

CONTENTS SHARE LETTER FROM THE EDITOR SHARE

## CONTENTS

Cover Photo: HRH Princess Marie of Denmark with pupil

Jason Davidson at our 50th Anniversary Conference.

Photograph by Tina Norris.



Dirt Works...
Page 12 -13



Positive Emotions and Wellbeing: Rethink Special Need Support

Page 14 -15



Charter for Involvement
- National Involvement Network.
Page 16-17

3 Letter from the editor: Alastair Clarkson, Researcher in Residence,

Scottish Autism

4-5 From Interprofessionalism
to Transprofessionalism –
A Bridge to Innovative Autism Practice?
By Jackie Ravet

6-7 Exploring Experiences of Educational Transitions for Pupils on the Autism Spectrum. By Hanna Kovshoff et al.

8-9 Learning from Autistic Pupils in Mainstream Secondary Schools: the Value of Inclusive Research Methods. By Emma Rice

10-11 'We Don't Know What her Barriers to Learning Are – How Could We?' Valuing lived experience as a method to improve inclusion. By Ruth Moyse

**12-13** Dirt Works... By Esther Gooch

14-15 Positive Emotions and Wellbeing: Rethink Special Need Support. By Michael Harboe Kvistgaard

16-17 Charter for Involvement:
National Involvement Network.
By Paddy Carstairs

18 Photos from our 50th Anniversary Conference

19 Associates: Meet the Centre's Research and Practice Associates

### **Guest Editor**



Alastair Clarkson
Researcher in Residence,
Scottish Autism

One of the main objectives of our first conference was to support autistic researchers, advocates and researchers and practitioners who choose to work outside a 'deficit' model of autism to share their valuable knowledge and promote innovation within practice. Within this special 50th Anniversary edition of *Share* we are proud to offer a snapshot of the many inspiring conference presentations that took place. Each article highlights the range of valuable outcomes and benefits that emerge when researchers and practitioners move away from a 'deficit view' of autism and create the space for a humanistic, 'capacity view' of the autistic individual.

Within this edition, Jackie Ravet highlights the need to 'surface' underlying influences in order to change our attitudes and behaviour when working collaboratively to support the autistic community, Paddy Carstairs describes the work of the National Involvement Network (NIN) who ensure fundamental rights to choice and control within services are respected and honoured. Hanna Kovshoff and colleagues identify why autistic voice should be seen as a unique and equally valuable source of information within research whilst Emma Rice describes how to nurture this voice within research by removing barriers to authentic consultation. Within practice settings, Esther Gooch describes highly effective strategies which alter the educational 'space' around autistic pupils to support wellbeing, whilst Michael Kvistgaard focuses on emotional health and discusses practical ways to increase positive emotions by undertaking new activities and ways of thinking.

The second part of our conference title 'The Future is Calling' refers to a time when we
are all prepared to stand clear of a 'deficit view'
of autism to see what the autistic community has
been waiting to teach the rest of society - that the
autistic experience has always been an integral
part of the rich and charismatic tapestry of human
life and is one from which we can all learn

more deeply.

Listening to the wisdom of the autistic advocate and artist John Adams within his inspiring keynote conference address, it was clear there is still much to be done in order that the autistic community can be welcomed and included where they have always belonged – at the heart of autism research and practice. But whilst intentions like these are easy to articulate, how can we ensure that we all make concrete progress towards this goal?

Ruth Moyse describes the school experiences of 'Rosie' an autistic young women whose voice was seldom heard throughout periods of extended trauma when the education system failed to meet her needs. As a result of being valued and consulted on her own terms, 'Rosie' offers a solution for all who work to support the autistic community- a solution which we should actively seek across every research, educational and support setting in order to establish a more positive and secure future for the autistic community:

'Listen. Listen and believe me'

Many thanks to all the contributors, presenters and delegates.

## From Interprofessionalism to Transprofessionalism - A Bridge to Innovative Practice in Autism?



### Jackie Ravet Senior Lecturer University of Aberdeen

Interprofessionalism has been a dominant leitmotif in UK health, social and educational policy and legislation for at least two decades. Interprofessionalism is defined as a process of collaboration between two or more professionals across service/discipline boundaries which involves the sharing of knowledge and skills<sup>i</sup>. Interprofessionalism is considered integral to good autism practice because autistic people frequently need support from many different services - health. education, social care, etc. In theory, at least, interprofessionalism should enable professionals to 'learn from each other, learn about each other and learn with each other' in order to enrich practice, foster innovation and improve outcomes for people with autism.

Research indicates that there are significant benefits associated with interprofessional learning e.g. enhanced communication, shared understanding and efficient use of time and funding iii/iv. Equally, there are many challenges for example - partners may have very different ways of approaching their work, different priorities and use different jargon v. A key barrier can be misuse of power, where individuals use assumed authority or seniority to dominate decision-making. These factors can undermine interprofessionalism, innovation and outcomes.

It might be argued that evolving our practice towards transprofessionalism could ameliorate some of these issues<sup>vi</sup>. Transprofessionalism is defined as a process of collaboration between two or more professionals across **and beyond** professional and discipline boundaries, such that boundaries blur and

new synergies flourish<sup>i</sup>. Arguably, 'going beyond' implies a much deeper form of collaboration where professional roles, identities and ways of working are more fluid and differences are transcended<sup>vi</sup>. It also implies the inclusion and participation of autistic people, their families and para-professionals who have not traditionally been given a voice within interprofessional decision-making. A flatter power structure is therefore presumed.

Pellicano and Stears<sup>vii</sup> propose that autistic people have a right to participation in collaborative decision-making processes because outcomes have direct consequences for their lives. Furthermore, professionals and researchers can benefit considerably from their expertise and insights, increasing the potential for innovation. However, where neurotypical and autistic people are working together, they may encounter the 'double empathy problem' i.e. a mutual lack of understanding of each other's behaviour and intentionsviii that can obfuscate communication, Indeed, Clark stresses that interprofessionalism, and by extension, transprofessionalism, is highly complex and essentially relational as it pertains to how people connect and the quality of their interaction.

autistic people have a right to participation in collaborative decision-making processes because outcomes have direct consequences for their lives.

On the next page, I briefly explore four key relational elements associated with transprofessionalism that must be squarely addressed if we are to enhance innovation and improve outcomes in the field of autism:

- 1. Client-centred: Transprofessionalism, by definition, includes people with autism and strives to be client centred. It is therefore an ethical practice that recognises the rights of the autism community to a 'voice' and empowerment, and acknowledges the importance of adapting the collaborative process to enable access to decision-makingvii. Use of augmentative and alternative communication (AAC) e.g. signing, pictures and symbols, etc. may be required to ensure genuine participation across the autism spectrumiv. 'Power-with', rather than 'power-over', relations are also vital to eradicate inequalities and ensure rich, open collaboration.
- 2. Teamwork: In the workplace we are continually "encultured" into particular values, beliefs and ways of being". Attitudes to autism and autism discourses are shaped by enculturation. In order to start team building, enculturation must be explicitly surfaced so that ontological and epistemological differences can enrich the collaborative process, rather than undermining it. Sharing, reciprocally, who we/others are and what we/they know is essential to this process (ibid), helping to facilitate knowledge transfer and shared understanding, whilst ameliorating the double empathy problem. Good communication, emotional literacy, conflict resolution and related skills are fundamental to successful teamwork.
- 3. Risk: Head<sup>ix</sup> suggests that 'functional' collaboration is just about getting things done. By contrast, 'effective' collaboration is where boundaries are crossed, creative ideas are nurtured and innovation can flourish. However, this will not happen if we approach the transprofessional process superficially, as a tick-box activity. Effective collaboration requires deep personal investment and engagement incorporating 'intelligent experimentation'x rather than random trial and error. It therefore involves risk<sup>vi</sup>.
- 4. Joint Reflection: Two ongoing reflective processes must be active during transprofessionalism: joint reflection on what we are doing and joint reflection on how we are doing it the relational process. Whilst we may be familiar with the former, the latter is vital if we are to develop appropriate 'habits' or 'dispositions to act'x that embed transprofessionalism in practice over time, establishing it as a professional 'norm'xi.

Arguably, if we prioritise these four elements within the transprofessional process, collaboration is more likely to be ethical, innovative and effective.

However, workforce preparation depends, crucially, on professional ownership and training, as well as leadership, funding and a supportive ethos across professional and academic contexts. More research is vital to develop models of good transprofessional practice and to evaluate their impact on the lives of autistic people.

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## **Exploring experiences of educational transitions for pupils on the autism spectrum.**



Hanna Kovshoff, Sarah Parsons, Jessica Baker, Keri Hoy, Felix Perkes, & Ellie White On behalf of the ACoRNS Network.

Transitions within and across levels of schooling pose challenges for all children as they adapt to new settings and teaching staff. It is often reported that autistic children may experience further challenges within educational transitions given the likelihood they may experience additional difficulties when adapting to new people, settings and routines. Conversely, we suggest that transitions need not be negative experiences. It therefore appears important to gain an insight into the effective transition practices that can support children and young people to feel accepted and thrive within new educational environments. The aim of this research programme was to gather the views of autistic children and young people, families and teachers in order to learn about what helps and hinders the educational transitions of autistic pupils across different levels of schooling. This includes the 'vertical' transitions between levels of schooling (nursery to primary school, primary to secondary school) as well as the 'horizontal' transitions (e.g., from year group to year group, from home to school and from break times to lessons).

Within the nursery setting, seven autistic children took part and observations were undertaken of their horizontal transitions. Seven parents and five nursery staff were interviewed about their views, worries, practices and hopes with regard to each child's transition to primary school. Key practices that emerged as supportive of children's horizontal transitions included an understanding of the child, enabling the child's voice and agency through effective communication practices and a focus on learning through play. With regards to upcoming vertical transitions, both parents and staff reported that an

in-depth understanding of each child's needs and preferences appeared key to the development and progress of successful relationships and transitions.

Transitions within primary school were investigated through the use of photo-voice and interview techniques involving three pupils in Key Stage 2 (aged 7-11) and parents and teachers. Key findings included the importance of the development of positive relationships between children, parents and teachers. Pupils reported they worried primarily about changes in the teaching staff with whom they had developed positive relationships and about peer relationships and peer difficulties, whilst parents reported concerns that their children may hide struggles in school from teaching staff.

Strategies suggested by pupils to enable positive transitions included spending time outside of the classroom setting when needed and being offered the opportunity to leave the classroom when autistic pupils felt overwhelmed. Teachers suggested that increasing the number of pre-transition meetings and visits would have positive benefit, whilst parents felt that getting to know the children as people and understanding their individual needs and personalities were crucial to positive pupil transitions.

Secondary school transition practices were investigated using a photo-voice activity followed by a semi-structured interview with five pupils aged 12-16 years, five parents and four teachers. All of the young people, parents and teachers reported positive experiences of their transition to secondary school and valued the opportunity to access a Learning Support base within the school. Use of the Learning Support base enabled pupils to access mainstream education, without having to negotiate potentially stressful transition practices within secondary school (e.g., moving between classrooms). Other effective practices included being flexible and focusing on individual needs (e.g. use of part time timetables to support transition), the use of motivating interests to engage and support autistic pupils and establishing visual supports and open communication between home and school.

The voice of autistic children, especially younger children and those with associated learning disabilities, tend to remain unrepresented and unexplored within the research literature (and more widely) because their views and experiences are often considered hard to reach or interpret. 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, rather than being viewed only as points of comparison with non autistic children.

Several overall themes emerged which were linked to effective transitions for autistic pupils across different educational settings and levels of schooling. These included a focus on the child or young person first and the importance of the incoming school or teacher learning about pupils as individuals - both in terms of their specific educational needs and autistic interests. The use of flexible timetables, visual supports and a place that pupils can access when feeling overwhelmed were also cited as important to effective transition practices by pupils, teaching staff, and parents.

Note: This project is part of the Autism Community Research Network (a 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. 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 place children and young people's views and experiences at the core of what we do.

# Learning from autistic pupils in mainstream secondary schools: the value of inclusive research methods



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Doctoral Researcher
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Some autism advocates identify that autism research frequently excludes autistic voice due to a predominant focus on the deficit model within autism researchi/ii. In aiming to enhance the inclusion of autistic voice, my research has utilised participatory and emancipatory approaches in order to redress the power imbalance between researcher and participant and better serve the interests of participants. Within this approach, the autistic participant is seen as the expert on their experience and research becomes a partnership where decision making about the research process becomes shared ii/iii. Alongside this, the researcher acts as facilitator, offering resources, various modes of expression and opportunities for engagement and adaptations in order to meet the needs of participants<sup>ii/iv</sup>.

the autistic participant is seen as the expert on their experience and research becomes a partnership where decision making about the research process becomes shared.

Ensuring that research methods were inclusive, became therefore a key aspect of my research project, which focused on autistic pupils between the ages of 12 and 16 within a mainstream secondary school. As part of a timetabled element within their curriculum, these autistic pupils attended a school club for one year to provide a varied, alternative learning experience to academic subjects. Here, pupils could undertake a

range of options, one of which was a club which I facilitated as part of my research. This club focused on each pupil's sense of self and explored the positive or negative impact of mainstream secondary schooling, whilst also evaluating research processes with pupils.

The research project included a range of methods available in order to meet the preferred mode of expression of autistic participants. These methods ranged from visual methods (photograph, video, drawing, collage), verbal and written methods (interviews, pair or focus group discussion) and kinaesthetic forms (organising topic cards). This range of methods aimed to support difficulties with verbal or written communication, reduce anxiety around face-to-face conversation and increase confidence by drawing on the existing skills of autistic pupils vi/vii. A central driving principle was that I would not make assumptions by choosing one set method for all autistic young people that took partviii, therefore choice and adaptation became key elements within the research process. Participants chose from a range of options and could adapt these according to their preference. For example, conversations could be recorded, answers could be written down by the researcher exactly as stated, submitted by the participant in writing or completed with a preferred partner other than the researcher.

The importance of choice was shown to be a key finding within my research project - that one size *doesn't* fit all. This was demonstrated in the choices made by all 8 participants across the range of visual, verbal and written methods available - with no one method being preferred across all participants. Choice was considered important by autistic participants in relation to motivation and enjoyment, as these pupils suggested that being asked to complete tasks in an unwanted manner would lead to lessened motivation and therefore less effort, enthusiasm and a reduction in participant contribution. Therefore, it appears that participant voice can be influenced not only by potential difficulties with modes of communication but also by the feeling of the participant towards that task itself.

The autistic young people who took part in my research project concluded that choice in how they participated was a positive element. This was due to a sense of freedom from control; ease in sharing their thoughts; increased motivation and enjoyment and a decreased sense of failure.

This also suggests that participant voice may be hampered by a sense of failure. Many participants commented on how they would not want to complete a method (e.g. film creation) that they thought they were 'bad' at. In this way, I found that a desire to avoid failure could lead participants to reduce or limit their contributions, which, in turn, could obscure key features of their lived experience.

The autistic young people who took part in my research project concluded that choice in how they participated was a positive element. This was due to a sense of freedom from control; ease in sharing their thoughts; increased motivation and enjoyment and a decreased sense of failure. Further to this, I found that the adaption of methods in order to increase accessibility may have a direct impact on research findings, in line with studies that examined autism in terms of self-concepts and used adaptive methods to engage with participants. The use of these adaptions produced data which challenged the deficit-led perspective that autism typically results in an impoverished sense of self<sup>v/x</sup>. Findings of this nature therefore appear to highlight the responsibility the researcher has to ensure communication within the research process is supported through individual adaptations, as adaptations to methods clearly have the capacity to impact on the findings which arise from research with autistic people. Whilst increased choice and variety may mean increased complexity in the data that is obtained, I strongly feel this is an essential element for enabling the full contribution of autistic participantsviii.

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## 'We don't know what her barriers to learning are - how could we?'

Valuing pupil voice and lived experience as a method to improve inclusion.



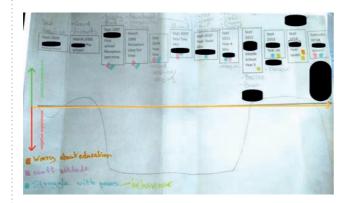
Ruth Moyse
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Rosie is fifteen. A bright, articulate and academically able autistic young woman, she aspires to become a large-animal vet and yet Rosie has been unable to attend mainstream education for over a year – a situation she shares with a number of other young autistic woman of school age.

We know today that many autistic girls have been missed from the diagnostic process entirely or have been mis-diagnosed and it seems that absence from school through quiet non-attendance" is another way by which autistic girls remain undetected within the system. Whilst the extent to which autistic girls at secondary schools in England are more likely to be recorded as persistent absentees when compared to neurotypical girls or autistic boys is statistically significant iii/iv, the experiences of autistic young women appear historically absent from studies which focus on autism and school exclusion. The scope of my PhD research seeks to make sense of this phenomenon, predominantly by empowering a number of autistic girls to share their experiences within a series of life history interviews. These girls are uniquely placed to identify not just the events and experiences that led to them being out of school, but also to identify meaningful recommendations about how their educational provision could be improved. Within my research I was also interested to find out whether any of the schools involved had asked these girls for their views on what they thought would constitute appropriate support whilst they were struggling to attend school.

These girls are uniquely placed to identify not just the events and experiences that led to them being out of school, but also to identify meaningful recommendations about how their educational provision could be improved.

In order to support the voice of the autistic girls that I consulted with, the research also needed to be led by the events and experiences which this group wished to talk about. I was conscious of the potential power imbalances within the researcher-participant relationship and mindful that their journeys out of school were likely to have been traumatic. In order to ensure an ethical process of engagement it was important that each participant felt in control of what was discussed and was able to decide themselves what was significant. To address this, I asked each girl to draw a life chart ahead of our interviews which marked their memories of significant positive and negative events within school. I built guestions based on each chart and sent them to the girls before we spoke, giving them the option to remove items they didn't wish to discuss (no questions were). Interviews were conducted via the Skype text messaging service, in-person at their home or within the University.



Rosie's life chart

What is striking from Rosie's accounts is that multiple opportunities for schools to understand and respond to her needs appear to have been missed throughout her education. She is now in her seventh placement since pre-school and has been absent from school for about a third of her life (which includes missing two full academic years of education). Rosie attempted suicide at the age of 14.

11 It feels like every school I go to, they mess it up for me and refuse to help fix what they've messed up.

A theme of feeling not being listened to, or not being believed appears to run through her story. At the Middle school she attended, chosen for its specialist autism base – Rosie reports her attendance fell significantly from about 60% in Y5 to about 40% in Y7. In addition, even when Rosie was in this school, she was rarely in class; she says that up to 90% of her time was spent in the unit (without work) rather than in lessons. She feels that little to no effort was made to understand why she left so many classes. She explains that she struggled to communicate with staff verbally, remarking that 'even if I wrote something and signed the bottom of it to say these are my words, no one ever really listened to it.'

Are Rosie's requirements of a school unreasonable? Her personal construct of her ideal school is somewhere she can do 10 GCSE's - somewhere that is 'tidy', 'quiet and calm', with 'lots of animals around to cuddle'. Adults that 'know everything they need to know about me and understand me'. A school that 'wants pupils to achieve their dreams, be happy and feel safe'. She talks of one setting that was 'really good' for the first year:

They didn't make me try to do things
I wasn't ready for. They let me lead my
own progress, so I didn't feel pressured.
I felt safe around the staff because I felt
listened to and understood.

Schools can be challenging places for all individuals and learning is not always easy. However, finding ways to listen earlier to Rosie's experiences of school may have enabled her to thrive within a mainstream setting and prevented the subsequent toll on her mental health. It is clear from the accounts of these autistic young women that a willingness to understand the stories of girls like her could be good for all pupils. As Rosie says:

'Listen. Listen and believe me.'

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### **Dirt Works.**



Esther Gooch
Managing Director
Outdoor Woodland
Learning School CIC

The OWLS CIC approach developed through my work as a Primary Teacher in mainstream education and while working out in the woods with OWLS CIC, a disability led third sector organisation. As a teacher, my approach has been to bring together strategies which are simple and work effectively to support pupils whilst requiring minimal financial expenditure. This ensures that everyone can discover the scientifically proven value of working outdoors with children!

To 'enthuse, enjoy, challenge and inspire' remains the focus of our vision out in the woods and on the beach, with the addition of nurture, love and care and our therapeutic horses. Children of all ages get wet, explore, make dens, build fires and get seriously muddy. These might seem just like fun experiences, but the outdoor natural world also provides a rich source of sensory engagement and integration opportunities. Imagine a narrow stream a few centimetres deep. It has been raining and so it bubbles and gurgles swiftly down the hillside. Children leap into it and immediately feel the water pressure pushing hard against their wellies and legs, causing deep sensory input. Wading upstream causes their muscles to work and their core strength to develop. If you are a hyposensitive autistic person, then this may support the development of your proprioceptive senses.

Children of all ages get wet, explore, make dens, build fires and get seriously muddy. These might seem just like fun experiences, but the outdoor natural world also provides a rich source of sensory engagement and integration opportunities.

The children remain in control of these experiences and they provide ongoing challenge at just the right level of excitement. Mud is supremely tactile, and you can create mud sculptures, or splat it on trees and/or even your face...but with a hypersensitive autistic child, children can still play with the texture at a level they can tolerate. The outdoors - with no fluorescent lights which flicker, has of course also no walls to contain or restrict - here children can choose their own boundaries. Noise isn't as painful, the sensory challenge may appear lower and the outdoors creates opportunities for collaborative purpose - collecting wood, lighting a fire or making a warming hot chocolate. If the challenge begins to exceed the child's ability to manage, children can retreat to the safety of the hammock or a quiet space set back from the fire, or even have fire-warmed rocks placed on their bodies to create deep pressure therapy.



Outdoor learning

Blood pressure, cortisol reduction, stress and anxiety are all reduced when out in the woodland with over 100 studies which appear to support this hypothesis. Japanese *Shinrin Yoku* is a forest bathing tradition exemplifying the knowledge of the benefits of spending time in nature. Combined with the natural forces already at work, we can provide outdoor sensory integration to meet the needs of the children. They tend to choose what they need naturally with little support from ourselves. Consider the visual aspects of the light filtering through the trees, the auditory input of the tree branches swaying, cracking underfoot,

the smells of the freshly damp earth, the movement input from the hammock, from climbing and stretching, moving heavy logs sliding on ice or perhaps burying oneself in the recently fallen autumn leaves which crack as they dry.

This simple relaxation offers opportunities to challenge children and enables them through the use of review to use their learning within a life-based context. Through the evidence of our impact assessments we are seeing that school exclusions are reducing and behaviours of concern reduce greatly or may stop altogether.

The process of nurture, collaborative problem solving and the knowledge that children are loved and nurtured no matter what they do enables them to develop their trust. We find that the relational skills of children also increase due to their contact with these settings - skills which we hope will enable pupils to develop future social and vocational opportunities with greater confidence.

The process of nurture, collaborative problem solving and the knowledge that children are loved and nurtured no matter what they do enables them to develop their trust.

So, to move our youngsters on and back into their mainstream or special school environments?

We work with the staff to create a non-judgemental space for each child. Collaboration with the youngster and not power based management is our theme here.

Following the strengths and interests of the child is huge...does it really matter if they don't want to learn about Vikings or Romans if their passion is for Egyptians? Does it really matter if they want to learn



Outdoor learning

about farming rather than Victorian Scotland? Why not support them to look at Victorian farming if farming is their passion? If we encourage strengths-based learning, then these amazing children will learn. A broad and balanced curriculum is important for most children, but we need to get it right for everyone and that includes our wonderful autistic children.

And the evidence backing up our work? We are collating evidence to show that autistic children within our program show a reduction in their stress reactions and that their level of task concentration increases. What's not to love when dirt works?

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### Positive emotions and wellbeing: Rethinking special need support



Michael Harboe Kvistgaard Consultant in Special Needs

What does every person in the world wish in their lives? According to Martin Seligman, founder of positive psychology and former president of the American Psychological Association, every person in the world would like to improve their wellbeing. Whilst this may be an accurate observation, Peter Vermeulen highlights that "it is remarkable that emotional wellbeing and the pursuit of it, although being highly valued for every human being, has received so little attention in research on the autism spectrum."

it is remarkable that emotional wellbeing and the pursuit of it, although being highly valued for every human being, has received so little attention in research on the autism spectrum.

According to Seligman, wellbeing can be understood as a concept which consists of five elements, as described within the **PERMA**-model: **Positive** emotions, **E**ngagement, positive **R**elations, **M**eaning and **A**ccomplishments<sup>ii</sup>. Within this model, in order to improve your wellbeing, you can:

- Find ways to increase the amount of positive emotions in life
- Be more engaged in what you do.
   Being absorbed in activities experience more flow states

- Spend more time with persons that you enjoy being with and with who you experience mutual care and respect
- Find purpose and see the big picture in what you do, or do more things which are meaningful to you
- Achieve various big and small things
  have success in different areas of life

Positive emotions in themselves may appear to be the "low-hanging fruits" as engagement and accomplishments appear more difficult to plan and predict (especially for others). As the domains of social interaction and social imagination constitute two central areas of difficulty for many autistic people, a focus on relations and meaning appear central to many programs of positive support. In light of this, in order to increase wellbeing within autistic individuals, it appears important to focus on the remaining element- that of positive emotions. Extending past the PERMA-model, positive emotions in themselves are clearly linked to wellbeing. For example, Barbara Fredrickson, suggests that "higher positivity ratios are predictive of flourishing mental health and other beneficial outcomes"." A positivity ratio is the expression of the amount of positive emotions present compared to the amount of negative emotions and can be understood as the balance between positive emotions and negative emotions. Fredrickson also found positive emotions appear to broaden the scope of attention and thought-action repertoires of individuals whereas negative emotions appear to narrow the scope of thought-action repertoires and attention.

So the question remains – just *how* do you increase positive emotions in your life or within the life of others? Should you just *decide* to be happy? Perhaps not - just relying on making a decision to be happy could be described as 'positivity-fascism', whereas the actual practical increase of positive emotions appears linked more to the experience of 'heartfelt positivity'.

Viktor Frankl proposed that "pleasure is, and must remain, a side-effect or by-product, and is destroyed and spoiled to the degree to which it is made a goal in itself". In light of this premise, a practical way to increase positive emotions may be to undertake new activities and mindsets which promote the production of positive emotions as a byproduct. For inspiration, I suggest the following two books: "Positivity"vi and "The how of happiness"vii, each of which contain a toolkit to enhance positivity or happiness. In this regard it is important to mention these toolkits are not designed specifically for autistic individuals and so may require some adaptation by support staff. The following strategies to enhance positive emotions are partly derived from these books and are meant to provide inspiration for a variety of activities and processes which staff may initiate within services.

- Savouring: To attend to, appreciate and enhance the positive experiences in life.
   Memory of past, sensation of present- and anticipation of future events
- Positive Emotion Profiles: Create an overview of what creates positive emotions, so this can be done more
- Positivity portfolios: Collages with images of individualised understanding of joy, amusement, love etc.
- Physical activity
- Meditation: Many guided meditations are not autism friendly and require adaptation
- Humour: Adapted to the individual slapstick humour over puns, simple jokes and to more sophisticated humour
- Identify and use strengths: What is the individual good at and what gives him/her energy - do it more!

a practical way to increase positive emotions may be to undertake new activities and mindsets which promote the production of positive emotions as a byproduct.

I believe there is a great potential to support and develop individual learning and wellbeing within autism services by remodelling work within services towards a more 'wellbeing-oriented' approach.

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## Charter for InvolvementNational Involvement Network



### Paddy Carstairs Development Worker

ARC Scotland

11 It (The Charter) gives me the choice to live the life I want to live. I can use it every day in my life to make decisions.

The National Involvement Network (NIN) is an influential network of over 80 people who use social care services. This group has been meeting since 2007 in order to bring about more choice and control within the lives of supported people and enable the voices of supported people to contribute to the decisions made about their services and communities. Alan Mackenzie currently supports the NIN as chairperson whilst Brian Robertson assists as vice - chairperson. In the last couple of years a number of local involvement networks have also been established in order to make participation more accessible for others.

To help achieve their aim, NIN members wrote the 'Charter for Involvement,' published in 2015. This charter contains 12 statements which were written to improve involvement for supported persons. The Charter also sets out how these statements should be put into practice. The main aim of the Charter is to ensure people who require support are respected and listened to more frequently.

So far, a total of 71 organisations have 'signed up' to the Charter for Involvement. This means their Chief Executive, Board of Trustees or senior officer, has made a formal commitment on behalf of each organisation towards putting the Charter statements into practice. These include health and social care partnerships, social care provider organisations of all sizes, advocacy and advice agencies, national bodies and a further education college. Scottish Autism was an early signatory. With the help of ARC Scotland, NIN members remain in contact with these organisations in order to provide support and guidance and promote examples of the differences that the NIN is making within supported people's lives.

The work supported by the NIN is a concrete and visible example of an asset-based model of care and support from which others can follow, learn from and be inspired by. It already directly benefits many thousands of supported people across Scotland.

Organisations that use the Charter told us in March 2018 that the lives of at least 10,600 supported people have been improved as a result of engagement with the Charter. Outcomes include improved choice and control, confidence, engagement with activities, increased quality of life, and reduced isolation.

NIN members have set a target of 100 organisations signing up to the Charter by 2021.

All of NIN's work is planned and led by people who require social care support. It builds on the considerable knowledge, capacity and motivation that members of the National and Local Involvement Network have developed through development and promotion of the Charter.

Of particular importance to their success has been the willingness of NIN members to directly communicate to others what the Charter means to them, the difference it has made to their lives and how the Charter can help others.



This work is underpinned and driven by the values and principles of choice and control and provides a unique resource to inform, understand and promote these essential principles from the perspective of supported people. For example, one person told us:

The Charter means I have got my choices. It means I can pick my own staff. When I pick my own staff I know who is working with me and I know they can understand me and be there for me. If we didn't have choices, we wouldn't be anywhere, people would just run our lives for us.

The principles and values of the Charter resonate strongly with the work of other policy areas and regulatory frameworks in Scotland, including Fairer Scotland for Disabled People, Self-Directed Support, National Health and Social Care Standards, Keys to Life and the Scottish Strategy for Autism. The difference is that the Charter represents the voice

of supported people themselves, describing in their own words how they want to be involved in the things that affect their lives.

Further information about the Charter for Involvement can be found on the ARC Scotland website - https://arcscotland.org.uk/

To download a copy of the Charter go to: https://bit.ly/2Cp0HvP

**P** 1 6

CONFERENCE PHOTOS SHARE ASSOCIATES SHARE

In November 2018 we hosted our 50th anniversary research conference, 'Innovation in Autism Practice: The Future is Calling' at the Grand Central Hotel in Glasgow. An array of speakers and delegates from across the globe joined us to focus on the development of innovative autism practice - sharing a wealth of knowledge and insight through a variety of thought provoking discussions. We were honoured to be joined by Her Royal Highness, Princess Marie of Denmark, who is a passionate advocate for greater

support and rights for autistic people and the patron of Autism Denmark. Below you will see some highlights from the conference including photographs of Iceberg Productions, a group of young autistic filmmakers supported in our services, who were thrilled to interview HRH Princess Marie at the event. Thank you to all who attended, exhibited and contributed to making our conference such a success.













### Meet the Centre's Research and Practice Associates

#### **Research Associates**



#### Ken Aitken

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



#### Sue Fletcher-Watson

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



#### Karen Guldberg

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



#### Andrew Jahoda

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



#### Tommy MacKay

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



#### **Richard Mills**

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



#### Anna Robinson

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



#### **David Simmons**

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

#### **Practice Associates**



#### Dehi Brow

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



#### Yvette Q. Getch

Yvette is Associate Professor at the University of South Alabama, and part-time Associate Professor, Department of Counseling and Human Development Services, the University of Georgia Athens, Ga.



#### Michael McCreadie - In Memory

We were deeply saddened by the recent passing of Dr. Michael McCreadie. He has been instrumental to the development of the practice ethos of Scottish Autism and made a considerable contribution to the field of autism with his knowledge, insight and his support of autistic people and their families.



#### Kate Strohm

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



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#### Peter Vermeulen

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

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

www.scottishautism.org/cpi

**P** 1 8

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



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