



Conference Abstracts

BEYONDAUTISM

Social constructs and the realities of disability and autism inclusion

20 June 2023

Making the invisible... still less visible?

Barney Angliss, SEND Consultant

Abstract:

From Lorraine O'Grady's jubilant 1983 performance, 'Art Is...' in Harlem's African-American Day Parade and the institutional critique in Hans Haacke's satirical art, to Paul Fletcher's work on vision, hallucination and psychosis, William Callahan's assessment of visuality and the challenge to neuroscience presented by Christiana Westlin, Lisa Feldman Barrett and others, Barney's sweeping and graphic keynote will examine the nature and impact of societal constructs. Through the work of Uma Khotari, Sheila Jasanoff and Bruno Latour, Barney throws open the conference space to consider how knowledge and social control defy resistance through the palliative of 'participation'. Between Socratic 'essence' and the celestial aspirations of Alexander Pope's 'An Essay on Man', do we fall into an abyss? Are we 'beings of fiction' and, if so, whose fiction? Turning to education, health care and our "special needs" system, we must ask into what may young people be included if not merely the 'horizontal identities' of Andrew Solomon's "Far from The Tree"? Is there a parallel with Genevieve Zubrzycki's 'civic' and 'ethnic' models of nationhood, summarised by Zygmunt Bauman as the "opposition... between belonging by primordial assignment or by choice."?

We don't need fixing, we need accessible

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

Abstract:

We have a crisis regarding the lack of accessible education provision for the Neurodivergent community.

Inappropriate training and environments, an inflexible curriculum and long waiting lists for assessments due to pressures within the NHS, is leading to autism burnout and trauma for our children. This leads to an increase in the numbers of families seeking alternative provision where there are insufficient appropriate places, meaning they are at home, or children are being withdrawn from school and home educated.

The need for things to change is growing, as this crisis impacts not only on the long-term development of the child, but also their family, the school staff team and society. The cost of alternative provision alone is significant and unsustainable but other monetary costs follow — mental health & social care support not only for the child but other family members, parents needing to leave their jobs to be able to care for their child who isn't in School, and the need for longer term professional care into adulthood. There is also the cost to society of the loss of skills being brought into the workplace and the loss of helping communities move forward regarding inclusion.

This talk explores how we can change culture and knowledge to create not only a more inclusive society and education provision for the ND community, but for everyone, thus improving outcomes for all emotionally, academically, and financially.

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

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

Abstract:

Traditional views of resilience describe it in terms of risk and protective factors, plus processes, that enable individuals to resist or quickly recover from adversity to achieve a positive outcome. This previously led to resilience being conceptualized as a linear, binary construct with some people being considered resilient and others not resilient.

Mothers of children with ASD have been found to suffer poor mental health, due to the challenges of parenting a child with ASD (Baylot Casey et al., 2012). Based on the traditional view of resilience, this might lead to a conclusion that these mothers were not resilient, thus adding further stigma to their burden.

However, the findings of a qualitative constructivist grounded theory study of the experiences of resilience in mothers of children with ASD, propose a new more inclusive model of resilience. By studying mothers facing an ongoingly challenging situation, it was found that all the mothers were resilient, and that resilience was a non-linear circular process. Furthermore, the mothers had a personal, signature style of responding to adversity. The findings provide a conceptual framework model that gives a kinder, inclusive conceptualization of resilience, which challenges the assumptions of resilience theory. The implications of this research provide a model of anti-discriminatory practice for those involved in the creation of social policies or the care of mothers of children with ASD. It also provides a new narrative for those who struggle with the daily challenges of life and those who seek to help them.

Social constructs disabling neurodivergent athletes

Caragh McMurtry OLY, Founder, Neurodiverse Sport CIC

Abstract:

Drawing from her lived experiences as an athlete with a late diagnosis of autism as well as insights from neurodivergent individuals, Caragh McMurtry sheds light on the challenges faced by neurodivergent athletes within sports environments. Key areas of discussion include the disabling nature of these environments, the impact of societal stigma and expectations on neurodivergent athletes, and the pressing need for increased support.

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

Suzi Sapiets, Postdoctoral Research Associate, Tizard Centre, University of Kent

Abstract:

Neurodevelopmental conditions (e.g., autism, learning disabilities, attention deficit hyperactivity disorder, dyspraxia) are lifelong conditions which affect the brain and influence how people think, perceive the world, and interact with others. Children who are neurodivergent have an increased risk of health and social inequalities, such as poorer mental and physical health. However, the provision of support during early childhood (0-6 years) can improve a range of child and family outcomes. Despite this, research suggests there are disparities in access to early support for neurodivergent children and their families. Findings from a survey of 673 families of young children with suspected or diagnosed neurodevelopmental conditions in the United Kingdom (UK) will be presented, including quantitative and qualitative data on their experiences of access to support, including: a) access to professionals and services across education, health, social care, and other support services in the early years; b) access to packaged intervention programmes; c) ease of access to support; d) unmet need for various support sources (i.e., support wanted but not accessed); e) barriers and facilitators of access to support; and e) child, family, and service-level factors predicting access to support in the sample. Implications of the findings will be discussed, focused on ways to improve the accessibility of early years support for neurodivergent children and their families across the UK. This will also include reflections on lived experience, as this research was conducted by a researcher who is neurodivergent.

21 June 2023

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

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

Abstract:

This study investigated four Black African parents of children with special educational needs & disability (SEND) living in England and their experiences of working in partnership with education professionals to support their children. Reforms to special education policy in England has emphasised the importance of parents being involved in decision-making about their child's education and greater control over their child's support. A critical approach was taken to understand how issues of power such as race, ethnicity, combined with their own African culture, affected their interactions with education professionals who hold an entirely different contextual disposition. The parents took part in individual, semi-structured interviews which were thematically analysed. Three overarching themes were identified: communication, cultural barriers, and the parent-professional relationship. Six subordinate themes were also found. The findings are discussed with reference to existing literature and theoretical concepts. Recommendations for professional practice and further research are also discussed.

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

Dr Ivana Lessner Listiakova, Associate Professor, Course Leader, University of Suffolk

Abstract:

While living in a rural coastal place is generally associated with the rural idyll, vast blue skies and outdoor lifestyle, coastal villages and hamlets in England suffer from lack of access to services and their inconsistent quality. In a qualitative research study, twenty-two families (49 individuals) from Cornwall and West Norfolk reflected on living with autism in these areas. This paper adopts a bio-ecological perspective in the analysis of data from semi-structured interviews. It specifically extracts themes of self-awareness of sensory processing needs in these families in relation to rural coastal places and space. Families living with autism appreciated open spaces that allowed them to "breathe", reducing anxiety and feelings of being overwhelmed. In addition, living in rural coastal areas provided opportunities to regulate and meet the recognised sensory needs of these families through engaging in outdoor sports, accessing facilities in the quiet times out of season, or being able to afford more spacious houses. Such match to sensory needs, however, came as double-edged sword with a lack of professional awareness of autism-related needs, sparse service provision and difficulties with transport. The bio-ecological perspective including sensory aspects of geographical locations as spaces of living is valuable in understanding the complexities of living with autism and can inform further provision of services.

Utilising the PERMA Model When Designing Person-Centred PBS Plans

Helena Lee, Service Lead PBSC Ltd

Abstract:

The PERMA (Positivity, Engagement, Relationships, Meaning and Accomplishments) model was proposed in Martin Seligman's 2011 book *Flourish: A new understanding of happiness and wellbeing*. Seligman (2011) proposed that interaction with the elements of the model would help people work toward finding happiness and meaningful life fulfilment. 12 years on, this presentation explores the current evidence base for the PERMA model and the correlations between its elements and positive life outcomes. Importantly, the presentation also explores practical applications of the model within a community-based Positive Behaviour Support (PBS) service for Autistic individuals. Focus is placed on the use of validated PERMA assessment tools and scope for their use as a service outcome measure of happiness and wellbeing. Furthermore, we will explore how the PERMA model can be embedded within person-centred PBS Plans through PERMA profiles and PERMA action plans, to ensure the individual's happiness and wellbeing is central to their PBS Plan and the support they receive. A case study will be presented, exploring the use of the PERMA model alongside complimentary evidence-based practices to increase happiness, wellbeing, and fulfilment, promote values-based living, and consequentially decrease dangerous behaviours of concern. This includes written feedback and insights from Autistic people who have received support rooted in the PERMA model and future directions for the use of the model within support services for Autistic people. The PERMA model provides scope to address current gaps in PBS service delivery regarding the active involvement of the individual in their own PBS pathway.

The impact of transitioning to a school implementing a Quality-of-Life (QoL) framework on autistic children and their families

Poppy Grimes, Research Associate and Kiran Hingorani, CEO, Swalcliffe Park School

Abstract:

Autistic children and their families experience a lower quality-of-life (QoL) than typically developing children and other SEND groups. Individualised, holistic education is pivotal for improving autistic wellbeing. At our school, we prioritise enhancing student and family QoL through tailored education. This practice-based study set out to determine the efficacy of a dynamic curriculum based on termly QoL feedback. We employ a peer-reviewed quality-of-life in autism questionnaire (QoLA; Eapen et al. 2014) and each child is assigned a 'keyworker' to facilitate weekly communication and to set QoL-based targets parallel to the student-family voice. We collected 1,246 survey responses to determine trajectories over 2019-23. After one school year, overall QoL saw a considerable increase in students and families. Despite the growth, scores were consistently lower in families. Over a broader four-year period, trajectories of self-perceived QoL and the impact of autism-associated behaviours demonstrate significant improvement. Transitioning is a significant challenge for autistic individuals, as maintaining and improving their quality-of-life during this time can be difficult due to heightened anxiety. However, a culture that emphasises well-being and independence, along with a QoL feedback-based educational framework and therapy strategies, can produce positive outcomes. Our work replicates findings of lower QoLA in families than in children, perhaps reflecting the wider impact that parents experience, across family and community contexts. Whilst family voice is integral to our keyworking, participation in surveys is difficult to establish. The school is improving this by highlighting the outcomes through QoL-focused workshops.

Defining and Applying Assent and Assent Withdrawal Procedures in Behaviour Analytic Services for Autistic People

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

Abstract:

It has been a long-established practice in the field of behaviour analysis, as like in any other medical, psychological, or social care industry, that informed consent must be obtained and maintained throughout the duration of care (Behavior Analyst Certification Board®, 2020; UK Society for Behaviour Analysis, 2021). However, given the vulnerability of many of the individuals behaviour analysts support this may not always be achievable should the individual be underage or lack capacity to do so. In these instances, consent is provided by a parent or legal guardian. However, there is a duty of care for behaviour analysts to also gain and maintain client assent (Reed, 2014), particularly when their work is supporting the most vulnerable populations such as young autistic children or those with significant communication needs. Yet, research on the application of assent is still nascent (Gover et al., 2023) and there are limited tools available on how to define and measure assent and assent withdrawal: the latter being just as important, if not more so, to ensure client voice is respected and upheld and behaviour interventions are not potentially traumatic. The purpose of this presentation is to outline the current literature on assent in relation to behaviour analytic support to autistic individuals. A summary of the most up to date research on the topic will be summarised and shared. In addition, a rationale and system to include assent procedures in each stage of support (i.e.: assessment, intervention, etc.) will be outlined using case examples and scenarios from across a range of individuals whilst the ethical application of extinction procedures will be discussed and challenged. Finally, a range of methods to define and measure both assent and assent withdrawal will be provided as best practice examples.

Making the difference for autism inclusion, challenges and opportunities

Dame Christine Lenehan DBE, Director of the Council for Disabled Children, National Children's Bureau

Abstract:

Autism and neurodiversity issues have an increasing public profile. This presentation looks at the issues and challenges for different groups of young people across the continuum, where we are now and what are the opportunities for a truly inclusive society.


20 June and 21 June 2023

“I was just the weird one with no friends” Blog-sourced accounts of autistic individuals experiences of mainstream primary school, An inductive thematic analysis

Robert Lawrence Jolliffe and Maggie Watkin, Manchester Metropolitan University

Abstract:

While the number of autistic children attending UK primary schools has risen over the last decade, their experiences are largely unheard. Research has focused on the perspectives of stakeholders and autistic secondary-aged children. A Thematic Analysis of 42 blogs of autistic adults explored their experiences of mainstream UK primary schools and deduced four themes: ‘The Mask Comes Down’, ‘Interpersonal Peer Relationships’, ‘Sensory Barriers’ and ‘Positive Learning Experiences.’ Authors contextualised sensory difficulties, interpersonal relationships, and masking through their autism, as negative experiences outweighed positive ones. Negative experiences impacted and interacted with one another, further damaging the authors well-being. Indicative of inclusive pedagogy, positive experiences highlighted the importance of developing meaningful relationships with staff and peers, alongside being challenged academically. The experiences discovered suggest that support overcoming sensory and social barriers to learning will provide autistic children more access to mainstream education.



Pathological Demand Avoidance (PDA) from a Behavioural Perspective

Sarah Hellawell, MSc, BCBA, UKBA(cert), Service Lead, positive Behaviour Support Consultancy

Abstract:

A recent increase in referrals for positive behaviour support services for children and young people (CYP) described as having Pathological Demand Avoidance (PDA) or PDA traits prompted a review of literature and further learning to ensure appropriate, person-centred interventions were provided. PDA is not currently a recognised diagnosis and there is much debate about where, or even if, it fits into the autism spectrum. The aim of the poster is to provide the audience with an overview of how knowing that a CYP may display PDA traits can support in a better understanding of the individual and how these traits might impact the success of particular behavioural strategies. Information from literature on PDA and case studies will be included to provide a basis for understanding. The poster will highlight not only which but why certain behavioural strategies may not be effective and will review how person-centred planning can increase engagement.

A Client's Perspective of PBSC's Behavioural Intensive Community Support, Suicide Prevention (BICS-SP) Model

Aisling Campbell, MSc, BCBA, UKBA(cert), Service Lead, positive Behaviour Support Consultancy

Abstract:

Positive Behaviour Support Consultancy (PBSC) has successfully applied their Behavioural Intensive Community Support-Suicide Prevention (BICS-SP) model to improve the quality of life of over 65 autistic individuals. This poster shares a case study through the lived experience of a 19-year-old woman. The individual was referred to PBSC for home and community-based support and was at risk of hospital admission at the time of referral. She suffered from frequent panic attacks, was out of education and was unable to leave the family home due to her high levels of anxiety and behaviours of concern (BoC). The poster will review the values-based crisis response plan that was coproduced and the intervention provided from the client's perspective. The results of which have been the individual becoming an active member of the community (attending concerts, family gatherings and holidays abroad), as well as, maintaining zero levels of suicide attempts since 2022.

