

# Life on the Edge of the Cliff

*Post school experiences of young people  
with Asperger's Syndrome, ADHD and  
Tourette's Syndrome*

**FINAL REPORT**

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The transition process

- Effective support before and during transition has to equip all young people to answer three fundamental questions:
- Where am I going?
  - How do I get there?
  - Who/what do I need to help me and how do I access this?

This is as true for young people with Asperger’s Syndrome, ADHD and/or Tourette’s Syndrome as for their peers, but they may face additional challenges.

Making the transition to adulthood successfully depends on the ability to plan ahead, conceptualise, and prioritise steps to achieve a goal, along with being able to organise time and activities in support of it.

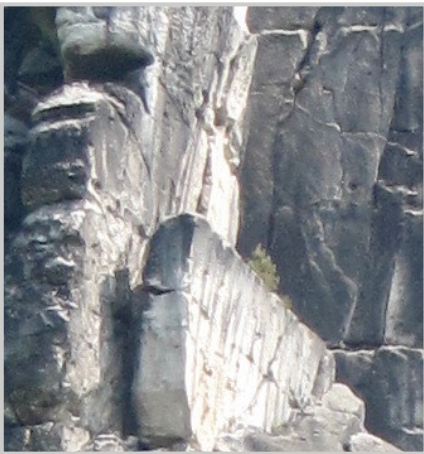
It’s worth bearing in mind that not one of these essential skills comes easily or naturally to young people with these conditions.

Navigating a new landscape with different professionals and expectations, a looser structure, and less involvement from parents and other support networks may be overwhelmingly stressful for those who already find it difficult to interpret the world around them. For some, adjusting to the world beyond home and school will mean developing new strategies to manage sensory issues or challenging behaviours. If they did not thrive in the school system their academic qualifications may not match their ability or aspirations, and they may not yet have acquired life skills that come more intuitively to their neurotypical peers.

No surprise, then, that taking responsibility for their own physical, emotional and social needs, and for achieving a personally fulfilling life, is unlikely to take place in the same way and to the same timescale.

The journey to adulthood arguably has a clear enough point of departure, when school ends and adult services replace those intended for children and families, but the point of arrival is far less clear cut. Young people with conditions that may lead to significantly higher levels of support needs than their peers will almost certainly fail to complete the journey successfully if these needs are not met. Where effective support services are lacking, parents and carers are frequently forced to fill the gaps, and it is not clear at what point they are expected to hand over the reins – or to whom.

This study identified three countries with strong legislative commitments to inclusion and integration of people with learning difficulties and



“If a leg doesn’t work, it’s obvious, and many of the things you can do about it are also obvious. But if the brain doesn’t work, the effects can be very widespread and difficult to understand.”

**This report is for the young people I met during this project, who were hugely impressive in their honesty, intelligence, friendliness and ability. Also their families, who are passionate, determined, and committed in supporting these young adults to find their place in the world. Together they are an amazing resource. We are lucky to have them.**



Study visits took place in Italy (23 May – 7 June 2015), Norway (23 October – 13 November 2015) and the Czech Republic (31 March – 15 April 2016). Individual reports on each visit are available.

For more details, visit [www.lifeontheedgeoftheclass.com](http://www.lifeontheedgeoftheclass.com) or contact [traceyfrancis1997@outlook.com](mailto:traceyfrancis1997@outlook.com)

Life on the Edge of the Cliff was undertaken with a Travelling Fellowship from the Winston Churchill Memorial Trust. For more information on the Trust and its activities, visit [www.wmct.org.uk](http://www.wmct.org.uk)

Quotations throughout are from interviews undertaken during the study visits.

University inclusion officer



# Summary and key points

disabilities in mainstream education, employment and community life. The aim was to explore how far these aspirations translated into support that made a difference in the lives of young people and their families.

In each country there were approaches and projects that demonstrated excellent and effective support for the young people who are involved in them, and some are shared here. But, in common with the UK, there is a warning we cannot afford to ignore. Too often, projects and programmes are not creating systems and support structures that ensure every young person has the same chance as their peers to fulfil their potential and contribute to the society in which they live. We need to ask why that is. Funding plays a part, but it is very far from the whole story. Far more important is attitude: a commitment to developing a culture of acceptance, aspiration and achievement; to building an informed and appropriately skilled workforce; to signposting information and services more effectively; and to creating structures that promote a collaborative, multi-service support structure.

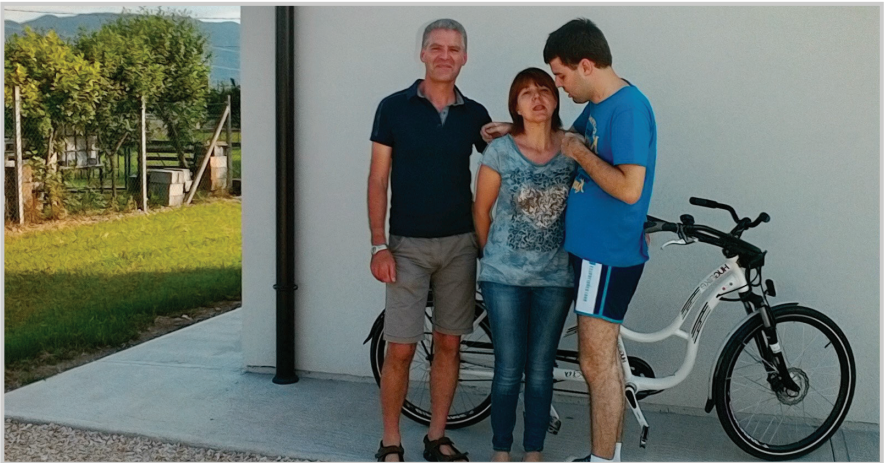
Many who participated in this project – professionals and practitioners as well as parents and young people – pointed to significant gaps between what was meant to happen and what took place in practice. Too often, people expressed the opinion that positive experiences were down to luck – which corresponds with experiences in Scotland and the UK as a whole. The big question for every country, therefore, is how much we want to tackle that inequality.



Statped is the Norwegian national agency providing special education services to municipalities and counties. Its mandate is to help children, adolescents and adults with special educational needs to be active participants in education, employment and society on an equal basis with others

*“In primary they have assistance all the time. In secondary it gets less and less, and disappears. And when you should manage by yourself you have no one to lean on. Maybe they don’t need all those assistants when they are seven. Maybe they should put them in at the end of the education system instead.”*

Assistive technology advisor



Parents with their 20-year-old son at Godega di Sant’Urbano, Italy, where Oltre il Labirinto is developing a model for lifelong support (see pp. 15 and 23)

Professionals and practitioners, as well as young people and their families, largely identified very similar challenges within their own systems despite the very different social, cultural and particularly economic backgrounds of the three countries.

These included:

- Too much focus on theory, not enough on making a practical difference.
- Failure to think, plan and fund long term.
- Service managers out of touch with the daily lived experiences of young people and families.
- Lack of understanding and specialist knowledge among service providers, particularly within education and health.
- Too little collaboration across service boundaries.
- Rigid systems and structures acting as a barrier to flexible provision.
- Widening services gap: existing services not meeting the need.

It was universally recognised that the last 10 years has been a period of unprecedented economic pressure, particularly for public services. However affordability of services or the need to develop new programmes (with the exception of the call for specialist training for practitioners) came surprisingly low on the list of challenges compared with the need to invest in sharing information and improving access to services that already exist.

This report focuses on five key themes relevant to this group of young people. These have been identified within an overall context that took into account workforce; rights, entitlements and benefits; employment; education and training; participation; inclusive working across age boundaries; and inclusive models for remote and rural areas. The themes are:

- Cultural approach.
- Arriving at a positive outcome.
- Getting the right support at the right time.
- Therapeutic interventions.
- Changing role of parents, carers and families.

*“It’s not the individual with a learning difficulty that’s the problem, or even the learning difficulty itself. WE are the problem, unless we can find a way to break down the social barriers.”*

Psychologist



# Key points

- **This is a pivotal time in the lives of young people.** Wrong decisions in the years after school can be difficult, and costly, to undo. Some never get back on track, with long term impact on their earning potential, health, and ability to live independently or with greatly reduced support.
- **Structured activities, therapeutic intervention and a clearly defined pathway are key** to maintaining momentum and motivation after leaving school.
- **There is an urgent need for more post school options** that allow time to develop social and life skills.
- **Post school pathways need to be clearer**, especially for those who are not ready at the time of leaving school to progress to further education or employment. Many young people in this group will require substantial additional support to explore their options and parents, support workers or others may need to be involved in these discussions.
- **Planning should be based on a holistic assessment** of a young person's capacities, abilities and potential as well as their academic achievements, personal interests and goals. There is an urgent need to identify who is responsible for coordinating planning and support beyond school.
- **A culture of aspiration and achievement is essential** in maintaining motivation and building confidence.
- **Diagnosis is only a partial indicator of what support may be necessary.** A diagnosis does not provide a full picture of challenges that exist or how they impact on the individual. Diagnoses can be incorrect, incomplete, or fail to reflect the full picture (such as the presence and impact of additional disorders).
- **Developing the ability to live independently, or with greatly reduced support, should be an explicit aim.** This requires identifying barriers specific to the individual and planning a systematic approach to addressing these.
- **Key skills** are resilience, self confidence, ability to work with others, flexibility and problem solving: support should focus on developing these alongside practical skills needed for independent living.
- **Therapeutic input is hugely important.** The availability of psychoeducation, counselling and therapy can make a difference to outcomes.
- **Services and support have to be accessible, not just available.** This requires a proactive approach to engaging with young people with these conditions and maintaining contact. The inability of some young people with Asperger's Syndrome to ask for help, for example, was mentioned by university inclusion staff and supported employment agencies as a significant barrier to accessing existing services. Support has to be clearly signposted and a flexible approach to communicating is essential: face to face, telephone/ text or email/online depending on the individual.
- **An "early intervention" approach to addressing problems and difficulties** can make a big difference to achieving a positive outcome. Services have to be more clearly signposted with better pathways.
- **It is important to be realistic.** This includes managing expectations and being realistic about the time investment needed both for planning and support.
- **There is a need to work closely with families**, particularly in the early years of the transition process. This is especially so if services are depending on families to play a key role in providing practical, financial or emotional support. Family circumstances and capacities must be taken into account.
- **The right to complete educational entitlement at a later date** is of enormous benefit for young people who miss school as a result of physical or mental health conditions.
- **Clear pathways back into services (including education and healthcare) and support systems are important.** Because these conditions are lifelong, requirements can be expected to fluctuate over time according to changing circumstances: it is important to be able to access appropriate services to develop new strategies if needed. For adults in particular, there needs to be a clear and obvious access point.
- **Develop strategies that promote integration.** This includes steps to build tolerance among the wider community, and to build the capacity of young people to integrate more successfully.
- **Skills development among professionals and practitioners is urgently needed.** This includes improving awareness; developing a team mentality with other disciplines and family members; and increasing numbers of specialists who work with young people with organisational and communication difficulties.
- **Investment in communication is essential** and cost effective in raising awareness, sharing information, increasing participation/engagement, and supporting self help strategies and peer support networks.

# Life on the Edge of the Cliff—the project

## What we can share, what we can learn

This is not an academic study. Its aims have been to gather the experiences of high functioning young people affected by Asperger's Syndrome, ADHD and Tourette's Syndrome, and their families, as they make the transition into adulthood; and to provide a European context by sharing the experiences of three of our European neighbours.

The clinical, neuroscientific and diagnostic profiles for these three conditions are well documented elsewhere by those working in this field. This study's concern is with the impact of the conditions on individual wellbeing, attainment and social inclusion.

It considers how best to meet the very particular needs of these young people and their families, how to ensure they are fully engaged and represented in the transition process, and how services can better support sustainable positive destinations for this group.

### Countries visited

Between May 2015 and April 2016, three European countries were visited: Italy (2 weeks), Norway (3 weeks) and the Czech Republic (2 weeks).

These countries were selected because of their shared legislative commitment to social inclusion for people with neurological or psychological disabilities, but different cultural approaches to delivering this – particularly in relation to the role of national and local government, current economic pressures, attitudes towards families and carers, and general public awareness of these conditions.

### Hidden difficulties

The study focuses on Asperger's Syndrome, ADHD and Tourette's Syndrome because one thing these conditions have in common is that the difficulties someone is living with may not be immediately apparent. This means young people can be at the back of the queue when it comes to recognising and providing the support they need: but without the right support, many may be unable to progress successfully to further education and training or employment despite having an average, or in some cases well above average, IQ.

When the right support is not forthcoming able and intelligent young people are facing significant barriers to social and economic inclusion, and potentially long term, high level dependence on welfare and social services. For most European countries this is economically unsustainable, as well as personally and socially undesirable.



*"Dykkaren" ("the Diver")  
by Ola Enstad at Aker  
Brygge, Oslo harbour*



*“Society has become more difficult to live in for people who are a little different.”*

Psychiatrist

## Next steps

It is time to look at what is needed to ensure these young people have the best possible chance of living independently or with greatly reduced dependency; taking opportunities available to them; engaging with their communities; and achieving personal fulfilment.

The project looked at the experiences of young people in the years immediately after leaving school, so approximately between the ages of 18 and 25 (although this was flexible according to individual experience).

The name of the project – Life on the Edge of the Cliff – refers to the feeling many people express when school and children’s services are coming to an end, but it is by no means clear what is going to happen next. In some cases, support drops away to such an extent that it is clear why the image is appropriate.

## Managing the project

In each country I met and interviewed practitioners and service providers in health, education and social services, along with young people affected by Asperger’s Syndrome, ADHD and/or Tourette’s Syndrome and their families.

All the background information to the project was available in the language of the home country in each case, including the questionnaires completed by young people and families, and participants chose whether to answer in English or their own language. Where necessary, I employed interpreters to ensure clarity.

Everyone who agreed to take part in the project did so freely, and gave consent for their experiences to be shared. All quotes and personal stories provided by young people and their families are used without any identifying information, other than the country in which the conversation took place.

## About the researcher

Tracey Francis is a freelance writer and researcher with extensive experience in communications and children and young people’s policy at national and European levels. She has worked for children and young people’s charities in Scotland since 2002, most recently as Communications and Administration Manager for Mindroom, a Scottish charity supporting people with learning difficulties and their families. In September 2015 she left to support her 19-year-old daughter through her own post school transition. She is particularly interested in improving the chances and life choices available to young people who face barriers to learning, and in sharing good practice across international boundaries.

*“If we can support young people enough in the transitional years the outcome can be quite good. But it can be bad as well, if we don’t.”*

Psychiatrist

## 1. Cultural approach

In **Norway** there is an acceptance of difference and a predisposition towards inclusion that underpins planning, provision and funding. There is a strong communal sense that the right support should be available to people who need it, when it will benefit them most, and a strong cultural sense of shared responsibility or obligation: an expectation everyone will play their part in making something happen. Central government only deals with and funds organisations that evidence a sizeable membership, meaning multiple competing charities rarely survive: this is closely regulated and supports a cohesive, centralised approach.

In **Italy**, there is heavy dependence on regional authorities to implement national policy, which contributes to a wide variation in priorities, practice and funding across the country. This, coupled with severe economic pressures, has led to a breakdown in services in some regions, particularly in the south. Two regions visited in this study have traditionally had a commitment to strong public services: the third leans more towards private provision. Families play a key role in supporting members who are vulnerable and some organisations, like the ADHD association AIFA Onlus, rely heavily on volunteers.

In the **Czech Republic** care and support was a family responsibility during the Communist years, and this pattern of thinking still has influence, especially outside the cities and among older age groups. The only other provider of support in these years was the state, and there can still be a lack of trust of private organisations and services. Non-governmental organisations (NGOs), dependent on government funding, play a key role.

*“Everyone has a role but they all need to be involved to make the person successful. If there is no effective communication, it’s really pointless.”*

Neuropsychiatrist

## NevSom: thinking as one

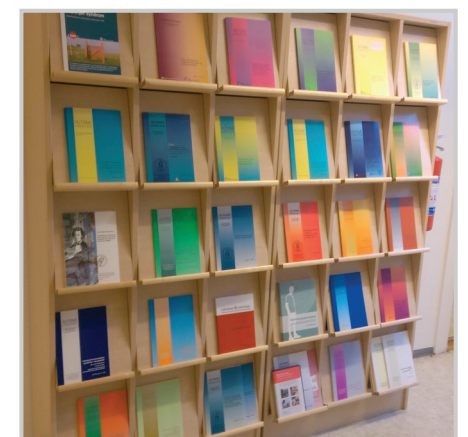
**NevSom, Norway’s new national competence centre for neurodevelopmental disorders and hypersomnias, opened in 2015 and is a merger of two former national units: for autism, and for ADHD, Tourette’s Syndrome and narcolepsy.**

Its focus is on improving policy and practice for individuals and families affected by one of the four conditions and it works across all age groups, from early childhood to old age.

Staff believe it is vital to close the distance between researchers, practitioners and families, and point

to the benefit of sharing knowledge and resources to create a centre of excellence for information, guidance and research.

NevSom is mostly funded by the Department of Health, but applies for alternative funding as required for particular projects. It collaborates with the four health regions, municipalities throughout Norway, and the parents’ associations for each condition to provide information, guidelines and resources. It also advises central government on national policy and practice.



Research and resources into autism, ADHD, Tourette’s Syndrome and narcolepsy at Norway’s new national competence centre NevSom in Oslo



## Putting the pieces together

Tuscany has a regional protocol for spectrum conditions accepted by education, health and social services, which has significantly improved cross sector collaboration: health and social services practitioners work within schools, and individual plans reflect aspirations for social integration as well as educational attainment.

Diagnosis includes functional as well as clinical assessments, and is the basis for customised therapy programmes comprising medical interventions, recommendations on adjustments, and assessment of individual potential. For older pupils and adults, individual plans include assessment of specific capacities and abilities as part of a pathway into further training and work. Schools and families are seen as an integral part of the system, with a role alongside other professionals in delivering specified



The ceramic industry is important locally and mosaics are in demand commercially: developing creative skills at Cerbaiola

interventions as part of the overall care and therapy plan. Progress towards social integration is the underlying principle for all individual plans.

For those with an autism diagnosis, there is flexibility over when they are transferred to adult services, with some young people able to remain within young people's services up to the age of 25.

## Making joined up working a reality

**In Norway an individual plan may be created at any age if multiple services need coordinating.** But in Tromsø, the *Bedre Tverrfaglig Innsats* ("better interdisciplinary effort") or BTI initiative is taking this further by introducing a partnership model for all children and young people from 0–23 years of age. This encourages simpler plans with a central point of contact at every stage.

Sampro, a web-based individual planning program, is being used to streamline collaboration. Details are held centrally and accessed remotely by those involved in delivering the plan – including young people

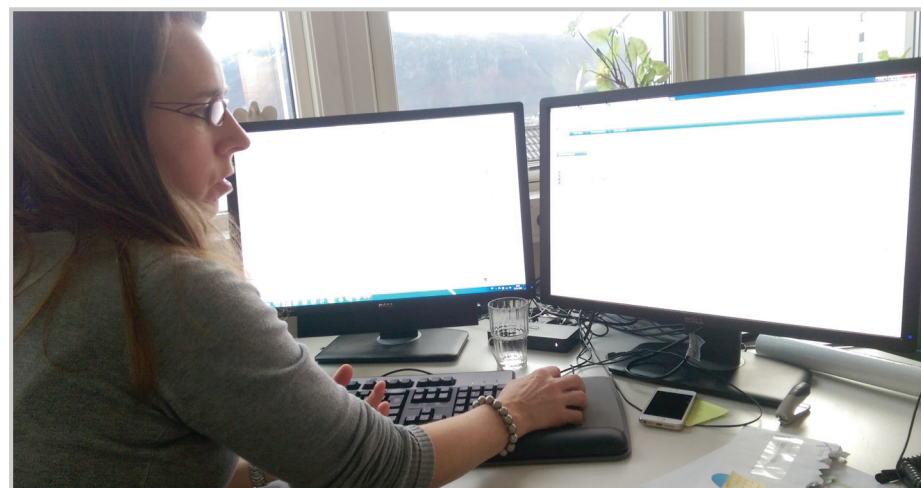
and families, through their own PCs. A lead professional from whichever agency is most involved manages online access and information can only be viewed by those with the necessary permissions.

The advantages are clear. All those involved can access the same information, avoiding the endless repetition many families find challenging. It is easy to see which services and professionals are providing support, and what actions are ongoing. Managing access allows the group around the individual to evolve as necessary, making it highly flexible and responsive.

The online platform can be accessed at any time, so queries or concerns can be posted as they arise and do not have to wait until a meeting can be arranged. This is particularly helpful when it is a challenge to bring multiple professionals together, or where communities are remote or geographically scattered. Minor issues can be dealt with more promptly, and major concerns identified earlier.

Another advantage is that online access can break down the social anxiety of physically meeting with multiple professionals, which can be a barrier to engagement and understanding for some young people. Taking away this stress factor, and having the chance to read, absorb and respond to information at their own pace, could contribute enormously to empowering and enabling some young people to take a more active role in planning their own support.

Heidi Matre of the coordination office in Tromsø demonstrates Sampro, a web-based individual planning program introduced into the municipality in 2014



## 2. Arriving at a positive outcome

Three categories of destination are open to young people leaving school: further or higher education, first employment or training, or neither of these.

Clearly the word "destination" is a misnomer, as none of these three are where any young person might expect to stay for the rest of their lives: they are staging posts on a journey. The distinction is important, because what represents a positive next step may be very different for each person.

For those who are clear about what they want to do and have the appropriate qualifications, identifying next steps can be more straightforward, although this does not automatically mean a young person is able to access and complete a course or a training programme: their ability to do so may well be limited by their individual support needs.

For those who did not leave school with qualifications at an appropriate level, may not have developed the social skills required for employment or training, are struggling with mental health issues such as anxiety or depression, or are unable to visualise what their next steps might entail, the situation is more problematic. A different kind of support may be needed to make sure ground is not lost in terms of motivation, aspiration and social integration.

Reducing the impact of the artificial 18<sup>th</sup> birthday cut-off for educational entitlement, and providing more seamless support from one stage of life into the next, is a big contribution to keeping aspirations alive for these young people and supporting them to keep learning skills they need to achieve the best next step for them.

*"I feel we really need some organisation or support that helps teenagers and adults to get into life. They have school then nothing. To start in independent life, it's a problem."*

*Parent of three young adults with Tourette's Syndrome and ADHD*

## Flexible schooling

**All the countries in this study have more flexibility in upper secondary education than is the norm in the UK.** All offer a technical alternative to academic study that can still lead to a university entrance level qualification. In Norway and the Czech Republic it is possible to take an extra year to complete upper secondary, and in Norway anyone who missed part of their school entitlement has the right to complete it. These provide paths back into the system for those whose education has been disrupted.



Borgund VGS (secondary) school in Ålesund, Norway. Pupils can extend their time in upper secondary to complete courses or gain extra qualifications. At Borgund pupils may have adapted learning programmes and extra support around transitions: the school also has a resident psychologist available to any pupil or staff member



*“The services in every university should be the same. Because the problems of these people are the same.”*

*Student counsellor*



**The Teiresiás Centre at Masaryk University in Brno has pioneered inclusive practice in higher education in Europe since 2000.**

Now it is developing support structures for students with cognitive and psychological difficulties, including Asperger’s and ADHD.

Preparation is everything, says the Centre’s founder and director Petr Peňáz. “Staff have to think about adjustments before the students are in front of us – not after,” he says. “It’s not logical to wait until something hasn’t worked.”

University entrance in the Czech Republic depends not only on school leaving qualifications but a university’s own entrance exam. This system has challenges, but one big advantage: the university will understand a student’s support needs well before a course begins, so lecturers and Centre staff, together with students and their parents, can agree and plan necessary adaptations.

The Centre offers practical support

– for example, showing students how to move easily between classrooms or facilitating supported learning groups to reinforce course teaching – alongside longer term therapies such as stress counselling. They advise students on choosing modules best suited to their own working styles and are involved in developing the advance individual study plans agreed with faculty heads each semester. Where a student has had particular adaptations in school, the aim is to ensure appropriate adaptations are also made at university and Centre staff liaise with schools, parents and other organisations to determine the best provision for individual students. They also advise lecturers on adapted teaching and materials.

“People with Asperger’s need lots of consultation,” says educational counsellor Iva Oulehlová. “When they don’t speak with us, it doesn’t mean they have no problems. Sometimes the opposite – they have big problems, but don’t want to say.” The key is to be proactive in maintaining contact, so difficulties are picked up before they escalate.

## Building an environment to make learning accessible



*Elinor Jeanette Olaussen (left) is based at the Norwegian University of Science and Technology (NTNU) in Trondheim with Universell, the national coordinator in higher education for universal design and inclusive learning environments. Universell provides information and hosts conferences and forums on everything from sensory considerations in the fabric of a building to teaching materials. It also represents inclusive learning on government committees. Its website has a wide range of information, including advice on designing buildings for students with social disabilities and how to make lectures fully inclusive.*

*For more information, visit <http://uukurs.universell.no>.*

## Supporting people into employment

**Success in finding sustainable employment means addressing the needs of the whole person, says Štěpán Hejzlar, head of social rehabilitation and supported employment for NAUTIS, the national institute of autism for the Czech Republic.**

The team is small—only four people—but multi skilled, and can connect with psychologists, social workers, pedagogues and counsellors within NAUTIS as necessary. They support 40 clients, most of whom are 23–25 years old: last year 24 found jobs.

The department isn’t a job agency: they help clients identify opportunities and find work on their own, providing careers counselling, advice on searching for vacancies and making an

application, and interview practice. They also provide training in assertiveness and social communication.

Agreements with clients are for 2 years, meaning if a job opportunity doesn’t work out the way back into the service is straightforward. Support can also continue into the workplace—if a client agrees, the team can offer employers advice on employment legislation and making the right adjustments, as well as help with



claiming tax relief for employing disabled people.

A debate for jobseekers is whether to make employers aware of their difficulties: many try to manage without additional support. In Štěpán’s experience most don’t succeed. Where employers and clients accept support, the chances of remaining in employment are better, he says: “This group can live and work independently, but they need special conditions to do it.”

## Building a business

**Spesialistbedriften is a technology consultancy established in 2014 in Ålesund, Norway: all its consultants have Asperger’s Syndrome.**

Employees must be highly skilled and preferably educated to degree level or beyond. In return, they join a business environment where they receive training and support to develop the personal and social skills to function in the workplace and engage with clients: mentors make sure contracts run smoothly. All profits are reinvested in the company.

A huge advantage to getting the business up and running has been the *arbeidsavklaringspenger*, a government benefit paid to an employee for 6 months or longer, which gives mentors time to assess competences, skill levels and support needs: this greatly increases the chance of successful long term placements.

Ability isn’t in question for Spesialistbedriften employees. The barriers to employment through conventional means lie elsewhere. Take action in these areas, and Spesialistbedriften believes much can fall into place.



*Staff and employees of Spesialistbedriften: clients include some of the foremost employers in the region, including satellite telecommunications company Inmarsat and industrial control systems developer ICD Software*

*“More assistance is needed when starting a job, to make it sustainable. For many, it’s too difficult to have an ordinary job.”*

*Leader of parents’ association for ADHD*



Expedition undertaken at a folkehøgskole (folk high school) by a student with Asperger's Syndrome

Learning skills, living life

**Folkehøgskoler** have been part of the Norwegian tradition for 150 years. Activities have changed, but the premise – offering learning the formal system doesn't or can't provide, to anyone who wants it – remains the same. More than 10% of school leavers enrol every year in the 80 schools across Norway.

Each folk high school is an independent, not for profit enterprise that decides its own focus. Many specialise in outdoor activities, others in theatre, music, technology, water sports, and opportunities including work experience and trips abroad. There are no entry requirements and no formal teaching programme.

The appeal is clear: with no leaving qualifications in the balance, the pressure is off. For many young people the schools are a breathing space before committing to a course, apprenticeship or job. For students with additional support needs they

are an opportunity to be part of a learning community that focuses on what you can do, not what you can't. Sometimes it's the first chance these students have had to be valued by their peers on completely equal terms.

*Folkehøgskoler* are a bridge between school and the adult world for those who aren't ready to make the leap themselves. They are regarded as further education and students apply for funding accordingly, making them widely accessible. All are residential, which many see as key to their success – a small, informal but structured environment that creates the perfect setting for learning essential life skills, social responsibility, and respect and value for others.

Their biggest strengths are undoubtedly diversity, with a huge range of choice, and flexibility, making individualised programmes possible for almost every student.

Developing life skills for the workplace

**A2G Kompetanse** was founded more than 60 years ago in Bergen with the aim of ensuring that all those who want to work, get the chance. Today their courses and support programmes tackle barriers to employment head on.

The groundbreaking three-phase MOLAS programme, originally developed in 2010 by labour and welfare administration department NAV together with education services agency Statped and private companies in Hordaland region, works intensively in small groups to support people with Asperger's Syndrome to build the social and life skills essential for a successful work placement, and to complete professional qualifications in

software testing and quality assurance to help the move into sustainable employment.

The approach, combining state institutions, labour market measures and private companies, proved highly successful and has received positive feedback from participants at every level.

Out of this has now come a separate programme focusing on *arbeidslivskompetanse* (work competence skills), offering individualised counselling and psychosupport weekly alongside practical experience in tasks such as handling telephone calls, interacting appropriately with colleagues, and role playing work-based scenarios.

**The MOLAS programme**

- Phase 1**  
Screening of individual adaptation needs within eight different areas important to integrate, function and adjust to working life.
- Phase 2**  
One year split into professional IT training (culminating in a certification examination) and work/life skills.
- Phase 3**  
Work experience in a private business with follow up support for as long as required.

3. Getting the right support at the right time

Among the biggest challenges of working with young people with these conditions is creating a service flexible enough to meet individual needs.

Without exception support services that manage this most effectively emphasise identifying an individual's specific difficulties and start by addressing how these impact on their ability to perform everyday tasks their peers may tackle with ease.

This is vital because these conditions affect every person so differently.

The aim of support should be to enable someone to function as effectively and independently as possible in the everyday world. Support fails when it does not meet the need, and therefore does not bring about a positive change.

Successful support is

- Individual (tailored to specific needs).
- Holistic (taking the whole picture into account).
- Multi-faceted (making use of different skills at different times).
- Realistic (practical and relevant).
- Aspirational (recognising capacity to achieve).
- Inclusive (aiming at social integration).
- Open ended (not time limited).

*"Sometimes vernepleier work like parents because someone doesn't have parents, or doesn't want mummy and daddy doing this when they are adults ... parents have been parents for a long time and maybe they've tried and tried. They need other people to help them."*

*Team leader, social services*

Creating the right professional skills

**There is a clear lack in the UK workforce of a professional role within adult services that is equipped to work holistically and across boundaries, to carry out the essential task of joining the dots between different services and agencies and coordinating a sustainable long term support plan.** This often leaves families with the task of linking services together—and filling in where there are gaps.

The three countries in this study have variations on the role of social educator or pedagogue who can support cross sector working and be flexible enough to carry out a wide range of tasks according to individual

need, including both practical care and social or emotional support.

In Norway the *vernepleier* operates in settings including healthcare and education facilities, social care settings and the home: they can support such skills as planning and managing finances, organising and carrying out basic household tasks, or attending meetings. Services can range from a daily phone call to supporting life planning: in many ways, the kind of flexible support parents often provide. Continuity of services can greatly reduce stress around taking steps towards independent living.

In Italy, Oltre il Labirinto (see p. 23)

trains its own *educatori*, many of whom already have psychology or social care qualifications, to provide ongoing, wraparound support for young people and their families to enable them to plan and prepare for lifelong support. The aim is to work closely with families to build a long term relationship of trust, with the eventual objective of taking responsibility for care when parents can no longer manage their adult son or daughter's support needs.

Equally in the Czech Republic, there are opportunities for the involvement of pedagogues at many levels where flexible support is needed from multiple organisations.





## Choosing the support that works best

**Hanne Kvello (left) is one of four disability officers supporting the student community at the Norwegian University of Science and Technology (NTNU) in Trondheim.**

Currently only 1.7% of NTNU students have diagnoses of ADHD or Asperger's, but Hanne says this group requires the most intensive support in terms of counselling time.

Since 2009 a drop-in support group for those with ADHD has met weekly, run by pedagogical studies students who are paid around 150 kroner an hour (about £13) to plan, coordinate and facilitate activities. As well as networking and sharing experiences, group members support each other in organising their lives and keeping on track with work: advice from peers with the same diagnosis often has a big impact.

In 2014 a similar group was established for students with Asperger's Syndrome, which Hanne

facilitates. This meets fortnightly in the evening, often with external speakers: sometimes members themselves present on topics such as how to socialise and make friends. Some had not spoken to any other students before joining the group.

A mentoring service is available for those who choose it: mentors are matched to an individual's preference, and are paid to meet with a student for 2–3 hours a week to focus on planning and motivation, or to help with specific difficulties.

Support costs are mostly borne by the Norwegian labour and welfare administration (NAV).

Together with NAV, the university is also beginning to work with local employers to widen the availability of work placements and internships for these students, and to provide increased support for the transition into employment at the end of the university course.

## Meeting the needs of the whole person

**Creating leisure and free time opportunities is an essential part of the work undertaken by the social rehabilitation team at the Czech national institute of autism NAUTIS, with a reader's club, yoga, music therapy, an art workshop, cooking classes and more available.**

A striking new initiative is a dating agency in collaboration with organisations whose client groups may share similar characteristics and inclusion difficulties.

This is a direct response to need, as Štěpán Hejzlar of NAUTIS explains: "Clients come to my office to find a job, but within 30 minutes they switch topics and say they are lonely and can't find relationships. Having friends, a girlfriend or a boyfriend, feeling respected in society – it's one of the most important things in life. If they can

overcome loneliness, for me that would be the best result of our work."

The group plans to link with other

organisations to build awareness of living with different diagnoses and challenges, and create a broader base of friendships and social contact.



Play written and staged by NAUTIS clients for World Autism Awareness Day. Directed by Dominika Linhartová and Markéta Těminová, with music by Zuzana Tökölyová

## Supporting independence: how technology can help

**Watches that show the passage of time by light displays; a headset with white sound to mask noise; smart door locks that switch off appliances as you leave the house.**

For people with conditions like Asperger's, ADHD and Tourette's, planning and organising everyday tasks, coping with sensory hypersensitivities, or managing time can be highly stressful.

Elin Svendsen works for the Norwegian labour and welfare administration's centre for assistive technology in Trondheim, advising on the use of technology in the workplace, schools, and homes to support people with disabilities to live more independently. She has been in this role for 20 years and seen the technology evolve.

"I saw very early how people with Asperger's, ADHD and Tourette's could benefit from simple aids," she says. "It's about reducing the stress of planning and organising. Take that away and difficulties can be much more manageable."

The first step is an individual assessment of need.

"I always start with the impact on the person's functioning in normal life," Elin explains. "When you get up, what do you have to do? What is required during the day? Maybe problems have arisen because something has changed – a longer journey to work, for example. New strategies need to be developed because the old ones don't work any more."

Someone else must commit to ensuring instructions are correctly applied, and to take responsibility for follow up: in the workplace this could be a line manager, at home a friend or carer. If equipment would have been bought anyway, for example a smartphone, the employer or individual usually pays for the item: for something out of the ordinary, or a specific adaptation, the centre negotiates a pay agreement with the individual or their employer.

"It's a really flexible system," Elin says. "If it's easier and just as effective for someone to use a cell phone they already have, there's no need to provide one for them. It's for the person to work out what meets their needs best depending on what they are used to and their cognitive and skill level. We try to find the easiest way to do things."

Elin finds most employers are happy to work with the service. She feels there is the need for a mentoring role, to train employers and co-workers in the impact of conditions and the adjustments required.

As well as providing equipment, her role includes helping people develop smarter ways to use what they already have: pointing them to the best apps and customising them, running training courses to show people how to use these better.

"Sometimes we overcomplicate things. Very simple things can make a real difference," she says. "People don't want to be dependent on parents at this age, but if they get used to using strategies and assistive technology they can manage themselves better. That's good for self confidence."

*"If someone needs an item they get it, because it's a right, not a budget decision. Public opinion, it's more 'Why don't they get that?' than 'Why do they get that?'. You very seldom hear that."*

Assistive technology advisor





## 4. Therapeutic interventions

Support and therapeutic interventions can be two sides of the same coin. Repeatedly young people and their parents identified mental health issues among the biggest barriers they faced in embracing the change and challenge of planning and preparing for the future—and also one of the biggest barriers to engaging with other sources of support.

These almost universally included severe anxiety, depression, obsessive thoughts, compulsive behaviours, and panic attacks, along with difficulties related to sensory issues, sleep, anger management and motivation. For some, food and drink were a problem, making it difficult to maintain a healthy body weight and active lifestyle; for others, there was concern around drug or alcohol use, or psychological addiction to prescribed medicines (this was expressed by parents: young people themselves did not identify their drug or alcohol use as a problem).

In addition there were issues around relationships and gender identity, while others had experienced bullying by supervisors or colleagues and/or fellow students.

While most young people who took part in this project had not been diagnosed as severely mentally ill (i.e. requiring hospitalisation, although several had been prescribed medication for depression or anxiety), the majority were regularly experiencing mental health issues to a degree that had a noticeable and disabling impact on everyday life.

In each country the ready availability of psychoeducation, counselling or similar therapies was seen as a key component of support, with qualified psychiatrists or psychologists part of the staff team. In particular, it was striking that staff were proactive in engaging with young people, especially those with Asperger's Syndrome, as it was recognised they would be unlikely to seek help themselves even if in need.

## Better mental health, better outcomes

**Across the three countries, both professionals and parents commented on lack of consistency in mental health provision for this group of young people.**

Pathways into assessments as adults were often unclear, meaning those leaving school without a formal diagnosis—or whose difficulties increased with the added stress of living and working in an unfamiliar, more adult environment—had

problems accessing help within a timeframe that would allow them to continue with a course of study or work placement.

The need for more responsive treatment, and therapies tailored to those who find talking therapies difficult, was highlighted: in particular, because this stage of life demands focus, resilience and motivation to be able to identify and access the right opportunities.

## Individual integration and inclusion



Staff and centre users share a hot lunch, taking it in turns to serve and clear away

**Casa di Ventignano isn't quite like anywhere else. As a model of integrated, seamless support and therapeutic care, it's a unique specialist centre for autism organised, structured, managed and funded by the national health system in Tuscany.**

The centre is a collaboration between the regional healthcare body in Empoli and a social cooperative: Tuscany's autism services organisation Autismo Toscana was also heavily involved in developing the project, which began in 2009.

It is a daycare facility for children and young people aged from 8 to 25, focusing on health and social habilitation, and complementing support work in mainstream education for those of school age and within the local community for those who are older.

The team is led by neuropsychiatrist Cinzia Pieraccini and includes psychologists, speech therapists, educators and social healthcare operators working alongside music and art therapists, pedagogues and specialised technical staff who manage the

market garden in the grounds of the old farmhouse.

The centre can cater for a maximum of 32 people at any one time. Eligibility is governed by the impact of the condition on the individual rather than particular behaviours, and referrals are made following a full clinical evaluation. One of the things that makes Ventignano unique is that activities are developed following this evaluation and tailored to individual needs, rather than offered as a predetermined programme: these can then change over time as objectives change. There is a clear emphasis on building the skills that are essential to functioning independently in everyday life: so, for example, speech therapy may work towards accompanied visits to the local coffee shop and being able to order and pay for food.

Once at Ventignano, young people can stay as long as they need: this could potentially even be on into adulthood, as consulting psychologist Leonardo Granchi explains.

"We think rehabilitation is needed life-long for people with autism," he says. "And actually, there aren't specific programmes for them afterwards so we think they should stay here as there is no specific treatment. It's not a temporary condition, so programmes should be followed lifelong."

Now the centre is developing job-centred programmes for the young adults already being supported. The first is building a business from the greenhouse within the grounds, the second is making ceramics: this is an important industry locally, and there are potential long term job opportunities for those with the right skills and experience. Cinzia Pieraccini describes this as "a good match" for people on the autistic spectrum, as the manufacturing process is clear and structured.

At present this is the only publicly funded centre of its kind, and while more facilities are clearly needed, this is dependent on investment. In the meantime, however, Casa di Ventignano remains a clear example of what is possible with coordinated and creative partnership working.

*"Everyone has a right to their own personality. We don't assume people who use the centre are all the same."*

Psychologist

*"The brain is still developing—what you see at 18 won't necessarily be what there will be at 25. Good support in this time is really important."*

Psychiatrist



*“My daughter is ambitious, she completed two university studies with great results, she speaks foreign languages, she used to take part in dance competitions. I think what she needs most now is psychological support.”*

*Parent of young adult with Tourette’s Syndrome*

## Psychoeducation in the ADHD school

**Psychoeducation takes place in various forms but its purpose is always the same: to empower individuals and their families to deal with their condition positively.**

Crucially, to be effective it must be led by skilled individuals.

Psychologist Bjørn Gjervan has been involved with an “ADHD school” in Trondheim for nearly 3 years. Participants are referred by therapists and meetings are very informal, with a roughly even split between men and women. Some have a history of substance abuse, or involvement with the police. The aim is to provide information about ADHD and to develop adaptive strategies to manage behaviour and situations.

“Most of these people are young, 18–25, and they start to believe they are stupid. That’s bad,” he says. “I explain ADHD isn’t wrong, it’s different. You’re not a bad person because you can’t control your temper, there’s a reason it happens, but it’s going to happen every time if you don’t do things differently. You have to find an ADHD way. It’s about believing you can control your behaviour and it doesn’t have to

control you. It gives you a chance to achieve without being like everyone else.”

Beyond childhood, the biggest difficulties for young people with ADHD tend to be inattention and impulsiveness. These are particularly problematic in the workplace, and in forming and sustaining healthy relationships.

Often it is the first time participants have discussed their experiences with someone who has the same problems.

“That’s liberating,” says Bjørn. “And it can be very funny, they have a great time, laughing at it together. Establishing strategies is an important part of managing behaviour. Every time the same thing is going to happen, if you don’t do it differently. How many times do you have to confirm that before you make a change? I’m not treating them as a therapist, I’m primarily teaching them smart tricks.

“The groups are about the participants taking control, that’s important. It’s giving them responsibility for their own learning and therapy.”



*Historic waterfront warehouses in the centre of Trondheim*

## 5. Changing role of parents, carers and families

Through adolescence and into young adulthood, it is usual for the parent-child relationship to change as young people take responsibility for their own physical, emotional and social needs and the level of parental support reduces.

However this is not the experience of most families in this study. They report no change in the level of parental support required to ensure the health, safety and wellbeing of their son or daughter, and many continue to be their main—sometimes only—source of support, providing not only physical care but financial, social and emotional support.

In the vast majority of cases where young people had jobs, a parent had made the initial contact or used their influence to provide the opportunity. Several young people still lived in the parental home through their twenties and into their early thirties. Those who lived elsewhere were mostly in apartments found or provided by their parents, sometimes in the same building: both parents and young people commented on feeling restricted in their lifestyle or movements as a result of requiring, or having to provide, parental support. Parents were frequently responsible for tasks such as house and garden maintenance, and domestic matters, ensuring bills were paid or providing prompts and reminders. Many parents were subsidising young people financially, topping up benefits or low level wages.

Several practitioners felt parents too often overprotect young people with these conditions, inadvertently preventing them from taking responsibility and developing essential skills for independent living. This may be true within some families, and clearly young people should be supported in developing as much autonomy and self sufficiency as possible.

However the view of many parents in this study was that they welcomed the prospect of young people taking responsibility for themselves but had a profound lack of trust in appropriate support being available, often based on experience of a lack of understanding of these conditions, failure of provision, and inadequacy of support services.

*“I still have to focus on problems all the time and I hate it. This is just bringing us down.”*

*Parent of young adult with Asperger’s Syndrome*

## Key to closing the specialist knowledge gap

**It is striking how many organisations that have gone on to become nationally significant support or research centres have been founded, or largely staffed, by parents with the desire to ensure others receive the help and support they themselves did not.**

Parents of young people in the age group covered by this study have often accumulated a wealth of knowledge and understanding about the conditions their children have lived with, along with an enormous amount of experience of what does, and does not, constitute effective support.

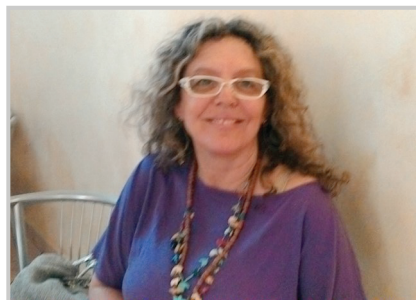
Many organisations express concern that low levels of awareness and competence among professionals can represent one of the biggest barriers to receiving

support of the right kind, particularly when overly rigid access criteria are applied.

Parents in this study commonly held the view that services and support agencies often failed to take seriously the full range of support they provided and the potential impact if that support was compromised or no longer available. They were also baffled, and in some cases angry, that their experiences and views did not seem to be taken into account as a matter of course.

Recognising the competence of other organisations, and in particular acknowledging and respecting the experience parents bring to the table, could be crucial for adult services in closing the gap in specialist knowledge.





Some of the parents' association members and peer support facilitators from the three countries

## Parents' associations and peer support

**Parents' associations in Norway are pivotal in peer support, awareness raising and policy development.**

A big difference from a UK perspective is the relative cohesion of these associations compared with the often fragmented, overlapping pattern of organisations here.

Each association is an affiliation of autonomous regional groups: head offices have few, if any, paid staff and are largely a support service for the regional associations.

Because central government only deals with and funds organisations that evidence a sizeable membership, multiple small charities rarely survive. This makes parents' associations powerful players both in representing their communities at policy level and providing services in their regions.

In Italy and the Czech Republic, peer support and parents' groups play a major role in providing information to young people and their families. In many regions, especially outside the cities, the family is the only source of support: in all three countries parents within the associations routinely give up their

own time to answer questions and direct others to sources of information, often offering their own telephone numbers as a helpline service and in some cases receiving calls 24 hours a day.

Many associations produce resources for schools, clinicians and employers as well as for young people and families, and are often the main drivers in raising awareness of conditions among policymakers and professionals as well as among the general public.

The downside can be leadership and direction. Parents' organisations often rely almost 100% on volunteers, meaning activity levels can fluctuate and capacity to build on successful programmes can be severely limited.

Where strong, consistent relationships existed between professionals and parents' groups, this often appeared to have been a game changer in generating mutual understanding and developing creative approaches to both research and support: exploring how to establish more and better links could be highly beneficial for more effective future planning.

## Equipping families in Italy



Parents are given information by Anna Maria Cava and Renato Moglia, volunteers for AIFA Onlus in Emilia Romagna. Anna Maria is the parent of a 21-year-old with ADHD and well aware of the level of support required into adulthood. Renato Moglia trained as an ADHD homework tutor: part of his role is to work with families to develop strategies that are right for them.

Nationally, AIFA Onlus is focusing on the impact of ADHD in adults to raise awareness of the issues and the knock-on effects on health, employment, relationships and social integration. Failing to identify ADHD can lead to symptoms being wrongly attributed to other difficulties, meaning psychotherapy may be less effective and waste time and resources.

The message from AIFA is clear: ADHD in adults requires the same level of attention as ADHD in children, with the same diagnostic help and medication; self help groups to share experiences, provide support, and create a social network; and psychotherapy based on a realistic picture of individuals and their everyday lives.

## Supporting families—for life

**Oltre il Labirinto – “Beyond the Labyrinth” – is a privately funded, not for profit social cooperative begun in Treviso, Italy in 2009 when parents came together to tackle a shared problem: the lack of support services to meet their children's social and developmental needs.**

The name reflects the tendency of individuals with autism to become lost in their own world: Oltre il Labirinto is about reconnecting them with their community. It could equally apply to the parents and families, many of whom experience social and economic isolation through caring for children and adults with significant support needs.

The intention isn't only to offer support tailored to the individual: it's to build a community where highly skilled therapists and befrienders work closely alongside young people and their families to create a network of relationships, opportunities and activities that connect people to each other and to the world around them.

The plan is to continue support for life, at a level that responds to changing needs.

What began with out-of-school activities and summer camps has grown rapidly to include overseas

trips, community partnerships and a highly regarded training programme for professionals. Now the organisation is planning for the future, and developing programmes to ensure a smooth progression to adulthood for its founding members as they approach school leaving age.

A key focus within the last year has been developing support for families and caregivers. Self help groups now take place twice monthly for parents across the region, facilitated by a psychologist specialising in autism. A new session for siblings aged 13–18 will begin soon.

Part of the family empowerment initiative has also seen the launch of “Mamme via”, targeted towards mothers, who frequently undertake the bulk of day to day care. Funded largely by the Foundation, the programme offers mothers a subsidised 3-day break in a European capital while fathers spend time with their autistic sons or daughters with the support of the Foundation.

Oltre il Labirinto trains its own support staff. The expectation is that they will build close, long term relationships with young people and families, becoming trusted friends as well as therapists and advisers and sharing care responsibilities.



**Oltre il Labirinto**  
Fondazione ONLUS per l'Autismo



Mothers on a trip to Paris subsidised by Oltre il Labirinto as part of the “Mamme via” initiative

*“We are not normal families. We live in a different world.”*

*Parent of young adult with Asperger's Syndrome*

## Information about Tourette's



Karlin, central Prague, where the peer support group run by ATOS, the national organisation for people with Tourette's Syndrome, meets twice a year.

People come from all over the country, and beyond. Some make the 10-hour round trip from Slovakia, where there is currently no patient organisation. Many have arrived at ATOS by process of elimination following their own research and self diagnosis—much like the organisation's founder, Ondrej Fiala. Now a neurologist, he and others from the ATOS board answer questions in an informal atmosphere of understanding, support and frequently, humour. Many are parents of children in their twenties.

As well as meetings, ATOS overcomes difficulties of distance by offering a volunteer-run helpline and counselling – face to face, by phone, or Skype.



# Recommendations

Each of these recommendations addresses a particular area of difficulty experienced by young people with these conditions in the years after leaving school, based on interviews and observations undertaken as part of this project. They represent four practical suggestions with the potential to improve transition experiences significantly for this group of young people, and to create a better, stronger platform for the next stage of their lives.

*“I speak for myself, but my biggest wish is to have a normal job and a function, you know?”*

*Young adult with ADHD*

## Greater access to specialist life coaching and planning

This needs to take a holistic approach, including careers advice, but also taking into account abilities, capacities and potential as well as personal interests and goals. Many young people in this group find conventional open questions about the future overwhelming, but at the same time benefit from having a structured approach to making the decisions and identifying the next steps appropriate for them. This should include not only exploring possible destinations, but also practicalities such as skills required for independent living and barriers to access: these should then become the basis for an individual support plan. The benefit of this is threefold: first, it provides structure, which is reassuring for the individual and helps reduce stress; second, it provides a model for an approach to planning that will be useful throughout life; and third, it helps with motivation, a major issue identified by many families in the years after leaving school.

### Actions:

- There is an urgent need to identify a professional to provide support in developing, coordinating and implementing a plan once a young person has left school.
- Careers and employment advice should include self employment, and support agencies should develop ways of supporting young people who choose this option.

## Preventing isolation needs to be an explicit aim for all services and support structures

One of the biggest dangers for young people in this group is social isolation. Not only does this have implications for individual mental health and wellbeing, it increases vulnerability and reduces opportunities to learn or develop essential skills for independent living. Within a year of leaving school a considerable amount of ground can be lost in terms of good habits around timekeeping, being in groups, and managing schedules: re-engagement can then become hugely challenging. There is an urgent need for programmes and support structures that combat this, both in and out of employment or education, to maintain positive momentum and motivation to engage.

### Actions:

- Clarify the aims and objectives of support, based on an aspirational approach that takes potential, ability and capacity into account.
- Distinguish clearly between care, which is based on an assumption of dependency, and support, which aims to increase independence.
- Ensure evaluation criteria include progress towards integration.

*“I think my life is worse than other people’s. My schoolmates, my classmates, they have family now and I am just with my mother and my sister and her family. And I am single right now, without a girlfriend.”*

*Young adult with Asperger’s Syndrome*

This study focused on three conditions that may coexist and can share similar challenges in understanding, acceptance, and barriers to social integration. It became clear awareness of the impact of ADHD in adults, and of Tourette’s Syndrome generally, is low and effective support limited. A national strategy that includes all the conditions jointly would be of benefit to help ensure every young adult’s support needs are properly understood and addressed.

## Greater focus is needed on addressing the mental health care needs associated with this group

Anxiety and/or depression can be an enormous problem for many high functioning young people, and for some is the biggest single barrier they face. Addressing other associated behaviours that have a negative impact – for example poor motivation; obsessive thoughts or behaviours; poor eating habits; poor sleep patterns – also need to be part of a support programme. Psychoeducation, advice on strategies, skilled one-to-one counselling, and where necessary medical intervention, need to be much more accessible to prevent these becoming a bar to inclusion.

### Actions:

- Support young people to make better use of assistive technology to help address stress/social anxiety, and organisation or planning difficulties.
- Create better signposting to available services, and clearer pathways into support and treatment.

## More effective joint working with parents and families is essential

There needs to be a recognition that although this group of young people have the ability to emulate their peers by progressing to greater independence, this will not take place at the same pace or in the same way. It is therefore important wherever possible for families to be respected as equal partners in planning, particularly early in the post school transition process, as effective progress often depends on their capacity to keep providing support. This places services under an obligation to establish a dialogue with families, share as much information as possible, and be responsive to individual circumstances. However, as transition involves a gradual transfer of responsibility away from the parent, it is important that the underlying aim remains independence or greatly reduced support needs: relying on families to remain central in support delivery is not sustainable as parents age or circumstances change. This, too, has to be a managed transfer of responsibility so as to avoid unnecessary crisis.

### Actions:

- Adult services need to develop a more holistic approach and build cross sector collaboration.
- Increase investment in targeted information, to raise awareness and ensure practitioners and professionals, as well as young people and families, are equipped with the information and skills they need.
- Better signposting to services, helplines and online resources.

*“He’s usually quite worried to start something new and to go to a new place so he prefers to be without a job. So this is a problem, with self confidence and motivation.”*

*Parent of young adult with Asperger’s Syndrome*

*“It’s very difficult to meet authorities and to be taken into account by authorities as a parent of an adult.”*

*GP and parent of young adult with autism*

# Conclusions

*“I feel the only person who sees how vulnerable my son is now at this moment of transition is me ... this is his life that is at stake. If this fails now his experiences will be connected to therapists, very dependent. So the doors are closing.”*

*Parent of young adult with Asperger’s Syndrome*

**It is clear many young people with Asperger’s Syndrome, ADHD and/or Tourette’s Syndrome face particular challenges in making the transition to adulthood.**

Some of these challenges result from the conditions themselves, and the strategies young people need to develop to allow them to function as independently as possible in the rapidly changing, increasingly complex and multifaceted world in which they live.

Support has to be available to ensure these young people, and their families, are equipped with the tools they need to do this.

But other challenges lie elsewhere, linked to levels of misunderstanding about the impact of these conditions, inconsistency of provision, and social barriers that reduce opportunities – not only at the point of leaving school, but for the next 10 years and on into adult life. Overcoming these should not have to be yet another task for young people and their families, but are for the structures, systems and communities within which they operate.

This study highlights clearly that funding levels alone do not necessarily bring about the change needed to improve inclusion for these young people. The projects visited in Italy and the Czech Republic are examples of excellent practice within systems facing significant economic challenges, while in Norway, where social funding has been at comparatively high levels over many years, people nonetheless shared the same feelings of lack of support and effective engagement.

Tackling these deficits depends far more on using existing resources effectively than on setting up new services and strategies. There is indeed an urgent need for support programmes for these young people at this stage of their lives, but just as pressing is the need for a cultural change in the services and agencies with which they come into contact.

Too many young people in this category are missing opportunities because services and support agencies are not recognising and helping them overcome the barriers that exist: there remains a great deal that could be done to improve outcomes and experiences for this group.

The bedrock has to be an education system that recognises the extent and complexity of their challenges, and responds with the understanding and flexibility that will give them the best possible chance of achieving qualifications that match their ability, potential and aspirations. This includes recognition of learning that goes beyond the boundaries of the curriculum; an approach that aims at integration, not just inclusion; and an increased focus on the purpose of education, not only the means of its delivery.

Academic qualifications, however, are only one aspect of what is required

for these young people to thrive in the world beyond school. If they are to develop the resilience, confidence, ability to work with others and flexibility that are key to success in the adult world, this needs to become a core aspiration along with academic opportunities and be supported accordingly by the services on which they depend.

There is a widespread misunderstanding of what it means to be “high functioning”: this must be challenged because it is misleading and contributes not only to poorer outcomes but also, as a result, greater long term dependency. For too many services, “high functioning” implies being able to manage with minimum support, when the opposite may be true: ongoing needs may be as great as for “lower functioning” individuals, but for support of a different kind.

Improving experiences and outcomes depends on how far we can develop consistent, multifaceted support that is flexible, person centred, and takes as its starting point the individual’s ability to function in everyday life. For many, a good model is what families typically provide: that is, focused on developing the capacity to manage as independently as possible, but with a safety net of ongoing support that is readily accessible when necessary – particularly if problems arise.

It is interesting that each country in this study has developed a professional role that supports this type of holistic, cross sector approach: in Norway the *vernepleier*, in Italy an *educatore*, and in the Czech Republic a pedagogue. This has potential benefits for vulnerable adults, especially when family members are unable to provide a coordinating broad-based support role.

We need to recognise the difficulties lie within neurological conditions that will not solve themselves. Support needs may change over time, but they will be ongoing and lifelong. The more we can develop young people’s capacity to manage their own conditions, and create workplaces and environments that accommodate diversity, the less intensive are the interventions that are likely to be needed.

Although it was outside the remit of this report, there is increasing evidence of the long term cost to health and welfare budgets of not taking these social changes seriously. Many young people who participated in this study are well equipped to support themselves to a large extent, if the conditions are right and their vulnerabilities appropriately taken into account.

It is clear there are able and intelligent young people with high levels of particular skills and abilities who are too often missing out on the chance to achieve their potential because the barriers they face are either poorly understood, or require collaboration and cooperation to solve.

Unless we can find ways to tackle these social barriers their journey into adulthood becomes that much harder: and we, as well as they, will be the poorer.

*“The biggest thing is to have expectations of someone, for them to grow up with the feeling they have something to contribute.”*

*Parent of young adult with Asperger’s Syndrome*





This Fellowship has truly been the most amazing opportunity, personally and professionally, and I am enormously grateful to everyone at the Winston Churchill Memorial Trust for placing their faith in this project and making it possible.

What began as an investigation into how our near neighbours address shared challenges turned into something more, as time and again people told me how important they felt this project to be. I have tried to live up to their enthusiasm and encouragement, and produce a series of reports that accurately reflects the picture they outlined to me: the interpretations and conclusions are entirely my own and do not necessarily represent the views of any individual or organisation that participated in the study.

In all the places I visited, I found professionals, practitioners and families eager for change: the time seems right to take the actions that will transform the lives and expectations of this group of young people. Supporting them to find their place in the wider world—with all that implies in terms of financial stability, physical and mental health, and personal fulfilment—frees resources for those less equipped to make the same transition. Failing to provide this support contributes to long term dependency that is undesirable and unaffordable—and largely avoidable. It is truly, to use the colloquial phrase, a no brainer.

So many people have been involved along the way that it seems unfair to single anyone out. However I am especially indebted to the first contacts I made in each country who became the gateway to further networks, contacts, programmes and services. Without them this project might have struggled to get off the ground. Special thanks, then, to Franco Doni, director of social health for Fiorentina Nord-Ovest, Astrid Göllner of AIFA Onlus and Carlo Giustini of Oltre il Labirinto in Italy; to Michael Lensing of NevSom in Norway; and to Ondrej Fiala of ATOS, Petr Peňáz of the Teiresiás Centre, and all at the therapy and social rehabilitation unit at NAUTIS in the Czech Republic.

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Thank you.