Autism awareness in the Netherlands

If you want to know about autism awareness in the Netherlands, the answer will depend on who you ask, and who you are asking about. Although I now speak Dutch and work with Dutch research groups, I remain an outsider looking in... one who finds what I see surprising, interesting, and sometimes disturbing.

The situation for children and families.

Autism awareness is widespread in schools and youth-oriented services but that doesn't mean that children with autism are being included. Having worked as an autism-specialist educator in the UK for many years, one of the greatest surprises I had upon moving to the Netherlands was how many children with disabilities are anything but part of mainstream education and neighbourhood life.

At least 3000 Dutch children nationally, some with autism, are officially described as “ineducable” and ineligible for any education services. Tens of thousands more are so-called thuiszitters (stay-at-homes): children with disabilities for whom no educational place has been found, whose parents try to cobble together solutions of their own. Last year I met a few of these children at Stichting Ark (www.arkstichting.nl), a small day centre for autistic children in Amsterdam—none were, in my professional opinion, particularly “severe and complex,” they were typical of children with autism and learning difficulties who in the UK might be either in an autism base within a mainstream school or in a specialist school.

In January of this year, a new national law promoting passend onderwijs (appropriate education), with a push towards full inclusion, came into effect. Technically, now every child should automatically have a place at his or her neighbourhood school, which is tasked with either creating an appropriate, adapted education programme or finding the right alternative placement. Extra money and advice is on offer.
However, this law represents the third effort at mainstream inclusion, and results remain to be seen. There is resistance from many mainstream teachers, who have no training in autism, and also from special educators, who fear that their jobs will disappear. There is also a severe shortage of properly trained classroom assistants.

As a result, there are a huge number of children in specialist settings. Not only children with autism or severe physical disabilities, but even children with ADHD are often placed in “special” schools in the Netherlands. Some of these schools are fantastic, but because they generally do not offer the same national exams as mainstream Dutch schools, pupils tend to end up on a track towards a separate kind of adult life, one in which further and higher education and most forms of employment will be closed to them.

More able children on the autism spectrum are the group most likely to be enrolled at a neighbourhood school, but there are issues around pesten (bullying), as documented in the Dutch film Ben X, about a teenage autistic boy severely bullied by classmates at Further Education (FE) college. Dutch schools also stream children from the age of 11 or even earlier, which, along with a high-stakes testing regime, makes flexibility difficult.

There are some reasonably good parent-run support services, and the national parents organization Nedrelandshe Vereneging voor Autisme (NVA: www.autisme.nl) supplies useful information and many local activities and services.

**The situation for adults.**

Most of this year’s World Autism Awareness Week activities in the Netherlands (www.autismeweek.nl) reflect the focus on children. Many activities are sponsored by specialist service providers, from hippotherapy centres to supported living companies, creating the impression that autism is about living, playing and learning separately from the rest of the community.

And so the picture for autistic adults is quite mixed indeed. As noted, exclusionary education means that unemployment rates are high, including for many able people. An excellent educational campaign run by autistic people, Autisme Ten Top (www.autismetentop.nl) is trying hard to change that. There are also some very interesting autism-focused workplaces, such as AutiTalent (www.autitalent.nl), which specializes in digitising archives.

Another bright spot for Dutch autistic adults is a higher rate of independent living in the community compared to the UK. I have visited a number of autistic people in their homes and seen the range of help they can receive, such as coaching-style support, house-cleaning, and help with budgeting. Personal budgets and person-centred planning are gaining in popularity, although some service providers retain a patriarchal
attitude. These gains may be threatened by another law that came into effect this year, moving commissioning from national to local level. Already concerns are emerging about lack of local expertise and cost-cutting affecting provision.

Adult self-advocates are impressed with the influence their counterparts in the UK have had nationally: so far, the NVA has not yet involved autistic people in governance and policymaking. There is, however, a large, active organization, Personen uit de Autistische Spectrum (PAS: www.pasnederland.nl), run by and for autistic adults. Its members have taken on some very impressive research and support projects.

There are, of course, autistic adults whose needs are not being met. For many Dutch people, the best-known “autist” is Kees Momma, a 44-year-old man who was profiled in widely viewed 1997 and 2014 documentaries, Trainman and Het Beste voor Kees; he has also written for a national newspaper and published two books. The second documentary focused on Kees’s inability to move from 24-hour care provided by his aging parents into a more independent life. Kees is an articulate man whose inflexibility and overprikkeling (sensory sensitivity) cause him serious difficulty. The film has been widely discussed by autistic adults as well, particularly the on-camera suggestion that euthanasia (which is legal in the Netherlands) or suicide might be the best solution.

There are aspects of Dutch culture that may be helpful for autistic adults. Speech tends to be blunt, with fewer nuances than in English. Working in areas like science, engineering, and logistics is still a popular choice, and quite a few very able autistic adults have found success in such careers, to the extent that the Eindhoven area (headquarters of Philips and other major engineering firms) has a noted “cluster” of autistic people, like Silicon Valley in the US. On the other hand, there is a strong push for social conformity and on socialising with school and work-mates, which isn’t easy for everyone.

Autistic adults have responded by setting up many initiatives of their own, such as iets Drinken (networking evenings for autistic adults: ietsdrinken.nl), to build islands of autism-friendly culture and improve the image of autism in wider Dutch society.