them financial incentives
- Uphold EU commitment to 'make lifelong learning and mobility a reality' for all by making relevant programmes, such as Erasmus+, accessible to autistic people
- Ensuring all universities and higher education establishments have disability support services that are trained in autism and accessible.



# 7- Other important related issues

### **Early Childhood Interventions**

Early childhood education (ECE) or early intervention (EI) is "the term used to describe the services and supports that are available to babies and young children with developmental delays and disabilities and their families" according to CDC. EI has been analysed through multiple research papers the past years. Overall, the results have been shown that autistic children who enrolled to education and support settings before the age of 5 have presented improved results in academic and social life in comparison to children who received the right support at a later stage<sup>23</sup>. The vast majority of EU counties provide interventions such as speech therapy right after the diagnosis as well as financial support for intervention services<sup>24</sup>. However, as mentioned above diagnosis for autistic people is not always happening at the earliest possible stage.

A study focused on the use of early intervention practices in European countries revealed some really interesting facts regarding the implementation of early childhood education for autistic learners. According to the results, well-educated parents made a better use of early intervention services for their children in comparison to parents with low level of education. Professionals also presented a lack of targeted training, which is necessary to improve their knowledge in early intervention practices for autistic children<sup>25</sup>. Concluding, early intervention is an ongoing practice which need to be secured for every autistic person in all Member States. Thus, budget should be accordingly allocated to encourage and ensure the implementation of required support for autistic people at the earliest possible stage.

## **Collaboration with parents**

Adequate support for autistic learners in education settings entails the collaboration and communication between parents and professionals. Numerous researches in early 2000 revealed essential facts on how beneficial is the teacher-parents collaboration for the academic and social progress of autistic individuals<sup>26</sup>. However, there is limited data on how sufficient and regular this cooperative approach is applied in EU Member States.

Setting up effective and active parental forums from early education onwards is a good way to address problems and foster parental participation in the educational process. This will encourage and empower parents to speak up and be adequately informed and involved. Streamlining methods of communication between departments and between professionals, including at transition times, to keep parents continually informed on the progress of the autistic learner's development is also a vital step.

The close involvement of parents in the education of the learner is a determining success factor!

To conclude, research to improve the quality of life and inclusion of autistic learners is required to promote adequate education for autistic learners.

<sup>23</sup> Hume, K., Bellini, S., & Pratt, C. (2005). The usage and perceived outcomes of early intervention and early childhood programs for young children with autism spectrum disorder. *Topics in Early Childhood Special Education*, 25(4), 195-207.

<sup>24</sup> eaf\_policy\_brief\_-\_sen\_children\_post\_copy\_edit\_15.10.13.pdf

<sup>25</sup> Salomone, E., Beranová, Š., Bonnet-Brilhault, F., Briciet Lauritsen, M., Budisteanu, M., Buitelaar, J., ... & Charman, T. (2016). Use of early intervention for young children with autism spectrum disorder across Europe. *Autism*, *20*(2), 233-249.

Azad, G., & Mandell, D. S. (2016). Concerns of parents and teachers of children with autism in elementary school. *Autism*, 20(4), 435-441.



## 9- Some good practices identified across Europe

Adopting principles of best practices and fostering mutual learning between member states to respond to the needs of autistic people in the field of education is necessary so we can ensure better results in the future. In order to gain a better understanding of the lived experiences of autistic learners and their families in the various member states when it comes to good education practices for autistic people in the general school system, AE has carried out a EU-wide survey.

Between November 2021 and January 2022, Autism-Europe run a survey of which the main objective was to identify and share examples of good practices at different levels of education to foster effective learning and inclusion of learners on the autism spectrum. Practices could refer to learning settings, support methods, teacher training, adaptations of the curriculum, etc.<sup>27</sup>

In the next section, you will find a selection of six good practices in education for autistic learners.

## **SPELL framework**

SPELL framework<sup>28</sup> developed in 1993, in the UK with several revisions and updates. AT-Autism, Tizard Centre, University of Kent at Canterbury and Materials published by Pavilion developed and implemented this framework. SPELL is aiming for education, social care, and health professionals dealing with autistic children and adults with a mixed range of support needs.

#### Why this is a good practice to foster access to education:

- · Reduces anxiety
- · Improves empathy for the autistic experience
- · Plays to strengths and enhances communication

#### In details...

The SPELL framework was initially developed by the National Autistic Society, based loosely on Montessori educational approaches, adapted for autism by a working group headed by Dr Lorna Wing. It was later further adapted to accommodate the needs of adults. Autistic people and families have been involved throughout in its design and delivery.

The framework is a way of thinking about and responding to the needs of autistic people based on what they tell us about what is helpful and unhelpful to them. It is socially valid in that everyone needs the key pillars of the approach in their lives to be successful. It is therefore essentially inclusive and compatible with the principles of Universal Design.

Teachers or other key professionals are trained in the practice at two one day workshops followed up by a one-day train the trainer workshop where they can learn and practice the skills needed. They are then able to train others in their organisation making it sustainable and at low cost.

28 www.atautism.org



#### The framework is helpful to autistic people in the following ways.

The mnemonic SPELL comprises :

**Structure** which allows the person to predict events. This reduces anxiety, improves agency and choice, and improves communication.

**Positive** attitudes and expectations about what the person can do and the opportunity to develop new skills and engage in favoured activities. This in turn again enhances self-esteem and changes the narrative around the person.

**Empathy** for how the autistic person sees and experiences the world plays a significant part. Learning to listen and engage with the person and adjusting in line with their understanding and lived experience. This can inform the environment and mode of interaction.

**Low arousal**. Takes account of the different sensory profiles of the person and how these affect emotions and coping abilities. Also, the avoidance of confrontation. This is important in reducing behaviours of concern.

**Links** concerns the importance of consistency between all parties having an involvement with the person. This includes the different teams within schools or services, and parents. Links is also about ensuring a good connection with the person, again to reduce anxiety, improve communication, and self-esteem.

The framework is flexible and able to be applied to a very broad range of autistic children and adults. Drawing on Aristotle's golden mean the framework is applied to the individual circumstances of each person. For example, Structure the golden mean between chaos and rigid routine, and the need will vary from person to person.

The framework is not a specific approach as such and can be used as a gateway to other approaches such as Universal Design or person-centred approaches. It is being evaluated by Kent schools.

As the framework is integrated within the broad approach there is no charge to implementation other than training, which is designed to make schools and services self-sufficient.

The SPELL framework is based on substantial practical experience and research into what works for children and adults with autism, and has received a positive evaluation in the only published critique (Tutt et al, 2006). Each of the elements of the framework has a strong evidence base, but the effect of the implementation of the framework as a whole has not been evaluated. Research on elements such as active support has included people with autism but has not explored specifically the effect on people with autism. In order to support implementation of the SPELL framework in mainstream settings as well as autism-specific settings, research in both special and mainstream settings is necessary, in particular to show that such a framework does not harm the development or quality of life of the other people without autism but rather that it is a useful framework for supporting learning, development and quality of life in any setting to which children or adults with autism are to have access.



## Case study:

#### SPELL applied in an employment context

Donald\* (20 years) had a diagnosis of autism and had been struggling to gain and retain employment since he left school. He had managed to get a few jobs, but these tended not to last, and he became unemployed and depressed, and was lacking confidence. We saw him as part of our '**Prospects'** supported employment programme and spent time going through some of the issues with him.

His job coach had been trained in SPELL and was able to go through this with Donald and to gather information on issues that were important to him, including an exploration of his anxieties. Donald then obtained an interview for a job that interested him with a national rail company on the information desk at Paddington Station London. We had some reservations about this as Paddington Station is a noisy, chaotic place with many sensory challenges. However, Donald was highly motivated and loved railways. The job coach and Donald engaged with the employer to ensure that as far as possible adjustments were made that would help.

These were around Structure; the work environment was highly organised and had clear procedures in place for dealing with most contingencies. The working day had clear expectations and break times. The flexible work schedule was fine as the changes in shift patterns were predictable and he was fine with that as he could adjust. Also, Donald would be meeting people one at a time and he would be in an advice booth. **Positive** attitudes and expectations were important, in that Donald was interested in railways and highly motivated to succeed. He enjoyed being at the station. He was respected and accepted by his colleagues- a small, close and friendly team. Empathy for how Donald experienced work was obtained by providing him with a coach and a mentor who could listen to any concerns and work with Donald so that HE could understand and resolve them. One example concerned Donald's anxiety about whether he was doing well as he was not coping well with a lack of feedback, which was worrying him. Once this was known, regular feedback was put in place. A Low arousal work environment was also possible in reducing sensory challenges, in that the information booth was soundproofed and calm. His supervisor was advised on how to deal with any concerns Donald might present when dealing with customers by not confronting but raising these calmly and at the right time. Donald received clear training in how to deal with difficult customers. Finally, Links were established with his work colleagues to ensure a consistent work environment through a teamwork ethos, where initially Donald had the support of an experienced mentor, who took him 'under his wing' and along with the job coach (who withdrew after three months), dealt with any transitional problems or issues. Over time he developed good natural links with his coworkers based on mutual respect and acceptance.

All of this was twenty years ago. Donald remains in his job at Paddington Station and is now the most long serving and experienced member of staff and has received an award for his and for customer service. He has coped well with the many changes, including the move to an open plan environment. He has a level of self-understanding that he links to SPELL, which helps him to take control of issues that might give rise to anxiety.

\*Name changed for confidentiality but all other facts as stated and verifiable



#### **List of references**

- Beadle Brown, J., Roberts, R., & Mills, R. (2009). Person centred approaches to supporting children and adults with autism spectrum disorders. *Tizard Learning Disability Review*.
- Beadle-Brown, J., & Mills, R. Understanding and Responding to Autism: The SPELL framework. Pav Pub 2018
- Mills, R., & Marchant, S. (2011). Intervention in autism: a brief review of the literature. *Tizard Learning Disability Review*.
- Milton, D., Martin, N., & Melham, P. (2016). Beyond reasonable adjustment: autistic-friendly spaces and Universal Design. Pavilion Publishing and Media.
- Milton, D. E. (2014). So what exactly are autism interventions intervening with? *Good Autism Practice* (*GAP*), *15*(2), 6-14.
- Robertson, K. (2011). Early Childhood Autism. BMJ
- Siddles, R., Mills, R., & Collins, M. (1997). SPELL-the National Autistic Society approach to education. *Communication, Spring, 1997*, 8-9.
- Sims, T., Milton, D., Martin, N., & Dawkins, G. (2016). Developing a user-informed training package for a mentoring programme for people on the autism spectrum. *Journal of Inclusive Practice in Further and Higher Education*, 7, 49-52.
- Roberts, R., Beadle Brown, J., & Youell, D. (2011). Promoting social inclusion for children and adults on the autism spectrum–reflections on policy and practice. *Tizard Learning Disability Review*.





## **Autism Education Trust Professional Development Programme**

Autism Education Trust launched its education professionals across Early Years, Schools, Colleges and transition into employment program in 2007 in England. Many of resources can be accessed for free via the resources page on the website: <u>https://www.autismeducationtrust.org.uk/resources</u>.

#### Why this is a good practice to foster access to education:

- Increases inclusion
- Increases the positive outcomes experienced by autistic children and young people in education settings
- Increases the knowledge, skills, confidence and resilience of the education workforce

#### The Autism Education Trust (AET)

The AET is the go-to destination in England for autism education expertise brought to life by our unique network of autism education specialists, autistic people, parents of autistic children, academics and education professionals. The AET was formed as a partnership in 2007 to help improve the quality of education for autistic children and young people across England. At the heart of the AET is the belief that good outcomes can only be achieved by working in partnership. The AET is a not for profit partnership organisation founded by two national autism charities – the National Autistic Society and Ambitious about Autism. Supported by the Department for Education, the AET promotes and supports partnerships throughout the education system to improve educational access, experience and outcomes for autistic children and young people.

AET vision is a world where all autistic children and young people experience a positive education that supports wellbeing.

AET mission is to empower the education workforce and support them in securing a positive education that supports wellbeing for all autistic children and young people.

#### **AET Values**

Central to successful social franchising is ensuring that a clear set of social values are embedded and replicated in every franchised organisation. AET values are:

- **Voice** take into account the views and needs of young people, parents/carers and professionals across the ethnic, cultural, social-economic, gender and disability diversity in developing the AET's governance, plans, and work.
- **Partnership** work collaboratively to run and deliver the AET programme. AET works through partners to deliver our work because our focus is on capacity building and system wide change.
- **Reach and sustainability** The AET Programme reaches across the different education settings, the whole autism spectrum, age ranges from early years, through school age and onto post 16 and reaches across the ethnic, cultural, social-economic, gender and disability diversity among the autistic population. By continuing to develop our reach, and working sensitively to meet the diversity of need, the AET remains current and sustainable.



 Impact, outcomes and evidence – AET aim is for autistic children and young people to learn and thrive in all education settings. Materials, resources and support remain evidence-based and current; and will work to measure outcomes and impact at an individual and strategic level so that to ensure what works and this feeds back into the evidence for future materials and resources.

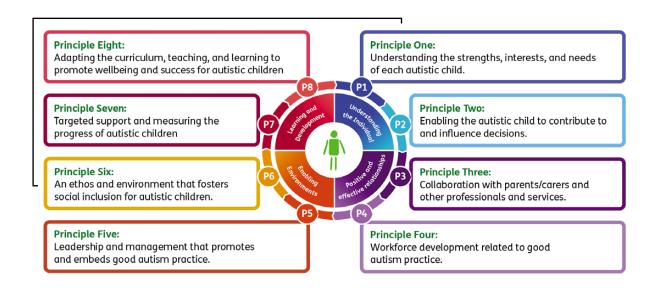
#### The AET Operating Model

Since the AET was set up by the Department for Education (DfE ) in 2007, the AET has gone from strength to strength. The current AET partnership consists of a range of organisations, including local authorities, the voluntary sector, and schools. These organisations apply to become AET Partners, appointed and licenced by the AET to deliver the AET programme. Each year the AET has appointed a greater number of delivery partners nationwide to deliver the programme, the AET currently has 108 partners that operate across England.

The AET partnership offers the only CPD accredited, DfE supported, co-produced national autism training programme in England for education-based staff, training an average of 40,000 education professionals every year through our licenced partner approach.

#### **Eight Good Autism Practice Principles**

At the start of its work in 2007, the AET commissioned two pieces of research. The first looked at the issues and challenges in educational provision for children and young people with autism. The second piece looked at what constituted good practice in education for this group. In 2019, the AET repeated this research to ensure the programme content and rationale remains current and at the leading edge. The AET Good Autism Practice Report (2020) was published. It highlights the eight principles of good autism practice.





#### **Three key AET frameworks**

The above research informs and underpins the development of the following three frameworks:

- 1. Evidence-based 'Autism Education Standards' for education settings to inform and support whole setting audit and planning
- 2. Evidence-based **AET Competency Framework** for practitioners working within education settings to audit and inform continued professional development
- 3. A **'Progression Framework'** to support education settings in the assessment, planning and evaluation of pupil progress outside the national curriculum.

#### **AET Training**

The research also informs the development of a suite of professional development (training) packages for staff working in educational settings to support them to make reasonable adjustments and create inclusive environments.

#### The core training packages comprise:

- 'Making Sense of Autism' (90 minutes awareness training for all who encounter autistic young people)
- 'Good Autism Practice' (full day training for 'teachers' and assistants and supporting the AET Competency Framework)
- 'Leading Good Autism Practice' (full day training for leaders and framed in the AET Education Standards)

#### These core training modules are complemented by the following opportunities:

- · 'Autism and Anxiety' (half day for practitioners wishing to further develop their practice)
- · 'Preventing Exclusions' (half day for senior leaders)
- · 'Using the Progression Framework' (half day to support staff in the use of the framework)

The promotion of the above frameworks and delivery of the above training programmes are the principal mechanisms for securing improved adjustment and access in education settings and the upskilling of existing practitioners. The AET Programme Managers work with the AET Partners to develop delivery plans. The delivery plans are a way of helping partners to plan how to effectively target, market and deliver the training in their local area to meet their local priorities.

#### **AET Autistic Young Experts**

The voices of autistic young people are at the heart of the AET professional Development Programme. The AET works with our panel of autistic young experts to ensure that their voice is threaded throughout the training. The panel have turned the eight good autism principles into a set of promises:



The autistic young people have been involved in making videos that populate the training delivered by our partners and they are involved in co-facilitating training. It is this partnership approach that continues to make the AET the go-to destination in England for autism education expertise and ensures a consistent approach to delivering high quality training, at high volumes across the education sector with a focus on upskilling the workforce and improving outcomes for autistic children and young people.

## The school toolkit- SEDSconnective (formerly Sussex EDS HSD SEDS)

**EDSUKSupport** funded the school toolkit focusing in implementing good and much needed practice in schools for autistic/neurodivergent and symptomatic hypermobile students by Jane Green MA Ed, Chair of SEDSconnective and using content from the school toolkit for EDS and JHS and other publications for teachers and education staff. It has been implemented in the UK but also reach outside UK, Australia, USA and Europe. The toolkit was launched in 2021<sup>29</sup> aimed at all educational staff, but suitable for allied professionals and parent/carers. Also useful for associated charities and grass route community and SEND groups supporting students

#### Why this is a good practice to foster access to education:

- Equal opportunity to attain in education
- Equal opportunity to attend school
- Equal opportunity to have social cohesion and to advance in their chosen careers or employment prospects.



#### The setting

Autistic Neurodivergent pupils/students are more likely to be missing from school, non attending and non attaining in education. Latest evidence shows that autistic, ADHD, TS people are more than two times likely to be hypermobile and suffer much more pain than the general population. They also suffer from trauma but often disbelieved to ill or in pain. (Csecs 2022)

#### The issues

Many autistic ND people are disbelieved, leave school early, are traumatised by school experiences and often not believeto be autistic or different but just 'bad' or not conforming. All education research autism up to now have been based on mental and sensory issues. This is particularly key in females, or those assigned female at birth. Symptomatic hypermobility if not formally diagnosed.

We know anecdotally that many autistic people do not continue schooling, leave early with poor grades despite good attainment in primary schools academically. If medical doctors are unaware due to no training in symptomatic hypermobility, then the school educators find it hard to work out what the autistic ND student is experiencing.

This can lead to disbelief, trauma for the student. Symptoms are pain, injuries, dizziness, brain fog from physical causes, racy hearts palpitations, allergies, and particularly key gastrointestinal issues. This can mean particularly for autistic ND girls that anorexia nervosa or mental health disorder is given to these students as a diagnosis which might be correct but often assumed straight away or a sensory eating disorder like ARFID due to assumed or diagnosed autism. However, we know gastrointestinal issues are physical and can affect the chewing, swallowing, reflux, stomach spasms, stomach blockages, bowel and bladder tracts. Often confused with irritable bowel syndrome too. These issues mean students are suffering from pain from eating or toileting issues but often not believed. Mental health approaches are used instead due to assumed or diagnostic autism but in fact is physical so they don't work. In some cases, extreme allergies due to connective tissues in the EDS HSD JHS body means that food or chemical substances can cause severe eating allergies as well and physical pain.

Some students have thick velvety skin and don't bruise but have serious injuries or pain but nothing can be seen. Others might have very fragile thin easily bruised skin that can occur without previous trauma or accident of incident. This can lead to issues of safeguarding for their parents/carers as well. As symptomatic hypermobility is often misdiagnosed, the parents/carers are often unaware they have it and misunderstood. This can lead to being accused of intentionally harming their children or exacerbating their children's health needs and being a hindrance to their education. This can result in fines or even in some cases the children being taken into care.

#### Inclusion

This practice supports inclusion as neurodivergence is part of the whole human experience and will mean students are not excluded due to physical health issues beyond their control, or experience.

#### **Benefits**

The benefits of the programme is that students will be believed, it's not all in their heads or from a mental only intervention. They will have reasonable adjustments made to accommodate their health needs and 'anxiety'. Pacing of the school day, week will be adjusted as needed. The attendance logs will not penalize students for missing face to face school days or lay blame at their attendance with them or their parents/carers. Attainment will be achieved by making reasonable adjustments to their educations, hybrid learning where possible despite non-medical diagnoses. Educators will benefit from maximizing their student's attainment outcomes, and in their learning academically and social cohesion. Longer term means autistic students will be able to go onto further higher education or employments routes.



#### **Evidenced based**

Statistical evidence from the Government of missing autistic students in educations and early school leavers. Also the amount of home based elective education.

The school toolkit is all evidenced based from various sources in the references. The anecdotal evidence from long established autism educationalists working in all phases of education has noted the issues regarding young students accessing physical education, eating issues, keeping weight on and having enough energy throughout the day. This only increased during secondary or high school levels where hormones mean increased missing attendance and attainment and home education as a last resort as the families feel school is unfit for purpose.

#### Outcomes

Better attainment and attendance. Improved social cohesion and less trauma. Less funds spent on approaches to these issues that will not succeed.

#### How will it be implemented?

This will be rolled out centrally through a group of schools, academy centres in different regions. The toolkit is free on line but for implementation of the understanding of symptomatic hypermobility (EDS JHS) It will be via bought in presentations, slides, websites and conferences. Further accreditation is being sought currently. Presently being brought in to present on it.

#### Parents/carers/ and students

Focus surveys, discussion groups and written blogs have all demonstrated this need to be believed in school to stop further trauma building up and particularly at secondary high school age females. All were clearly supportive of this project throughout and continue to be so.

#### **References – Evidence Base**

https://www.frontiersin.org/articles/10.3389/fpsyt.2021.786916/full

Csecs, J., Iodice, V., Rae, C. L., Brooke, A., Simmons, R., Quadt, L., Savage, G. K., Gowell, N. G., Prowse, F., Themelis, K., Mathias, C. J., Critchley, H. D. and Eccles, J. A. (2022). Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain. *Frontiers in Psychiatry*. Available at: <u>https://www.frontiersin.org/articles/10.3389/fpsyt.2021.786916/full</u> [Accessed: 4 February 2022].

Jelsma, Lemke D., et al. 'The Relationship between Joint Mobility and Motor Performance in Children with and without the Diagnosis of Developmental Coordination Disorder'. *BMC Pediatrics*, vol. 13, Mar. 2013, p. 35. *PubMed Central*, doi:10.1186/1471-2431-13-35.

Jelsma, L. D., Geuze, R. H., Klerks, M. H., Niemeijer, A. S., Smits-Engelsman, B. C. M. (2013). The Relationship between Joint Mobility and Motor Performance in Children with and without the Diagnosis of Developmental Coordination Disorder. *BMC Pediatrics, Vol. 13.* Available at: <u>https://bmcpediatr.biomedcentral.com/articles/10.1186/1471-2431-13-35</u> [Accessed:1 July 2020].

https://www.hypermobility.org/hormones-and-hypermobility

Kindgren, Erik, et al. 'Prevalence of ADHD and Autism Spectrum Disorder in Children with Hypermobility Spectrum Disorders or Hypermobile Ehlers-Danlos Syndrome: A Retrospective Study'. *Neuropsychiatric Disease and Treatment*, 10 Feb. 2021, doi:10.2147/ NDT.S290494. accessed 13.2.21

Kindgren, E., Quinones Perez, A. and Knez, R. (2021). Prevalence of ADHD and Autism Spectrum Disorder in Children with Hypermobility Spectrum Disorders or Hypermobile Ehlers-Danlos Syndrome: A Retrospective Study. *Neuropsychiatric Disease and Treatment* [online]. Available at: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7882457/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7882457/</a> [Accessed: 1 March 2021].

Green J https://www.sussexeds.com/post/understanding-hypermobility-disorders-syndromes-in-schools published by NASEN 2019

Green, J. (2019). Understanding Hypermobility Disorders/syndromes in schools. *Spotlight* [online]. Available at: <u>https://www.sedscon-nective.org/post/understanding-hypermobility-disorders-syndromes-in-schools</u> [Accessed: 15 December 2019].

Green J 2022, https://www.tes.com/magazine/teaching-learning/general/autism-5-adjustments-needed-your-classroom



#### Striving for more inclusion in education in Basque Country: two case studies

Comparative analysis of two good practices in education of autistic learners implementing in the Basque Country, Spain. Both practices are focusing on the better inclusion of autistic students in mainstream schools. In order to achieve this goal, the first good practice implementing in Basque Country is targeting classmates and peers of the autistic children. The next one is directing teachers' comprehensive training aiming for teachers and professionals to be prepared to accommodate the needs or autistic students.

## Supporting each other (Elkarri Lagunduz)

The GAUTENA Education Service and local mainstream school in Errenteria (Basque Country – Spain) launched the 'Supporting each other" program in 2016. The target group of this practice are 6<sup>th</sup> grade learners in mainstream classroom and learners on the autism spectrum or equivalent needs, aged 8-12 and with medium or high support needs.

#### Why this is a good practice to foster access to education:

This is a good practice to foster inclusion in educational environment. Because:

- · It foster mutual understanding with peers in mainstream education
- It is the base for a permanent inclusion program throughout the school year
- It includes "inverse inclusion" activities (learners from mainstream taking part of activities in the open class)

#### In details..

Gautena runs nowadays 21 open classes in mainstream schools. Most of the learners are autistic, and all of them have medium or high support needs. There are usually 4-5 learners per class, and not more than one open class per school.

Attending an open class in a mainstream school combines two critical elements: a specialized and personalized educational program, with a presence and participation in ordinary contexts. Presence and participation are key to create inclusive contexts and to create relevant learning for all learners in the school context.

Main challenge of the project is therefore to create mutual knowledge and understanding between open class and ordinary class learners, to foster natural and permanent inclusive activities.

For this pilot project, we selected one of our groups, with 5 learners aged 8-12, and one group of peers from 6th grade (around 25 learners). Practice was designed between professionals of both Gautena and the school. Collaboration of teachers from mainstream context is critical, since this program has to be inserted in their own educational programs. In the case of this practice, we counted with a permanent support from them, and it was one of the key elements of the success of the project.



#### Process of the practice was as follows:

- Peers in mainstream think about inclusion and special needs, based on a structured sheet they fill in (including: perception of diversity, physical and emotional elements, and the doubts that they may have). The goal is double: from one side, learners have a preliminary personal reflection; from the other side, professionals identify which are the aspects that have to be worked
- Peers film a video that shows the day to day of Gautena's learners. This includes: their arrival at school, the work they do in their class, the tools they may use to communicate (pictograms, tablets), their games in playground, their routines in lunch room, etc. Filming the video is just a vehicle to enhance contact and understanding of all of them.
- Once video is filmed, it is viewed by all the learners. Gautena professionals also take part of this session and clarify any doubt that may have arisen while filming: why is this, how is that... Peers share their feelings, doubts. Important is the focus on the strong points that the learners have identified, and the activities that they suggest that can be done together.
- Launch activities and follow up. After the preliminary work, proposed activities are launched. One of the activities is the "inverse inclusion", according to which, peers from mainstream attend the open class to take part of it. Activities can be defined for the whole class, or one by one. Activities are designed taking into account affinities and interests of the learners, so that they create substantial learnings. Critical aspects for selection of activities are:
  - To have a deep knowledge of the person and to adapt contents to each situation
  - Plan the supports the person will need in order to ensure a positive participation
  - Organize the process of teaching learning
  - Go beyond educative contexts as long as possible. Foster community alliances
  - Properly plan transitions
  - Evaluate inclusion and identify improvement areas

Main benefit of the process is that the barriers that may exist are broken, based on day to day activities and on personal affinities and interests. Playground and lunch hall interactions are specially reinforced. Educational staff also use this project with a more general view: they work personal thinking, values such as diversity and inclusion, thinking sharing, etc.

Despite not having gone through evidence-based analysis, learners, families and educational staff have shown their satisfaction and positive feedbacks with the project.



### Autistic children in primary education in mainstream schools in Bizkaia: Making it a reality

Apnabi<sup>30</sup> – ALDAMIZ SCHOOL in Bizkaia, Basque Country is implementing a program for autistic children in primary education since early 80's. It is targeted educational teams, specialists, education departments, management teams. It can be helpful for all the children, or teenagers in the autism spectrum, throughout the different educational stages (nursery, primary, secondary and post-secondary).

#### Why this is a good practice to foster access to education:

- Inclusion: Development, this practice keeps alive the process, it makes the inclusion grow
- Autistic children: Personalization of education, it takes care of every child's need, circumstance, or context
- Teachers: Reflection, the importance of reflection, make agreements, rethink, it's the moment to learn between us

#### In details..

APNABI- AUTISMO BIZKAIA, is the leading association in Autism, in the Province of Bizkaia, Basque Country, Spain. Providing services which are funded and agreed by different public administrations of the government of Basque Country since 1982. Among these services it has a Special Education School: ALDAMIZ SCHOOL.

Since the 1980s, from this school we designed and arranged a specialised service (funded by education department of the government of Basque Country, like an institutional collaboration) available in mainstream schools, for guidance and to monitor children with ASD, in processes of what was then called "Integration in mainstream schools". This service is provided by Specialised teachers, who visit each school, to support teachers, a personalised assessment for each case, situation and context.

The approach is based on "teachers advising teachers, support from special education school, to mainstream schools". The practice is aged more than 30 years, coordinating meetings in more than 300 schools; getting to know each case throughout their personal process (more than 700 over the years). It started supporting 6 cases in the 80's, to more than 500 at this time, throughout the different educational stages (nursery, primary, secondary and post-secondary), managing the following actions:

- Meeting with educational teams, specialists, advisers from education department "berritzegunes", visiting schools periodically
- Talks to teaching teams, working with management teams, providing training
- Conducting tutorials and talks to the group of peers of children with ASD in the classrooms
- Support families throughout all the processes



This has given the opportunity to know and learn from different child profiles, different schools and multiple professional styles, helping us to adapt and reflect on each case and context. All those experiences have lead the school to study and analyse different elements that favour and/or hinder inclusion processes.

#### We would like to highlight some considerations as a starting point:

- · Inclusion is a slow process that offers learning opportunities to all the children-
- "one size doesn't fit all" but there is a basic framework
- Not all autistic children require the same, their needs are different, they change through different moments. Each case is unique.
- · It isn't always the case that "more support means better results"

The key is designing the right programme, combining needs, educational context and personal needs.

It's known that for a good development of inclusion, inclusive policies, cultures and practices are essential. Political willingness and legislation are sorely needed. Policies that respect the UN declaration of rights of persons with disabilities and aligned with the Sustainable Development Goals, to commit to equitable and quality education.

Inclusion must be a process in a continuous evolution, grown by all people within the process, it's done by people, it's not an action, it's an attitude, it's a live process within a sustained development, inclusion is a model of education.

# Through the practice of these years, participants concluded that the keys for good development of inclusion are:

- The learning environment is a priority: every school's context is different, and not easy to manage, we must make a plan not only for class time but also for social times, like playground, dining area, after class activities, generating a plan for safe school for presence and participation
- Continuity is a process: the sooner we start the intervention, the better, going across all of primary, and all the stages after. Based on participation and personal development
- Academic and professional learning are essential and must be updated, but skills and attitudes are even more important. Permanent development of technical and personal skills is required.
- Methods and techniques, the most important are accessibility and communication. It is necessary to know evidence-based methods, and we can't forget that method can't be more important than the child.
- Personalised plan: every child needs us to develop his/her own plan, promoting his/her wellbeing, self-management and social participation, quoting Hilde Le Clercq : "Children with autism can't be pushed to act like other children, not at any price"
- Work with their peers, through tutorials and talks, so they can learn to be supportive. The goal is to raise awareness towards equal rights and towards the understanding and support of classmates with ASD. Equality for rights but also for daily commitments.
- Coordination and collaboration between all the educational departments and individuals: we have to create meetings to reflect, make agreements, rethink, it's the moment to learn between us, to learn to listen to children and families. A collaboration based on reflection not on enforcement
- Support: designing learning packages, doesn't always mean additional staffing, sometimes the increased staff can create more stress than safety, we should make the educational environment a support itself, thinking of the future, not only the present situation
- Be aware of transitions between the educational stages, supporting children and families throughout these changes
- Learn to listen with to each autistic child and their families.



APNABI AUTISMO BIZKAIA collaborates and leads to make a reality the inclusive education. Its work is based on reflection, personalized programs for every child, and of course to contribute to achieve a more just and equal society

The education department supports and funds this outreach programme. The satisfaction of children, families, teaching staff, leads professionals to the conclusion that all the effort from all the team for the best results of the project is worth it.

## Informal education: making museums accessible

#### Title of the practice: Autism project<sup>31</sup>

The Autism project launched in 2022 in Marche, Italy. **Museo Tattile Statale Omero** in collaboration with Centro Autismo Età Evolutiva Regione Marche, Comune di Ancona, Associazione ragazzi Oltre - Ancona, Associazione Omphalos - sedi di Fano e Acquaviva Picena, Fondazione Anffas -Macerata, Amici disparati Aps - Pagliare del Tronto e Angsa Marche Aps – Agugliano worked together for this project. Autism project in museums is targeted autistic people from 5 years old with medium/ low support needs, educational staff and families of autistic children.

#### Why this is a good practice to foster access to education:

- · freedom to access the museum at any time without reservation
- possibility of accessing the contents of the museum through didactic aids also agreed with teachers, educators and families
- possibility of agreeing visits and inclusive educational workshops with the entire class of the autistic student
- possibility of carrying out educational and recreational activities by choosing where to position oneself inside the museum (in the museum there are mobile stations and a space for relaxation)

#### In details...

The purpose of the project is to encourage the social inclusion of autistic people by promoting the transformation of museums and places of culture into favorable environments.

A recent research in Italy shows that museums and cultural sites are practically inaccessible to autistic people. In particular, the very few documented experiences are often of a temporary and irregular nature and do not allow autistic individuals to be guaranteed their right, already enshrined in the Charter of Rights of Persons with Autism adopted by the European Parliament in 1996, to access culture, leisure, to recreational activities.

https://www.museoomero.it/notizie/progetto-autismo-domenica-gratuita-fine-stato-di-emergenza/



The actions of the project aim to study and implement a model that can be replicated, for the transformation of museums and places of culture into autism friendly environments. This means allowing people in the autism spectrum to freely choose when to go to the museum and to find experiential opportunities for growth and leisure in the places of culture. It means allowing autistic people to experience moments of normality and inclusion in the places of the community with their family and friends, with the educators who accompany them and assist them at home or during school hours. All the actions are agreed with the project partners and in particular with the associations of families with children with autism.

#### Preliminary steps of the project :

- Comparison between all project partners for a general analysis and preparation of the implementation phases of the project;
- Analysis of the environment (Homer Museum) and its predisposition to make it favorable to autistic people (environment, hospitality, social history, etc.);
- Analysis of the space inside the Homer Museum dedicated to educational and playful experiential activities and moments of relaxation and its subsequent structuring for the benefit of people in the autism spectrum;
- Definition and implementation of educational and play activities to be carried out in the dedicated space;
- Acquisition of necessary materials, tools and aids;
- Test the environment and activities with autistic individuals themselves;
- Organization of a training course for the operators of the Omero Museum and for all the cultural operators of the Marche Region interested in the project;



Relax area in the museum



## Conclusion

Access to suitable education for each autistic learner is a fundamental right, enshrined in multiple conventions and in the United Convention on the Rights of Persons with Disabilities. Despite the progress that has been made over the past years, autistic children are still not receiving the right educational support at the earliest stage. Late diagnosis and the lack of reasonable accommodation in education settings increase discrimination challenges for autistic individuals' education. Nowadays, the growing number of autistic children in education settings, the urgent need for inclusive online learning and the prerequisite to support autistic people till higher education and employment forms a challenge for European Union.

This report highlights examples of good practices to resolve the shortcomings in the provision of educational services to autistic learners. This good practices report aims to become a reference for other organisations and professionals working in the field of inclusive education who may implement similar practices. Professionals can make use of the practices as adapting and enriching them in the process based in their own schemes.

In this report, we have incorporated several practices which have been developed in universities, mainstream education settings and out of school settings all aiming to improve inclusion of autistic learners. Most of these practices use innovative materials and techniques targeting school setting at national level while others have developed inclusion practices based on their community.

Supporting people with autism to thrive in inclusive education requires public investment in education, professional training, supported alternative education programmes and awareness-raising initiatives in school settings. This investment benefits society as a whole as through inclusive education and adequate support at the earliest stage autistic people have the opportunity to participate in society and economy.

EU Member States should continue focusing on both inclusive education policies . Effective monitoring and evaluation strategies for education contribute to adequate inclusive education for every autistic person. Overall, European Union should put greatest efforts and use robust approaches to safeguard the right to education for autistic individuals.

