

How ASK began – by Ava Ruth

ASK was born in Hamilton in 1998. It all began with the following plea by “H. Stone” in the March newsletter of Autistic Association of NZ (since re-named Autism NZ):

“People with an autism spectrum disorder can you help?”

“Recently I needed help with being wound up. Nobody could recommend an autistically friendly psychiatrist to help out, nor was there a group I could talk to who knew what I was going through.

Lacking totally in New Zealand at the moment is a network of people with an autism spectrum disorder (ASD) that can help others to function in society successfully. A group/ network is needed to help others when and if they need it in the following areas:

- To help others with an ASD when they need someone to talk to – an autistic ear – to hear the autistic needs and swap notes on how to cope
- To act as a friend and support when the going gets tough in employment, school, at home wherever. To help out in liaison between the person and the area of bother
- To talk to doctors / psychiatrists / health workers and to explain autism from the inside as regards sensitivities, language bother, drug doses, routines, loop thinking and wind ups
- To speak when required with the newly diagnosed and / or their families, sharing coping strategies and reassuring them about the future
- To be on panel discussions to give our point of view as regards the way our lives differ to the ‘ordinaries’

If you have any ideas that can help us help other autists, write them down. If you need help in any of the above areas, let us know.”

I was the sole respondent to H’s plea. A period of correspondence ensued (back in the days of ‘snailmail’ – it took us several exchanges of letters to even establish which gender we each were, as H. introduced xself by initials, and I used a pseudonym, at a time when ‘coming out’ was even more treacherous than it is today). Finally, on New Year’s Eve 1998, while the ‘ordinaries’ as H. called them partied in their customary way, Harold and I met in Hamilton, and drafted out a letter (a rather quaint mix of our two very different literary styles and grammatical fixations) to the few ASD adults we each knew, inviting them to join us to form a peer-support group called ‘Autism Spectrum Kiwis’ (ASK for short). Thus began the ASK Initiative, centred in the North Island initially, with a small but growing membership throughout the country.

Another milestone was our first conference presentation in 2000: Several of us had attended the Autistic Association’s 1997 conference at which an ‘expert’ described the key difference between autism & Asperger’s as the ‘selfishness’ of those with Asperger’s, which the aspies among us, listening aghast, were denied chance to challenge. This helped inspire the first NZ conference presentation by ASD adults, at the Autistic Association’s 2000 conference, when Harold, Candy & I took the audience on a brief “tour of the Isle of Autism,” to dispel some of the myths; transported by Harold’s apt metaphors of the trains of the Isle of Autism, trams of Aspergia, and cars of Neurotypia.

During those early years, adult ASD groups began meeting in Christchurch (started by Candy, Ludovic & me) and Auckland, while Harold was the legendary roving liaison person, meeting with ASD adults and families from Waikato & Bay of Plenty through to Gisborne. Gradually other members began speaking out, providing 'insider perspectives' to community groups, conferences, media etc., and even publishing books.

The next major milestone was at the age of four, when Christchurch members Candy, Ross, April & I, on behalf of the national group, took the legal plunge to incorporate ASK as a charitable trust in 2002 (via a series of somewhat hilarious legal meetings in which our odd combinations of eccentricities and talents clearly mystified our NT legal advisers) ... And from thence ASK, thanks to a wonderful succession of auties and aspies who've served on its two-yearly Trust Boards, whose names and tales may be traced in our Annual Reports, has developed into the adolescent ASK of today ... Yay!