

Submission to the Senate Select Committee on Autism 2020

## Raising Awareness of The Impact of Autism in Long-Term Intimate Adult Relationships in Australia

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As we move into 2020, the newly formed Senate Select Committee on Autism is recognizing not only the incidence of this condition in children, but the impact of the condition on adults through 'whole of life'. Given the social communication and relationship difficulties related to autism, the adult long-term relationships of people with an autism profile is of critical consideration.

The Australian Bureau of Statistics Autism Report in 2018 states that over 3% of children aged 5-14 are diagnosed autistic and there was a 25% increase in diagnosis from 2015 to 2018. In history, females with autism were unrecognized because they had a different presentation of the condition but we are starting to estimate the true ratio of male to females with autism to be around 2:1. Research is also suggesting that autism is approximately 83% heritable – passed down from a parent.

Continuing research asserts that autism rates have been constant in human history, but we have become significantly better at recognizing this neurological profile. It is reasonable to state, therefore, that about 3% of adults in Australia are autistic. Sadly, many autistic adults over the age of 25 are undiagnosed, misdiagnosed or unaware of their condition. Now, these adults experience significant difficulties in forming and maintaining long term relationships with friends, family, co-workers and intimate partners, but without the support the younger generation is currently receiving.

When an adult with an autistic profile enters a long-term intimate relationship with a neurotypical partner it is described as a 'neurodiverse relationship'. Neurodiversity describes the wide differences in individual brain function and behaviours. The ABC series *Love on the Spectrum* briefly shone a light on these couples. Such relationships are frequently challenging due to different perspectives, styles of communication, expression of emotions, social needs and neurological processing. In Australia, we are just beginning to recognize the existence of the neurodiverse couple and acknowledge their unique issues that are different from (neuro) typical couples.

Currently, couples are presenting their children to clinicians for a formal diagnosis of autism. During this process couples are recognizing that one or both share similar characteristics as their children. Initially, couples are self-diagnosing or 'spouse diagnosing' using the many checklists available on the internet. Many are then seeking a formal diagnosis of their own. To such couples their diagnosis comes as a relief that they are not bad, mad, crazy, lazy or apathetic and so they seek couples counselling to help with their relationship difficulties.

Problems arise when they seek such counselling because most psychologists and counsellors use traditional methods that don't work because of the atypical profiles noted herein. For example, the neurotypical partner will often appear traumatized, distressed, emotional and with difficulty explaining to therapists, family and friends that they feel isolated and alone in a seemingly close relationship. Their autistic partner is likely to be calm, logical and yet lacking the emotional or empathic responses expected of a partner.

We, ourselves, are a neurodiverse couple who have remained in love and committed for 37 years but challenged daily. We have sought the help of many experienced and well-meaning counsellors, psychologists and psychiatrists, but due to their lack of awareness of

our neurodiversity and ways in which to help us understand each other's needs, our relationship remained tough. We have felt distress, frustration, blame, shame, depression, anxiety, pain and isolation. Tragically, we have also been disbelieved because our neurodiversity has been invisible to others as the problems involved the intimacy of the relationship.

Fundamentally, conventional couples counselling strategies can be counter-therapeutic, and it is unwise to commence therapy without a comprehensive understanding of the neurological differences.

Recently it became clear to us that our unique differences required very different counselling approaches from the norm. As a couple we eventually benefited greatly from the philosophy and generosity of the AANE Neurodiverse Couples Institutes in the USA. Their approach explained our different neurology, in other words, that we experienced many things differently and that our relationship should be interpreted through a neurodiverse lens. Simply, we have been encouraged to see ourselves as speaking two different languages and need to learn to speak and understand each other's language. It is the role of the counsellor/coach to act as our interpreter and to help us to understand each other's perspectives and needs.

The first step to improving this situation is to place the challenges within the relationship under the concept of neurodiversity. We then need to inform and educate the psychologists, counsellors, therapists, lawyers, police, educators, community and social services about this type of relationship. Such support will prevent relationship breakups, family dysfunction, children's educational difficulties, mental health breakdowns, community service interventions and domestic violence incidents.

In conclusion, we ask the Australian government and agencies to recognize the existence of neurodiverse couples and develop policies and funding that support them. Next, work with specialist counsellors and existing relationship counselling organisations to identify this type of relationship and adapt counselling models that will accommodate the unique issues faced by such couples. Finally, bring the attention of autism research to neurodiverse relationships and measure the benefit to our community that results from improved support of these relationships in Australia.

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