1. Background

‘Autism Dialogue’ started as a collaborative community project at the University of Sheffield in Summer 2017 between Jonathan Drury and Dr. Liz Milne (Director, Sheffield Autism Research Lab). It was attended by several leading autistic scholars and community members, including Professor Matthew Belmonte (MIT / NTU), Liz Friend MBE and James Pelham (Autistica). The initiative has organically developed to also incorporate Jonathan’s coaching and mentoring activities under the name, ‘Flow Dialogue & Coaching’.

At the time of his own diagnosis in 2014 (then ‘Asperger Syndrome’ and ‘ADHD’), Jonathan perceived a widely fractured autism arena with many competing ideologies, which he felt compelled to try and re-unite. He ran a series of dialogue circles among autistic and non-autistic people, which proved particularly successful, based on the appreciation and informal feedback it subsequently generated. After a short series at Sheffield Hallam University’s Students Union the public project was launched at the Sheffield Quaker Meeting House, a suitably ‘autism-friendly’ venue, still used today. These dialogue sessions took place once a month for 3.5 hours on a Friday afternoon and on seven subsequent months. By the end of 2018, well over a hundred people had taken part, including at the conference, and had travelled from all around the UK.

A full day conference was held in December 2018 where presentations were given from autistic delegates, therapists, researchers and experienced facilitators. Carol Povey (Director
of the Autism Centre, National Autistic Society), also gave a speech on her views of the methodology and the importance of new ways to communicate in the wider autism community. Three parallel dialogues took place as part of the conference. Most of the presentations talk can be heard on the AD website, (Autism Dialogue, 2018)

2. Aims

In line with a wide range of current identified needs put forward by UK autism organisations and the government (NICE, 2016. NAS, 2019. Gov UK, 2009 & 2014. NAT, 2019) the principal aims of Autism Dialogue are to:

• Increase well-being and improve independence for autistic people, by supporting reduction of psychological stress and anxiety in social settings and interactivity

• Support people with a wide variety of views on autism to communicate together, thereby increasing familiarity and promoting deeper awareness, respect, openness and understanding.

• Reduce pressure on existing waiting lists and service demand by referrals and signposting. There is a 24-month waiting list for diagnosis and thus post-diagnosis care in Sheffield.

In addition to the guidance put forward by the above organisations, we propose to:

• Identify and support autistic leaders and create a network for the professional development of public and cross-sector Dialogue, Coaching, Mentoring and Leadership programmes.

3. Autism & Communication

Autism Dialogue will be best understood by the scientific community as an applied psychosocial therapeutic intervention, although it is important it is not understood as therapy. It works with delegates holistically, on aspects related to quality of life and well-being, by stress reduction through supported communication in a safe, autism-focussed peer-group setting. It therefore addresses issues such as those related to sense of self, family support, social and community integration, leadership and employment. Obvious challenges we want to embrace and bring into our Dialogue include those brought by non-speaking autistic people and children, as well as the more common mental, social and sensory issues.

Autistic people report the sensation of talking through a veil of uncertainty and find it difficult or impossible to behave the way people seem to expect. Many people, both autistic and not, see the phenomenon of autism as an environmental or sociological issue as well as a medical one, which creates a very complex, multi-faceted situation.

Autism is a phenomenon which raises many complex questions including those around the nature of self, identity, science and society, with a wide range of often competing theories and ideologies. Yet autism remains situated within a medical deficit paradigm, despite a steady increase of strengths-based perspectives. A dominant normalising agenda has silenced the autistic voice and there is minimum pro-active engagement with autistic people, so research design, policy creation and community practices are inherently lacking. This
furthers a disabling and deprived social environment and rhetoric of deficiency, tragedy and scientific sadness. (Duffy and Dorner, 2011)

Many autistic people ‘hide’ their differences for self-preservation, often to their detriment, with deep psychological issues arising later in life. Camouflaging (or ‘masking’) may impact diagnosis, quality of life, and long-term outcomes, but little is known about it. Camouflaging is also a major reason why a single cognitive theory of autism is difficult. More crucially, the decisions families and individuals make about autism diagnosis and treatment are directly influenced by cultural background (Ennis-Cole, Durodoye & Harris 2013).

Human beings form self-image through interactions with both people and environments surrounding them. Autism is a dynamic state, not static or hardwired. There are studies in environmental influences, neuropasticity and causes of atomic excitation. For example, one brain imaging study suggests that neural connections are not actually "broken" in autism, but subject to greater intra-individual variability across time, indicating the need for dynamic approaches. (Falahpour, Thomson, Abbott et al, 2016).

As autism is an innate part of a person so is not subject to cure in any typical sense, we believe national spending priority should be directed to applied research to help people living with neurological differences, instead of on basic genetic and biological research.

4. The Concept

Autism Dialogue is a unique application of Professional ‘Bohm’ Dialogue into the autism community setting. Bohm Dialogue is a special form of group conversation set out by quantum physicist Professor David Bohm FRSc (a colleague of Einstein) and colleagues in 1981. The method facilitates open and honest sharing of thinking, by the free exchange of ideas, without an agenda. In dialogue, everyone can experience everyone else’s point of view fully and equally. Bohm’s work in the quantum field was augmented by what he saw as a ‘crisis in communication’ in the world. We view the phenomenon of autism as a symptom of a universal ‘crisis of the self’ (the word autism literally means ‘self’ – ism).

Professional Dialogue could play an important role in accelerating discussion via a common understanding and increasing professional cohesion of the whole autism arena. Dialogue could be highly beneficial in the realm of autism and other ‘therapeutic’ settings and has the potential to make a positive difference in the way that autism, and perhaps other modalities, are understood by all.

Jonathan has a Postgraduate Certificate in Autism and is an active member of the Academy of Professional Dialogue, the international professional body for the Bohm Dialogue practice. This organisation was co-founded by Peter Garrett (a colleague of Bohm) and Jane Ball (also founders of the pioneering Prison Dialogue), who are now Jonathan’s supporting mentors. Jonathan led a dialogue session at the Academy’s international conference in 2018 and his paper ‘Autism Dialogue’ will be published by the organisation in 2019. (AoPD, 2019) He leads a regular international Autism Dialogue Practitioner video-conference group for members.
5. Outcomes

Statements from autistic participants of Autism Dialogue:

“Attending Autism Dialogue for the first time was a wonderful experience and I would enthusiastically recommend it to other autistic adults who would like to have an open and compassionate discussion about autism, their own experiences and lives, and the ways that autism can be approached, shared, and even celebrated through this style of group conversation.”

“I found it empowering and eye-opening to be able to talk about autism with my peers in the unique manner that Autism Dialogue provides and I think I’ll be able to carry this approach forward into my everyday reflections on my life.”

I would encourage any autistic adult who can attend independently and express themselves verbally to come along and give it a try. There is no pressure to speak if you don’t want to, just to be there, listen, and engage if, and when you choose to.”

“I could not imagine a more autism-friendly approach to discussing autism and everything that comes with it.”

“What a wonderful group of people. I can’t really adequately describe the combination of compassion, respect, affinity and engagement with others that I’ve had – it seems somewhat unique.”

“I would recommend it to anyone interested in mindful interaction (dialogue?) who may, or may not, still be trying to ‘suss out’ a diagnosis. I hope I will learn lots from others as I have already after one session. I have also been able to reflect on other attendees experience and reflected that on my own experience. It’s made me remember how isolating it is not to be able to be honest in the ‘real’/NT (?) world and it’s helped that loneliness for a while.”

“The conversation was very free flowing, and it was clear that nothing was wrong – that meant interesting links were made between really different subjects, all with the threads of an autistic perspective running through. Afterwards I felt a mixture of elation at having participated in something exciting and new and disappointment that the time had gone so quickly. I would really recommend it to any autistic person who would like to join with others and explore what an autistic perspective on the world and everything in it might look like.”

“There was a feeling of wanting to improve the world for those affected by autism, and even tho people had different, and sometimes conflicting, ideas, there did seem to be a unity of purpose, which was most heartening. I also enjoyed being asked about my experience as an autistic person by research professionals – I felt very valued in those moments. I very much hope that there will be more such events like these – I’m a strong believer in the power of dialogue to change the world for the better.”

– Autistic participants at Autism Dialogue.
The effects by non-autistic participants are also perceived as enlightening and positive changes have been made in their professional practice environments thus, in a transfer of power in favour of the autistic patient. Rachel Yates, a Clinical Lead Occupational Therapist states that because of her and her team attending Autism Dialogue sessions in 2018, they gained a much clearer perspective into the wants and needs of new autistic patients at their mental health unit. Changes to the registration processes were consequently made, which now give more choice and rights to those patients.

6. Today

‘AD19’ - this year’s programme, is underway with around 22 committed participants. 15 of these are disclosed as autistic and five already attended last year. Sessions are co-led by Jonathan Drury and Caroline Pakel of totheheart.com, an experienced facilitator, trainer and coach with a background in cross-cultural, global qualitative research (Disney, PWC). The programme consists of eight (three hours) monthly sessions with the group, a second annual conference in November 2019 and an optional seminar / developing skills weekend in December.

We are currently collecting feedback from each session in the form of a set of simple questions sent via email and findings will inform future report and help shape the design and production of future activities. We are currently discussing the implementation of the Autism Quality of Life measure (see below).

7. Leadership and Employment

Leadership initiatives and an inclusive employment culture needs empowerment programmes and an increasing number of companies worldwide are seeing the potential of autistic employees. Auticon in the UK is a unique, multi-national IT consultancy and social enterprise, which exclusively employs autistic adults as IT consultants. In the US, the Autism at Work Roundtable was set up by a group of international corporations with the belief that many individuals on the autism spectrum have the capabilities businesses need (Disability:IN, 2017). Regarding the critical co-design aspect and social responsibility of such organisations who are open to change, disabilities and inclusion expert consultant Jonathan Kaufman writes:

“It is essential that companies utilize both their internal disability employee resource groups as well as cultivate partnerships with the local autism community to establish an ongoing dialogue and illicit internal and external feedback. This method not only allows companies to develop a deep dive into the local autism community’s resources, needs and preferences, it also creates a more efficient hiring process by showing what can be leveraged internally and what should be outsourced.” (Kaufman, J. 2019).

As well as identifying supportive partners, another key aim for our organisation is to identify and support autistic leaders and create a supportive network to encourage the use of Dialogue and peer coaching and mentoring. A pair of British researchers have developed methods for understanding cross-neurological interactions and interactions between autistic people; initial findings suggest that neurodivergent intersubjectivity reveals potential for unconventional forms of social relating (Heasman, B., Gillespie, A. 2018).

8. Autistic Identity
Aligned loosely with the values of the growing neurodiversity movement, we believe that Autism Dialogue can support a positive common identity:

“There needs to be greater recognition that the autism identity is a social construction with the potential to constrain and degrade. In identity terminology, individuals need to be enabled to identify with a group that is perceived as constructive and empowering rather than detrimental and limiting.” (MacLeod, Lewis & Robertson, 2013)

People who identify as autistic (or might be waiting for a diagnosis) can benefit from direct joint interactions with others who may or may not identify as autistic. Autism Dialogue takes place within a safe space whose agenda is generosity and care, and whose aims are unification, deeper awareness, stronger participation, better respect and a greater openness and sense of potential.

Whilst society can be disabling and frightening, Dialogue allows rules-based, safe exploration of potentially harmful feelings and co-creatively enables subtler thoughts and feelings and once hidden unique strengths. Erin Manning attempted to address autistic perception as ‘the direct perception of the forming of experience’ (Manning, 2018), which can be debilitating. Providing access to a safe place with an open, self-therapeutic approach where people can share openly and authentically, can support a decrease in the level of stress and anxiety and thereby increase well-being. Psychological distress from autism, a cognitive impairment, is at the core of many autistic people’s disabilities and one main reason they can often struggle to live an independent life.

Participants from all backgrounds and experiences can explore individual and collective consciousness and barriers to group settings, and normative social communication can be explored as part of the overall process. It is believed that iteration of the dialogue experience aids the emergence of bonds and familiarity among participants, it is key for autistic people to have the choice to share more freely with others.

9. Research

We are keen to carry out research into the benefits of Autism Dialogue. Research will study the efficacy and effectiveness of Dialogue in Autism, demonstrating that it can lead directly to improved well-being, empowerment and confidence and reductions in anxiety. Research proposals for Autism Dialogue have been written and can be viewed on request, including the latest put forward by Caroline Pakel. One interesting area already mentioned that could be developed, is neurodivergent intersubjectivity and the idea that within-interaction analysis is a viable methodology for exploring neurodivergent communication. This would be aligned with values already proposed by many researchers, advocating for co-designed and fully participatory research, for example as held by the UK Participatory Autism Research Collective.

It is crucial to develop a methodology that includes the full, dynamic range of autistic experience in theory, research and practice and practice-based research interventions, to be able to claim work is truly participatory. Holistic approaches could support an open culture of autistic-led and co-led research. This could have a profound effect on the way theory development and diagnostic procedures are formulated and tested.
“It is both epistemologically, as well as ethically, problematic if the autistic voice is not heard in relation to social scientific research seeking to further develop knowledge of autism. Ever since autism first emerged, it has remained medicalised and almost exclusively the preserve of non-autistic researchers.” (Chown, Robinson, Beardon et al 2017).

The ‘Autism Quality of Life Measure’ developed at Newcastle University as an add-on set to the WHO QOL (World Health Organisation) measure. It is the first of its kind and we are working towards its implementation in our research.

Outcome data could eventually be collated and used in a similar way to NHS codes, which can help to inform practitioners.

There is no exact empirical evidence for effectiveness of Professional (Bohm) Dialogue although several related studies exist, including around Open Dialogue, an intervention for mental illness based on similar principles, founded in Finland and currently in operation in some areas of the NHS.

10. Facilitator Network

A newly identified aim is to identify natural leaders and train a network of both autistic and non-autistic people to run parallel programmes across the UK and beyond. A network is being established, including abroad where several fellow Dialogue Academy members in health care are in discussions with us via regular practitioner conference calls.

As an autistic facilitator and thought-leader, Jonathan has identified his own, once disabling hyper-literal mind-set, hyper-empathy and a low tolerance of the limiting nature of language, which can now be channelled through an ecology of deep communication, environment and with the self; this formula is transferable to others. Untethered communication with self and congruence with environment is the at the core of human endeavour and potential, and it is for this reason that the fusion of autism, dialogue and coaching could have far-reaching implications in both open and closed systems. Vocation, employability and enterprise can be factored here.

Some very interesting research has been carried out by Olga Bogdashina into the parallels between Autism and Gestalt Perception (Bogdashina, 2011) and Jonathan is currently exploring 1:1 coaching as part of a Masters degree (of autistic people as well), with some equally interesting outcomes. FlowDialogue.org is Jonathan’s temporary holding place for this developing aspect of his work (named in relation to Csikszentmihalyi’s Flow concept) (2002). ‘Flow; also relates to the root of the word ‘dialogue’ – ‘dia’ from the Greek meaning to flow / across / between and ‘logue’ from ‘legein’ meaning ‘words’.

11. Funding

All activities are currently self-funded and there is no external funding apart from some private donations via a JustGiving page to support costs (room hire, travel, etc). Jonathan is self-employed and the organisation is about to formed as a Community Interest Company, which will also incorporate specialist coaching for autistic people and those researching and working in the field as well as a platform for related initiatives, for example leadership programmes.
12. Partnership

We are very keen to engage with any individuals and organisations, either academically or commercially, who share our values and visions. We offer a range of services to external organisations, such as dialogue facilitation and coaching, not limited to autism and inclusion. Please contact us for more information and fee details.

A final comment
- from Dialogue practitioner, scholar and author Linda Ellinor:

“You break incredibly new and challenging territory by taking Dialogue into a therapeutic context. I feel that it may have greater applicability than we ever thought from the point of view of flattening the hierarchical nature of how we view, work with and even study mental or emotional disorders. Also, by allowing the free flow of ideas from both those who are autistic, those who live with people who have been so diagnosed, and from those who might be treating them, the global understanding of the nature of autism is enriched.

I wonder what might arise if we used Dialogue in such contexts as with people suffering from personality disorders, anxiety disorders, or even from depression. My gut tells me it offers new territory for exploration.

However, it might also threaten the current therapeutic paradigm. Care will have to be taken in how it is articulated so that it isn't seen as necessarily competing with the existing therapeutic community, but a possible addition to it.“

- Linda Ellinor, The Dialogue Group, USA.

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Resumé
Jonathan has a background in creative personal development, special education and metaphysical practices. He has an Honours degree in Contemporary Fine Art, a Postgraduate Certificate in Autism and numerous qualifications and experience in health care, group facilitation, disabilities and employment research work, counselling, mediation, chaplaincy and international retail and food manufacture. He is working on an Autism Dialogue book and his memoirs. He lives in Sheffield, UK and has five children, one granddaughter and a cat.

Any errors in this report are his and should be reported directly.
REFERENCES


Newcastle University Autism Research Team (2017) Autism Spectrum Quality of Life (ASQoL) measure.


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“The state of Being, the sense of integration and belonging to the whole, is at exactly the same time both enhanced and diminished. For me this means there is enormous potential for insight in the experientiality of the individual and group interpersonal dynamics, but also this brings a sense of separation and outside-ness, which can be isolating and distancing. Overall, it is as if this matter of the parts and the whole is the most important thing to my life, and I can get obsessed by it, such is demonstrated by a geeky interest in quantum mechanics or an over-attachment to others.”

- Jonny Drury, April 2019