

Social Policy – TRAIL: the road with autism to independent living

Autism is recognised as a neurodevelopmental condition across all partner countries.

There were 26 useable survey responses as well as a variety of policy documents provided.

Information for all topic areas (education, employment, training and daily living) was inconsistent across countries, meaning that some partners may have gaps and others appear to dominate good practice examples. This is not necessary the case, but all detail within this report is based on information available at the time and is as representative as possible.

Country	Disability Policy	Autism-specific Policy
Spain	<ul style="list-style-type: none"> • 1982 Social Integration for Disabled People • 2003 Non-Discrimination Act • 2007 Equal Opportunities Act • National Disability Action Plan and Strategy 2014-20 	<ul style="list-style-type: none"> • Spanish Strategy for Autism
Greece		<ul style="list-style-type: none"> • National Policy for Autism Spectrum Conditions • Social inclusion in school and transition to work for people in the autistic spectrum: Theoretical issues and educational interventions 2007
France		<ul style="list-style-type: none"> • Autism Plan 1: 2005-8 National guidance • Autism Plan 2: 2008-10 • Autism Plan 3 :2013-17 • Coordination, education and treatment interventions in children and adolescents 2012 • Diagnosis and evaluation in adults 2011 • Autism and other PDDs: state of knowledge and basic research 2010

Country	Disability Policy	Autism-specific Policy
Sweden	<ul style="list-style-type: none"> • General disability policy • Social Services Act • Health and Medical Services Act • Education Act 	<ul style="list-style-type: none"> • Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS)
UK	<ul style="list-style-type: none"> • Special Educational Needs and Disabilities Code of Practice 2014 • Care Act 2015 • Equality Act 2010 	<ul style="list-style-type: none"> • National Autism Strategy 2009 and 2014 (England) • Statutory Guidance 2015 (England) • Scottish Strategy for Autism • Northern Ireland Autism Strategy and Action Plan 2013-20 • Welsh Autism Strategic Action Plan 2008

Overview of social policies

All partner countries vary in the age young people move between adult and child services, and how they are supported. Sweden is the most consistent, with social care support provided across the age range. While some educational and social care support is available up to age 21 (Spain), and 25 (Greece, UK, France), the focus on the needs of young people age 18 tends to be around work/employment and health. Access to social care services after age 18 is much more limited, although there are some benefits available.

Some countries have specific pathways for young people in education, health or social care. There is recognition that these do not always align, and that there are different levels of support available for children and adults. The biggest gap for adults is around life skills, community activities and advocacy/personal autonomy.

National ethos/aims

In general, the aims of national policies are very similar, based around:

- Respect for independent living
- Training
- Empowerment of individual rights
- Equal participation in community and employment
- Involvement of parent carers and people with autism in care planning and support

General disability policies

Partner countries have robust disability policy to support equal opportunities and minimise disability discrimination. This is reinforced by the European Convention on Human Rights.

National benefits

Some young adults with autism may be eligible for various disability support and benefits.

Financial benefits are paid at differing levels of need in Spain, Sweden, UK and France. Applicants have to meet specific criteria.

Summary of partner countries autism specific policies

All partner countries have autism specific strategies. France has been working to an autism strategy for the longest, since 2005, and is now on its third version of the plan. France, Spain and Sweden's strategies cover children and adults. The UK strategy focuses on adults, but does include reference to young people age 14+, and has been replicated at a local authority level, identifying local developments required. The policy in Sweden incorporates other 'functional impairments' as well as autism.

There is very similar focus in all strategies, covering diagnosis, awareness, training, independent living and education/employment:

- Spain: awareness and sensitisation, accessibility, investigation, professional training, detection and diagnosis, early support, specific and integral intervention, health and healthcare, education, employment, independent life, social inclusion and citizen participation, justice and empowerment rights, family support, and quality, equity and services sustainability.
- Greece: vocational education and training, work and employment, health and social welfare
- France: diagnosis and early intervention, support through life, supporting families, continuing research, education and training
- Sweden: right to counselling and personal support, personal assistance, companion service, personal contact to support in community, relief in home, short breaks, childcare, living in special family homes, residential services for adults, daily activities,
- UK: making sure that more people understand about autism, making it easier for adults to get a diagnosis of autism, making it easier for adults with autism to choose how they live and get the help that they need to do this, helping adults with autism to find jobs, helping local councils and health services to write plans so that the adults with autism who live in their area get the help that they need.

Autism strategy good practice

Key policy points relating to young people with autism detailed in national strategies:

France

- A recommendation of good practice is being implemented through TRAIL as part of the action "autism and other PDDs: interventions and personalized project in adults" (to be released in December 2016); the purpose of this recommendation is "to ensure continuity of interventions to be implemented with children and adolescents in the transition to adulthood and throughout their lives, and to adapt the methods of intervention and organization to support for adults." (Marie-Arlette Carlotti, Minister for Disabled People and the fight against exclusion, May 2013).
- Functional organizational scheme at regional level will be implemented to ensure the efficiency of the care path continuity by supporting the cooperation between different devices involved in the diagnosis, medical and social support or care together with the Departmental Houses For People with a Disability (MDPH).
- Support the educational inclusion of children as well as the accompaniment of young adults growing old.
- The recommendations of good practice of the HAS and ANESM, especially those which focus on the interventions for children and teenagers (March 2012), must be disseminated and implemented.

Spain

- Promote the implementation of effective interventions for ASD people.
- Get a useful coordination system between key sectors (education, health, employment, etc.) to achieve the goal above; promote the development, implementation and evaluation of this coordination.
- Enhance services to guide ASD people in their transitions between different educative cycles
- Promote coordination mechanisms to facilitate the support through the whole life of ASD people.

Sweden

- Schoolchildren over the age of 12, who are no longer covered by general childcare services, can receive supervision before and after the school day and during school holidays.
- Children as well as adults can have personal assistance.

Greece

- The attendance of students with diffuse development disorders (autism spectrum disorders) at special schools (SMEAE) can be prolonged beyond the age of 23, depending on their special educational needs.
- Development of a preferential compulsory quota system which ensures the employment of socially vulnerable groups not only in the public but also in the private sector.

UK

- Where individuals do not fulfil referral criteria for adult services, there should be clear signposting to other sources of support and information; however, commissioners should also be vigilant to spot discontinuities between provision for young people and adults.
- Young people with autism, whether they have an Education Health and Care (EHC) plans or not, can expect to be helped with their transition from school or college to adulthood. Local authorities have duties under the Children and Families Act 2014 at the annual reviews of a child's EHC plan from Year 9 (age 13 to 14) onwards to consider what provision is required to help the child or young person in preparation for adulthood and independent living. The expectation is that consideration of preparation for adulthood should begin right from the earliest point that special educational needs are identified.
- Local authorities should work together with education providers and their partners to help children and young people realise their ambitions in relation to: higher education and/or employment – including exploring different employment options, such as support for becoming self-employed and help from supported employment agencies; independent living – enabling people to have choice and control over their lives and the support they receive, their accommodation and living arrangements, including supported living; planning in relation to the provision of services for people with autism as they move from being children to adults 25; participating in society – including having friends and supportive relationships, and participating in, and contributing to, the local community; being as healthy as possible in adult life.
- Children, parents and young people should be provided with information about the provision that is available on transitions to adult life, for example, through the Local Offer.
- Planning for transition should start early, and for children with EHC plans, must start in Year 9 (age 13-14).
- Agencies across education, health and care should work together, perhaps setting up a transition pathway, to support good transitions to adulthood. Transition planning should cover all relevant areas of service provision, including housing and employment support.
- The local authority should co-operate with health services to ensure that young people's EHC plans and health care plans are aligned.
- Local authorities should consider effective planning for the transition to adult health and care services and, where a young person with autism is nearing the end of formal education, consider good exit planning when carrying out transition planning.
- Local authorities should work with schools, colleges and other post-16 providers, as well as other agencies, to support young people to participate in education or training and to identify those in need of targeted support to help them make positive and well-informed choices.

- Post-16 providers (including school sixth forms) are expected to offer all students a study programme which is coherent, appropriately challenging, and supports the progression of the individual. Study programmes are programmes of learning for 16-19 year olds, or 16-25 year olds where the student has an EHC plan (or a statement or LDA issued under the previous SEND regime). They are based on a young person's prior attainment and designed to meet clear educational and career aspirations.

Education good practice

All partners have access to public school, special school or vocational training dependent on young people's individual ability. Some countries provide additional support for students in mainstream education. There are a range of qualifications and employment routes after education.

There is a focus on training for schools around developing curriculum, autism awareness, resources and family support. There are several education plans for children and young people.

Good practice example: education

In Greece, there is investment in the education of young people with Special Educational Needs until age 25. Special vocational high schools and centres of vocational education and training provide support and qualifications up to degree level.

- France: support in mainstream education, and adapted education
- Greece: support in mainstream education includes training for schools, curriculum, software, family support
- Spain: developed network of specialised school centres
- UK: Education Health and Care Plans for young people, with a duty to meet identified needs, planning for adulthood starts age 13-14

Employment

There is a strong desire to improve access to work and employment for people with autism. Countries have various initiatives to support disabled people into work, some of which are eligible for people with autism.

Good practice example: employment

In Spain the government sets a quota of disabled people to be employed (2% workforce), or businesses have to pay a donation to charity.

- Spain: Employer access to grants to support disabled people
- Greece: three-year subsidy programme for employers to support disabled people, plus commitment to support people for a further 12 months
- Sweden: daily activities under the LSS are measures to which people with intellectual disabilities, among others, are entitled, it is oriented towards people of working age who have no job or other meaningful occupation, and who are not participating in work; the overall goal of the activities is to improve the individual's chances of getting a job or to participate in a meaningful occupation during the day; the measure covers both habilitation and more production-oriented activities, and is to promote personal development and be adapted to the individual's wishes and needs
- UK: Education Health and Care (EHC) plans include employment aims and activities; Access to Work is a government funded programme to support disabled people into work

Living support good practice

There are different levels of support available through social care and housing. While many countries aspire to the provision of social care services, to increase independence and support, the success and consistency of access is unclear. Sweden, France and the UK seek to offer short break/respice care to children and young people with autism, although amount available varies.

All countries seek to involve young people and families in care support planning, ensuring their wishes and needs are reflected in actions. If people have a care plan, many of these are reviewed annually.

Good practice example: living support

In Sweden, adults with disabilities (including autism) have a right to counselling and personal support as a supplement to statutory social welfare services.

- UK: Legal right for an assessment of needs from social care services if diagnosed with autism
- Sweden: access to childcare for children 12+ with autism, before/after school and in holidays
- France: planned development of 1500 new housing placements for autistic people with medical and social care needs
- France: increase of 'time off' childcare places for children with autism from 40 to 350
- Greece: monitoring support unit 'Psychochargos', to facilitate early organisation of integrated services
- Spain: must receive free assistance guaranteeing access to education, health, employment and training to achieve social inclusion and development

Other good practice

All strategies include reference to the need to increase training for professionals, and improve skills and knowledge, particularly for health, social care and education practitioners.

Good practice example: other

In the UK there is bi-annual monitoring of national strategy progress at local authority level (through Autism Self-Assessment Form), including questions on transition from child to adulthood.

- France: Autism Resource Centres (CRAs) quality assure and coordinate diagnosis, training and local services; also coordinate research studies and projects
- Spain: two autonomic action plans for autism
 - Madrid 2012 - collaboration with different disability organisation, creating an interdisciplinary work team to get a real understanding of autistic people and resources required to support
 - Catalonia 2008 – protocol to enhance early diagnosis, organise autism support and education
- Greece: limited liability cooperatives and social economic enterprises set up to support disabled/autistic people
- UK: Good practice guide to transition www.autism.org.uk/about/strategy/practical-guidance.aspx

Gaps in social policy

From the information provided by partners to date, it is not possible to be precise about specific policy gaps for each partner country. However, some broad conclusions can be drawn. See appendix 2 for a more detailed analysis.

Lack of policy at a local level

The largest gap in policy appears to be at a local/organisational level. While there are some good examples (such as the regional policies in Catalonia and Madrid, and local strategies in the UK), the picture is inconsistent across each partner country.

A lack of networks for sharing good practise

Currently there are no strong networks for sharing good practice in each partner country or between countries. Developments achieved by organisations and/or countries have no obvious forum to enable learning from neighbours.

Outcomes not defined or measured

Many policies and strategies have aims and outcomes that are not clearly defined, nor are there any obvious systems in place to measure outcomes in each country. There is a lot of positive drive towards improvements, but a lack of detail as to how those achievements will be made. Apart from Sweden, which has a very detailed Act covering social care and community support, there seems to be a gap in community engagement and support provision for other countries.

Conclusion

Whilst it may look like a few countries dominate good practice examples; this is not necessarily the case but is based on the available information provided by partner countries when the Survey 1 data was collected

There are robust strategy and policy structures supporting the development of services for young people with autism. These are important to provide guidance at a national and regional/departmental level.

The collation of examples of innovative practice will enable a more thorough analysis of national developments, and whether policy aims and objectives are being delivered in practice. While all countries have clearly positive ambitions for young people with autism, it remains to be seen whether the policy and strategy framework successfully delivers on these.

Appendix 1: Headline Table – Social Policy

- Autism is recognised across all partner countries as a neurodevelopmental condition
- Survey responses: 13= Greece, 8 = UK, 5 = Spain, 1 = Romania (excluded from partner evaluation)

	Policies and Laws	Aims	Education	Employment/Training	Living support	Good practice
SPAIN	<ul style="list-style-type: none"> -1982 Social Integration for Disabled People -2003 Non Discrimination Act -2007 Equal Ops Act -National Disability Action Plan and strategy 2014-20 	<ul style="list-style-type: none"> -Respect for independent living -Autonomy -Training -Empowerment of rights and promotion of justice -Reduce unemployment 	<ul style="list-style-type: none"> -Transition age 18-21 -Difficulties in system for teenagers, and lack of early intervention 	<ul style="list-style-type: none"> -Employer access to grants to support disabled people 	<ul style="list-style-type: none"> -4 x rates of social security available -Housing options include own home, family, supervised, assisted and residential care 	<ul style="list-style-type: none"> -ASC recognised as developmental disorder -Employers obliged to employ disabled people as 2%+ of workforce or make donation to charity -National Disability Action Plan 2014-20 -Participation and quality of life (model in Basque country) providing care and support to people with intellectual disabilities – based on care ethics supported by quality management

	Policies and Laws	Aims	Education	Employment/Training	Living support	Good practice
GREECE	-National Policy for ASC	-Compulsory special education -Equal participation in society -Self-sufficiency and autonomy -Diagnosis and interventions	-Public school education free - Some special schools with specific PDD education programmes -Investment of Special Educational Need until age 25 -Special schools and vocational training can support up to age 19 (certificate of work) or 23 (degree) -Support in education includes training for schools, curriculum, software, family support	-3 year subsidy programme for employers to support disabled people – they commit to supporting for further 12months -Non-profit ‘Greek Company of Assisted Employment’ promotes rights of disabled people, sets up personal placement services -Limited liability social cooperatives and social economic enterprises available -Consider teleworking option for people unable to do regular contracted employment	-Provision of MH services to diagnose, treat and support - ‘Psychocharges’ – monitoring support unit, tool to facilitate early organisation of integrated services	-ASC recognised as life-long developmental disorder -Varied education options for young people up to 23y -Promotion of employment rights for disabled people

	Policies and Laws	Aims	Education	Employment/Training	Living support	Good practice
FRANCE	<ul style="list-style-type: none"> -Coordination education and treatment interventions in children and adolescents 2012 -Diagnosis and evaluation in adults 2011 	<ul style="list-style-type: none"> -Rights, dignity and personal choice respected -Parent carers and people with autism are informed and involved in care planning 	Nothing identified from documents provided – all heavily focused on diagnosis	Nothing identified from documents provided - all heavily focused on diagnosis	<ul style="list-style-type: none"> -Assessment to identify needs before diagnosis -Further assessment 3m after diagnosis to review needs -Annual care review and feedback meeting with families -Interventions focus on support needs -Prepare families for transitions 	<ul style="list-style-type: none"> -Professionals involved in diagnosis and assessment have access to tools and training specific to developmental disorders: should update every 2-3y -Diagnosis based on observations and information from all professionals/settings

	Policies and Laws	Aims	Education	Employment/Training	Living support	Good practice
SWEDEN	<ul style="list-style-type: none"> -General disability policy -Social Services Act -health and Medical Services Act -Education Act -Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS) 	<ul style="list-style-type: none"> -Equal part of community and living conditions -Identifying and dismantling obstacles in society for full participation -Providing tools for independence and self-determination 	Nothing identified from documents provided	Nothing identified from documents provided	<ul style="list-style-type: none"> - Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS)= 1. Right to counselling and personal support (qualified expert help) as supplement to social welfare services 2. Personal assistance (local and national funded) 3. Companion service if not eligible for 2. – make easier to participate in community 4. Personal contact to support in community 5. Relief service in home 6. Short breaks 7. Childcare age 12+-if not covered by general childcare, before/after school and holidays 8. Living in special family homes if cannot live with own parents 9. Residential services for adults 10. Daily activities if not in employment 	-Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS)

	Policies and Laws	Aims	Education	Employment/Training	Living support	Good practice
UK	National Autism Strategy and Statutory Guidance (England) SEND Act Care Act Scottish Strategy for Autism	-Independence and self-determination -Access to services and support when people need it -Support and guidance to achieve potential and positive outcomes	-Special and mainstream schools available; Education Health and Care Plan (EHCP) to identify support needs – schools have duty to meet identified needs -Planning starts 13-14 years through school review -Scottish transitions forum - http://scottishtransitions.org.uk/	-EHCP and care plans cover employment and living plans -Access to Work supports disabled people into work -Employment Support Allowance benefit if preparing to work/unable to work due to disability -Plans for JobCentre and Department of Work and Pensions to have access to autism awareness training	-EHCP communication of identified needs across services -Right for an assessment of needs from social care (if diagnosed with ASC) -Parent carers and young people involved in all support planning	-NAS Good practice guide: Transition and Employment http://www.autism.org.uk/about/strategy/practical-guidance.aspx -EHCP process, partnership communication and early planning -Overarching strategy encompassing health, social care, employment and support

Appendix 2: Identified gaps in transition support and policy for children and young people with autism

These are gaps identified through policy documents and survey responses – partners may provide more information to prove otherwise

UK	Greece	Sweden	Spain	France
Lack of interagency policies				
Good practice is not widely shared – whether in local, regional, national or international frameworks	Equity of access to education support	Development of guidelines for psychosocial support and evidence-based interventions	Development of guidelines for psychosocial support and evidence-based interventions	Good practice is not widely shared – whether in local, regional, national or international frameworks
Community engagement and social care support provision	Development of guidelines for psychosocial support and evidence-based interventions	Good practice is not widely shared – whether in local, regional, national or international frameworks	Good practice is not widely shared – whether in local, regional, national or international frameworks	Planning from a young age for young people moving to adult services
	Good practice is not widely shared – whether in local, regional, national or international frameworks		Planning from a young age for young people moving to adult services	
	Community engagement and social care support provision			