STATE OF THE ART REPORT

AuTrain

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(1) Introduction

The idea to the project does directly stem from practice or, more precisely, from the tangible practical-professional experience that interactions with people on the Autism Spectrum can be tricky and can easily and/or unintentionally result in situations of mutual discomfort, misunderstandings or even non-understanding – in deadlocks of communication that are quite hard to dissolve and in settings where the actual caretakers feel, and in fact often are, rather clueless; in other words, in situations where there is still the will and thrive to help and ease these “disturbances”, but where the strategies to do so have failed or simply run out. In short: We are speaking about situations that are to the disadvantage of everyone involved, first and foremost for the clients (resp. people on the Autism Spectrum in general) themselves, but also for the professionals (resp. non-autistic communication partners) whose relative insecurity and unease may affect the whole structure of the client-caretaker (or any other functionally equivalent) relationship and may implement this sort of residuum (on both sides) for the foreseeable future. And we are also speaking about experiences that nearly everyone who is regularly or only occasionally in contact with people on the autism spectrum – in professional contexts or not – is somehow familiar with. They all had their “clueless moments” even if they were very well knowing their clients/counterparts and quite familiar with their personal traits and their very individual inclinations, habits and preferences.

This is at least what staff members of the project coordinator’s institute (VINCO) where repeatedly reporting from their day-to-day contact with people – in this special case mostly children – with Autism Spectrum Disorders (ASD), all of whom specialists in a broader sense, trained and experienced in the professional work with people with special needs (but neither decidedly or exclusively nor necessarily with “autistic people”). So we were not all too surprised to hear from similar reports in other parts of Europe, from professionals who were going to be – and now thankfully are – our project partners. Those working in the field in more or less direct care-contact as our Italian and Greek partners kind of intuitively knew what we were talking about. And our academic, our Swedish und Portuguese, partners did not hesitate to confirm that in addressing these issues we were definitely hitting a vital nerve. Getting all these reactions we finally knew that our “feelings” and the idea to the project were substantial – and that the plans and objectives we were working on were of particular urgency.

Thus the pillars of the AuTrain Project did take shape quickly. Based on the genuinely humanistic effort to improve social inclusion of people with ASD in Europe in general and within the overarching frame to enhance vocational expertise and skills throughout different professional fields – theoretically all-encompassing, in practice especially those sectors which show an increased likelihood, frequency and acuteness of autism-related encounters and challenges (from educators and caretakers of all sorts to staff departments, from public health to administration authorities etc.) – we built on a combination of goals, means and methods as it follows:

(1) On the development of a **curriculum** and **course** for **“autism officers”** (representatives of their organizations/institutions and/or occupational groups rather than “officers” in the stricter sense of the word), who after having attended the course should have the competence, self-assurance and confidence to apply the acquired ASD-skills and knowledge in a proper respectively more appropriate way. The curriculum/course itself will be of ISO 17024 certification status so that it can be “exported” and transferred across borders and to different contexts.

(2) On the development and implementation of a corresponding open source **online-platform** containing approved and comprehensive material on autism, its forms and characteristics and on central strategies on how to interact and communicate with autistic people (including all of the course-material and -tools and the curriculum itself) – and all of it selected and arranged in accordance to academic standards and the current state of science.

(3) And, as a sort of consequence of the aims mentioned above, on the establishment of a **forum of pan-European exchange** of information and opinions of experts in science and practical work in the field of autism in order to keep the projects’ impact alive, up to date and sustainable.

Agreeing on this framework and considering the vastness of the field of autism itself – both in terms of science as well in the practical treatment of ASD-issues (including immense numbers of websites, guides/handbooks and experience reports of different kinds and quality) – another prerequisite soon became clear: There shall and will have to be a stringent and reasonable restriction to central themes and topics in order to guarantee the practicability and usability of the skills and knowledge imparted in the course of the AuTrain-training. The curriculum and course will therefore have to be precise and concise and based on a high level of fundamental ASD-knowledge at the same time. These basics – and what it means to have a solid basis of this knowledge – will have to be identified and described and there will have to be arguments for those parts of ASD-knowledge which will be left aside or only mentioned in the margins of the course's contents (such as the long and sometimes irritating lists and discussions about symptoms and their weighting in terms of combination, severity and so on, or the widespread and ongoing debate about causes, gradations and/or correct names and typologies). But in tailoring them to practical and day-to-day demands these contents should in turn not be superficial or volatile. And on the other hand they shall not overload or overwhelm the attendees either. Because the central goal of the project is not to "produce" new specialists – which we cannot even think about – but practitioners with an array of means and methods of intervention at hand, and – on that basis – a higher propensity to really react, to moderate or calm down and/or navigate through challenging situations if necessary; practitioners who are able to live up to their claims and responsibilities and practitioners who are aware of the complexity of nexuses (e.g. the interplay of "typically" autistic behavior patterns and individual characteristics, which of course are of essential importance too – from an ethical standpoint as well as out of the urge to know and get a feeling for the kind of "case management" that could work and be adequate, for the simple reason that "autistic people" self-evidently are just as diverse as anybody else) and who do also know the limits of their own expertise and can detect the moment when resp. the realms where the "real", the scientifically and clinically approved, experts are need. If we would have the find a motto for the projects' main intentions, we could say: Keep it simple but accurate and of high quality and knowledgeability at the same time – quite a challenge if you take a closer look.

In order to deepen our understanding of the central needs, expectations and desires in these respects the project consortium furtherly agreed to conduct an online-survey in all of the partner countries – in fact in a twofold manner: One addressed to the central target group of professionals out of various occupational fields, the second to the first-hand experts on autism-related sensitivities, e.g. to people on the autism spectrum, themselves (not least for the reasons just mentioned and to avoid a know-it-all manner perspective coming strictly or only from outside, which is quite often the reason to not really “get through”, right from the start). Even if the process of data collection itself was affected by the upcoming Covid-19 implications – there were some delays (simply due to differently accentuated worries at that time) and obstacles (such as an abundance of surveys and interviews concerning these issues and, as a result of these obligations, a slightly reduced number of responses to our own investigation) we deliberately did not want to ignore – the results were quite impressing in terms of the pre-survey beliefs and “premonitions” we had. Given the prevalence rates in Europe, in the partner countries and beyond, elucidating that autism in not just a phenomenon in the niches of society, and given the fact that – despite significant national differences in the details – the general levels of autism-training are still quite modest and fragmentary across the continent and across different grades of professional specialization (even in fields with dedicated emphases on special needs) we were nonetheless surprised by the benevolence and hopefulness people dedicate to the prospect of relevant support and remedy. Amongst others we took this as a sign of a lack or shortage deeply felt, the missing of easily achievable and just as easily applicable means to meet challenges as common as autism-related ones – and as a chance for the AuTrain project to at least partly fill a gap.

This assessment of the situation was additionally validated by an evaluation of autism projects already existing, which on the one hand show a wide range of ideas, activities and aspects in focus (with an obvious preponderance on scientifically oriented basic research and a tendency to skip, neglect or put aside real life experiences) but a maybe telling reluctance in trying to conceive “crude” concepts to facilitate everyday lives of autistic people and those persons who live and work in their company, such as a “simple” and rather generalized but – in terms of adaptability to individual needs and inclinations – also flexible toolkit to enhance communication patterns, create autism friendly environments and so on, purposes inherent to the conception of the AuTrain course and curriculum. Apart from that the strong demands for products of this kind of sort could also result from the simple fact that effective therapy sessions or professional advice are not always easy to find and often costly as soon as state support services or other means of financing are beginning to run short (although it needs to be mentioned that these support systems are surprisingly different from country to country) – even if the goals and effects of these types of care are, cannot and should of course not be the same as those a trained layperson like an “autism officer” can offer. But it is the combination and matching up of these different approaches of support that could possibly lead to those synergetic effects that are so frequently invoked. And in general: Having more and more people who know what to do (to get and stay in contact with people on the autism spectrum) and have the courage to do so (and have the faith and strength to stick to them even if common expectations to functioning communication may be undermined or something similar to that) can only be beneficial for everyone involved. It will and can also enhance the autistic peoples’ trust and courage – an aspect that can and will make the relevant techniques more and more attractive even for people “outside” of the central target groups, for family members and friends, but also for “ordinary” people who are not confronted with pertinent challenges on a daily basis and maybe will not ever be. But at least their awareness would have been raised by then.

So even if we are only trying to make some first steps in this direction we do nonetheless guess that the AuTrain project could have an impact on quite some of the areas identified as important and pressing by current specialists in the field of autism research. To start with the youngest part of the population, it could maybe help to weaken the effect to drop-out of school, which is significantly stronger when ASD – which of course is not the only possible factor to prematurely leave school – comes into play, as Andreas Brede has pointed out (see: Brede et. al. 2017); but it would at least be a chance to make autistic pupils feel more comfortable at school. In parallel it could also play its role in tempering job-related difficulties people on the autism spectrum are usually confronted with (see: Scott et. al. 2018). And even in a more general sense, in the wider context of public attention and awareness it may show some effects – it may "encourage urgent local action on policies, systems and structures […] to the ideal of inclusion", as Liz Pellicano (Pellicano et. al. 2018) put it – simply in demonstrating that skillful intervention does in fact work. And finally and as a matter of fact it will for sure assist "to understand the living experiences of individuals with Autism Spectrum Disorder (ASD) from a broader perspective, taking into account many areas of an individual's functioning and environment" (Mahdi et. al. 2017), a goal that is at the very center of the AuTrain project as we have already mentioned.

So here is a closer look at some of the premises, prerequisites and structural conditions that have to be taken into account when trying to bring a project like this to life. The report we are presenting here consists of four main parts. The (1) *Introduction* was the place to talk about the ideas to and the underpinnings of the project. The second chapter, (2) *Empirical Issues*, will mainly be dedicated to methodological aspects of the investigations we are aiming at, whereas the (3) *Results* part will be presenting both the national reports on ASD contexts as well as the findings from the surveys we conducted, before trying to draw our conclusions from that output in (4) *Summary and Outlook* and assess the consequences they should and could have for the design of the AuTrain project in general and particular. And finally, in chapter (5), the *Annex*, you can find the two questionnaires in its original English version (Annex I & II) and the inquiry concerning already existing EU-projects on autism (Annex III)

And there is one more thing that can and has to be stated within these introductory words yet: The AuTrain course and curriculum, originally thought of and conceptualized as resp. for face-to-face settings (2 to 3 days of training in small groups) for now will have to be converted and aligned into a vocational training program primarily based on online solutions. We will try to keep it as flexible – and “re-transferable” – as possible. But this shift of focus is what the current situation concerning the COVID-19 virus is demanding from us.

(2) METHODOLOGICAL ISSUES

a. Objective

The aim of this State of the Art Report is to create a sound basis for all further steps and content in the AuTrain project. A comprehensive analysis of the current starting situations in the different partner countries, as well as a possible need for further steps and offers in the field of the realities of life of people who work or have contact with people affected by autism spectrum disorders in their daily lives, is to be summarized here and serve as a decision-making aid for the contents of the planned curriculum as well as the training and teaching materials. The resulting offer should be low-threshold and is primarily aimed at non-professionals.

b. Key issues

The starting point for all the work and analyses in this report were 4 important key questions:

- What is the life situation of people with ASD in the partner countries?
- What support offers does the current system offer?
- What support offers are experienced as helpful?
- What needs are identified?

In order to be able to take sensible and helpful measures, an overview of the current situation is necessary first of all, both on a national and international level. In order to gain an insight into the current situation, including the differences between countries, a pre-research was carried out at the beginning in the partner countries. To make the information reasonably comparable, 4 key questions were identified, which were answered by all partner countries at national level.

- National Prevalence rate and estimated number of affected people
- Options and areas of support for people with ASD

- Legal conditions and funding guidelines for support
- Public sentiments about the support system (views of people affected, professionals, interest groups,…) - qualitative data

Subsequently, the question amounted to what has already been done in this field, especially in the context of EU projects. The key issue in this area:

Which (EU) projects on ASD already exist, how were they structured and what are the results of these projects?

We were particularly interested in the following qualitative and quantitative aspects:

- Qualitative aspects: contents, used methodologies, target and age groups, regional coverage, notification possibilities
- Quantitative aspects: number of activities per region and year, number of participants

In addition existing resources in the field of technical implementation have also been looked at in more detail, to investigate the question:

- Which online platforms exist in the field of social inclusion of people with special needs and which of them are useful for the development of the planned AuTrain platform?

c. Collection methods

In order to obtain answers to the questions mentioned above, different survey methods are necessary, which subsequently leads to a mixed methods design. The mixed methods design offers the opportunity to obtain a more comprehensive picture of the phenomenon of interest by examining different facets (Frankel & Wallen, 2009; Creswell & Plano Clark, 2007).

Methods used in the present mixed methods design:

- Desk research
- Survey/questionnaires (cross sectional)
- Evaluation/overview work (projects and online platforms)

As a first step, qualitative data were collected to gain an insight into the current situation in the respective countries and to provide guidance on the development of the items in the following questionnaires. Initially, the partners analyzed the current situation in the form of an in-depth and intensive desk research. These qualitative preliminary studies were the basis for the item design of the following questionnaire study.

In addition, databases and Internet resources were also searched to get an overview of EU projects already carried out on ASD, as well as online platforms and tools. This analysis and evaluation serve as the basis for the planned AuTrain platform. The methodology for this is described separately in chapter d. “Methods of evaluation of existing projects and programs”.

The next step was the development of a questionnaire to obtain evaluable data base and comparable information from partner countries. Initially, only one questionnaire was planned for professionals to raise the need for education and training content. During the first project meeting, the idea of including people affected by ASD themselves in the needs analysis was taken up. For this reason, a 2nd questionnaire for people with ASD was also designed.

The phase of a pretest or test-run of the questionnaires was dispensed for time reasons, the peer review procedure was used instead. After some changes, the final versions of the questionnaires were created.

In the design of the questionnaires, an attempt was made to follow general recommendations in the specialist literature. Therefore, the items should meet the following characteristics (see Lang, 2010)

The key issues in the 2 questionnaires are as follows:

In structuring *professionals’ questionnaire*, focus was placed on the following objectives:

- Determining whether the interviewee had any knowledge or previous experiences connected to ASD
- Determining the knowledge of ASD on an interviewee´s working environment;

- The collection of personal data of the interviewee to whom the questionnaire was distributed;

In structuring *“insiders´” questionnaires*, focus was placed on the following objectives:

- Determining their experience as insiders: by asking them to explain the kind of problems they face, as well as to give examples of the difficulties in their everyday life;
- Asking of their opinion about experts, the need of further training and what they consider that this training should include
- Determining personal background: collection of personal data (age, gender, country of origin)

The questionnaires were presented as an online version, which the participants could access via a link by e-mail. An introductory text has been added to the online versions. (The items of the questionnaires and the questionnaires themselves can be found in the respective additions to the report.)

d. Methods of evaluation of existing projects and programs

In the present case already implemented EU projects as well as online tools and platforms have been looked at in more detail, collected in the sense of an overview and evaluated with regard to previously defined qualitative and quantitative criteria. The aim here is to use results and find usable content for the planned AuTrain platform and the curriculum/course itself as well as a decision regarding the technical implementation of the online platform.

According to the definition of deGEval e.V., evaluation is "the systematic investigation of the usefulness and/or quality of an object on the basis of empirically obtained data". Depending on the purpose of the evaluation different forms of evaluation exist. In the present case, projects and programs have been evaluated after their development or termination, so we deal with an *ex-post evaluation*, respectively a *summative evaluation*.

Ex-post Evaluation: evaluation, which evaluates a program retrospectively after its termination

Summative evaluation: evaluation, which is intended to serve the purpose of decision-making on the subject of evaluation

In general, according to the Society for Evaluation e.V. (2016), evaluations should cover 4 basic features: Usefulnes, Feasibility, Fairness, Accuracy.

Furthermore, three main purposes of evaluations can be generally distinguished:

- Provide information that is suitable to give orientation to the step-by-step design of the evaluation object, e.g. regarding the optimization of concepts or processes (formative eval.)
- Provide information that is likely to guide a fundamental decision on the subject of evaluation, e.g. the introduction, continuation, extension or cessation of a programme (summative eval.)
- Provide insights that can offer input to public and political or scientific discussions (see deGEval, 2016)

In addition to the evaluation in the present case various projects have been described in order to enable an appreciation, which comes close to an overview article in the sense of a narrative review.

A narrative review is a qualitative summary of the results of individual studies. It provides a broad overview of a particular topic and is therefore well placed to quickly find out about the current state of research on a topic. However, the selection of the articles taken into account is subjective and unsystematic (see Ressing, Blettner & Klug, 2009).

The questions to be answered in this context are:

- Which (EU-) projects on ASD already exist and how were they structured, what are the results of these projects?
- Which content is usable for the planned curriculum as well as for the AuTrain platform?

In particular we are interested in the following aspects:

- Qualitative aspects: contents, used methodologies, target and age groups, regional coverage, notification possibilities

- Quantitative aspects: number of activities per region and year, number of participants

In the field of technical implementation, we were interested in the following aspects:

- Which online platforms exist in the field of social inclusion of people with special needs and
- Which of them are useful for the development of the planned AuTrain platform?

e. Description of the implementation of the survey, the data material and used analysis methods

The questionnaires were developed in English and translated into the respective national language by the partner countries. Thus, the questionnaire was available in 6 language versions: English, German, Swedish, Portuguese, Italian and Greek.

The surveys were administered online. For participation in the survey links to the questionnaires were sent by e-mail to the target groups (public administration, health care, education) – members of associated partners, contacts of the partners as well as various institutions that are part of the target groups that have been selected for participation.

EELI decided to approach teachers/trainers directly and ask them to fill in printed copies of the questionnaire.

The results were transferred to Excel tables and analyzed that way. In the processing of quantitative data we limited ourselves to frequency analyses and the calculation of percentages.

With the answers to the open questions contained in the questionnaires a qualitative analysis was conducted with a description of everything emerging, in a narrative form.

The number of questionnaires answered in the partner countries varied, mainly due to the limitations of the global corona pandemic. We therefore have a very small sample in some countries. Where appropriate, the data was analyzed at national level. For samples below 10 we did not use the national analysis, but these data are included in the overall evaluation at European level. As Questionnaire II has very small sample sizes in several countries, it has only been analyzed at European level.

Overall 250 people took part in the surveys. Questionnaire I was answered 169 times. 67 times in German, 41 times in Italian, the Swedish version was completed 24 times, the Greek version 23 times, 11 questionnaires were filled in in Portuguese and 3 times in English.

Questionnaire II was answered by 81 people. 50 completed the Swedish version, 13 the Greek one, the German and the Portuguese version was answered 6 times each, the Italian and the English version 3 times each.

Figure 1 and 2 show the distributions for Questionnaire I and Questionnaire II.

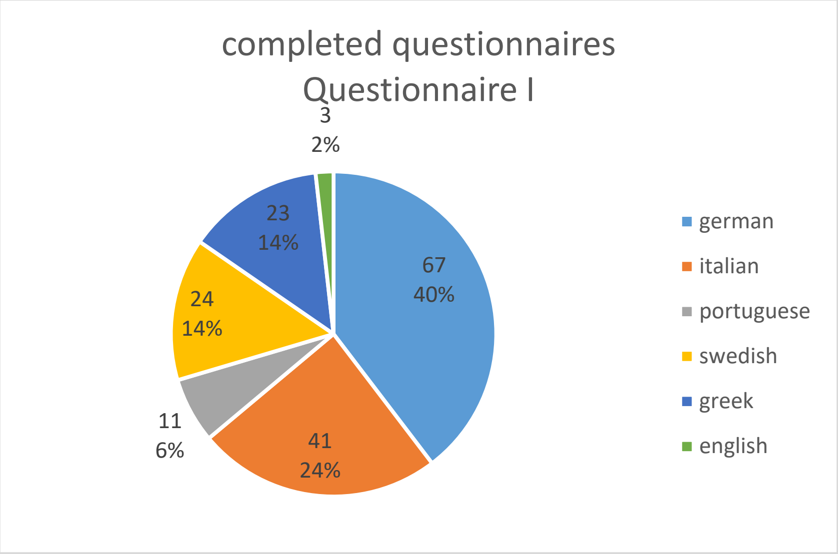

Figure 1: completed questionnaires; Questionnaire I

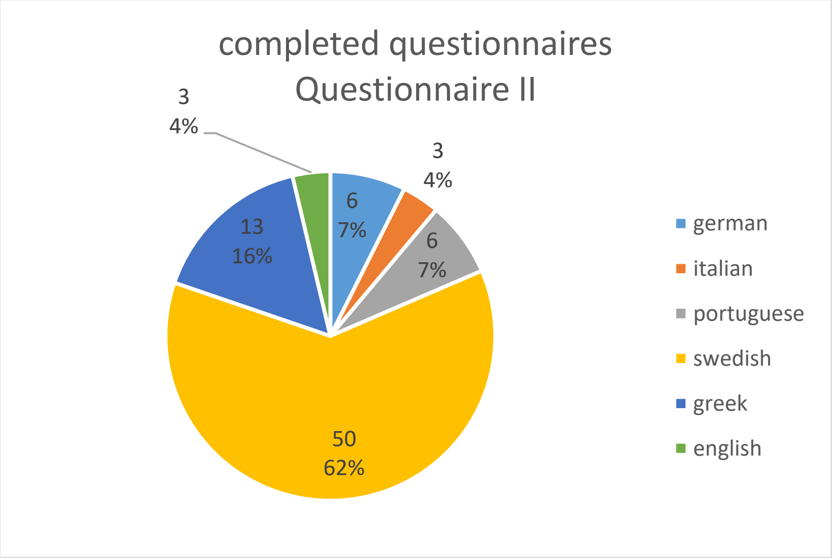

Figure 2: completed questionnaires; Questionnaire II

A total of 84.5% who completed Questionnaire I are female, 14.6% male, 0.9% diverse (66 missing data). For Questionnaire II, the distribution is 66% women, 29% men and 5% diverse (52 missing data). The age of the participants is ranging from 18 to 68.

The higher number of interviewees (49.5%) are occupied as Educators. The next higher number of interviewees are occupied in the field of Health/Social (39.6%). A few are working in the field of Office/Administration (4.5%), Science/Research (3.6%), Tourism (1.8%) and Law (0.9%). The question concerning the professional position was only part of Questionnaire II.

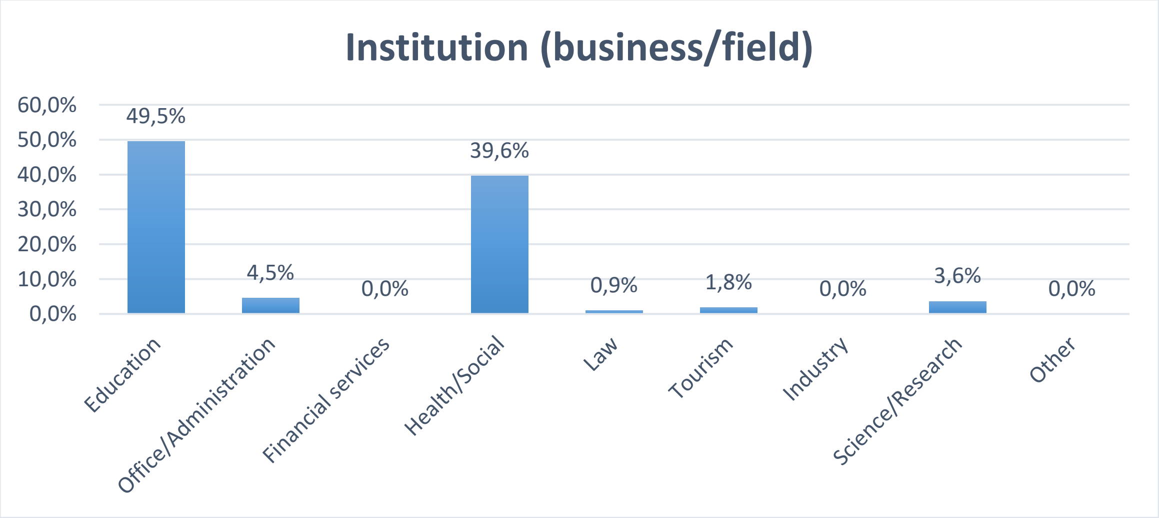

Figure 3: Professional position

(3) EMPIRICAL DATA & RESULTS

a. Current situation at national level

This section is followed by the reports of the partner countries as a result of the pre-research, which was carried out in the form of desk research. In order to obtain comparable information, 4 areas were placed in the foreground, which were examined by all participating partner countries:

- National Prevalence rate and estimated number of affected people
- Options and areas of support for people with ASD
- Legal conditions and funding guidelines for support
- Public sentiments about the support system (views of people affected, professionals, interest groups,…) – qualitative data

ITALY

1 National Prevalence rate and estimated number of affected people

Autism spectrum disorders affect, in Italy alone, between 300 and 500 thousand people.

It is, in fact, an estimate: the number of people suffering from autism is uncertain, also because they are disorders of a complex nature. In fact, this type of disorder includes, in addition to autism, also Asperger's syndrome and female autism (still difficult to diagnose) and diagnosed only on the present comorbidities.

Today there is talk of an incidence on children of 1 case on about 88 children but the data are still uncertain.

If we also consider subclinical or otherwise diagnosed situations probably the number would rise.

In 2018 there were 3,769 minors (up to 18 years) suffering from autism spectrum disorder in charge of the territorial structures of child neuropsychiatry of the Ausl of Emilia-Romagna; with the transition to the age of majority, the patients are assisted by the local services for the disabled, except for those (489 in 2018) for which it was necessary to take charge by the Mental Health Centers.

2 Options and areas of support for people with ASD

Thanks to the specific regional integrated assistance program, since 2008 a network of early and targeted interventions has been active throughout Emilia-Romagna, integrating therapeutic and educational tools according to the Hub & Spoke organizational model: Highly specialized centers, in connection with local hospitals and specialists, authorized to make diagnoses and to provide treatment paths. The program, revised in 2011 and later in 2016, has made it possible to significantly lower the age of the first diagnosis, to the advantage of taking it early. Work is now underway to improve the care of the young adult person with autism, through the construction of dedicated paths between the neuropsychiatric facilities of childhood and adolescence of Ausl, the services of adult mental health and services for disabled adults.

Pediatricians at 18 months administer to parents in charge a questionnaire (M-CHAT) which identifies the risk factors of children and if the conditions exist, they send the child to the service of child neuropsychiatry which within 2 months proceeds to the diagnostic evaluation.
If the operating characteristics are not detected at 18 months by the pediatrician, it is often the school that tells the parents the need for the child to be evaluated by the health service.
Subsequently in our region (the implementation of the law on autism with relative dedicated budget is the responsibility of the regions):

The early intervention provided by the territorial health service is implemented and consists of 4 hours per week (1 hour of speech therapy and 3 hours of cognitive behavioral intervention both in the clinic and at home) and the health service also takes charge of supervising schools so that work on the child is as consistent as possible.

The hours devoted to the autism program and the variety of proposed interventions vary from region to region and the Emilia Romagna region and in general northern Italy has more services and more coverage than in the south.

The autism program thus outlined continues until the child's 7th year, after which the child is still in charge of the health service but there are no longer 4 hours of treatment for the little ones.

This is to favor early and intensive intervention on the first steps taken.

After 7 years the services of psycho-educational treatments are private and therefore borne by families or associations.

From this year, however, the Emilia Romagna region has allocated funds of around 300,000 euros to guarantee at least 1 hour of treatment for people with ASD aged between 7 and 17 years.

At school level, ASD children (regardless of their functioning) are included in the classes of ordinary schools and benefit from the support of a support teacher (specializing in special education), educators (also specialized) and in some situations even from communication assistant (if the child uses a non-voice channel to communicate).

The Plan for inclusion

The head teacher, on the basis of the directives established by the ministry, draws up the proposal for the Inclusion Plan for all students and students.

The Plan, approved by the teaching body, indicates the barriers and the facilitators of the reference context as well as the interventions for improving the quality of school inclusion and is an integral part of the school's school project.

Individualized educational plan: It realizes at-school-inclusion in the dimensions of learning, relationship, socialization, communication and interaction; in the school of the second cycle it identifies the tools for the effective performance of school-work alternation, ensuring the participation of the subjects involved in the inclusion project.

3 Legal conditions and funding guidelines for support

In 2011 the 21st guideline of the Higher Institute of Health was published in Italy on treatment for autism. This guideline, which analyzed only experimental evidence-based research, made the following recommendations.

Early treatment, when combined with specific school programs, parental involvement and adequate medical care, when needed, can greatly reduce the symptoms of autism and increase the child's chances of learning new skills.

Treatment should respect a number of principles:

- Consider behavioral and cognitive psychoeducational intervention as an elective intervention included in a network strategy
- Share the results of the diagnostic and functional evaluation with the other figures of reference in the child's life and extend the intervention to all the living environments of the child
- Consider the need for services throughout life and in all walks of life
- Individualize programming and pay attention to individual needs
- Involve families
- Provide a specific training for caregivers (people who take care of the child, who may or may not correspond to the parental figures.

National guidelines (under review in 2020) and the autism law (134 of 2015) guidelines are guidelines and the implementing decrees and essential levels of assistance (LEA) are the responsibility of the regions. In Emilia Romagna the Autism Integrated Regional Plan (PRIA) was approved.

Thanks to the specific regional integrated assistance program, since 2008 a network of early and targeted interventions has been active throughout Emilia-Romagna, integrating therapeutic and educational tools according to the Hub & Spoke organizational model: Highly specialized centers, in connection with local hospitals and specialists, authorized to make diagnoses and to provide treatment paths. The program, revised in 2011 and later in 2016, has made it possible to significantly lower the age of the first diagnosis, to the advantage of taking it early. Work is now underway to improve the care of the young adult person with autism, through the construction of dedicated paths between the neuropsychiatric facilities of childhood and adolescence of Ausl, the services of adult mental health and services for disabled adults.

Actions of the Pria Activation of a permanent collaboration table with the Ministry of Education, University and Research to update and adapt, in university and post-university programs, the educational contents related to autism spectrum disorders in line with evolution of scientific evidence.

Activation at national, regional and local level of training projects aimed at updating, preferably with integrated modalities, of all the professional figures related to the health, social and educational fields, both in the developmental age and in adulthood. The training activities should include specific qualification pathways for the personnel involved in the diagnosis, treatment and overall responsibility of the person on the autistic spectrum on interventions aimed at implementing skills for independent living.

Activation at national, regional and local level of training activities specifically aimed at the families of people on the autistic spectrum, including training activities related to the role of the family member as an active partner from the stage of the diagnostic path to that of the intervention.

Activation and / or strengthening in the school sector of training activities and support to schools to ensure an effective psycho-educational intervention, enhancing the professionalism of teachers and educators.

Promotion at national, regional and local level of training activities aimed at the general population in order to promote awareness and respect for the dignity and full inclusion of people on the autistic spectrum.

Enhancement of training activities aimed at promoting independent living, integration with the surrounding social fabric and work experience.

As for the financial support to families, they depend on the level of support defined by the functional diagnosis and can include checks for the accompaniment (in levels 2 and 3) only to a scholastic allowance check for the purchase of compensatory instruments (for levels 1) and also to no financial support but only the taking in charge and the assignment of the scholastic support if necessary (for the level 1 and subclinical).

4 Public sentiments about the support system (views of affected people, professionals, interest groups etc.) – qualitative data

In Italy, awareness of autism is not yet high in society (even if we work hard). There are still many stereotypes about this condition that is still called pathology or disease. Unfortunately, there are many false myths that are still very strong and difficult to fight (vaccines, diets and chelating therapies), including the belief that autism refers only to people with low functioning and not able to be autonomous and self-determination. When in fact the increase in diagnosis so significant refers above all to the increase in diagnoses on higher operations that in the past escaped diagnostic radars. There are two types of associations in Italy that are very active on the subject of autism (Angsa, the national association of autistic subjects and Asperger associations as Spazio Asperger, Onlus, which however are still little recognized even by clinicians).

These associations have worked a lot (each bringing their own vision of autism) to foster awareness and to put pressure on the local institutions they were guaranteed to be guaranteed or levels of assistance. But all in all we are still far from the awareness that an ASD individual can lead an independent life, work, get married etc.

PORTUGAL

1. National Prevalence rate and estimated number of affected people

Until the 1990s, Autism Spectrum Disorder (ASD) was seldom diagnosed in Portugal, and there was no specific policy on education or health provision for individuals with autism (Oliveira et al., 2017). In our days, main Portuguese hospitals/clinical/private settings use a set of formal instruments for ASD diagnosis, which contributes to a more precise and valid diagnose of ASD in early childhood. In Portugal, there has been a growing concern about the diagnosis of ASD, a growing development of the instruments to do so, and the prevalence rate tends to increase.

The last country-wide epistemological study conducted in Portugal by Oliveira et al. (2007) had the aim to estimate the prevalence of ASD and identify its clinical characterization, and medical conditions. A school survey was conducted in elementary schools, targeting 332 808 school-aged children in the mainland Portugal and 10 910 in the Azores Islands. The global prevalence of ASD per 10 000 was 9.2 in mainland, and 15.6 in the Azores, being the relationship between boys and girls in this study from 2 to 1 (Oliveira et al., 2017). Children in this study were directly assessed with the following tools: The Diagnostic and Statistical Manual of Mental Disorders (4th Edition), the Autism Diagnostic Interview–Revised, and the Childhood Autism Rating Scale.

The findings in the study, at the time, showed that prevalence rates of ASD in Portugal were lower when compared to other countries (Oliveira et al., 2017). The authors of this study suggest that there are regional differences for these findings (Özerk, 2016). This observation suggests that genetic population characteristics or regional environmental factors may contribute to the discrepancies found in prevalence estimations of ASD across studies. The large majority of the children diagnosed with ASD were regularly followed in healthcare facilities (94.2%).

2. Options and areas of support for people with ASD

Support by education institutions

Early Childhood Intervention in Portugal supports children at risk and special needs between zero to six, including children with ASD diagnosis. “In recent years, Early Intervention was characterized for considerable advances in its domain, in result of a set of practical, conceptual and theoretical influences, which had had great repercussions and implications in the implementation and organization of the Family Centered Approach. The specificity of the meaning of this approach inhabits in the recognition of that the families are the main context for the promotion and development of the child; in the respect for the choices of the family and its processes of decision; in the emphasis on the abilities of the child and of the family, and in the professional/family partnerships (Pereira, 2009).

Between 2008 and 2018 preschool education, primary, and secondary education in the public, private and cooperative sectors provided specialized support to children and youth with ASD, under Law 3/2008. For those who needed, there were *Structured Education Units* allocated in several specific school clusters in the country. Each student would also have an individual educational program (IEP) and an individual transition plan (ITP), both required for these children. Specialized support was “provided in state, private and co-operative pre-school, basic education and upper-secondary education and aims to create the conditions for the adjustment of the educational process to pupils’ special educational needs. Teachers from the special education recruitment group, with specialized training in specific areas, are placed in schools to promote support activities for students with permanent special educational needs” (European Agency for Special Needs and Inclusive Education, n/d).

In 2018, the Law changed and Law 54/2018 creates the conditions for schools to be places of inclusion capable of recognizing the diversity of all students and responding to their capabilities and individual needs. According to this law specific resources to support learning and inclusion will be in place in schools, and the following skilled human resources are essential to achieve inclusion in schools:

- special needs education teachers
- skilled professionals
- operational assistants, preferably with specific training.

In addition, multidisciplinary teams and learning centers are supposed to support inclusive education.

The goals defined in the action plans will be met through a set of measures to support learning and inclusion with special attention on the curriculum and learning methods. There will be three different types of measures: universal (for all students), selective (to fill potential gaps in the implementation of universal measures), and extra measures (to solve proven persistent problems not overcome by universal and selective measures). A process is created to identify the necessary measures of learning support and inclusion. This process will be based on evidence identified by school professionals with the participation of parents, guardians and professionals or support services that engage with the child or student (Law 54/2018, as cited by DRE, 2018).

Support by private social solidarity institutions

Besides the support of inclusive schools, in Portugal, support can be provided by private social solidarity institutions such as, *The Portuguese Autism Federation* (FPDA) based in Lisbon, founded in 2003 but started its activities in January 2004. In our days it has the following units around the country, namely in big cities/regions of the country: APPDA-Lisbon, Portuguese Association for Developmental Disorders and Autism, APPDA-Norte, Portuguese Association for Developmental Disorders and Autism, APPDA-Coimbra, Portuguese Association for Developmental Disorders and Autism, APPDA-Viseu, Portuguese Association for Developmental Disorders and Autism). It has national scope and replaces the national organization APPDA, *Portuguese Association for the Protection of Autistic Disabled* (formerly *Portuguese Association for the Protection of Autistic Children*), founded in 1971, a member of the International Autism-Europe Association since 1988. Members of the Federation are non-profit development NGOs, Private Social Security Institutions, partially funded by the Ministry of Labor and Social Security. The remaining funding is made through membership fees, donations and sponsorships.

The Portuguese Autism Federation should promote and support its members' initiatives and help implement new organizations. It represents its members with public and private organizations, Portuguese or foreign, that pursue the same purposes.

Support at work

In Portugal, there is a national scholarship for (socio-professional) skills of young people and working age adults with ASD. The Online Platform has an innovative nature where young people with ASD can receive job offers. To do this, the young people/ adults with ASD simply need to register online. The application form is available online to the companies involved in the project. The Platform is an active employment tool, dynamically articulated between companies, local associations and other organizations at regional and local level. All young people/adults should have the support of a federated or other association recognized by the Portuguese Autism Federation.

Online platforms:

http://plataformainclusao.fpda.pt/
http://autismoetrabalho.fpda.pt/search/job
http://autismoetrabalho.fpda.pt/
http://www.fpda.pt/associacoes-federadas

3. Legal conditions and funding guidelines for support

Students with special educational needs, including the ones with ASD, have been supported in regular inclusive schools according to what is stipulated in Legislation since 1991, with Law 319/91 between 1991 and 2008, with Law 3/2008 between 2008 and 2018, and nowadays with Law 54/2018. Early intervention is ruled by Law 281/09.

4. Public sentiments about the support system (views of people affected, professionals, interest groups...)

The following section presents main results of several studies/papers that have been developed by students and faculty members of the University of Minho in the last five years.

1. Specific intervention for students with Autism Spectrum Disorder in Portugal, by Alves, Ana Paula Antunes, 2014, PhD:

This research had as its primary aim the understanding of how different specific approaches provide the answer to the characteristics and needs of children with autistic spectrum disorders in Portugal. This work has been organized around the conceptual, organizational and interventional structure of three specific programs for students with autistic spectrum disorders currently being applied in Portugal. We crossed referenced the perspectives of experts, professionals and families with the ethnographic narrative that was developed during this research. This research was guided by a qualitative/interpretative paradigm, applying case study methods and an ethnographic narrative (Ellis, 2000) in order to gain access to the various voices immersed in this area. The use of exploratory interviews to privileged informants, semi structured interviews to families, professionals and the consultation of specialized documentation connected to the programs in the study allowed access to different interpretations regarding ASD, and contributed to the reflexion about educational quality practices capable to meet the characteristics and needs of students with ASD. Different forms of information resources and instruments of data collection were applied in such a way to ensure the internal and external validity of the research (triangulation/ crystallization). From the narrative produced in this research it is possible to identify a set of essential conditions based on evidences. By listening to the different voices involved in the life span project of students with ASD, this has allowed us to perceive some of the implications and gaps between the theoretical, legislative and practical components. The results of this study show that the programs applied in Portugal are supported by a conceptual and organized structure based on cognitive, behavioral theories, which show that they are adequate to the population with ASD as is shown in international studies of meta-analysis (National Autism Center, 2009, 2011). The study participants have clarified the practices used and identified key aspects in order to choose an intervention program that fits the international recommendations (Barthélémy, Fuentes, Howlin, & Van der Gaag, 2008; National Autism Center, 2009, 2011; Reichow, 2011). These results have allowed us to conclude that although every program fits the international recommendations about evidence practices, it is necessary therefore that ASD intervention programs be regard: the heterogeneity of the ASD; the characteristics of each student and its family; the collaboration between the different services; the coordination between theory and practice; pre and in-service training of teachers and other professionals involved; the regional geographical asymmetries and above all, consider the rights of the family in the choosing of the specific interventional approach (Bagnato, 2007; Barnbaum, 2008; Boyd et al., 2013; Charman, 2010; EiKeseth, 2008; Filipek et al., 1999; Howlin, Magiati & Charman, 2009; Kazdin, 2008; Mesibov & Shea, 2010; National Autism Center, 2011; Serrano & Pereira, 2011; Rapin & Tuchman, 2008; Roberts & Prior, 2006; Rogers & Vismara, 2008).

2. Perspectives of futures teachers about inclusion of students with Autism Spectrum Disorder by Ana Filipa Soares de Carvalho, 2018, Master:

The present research aim to analyze the perspectives of future teachers regarding inclusion of students with Autism Spectrum Disorder (ASD) in regular schools. A quantitative methodology was used and data was collected with a questioner from 61 master students. The results analysis were descriptive and inferential. The main conclusions drawn from this study were the following: a) future teachers consider that inclusion of students with ASD was beneficial to themselves, their peers, teachers, their families and society; b) the majority of future teachers consider Regular class as the most suitable environment for students with ASD, reinforcing the right of inclusion; c) the future teachers consider that inclusion has a more significant impact on the social development than in the academic development of the student with ASD; d) the variable type of Master’s degree had an impact on the perception about inclusion in the regular class. Students of the Master's Degree in Pre-School Education and of the Master's Degree in Pre-School Education and Teaching of the 1st Cycle of Basic Education were those who demonstrate the most positive results; e) the sex variable had an impact on the perception about inclusion in the regular class, with female participants presenting the most favorable perceptions.

Link: http://hdl.handle.net/1822/59703

3. Perspectives of the educators of the Regular Education and Special Education on inclusion of children with Autism Spectrum Disorder about inclusion, by Ana Isabel Teixeira Valente, 2017, Master:

The purpose of this study is to contribute to deepening the knowledge and understanding the perspectives of the educators of the Regular Education (RE) and Special Education (EE) on inclusion of children with Autism Spectrum Disorder (ASD) of the benefits and difficulties inherent to this inclusion process. With this intention, the present study assume a qualitative methodology, through semi-structured interviews with six RE educators and two educators with at least 1 year of experience in the ASD, in the District of Vila Real. Overall, the participants' perspectives allow us to conclude the notorious importance to the inclusion of children with ASD in preschool rooms. All the participants consider that the inclusion of children with ASD, in preschool rooms, is mutually beneficial for children with ASD and without ASD. However, a totality of participants concerning the existence of difficulties process of inclusion of children with ASD in pre-school rooms, due to the lack of training of ER educators; lack of human and material resources and frequency of Special Education / Early Intervention support. The participants also indicated that they use, preferably, the support of as a promoting strategy for the participation of children with ASD in the activities and preschool routines.

Link: http://hdl.handle.net/1822/51174

4. A comparison of parent and professional perceptions of children with autism spectrum disorder in Portugal by Helena Isabel da Silva Reis, Ana Paula da Silva Pereira, & Leandro S. Almeida, 2017, published paper:

Improving early intervention in Portugal for children with autism spectrum disorder (ASD) requires parents and professionals to collaborate in assessing and planning intervention programmes. This article analyses parental and professional assessments of children with ASD, in the dimensions of social communication, repetitive behaviours and restricted interests, and sensory processing. The study presents contrasting perspectives from professionals and parents from a range of socio-academic backgrounds. The sample consists of 136 Portuguese children (aged three to six years old) with ASD and involves children, parents and professionals from across the country. All children, at the time, were in preschool and receiving early special education intervention. Parents and professionals used the Assessment Scale for Children with ASD to complete the assessments. The results show that parents rate children's development and learning more positively compared to professionals; and that this difference is more significant in the field of social communication. Further, parents with higher academic qualifications showed statistically significant differences in comparison with professionals in the social communication dimension. These findings are discussed in relation to the literature and some suggestions are made regarding certain practices related to intervention in early childhood.

Link: http://hdl.handle.net/1822/51006

5. Early intervention in autism spectrum disorder: concerns and support of Portuguese mothers by Magalhães, Lúcia S. & Ana Paula da Silva Pereira, 2017, published paper:

Families of children with autism spectrum disorder (ASD) face a series of daily challenges, from which emerge a number of concerns that are inherent to the reality of living with a child with ASD, as well as the demand for formal and informal supports that are required for these families. This study's main objectives were to: (1) identify and consider the concerns of Portuguese mothers with children with ASD; (2) identify and consider the required forms of support that those mothers need; and (3) understand if the support networks that are given to these mothers are adequate in face of their concerns. Results showed that these mothers hold concerns and support that are consistent with most of the scientific studies in this area. Results also indicate a greater demand for formal support throughout the life of the child with ASD, rather than informal support. The inadequacy of support provided by the primary health care system is highlighted by the mothers, especially at the initial stage and in the diagnostic process. Finally, results suggest the adequacy of specialized formal support, especially in the context of early intervention, although mothers complain about the amount of existing supports, as well as the frequency and duration of sessions provided by therapeutic services and early intervention programmes.

Link: http://hdl.handle.net/1822/51012

6. Social communication characteristics and specificities in autism spectrum disorder by Helena Isabel Silva Reis, Ana Paula da Silva Pereira, & Leandro S. Almeida, 2016, published paper:

This article describes and discusses the characteristics of Social Communication in Autism Spectrum Disorder (ASD) based on the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders, DSM 5. It highlights, among others, the merger of social interaction and communication and its importance for diagnosis and intervention of children with ASD. It also confronts the different perspectives that underpin arguments and criticisms to the classification proposed by DSM-5. It analyzes the specificity of language, discourse, pragmatics, syntax prosody, morphology and semantics in children with ASD as well as their implications for adaptation and development of their communicative skills. Identifying these skills reinforces the importance of the earliest intervention possible, conducted in the child and family’s natural contexts aiming to enhance involvement levels and participation of the child, promoters of learning opportunities and development of their communicative and social skills.

Link: http://repositorium.sdum.uminho.pt/handle/1822/42508

7. From assessment to intervention in autism spectrum disorder by Helena Isabel Silva Reis, Ana Paula da Silva Pereira, & Leandro S. Almeida, 2016, published paper:

The evaluation of disorders characterized by atypical development and behavior patterns such as the Autism Spectrum Disorder is at least complex. From diagnosis to the sole discretion of PEA that contradiction, uncertainty and disagreement arise between the various professionals and, despite the Diagnostic and Statistical Manual of Mental Disorders provide a thorough description of the child’s symptomatic profile with ASD, the observation, the use of checklists and standardized tests, together with the family, remains crucial for determining an individualized plan of intervention. The design quality of instruments determines the accuracy and reliability of the information and higher capacity in relevant information provided, the greater validity of the instrument and more complete information will be obtained by researchers and clinicians as they pretend. Despite the significant increase in research on the labor force and rapid advances in science, efficient evaluation of this disorder remains a challenge, especially to determine an effective early intervention.

Link: http://hdl.handle.net/1822/42474

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Oliveira, G., Ataíde, A., Marques., C., Miguel, T.S., Coutinho, A. M., Mota-Vieira, L., …Carmona da Mota, H. (2007). Epidemiology of autism spectrum disorder in Portugal: Prevalence, clinical characterization, and medical conditions. *Developmental Medicine & Child Neurology*, *49*(10), 726–733.

Özerk, K. (2016). The issue of prevalence of autism/ASD. *International Electronic Journal of Elementary Education*, *9*(2), 263-306.

Pereira, A.P.S. (2009). *Práticas centradas na família em intervenção precoce: Um estudo nacional sobre práticas profissionais* (Tese de doutoramento não publicada). Universidade do Minho, Braga, Portugal.

AUSTRIA

Prevalence rates and number of affected people:

Austrian epidemiological data on the prevalence of developmental disorders are generally inadequate.

So far, there is hardly any systematically collected data on ASD in Austria, so we have to rely on estimates and international prevalence rates.

Epidemiological studies, based on current diagnostic criteria and thus covering the entire autistic spectrum, show prevalence rates of 3 to 6 per 1000 people (Fombonne, 2005).

In other studies - depending on the different diagnostic delineation of the spectrum disorder - international prevalences in the range of 0.4 - 1% affected in the general population are mentioned.

Based on these rates, it can be assumed that about 30-80.000 people live in Austria with different degrees of autism (Hippler, Sommerauer & Vavrik, 2012).

The “Autistenhilfe Österreich” estimates the number of people with ASD in Austria with 87000.

Legal conditions & funding guidelines for support:

In Austria Autism Spectrum Disorders are recognized as a disability. Depending on the degree of impairment, affected people are entitled to benefits under the Disability Act. But in Austria there are 9 federal states, each with its own disability laws, as well as a national Austrian Disability Act. So services and cost subsidies are not uniformly regulated nationwide. In general opportunities of support for people with autism in Austria vary depending on the federal state, for example subsidies for therapies or support for kindergartens and schools.

Throughout Austria, parents of disabled children are entitled to the increased child allowance and, in the case of an increased need for care, also to care allowance.

Therapy centers – where all the costs for therapy are paid by the state or health insurances – are only occasionally found in larger cities.

In Germany, about 70% of the treatment costs of an ABA-therapy are paid by public authorities. In Austria, affected persons have no comparable offer from public side available. Only the general services covered by the Disability Act are paid, whereby usually only one therapy unit per week is available.

Options and areas of support:

Overall the range of autism-specific therapies is very low and varies from region to region. Especially rural areas are clearly underserved. Diagnoses are made late and sometimes inaccurate.

Offers, where impairments of ASD can be validly examined by state of the art instruments are rare. There are only some center-oriented opportunities at few places in Austria. In addition, there is the overwhelming lack of evidence-based treatment methods in Austria.

General services covered from the Disability Act (Austria-wide):

- Early Intervention
- Cost subsidies for therapies (speech therapy, physical therapy, ergotherapy)
- Work Assistance Services
- Day and employment structures (occupational therapy)

Within the scope of these services, specialists with knowledge in autism are rarely available.

For the purposes of inclusion, all children with ASD are entitled to attend a regular kindergarten and then a regular school. Therefore, school assistants are available in most of the federal states.

If there is an intellectual impairment, there is also the possibility of special education in regular schools.

In this framework, the child receives an individualized curriculum and a special education teacher for a few hours a week.

Dealing with children / adolescents with ASD, however, always faces regular schools with challenges and staff with knowledge in Autism is not always available.

In the federal state of Lower Austria, an autism section has been set up for the school sector to at least partially cover the need for counselling and support for teaching staff.

Public sentiments:

From time to time there are brief reports in the media about the (insufficient) supply of people with ASD in Austria. Most of these are initiated by solicitous organizations that want to improve this. Overall, however, the knowledge of autism in Austria is quite poor. Most of the time the film "Rain Man" is still used as an example of the "classic" autistic person. There is also a significant need to improve the knowledge about autism in social institutions, kindergartens and schools.

Families of affected children and adolescents usually have a very long odyssey behind them until they receive a diagnosis. Lack of therapy places, incomprehension of pedagogues and the environment make the situation even more difficult.

The Austrian League for Child and Youth Health also stated in a statement on the diagnostic and therapeutic offer for autistic people in Austria, that the supply was altogether too low and regionally insufficiently available. In addition, more educational institutions with autism specific expertise and appropriate offer are required.

In the field of autism specific diagnosis and therapy as well as pedagogical support for children and adolescents with ASDs, in international comparison Austria has to do a lot to catch up.

The “Autistenhilfe Österreich” started a petition about 5 years ago, in which it demanded the takeover of the therapy costs for autistic persons from the health insurance fund. With only 1000 supporters the participation was however quite low.

In the petition they described the situation as follows:

Because of poor autism-specific training of professionals many children cannot be adequately treated (e.g., doctors, psychologists, therapists) or have to expect very long waiting times at clinics and hospitals.

Also, for specialists at the clinics, kindergartens, schools, competence and training centers, this situation is highly unsatisfactory and frustrating – since it is known what would be necessary, but this is not available in Austria.

Autistic people therefore are not at all, too late or inadequately treated, which leads to devastating consequences for those affected and the health system (high follow-up costs).

GREECE

Autism Spectrum Disorder (ASD) is a neurological and developmental disorder that begins very early in childhood and lasts throughout a person's life. It is characterized by impaired social interaction, impaired verbal and non-verbal communication, and restricted and repetitive behaviour. According to the tool kit “Is It Autism and If So, What Next? A Guide for Adults”, available on Autism Speaks “With the May 2013 publication of the fifth edition of the DSM - American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (commonly referred to as the DSM-5), **all autism disorders were merged under one umbrella diagnosis of ASD.** Previously, they were recognized as distinct subtypes, including autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger Syndrome.

Even though there are many different studies that try to determine the prevalence rate and estimated number of people with ASD, different methodologies are used so it is not possible to determine the exact rate and number. **According to Autism Speaks, today 1 in 50 people are diagnosed with autism,** making it more common than childhood cancer, diabetes and AIDS. ASD appears in all racial, ethnic and social groups and is **4 times more common in boys** than girls. In Greece there are no studies to determine the exact rate and number of children and adults with ASD, but according to Children's Psychiatric Hospital of Attica, “**Epidemiological studies have shown that the rate of the typical form of autism (Kanner syndrome) is 4-6 per 10,000.** Regarding the Pervasive Developmental Disorders, the results differ. Some researchers report about 50 per 10,000 and others increase that number up to 90 per 10,000, counting all different syndromes, forms and types of Autism Spectrum”. According to that, it is estimated that **in Greece there are 4.000 to 6.000 children and adults with autism and 50.000 to 90.000 people with autistic developmental disorders.**

Autism is mentioned for the first time in Greek laws only in **1999**, Law 2716/1999 on Mental Health and in 2000, Law 2817/2000 on Special Education, in which **people with autism are included in the category of people with special educational needs.** Until then there was no State Law, so there was no special support and benefits for the people with ASD. The above-mentioned laws were the basis of the legal and institutional framework that exists now in Greece. Some more important Laws are: the Law 3518/2006 Article 73, the Law 4115/2013 Article 39, the Law 4186/2013 Article 28 on special education, the Law 3966/2011 on Special Education and most important the Law 3699/2008 on Special Education of people with disabilities or special educational needs and more.

Some important services for people with autism in Greece

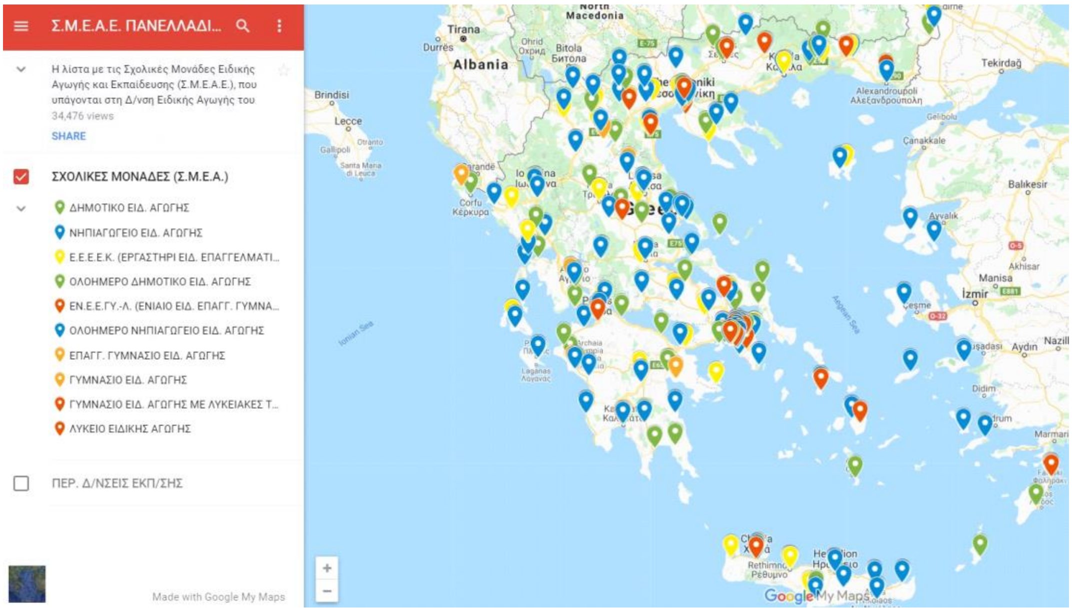
Diagnosis is a very complex issue for children and adults with ASD in Greece, but important steps have been taken by changes in legislation and the establishment of multi-disciplinary teams for the diagnosis of autism and other special needs in each prefecture of Greece. **Most families received the first assessment from a public hospital (39,9%), a family doctor (30,1%), a psycho-educational public centre (19,7%), a multidisciplinary team (KEDDY) (5,2%) or other institution (5,2%). KEDDY are the public Diagnostic, Evaluation and Support Centers of multidisciplinary teams, which are under the Ministry of Education.** There are approximately 30 KEDDY in Greece. According to the assessment, the evaluation and the percentage of disability of the child or adult, there are some services, educational support and entitlements that the law provides to the people affected. The state benefits and state allowance are proportional to the disability percentage.

Specialized centers for the diagnosis, evaluation and periodic monitoring of children with autism:

- At the Pediatric Psychiatric Hospital of Attica,
- At the Pediatric Psychiatric Hospital "Agia Sofia" and
- At the Psychiatric Hospital of Thessaloniki, and more.

The data of the Ministry of Education and Religious Affairs show that **there are more than 480 public special schools** (kindergartens, elementary schools, high schools, special vocational high schools and centres of vocational education and training provide support and qualifications up to degree level). **More than 4,5% of the students in special schools in Greece, are students with ASD.**

The map below offers a quick view of all the special schools in Greece:



Η λίστα με τις Σχολικές Μονάδες Ειδικής Αγωγής και Εκπαίδευσης (Σ.Μ.Ε.Α.Ε.), που υπάγονται στη Δ/νση Ειδικής Αγωγής του

Source: https://www.noesi.gr/pronoise/eidika-sxoleia

In addition to that, in Greece there are some **Guest houses** for children and adults with ASD, for long or short-term accommodation:

- At the Pediatric Psychiatric Hospital of Attica, the “Aggelia” guest house for 10 adolescents with autism
- At the Greek Center for Mental Health and Treatment of Children and Family, for a short-term stay of children 3 - 12 years old, "To Perivolaki 2".
- Association of Parents, Guardians and Friends of Autistic Individuals of Larissa Prefecture
- “Eleftheria” Boarding house, that hosts 12 adults with autism in Larissa
- Hellenic Society for the Protection of Autistic Individuals (EEPAA)
- “Eleni Gyra” Guesthouse, in Zitsa Ioannina.

The list of the Day Care Centers that exist in Greece is:

- Day Care Center “Litharaki”, in Athens
- Specialized Unit for the Treatment of Children with Autism and Pervasive Developmental Disorders (ΕΘΜΑ), in Athens
- To Perivolaki - Greek Center for Mental Health and Treatment of Child and Family - Day Centers “To Perivolaki” I, II and III
- Mental Health Center - Therapeutic Unit for Autistic people, Athens
- Foundation for the Child “The Pammakaristos”, in Attica
- Day Care Center for Adults with Autism, in Attica
- DI.KE.PSY. - Interdisciplinary & Research Psychosocial Support for Children and Adults, in Attica.

- Association of Seafarers Parents "The Argo", in Piraeus
- Association of Parents-Guardians and Friends “S.O.S.”, in Attica
- Association of Parents and Friends of the autistic child “Elpida”, in Thessaloniki
- Association of Parents, Guardians and Friends of maladjusted Persons "Zoodochos Pigi", in Heraklion Crete.
- Association of Parents-Guardians and Friends of Autistic People
- The Society for the Protection of Autistic Children "Megalochari"
- Child and Adolescent Mental Health Association of Etoloakarnania, in Mesologgi
- Association of Parents Guardians and Friends of People with Autism Prefecture of Messinia, in Kalamata.
- Stin Avli toy Kosmou, in Athens
- E.PSY.ME PIREUS, in Piraeus
- K.E.E.R.E.A. “Orizontes”, in Athens
- Child and Adolescent educational Center “EKSELIKSI”, in Attica
- Proseggisi, in Athens

Last but not least, extremely important is the role of the **Associations of Parents, Guardians and Friends of people with ASD,** not only for the support, but also for the assertion of the rights of the people affected and also, to claim higher state allowance and more benefits. There are more than 20 non-profit, non-governmental associations in Greece aiming to support individuals with ASD, alongside their families, active not only on a regional but also on a national scale.

Even though the public awareness towards the rights of people with Autism Spectrum Disorders is higher in Greece in the recent years, there are still many people who face stigma, discrimination and, consequently, social isolation every day. There are so many things that need to be done, not only for the promotion of scientific knowledge, research and data collection regarding ASD, but also to support the people with ASD, to better understand autism and how to communicate and deal with people on the spectrum. For this reason, the AuTrain project is very important and the "Autism Officers" in public institutions is a big step forward for the social inclusion of the people with Autism Spectrum Disorders.

Sources and useful links:

www.moh.gov.gr - Hellenic Ministry of Health
https://www.minedu.gov.gr/ - Hellenic Ministry of Education and Religious Affairs

www.autismhellas.gr
www.noesi.gr/
http://www.autismthessaly.gr/ - Association of Parents Guardians & Friends of People with Autism
www.autismnet.gr - Hellenic Scientific Network for ASD
www.autismgreece.gr -
www.psychargos.gov.gr
www.pavefs.com/

SWEDEN

Autism spectrum conditions (ASC) are today common diagnoses in Sweden, and diagnoses rates have been increasing in the last two decades. Clinical registry data on all cases of ASC from Region Stockholm in 2016 show a prevalence of 1.4% for ages 0 to 12 years (n=5142), 3.1% for 13 to 17 year olds (n=3,806), and 2.4% for 18-24 year olds (n =4,335). National data on unique ASC related service contacts in 2017 provided by the Swedish Board of Health and Welfare (Socialstyrelsen) in 2017 yielded 0.18% for ages 0 to 5 (n= 1,322), 0.53% for 6 to 9 year olds (n=2,557), 0.98% for 10 to 17 year olds (n=8,777), 0.73% for 18 to 24 years olds (n=6,188), 0.2% for 25 to 64 year olds (n=10,310).

The available support for people on the autism spectrum and their families is divided among federal, regional and municipality services. Although there are comparably many services and aids available, the access is limited by the complexity of services organization, application procedures and cues/waiting times. Diagnosed individuals and their families often need to handle up to 40 contacts to get the support they have the right to, which for many is a burdensome, and sometimes impossible task. In addition, in many places, even within clinical services a deeper autism-specific awareness and expertise is still often a challenge. The County Councils (now called Regions) are in charge of the clinical services around ASC. There are several regional guidelines for assessment and treatment, and national guidelines by the Swedish Board of Health and Welfare are underway. Clinical services are organized somewhat different between Regions, but the most important services providers are the habilitation services (e.g. main responsibility; psychoeducation, early intervention, assistive technologies, parent training) and public and private child and adolescent psychiatry (assessment, comorbidity), and pediatrics (somatic issues). Health care is covered by the national health care insurance.

In education, there is a primacy of inclusion, in case of average intellectual capacity. Children with ASC and intellectual disability are generally educated in specialized schools. Although inclusion of pupils with ASC at average intellectual capacity is a goal, schools are still struggling to develop inclusive classrooms. A study conducted at the Center of Neurodevelopmental Disorders at Karolinska Institutet (KIND) in 68 school and 4778 school employees of diverse professions showed that knowledge of ASC and inclusive practice is quite far from being established. The regular university education in pedagogy includes no courses on ASC or other neurodevelopmental conditions, and even special education teachers receive only little specific knowledge during their education. The same is true for many clinicians (physicians, psychologists, nurses), so that most education is mostly post curricular.

In adulthood, the employment rate of people with functional disabilities including ASC is 71.4% compared to 85.1% in the general population An important state-owned employer for people with functional impairments is Samhall. It operates nationwide under market conditions in competition with other companies. Samhall operates nationwide and has more than 23,000 employees. The Swedish Public Employment Agency (Arbetsförmedlingen) offers a range of support to facilitate opportunities on the labor market for autistic people, such as help in finding a job that is adapted to their circumstances, including to create jobs with an employer that are adapted, and financial compensation to employers if necessary. The agency also provides personal support, such as a personal representative, providing training courses. These aids are coordinated and conducted by a support person before and during a period of employment, known as an SIUS consultant.

Once diagnosed, people with ASC and their families formally have the right apply for various means of support via the National Health Insurance (Försäkringskassan), such as sickness compensation for long-term inability to work full time due to illness, injury or disability, and activity compensation for those who are young and will probably not be able to work full time for at least one year due to illness, injury or disability. Young people who have to extend their schooling due to a disability can receive activity compensation during the time that the schooling lasts. Other forms of support from this authority are attendance allowance, disability allowance, additional cost allowance for adults, car allowance, housing supplement, child carer’s allowance, attendance allowance, special dental care allowance, assistive devices, and assistive devices needed to be able to perform your work.

The most significant act concerning individuals with ASC and their families is the The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments [Lagen om stöd och service till vissa funktionshindrade] (LSS) is an entitlement law that guarantees good living conditions for people with extensive and permanent functional impairment, ensuring that they receive the help they need in daily life and that they can influence the support and services they receive. The realization of the act lies in the responsibility of the municipality and social services (Socialtjänsten). Eligible people can apply for:

(i) Advice and other personal support from experts who, in addition to their professional knowledge, also have special knowledge about what it is like to live with serious functional impairments. A social worker, psychologist, physical therapist, preschool adviser, speech therapist, occupational therapist, or dietitian can provide such support. Advice and support shall be a complement to and not a replacement for measures such as rehabilitation and social services.

(ii) Personal assistance for individuals with serious impairments in personal nutrition, hygiene, dressing and undressing, communicating with others, or need some other assistance that requires extensive knowledge of people with functional impairments. The municipality may provide assistance directly or the individual may obtain financial aid, in which case the individual acts as an employer and hires someone to provide assistance.

iii) Companion Service for individuals who do not have personal assistance may be entitled to companion service. Companion service shall be personalized, tailored to meet the needs of the individual to have an active social life.

iv) Contact Person in order to reduce social isolation, assist in participation in leisure activities, and provide advice in daily situations, individuals may sometimes need help from a contact person, who can make it easier for the individual to live independently. Sometimes a family, known as a support family, can provide support.

v) Relief service in the home as a regular service and for unexpected situations.

vi) Short stay away from home for recreation and a change of environment while providing relief for relatives.

vii) Short period of supervision for schoolchildren over the age of 12 before and after school and during holidays.

viii) Living arrangements in a family home or in a residence with special services for children and adolescents who cannot live with their parents may be entitled to live with another family or in a residence that provides special services.

iX) Residence with special services for adults or other specially adapted housing, most common being forms are group housing and service housing. The individual may also be entitled to a specially adapted home that is assigned by the municipality.

x) Daily activities for individuals who are not gainfully employed or studying are entitled to assistance participating in daily activities if they qualify.

In general awareness of ASC is high in Sweden through the media, activists, debate and interest organizations, above all the Autism and Asperger Society (autism.se) with 18,000 members and the Society Attention (attention.se) with 16,000 members, with many regional and local units. Another important organization is Organized Aspergers, a self-advocacy society (aspergare.org). These interest organizations also drive many projects to increase awareness, provide information material and conduct conferences to improve the lives of autistic people. They are the primary contact for policy makers.

Still, in reality ASC is still stigmatized, and not strictly perceived as a societal responsibility, and educational challenge, but a clinical service one. For instance, in Sweden people with a ASC diagnosis are excluded from military, police and fire fighter service. In clinical services, there is a focus on assessment, rather than intervention and prevention of psychiatric comorbidity. While the terminology in Sweden for ASC has a focus on “functioning” is generally not viewed a disease, the focus is on clinical diagnosis, not functional abilities and disabilities, and quality of life. Many people in many parts of society that meet people on the spectrum, and have a strong impact on their lives, have little to no autism-specific education or experience. Therefore, the AuTrain project is of paramount significance.

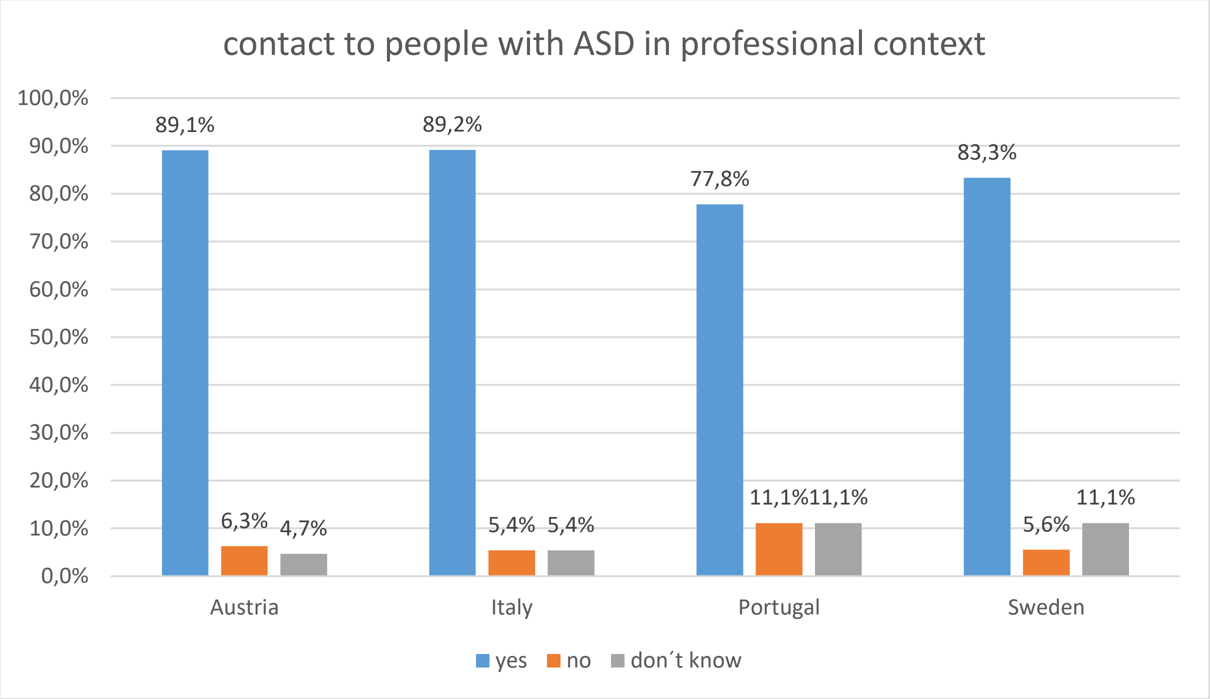
b. Needs analysis at national level

The survey’s results reported in this chapter are derived from the analysis of 166 questionnaires (Questionnaire I). EELI decided to ask the participants to fill in printed copies of the questionnaire. In the 4 other countries (Austria, Sweden, Portugal and Italy) the questionnaires were administered online.

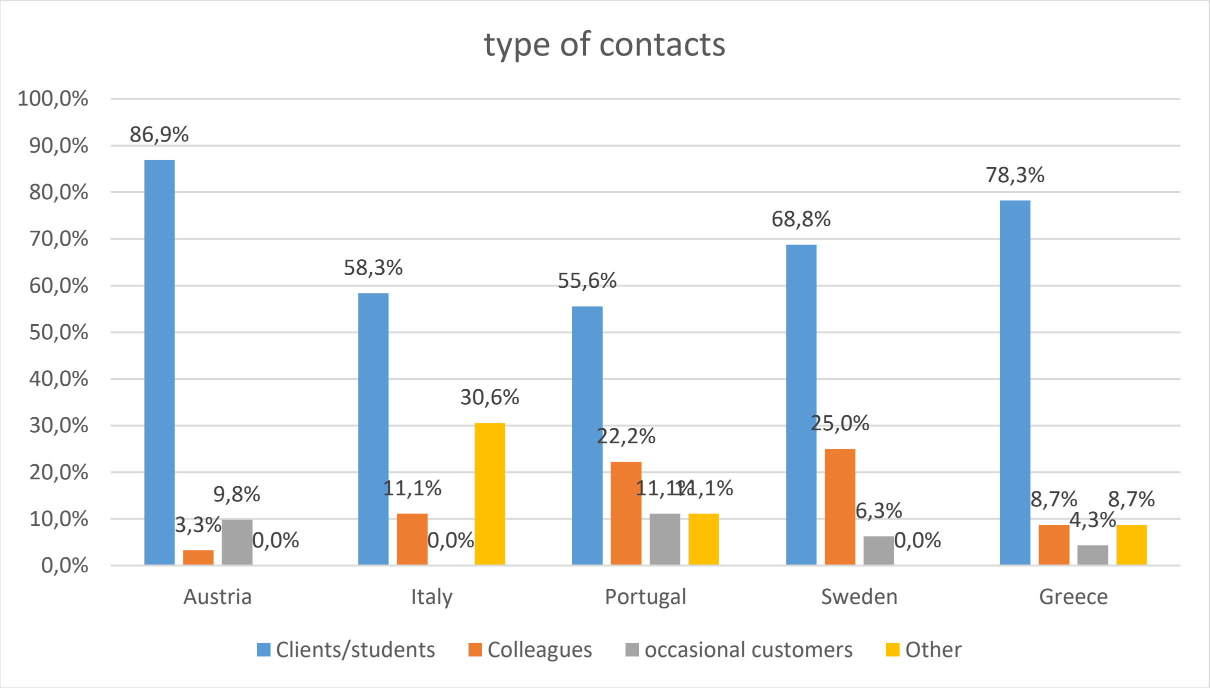
The data analysis is divided into paragraphs that match the information and the questions asked in the questionnaire.

Contact to people with ASD

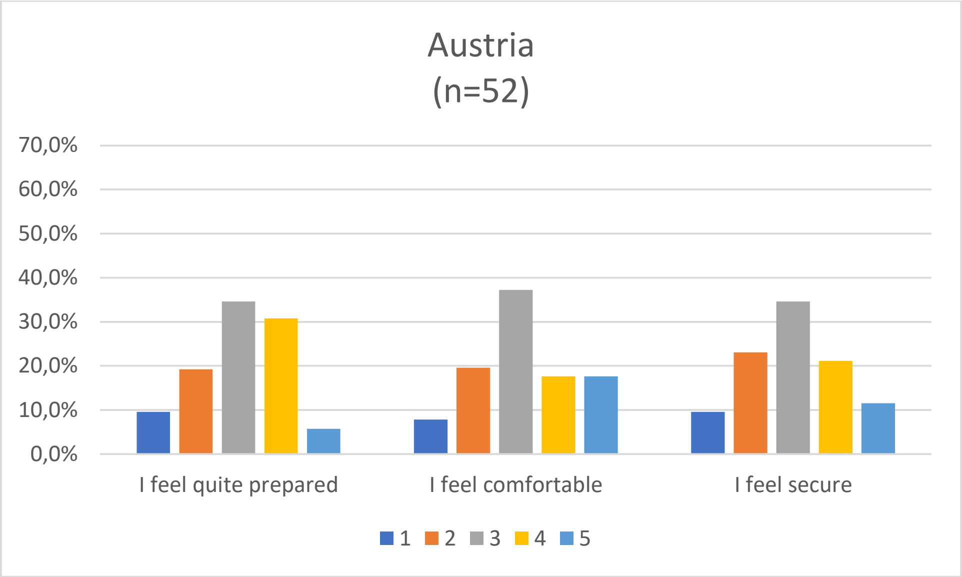
In all partner-countries more than 3/4 of the interviewees say they already have contact with people with ASD. The percentage is over 89% in Austria and Italy, over 83% in Sweden and 79% in Portugal. In addition, there is a percentage between 4.7% and over 11% of people who "don´t know" whether they have or had contact to people with ASD in their professional context.



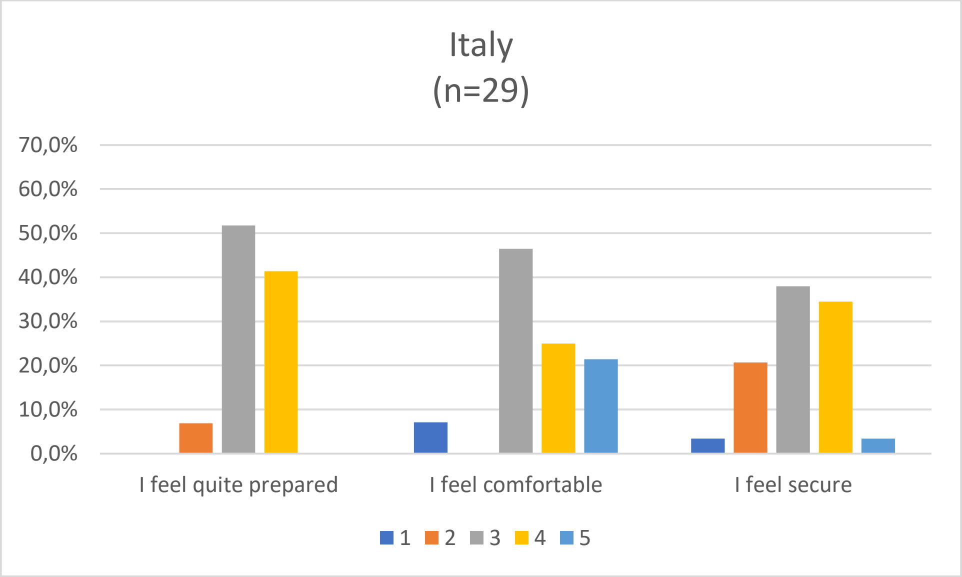
In all countries the contacts are primarily clients or students. In the category "others" mainly private contacts from the circle of family and friends were mentioned.



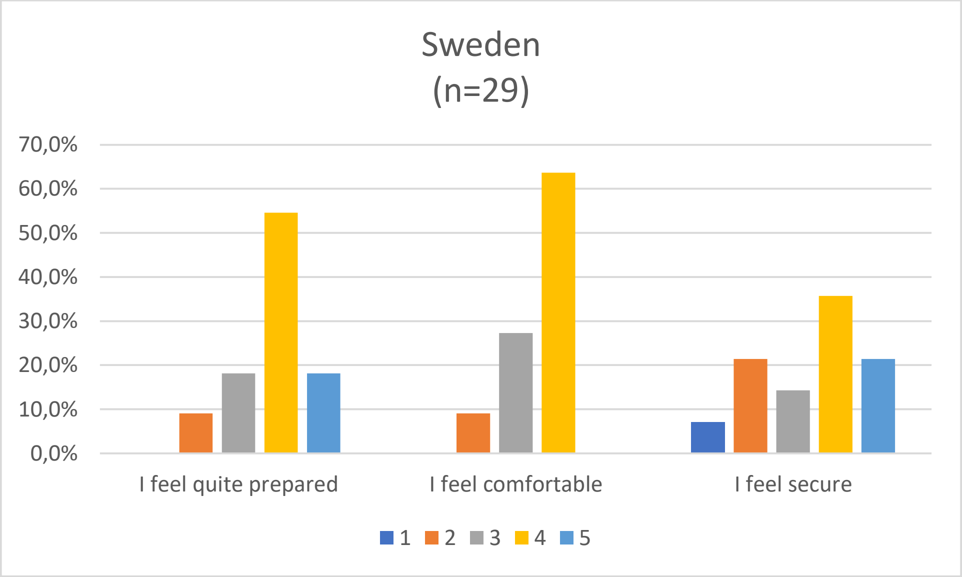
In the following items the interviewees should indicate on a scale of 1 (not at all) to 5 (definitely), how prepared, comfortable and secure they feel in situations where they get in contact with people with ASD.



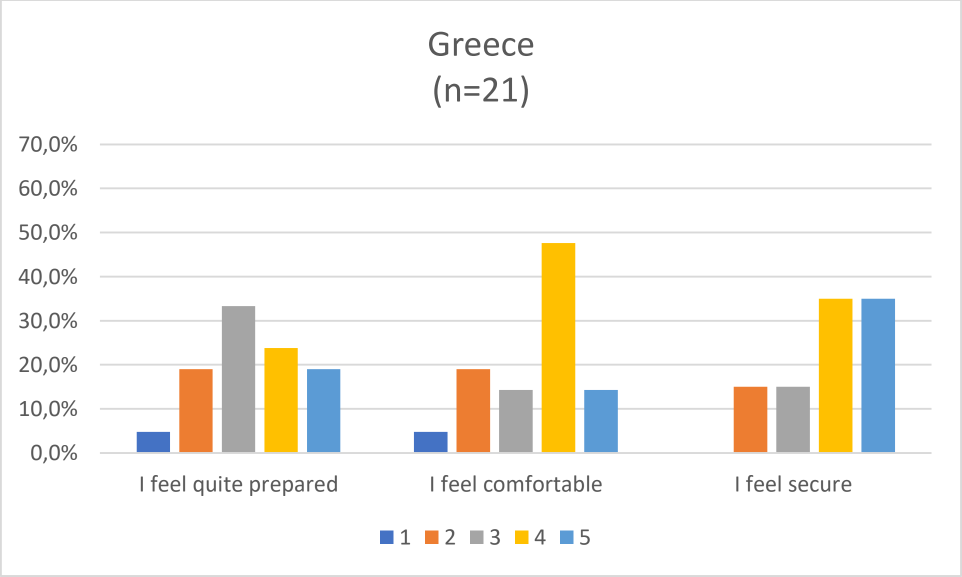
In Austria most of the interviewees show the tendence to the middle of the scale. The distribution for “prepared”, “comfortable” and “secure” are quite similar.



In Italy, the responses also show a tendency towards the middle. Most of the Italian interviewees feel prepared and comfortable in situations where they have contact with people with ASD.



In the Swedish sample, interviewees showed a quite high level of support for the statements "I feel quite prepared" and "I feel comfortable", but a lower approval of the statement "I feel secure".



Most of the Greek respondents feel quite comfortable, fairly prepared and very secure.

In Portugal only 4 persons answered the questions in this section, so the data was not analyzed at the national level but is included in the European analysis.

In addition, people were asked if there are other sentiments about the contact with people with ASD with free space for answers.

In Austria most of the comments particularly involve difficulties in getting in touch and accessing those affected. Some report that they feel clueless.

In Italy, the comments report many positive aspects, such as joy and passion in dealing with those affected. But also fear of aggressive behavior and the desire for more knowledge about ASD is called here.

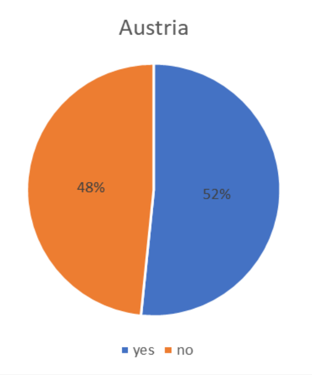
The Swedish comments especially the interesting about contact with people who are "different" is mentioned.

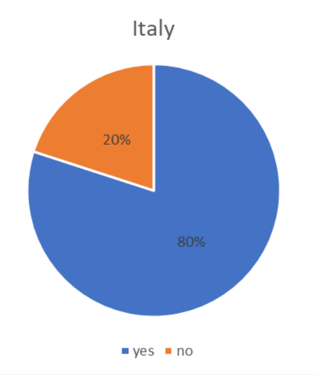
Prior knowledge and support

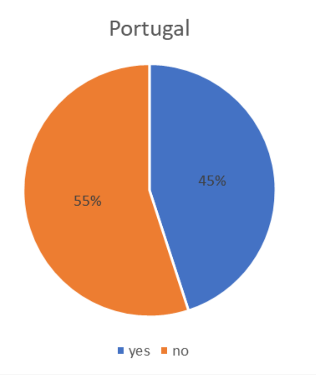
This section asked about prior knowledge, the possibilities of support if needed as well as need for further support.

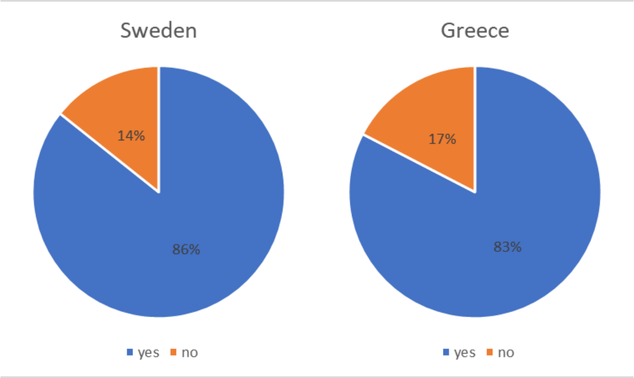
The first question here was “do you have any prior knowledge on ASD?”.

In Austria 48% of respondents said they had no prior knowledge on ASD. In Italy only 20% have no prior knowledge, in Portugal 55%. In Sweden the percentage was 14% without prior knowledge and in Greece 17%.









In Austria people got this prior knowledge especially from self-teaching/personal experience (17 times) and as part of vocational training (17 times). 10 participants got knowledge in courses and 5 participants indicated other sources (reading, conversations with experts, job). The sample size in this question was 32 in Austria, the answer format was multiple choice.

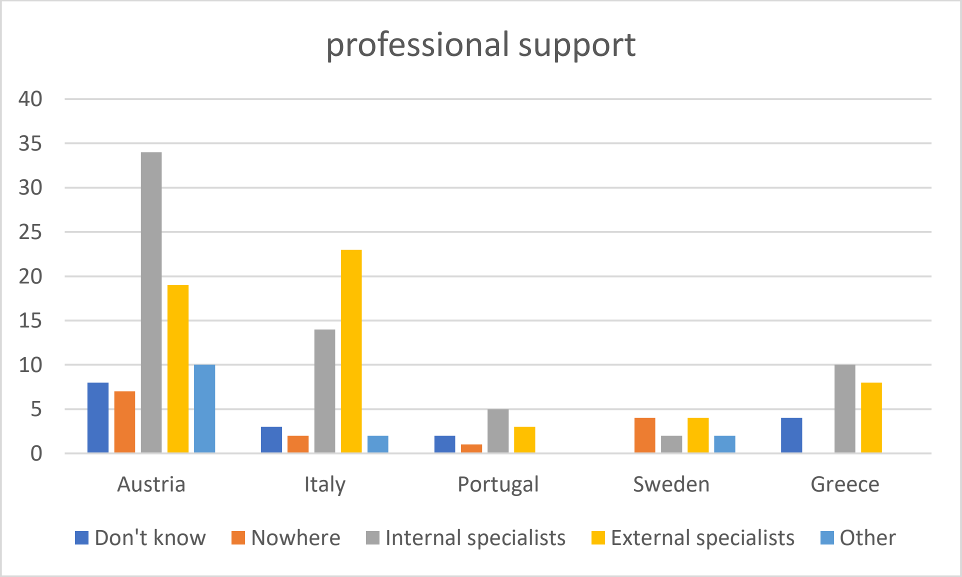
In Italy (n=24), courses were most often mentioned as source of prior knowledge (17 times), followed by vocational training (14) and self-taught/personal experience (9). Other sources were mentioned 1 time.

Portuguese participants (n=9) mentioned most often self-taught/personal experience as source (6), followed by courses (2), other (2; through other people and readings) and part of vocational training (1).

Also, in Sweden (n=12) most interviewees got their knowledge self-taught/from personal experience (7), 5 times courses were mentioned and the answer “as part of vocational training” has also been selected by 1 person.

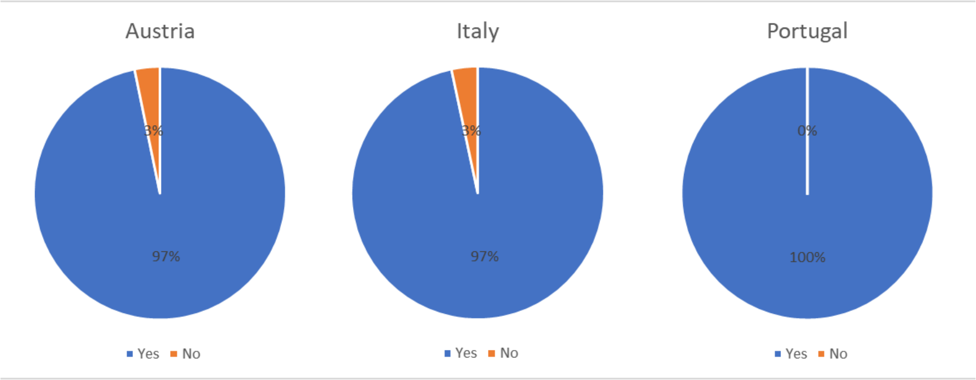
In Greece (n=19) more than half of the participants asked had prior knowledge acquired as part of their professional training (11).

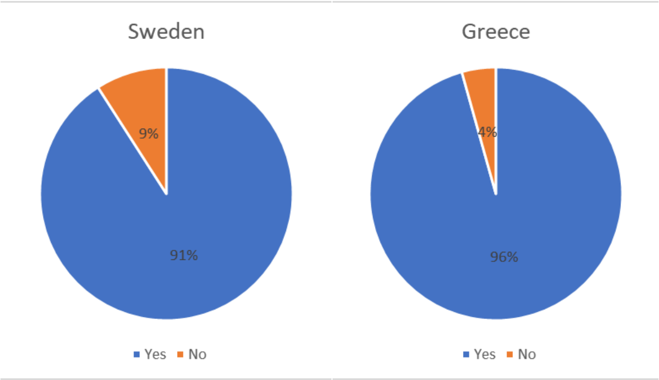
In the next question the participants were asked was where they can find professional support for ASD matters. Five options were given to answer, and more than one answer was allowed in this question.



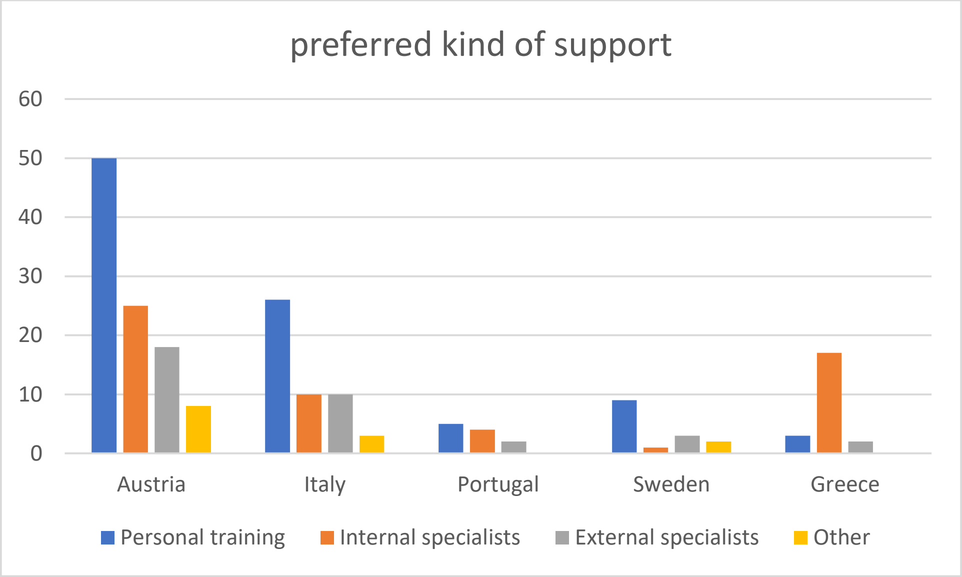
In Austria participants can get professional support most common from internal specialists, followed by external specialists. In Italy external specialists were more often mentioned as option than internal specialists. The Greek respondents also most often mentioned internal specialists as possibility to get professional support on ASD matters if needed. In Portugal and Sweden only few participants answered this question (<10).

The next question in Questionnaire I was “Do you think there should be more support in ASD matters? If yes, what kind of support would you prefer?”. In the second part four options were available for selection: Personal Training, Internal Specialists, External Specialists, Other.





In all countries more than 90% of the interviewees think that there should be more support in ASD matters.



In Austria, Italy, Portugal and Sweden the preferred kind of support is personal training. In Greece support by internal specialists is favored by the participants.

Finally, it was asked “in which ASD-related issues do you see the greatest needs for more information?” as an open question and at the end participants had the possibility to write further comments.

The Austrian participants cited as an area in which they would need more information, especially assistance in dealing with autistic people, in communication, but also in the recognition of autism. In several comments, the project idea was welcomed, the participants hope for training and collected information on the topic, which they can access independently if necessary.

In Italy, participants think networking with specialists and generally more knowledge about ASD would be helpful, as well as information about therapy options and help in dealing with problem behavior. An idea was also training for families.

The Portuguese participants expressed a desire for greater understanding in society and a need for information on how to deal with emotions. Awareness-raising in society was also mentioned as a wish.

Participants from Sweden want practical examples and concrete solutions. The comments mention the general need for information on ASD, especially among school leaders, employers and health services. More focus should be placed on strengths and ASD in the adult sector.

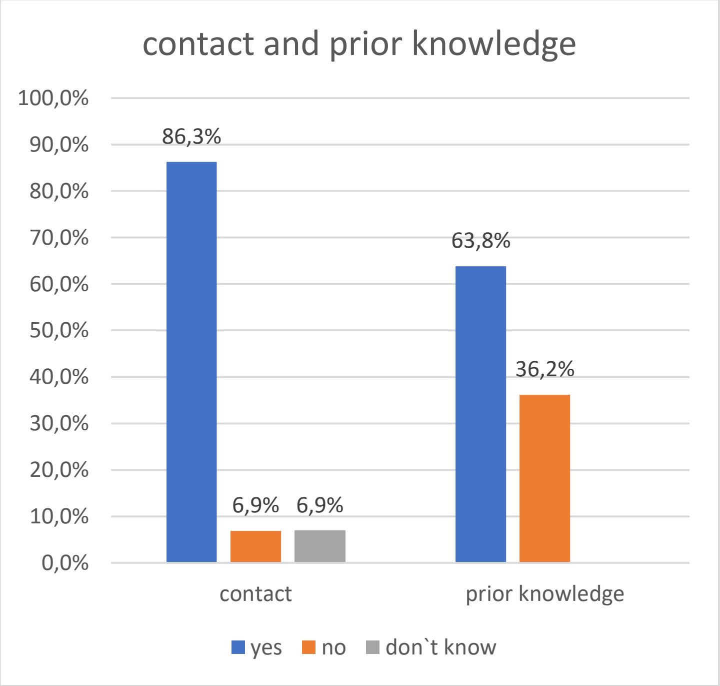
c. Current situation and needs analysis on European level

This section reports the results of the overall evaluations of the questionnaires, starting with Questionnaire I, followed by the results of the survey of persons affected by ASD in Questionnaire II.

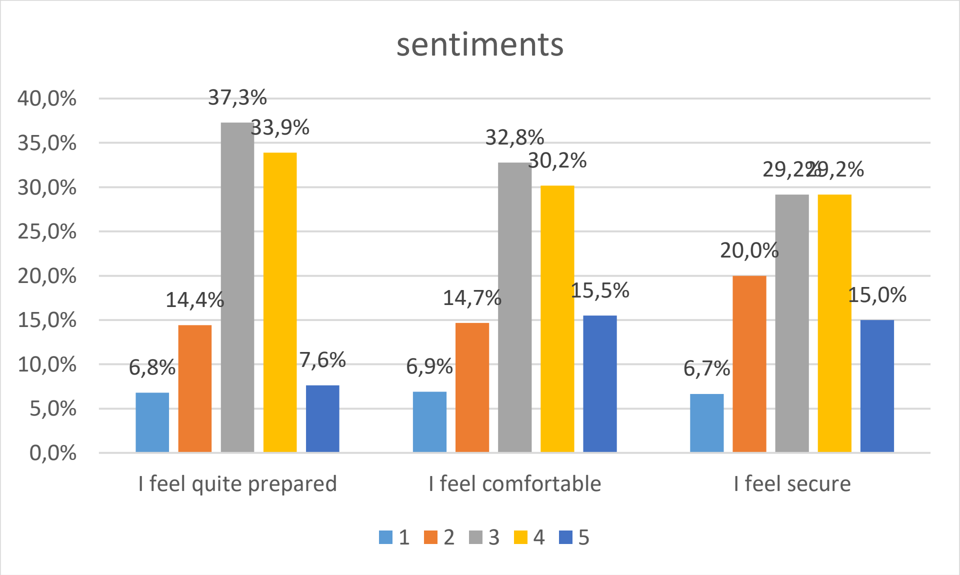
Questionnaire I- professionals:

The respondents, who were mainly (84%) part of the target group (professionals in administration, health-care and education), 86% said that they have been in contact with people with ASD. The contacts are mainly (74%) students and clients.

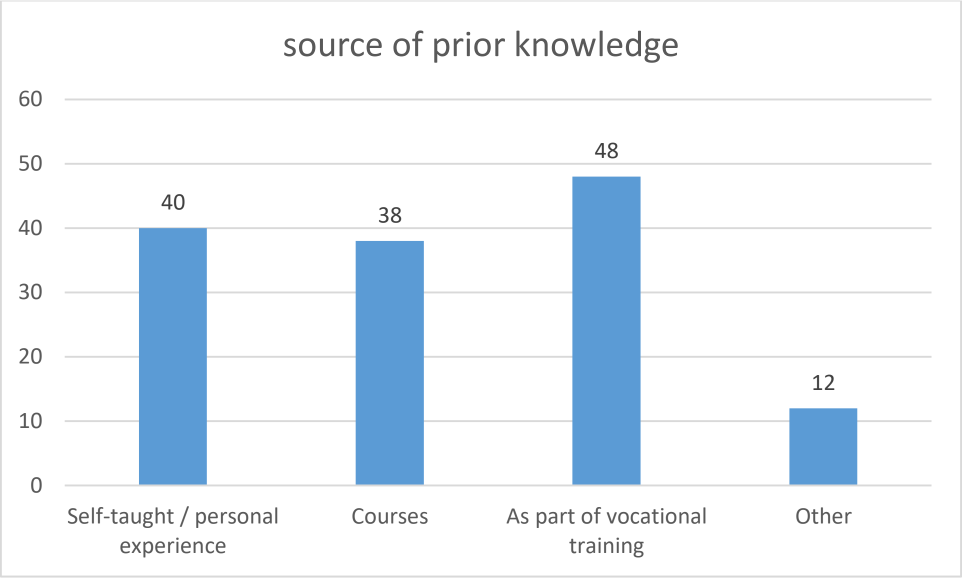
Although around 86% of respondents have contact with people with ASD in their professional context, only around 64% say they have prior knowledge on the topic.



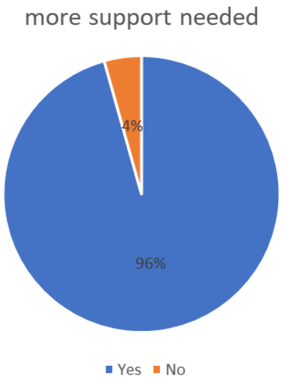
Asked about their sentiments about situations where the interviewees get in contact with people affected by ASD (1= not at all to 5=definitely), only 7.6% indicate that they feel definitely prepared. As a result, even only 15.5% feel definitely comfortable or safe.

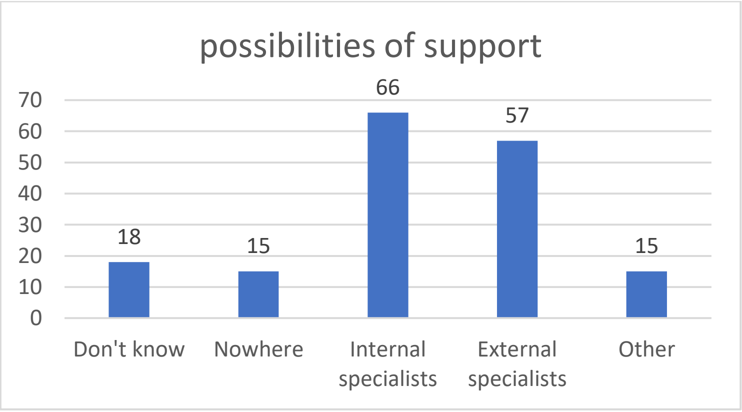


Of those who already have prior knowledge on ASD (a total of 97 times this question was answered with “yes”), 40 said they got this by vocational training. Thirty-eight of the respondents with prior knowledge attended courses, 40 times self-taught/personal experience was mentioned as source of knowledge. In addition, reading, conversations with experts, job and other people were named as sources.

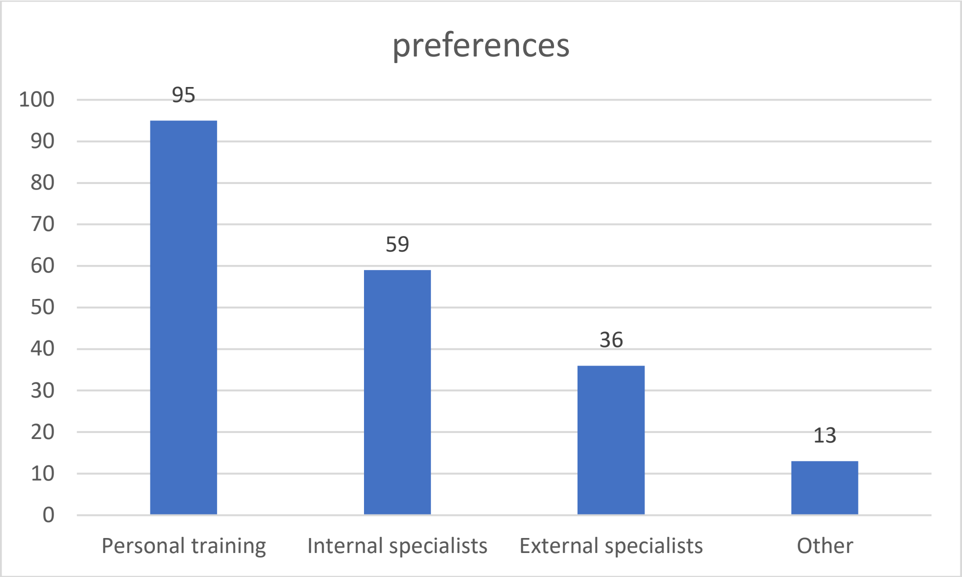


96% of the participants think that there should be more support in ASD matters. If needed, they actually can get support by internal specialists (66) or external specialists (57). 33 interviewees have no options for support (18 don´t know where to get it and 15 report that they nowhere get support).





95 of the 132 people who said they needed more support, would prefer personal training. 59 would like to have internal specialists and 36 would like to have external specialists available.

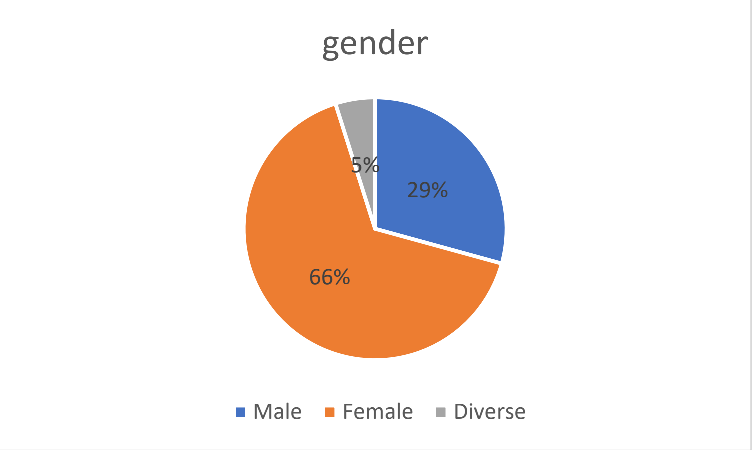


The greatest need seems to lie in dealing with difficult behavior, but also ways of communication, practical examples and concrete solution strategies. Overall, participants welcome a raise of acceptance and understanding in society for people with ASD and their specifics and needs.

Questionnaire II- “insiders”:

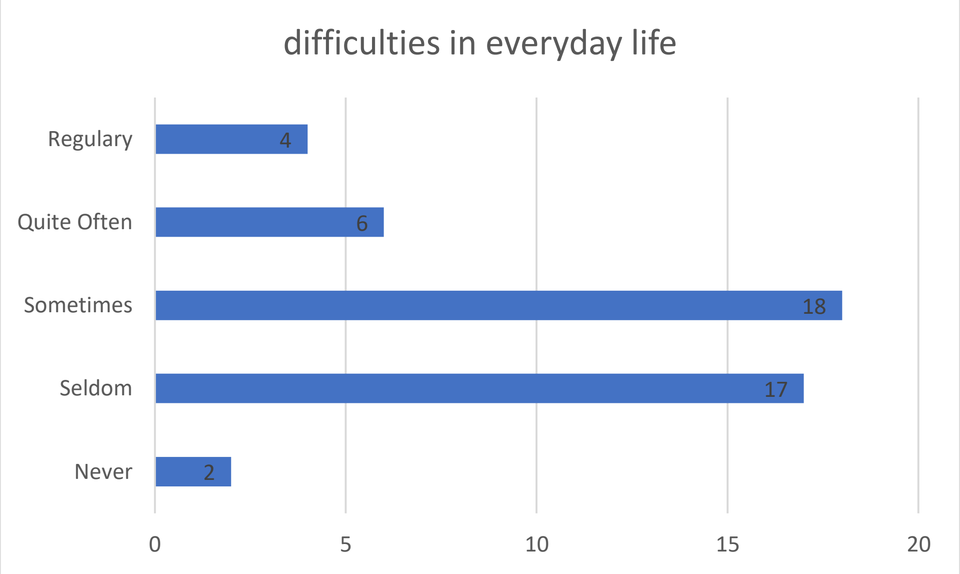
Questionnaire II is addressed to persons affected by ASD. It is intended to provide an insight into the current life situation of people with ASD, as well as to record their attitudes and needs.

The questionnaire was completed online by 81 people from Austria, Italy, Portugal, Sweden and Greece. 66% of the participants are female, 29% male and 5% diverse. The age of the participants ranges from lowest (18-28) to highest (59-68) category in the questionnaire.

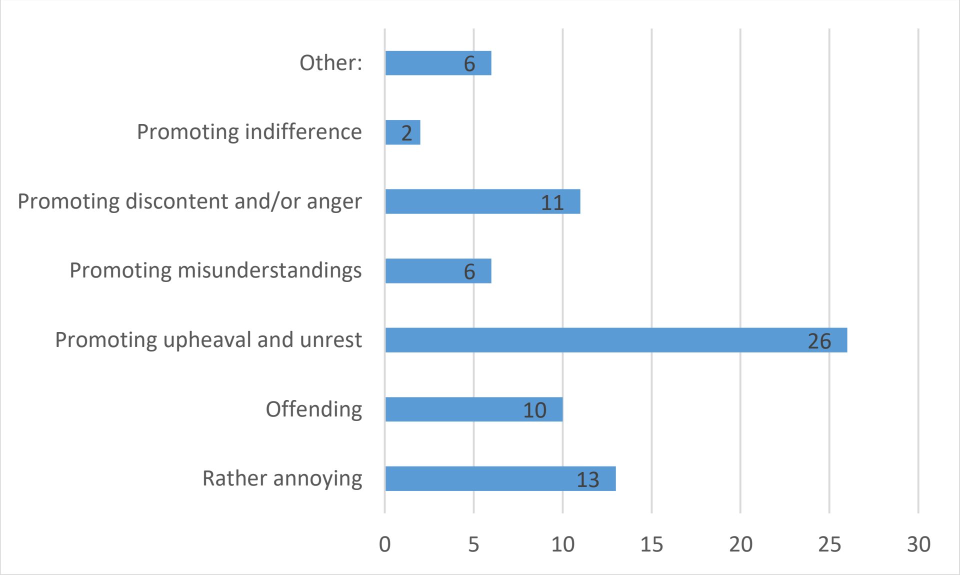


People with ASD were asked what they enjoy and appreciate within their day-to-day environment. A pretty long list came out here: home, school, library, nature, garden and the workplace were mentioned as places, the school day, break and morning coffee, walks, cooking and music as routines that are enjoyed. People like the activities computer, music, handcrafts, sports and reading and enjoy contact with family members, colleagues, partners and friends. Pets were also mentioned in this item.

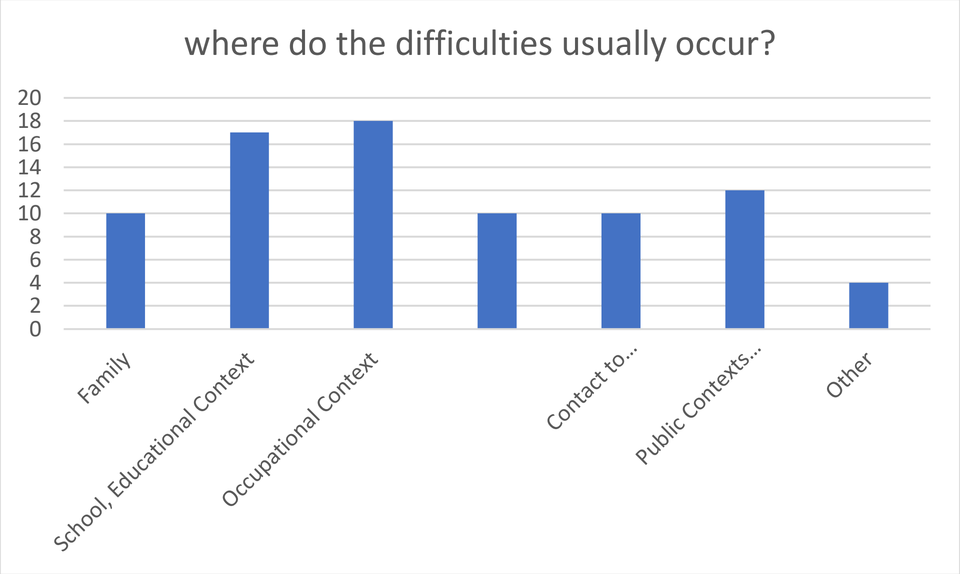
Asked about “autism-related” difficulties in their everyday life, 10 out of the 47 people who answered this question, say they are quite often or even regularly faced with difficulties. 18 mentioned they have sometimes difficulties and 17 seldom. Only 2 participants don´t experience difficulties in their everyday life.



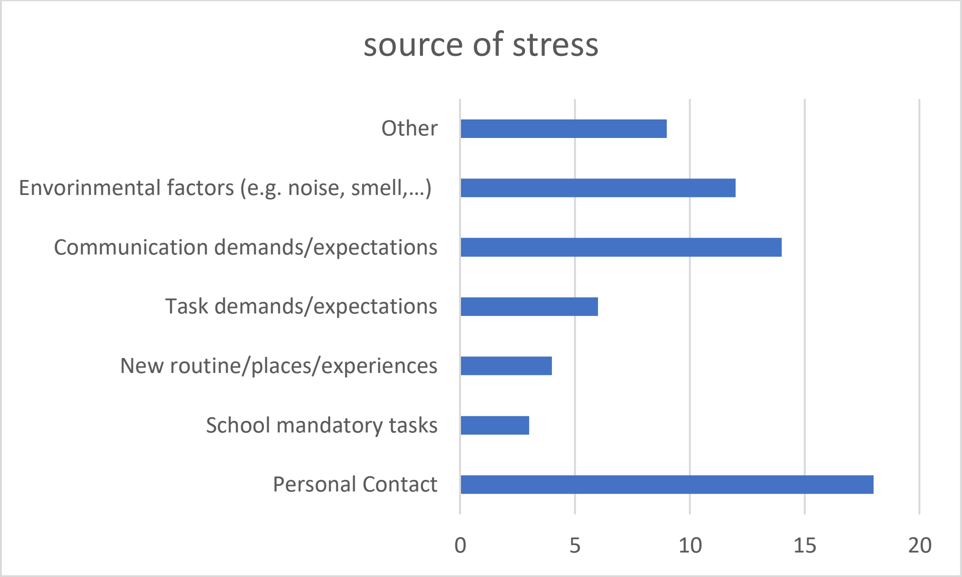
According to the results, most issues cause upheaval and unrest; 13 find them rather annoying. For 11 they cause discontent and/or anger and 10 find them offending.



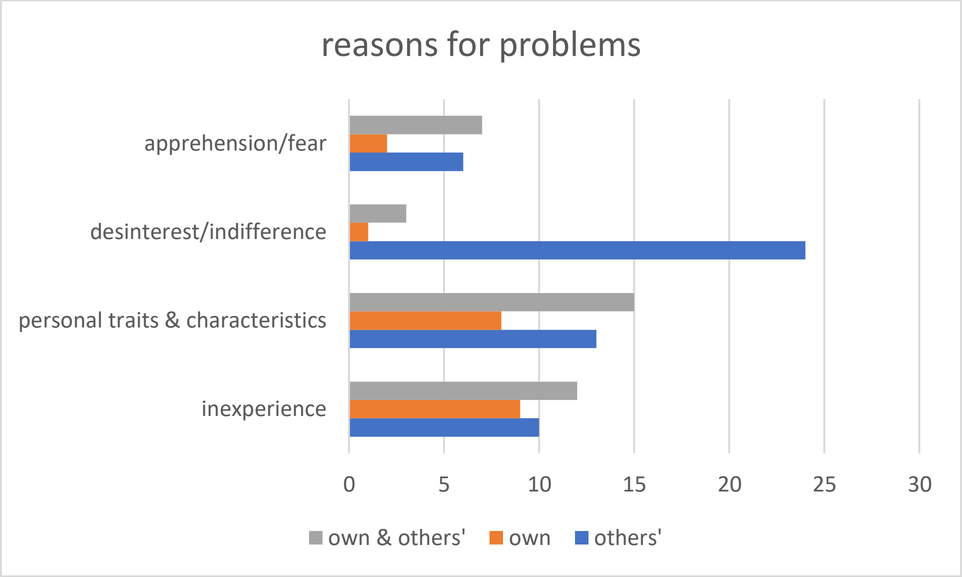
The participants indicate that the difficulties occur especially in school/educational context and the occupational context. But also family, public contexts, contact to administrations/authorities, public contexts (like restaurants, public transport, stations, airports, coffee-Shops, shopping centers etc.) and health services (like visits to the doctor, hospital, therapeutical settings etc.) can apparently lead to difficulties.



Most of all the personal contact (18 mentions) and communication demands/expectations are mentioned (14 times) here as sources of stress. But also environmental factors like noise or smell can cause stress for people affected by ASD (12 mentions). School mandatory tasks, new routines/places/experiences and task demands/expectations seem to be a minor problem.

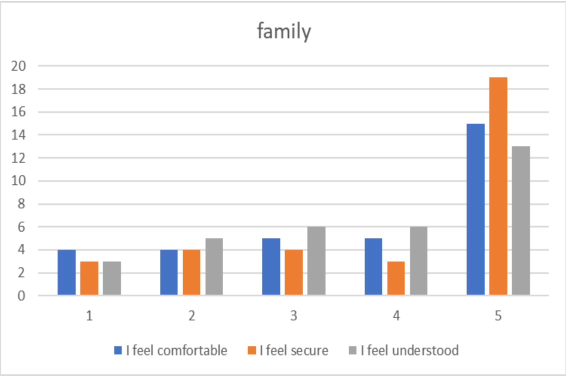


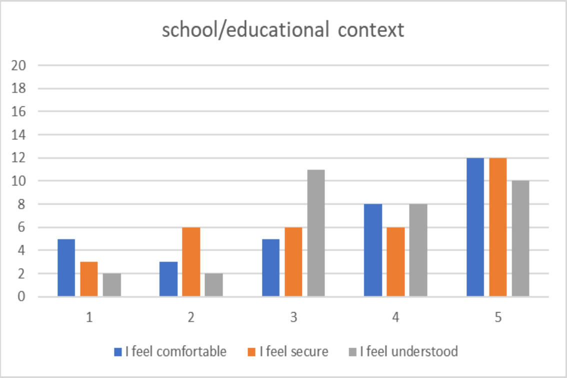
Most people think that the reasons of the above issues are mainly the disinterest/indifference of others. But also, personal traits and characteristics and inexperience of both theirs and others. Only a few participants think that apprehension/fear is the reason for the difficulties.

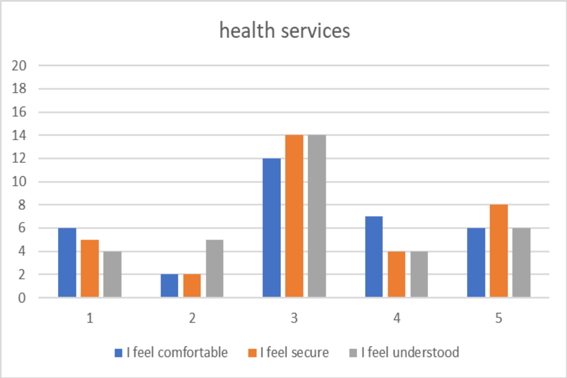


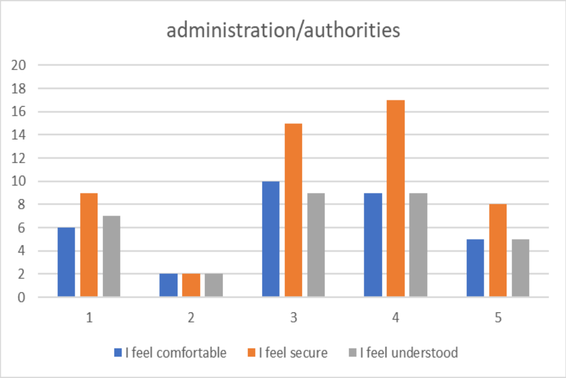
Participants were asked what their sentiments are about certain settings: family, school/educational context, health services (doctor, therapist/hospital) administration/authorities and public situations (bus, crowded places etc.).

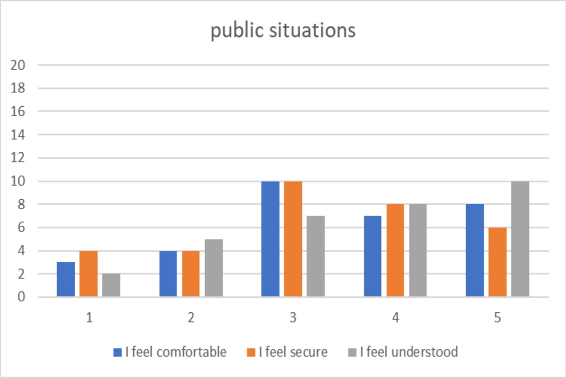
According to the results, people feel the most comfortable, secure and understood within their family context, followed by school/educational context. At interacting with authorities/administration people feel quite secure. Most of all public situations were rated very differently by the participants, so that no real trend can be discerned.





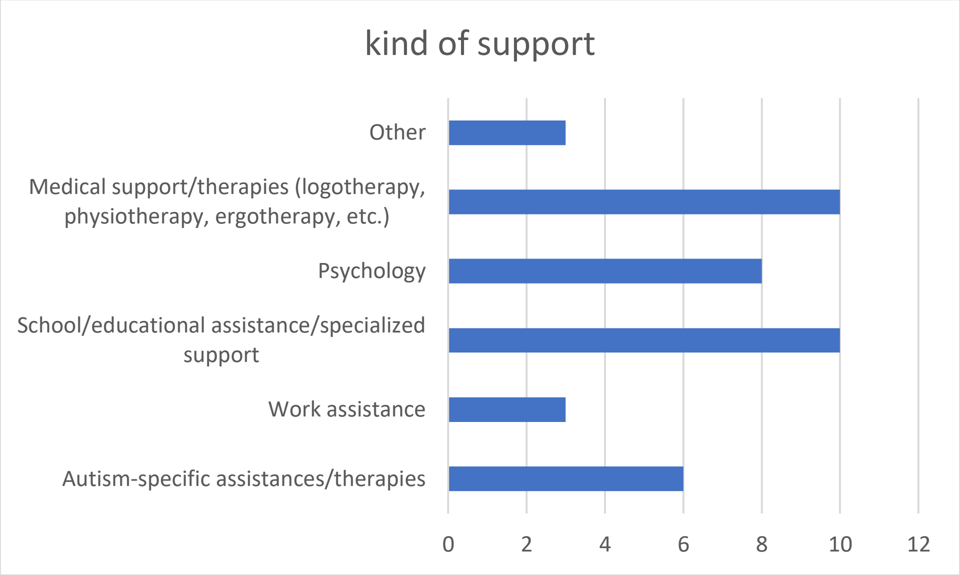




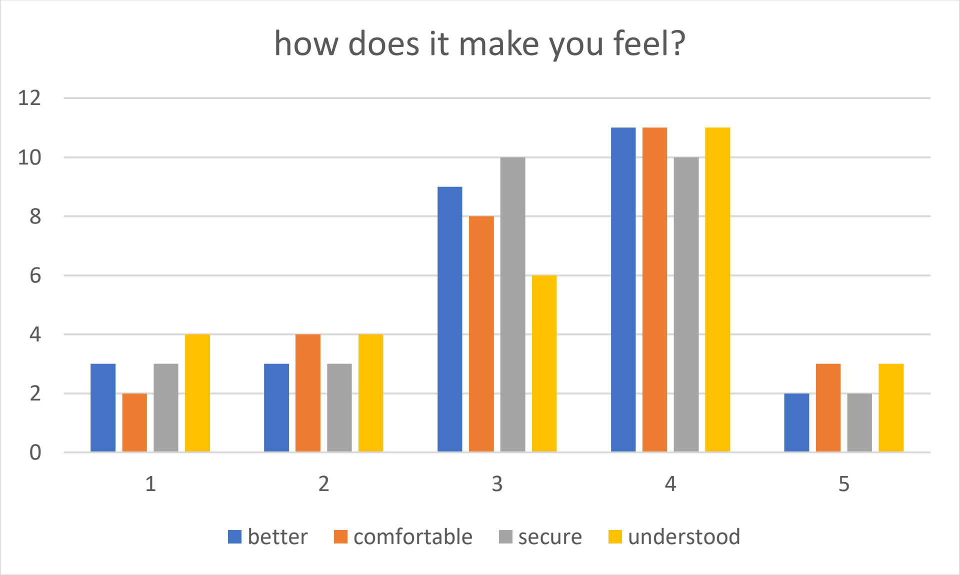


Another part of the questionnaire covers professional care and support resources in the field of ASD. 60% of the people asked, make use of professional help, 40% do not.

Most participants receive medical support/therapies and assistance services in school, followed by psychology. Autism-specific assistances/therapies are used by 6 participants and 3 receive support in form of work assistance.

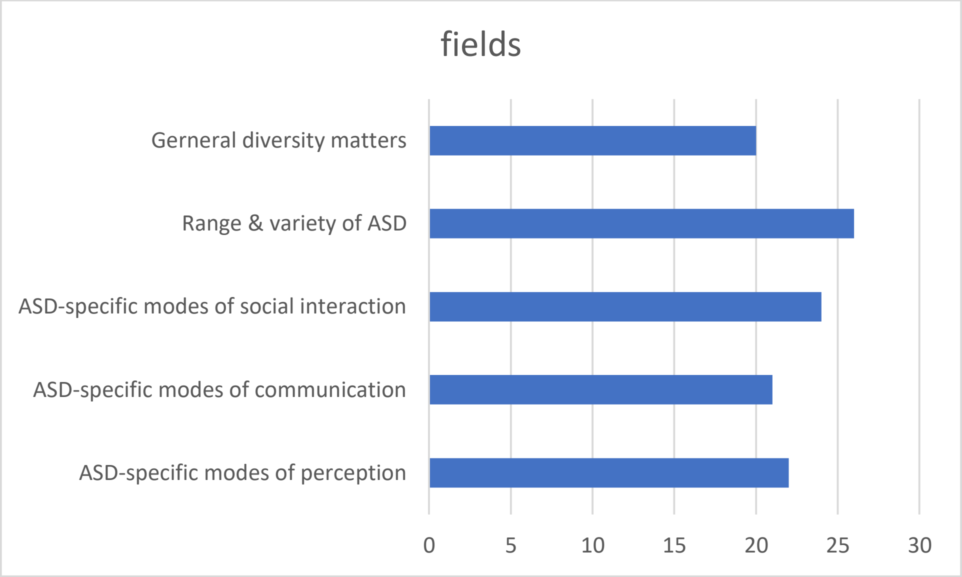


Overall, the participants rate the therapies used quite positively. Most feel better and quite comfortable, safe and understood.



At the same time, however, many (21) also think that the offer is available only insufficiently and the waiting periods are too long (14).

Asked if caretakers should have more knowledge about ASD, 90% of the respondents answered with yes, only 10% think that caretakers have enough knowledge about ASD. Respondents think that there is a need for more information and knowledge in all mentioned areas.



(4) SUMMARY & OUTLOOK

Having considered our joint pre-project experiences and expertise, having gathered insiders' as well as professional views on needs and expectations and having evaluated existing projects and platforms dealing with the same and/or similar issues and tasks (see Annex III), we can now try to look upon our project and its aims in a broader context.

What we were already able to say at an early stage of our inquiry was that our "impressions" about the subject matter were not out of thin air or all too fallacious. On the contrary: What was emerging out of the data-collection carried out in all of the partner countries was that those needs were quite the same in all places – despite and beyond national differences in the "culture" to deal with ASD-issues and the practical-administrative handling of the corresponding challenges (apart from the fact – another finding – that these differences are not as far-reaching as one might expect). In a general sense we were confirmed in our view that the outcome we are aiming at with the AuTrain project is (1) *really strongly demanded*, by professionals as well as by people on the spectrum themselves (throughout Europe as we would dare to think even if our own data basis is not reliable enough to firmly state that), that (2) the relevant *needs and expectations* are very *similarly accentuated* (within the two groups of pollees) and (3) nearly *consistently consensual* in the need and hope for both *easily accessible, intelligible and practicable* hints and tools to cope with “normal” day-to-day as well as with challenging situations.

On the side of the respondents with ASD this unanimity does really have the force to make one feel uncomfortable and guilty for not having reacted more appropriate so far – indirectly a real bad report for those in care and power. There are for instance more than 90% of the affected who think that caretakers of all kinds should know a lot more about them – about autism in general and themselves in particular, about all the fields and areas that are up to debate (modes of communication, of social interaction, of ASD-perception etc.) and about the factual individual manifestations of range and type etc., and of their special resp. individual character of course. And they do inform us that only a small fraction of them (and again we dare to think that some careful attempts to generalization could be made here) do *not* get into trouble and discomfort in their everyday lives (even if they do not dramatize their personal circumstances either). Most of them do, most of them regularly – and in just about all of the social settings and with all of the people they are confronted with, relatives and “confidants” included. And they do additionally tell us that it is predominantly the field of communication – the expectations placed on them and the insistence of others – that stresses them the most.

The professionals for their part – not surprisingly – show some more variety, but only concerning “secondary” topics like the question about whom they would prefer as their advice-giving authority (or whom they would prefer the most – results: more that 90% would like to be able to rely on themselves after having been instructed properly, nearly 60% do also opt for internal, more than 30% for external specialists they could ask when there is a need to know). In the “primary” issues they do also agree to a great extent. There is an astonishingly high number of 96% of respondents – more than 80% of them in more or less constant contact with autistic people (clients, students etc.) though – who give expression to the view that there should be more support for the social intercourse with people on the autism spectrum. And – the second decisive finding for our purposes (apart from the ever-pervasive urge to be supplied with “realistic” and pragmatic tools and skills) – a great majority of them would not only be ready to attend a course to acquire the relevant information and techniques, but would also like to do so; many of them voluntarily, some of them even at their own expense. And although there were around 64% of people who considered themselves as fairly informed and educated in the field – though we did not specify on the details here – they do apparently feel that there could and should be more: more information, more strategies, concrete options for intervention, case studies etc.

Given these insights and “confessions” on the one hand and the needs, worries and afflictions of many people on the autism spectrum on the other hand, the incentives to get started are not only strong but demanding. And even if all of those sentiments imply at least some sort of pressure (not to fail) too, the consortium of AuTrain will be trying to meet them.

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(5) ANNEX

a. Annex I: Original English version of the questionnaire for professionals

AuTrain Questionnaire I

AuTrain is a project that started in autumn 2019. It is funded by the Erasmus+ Program of the European Union and will run for two full years.

Carried out by six partner organizations (universities from Sweden, Portugal and Austria and social facilities from Italy, Greece and Austria), its central goal is to develop a curriculum for "autism agents", who will subsequently be able to ensure an Autism friendly environment as well as skills and patterns to interact and communicate with people on the Autism spectrum in appropriate and well-versed ways - within their own professional contexts (companies, departments and institutions) and beyond.

To be able to adjust the content of the training program to the substantial needs of its users and beneficiaries, we would need your help. Therefore we would kindly ask you to participate in the survey listed below. It is very short and your answers will of course be kept anonymous.

If you have questions, please send us an email to: vinco@aon.at

We are looking forward to your feedback!

Thank you in advance.

There are 17 questions in this survey.

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CONTACT ON ASD

Have you ever been in contact with people with ASD in your professional context? (Choose one of the following answers)

Yes
No
I don’t know

In what kind of setting did you get in contact? (Check all that apply)

clients
colleagues
occasional customers
other

How often do you get in contact? (Comment only when you choose an answer)

Regularly (frequency)
Unregularly (number of contacts/frequency)

What are your sentiments about these situations? (Choose on a scale of 1 (not at all) to 5 (definitely)

I feel quite prepared
I feel comfortable
I feel secure

Are there other sentiments about the contact to people with ASD?

…

SUPPORT AND KNOWLEDGE ON ASD

Do you have any prior knowledge on ASD?

Yes
No

How did you get this knowledge? (Check all that apply)

Self-taught/personal experiences
courses
as part of vocational training
other …

If needed – where can you get professional support on ASD matters? (Check all that apply)

Don’t know

Nowhere

Internal Specialists

External Specialists

Other …

Do you think there should be more support in ASD matters?

Yes

No

What kind of support would you prefer? (Check all that supply)

Personal training

Internal specialists

External specialists

Other …

ASD-RELATED ISSUES AND FURTHER COMMENTS

In which ASD-related issues do you see the greatest needs for more information?

…

Any further comments?

…

PERSONAL BACKGROUND

Gender (Choose one of the following answers)

Male

Female

Diverse

Age

…

Country/Region

…

Institution (business/field): (Choose one of the following answers)

Education
Office/Administration
Financial Services
Health/Social Services
Law
Tourism
Industry
Science/Research
Other …

Number of people working with you: (Choose one of the following answers)

<10
10-49
50-99
100-249
>250

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b. Annex II: Original English version of the questionnaire for people on the autism spectrum

AuTrain Questionnaire II

AuTrain is a project that started in autumn 2019. It is funded by the Erasmus+ Program of the European Union and will run for two full years.

Carried out by six partner organizations (universities from Sweden, Portugal and Austria and social facilities from Italy, Greece and Austria), its central goal is to develop a curriculum for "autism agents", who will subsequently be able to ensure an Autism friendly environment as well as skills and patterns to interact and communicate with people on the Autism spectrum in appropriate and well-versed ways - within their own professional contexts (companies, departments and institutions) and beyond.

To be able to adjust the content of the training program to the substantial needs of its users and beneficiaries, we would need your help. Therefore we would kindly ask you to participate in the survey listed below. It is very short and your answers will of course be kept anonymous.

If you have questions, please send us an email to: vinco@aon.at

We are looking forward to your feedback!

Thank you in advance.

There are 23 questions in this survey.

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EVERYDAY WORLD

What do you enjoy and appreciate within your day-to-day environment? (Comment only when you choose an answer)

certain places (which ones?) …
certain routines (which ones?) …
certain activities (which ones?) …
certain persons (whom in specific?) …
other …

And on the other hand: Do you also encounter “Autism-related” difficulties in your everyday life? (Choose one of the following answers)

Never
Seldom
Sometimes
Quite often
Regularly
Very often

What are they usually like? (Check all that apply)

Rather annoying
Offending
Promoting upheaval and unrest
Promoting misunderstandings
Promoting discontent and/or anger
Promoting indifference
Other …

Where do these difficulties usually occur? (Check all that apply)

Family
School, Educational Context
Occupational Context
Health Services (Visit to the Doctor, Hospital, Therapeutical Settings etc.)
Contact to Administration/Authorities
Public Contexts (Restaurants, Public Transport, Stations, Airports, Shopping Centers etc.)
Other …

What exactly is it that stresses you the most? (Check all that apply)

Personal contact
School mandatory tasks
New routines/places/experiences
Task demands/expectations
Communication demands/expectations

Environmental factors (e.g. noise, smell etc.)

Other …

What do you thing are the reasons for these inconsistencies and/or problems?

	others’	own	own & others	no problem
Inexperience				
Personal traits & characteristics				
Disinterest/indifference				
Apprehension/Fear				

Are there other reasons for these inconsistencies and/or problems?

…

What are your sentiments about your family? (Choose numbers from 1 (not at all) to 5 (definitely))

I feel comfortable

I feel secure

I feel understood

What are your sentiments about your school/educational context? (Choose numbers from 1 (not at all) to 5 (definitely))

I feel comfortable

I feel secure

I feel understood

What are your sentiments about (your) doctors and/or therapists, about hospitals? (Choose numbers from 1 (not at all) to 5 (definitely))

I feel comfortable
I feel secure
I feel understood

What are your sentiments about administration/authorities? (Choose numbers from 1 (not at all) to 5 (definitely))

I feel comfortable
I feel secure
I feel understood

What are your sentiments about public situations (bus, crowded places etc.)? (Choose numbers from 1 (not at all) to 5 (definitely))

I feel comfortable
I feel secure
I feel understood

Do you make use of professional care resources?

Yes
No

What kind of support do you employ? (Check all that apply)

Autism-specific assistances/therapies
Work assistance
School/educational assistance/specialized support
Psychological support
Medical support/therapies (logotherapy, physiotherapy, ergotherapy etc.)
Other

How do you get along with this support? How does it make you feel? (Choose on a scale of 1 (not at all) to 5 (definitely)

Better
Comfortable

Secure

Understood

What do you think about the supply of professional support? (Check all that apply)

Sufficiently available

Insufficiently available

Too far away

Too long waiting periods

Other …

And what do you think about its general quality? (Choose one of the following answers)

Excellent

Good

Sufficient

Insufficient

Bad

Do you think caretakers should have more knowledge about ASD?

Yes

No

What is it that they should know better? Which ones are the fields where more information would be needed? (Check all that apply)

ASD-specific modes of perception

ASD-specific modes of communication

ASD-specific modes of social interaction

Range & variety of ASD

General diversity matters

Other …

Do you have any further comments?

…

PERSONAL BACKGROUND

Gender (Choose one of the following answers)

Male
Female

Diverse

Country/Region

…

Age

…