

Life on the Edge of the Cliff

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

STUDY VISIT 1

Italy

23 May – 7 June 2015

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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 doesn’t finish with going to school. Because after school you have someone that grows, 18, 19, adult, with the same problem, and it doesn’t go away.”

Between 23 May and 7 June 2015 I visited the following regions:

Tuscany (*Toscana*—regional capital, Florence)

Tuscany has a population of 3.75 million in an area roughly the size of Wales. Tourism is important in the region, which has seven world heritage sites including Florence, Siena, and Pisa. Industry is dominated by mining: also chemicals and pharmaceuticals, textiles, paper, metalworking and ceramics. Agriculture is significant in the region’s economy, but less dominant than previously.

Emilia Romagna (regional capital, Bologna)

Urban and industrial areas expanded rapidly up to the global economic downturn in 2008. The region’s 4.5 million people are largely concentrated on the plains which represent half the land area. There is a long standing tradition in automotive, motor and mechanical manufacturing, and Emilia Romagna also has Italy’s biggest agricultural sector. The University of Bologna has a strong claim to be the oldest university in Europe.

Veneto (regional capital, Venice)

The region stretches from the Dolomites in the north to the Adriatic coast and includes the cities of Padua, Verona and Vicenza as well as Venice. It is an important wine growing and market gardening region, but industrialisation has also spread with industries congregating in particular districts. It has a population of 5 million people and is the foremost tourist destination in Italy.

Italy – an overview

Italy has a population of 60 million, with just under a quarter in the regions of Tuscany, Emilia Romagna and Veneto.

The national economy has been slow to recover from the global downturn in 2008. Unemployment fell in March 2016 to 11.4% but this masks huge regional variations, while youth unemployment is among the highest in Europe at 36.7%.

The country is under pressure as a first European landing point for migrants and refugees from north Africa and the Middle East. It became a member of the precursor to the EU in 1958 and is part of the Schengen area, allowing free movement of goods, people and services: it belongs to the G7 group of countries and is a member of NATO, OECD, and the UN. It has a significant historic and cultural importance and is home to 51 World Heritage sites.

Government

Italian politics has been volatile. The current prime minister, Matteo Renzi, presides over a left of centre coalition comprising the Democratic Party with the Left Ecology Freedom, Democratic Centre, and South Tyrolean People's Parties. The main opposition is a centre right coalition under former prime minister and media tycoon Silvio Berlusconi. General elections are every 5 years with the next in 2018.

The head of state is the President of the Republic, elected by parliament and regional representatives for a 7-year term.

National government defines the policy agenda and framework but implementation is down to 20 elected regional councils (*consigli regionali*), who have varying degrees of autonomy, and local municipalities (*comuni*). Of the councils, 15 are currently controlled by the Democratic Party, including Tuscany and Emilia Romagna. Veneto is controlled by the centre right party Liga Veneta—Lega Nord.

Education

Education is free and compulsory between 6 and 16 years old. The *scuola primaria* or *elementare* lasts 5 years; the *scuola secondaria di primo grado*, 3 years; followed by the *scuola secondaria di secondo grado*, or high school, up to 5 years.

High school may be a *liceo*, where the focus is academic; an *istituto tecnico*, combining theory and practice and often including an internship; or an *istituto professionale*, which prepares pupils for employment when they leave, which may be after 3, rather than 5, years. The *esame di maturita* or *esame di stato* is required for university entrance.

The Ministry of Education, University and Research oversees education at every level, except for the *istituti professionali*, which are administered by the regions and offer non-university education leading to a diploma.

Most universities are state run with low, income related fees: fees are higher in private universities. Degrees (*laurea*) require 3 years for a bachelor's programme and a further 2 years for a master's. Some, for example law and medicine, require longer study.

A few specialised institutions, such as military academies, also offer tertiary education.

Adult education (*educazione degli adulti*) is open to people aged 16 and above and can be organised by schools, involving employers and other social partners. It can extend learning or replace compulsory education for early school leavers, and may or may not lead to a formal qualification.

Systems are under development for accrediting non-formal learning, acquired for example through work, home and leisure activities, to be assessed and validated by a public institution or other authority.

Integration and support measures for special needs should be available to all pupils and students with physical, psychological or sensory disabilities that cause learning and working difficulties, social detriment and alienation.

Health

Servizio Sanitario Nazionale (SSN) is the national health service, financed by taxes and through revenues of the local health agencies, with full or partial means-tested charges for many services. Under the overall direction of the Ministry of Health (*Ministero della Salute*), implementation of national policy is through the regions, which control the health agencies and set the charges. Variations in regional wealth, local government agendas, and competences, has led to a varied picture of health provision and outcomes across Italy as a whole. In general regions to the north are considered to provide better healthcare structures than the south, and Tuscany and Emilia Romagna are among the regions believed to offer the most comprehensive, accessible and universal healthcare provision. Veneto is considered good but expensive.

Hospital investigation or care requires referral from a family doctor except in emergencies. Diagnostic and laboratory tests are usually chargeable. As well as family doctors, general medical assistance is provided by local health centres (*azienda sanitaria locale*). Psychological and neurological conditions remain underdiagnosed in many regions.

Welfare and social services

Official figures indicate there are 2.6 million disabled people in Italy. People unable to work through disability are entitled to an incapacity pension.

The Italian social security system is financed through taxation and managed by regional councils through the *Istituto Nazionale Previdenza Sociale* (INPS). Benefits are generally low compared with the UK and are reviewed every year to reflect inflation and cost of living: in 2015, incapacity pension was €279.75 a month. A report by the Academic Network of European Disability in 2009 found the funds disabled people received in Italy were not sufficient to support independent living. Social assistance and care is first and foremost considered a duty of the family. The same report found wide regional disparities in promoting independent living, and a very much higher risk of poverty among disabled adults compared to their peers.

Figures quoted are taken from the article "Which are the best countries in the world to live in if you are unemployed or disabled?" published in The Guardian in April 2015



Michelangelo's tomb in the Basilica di Santa Croce in Florence

“The aim of integration at school is the development of the potentials ... in learning, communication, relationships and socialisation. The right to education cannot be hindered by learning difficulties or other difficulties deriving from disabilities”

Italian Framework Law 104/1992

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

Awareness and policy – the national picture

Italy has a clear national framework but implementation is largely down to regional authorities, and subject to local priorities, agendas and finances. The result is a variation in resourcing and practice from region to region, and a particularly sharp north/south divide.

There is a high level of awareness of the principles of Italian policy relating to disabilities, set out in Law 104 in 1992: it was widely quoted by policymakers, practitioners and service providers alike. This explicitly supports the dignity and autonomy of disabled people; their civil rights and participation in community life; measures to make workplaces and transport accessible; the right to vocational training; and extends employment rights to people with psychological impairments. Employers with more than 35 workers must recruit 15% of staff from people with disabilities and provide training. However many prefer to pay a financial penalty rather than comply.

Many commented that in practice, obtaining recognition and support for neurological or psychological conditions is much more difficult

than for physical disabilities.

Awareness and provision appears much stronger in the north than the south. This is particularly true for ADHD, but also for high functioning autism – and for both autism and ADHD in girls.

Transition to adult services can be complex. Below the age of 18 neurological and psychiatric disorders are addressed within the same service, so illnesses such as depression or anxiety disorders are treated alongside therapies to manage conditions or behaviours. Within adult services there is a sharp divide between the two, which can lead to misunderstandings where patients have been used to joint working, and difficulties sharing records and information. Adult psychiatric services can be ill equipped to diagnose the three conditions. Debate is ongoing around medication for ADHD, and currently Ritalin cannot be prescribed for those over 18.

Health and social care relies heavily on practitioners employed by social cooperatives and deployed as necessary: these organisations are commonplace and are set up with

the objective of benefiting the community and promoting social integration. Many public services depend on cooperatives for staff, but differentials in pay and working conditions has led to a two-tier system with higher salaries and better working conditions for staff employed directly by centres or clinics. This contributes to high staff turnover, which can be problematic where continuity contributes significantly to the effectiveness of available support.

The **role of the “educator”** in Italy does not have a direct correlation in the UK: the term usually equates to a pedagogue, educated to degree level and with a broad-based training in the theory and practice of holistic education and social care. Educators work in a range of settings, from medical centres and schools to municipal services and social cooperatives, and can act as an important link across disciplines to improve holistic care.

There is a significant **gender imbalance in the workforce**, especially among people working with adults: far more women work as educators than men, especially in



Entrance to the Ospedale Psichiatrico Provinciale Roncati, Bologna

the north. Pay is usually below average: an educator, even when highly qualified, expects to earn around €1200 per month compared with €1500 for a teacher.

A recent development has been the *Centri Provinciali per l'Istruzione degli Adulti* (CPIAs), now a cornerstone of **adult education and lifelong learning**. These centres are open to people aged 16 and over (or 15 in special circumstances), and run programmes corresponding to compulsory education, along with language and literacy classes and a school leaving certificate. Courses are flexible and allow for personalised study paths and the recognition of prior or non formal learning: up to 20% can be distance learning. They are free and potentially offer the chance to gain competences and qualifications outside normal school age.

It was interesting to compare public service provision in Tuscany, with a more privately managed model in Veneto. Both approaches have strengths, and weaknesses. What they shared was a commitment to ongoing support; a highly skilled workforce; creative and flexible thinking; access to therapeutic interventions, including psychiatric support; a practical understanding of the impact of the condition on the individual; an aspirational approach to building competence; encouraging strong relationships; and developing links with the wider community.

These both appear, in their different ways, to be models with the potential to make a real difference to young people's lives.

In general, **invalidity benefits** are subject to very strict criteria, and the perception is that these are becoming stricter as a result of economic pressures. In most cases benefits stop if someone is in employment.

Many commented on **progress over the last 10 years** but everyone felt services are under resourced and in some areas struggling to cope. There are areas of excellent practice, but much is still channelled through schools and aimed at children. A frequently mentioned reference point for care was the work of Franco Basaglia, the 20th century leader in Italian psychiatry, influential in abolishing mental hospitals in Italy and implementing social integration and community care for those with neurological and psychiatric disorders. Some commented that under current pressures this approach was being forgotten.

There can be flexibility over when a young person is transferred into adult services, but of course this has to happen at some point. There is a clear need for more services targeted towards supporting young adults – particularly those who do not have a specific diagnosis by the age of 18 – if national aspirations for inclusion and integration are to become a reality.

Autism

Autismo Italia is the national association for people with autism and their families. Each region has its own affiliated organisation: one of the strongest and most active is Autismo Toscana under president Marino Lupi, which has been instrumental in establishing the centre at Casa di Ventignano, along with other initiatives.

www.autismoitalia.com;
www.autismotoscana.it

ADHD

AIFA Onlus is the national association for the support of people with ADHD, and has local coordinators in every region of Italy. It promotes awareness, supports those affected and their families, and shares the latest scientific knowledge about treatment and therapy. It depends heavily on volunteers for providing information and support at a local level and there is considerable regional variation in the support available. Awareness of the impact of ADHD into adulthood remains low.

www.aifaonlus.it

Tourette's

AIST Onlus is the national association for Tourette's Syndrome. Sadly it proved impossible to establish contact with the association's office, members of its team, or other practitioners working with or researching Tourette's. Awareness of the disorder was low, which may be because a high number of people develop strategies to manage tics in everyday life, and difficulties may be camouflaged and masked within other disorders.

www.tourette.it

Regional case study—Tuscany

In Tuscany, routine screening programmes in preschool have greatly improved early identification of some difficulties, allowing support to begin promptly based on the needs of the individual child and without requiring confirmation of a particular condition.

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

Diagnosis includes functional as well as clinical assessments, and is the basis for customised therapy programmes

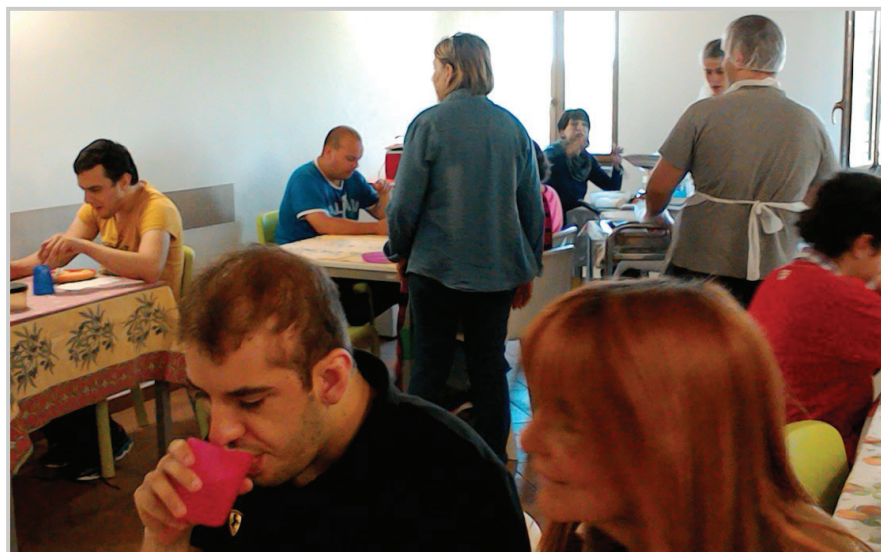
comprising medical interventions, recommendations on adjustments necessary for full integration in school, and assessment of individual potential. For older pupils and adults, the individual plans include assessment of specific capacities and abilities as part of a pathway into further training and work. Schools and families are regarded as an integral part of the system, with a role alongside other professionals in delivering specified interventions as part of the overall care and therapy plan. Progress towards social integration is the underlying principle for all individual plans.

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



Tuscany: a different approach to support

Individual integration and inclusion



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

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

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

It is a daycare facility for children and young people aged from 8 to 25, focusing on health and social habilitation, and complementing support work in mainstream education for those of school age

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

and within the local community for those who are older.

The team is led by neuropsychiatrist Cinzia Pieraccini and includes psychologists, speech therapists, educators and social healthcare operators working alongside music and art therapists, pedagogues and specialised technical staff who manage the market garden in the grounds of the old farmhouse.

The centre can cater for a maximum of 32 people at any one time. Eligibility is governed by the impact of the condition on the individual rather than particular behaviours, and referrals are made following a full clinical evaluation. One of the things that makes Ventignano unique is that activities are developed following this evaluation and tailored to individual needs, rather than

offered as a predetermined programme: these can then change over time as objectives change. There is a clear emphasis on building the skills that are essential to functioning independently in everyday life: so, for example, speech therapy may work towards accompanied visits to the local coffee shop and being able to order and pay for food.

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

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

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

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

Skills for the real world—supported employment opening new horizons

There's now a farm shop next door to the main building at Casa di Ventignano—a new venture to sell home-grown fruit and vegetables direct to the public, alongside the existing thriving business supplying vegetable boxes to order. Up to 50 boxes a day are delivered throughout the local area.

Samanta Cantini and Sabatina Benelli head up the market garden programme.

Sabatina is a trained agriculturalist who has been at the centre from the beginning. The soil, she says, is poor, but they still grow a wide range of herbs, vegetables and fruit in the fields and polytunnels. There are also flowers, for decoration and sensory stimulation: many have medicinal properties. The day we visit the team comprises Sabatina, Alberto (a gardener employed by the centre), Andrea, Maurizio and Gabriele. Maurizio splits his time between the centre and agricultural college: Alberto tells us he is very skilled, particularly with flowers. "Maurizio has definitely found his future career," he says. "He can easily earn a living with this."

Samanta is a psychologist who works 20 hours a week at the centre. She is part of the garden team and supervises the preparation and packing of orders. A timetable on the wall of the packing shed gives visual explanations of the tasks required, with the supervision needs of those carrying them out:

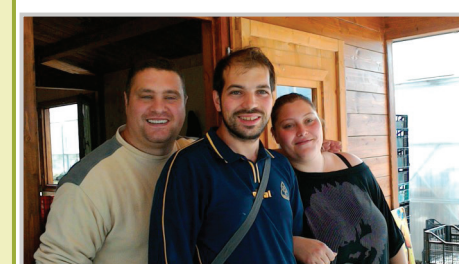
people can work before the centre opens in the morning if they choose, and the business continues all year round, even when the centre closes for a month in August.

Produce is sold at the going market rate, and profits fund future development. The young people are paid for their work in ways appropriate to the individual: some receive cash in hand, to reinforce the connection between work they have done and receiving wages, others are paid monthly by cheque, sent to their home, similar to a normal salary.

Each person is allocated an educator and agricultural tutor, and all staff meet regularly with Cinzia Pieraccini and Leonardo Granchi to ensure they understand each person's specific learning challenges and how the activities fit with their individual therapeutic programme.

The centre plans to consolidate contacts with other cooperatives, and build links with local farmers. Sabatina is committed to integrating people working at the centre with their peers in other local concerns.

"Social skills are sometimes neglected," she says. "That's not good, obviously, because then often autistic people start to isolate themselves and spend time alone – exactly the contrary of what should happen. They should be integrated and be with others."



Right, from top: planting and managing the Ventignano garden; the sales team pack boxes to order for local delivery; another good day's work



Oltre il Labirinto
Fondazione ONLUS per l'Autismo

Veneto: individual support for life

Connecting communities for the future

Oltre il Labirinto has a big vision.

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

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

Oltre il Labirinto – “Beyond the Labyrinth” – is a not for profit social cooperative begun in 2009 when a group of parents came together to tackle a shared problem: the lack of support services to meet their children's social and developmental needs. The name reflects the tendency of individuals with autism to become lost in their own world: Oltre il Labirinto is about reconnecting them with their community. It could equally apply to parents and families, many of whom experience a high level of social and economic isolation through caring for children and adults with significant support needs.

What began with out-of-school

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

A key component in the Foundation's plans is its centre under development at Godega di Sant'Urbano, about 30 km north of Treviso. Sustainable businesses, supported housing and a social hub are all part of the vision for a site that is already home to a small market garden, a recycling operation, a wine labelling business and an assembly and sales point for the Hug Bike – an exclusive design marketed by the Foundation that allows people with disabilities to cycle safely with an accompanying rider.

A key focus for Oltre il Labirinto within the last year has been developing support for families and caregivers. One of the newest projects has been the establishment of an information hub in Mogliano dedicated to autism—one of the first of its kind in Italy—providing information, advice and support guidelines to families. Self help



Above, Oltre il Labirinto founder and director Mario Paganessi; below, development and funding director Carlo Giustini

“No organisations in this area were looking ahead and that's important. We need to start projects now to create a future for this child that will one day become an adult.”



Left, parents in Paris through “Mamme via”; right, the specially designed Hug Bike



Pasticceria Savoia, where owner Gennaro Immobile (above) provides an 18-year-old with a work placement arranged by the Foundation. The young man works 4 hours on Friday mornings in place of school, mostly in the kitchen making cookies and pastries, and carrying out general duties. He needs close supervision, but Gennaro doesn't see this as a problem. “I'm happy to offer the placement,” he says. “He sees he's learning something useful and that's satisfying for him – and for me. It's important to offer this.”

The placement has worked so well it has been extended, and Gennaro says he would be happy to offer someone else a similar opportunity in future.

groups now take place twice monthly for parents across the region, facilitated by a psychologist specialising in autism, and enabling carers to share experiences, learn from one another, and gain new insights into autistic spectrum conditions. A new session for siblings aged 13-18 will begin soon.

Part of the family empowerment initiative has also seen the launch of “Mamme via”, targeted towards mothers, who frequently undertake the bulk of day to day care for autistic children and young people. This programme, funded largely by the Foundation, offers mothers a subsidised 3-day break in a European

capital, giving them space to relax while fathers spend time with their autistic sons or daughters with the support of the Foundation.

The team at Oltre il Labirinto is led by Mario Paganessi, whose son is supported by the organisation. He took on the directorship for 3 months to stabilise the organisation: 6 years later he is still in post. With a background in engineering, marketing and retail across three continents, Mario believes a head for business is essential to effective future planning.

The Foundation employs support staff (“educators”), whom it trains in the skills it feels are most essential to providing good support to autistic

Real life: a family's experience

Anna Cilea is a psychologist who took the Foundation's autism awareness training course 3 years ago. She believes transition is important psychologically and developmentally, and that planning and early intervention at this stage is essential.

She has worked for 2 years with Simone, 20, and knows him and his parents, Domenico and Lorena, well.

They share the same goal: creating community connections that include strong sustainable relationships that come as close as possible to replicating the individual knowledge, support and care parents often continue to provide. The aim is that by the time parents are less able to maintain a caring role a network of contacts has been established, providing not only professional skills but a relationship of trust.

“This is where the *Fondazione* comes in,” Domenico says. “You aren't alone confronting the challenges. There are other people who know what you are experiencing and who can help plan and support you. That's so important, especially as children get older.”



The centre at Godega. From left: Domenico, Lorena and Simone; in the polytunnels; corks collected for recycling



Life stories: Living with ADHD

people. They are highly selective: for every 10 people trained, on average only one will be offered a role. The expectation is that they will build close, long term relationships with young people and their families, becoming trusted friends as well as therapists and advisers. The aim is to equip the Foundation increasingly to share responsibility for a young person's care, encouraging greater independence from parents and families, and eventually to take over responsibility when parents can no longer manage their adult son or daughter's support needs.

In the last 7 years the Foundation has become a frontrunner in service provision and practice, with other organisations beginning to copy the operational model and increasing interest from other professionals and from government.

Skills for the long term

Anyone interested in working with the Foundation to support young people and their families must first complete one of the organisation's own training courses, run three times a year by a national expert in autism. No qualifications are needed to enrol, but in practice many applicants are already working as psychologists or within social services: the reputation of the courses has grown and delegates come from all over Italy as part of their own professional development. Those with the right skills will be offered the chance to become an operator with the Foundation. This is based more on aptitude and personality than previous experience or knowledge, as the Foundation prefers to recruit people with the right qualities and provide further training if necessary.

"My son is 24. When he was a child, ADHD wasn't recognised in Italy. It didn't exist. They thought it was an issue with parenting, that you couldn't bring up your kids. It caused divisions in my family because some of them didn't understand and weren't supportive. That persists today.

When he was born we realised there was something strange, he slept very little. Already in preschool they weren't able to control him and it was the same when he started primary school. I read an article by Russell Barkley in *Scientific American* that described ADHD, and then I realised 100% it is this.

We went to the ADHD centre near Treviso and he was prescribed Ritalin, but he started to have stomach aches so it was stopped. When he was 12, he was prescribed atomoxetine as part of an evaluation but it didn't work for him at all, so he ended up with Ritalin again.

After secondary school, he went to professional school for hotel management and had a support teacher for 2 hours every day, but he didn't like it because he didn't want to seem different. And in this period he wasn't taking medication so he wasn't supported chemically either. He said he couldn't continue, and left school at 18. High school was the only time he had good connection with his teachers, a good feeling. After he left he started doing some work through a social programme in the region. He works now in a private restaurant 4 or 5 hours a day and is paid €200 each month. That isn't enough to live on, so I support him for the rest.

He's very intelligent but his qualification levels are low. I think if he had support when he needed it, he would have done much better in school. Now he's organising an appointment to see another doctor, the only person in Italy who really treats ADHD in adults. He's never been in problems with the police or drugs or anything, he smokes, that's all.

I am divorced and he lives with me. His mother didn't accept he had ADHD and this was partly the reason we split up.

When he isn't working, he likes basketball, roller skating, swimming, soccer. But he's interested in computers too and he spends many, many hours a day on this. I think it's too much. I hope he can find the right job and get the right medication. Then I'll feel he's on the right path."

A parent from the Italian ADHD Association—AIFA Onlus

Building awareness of ADHD



Sharing information about the work of AIFA Onlus at a support group where parents put questions to AIFA representatives and psychologists

For young adults affected by ADHD in Italy, the biggest challenge is lack of understanding and awareness, followed by the urgent need for effective therapies.

Access to clinical assessment and diagnosis is very limited for those over 18: only one clinic, in the northern town of Bolzano, works specifically with adults with ADHD and offers psychotherapy to their families. Even when there is an existing diagnosis, accessing medication and appropriate therapies is difficult. Ritalin is not prescribed for those over 18.

However the picture is a lot brighter than 10 years ago, says Dottorressa Simona Chiodo, director of child neuropsychiatry at the Ospedale Maggiore in Bologna and leader of clinical activities for ADHD in the Emilia Romagna region.

"In this district we made a protocol for diagnosis over 10 years ago," she explains. "Now we are working to make a kind of transition pathway. Every year there is a congress for professionals, and we run regular information groups for parents and teachers."

Anna Maria Cava is the region's voluntary coordinator for AIFA Onlus, the national ADHD association. As

the parent of a 21-year-old with ADHD, she is well aware of the level of support required into adulthood. One problem in Emilia Romagna, she says, is a strong lobby opposing medication for ADHD, which she feels is making it harder for some families to access help they need.

"There's a lot of prejudice," she says. "People I meet are often depressed because they feel alone with this problem. The organisation aims to bring them together."

Renato Moglia trained as an ADHD homework tutor to help young people of high school age complete homework and school tasks. Part of his role is to work with families to develop useful strategies, although he feels some expect a quick solution and may not be prepared for the commitment needed. Also, where parents and other family members have undiagnosed ADHD, it could be more difficult for them to work systematically with the tools the homework tutor provides.

Anna Maria and Renato hope to apply for funding to develop a

"Often there are not cognitive problems. ADHD people are very strong intellectually, often. The problem is to build connection, organisation, self esteem."

summer camp, and other support groups. But both know this can only go so far in meeting the need.

"The big problem in Italy is ADHD in the adult," Anna Maria says. "The psychiatric system isn't prepared for this. They use other labels, problem behaviour, oppositional behaviour. They don't want to say ADHD."

Nationally, AIFA is focusing increasingly on the impact of ADHD in adults, to raise awareness of the issues involved and the knock-on effects on health, employment, relationships and social integration. The Ministry of Health has begun to develop a therapeutic path for adults, but implementation will depend on regional health policies and capacity in the system so may take time to become effective.

Failing to identify ADHD can lead to symptoms wrongly attributed to other difficulties, for example anxiety, depression, bipolar disorder or substance dependency. That can mean psychotherapies may be less effective and waste time and resources.

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

What people said ... authentic voices

*“All people look to the government, but forget it, the government is squeezing investment. When they say I have put this figure in, it's a lot of money – bullsh*t, it isn't a lot of money, it's nothing. So we need to change our thinking, our ideas, because the government will never change.”*

“The big problem in Italy is ADHD in the adult.”

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

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, 11 were gathered in Italy.

Responses highlighted the following:

- Everyone recognised the impact of economic uncertainty on the ability of organisations and authorities to deliver services at an appropriate level.
- Several people commented on improvements and progress in the last 10 years, and felt parents of young children are more aware of support organisations, rights and entitlements than previously.
- There remained a feeling that provision, information and support after leaving school was significantly under resourced and underdeveloped, and that there was a lack of options available.
- Many people mentioned the difficulty of obtaining proper assessment and diagnosis as an adult.
- Recognition and awareness of the impact of ADHD is significantly lacking.
- Ongoing therapeutic intervention based on clinical evaluation was generally considered a major factor in producing the best outcomes, both for young people and, indirectly, their families. In most cases this meant support from psychologists, although music, art and speech therapy were also mentioned, along with psychiatrists (usually where medication was involved).
- Everyone commented on the impact of caring for a young adult on wider

- family relationships, including with partners, siblings and grandparents. Many had encountered unsupportive attitudes within the family, largely as a result of unwillingness to recognise and tackle problems.
- Several parents had separated or divorced and believed the stress of caring for a child with difficulties had been a contributory factor.
 - In all cases young adults were still living with their families and all remained financially dependent on parents, including those receiving invalidity benefits or in paid employment, as this was insufficient in all cases to cover the cost of independent living.
 - The importance of connecting people to the community and keeping horizons as open as possible was stressed as a key factor in integration and inclusion.
 - A high level of awareness of the specific conditions, and specialised training – even where someone already holds a health, education or social work qualification – was identified as essential in building trust and providing advice and support with the potential to make a difference.
 - Personal qualities, and aptitude to work with people with these conditions, was considered as important as professional qualifications to offering effective support.

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.

“People didn’t understand he had ADHD, many times they think it’s a problem with parenting. You and your family end up divided because the family doesn’t understand and they aren’t supportive.”

“The community needs to be one of the protection factors for people.”

“When you get to this age the more you have to do it yourself. So the more networks, better connections you created, the better the lifelong chances .”

“Honestly, who knows me knows I am a warrior, I fight every day for the future of my son, but as far as hopes are concerned, I have no hopes he will have a different future from being in an institute.”

“There are no structures that are prepared to take people like our son, it’s all left to the families to think of your own plan.”

“We were sad for this [breakdown in transition planning], we felt we hadn’t prepared well enough and we wish we had done better.”

“It would have been better if a psychologist could have been there from the beginning and that might have helped. But it wasn’t there.”

“The most important thing is to create networks and as much collaboration as possible.”

“We are alone, we and our son, because the only protection you can have is if you are handicapped. If you are you can have some work, but if you don’t have this you are alone.”

“I always need to take the hand of my child, and one day my dream is to let him go, for him to be as independent as possible. This is the real goal, the real target.”

“One day when you become old your force will decrease and there will be a weakness, you will not be able to manage or support this boy. You need to have someone, you need a structure, a building, a place to go.”

“If you have a neuropsychiatric disorder and you are over 18 you have nothing. There are no resources.”

“The best things about him are he’s funny, makes you laugh. Sometimes he learns things very quickly. He has empathy for people, he shares your feelings, even if it doesn’t look like it – he pays attention to what is going on around him.”

“You have to make the reality worse so the welfare can help, that’s the paradox.”



For this first study visit I could not have wished for a better, more supportive or more informative network of contacts.

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