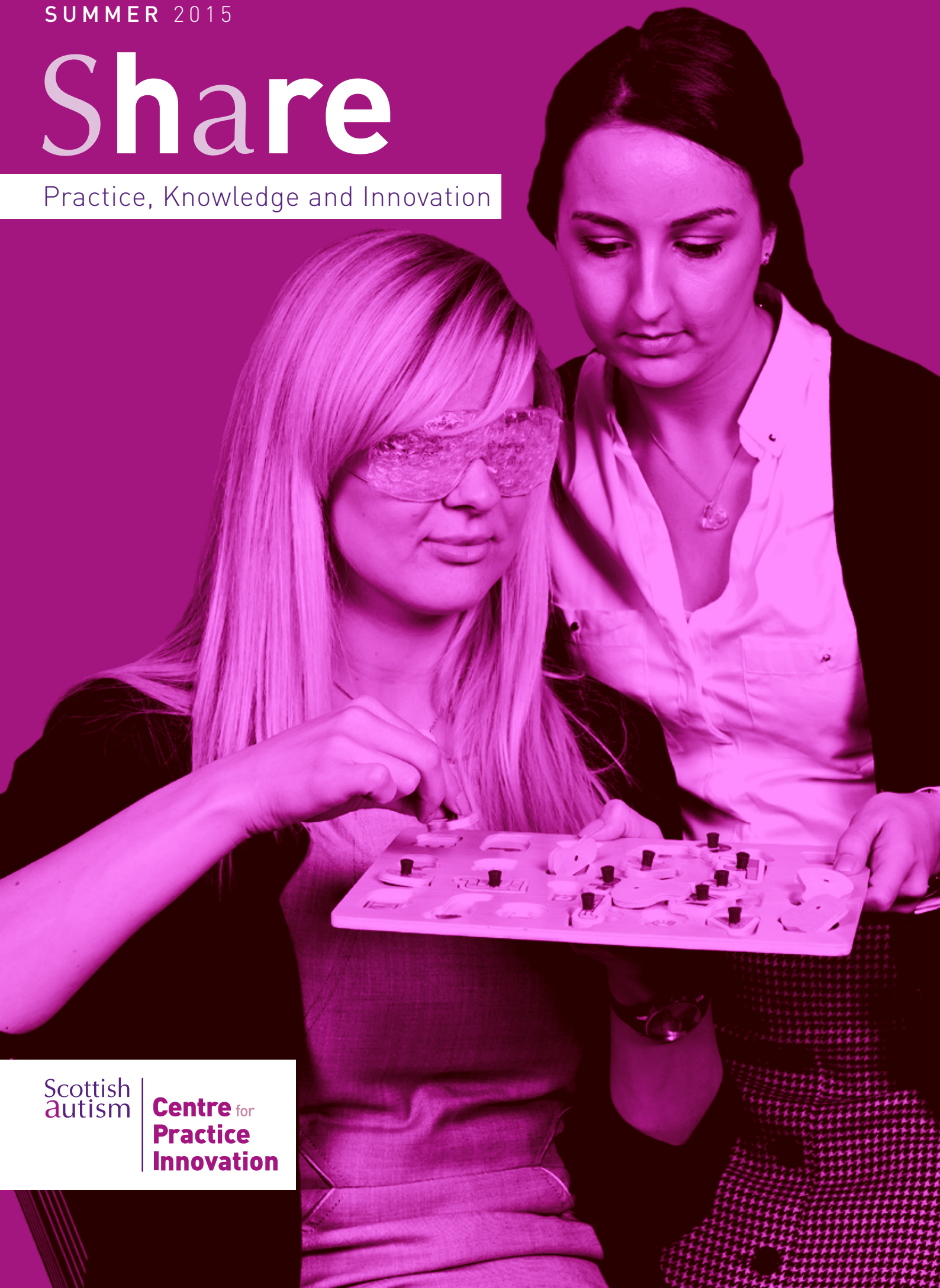


SUMMER 2015

Share

Practice, Knowledge and Innovation



Scottish
autism

Centre for
Practice
Innovation

CONTENTS



Being on the spectrum – unfettered humanness. Page 7.



Building bridges to vision: partnership working on autism and sight loss. Page 8-9.



Transform Autism Education. Page 10-11.

- 3** **Letter from the editor:** Charlene Tait, Director of Development, Scottish Autism.
- 4** **Welcome:** Introduction to the Centre for Practice Innovation.
- 5** **Associates:** Meet the Centre's Research and Practice Associates.
- 6** **News and Events:** Round up of recent news and events.
- 7** **Being on the spectrum – unfettered humanness:** By Debi Brown.
- 8-9** **Report:** Building bridges to vision-partnership working on autism and sight loss. By Joe Long, Research Manager.
- 10-11** **Case Study:** Transform Autism Education. By Karen Guldborg.
- 12-13** **Burning Question:** Why participate in research? A researcher's view. By David Simmons. And a participant's view. By E.G. Douglas.
- 14** **Opinion Piece:** Research into practice, practice into research: Learning to speak each other's language. By Sue Fletcher-Watson.
- 15** **Conference Review:** Meeting of minds – Wellbeing and people with autism. By Professor Andrew Jahoda.

Letter from the editor.



Charlene Tait
Director of Development,
Scottish Autism

In October 2014 Scottish Autism launched the Centre for Practice Innovation. Our aim is that the Centre will become a focal point for our practice research and knowledge sharing and will lead to establishing relationships and partnerships that will result in innovation and development in autism practice.

“Share” is one of a number of ways we will be communicating the work of the Centre. We are delighted to have the support of our Research and Practice Associates (featured on P5), in bringing our first edition to you.

We hope you will find the eclectic mix of features, case studies and opinion pieces thought provoking and informative. Our “burning question” article aims to stimulate debate on relevant topics. At a time when there is increasing emphasis on people with autism being central to research as planners as well as participants this could not be more timely.

Given that a major focus for us at Scottish Autism is the meaningful participation and involvement of the people who use our services, the personal insight people with autism offer us is vital to our learning and is therefore an essential feature for our Centre publication.

I am grateful to everyone who has contributed to this edition and to the many people who have been so willing to share their time and expertise in supporting us to establish the Centre.

Please do get in touch if you would like to know more or if you would like to get involved with any aspect of our work.

Welcome to the Centre for Practice Innovation.

This magazine is the inaugural publication for Scottish Autism's Centre for Practice Innovation, launched last October. It therefore seems a fitting place to outline our rationale and vision for the Centre and what we hope to achieve.

The Centre will be a home for Scottish Autism's knowledge exchange activities, a forum within which our autism support and education practitioners come together with researchers, professional partners and, most importantly, individuals with autism and their families to develop our understanding of autism and our practice. We recognise that the best support practice is informed by a broad range of knowledge and evidence within a sound ethical framework. We also recognise that practice should be constantly developing, absorbing the most up-to-date thinking to create innovative ways of enabling people with autism. The Centre brings together a number of recent initiatives undertaken at Scottish Autism that are based on this principle.

Knowledge Exchange

Knowledge sharing between our practitioners, individuals with autism, families and professionals outside our organisation is a key part of our mission. Our Knowledge Share Seminars, launched in 2012 have been an important forum for passing on our own experience and learning from the experiences of others. The work of our Autism Support Team in running our Autism Advice Line, the Right Click online support programme and internal support for our own services will expand and evolve within the opportunities offered by the Centre.

Research

There has been a flourishing of autism research in recent decades, much of which has been crucial to our understanding of the condition. The challenge we face as a service provider is often in translating scientific research into day-to-day support practice. Through the Centre we will be looking to promote research with a particular focus on support and education – research that captures effective practice and the lived experience of people that we support, and leads to insights and resources that can usefully inform the support that we provide. In 2013 we started our own programme of practice-focused research in which our practitioners, the people that we support, and their families have all been involved. As we look to grow this work we aim to foster further research partnerships.

Collaboration

The Centre for Practice Innovation will be an important focus for our collaboration with partner organisations – including other third sector organisations, higher education and research institutions. For example, we are currently running a project on 'Autism and Sight Loss' with the RNIB (Royal National Institute of Blind People) and Edinburgh Napier University (detailed on P8-9), we will be jointly supporting a project on 'Autism and Ageing' together with Research Autism later this year, we also work together with Studio 3 and partners from the Heimdal organisation in Denmark on a programme of low-arousal interactions and we have a number of similar collaborations in development. We hope that these collaborations will flourish and grow within the framework provided by the Centre.

Practice Innovation

All of these relationships and initiatives are aimed at ensuring our practice is continually evolving. For example, the Atlass programme, led by our partners at Studio 3, places wellbeing, happiness and stress-free interactions at the heart of our practice. More broadly, our new Autism Practice Improvement Framework (APIF) will also be developed and evaluated as a means to ensure that the principles of good practice and continuous development are consistent throughout our services. The involvement of our own Learning and Development Team, service managers and practitioners is therefore integral to the development of the Centre as we look to nurture innovative practice that enriches the lives of those we support.

To help us achieve our goals for the Centre, and in order to draw on a broad range of knowledge and experience we have an excellent team of experienced Practice and Research Associates. Our associates share our goals and will help to guide the direction of the Centre's activities as we build on our existing programme of work.

As well as the input of our Associates we welcome suggestions and input into the direction of the Centre from our practitioners, people that use our services and their families, and organisations and professionals that would like to work with us.

Please contact CPI@scottishautism.org if you would like to discuss the work of the centre.

Research and Practice Associates.

Research Associates



Andrew Jahoda

Andrew is Professor of Learning Disabilities in the Institute of Health and Wellbeing at the University of Glasgow.



Karen Guldborg

Karen is a Senior Lecturer in Autism Studies at the University of Birmingham as well as Director of the Autism Centre for Education and Research (ACER) and a Senior Fellow of the Higher Education Academy.



Sue Fletcher-Watson

Sue is a Developmental Psychologist with an interest in using research methods from psychology to address questions with clinical, educational and societal impact.



Ken Aitken

Ken is a practicing Clinical Psychologist. He has been Chair of the Research Subgroup of the Scottish Autism Strategy and an active member of the main strategy Group since its inception.



David Simmons

David is a Lecturer of Psychology at the University of Glasgow.



Tommy MacKay

Tommy is one of the UK's leading psychologists who works across the fields of educational and child psychology, health psychology, clinical neuropsychology, psychotherapy, teaching and research.



Anna Robinson

Anna is an Emotion-Focused Therapist, and is the Autism Courses Leader for the MEd in Autism programme at the University of Strathclyde.

Practice Associates



Michael McCreddie

Michael is a Health Psychologist with a specialist knowledge and experience in Neuro-Developmental conditions and Acquired Brain Injury.



Peter Vermeulen

Peter has a MSc and a PhD in Psychology and Educational Sciences. He has worked with people with autism and their families for more than 25 years and is currently Co-Director of Autisme Centraal, a training and education centre for Autism Spectrum Disorders in Belgium.



Debi Brown

Debi was diagnosed with Asperger's Syndrome seven years ago and has since written and published two books about autism: 'Are you Eating an Orange?' and 'The Aspie Girl's Guide to Being Safe with Men'.



Kate Strohm

Kate Strohm is the Founder and Director of Siblings Australia, the only organisation in Australia focused on the needs of siblings of children living with disability/chronic illness.



Yvette Q. Getch

Yvette is the Executive Director of the Suzanne Vitale Clinical Education Complex and an Associate Professor in the Department of Diversity and Community Studies at Western Kentucky University.

To find out more about the Centre's Research and Practice Associates, please visit our website:

www.scottishautism.org/cpi

NEWS.

RIGHT CLICK- LAUNCH OF ONLINE SUPPORT PROGRAMME

To date, over 500 parents have registered for our online support programme, Right Click. Later this year, we will be adding to our existing programmes for parents of young children and teenagers by launching a programme for parents who are supporting adults. The programme will include a wide range of information and resources on topics such as health and wellbeing as well as practical issues such as financial planning.



NEW FUNDING TO DEVELOP ONLINE SUPPORT PROGRAMME FOR WOMEN AND GIRLS

We have received funding from the Scottish Government Adult Community Care Grant Scheme which will enable us to develop a Right Click programme for women and girls. Content will be underpinned and informed by research conducted by Dr. Catriona Stewart. We will also be seeking the active involvement and participation of women with autism throughout the planning and development of the programme.

AUTISM TRAINER AWARD

Twenty two candidates are enrolled in the pilot delivery of The Autism Trainer Award. The award, funded from the National Autism Strategy Development fund, aims to raise standards particularly in non-award bearing training. Candidates are required to successfully complete a range of assessed work including a live observation of their training practice.

EVENTS.

KNOWLEDGE SHARE SEMINARS

Scottish Autism's Knowledge Share Seminars are taking place in **Renfrewshire, Falkirk and the Borders**. Three new topics for discussion include; **Personal Coping Skills & Strategies, Thinking about Independence and Relationships & Sexual Health**.

For more information about Knowledge Share and other Scottish Autism events please visit:

www.scottishautism.org

OTHER EVENTS ACROSS SCOTLAND

Shaping Autism Research

Shaping Autism Research in Scotland is a group of researchers, all dedicated to working together with members of the autism community, researchers and practitioners, to shape the agenda of future research. To find out more visit:

www.shapingautismresearch.co.uk

Autism Network Scotland

Autism Network Scotland provides reliable and impartial information that connects and communicates with individuals on the autistic spectrum, their families and carers, and practitioners working in the field of autism. For forthcoming events across Scotland, please visit:

www.autismnetworkscotland.org.uk

Kidz Scotland

17 September

Royal Highland Exhibition Centre

Edinburgh

EH28 8NB

For more information visit: www.disabledliving.co.uk/Kidz/Scotland

Scottish Learning Festival

24-25 September

The Scottish Exhibition and Conference Centre

Glasgow

For more information, visit: www.educationscotland.gov.uk/slf/

Being on the spectrum – unfettered humanness?



Debi Brown
Author

Some think diagnosing/labelling people is a good thing – to get services (maybe, if they exist) and self-understanding and perhaps a means of explaining to others why you can't be exactly like everyone else.

Others think this is unhelpful and counter-productive. I suspect that both are true. Many labels could apply to me, but do they help? And what's the alternative?

Rosenberg (2003), argues against labelling, and instead, proposes that people can be better helped by focussing on their feelings and needs.

Any label can be reframed into feelings and needs. For example, if I want more affection from you than I'm getting, I would probably label you as cold and unfeeling. Conversely, if you want more affection from me than I can give you, I would label you as clingy and needy. Both of these things would be me accusing you of being something, because of my own unmet needs.

Rosenberg suggests these labels and accusations could be reframed into feelings and needs. E.g. instead of accusing you of being cold and unfeeling, I could own my feelings of loneliness and ask if you could spare me some quality time, a hug, or whatever my need might be. Instead of labelling you as clingy and needy, I could own my own feelings of discomfort and see if we can set a boundary that meets both our needs.

But admitting our own painful feelings and needs makes us vulnerable, and we, as a culture are not used to this.

Recently, I've had a lot of grief and loss, this has been difficult. Expressing strong emotions and distress makes other people uncomfortable. Reactions include being told that my need for a hug wasn't normal. In this case the person was afraid that if someone saw us hugging then other people would think "something was going on". Anything about me being called "not normal" is a big trigger for an emotional whirlwind, because I have tried so hard to be normal all my life. I'm pretty sure that my need was normal in that situation, and it was rather the other person's feelings of discomfort about what other people may think and their need to be perceived in a particular way that

was the real issue. Rosenberg would offer that, instead of taking offence to what you are being labelled as, you can instead choose to focus on the other person's underlying feelings and needs.

Strangely, the same person labelled someone with Down's Syndrome who was "huggy" (essentially my behaviour) as very loving. Where did such a gulf of difference come from? There are many similarities between me and the girl with Down's (we both love Frozen, for a start!), and many ways that neither of us conform to standard "normal" adult operating behaviours. But of course, I don't appear to have a Syndrome because I look so normal... here I am again running into disadvantages of having an invisible disability.

When I am distressed and I get negative reactions from others, I feel shame on top of what it was that I was already feeling. I've been learning from these reactions that the socially-skilled thing to do is to hide one's emotions, but I'm not sure this is the healthiest thing – for anybody, never mind just me. I researched grief on the internet, and found something which said that animals deal with grief better than humans in our western culture, because animals simply express their grief instincts to cry and shake, without worrying how they will be perceived when they do that. I found that when I do react and just wail my head off, it really helps to get some of the grief out of my system and my emotions became less stuck.

When did our society become so unable to deal with emotions? Why is the same behaviour, that if it were done by a child, would receive love and care, a cause to reject an adult? What do we think magically happens when someone hits 18 to change all the rules?

I think we all have the same needs, young and old. Universal needs that we all share include warmth, food, light, rest, touch, comfort, autonomy, safety, emotional safety, relationships, support, connection, meaning, self-expression, sexual expression, love, nurturing and respect.

I conclude that people on the spectrum like me, and probably people with Down's Syndrome too, are just more likely to express our needs and instincts – our "unfettered humanness" innocently, without thinking of the possible consequences and how we may be perceived.

You could label us wrong or not normal. Or look at us and see what it means to be human.

RESOURCES AND LINKS

The Centre for Non-Violent communication: www.cnvc.org
The Enneagram: www.enneagraminstitute.com/intro.asp

Building Bridges to Vision

Partnership working on Autism and Sight Loss.



Joe Long
Research Manager,
Scottish Autism

Would you know how to detect sight loss or visual difficulties in someone with autism? That question might be particularly hard to answer if that someone is unable to communicate their daily experiences verbally, displays repetitive gestures, or whose reaction to their environments is usually put down to 'their autism'. But it is a question that Scottish Autism's practitioners are becoming better equipped to answer in the affirmative.

Since 2013 Scottish Autism and the RNIB (Royal National Institute of Blind People) have been working in partnership to raise awareness of sight loss and vision issues among our staff teams. Previous research on vision problems shows that those with sight loss often present behaviour similar to those with autismⁱ. These may include stereotyped and repetitive behaviours such as eye flicking, rocking or gazing at light as well as linguistic features like echolalia.

Research has also shown that sight loss is often undetected in people with complex needsⁱⁱ and so autism support services need to be particularly alert to potential visual impairment. A person's quality of life can be severely impaired by undiagnosed sight loss and if an eye condition is not diagnosed a person may lose further sight.

The RNIB's 'Bridge to Vision' training programme has been developed to provide practitioners in a range of fields – from dementia care to learning disability services – with the skills to detect potential signs of sight loss. It involves two stages: first, vision awareness training for a large number of staff and second, the recruitment of 'Vision Champions' within our services. During this project 57 staff in Central

Area, Fife and Tayside, and New Struan School undertook vision awareness training. Participants learned about the functioning of the eye, common vision problems and undertook a series of exercises that simulated different eye conditions. This experiential learning proved very powerful for staff in understanding what it might be like to have impaired vision. As one practitioner told researchers: "A lot of the guys we work with, it makes you appreciate just how difficult their day-to-day life is."

“ A lot of the guys we work with, it makes you appreciate just how difficult their day-to-day life is. ”
Support Worker

A core part of the training was also recognising signs of sight loss that may present as autistic behaviour. As one practitioner told researchers: "a lot of the stuff we were taught is very similar to what we for years have been putting down to somebody's autism". The training has really got practitioners thinking about what might lie behind certain presentations – walking warily across zebra crossings or stairs, standing very close to staff, or disliking laminated communication aids. Someone we support may look away during communication and this may be a characteristic of autism, but this may also be a sign of macular disease. This is not to say that everybody displaying particular behaviours has a sight loss issue, but it gives practitioners some warning signs to look out for. These signs can then prompt an optometry referral and sight test so that sight loss can be ruled in or out. As one Autism Practitioner summarised to me: "This won't make a difference to everyone we work with, but for those it does it will make all the difference."

“ A lot of the stuff we were taught is very similar to what we for years have been putting down to somebody's autism. ”
Support Worker



Scottish Autism staff participate in RNIB's Bridge to Vision training to learn about the experience of sight loss.

As well as improving detection of sight loss, practitioners have learned some changes that they can make to their practice and to their service environments in order to make life easier for those with sight loss. One Vision Champion explained: "even if there is an eyesight problem and they wear glasses, there's stuff that we could do to the environment that would make things better." Project participants have reported homes being repainted, handrails being installed, and practitioners learning to approach people they support in different ways.

“Even if there is an eyesight problem and they wear glasses, there's stuff that we could do to the environment that would make things better.”
Autism Practitioner

Much of this work has been led by our Vision Champions. These six support practitioners undertook an advanced level of training that has enabled them to make detailed observations where there is a suspicion of sight loss. The team use an established RNIB toolkit to enable detailed referrals to optometry. Our Vision Champions have also audited the visual information in our support plans and have made recommendations for the improvement of vision information in service documents.

The impact of this training has been tracked by a research team that includes colleagues from Edinburgh Napier University as well as RNIB and Scottish Autism. The team have undertaken surveys and focus groups to capture the experiences of staff that have taken part in the programme.

The research, to be published later this year, will show that not only are practitioners better equipped to notice sight loss, but more confident in making referrals and adjusting environments. As well as demonstrating the increased skills of practitioners, the data shows where we can do more as organisations to support the work of Vision Champions, and where we need to work with optometry professionals in order to ensure that there are autism friendly pathways to eye care available in Scotland.

Most importantly, the question that opened this article is one we have asked of practitioners before and after the 'Bridge to Vision' training and the answer is increasingly a clear 'yes'. Our relationship with RNIB has been a positive and enriching one as we have learned more about vision issues, our colleagues have also learned from our practitioners about the practicalities of working with autism. The relationship is set to continue as we ensure that those we support have access to appropriate eye care and that has surely been a bridge worth building.

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Scharre, J. E. and M. P. Creedon (1992) "Assessment of Visual Function in Autistic Children." *Optometry and Vision Science* 69(6): 433-439.

Turner, M. (1999) "Annotation: Repetitive Behaviour in Autism: A review of Psychological Research." *Journal of Child Psychology and Psychiatry* 40(6): 839-849.

ii See:

Emerson, E. and J. Robertson (2011) *The Estimate Prevalence of Visual Impairment among People with Learning Disabilities in the UK. Improving Health & Lives: Learning Disabilities Observatory.*

van Splunder, J., J. S. Stilma, et al. (2006) "Prevalence of visual impairments in adults with intellectual disabilities in the Netherlands: cross-sectional study." *Eye* 20: 1004-1010.

RESOURCES AND LINKS

For more information please visit the RNIB website:

www.rnib.org.uk/services-we-offer/learning-disability-services

Transform Autism Education.



Karen Guldborg
 Director of the Autism
 Centre for Education
 and Research, University
 of Birmingham.

Given the unique needs of autistic pupils and with rising numbers of children and young people being diagnosed on the autism spectrum, there is a pressing need to increase the awareness, knowledge and skills of the school work force and to improve the capacity of settings to meet the needs of children with autism.

'Transforming Educational Practice in Autism: enhancing the skills, knowledge and understanding of teachers in the UK, Italy and Greece', also known as 'Transform Autism Education', is a three year research and development project funded by the European Commission, through their Erasmus Plus programme, Key Action 2, Strategic Partnerships.

Our overarching objectives with the 'Transform Autism Education' project are to gather a community of researchers, policy makers and practitioners in the UK, Italy and Greece to research current educational practices in autism in those respective contexts and to create professional development programmes in Greece and Italy.

The project promotes equity and inclusion in autism education by enhancing the skills, knowledge and understanding of teachers and other school staff who work with children aged between 5 and 10. It does this by modelling itself on the successful Autism Education Trust (AET) national partnership between Universities, local authorities, voluntary sector organisations, and schools in England. Funded by the Department of Education (UK), commissioned by the AET, and with the content developed by the University of Birmingham's Autism Centre for Education and Research (ACER), it consists of quality indicators describing the key factors common to current good practice in settings, three levels of training materials in autism education and a competency framework for practitioners. The AET programme was developed through an innovative partnership model that included researchers, local authority personnel, schools, voluntary organisations, individuals on the autism

spectrum and a creative agency, all of whom developed a shared ethos and a vision for autism education, which linked the public, private and voluntary sector together. The programme has received excellent evaluation, with clear evidence of enhancing the knowledge, understanding and practice of autism practitioners.

The 'Transform Autism Education' project builds on the AET project and it is led by Dr Karen Guldborg, Director of the Autism Centre for Education and Research (ACER) at University of Birmingham, UK. The partners consist of two Universities, a non-profit organisation, a school district and a creative agency. They include the University of Birmingham Autism Centre for Education and Research, Aikaterini Laskaridou Foundation; Autism Education Trust; Genium Creatives, Universita Cattolica del Sacro Cuore and Ufficio Scolastico Regionale per la Lombardia.

This strategic partnership focuses on:

- **Sharing educational practices in the training of teachers who work with children with autism aged between 5 and 10.**
- **Developing the skills, knowledge and understanding of educational professionals in each country.**
- **Adapting the AET professional development programme to create ecologically valid materials for these educational contexts and standards of practice.**
- **Creating a framework for international collaboration and a method of delivery that can be applied to other countries to research/evaluate and develop their own educational practice in autism.**
- **Creating a website with Open Educational Resources developed from the project to support the education of pupils with autism internationally.**

By learning from the processes and experiences of the AET programme, we plan to reflect and build on current autism education training programmes in the partner countries, and will employ an innovative and participatory methodology that integrates the use of ICT in novel ways. We will carefully examine the AET partnership model and analyse how it has been delivered to over 50,000 people since February 2012 in over 100 local authorities in England.

We will then consider whether aspects of this methodology can be employed to the development of similar professional development programmes in Greece and Italy and to the construction of a website with Open Educational Resources, which will be targeted at school staff who work with children with autism internationally. Through an iterative developmental approach involving feedback from training deliverers and other stakeholders throughout the creation of the materials, we will ensure that the content is clear and accessible, and relevant to the local educational context and practitioners in partner countries.

In the first phase of the project, we are researching 'state of the art' in good autism practice in the three countries. We aim to review the literature on the state of the art in autism education (e.g. research papers, reports, policies) within each national context and get stakeholders and practitioners' opinion on autism practices (e.g. attitudes towards inclusion, teaching strategies, training needs) using questionnaires, focus group interviews and 1:1 interviews. Researchers in the UK will also produce a written overview describing the AET model and a case study of a hub from the UK. After this phase, we will develop the content of the training for Greece and Italy. Our partners will be able to use the materials developed in the UK, but the focus will be on adapting those to their linguistic and cultural context, starting from where they are at in terms of the state of autism education. Phase three will be about train the trainer, piloting, quality assurance processes and evaluation of the training materials and delivery. Phase four will be devoted to the adaptation, translation and evaluation of the quality indicators and competencies, with phase five focusing on evaluation, the development of a sustainability framework and website creation. Phase six will focus on dissemination of the findings.



The Transform Autism Education team at their first transnational meeting.

We are currently in the middle of the first phase, and we are immersed in analysing data from questionnaires, focus groups and interviews, as well as conducting literature reviews on autism provision and practice in all three countries. There are some initial preliminary findings emerging from discussions within the project team.

Some of the similarities between the countries are as follows:

- Good educational autism practice works for all children.
- All countries have an ethos of inclusion.
- There are similarities in the diagnosis and understanding of autism (DSM V) and educational practices.
- There is a need/desire for training and there is a market for that.
- There is a recognised need for a global model of training professionals in autism.
- There is recognition that pupils with autism have unique needs and also need special planning.

There are also some differences emerging and these include that:

- Individual Education Plans are not enforceable by law in the UK and Greece, whereas they are in Italy.
- In Italy, parents can choose how long the school week should be for their child.
- In Greece, most education happens in private centres by therapists whereas in Italy psychologists do not get involved in education.
- Italy has hardly any special schools and mainstream schools have to accept a child if the parents choose the school.

The Transform Autism Education project team are excited to be undertaking this project and are totally committed to making a difference to pupils with autism and their families through enhancing the skills of the teachers. We started the project at the end of November 2014 and have already made great strides forward! Most of all, we really enjoy working together and are all passionate about our project.

RESOURCES AND LINKS

For more information visit Autism Centre for Education and Research (ACER): www.birmingham.ac.uk/research/activity/education/acer/index.aspx

Why Participate in Research?

A researcher's view.



Dr. David Simmons
Lecturer of Psychology,
University of Glasgow.

In a few weeks' time, a small army of autism researchers will descend on Salt Lake City, Utah, to attend the International Meeting for Autism Research (IMFAR; www.autism-insar.org/imfar-annual-meeting/imfar-2015) and share their latest research findings. Of the research presented, all but a small proportion of it will have involved participants from the autism community in some form: either by donating their time, the brain tissue of their deceased relatives or their genetic information.

Our research group works on psychological aspects of autism, and one of the key challenges for us is involving participants in our research. There are many checks and balances in place, including at least one and sometimes two levels of ethical review (in our case at the University and NHS levels) before we are allowed even to approach potential participants with autism. What then follows is the equally challenging task of persuading these participants, and often also their families, to give up some of their precious time to take part in our experiments. Sometimes this will simply involve filling in a questionnaire, but at other times more lengthy procedures like undergoing a diagnostic interview, or having a brain scan, will be required.

Why should you bother?

A complaint that I have heard a few times from members of the autism community is that, despite the huge amount of autism research going on worldwide at the moment, very little of actual worth has been achieved. Whilst it is true that the evidence base for interventions, for example, is still rather poor, my view is that we have made great strides

in terms of understanding the genetic basis and the neuroscience of autism, and there have been other notable successes, such as demonstrating that some forms of therapy are ineffective (e.g. Facilitated Communication Therapy). As most of the readers of this article will appreciate, autism is a hugely complex and variable condition. This complexity makes it a fascinating research topic, but also very difficult to study, so it is going to take considerable time and a lot of resources to reach an adequate understanding of it.

Another common complaint, highlighted by the recent report "A future made together" (<http://crae.ioe.ac.uk/post/64979963005/a-future-made-together>) is that only a small proportion of autism research currently funded focuses on issues of direct relevance to the autism community, like services. To try and address this funding gap, an increasing trend is to involve the autism community not only in the participation aspects of the project, but also in the planning phases. This practice helps to identify opportunities to translate research into practice at an earlier stage. I myself am on an advisory panel to the Autism Spectrum, Adulthood and Ageing research project based at the University of Newcastle (<https://research.ncl.ac.uk/adultautismspectrum/>) which is aiming to build up a large cohort of adults with autism across the UK to investigate the ageing process. This has grown out of the ASD-UK project (www.asd-uk.com) which has been focused more on children. In Scotland we are planning to partner with these researchers to build our own Scotland-wide participant community in the near future, which we hope will help to coordinate and focus our research efforts across the country. We also plan to employ the same participatory model, with the autism community engaged in every stage of the research process.

A particular challenge for autism researchers is how to communicate their research findings in a way that is understandable to the general public, and giving timely feedback to their research participants. Universities and funders of research across the world are putting much more emphasis on "public engagement" skills these days (in fact, you could say that this article is in itself a result of that, although I like to think I would have written it anyway!).

Also, various nationwide initiatives are trying to address this problem, including the re-launched Scottish Autism Research Group (www.sarg.ed.ac.uk) and Autism Network Scotland (www.autismnetworkscotland.org.uk), as well as Scottish Autism and many other smaller charities and local organisations.

Participation in research by the autism community is extremely important, because understanding the

complexities of autism is the key to developing effective and useful support. Researchers are working hard to engage more effectively with the community and are trying to translate the results of their research into helpful developments as soon as they can. One thing that I should mention finally is that participation in experiments can be an enjoyable and informative process (see the associated article by E.G. Douglas). Please take advantage of these opportunities to help us progress autism research together.

Why Participate in Research?

A participant's view.

By E.G. Douglas

Aside from the personal benefit of taking part (I got to see my brain!), I would say that participation in these types of studies is important, for both autistics and not, in trying to understand what autism is and how it manifests, and thus how measures can be developed and enacted to make life easier for us all.

That autistics have advantages and strengths is something I not only believe but experience, living with it. However the difficulties we face are also not insignificant. Trying to mitigate the one whilst applying the other is daunting, and not something that regular people can be expected to devote time to figuring out; they have their own troubles

after all. But with knowledge, ways to allow autistics to contribute and thrive can hopefully become apparent.

If that's all a little too idealistic though, there is another reason that I considered: being a part of our own situation. Some, but few, of the researchers studying autism are themselves autistic, and we should be grateful for people who want to understand and help us. But at the same time, we have a certain perspective on living with autism that cannot be understood from the outside, and could be of use. Helping the effort to understand our condition makes sense, and allows us to contribute perspectives and points of view that can help correct mistaken assumptions and prevent wasted time and attention. It also helps us establish ourselves as people, with differences, rather than sufferers of disability, and that helps not only those of us who happen to be High Functioning but also those autistics who are less able to communicate and live by themselves.

RESOURCES AND LINKS

International Meeting for Autism Research (IMFAR) website:
www.autism-insar.org/imfar-annual-meeting/imfar-2015

Pellicano, E., Dinsmore, A., & Charman, T. (2013) A future made together: shaping autism research in the UK. London: Institute of Education. View report here:
<http://crae.ioe.ac.uk/post/64979963005/a-future-made-together>

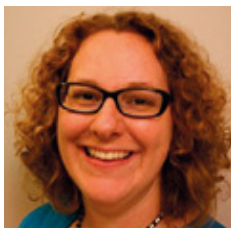
Autism Spectrum, Adulthood and Ageing research project:
<https://research.ncl.ac.uk/adultautismspectrum/>

Autism Spectrum Database website:
www.asd-uk.com

Scottish Autism Research Group:
www.sarg.ed.ac.uk

Autism Network Scotland:
www.autismnetworkscotland.org.uk

Research into Practice, Practice into Research: learning to speak each other's language.



Sue Fletcher-Watson
Developmental
Psychologist,
University of Edinburgh.

The Centre for Practice Innovation recently launched by Scottish Autism aims to allow “practitioners, researchers and organisations... to learn from each other and contribute to the growing body of knowledge about what constitutes effective autism practice.” At the same time, the Scottish Autism Research Group (SARG) has recently been re-launched, with one stated goal being to “facilitate links... in order to promote a coherent programme of scientific research which responds to the requirements of the autism community.”

A match made in heaven? Perhaps. But for these two groups to work together effectively to promote the best quality autism research and practice in Scotland, some fundamental differences need to be acknowledged.

As a researcher, I am convinced of the power of independent, high-quality, research evidence. When commercial providers of supports for people with autism make grandiose claims, without having the appropriate evidence to justify these, it smacks of ignorance at best, exploitation at worst. In contrast, I greatly admire the way Scottish Autism is totally committed to engagement with the research community and to delivering the best service they can to their clients, by drawing on the relevant evidence.

However this process of using research evidence to inform practice is not necessarily one of translation. Let's take a best case scenario: you are a practitioner, interested in a support model which you think will suit your autistic client, for which there is published evidence from quality trials. These trials, however, only report average data from a group of kids, not information about how it worked for each child individually.

Perhaps your client is also very anxious so you're wondering if you can modify the approach to take account of that. Maybe the published trial measured the effect of three appointments per week, at home, but you only see your client once a week, in school. Maybe most of the kids in the trial were boys but your client is a girl. All of these factors and more mean that the practitioner must interpret the evidence and combine it with their training, knowledge of their client and setting, and their personal experiences to apply it to their practice.

More often, practitioners might like to gather data on an innovative approach they think is promising, where there is no quality published evidence at all. In sharing this information with the research community, again a process of translation has to occur. The practitioner must downplay their personal experience and sacrifice flexibility for consistency. Researchers want to read about a rigid application of a system, ideally across a number of cases, or a group. That way they can make the generalised statements which are their bread and butter.

So this brings me to the essential difference, as I see it, between research and practice. Researchers are in the business of making generalisations. Practitioners are concerned with specific, personalised care. This difference needs to be acknowledged and embraced. It is generalisability which makes research such a powerful tool – a published trial can influence autism practice worldwide, provided practitioners have the confidence and access to translate the work into an approach which works for their client. Likewise, if correctly framed, examples of good practice in education, health or social care can allow innovative practitioners to share their pioneering skills with others, and inspire new models and concepts of autism.

In working together, I hope that SARG and the CPI can draw on the best aspects of research and practice to deliver results which make a difference to our society. By coming together, sharing information, finding a common language and common ideals I think we can make the translations easier and easier – maybe even learning to speak both the language of practice and of research fluently.

RESOURCES AND LINKS

The Development Autism Research Technology (DART) project explores the uses of technology to support, educate and engage children with Autism. Visit: www.dart.ed.ac.uk

Meeting of Minds – Wellbeing and people with autism.



Andrew Jahoda
Professor of Learning
Disabilities, Institute of
Health and Wellbeing,
University of Glasgow.

A host of initiatives to improve people's lives now come under the label of wellbeing. Although people can have an intuitive grasp of wellbeing, it is an elusive concept to define in practice and risks being something of a catchall term.

This makes organising a conference on the subject rather difficult, with the danger of a fragmented set of presentations. To avoid this outcome, the conference organisers planned a series of carefully themed sessions, to try and throw light on the concept of wellbeing; what it means to people with autism themselves, how it is measured and how it relates to key research trends in the field. Perhaps the only source of regret for me was that the majority of the contributors were from the UK, as I was keen to hear more about what is happening in Scandinavia.

Aage Sinkbaek gave a key address about wellbeing from the perspective of someone with autism. Perhaps one of the most interesting insights I obtained from the conference was the importance of self-acceptance for the wellbeing of people with autism. This theme emerged from the work of several speakers and was echoed by the comments from audience members with autism. Examining how a positive autism identity helps to increase peoples emotional resilience is a potentially important area for future research.

A number of talks also addressed the needs of populations that are typically underrepresented in research. This included children in residential schools, women and elderly people. Judith Gould emphasised in her talk that the starting point for promoting the wellbeing of women with autism is to recognise their particular needs and life circumstances.

One of the challenges in research concerning attempts to improve wellbeing is finding robust ways of charting change.

Richard Mills talked about using approaches from quality of life research, to frame discussion with study participants. There seemed to be a recognition that recent research has not shed new light on the measurement of wellbeing. Nevertheless, the innovative approaches adopted by Liz Pellicano to examine children's reports of their own wellbeing shows that helping participants to express what is important in their own lives is an important starting point. Psychosocial research should not be the poor relation of experimental or biological research in this area. Francesca Happe tellingly recounted that she had far less success in obtaining funding for her research into the lives of older people with autism, compared to her cognitive science research.

While it was important to hear about the distinct experiences of people with autism, many of the themes one would expect to matter to any group in society; a desire for good health, both physical and mental; the need to have purposeful lives; to belong and to be understood. Depressing statistics were presented by Tatja Hirvikoski, who looked at the mortality figures for people with autism, compared to matched controls from the wider population. Her findings showed increased mortality rates in people with autism compared to the control group. This emphasises the need to combat inequalities in the health system.

More positively, new research was presented about adapting psychological interventions to ensure they are accessible and relevant to people with autism. Anna Robinson talked about adapting Emotion Focused Therapy for adults with high functioning autism. Esther de Bruin described her mindfulness programme to tackle young people's anxiety.

The final conference presentation concerned people with autism as perpetrators and victims of cyber crime. Rebecca Ledingham gave a lively and fascinating talk on a matter of real concern for some professional audience members. Rebecca highlighted a relatively hidden vulnerability that can have devastating consequences for individuals' lives, whether perpetrators or victims. Yet she also pointed out that being a computer expert could be a highly valuable skill. Perhaps much of the effort on wellbeing needs to be focused on people's particular strengths and the contributions they can make. Of course, this must include those with intellectual disabilities, who were notably absent from most of the conference.

The Centre for Practice Innovation provides a focus for practitioners, researchers and organisations to come together and collaborate, share knowledge and ideas and shape innovative autism practice.



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