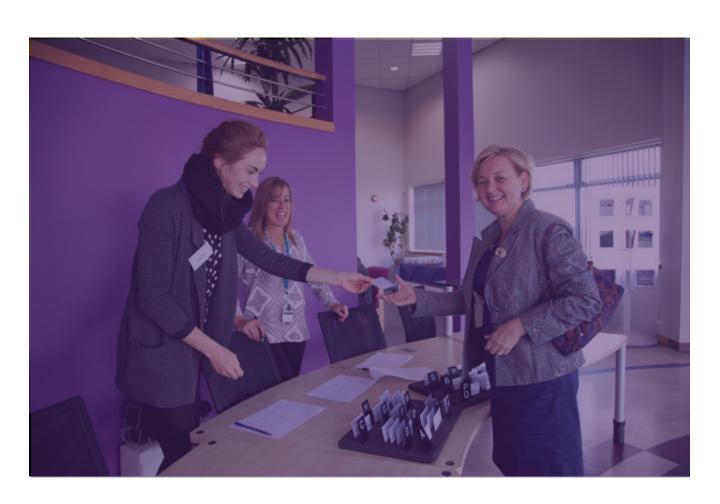# Scottish autism

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Oral Abstracts

A Cross-Cultural Study of Building Resilience Among Parents of Children with Autism Spectrum Disorder

Oral

Fathima Kodakkadan (Anglia Ruskin University), Steven Stagg (Anglia Ruskin University), Eimear Lee (Anglia Ruskin University), John Lambie (Anglia Ruskin University)

Abstract:

The current study aims to establish and test a model of stress and resilience and examine the differences in the experiences of the parents of children with Autism spectrum disorders(ASD) cross-culturally between India and UK. To examine parental stress (PS) and resilience, this research developed a multidimensional model based on the Double ABCX theoretical model by (McCubbin and Patterson, 1983). This research argues that the result of parental stress and resilience depends on the following social and cultural factors such as adaptive behaviour of child, perceived social and emotional support, parental attitudes towards children and affiliate stigma.

Research Purpose: The purpose of this study is to examine the extent to which the social and cultural factors influence parental stress and resilience among parents of children with ASD in the UK and Indian contexts.

Research Design:Data collection is currently underway, and by July 2018, expect to have approximately 300 participants. A cross-cultural study is conducting with a convenient sample of 150 parents from India and 150 parents from the UK. Participants completed a set of online questionnaires about their experiences of caring for their child with ASD, including: Vineland Adaptive Behaviour Scale(VABS), Parenting Stress Index(PSI), Brief Resilience Scale(BRS), Multidimensional Scale of Perceived Social Support(MSPSS), Perceived Emotional Support Scale(PES), Family Impact Questionnaire(FIQ), Affiliate Stigma Scale(ASS) and demographic questionnaire through online survey.

Research Findings:With the complete dataset, correlation and regression analyses will be utilised to find out if stress and resilience will be predicted by independent variables such as adaptive behaviour of child, perceived social and emotional support, parental attitudes towards children and affiliate stigma in the UK and Indian sample. If predictability is proved, structural equation modelling will be done to establish the path and direction of the predictability. We expect to find the parental stress is negatively associated with perceived social and emotional support, parental attitudes towards children, resilience and positively associated with affiliate stigma. The adaptive behaviours of children are positively associated with perceived social and emotional support, parental attitudes towards children, resilience, along with a negative relationship with parental stress.

Research Conclusions:This research might help to develop new culturally specific strategies to provide interventions that will help parents overcome stress and enhance resilience, based on the relationship of stress and resilience with the social and cultural factors.Findings from this study will also help to discuss in the context of their implications for practice and future research.Furthermore, results from this study have the potential to increase clinicians' awareness and cultural responsiveness in order to support UK and Indian parents of children with ASD.

Key words: Autism Spectrum Disorders; double ABCX model; parental stress; resilience; adaptive behaviour; parental attitudes; perceived supports; affiliate stigma.

A Participatory Action Research approach to supporting mental health and wellbeing for autistic women and girls: the Right Click/SWAN partnership mentoring project

Oral

Catriona Stewart (SWAN: Scottish Women's Autism Network/ Scottish Autism)

Background

Autism and gender stereotyping have intersected to make autistic females 'invisible' within society and in ways, 'invisible' to themselves. The 'swan' analogy describes a process of self-denial as coping strategy, with stigma, disrupted self-identity, poor self-esteem and profound consequences. Described as internalised pain and disabling beliefs these may impact on the individual's mental health, life choices and life trajectory (Snow 2014, Humphrey + Huws 2008)

Participatory Action Research (PAR), is defined as "community-based and co-operative enquiry, used for improving conditions and practices... with an explicit value basis, founded on partnerships between researchers and participants". and 'study of a social situation carried out by those involved in that situation in order to improve both their practice and the quality of their understanding' (Winter and Munn-Giddings 2001)

Methods

A PhD study on experiences of anxiety for autistic girls was committed to the lived experience as a valid form of data and carried out within an in-depth qualitative research framework. To facilitate the girls' authentic voices, licensed software *In My Shoes*(Calam, D et al 2002) was used to interview the girls. Data was analysed thematically (Stewart 2011; 2012)

Key findings: "Where can we be what we are?". Uncomfortable in most environments, girls experience high levels of anxiety and are vulnerable to associated symptoms including headaches, insomnia, GIT problems, school refusal, self harm, suicidality.

The study inspired the founding of SWAN, Scottish Women's Autism Network, with aims including to: provide peer-support, recognition and community 2. improve awareness, increase the knowledge-base and understanding within wider society. SWAN holds peer-led monthly groups in 4 cities in Scotland (for numbers eg March Glasgow, 17 adult women and 9 young women accompanied by mothers attended), reaches 100s of women online; members input into conferences, consultations and advisory bodies, with increased confidence, self-esteem reported - described as 'life changing' and 'sanity saving'. SWAN has been shortlisted for an SSSC 2018 award.

The study was also the inspiration behind the Right Click for Women and Girls, an online resource developed by Scottish Autism and funded by Scottish Government. The SWAN network has contributed to Right Click in many ways, as survey respondents, interviewees, in focus groups and as resource reviewers.

Scottish Autism, through its Right Click programme and SWAN, are partnering to run a pilot peer-mentoring programme for 10 mentors/mentee pairs (n=20), launching in May 2018; the project will be externally evaluated over 12 months.

Implications:

Peer support and mentoring are not widely resourced or evaluated responses to mental health issues, and therefore this line of enquiry requires flexible and creative thinking to develop appropriate research methodologies. PAR may be seen as a useful framework and research model in the context of peer-support and mentoring for mental health and wellbeing in autistic females. This presentation will discuss some of the implications of what we are learning about the importance of peer-support and mentoring within the context of a participatory and partnership initiative.

A series of unfortunate events: safeguarding the rights of autistic children and their autistic parents during state-led child protection proceedings

Oral

Claire Evans-Williams (The Autism Academy UK), Bill Colley (CLC Consultancy)

It is of the utmost importance that Scotland's autistic children and young people are protected from harm or the potential risk of harm, and be given every feasible opportunity to flourish and thrive to ensure the best possible outcomes for physical, cognitive, and emotional wellbeing and development. To this end, not only is there a role for health and social care practitioners in keeping autistic children and young people safe, but members of the public hold a pivotal role in remaining vigilant to child safety and in so doing, providing robust support for child protection . Only through an explicit acknowledgement of our collective and shared responsibility for autistic children and young people in our society, can we attain The Scottish Government's goal of Getting it right for every child.

In addition to emphasising the importance of collective responsibilities,The National Guidance for Child Protection (2014) asserts that the availability of procedures and guidance alone is wholly insufficient in the pursuit of protecting children and young people. Crucially, what is required is a competent, skilled, and confident workforce among Scotland's health professionals, social workers, police, educational staff, and voluntary and third sector organisations. An area of priority therefore, must be in shaping and improving methods of assessment and analysis that inform relevant and effective actions and critical decision making used by professionals in child protection proceedings.

In this presentation the authors explore their growing concern for the often misattributed and underrepresented needs and rights of autistic parents and caregivers (particularly autistic mothers) by reviewing a number of pertinent case examples from their experiences and involvement within state-led child protection proceedings. They will provide key recommendations to improve current procedures and processes under the Children and Young People (Scotland) Act 2014; and conclude by calling for urgent revisions to child protection policy and legislation in relation to the varied needs and rights of autistic parents/caregivers, autistic children, and autistic families.

A Vision Pure and Bright: Autism and Film Literacies

Oral

Aline-Wendy Dunlop (University of Strathclyde), Noel Wray (Glasgow City Council (Education))

In a project supported by Scottish Film Education over a period of 15 months, a group of eight neuro-diverse school students, seven of whom have a diagnosis of autism, their teachers and a researcher, have been continuously involved with classroom-based approaches to film and multi-media literacies. Media, texts and literacies are changing and challenging in 21stcentury lives. Exploring the question "What do autistic pupils and their teachers learn when engaged in film making?", this collaborative project combines the experience of the teachers to observe, teach and take part in a range of media processes with their school students, including written texts, storying, film, animation and digital literacies; and the extensive experience of both schools and autism held by the researcher. The sessions are normal day-to-day learning and teaching situations but also offer an organic process of co-production which is part of everyday practice.

Through shared discussion, observation and reflection we hope to enhance students' technical knowledge and their capacity to benefit from film involvements; theirs, the researcher's and teachers' knowledge of the particular young people's ways of thinking and learning, and their creative imagination. We see school students with autism not only as audience at the receiving end of film, animation, life-storying and documentary but actively engaged in their production as directors, script writers, actors and more. Film literacy has the potential to be a strong pedagogical tool. There is great potential in visual media, including animation, for school students and their teachers in making learning more accessible (Holmgaard et al, 2013).

Taking a narrative inquiry observational approach (Clandinin, 2006) allows a responsive approach to recording curricular experience, classroom dialogue and affect. Narrative observation recorded by the researcher and two teachers and shared reflection has allowed the teachers and researcher to identify the benefits of, and formulate the learning and teaching process.

Using Robinson's 2014 typology for cognitive and emotional empathy, Dunlop's 2003 typology of classroom interaction and the BFI Film Education Framework and the National 4 Media units of study: Analysing Media Content and Creating Media Content, we can illustrate the impact of classroom discourse, the level of engagement of students and their communicative responses to visual media.

Implications of film and multi-media literacies for learning and teaching in school settings, cognitive and emotional empathy, peer group relationships, classroom interaction and the qualities of curiosity, empathy, aspiration, tolerance and enjoyment, referenced by the BFI Framework for Film Education (2015) will be discussed: each resonate with enhancing agency in students with autism. The importance of evidence through research is emphasised.

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Assessing and addressing the needs of autistic individuals to promote health and well-being

Oral

Damien Williams (The Autism Academy UK), _Claire Evans-Williams_ (The Autism Academy UK)

When working with autistic individuals it can be tempting to focus on the most visible, and seemingly easily identifiable needs. Such a misplaced approach is often the result of limited understanding of autism and/or ineffective needs assessment. If the needs of autistic individuals are neglected or inappropriately identified/addressed it can adversely impact their health, and exacerbate underlying health conditions.

The concept of _need_ is inherently complex and widely used, often to mean different things. For instance, Bradshaws (1972) _Taxonomy of social need_ differentiates four perspectives on need:

Normative = prescribed by professionals

Comparative = deficit identified through comparison

Expressed = verbalised (explicit) or service utilisation (implicit)

Felt need = unexpressed

Significantly, the taxonomy legitimises subjective views of need, and emphasises their important role in needs assessment. Indeed, the rights of individuals to participate in defining their own health needs is enshrined in the 1978 World Health Organisation _Alma Ata Declaration_.

The Hierarchy of Needs (e.g. Maslow, 1970) presents a powerful conceptual framework to guide the process of exploring health needs. The original hierarchy represents a theory of human motivation and comprises six layers of increasingly complex need (i.e. and 6. ego transcendent). What is more, the hierarchy is fundamentally concerned with achieving conditions that are aligned with human rights (see UN Declaration of Human Rights, 1948).

In this paper, the authors will draw upon their practical and theoretical work to provide justification for a needs-driven approach to working _with_ Autistic individuals. In so doing, a critique is offered of traditional approaches to health needs assessment; reflection on the utility of the Taxonomy of social need; and the role of the Hierarchy of needs. However, it is likely that condition- and context-specific adaptations of the original hierarchy will better serve the unique and evolving needs of autistic individuals, and we will present the autistic hierarchy of needs, with examples of how the hierarchy can and has been used to guide the identification of the needs of autistic individuals and addressing those needs to promote health and well-being. It is asserted that any approach that fails to identify, acknowledge, and address the actual needs of autistic individuals is, in essence, neglecting their human rights. The autistic hierarchy of needs offers an approach to identify and address the needs and rights of autistic individuals.

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By identifying stressors and work with stress reducing strategies in families, where there are children with special needs, we support the families in reducing the conflict level and enhance the wellbeing for the families

Oral

Kasper Kock Nielsen (Center for Specialpædagogiske Børnetilbud (Centre for Children with Special Needs))

In families with children with special needs the conflict level sometimes can be raised.

We think the that a raised stress level often can be a reason. The families can be facing a lot of extra challenging situations.

That is why we work with a systematic approach for identifying stressors and work with stress reducing strategies to try to support the families in reducing the conflict level and enhance the wellbeing for the families – the parents, the siblings and the children with special needs.

In this presentation, we will give practical examples on our work with stress in families and we will present our model of work and our collected data.

Conversing at the edge of meaning: Daring to understand the 'other' in cross-dispositional communication

Oral

Gemma Williams *(University of Brighton)*

Pragmatic 'deficits' in autistic language use are commonly attributed to an impaired theory of mind: the onus of failures in mutual understanding is placed within the minds of the autistic individuals involved. Contemporary critical autism studies and some sociological autism research offer an alternative account for this kind of pragmatic breakdown, reframing the communication more equally within a reciprocal sociality. This talk provides an overview of these accounts and explores how autistic language use can be better understood from a difference-not-deficit perspective.

What is commonly assumed to be a lack or impairment of theory of mind will be reframed using Milton's Double Empathy Problem; 'a disjuncture in reciprocity between two differently disposed social actors' (2012). According to this approach, misunderstanding is not just a consequence of autistic 'impairment', it is mutual. Normativity should not be conflated, though it often is, with 'being right'.

In much research into autistic language use, there is evidence of what Sterponi & de Kirby (2016) call the 'constraining influence of the interlocutor'. Under these constraints, when autistic speakers perform outside of the expectations of their interlocutors, the assumption is often made that there is some kind of pragmatic deficit at play. In those cases, however, where both speakers take the 'risk of going on', and language is allowed to 'run along the edges of meaning' previously unnoticed pragmatic flair can sometimes be observed (Sterponi & Fasulo 2010).

In looking for further examples of markedly cross-dispositional communication, this talk turns toward English as a Lingua Franca (ELF). Despite the characteristic lack of shared cultural or sociolinguistic schemata, ELF talk (as distinguished from English as a Foreign Language, where native speaker norms are the linguistic goal) exhibits a highly 'cooperative and consensual nature' (Pullin 2013). Here cultural, and arguably, by extension, conceptual and cognitive, differences are overcome through the *extra efforts* made in the form of accommodation: a 'bilateral process of speech adjustment...seeking convergence for the purpose of being understood' (Jenkins 2000:21). This talk will conclude with some questions around whether there is anything we can learn from ELF talk that might benefit autism language use studies.

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Developing a Training framework for prison officers within the Scottish Prison Service

Oral

Frank Slokan (The Richmond Fellowship Scotland / University of Huddersfield)

It has been suggested that autism may increase an individual's vulnerability, both for becoming a victim of crime or becoming an offender. Although there is a suggestion of overrepresentation, there is no clear evidence around prevalence of autistic offenders in prison. There have been a range of studies indicating a higher rate of autism diagnosis in prison settings, when compared to the general population (Cashin & Newman, 2009; Fazio, Pietz & Denney, 2012; Robinson et al. 2012). Prevalence rates range from 3% to 27%, compared to an estimated rate of 1% in the general population (King & Murphy, 2014). Prisons pose a particularly difficult environment for autistic individuals, with research suggesting that they will often be marginalised, bullied, isolated and may receive more severe treatments due to their presentation (Allely, 2015; Allen et al., 2008; Browning & Caulfield, 2011; Myres, 2004; Paterson 2007)

Mixed qualitative and quantitative measures were used to identify the training needs of staff within the Scottish Prison Service (SPS). Two focus groups were completed, with health care professionals and the learning and development team at the SPS College. A survey was handed to staff working within a prison environment to assess knowledge and needs. Thematic analysis was completed to identify any gaps in knowledge and support the development of a training framework for SPS. The study identified the gaps and developed a training framework for staff within the SPS, to support autistic individuals in a more effective manner. Results are currently being written up as part of a Masters Dissertation with the University of Huddersfield.

Does the WHO quality of life questionnaire capture wellbeing for autistic individuals?

Oral

Line Gebauer *(Langagerskolen, Aarhus)*

Background: People with Autism Spectrum Conditions (ASC) experience a number of challenges in their daily life related to their symptom profile, comorbidities, but also constraints on their inclusion in social communities and the greater society. These issues might severely compromise the individual's experienced quality of life (QoL). *WHO defines QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".* As such, it is possible that factors that are negligible for some individuals may have a significant impact on the QoL of others. If this is correct, QoL-measures need to display some sensitivity to the specific features of specific individuals/populations. This presentation will present findings on the QoL of people with ASC, and discus whether autism-specific items are necessary and important for describing their QoL.

Objective: Our aim was to answer three questions: 1) do autistic adults experience diminished QoL relative to the general population, 2) are the questions of the WHOQoL relevant to autistic adults, and finally 3) are there themes, not addressed by the WHOQoL, that are central to the experienced quality of life for people with ASC?

Methods: 35 adults with ASC (20 women) completed the WHOQoL-BREF, which is a 26-item questionnaire evaluating four QoL domains (physical, psychological, social and environmental). Participants were then presented each question from the questionnaire again and asked if they found the question relevant for describing their QoL, if they did not find the question relevant participants were asked to elaborate on why. Finally, we asked all participants if there were any questions or aspects that they found missing from the questionnaire. All qualitative responses were analysed using thematic analysis.

Results: Adults with ASC displayed significantly lower QoL compared to a general population sample. Four overarching themes emerged from the written responses to the question of which aspects the participants found missing from the WHOQoL questionnaire, relating to: 1) social care, 2) personal development and seeing a positive future, 3) social relations and normality, and 4) energy and stress management. The theme of social care was constituted by units representing contact with the social system, lack of control over own life, to be understood by others (professionals), the difference between neurotypicals and autistics (dealing with neuronormativity). The next most commonly expressed theme concerned personal development and seeing a positive future. This theme consisted of units representing self-understanding, hopefulness, and the ability to imagine one's own future.

Conclusion: Relative to a general population sample, the autistic participants in this study experienced significantly lower QoL across all four domains (physical, psychological, social and environmental). Overall, the WHOQoL-BREF scale seemed to be a valid measure of the QoL construct for people with ASC, however, there was agreement across participants that more items relating to: dealing with the social system, personal development, social relations and energy and stress management were needed to fully capture the domains that had the greatest impact on their QoL.

Enabling Participation through Personalisation

Oral

Louise Storie *(Scottish Autism)*

Exploring and overcoming the challenges of participation, whilst being mindful of the importance of consultation, consent and informed choice. Examples of strategies to ensure a holistic approach to wellbeing.

Enabling Participation through Personalisation

Oral

Enhancing positive emotions and wellbeing in autism - Perspectives from positive psychology and experiences from real life

Oral

Michael Harboe Kvistgaard (Center for Specialpædagogiske Børnetilbud (Centre for Children with Special Needs))

In the field of special needs it´s easy to forget to work on enhancing wellbeing, and instead focus one´s attention on deficits and challenges. Based on my experiences as a special need consultant and pedagogue however, there is a huge potential for not only increased wellbeing and quality of life for individuals, but also for the individuals to develop further competence of life, if we as supporters change our perspectives. The presentation will be based on 1) scientific theories and 2) practical experiences from special need work with one of the elements (Positive Emotions), in the PERMA framework of wellbeing. PERMA is made by Martin Seligman, one of the originators of the field of positive psychology, which is the science of human flourishing and optimal functioning. PERMA consists of the following elements "Positive emotions, Engagement, positive Relationships, Meaning and Accomplishment. I will talk about different ways to enhance positive emotions. When focusing on positive emotions, it´s obvious to search within the area of positive psychology for tools and understandings. Thus the "Broaden & Build" theory by Barbara Fredrickson will become a central element. Also, it would be likely to stumble over the concepts of "Character Strengths" and "Flow" – both concepts that in themselves can be understood as enhancing positive emotions and wellbeing.

Since the PERMA framework is not developed to support people on the autistic spectrum, and since there are almost none research on the benefits of positive emotions in autism, it´s essential to pay mindful attention to how these concepts fits the individual person. I believe there´s a great potential (for wellbeing and learning) in rethinking the special need work into a more happiness and wellbeing oriented approach. Autism is far more than deficits.

Exploring experiences of educational transitions for pupils on the autism spectrum

Oral

Hanna Kovshoff (University of Southampton), Sarah Parsons (University of Southampton), Jessica Baker (University of Southampton), Kerry Hoy (University of Southampton), Felix Perkes (University of Southampton), Ellie White (University of Southampton)

Autistic children, especially young children and those with associated learning disabilities, tend to be silenced in the research literature (and more widely) because their views and experiences are often considered too hard to reach. This study is based on the principle that autistic children have unique perspectives on the world and on their own experiences, and these perspectives have value and validity in their own right, not merely as points of comparison with children without autism (for example). Young autistic children may not be able to express or communicate their views in typical ways and so, rightly, the onus is placed on us as researchers and practitioners to find ways to reveal authentic insights into their experiences and capabilities.

The aim of this programme of research is to gather the views of children and young people on the autism spectrum, their families and their teachers, on experiences of educational trajectories and transitions. This includes bigger transitions between levels of schooling (nursery to primary school, primary to secondary school) as well as the smaller transitions (e.g., from year group to year group, from home to school, from activity to activity). We have worked to support autistic children and young people to share their stories of educational transitions including the use of photo-voice, observation schedules, and interviews. Specifically we have sought to understand aspects of educational practice across different levels of schooling that have both helped and hindered experience of school transitions from multiple perspectives for 13 pupils on the autism spectrum from nursery, primary, and secondary school settings.

This project is part of the Autism Community Research Network @ Southampton [ACoRNS; www.acornsnetwork.org.uk] initiative that brings together researchers and practitioners to jointly identify and construct a research agenda that is mutually informed by, and informing of, practice. In other words, we jointly agree on research questions that are of direct interest and importance to practitioners and devise projects that will help to answer those questions. Our agreed priorities are the transitions and trajectories of children and young people with autism, with the aim of understanding what best practice looks like and how we can share evidence-based knowledge more widely. ACoRNS places children and young people's views and experiences at the core of what we do.

Fantastic Friends –a place where we belong

Oral

Angie Ferguson (Perth Autism Support), Lynsey Paterson (Perth Autism Support)

With increasing research looking at females on the autism spectrum, we know that many girls are often not diagnosed until they have entered adolescence when the complexity of all our social relationships increases and the limitations some females can have to maintain social interaction can become inadequate (Cridland, E.K. et al, 2014). Evidence has suggested that females build relationships and socially interact by sharing thoughts and emotions where males will build relationships on activities, hobbies or interests. To build relationships requiring thoughts and emotions requires much more social communication skill to be able to do this successfully (Rivet, T.T., Matson, J.L., 2011). Girls are more likely to display relational aggression, displaying anger in subtle, indirect ways such as gossip, exclusion, ignoring, giggling and eye rolling compared to the overt aggression of boys, this relational aggression is much more socially complex and therefore girls on the autism spectrum are more likely to have difficulty reading, acknowledging and responding to the peers appropriately (Nichols, S. et al, 2009).

The difficulties the girls can face in terms of social isolation can lead to being a key factor in developing mental health issues such as depression and anxiety in adolescence, a theme we observed within our girls on the autism spectrum registered with our organisation.

Fantastic Friends is a highly supported weekly social group aimed to facilitate social communication and friendships for girls on the autism spectrum aged 10-16 years who have a high level of anxiety. The very small group format has supported a number of girls who were unable to access our regular girls groups activities to undertake some project work, build friendships, reduce social isolation and have opportunities for extracurricular activities.

Friendships and Sociality in Services

Oral

To be confirmed To be confirmed (Scottish Autism)

Difficulty in building and maintaining social interactions with others is often seen as key characteristic of what it is to be autistic. However many argue, including individuals themselves, that autistic people build strong bonds and attachments with those around them. This practitioner led research looks at the ways in which relationships and friendships are built with services and how autistic individuals define their relationships. It poses questions surrounding relationships between staff and service user, as well as expectations both groups have surrounding reciprocal relationships. The seminar with explore what we mean by meaningful relationships and challenge the normative idea of what it is to be social.

Gender Dysphoria: Joining the dots when it comes to gender and autism

Oral

Wenn Lawson *(Autism CRC , Queensland)*

Statistically autistic individuals are 9 times more likely to commit suicide (7.5%-15%) than individuals in the typical population (see: Cassidy, 2015; Pelton & Cassidy, 2017). When living with gender dysphoria (GD) and autism, however, individuals are doubly disadvantaged. While individuals in the typical population living with GD are 40-50 times more likely to attempt suicide, than those living without GD (Peterson, et al 2016), we are uncertain what this means in autism.

This presentation explores autism, gender dysphoria and gender variance in practical ways that offer understanding and guidance to those who attend. Mis-understanding, applying typical perspectives to gender issues and autism will only push this population into further mental health issues. Knowledge is power and power, used appropriately, can empower those we support.

How can we ensure every voice is heard? Enabling meaningful participation within survey research

Oral

Alastair Clarkson (Scottish Autism)

Scottish Autism understand that the development of specialist individualised services able to fully meet the specific needs of autistic individuals depends upon supported persons being actively involved within processes of engagement and consultation. Within day to day practice however, the task of creating and delivering meaningful processes of engagement for individuals who are autistic, have a learning disability and or, who have significant and complex communication needs continues to present a significant level of challenge for service providers and staff.

Although some autistic individuals can engage directly with service providers and are capable and articulate self advocates, most individuals with complex developmental profiles require significant personalised support, augmentative communication and patient, well planned engagement to enable their voice to be heard. In response to signing the Charter for Involvement in 2015, Scottish Autism designed and developed the Service Experience Survey to obtain a more accurate understanding of the experiences of supported persons within services. Using a highly adaptive methodology, the survey utilises individual autistic interests and a cognitive workspace in order to ensure the voice of every autistic supported person can be interpreted within the survey process. This talk will discuss the principles behind the development of the survey and share the positive outcomes arising from the organisational sharing of individual voice and experience.

How do sensory issues affect school absence in children with autism?

Oral

Regnar Thisted (Langagerskolen), Line Gebauer (Langagerskolen, Aarhus)

Many children with autism spectrum disorders have difficulties attending school regularly throughout their school years. Extended periods of absence may lead to educational problems and social isolation, thus the longer a child is absent from school, the harder it is for them to return and attend regularly. Children who are absent 10% or more of the schooldays will over their 10-year school period lose, what corresponds to, an entire school year of social and learning opportunities. Consequently, they might not be able to attain the education they would like and might not be able to provide for themselves as they grow up. In addition to the negative impact absence from school has on the child, it is also major challenge for the family. Parents may be unable to work, since they need to be at home with the child, and siblings may feel left out since so much of the family's resources go into the child who are unable to attend school.

To help children with autism, who have problems attending school regularly, there is a great need for a more nuanced description of the factors that might hinder the child from attending school and maybe most importantly, to include the children's own descriptions of which challenges they experience when going to school. Existing theories on school refusal primarily focus on the child's anxious avoidance of things in the school or activities at home that they might prefer over going to school. In addition to these factors, our experience is that sensory challenges often hinder children with autism's participation in school. Children with autism often have increased levels of stress, which makes them less able to filter sensory information from the surroundings, which then in turn increase stress further. Thus, extensive sensory stimulation (noise, flickering lights, smells, touch etc) at the school may increase the pupils' stress levels, and impair their abilities to engage in social interactions and their learning.

We are in the process of developing a questionnaire that can be used to describe aspects of the school that might lead to sensory overload, and increase stress-responses in the children. We'd like to present questionnaire data from our own sensory questionnaire, and the School Refusal Assessment Scale, collected from a group of children from our school who has had more than 10% absence from school over the last year. In addition to this, we will present data from semi-structured interviews with children with autism, parents, and school personnel, to include their perspective on the factors that may pose sensory challenges to the children during the school day. Our hope is that the addition of sensory challenges can contribute to a more nuanced understanding of the numerous factors that make it challenging for children with autism to attend school regularly. Furthermore, we hope the questionnaire can be available tool for teachers and staff at the school for designing a school day that causes as little stress as possible for children with autism.

How to involve service users in staff recruitment

Oral

Kellie Calvert (Scottish Autism), Ingrid Richardson (Scottish Autism)

An innovative approach to staff recruitment has been developed in Fife ensuring service users have a voice in the process of choosing staff.

This has been developed successfully over a period of time, and has greatly enhanced staff recruitment across Fife services on every level, including promoting the choices of service users and providing both staff and potential employees with valuable insight into the role. Managers discuss the process and how this has supported what we do to actively involve those who use our services, and the benefits of this.

Innovative education using PACE outdoors with autistic children.

Oral

Esther Gooch (Outdoor Woodland Learning School CIC)

The Outdoor Woodland Learning School CIC have been fostering an innovative approach to education using PACE (playfulness, acceptance, curiosity and empathy Golding and Hughes 2012) in the outdoors with autistic children who are finding their mainstream setting or special school challenging. OWLS CIC are based in Scotland and have been developing this methodology for the past five years.

This ongoing development began through my work as a primary teacher in mainstream education and developed while working out in the woods with OWLS CIC.

From a primary teaching perspective, my approach has been to bring together strategies which are simple and work effectively to support pupils and that do not require a huge amount of financial expenditure. This ensures that strategies are accessible to all who wish to discover the scientifically proven value of working outdoors with children! Our approaches can easily be used by teachers and support staff although there is a need for appropriate risk assessment.

In learning through their experience that the outdoor natural environment is one in which they can relax and re-engage with themselves, children are learning to utilise this knowledge and skill now. Through supporting the schools in creating a more inclusive environment of learning for each individual autistic child, we are supporting the development of a strengths based curriculum that can only benefit each autistic child in their own lifelong learning.

Learning Outcomes

- Understanding of our collaborative and nurturing approach.
- Understanding of how experiences in the outdoor environment enable children to reduce their anxiety and re-engage with their inner selves and others.
- Examples of simple experiences and the effects on autistic children with unwanted behaviours.
- Understanding how simple changes to a school ethos and approach can have an enormous impact on the child and their potential unwanted behaviours.
- Understanding of how a strengths-based curriculum can create the inclusive educational approach an autistic child needs.

Leave inspired to try some of our successful approaches with your autistic youngsters!

Learning from autistic pupils about sense of self in mainstream secondary schools: the value of inclusive research methods

Oral

Emma Rice (Sheffield Hallam University)

Autism advocates critique autism research for the exclusion of autistic voice, its predominant focus on identifying deficit development, which positions autistic people as abnormal, and its subsequent focus on 'normalising' through treatment (Chown et al., 2017; Milton, 2014; Milton & Bracher, 2013). Responding to the call for more participatory and inclusive research methods, the research project set out in this conference paper, draws on participatory paradigms to enable autistic young people to articulate their sense of self- to tell the story of 'who am I?' with their own voice (Chown et al., 2017; Milton, Mills & Pellicano, 2012). Alongside this, the mainstream secondary school environment and its influence on autistic young people's positive or negative self-views is explored. Focusing on an inclusive research approach, resulted in the use of a plurality of research methods, as advised by Stone and Priestley (1996). The autistic young people involved in the research project employ individualised modes of expression to enable their opinions and experiences to be shared. Consequently, this research project draws together visual, verbal and written methods to consider how autistic young people conceptualise their sense of self, including the impact of mainstream schooling on this. Within this presentation, I will explore how drawing on a participatory paradigm and providing a range of choices, including in methods of expression, has enabled autistic voices to be shared. This presentation will include autistic pupils' evaluations of the participatory methods employed, together with their experiences, thoughts and opinions in relation to sense of self and mainstream schooling.**Key words: autism, voice, participatory, sense of self, mainstream secondary school.**

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Lifespan Development in Autism: A grounded theory study of the life experiences since leaving school in a cohort of adults in middle life

Oral

Anna Gilleard (University of Glasgow), David Simmons (University of Glasgow)

Autism is a lifelong neuro-developmental condition with known impacts throughout the lifespan. Whilst Autism research has historically focused on child and adolescent development, there is little known about the trajectory of development of Autism into adulthood. Even less research has examined the development of people with autism through mid- and late- adulthood (van Heijst & Geurts, 2014) and their changing needs with age (Povey & Michael, 2010. The present study explores the life experiences of mid-life adults with Autism with the aim of furthering theory on lifespan development. Seven semi-structured interviews were conducted with the families and caregivers of adults who had previously attended a specialist school run by a national Autism charity. Grounded theory analysis was used to analyse the experiences of these adults as reported by their caregivers since graduating from the school. Two major themes emerged (1) Continuing Development, and (2) Parents as Champions, which seemed to capture both the challenge and promise of Autism spectrum conditions through adulthood and middle age. These are discussed alongside other emergent minor categories and how they might inform the provision of age-appropriate, person-centred support services for this group. Better understanding of lifespan development alongside the changing needs and goals of mid-life adults is needed to help improve the quality of life of people with Autism and support their opportunities for continuing development. This is particularly pertinent in today's ageing society (ONS, 2017) and to avoid facing a crisis of unmet needs for such individuals and their families (Charlton, 2017).

Lived Experiences of Applied Behaviour Analysis: Adult Autistic Reflections on Childhood Intervention

Oral

Owen McGill (University of Strathclyde), Anna Robinson (University of Strathclyde)

Background: Applied Behavioural Analysis (ABA) remains the 'gold standard' for 'positive' autism intervention, with recent research focusing on the pursuit of early intervention at the most initial stage of development (Dennis et al., 2013; Ismail et al., 2017) to entail the strongest possible outcomes for the individual. Despite the perceived success, little of the autistic narrative is conceptualised into practice and outcomes.

Reasoning: Approaches within academia are taking a gradual turn, encompassing the autistic narrative into areas considered in the macro social sense (see Kenny et al, 2016; Cage et al, 2018). One of the more commonly adopted methodologies, ABA has been implemented over more than four decades, yet autistic reflections of this intervention are altogether absent from findings. Given the reportedly dialectic differentials between positive and negative reflections through personal blogs (see Kedar, 2011; Lowery, 2017; "My experiences with ABA", 2017) and ABA-led organisations, paired with a move towards stronger participatory and voice focused research, exploring this lived narrative is, in terms of this research, the next plausible act. Utilising challenges to 'challenging behaviour' and applications of 'Double-Empathy (Milton, 2012), this research looks to the personalised narrative to address discrepancies in outcomes.

Aims and Method: The research aimed to evaluate and disseminate experiential narrative to promote voice in the autistic experiences of ABA in childhood. No specified profile of autism was adopted in order to allow for wider voice participation and develop a narrative centred on those most likely to be perceived as attaining 'benefit' from ABA participation. Reflection of these narratives alongside both empirical literature and practice implications were evaluated and discussed.

Links to questionnaires or details for possible participants to contact were shared through social media and Autism Research based websites. Participants were able to either complete an anonymous questionnaire or contact the researcher to arrange an interview or communicate narratives.

Results: Grounded Theory analysis provided an insight into voice and narrative not yet touched upon within empirical research. Reflections from 13 participants were indicative of a predominantly detrimental impact of ABA (n=10), although some individuals reasoned resolve with certain characteristics being perceived as positive for their own development (n=3). Some emerging themes include reflection on 'removal of autistic self', 'increased vulnerability', 'missed empathic response' and 'autistic led alternatives', with more detail being discussed. Reflections also entail a clear divide between ideology of practice implications, with participants deliberating on the perceived differences between behavioural practice and peer-driven methods.

Discussion: Emergent themes demonstrate a clear antithesis between ABA practices and perceived wellbeing in comparison to experienced quality of life. Participant reflections also highlight significant discourse between empirical conclusions and actualised outcomes; one area in which reflections mirror research follows the recent findings of raised levels of Post-Traumatic Stress Symptoms emanating from ABA experiences (Kupferstein, 2018) through 'Trauma' and 'Mental Health' themes. Through evaluation of lived experiential narratives, the application for practice is also addressed alongside emulation of the autistic voice in implementation of changes to increase both participation in life-intervening applications and progression of self and self-understanding.

Methodologies and ethics in participatory research: facilitating the voices of the 'unheard'

Oral

Catriona Stewart (Scottish Autism)

Genuine participatory approaches require methodological flexibility and a clear ethical framework. This short presentation asks questions about how researchers may facilitate the inclusion of those who are often marginalised or excluded through factors including gender, ethnicity, learning disability and those who are non-speaking.

Mindfulness (MBSR) for parents as a way to enhance resilience in families with Autism?

Oral

Ruth Lehm (Aarhus kommune), Lenette Johansen (CSB, Aarhus kommune)

There is good evidence that the 8 weeks Mindfulness Based Stress Reduction program (MBSR) can reduce stress, depression and anxiety. We know from our daily work that parents of children with Autism is more challenging and think other parents and often are quite stressed and fearful about the future.

This presentation will cover our first experiences of running an 8 weeks Mindfulness training program for 12 parents to children with Autism and severe behavioural problems in Center for Special Needs, Aarhus Kommune, Denmark.

We will present the structure, the background for the training and the preliminary results from the parents reports of the outcome of the program. And some quotes from the parents from our qualitative follow up interview.

One further said:" the program should be mandatory for all parents to children with autism - it has been a true life saver for me and my family.

Missing: autistic girls absent from mainstream secondary schools

Oral

Ruth Moyse *(University of Reading)*

A growing body of work has recognised that the prevalence of autistic girls is much higher than previously thought. Recent research has revealed a 'diagnostic gender bias' (Loomes, Hull, & Mandy, 2017), with girls less likely to be diagnosed as autistic than boys when presenting with the same symptoms (Dworzynski, Ronald, Bolton, & Happé,2012), when they are cognitively able, have superficially better communication skills and when they mask their difficulties (Dean, Harwood, & Kasari, 2016). Moreover, they are often diagnosed later than boys (Idring et al., 2012), and thereby do not have access to early support. These studies are important because they demonstrate the necessity of making suitable educational provision for autistic girls, even when the perceived impact on them is small.

There is some evidence that a growing number of adolescent autistic girls are dropping out of mainstream secondary schools, missing out on a fundamental human right to education, but little is known about the scale of the issue or why it is happening. The missed and mis-diagnosis of autistic girls (Gould & Ashton-Smith, 2011) has resulted in their stories being historically absent from studies about autism and about exclusion from school. This study recognises that these missing girls are uniquely placed to identify the events and experiences that led to them being out of school, and to make recommendations about how provision can be improved (Osler, 2006). It focused on engaging the girls as participants (Pellicano, 2014), and enabling them to give voice to their own experiences, to problems as they interpret them, and to their own aspirations and ideas of success, with analysis underpinned by a socio-cultural approach.

Topical life histories were collated over three sessions of semi-structured interviews, either in person or online using the text function of Skype, to explore the lived experiences of ten autistic girls who had started mainstream secondary schools but were not currently attending. The life history process sought to understand past school experiences and help the girls take ownership of their past, plus give them the opportunity to look forwards and extend their pathways towards ideas of a positive future (Goodley,1996). Timelines created using Tiki Toki software charted their pathways to absence. Chances to discuss and create meaning over multiple opportunities were provided (Cook, 2012), and the girls were encouraged to reflect back on their participation and supply further thoughts and additional details in a format with which they felt most skilled or comfortable (Morrow, 2008).

Preliminary findings identify that disengagement from school is a fluid and gradual process, resulting from the complex interaction of a range of factors. They show the multiple, often subtle ways in which autistic girls can be excluded from mainstream education, sometimes unnoticed, with economic, health and social consequences. The findings may alert schools to the signs and situations that can ultimately lead to the breakdown of a place-ment, plus reveal gaps in knowledge and understanding in schools that have implications for the provision of individual support as well as wider strategic planning.

Nothing about us without us! The centrality of autistic participation and lived experiences to communities of practice

Oral

Marion Hersh (*University of Glasgow*)

The paper uses the lens of the new DRILL-funded AnAuternative research project to reflect on the transformation of communities of practice on autism research through making autistic participation and lived experience a central value. The project originated in awareness of the limited involvement of autistic people in affecting decision making and determining interventions, which consequently did not always best meet our needs. About 1% of the UK population is autistic. Life experiences of autistic people are poor, with e.g. only about 16% in full time paid employment, compared to 47% of disabled people and 80% of non-disabled people (Office for National Statistics, 2016) and only 25% of young autistic adults having any post-school education or training (Paradiz, 2009). Existing research is largely biomedical rather than focusing on improving autistics' experiences and life chances (Pellicano et al., 2013). Various barriers exclude autistics from decision making, control over their own lives and community participation. Interventions often focus on 'normalising' autistic people e.g. through learning social skills and to recognise facial expressions rather than overcoming barriers and developing the existing abilities, skills and approaches of autistic people. They also rarely involve autistic people in their development and delivery.

The project is innovative in bringing together seven autistic people from a variety of different backgrounds, academic and non-academic, supported by an all-autistic Advisory Committee to carry out research from an autistic perspective. The research questions relate to the strategies used by autistic people in interactions with bureaucracy and to empower themselves and the barriers to greater participation of autistic people, including in decision making.

The project uses a mixed methods approach which draws on the diverse skills and different lived experiences of the seven researchers. Understudied intersectional issues and their impact on experiences, needs, strategies and barriers are an important component of the work. The project highlights process as well as outcomes. This has included developing ways of communication and working that involve and validate all participants' diverse accessibility and other requirements. The fact that we are members of the community we are researching will strengthen our research outcomes by enabling us to combine research skills with understanding of lived experiences in line with suggestions that involving autistic people (their families, schools and workplaces) in research will lead to stronger outcomes (Wright et al. 2014). In addition, our experiences as autistics has sensitised us the need to counter the disempowering negativity and deficit and deficiency language of much of the existing research to remove one of the barriers to the participation of autistic people in research.

The paper will draw on the experiences of AnAuternative and other positive examples, such as AASPIRE (Academic Autism Spectrum Partnership in Research and Education) (Raymaker and Nicolaidis, 2013) to draw up recommendations for communities of practice with central involvement of autistic people and our lived experiences.

Nothing about us without us: Capacity building to enable the benefits of participatory research

Oral

Wenn Lawson *(Autism CRC , Queensland)*

Abstract

Research co-production has been heralded as an important and necessary part of autism research. *'Collaborative co-production requires users to be experts in their own circumstances and capable of making decisions, while professionals must move from being fixers to facilitators' (*The Health Foundation, 2010. 3).

Some of the benefits of co-production such as targeted research direction, relevant research questions, appropriate processes for engaging autistic participants, improved utilisation of outcomes and dissemination are, without question, too important to overlook. However, in order for research co-production to become a reality, there is a need to capacity build both members of the autistic community (namely those on the autism spectrum) and researchers in co-production practices. This talk outlines aspects of both, including a developed set of inclusive research practice guides and checklists for researchers, as well as data from an Australian first research co-production workshop. The workshop enabled the graduation of attendees into our Research Academy.

This presentation provides an outline of co-production and its importance. The outputs and evaluation of the week long workshop, attended by 14 adults on the spectrum over 5 days and researchers (n=14) on one day, will be offered as an example. The workshop objectives, content, preparation, teaching and learning processes will be outlined, as well as the evaluative feedback from participants. Reflections of the project team will also be included by way of suggesting recommendations for the conduct of such activities in the future.

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Outcomes from The Autism Practice Improvement Framework – Professional development through creative communities of practice

Oral

Joanna Panese (Scottish Autism)

The Autism practice improvement framework looks at ways to recognise the intrinsic value of staff knowledge and how the understanding support staff have of those they directly support enhances the lives of autistic people within services. The APIF provides a robust and systematic framework for staff to take on ownership of the development of their own practice via self-assessment and keeps them at the heart of any practice development outcomes. APIF facilitators provide opportunities for communities of support staff to develop 'for staff by staff' outputs that feed into the overall development of practice across the whole organisation.

This seminar will explore the value of APIF and some of the outputs that have been created.

Practice Innovation: Lessons learned the hard way from an Aspie life

Oral

Debi Brown (N/A)

What does practice innovation mean if you're practicing your own life and you're not in an autism service? Autism involves a developmental delay and affects learning, but learning continues throughout life - we are always learning. In fact, we have extra learning to do: some social stuff that is obvious to other people, how to handle hyper-sensitive senses and emotions and our mental health, as well as how to cope as an autistic person in a world designed for non-spectrum people. Now aged 40, Debi looks back and describes her adult life journey and some of the hard-won lessons which have come from this.

Reaching Autism Families Together (RAFT): An Autism Specific Early Intervention Research model in Practice

Oral

Audrey Mullan (Autism NI), *Christine English* (Autism NI)

Research has found that Autism specific early intervention models that enable parents to participate and contribute skillfully can show effectiveness in supporting and improving outcomes for the child and family (Oono, Honey and McConachie, 2013).

The KEYHOLE® Early Intervention model was developed in Northern Ireland by Autism NI in conjunction with Speech and Language Therapists and Early Childhood Educators. Home based intervention within the model focuses on an individualised programme of activities implemented with parents to further a child's communication, play and social interactions. Several pilot programmes have been evaluated within the model to ensure its effectiveness.

A communication focused, home-based intervention was delivered to 35 families through 15–18 home visits over a nine-month period, showing significant improvements greater than any changes reported in a contrast group not receiving the KEYHOLE® home-based intervention. The research found significant improvements in the children's communication and related functioning and an increase in parental ratings of improvements for the child (McConkey et al, 2010).

In a further KEYHOLE® based intervention, 29 families completed a 6-week home intervention that included provision of a 'Rainbow Resource Kit', providing families with practical resources and information to use with their child. The study found that children showed improved play skills and that parents reported reduced stress when interacting with their child (McConkey et al, 2009).

This research has been used to underpin a current home-based early intervention service, Reaching Autism Families Together (RAFT). The RAFT service was developed to build and strengthen family relationships in families who had children with Autism under 12 years.

The RAFT Service introduces bespoke visual structure in the child's home environment through working with the child and by supporting the parent in their understanding and skill development. The programme is aimed to increase skills and independence for the child and decrease anxiety by promoting positive routines. It also aims to support parents in introducing daily living, play and organisational skills within their family.

In the first 3 years of the service (2015-2018), up to 7 weeks of support and intervention for 418 families has been facilitated. Parents report that bespoke visual structure for the child resulted in reduction in the child's and parent's anxiety and stress levels. Parents report a positive impact on their child with Autism and an improvement in the family's quality of life.

The project also provides practical skills training to parents and referral to family support groups in the local area to promote long term support for the family. Due to the parent-led nature of the service, the RAFT project has also been able to provide additional supports such as music therapy, Autism specific summer schemes and sibling support programmes. The service is currently developing a Sleep programme to further support families within the service.

The RAFT service highlights a good example of how an Early Intervention service can be grounded in Evidence based research but collaborative and flexible in nature to best meet the needs of the family.

Recognising and Valuing the Communication of Autistic Children in Schools

Oral

Rebecca Wood (University of Birmingham), Kabie Brook (Autism Rights Group Highland)

In this joint presentation, Rebecca Wood and Kabie Brook will discuss the communication of autistic children and the crucial role it plays in terms of their participation, well-being and inclusion in schools.

Rebecca will first explore these issues by employing empirical examples drawn from her PhD research based in five mainstream primary schools and including 20 autistic child and adult participants, as well as school staff and parents. Informed by an interpretative paradigm, her case study revealed some of the difficulties which can arise for autistic children as a result of the unquestioned association between autism and communication impairments (1, 2). This can be despite or even because of some of the strategies and interventions implemented in schools, ostensibly to provide communication support (3). Indeed, even though some of the autistic children experienced difficulties with pronunciation (2), word retrieval and narrative order (4), for example, this did not necessarily equate to communication difficulties in all cases. Moreover, Rebecca found not only that the communication of the autistic children varied significantly according to the context and general circumstances of their time in school, but that their diverse forms of self-expression were not necessarily recognised or valued by school staff. This was particularly if the communication of the autistic children did not correspond with the wishes or expectations of school staff, either in the mode of expression or the message conveyed. This led, in some cases, to frustration on the part of the children and a denial of their individual agency.

Kabie, who is autistic, will then develop this discussion further by reflecting on the vagaries and inconsistencies of the communication of non-autistic people from an autistic point of view, an issue which was also raised in Rebecca's thesis. Kabie will explain how the communication of non-autistic people creates its own difficulties, leading to misunderstandings and problems of interpretation, demonstrating that the link between autism and communication impairments should not necessarily be made. Both speakers will then reflect on examples of good practice in the support of the communication of autistic children, providing important lessons for researchers and practitioners in the autism and education fields.

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Robustness, reliability, and reflexivity in autism research for informing policy: lessons from the Benchmarking Autism Services Efficacy report

Oral

Karen Guldberg (University of Birmingham), Sarah Parsons (University of Southampton)

This seminar will focus on assessing the credibility of research that informs policy and practice. We will draw on our scientific review of the Benchmarking Autism Services Efficacy (2015) report to outline what we consider to be the key components of high quality research. We reflect on some of the implications that arise for policy and practice.

*This scientific review was funded by the John and Lorna Wing Foundation.

Systemic relational dynamics between autism practitioners and clients in professional care settings.

Oral

John McDermott (Studio III Clinical Services)

This study examines the nature of the practitioner/client relationship in autism care settings, exploring the role of relational dynamics in client experience. Research among parent caregivers suggests that people who have an autism diagnosis may have experiences of relationship which are not normative or typical. A qualitative research design was therefore chosen in an attempt to comprehend the individual experience of participant practitioners and set aside *a priori* assumptions or hypotheses. 6 autism care practitioners engaged in semi-structured interviews, which were then analysed within an interpretative phenomenological analysis framework. Findings suggested that professional and diagnostic imperatives often compete with practitioner desire to be "emotionally available" to the people they support. Relational dynamics were also felt to influence the relational and emotional competence of clients. These findings suggest that it may be helpful to focus future research and practitioner training interventions on interventions which place greater emphasis on facilitation of relational engagement in autism care settings.

Ten Rules for being a bad employer for someone on the autistic spectrum - and maybe what to do about it

Oral   35

Richard Mills (AT-Autism and University of Bath), Damian Milton (University of Kent), Sandra Robilliard (Scottish Autism)

Autistic adults often have a very strong motivation to work and possess high level of skills and competencies. Despite this they are underrepresented in the workforce. This short presentation explores why this might be and some ways forward.

Ten Rules for being a bad employer for someone on the autistic spectrum - and maybe what to do about it

Ten Rules for Ensuring People with Learning Disabilities and Those Who Are On The Autism Spectrum Develop 'Challenging Behaviour'…and maybe what to do about it

Oral

Richard Mills (AT-Autism and University of Bath), Damian Milton (NAS and PARC)

The '10 Rules for ensuring challenging behaviour' was first presented at the Learning Disability Today conference in 2016 and was later turned into a short book by Pavilion. It is a tongue-in-cheek but deadly serious approach to identifying what we still see in many areas of practice that result in people being stigmatised and described as 'challenging'.

Ten rules to ensure autistic people obtain poor mental health support

Oral 37

Richard Mills (AT-Autism and University of Bath), Damian Milton (University of Kent)

We are aware that a substantial number of autistic children and adults additional or overlapping mental health difficulties are significant yet they will often encounter huge barriers to getting their needs understood and met. This session will explore some of these difficulties and some of the possible solutions to them.

The development of the Participatory Autism Research Collective (PARC)

Oral

Damian Milton (University of Kent)

PARC is a network set up to bring together autistic people,including scholars (and also students, non-academics and activists), with earlycareer researchers and practitioners that work with autistic people. The aim of this network is to build connections between those who wish to see more significant involvement of autistic people in autism research, and to provide a space for sharing knowledge and expertise. The PARC network follows in the footsteps of previous autistic-led projects such as the Autonomy journal and the Theorising Autism Project. The project was initially based at London South Bank University, where PARC has held a number of events and meetings since 2015, hosting visiting speakers such as Dr. Wenn Lawson, Dr. James Cusack and Dr.Sarah Cassidy, as well as holding book launches for those involved in the group. Since these initial meetings, the group has recently expanded to holding meetings in Birmingham and Sheffield, and initial discussions have begun in Edinburgh and Canterbury.

This presentation would review the progress of the PARC network thus far and its hopes for the future. For example, members of the PARC group have contributed to major projects such as The National Autism Project and The Westminster Commission on Autism and will be looking to expand upon these links in future. The PARC group has also led to a number of publications through Pavilion Press and will be involved in editing special editions of the Scandinavian Journal of Disability Research (SJDR) and Advances in Autism, as well as organising streams at a number of conferences.

The Importance of Sensory Aspects of Autism: A strong example of community and practice-led research?

Oral

David Simmons *(University of Glasgow)*

Despite sensory aspects of the condition being mentioned in the earliest descriptions of autism in the 1940s, it was not until the publication of DSM-5 in 2013 that their importance was fully acknowledged in diagnostic criteria. Why did this take so long? Autistic individuals and their families have long known that the combination of sensory hyper-sensitivities and hypo-sensitivities which are characteristic of autism are a major factor in everyday life and can often be associated with high levels of anxiety. Practitioners are similarly acutely aware of how much sensory factors can affect the day of the individuals they work with. However, when I first became involved with autism research in the early 2000s I was surprised that there was so little academic research about these sensory aspects of autism. Fast-forward 15 years and we now have special sessions of autism conferences, a variety of experimental approaches and even whole theories of autism built on the primacy of sensory factors in the autistic phenotype. In addition, governments, public institutions and businesses have woken up to the difficulties caused by sensory stress and have taken steps to reduce it as part of efforts to make environments more "autism-friendly". In this presentation I will give an overview of what we currently know about sensory aspects of autism and chart how the efforts of individuals, families, practitioners and a few enlightened researchers have brought about this greater acknowledgement of this crucial feature of autism.

The use of Mindfulness in a specialist school for autistic and ADHD students

Oral

Birgit Drasbaek Soegaard Isene (Langagerskolen), Susanne Hvidtfeldt (Langagerskolen, Aarhus)

Our project investigates whether mindfulness reduces stress and improves well-being for children and adolescents in a special school context.

Langagerskolen is a public school in Aarhus, which provides special education for children with autism and/or severe ADHD. The specialized pedagogy and teaching at the school is based on the visualized, structured learning approach, low arousal approach, and the Atlass program and Mindset.

In the last couple of years Mindfulness interventions has become widely recognised and applied. One example is Mindfulness Based Stress Reduction, which is an evidence based course developed by Jon Kabat-Zinn. At Langagerskolen, we offer all staff the possibility to attend an 8-week Mindfulness Based Stress Reduction course, as a way of supporting their well-being.

In addition, we (the authors) have been trained in administering the MyMind program, which is a Dutch Mindfulness program for children and adolescents with Autism Spectrum Disorders and have been part in a Danish research program examining the effect of a 9-week Mindfulness intervention, administered independently (but in parallel) to both parents and children.

Based on these experiences, we have developed a research project, where we select and develop exercises, focusing on psychoeducation, mindfulness and training of attention for two different age-groups; the younger group from 6-11 years old, and the older group from 12-17 years old.

This presentation aims to show our project with Mindfulness in a specialist school setting with children with autism and/or severe ADHD.

Our research question is:

Do Mindfulness training complement other interventions at Langagerskolen, and increase mood and reduce anxiety

The oral presentation focuses on the following:

Presentation and background

What is Mindfulness

Why Mindfulness in a special school setting

A clinical question is described within the frame of the PICO model: Population, Intervention, Comparison and Outcome. Examples from the manual is shown.

The voices and experiences of children with autism, and their families, in their transitions from nursery to primary school

Oral

Sarah Parsons (The Centre for Research in Inclusion, Southampton Education School, University of Southampton, UK), Hanna Kovshoff (The Centre for Innovation in Mental Health (CiMH), Psychology, University of Southampton, UK), Kathryn Ivil (Aviary Nursery, Eastleigh, UK), Gareth Shaw (Aviary Nursery, Eastleigh, UK), Efstathia Karakosta (The Centre for Research in Inclusion, Southampton Education School, University of Southampton, UK)

Young children with autism are amongst the most scrutinised and assessed in their everyday lives, often leading to characterisations and descriptions that focus on their difficulties and challenges rather than on their abilities, strengths and positive experiences. Consequently, much discussion about children with autism tends to forget that they are children first. While research has considered the transitions of children with autism from primary to secondary school, and from secondary to post-compulsory contexts, there is almost no research focusing on transitions for young children with autism from nursery to primary schools. There is also very limited representation of their voices and experiences being explored, promoted, and valued directly as evidence in their own right.

Our presentation is about our current project that is funded by the Froebel Trust and co-produced with practitioners, families, and children. The project aims to capture, through digital storytelling, the experiences and perspectives of young children with autism (aged 4-5 years), and their families, as the children prepare to make the transition from nursery to primary school. The setting, Aviary Nursery, is an inclusive day nursery in Eastleigh, Hampshire that prioritises children's play, interests, friendships, and different ways of communicating and interacting with each other.

This project will follow 4-6 children during the months before their transition, placing children's voices/views at the centre of the research through highlighting their unique trajectories via individual digital stories. The stories will illustrate both the positive experiences and the challenges that children and their families face as well as model how these challenges are mitigated by school-based processes. The digital stories are important in terms of their co-creation with teachers and families, giving validation and voice to diverse experiences and views, and offering new insights and approaches to evidence-based practice. The stories will also be used in a novel way as a tool for facilitating the transition by introducing the primary school to the child *as a child*, rather than as a paper-based description of needs and difficulties. Our presentation will give an overview of the project and present an example of the stories produced.

This project is part of the Autism Community Research Network @ Southampton [ACoRNS; www.acornsnetwork.org.uk] initiative that brings together researchers and practitioners to jointly identify and construct a research agenda that is mutually informed by, and informing of, practice. In other words, we jointly agree on research questions that are of direct interest and importance to practitioners and devise projects that will help to answer those questions. Our agreed priorities are the transitions and trajectories of children and young people with autism, with the aim of understanding what best practice looks like and how we can share evidence-based knowledge more widely. ACoRNS places children and young people's views and experiences at the core of what we do.

Using Acceptance and Commitment Therapy with autistic people: The importance of mindfully exploring autistic values in the pursuit of mental wellbeing.

Oral

Claire Evans-Williams (The Autism Academy UK)

Acceptance and Commitment Therapy (ACT; spoken as the word "act"), is an empirically evidence based psychological or "talking" therapy that has been an extremely effective method for supporting neurotypical adults and children with various mental health difficulties. Despite the paucity of rigorous research in using ACT within the autistic population, evidence of it's benefit in combating the mental health difficulties of autistic people is tentatively emerging.

A criticism of traditional Cognitive Behavioural Therapy (CBT) is that it aims to achieve a level of control over a person's thinking style, emotions, bodily sensations, and attempts to challenge the memories, private events, and lived experiences of the participant. In so doing, one could argue that the processes of traditional CBT come uncomfortably close to undermining and potentially denying the challenging reality of living as an autistic person in a neurotypical world.

Unlike other psychological therapies, ACT does not aim to eliminate the experience of difficult and unpleasant emotions; rather it's central feature is in inviting the participant to be present in the moment, be willing and open to the experience unpleasant feelings, and crucially not to attempt methods to avoid or escape situations in which these feelings arise. Importantly, participants of ACT are guided to explore and connect with their personal values, leading them on a fruitful journey of self-discovery, and opportunity to find meaning in their life, and gain improvements in psychological flexibility.

This presentation will very briefly describe the ACT framework and then consider some potential challenges of applying ACT to the autistic population. Thereafter there will be exploration of useful modifications to ACT that can be implemented to adapt and attune ACT for the autistic community.

Utilizing the lived experience of autistic people to successfully participate in work and training

Oral

Tomas Pattison (Kibble Education and Care Center)

Participation – valuing the lived experience of autistic people

A few weeks ago, I read on the National Autistic Society website that only 16% of autistic adults are in full-time paid employment. At the moment I am lucky enough to be in that small group. I am child and youth care worker at a residential school catering for young people with complex needs. However, I have been unemployed for over half my adult life. My lived experience is that I have difficulty maintaining employment as opposed to finding it. I have had over twenty four different jobs, mostly only lasting from a few months to a year

I was diagnosed as autistic at forty four, and since then I have spent considerable time self reflecting on things I have always found problematic, such as my employment history. I realized that participation was always at the core of the majority of problems I faced in the past that resulted in me leaving employment. Social phenomena that I don't participate in such as Christmas, staff nights out, world cup, or pop culture in general have historically been problematic times for me at work. My indifference to the majority's participation in such things is often misread negatively and on a few occasions the situation has escalated to leave me sufficiently isolated from my colleagues that I have quit or been sacked.

Personally, the greatest challenge I face when maintaining employment is staff training. More often than not it will be related to group work, specifically role-play. In two occasions. I became over stimulated and went into meltdown which led to me to almost being sacked.

Post diagnosis, I have made employers aware of my condition and explained how I can find training difficult. However, all this usually does is generate a response of 'it's okay this training is autism friendly'. One such session sent me into a state of over stimulation so extreme that I had to leave the training and it resulted in two days off sick.

I explained to my current employers that, unfortunately a great deal of their training programme was inaccessible to me despite my desire to participate in it. Fortunately they have taken this very seriously and value my lived experience as an autistic person when it comes to identifying how their training programme can be accessible to autistic workers.

It was suggested to me that I could simply sit out any parts of staff training that I didn't feel comfortable with. I pointed out that say I was a wheelchair user and was on a training course which involved running on the spot as an icebreaker, I would not be given permission to just 'sit it out' as this would isolate me and draw attention to a my disability whilst emphasizing one of it's limitations. So why do the same to me. This was taken on board, and is an example on how we as autistics need to share our lived experience to promote inclusivity and participation.

Voice, Participation and Involvement in autism services – development of an evidence informed guide for practice

Oral

Joanna Panese (Scottish Autism)

This seminar will explore the value of including the voices of autistic people in research that directly enhances their lives, alongside the voices of support staff that work directly with them. The guide was produced by a group of education and support practitioners in collaboration with a number of autistic individuals who access services through Scottish Autism. The guide considers support and education strategies that harness individuals' unique ways of communicating in order to exercise greater choice in their lives: in choosing day to day activities, in being included in major life decisions, taking part in service review processes and being heard as part of their community. The guide was produced as a means of disseminating this learning across the organisation and as a well to help enhance practice in this area.

Why autism works - tapping the advantages in employment

Oral

Adam Feinstein (Autism researcher and historian)

In this presentation, **Adam Feinstein** - author of a new book on autism and employment to be published by Routledge in August 2018 - will examine the considerable strengths of many people on the autism spectrum which make them a vast untapped human resource in the workplace. Never has this presentation been more relevant. The prevalence of autism spectrum conditions is reported to be as high as one in 68 by the US-based Centres for Disease Control and Prevention. That would mean there are more than 600,000 people with autism in Britain. However, according to the National Autistic Society's 2016 report, 'Autism Employment Gap,' just 16 per cent of autistic adults are in full-time employment in Britain and only 32 per cent are in any kind of paid work at all. The NAS says this figure has remained the same for the past decade, indicating that people on the autism spectrum are not benefiting from Government employment programmes. Moreover, the emotional benefits of being employed are immense. As the world's most famous woman with autism, Temple Grandin, who designed a third of all the cattle ranches in America, puts it tellingly: 'Without work, no matter how big or small the job, life would become small and unsatisfying.' Using many illuminating research studies and individual case studies, Feinstein will analyse previously neglected aspects, including the very real potential openings available for some individuals on the so-called 'lower-functioning' end of the autism spectrum, even those without any language at all, and the crucial issue of gender differences in the workplace (autistic females tend to be more able to 'camouflage' their condition, but this masking effort can often lead to stress and depression). He will demonstrate why employing autistic people makes sound economic sense and demolish the well-meaning, but misleading, stereotypes about autism which prompt some employers to adopt misguided approaches to managing their staff members on the spectrum. Finally, Feinstein will not ignore the very real challenges faced by autistic individuals in the workplace – and will, indeed, tackle the advantages and disadvantages of entering the world of self-employment, instead.

Working in partnership: A project example focused on Autistic parenting

Oral

Sue Fletcher-Watson (Patrick Wild Centre, University of Edinburgh), *Kabie Brook* (Autism Rights Group Highland)

To follow

Poster Abstracts

'Keeping up is hard to do'

Poster

Ken Aitken *(University of Glasgow; Napier University; NHS Lothian)*

Successful innovation relies on knowing what has been done and what research is currently underway. Otherwise it is all too easy to replicate, plagiarise or repeat blind-alley studies, wasting time, money and the most important thing in practice innovation, enthusiasm.

Unfortunately the number of books, papers, stories, websites, films and TV documentaries on ASD is now enormous and increasing at such a rate that it is almost impossible to keep track. As the volume of new information is now so great, and the rate of new publication so high, the idea of a single Handbook or Encyclopaedia daunts most publishers. Any updating can be more extensive and expensive than the original, and increasing prices make sales of new editions lower. Moving to a format that allows material to be updated as needed can help to limit this problem.

It is easy to be deterred from thinking about exploring an innovative idea by thoughts popping up in the back of your head: "Is this my idea, or did I see it in a documentary/ at a meeting last year/ hear it in a course lecture/maybe I overheard people talking about it at a conference or over coffee."

This year sees the launch of a novel system that should help to make the task of keeping up-to-date much easier: An on-line, updated as necessary multi-authored system called 'Elements of ASD'. Each element is a stand-alone summary, but is also linked to both the literature and the rest of the system. Each element will be updated as progress is made, with updated system and literature links.

This talk will introduce the Elements system, explain it's layout, depth and coverage, and help to show how Scotland is maintaining it's place at the forefront of innovations in autism practice.

A mixed methods investigation into loneliness in autistic adults

Poster

David Zammitt (*University of Glasgow*)

According to the National Autistic Society, autistic adults often experience social isolation. Related to this, studies have found increased levels of loneliness in adolescents on the autism spectrum (e.g., Whitehouse, Durkin, Jaquet, & Ziatas, 2009; Lasgaard, Nielsen, Eriksen, & Goossens, 2010). There is, however, a lack of research looking at those over the age of 18.

More than 1% of the UK population have a diagnosis of autism (Brugha et al., 2012), with 32% of this population reporting depression (Cassidy et al., 2014). Loneliness, meanwhile, has been found to be linked to affective disorders (e.g. Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006). It is vital, therefore, to understand the relationship between loneliness and autism in adulthood. We must recognise the factors which contribute to it and, most importantly, we must gain an understanding of its lived experience if this problem is to be addressed. To achieve this, the present study will use a mixed methods questionnaire to compare an autistic group and a non-autistic group in order to explore how these populations' experiences of loneliness, and mental health in general, differ.

The questionnaire incorporates the UCLA Loneliness Scale (Russell, Peplau & Ferguson, 1978) to measure loneliness, while the Depression Anxiety Stress Scale (DASS) (Lovibond & Lovibond, 1995) is used to measure levels of anxiety and depression. In order to ascertain perceived social support, the Interpersonal Support Evaluation List (ISEL) (Cohen, Mermelstein, Kamarck & Hoberman, 1985) is also included. In addition to this, a qualitative component, using open-ended textboxes, is designed to capture the lived experience of loneliness in autistic individuals, including perceived solutions to this problem from within the autistic community. Recruitment, via social media, has begun strongly, with data for 65 participants (25 autistic participants, 40 non-autistic) already collected. This includes over 3,000 words of qualitative information. This is ongoing, and the recruitment end date is 31st May 2018.

It is hoped that the results of this study will be useful for the autistic community and for a wider society which is often poorly-informed in relation to autism. It is also hoped that the outcomes will be used by professionals in applied settings, such as clinicians, educators and public bodies.

An investigation of social aspects of mental health in autism

Poster

Clara Davidson *(University of Glasgow)*

Background

Autism Spectrum Disorder (ASD) has traditionally been characterised by a triad of impairments in social communication, social interaction, and flexibility of thought and action. Understanding how the aspects of this triad – now thought of as a dyad of social communication and repetitive behaviour - affect social interaction and overall emotional wellbeing of autistic adults is an important research aim. Mental health in autistic individuals was a main goal identified by Autistica through consultation with community members. Most research in autism focuses on children and uses older (pre-DSM 5) nomenclature, allowing this study to contribute to a modern wave of autism research.

Adults with autism may be particularly vulnerable to further mental health conditions, such as anxiety and in particular social anxiety, due in part to their impairments in social interactions. In particular, over 75% of autistic adults have a comorbid mental health diagnosis, the majority of which involve depression or anxiety disorders. It's also been found that autistic individuals experience higher levels of social anxiety than the general population – these mental health issues likely reduce the quality of life in this group. The present study seeks to understand how camouflaging, paranoia, fear of negative evaluation, and internalised stigma affect an individual's social anxiety as well as their overall mental health.

Methods

Recruitment for this project is currently ongoing. This is taking place via social media, with a recruitment end date of May 31st – 19 participants of a planned 50 have been recruited thus far. This study will use a series of previously validated and statistically reliable measures to investigate predictors of social anxiety in autism, and it is hypothesized that these will include mood disruption, social evaluative concerns, experiences of internalised stigma, and camouflaging.

Results

The data collected in this study will be subject to multiple linear regression to better understand the aforementioned predictors of social anxiety.

Implications

The results of this project will therefore be useful in helping to understand social anxiety in autism, which is currently not well understood or researched, and its possible contributing or maintaining factors. Social anxiety is generally a significant predictor of distress in the general adult population, and has an estimated prevalence rate of 12%, though it's likely that this rate is higher for autistic adults. The results of this study will therefore be distributed among clinicians with the hope that they'll be useful in informing practice that prioritizes autistic individuals' mental health.

Applying cognitive enhancement therapy to improve functional outcomes in autistic adults: A case study

Poster

Damien Williams (The Autism Academy UK), _Claire Evans-Williams_ (The Autism Academy UK)

The often disabling nature of the social world means that autistic adults may struggle to engage in everyday activities. In order to function effectively, autistic adults need physical, emotional, _and_ cognitive health. Thus, difficulties with executive functions that characterize autism (e.g. attentional control, cognitive inhibition, memory, and cognitive flexibility) can impede engagement with the social world. While the optimal outcome in the design and delivery of real and virtual interfaces to common activities would be to assimilate neurodiversity, this may not come to fruition in time for the current and next generation of autistic adults to lead the fulfilling life they deserve. The alternative is to adopt an approach to working _with_ autistic adults that serves to enhance their executive functions thereby developing functional outcomes.

Within the therapeutic toolbox, cognitive enhancement (CE) is one approach that focuses on improving functional outcomes. However, CE has traditionally, and most successfully, been applied in therapeutic working with individuals diagnosed with schizophrenia (along with other forms of psychosis, i.e. bipolar disorder type I). Despite this, CE holds promise as a means of working with autistic adults to enhance functioning.

This paper presents a case study describing our work with an autistic adult – SJ. The focus of the work revolved around SJ's desire to 1. enhance their sequencing abilities, and 2. enhance their ability to navigate different transport networks. Given the practical nature of these needs, a strategy-based/compensatory training approach to CE was applied. This involved scaffolding of planning and implementation activities of increasing sequencing complexity in the area of transportation. An initial 6-meeting programme was co-produced that incorporated "paper"-based planning (i.e. reading and using timetables) and supported, real-world implementation activities (i.e. journeys of varying lengths on different modes of transport). The assessment of CE occurred through direct observation of functioning, particularly command of sequencing. In conclusion, not only did CE prove to be effective in enhancing the functioning priorities identified by SJ, but the real-world, practical nature of CE was reported as being particularly beneficial to SJ whom had been dissatisfied with previous exposure to cognitive behavioural therapy which was ultimately unsuccessful in fulfilling their needs.

ASK:Autistic Space Kit. Autistic Empowerment for the 21st Century

Poster

Kabie Brook (ASK), Dinah Murray (ASK), Kevin Brook (ASK)

The focus of ASK, Autistic Space Kit, is the empowerment of Autistic individuals as well as ways to equip professionals in order to support them better, such as supporting and enabling communication, translating theory into practice, and autistic rights.

About the ASK - the Autistic Space Kit

What it is? Specific autistic owned and designed app for both the iPhone and Android phones to extend the potential of autism alert cards via 21st century electronics, so as to empower the individual using them by giving them control of situations which could otherwise escalate catastrophically.

The project is entirely under autistic ownership, from the original concept through to design; autistic people working together to produce solutions for ourselves and for others who will benefit from the end product.

Empowering autistic people by

- Increasing their confidence in their ability to handle difficult situations
- Enhancing mutual understanding,
- Providing other people with immediate suggestions of best approach for each specific person.
- Resolving and shortening communication crises,
- calling upon needed support,
- Informing self and chosen others re location

The app can be fully personalised and is simple, fast, and direct to use.

Awareness within local authorities in England of autism spectrum diagnosis of Looked-After children

Poster

Sarah Parsons (The Centre for Research in Inclusion, Southampton Education School, University of Southampton, UK), Alice Mccullen (The Autism Community Research Network @ Southampton), Tracey Emery (The Centre for Innovation in Mental Health (CiMH), Psychology, University of Southampton, UK), Hanna Kovshoff (The Centre for Innovation in Mental Health (CiMH), Psychology, University of Southampton, UK)

While there is considerable research into specialised autism interventions, and increasing awareness about the school-based experiences of children and young people on the autism spectrum, there is very little information about, or study into, the experiences of those being Looked-After by their local authority (i.e. those 'in care'). What we do know is that educational outcomes for these children are significantly poorer than for autistic children not being Looked-After by the local authority, suggesting that autism diagnosis is an important factor that interacts with experiences of provision (Sebba et al., 2015).

This study used Freedom of Information (FoI) requests, sent to all 152 local authorities in England in 2017, to ascertain the numbers of autistic Looked-After children and whether these numbers, and children's needs, are reported and monitored at a strategic level within the local authority. This paper reports the data from the 147 local authorities who provided a response. Approximately 3% of Looked-After children in England are recorded as having an autism spectrum diagnosis although this is very likely to be an underestimation. The majority of local authorities do not routinely monitor or report on thediagnostic status of Looked-After children with an autism diagnosis at a strategic level. This raises important questions for whether and how diagnostic status is appropriately monitored by Corporate Parenting Boards when planning for, and overseeing, children's placements, development and progress.

This project is part of the Autism Community Research Network @ Southampton [ACoRNS; www.acornsnetwork.org.uk] initiative that brings together researchers and practitioners to jointly identify and construct a research agenda that is mutually informed by, and informing of, practice. In other words, we jointly agree on research questions that are of direct interest and importance to practitioners and devise projects that will help to answer those questions. Our agreed priorities are the transitions and trajectories of children and young people with autism, with the aim of understanding what best practice looks like and how we can share evidence-based knowledge more widely. ACoRNS places children and young people's views and experiences at the core of what we do.

The current study was initiated from the community by a parent, one of the co-authors (AM), who had concerns about the extent to which Looked-After children with an autism diagnosis were known to local authorities, and their own experiences of the care system. Using FoI requests in research is a rich but underused source of data for systematic investigation (Walby & Larsen, 2011). Such a methodology also performs important democratic functions, both in terms of holding public authorities to account through making their workings more explicit, and through enabling wider participation of the public in research. In line with our co-production values underpinning research via the ACoRNS initiative, the use of FoI requests as a data collection tool is, therefore, highly appropriate, as Savage and Hyde (2014; p.304) note:

'...freedom of information has the potential to democratise the conduct of research beyond professional researchers by allowing a broader selection of the public to become engaged in research'.

Conducting Interviews with Autistic Older Adults; Methodological Reflections from a participant led interview research study

Poster

Jennifer kirton (Edge Hill University), Tony Ryan (Sheffield University), Angela M Tod (Sheffield University)

Title
Conducting Interviews with Autistic Older Adults; Methodological Reflections from a participant led interview research study.

Abstract

Background

In recent years there has been growing emphasis on the importance of qualitative research involving autistic 'participants'. It is felt that high quality qualitative research involving autistic people themselves as opposed to proxy accounts which tends to be more common, is more appropriate and applicable. Autistic people can be viewed as the true experts in autism and as such evidently it is important that their experiences and insight should be explored and shared.

Currently there is a lack of qualitative research involving autistic people and an inadequate amount of published guidance available on how to ensure that the research process is accessible and equitable for autistic co-researchers.

Rationale

Presented are reflections from an in-depth interview study of methodological experiences and insights into conducting qualitative interviews WITH autistic people. Data were gathered from 20 separate in-depth interviews (where each of 10 autistic people were interviewed on two separate occasions). Interviews were conducted as part of a qualitative interview research project exploring the experiences of autistic older adults.

Drawing on the experience of both the autistic person being interviewed and the academic researcher, suggestions are made on adaptations/considerations that can be made to the research process to assist with accessibility.

Main points

Recommendations are made on how the process can be adapted in the following areas:
Documentation, managing expectations, location of interviews, ethical considerations, person-centred approach, power balance/imbalance, agreeing terminology/language, individual ways of working, reflective working, creating a structure, the researcher relationship, adaptation of environment, appropriate communication styles and strategies to minimise the impact of neurotypical analysis on autistic voices.

Conclusion:

Presented are the subtle differences in ways in which the research process can be managed and designed to make it accessible for autistic 'participants'. Consideration and information gathering regarding specific individual's needs can help to enable both researcher and autistic 'participant' to engage fully with the research and to aid effective and equitable communication. A secondary meeting to discuss analysis can help minimise the

impact of neurotypical misinterpretation of autistic opinion and open and honest and direct communication can help to ensure better accessibility for the autistic 'participant'.

Author Jennifer A Kirton, T Ryan, A Todd

Jennifer is a Research Associate in the Faculty of Health and Social Care at Edge Hill University. Jennifer's first degree was in Psychology and she has an MSc in Social Research & Evaluation from University of Huddersfield; a Postgraduate Certificate of Education from Leeds Metropolitan University and she is currently enrolled on her doctoral studies at Sheffield University. Her doctoral study focusses on the lived experience of older autistic adults.

Enhancing positive emotions and wellbeing in autism - Perspectives from positive psychology and experiences from real life

Poster

Michael Harboe Kvistgaard (Center for Specialpædagogiske Børnetilbud (Centre for Children with Special Needs))

In the field of special needs it´s easy to forget to work on enhancing wellbeing, and instead focus one´s attention on deficits and challenges. Based on my experiences as a special need consultant and pedagogue however, there is a huge potential for not only increased wellbeing and quality of life for individuals, but also for the individuals to develop further competence of life, if we as supporters change our perspectives. The poster will be based on 1) scientific theories and 2) practical experiences from special need work with one of the elements (Positive Emotions), in the PERMA framework of wellbeing. PERMA is made by Martin Seligman, one of the originators of the field of positive psychology, which is the science of human flourishing and optimal functioning. PERMA consists of the following elements "Positive emotions, Engagement, positive Relationships, Meaning and Accomplishment. The poster presents different ways to enhance positive emotions. When focusing on positive emotions, it´s obvious to search within the area of positive psychology for tools and understandings. Thus the "Broaden & Build" theory by Barbara Fredrickson will become a central element. Also, it would be likely to stumble over the concepts of "Character Strengths" and "Flow" – both concepts that in themselves can be understood as enhancing positive emotions and wellbeing.

I believe there´s a great potential (for wellbeing and learning) in rethinking the special need work into a more happiness and wellbeing oriented approach. Autism is far more than deficits.

Enhancing wellbeing for siblings to children with ASD and other disabilities – perspectives from training and the companionship with the siblings

Poster

Merete Kirkfeldt (Center for Specialpædagogiske Børnetilbud (Centre for Children with Special Needs)), Anne Thomsen (Center for Specialpædagogiske Børnetilbud (Centre for Children with Special Needs)), Camilla Røy (Center for Specialpædagogiske Børnetilbud (Centre for Children with Special Needs)), Camilla Hellegaard (Center for Specialpædagogiske Børnetilbud (Centre for Children with Special Needs))

The poster exemplifies selected elements of the sibling program and the poster also contains short quotes from children and parents.

The content of our program is to introduce the sibling to:

- The development of the brain

- Different diagnoses

- Mindfulness

In the program, we present the siblings with kid friendly versions of the above mentioned, we watch a film together that concerns issues of being a sibling to a child or youngster with disabilities and we strive to give them tools to their own daily life in their families. We also have dinner together every time to create a nice atmosphere.

- All the siblings get to tell the group about themselves, their family and their disabled sibling and they often form a bond between each other.

  The program lasts 4 weeks. We meet once a week in a duration of 2½ hours.

  One of our goals with this program is to give the siblings a feeling of shared life circumstances apart from the knowledge of the different subjects mentioned above.

  We have discovered that we with our program make a difference to these siblings.

Going from strength to strength: building capacity and promoting individualism in autistic teenagers using a values-focused approach

Poster

Samantha Roberts (Edge Autism Limited)

Abstract: The idea of Edge Autism began in 2015 following identification of a significant gap in service provision for *so-called* "high-functioning" autistic teenagers. The needs of this population are often missed or underrepresented due to the misattribution of their clinical presentation as seemingly "high functioning" and therefore not in need of community-based support. The successful adaptation of developed coping strategies such as camouflaging/masking, and mimicking of others often results in an incongruence between perception of functional ability and the reality of an autistic teenager's struggle to manage basic, activities of daily living within neurotypical society. Consequently, this group frequently fall short of local authority and NHS mental health service assessment parameters for support. The inception of Edge Autism in 2016 addressed this gap in service provision by responding to the urgent need for support in serving the autistic teenage community.

Edge Autism has a unique, innovative, and highly successful model of working, which prioritises the needs, values, and opinions of the autistic community. This presentation will explore each of the factors that contribute to Edge Autism's growing success and popularity: 1. Use of qualitative methodology in scoping exercises to capture the views and needs of autistic teenagers and their families. For instance, autistic teenagers expressed concern regarding their peer-image and how the presence of a support worker may influence this; 2. Staff recruitment has been guided by autistic-teenager's requests for support staff to be well matched to a number of variables including age, gender, personality, and hobbies and interests. For instance, Edge Autism recruit educated and talented staff with varied experiences such as musicians, surfers, and film-makers.3. Clinical consultation and supervision with highly trained health care professionals enables safe and ethical support of the autistic teenagers we work with; 4. Our values and principles are grounded in the Social Model of Disability which guide us towards participatory and inclusive approaches in all of our work. For instance, we do not prescribe goals to achieve based upon a socially-constructed concept of *normality*. We respectfully listen and learn from the teenagers we work with – and our goal is to support them towards the attainment of their needs and goals. The last segment of the presentation will offer some brief case examples to illustrate positive outcomes from this model of working.

iPad applications for children with autism

Poster

Alexia Achtypi (University of Birmingham)

Over the past decade the prevalence of autism in the United Kingdom has increased, with the latest studies suggesting that more than one in one hundred people in the population has autism (Brugha et al., 2012). Some of the most significant difficulties that these individuals experience relate to social communication and emotional regulation (Eigisti et al., 2008). Thus, their social and educational inclusion can be challenging, holding them back from reaching to their full learning potential (Crosland & Dunlap, 2012).

Recent research findings suggest that individuals with autism show great interest in technology, such as computers and tablets (Orsmond & Kuo, 2011). Consequently, many studies have focused on the benefits of Technology Enhanced Learning (TEL) interventions for people with autism (Grynszpan et al., 2013). However, most of the research is limited in scope and does not explore the effectiveness of TEL strategies in real-world classrooms, creating a persistent disconnect between theory and practice (Fletcher-Watson, 2014) Thus, the proposed study aims to contribute to the growing area of TEL research, by investigating how iPads are used to support the social communication and emotional regulation for children with autism and the extent to which the use of iPad practices impacts on their level of motivation and engagement.

More specifically, my poster aims to provide an overview of the research design, methodology and methods that have been used for the data collection. In addition, it will be briefly outlined the underlying theoretical approach of the study and how it has informed the data collection and analysis process. Finally, some of the preliminary findings will be presented, focusing also on the next steps of the research project.

iRoam- How interactive video tours can reduce anxiety

Poster

Adam Barrett (Access Social Ltd), *Anthony Curran* (Access Social Ltd)

We have developed software, iRoam, which enables visitors to explore spaces and venues before visiting in person. The Key difference between this and other formats like Google Maps, is that the videos include key details like toilets, navigation videos from the front door to assets in the building. Probably the most important is the inclusion of audio. We like to film the venues when open if possible as to best capture the essence of the building. We hope our videos will enable all visitors to plan their visit from the comfort of their own home. Please visit www.accesssocial.co.uk for examples of our work.

Mathematical Problem Solving, Bar Modelling and Autism - Negotiating the journey towards an inclusive curriculum

Poster

Shaun Thompson (Bishop Grosseteste University/Durham University)

There has been a noticeable increase in the number of students being diagnosed with an autism spectrum disorder (ASD) over recent years (Lindsay, Proulx, Thomson, & Scott, 2013) with a steady increase over the last four decades (Baron-Cohen et al., 2009), and more than 70% of these pupils attend mainstream schools (APPGA, The National Autistic Society, 2017, p. 9). The latest government data suggests that 14.4% of pupils educated in English, state funded, mainstream primary schools, have a recognised Special Educational Need (SEN). Of these, 4.4% have SEN support for autism and 27.8% have an education health care plan (EHCP) in place for autism, thus equating to 4.64% of all pupils in these settings having a diagnosis of autism. (Department for Education, 2017). This increase in awareness and diagnosis has driven the need for a more 'inclusive education', which Lindsay et al (2013) suggest can lead to increased student engagement in social interaction, higher levels of social support, social networks and advanced education goals compared with their counterparts in segregated settings (Lindsay et al., 2013, pp. 347–348). They go on to argue that applying best-practice elements of inclusion, which incorporates curricular adaptation, may be particularly difficult for those teachers who are including students with high-functioning autism within their class (p.349), as many of the resources provided to drive an inclusive curriculum are guided towards those individuals with lower cognitive abilities. The challenges of such inclusive practice are also supported by Agrawal, where recognition is paid to the heterogeneity of cognitive abilities of those on the spectrum (Agrawal, 2013).

When considering the underlying cognitive theories of autism, such as Theory of Mind, Executive Functioning and Weak Central Coherence (Levy, 2007), in line with various proposed models of solving mathematical word problems (Kintsch & Greeno, 1985; Polya, 1945; Skemp, 1978), we can begin to explore how a representational model, such as the bar model, may offer support for some pupils with HFA, in terms of deconstructing the problem into detailed, focused parts. However, the global understanding and generalisation of the transfer of knowledge to new situations may be found to be problematic particularly for those individuals with WCC, unless they have adopted strategies to overcome these challenges. Consequently, as the bar model, along with other visual representational models, 'consists of a series of rectangles in which the relationships of the rectangles are specified and presented globally' (Ng & Lee, 2009, p. 285), it may be that those autistic individuals, particularly those demonstrating weak central coherence, may well find such an approach to problem solving less than supportive.

This study aims to explore some of the necessary and sufficient conditions required, with a focus on the Singapore Bar Model approach, for pupils with high functioning autism (HFA) to solve real life, mathematical word problems to enable them to make expected or better progress in mathematics.

Positive Behaviour Support and Martial Arts - Supporting Young People On The Autism Spectrum to Develop Essential Life Skills and Secure Employment

Poster

Alison Morrison (N-COURAGE JCM LTD), *John Miller (N-COURAGE JCM LTD)*

N-Courage is a brand new socially driven business that provides Martial Arts to children and young adults with Autism. N-Courage programmes are based on the scientifically proven principles that underlie Positive Behaviour Support. Our Martial Artists are taught in an Autism friendly environment using the proven techniques of errorless learning, breaking complex tasks down into simple steps and harnessing each individuals motivation to ensure successful learning in a fun environment.

Progress for every individual is documented and tracked and the data collected used to decide when and how to move programmes on and to identify targets for learning. N-Courage programmes build self confidence, communication and social skills as well as optimising the physical capabilities of each individual. As well as supporting and promoting the physical and mental health of those with Autism, ultimately N-Courage programmes are designed to lead individuals on the Autism Spectrum into meaningful, supported employment. All of our N-Courage facilities will be staffed wherever possible by young adults on the Autism Spectrum. Our Centre of Excellence is based in the Forth Valley area but N-Courage services will be rolled out across the UK from May 2019. This will be achieved by harnessing the power of technology to provide education, training and on-going support to our Martial Arts Ambassadors.

The N-Courage concept and approach is unique in the UK. N-Courage is supported by Stirling University School of Management and the success of our programmes will be the subject of research to establish the impact and success of the approach. The Positive Behaviour Support element of our programmes will be transferred to a range of physical activities that promote health and well-being such as yoga and dance.

N-Courage aims to fully include those on the Autism Spectrum and to support their families and carers. The N-Courage approach ensures each individual achieves their full potential physically and emotionally. We aim to demonstrate that this community can lead the way in making a valuable contribution in the workplace, successfully driving the economic success of a unique and innovative business. The N-Courage concept is visionary and is underpinned by methods that have decades of science behind them proving their effectiveness. N-Courage respects difference, sees ability not disability, focuses on seeking opportunities not on seeing challenges, promotes inclusion and understanding and is driven by evidence based science.

Most importantly, N-Courage places young people on the Autism Spectrum at the heart of everything it strives to achieve.

Siblings: Valuing their Perspectives and Supporting their Needs

Poster

Tricia Laing (PRESTON MANOR UPPER SCHOOL)

Have siblings of autistic individuals been overlooked? Research and intervention has often focused on the person with the diagnosis. However as the saying goes, 'It takes a village...', siblings can offer a valuable perspective into family dynamics and even help to be a voice for some children and adults. Recently this area has come to light through both informal and formal research because professionals want to work alongside the family, and the siblings can offer a very helpful insight into priorities and outcomes. As practitioners working with autistic individuals, we aim to include parents/carers so that they are involved in the plan of care and we also want to guide and provide for them, when necessary. Siblings may also benefit greatly from support, and by taking an interest into their needs, we are offering another layer in the foundation as we value the lived experience of autistic people and their families.

A new small-group intervention run at a mainstream comprehensive secondary school for siblings of autistic students will be shared, along with further ideas about how to ensure we are valuing the siblings' perspective and supporting their needs.

The participation of pupils with autism in decision-making about their school experiences: A case study of one school

Poster

Chantelle Zilli (University of Southampton), Hanna Kovshoff (The Centre for Innovation in Mental Health (CiMH), Psychology, University of Southampton, UK), Sarah Parsons (University of Southampton)

Chantelle Zilli*[1,4], Hanna Kovshoff[2,4], Sarah Parsons[3,4] on behalf of the ACoRNS network

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Research has highlighted the importance of increasing the participation of children with autism in decision-making, however there is little practical guidance on how organisations, such as schools can do this. This is a timely and relevant area to explore because there is more emphasis on collaborative decision-making in schools due to national policy changes that prioritise the full participation of children in decisions that affect their lives. The aim of this research is to do a case study of one school, examining the practices that help pupils with autism to participate in everyday decisions about their school experiences. Multiple sources of data were collected around four pupils with autism. This included observations in decision-making contexts such as the classroom; photographs pupils took of places they felt listened to; and semi-structured interviews with pupils, their carers and the school staff who work closely with them. Data is analysed deductively using Black-Hawkins (2010, 2014) Framework for Participation. The aim of the analysis is to generate new knowledge about the participation of pupils with autism in decision-making that informs improvements to school practice.

This project is part of the Autism Community Research Network @ Southampton [ACoRNS; www.acornsnetwork.org.uk] initiative that brings together researchers and practitioners to jointly identify and construct a research agenda that is mutually informed by, and informing of, practice. In other words, we jointly agree on research questions that are of direct interest and importance to practitioners and devise projects that will help to answer those questions. Our agreed priorities are the transitions and trajectories of children and young people with autism, with the aim of understanding what best practice looks like and how we can share evidence-based knowledge more widely. ACoRNS places children and young people's views and experiences at the core of what we do.

Black-Hawkins, K. (2010). The Framework for Participation: a research tool for exploring the relationship between achievement and inclusion in schools. *International Journal of Research & Method in Education, 33*(1), 21–40. http://doi.org/10.1080/17437271003597907

Black-Hawkins, K. (2014). Researching inclusive classroom practices: the Framework for Participation. In *The Sage Handbook of Special Education* (2nd Editio). London: Sage.

Abstract format: Oral presentation

Topic category: Our work aligns with many of your categories, specifically:

- Participation – valuing the lived experience of autistic people
- Enabling voice and choice
- Research to practice – models of support that have been informed by research or evaluation
- Communities of practice that support the development of good autism practice

- New perspectives on the use of evidence within autism research

- New perspectives on the use of evidence within autism research

Using design-based methods with autism practitioners to enable technology-mediated social play in autistic children

Poster

Margaret Laurie (Patrick Wild Centre, University of Edinburgh), Andrew Manches (Moray House School of Education, University of Edinburgh), Sue Fletcher-Watson (Patrick Wild Centre, University of Edinburgh)

Technology is a popular tool for supporting autistic children and can successfully promote academic learning (Pennington, 2010), educational engagement (Neely, Rispoli, Camargo, Davis, & Boles, 2013), as well as social and communication skills (Ramdoss et al., 2011, 2012). However, the majority of research has focused on technologies which are not commercially available (Ramdoss et al., 2011), and, conversely, few available technologies have been evaluated appropriately by research (Kim, Nguyen, Gipson, Shin, & Torous, 2018). Additionally, there is little work which prepares practitioners for new technologies which are rapidly being brought into the curriculum.

Technology has the potential to do more than simply teach skills or contribute to curriculum learning goals. It has been suggested that digitally-mediated interactions might be especially enabling for autistic people (Rajendran, 2013). This theory is supported by a number of studies which have reported that autistic children more readily engage (Neely et al., 2013), communicate (Tjus, Heimann, & Nelson, 2001), and interact with others when presented with digital activities compared to non-digital activities (Farr, Yuill, & Raffle, 2010).

Here we aim to understand how practitioners can use technology as an enabler for social play in autistic children. We are using design-based methods to provide a structure for collaboration with autism practitioners, aiming to create environments which promote digitally-enabled social play in the classroom. This nuanced approach allows us to explore factors relating to the individual and technology that might influence social play. We are working with a group of 9 children, conducting eight iterative observations and evaluations over the course of a school term. We will observe small groups of children using new and different technologies (e.g. tablets, tangibles and robots) across different classroom contexts and activities (e.g. shared use of devices, turn-taking). The video-recorded observations will be interleaved with discussion and reflection with the classroom practitioners, focusing on methods which could enable social play with the children. The data collected includes demographic information about the children and their scores on the Social Responsiveness Scale and Vineland Adaptive Behaviour Scales, detailed and qualitative video annotations of the children's interactions whilst using technology, standardised assessment of social play by Rubin's Play Observation Scale (1989), and recorded discussion and reflection with practitioners about what methods can promote social play in a digital environment. Together, these data will inform both researchers and practitioners about what influences social play in a digital context, covering aspects related to child characteristics, environmental factors, activity and context, as well as staff practice.

Data collection is ongoing. We will report patterns of social play behaviour observed in different digitally-mediated contexts, drawing conclusions about best practice for the use of technology to enable social interaction. The project is an exemplar for rigorous, collaborative research with practitioners and the design-based method will allow us to extrapolate findings to technologies of the future.

Using group dialogue to facilitate communication and increase participation across society

Poster

Jonathan Drury (Sheffield Hallam University), Elizabeth Milne (University of Sheffield)

Autism Dialogue is a radical form of conversation that facilitates open and honest sharing of views and opinions, by generating a free exchange of ideas and information without an agenda. Dialogue in various forms has been predominantly used in the context of business and organisation development, to increase communication and creativity within a workforce (Harris, 2008) as well as successfully in prisons internationally for nearly thirty years (Prison Dialogue, 2018).

Bohm Dialogue (hereafter, Dialogue) takes the name of David Bohm FRS - an American theoretical physicist who worked with Albert Einstein at Princeton University.

Autism is an ideal focus for Dialogue because of a perceived growing disparity between viewpoints (particularly between autistic and non-autistic people) and the way in which dialogue can address this issue in a uniquely participatory way. Lack of understanding between autistic and non-autistic people is a 'two-way street' and has been dubbed a "double-empathy problem" (Milton, 2012).

There is existing energy around discussions of autism and a growing voice from autistic people, who feel unrepresented and overlooked in medical research (Pellicano et al. 2013). Often views can be polarised and expressed via electronic media, providing little scope for nuanced discussion and active listening.

A principle of Dialogue is that individuals try to build upon others' ideas and experience everyone's point of view fully, equally and non-judgmentally, and suspending judgement and assumptions, so that new knowledge and a collective understanding can be formed (Bohm, 2013).

Participants from all backgrounds and experiences will freely explore individual and collective consciousness. Autistic identities and emerging autistic sub-cultural groupings will benefit from direct interactions within a container whose agenda is compassion and care and whose aims are unification and understanding. Barriers to group settings and normative social communication can be explored as part of the overall process and other forms of access potentially opened up. Co-production with autistic people will ensure good measures from the outset.

As far as we are aware there hasn't yet been a platform upon which the full spectrum of the autism community has had the opportunity to truly participate together. A national research programme is planned, which aims to directly explore quality of autistic lives and how, along with professional and academic realms, might work more cohesively towards the overall goal of a better lived experience for autistic people.

Dialogue has the potential to make a positive difference in the way that autism is understood by all and could play an important role in accelerating discussion and increasing professional and academic cohesion. For example, increased understanding of healthcare, particularly mental health (although autism isn't a mental health matter as such), could be achieved by facilitating dialogic communication between people with different perspectives on a condition, including service-users, their family members, clinicians and health care commissioners.

There is evidence that certain forms of dialogue can address other psychological issues, such as Open Dialogue, which in Finland is the main intervention for psychosis and has an extremely high success rate for rehabilitation (Open Dialogue, 2018).

What do older autistic adults feel are the most important factors that have assisted them in maintaining their own physical and mental well-being?

Poster

Jennifer kirton (Edge Hill University), Angela M Tod (Sheffield University), Tony Ryan (Sheffield University)

Rationale

There is only a handful of studies that presents findings from research with older autistic adults, as much of the current research is focussed on children and and proxy accounts. Moreover, as autism is a relatively new diagnostic category it is only in recent years that the number of older adults with a diagnosis has increased. Indeed recommendations have been made to ensure that there is further research into adults with ASC.

It is estimated by the National Autistic Society that approximately 1% (600,000) of children and adults in the UK population have ASC. If we follow this through and recognize that autism is a lifelong disability, it means that approximately 1% of the older adult population (aged 65+) will also have ASC. Using current population estimates from the Office of National Statistics approximately 14,400 over 65s have ASC and this is set to rise to 35,000 by 2035.

Background

This research is a grounded theory study using in-depth qualitative interviews to explore the life experiences of older autistic adults. The life experiences of older autistic adults are a rich source of valuable information that provide insight into autism across the lifespan and how autistic individuals adapt to older age.

Specifically this project explored the perspectives of these older adults on how autism has had an impact on their lives and how they have coped/adapted to situations, what they feel has helped them, what they feel has disadvantaged them and how they feel they have changed over time.

Methods

Ten older autistic adults (aged 50+) took part in the research. An initial in depth unstructured interview was conducted with each person. .Thematic analysis was then conducted on the transcript and then a second interview was conducted to discuss themes identified and to ensure clarity of researcher understanding and gain further information on points of particular interest.

Main points

Insights have been shared in regards to health, wellbeing (both physical and mental), education, access to services, social groups, diagnosis, special interests, home administration and daily living amongst others. Thoughts were also shared on growing older and what would be suitable support in older age.

Conclusion:

It is clear that we have much to learn about autism from the individuals that have a lifetime worth of experience living as autistic.

(N.B. data collection for this project is ongoing but will be completed by august 2018)

Authors Index

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