

Autistic Women and Girls

Resources for Professionals

Being a Mother

These resources have been collated from information collected through an online questionnaire, focus groups, interviews with individual practitioners and autistic women, and other recent research studies. Our aim is to summarise all this information, to present it in a succinct and useful form for busy professionals. Each resource contains a summary of key points, with links to appropriate items within the Right Click programme itself and other resources, from websites, online information and books. If you'd like more information on any of the areas covered, or have a specific enquiry, please contact us at rightclick@scottishautism.org

Key Messages

1. Historical lack of recognition of autism in girls and women with little or no research in this area has impacted on service strategies, planning and provision.
2. Pregnancy, childbirth and early parenthood are major transitional experiences for women and for autistic women, there may be specific experiences and areas of need.
3. Most of the areas of concern described by autistic mothers relate to issues of communication within health, education, social services contexts and anxieties around stigma and judgement.

The fact that autistic girls grow up, may get married, and may have children has been historically not well recognised which means there has been little to no research in this area and very little specialist training for professionals in relevant services, including health and social services.

In 2016, for the Scottish Autism Right Click Women and Girls programme, we created an online survey of 30 questions, which included a section on parenting. We held focus groups and interviewed individual women. This work has been additionally informed by Scottish Women's Autism Network (SWAN). There are many filmed interviews with autistic women, including on parenting and these are presented on the Right Click for Women and Girls programme.

Pregnancy, childbirth and early motherhood are life changing transitional experiences. For autistic women, there may be specific sensory issues in pregnancy and in labour, communication with medical staff may be difficult and demands for social interactions increase e.g. health visitors and school staff, increasing the burden of anxiety on autistic mothers.

In our research for this resource, we found that autistic women sometimes feel misunderstood or judged, both within the wider community and within health care, education and social care contexts.

Disclosure as a complex and difficult choice for autistic women was reported with anxieties around potential stigma or preconceptions about autism, for example, relating to how capable they might be as parents. These anxieties can cause barriers to accessing appropriate support and care services, antenatal, maternity and post-natal support for example.

As well as challenges and difficulties, the mothers in our study expressed their feelings of love for their children, sense of responsibility and determination to be 'good mothers' and described some of the strategies they employed to achieve this.

Becoming a Parent

- 80% of survey respondents have considered being a mother
- 75% of these are already mothers
- The majority of mothers have two or three children
- Girls:boys ratio was approximately equal
- Approximately 1/2 of children had been diagnosed with ASD

Pregnancy and Labour

Some key issues highlighted by respondents were:

- Having to deal with unfamiliar and constantly changing environments
- Having to deal with other people, including other mothers, health practitioners and hospital staff.
- Lack of clarity of communication:
 - Between consultants and other staff to the women
- Women feeling unable to ask the questions they wanted to or express themselves
- Issue of pain thresholds which has been spoken about in other contexts, with women reporting they were much 'further along' in their labours than midwifery staff realised.

Illustrative Quotes

“Not feeling in control, not understanding what was happening and not feeling able to speak or listened to.”

“Total lack of awareness of how autism might impact my pregnancy/labour/motherhood – I had to educate every healthcare professional I dealt with.”

“Lack of communication as to what was happening when in hospital; possible increased pain threshold - not realising I was in labour and midwives not realising I was so far along.”

What Helps?

“Autistic-specific advice on pregnancy”

“In every area: specialist training and knowledge of autism, and specifically autism in women.”

New Motherhood

Women reported finding some challenges as new mothers around:

- breastfeeding
- health visitor and other checks
- confidence in parenting skills

Illustrative Quotes

“It was the best experience of my life, having the children...I was a natural mother.”

“[greatest challenge was] the isolation”

What Helps?

“Guidance as a new parent: what is important, what you can ignore.”

“In every area: specialist training and knowledge of autism and women, for example, breast-feeding counselling with awareness of potential sensory issues.”

“I would have liked information on how to get baby into a routine when I had my first child.”

“Ideas for a daily routine for mother, including menu planning, shopping list, time with kids, house work, time out etc.”

As Children Grow

Confidence in parenting skills was again reported as an issue, especially in emotional terms. It's important to note however that lack of confidence does not equal lack of competence. Well over ½ of respondents ticked all areas involving dealing with people as causing stress or difficulties, causing barriers to accessing professional and peer support:

- teachers
- other parents
- accessing groups
- talking with teachers about their children
- accessing extracurricular activities for their children (possibly inaccessible for the children, rather than for the mothers – or both?)
- others: maternity staff (e.g consultants), labour ward staff, health visitors, GPs

Illustrative Quotes

“I feel not one single professional at school, who knows about my diagnosis, can understand me as a parent.”

“Hated having to mix with other parents especially those that made it clear that they did not approve of autistic children in mainstream.”

“The challenge of not being constantly judged unfairly if you don't or your child doesn't attend or want to go to after school activities and the pressure you are under by the majority to explain yourself and your children to them.”

“I went through a kind of transition phase and said I had to get myself out my shell for the sake of my daughter. I went out every day, I went to parent and toddler groups every day, I ended up running one.”

The Greatest Challenge for Spectrum Mothers is Exhaustion

“I find it hard to navigate through the various online support forums and find something that is appropriate for me but I know other parents who manage this very successfully. Access to advice from trained staff about any parenting/educational issues would be good.”

“Information on any group for mothers and their children to attend”

“Self-awareness and insight”

“Just not being cross with them because of whatever. Being able to step back and say it is because you have hit sensory overload, you are exhausted, you are overwhelmed because the sensory environment is off the scale.”

“Limiting stress in other parts of your life so that when you do have to go out there and do something that is stressful and difficult and out [of] your comfort zone you have got a kind of camel hump of resilience built up and you can cope with it.”

“Peer support forums”

“It’s that validation word, isn’t it? It’s the business of keeping the self-esteem at a level that allows you to function. That somebody else is saying ‘I’ve been there too’ or, ‘I get where that’s coming from.’”

To learn more about autism in women and girls, register for our Right Click Women and Girls programme where there are in-depth discussions on being a mother from the perspective of autistic people and professionals.

Resources

Scottish Women's Autism Network (SWAN): www.swanscotland.org

Hendrickx, S. (2015). Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age. Jessica Kingsley

Grant, L. (2015). From Here to Maternity: Pregnancy and Motherhood on the Autism Spectrum. Jessica Kingsley

National Autism Project: <http://nationalautismproject.org.uk/the-future-id-like-to-see-dr-catriona-stewart>

Spectrum Women: Walking to the beat of Autism <https://www.jkp.com/uk/spectrum-women-1.html>

Sarah-Jane Critchley (parent): <https://www.differentjoy.com>