Understanding, Inclusion and Participation:

A Manifesto for policy and practice with young people with Autism Spectrum Conditions

Authors: Dr Breda Friel, Jane Hickey, Eliz McArdle, Clare Harvey, Dylan Clark, Darragh Fullerton and Liam Gill

Inclusion is belonging, inclusion begins with you

Dylan Clarke, SONAS Youth Club: 2019

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Introduction and Rationale

Emerging trends and developments across the Community Youth work sector resulted in the organising of Community Youth Work Practice and Autism Spectrum Conditions - Understanding, Inclusion and Participation. This conference, convened on January 25th 2019, was a partnership between the Community Youth Work Department at Ulster University, Youthpact and YWelp (www.youthworkandyou.org) and aimed to facilitate the sharing of best practice in the area of ASC and to develop a manifesto to support policy and practice in CYW with young people. The key aim of the conference was to provide information, tools, and strategies to support young people with Autism Spectrum Conditions across the community youth work sector. This paper represents the distillation of themes from the conference and a manifesto for policy and practice that includes and engages young people with autism spectrum conditions.

Autism: Defining and Understanding

A strengths-based approach challenges the established definitions, the nomenclature and description of autism, which traditionally derived from a medical model and deficit approach to describing human behaviour.   An example was the term "disorder" implying malady, sickness or disarrangement from the "norm" (Friel 2020), a commonly used word to define the spectrum of presentations and individual characteristics associated with Autism. Such

definitions include Sicile-Kira (2006) who describes autism as the outcome of a neurological disorder that impinges on the functioning of the brain. The word derives from the Greek word "autos" or "self" and the term autism was articulated by psychiatrist Eugene Bleuler (1911) in describing patient behaviour as the presentation of an isolated self. Sicile-Kira (2006) states that 'The acuity of autism, as a label, was introduced by psychiatrist Leo Kanner (1943) who termed 'early infantile autism' in portraying patterns of behaviour in children, most notably impairment in social interaction or communication, and robust opposition to change. Autism Spectrum Disorder (ASD) emerged as the prevalent clinical term used in describing what was called "specific developmental disorders". Generally, it is accepted that those experiencing autism exhibit social communication and interaction uniqueness, and there is a vast variability in those who may be non-verbal and highly withdrawn to those with less complex presentations.

Challenging the Deficit

The medical perspectives of autism have shifted over the last century, from early assumption of autism as the childhood onset of schizophrenia, to the blame-based belief that mothers displayed a lack of empathy, were referred to as 'refrigerated mothers' – and were to blame for their child's condition (Waltz 2015). These early clinical understandings of Autism as a collection of deficits are indicative of the previously described medical model which locates disability as a problem within the individual, and hence places emphasis on diagnosis and on treating or curing the individual (Oliver 2013).

Developments in later perspectives depicted autism as a linear spectrum, described as a "vertical length of string" (Hickey 2019), with high functioning at the top and low functioning at the bottom, thereby assigning a perception of lower social value to those at the bottom of the spectrum. Hickey describes this as associated with an individual's perceived contribution to the economic life, the focus of this linear view of autism being to move people 'up the line' and increase their functioning. Like the medical model, this ontological view of autism depicts a limited and static understanding of autism and leads to a focus on fixing individuals for them to 'fit' within society.

The significant influence of disability activists transformed the assumptions about autism in the 1980's. The social model (Shakespeare 2018) identifies disability as a social construct whereby people with impairments are faced with disabling barriers created by an environment which excludes them. This shift from the medical to the social model has had a

profound impact on interventions across a range of disciplines, including CYW. The social model tasks society to create an inclusive community which enables *all* people, rather than *some*. (Miller & Katz 2002).

Hickey's perspective (2019) contends that the current understanding of autism rejects the notion of a linear and static spectrum and proposes that a sphere of inter-related elements is a more helpful representation. The dimensions of the sphere indicate the non-static, diverse and complex nature of autism. She highlighted Jacquiline Den Houting's view of neurodiversity, which says that the autistic brain is neurologically different and so autism should be accepted as a "way of being" – as a diversity rather than a deficit (Den Houting 2018).

Overwhelmed: Living in an Intense World

A more intricate community youth work practice considers the emotional, psychological and mental health of young people with autism, the gifted Asperger (AS) young people who wish for social communication yet struggle with social processes to achieve the same. The intensity experienced by young people with autism as they navigate difficult environments and deficit approaches across a range of contexts, challenges CYW to critically reflect on practice themes of inclusion, participation and diversity in real-world practice. The intensity of masking and trying to fit in can result in emotional damage for those negotiating neurotypical social world. This is a particularly acute stress for those labelled Asperger or High Functioning who sense the misfit between the mode of being and their social world (Rutter 2005; Hodge and Rutter 2017).

For young adults, overwhelmed and living in an intense world, negative coping strategies can develop. The result can lead to exhaustion, anxiety, and even selective mutism. Worryingly, statistics show that young people with Asperger have a higher risk of suicide in comparison to other clinical groups (Cassidy et al, 2014). Young people who feel overwhelmed believe that 'being me' is not enough, they may feel incongruent and that they 'don't fit'. These young people face emotional damage when trying to negotiate a neurotypical world, in which there is a mis-fit in how the social world interacts with them. Issues of social context and understanding of social roles can lead people with autism to struggle in many ways, this can manifest in depression, loneliness, fear, social isolation, underachievement and unemployment.

The deficit approach to mental health is challenged and increasingly CYW recognises the benefits of positive psychology strengths-based approaches. As youth workers our role is to trouble against, to challenge the terminology surrounding concepts of 'normal', and to modify our understanding of aspects of autism (e.g. when talking about repetitive behaviour, we should appreciate that this can be a learning approach by young people rather than a problem behaviour). Young people can mask their difficulties very well and therefore drift, or go under the radar, experiencing years of isolation, bullying, feeling different and overwhelmed in the environment. Practitioners within education and social and youth work should be cognisant that crisis points can occur particularly at times of transition such as school change and employment.

The 'gifted' are often very misunderstood, too often perceived as excessive, troublesome and over-excited. Persistent curiosity may be misconstrued as aggression, the tendency to question considered as undermining, traits of deep sensitivity may be misinterpreted as immaturity, self-directness may be viewed and labelled oppositional.

Normal or Optimal

Close scrutiny of the concept of 'normal' suggests this as an inappropriate measure within the life sciences. A more appropriate focus is 'optimal' or well-developed, rather than what is normal or average. Regardless of professional discipline, we need to realise the experience of intensity felt by young people with autism, the intensified pain, overstimulation and conflict, described by Kazimierz Dabrowski (1902-80) as 'over- excitabilities'.

Therapeutic Presentations

Case study practice of clinical therapeutic interventions with young adults, (Friel 2019) reveals high levels of critical and negative thinking, frustration and feeling inferior in the self. Young adults have high levels of self-blame, consider themselves at fault and believe themselves to be social failures. The question for youth work practice is how to support young people. A constructive approach, (Dabrowski 1967), describes a positive disintegration, asserting that 'inner fragmentation' is part of human development and in response Friel points to core elements for therapeutic and youth work interventions:

1.   Confirmation that I am not flawed (human excellence)

2.   Affirmation of self as I am (allowing immediacy)

3.   Work to the individual's capacity (optimal functioning without impediment)

4.   New Knowing (sensing and experiencing emotion)

To consider these aspects of human development, inclusive community youth work practice must go beyond traditional approaches to strive for opportunities that aim towards optimal well-being. The case studies of SONAS and ICARE tease out micro-skills that build engagement and a sense of belonging.

Participation and Inclusion – Lessons from SONAS and Project SPARKS

SONAS is a youth club for young people with autism in Inishowen. The very different characteristics and interests of three individuals attending SONAS were outlined by Liam Gill (2019). The variation between them illustrates the width of the spectrum and diversity of young people with autism. Sharing the same core aspirations as any young people, participants aspire to be happy, healthy, have good mental health and enjoy a sense of autonomy. Sonas supports the achievement of the aspirations by creating a supportive environment, using positive reinforcements, realistic goals, schedules and structure and negotiated care plans. Workers mitigate environmental barriers which may trigger behaviours (such as lighting, high-pitched sounds, open doors etc).

The Lundy Models of Participation (2007) offers a foundation for practice and Gill (2019) describe four elements that enable young people's right to participate:

•   Space - young people must have safe opportunities to express themselves

•   Voice - they must be facilitated to express their views

•   Audience - they must be listened to

•   Influence - their views must be acted upon, as appropriate

Building voice and influence would be a lonely place without building connectedness.

Dylan Clark describes just this. Dylan, a member of SONAS for seven years, spoke of his childhood, his late assessment with ASC, his passions and his difficulties. Having graduated

from their Leadership for Life programme (2018), he spoke movingly about the positive impact of his participation in youth work:

> *"It has helped me to see things differently but allows me to be myself"*.

Youth work is a key feature of his social life, a space where he has made friends and has developed a support network:

> '*For me, inclusion is about belonging. Inclusion begins with you*'

Darragh Fullerton's experiences echoed those of Dylan. Darragh, been a member of SONAS for the past six years, he spoke passionately about the importance of friendships, of feeling included, and having shared interests and common experiences. He reflected that the Leadership course facilitated self-reflection which helped him to

> '*appreciate who I am and what I can do*'.

Project Sparks is a pilot project in music education, training young people with disabilities who are gifted in the arts, to teach music to children in schools. Although the structure and format of Project Sparks differs greatly from SONAS, both employ a similar approach – in engaging and evolving the strengths of young people with ASC.

Owen Coyle, Erica Curran and Eamon McCarron highlighted empathy as a latent strength for their young leaders, having navigated failure and barriers persistently throughout their young lives. Project Sparks works with the young leaders to build facilitation and teaching skills on existing foundations of empathic understanding. The skills acquired and cultivated for and by the young leaders are ranked in a hierarchy as follows:

- Resilience

- Charisma

- Making connections

- Correcting mistakes

- Feedback

- Listening skills

- Structure

This approach to upskilling gives trainee leaders 'a focus outside of themselves', and the shared mantra is 'Leader looks different for everyone'. To build these leadership skills, Project Sparks uses specific approaches to boost personal cognitive and emotional development:

1.   Developing meta-cognition – which means identifying our own thoughts, how we regulate these and the ability to alter thoughts and behaviours that are self-limiting.

2.   Exposure to failure – the young leaders are deliberately challenged and are given time and support to fail and to rise again.

3.   Persistence – each young leader has had to face their fears. Ultimately, this programme is not suited to all young people with autism spectrum conditions, as it requires going out of personal comfort zones and coping with challenge.

4.   Adapting their role – there is a weekly reflection of progress with the young leaders, with a shared appreciation of the value that 'Leader looks different'

5.   Dismantling limiting beliefs – the training process requires young people to 'dismantle their own chains' and to free themselves from limiting self-perceptions

Eamonn and Erica concluded that evaluation data has been extremely positive, not only in terms of the social impact on young leaders, but also in providing evidence that the programme has promoted a significantly more affirmative perspective of disability among school children.

A Manifesto for policy and practice with young people with Autism Spectrum Conditions

This manifesto is a distillation of themes and proposals arising from this multi-disciplinary conference. Training, practice and policy form three core areas of considerable improvement if transition from the medical model to the social model is to be fully realised:

Training

- Agencies should be mindful of the support needs of staff in this area of work to avoid 'burn-out'.
- There should be a focus on self-care and self- awareness, supervision, support and staff- wellness.
- There is a need for more training in the sensitive area of work in mental health and well-being.

- Specific and targeted training is needed to equip workers beyond basic care and intervention.
- Workers need to be upskilled and have increased awareness of issues surrounding autism spectrum conditions - key pieces of training should enable the worker to deliver a more supportive role.
- The training of young people should also be a matter of priority. This would enable them to support their peers with autism spectrum conditions in everyday settings.

Practice

- Our practice must go beyond traditional approaches to strive for opportunities that aim towards optimal well-being. We must challenge the deficit approach, the myth of 'the normal' - the average- in our understanding of inclusion and participation.
- Direct engagement with young people is crucial – there is a need for practice to be based on young people's experience and allow young people to take control. Models of participation such as the Lundy model offer guidelines for meaningful participation.
- The youth service in its broadest sense should look more holistically in terms of actively reaching out to and engaging the diversity of young people in their communities.
- The youth service should adopt the Finnish model which formally links human rights with youth work, in such a way that human rights are interwoven and strategic.
- There is a responsibility for everyone to be inclusive.
- There should be increased opportunities for practitioners to come together outside of frontline delivery to test out new ideas and methods (where necessary) and refine skills in advance of using them with groups.
- There is a need for increased 'normalisation' of inclusive practice – this would look like a more integrated approach to practice.
- Where it is possible within budget and staffing confines, youth workers should adopt the proven model of also working closely with the parents of young people with autism spectrum conditions.
- As practitioners, we need to think much harder about the youth work environments we create to ensure these are accessible and inclusive for all young people.

Policy

- We should consider disability inclusion more broadly, acknowledging the social model of disability and the rights-based requirements to involve and accommodate people with disability in all aspects of community life.
- This type of work needs significantly more resources due to its concentrated nature, slowness of pace and the labour intensiveness (with small groups and individual work). Funding allocation and resources should be distributed on an equitable basis to support the intensity of this type of youth work.

- Waiting lists for the assessment of young people with autism spectrum conditions, mental health, and learning disability/additional learning needs must be addressed. With over 2000 young people currently on waiting lists, the knock-on effect in terms of access to support services is potentially life limiting and only exacerbates the sense of crisis.
- More research is needed to support young women with autism, as there are disproportionately fewer females being diagnosed than males.
- The development of strong partnerships across sectors is essential, and this should also include the provision of holistic services for 18+ year olds.
- There should be a universal design for learning, reflecting the view that education is focused 'on the all' and not the few, and that learning is supported in a variety of creative ways.
- Youth service policy and programmes which concern diversity need to take a broader focus, e.g. extending beyond ethnicity and religion to include autism spectrum conditions.
- The media should more accurately depict the lived experiences of those with autistic spectrum conditions.

Conclusion

The youth sector has witnessed a recent proliferation in work with young people with ASC - increased provision, growing numbers of programmes, and research development on the experiences of young people with ASC. The development of this provision has been framed in a strengths-based approach building on the social model of understanding ASC. For these initiatives and approaches to become well established, training, research and policy must develop in parallel with therapeutic and youth work practice.

This manifesto lays out a roadmap to inform teaching, course developments, policy directions to support inclusive practice across the sector.

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