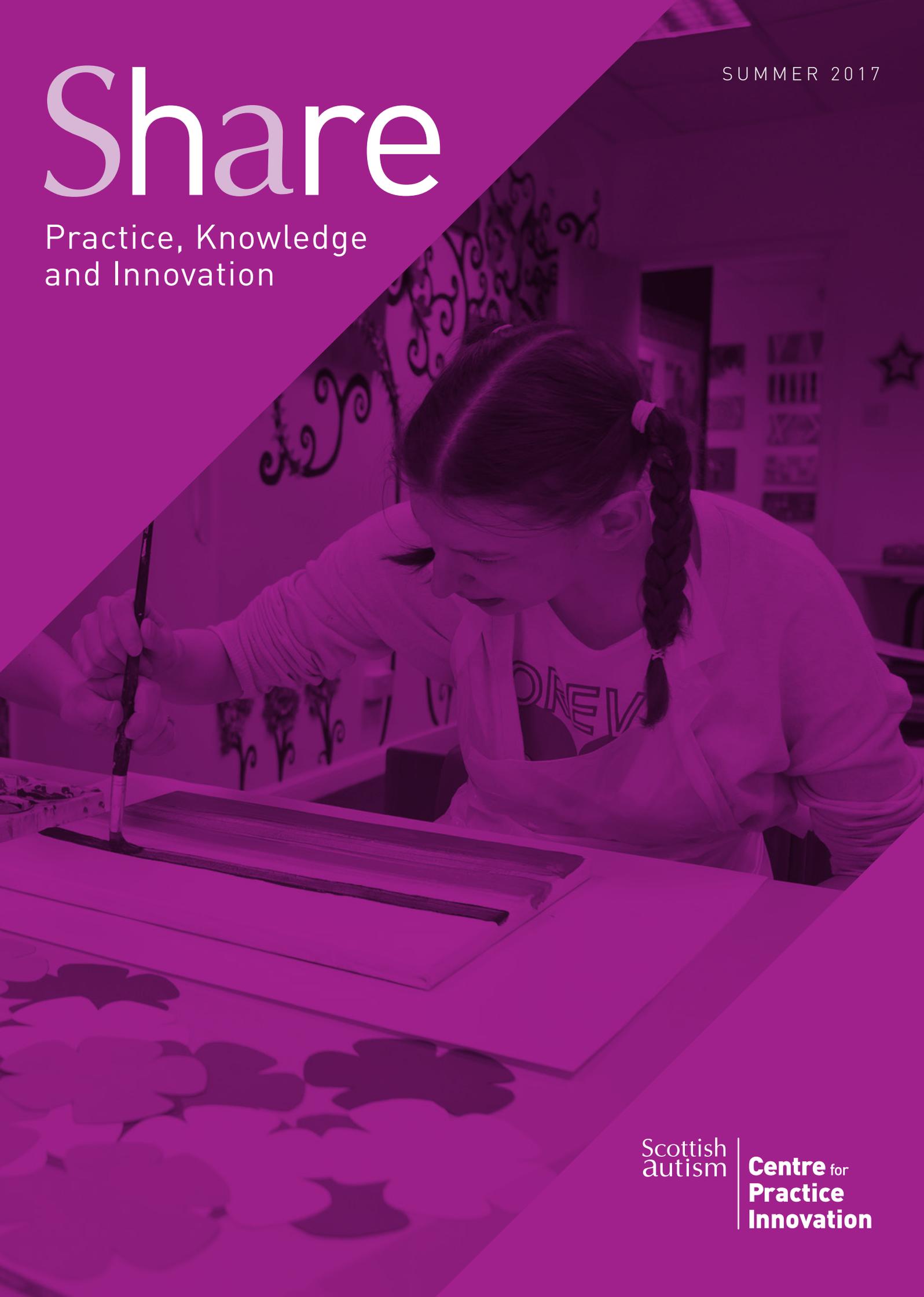


SUMMER 2017

Share

Practice, Knowledge
and Innovation



Scottish
autism

Centre for
Practice
Innovation

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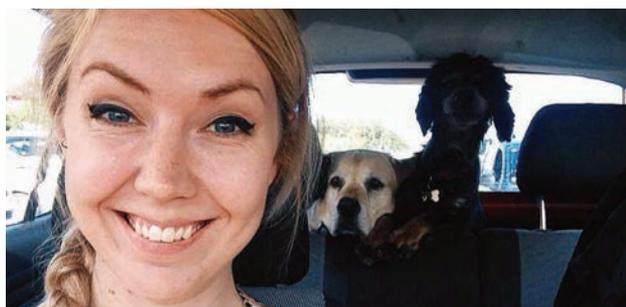
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Guest Editor



Alastair Clarkson
Researcher in Residence,
Scottish Autism

When seeking to understand others, the medical philosopher Alfred Tauber has argued that any 'fact' held about an individual or group does not exist in a vacuum but links to values which frame our knowledge in the world. The majority of autism studies use methods that seek to quantify differences within autistic people. These medicalised approaches aim to establish facts which are often about physiology or 'behaviour'. These forms of evidence remain inconclusive, partly due to their disconnection from the source of 'value' which provides context to knowledge about all individuals - that of the unique lived experience and respect for the intrinsic quality of relationships within life.

Moreover, what we 'know' about each autistic individual and what is important to autistic people can change across relationships, time and environment. Informed by their ethical understanding of support, staff are guided by practice values within Scottish Autism to deliver personalised programmes which can support autistic wellbeing throughout these changes. In the relation of fact and value, successful support brings a holistic context to our factual knowledge about autistic persons by linking what we 'know' about each individual to the values that staff actively promote within their practice. Although sharing knowledge within these processes can be challenging, these programmes are supported by a shared sense of values and respect for difference that staff hold across Scottish Autism.

This edition of Share brings together a range of articles which focus on knowledge within our autism services. They highlight our awareness of the value of knowledge held by staff and professionals, families and the people we support

and identify the benefits of the approaches we use to manage this knowledge.

Our opening personal perspective from Ewan Dunn illustrates how knowledge of autism at the personal level and the provision of the right opportunities for transition and growth stem from our perception and response to individual expression and voice. Clare Brogan reports on the innovative Get Set 4 Autism programme, where as project co-ordinator Clare brings sources of organisational knowledge together for families at the pivotal point of post diagnosis. This programme also uses the experiences of families to further support the empathic understanding of linked professionals. Shauna Donaldson presents a case study of a services forum within Fife, where the development of a safe structure for autistic people to share their opinions, views and expectations has supported various types of knowledge share.

Kate Leavy and Charlene Tait report on the development of an organisational culture of learning within Scottish Autism using the principles of knowledge management. They describe a variety of initiatives developed to utilize knowledge and practitioner expertise within the organisation and discuss the evolution of outcomes from a variety of innovative programmes. Showcasing this evolution within our feature article, Joanna Panese and Lucy McMath each present a case study within services which illustrate practice improvement outcomes arising from Scottish Autism's own practice based self-assessment framework.

Within our conference review, Laura Hill discusses the importance of listening to the autistic people we know and support in order to better inform autism research. By appreciating the value of differences between types of cognition and communicative style Laura suggests we can move towards improving autism research and practice in a more meaningful way.

Many thanks to all the contributors.

NEWS

Publications on Autism and Sight Loss

The results of Scottish Autism's partnership working with Royal National Institute of Blind People (RNIB) Scotland and Edinburgh Napier University on Autism and Sight Loss, has recently been published in two peer reviewed journals. 'Autism and Visual Impairment: A Review of the Literature' is published in the *Review Journal of Autism and Developmental Disorders* and 'Improving vision awareness in autism services: evaluation of a dedicated education programme for support practitioners' appears in the *Journal of Applied Research in Intellectual Disabilities*.

Shaping Autism Research Seminars

In March, Scottish Autism researchers Alastair Clarkson and Joe Long took part in the final 'Shaping Autism Research' seminars funded by the Economic and Social Research Council and co-convened by Research Associate Sue Fletcher-Watson. The Scottish Autism team presented our development of an inclusive survey process for people with complex communication and contributed to discussions on the promotion of participatory research. Information and outcomes from the seminar series can be found at:

www.shapingautismresearch.co.uk

Sharing Knowledge

- Joe Long and Catriona Stewart of Scottish Autism's Centre for Practice Innovation recently presented papers at the international symposium 'The Globalisation of Autism' at Queen Mary University of London. The symposium was funded by the Wellcome Trust.
- Jill Ferguson (Service Manager) and Joanna Panese (Senior Autism Practitioner) from Scottish Autism's Central Area Services presented on practitioner research and Autism Advisor Catriona Stewart presented on the needs of autistic women and girls at the Scottish Autism Research Group's (SARG) postgraduate workshop on 22nd April. For more information on SARG, a cross-institution network of autism researchers in Scotland, see www.sarg.ed.ac.uk
- A poster on the experiences of autistic mothers, co-authored by Catriona Stewart, Joe Long, and Charlene Tait from Scottish Autism with Bonnie Aeuyung of Edinburgh University was displayed at the International Meeting for Autism Research on 10-13th May in San Francisco.

EVENTS



Knowledge Share

Scottish Autism's Knowledge Share seminars are taking place in Orkney and Fife. Three topics for discussion include **Personal Coping Skills & Strategies, Voice, Participation & Involvement** and **Relationships & Sexual Health**.

For more information about Knowledge Share and other Scottish Autism events please visit: www.scottishautism.org



Scottish Learning Festival

20th - 21st September, The Scottish Exhibition and Conference Centre (SECC), Glasgow.

For more information visit: www.slfexhibition.com

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

Social Work Scotland Annual Conference and Exhibition

14th - 15th June, Crieff Hydro Hotel, Crieff

For more information visit: www.socialworkscotland.org/Events

NHS Scotland Event

20th - 21st June, Scottish Event Campus, Glasgow

For more information visit: www.nhsscotlandevent.com

The Autism Show

30th June - 1st July, EventCity, Manchester

For more information visit: www.autismshow.co.uk

Support Through the Life Journey

Ewan Dunn with Kate Leavy, Autism Practice Improvement Advisor, Scottish Autism



Ewan Dunn



Kate Leavy

Scottish Autism's mission statement, 'to enable people living with autism in Scotland through the whole life journey', reflects the understanding that the lifespan of any individual is complex and involves periods of transition and change.

To maintain relevant support within individualised services we are required to continually listen to the individual voice of our supported people in order to adapt the delivery of their services. Processes of individual assessment, review and internal knowledge sharing among staff ensure that services are able to respond accurately to changing needs over the life span and are best placed to enhance wellbeing and support the realisation of each autistic person's potential.

Ewan's experience

At 16, Ewan joined New Ridgepark, our specialist assessment and transition service. After developing independent living skills and accessing local voluntary work opportunities, Ewan moved to his own supported accommodation and started work within our nearby vocational service, Cafe Kudos - gaining a variety of skills and qualifications. Ewan spoke recently to Kate Leavy, Autism Practice Improvement Advisor, about his experience of Scottish Autism services and his thoughts for the future.

K: What has changed since you have started at Scottish Autism?

E: I live in my own house independently...I have had loads of keyworkers in my life I did as well. They have been good, not too bad to work with. They have been excellent and they help me out, and if I have any problems I can talk about them.

K: And what is different between Ridgepark and here?

E: Ridgepark I only stayed there for two years because I was learning to get my own house, my own independence and staff showed me what to do when I was there.

K: What kind of support do you get from Scottish Autism?

E: We have got my keyworker - we work with her most days of the week we do, she looks after me. She makes my dinner, does my paperwork and check I am ok in general and hear all my news. I make them [staff] a cup of tea or coffee and then I give handover to staff at nightshift and I say bye Ewan I will see you tomorrow.

K: What has changed in Cafe Kudos in the time you have been there?

E: Making loads of friends and then she is a good keyworker she is.

K: Do you have any goals or reviews?

E: Yeah I have reviews every six months I do. I have my keyworker, Louise is the Service Manager and Gaynor is the Senior Autism Practitioner. We talk, Ailie brings a point she does about this and that, if there any changes for Ewan, or if Ewan has any problems. When I want to do something it gets discussed.

K: Do you feel ready for a new change?

E: I do, cause I am getting older I am too [laughs], getting older it is time to move on to get a new job somewhere else...Get a new job in the future somewhere. It was my own idea...I just fancy a change, see what else I could do. I will still work in the cafe for now, cause at times it is hard to get a job. And the other thing I want to do is horse riding. The choice I made I would like to work in a corner shop or another choice was a cafe. They are the places I thought of and chose.

K: Do you think Scottish Autism are good at helping you finding new things?

E: Yes they are to me. They talk to me about it and help me they do.

Post diagnostic support and knowledge sharing within Argyll and Bute



Clare Brogan
Autism Advisor,
Scottish Autism

The Get Set 4 Autism (GS4A) project provides post diagnostic support to parents and carers of children and young people in Argyll and Bute under the age of 19 with a diagnosis of autism. The project commenced in February 2015 in partnership with Autism Argyll and has been funded for five years by The Big Lottery.

Family support in rural Scotland

It is widely recognised that from the point of diagnosis, families need access to support and good quality information. In Argyll and Bute, the remote and rural geography of the region can contribute to an increased sense of isolation at what can be an already difficult time for families. GS4A recognises the local context, provides a positive and proactive start for families and will support the ongoing needs of the family. One of the key aims is to enable parents by building skills, knowledge and resilience within families so that they can be proactive in their parenting, nurturing and support of their child or young person.

GS4A combines use of the comprehensive online support programme Right Click with face-to-face home visits, emails and phone call support from Autism Advisors. Over the contact period, the advisor signposts parents and carers to sources of ongoing support and information. The model involves family referral by locally-based diagnostic teams at the point of diagnosis, or self-referral using an online form.

An advisor arranges an initial home visit, and up to four supportive visits are arranged around the Right Click (five week) online programme, however this model remains flexible to allow information and support to be tailored to the needs of each family. Some families choose not to engage with Right Click and some require more or less visits depending on their circumstances and

the issues faced at the time. Access to GS4A and Right Click is free and the duration of a visit can range from one hour to several hours.

The advisors use a brief questionnaire to collect data before and after their period of involvement with a family. Parents are asked to rate their own knowledge of autism, their feelings about coping and resilience in raising an autistic child, the frequency and intensity of daily difficulties related to their child's behaviours, and a measure of parental wellbeing. This information provides an indication of the issues a family is facing at the point of diagnosis, and provides a second picture of the family situation after support from the GS4A project.

To date, the project has supported 62 parents with data indicating a clear trend of positive change across all self-report measures. These results clearly demonstrate that this model of post diagnostic support results in increased parental knowledge of autism and child understanding, and highlights an increase in the confidence and capacity of parents to teach their child or young person the range of skills and coping strategies needed during key aspects of their development.

Library of sensory resources

From this strong foundation, three further resources have been developed including a library of sensory equipment which includes weighted blankets, weighted jackets/waistcoats, ear-defenders and wobble cushions. These resources can be made available to families via the GS4A advisors and their use often illustrates that the child or young person is coping with sensory issues which parents and/or professionals may not always be aware of. Families are given the opportunity of a free loan of products to try over a number of days or weeks, which they can take into different settings including school and on holiday. This gives families confidence in a product before they consider buying it (which is particularly useful when items are expensive) and advisors can also signpost to possible sources of funding that might help with purchase costs.



Examples of sensory equipment that can be loaned

Go For It companion guide

To accompany the Right Click programme, a companion guide and notebook has been designed for use by parents with a young child. Titled 'Go For It', the guide encourages note-taking and reflection as part of the online learning experience. It supplements online content with a comprehensive workbook supporting further exploration of Right Click material and helps parents develop a better understanding of autism and their own child. Go For It is a flexible resource that can be used in part or as a whole by parents and advisors, and has been positively received.



Go For It workbook

Professional learning resource

Together with the funder (The Big Lottery), the GS4A project has developed an online learning resource for professionals in Argyll and Bute, with content which compliments Right Click material. This resource is designed to promote a shared understanding of the impact of autism on family life for professionals working alongside these families, and develop empathy for the autistic family experience. The online programme is strongly underpinned by parent voice and includes video contributions from families involved with the GS4A project who share many aspects of their experiences of parenting an autistic child. This resource has recently been launched in Argyll and Bute and will hopefully be taken up by professionals across Health, Education,

Social Work and the Third sector, and may potentially be incorporated into training and service development.

Knowledge sharing

An important contribution of the GS4A project is the sharing of information about the project set up and the ongoing development of this practice model. This dissemination has taken many forms including close working with colleagues within Scottish Autism and a presentation at the annual Staff Conference. The sharing of project knowledge at a national level recently occurred during a poster presentation at the Autism Europe Conference in Edinburgh last Autumn.

Over the past six months, GS4A has held seven information events in various locations across the region, taking in some of the more remote locations (Islay, Campbeltown, Oban, Lochgilphead, Dunoon, Rothesay, and Rhu/Helensburgh). These events raised the profile of the project within the communities and gave an opportunity for parents and practitioners to come together within an informal setting to hear about the work of the project, the wider work of Scottish Autism, and share information amongst themselves about what was happening in that local area. As a result, there are new parent support groups and stronger working relations between parents, professionals and the GS4A advisors.

The GS4A advisors regularly link with professionals in public and the third sector within Argyll and Bute to establish networks for information sharing. Examples include close working with those in the Diagnostic Network Teams (comprised of Paediatricians, Educational Psychologist, Speech and Language Therapists, Occupational Therapists), Community Child and Adolescent Health Teams, Social Workers, Advisors for Self-Directed Support, Advisors in the Department of Work and Pensions, Royal Navy Welfare services, Carer's Support, as well as nursery, primary and secondary school teachers and support staff. All of these communications (and there are too many to mention here) raise the profile of the needs of people on the autism spectrum and their families and contribute to the synthesis and dissemination of applied autism knowledge within a variety of contexts and settings.

In summary, the Get Set 4 Autism Project has proven a successful model of family support within rural areas. By seeking to enable and empower families, this project has sought to foster more inclusive and dignified family and community experiences for people on the autistic spectrum.

A shared commitment and vision: facilitating the Fife service user forum



Shauna Donaldson
Autism Practitioner,
Scottish Autism

The service user forum in Scottish Autism's Fife services aims to promote, support and empower service users to use their voice. Participating in the forum enables the individuals we support to speak up for themselves, and provides an opportunity to gain more control over their lives.

As practitioners and supported individuals work together we can look at what is working well and the ways in which any improvements can be made to the delivery and quality of autism support services. Empowering the individuals we support to speak about their thoughts and experiences allows us to provide a person-centred service and address the relevant issues which reflect the views, needs and preferences of supported individuals. The involvement of those we support can provide insights that prompt practitioners to re-evaluate their work, challenge traditional assumptions, and highlight key priorities that supported individuals would like to see addressed. Through this partnership working, different views of problems can be identified which can lead to imaginative, innovative and meaningful solutions.

Research shows that social networks are good for physical and emotional wellbeing. Identifying with groups in a meaningful way can improve our self-esteem and pride. The notion of belonging, or social identity, is a central aspect of how we define who we are and is a fundamental aspect of what it is to be human. Involvement within forums is therefore as much about being respected and accepted as a valued group member as it is about addressing the issues at hand: user involvement can be therapeutic as well as instrumental. Helping to shape services, particularly

when supported people work together collectively, can help to increase confidence, raise self-esteem and develop new skills. Here we share a few of the ways in which members in Fife have arrived at an inclusive and respectful approach to the forum.

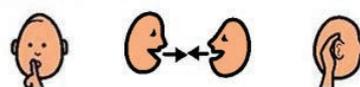
The 'comfort agreement'

The service user forum is a safe space for individuals to discuss personal thoughts and experiences free of fear or prejudice and so it is important for the group to understand confidentiality and to respect others. This is why we implemented the 'comfort agreement' as a support tool that promotes safety, supports the group's overall goals, and identifies rules of etiquette such as courtesy and respect for others.

This agreement was created by the members, who determined the rules and etiquette that forum members can follow to ensure everyone feels safe and respected in the group. Having a 'comfort agreement' highlights what is expected of everyone at the meeting and gives a sense of unity and mutual respect.

Comfort Agreement

- What is said in the forum stays in the forum
- We will respect each other opinions even if we don't agree with them
 - We shouldn't criticise others
 - We shouldn't talk over people
 - We should allow everyone the equal opportunity to talk
- You don't have to share if you don't want to



Potential discussion topics

Discussion is encouraged to occur openly and organically, however when discussion was focused on particular topics, we found that we often gained more rich detail from members on their own thoughts and experiences. Initially the forum did not have firm structure, here discussion often veered into social affairs and members felt that they needed to remain closer to the forum's goals of service improvement. One thing we found to be important was to ensure discussions did not become too structured. Our experience taught us that reaching a balance between structure and direction and remaining flexible became essential to making discussions effective.

The peak and pit system

When the forum was first launched it felt as though discussion focused too much on the things members of the forum did not like about their service. Although this information is useful, and was not discouraged, it is also important to know what works so that practitioners can continue to facilitate the things that members of the group enjoy about their service and have a positive impact on their lives. Having successfully used this system in previous group settings, we implemented the 'peak and pit' system in order to consider things that are working well and areas where improvements can be made and discussed. This system encourages each individual in the group to share with the group something positive that has happened since the last forum and something that has recently been challenging or difficult. We found that sharing these experiences, opened discussion for other members of the group to share similar experiences. Hearing from others who are contending with the same adversity and making progress in their lives is inspiring and encouraging to members, and from this structured starting point organic discussion can occur.

Roles and responsibilities

Individuals who belong to the forum are supported to take ownership of the meetings. Having particular roles and responsibilities facilitates this sense of ownership and can increase self-esteem and pride among group members. Members report that taking leadership roles helps them feel more committed and invested in the group and it is important that practitioners make sure members know their help is appreciated. Roles such as minute taking, chairing the meeting, providing refreshments, and creating a newsletter are all taken on by forum members. The service user forum also takes an active role in fundraising to promote and support

various Scottish Autism activities and initiatives such as an annual camping trip. The forum's fundraising efforts increase opportunities to engage with the wider community, and host events that are meaningful and exciting to members.

Contributions and outcomes

The forum has had many successful outcomes from our discussions. When discussing the Scottish Government's Keys to Life strategy the group learned more about their rights and responsibilities as members of their communities. Consequently, members of the forum expressed interest in learning more about the emergency services. Some members expressed feeling unsure of police presence and of when something would be classed as an emergency or not. One member of the group volunteered to write a letter inviting the emergency services to come and speak to the forum. Consequently, Police Scotland is now scheduled to speak to the group about personal and home safety and inform them about what a local police officer's role entails. In response to discussing the Association for Real Change's Charter for Involvement, members expressed an interest in taking a greater role in staff recruitment and have subsequently attended Scottish Autism's recruitment evenings and reviewed the staff profile tool. This has allowed work examining individual member's preferences for new staff who may work within their service. The group also felt that asking autism specific questions to potential new employees is really important, suggesting that questions such as, "what is your knowledge of autism and women with autism?", "what experience could you bring to our service?" and "would you treat everyone individually?" be added to the local interview process.

When asked for reflections for this article the group were very positive about the forum. One member expressed feeling safe, "because of the 'comfort agreement'" whilst the group felt they could share anything about their service whether that be positive or negative. The group liked that the forum was an opportunity for staff and other supported individuals to come together to talk about a variety of things that were important to their lives saying, "we can talk about everything".

RESOURCES AND LINKS

- i Charter of Involvement - <http://arcuk.org.uk/scotland/charter-for-involvement/>
- ii Keys to life - <http://keystolife.info/>

Innovate, share, improve: the role of knowledge management in practice development



Kate Leavy
Autism Practice
Improvement Advisor,
Scottish Autism



Charlene Tait
Director of Autism
Practice and Research,
Scottish Autism

Scottish Autism has, for almost fifty years, been providing services to autistic children and adults. During this time there have been developments, in terms of the geographical reach, range and nature of services provided. Relatively recently there has been recognition that we are a knowledge rich organisation with the potential to identify and disseminate what constitutes good autism practice and also to contribute to the dearth of research relating to service provision for this population.

A number of strategic initiatives have been developed to enable a systematic approach to harnessing the collective knowledge and expertise of practitioners across the organisation. A culture of organisational improvement and innovation has been supported by adopting principles of Knowledge Management.

The concept of Knowledge Management is based on the recognition that knowledge is an asset that should be harnessed, analysed and used to maximum effect. As a result, knowledge is valued, as are the staff who hold much of this knowledge tacitly. Expertise and knowledge in personalised approaches to supporting individuals is accumulated from the experience of working in services.

The first stage in developing a Knowledge Management Strategy was to undertake an organisation wide knowledge audit of the 600 plus staff within the organisation at the time. A three prong approach was taken to the audit. Focus groups were conducted which addressed perceptions of organisational knowledge and sought views on thought leadership on autism, key influences on practice, philosophy and values. Individual

knowledge was audited by adding a series of questions to the Staff Survey that was being undertaken by the organisation's Human Resources team. Finally an explicit knowledge audit was conducted where all service locations were invited to identify sourced resources. The audit provided three strands of data that were used to directly inform the development of the Knowledge Management Strategy.

Critical to the success of embedding a Knowledge Management culture are approaches that endeavour to involve staff. Scottish Autism placed the development and nurturing of 'communities of practice' at the centre of our Knowledge Management Strategy. These communities create opportunities for knowledge exchange between staff, promote collective learning and stimulate reflective practice. Establishing communities that transcend job roles and geographical boundaries strengthens opportunities for meaningful knowledge sharing. The harnessing of practitioner expertise in this way coupled with the support and sponsorship of the Senior Management Team creates an organisational learning culture¹.

A focus on services and issues that directly impact the lives of autistic people is massively underrepresented in the research literature and indeed does not appear to be a funding priority². Practitioner research has the potential to redress this and therefore had to be a vital strand in a strategy that aims to harness organisational knowledge. The development and delivery of projects that generate practice based evidence that is meaningful and useful to practitioners and have a direct impact on the people we support, not only bring about change and innovation in practice, but provide a vehicle for vibrant staff learning and development opportunities. These outcomes have the potential to bridge the theory to practice gap which often arises due to the failing of learning outwith the practice context.

Due to the heterogeneity of autism and the individualised support offered by Scottish Autism to autistic people, practitioner researchers explore effective strategies and key principles that are based on good autism practice rather than focusing on evaluating

named interventions. This has the added value of creating a culture of inquiry where staff can employ research methods to investigate challenges in practice. The well established principle in our services of personalisation also leads to the development of innovative adaptation of methods and indeed the potential for the generation of new methodologies.

One such project investigated the area of 'Communication, Voice and Participation'. Practitioner Researchers conducted a series of case studies concentrating on the use of Information Communication Technology (ICT) in decision making and the recording of choice for individuals on the autism spectrum. This project identified good practice examples within the use of visual media in review meetings and case records and the development of service user forums and their role in service development. Another project looked at the topic of 'Friendship and Social Opportunities in Autism Services' by asking autistic individuals and their support staff what meaningful friendships look like for them. A large project concentrated on 'Supporting People with Autism and Sight Loss', leading to an increase in the number of individuals undergoing optometry assessment and staff knowledge on how to adapt environments for individuals with sight loss and autism.

The outcomes of these projects effect change in practitioner knowledge and practitioner's direct practice with individuals. It is also important to note that the individuals supported by Scottish Autism are rarely represented in research.

The establishment of an annual staff conference for Scottish Autism has opened up the opportunity for practitioners to share examples from their practice, learn from their peers and gain experience in presenting. Now in its fifth year, a dedicated staff conference ensures a space where staff can deliver workshops that relate to topics that are of relevance to them. 'Positive Approaches in Reducing Restrictive Practices', 'Stress Reduction in Action' and 'Later Diagnosis and the Continuing Journey to Flourish' are just some examples of the thought-provoking workshops produced by staff. As these have foundations in reflective practice, these enable thoughtful discussions and knowledge sharing.

The development of 'Source', Scottish Autism's dedicated intranet has been instrumental in the dissemination of information, promoting staff discussion and sharing knowledge. Source is promoted to staff as a vehicle where they can 'Connect. Share. Learn'. With their own profile, staff can share their latest work

or any relevant updates, gain access to a library of documents to ensure consistency in recording and benefit from a rolling news feed which provides up to date information. Integral to Source are the discussion forums and blogs - here staff can pose questions, offer points of view and suggest solutions to colleagues. With the introduction of Source, Scottish Autism has introduced a virtual community of practice to staff - this provides benefits to all staff but particularly those within more rural and remote locations who are now exposed to the same knowledge sharing opportunities as their peers.

Scottish Autism's development of a Knowledge Management Strategy is married with its commitment to quality with the employment of our own bespoke practice based self-assessment framework, the Autism Practice Improvement Framework (APIF). APIF was developed by Scottish Autism and is based on our ethical framework and what we believe to be at the core of good autism practice. Staff from across the organisation have evaluated their practice using the framework. This tool has been extremely useful for reflecting on practice, learning from experiences and considering ways to improve. Creativity is promoted during the development of action plans which identify areas of improvement in relation to autism practice. Examples of projects include the development of staff knowledge sharing events within a region, increasing participation in a regional service user forum, and supporting the delivery of review outcomes. The use of APIF evidences a commitment to continuous improvement, while sustaining a focus on autism practice in the context and culture in which it is delivered.

Adopting Knowledge Management principles and practices has been very beneficial for Scottish Autism. The employment of various strategies has ensured staff involvement, promoted staff voice and ownership, reduced the chance of lost assets and developed a multitude of new resources. To date, the experience of Scottish Autism is that our efforts have been driven by the individuality of people on the autism spectrum and the acknowledgment that if we are to continue to deliver excellence we must take full advantage of what each individual has to teach us.

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'Sharing and owning knowledge in services'

Outcomes from the Autism Practice Improvement Framework (APIF)



Joanna Panese
Senior Autism
Practitioner

Introduction

The development, synthesis and sharing of new forms of autism knowledge within Scottish Autism has a clear goal - to improve the quality of the services we provide for autistic people. Whilst traditional 'top-down' organisational approaches are often tasked with improving quality, hierarchical initiatives are not frequently linked with a sense of staff autonomy and ownership. Scottish Autism recognises that our key processes and support environments have always developed expertise and innovation within practice, as autism services require staff to constantly adapt to improve the quality of life for autistic persons.

The development of the Autism Practice Improvement Framework (APIF) builds upon this recognition. It provides a systematic and robust framework for staff teams to take formal ownership of the need to develop services via self-assessment and supports the development of programmes to improve practice. The APIF framework and the support of the APIF Advisor essentially create an autonomous organisational space where staff can design self-identified programmes to improve practice in a way described as 'by staff for staff'. This framework gives greater autonomy to the 'communities of practice' which generate new learning within Scottish Autism and supports the dissemination of this knowledge.

To highlight this process, Central and Lothian APIF teams describe their own experiences of APIF and the outcomes from the process:

Central APIF team case study

Joanna Panese, Senior Autism Practitioner

The Central APIF team has focused on a number of projects highlighted through the APIF assessment process which have included improving and quality assuring changeovers, supporting the transfer of review outcomes into individual support plans, and improving the way in which staff access key information about supported persons.

The APIF process posed a number of questions throughout the initial assessment - what does good practice mean to front line support staff? What does it look like and how can we adopt real strategies that realistically work to improve what we do? It also wanted to highlight areas of good practice and share these throughout the organisation. The APIF process allowed practitioner voice as well as service user voice to be held at the heart of any developments.

The first project developed by the Central APIF team was the creation of a 'changeover' document to support the exchange of information between staff during shift changes. The APIF assessment process highlighted that whilst changeovers within Central services consistently involved a high level of detail, staff faced challenges when recording this information and passing it accurately from team to team.

The document focused on illustrating the ways changeovers could be delivered based on the experiences of staff across the region. A survey of frontline support staff highlighted each team retained a different method of recording changeovers. The use of changeover guidance aimed to support staff to adopt a 'best practice' model when delivering changeovers to produce consistent practice across the region.

The documents were designed with a clear 'for staff, by staff' approach which generated positive feedback from staff; many indicated that this approach spoke to them on a practical level and allowed them to adopt the strategies straight away. Staff also found that real practice examples within the document meant they

could see what a model changeover should look like.

The Central APIF team are currently looking at developing a quick reference guide which will allow staff to access key information about supported persons. This will include core strategies for successful support across services and the identification of key communication needs. This document is not designed to replace the staff requirement to read and maintain support plans, but was developed after feedback highlighted when staff arrive on shift they often require certain immediate information about their supported person. Staff can then use the support plan to deepen their knowledge at a later point.

Laura Lamont APIF team member and Support Worker within central commented:

“The APIF quick reference guide that the team has put together is really easy to fill out - the guide is split into each part of the day which lets you get the information you need quicker than before. The guide has been received well by the staff team and they are keen to use it when new staff come to work with those we support. The quick reference guide offers a streamlined version of the most important parts of each supported person’s day and gives reference points so this can be used alongside the full support plan if more information is needed.”

A dual focus has been apparent throughout the APIF process; how to develop practice approaches that can

“The guide has been received well by the staff team and they are keen to use it when new staff come to work with those we support.”

be easily transferred ‘on the floor’, and continuing to keep the individuals that we support at the heart of what we do. As APIF continues, so does the reflection and refinement process which I think remains one of the strengths of APIF - it can be used flexibly by the APIF teams so that the outcomes mean something for that region and although these outcomes are shared, the ownership still lies with the staff that create them.

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Lothian APIF team case study

Lucy McMath, Autism Practitioner



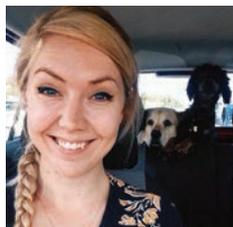
In early 2016, the Lothian and Borders APIF team prioritised three key areas for improvement across our services. At this point we agreed our aim would be to develop projects that benefitted all services and staff members.

Our first project ‘The implementation of a joint meeting between all teams in Lothian and Borders to promote knowledge share and development’ focused on the staff integration and sharing of knowledge. It was interesting to see the range of knowledge and experience we could share even within our small APIF team. In order to learn more about the practice areas that staff wanted to develop, we conducted a survey within the service region and selected areas for improvement from the results. Topics included learning more on nutrition, stress and sensory issues, as well as developing the range of community activities we could offer.

From our meetings, we identified a specific need for ‘community mapping’ within our area. We knew that both our staff and supported persons had a significant knowledge of opportunities and resources in the community which could be valuable to others when selecting day trips or planning an activity. As a team we created a Community Mapping form which we called ‘Source Explore’, which is now accessible on Source, our staff intranet.

With the use of this resource, staff are able to upload reviews of cafes, museums, castles and general places of interest which all Scottish Autism staff can access. This can be useful when planning a day trip or holiday for those we support as reviews can be searched by type of activity or area. It is also a great tool to use if our autistic individuals have a favourite place but would potentially benefit from new environments and experiences – this tool also offers the opportunity for individuals to review places they have visited and share their own experiences. This gives a valuable insight as it allows supported persons the opportunity to make clear what they really thought about the places they have visited with staff. In the future we hope that this can be made available to all carers, support workers and families of autistic persons.

Reflections on the Scottish Autism Research Group 2017 Seminar



Laura Hill
Support Worker,
Scottish Autism

Wellbeing has become an increasing focus of recent research and has been an area of particular interest for me as a Support Worker and whilst studying for my masters. The topic of wellbeing was also a prominent focus at the recent Scottish Autism Research Group (SARG) seminar which consisted of talks by speakers from various academic and practitioner backgrounds, covering a wide range of topics related to mental health and autism.

The 'research in a flash' talks provided brief glimpses of current research projects. Cameron Maitland, a PhD candidate at Edinburgh University, introduced recent work examining autism in terms of social identity, and discussed how a shared sense of identity may be associated with lower levels of anxiety. This premise is interesting because when autism is viewed in terms of a social identity rather than as a product of current societal norms or expectations, it can shift the balance of focus towards the lived experience of autistic individuals and validate autistic identity rather than promote a view of deficit.

This mirrors the World Health Organisation (WHO) definition of quality of life and in particular, how a person perceives their position in life within the context of their culture and values. To improve the wellbeing and quality of life for the people we support, I think it is important to focus on their individual goals and aspirations rather than focus on what might make someone else feel happy or fulfilled.

Another interesting talk was delivered by Kirsty Ainsworth, a doctoral candidate at Glasgow University who discussed work examining the experience of anxiety in adults with autism from a practitioner perspective. I found her talk encouraging as it provided a focus on life experience and included the rounded views of autistic individuals and

their network of support. Recent autism research has encountered a call to move away from 'neurotypical priorities' (such as investigations into the underlying causes of autism) towards a greater focus on the actual lived experience of autistic individuals. Developing this type of experiential research can greatly aid our understanding of the needs of autistic individuals and inform autism practice further.

The closing presentation came from the seminar's keynote speaker Jacqui Rodgers, a Senior Lecturer at Newcastle University. Jacqui discussed the relation of an 'intolerance of uncertainty' framework, to anxiety within autistic individuals and detailed how a successful strategy to reduce anxieties around uncertainty could involve making the environment more predictable. However, as this isn't always going to be possible, she discussed a programme of positive support involving parents which included relaxation techniques, social stories, and other person specific tools. This presentation generated some interesting discussion and feedback from the audience, highlighting that there will never be a single programme or approach that works for every autistic person. However, it is clear that listening carefully to people with autism and capturing their perceptions and experience is fundamental to the future of autism research and practice.

Following the seminar, the aspect I have reflected upon most, has been the importance of listening to autistic people. With an empathic recognition for verbal and non-verbal communication, we can appreciate the value of differences between types of cognition and communicative style and tackle the problem of 'double empathy'¹. To solve this problem requires seeing past our singular concept of an autistic deficit of 'theory of mind' to take responsibility for understanding an 'autistic theory of mind' and the challenges that autistic individuals encounter when interacting with others. With this resolution in place we can work towards improving autism research and practice in a more meaningful way, and ultimately improve the wellbeing of autistic people throughout their lives.

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- ¹ Milton, D.E. (2012). On the ontological status of autism: the "double empathy problem." *Disabil. Soc.* 27, 883-887.

Meet the Centre's Research and Practice Associates

Research Associates



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.



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.



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.



Andrew Jahoda

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



Richard Mills

Richard is the Research Director of Research Autism, London and Research Fellow at the University of Bath. He is also a Senior Research Fellow at Bond University, Queensland, Australia, consultant at the ARC Singapore and an Associate of the Tizard Centre at the University of Kent and AT-Autism. Richard is an editor of *Autism, the International Journal of Research and Practice and Advances in Autism*.



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.



David Simmons

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

Practice Associates



Debi Brown

Debi was diagnosed with Asperger's Syndrome as an adult 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'.



Yvette Q. Getch

Yvette is Associate Professor, Department of Diversity and Community Studies at Western Kentucky University Bowling Green, Kentucky, and part-time Associate Professor, Department of Counseling and Human Development Services, the University of Georgia Athens, Ga.



Michael McCreadie

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



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.



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.

To find out more about the Centre's Research and Practice Associates, please visit our website: www.scottishautism.org/cpi

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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