



TRAIL PROJECT
Survey Two, Three and Four Findings
Final Report

Trail Project Survey 2 Report

Introduction

This survey is part of a cross-country European project to improve support for teenagers on the autism spectrum; TRAIL - Teenagers: the Road with Autism to Independent Living. It has been designed to understand how support is currently provided for teenagers and young people with autism by local, regional and national organisations across partner countries (Greece, France, Sweden, Spain and the UK).

The survey was designed by partners, and distributed from December 2016 – March 2017. It was translated with minor modifications for France, Spain and Sweden, to increase the response rate and best reflect national structures.

Total number of respondents from partner countries: 310	
France	74
Greece	84
Spain	62
Sweden	21
UK	90

Limitations

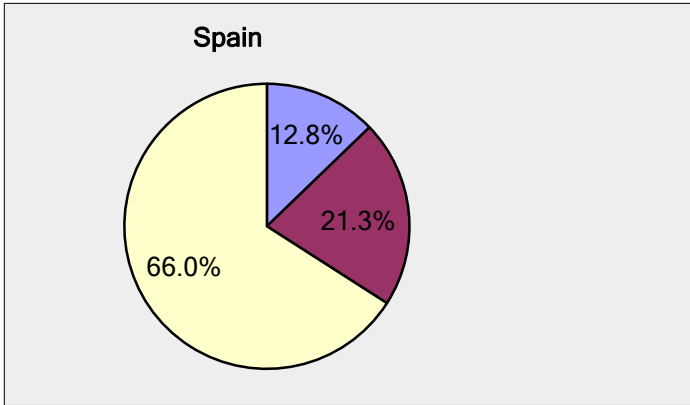
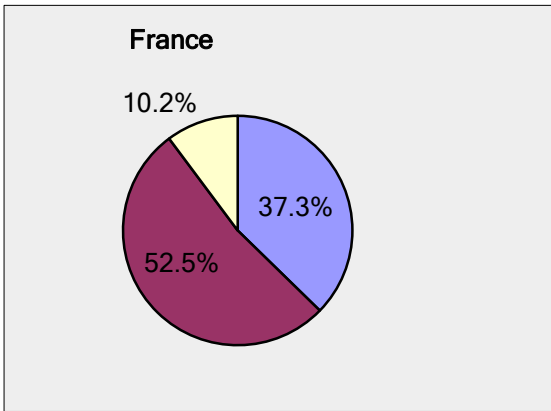
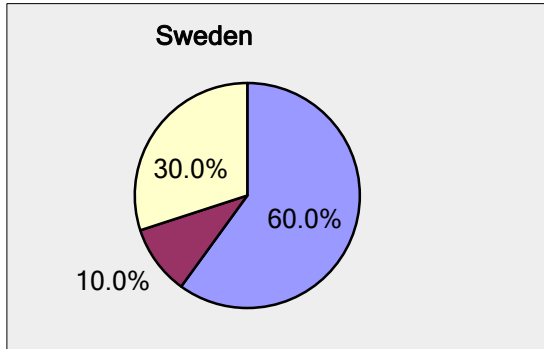
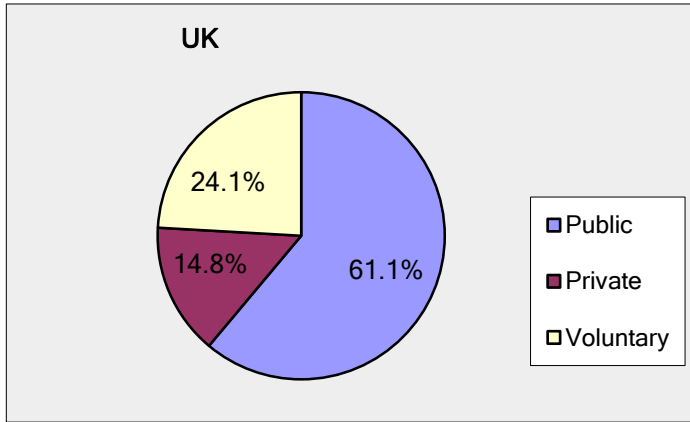
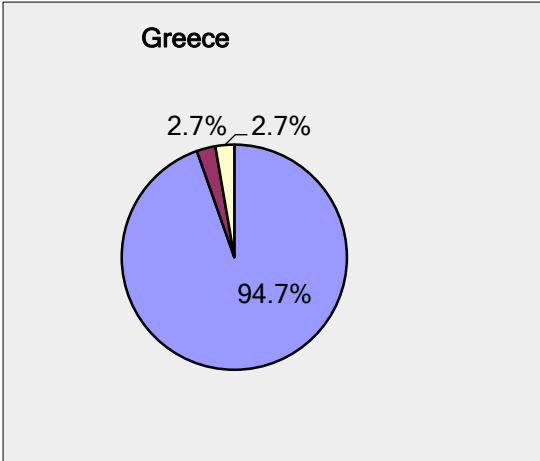
There are some limitations to the data collected:

- The overall response rate was enough to make measured assumptions, however more data would be needed in future to draw any firm conclusions.
- Not all respondents completed all questions – this leaves some gaps in the data.
- The data may be skewed by higher responses from some sectors over others, such as education.
- It's hard to know whether this a reflection of the number of professionals in each sector working with autistic teenagers, or whether this is due to problems reaching professionals in other sectors.
- Accommodation was made for differing language and terminology across countries, however the same interpretation by individual respondents cannot be guaranteed.

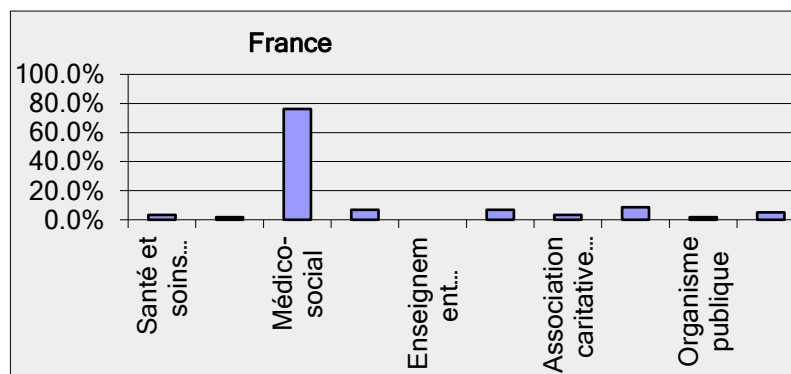
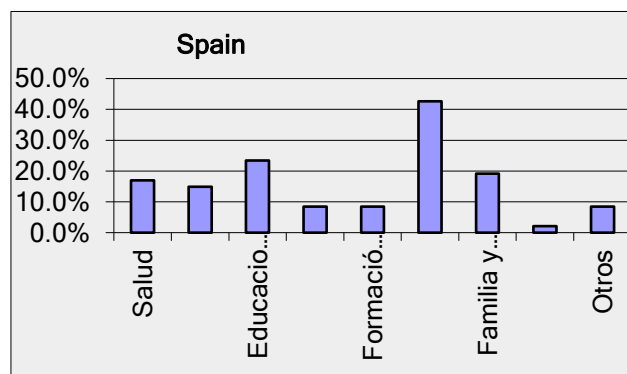
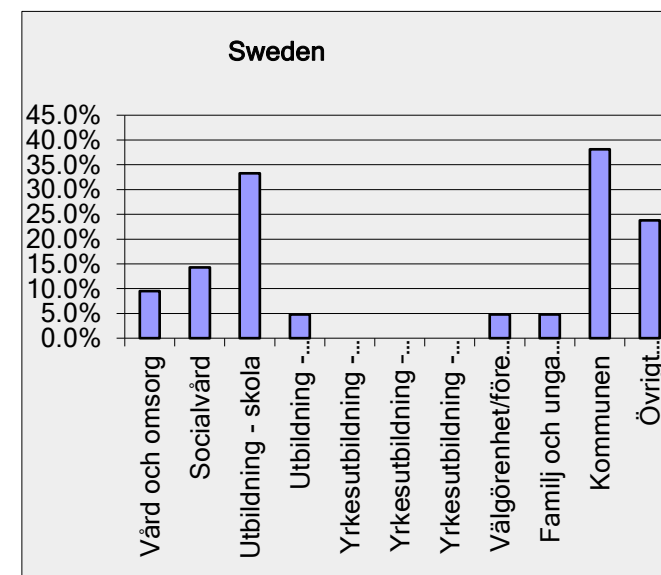
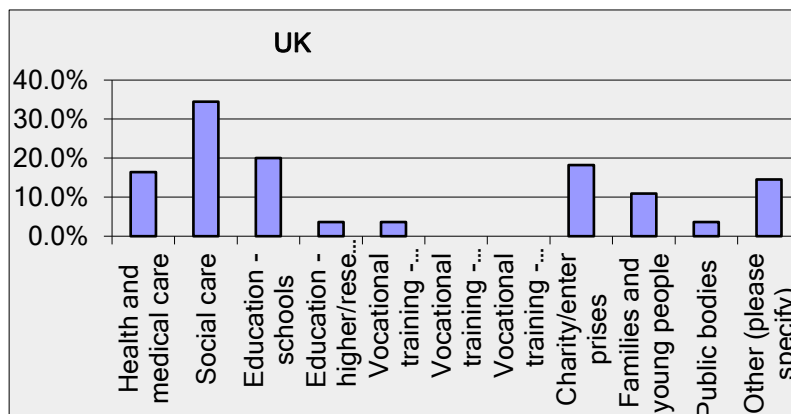
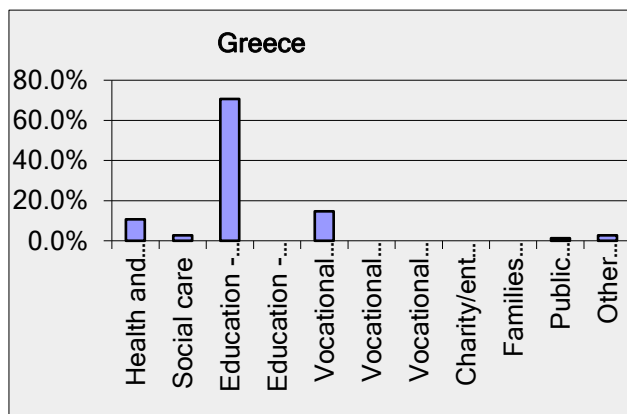
Survey response

From the data gathered, there appears to be key differences between countries regarding the sectors involved in supporting autistic teenagers.

In Greece an overwhelming number of respondents work in the public sector – 95%. This is likely due to the majority working in education. There was a similarly high number in Sweden (60%) and the UK (61%). In contrast in France it was the private sector that dominated (52%). Spanish respondents came mostly from the voluntary sector (66%). It is difficult to conclude from the data whether this is true reflection of the spread of professionals working with autistic teenagers across sectors. It could be that the data reflects the difficulties reaching professionals in some sectors over others.



The survey also collected data on the type of organisation worked in by professionals responding to the survey. The varied types of organisation represented across countries demonstrates the culturally differing set up of service delivery, responsibilities and funding. The three sectors with greatest representation are education (Spain, Sweden and Greece), social care (UK) and health (France); this demonstrates those most likely to be engaged with young people at this stage of their lives. Based on the current data, it also shows key differences between each partner country in terms of which sectors appear to dominate service provision for autistic teenagers. The education sector has the greatest response overall. There was low/no response from employment and vocational training sectors, apart from a minimally higher response in Greece.



Respondents to the survey were from a wide range of organisations and professional backgrounds and the majority provide direct support to young people with autism. The following roles are represented in respondents from all partner countries:

- teacher
- social worker
- carer
- manager/director/president of service
- psychologist

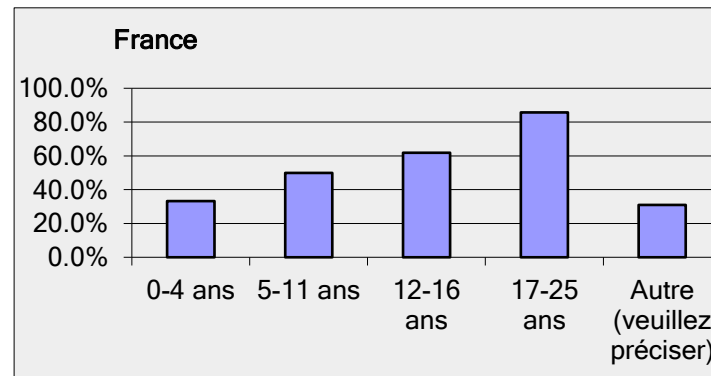
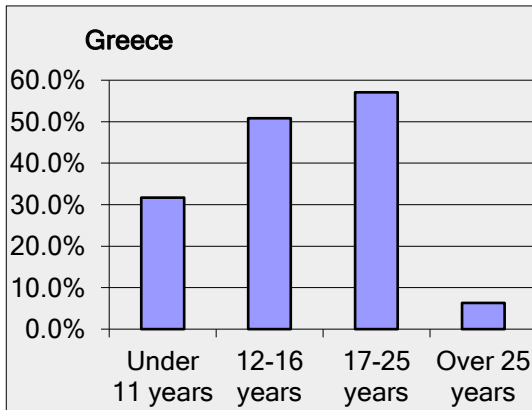
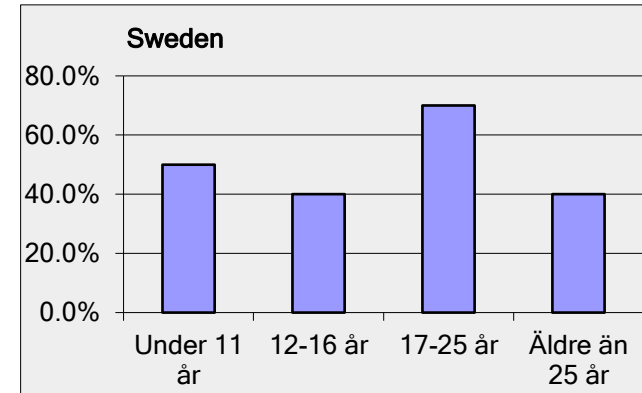
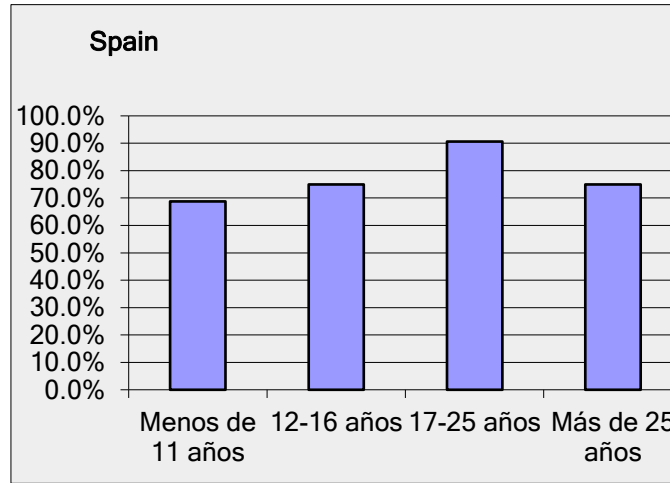
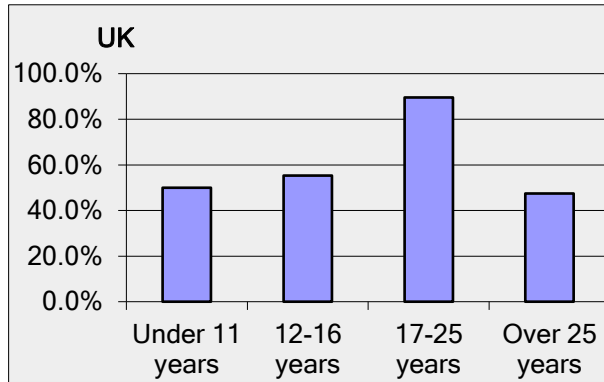
It suggests these positions are key to supporting young people with autism across countries.

This table shows a representative sample of respondent roles for each sector, grouped by country.

Sector	UK	France	Spain	Sweden	Greece
Health	Psychologist Nurse	<u>Medico-social sector</u> Psychologist Doctor Nurse Therapists – speech, physiotherapy, psychomotricity	Psychologist Doctor Nurse Occupational therapist	Care giver	Psychologist Medical student Speech and language therapist Diagnostician
Social Care	Social worker Team manager Support worker Autism practitioner Young people’s worker Carer’s lead Assessor	Social and professional advisor Service manager	Family support director Care staff Social integrator Day centre manager	Social worker Care manager	Social worker
Education	Head teacher Teacher Teaching assistant Nursery assistant Transition coordinator	Manager of education services Inspector of national education	Teacher Vice-dean Professor President	Teacher Head of staff Student assistant	Director Assistant director Head teacher Teacher School nurse
Employment	Training liaison		Job coach	Labour consultant	
Other	Volunteer Commissioner Trainer Advocate Family carer	Volunteer Family carer	Lifeguard Administrator Secretary	Art director Carer Music administrator	Administrator School agriculture Private tutor

Young People

All age groups (0-25 years+) were covered by all countries in the survey responses. This demonstrates that respondents have insight at different stages of child and adult life.



The majority of organisations provide direct support to young people; this shows similarity in the way services are set up for young people (see Appendix).

Young people age 17-25 are the group most respondents engage with. In France, 'other' responses include several where organisations are supporting people 18-60 years, and some that indicate services continue to deliver support beyond the age they are commissioned to provide for.

Across countries, the most common age for young people to move to adult services is 18 years. However in Greece young people seem to move into adult services at a younger age and there is also a more diverse spread of ages at point of movement than other countries. No comparable data was collected from Sweden.

	Most common age of movement to adult services	Second most common age of movement to adult services	Other ages represented
UK	18 = 55%	16 = 21%	14, 17, 25
Greece	13 = 22%	18 = 19%	14, 15, 16, 17, 19, 20, 21, 22, 23, 25
France	20 = 63%	18 = 22%	16, 21, 22
Spain	18 = 26%	21 = 23%	13, 14, 16, 17, 20
Sweden	No comparable question asked		

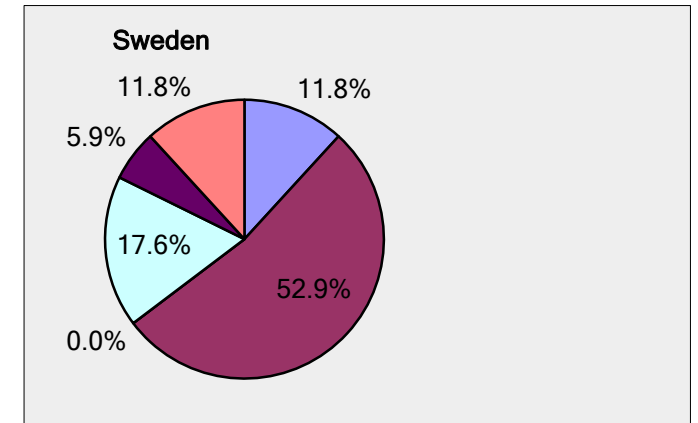
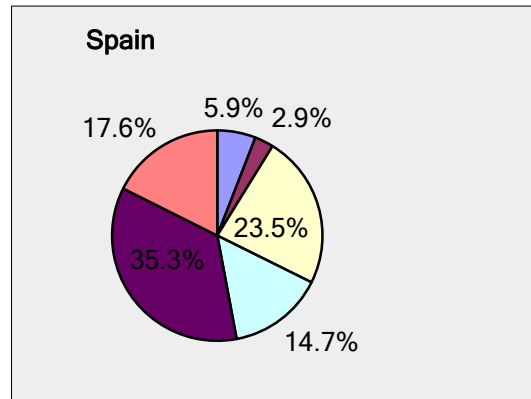
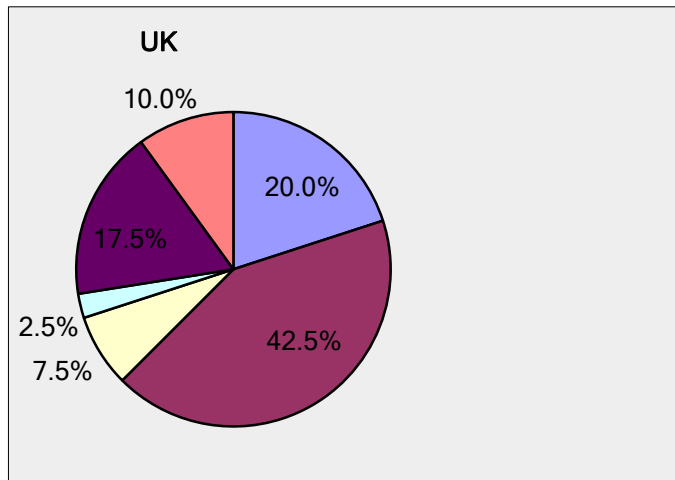
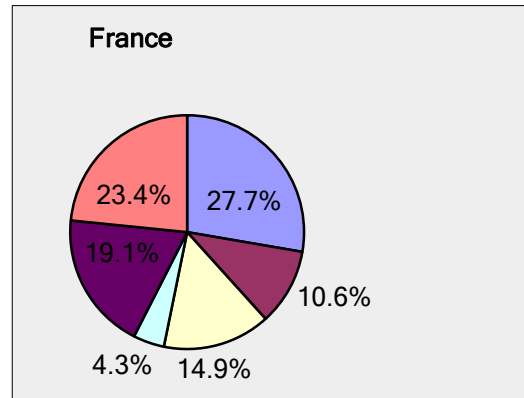
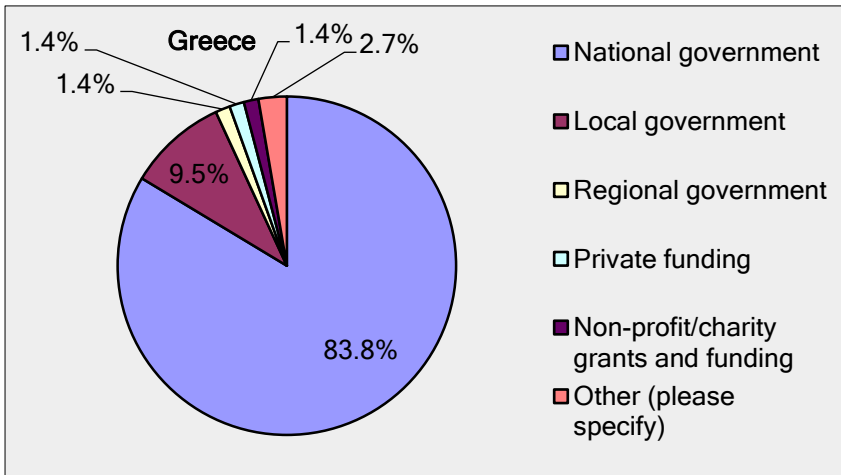
Organisational funding

Respondents were asked how their organisation is funded:

- national government
- local government
- regional government
- private funding
- charity grants
- other

Responses show that all funding sources are represented across all countries. Represented organisations from Greece are predominantly funded by national government, whereas other countries have a more varied funding pattern; this may be because the majority of Greek respondents were from the education sector, thus skewing the available data.

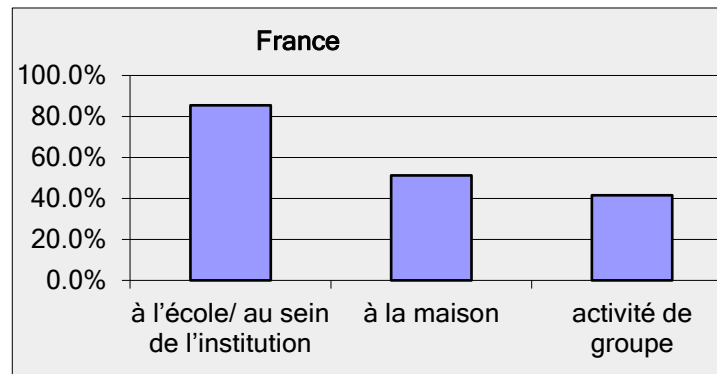
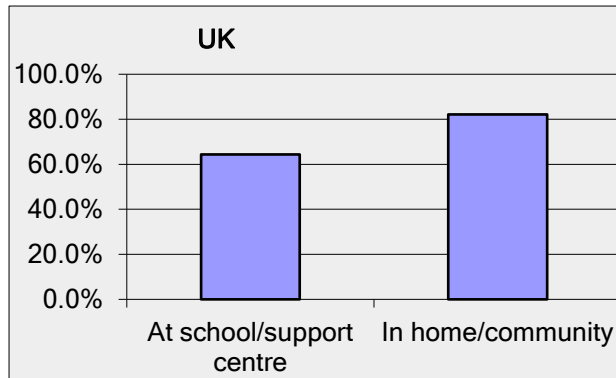
National/regional/local government funding combined covers at least 50% of funding across organisations, and private funding is the least accessed source. Sweden, UK and Spain had higher levels of funding from charity/non-profit grants.



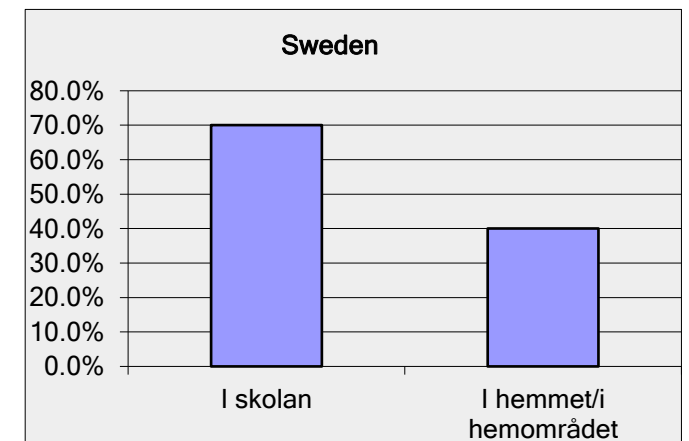
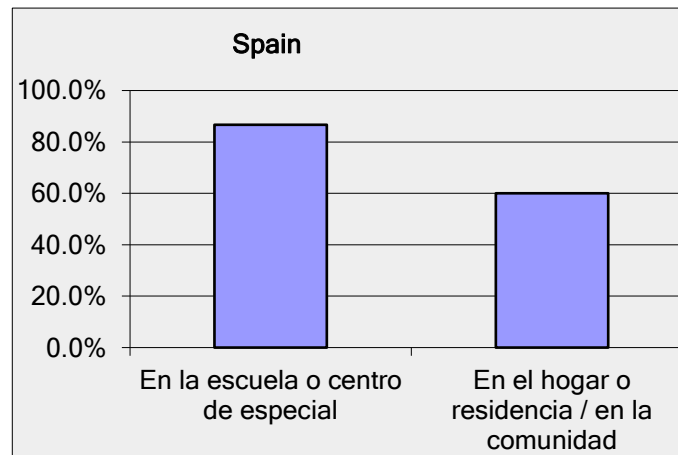
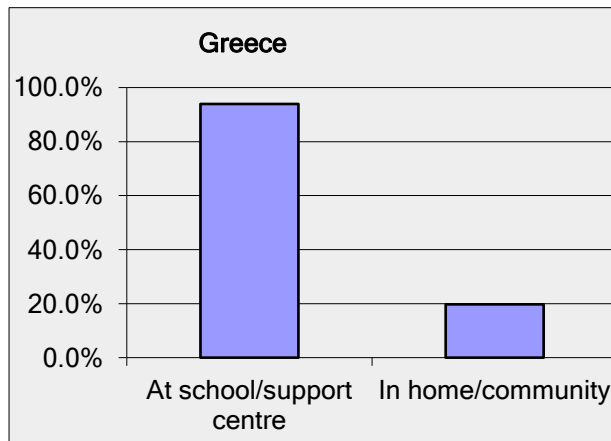
Types of support for young people

The remaining survey questions focused on the different types of support available to autistic teenagers. Professionals were asked to indicate the range of support available from their perspective and whether their organisation provided services through a school/support centre or at home/in community.

The current data demonstrates that the UK and France provide slightly more support in the home/community.



In contrast Greece, Spain and Sweden show a preference for more school/centre-based support. However, once again this may be because of the increased number of education respondents for these countries who are centre-based and reporting their own circumstances, rather than the overall picture for that country.



Support for young people on the autism spectrum to move to adult services

Respondents were asked about whether they offer (or plan to offer) the following services to support young people on the autism spectrum moving into adult services:

- planning meetings with professionals/young people/families
- formal written plans
- resources
- digital tools
- face to face named workers for young person
- referral to other organisations, support group/activity

Responses reveal variation in the support for teenagers and their families across all countries, however all services are available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change and expand.

The most common services offered across all countries are referrals to other organisations and planning meetings; this is a positive demonstration of the active engagement with young people and professional knowledge about further sources of support. Encouraging data also comes from Sweden where the main service available is face to face workers (73%), significantly higher than other partner countries. This could suggest the broader prioritising of personalised, practical support in the country, however it may be more reflective of nature of the organisations represented by respondents.

The least common services provided are resources and online tools, and organisations are also unlikely to offer are a named worker and written plans.

See Appendix for full survey results.

Support for parent carers and families

Respondents were asked about whether they offer (or plan to offer) the following services supporting parent carers and families of autistic teenagers:

- involvement in planning meetings
- carers support services
- guidance on future caring
- digital tools
- resources
- face-to-face named workers
- referrals to other organisations

There is varied support for teenagers and their families, with all services provided across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change and expand.

The most common services offered across all countries are referrals and involvement in planning meetings; this is a positive demonstration of the active engagement with families and knowledge about further sources of support. Again, there is encouraging data from Sweden where the main service available is face to face workers (57%), significantly higher than other partner countries. This could suggest the broader prioritising of personalised, practical support in the country, however it may be more reflective of nature of the organisations represented by respondents.

The least common services are digital tools; this is perhaps indicative of the limited funds available to spend on anything but the most essential services that have an immediate impact. However the importance of this service is demonstrated by the fact that organisations would most like to be able to offer them in future.

The services least likely to be offered are guidance on caring and carer support services. It may be that these are felt to be less importance, or that other organisations are seen as being better placed to deliver.

See Appendix for full survey results.

Advocacy and autonomy support for young people

Respondents were asked about whether they offer (or plan to offer) the following services to promote advocacy and autonomy of teenagers on the autism spectrum:

- involvement in planning meetings
- person-centred planning
- action plans
- referrals to local organisations
- digital resources
- support in skills training

There is varied support for teenagers and their families, with all services available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change.

Greece has a greater percentage of advocacy services offered in general, and considerably more people answered this question than in other countries (nearly 80% of respondents rather than 50-60%); this may be related to the prevalence of education respondents. Significantly however, this is the opposite picture to Sweden, which has a much lower percentage of advocacy services available (but also has a large number of education respondents). It suggests that partner countries may be quite different in the way they prioritise and deliver services.

The most common services for Greece, UK, Spain and France are referral and person centred planning; this is a positive demonstration of the focus on individual needs and knowledge about further sources of support. Sweden differed from other partners and referral was not widely offered. The service most available in Sweden is support in skills training.

The least common service offered by partners is digital resources. There was a similar response for Greece, Spain, Sweden and the UK, with France offering digital resources the least (only 10%). Involvement in planning meetings was also low, which seems a contradiction to the person-centred focus many services show, however it may be that organisational structures have not historically been flexible to offer this and are slow to reflect change. There is a divide around this service (involvement in meetings), with respondents split between saying they would most like to offer this in future *and* are least likely to offer it; this may reflect the complexity of delivery, whilst recognising it as being very important.

See Appendix for full survey results.

Daily living support

Respondents were asked about whether they offer (through digital technology, 1:1 support, resources and group activities) the following to support autistic teenagers with daily living:

- self/personal care
- home organisation
- shopping, budgeting
- travel training
- social skills
- accessing leisure activities
- citizenship

The results reveal varied support for teenagers and their families, with all services available across partner countries. France, UK, Spain and Greece offer these in all formats. Sweden has more mixed availability, likely due to the organisations represented by respondents, some of which are focused on a particular remit (e.g. drama education).

There is similarity in the delivery of services across the countries represented, although Greece has a smaller number offered through digital technology; these resources are typically expensive to initially invest in, and the majority of Greek respondents are in government-funded organisations which may have an impact on the availability of funding for innovative initiatives.

Services are most likely to be provided through 1:1 workers and group activities, positively indicating the active engagement with young people.

The most common types of daily living support offered across all countries are social communication and self-care; these may be valued as being of greater importance to increase young people's autonomy and independence.

The least common types of daily living support offered are budgeting and travel training; these may be services seen as 'nice to have' rather than being essential development skills.

See Appendix for full survey results.

Community support

Respondents were asked about whether they offer (or plan to offer) the following community support services:

- activities and groups
- personal safety awareness
- community awareness
- social care
- social media

There is varied support for teenagers and their families, with all services available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change.

The most common services offered for community support are activities and social care support; this positively indicates active engagement with young people.

The least common services offered are social media and community awareness; these are relatively new initiatives, the impact and benefits of which are harder to evaluate to assess potential outcomes. This can be an issue for publicly-funded organisations (which is the majority funder of respondents). It is clear that organisations would like to offer these in future though. There is slightly more representation of social media in the UK and Spain. Potentially Greece, Sweden and France could look to these countries for ideas on increasing this medium of support.

The responses show that the service least likely to be offered in future is personal safety awareness; there are fewer innovations around this subject, and it may be that organisations feel ill-equipped to provide this service within their core offer.

See Appendix for full survey results.

Employment

Respondents were asked about whether they offer (or plan to offer) the following services:

- career guidance
- employer awareness
- job preparation
- job searching
- apprenticeships
- supported internships
- traineeships
- workplace support
- supported employment
- referral to other organisations
- accredited training programmes
- vocational training

There is varied support for teenagers and their families, with all services available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change and expand.

The mix of employment support across partner countries is diverse. Greece has a very high percentage of career services available (48% respondents), but only 10% provide supported employment services. In contrast, Spain has a more consistent pattern of services (average 26%). The exceptions in Spain are professionally accredited training and vocational training, which also show a much smaller response from the other countries. There is potential for considerable learning about different schemes and initiatives across countries to expand national provision.

The most common services are referral and job searching; from a practical perspective, these are the most simple/least time-intensive services to provide.

Sweden has a very high percentage of traineeship/apprenticeship schemes available (58%) and France and Spain are also considerably higher (25-30% respondents). In Sweden, this may be related to the daily activities for which people with intellectual disabilities, among others, are entitled to receive support. In Spain, this may be linked to the national quota for employing disabled people (set at 2% of the company workforce) and/or government grants available for employers. This could be useful guidance for other countries.

The services countries are most likely to offer in future are traineeships and employer awareness. Those least likely to be offered in future are supported employment and vocational training; these services are time-intensive and rely on good employer and workplace engagement.

See Appendix for full survey results.

Education

Respondents were asked about whether they offer (or plan to offer) the following services:

- further education
- higher education
- vocational training
- information and guidance
- education support
- financial guidance
- referral
- supported education

There is varied support for teenagers and their families, with all services available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change and expand.

Education support is mixed across countries, and in general further and higher education opportunities are offered by fewer respondents. The most common services provided are information and guidance, and referral. This is likely to be because non-education sector organisations (social care, health etc.) may have strong working links to education, and can provide some guidance and referral services in addition to their core offer. Sweden has a high percentage of education/classroom support (50% respondents) compared to other partners.

Across countries, there was a greater percentage of respondents (averaging 25-50%) unlikely to provide selected services in future. France is noticeably highest, up to 76%. This may reflect those respondents who do not provide an education-specific service, or it may be because education services are commonly very specific in their delivery (e.g. school-age provision). In this case, additional services may be deemed unnecessary, or the existing structure of the service may not allow for development.

The least common services provided are higher education and financial guidance, and these are also the services respondents are most likely to offer in future. In the UK, young people are required to stay in some form of education or training until 18 years, which has seen a recent development in further education

opportunities. This may offer learning opportunities to share with partners about different initiatives. Providing information about financial funding for young people is seen as important to respondents across countries, perhaps reflecting the increased financial pressures around education funding throughout Europe

See Appendix for full survey results.

Housing

Respondents were asked about whether they offer (or plan to offer) the following services:

- accommodation planning
- supported living
- assisted living
- group home
- co-operative
- foster home
- communities
- independent living support and outreach
- financial support

There is varied support for teenagers and their families, with all services available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change and expand.

Housing support availability is mixed across countries, with supported and independent living services most commonly offered. There are very few cooperative housing options (average 4% respondents). While Greece has a smaller percentage of housing services available than the other countries, its co-operative provision is highest of all countries at (the still low) 6%. The reason supported living and independent living may be most common, is possibly because they have lower running costs and/or greatest demand (demonstrating the balance between support and independence).

The least common services are co-operative living and foster homes; these are quite original and reasonably new ideas. Historically, organisations have shown that they tend to stick to what they know, or offer services that enable them to demonstrate clear outcomes in order to secure more funding. This may also be most respondents say they are unlikely to offer these services in future.

See Appendix for full survey results.

Health support

Respondents were asked about whether they offer (or plan to offer) the following services through inpatient or outpatient delivery:

- psychology
- psychiatry
- physical health
- family doctor
- general health
- dental services
- occupational therapy
- speech and language therapy
- counselling
- specialist services

There is varied support for teenagers and their families, with all services available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change and expand.

Predominantly outpatient services are offered across all countries; these generally have higher demand and are less costly to deliver.

Health support is delivered mostly through mental health (both psychology and psychiatry) and occupational therapy or speech and language therapy services. These services are directly linked to the diagnosis and support of many people with autism. Sweden and Greece have noticeably higher levels of counselling support (35-40%). It is not clear how this service is accessed and delivered.

There is minimal GP or general health provision within organisations but this is probably to be expected due to universal access to these services at a local level. Dentistry is least offered currently, and respondents are also least likely to offer this in future, along with family doctor services. This is probably due to dominance of universal provision or private delivery of services.

See Appendix for full survey results.

Financial support

Respondents were asked about whether they offer (or plan to offer) the following services:

- managing money
- benefits advice
- financial planning
- advice on trusts
- signposting

There is varied support for teenagers and their families, with all services available across partner countries. Where services are not available, there is a desire to offer these in future, indicating a drive to change and expand.

Financial guidance support is mixed. Spain has a lower number of respondents to this question, but the percentage of services available in general is very similar (with 25-50% offering various services). Sweden has less services available in general, likely due to the organisations represented by respondents, some of which are focused on a particular remit (e.g. drama education).

The most common service provided is signposting. Benefits advice is also common (apart from in Sweden); this may be due to lower running costs and ease of delivery.

The least common services are financial planning and advice on trusts; both services require knowledge of complex legal and benefits systems, which is likely to require specialist expertise. This is also reflected in the fact that advice on trusts is least likely to be offered in future.

The service most likely to be offered in future is managing money; this has the potential to directly impact and improve the life skills of young people with autism. It is noticeable that in the section on daily living support, countries also wanted to offer increased budgetary guidance for young people. Greece has a high percentage of respondents already offering this and the UK has a various practical resources. Both may be a source of valuable information to support partners to develop services.

See Appendix for full survey results.

Training

All training methods are offered across Greece, Spain, UK and France. These are:

- online
- face to face – internal
- face to face – external
- information resources
- online resources
- team meetings
- multi-disciplinary meetings
- conferences and events

Sweden offers all of the above apart from face to face – external training.

The most common training accessed by respondents are in-house workshops (average 51.6% respondents) and online training. France, Spain and UK have more people accessing in-house training while Greece and Sweden have the highest percentage of people accessing online training.

France has the highest percentage (25% respondents) accessing vocational training; this is significantly greater than any other country. This may provide valuable learning for partners to develop similar opportunities, particularly UK and Sweden that do not provide evidence of its availability locally.

Respondents accessed a wide range of training across varied formats however individual feedback indicates an inconsistency of approach by organisations and lack of access to training for some professionals.

There are several training programmes commonly accessed across countries (minimum of two countries must have had a respondent specifically mention), indicating some consistency of methodology and approach. This includes:

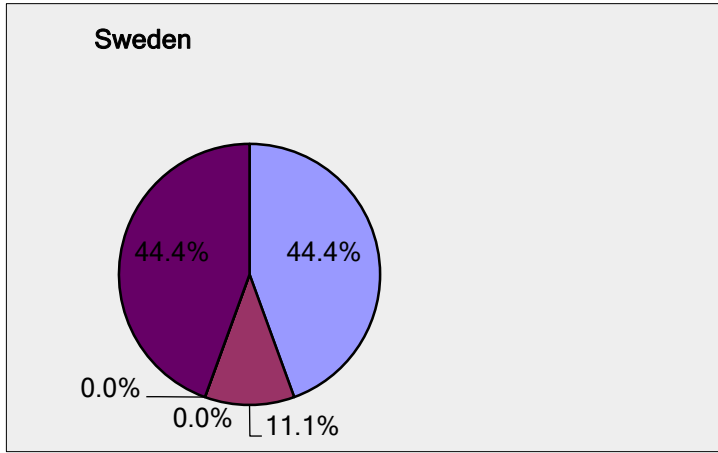
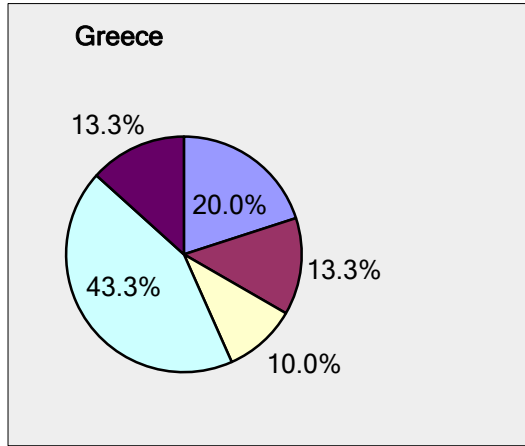
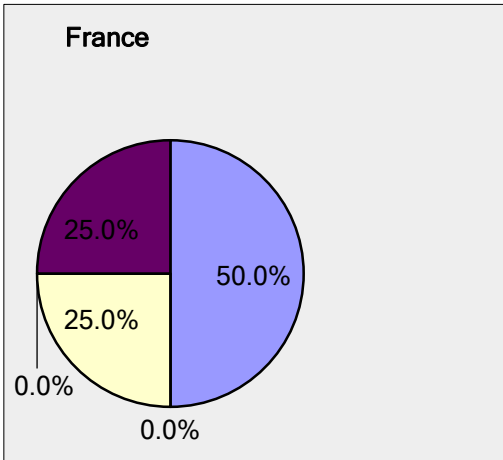
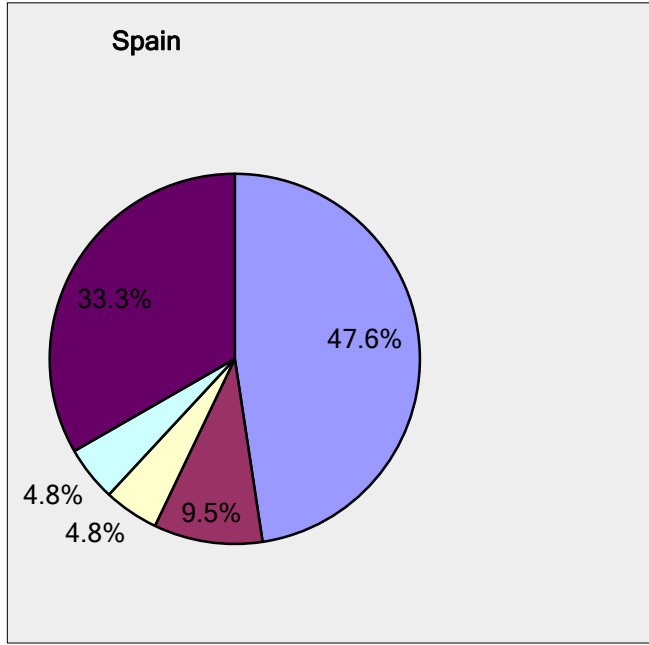
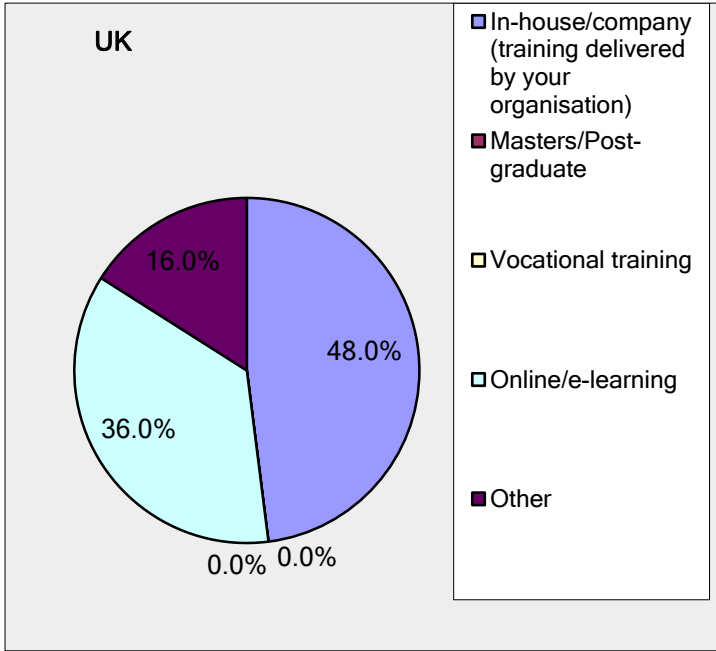
- PECS
- TEACCH
- Person Centred Planning (PCP)
- ABA
- Social skills
- Understanding autism

Specific training topics attended and referenced by respondents from at least one country include:

- Employment
- Music therapy
- Behaviour
- Social skills
- Sensory
- Sexuality
- Women and girls
- 'Experts by experience' – delivered by people with autism

The most commonly accessed training are conferences and information resources; these are widely available and accessible at a range of costs.

The least commonly accessed training are face to face workshops; this may be because organisations can struggle to release staff from their day jobs to attend training, and may prioritise resources on critical service delivery.



Safeguarding

While autism-specific safeguarding policies are available, these are considerably fewer than universal and disability safeguarding policies, this may be because the specific-nature of autism is still not fully understood by society.

Autism-specific policies are available across all levels (service, organisation, local/regional government and national government) across all countries. The national autism plans for France and UK were specifically referenced by respondents, but no others were mentioned by name. This could suggest the scope of the national policies has impacted services more widely in their delivery and understanding. See TRAIL Survey 1 for further details of the social policy content across each partner country.

Conclusions

While we can draw some broad conclusions, we acknowledge that the data may have been skewed by the respondents that each partner country had access to. For example, Greece and Sweden may have had a greater number of responses from education professionals because our partners have strong education links. More data would be needed confirm the survey results, but they are robust enough to draw some meaningful analysis from.

It is demonstrable that across partner countries, young people with autism have a considerable range of services and support structures available to them to support them to move into adult life. This is significant, because it displays an increased understanding about the specific needs of young people with autism, and the desire to structure services appropriately. However, what is also clear is that these services are not universally available. Geographical data for respondents is sparse, but indicates that organisations represented in this survey are from a broad area within each country. For example, respondents from the UK included those in Wales, Scotland, London and Cornwall - across the breadth of the land. Their responses differ hugely. In addition, as this report defines, there are some variations in between countries in the services provided. This suggests that young people with autism are likely to have inconsistent or 'patchy' access to supportive services that are local to them; there is not a common picture of provision across all areas.

There is considerable learning that can be taken from these findings; partners now have a greater understanding of their country's provision. Where there are gaps, there is another partner country who may be able to guide and advise based on their increased service availability and/or expertise. This can also assist partners to identify their country's areas of good practice, which can inspire and promote increased delivery at a national level. Combined, this can inform and support innovation internationally, spreading individual learning to a wider audience.

Trail Project Survey 3 Report

Introduction

This survey is part of a cross-country European project to improve support for teenagers on the autism spectrum; TRAIL - Teenagers: the Road with Autism to Independent Living. It has been designed to understand how support is currently provided for teenagers and young people with autism by local, regional and national organisations across partner countries (Greece, France, Sweden, Spain and the UK).

The survey was designed by partners, and distributed from April-June 2017. It was translated with modifications for France, Spain and Sweden, to increase the response rate and best reflect national structures. Young people responding are age 14-25 years.

	Total number of respondents:	Total number of parent carer respondents from partner countries:	Total number of young people respondents from partner countries:	Other respondents:
France	55	22	12	21 = Adults with autism
Greece	8	7	1	0
Spain	30	16	5	1 = Professional 8 = Adults with autism
Sweden	12	Not known	Not known	Not known
UK	6,145 Main Omnibus survey = 6,093 Transition support survey = 52	4,400 Main Omnibus survey = 4,348 Transition support survey = 52	1,745 Main Omnibus survey = 1,745 Transition support survey = 0	0

Limitations

There are some limitations to the data collected:

- Partner countries asked slightly differing questions of their young people and families – this means quantitative data is difficult to compare
- Minimal data collected from some partner countries – the narrow age range was found to be quite restrictive
- Partners feel that some parent carers with young people with autism who have not received the necessary support do not believe that research can help or change something in their lives – this may have impacted their desire to engage
- Language and terminology was modified and translated for each country, therefore the same interpretation by individual respondents cannot be guaranteed

The numbers of responses from partner countries varies hugely and should only be read as a possible interpretation of the national picture. However all experiences are valid and may inform the development of future provision.

Survey response

There are very few differences between the experiences shared.

Common themes across partner countries:

- More autism awareness is required to improve public understanding
- Employment support and training are key to increasing opportunities and independence for autistic adults - autistic people want access to work that takes into account their abilities, needs and interests
- Local community services need an improved understanding of autism to increase accessibility
- People on the autism spectrum want to be able to develop personally, socially and culturally, and to be autonomous within society
- Autistic people require life-long, but variable assistance (from people, resources and finances) to develop and live independently
- Housing, social care, financial and education services require improvements for autistic young people and parent carers
- There requires increased understanding of autism in statutory services to improve integration and support
- The needs of parent carers are not well recognised or supported
- Feedback from parent carers and young people from all countries indicates a lack of services available
 - Greek families indicate that there is 'very little support', 'limited support' and 'no organised assistance'
 - Spanish families fed back that 'help and local support is missing' and '[there] should be more assistance, facilities and employment options for autistic adults'

- In France, families feel there is a ‘lack of information about autism in society’, ‘lack of recognition of the place of the family’ and that there has been ‘mostly no help received’
- UK families find ‘few options available locally for support’, ‘[a] lack of understanding’ and that ‘you only get support if you fight for it
- Families in Sweden said ‘everything arrives too late’, ‘he didn’t get the support he need in time’, and ‘we’re in a deadlock in every right he’s got’

UK

There is a wide range of transition support available, but considerable gaps in provision, which means that many people are not satisfied with their experiences of support services. Increased community understanding of autism is a priority for autistic young people and parent carers. The impact of the National Autistic Society (NAS) Transition Support Service has a positive impact on people’s knowledge of transition and feelings around future planning. This indicates that specialist services may be a valuable resource to improve families’ experiences.

Main Omnibus NAS survey results

In 2016, the NAS surveyed parent carers and autistic people about transition as part of a wider national. The age group of young people consulted was 16-29 years (varying slightly to TRAIL 16-25 years remit).

- Most important issues for parent carers = support when leaving education, support for families, public understanding
- Parent carers most want improved understanding of autism from: employers, teachers, benefits agency staff
- Parent carers most want the following activities to be more accessible: department stores and shopping malls, supermarkets, leisure centers and swimming pools
- Most important issues for young people are mental health for adults, public understanding, support when leaving education
- Young people most want improved understanding of autism from: employers, teachers, GPs
- Young people most want the following activities to be more accessible: public transport, restaurants and bars, supermarkets
- Less than 10% of parent carers and young people are satisfied with housing
- Less than 12% of parent carers and young people are satisfied with social care
- Less than 19% of parent carers and young people are satisfied with financial support
- Less than 19% of parent carers and young people are satisfied with education provision

NAS Transition Support Service survey

In 2016, 52 parent carers were asked about the impact of using the NAS Transition Support Service:

- 67% now know more about their/young person's rights and entitlements around transition
- 71% feel better able to make informed decisions about their/young person's transition and future
- 60% feel more confident about to express their/young person's views on transition and future
- 63% feel more hopeful about their/young person's transition and future
- 84% would recommend the Transition Support Service to others

Spain

There is a wide range of transition support available, but considerable gaps in provision. Local autism and disability organisations are more accessible than professional services.

- Main respondents are relatives of people with autism
- Main support accessed is assistance from a professional or service (33%)
- Other support accessed includes information (23%), activities and training (23%), and support and advice (21%)
- Specialist support accessed includes psychiatry, special employment centre, teachers
- Main help seen as indispensable includes professional support (53%), educational provision (18%), and labour/skills training (14%)
- Other support services identified as important are groups, extra-curricular education activities, financial guidance and housing support

- Main difficulties/barriers for young people during transition are social inclusion and relationships (32%), learning difficulties (22%), behavioural difficulties (19%)
- While professional support is seen as most important, only 33% of respondents have received this assistance

- Additional comments from respondents:
 - 'The most important thing is economic independence through employment and work'
 - 'I have always been a member [of the autism organisation] since I was diagnosed and for this reason I have never felt alone'
 - 'There is no specialist assistance and organisations do not have sufficient training'
 - 'We have requested the assistance of a professional person but have heard nothing'
 - 'There is not enough support for good development of the person'

Greece

There is a wide range of transition support available, but considerable gaps in provision. Individual and multi-agency professional support is available but this does not appear to be accessible for everyone. Many respondents indicate the need for improved family assistance, to better meet the needs of the autistic person.

- Main respondents are parent carers
- 100% respondents experienced difficulties during transition
- Main general support accessed during transition is information resources (75%)
- Of the general support provided, the most helpful are multi-professional meetings and individual professional support
- Main education support accessed are information resources (50%) and individual professional support (50%)
- Main professional support accessed are multi-professional meetings and individual professional support (both 42.9%)
- Main daily living support accessed are individual professional support, referral to other organisations, digital resources, and group activities (all 28.6%)
- Main support to increase personal autonomy accessed are multi-professional meetings (66.7%), individual professional support (50%) and group activities (50%)
- Main support to access health services accessed is referral to other organisations (50%)
- Main social activity support accessed are information resources (57.1%), digital resources and group activities (both 42.9%)
- Information, individual professional support and multi-professional meetings are the most available sources of support
- All participants believe that they should receive permanent family support; families require information and support in order to be able to effectively support their autistic relatives

- Key difficulties include making friends or sustaining contact with peers, and accessing work and education
- While some support services are available, these are not always accessible

- Individual comments include:
 - 'Difficulty finding specialists in autism'
 - 'Would like more directional activities for teenagers with autism'
 - 'I had no [professional support]'
 - 'The help of the autism association to support parent carers of people with autism is very important'

France

There is a wide range of transition support available, but considerable gaps in provision. While information and advice is available, there is less availability of professional support or practical skills. Family support is seen to be particularly important. The age range and responses of autistic respondents indicates how services have positively evolved over the last 30 years, however people feel that substantial improvements are still required.

- 92% respondents experience difficulties during transition
- Main areas respondents require support are education (73%), social relationships (62%) and practical life skills (42%)
- Main education support accessed are information and advice (49%) and professional support (36%)
- Other education support accessed are adaptations (33%), activity groups, autism associations
- Main vocational support accessed are adaptations and learning activities (both 13%)
- Main job search support accessed are family assistance (27%) and professional organisation support (24%)
- Main employment support accessed are support adaptations and assistance (both 15%)
- Main financial support in the management of a budget accessed is information and advice (46%)
- Main support at home accessed is information and advice (61%); of those requiring support, 50% said they relied on family support
- Main health support accessed is information and advice (50%); of those requiring support, 34% said they relied on family support
- Main social relationship support accessed is information and advice (43%)
- Professional, adaptations, resources, learning activities are most frequently accessed for support in education settings
- The importance of family support is emphasised by many respondents, in part due to the lack of professional services available

- Only 8 respondents (of 28 autistic people age 18-32 years) are in employment
- Families identify the need for increased training and resources to enable better communication between professionals and autistic people

- While universal services are felt to require improved autism awareness, it is also important for families that specialist provision be available where appropriate
- Young people want access to services that enable them to develop their independence, take their needs and interests into account, and demonstrate that their interests and skills are valued
- The adaptation of existing statutory services and the development of services may be required due to insufficient numbers of existing structures and accompanying services

Sweden

There is a wide range of transition support available, but considerable gaps in provision. Compared to partner countries, Swedish respondents indicated a much greater number percentage accessing services listed. Professional support and services, and practical adaptations appear to be more widely available. However, training and understanding of professionals was noted as requiring improvement by several respondents.

- 100% respondents encounter difficulties during transition
- Main help identified as being most important is information and advice (83%), specific adaptations (83%) and support from professionals and services (67%)
- Main help received is information and advice (89%) and specific adaptations (56%)
- Main education support received is specific adaptations (92%), support from professionals and services (75%) and listening support (67%)
- Main support received into employment is specific adaptations (100%) – all other support options were also accessed by 50-80% respondents
- Main life skills support (including finance) received is listening support (100%), and support from professionals and services (83%)
- Main daily living support accessed is information and advice, and listening support (both 80%)
- Main health and medical support received is support from professionals and services (91%), information and advice and listening support (both 64%)
- Main social relationship support accessed is support from professionals and services, listening support, and activities/group learning (all 73%)

- Concerns about training and staff knowledge indicate that this impacts on accessibility of services, even if they are available:
 - ‘Activities...won’t work because the personnel don’t know how to cope with autistic people’
 - ‘Generally speaking, knowledge about ‘autism is lacking everywhere’
 - ‘[We need] better educated personnel’

- Families said that they would find the following support indispensable:
 - ‘Personnel who are up for a challenge’
 - ‘Assisted living with the focus on autism’
 - ‘Specialist support in school’
 - ‘Habilitation and the autism societies support’

Conclusion

Support and advice on transition and future planning can increase confidence, understanding, knowledge and hope for parent carers and young people on the autism spectrum. However, while some transition (and related) services are available across partner countries, support is patchy and inconsistent. There is a need to increase autism knowledge within services and improve existing, support structures, as well as to create new provision.

A large number of respondents from all countries identified that families provide a huge amount of caring and intervention for young people on the autism spectrum. Some parent carers are angry, upset and tired at the lack of support from professionals, and lack of acknowledgement of the level of assistance families have to provide. Families should be central to the evolution of services, so that they are appropriate and fit for purpose. However there currently seems to be an over-reliance on families to fill in for professional service support.

The similarity in feedback across partner countries indicates widespread change around transition support is still required, despite pockets of good practice and positive experiences. Increased and more frequent consultation should help partners to understand the changing pattern of needs, and how any local or national developments impact the lives of autistic young people and their families.

Engagement with decision makers and organisational leads

Partners contacted a range of lead professionals, organisations and policy decision makers within their country. They were asked what they knew about the needs of autistic teenagers, and what they did to support them.

UK	Local data on young people with autism	Services would like to see developed	Local practical support available	Local strategic support available
Greater Manchester Autism Consortium	<ul style="list-style-type: none"> • Struggle to collect local data • Tried to collect through GP registration, CAMHS (Child and Adolescent Mental Health Service), education services – autism identified as primary need • Issues: no one data set feels accurate, and there is no clear way of cross-matching to avoid duplication 	<ul style="list-style-type: none"> • Increased autism awareness in schools (and other children’s services) to understand transition assessment processes so that they can be more proactive with parent carers 	<ul style="list-style-type: none"> • Proposal to offer a transition assessment in school year 9 for all young people who have an Education Health and Care Plan (EHCP) • Autistic pupils who do not have an EHCP can access a self-checking system to assess eligibility for support • Mandatory autism awareness training for all council staff 	<ul style="list-style-type: none"> • Developing SEND (Special Educational Needs and Disability) Transition to Adulthood pathway • Autism strategy due to be published late 2017
The National Autistic Society	<ul style="list-style-type: none"> • Frequent engagement with families with autistic young people enables collection of qualitative and quantitative data to inform organisational understanding and promote awareness • Analysis of national and local reports and research to identify gaps in provision 	<ul style="list-style-type: none"> • Many young autistic people find that they are not considered eligible for statutory service support when they reach adulthood and the process can be unclear. • Less than half (45%) of local authority transition pathways between 	<p>The NAS has a free transition support service that offers:</p> <ul style="list-style-type: none"> • Information and advice by phone and email • Explanation of rights and entitlements • Information about other services that may be useful during the transition process 	<ul style="list-style-type: none"> • Consultation with families and young people helps inform the information we take to local and national government to push for change and development in policy and governance

	<p>across the UK, e.g. 2014 UK Self-Assessment on autism found that fewer than four in 10 (38%) local authorities include a focus on the employment wishes and support/development needs in their transition processes</p>	<p>children and adult services are an automatic process</p> <ul style="list-style-type: none"> • Only 38% of local authorities include a focus on employment and development needs in their transition processes • 55% families find it difficult to access information about transition support from their 'local offer' of services • 66% of children and young people want teachers to be more understanding of autism, which would improve their experience of school 	<ul style="list-style-type: none"> • Guidance and support on specific issues such as engaging the young person, finding suitable provision, making a complaint or appealing against a decision • The NAS has previously run various campaigns relating specifically to young people, including around education and mental health 	
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France	Local data on young people with autism	Services would like to see developed	Local practical support available	Local strategic support available
	Despite considerable effort by French partners, no responses were received from professionals contacted			

Greece	Local data on young people with autism	Services would like to see developed	Local practical support available	Local strategic support available
Ministry of Education	<i>No reference made</i>	<p>Increased provision of:</p> <ul style="list-style-type: none"> • Special Needs Upper secondary schools, and vocational schools • Centres of Special Vocational Education and Training • Schools or departments that operate as autonomous units or annexes of other schools within certain hospitals, rehabilitation centre • Home tuition and Medical -Education Centres • The provision and implementation of Individual Education Plans • The design of accessible educational material • Special arrangements when taking exams (including entering University without taking exams) • Special arrangements regarding attendance 	<ul style="list-style-type: none"> • Classes in mainstream schools with parallel support • Specially organised and staffed inclusion classes • Educational support specialised programmes for 15 hours per week per pupil • Educational support specialised group or individual programme for pupils with significant educational needs • Classes in mainstream schools, supported by the class teacher • Vocational schools offer various courses that prepare pupils for employment and teach skills e.g. gardening, weaving, crafts, confectionary etc. • Vocational Training Institutes for young adults which function as post-secondary institutions for 	<ul style="list-style-type: none"> • Aid programme (currently running for last three years) for employers, providing subsidy for hiring unemployed people with disabilities

		<ul style="list-style-type: none"> • Provision of school nurses and special support staff on a one-to-one basis • Participation in co-education programmes • Centres for diagnosis 	<ul style="list-style-type: none"> • professional specialisation • Protective laboratories, cooperative associations and Centres of Vocational Training • Associations of Parents, Guardians and Friends of People with Disabilities have established several institutions, such as Day Centres, Vocational Training Centres, as well as supportive societies and special accommodation units 	
School Consultant	<i>No reference made</i>	<ul style="list-style-type: none"> • Smoother transition to school units and universities • Social integration and functional autonomy • Professional integration 	<ul style="list-style-type: none"> • Interventions in secondary school education 	<ul style="list-style-type: none"> • Engagement and professional integration with other sectors such as health • Information and awareness programmes which target society as a whole
KEDDY (Centre for Differential Diagnosis, Diagnosis and Support), Larisa	<ul style="list-style-type: none"> • Lack of any knowledge of how many people there are on the autism spectrum, who they are and what services they use 	<ul style="list-style-type: none"> • National Action Plan for teenagers on the autism spectrum • Independent living scheme for autistic teenagers 	<ul style="list-style-type: none"> • Centres for Differential Diagnosis, Diagnosis and Support (KEDDYs) • Teacher-education programmes • Transitions between different levels of education for all students with disabilities especially for autistic teenagers 	<ul style="list-style-type: none"> • Creation of national legislation especially for autistic teenagers

			<ul style="list-style-type: none"> • Early childhood education and care for pupils with disabilities • Links with schools, support services and other external agencies 	
KEDDY, Volos	<ul style="list-style-type: none"> • Lack of understanding of educational needs, work experience and personal independence of people on the autism spectrum 	<ul style="list-style-type: none"> • Independent living skills • Equal opportunities for social inclusion • Job training, professional qualification programs and tools to develop independence 	<ul style="list-style-type: none"> • Partnerships between schools, social services, workforce development entities, post-secondary institutions, parents and others associations 	<ul style="list-style-type: none"> • Need to develop a comprehensive statutory and policy framework among ministries for inclusive schooling • Implementation of a comprehensive action plan for the collection and analysis of statistics in the field of special and inclusive education

Spain	Local data on young people with autism	Services would like to see developed	Local practical support available	Local strategic support available
AUTISMO ESPAÑA	<ul style="list-style-type: none"> • Little awareness and anticipation of educational services on the needs associated with autism 	<ul style="list-style-type: none"> • Absence of resources (professional qualification programs, transition to adult life, etc.) that enable people to have employment and live independently • Absence of resources, programs and tools to promote vocational guidance and support for training towards employment • Absence of vocational guidance programs 	<ul style="list-style-type: none"> • Increased awareness in the education system to respond to the needs of autistic students • Training of professionals • Publication and dissemination of good practice guidelines on students on the autism spectrum • Proposal, coordination and management of employment training programs for autistic young people (dual training, socio-occupational skills etc.) 	<ul style="list-style-type: none"> • Participation in platforms for representation and advocacy • Forums address educational reforms and the resources that need to be promoted in the education system (CERMI, Ministry of Education, etc.) • Research on the needs of autistic students and on educational practices (based on evidence)
ANCCP (National Association of Professional Certification Centres)	<ul style="list-style-type: none"> • Good knowledge of the needs of teenagers on the autism spectrum • Needs vary according to the impact of autism on the individual and the level of education they have reached • Needs also relate to level of family involvement and the young person's ability to access ongoing support 	<i>No reference made</i>	<ul style="list-style-type: none"> • Inclusion of autistic teenagers in training centres, where they can learn employment skills • Assistance in development of social skills 	<i>No reference made</i>
CONACEE (Spanish National Confederation of	<ul style="list-style-type: none"> • More than 8% of the Spanish population have some type of 	<ul style="list-style-type: none"> • Increased access to adequate training and job support through pre- 	<ul style="list-style-type: none"> • Personal and social adjustment teams 	<ul style="list-style-type: none"> • In Spain the legislation of Dual Training applies to young people under 30

Sheltered Employment)	disability, more than 3.5 million people	<p>work practices in the workplace</p> <ul style="list-style-type: none"> • CONACEE has asked for the linking of practices in Special Employment Centres to promote work among groups of people with disabilities 	<p>support the work activity of groups with disabilities</p> <ul style="list-style-type: none"> • Workers with autism within work centres associated with CONACEE employers usually choose to work with analytical content • Engagement with companies at a local level to reinforce the hiring of people with disabilities 	<p>years but does not limit the age in the assumption of people with disabilities</p> <ul style="list-style-type: none"> • Currently by law it is mandatory for employers to have at least 2% disabled workers (marked by LGD 1/2013)
Individual professional (ASD)	<i>No reference made</i>	<ul style="list-style-type: none"> • Social skills development • Adaptive teaching programmes taking into account the development and needs of each person • Preparation for life in the community • Increased opportunity for learning - lectures, conferences • Increased opportunity for meeting spaces to share experiences 	<i>No reference made</i>	<i>No reference made</i>
Social Work Faculty, Complutense University	<i>No reference made</i>	<ul style="list-style-type: none"> • Development of independent living skills • Theoretical learning transformed into practical skills to fully engage in community • Research and interventions for autistic 	The Office for the Integration of Persons with Disabilities (OIPD) attends directly to the whole university community (students, teachers, administrative and service personnel) providing:	<ul style="list-style-type: none"> • Complutense University has more than ten years of specific policy for supporting people with diversity, including Autistic Spectrum Disorder, from age 18

		<p>people (education, psychology, social work etc.) should be promoted from various faculties of the Complutense University</p> <ul style="list-style-type: none"> • Greater awareness from the university community and greater training in order to increase support for people with autism 	<ul style="list-style-type: none"> • Support, information, and guidance • Information on grants and financial assistance • Assistance in planning internship programmes and career advice • Awareness-raising activities within the University to ensure that everyone receives equal treatment • Permanent contacts with the secondary studies centres of the Comunidad de Madrid in order to know the necessities of the future students 	
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Sweden	Local data on young people with autism	Services would like to see developed	Local practical support available	Local strategic support available
Sweden	No information available	No information available	No information available	No information available

Steering committee responses to survey findings for each country

Spain

The different surveys show the realities in Spain for people on the autism spectrum. We are glad and proud that people participated and that this can influence the professionals who work every day with autistic people.

In general, the surveys provide an honest depiction of the situation in Spain for autistic people, and those with other disabilities. These situations are influenced by the government autonomic system, because the support available is dependent on where in Spain you are resident.

The central government is the main legislator of the relevant policies and laws, but each region makes its own decisions around education, social services, health, etc. This means that there may be different priorities in each regional government.

Since 2015 Spain has a very avant-garde and innovative plan around autism. This plan sets the guidelines that have to be established throughout the state, and refers to early care, education, transition to adulthood, employment etc, and also to the promotion of all important areas of a person's life. The difficulty is that each region is completely free to apply it how they see fit. This leads us to think that it is dependent on autonomic government and the financial resources that can be allocated. This fact, added to the current lack of economic resources and budget cuts in social services, leads us to think that this innovative plan is still in the drawers of different departments or autonomous governments waiting for real application.

Greece

The results of the TRAIL surveys show that in Greece there is not enough timely planning for pupils with autism to make the necessary links to support when they leave school. In Greece, people on the autism spectrum are not favoured through existing structures and do not have appropriate preparation to acquire skills that are useful in the professional field (e.g. pre-vocational skills, social skills, self-determination). These skills are an important factor in the success of transition into work and autonomous living.

According to the results of the survey, in Greece, the sectors working in socialization, sensory processing, advocacy and daily life, education and health are not adequately supported by public or private structures. Special therapists may help autistic teenagers by enhancing socialization, improving communication, treating sensory needs, organisational skills and empowering important decisions.

Greece lags behind other countries regarding infrastructure and practices of protection, institutional care and post-employment social inclusion for young people on the autism spectrum. Insufficient staffing of existing structures, lack of specialist staff in social care, health and welfare structures and services are some of the shortcomings identified by respondents. The priorities of autistic people are to raise awareness of autism. Developing strategic alliances between countries with different cultures, levels of experience and existing service infrastructures is crucial to achieving this goal.

France

People on the autism spectrum are individuals, and have individual needs that require personalised support.

The French government is invested in autism, and will draft the fourth autism plan for 2018/2021. National recommendations have been disseminated in order to help professionals from different medical, and medico-social sectors. The policies around autism are an important part of other disability policies.

There are, however, significant differences in the services available in different areas, and they may have a lack of information or training about autism. While there are many support services in France, they are unevenly distributed. Those that are available are often as a result of the actions of families concerned by the unmet needs of their child leading to the creation of a new service or support structure. Families play an important role in supporting their child during this transitional period and often lack assistance.

There are Autism Resources Centers in each region and they are an important source of information but families are not always aware of them. Professionals point to a lack of knowledge, communication, and existing tools, hence the interest of identifying what is done in France, for the creation of the TRAIL guide.

UK

There are national autism policies across the UK, but the implementation of guidance varies around the regions. This means that support and services for autistic people are inconsistent and access can vary. Training and awareness-raising are seen as very important to increase understanding of autism and make communities more accessible.

Budget cuts over a number of years has impacted the diversity of services available. While there is knowledge about the structures that can be helpful and supportive to children on the autism spectrum and their families, many areas struggle to provide the range required. Gaps are filled by voluntary and charity groups where possible.

Transition is recognised as an important period, but the movement between child and adult services can be unsettling, and eligibility criteria may shift. This leaves autistic people and families vulnerable.

While policy and legislation seek to address these vulnerabilities and gaps in services, the application of policy is patchy and requires further work to ensure there is equal access to a wide range of support.