



Life on the Edge of the Cliff

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

STUDY VISIT 2

Norway

23 October – 13 November 2015

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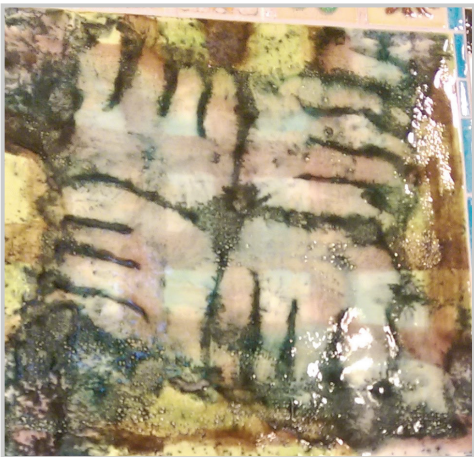
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Teenage years bring challenges for all young people: self discovery, rapidly changing social patterns and relationships, working out where you “fit”. Successfully navigating the transition to adulthood depends a lot on having the ability to plan ahead, conceptualise, and prioritise steps to set and achieve a goal, along with being able to organise time and activities in support of it.



The aim throughout adolescence is to progress towards taking responsibility for your own physical, emotional and social needs, and achieve a life as personally satisfying and fulfilling as possible.

It’s worth bearing in mind that not one of these essential skills comes easily or naturally to a young person with Asperger’s Syndrome, ADHD and/or Tourette’s Syndrome. If the teenage years are challenging for those who are neurotypical, the impact on young people who struggle in precisely these areas can be overwhelming.

None of these skills are intrinsically connected to ability or knowledge. So there is no innate reason why a young person with one or more of these conditions should be less well placed than their peers to achieve personal independence, find work and contribute to their communities.

But evidence is mounting that many face an uphill struggle. Only 15% of people with autism are in full time paid employment in the UK;¹ estimates are that at least 30% of the prison population has a learning difficulty of some kind;² many people with these conditions self medicate with alcohol or drugs and run into problems as a result.

Existing structures are clearly not working effectively enough in many cases. Perhaps that shouldn’t come as a surprise: after all, education, health and social systems have usually developed in ways that best meet the needs of the majority, who can readily identify what they need and make adjustments as necessary to engage with the services available.

Unfortunately many young people affected by these conditions may not be able to make such adjustments without a great deal of support, and may take longer than neurotypical young people, to whom such things come more intuitively, to arrive at the same point.

When resources are under pressure, we need to ask how we can ensure intelligent, highly able young people – living with difficulties that are largely social, not intellectual – can be best equipped with the skills to manage the challenges of their condition, and the opportunities to put their abilities to best use.

¹ National Autistic Society; ² Prison Reform Trust

Quotations throughout are from interviews undertaken as part of this study.

“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.”

Between 23 October and 13 November 2015 I visited the following municipalities:

Trondheim, in Sør-Trøndelag

In central Norway, with a population of around 180,000, Trondheim is dominated by the Norwegian University of Science and Technology (NTNU), St Olav’s University Hospital and SINTEF, the largest independent research organisation in Scandinavia. Students comprise almost a fifth of the city’s population.

Tromsø, in Troms

Tromsø lies 350km inside the Arctic Circle. A population of 72,000 rises to over 75,000 during termtime at the University. The area has a rich Norse and Sami cultural heritage and was a major centre for Arctic trade and exploration.

Ålesund, in Møre og Romsdal

Ålesund is on the west coast on the edge of the Sunnmøre Alps. Noted for its Jugendstil (Art Nouveau) architecture, Ålesund is home to the most important fishing harbour in Norway and was traditionally a centre of shipbuilding and marine technology. It has a population of around 45,000.

Bergen, in Hordaland

Bergen is the second largest city in Norway, with a population of over 277,000. Founded on trade and historically an accessory to the Hanseatic League, it is an international centre for aquaculture, shipping, offshore petroleum and subsea technology, and a national centre for higher education, tourism and finance. Bergen Port is the busiest in Norway. It is known for its mild climate.

Oslo, a municipality and a county

As the capital city, Oslo is the economic and governmental centre of Norway. With a population of around 648,000, it is currently the fastest growing major city in Europe, and more than 25% of the population is now non-native Norwegian. It is the only city where the two administrative levels of *kommune* and *fylke* are integrated.

Norway – an overview

Norway has a population of just over 5 million. It is among the world's wealthiest countries per capita, based largely on the energy industry and oil and gas exports, and fishing. However with falling prices this has become less secure, and unemployment – at 2.6% in 2012 – has begun to rise.

While not a member of the European Union, as a NATO member Norway participates in EU security and defence groups and is a member of the European Economic Area and European Free Trade Association. This brings free movement of goods, capital, people and services with EU members.

Government

Since 2013 government has been a minority right of centre coalition between the *Høyre* ("conservative") and *Fremskrittpartiet* ("progress") parties. The coalition is in a formal collaboration agreement with two minor parties – *Venstre* ("left") and *Kristelig Folkeparti* ("Christian folk party") – for the duration of this parliament. *Høyre* was elected on a pledge to increase investment in education and infrastructure.

Many powers are devolved to the country's 19 *fylker* (counties), administered through directly elected assemblies. Each *fylke* has a District Governor who represents central government.

The *fylker* are divided into 428 *kommuner* (municipalities), each administered by a directly elected municipal council headed by a mayor and a small cabinet. They are responsible for organising and delivering compulsory education (up to age 16) and primary healthcare services.

Education

Kindergarten attendance is a right for every child aged 1–6. *Barneskole* (primary school) is compulsory from the age of 6. At 13 years old children progress to the *ungdomsskole* (lower secondary school) until compulsory education ends at age 16. The majority go on to *videregående skole* (upper secondary) for a further 3 years of general education or 4 years of vocational training (made up of 2 years in education and 1 or 2 years of practical training in the workplace). There is considerable flexibility within the system. The *fylker* are responsible for education beyond the age of 16, although some bodies are funded directly by the Ministry of Education and Research.

There is no formal distinction between vocational and non-vocational higher education, but the eight universities tend to concentrate on academic subjects. The 25 university colleges provide a wider range of choices, with private colleges offering popular courses such as business management, IT and marketing. Typically it takes 3 years to complete a degree at bachelor level, 2 further years of study to complete a master's degree, and a further 3 years to complete a PhD. Admission normally requires a *generell studiekompetanse* (general university admissions certificate).

Students with lower qualifications can sign an apprenticeship agreement, leading to a trade or journeyman's certificate (*fagprøve* or *svenneprøve*), or if appropriate a training contract leading to a competence exam (*kompetanseprøve*).

Adults over 25 are entitled to complete primary or lower secondary education if they have not previously done so. An adult also has the right to apply to complete education at upper secondary level.

Education is free of charge at every level.

Health

Folkhelse (public healthcare) is administered by four regional health authorities directly funded from the state budget through the Ministry of Health and Care Services. They administer special healthcare services – including mental health – and manage hospitals, ambulance services, emergency services, research, training for medical staff, and hospital pharmacies. Primary healthcare, including GPs and some clinics, is the responsibility of the *kommuner* (municipalities).

Norwegians choose their own GP, who will refer patients to district centres, including mental health centres, as necessary. Child and adolescent mental health (*barn og unges psykiske helse*, or BUP) is responsible for children from birth to age 18 years.

Healthcare is largely funded through a centrally administered National Insurance Scheme, and is free of charge to those under 16 (psychological treatments remain free to the age of 18). Thereafter, as of 2014 medical visits incur a partial charge.

Under the Work Environment Act, firms of a certain size must provide company healthcare, most of which now includes psychological services.

Welfare and social services

Responsibility for welfare and social services lies with NAV, the Norwegian Labour and Welfare Administration (*Nye arbeids- og velferdsetaten*). This was established in 2006, when social security and employment offices were brought together. There are 456 NAV offices throughout Norway, liaising closely with municipalities over service provision and delivery. Their main goals are to encourage people into work and reduce dependence on benefits; to act as a job centre; to provide services and benefits tailored to users' needs, at the right time; and to ensure efficient labour and welfare administration.

In 2011 the government launched a Job Strategy for People with Disabilities, and NAV supports both job seekers and employers. They can become involved at any point a need is identified, regardless of age. Intervention is often open ended and services can be suspended or reactivated as necessary.



Olav Trygvasson, king of Norway from 995 and founder of Trondheim

"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."

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

Awareness and policy – the national picture

As well as targeted programmes and interventions for these conditions, there are general aspects of the ethos and delivery of services in Norway that contribute to effective support.

First, the **education system** is highly flexible, with entitlements to enter or re-enter education at every level, usually following assessment. It is possible to take a further year or more to complete courses in high school and at university, while those who missed school can apply as adults to complete qualifications.

This is very beneficial where social and cognitive difficulties, including organisational and life skills, are a major barrier to academic attainment within a typical timescale.

The entitlement of up to 8 years in higher education can be used flexibly – so, for example, a year in an alternative educational setting such as a folk high school followed by a bachelor's and a master's degree. This gives individuals the chance to make choices best suited to their own developmental needs.

However, a concerning trend reported was an increase in the number of schools that feel unequipped to manage some conditions, with parents called repeatedly to remove their children from school.

In many areas **divisions between**

children's and adult services are less rigid than in the UK, and there are examples of services operating relatively seamlessly across the age range: in the coordination teams, for example, and some of the work done through NAV. Support can be disrupted when professionals move or change roles, but some staff have been in their region or their professional roles for 10 years or more, and continuity has contributed to stability and a relationship of trust.

Continuity of services and predictability is enormously helpful in building positive relationships for the young people in this study, who find uncertainty and change highly challenging.

Repeatedly, people referred to **a communal sense that the right support should be available to people who need it**, at the time it will benefit them most. It was accepted this did not always happen as effectively as it should, but as a principle underpinning planning, provision and funding this clearly makes a difference in attitude. In addition the Norwegian sense of *dugnad* was mentioned again and again, which can most easily be translated as **communal responsibility or obligation**: the expectation everyone will play their part in making something happen. This can be seen in practice at local level, for example in the parents'

associations, but the pattern of thinking also has a bearing on policy development and service delivery.

The biggest criticism was reserved for the **welfare and labour administration**, NAV. Entitlements to support in and out of employment, including financial support, are generous, and the system is flexible enough to accommodate individualised assessments as well as people leaving and re-entering the benefit system, which is helpful for some young people in this study, who often have a disjointed path in and out of employment and support.

However, people commented the current system encourages people to be over reliant on benefits and may be a barrier in the search for work if an employer cannot match income available through NAV. Some young people in employment, but still being paid by NAV, resented the fact they were not receiving what they regarded as a "proper" wage and found this stigmatising.

Bringing together welfare payments and employment support was perceived to have created an overcomplicated, bureaucratic structure within which employers and employees reported difficulty navigating support pathways and accessing information. There was also a perception that specialist knowledge available previously had been replaced by a general approach



that was believed to be less helpful for people who did not match a standard welfare profile. In particular, young people and families reported a mismatch between their aspirations for apprenticeships and potential employment, and what NAV delivered, leading many to conclude the service is failing in supporting young people into work appropriate to their skill level and potential.

There is a **broad acceptance of difference** and a **predisposition towards inclusion**, that extends to the area of mental health: for example, frontline politicians – including former prime minister Kjell Magne Bondevik while in office – have been open about their own mental health issues without this being a subsequent barrier. However

even among professionals understanding of the impact of these conditions can vary, and there is a universal sense that much remains to be done in awareness raising among the general population.

It is widely accepted that spectrum conditions can and frequently do co-exist, and that any interventions need to take **the full diagnostic picture** into account for each individual. Although it is still not typical for diagnosis of one condition to lead automatically to investigation for others, it is possible for diagnoses to be reviewed and reassessed. This can be helpful in obtaining the most effective support over time.

By far the biggest problem identified by professionals, young people and families, was the **lack of flexible**

employment opportunities – particularly entry-level opportunities – for people who do not fit the typical profile in terms of qualifications, work experience and social skills. Almost universally this was the one thing above all others that people believed would make the most difference to young people's independence, self esteem and long term wellbeing.

Many felt there had been **positive progress over the last 20 years**, since they or their children first entered the system. However there was also concern that specialist skills are in danger of being lost from the workforce as older people retire. This, plus concerns over wider economic pressures and restructuring, led to a feeling that the future was by no means secure for these young people.

NevSom: a new centre of excellence

NevSom, the national competence centre for neurodevelopmental disorders and hypersomnias, is a merger of two former national units: for autism, and for ADHD, Tourette's Syndrome and narcolepsy. It opened in March 2015 and is based at Oslo University Hospital.

The new centre's remit is still evolving, but already a key focus is on improvements in policy and, crucially, in practice for individuals and families affected by one of the four conditions. It will work across all age groups, from early childhood onwards.

Sylvi Storvik, a former headteacher, and Knut Bronder, who trained as a psychiatric nurse, have spent their careers in different areas: both were on the boards of parents' associations, Sylvi for autism and Knut for ADHD. They see the change as an opportunity to benefit from sharing knowledge and resources, and to create a centre of excellence for information, guidance and research. Both believe it is vital to close the distance between researchers, practitioners and families.

"The professionals need contact where people are," Sylvi says. "Otherwise their competence goes down."

NevSom collaborates with the four health regions, municipalities throughout Norway, and the parents' associations for each of the conditions, providing information, guidelines and resources. It also advises central government on national policy and practice. It is mostly funded by the Department of Health, although it can seek out alternative funding for particular projects.

In the past the units linked up with the parents' associations to run courses, conferences and camps for individuals and their families, and Knut previously delivered a very successful course for prisoners with ADHD. Both would like to see this kind of work continue and develop.

Sylvi is clear about the point and purpose of it all: "It raises awareness of what you need so you can be included in society."



Sylvi Storvik and Knut H Bronder of NevSom

Parent associations and peer support

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

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 that manage their own activities and budgets. The head offices have few, if any, paid staff and are largely a support service for the regional associations, not the other way round.

Central government only deals with and funds organisations that evidence a sizeable membership, meaning 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. The downside can be leadership and direction: relying almost 100% on volunteers means activity levels locally can fluctuate. However the model cuts down on administration and duplication of activities, creates a strong local presence where it works well, and encourages organisations to speak with one voice, which as a result has a strong chance of being heard.

Funding, including from central government, is allocated to association boards and regional groups apply to them for local projects. Money also comes from subscriptions and donations.

The close link between funding and membership levels is a strong incentive for organisations to retain the confidence and loyalty of parents.

Norsk Tourette Forening

The Tourette's association celebrates its 30th anniversary in 2016. It began with eight parents: now 1600 members in nine chapters across the country makes it large compared with other European countries. Their annual conference for parents and others is always oversubscribed.

"It's great, but sad too," says chair Anne-Line Gausdal. "Because we are the only ones who give information to parents. Why is this organisation the one who has to do this? It should be available at the diagnosis."

Anne-Line and her son, now 20, both have Tourette's, while association CEO Liv Irene Nøstvik has a 19-year-old son with the condition.

Liv Irene agrees. "The tics are the tip of the iceberg, and underneath you have everything that is really making the problems for most people. It's not tics that are the biggest problem, it's obsessions, the sensory issues."

Doctors often fail to recognise internal tics, and the muscle pain, digestive problems and disrupted sleeping patterns associated with

them. The association also believes patients are often wrongly diagnosed with OCD.

"It's important, because you have treatment for OCD, but it doesn't work with Tourette's," Liv Irene explains. "Obsessional thinking, for example – it can be part of Tourette's. But OCD is catastrophic thinking – if I don't wash this many times something bad will happen. In Tourette's it's about just having a right feeling."

Anne-Line agrees: "It can be really difficult to make people who treat these patients understand they have to approach it in a different way."

Money and attention often follows higher profile conditions, at the risk of leaving Tourette's marginalised and masking ignorance among professionals. The association collaborates with other agencies, publishes a members' magazine four times a year

and produces resources for parents, professionals and employers.

Both Liv Irene and Anne-Line would like to see faster diagnosis, that includes screening for other conditions, and willingness of professionals to consider the whole picture of behaviours and their impact on the individual and the family. They are anxious about the low level of awareness and competence nationally, and would like to see specialist Tourette's centres as a diagnostic and information resource.

They also plan to share knowledge with OCD teams in each region, to enable them to recognise Tourette's patients and offer therapies like habit reversal training, which is proving effective with some people.

Recognition of the association's competence could be crucial in closing the gap in specialist knowledge.



NTF Chair Anne-Line Gausdal (left) and CEO Liv Irene Nøstvik

ADHD Norge

ADHD Norway was founded in 1979 and has around 9000 members organising activities, courses, meetings and forums in regions across the country. Its purpose is to spread knowledge and understanding, keep members informed about their rights and support possibilities, and promote social equality for people with ADHD.

Knut Bronder of NevSom was among the first adults in Norway diagnosed with ADHD, and has a son and two grandchildren with the condition. He has been involved with the association almost from the beginning, and was instrumental in establishing the first treatment guidelines for ADHD in 2005 which stipulated the right to be evaluated for a diagnosis and treated with medication if necessary. Today around 13,000 adults are receiving treatment in Norway.

"ADHD has come a long way. There's less awareness of Tourette's because it's a rare condition and few people are working on it."

“It’s often difficult for parents to get appointments with professionals, but at the family camps people can get specialist advice. Siblings meet others in the same situation.”

The association is led by an elected national executive committee, which includes a representative of ADHD Norway Youth. A board of professional advisers supports the organisation’s work, particularly its lobbying activities. Parents and professionals working together is seen as key.

Autismeforeningen i Norge

The national autism association was founded in 1965.

At the head office in Oslo, CEO Tove Olsen is one of only five paid staff and the first in the organisation’s history with a professional background in disabilities. The office operates an advice service by telephone and email, and leads on political activities and media relations: but the 19 local groups, one in each county, are completely autonomous and run entirely by volunteers, mostly parents. In some regions, people with Asperger’s are also involved in running the groups.

The Oslo office is allocated funding from central government, which it distributes among the regional groups. Income also comes from membership subscriptions and some groups run their own fundraising programmes. All groups have signed up to guiding principles agreed at the annual general assembly.

As well as running seminars and training, the Oslo office gets involved in campaigns such as one that targeted the *Barnevernet*, Norway’s agency for looked after children, to raise awareness of Asperger’s.

Historically the association has had a high profile among policymakers and the public at large, owing to connections established by the founders and effective use of media channels. In future, it sees itself working more closely with organisations for other conditions on issues that are common to all – social benefits, for example. The hope is that organisations might reduce duplication of effort and support one another more effectively in teaching, training and political activity.

Another challenge for the future is work with immigrant families and ethnic minorities. Oslo has a fast-growing diverse population and the association has begun to reach out to these communities, particularly mothers, to promote themselves as a source of information and support – particularly around rights and entitlements. Similar issues can apply in some of the indigenous Sami communities, which have a very distinct identity and may have limited contact with other services: the group in Finnmark, in the north, is developing work in this area.

Manager Eldri Ytterland has been on the association’s staff for 10 years, since she started as a student: her father led the organisation from 1987. She believes Norway generally has good rights in theory: the problem is divided responsibilities (Asperger’s is the responsibility of psychiatry, autism of support services) and the division of age. “I think they should talk now about having one service for the whole life span, and not dividing the spectrum,” she says. “It’s coming. The professionals know a lot but they think in boxes. I wish they were brave enough to think outside the box.”

Ensuring a smooth progression



Tidelingskontoret—the coordination office—for Tromsø kommune

In Norway, services and the boundaries between them tend to be more flexible than in the UK.

There are several roles within the service structure that specifically promote involvement across several different aspects of care and support.

Many municipalities have highly effective coordination teams that support better cross sector working around the individual, and staff may remain a consistent point of contact for queries or difficulties for years down the line. Rather than ending abruptly at age 18, many services continue at least until age 23, as this is the extent of the state’s responsibility for young people who are looked after: some will continue even longer. One youth team in Tromsø had supported people until the age of 30. These extended limits reflect the realisation that these are the years when many problems can arise, as young people – particularly those who are vulnerable – are moving into their own homes, entering the labour market, and for a significant number starting their own families.

Another role is that of the *vernepleier*, or social educator, qualified to work with individuals across the full age range from birth to old age. These teams operate in settings including healthcare facilities, schools, and in the home to provide a service based on individual need: for young people with these conditions, it could involve supporting 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 and smooth the way.

Some agencies, such as the labour and welfare administration NAV, also follow the individual seamlessly from childhood upwards.

“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.”

Tromsø— a pattern of cross sector working

Where a young person is affected by Asperger’s Syndrome, ADHD or Tourette’s Syndrome, multiple individuals and professionals may be involved in their support, according to need.

This could include social services and welfare staff; health workers and therapists; education staff, for example in university or college; agencies and networks supporting independent living; family members; and others.

Managing multiple relationships is a

major challenge where young people are of an age to assume responsibility for themselves but may not have yet mastered the organisational or social skills.

If assistance is needed over a long period from different parts of the care system, an Individual Plan will

be established and a coordinator appointed.

The coordinating team also supports those responsible for the plans, through training, supervision and monitoring, and maintains an overview of plans and coordinators in the municipality.

Building professional competence

“Norway is organised this way. For us it is very natural to join together with other organisations, we think like that.”

Interdisciplinary networks for those working with autism, ADHD and Tourette’s Syndrome are well established in Norway. NevSom, the new national competence centre, was modelled in part on practice already operating in the regions.

The network R-Faat operates across all parts of Helse Nord (the northern region) through centres and hospitals to promote cooperation among services and encourage appropriate, consistent and good quality care and support that reflects individual need. It also builds competence among professionals through interdisciplinary forums as well as conferences, courses and teaching.

Based at the University Hospital of North Norway in Tromsø, coordinator Kari Anne Pedersen oversees activity across the region. The network’s steering group brings together representatives of the three parents’ organisations, education and health sectors, and the director of NevSom.

Collaborative working supports education

Statped is the national agency providing special education services to municipalities and counties. Under the Directorate of Education, it is divided into four regions with a head office in Oslo.

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. It is currently

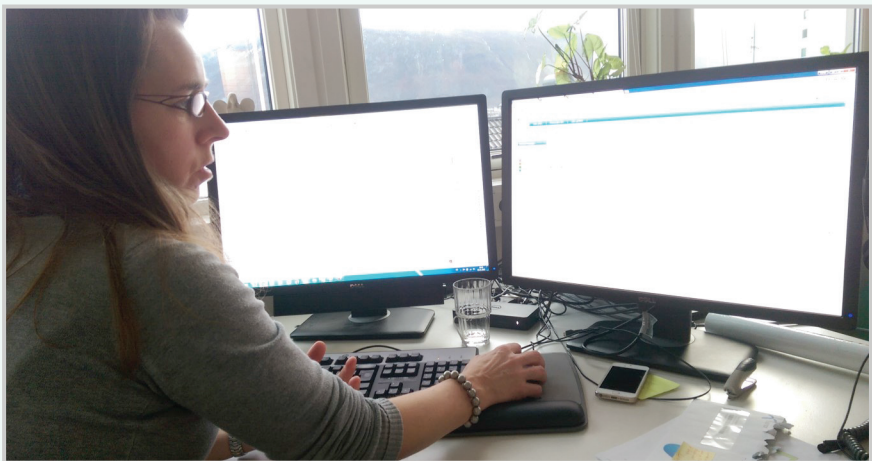
undergoing restructuring, due to finish in 2016.

Each municipality also has an educational psychology service or PP-tjeneste (PPT). Its intention is to help children, adolescents and adults experiencing developmental difficulties or difficulties related to education. Advisers can be contacted directly.

Both services work mainly in schools and kindergartens, but also have a remit covering adults. They provide advice, training and support to teaching staff to help them organise learning in better ways.



Keeping everyone on the same page



In Norway an individual plan may be created at any age, where needs are identified and multiple services need to be coordinated.

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 the creation of a similar but simpler plan – a *stafettlogg* – for every child from kindergarten upward, providing a central point of contact for parents and relevant professionals at every stage. Project leader Bente Høiseth is excited about its progress so far as a means of identifying and addressing difficulties much earlier than previously, and supporting more effective coordinated intervention where necessary.

In 2014 the municipality adopted Sampro, a web-based individual planning program, to help streamline collaboration. It is

being rolled out by the coordinating team at the *tildelingskontoret* led by Heidi Matre, who with colleagues Liss Johansen and Bente Høiseth is training people across the municipality to use the system.

Both individual plans and *stafettlogger* can be held centrally using Sampro and all existing plans will be transferred into the system by the end of 2016.

The principle is simple: an individual’s details are held centrally, and can be accessed remotely by those involved in administering the plan – including the young person concerned or their families, through their own PCs. A lead professional, normally from whichever agency is most heavily involved, manages the online plan. Strong security ensures information can only be viewed by those with the necessary permissions.

The advantages are clear. All those involved in someone’s care

can access the same information, avoiding the endless repetition many families find challenging. It is also immediately apparent which services and professionals are involved in supporting the family, and what actions or interventions are ongoing. Managing access appropriately allows the group around the individual to evolve as necessary, with participants added or removed as required, making it highly flexible and responsive.

Because the online platform can be accessed at any time, 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 much more promptly, and major concerns identified earlier.

Another major advantage is that online access can also break down the social anxiety of physically meeting with multiple professionals, which can be a real 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.

Next steps—post school options

“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.”

Academic qualifications are the gateway to employment, higher education and training – but it’s no secret the keys to success lie elsewhere. Resilience, self confidence, ability to work with others, flexibility, problem solving: without them you’re at a disadvantage, however highly qualified.

If you didn’t thrive in the school system, these qualities are doubly important because they may be all you have to rely on.

A big challenge is providing options to keep aspirations alive for young people such as these and to support them in continuing to learn skills that will take them to the next step.

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.

“Psychoeducation takes place in a group because it’s very valuable for participants to discuss, say, inattention, and their own experiences with it, together. Often

it’s the first time they’ve discussed it with someone who has the same problems. That’s liberating. And it can be very funny, they have a great time, laughing at it together.

“Establishing strategies is an important part of psychoeducation. Every time the same thing is going to happen, if you don’t do it different. 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 participant led – they are taking control, that’s important. It’s giving them responsibility for their own learning and therapy.”

Military service

Officially this is still compulsory in Norway. People with diagnosed conditions have difficulty getting into the armed forces, although

there is a realisation among security services that some people with Asperger’s can contribute greatly to electronic warfare and intelligence.

Folk high schools—a positive alternative

Folkehøgskoler have been part of the Norwegian tradition for 150 years and more than 10% of school leavers enrol every year. They represent a highly flexible, practical destination that bridges a gap for many young people in Norway who are not ready at the time of leaving school to progress straight into education, employment or training.

The term “school” is misleading: there are no entry requirements, no formal teaching programme and no leaving qualifications. Each of the 80 schools is an independent, not for profit enterprise that decides itself what activities to specialise in. But

all emphasise practical, community based activities that encourage students to follow their interests, challenge themselves, and develop essential life skills. Their biggest strengths are diversity, offering a huge range of choice, and flexibility, making highly individualised programmes possible.

For students with additional support needs it’s a chance 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.



Expedition undertaken at a folkehøgskole by a student with Asperger’s Syndrome

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 NAV together with 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.

Education, employment and training

Inclusion in higher education



Hanne Kveller, disability officer at NTNU, supports individual students and advises staff on inclusion. As well as counselling, she facilitates an Asperger's peer support group. A similar ADHD support group is run by students employed to coordinate the regular meetings. These combat isolation and are an important way of sharing learning strategies and life skills. Mentors are also paid to work one-to-one with students who want this service.



Elinor Jeanette Olaussen is based at NTNU with Universell, the Norwegian 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 new website makes a wide range of information available, 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>.

Students with these conditions are more evident in higher education than ever before: partly because they are better recognised, but also simply because there are more of them as nearly all jobs require a degree.

Government guidelines encourage having an action plan for an inclusive learning environment, and a named contact for information about entitlements and support. Universell, a nationwide agency with its base at the Norwegian University of Science and Technology (NTNU) in Trondheim, was founded in 2003 by the Ministry of Education to coordinate activity and offer advice and training nationally.

Universities and colleges also have their own disability inclusion staff, though teams vary widely. Their roles are set to change with more than 40 institutions merging into eight or nine centres, devolving responsibility for inclusion to academic staff and locally based support teams. Building capacity of other staff will be hugely important.

The disability inclusion team at NTNU is one of the best resourced in the country. Drawing on paid student mentors, it offers a highly individualised service. It is also in the process of developing a careers counselling pilot programme to smooth the path into work for students with disabilities. In 2014, building on a previous project, the university together with NAV began to contact companies signed up to governmental initiatives on inclusion in the workplace and to place students in paid work experience. This turns on its head the traditional approach of "these are your difficulties, what can we find for you?", focusing on competence instead. By actively supporting work experience the programme promotes equity with other students, most of whom take jobs while studying, by increasing the ability to compete in the job market.

Supporting employment

Statistics are thin on the ground for how many people with these conditions find employment. Some individuals are compiling regional figures independently, but the national body, Statistisk Sentralbyrå, provides no results for this group.

Around 26% of enterprises have signed a government agreement intended to promote inclusive working, but for many people with these conditions this has yet to translate into job opportunities.

Norway offers a high level of support to employers of people with learning difficulties. Through NAV, employers can reduce their liability for sick pay if an employee has a disability; there is protection around sacking staff if a job doesn't work out; employees can continue to receive benefits for a period of time when starting work; and the government may subsidise salaries by up to 50-60% for up to 3 years if certain criteria are met, allowing time to determine capacity and suitability for any given role.

For employees, NAV offers advice and support in finding work: but both employers and young people commented this no longer works as well as in the past. These services are mainly provided by external suppliers appointed through competitive tender. The majority of young people who were in employment said their most significant support had come from parents who provided work experience, sourced job possibilities, and supported placements.

Arrangements around benefits are generous: if disability is registered while still in school, disability benefit is awarded for life. The system allows income to be split flexibly between

work and benefit, so part time income may be topped up by benefits. Benefits cease when salary reaches a certain level, but if employment ends it is relatively easy to plug back into the system.

Despite this, young people and families see sustainable employment as very difficult to achieve. There was also a feeling among some that it was a stigma to have your salary paid by NAV, and definitely less preferable to being paid by an employer. It is universally agreed that sustainable employment is the single biggest factor in making a difference to self esteem and lifestyle. For many jobs completing high school is a minimum requirement, meaning the path into work is harder for those struggling with increasingly academic demands. Self employment is an option for some, but most felt the administration and organisation required would be a barrier without tailored support.

All the young people who were in employment had had multiple jobs and work placements, punctuated by periods of unemployment. In every case parents had been the principal motivators to get back into the workplace. None were working in their choice of career, despite in some instances being highly skilled in areas they had hoped to pursue. The most common reason for this was the breakdown of work placements or apprenticeships.

Some organisations have been established on a business footing to provide careers, notably Unicus in Oslo, which was founded in 2009. It remains to be seen, however, if this kind of model could transfer into careers other than technology and remain sustainable.

"It would be good to have more personalised help in finding a suitable job."

"More assistance is needed when starting a job, to make it sustainable. For many, it's too difficult to have an ordinary job."

Spesialistbedriften: looking to lead by example



Photo: Arve Hasfjord, Spesialistbedriften

Spesialistbedriften was established in 2014 in Ålesund to offer job opportunities to people with Asperger's Syndrome.

The organisation was the brainchild of Arne Bjørdal, who became aware of the potential of young people with Asperger's as a teacher in a local high school. The development and day to day running of the company is in the hands of Merete Alnes Mostue, a business executive with experience at management and board level across Europe.

Mostue is clear: this is a consultancy, not an employment agency. The aim is to build a knowledge based technology company that can compete with commercial concerns across Norway and beyond. They have been highly successful in generating support from businesses in the Møre og Romsdal region.

"People have been happy to be involved," Mostue says. "They like to take social responsibility. We are not paying dividend, but we've had companies putting in 100,000 kroner [around £10,000] and thanking us for starting this business."

Candidates must be highly skilled and preferably also educated to degree level or beyond. Spesialistbedriften sells their skills to

clients on a consultancy basis. Customers have come from some of the foremost employers in the region, including satellite telecommunications company Inmarsat and industrial control systems developer ICD Software.

"A principal selling point is that the client is always in control of the relationship," Mostue explains. "It takes away risk for them. If a placement doesn't work, we can withdraw the consultant and provide another. If the client isn't happy ultimately they have the ability to terminate the contract."

Those employed as consultants benefit from the opportunity to apply their skills in a salaried, real-work environment, while receiving training and support in developing the personal and social skills they need to function in the workplace and engage with clients.

Key to success is the support on offer, both for employees and clients. Mentors Linda Nygård, Aud Solveig Reitan and Arve Hasfjord ensure the path into work is as smooth as possible on both sides. All have backgrounds in social and support work: Nygård also has experience of business management while Reitan has specialist knowledge of ADHD and

autistic spectrum conditions.

Consultancies are either on the client's premises or at the Spesialistbedriften office, with contracts negotiated individually with each client. The consultants receive a salary based on skills and experience. This is currently lower than the Norwegian average, but as sales income increases over time the intention is to bring salaries in line with market rates. All profits are reinvested in the company: a model Mostue describes as "using business terms to solve a social challenge".

The real advantage is the *arbeidsavklaringspenger*, a benefit from NAV provided for the first 6 months or sometimes longer, which allows time to assess an employee's competences, skill levels and support needs, greatly increasing the chance of successful placements.

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

"The biggest challenge we encounter is not the Asperger's diagnosis," says Linda Nygård. "It's poor mental health, overprotection by parents, low expectations. If it was just the Asperger's it would be quite easy."

Health and independent living

Health

Challenges were identified around mental healthcare, with practitioners not always having awareness or knowledge to treat difficulties appropriately. This was particularly felt to be the case for Tourette's.

Anxiety was a common problem for many young people and access to treatment appeared to vary. The decentralisation of psychiatric

services was felt to have been an unhelpful development as smaller localised services did not always have the tools to use when speaking to someone with these conditions.

People reported medication being prescribed long term, sometimes without a proper review.

Transition from children's to adult

services in mental health were described as "a bumpy ride" at times, and it was felt diagnostic and treatment services for over 18s could be better streamlined. In particular, it appeared there could be benefit in strengthening pathways to support following diagnosis for adults, as there was not always clarity over which services could be most beneficial for particular individuals.

Housing

In theory there are options for young people to live independently of the family. In practice, however, young people who are high functioning rarely receive support of the right kind. Many parents were renting, buying, or even building accommodation on their children's behalf. The younger the person the more likely they were still to be living in the family home.

An experiment in 2010 to pilot the first residential homes in Norway for people with Asperger's was short

lived. Eldri Ytterland of Autismeforeningen explained: "Many were given flats connected to psychiatric residences, people with drug problems and dementia, without the professional care they needed. The municipalities don't understand what services they need and won't touch the price even if it might be cheaper long term."

Looked after young people may have extra support to assist independent living for up to 5 years after leaving the care system at age 23.

"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."

Justice system

People with these conditions are over represented in the prison population in Norway, as elsewhere.

NevSom is running a project to collect experiences of people with Asperger's Syndrome in prison, and the ADHD parents' association ran a course that was successful for prisoners and prison workers.

Knut Bronder of ADHD Norge helped deliver the course. "The feedback from one of the inmates was: don't put me on medication when I still have 20 years of my

sentence, because then I start to think. And I think clearly, and I look out of the windows and that is 20 years, and that is the way to become suicidal. Come back with the medication when I have a couple of years left."

Although experiences of the justice system did not form a major part of this study, discussions did touch on support for those ending custodial sentences, and highlighted the need for very specific support around planning and structuring time and activities for people who are highly vulnerable.

"They put the TS boy with people who have drug problems, that happened to my brother, he lived with people that wasn't good for him."

“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.”

Right support at the right time

There is an ethos in Norway, backed by legislation, that support should be available as necessary to those who need it.

The Work Environment Act provides for employee health services, which have sometimes been instrumental in identifying issues and providing follow up support in addition to other adjustments. A second key piece of legislation is the Assistive Technology Act, under which someone with a lasting disability – that is, a condition likely to affect them for more than 2 years – is entitled to access equipment to support independent living. Increasingly this includes smart devices, apps and IT.

The equipment is bought and distributed through the *Hjelpemiddelsentral* (Centre for Assistive Technology), a division of the welfare and labour administration office, NAV. Each county has its own centre. People may be referred by doctors, lecturers or other professionals, or families, and employers can contact the centre directly. Once it is agreed what equipment would be beneficial, this can be borrowed free of charge for as long as it is needed.

The centres work with all conditions and across all ages, meaning equipment can be upgraded and evolve to meet changing needs. A lot of the technology is developed in Scandinavia and many centres have a close relationship with developers and suppliers, shaping product development through suggestions and feedback from service users.

Funding for this is currently ring fenced, though there is discussion about how the service might operate differently in future. But a strong commitment to the principle of support is expected to remain.

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.

Elin Svendsen works for the NAV 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 assessment of need. It’s important someone else is involved: in the workplace a line manager, at home a friend or carer. They must ensure instructions are correctly applied, and are responsible for follow up. If a piece of 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.

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 there’s a weakness in the system, Elin feels it’s the lack of resources to follow up with clients. She would like regular reviews to track how equipment is being used and ensure the individual is continuing to benefit.

What people said ...

Across the project as a whole 50 young people with a relevant diagnosis, or family members of a young person in this category, are answering questions about their experiences since leaving school. Of these responses, 22 were gathered in Norway.

Responses highlighted the following:

- Dissatisfaction with NAV, specifically around support into work. In some cases parents’ ongoing support (e.g. alarm calls in the morning, help with transport) was crucial in making work sustainable.
- Most parents said they have to remain actively involved in a young adult’s life to ensure basic requirements, such as accommodation, are met. Usually it is parents who seek out work experience and job opportunities; provide motivation and support to engage in social activities; and enable holidays (both paying for these and travelling to support the young adult).
- Only three young adults were still living under a parent’s roof, but nearly all were in properties owned by a parent. Many parents and other family members helped with routine maintenance, while some also paid for any maintenance required.
- Several young adults felt dependence on their families for support made it difficult for either party to move away should they need or want to.
- Everyone felt the diagnosed condition had impacted the whole family, financially and emotionally. All pointed to increased family tension: many parents were separated and cited related pressures as a contributory factor. Some reported estrangement among siblings.
- The younger the person, the less clear they were likely to be about options and possible next steps. This made it more difficult to find the right support and make progress towards a goal.
- Everyone agreed employment that was free of stigma, appropriate to the young adult’s interests and personally rewarding, was crucial.
- A great deal of improvement remains to be made in training and equipping young adults in the skills needed to organise and manage their own affairs.
- Nearly all the young adults either had been treated, or were currently receiving treatment, for anxiety/depression.
- Luck was felt to play a great part in whether you had a good experience of the system, or not.
- There is a need for specialised careers advice for these young people.
- Parents expressed concerns for young people about social isolation, dependence on medication, alcohol/drug use, and “learned helplessness”.



Please note: this is an observational, not an academic, study. As such the views represented here are not intended in any way as a statistically representative sample.

Authentic voices

“Early school, I didn’t like being different, but I came to the realisation I had ambitions to do something, and I stopped caring about that.”

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

- Three young people were in a relationship. Most were in contact with people beyond the family primarily through college or work, or through social media with people from university or folk high school.
- It was felt there was reasonable awareness of ADHD and autistic spectrum conditions in children, but less understanding of the impact of the conditions on adults—in particular, of the very different support requirements. Understanding and awareness of Tourette’s Syndrome and its effects was believed to be much less, across the board.

“They look at your file and see written on the front ADHD and put it away and say just stay home. It’s easier than trying to help find work.”

“When I was studying ... We had a teacher who tried to teach us about ADHD and I basically just gave up and told her either I take over or I just go.”

“My life is really good right now but before not so much. I especially feel sorry for my dad and my mum, she’s been a punching bag for me, not physically but mentally. Also my friends. But before medication. With Ritalin, I’m a nice girl.”

“She was working in a senior citizens home and she’s been a cab driver, she’s tried all different kinds of things. And then she found something is wrong. She went to the psychiatrist and ended up with a diagnosis of ADHD and got treatment. She finished school, took a good degree.”

“I look calm on the outside but I’m acting. It’s a good thing to be able to do because then people assume you are confident, which can be useful.”

“I have some wounds inside me. There’s something in me that is ruined, that is hard to fix in a way. That makes me still have a really hard time doing some things I have experienced over and over again.”

“I have stopped caring, I have started living my own life. I start breaking their rules, that you can’t break, and I feel good and relaxed by doing it. It feels really good.”

“I did the whole apprentice period, but I couldn’t take the exam there. It’s like going to the finish line and there’s a piece of glass. You can look at it, be almost there, but you can’t get it.”

“I think I’m smart but ... it ends up with me being overwhelmed, studying way too much, bothering the professor, getting stressed and more. It would make things a whole lot easier if for example the professor could talk me through the book and point out how deep I am supposed to go and what is important.”

- Young people and families felt customary measures of attainment and progress, particularly within education and training, did not adequately reflect ability or recognise achievement where social and cognitive impairments were a factor.
- All parents expressed anxiety about the future, and a sense of pressure around future planning. None of the young people expressed the same anxiety, but many said they felt disappointed or disillusioned with their present circumstances.

“My son, he’s living with me now, doesn’t have a job or support. I don’t know if he’s told NAV he has Asperger’s. He’s afraid to do so.”

“We had an individual plan, and I struggled for years to make that happen, and it didn’t work at all. All that work, that activity, meetings, planning, almost forcing people in the group to meet, it wasn’t worth it at all. I was totally exhausted for nothing.”

“The idea of socialising on normal terms, that can be a huge problem actually.”

“If your child is high functioning, support is limited and allowances can be very difficult to get.”

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

“What scares me is it gives him the experience and creates the condition of learned helplessness.”

“We should be a lot more flexible about when you can do things.”

“How can he get a job when the first step is so hard to take?”

“I feel the only person who sees how vulnerable my son is now at this moment of transition is me. I see if we don’t get it right now we might never ... this is his life that is at stake. That scares me ... if this fails now his experiences will be connected to therapists, very dependent. So the doors are closing.”

“We are trying to get a second opinion. We all see he needs help. The problem is he doesn’t have all the diagnostic criteria. His function has to be lower to get a diagnosis.”

“Tourette’s is a very tiring condition, hard on your body. So you have to have an employer that gives you flexibility and that’s really difficult. A lot are on sick leave or benefits unfortunately. A lot who do work don’t work 100%.”

“The challenge is to keep him motivated.”

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

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

“We usually joke about it. We say autism mothers live forever.”



I am grateful to everyone who has helped in this study by sharing their knowledge, insights and experiences.

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