

Peer mentoring for autistic girls and women

Historically it has been believed there are more autistic males than females, but it is becoming increasingly understood that more females may be autistic than previously thought.

Academics, clinicians and autistic advocates have over the past 12 years highlighted issues around the identification and diagnosis of females (for example Bargiela et al 2016; Gould 2017), but the empirical evidence suggests that there is still a long way to go.

Related to this is autistic women's and girls' experiences of poor mental health. Autism and gender stereotyping have overlapped to make autistic females 'invisible' within society and to themselves. The 'swan' analogy, adopted by the charity [Scottish Women's Autism Network \(SWAN\)](#), describes 'masking' and self-denial as coping strategies, resulting in disrupted self-identity and poor self-esteem. Stigma and society's focus on the "deficits" of autistic people impose additional burdens (Snow 2013, Stewart 2012).

All these impact on an individual's mental health, life choices and life trajectory. High levels of masking have been associated with both females and poor mental health (Hull et al 2017)

Under our wing project

A PhD study on autistic girls' experiences of anxiety (Stewart 2011) inspired the founding of SWAN to:

- provide peer-support
- increase the knowledge-base and improve understanding.

SWAN's peer-led monthly groups across Scotland and online peer-support forums have been described by participants as 'life saving' and 'life changing'.

Peer support and mentoring as a response to mental health issues are not widely resourced or evaluated. In response, SWAN and [Scottish Autism](#), with funding from the Scottish Government, partnered in 2018 to run a one-year pilot project of peer-led mentoring for, and designed by, autistic women and girls.

Participants were invited to take part in a programme of rich and varied

training and learning events in the company of their autistic peers. Those that became mentors were [PVG checked](#) and then paired with mentees for a set time-period, with goals and outcomes set in agreement by both parties.

The training has included 'Autism from the perspective of the autistic woman and girl', delivered by the project management team.

There have been sessions on:

- mentoring skills
- networking (for the autistic woman)
- understanding different thinking styles.

There has also been art and IT workshops and a lovely 'Away Day' in the beautiful Trossachs hills.

The training throughout the programme has been delivered by autistic women, non- autistic specialists in training and mentoring women, and with additional input from Scottish Forestry in the form of self-development and learning through experience, via woodlands sessions.

Under Our Wing has been modelled as a co-production between all involved - the participant trainee mentors, the trainers, the SWAN management team - with ongoing feedback encouraged, evaluated and responded to throughout. The mentoring trainer, Dinah Bennett from ICEE and myself have been co-mentors for each other. Dinah brings decades of experience of working with women's groups worldwide, I bring my 'insider researcher' knowledge and experience of autism!

The pilot is just coming to an end. I felt it was crucially important to formally evaluate any benefits, barriers or limitations to using this model and so it has been externally evaluated by the Societal Innovation and Enterprise Forum (SIEF) at [Durham University](#) using:

- an existing Quality of Life (QoL) tool
- reflective diaries kept by participants
- qualitative interviews

- a modified bespoke QoL tool.

Under Our Wing has been a privilege and a joy to be involved with, and challenging at times. Much has been learned, with more to come as the evaluation unfolds.

Some barriers have been identified, as it is a substantial commitment for individuals participating on a voluntary basis. The project budget included travel and lunch expenses, but participants have given up regular days over a period of months, unpaid. Some have used up annual leave, others have travelled across Scotland to join us. Some found the regular commitment too much, and/or experienced personal circumstances and issues around capacity.

The benefits have still to be formally reported but they are clearly apparent:

- increased self-assurance, including the ability and confidence to know when to say 'I'm overwhelmed, I can't do this right now'
- the development of skills and sharing of creative talent, ideas and ambitions
- the sheer joy of learning and growing in an environment of positive shared experience and community.

The evaluation report should be ready by the end of summer 2019.

Meantime, SWAN is in discussion with existing and potential partners as to future projects. There is a great deal of enthusiasm and passion to continue this work, from everyone who has been involved so far and others who would like to be. It is worth pointing out here that this model is low-cost 'per capita' with potential for long-term sustainability and expanding outcomes. Funding is required to support the management team and mentors, and finding this will be a key priority over the coming months.

References

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