



# Life on the Edge of the Cliff

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

**STUDY VISIT 3**

## The Czech Republic

**31 March – 15 April 2016**

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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;<sup>1</sup> estimates are that at least 30% of the prison population has a learning difficulty of some kind;<sup>2</sup> 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.

<sup>1</sup> National Autistic Society; <sup>2</sup> Prison Reform Trust

Quotations throughout are from interviews undertaken during this study visit.

“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.”

Between 31 March and 15 April 2016 I visited:

**Prague, in Bohemia: (Hlavní město Praha)**

Prague is the Czech capital and its largest city with around 2 million residents. The cost of living is low compared with other European cities and many international companies are based here. Unemployment is low and wages are significantly above the national average. Reliance on heavy industry has reduced and around 80% of the workforce is employed in service related jobs. Prague welcomes more than 6 million tourists every year.

**Ostrava, in Moravia—Silesia: (Moravskoslezský kraj)**

With a population of over 300,000, Ostrava lies 10 km from the Polish border. Built on coal and steel production, and with high levels of pollution, the city’s future looked bleak following the collapse of the Communist government. But Ostrava now plays host to major global companies such as Hyundai and Siemens, and hosts cultural and tourist events including the annual Colours of Ostrava (world music) and Summer Shakespeare festivals. The city has two universities and a business school.

**Brno, in South Moravia (Jihomoravský kraj)**

The Republic’s second largest city with a population around 400,000, Brno is the seat of the Constitutional Court, the Supreme Court, and the Supreme Public Prosecutor’s Office, along with other state authorities. Until 1918 the city was mostly German speaking, but the German community was forcibly expelled at the end of the Second World War, and today the population is predominantly Czech. It is an important university city and centre of technical research and development.



# The Czech Republic – an overview

The Czech Republic came into being on 1 January 1993 when Czechoslovakia, established at the end of the First World War, was formally dissolved.

With a population of 10.5 million, it lies at the heart of Europe and has been shaped by external social and political forces throughout history. Most recently, 41 years as a one-party Communist state under Soviet influence has been followed by 27 years of reconstruction and economic development after the “Velvet Revolution” deposed the socialist government in 1989.

During the Communist years there was emphasis on developing mining and heavy industry, along with agriculture. After 1989 this went into rapid decline: however machinery and transport equipment, raw materials and chemicals are still important exports.

The Czech Republic joined the European Union in 2004. It is a member of the United Nations, NATO, the OECD and the Council of Europe, and has close ties with Slovakia, Poland and Hungary as part of the Visegrad Group. It shares free movement of goods, capital, people and services with EU members, but has joined Visegrad members in resisting EU quotas over resettlement of migrants and refugees.

According to Eurostat, the European Commission’s statistics directorate, the unemployment rate for the Czech Republic stood at 4.5% in December 2015 – the lowest in Europe.

## Government

The current constitution came into force when the Czech Republic was established in 1993. The prime minister controls the policy agenda: an elected president is the formal head of state. Since 2013 a coalition government has been led by the centre left ČSSD party with representatives of the centrist ANO 2011 and centre right KDU–ČSL. Opinion is sharply divided on current president, Miloš Zeman: some regard his behaviour in office as inappropriate, but popular support appears to remain strong.

There are 13 administrative regions (*kraje*) plus the capital, Prague (*hlavní město*). Each has its own elected assembly (*krajské zastupitelstvo*) and regional governor (*hejtman*). Local municipalities are responsible for primary education (age 6–15), social services, housing, development and planning: however in practice much remains in transition from the former “committee” approach of the Communist party and some municipalities operate more effectively than others. Some functions, for example justice, remain the responsibility of older administrative districts (*okresy*): others have proved difficult to decentralise. This can make for a complicated relationship between national and regional responsibilities and accountabilities.

Parliamentary elections to the lower chamber are every 4 years, with elections every 2 years for a proportion of the senators in the upper chamber. Once elected, their term of office is 6 years.

## Education

Education is free, although discussions around university tuition fees are ongoing. Private schools and universities are financially inaccessible for most people, but state provision is highly regarded. Integration of pupils with special needs into mainstream education is becoming more common, with

the assistance of a special teacher: however outside the cities this can be patchy and poorly resourced. Teachers’ salaries are generally regarded as low compared with equivalently qualified members of the workforce.

Preschool education is available from age 2, mostly paid for by parents: the last year before school is free. “Primary school” (*základní škola*) covers age 6 to 15 years old and is compulsory.

The next level offers a range of choices according to ability and interest. To apply to university, a pupil must hold the *maturita* or school leaving qualification, available through either vocational or academic routes. Typically pupils study for 4 years beyond compulsory education and attend a professional high school or grammar school, or a vocational school where they must pass a vocational qualification as well as the *maturita* to graduate.

Shorter certificated vocational courses of 2 or 3 years lead directly to employment in certain fields, or self employment.

There remains a network of “practical” or “special” schools geared to pupils with learning difficulties, focused on independent living and employment skills: in 2010 the European Court of Human Rights criticised the government for placing ethnic Roma children in these settings without appropriate assessment. Courses typically last 1 or 2 years.

All *maturita* qualifications allow pupils to apply to all types of universities, but acceptance depends on passing a university’s own entrance examination. Typically 3 years are required to obtain a bachelor’s degree, then a further 2 years for a master’s. This can be extended in special circumstances. Another 3–4 years are needed for further postgraduate study or PhD research.

The Ministry of Education, Youth and Sports sets national policy at all levels.

## Health

All taxpayers pay state health insurance, after which services are free at the point of delivery. There is a strong widespread presumption of state provision and private clinics are relatively unfamiliar to most people.

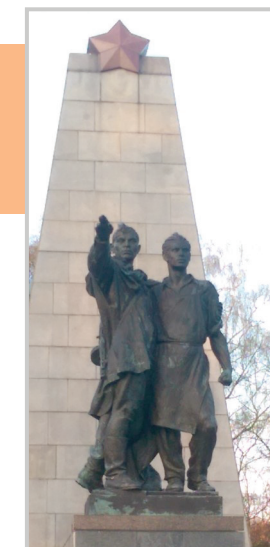
There are separate general practitioners for adults and for children and young people, but patients may visit specialists without a referral from a primary care physician. Inpatient care is provided in hospitals and specialist institutions.

## Welfare and social services

Welfare is the responsibility of the Ministry of Labour and Social Affairs.

Disability pensions are awarded at full or partial levels following assessment, and on an equal basis for physical and mental disabilities. It is possible to continue receiving benefit while earning income to a specified level. Recipients of invalidity benefit can apply for additional support for living costs such as rent. Those aged 26 and under, and not in employment, can have their public health contribution paid by the state.

The unemployment rate in the Czech Republic is low, but increases sharply for those with less education: adults with university level qualifications earn on average 75% more than those who only completed upper secondary.



The Red Army Memorial in Komenský Park, Ostrava

*“High functioning implies you can work like anyone else but that’s not accurate. Of course you are high functioning in the physical sense but in the social and communicative sense you need the adjustments and the right kind of help.”*

*“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.”*



# Awareness and policy – the national picture



Central Prague

**Provision of services and entitlements is well represented in legislation, but the Czech Republic shares with other countries the challenge of applying these consistently enough, and universally enough, to make a significant difference in the lives of young people with these conditions.**

**Excellent initiatives and support programmes** exist but the overall landscape can be fragmented and difficult to navigate, which impacts on accessibility for service users.

The three conditions considered by this study are classified differently, which may partly explain **differing levels of awareness and understanding**, among medical practitioners as well as professionals and the general public.

Asperger's Syndrome is classified separately, along with autistic spectrum disorders, as giving rise to distinct challenges. Many programmes and organisations exist to offer support of various kinds.

This is less true for ADHD and Tourette's Syndrome, which are included among the conditions

termed "specific learning disorders". Awareness of ADHD is increasing within schools but its impact on adults appears to be far less understood, and the majority of support programmes and therapies focus primarily, or exclusively, on children. Awareness of Tourette's Syndrome is low, and peer support is the most reliable source of information and advice.

In the Communist years, unless there was evident physical disability, care and support was largely a family responsibility. People feel 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 some professionals felt this had influenced peoples' expectations in relation to

health and welfare provision.

**Families remain a key source of support** and are strongly connected, with many young people returning weekly to the family home. Family background is closely correlated with attainment: over 70% of young adults have the same education attainment levels as their parents.

**Many support services depend on non governmental organisations (NGOs)** which can be vulnerable to fluctuations in funding, often due to shifting government and policy agendas, that can result in closure of effective programmes. Increasingly, some service providers are turning to private donors and other funding sources: this model can offer sustainability and more flexible provision, but requires experienced management and a high level of transparency. It is considered uncommon by many Czechs and there can be a lack of trust around private organisations and services.

Low unemployment rates undoubtedly benefit the young people in this study. There appear to be **far more employment opportunities** than in the UK for flexible, paid work for people who do not fit the typical profile in terms of qualifications, work experience and social skills. Although much is comparatively low-skill and low-wage, the low cost of living means rented accommodation and independent living is still within reach, especially where there is eligibility for state support. Some young people find this works well as the level of flexibility meets their individual needs. Others express frustration at being unable to find work appropriate to their skills

and interests, and a lack of opportunities to progress.

**Understanding and tolerance of difference varies.** Some described bullying and exclusion in the workplace, while others felt they had received good levels of support and adaptation. But in general, people believed more information and advice for employers is necessary to make them aware of the benefits of employing people with learning difficulties, and helping them implement any adjustments.

Organisations with more than 25 employees must employ people with disabilities as up to 4% of their workforce, though in practice many pay a financial penalty to avoid this obligation. Money is available through the Labour Office for employers to create and maintain sheltered work for people with disabilities, and the cost of work-

related training for disabled employees may be subsidised or paid in full. People with disabilities are protected in the labour market, and the Labour Office can help find and maintain suitable employment, although in practice this can be complicated to access. Most who found work had done so through family connections, the internet, private agencies, or supported employment programmes by NGOs.

**Education** offers a range of vocational courses that reflect the need to support independent living and access employment. However academic high schools only prepare pupils for entry to higher education: if a pupil does not progress to university, their school leaving qualification has little value in the search for work, and they will have had no opportunity for internships or work experience as part of their

education. This can limit the choices available to academically able pupils.

Progression to higher education is dependent on passing a university's own entrance examination in addition to the school leaving qualification, which can present an additional hurdle to those who find formal examinations challenging.

There is a **range of benefits** to support independent living, but financial support is seen as limited and taking a long time to access. There was a feeling this does not work as well as it should.

A particular need repeatedly identified by both individuals and support organisations was for **raised awareness of these conditions** and their impact on daily living. Among the general public, it was felt that stigma and lack of understanding remain a problem.

## Deserving APLAUS

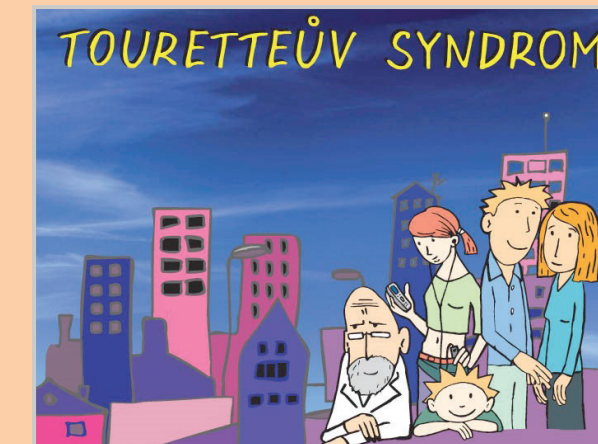


APLAUS 2016 awards, designed by Radomir Veselý

The APLAUS awards, launched by the national institute of autism APLA Praha (now known as NAUTIS) in 2013, recognise individuals and organisations that raise awareness and improve the lives of people with autism.

The awards are presented annually to coincide with World Autism Awareness Day in April.

## Over to you...



ATOS, the national association for Tourette's Syndrome, is launching a new interactive website this summer to help people of all ages recognise the challenges of living with the condition. Visitors work through everyday scenarios and choose how they would respond.



# Service provision



## NAUTIS: the National Institute of Autism

**NAUTIS, the Czech National Institute of Autism, offers a wide range of lifelong services to people with autistic spectrum conditions and their families, including diagnostic and assessment services, and advocacy.** It also provides information and training for professionals and institutions, participates in policy and practice development, and works to raise public awareness.

The organisation was founded as APLA in 2003, to address the need for more comprehensive and systematic support around autism within the social care system. Funding is through the Ministry of Labour and Social Affairs, along with municipal and regional grants plus European Funds and other donors. It is an officially recognised social services provider, and offers many services free of charge or heavily subsidised, which widens access: some therapies, for example, at 400 Czech crowns (around £11), are half the cost of private providers.

Around 1000 clients across the country access the individually tailored support services—some repeatedly—and NAUTIS trains over 2000 people a year, across the country and beyond: recent projects

include development work in Georgia and Kosovo.

Therapy and social rehabilitation combine within one unit at NAUTIS under the leadership of therapist Roman Pešek. The department has two full time therapists, supported by a mixture of specialist staff working part time within the team. The service supports around 200 children and their parents annually, plus 100 adults.

The focus is on individual and group therapy for people with high functioning autism at any age from 6 years upward, with referrals most frequently from within the organisation or through a family doctor. Family counselling is also available, as Roman explains: “You have to look at the family as a whole,” he says. “Sometimes it’s more important to work with the parent than the person with autism, because a therapist can only be there for a short time but parents are there all the time.” The groups often become peer support networks, learning from others’ experiences and helping prepare for future changes and challenges.

Therapy addresses anxiety, and can also cover social skills training,

### Together We Can Manage

NAUTIS (as APLA) managed the Together We Can Manage programme, which ran from 2012 to 2015, in partnership with Autism Europe. The aim was to compare and assess tools used for supported employment, to share knowledge and good practice, and to create a policy for supported employment and work possibilities for people with autism spectrum conditions in the Czech Republic. The programme actively involved people with autism in drawing up the policy and presenting to policymakers.

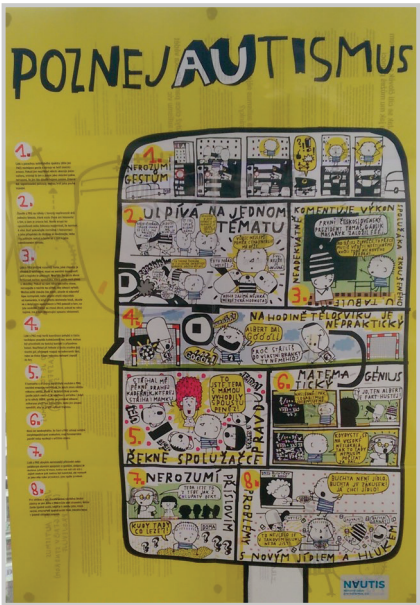
including how to recognise and react to others’ emotions, and anger management.

There is close collaboration across the organisation to coordinate support around the individual’s needs, which goes a long way towards creating a clear service pathway for clients.

Roman specialised in addiction therapy, but he finds Asperger’s a particularly interesting disorder. “These people are smart, they have a lot of skills,” he says. “I’m very interested in helping them make the most of the skills they have.”

### Services available within NAUTIS

- Psychological and psychiatric services, including diagnostics.
- Support services (early care, social and special needs counselling, social rehabilitation, supported employment, supported accommodation, residential care for challenging behaviours, respite and personal care).
- Employment and social training programmes (including development of cognitive and communication skills, and leisure activities).
- Educational programmes for parents, conferences and workshops.
- Support for families and carers, including stress management and relationship counselling.



Poznej Autismus: “Know autism”

## Other transition programmes

**Rytmus, in Prague, supports people with disabilities to integrate into the everyday environment.**

Their transition programme offers students in their last year of school the chance to explore different types of work, visit workplaces, and try possible jobs with personal support from an experienced adviser. At the end, the student can receive help to find paid employment. The programme is a chance to develop social and work skills, and to build confidence and independence ahead of leaving school. Planning is tailored to the interests and also the support needs of the individual.

In Brno, the organisation AGAPO runs a similar programme targeted towards students preparing to leave special schools.

### Real life: facts and figures

- 73% of adults with autistic spectrum conditions do not work
- The average time someone with Asperger’s stays in a job is 2–3 years
- Around 44% of people with autistic spectrum conditions who are in employment earn less than 10,000 crowns (minimum wage is 9900 crowns, or 9300 crowns for those receiving the invalidity pension)
- 80% of people with Asperger’s don’t have a long term relationship
- 5% have children
- 75% of adults continue to live with their parents

Figures: NAUTIS, 2014

## ADHD

**Although ADHD is recognised in children, awareness of its impact beyond school and into adulthood appears to be much lower.**

Organisations contacted for information included: ADHD ([www.adehade.cz](http://www.adehade.cz)); ADhyperactivita ([www.adhd.cz](http://www.adhd.cz)); CRSP (*Centrum Pro Rodinu A Socialni Peci*, [www.crsp.cz](http://www.crsp.cz)); ADHD Europe; Ministry of Education, Youth and Sport ([www.msmt.cz](http://www.msmt.cz)); and the General University Hospital in Prague, along with individual psychiatric specialists.

Unfortunately none of the organisations were able to advise of programmes specifically targeted at young adults, and it consequently proved impossible to identify families affected by this disorder to participate in this project.

When asked, few people considered they had encountered young people with ADHD outside a school environment. It appears likely this lack of awareness could be linked to the inclusion of ADHD within the wider group of conditions classified together as “specific learning disorders”, rather than being identified as a distinct condition in its own right in the same way as autistic spectrum conditions.

This collective grouping could be contributing in turn to lower levels of recognition and awareness, and leading to lower levels of diagnosis and targeted therapeutic intervention.

This may change in future as children currently in the school system progress into adulthood.



## ATOS: the national association for those affected by Tourette's Syndrome

### Coordination the key to a better service



Reception at INEP, where joined up treatment, support and therapy is a priority

Neurologist Ondrej Fiala currently wears two hats: founder of ATOS, the Czech association for those affected by Tourette's Syndrome, and head of INEP (*Institut Neuropsychiatrické Péče*), a groundbreaking centre opened in 2014 to address the full range of patients' psychiatric and neurological needs.

"No other centre in the Czech Republic offers complex care, with diagnosis, psychotherapy, psychiatric or neurological treatments and group therapy, all in one place," he explains. "That's what we do here."

Central government funding often goes to higher profile areas such as sport or is directed into NGOs (non governmental organisations).

"Everything has traditionally been run by the state," Ondrej says. "I know from colleagues, you can plan a good project and get support for 2 years and everything is great, but then you apply again and they say no, sorry, and you have to stop. That's not good and it's happened quite often."

For that reason, INEP relies on private donors, fundraising and income generation through resource development. It's a relatively new and unfamiliar approach in the Czech Republic, but one Ondrej believes gives the new centre more flexibility and control that benefits patients.

"The financial situation in state hospitals isn't good, so if you want to develop something new you don't have space or money for it. Here we can do everything according to our vision, I can invite people to collaborate, we are more open. For example, we have no specialist in the Czech Republic offering habit reversal therapy, which seems to be effective, so a colleague is going to study this and I hope she can offer it to our clients. I think that's almost impossible in the state system."

The INEP centre treats a range of neuropsychiatric conditions including, currently, 25 clients with Tourette's and comorbid conditions.

## Meeting a need the hospitals can't

It's a glorious spring afternoon outside, but the room on the second floor in central Prague is full almost to overflowing.

This peer support group is run by ATOS, the national organisation for people with Tourette's Syndrome, and people come from all over the country – and beyond. Some have made the 10-hour round trip from Slovakia, where there is currently no patient organisation.

Ondrej Fiala founded ATOS in 2001. The organisation offers the chance to ask questions, find out more about the condition, and meet others facing similar challenges. Many have arrived at ATOS by process of elimination following internet research and self diagnosis. It's a similar path to that taken by Ondrej himself 20 years ago when he began researching his own symptoms.

"There was no information about Tourette's then," he says. "Everyone was worried, even me, because I had a lot of tics and wanted to know what is my disease." The search led him to the national medical library, where as a 16-year-old he was alongside university students and staff.

"I met a professor from the university hospital who later became my supervisor," he says. "I found I had Tourette's. And I said, OK, I want to meet other people who are the same, but there wasn't the possibility for this. So when I was 21 we decided to establish a support group."

ATOS has grown steadily. The demand for support is clear, but there are obvious limitations. Most of the board have personal or clinical experience of living with Tourette's, but all have other jobs and their time is limited. Ondrej's aim is to appoint someone with the knowledge, skills and leadership to take the organisation forward.

This group meets twice a year, with a mix of regular attendees and first-timers. The biggest need is for information, followed by practical coping strategies and therapeutic interventions. Participants quiz Ondrej and other board members, and each other, in an informal atmosphere of understanding, support and frequently, humour.

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



ATOS director Ondrej Fiala and vice convenor Pavlina Radová



Left: the building in Křižíkova that is home to INEP and the central office of ATOS

*"I see people going to a neurologist in one place, a psychologist in another, backwards and forwards. Maybe communication isn't good, maybe they aren't synchronising medication well, patients receive conflicting advice and eventually it's not very good care."*



# Education, employment and training

## Finding what works for the individual

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

Led by founder and director Petr Peňáz, its 150 staff provide a range of support services, from counselling and therapeutic interventions to publishing adapted study materials, including braille and visual translations of mainstream lectures and texts. Around 30% of funding is through the university: it generates the remainder from other sources, including marketing services, and the European Social Fund.

The proportion of disabled students at Masaryk matches that within the population as a whole. With services under pressure, staff across the

university share responsibility for implementing universal design of learning\* on one hand, and individual adaptation on the other, supported by staff from the Centre at every stage of the process.

Creating accessibility from the start is crucial.

“Staff have to think about adjustments before the students are in front of us – not after,” says Peňáz. “They need to be able to say what is their proposal to adapt for this or that disability, before accreditation. It’s not logical to wait

until something hasn’t worked. It needs a change in thinking.”

The other aspect is individual adaptations, including time extensions; classes to address knowledge deficits that may have an impact on completing a course (for example maths or a foreign language); and sourcing personal support as required from external organisations or NGOs. Many of these supports take place in the Centre, supervised by Centre staff.

University admission, requiring entrance examinations in addition to school leaving qualifications, can present challenges to applicants with learning difficulties or cognitive impairments. However a significant advantage is that by the time a place is confirmed, staff are usually well acquainted with particular students’ study needs. As Peňáz explains: “In countries where there is no formal contact before admission colleagues face difficulties without any warning. That’s not our situation. We have more time to prepare adaptations properly.”

Currently the Centre is prioritising improved support for dyslexic students, but Peňáz is alive to the increase in students with neurological conditions, particular Asperger’s and high functioning autism.

“People always ask why the number is growing. Was it the same before and we ignored it? Or are people different? I think both. In the past maybe you didn’t have a diagnosis but people provided strategies. In an increasingly complex world, finding what works for the individual will be as much a matter of common sense as professional specialisms.”



The library of adapted learning materials at Masaryk University’s Teiresiás Centre in Brno

### \*What is Universal Design for Learning?

**Universal Design for Learning (UDL):** an educational framework based on research in the learning sciences, including cognitive neuroscience, that guides the development of flexible learning environments that can accommodate individual learning differences.

## Preparation now the key to future support

### The Teiresiás Centre serves the whole of Masaryk University in Brno.

Originally established to support the integration of visually impaired students, it quickly extended its expertise to the full range of physical disabilities. Now it is developing support structures for students with cognitive and psychological difficulties, including the conditions relevant to this project.

Educational and psychological counsellors Iva Oulehlová and Miroslav Zítko are the main points of contact for these students. Numbers are currently comparatively low, but increasing, and both acknowledge the future demands this could potentially place on time.

“People with Asperger’s Syndrome need lots of consultation,” says Iva. “When they don’t speak with us, it doesn’t mean they have no problems. Sometimes the opposite – they have big problems, but they don’t want to say. So I try to meet with them regularly, even if they just say it’s all OK, bye. But I need to communicate with them.”

Face-to-face meetings aren’t always necessary: email works well. But the key is to be proactive in maintaining contact.

Teaching and academic staff are supported by colleagues in the Centre’s study department, where each member of staff is a named contact for at most two faculties. Closer collaboration and information sharing is bringing benefits for staff and students during periods of transition or when difficulties arise. Both admit their knowledge of these conditions has mostly come through

working with the students: awareness among other staff can be low, but they now provide condition specific information in advance to those with a student taking their course, and feel knowledge is beginning to spread.

They are also collaborating on a manual, to be shared with every university in the Czech Republic, outlining the challenges and needs students with these difficulties face. This will include general advice along with tips for problem solving and crisis management, plus where to access further information and support if necessary.

The Centre offers short term, 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 individual 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 the university and Centre staff take responsibility for liaising with schools, parents and other organisations to determine the best provision for individual students.

One problem is difficulty finding therapists to work with those who have Asperger’s, as there are long waiting lists in the Brno clinics. Iva now plans to take a qualification in cognitive behavioural therapy so she can work with this group in the university.



Educational and psychological counsellors Iva Oulehlová (top) and Miroslav Zítko

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





Štěpán Hejzlar, head of social rehabilitation and supported employment at NAUTIS

## Supported employment

**Effective support that makes employment sustainable 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.**

“This group can live and work independently, but they need special conditions to do it,” he says.

The team is small – only four people – but multi skilled, and can connect with psychologists, social workers, pedagogues and counsellors as necessary. Currently they support 40 clients, with around another 30 accessing courses and leisure activities through the service: last year 24 found jobs. The majority of clients are 23–25 years old, with around half contacting NAUTIS on their own initiative and half through concerned parents.

Around 15% are university educated, which can make them easier to place, but can also put them at a disadvantage, as Štěpán explains.

“Paradoxically the most skilled and least obviously affected people can be the most vulnerable,” he says. “If your needs are clear and you qualify for a disability pension, you can work at a place created for handicapped people and the probability of staying there is much higher than for those who have to compete in the free market. In many cases people in this situation don’t survive the probation period and are back in the service in 2 months. So I would say this group is the most vulnerable of all.”

The department is not a job agency: the aim is to provide support that enables clients to find work on their own. This includes advice on

developing CVs, job interview practice, courses in assertiveness and social communication, and help with applications. The state Labour Office is responsible for promoting apprenticeships and work experience for those who have low, or no, qualifications. But for some, the absence of a clear pathway at the end of school has already had an impact.

“Often when clients enter our service, they have already been out of the school system for a few years and they’ve lost ground in that time,” Štěpán says. “Their habits – getting up at 7.00, being on time, being in contact with other people as they did in school – have changed. For some it’s an uphill task because they’ve had that gap.”

The team offers assistance in the workplace for those who wish it, though many prefer not to be identified as having Asperger’s and try to manage without additional support. In most cases, says Štěpán, they don’t succeed. Support for employers includes advice on legislation and the financial benefits of employing people with disabilities; advice to employers and colleagues on adjustments needed; and help with claiming tax relief for employing disabled people.

There is a common misconception that people with Asperger’s are mostly suited to technical roles, but Štěpán doesn’t agree.

“I don’t find a correlation between Asperger’s and any particular job,” he says. “Of course you need work to be structured well, and roles that need improvisation, like customer services, aren’t so good. But apart from that I think we have people from all fields.”

### Life stories: working life

“I left school with the qualifying exam, and had an internship on a railway station. I’m unemployed right now. I’d like to work in book keeping and accounting, I’m looking for a part time job. I liked my last job, it was as a customer services assistant with a transport company, it was very good and I was sad because they moved part of the agency to Slovakia and I lost the job then. I was there 5 months. Before this I was in the national museum for a month, working full time as a caretaker, but it wasn’t the job for me. Before that I worked as an administrative assistant with IBM on a 6-month contract and I also had an administrative post in an intercontinental cargo company which was my mother’s. But she sold the company and there was a new manager. It wasn’t a good atmosphere and they told me I must leave.”

*“In some situations relating to a disabled employee is easy, in others not. But it is always enriching.”*

## Postgraduate employment

**Building relationships with potential employers is challenging when disability awareness in general remains low.**

“Sheltered workplaces rarely offer intellectual jobs,” says Petr Peňáz of the Teiresiás Centre. “The frustration is employers ask if we can provide disabled persons ready to work, but the jobs [they offer] are nothing to do with skill level or qualifications and they still don’t understand that.”

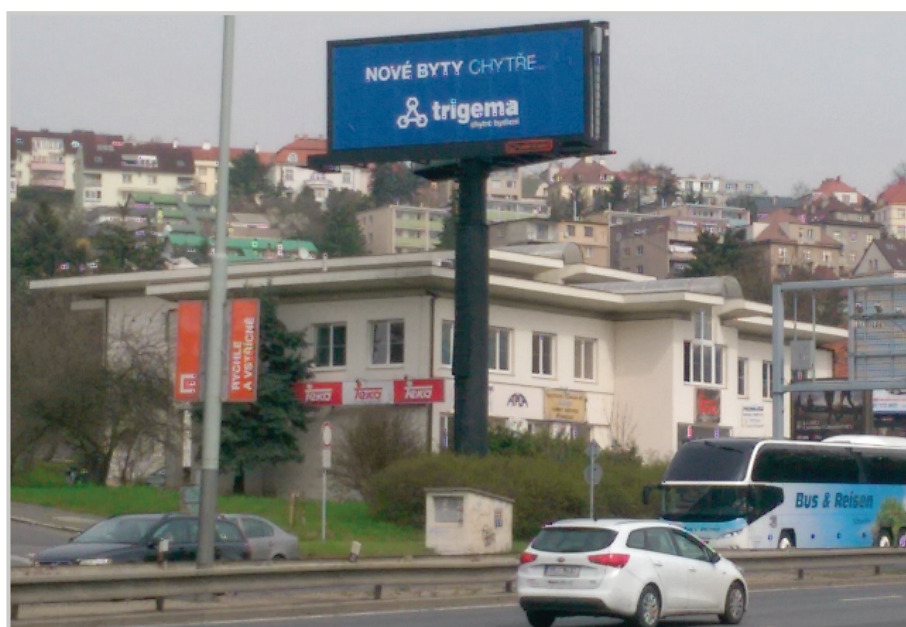
Some employers make posts available for financial or political reasons, but without the understanding or motivation to make

the necessary adaptations. Others do not make full use of their disabled employee’s skills or support them to develop their career.

“It isn’t easy in advance to identify those who are not really motivated but feel politically forced to comply,” says Peňáz. “I say to our students, this company came to us, check it out. They come back and tell us what it means in practice.”

The university’s careers office can support someone in their job search but in practice this is often easier through NAUTIS and other job agencies with specialist knowledge.

*“There’s a very paradoxical fact, and that is people with fewer support needs can be less successful at keeping jobs.”*



Offices of the social rehabilitation department of NAUTIS on V Holešovičkách, Prague



## Next steps—-independent living

*“In my experience most people are over cared for. Their skills are high level but their families do so many things they don’t learn the independence they need.”*

**Taking responsibility for your own physical, emotional and social needs is an important aspect of the progression to adulthood.**

A sustainable income at a level that allows individuals to access realistic choices and life chances remains arguably the single greatest contributor to building self confidence, maintaining physical and mental health, and achieving a life that is as personally fulfilling and satisfying as possible.

However some of the greatest challenges young people in these groups identified for themselves were loneliness, social isolation, and the desire for friendships and relationships. This was the case even among those for whom severe anxiety made social contact difficult.

There appears to be a clear need for skilled support around establishing and maintaining good relationships, including sexual health—particularly since this is an area many parents and families find especially challenging.

### Health

**Autism and Asperger’s Syndrome are jointly recognised as a distinct condition, with ADHD and Tourette’s Syndrome grouped among a collection of “specific learning disabilities”.** This may contribute to lower awareness of the particular challenges of living with these conditions.

More young adults are contacting diagnostic services for assessment. Both children and adults can expect

to wait approximately a year, or sometimes longer. Experiences following diagnosis vary according to therapist and location, but the national institute of autism (NAUTIS) routinely provides a full range of subsequent support services and therapies, including information on specialists and referrals if necessary.

A diagnosis or medical assessment is required to claim invalidity benefit from the state.

### Housing

**The availability of paid employment and affordable rents clearly makes an enormous impact on the ability of some young people in this category to live independently.** All the young people in this study either rented their own homes or lived with parents. Supported housing was largely reserved for those with more obvious needs, including overnight or 24-hour supervision.

*“Living in my own house would be very difficult, not to afford it but to maintain the house. It’s a big responsibility.”*

#### Real life: renting in Prague

Marek found a flat to rent himself, over the internet. As a disabled person he receives help with rent from the state. He pays 6500 crowns (£190) a month in a comfortable area of the city and says he has a good relationship with his neighbours. He lives alone and cares for himself.

## Social life and relationships



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

**Creating leisure and free time opportunities is an essential part of the work undertaken by the social rehabilitation team at autism network 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.”

It is hoped linking with other organisations will help build awareness of people living with different diagnoses and challenges, and create a broader base of friendships and social contact in a supportive environment.

Leisure activities depend heavily on volunteers: red tape around the recruitment and role of volunteers is much reduced compared with the UK, but a NAUTIS staff member always leads activities working directly with clients.

### Justice system

**Criminal responsibility begins at age 15, so long as someone is considered mature enough to understand lawlessness and control their actions.**

For small scale crimes, psychotherapy is not currently available in prison, although review of this aspect of the prison system is underway and this may

change in future. In general, custodial sentences for these crimes are short and give little time to address problems.

There is a need for well qualified people in the system to work in a coordinated way with young people with these conditions, both in custody and on release, as the rate of reoffending for this group is high.

#### Life stories: the mother

“My oldest son is 28, the middle 26 and the youngest 21. They all have Tourette’s and ADHD with behaviour issues. It was too much for my husband, he left when they were teenage. They only see him now if they need money.

The oldest is in prison. He had a business but lost it. He stole metal for a group of guys and was caught. He was warned, but did it again, it was like an adventure, a game. He’s been sent to prison for 10 months. He’s OK there, which is a bit surprising, but he’s made a good connection with guys inside and maybe good will come from it.

The middle one has been working for 15 months. It was very difficult to find this job. He’s a lorry driver and goes to Germany and back twice a week. He has problems in the morning to get up but he can drive in the night, so he can do this easily and it’s very important for him. He has problems to cooperate with others so he prefers to be alone or with just a second driver. He doesn’t always like the work but it’s a good salary, and his employer is a good guy: he said I’ll try you for 2 months, if you can do it you can stay. So he was motivated, and he’s in a much better situation than the oldest one.

The youngest is repeating his last year in school so he can graduate. He had problems last year when he separated with his girlfriend, and didn’t go to school, but I believe he will do it this year. He has medication now from the clinic, it’s better. I don’t know right now what is waiting for him.”

# What people said ... authentic voices

*“People kept telling me I was not doing the job properly, that I was slow, that I was useless and they can take anyone else with better qualifications.”*

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, 15 were gathered in the Czech Republic.

- Wider availability of psychotherapy and psychological support to young adults is essential and urgently needed to help address barriers of severe anxiety and low motivation, along with building confidence and managing other challenging behaviours.
- Psychotherapy and psychological support also needs to be available within the criminal justice system.
- Everyone commented on the need for greater awareness of these conditions among professionals, particularly mental health and social workers, and wider recognition of the impact on everyday life.
- An expansion in the workforce and investment in skills is needed now to support the increasing number of people being diagnosed with

difficulties and offset the economic impact on health and welfare budgets.

- The majority felt the diagnosed condition had impacted the whole family, with increased family tensions and in some cases relationship breakdown.
- Young people commented on social isolation and in particular on the lack of friendships or relationships. None were in relationships currently though most regarded these as “important” or “very important” in their plans for the future.
- More information, particularly about Tourette’s and ADHD in adults, was thought to be urgently needed.
- Of the young people who were employed, all but one expressed dissatisfaction with their work and would change if flexibility of working and part time hours could be matched within a different setting.

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.

*“My hobby is electronics, I work with electronic parts, transistors, diodes, do you know what I mean? I think in electrical circuits.”*

*“I almost cried when one of the colleagues left because we shared lots about each other, each other’s personal lives. I was very sad. And when the other colleague left, myself I wanted to leave, to end the place. I was both sad and angry.”*

*“The teacher told me I had too long hair, I should cut it, that’s why I’m doing this with my head. In front of the class. It was a really stressful moment, I was 17 years old, and when I remember it, it hurts me a lot.”*

*“At the moment if they don’t f\*\*\* up with me I will stay there. But if I find something better or more suitable for me I will take it.”*

*“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.”*

*“When I’m not working, I attend church occasions, talks, Alpha courses. That’s where I run to from my problems at work.”*

*“In my opinion, I can deal with Tourette quite well and can control my symptoms to a large extent, therefore they are not a big obstacle to me. Of course, there were times when it was worse, primarily at a younger age – this was supported by doubts about myself and fear of the future.”*

*“We cannot see into the future. Not even the most modern devices can make predictions for tomorrow, not to mention years to come.”*

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

*“They have ADHD, all three, and 10 years I am alone with them because it was too much for my husband ... They needed some male example to care and show them how it works in life, and that’s one reason why they find it difficult.”*

*“He must work, but unfortunately he’s not very self confident and not very motivated. 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.”*

*“He will have a prison record and finding a job with this is very difficult. And with this condition it was already hard to find a job.”*

*“When someone has very noticeable or disruptive tics it’s difficult to find a job. If you are educated and a lawyer it’s fine, you can sit at a computer or something, you’ll be OK. But if your education is not very high and you are surrounded by people whose education is not high you will have a more difficult time. They maybe don’t tolerate this. To be a shop assistant, for example, is a problem.”*

*“The parents assume responsibility for everyday life even after their son has reached adult age, which can be a big burden for the whole family.”*

*“I expected it [work] would be more creative.”*

*“It is hard to be among people when having tics—people who don’t know what it is think I have a mental disorder or bad habit.”*

*“I think a calmer job would be better for me, somewhere where I wouldn’t have to encounter stressful situations with clients, because I am very sensitive about everything.”*





In the Czech Republic I experienced the warmest of welcomes and extraordinary hospitality everywhere I went. Thank you to everyone—including those whose homes I stayed in—for sharing experiences, insights and aspirations, and for including me so readily in your work and in your lives.

I am grateful to NAUTIS, the national institute for people with autism, where Roman Pešek, Veronika Šporclová and Jana Sirotková provided an invaluable introduction to the Czech system and the organisation's work. Particular thanks go to Štěpán Hejzlar, who despite a demanding schedule organised interviews on my behalf and interpreted for me, and to Dominika Linhartová for the chance to attend the theatre performance for autism awareness week: it was an exceptional piece of work. Thanks also to the board members and volunteers of ATOS, particularly Ondrej Fiala, for inviting me to their support group and giving me the opportunity to meet families and young people with Tourette's Syndrome; their work in raising awareness is inspiring.

I'm grateful to the staff of the Teiresiás Centre at Masaryk University in Brno, who allowed me to fulfil a long held ambition to explore how they support students with a range of additional needs: thank you to Petr Peňáz, for excellent insights into the many changes and challenges that have shaped central Europe over the last 40 years, and to Iva Oulehlová and Miroslav Zítka for a fascinating discussion around the special approaches needed to support students with Asperger's, ADHD and Tourette's. An added bonus was the chance to spend time with representatives of inclusion teams in Hungary, Germany, Norway, Poland, Lithuania and Slovakia. We face many of the same challenges and it was a great opportunity to hear more about how other countries are responding.

Last, but most definitely not least, I want to thank the young people, parents and families who shared their stories and experiences with me. Without exception, they have an amazing amount to offer. If we fail to smooth their path into employment, education, and social interaction, we let them down—and undoubtedly we, as well as they, will be the poorer.