



Conference report

BEYONDAUTISM

Social constructs and the realities of disability and autism inclusion

INTRODUCTION

On the 20th and 21st June, a group of researchers, practitioners and those with an interest in inclusion came together at the 3rd BeyondAutism annual conference in Ipswich, Suffolk. Hosted in collaboration with the Childhoods, Children and Young People Research Theme, Institute of Social Justice and Crime, at University of Suffolk, the conference aimed at building multi-sectoral dialogue emphasising the lived experiences of autistic individuals.

Drawing over 50 delegates from a diverse range of backgrounds, including a mix of students, analysts, education practitioners and charity representatives, the conference provided a dynamic platform for professionals to share research and insight on the theme of 'Social constructs and the realities of disability and autism inclusion'. It sought to bring together latest research, policy and practice, alongside lived experience, to really explore what it is within society that needs to change to make a meaningful difference to how inclusion is framed, and actioned.

Central to the conference were some key objectives that we wanted to achieve:

- An inclusive and open ethos that brought together individuals with different perspectives into one room, to start real conversations that serve as the building blocks to change on a societal level
- To hear from researchers and practitioners with lived experience – either their own, or that of a close family member
- Presentations from across all aspects of society, including education, health care, social care, and intersectionality.



WELCOME AND OPENING SESSION

Welcome address

Tracie Coultas-Pitman
CEO, BeyondAutism

Keynote speaker

Barney Angliss, autistic researcher,
author and consultant in SEND

The conference kicked off with a short welcome address from Tracie Coultas-Pitman, CEO of BeyondAutism that set the scene around what we hoped to achieve across the two days, encouraging participants to truly explore what inclusion means, and use the networking opportunities to drive forward the topic.



This was truly brought home through a compelling, visual presentation from Barney Angliss titled Making the invisible... still less visible. Through the use of metaphors and art, Barney demonstrated how a snapshot of inclusion shows what the person creating that frame wants us to see. He challenged the audience to consider whether this is real, or just a construction of the truth put forward by the person framing it, and how we as society need to look beyond that frame at the individuals involved.

The inference being, are we doing the same with support and services for autistic and disabled people? Making decisions without truly involving them, based on what we believe to be right, and based on the systems that we already have in place, rather than challenging ourselves to take a different, more conscientious approach.

DAY ONE: AFTERNOON SESSIONS

Dr Annie Clements Hons, Founder & CEO, Autism and ADHD

Moving forward in challenging times

Dr Clements continued the theme of inclusion, with a focus on the education sector. The overall theme of the presentation was around why, in a world of thresholds, we don't have minimum standards that ensure equity in the classroom, to benefit all.

How do we teach difference in school, as a positive and normal aspect of society; as ultimately that will drive inclusion. Make environments neurodivergent as the norm, and all will benefit. Annie highlighted this beautifully with a simple example. In your average Early Years setting, the norm is for bright colours, artwork hanging from the walls and ceilings, spaces full with 'creative' tools. It's overwhelming for any child – who would learn at their best in this space? By taking the time to simplify the space, use calmer colours, all children will learn better.

The system focuses on getting a diagnosis, however the piece of paper you receive isn't making school environments more accessible. A huge culture and mindset shift is needed, and everyone has a responsibility for making this change.

“Do not change people with autism, but rather change the world to make it more friendly for everyone.”

Delegate feedback



DAY ONE: AFTERNOON SESSIONS

Dr Alison Bishop, Lecturer in Childhood Studies, University of Suffolk

Resilience cycles: A grounded theory study of the experiences of resilience, in mothers who have children with an autism spectrum disorder

Dr Alison Bishop shared with us some compelling research around the theme of parental resilience. The ethos of her research was to show that resilience, and overcoming adversity, rather than being a linear process, is actually a cyclical process. Part of this is having a resilience signature – a way for individuals to map out how they response to adverse events and taking the time to learn what this means about managing future events, with a set of tools / strategies that works for them.

As a society we often talk of providing people with resilience. We should stop talking of increasing resilience and rather focus on enabling people to use the resilience skills they already have.

Caragh McMurtry OLY, Founder, Neurodiverse Sport CIC

Social constructs disabling neurodivergent athletes

We were honoured to have former Olympian Caragh McMurtry share her experiences of being a neurodivergent athlete in elite-level sport. Caragh's journey is one that is commonly seen across different disciplines – in particular amongst autistic girls and women – that of misdiagnosis and a lack of appropriate support and understanding as a result.

As Caragh progressed into elite sport, she started to struggle with the environment, and was misdiagnosed by her team with bipolar disorder. She was put on a cocktail of drugs that affected her performance and mental health. Rather than understanding and asking the right questions, she was criticised for her failing performance. It took a switch in management coming on board with a person-centred approach for that to change – they sought a re-diagnosis for her, of autism, which was a turning point in her career.

Caragh believes that all coaches should have the skills to work with the individuals in this way.

Elite sport has a role to play in driving change at a wider societal level, bridging the gaps between pockets of society, and opening up new opportunities for neurodivergent athletes.

DAY ONE: AFTERNOON SESSIONS

Dr Suzi Sapiets, Postdoctoral Research Associate, Tizard Centre, University of Kent working with the Sharland Foundation Developmental Disabilities Research and Impact Network

Access to support in the early years for neurodivergent children and their families

Dr Suzi Sapiets' work looked at factors that affect access to early support, both the barriers and facilitators. The research comprised of three different studies. The first was a narrative review of the factors that influence access to early support for families of neurodivergent children. The second was a parent caregiver study into barriers and facilitators of access to support. The third looked at predictors of access.

Together these three pieces of research highlighted that there are multiple barriers to families accessing support – many are not surprising, such as socio-economic status. However, by highlighting these, it's the first step towards making changes to redress the imbalance.

One factor that influenced early access to support was diagnosis, reinforcing the question raised by Dr Annie Clements. Why does diagnosis remain a necessary step before change can happen for an individual?

The key conclusion that could be drawn is that factors affecting access are complex and multifactorial. A system-wide review and investment is therefore needed across multiple factors to be effective – not forgetting the need to consider the individuals at the heart of this.

Day one concluded with an opportunity for speakers and delegates to come together to share their reflections of the day and to build contacts that see us work together to influence change.



DAY TWO: OPENING ADDRESS AND KEYNOTE

Opening address

Tracie Coultas-Pitman, CEO, BeyondAutism

Andy Swartfigure, Director of Research & New Business, BeyondAutism

Keynote speaker

Chike Nnalue, Head of SEND Strategy & Development at Ealing Council

The experiences of Black African parents on partnership working with education professionals in the SEND system

Day two of the conference kicked off with a thought-provoking talk from Chike Nnalue, who shared his research with Black African parents on their experiences of navigating the SEND system, in particular working with education professionals. At the core of his research was the need for us to understand that individual experiences and journeys shape who we are, and without taking the time to listen to, and understand, those journeys we can't possibly hope to provide the right support for these families.

Chike reflected on the fact that we have one system to support all, but that not everyone has the same opportunity to access the system, or the same experience when they do. In order to have equity of service provision, we first need to ensure all voices are being heard equally. Through the research, Chike was able to share the way that cultural differences can lead to challenges with families accessing the right support. One example is where there might be a stigma of diagnosis holding families back; however, as we heard in the talks on day one, without the diagnosis you're unlikely to get access to support.



Chike left delegates with two questions that we should all be seeking to answer. Are some parent groups hard to reach, or are the professionals hard to access? Do we truly take the time to understand a family's journey to where they are now, as a way of unlocking what success can look like for the individual?

DAY TWO: RESEARCH SESSIONS

Dr Ivana Lessner Listiakova, Associate Professor in Childhood and Education, School of Social Sciences and Humanities, University of Suffolk

Sensory aspects of living with autism in rural coastal areas of England

Dr Listiakova shared her research undertaken with Dr David Preece, Associated Professor in the Centre for Education at the Faculty of Health, Education and Society, University of Northampton (retired). It was funded by the British Academy / Leverhulme Trust.

The research was carried out due to the lack of UK-based research into factors that affect autistic people living in rural / coastal towns; there is common knowledge that they face more hardship than inland areas, however this had yet to be formally documented through research. In particular this research focused on the sensory needs of these autistic communities.

At the crux of the research was an identification of a delicate balance between the benefits that the physical environment of rural areas can bring, from a sensory aspect, alongside the challenges of the poor quality or lack of access to services in these areas.

The conclusion from this research is that making improvements in the quality and access to services could have a significant positive impact on autistic individuals living in remote areas and provide them with the perfect balance of quality of life.



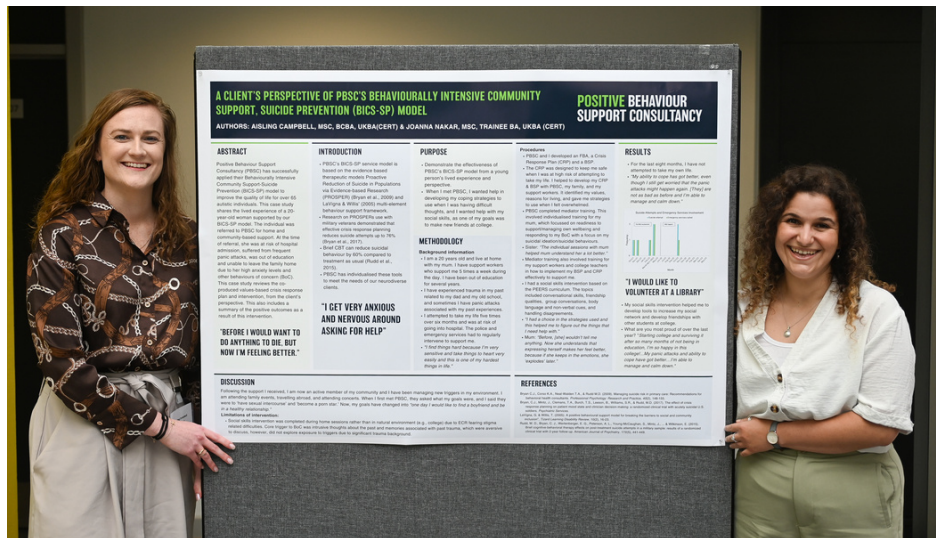
DAY TWO: RESEARCH SESSIONS

Helena Lee MSc, BCBA, UKBA(Cert), Behaviour Analyst and Service Lead, Positive Behaviour Support Consultancy Ltd.

Utilising the PERMA Model When Designing Person-Centred PBS Plans

The PERMA model is based on the principles of positive emotion, engagement, relationships, meaning and accomplishment. At PBSC Ltd, they have embedded the use of the PERMA model into their support for learners, using a particular tool that focuses on matching, engaging, understanding, delivering and celebrating, producing a personalised report that prompts goal setting and maps what makes an individual happy and engaged in life. Fundamental to all of this is including the individual in the creation of this report and ensuring that it can be shared with their wider network so that they have the right support in following their chosen pathway. This step of inclusion of the individual is often what is missing from support that is offered.

A final reflection from the session – too often tools such as assessments take a deficit approach, highlighting what isn't working for an individual, or where weaknesses lie. The PERMA Model takes a strength-based approach, which can have a more positive impact for the individuals involved.



“I found the PERMA model talk by Helena Lee interesting as I feel I could directly use this in my own role.”

Delegate feedback

DAY TWO: RESEARCH SESSIONS

Kiran Hingorani, CEO Swalcliffe Park School, Banbury, Oxfordshire

A framework and approach for improving 'Quality of Life' outcomes

The morning of day two ended with an engaging talk by Kiran Hingorani, the CEO of a school in Oxfordshire for autistic learners. His presentation focused on the importance of embedding quality of life into the education students receive – essentially, that good education needs to include good quality of life, and what makes us happy is very different from person to person.

Kiran shared a framework they use within their school, which sees the young person, their family and the school team all integral in identifying what good quality of life means to the individual, and how this can be developed in the school environment. Its personal, dynamic and multi-dimensional; by having a tool that can pinpoint what this looks like for the individual means we're able to measure it to track success.

Quality of life should be given the same level of importance in a child's education as any other subject, as an integral part of their curriculum.

“Kiran's talk gave me some new strategies to consider/ add to my tool box when supporting autistic students.”

Delegate feedback

Lauren Beadle, MSc, BCBA, UKBA(cert), SEL Service Lead and Susan Tirella, M.Ed., BCBA-LBA, UKBA(cert), Clinical Lead, Positive Behaviour Support Consultancy Ltd

A framework and approach for improving 'Quality of Life' outcomes

Susan Tirella and Lauren Beadle brought us back for the afternoon with a crucial session around the importance of recognising assent.

They discussed the importance of assent, not just informed consent, in any services that we provide to people, and as a fundamental part of that considering assent withdrawal, especially when working with vulnerable children and young adults. Assent withdrawal can look very

different in different scenarios. It's the job of the professionals to be looking for actions that might represent signs of assent withdrawal – it isn't limited to verbal indications and can include multiple behaviours.

Assent withdrawal is dynamic – we should always be looking for it, and ensuring we honour it.

Keynote session: Dame Christine Lenehan DBE, Director, Council for Disabled Children

Making the difference for autism inclusion, challenges and opportunities

Our final presentation of the day was a keynote from Dame Christine Lenehan DBE, Director of the Council for Disabled Children. Her presentation started with a look at some of the changes that are happening at a government level around SEND support for children and young adults; and a reflection on the lack of research that exists to support children with SEND. As such, her research programme is seeking to understand what works in SEND, and what the tenets of a system need to look like for it to work.

Bringing us back to the themes of the past two days, she addressed the need to shift from it being a tick box exercise of having a label to access to support, to a system where we seek to understand the needs of the individual and what needs to change to deliver these.



Is the long path to diagnosis the challenge, or is it the fact that a diagnosis is needed to unlock support? Is the problem not that our aim is too high and we miss it, however that our aim is too low and we reach it.

DAY TWO: PANEL DEBATE

Discussant

Tracie Coultas-Pitman, CEO, BeyondAutism

Panellists

Barney Angliss, autistic Researcher, Author and Consultant in Special Education Needs & Disability

Chike Nnalue, Head of SEND Strategy & Development at Ealing Council

Dame Christine Lenehan DBE, Director, Council for Disabled Children

The professional conference wrapped up with a lively debate amongst our keynote speakers on topics raised by delegates over the two days. Tracie Coultas-Pitman directed our panellists through three questions.

What would you do to change the system, if we could start from scratch?

The discussion centred around the need to redress the relationship between the state and the parents; with clear pathways that enable parents to be in control of the support for their child. We need to lose the sense of professional superiority, so that the child stops getting lost in the middle.

Focusing on the world of education and the classroom, are there a set of standards that can be applied without too much room for misinterpretation?

A few themes emerged. Whatever is brought in should not be a minimum standard – that's not aspiring enough. You need a dynamic standard that you can exceed. And that until accountability is addressed, any standard brought in won't have the impact it needs. The currently status is not the lack of guidance, there is plenty, its that people are reading or using the guidance, and its not being consistently applied.

What one simple thing can we do to make a change when leaving the conference?

Embrace individuality. If you talk in big numbers you risk the danger of abstraction; you lose the individual journeys that might have a more significant impact on how we practice at a macro and micro level.

“I appreciated the fact that all of the speakers were discussing the subject from very different angles, resulting in a broad spectrum of the topics being discussed.”

Delegate feedback

CONFERENCE REFLECTIONS

“This was a great opportunity to widen the conversation around autism regionally and nationally with a diverse group of attendees and delegates that included policymakers, academics, practitioners, and students. The conference was a unique platform emphasising the lived realities of disabilities, challenging notions of inclusion and reframing the 'gaze' on autism in society.”

Pallawi Sinha, Co-Organizer,
University of Suffolk

Key Takeaways

- Significant systemic change is needed that addresses the balance of influence. Too much power sits with the professionals, and not enough with the individuals and their family.
- Neurodivergence should become the societal standard. As opposed to viewing difference as a problem, we should embrace difference and establish environments that are beneficial to all.
- Always empower individuals to make their own decisions, rather than imposing decisions and choices on them.



Moving Forward

- Emphasize the importance of listening to all individuals involved and enter each conversation without pre-conceived notions.
- Continue to encourage and facilitate open conversations surrounding neurodivergence. The more we talk, the more it becomes part of society.
- Build on these conversations with our next conference and ensure we continue to bring these voices together.





“It was thought provoking and stimulated conversations that are much needed.”

Delegate feedback

“It was an interesting and varied two days which included a range of lived experiences, research, practice, discussion and thinking points.”





Our heartfelt thanks to all of the speakers and poster presenters for giving their time to be a part of the conference, and to the delegates who came and made this an interactive and progressive event. Please contact info@beyondautism.org.uk for more information regarding our 2024 Professional Conference. We look forward to seeing you there!

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