

## NOMINATION DETAILS

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**Who is being nominated?**

Organisation

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**Please provide the name of the organisation being nominated as it should be on publicity, including any organisations or partners that should be mentioned:**

Scottish Women's Autism Network (SWAN)

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**Name of organisation:**

SWAN

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## AWARD DETAILS

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**Which category are you entering?**

Category 9: Head Above the Parapet

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**Please confirm that the work carried out relates to the last two years (up to January 2018):**

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## SSSA Entry Form 2018 :

- Yes

### Q1. Overview: (max 200 words)

Established in 2012, the Scottish Women's Autism Network (SWAN) aims to provide a network for autistic women in Scotland, to identify strengths as well as challenges, increase confidence and maximise individual potential. It seeks to create a route to practical support for autistic women and girls throughout the lifespan. Sharing information, learning from the lived experience of women, girls, parents and carers, identifying common needs and creating an alternative to prevailing negative narratives of autism, form the bedrock of the network. SWAN was founded on the basis of Dr Catriona Stewart's PhD study, which focused on experiences of girls with Asperger's Syndrome and their mothers. Exceptionally, SWAN has, since its foundation, been led, run and developed on a voluntary basis by a group of autistic women.

SWAN gained charitable status in November 2016. Its constitutional aims include:

To actively seek and widely promote a greater understanding of the lived experiences of autistic girls and women by:

- challenging misconceptions and ignorance surrounding the existence, prevalence and presentation of autism in females, through research, practice and the collecting and sharing of knowledge of lived experiences
- working to dismantle unhelpful stereotypes and misunderstandings
- forming and developing working partnerships with professions, agencies and organisations

## SSSA Entry Form 2018 :

### Q2. What did you do? (max 500 words)

SWAN Meet-ups: These are held monthly in Glasgow and Edinburgh by and for autistic women, to meet, chat and share experiences. Fledgling groups are also emerging across Scotland.

Groundbreaking Learning Events: In 2016 at Strathclyde University, our third event, 'Cygnet to Swan' was led and featured presentations by autistic women. In 2017 our fourth event, 'Practical Strategies for Daily Living', was facilitated by Scottish Autism and Inspiring Scotland and again was led and featured presentations by autistic women. It was oversubscribed within two days of advertisement. There are filmed presentations from the events available on the SWAN website [www.swanscotland.org](http://www.swanscotland.org) which was developed by an autistic designer.

The networks: The SWAN Facebook network provides information and a portal to a 'safe space' online forum for autistic women based in Scotland, an alternative route to peer support for those who can't get to the meet-ups or prefer to engage socially online. There are currently around 80 women signed up to this, while the main Facebook page reaches thousands. SWAN work is maintained by autistic women on a voluntarily basis.

Advice, advocacy, support: SWAN receives a steady stream of requests for advice and support from practitioners, autistic individuals and family members to which volunteers offer advice, signposting and empathetic listening.

Right Click: In 2016 funding was given by the Scottish Government to Scottish Autism's Centre for Practice Innovation, which employed Catriona as academic consultant to develop an online resource for autistic women. The SWAN network has contributed to the resource through participation in research surveys, focus groups, a review panel and filmed interviews. Catriona is now employed full-time by Scottish Autism as an advisor.

SWAN/Right Click partnership going forward: Further funds have been raised for a one year mentoring project, co-produced by Scottish Autism and SWAN to facilitate autistic women gaining and developing mentoring skills for the support of younger women and girls.

The wider community: Taking the messages at the heart of SWAN's aims to the wider community is ongoing. Members of SWAN have been involved in a range of consultations (SIGN; NES training framework, Scottish Autism Strategy), conferences (National Autistic Society, National Autism Employment Network), and hustling events. Catriona has presented to conferences in Toronto, Copenhagen and London and events in Birmingham, Harrogate and Airdrie. At the Autism Europe Congress in 2016 Right Click received enthusiastic attention from as far afield as Harvard USA.

Risk: The decision to disclose as autistic in many contexts - professional, social or as a mother - is a complex one in a society where information on autism is often partial and misleading and may lead to stigma, marginalisation, or even victimisation. Autistic people are often 'othered' by society, patronised and judged. Most of the core SWAN volunteers, including Catriona, as its chair, are open about their neurodevelopmental status, conscious of challenges that can bring, but passionately determined to increase the visibility of this previously 'hidden' population, to change social perspectives and to provide routes to identity and role models for younger autistic women and girls.

## SSSA Entry Form 2018 :

### Q3. What did you achieve? (max 500 words)

A historical lack of knowledge and understanding of autism in girls and women can cause barriers for individuals, their families and carers. Difficulties in accessing diagnostic services as well as social issues associated with autism, including stigma, marginalisation and bullying, can have profound negative effects on self-esteem, self-identity, mental health and physical wellbeing and create barriers to social inclusion. SWAN works to create the conditions for girls and women to feel included, empowered, and supported in developing their personal capacity and citizenship. Every month through SWAN meet-ups and daily via the online forums, autistic women exchange experiences, insights, share their achievements and celebrations.

Scottish Autism's support and partnership between the charities has created an invaluable resource for autistic young girls and women, their families, carers and practitioners. Right Click for Women and Girls includes original research data, professional expertise and most of all authentic voices of women - 14 years to 70 - as they share lived experiences, insights and wisdom. Topics covered include diagnosis, education, employment, work-life balance, self-care, being a mother and getting older. This resource is unique and ground-breaking; it offers information and inspiration.

SWAN has had real impact on awareness and understanding in the wider society; collecting research data and recording lived experience is creating an evidence-base for our ongoing work. SWAN leaflets are included in the Royal College of General Practitioners Autism Toolkit. The NES training framework also includes input from women and there has been visibility at hustings events and Scottish Government consultations. In 2017, Catriona was invited to submit a report to the Scottish Government on the fourth SWAN Learning Event.

In her role as chair of SWAN, Catriona was a member of the advisory panel to a three year UK initiative, the National Autism Project (NAP). As a consequence, within NAP's report, The Autism Dividend (launched by Westminster and Holyrood in 2017) there is visibility and references to the profound transitional life events that are pregnancy, childbirth and parenthood. Taking up opportunities such as these is vitally important to create greater acknowledgement of autistic women as having specific life experiences and needs.

There are challenges in representing the authentic autistic female voice within any context, social or professional. Skepticism, dismissal, stigma, patronage - all of these are experienced responses to raising issues around autism in girls and women. Volunteers involved with SWAN have taken on those challenges with determination and commitment to improve visibility, knowledge and understanding of the needs of autistic girls and women.

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### Q4. Why should you receive an award? (max 100 words)

"Catriona realised the problems facing autistic girls and women [and] set about developing SWAN, to help meet unmet needs and provide a model of support that can be followed elsewhere across the UK and beyond. Volunteers put a lot of time and energy into supporting the group and raising awareness in the wider community.

Autism is often called a "hidden" disability and within this, women and girls are a minority, making us almost invisible. [SWAN] shines a light on us and makes us visible. I don't know of another organisation that does this...it is unique."

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