

The future of Scottish Autism Research – what do we need to make Scottish autism research great?

Key concepts:

- *Connections.* Between researchers, the community and practitioners, in both directions.
- *Insight.* Researchers understanding what needs to be done 'on the ground'. Practitioners and communities understanding constraints on research.
- *Impact:* Translation of research evidence into practice recommendations. Policy based on the cost of doing something vs the higher cost of doing nothing.
- *Outcomes.* High quality measurement of meaningful progress.
- *Scale:* research tends to deal in 'average' behaviour in a group, but practitioners and community members need individualised supports
- *Funding:* the perceived priorities of major research funders seem rarely to correspond with community priorities
- *Time:* this resource is always in short supply and prevents practitioners from drawing on research evidence, researchers from sharing their findings, and community members from either taking part in research, or sifting through the myriad options being offered by commercial operators.

Components of 'great' research – towards a shared definition:

- Meeting a need, wholly or in part, identified by members of the autistic community.
- Resulting in a practical outcome and having an impact on society
- Cost and time effectiveness: including practical strategies which autistic people can apply and use for themselves. Practitioners might only have one hour per week with a service user.
- Buy-in from the whole community: ethical and inclusive research practices which reach out to disenfranchised individuals
- Focus on abilities, not just a deficit model of autism
- Inspiring change within research communities as well as outside them

Resources for 'great' research:

- Involving people on the spectrum in design etc. of studies: doing this requires getting the working environment right and investment in long-term relationships
- Clearly defined outcomes, and ways to measure them, which are meaningful to all stakeholders: community, practitioners, researchers
- An enjoyable participant experience: reports on participants' views on their experience of participating in the research should be shared, and ideally published in academic journals

SARG Re-launch Feb 2015: summary of small group discussions
Sue Fletcher-Watson on behalf of the SARG committee, May 2015

- Opportunities to build connections between researchers and other stakeholders. Mixed placements (e.g. clinical & research) can help, but building good relationships requires time and long-term investment between different professional and community groups.
- Funding specifically ear-marked for implementation of research findings: this could be delivered through Scotland-based research funding body incorporating representation from participants, the third sector and so on.
- A co-ordinated approach to funding to reduce duplication, with a focus on practical needs rather than 'blue sky' scientific advancement.
- A centralised & transparent method of research priority-setting, with a system to involve the autism community.
- An independent database of research that is currently happening (with registration to this a prerequisite of funding), then contributing to an archive of completed projects
- Training for students/researchers in autism awareness (ideally via practical experience) before they begin research
- Templates of information and consent sheets for early career researchers
- Encouragement, training and resources to support practitioners to be researchers and to contribute to the research agenda: funding for this and access to good outlets for sharing results (e.g. *Good Autism Practice* journal)

Differences between stakeholder groups

- Non-researchers, and practitioners outside health, place higher value on qualitative methods, especially when these report on direct engagement with communities and their representatives.
- Researchers raised a range of issues not mentioned by other groups including: large sample sizes; accessible participant recruitment pipelines; high quality designs including randomised controlled trials; replication of key findings; interdisciplinary collaboration between academic departments; longitudinal studies; theoretical foundations;.
- Researchers did not only emphasise these specific professional priorities but also echoed concerns of the other stakeholder groups including valuing "buy-in" from the autism community and seeking more opportunities to share research outputs

Future directions for SARG?

- A National Centre for Autism Research? Encouraging a national commitment to a specific autism research strategy.
- Making Scotland a more inclusive and friendly place (not just for autistic people but for everyone). Can we make relevant adaptations to society and structures?
- A universal pack of good quality resources for parents and practitioners in Scotland
- Providing education on autism to services and businesses including: criminal justice system; education; employers; frontline health care practitioners (e.g. GPs, A&E staff)
- An online Research Hub – any information could be posted; projects that clinicians, educators etc. would like researchers to help carry out; new papers, calls for collaborations etc.
- Continuing Professional Development for practitioners, policymakers, parents

Stakeholder-recommended Research Topics:

- Quality of life, across the whole lifespan and the variety of autistic profiles. Individualised and adapted to life stage / need.
- Helping children understand their diagnosis.
- Understanding the role of diet in the experience of people with autism
- Effective social skills training for children
- Making school a better environment – what works for all children? What constitutes an autism-specific learning environment? How do autistic children learn?
- Effective interventions and useful outcome measurement systems for education settings: ways to chart progress
- Everyday functioning – daily living skills and support
- Connecting up services for young people to services for older people: managing transition well.
- Employment: does a job itself provide self esteem? What strengths can autistic people bring to the workplace?
- Mental health: treatment for co-morbidities and related to health (not just core aspects of autism)
- Parent experience: how do parents experience interventions? What works for the whole family?

Recommendations for everyone:

- All stakeholders in autism research – researchers, practitioners from multiple disciplines and settings, autistic people and their families – need to seize opportunities to engage with each other in order to promote great research, and research-based practice.
- Acknowledging the lack of time and structures to support collaborative working, the autism community in Scotland (including practitioners and researchers) should all try to make time to build relationships, share information and develop meaningful partnerships.
- Researchers should evaluate and share results regarding the experiences of participants in their research, considering aspects such as the acceptability of any assessments and the experience of all family members involved in an intervention study.
- Researchers in Scotland can be a team, working together to create a strong foundation for autism services and practice in Scotland, building on strengths and avoiding needless competition or duplication
- Non-research stakeholders are requested to respect the constraints placed on researchers by their employing institutions, ethics review boards, funders, requirement for scientific rigour, and available resources. All of these can make directly applicable research outcomes very hard to achieve.