



Women, girls & the autism spectrum

Scottish Women with Autism Network

SWAN

in partnership since 2012

Autism Network Scotland ANS

Women, girls & the autism spectrum

Dr Catriona Stewart April 2015



Autism gender bias

- ASD previously/currently believed more common in males than females: male to female ratio of 4.3:1 (Fombonne 2003)
- = most research has involved males.
- there are few studies of gender differences in symptoms, and available findings are inconsistent (Van Wijngaarden-Cremers PJM et al J Autism Dev Disord (2014) 44:627–635)

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Recent research

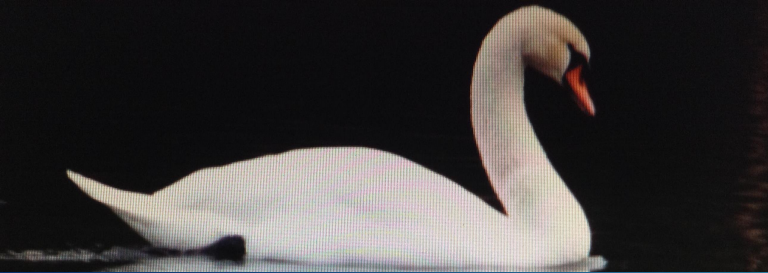
1. “Many females with normal to high intelligence could be overlooked or misdiagnosed because they do not present the male phenotype of autism”
2. “Some girls with ASD may not be identified by our current screening instruments”

1 Van Wijngaarden-Cremers PJM et al 2014

2 Westman Andersson, G., Gillberg, C. & Miniscalco C. (2014) Pre-school children with suspected autism spectrum disorders: Do girls and boys have the same profiles? Research in Developmental Disabilities Volume 34, Issue 1, January 2013

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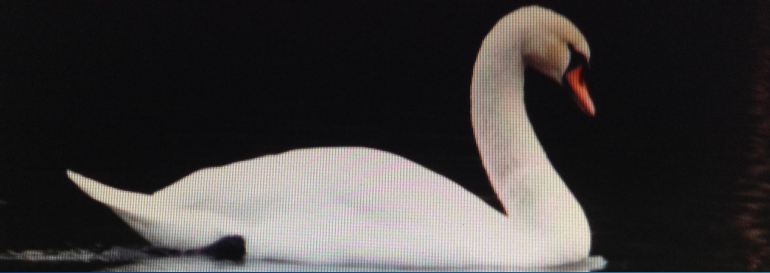


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- PhD Thesis
- “Where can we be what we are?” – girls with AS
As per Van Manen’s (1990) definition of home as ‘where we can be what we are’
- “Only a breath away” – mothers of AS girls
- Stewart, C. (2012) ‘Where can we be what we are?’: the experiences of girls with Asperger syndrome and their mothers Asperger syndrome Girls GAP (BILD) 2012 May 40-48

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SWAN analogy, what it means in practice

- Appears to be coping, actually not really or at cost

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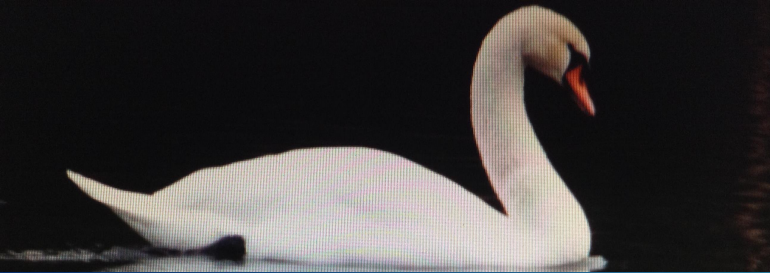
Appearing to glide across the surface of life

but frantically paddling underneath just to stay afloat...

*Occasionally turning
upside down Paula R 2014*

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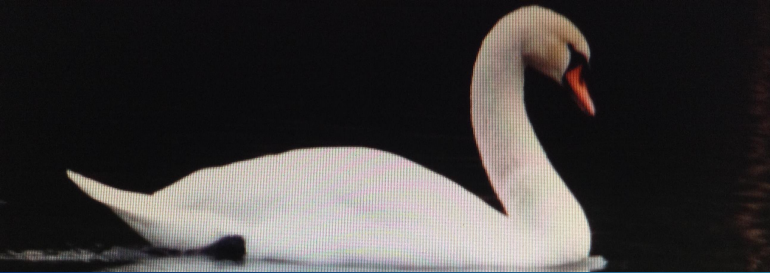
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*Sensory Overload, Monotropic
(coping) behaviours (Murray et al 2005)*

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under pressure to conform to societal expectations of femininity: appearance, interests, language etc. (Stewart 2014) issues of gender stereotyping

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Appearing to glide across the surface of life

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Anxiety
being overwhelmed
exhaustion
withdrawal loneliness,
depression

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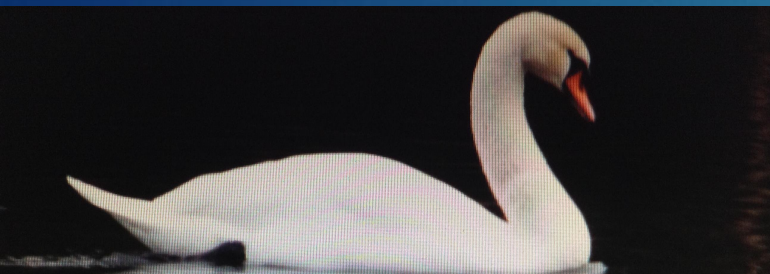
Appearing to glide across the surface of life

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High risk behaviours
self harm,
School refusal
Anorexia nervosa?
suicide

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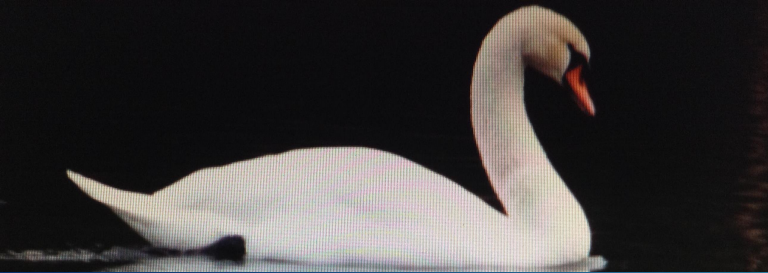
Scottish Women with Autism Network 2012

Padding alongside...

Connection
Peer support
Information exchange

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Key issues

DIAGNOSIS

EDUCATION: opportunities for girls; school environment; expectations, peer pressure; anxieties for the future; transition ...

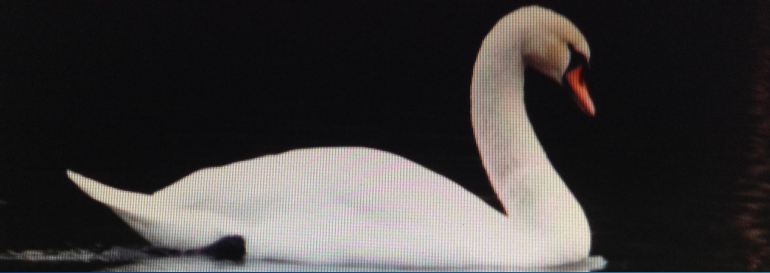
HUGE gap in provision for ASC girls

GIRLS GROW UP: relationships, sexual health and safety, employment; spectrum women as mothers; ageing

Health and WELLBEING

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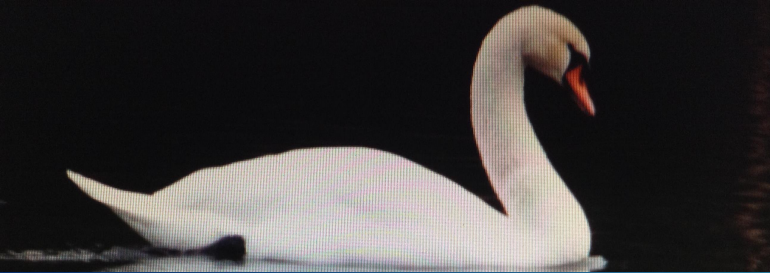


SWAN

- contacted by women from as far afield as Shetland and from other parts of UK for advice, support; we offer peer support and opportunities to meet; entirely voluntary self-directed
- parents, including fathers of girls with recent diagnoses
- practitioners and other organisations

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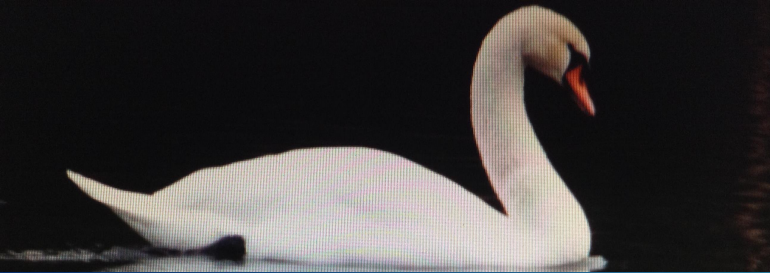


SWAN ripples...

- Williamwood school East Renfrewshire after-school Asperger's girls group: Alina Spence and colleagues

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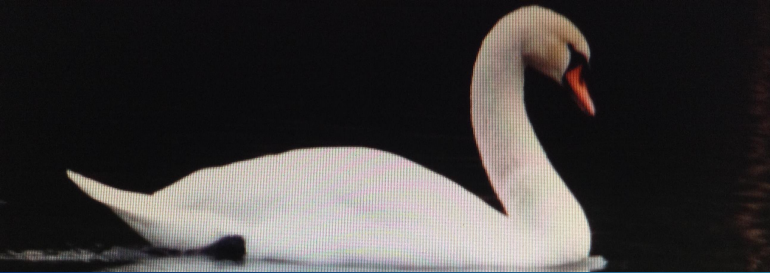
SWAN ripples...

- NES: Input by SWAN = embedded throughout the document

<http://tailoredfoundation.co.uk/wp-content/uploads/2014/12/NHS-Education-for-Scotland-Autism-Training-Framework-Optimising-Outcomes.pdf>

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Key issues

- looking to disability, citizenship or human rights models and challenging the 'normalcy' narrative and definitions of autism as deficit and impairment
- not only in terms of the criteria for ASC but as internalised beliefs held by autistic people themselves; a disability studies perspective supports an opportunity for people on the spectrum to reframe both their challenges and their strengths and abilities

(Snow 2013 Beyond Visions of Repair: Evoking a parlance of capacity and competence in research on Asperger Syndrome and Schooling)

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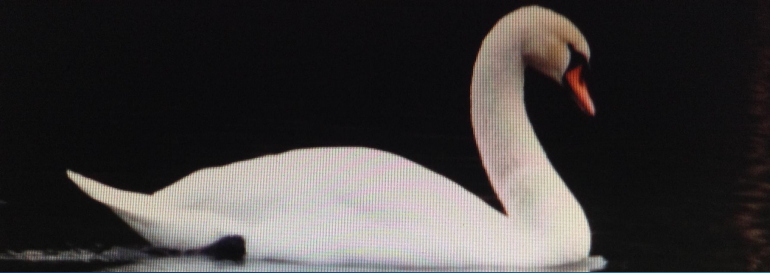


Key issues

exposes ways in which these narratives work to disempower and diminish the life choices and quality of life of young autistic people

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Key issues

- retrieving the 'experienced world as a source of reliable information' (Smith 2004 p 24)

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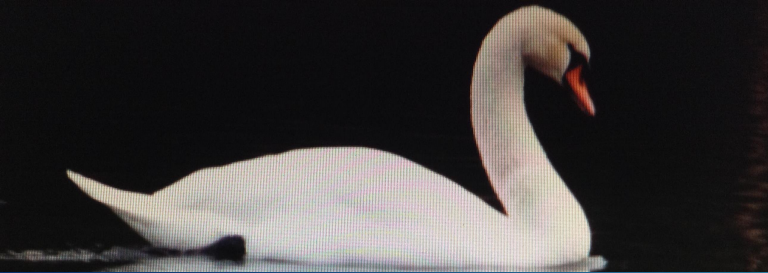


SWAN

- retrieving the 'experienced world as a source of reliable information' (Smith 2004 p 24)

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SWAN ripples...

- SWAN offers a valuable contact point, peer support, networking, information & knowledge exchange
- swan.scotland@gmail.com
- www.facebook.com/swan.scotland
- <http://www.autismnetworkscotland.org.uk/swan>