Autistic Voices in Autism Research: towards active citizenship in Autism research

Krysia Emily Waldock and Nathan Keates

1. A lack of active citizenship in Autism research

Autism research is a dynamic and broad field covering many disciplines. However, the Autistic voice is not always present in Autism research, notably empirical Autism research, in spite of its necessity for epistemological validity (Woods, Milton, Arnold & Graby, 2018). In this chapter, we will examine Arnstein's (1969) Ladder of Citizen Participation (from hereon in, we will state 'the ladder') as a model for good practice for inclusive Autism research due to its prospective beneficial impact; evaluate the scope of current Autism scholarship in regards to 'the ladder' and the potential impact on Autistic people; explain how such an approach is compatible with taking an intersectional approach and why the voices of marginalised Autistics are important; explore benefits and limitations of encouraging active citizenship in Autism research and the practical aspects researchers may need to undertake; and give a short checklist at the end of the chapter for researchers to consider if they wish to undertake this.

We will resist using person-first language (e.g., person with autism). The first author is an Autistic academic, and both authors wish to respect the voice of the British Autistic community, where among Autistic people, identity-first language is generally preferred (Kenny et al., 2016). Reasons for this include the experience of being Autistic as innate to the individual's lived experience (Williams, 1996, p. 14) and therefore influencing how the world is processed and understood. Furthermore, many Autistic people also see being Autistic as inseparable

from their identity (Sainsbury, 2000, p. 12) and identity-first language resists this separation of identity and self.

The ladder is a useful framework for understanding citizen power. Envisaged within a post-war context in the literature on city and town planning, it remains highly used and referred to in contemporary academic literature and is the most cited article from the urban development planning literature (Innes & Booher, 2004). However, it is not only applicable to city and town planning, and remains applicable to a variety of fields, notably participatory and inclusive literature in the case of Autism research (as argued by Gowen et al. 2019; Pellicano, Dinsmore & Charman, 2014) and intellectual disability research (Ham et al., 2004; Ward & Trigler, 2001). This is important with the growing dialogue around participatory and inclusive research methods in regards to Autism (e.g., Fletcher-Watson et al., 2019; den Houting, Higgins, Isaacs, Mahony & Pellicano, 2020; Pellicano, 2014; Pellicano et al., 2014).

An eight-rung ladder represents the framework that illustrates the differing levels of citizen power within participation (Arnstein, 1969) (see Figure. 1); however, Arnstein has alluded that there may be up to 150 levels. Within this chapter, we will only refer to the main eight rungs that Arnstein refers to in her seminal work. The eight rungs include: manipulation; therapy; informing; consultation; placation, partnership; delegated power; citizen control. In 'the ladder', participation is equal to citizen power, as Arnstein (1969, p. 216) describes: 'It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes, to be deliberately included in the future'. This is critical in reference to contemporary Autism research and science, as part of Critical Autism Studies is a reflexivity on power differentials (Waltz, 2014; Woods & Waldock, 2020) and criticality more widely (Woods et al., 2018), and therefore improving the current evidence base. There needs to be an examination of who holds the power in Autism research currently.
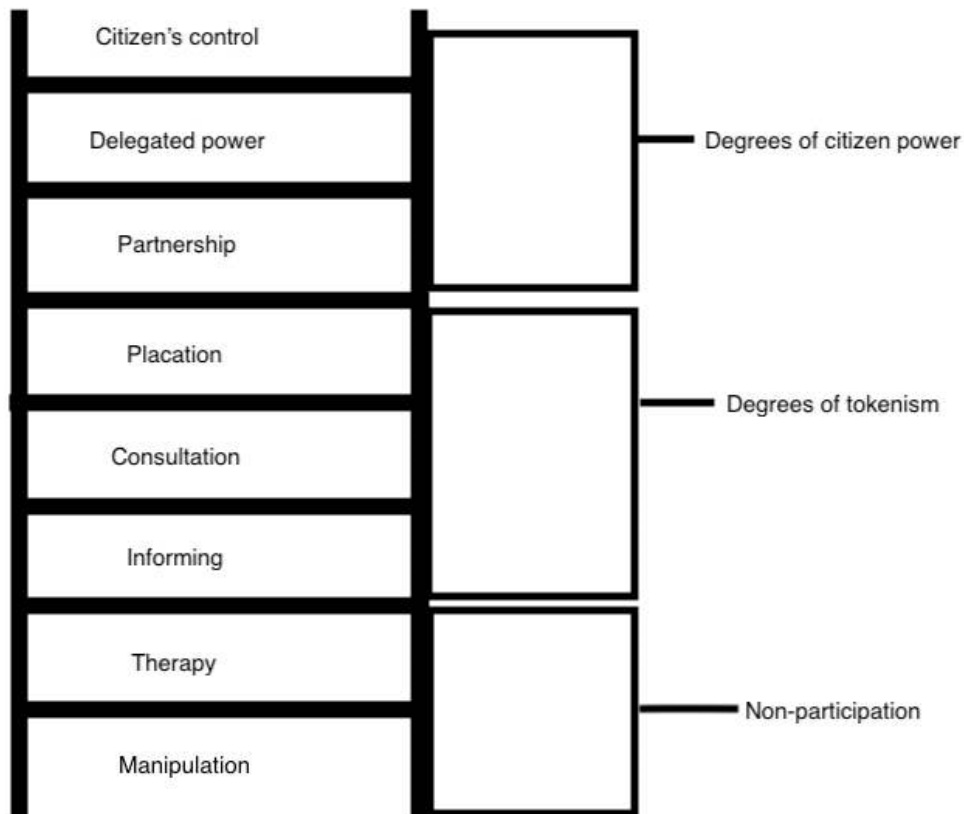
Figure. 1. [The eight rungs from Arnstein's Ladder of Citizen Participation (1969) {Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of planners, 35(*4), 216-224. } reprinted by permission of The American Planning Association, www.planning.org.

Participation and power are often seen as different things, however in regards to the impact, it is important to consider participation and power alike. Arnstein's (1969) model describes a 'emancipatory claiming of rights by citizens' (Blue, Rosol & Fast, 2019, p. 364). This demonstrates clear social justice leanings of the framework which is key to critical disability studies. Furthermore, participation is also considered as a neutral entity in many instances, however as Blue et al. (2019) argue, normative assumptions about how things are done can underpin the ability and desire to participate. This further increases our need for criticality and guidance within the realm of Autism research.

The stigmatised nature of being Autistic means that Autistic people have reduced citizen power, particularly within research. With our current understanding of Autism consistently growing and developing, it is vital to remember that some Autistic people would have been counted among the mentally ill, the eccentric, and among other stigmatized groups of individuals not long ago. Many Autistic people would have been in institutions historically. Beginning with deinstitutionalization, disabled people, including Autistic people, were brought into the community to live an 'ordinary life' (Nirje, 1964; Wolfensberger, 1972). However, this normalisation has been critiqued by scholars (e.g., Szivos-Bach, 1993; Walmsley, 2001), including Autistic scholars (e.g., Chown et al., 2017; Milton & Moon, 2012); normalisation of this accord places responsibility on the disabled party. Those who cannot, or wish not to 'normalise' in this manner may face higher levels of 'othering' and psycho-emotional disablement (Milton, 2013; Reeve, 2011). Notably in regards to Autism, there has been continued negative stereotypes and infantilisation of Autistic people (Huws & Jones, 2011). This has reduced the power of Autistic people i.e., people who 'appear' Autistic or identify as 'Autistic'. Therefore, this relates to the potential citizen power they have, in particular in regards to Autism research.

1.1. Neglecting the Autistic Voice

Historically numerous groups of Autistic people have been neglected within research; mainly due to the developing understanding of the phenomenon of 'Autism' being shaped by these changes. This has included Autistic women, people who identify as LBGTQIA+ (including non-binary and Transgender people), ethnic minorities and older Autistic people (e.g., Crompton, Michael & Fletcher-Watson, 2020; Hickey, Crabtree & Stott, 2018; Mason et al., 2019). It is of note that not all of the groups would have been conceptualised as groups historically, for example non-binary people. However, as the conceptualisation of identities progresses, so should research.

Historically Autism research participants have been limited to a narrow demographic which creates a bias and difficulty in how that research may be interpreted - notably the underrepresentation of Autistic people from ethnic minorities, although there exists also a gender bias (male-driven diagnostics and screening tools) in historic conceptualisation of autism, and subsequent diagnostic materials (Haney, 2016; Loomes, Hull & Mandy, 2017; Parish-Morris et al., 2017; Young, Oreve & Speranza, 2018). Considering this in relation to being 'active citizens' in Autism research in accordance to 'the ladder', these people gained no inclusion in the research: they were experimented *upon* and not *with.* Therefore, there is not even an attempt to delegitimise their existence. It is possible that there are other factors that will impact this underrepresentation, including a lack of culturally sensitive information on autism disseminated and cultural stigma, beliefs and understanding of disability more broadly (e.g., Daley, 2004; Singh & Bunyak, 2019). One example of this is the role religious beliefs play in understanding disability, for example Waldock and Forrester-Jones (2020) identified in a small exploratory study that some church-goers may use their belief system (in this case, interpretations of Biblical teachings and scripture) to help make sense of phenomena such as disability (in this case, Autism and Autistic people).

Using Goffman's social stigma theory, Autistic people who 'appear' Autistic and/or openly identify as Autistic are 'stigmatised' as having a 'blemished' identity (Goffman, 1963, p. 1). This demonstrates how stigma operates in society, which buys into an entactment of the pathology lens of Autism, which is often the main narrative surrounding being Autistic, presenting Autism as a deficit which 'blemishes' the Autistic individual and discrediting their voice. In this manner, individuals are taught that they as people are 'wrong'. This refers to the manipulation rung on 'the ladder' and conceptualises Autistic people within a medical model framework (Milton & Moon, 2012). Not being stigmatised is further favoured in wider society through the endorsement of those that comply with the norms of sociality and emotionality (O'Dell, Bertilsdotter Rosqvist, Ortega, Brownlow & Orsini, 2016). Stigma may also have a

differing effect on the stigmatised individual, particularly in regards to their cultural background. In collectivist cultures, the stigma of having a disabled child is wide reaching, potentially leading the family to hide their child in some cultures. In others, medical racism may be rife (Jones et al., 2020). This shielding of the child and medical racism lead to not accessing a diagnosis or support, and inadvertently misses the support needs of Autistic people.

1.2. Ableism and the 'therapy' of autism research

'The ladder' suggests that the focus on changing the citizens ('therapy' rung), in this case Autistic people, is a method to cure and pathologise their 'wrong-ness'. The language often used in Autism research reflects the medical model of disability and how Autistic people are in deficit of the necessary components (e.g., Theory of Mind, Baron-Cohen, Leslie & Frith, 1985; Weak Central Coherence, Happé, 1996; in some cases casting them as subhuman, see first sentence in Baron-Cohen, 2000, p. 3: "A theory of mind remains one of the quintessential abilities that makes us human"). Autistic people who 'appear' Autistic (e.g., showing signs of distress at stimuli not considered 'normative' by society, communicating in a literal manner, having sensory processing differences, having preferred routines) can be perceived as 'other' (e.g., Botha, Dibb & Frost, 2020; Farrugia, 2009; Grinker, 2020; Kinnear, Link, Ballan & Fishbach, 2016; Milton & Sims, 2016). Definitions of Autism as a phenomenon have historically been defined from an outsider's perspective, that being of a non-autistic person or at least someone who does not identify as Autistic. This is in much the same manner that Simone de Beauvoir argues what it means to be a woman is defined from a male perspective (1949, p. 16). This is exemplified by normativity as preponderant and valued in society and social structures (one example being the valuing of verbal communication over alternate methods when face to face), further placing Autistic people as the 'othered outsider' (Milton,

2013). Although some more 'partnered' research studies (as per 'the ladder') may take place, ableism may still occur. The 'call for participants' could be normative and 'othering' through its use of ableist language (for example, using functioning labels to describe participants sought), or procedures not taking into account Autistic lived experience (for example, not considering the sensory environment of an interview and requesting only verbal communication in an interview).

1.3 Power, stigma and 'getting heard'

As Autistic people learn the apparent need to be 'normal', this can produce autistic camouflaging, which in turn reduces stigma (e.g., Cage, DiMonaco & Newell, 2018; Gray, 1993, p. 114; Pearson & Rose, in print). 'Masking autism' covers the so-called 'blemished identity' that Autistic people have, further complicating the landscape. Camouflaging amongst the Autistic population is not a homogenous phenomenon, and camouflaging successfully, as Goffman argues (1963, p. 73) can hide the social stigma, therefore making that individual not 'othered'. This adds complexities to the degree of discreditation of the Autistic voice and who is listened to, with potentially only certain 'types' of Autistic voices listened to, again highlighting the importance of taking considerations of intersectionalities (e.g., race, gender identity, sexual orientation, other disabilities). Autistic people who are 'othered', for example, non-speaking Autistics, Autistics who do not camouflage or Black Autistic people, may therefore be seen as less 'credible' than their non-othered counterparts. These individuals are therefore branded as 'not able to participate' and excluded from having any voice or citizen power in regards to 'the ladder', not even placing them on a rung of the ladder. Autistic people being stigmatised and the complexities surrounding this impacts the information base (for example, practitioner knowledge and information imparted in teaching) that is available; this may potentially have an impact on the subsequent research base, echoing what Milton

(2014a) argues (translating it for research followed and carried out) regarding the varied and polarised information and resources available in relation to Autism interventions.

1.4. The implications of this for Autistic people

Previous stereotypes of Autism continue to inform current ideas (for example, the historic idea that Autistic people were incapable of empathy; Nicolaidis et al., 2018, and the infantilising of Autistic people; Stevenson, Harp & Gernsbacher, 2011). It has been argued that these enduring stereotypes have been harmful and the relationship between autistic people and those who are not (Stevenson et al., 2011), and Autistic voices are needed to inform a more honest and realistic understanding of Autistic people and living as an Autistic person (Milton 2014b).

The impact of being on the 'therapy' rung of the ladder is that Autistic people are seen as people upon whom to experiment, rather than people with agency. In this chapter we use Schalock et al.'s (2002) Quality of Life (QoL) framework when discussing the conceptualisation of QoL, as it gives useful domains which are relevant to all populations. It is the domains as broadly defined which are of interest rather than the specific components of which may constitute the domains. Using Schalock's et al. (2002) QoL framework, Autistic people may be determined as lacking self-determination at the 'therapy' rung (otherwise stated as being voiceless). Potentially, this could lead to diminishing respect, inflicting a decrease in emotional wellbeing (Schalock et al., 2002). Given that respect is a key element of person-centred care and 'quality' within services supporting Autistic people and people with intellectual disability (Schalock, 2000), viewing stakeholders as having agency is vital in terms of the research process. Feelings of exclusion from the processes of research could potentially lead to social exclusion (Kroll & Morris, 2009), especially if dissemination of information sustain misconceptions of Autistic people to wider society. The views that remain unaccounted for are the voiceless people in research: there is research about Autistic people without Autistic

people's inclusion which identifies bad practice that must be examined and its replacement of Autism research *with* Autistic people. Research not using a citizen control or delegated power model could lead to disempowered people who are not valued (Chambers, 1994; Milton, 2014b); fractious dialogue where polarised disagreements may occur (see, for example, Oliver, Kothari & Mays, 2019 in regards to relationships between stakeholders in health research); and distress (both physical and emotional wellbeing) (Murdoch & Caulfield, 2016). Fundamentally, this would lead to 'lost scholarship,' which means further knowledge which could be useful may not be discovered (Milton 2014b).

2. How can researchers improve their practice

2.1. Current Research

The current research landscape is slowly opening to examining a greater variety of lived experiences of Autistic people and their families, including Autistic women (e.g., Bargiela et al., 2016; Leedham, Thompson, Smith & Freeth, 2020; Sedgewick, Crane, Hill, & Pellicano, 2019); gender expression amongst Autistic people (e.g., Kourti & Macleod, 2019); traveller families experiences of Autism (e.g., Gray & Donnelley, 2013) and Black families of Autistic children (Munroe, Hammond & Cole, 2016). The freshness of these research studies demonstrates a recent push towards increasing the diversity of voices present in research, and away from a homogenous interpretation of Autism, and therefore Autistic people. Recent research on camouflaging (Hull et al., 2017) has additionally complicated perceptions of how we may envision Autistic people (e.g., further disrupting preconceptions and stereotypes of our expectations of how Autistic people 'should' behave or appear). This can be seen through the perceptions of Autistic people from different socio-cultural backgrounds, particularly through how stereotypes impact our image of what an Autistic person should be like.

The current research landscape is also beginning to include work by Autistic scholars, amongst the most influential being Dr Damian Milton, Dr Steven Kapp and Dr Melanie Yergeau in our field, and an increasing number of Autistic people seeking to do research. This is demonstrative of pockets of the top rung in Arnstein's ladder (1969): Citizen Control. Autistic people in the research landscape can challenge our perceptions of Autistic people and how Autistic people are defined, and bring original research ideas which have the potential to positively impact the QoL of Autistic people in particular (Bölte, 2019; Fletcher-Watson et al., 2019; Pellicano, 2020).

2.2. An intersectional approach

A variety of voices are needed due to the differing lived experiences that Autistic people can have. Much like the general population, not all Autistic people will experience life in the same manner. It is essential this is considered, as Autistic people have the potential to be misunderstood due to heterogeneous experiences (Williams, 2020, p. 35). Intertwined with issues pertaining to identity (Ortega & Choudhury, 2011), this may cause misunderstanding of support needs or 'homogenisation'. One example includes the assumption that Autistic people are all under- or over sensitive to the same stimuli (Crane, Goddard & Pring, 2009). This also links to the stereotypes mentioned above, as we can often embody Autistic people within a particular 'body' or 'space', for example a white, cis-male child in a Western country. This can be exemplified by the under diagnosis of Autistic women in comparison to men (Halladay et al., 2015) due to a 'stereotypical male' bias in the screening tools (Young et al., 2018) and the 'whiteness' of the Autism landscape (Jones et al., 2020; Gina Onaiwu, 2020). For example, much information available to parents of ethnic minority Autistic children is not culturally appropriate and information is often assumptive that the recipient is white and Anglophone.

There is also a current lack of Autism research originating from the Global South (O'Dell *et al.,* 2016), with a need to break away from the current bias. We believe intersectionality to be necessary in understanding the differing lived experiences among Autistic people alongside 'the ladder' and acquiring citizen power. In one way, this is a meta-'partnership', due to the researcher including (or partnering with) all voices. This forms *accountable* research that provides citizen power in a different way. Furthermore, an intersectional approach can add nuance to our understanding of the phenomenon we call Autism, and of the lived experiences of Autistic people. As Shmulsky and Gobbo (2019, p. 648) argue, intersectionality 'more accurately conveys real life complexity', allowing the phenomenon we know as Autism to not only be seen in one dimension, i.e., homogeneously. This is vital if the citizen control rung is to be aimed for on the Ladder of Citizen Participation (since this is an ever-evolving goal; Rosen & Painter, 2019).

Intersectionality fundamentally provides insight into the social inequalities and prospects for social change (Collins, 2019). This is key given the social justice focus within 'the ladder' and the focus of authentic dialogue, interaction and collaboration (Innes & Booher, 2004). Crenshaw (1989) produced the seminal work on the intersection of Black women in the Criminal Justice System, however, Patricia H. Collins (2015, 2019) remains one of the key academic thinkers on intersectionality. Intersectionality however now scopes a much wider range of personal identifiers. Social problems can arise from the intersection of race, gender, class, sexuality, age, ethnicity, ability, capitalism and colonialism (Collins, 2019). Furthermore, some aspects of race, ethnicity and nation can encapsulate religion, which Carbado and Harris (2019) include in their intersectional research, as a belief system can be an integral part of culture. In the past, having two or three identifiers has been termed as double or triple jeopardy (Fujiura, 1998, p. 7). These were viewed as being added onto the struggle, but for King (1988), multiple jeopardy leads to more intensifying experience – multiplying the issues.

Thus, this is a long-term and systemic issue. No one solution will automatically create a more inclusive dialogue on Autism involving Autistic people, especially in avoiding tokenistic inclusion (as is necessary for 'Active Citizens'). We recommend a multi-faceted approach including multiple stakeholders to address this issue and to take steps towards using a more intersectional approach in research and increasing citizen power. In regards to looking at marginalised populations which may not otherwise be heard, some research has taken an intersectional approach in elucidating experiences of Autistic people (Singh & Bunyak, 2019; Toft, Franklin & Langley, 2019; 2020), showing the value of this approach in understanding the heterogeneous nature of autistic people and the multiple identities they can have. This knowledge is likely to be of high importance in terms of understanding those who are currently voiceless and invisible in regards to citizen power. As part of this, further qualitative and mixed-methods studies and approaches are keenly recommended in eliciting the views, perspectives and world views of Autistic people. This would effectively ground further work not only in the lived experiences of a broader pool of Autistic people, it would also allow for greater depth in the nuances of the phenomenon called Autism and Autistic people.

2.3. Autistic stakeholders

Partnership in research and other projects between Autistic and non-autistic stakeholders is a phenomenon that is starting to take hold in some projects (as per 'the ladder'). For example, the *Playing A/Part* project (for further information see: University of Kent, 2021). Both authors are actively seeking to involve Autistic people meaningfully in their research through advisory groups, steering groups and participatory methods. We see this as central to the aims of our research, contrasting the paucity of research acquiring experiential and embodied knowledge

from Autistic people (Dossa, 2008; Milton, 2014b; Duncan & Oliver, 2017; Stewart & Liambo, 2012). However, care needs to be taken when involving marginalised groups, that merely tokenistic involvement is not reached, thus stunting the potential for growth and true ownership of projects by Autistic people. This includes potential creativity and breaking away from norms in roles. For example, advisory group roles and co-researchers' roles need to be designed flexibly and creatively to meet the needs (e.g., physical, sensory) of the populations being sought for the role. Without such creativity, it is possible that roles may be conceptualised which inadvertently exclude the very people sought for the role. It is important not to stunt the citizen power and control of Autistic people in research, notably through not limiting Autistic input to steering groups, advisory group members or informal advisors.

Another aspect to consider is the historical mistrust that some Autistic people have in regards to Autism research and researchers (Milton, 2014b) and the impact this has on the current Autism research landscape. Transparency of research aims and goals (Harrison et al., 2019) is of vital importance in participatory work, which can also be considered with Autism research in regards to aims and processes. One example is clarity regarding the recruitment process and subsequent write ups and/or publications. Autistic academics are a key part of furthering citizen power, with Autistic-led projects and scholarship a crucial part of this. This is one avenue into the development of trust between researchers and participants, especially where the researchers may share ideology with participants (e.g., the social model of disability). However, systemic barriers in academia more broadly can disadvantage disabled and neurodivergent people (including Autistic people) leading them to be 'invisible' (Brown & Leigh, 2018).

Much current research that seeks to be participatory or inclusive remains at the tokenistic inclusion level of citizen control on 'the ladder', with full citizen control (projects being led by Autistic people) yet to be reached. . Reasons for this are plural, including time constraints from research budgets and grants, to difficulty in the reparation of potential co-researchers, especially if they are not academics or in newly defined roles, and a lack of precedence of such work in certain fields. Participatory research may be regarded with caution by some other researchers, possibly in regards to the time implications it may demand (Chambers, 1998) or the ending of research relationships in participatory work (Northway, 2000). However, as Christopher, Watts, McCormick and Young (2008) argue, including the voice of the community you are working with, is vital in incorporating them into the academic literature.

2.4. Meaningful inclusion of Autistic people in research

Meaningful inclusion in research involves engagement with knowledge already accrued by Autistic people and rightful attribution. An 'Autistic culture' encapsulates a shared knowledge amongst many Autistic people of varying support needs, backgrounds and ages (Sinclair, 2012). This fits the current understanding of a culture, as argued by Schein (1991, p. 313), where a key part of a 'culture' is shared knowledge. The Autistic and neurodivergent communities have influenced scientific work, both academic and non-academic, within the Autism field increasingly over the last twenty years (e.g., the Participatory Autism Research Collective, Milton et al., 2019). Enabling dialogue between this epistemic community (composed of activists and self-advocates, as described by Kapp, 2020, p. 306) and the research community has the potential to produce further ideas for research which may further benefit Autistic people.

Meaningful involvement is a significant part of ethical Autism research (Milton, 2014b), as the voices of Autistic people then become a key part of the research itself. Gillespie-Lynch et al. (2017) recommend that Autistic people, as experts in Autism, should be research partners. Guidance and checklists have been published citing steps researchers can do to increase the inclusivity of their research both on a practical and theoretical level (Chown et al., 2017; Fletcher-Watson et al., 2019; Gowen et al., 2019). These papers are Autistic-led (Chown et al., 2017) or have significant Autistic input into them, demonstrating positive collaborative practices (Fletcher-Watson et al., 2019, Gowen et al., 2019). Gowen et al. provide guidelines on pre- and post-study considerations, recruitment of participants, and addressing the anxiety provoking nature of travelling to and visiting buildings for research. Furthermore, Chown et al. (2017) have produced guidance on each step in research with advice on how to avoid conflict of interest between funders and the Autistic community. The aforementioned papers, as complementary to our chapter, are a key part of building a more comprehensive, participatory and inclusive research base in the field of Autism.

2.5. The research-to-practice gap

The authors of this chapter, alongside other researchers (e.g., Dingfelder & Mandell, 2011; Parsons et al., 2013), have also noted a research to practice gap amongst work in this field. A bridging of this gap is not likely to be a quick or easy solution, however bridging knowledge across epistemic communities may increase the knowledge shared, including cultural knowledge among Autistic people. This is vital in terms of hearing the variety and multiplicity of Autistic lived experiences, and to resist homogenizing Autistic persons by reducing them to their diagnostic label and the stereotypes associated with this label. The 'citizen power' of individuals within such dialogue would also need to be considered by the involved parties and stakeholders, which in itself is a step to be taken. Reflecting on standpoints, beliefs and views is acknowledged by the authors as potentially novel for some involved parties, given the vested interest of some stakeholders of the phenomenon we know as 'Autism'. However, as

exemplified by Brookfield (1998) in regards to educational practices and 'the reflective teacher', reflection encourages growth; it is only through the consideration of how others view us that some of our preconceptions can be challenged. Reflexivity is also a key component of high quality qualitative research (Finlay, 2002). Models and provision of support for Autistic people are likely also to be positively impacted through the acknowledgement of the experiences of Autistic people, including barriers to such support. This may have a subsequent impact on improving the QoL of Autistic people from different backgrounds, cultures and lived experiences, and further research in this area is necessary.

2.6. The benefits for the Autistic community and Autism science

As a culmination of thought, it is important to identify the potential benefits of this approach. The 'A Future Made Together Report' (Pellicano, Dinsmore & Charman, 2013) highlights the discrepancy between the research carried out in the field of Autism, the funding distribution, and research that Autistic people feel would improve their QoL. While we understand that research that is not participatory or inclusive in nature might also benefit Autistic people's QoL, the value of the Autistic voice in research, and the subsequent impact on QoL must be acknowledged as key stakeholders within the research process. Autistic led papers (for example Robertson, 2009, Waldock, 2019) have argued for the QoL of Autistic people to be differently conceptualised, supporting other work on the ASQoL[i] (McConachie et al., 2018). This is not to say that only Autistic people should research Autism, rather to celebrate the richness of the scholarship they bring and how it complements research by researchers who are either non-autistic, or undisclosed. The presence of the Autistic voice in Autism research improves epistemic validity (Woods et al., 2018) and is vital (Milton, 2014b), and is an example of new undiscovered knowledge, bringing 'richness' to academia. Through the delegation of power to Autistic people research projects, and subsequent empowerment, less pejorative

attitudes towards Autistic people, notably those who are 'stigmatised' may be facilitated. In turn this would lead to further new, yet undiscovered knowledge.

Barriers faced by the academic community in acting on this are important to consider. For example, the way academia is constructed may be difficult for intersectional autistic people with ID to lead a research project. Nonetheless, citizen control will enable a building of trust and dialogue to build between Autistic people and researchers (for example, in Autism research, Milton, 2014b; in other fields, Goodman & Sanders Thompson, 2017; Harrison et al., 2019; Trimble & Berkes, 2013).

Through successfully achieving this, the research process and citizen power will improve; the Autistic community will be empowered and feel valued. Through gaining lived experiences, Autism science will develop and enhance the accuracy and fit of the findings to the heterogeneity of the Autistic population. The knowledge developed will account for more Autistic people's experiences. The priorities in Autism science will be better guided to those that would most benefit the research to practices and lives of those within the Autism community. This is echoed by the assertation that many Autistic scholars are aiming for the emancipation of the Autistic population (as originally described in Woods et al., 2018 in regards to Autistic scholars) through their research. Thus, this is a practical development for the stakeholders (Pellicano et al., 2013).

3. Conclusion

In conclusion, 'the ladder' is an important tool in relation to the growth and future of Autism research, as well as taking an intersectional approach to this field of study. Much research is

stuck at the 'therapy' rung and there is scope for growth in terms of citizen power. There is a need for research with cultural considerations and sensitivity, and increased knowledge dissemination to support the lives of autistic people from all cultural backgrounds. With a past focus on Autism in the Global North and on cis-male gendered Autistic people, meaningful inclusion of all voices is yet to happen. Autistic stakeholders must gain citizen control or delegated power. Furthermore, the requirement for creativity to enable and encourage citizen power through the way Autistic people are involved in and engage with research. Finally, there are various benefits for Autistic community and Autism science (e.g., increased epistemic validity, potential for undiscovered knowledge to be found, increased trust in researchers).

3.1 A summary of what is needed

- a bridge between research-to-practice to overcome the current gap;

- further diversity, including further QoL research to understand the nuances of Autistic lives;

- research must seek under researched populations and their voices;

- time must be taken to gain trust (which is a longitudinal goal), through being transparent in research aims and processes, and welcoming dialogue in regards to the topic

- reflexivity on the researchers' own position as a researcher and the outcomes sought by themselves as a researcher;

- and creative thinking in terms of roles and how to accredit 'citizen power'.

References

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of planners, 35(*4), 216-224. https://doi.org/10.1080/01944366908977225

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of autism and developmental disorders*, *46*(10), 3281-3294. https://doi.org/10.1007/s10803-016-2872-8

Baron-Cohen, S. (2000). Theory of mind and autism: A review. In *International review of research in mental retardation* (Vol. 23, pp. 169-184). Academic Press. https://doi.org/10.1016/s0074-7750(00)80010-5

Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind". *Cognition*, *21*(1), 37-46. https://doi.org/10.1016/0010-0277(85)90022-8

Blue, G., Rosol, M., & Fast, V. (2019). Justice as Parity of Participation: Enhancing Arnstein's Ladder Through Fraser's Justice Framework. *Journal of the American Planning Association, 85*(3), 363-376. https://doi.org/10.1080/01944363.2019.1619476

Bölte, S. (2019). Hey autism researcher, what's on your mind today about inclusion?, *Autism, 23*(7), 1611-1613. https://doi.org/10.1177/1362361319870994

Botha, M., Dibb, B., & Frost, D. (2020). "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 1-27. https://doi.org/10.1080/09687599.2020.1822782

Brookfield, S. (1998). Critically reflective practice. *Journal of Continuing Education in the Health Professions*, *18*(4), 197-205. https://doi.org/10.1002/chp.1340180402

Brown, N., & Leigh, J. (2018). Ableism in academia: where are the disabled and ill academics?. *Disability & Society*, *33*(6), 985-989. https://doi.org/10.1080/09687599.2018.1455627

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, *48*(2), 473-484. https://doi.org/10.1007/s10803-017-3342-7

Carbado, D. W. & Harris, C. I. (2019). Intersectionality at 30: Mapping the margins of anti-essentialism, intersectionality, and dominance theory. *Harvard Law Review, 132*(8), 2193-2239.

Chambers, R. (1994). The origins and practice of participatory rural appraisal. *World Development, 22*(7), 953-969. https://doi.org/10.1016/0305-750X(94)90141-4

Chambers, R. (1998). Foreword. In J. Holland & J. Blackburn (Eds.) *Whose Voice? Participatory Research and Policy Change*. (pp.xv-xviii). Intermediate technology publications.

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., ... & MacGregor, D. (2017). Improving research about us, with us: a draft framework for inclusive autism research. *Disability & Society*, *32*(5), 720-734. https://doi.org/10.1080/09687599.2017.1320273

Christopher, S., Watts, V., McCormick, A. K. H. G., & Young, S. (2008). Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health*, *98*(8), 1398-1406. https://doi.org/10.2105/ajph.2007.125757

Collins, P. H. (2015). Intersectionality's definitional dilemmas. *Annual Review of Sociology, 41*, 1-20. https://doi.org/10.1146/annurev-soc-073014-112142

Collins, P. H. (2019). *Intersectionality as critical social theory*. Duke University Press. https://doi.org/10.1215/9781478007098

Crane, L., Goddard, L. & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders, *Autism*, *3*(3), 215-228. https://doi.org/10.1177/1362361309103794

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum, 1*. http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8

Crompton, C. J., Michael, C., Fletcher-Watson, S., Crompton, C., & Tower, K. (2020). Co-creating the Autistic Satisfaction with Care Holistic Interview (ASCHI) to examine the experiences of older autistic adults in residential care. *Autism in Adulthood*. 2(1), 77-86. https://doi.org/10.1089/aut.2019.0033

Daley, T. C. (2004). From symptom recognition to diagnosis: children with autism in urban India. *Social Science & Medicine, 58*(7), 1323-1335. https://doi.org/10.1016/s0277-9536(03)00330-7

De Beauvoir, S. (1949). *The Second Sex.* Random House Group Ltd..

Dingfelder, H. E. & Mandell, D. S. (2011). Bridging the research-to-practice gap in autism intervention: An application of diffusion of innovation theory. *Journal of autism and developmental disorders, 41*(5), 597-609. https://doi.org/10.1007/s10803-010-1081-0

Dossa, P. (2008). Creating alternative and demedicalized spaces: Testimonial narrative on disability, culture, and racialization. *Journal of International Women's Studies, 9*(3), 79-98.

Duncan, S., & Oliver, S. (2017). Motivations for engagement. *Research for All*, *1*(2), 229-233. https://doi.org/10.18546/RFA.01.2.01

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, *31*(7), 1011-1027. https://doi.org/10.1111/j.1467-9566.2009.01174.x

Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative health research*, *12*(4), 531-545. https://doi.org/10.1177/104973202129120052

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., ... & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943-953. https://doi.org/10.1177/1362361318786721

Fujiura, G. T. (1998). Demography of family households. *American Journal of Mental Retardation, 103*(3), 225-235. https://doi.org/10.1352/0895-8017(1998)103<0225:dofh>2.0.co;2

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in psychology, 8*, 438. https://doi.org/10.3389/fpsyg.2017.00438

Giwa Onaiwu, M. (2020). "They Don't Know, Don't Show, or Don't Care": Autism's White Privilege Problem. *Autism in Adulthood*. http://doi.org/10.1089/aut.2020.0077

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Penguin Books.

Goodman, M. S., & Sanders Thompson, V. L. (2017). The science of stakeholder engagement in research: Classification, implementation, and evaluation. Translational Behavioral Medicine, 7(3), 486-491. https://doi.org/10.1007/s13142-017-0495-z

Gowen, E., Taylor, R., Bleazard, T., Greenstein, A., Baimbridge, P., & Poole, D. (2019). Guidelines for conducting research studies with the autism community. *Autism policy & practice, 2*(1), 29.

Gray, C. & Donnelly, J. (2013). Unheard voices: the views of traveller and non-traveller mothers and children with ASD. *International Journal of Early Years Education, 21*(4), 268-285. https://doi.org/10.1080/09669760.2013.842160

Gray, D. E. (1993). Perceptions of stigma: the parents of autistic children. *Sociology of Health & Illness, 15*(1), 102–120. https://doi.org/10.1111/1467-9566.ep11343802.

Grinker, R. R. (2020). Autism, "stigma," disability: a shifting historical terrain. *Current Anthropology*, *61*(S21), S55-S67. https://doi.org/10.1086/705748

Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., . . . & Singer, A. T. (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism, 6*(1), 36. https://doi.org/10.1186/s13229-015-0019-y

Ham, M., Jones, N., Mansell, I., Northway, R., Price, L., & Walker, G. (2004). 'I'm a researcher!' Working together to gain ethical approval for a participatory research study. *Journal of Learning Disabilities*, *8*(4), 397-407. https://doi.org/10.1177/1469004704047507

Haney, J. L. (2016). Autism, females, and the DSM-5: Gender bias in autism diagnosis. *Social Work in Mental Health, 14*(4), 396-407. https://doi.org/10.1080/15332985.2015.1031858

Happé, F. G. (1996). Studying weak central coherence at low levels: children with autism do not succumb to visual illusions. A research note. *Journal of child psychology and psychiatry*, *37*(7), 873-877. https://doi.org/10.1111/j.1469-7610.1996.tb01483.x

Harrison, J. D., Auerbach, A. D., Anderson, W., Fagan, M., Carnie, M., Hanson, C., ... Weiss, R. (2019). Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. *Health Expectations, 22*(3), 307-316. https://doi.org/10.1111/hex.12873

Hickey, A., Crabtree, J., & Stott, J. (2018). 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism*, *22*(3), 357-367. https://doi.org/10.1177/1362361316680914

den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2020). 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. *Autism*, 1-16. https://doi.org/10.1177/1362361320951696

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C. & Mandy, W. (2017). "Putting on my best normal": social camouflaging in adults with autism spectrum conditions. *Journal of autism and developmental disorders, 47*(8), 2519-2534. https://doi.org/10.1007/s10803-017-3166-5

Huws, J. C. & Jones, R. S. (2011). Missing voices: Representations of autism in British newspapers, 1999–2008. *British Journal of Learning Disabilities, 39*(2), 98-104. https://doi.org/10.1111/j.1468-3156.2010.00624.x

Innes, J. E., & Booher, D. E. (2004). Reframing public participation: strategies for the 21st century. *Planning theory & practice, 5*(4), 419-436. https://doi.org/10.1080/1464935042000293170

Jones, D. R., Nicolaidis, C., Ellwood, L. J., Garcia, A., Johnson, K. R., Lopez, K., & Waisman, T. C. (2020). An expert discussion on structural racism in autism research and practice. *Autism in Adulthood*. http://doi.org/10.1089/aut.2020.29015.drj

Kapp, S. (2020). Conclusion. In S. K. Kapp (Ed.). *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. Springer Nature, pp. 305-318. https://link.springer.com/book/10.1007%2F978-981-13-8437-0

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462. https://doi.org/10.1177/1362361315588200

King, D. K. (1988). Multiple jeopardy, multiple consciousness: The context of a black feminist ideology. *Signs: Journal of Women in Culture and Society, 14*(1), 42-72. https://doi.org/10.1086/494491

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, *46*(3), 942-953. https://doi.org/10.1007/s10803-015-2637-9

Kourti, M., & MacLeod, A. (2019). "I Don't Feel Like a Gender, I Feel Like Myself": Autistic Individuals Raised as Girls Exploring Gender Identity". *Autism in Adulthood, 1*(1), 52-59. https://doi.org/10.1089/aut.2018.0001

Kroll, T., & Morris, J. (2009). Challenges and opportunities in using mixed method designs in rehabilitation research. *Archives of Physical Medicine and Rehabilitation, 90(*11), S11-S16. https://doi.org/10.1016/j.apmr.2009.04.023

Leedham, A., Thompson, A. R., Smith, R. and Freeth, M. (2020). "I was exhausted trying to figure it out": The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism, 24*(1), 135-146. https://doi.org/10.1177/1362361319853442

Loomes, R., Hull, L. & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry, 56*(6), 466-474. https://doi.org/10.1016/j.jaac.2017.03.013

Mason, D., Mackintosh, J., McConachie, H., Rodgers, J., Finch, T., & Parr, J. R. (2019). Quality of life for older autistic people: the impact of mental health difficulties. *Research in Autism Spectrum Disorders, 63*, 13-22. https://doi.org/10.1016/j.rasd.2019.02.007

McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a quality of life measure for autistic people. *Journal of Autism and Developmental Disorders, 48*(5), 1596-1611. https://doi.org/10.1007/s10803-017-3402-z

Milton, D. (2013). Reversing the vicious circle of psycho-emotional disablism in the education of autistic people. In: P. Banajee, R. Barrie and M. Hand, Michael, (Eds.) *Championing research, educating professionals: how compatible are elitism, inclusion and social justice? Annual Conference (11).* University of Birmingham, Birmingham, UK, pp. 127-134.

Milton, D. E. (2014a). So what exactly are autism interventions intervening with?. *Good Autism Practice (GAP), 15*(2), pp. 6-14.

Milton, D. E. (2014b). Autistic expertise: a critical reflection on the production of knowledge in autism studies. *Autism, 18*(7), 794-802. https://doi.org/10.1177/1362361314525281

Milton, D., & Moon, L. (2012). The normalisation agenda and the psycho-emotional disablement of autistic people. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, *1*(1).

Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults?. *Disability & Society, 31*(4), 520-534. https://doi.org/10.1080/09687599.2016.1186529

Milton, D., Ridout, S., Kourti, M., Loomes, G. & Martin, N. (2019). A critical reflection on the development of the Participatory Autism Research Collective (PARC). *Tizard Learning Disability Review, 24*(2), 82-89. https://doi.org/10.1108/tldr-09-2018-0029

Munroe, K., Hammond, L. & Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: an interpretive phenomenological analysis. *Disability & Society, 31*(6), 798-819. https://doi.org/10.1080/09687599.2016.1200015

Murdoch, B., & Caulfield, T. (2016). Doing Research with Vulnerable Populations: The Case of Intravenous Drug Users. *BioéthiqueOnline,* 5. https://doi.org/10.7202/1044290ar

Nicolaidis, C., Milton, D., Sasson, N. J., Sheppard, E. & Yergeau, M. (2018). An expert discussion on autism and empathy. *Autism in adulthood, 1*(1), 4-11. https://doi.org/10.1089/aut.2018.29000.cjn

Northway, R. (2000). Ending Participatory Research? *Journal of Learning Disabilities, 4*(1), 27–36. https://doi.org/10.1177/146900470000400102

Nirje, B. (1969). The normalization principle and its human management implications. *Changing patterns in residential services for the mentally retarded*, 179-195.

O'Dell, L., Bertilsdotter Rosqvist, H., Ortega, F., Brownlow, C. & Orsini, M. (2016). Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism. *Disability & Society, 31*(2), 166-179. https://doi.org/10.1080/09687599.2016.1164026

Oliver, K., Kothari, A., & Mays, N. (2019). The dark side of coproduction: do the costs outweigh the benefits for health research?. *Health Research Policy and Systems*, *17*(1), 33. https://doi.org/10.1186/s12961-019-0432-3

Ortega, F. & Choudhury, S. (2011). "Wired up differently": Autism, adolescence and the politics of neurological identities", *Subjectivity, 4*(3), 323-345. https://doi.org/10.1057/sub.2011.9

Parish-Morris, J., Liberman, M. Y., Cieri, C., Herrington, J. D., Yerys, B. E., Bateman, L., ... & Schultz, R. T. (2017). Linguistic camouflage in girls with autism spectrum disorder. *Molecular autism*, *8*(1), 48. https://doi.org/10.1186/s13229-017-0164-6

Parsons, S., Charman, T., Faulkner, R., Ragan, J., Wallace, S., & Wittemeyer, K. (2013). Commentary–bridging the research and practice gap in autism: The importance of creating research partnerships with schools. *Autism*, *17*(3), 268-280. https://doi.org/10.1177/1362361312472068

Pearson, A., & Rose, K. A. (in print). Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice. *Autism in Adulthood*.

Pellicano, E. (2020). Commentary: Broadening the research remit of participatory methods in autism science–a commentary on Happé and Frith (2020). *Journal of Child Psychology and Psychiatry*, *61*(3), 233-235. https://doi.org/10.1111/jcpp.13212

Pellicano, E., Dinsmore, A. and Charman, T. (2013). *A future made together: Shaping autism research in the UK*, Institute of Education.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the United Kingdom: A mixed-methods study. *PLoS One*, *9*(10), e109946. https://doi.org/10.1371/journal.pone.0109946

Pellicano, L. (2014). A future made together: new directions in the ethics of autism research. *Journal of research in special educational needs*, *14*(3), 200-204. https://doi.org/10.1111/1471-3802.12070_5

Reeve, D. (2011). 'Ableism within disability studies: The myth of the reliable and contained body.' *Theorising Normalcy and the Mundane, 2nd International Conference.* Manchester Metropolitan University.

Robertson, S. M. (2009). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, *30*(1). https://doi.org/10.18061/dsq.v30i1.1069

Rosen, J., & Painter, G. (2019). From Citizen Control to Co-Production: Moving beyond a Linear Conception of Citizen Participation. *Journal of the American Planning Association*, *85*(3), 335-347. https://doi.org/10.1080/01944363.2019.1618727

Sainsbury, C. (2000). *Martian in the Playground: Understanding the Schoolchild with Asperger's Syndrome*. Lucky Duck Publishing.

Schalock, R. L. (2000). Three decades of quality of life. *Focus on autism and other developmental disabilities*, *15*(2), 116-127. https://doi.org/10.1177/108835760001500207

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., ... & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental retardation*, *40*(6), 457-470. https://doi.org/10.1352/0047-6765(2002)040<0457:cmaaoq>2.0.co;2

Schein, E. H. (1991). What is culture? In M. Godwyn and J. Hoffer Gittell (Eds.), *Sociology of Organisations: Structures and Relationships* (pp. 312-314). Pine Forge Press.

Sedgewick, F., Crane, L., Hill, V., & Pellicano, E. (2019). Friends and lovers: The relationships of autistic and neurotypical women. *Autism in Adulthood*, *1*(2), 112-123. https://doi.org/10.1089/aut.2018.0028

Shmulsky, S., & Gobbo, K. (2019). Autism support in a community college setting: Ideas from intersectionality. *Community College Journal of Research and Practice*, *43*(9), 648-652. https://doi.org/10.1080/10668926.2018.1522278

Sinclair, J. (2012). Autism network international: The development of a community and its culture. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking* (pp. 17–48). Washington, DC: The Autistic Press. Accessed 30 October 2020. Retrieved from http://www.autreat.com/History_of_ANI.html.

Singh, J. S., & Bunyak, G. (2019). Autism disparities: a systematic review and meta-ethnography of qualitative research. *Qualitative health research*, *29*(6), 796-808. https://doi.org/10.1177/1049732318808245

Stevenson, J. L., Harp, B., & Gernsbacher, M. A. (2011). Infantilizing Autism. *Disability Studies Quarterly, 31*(3). https://doi.org/10.18061/dsq.v31i3.1675

Stewart, R., & Liabo, K. (2012). Involvement in research without compromising research quality. *Journal of health services research & policy*, *17*(4), 248-251. https://doi.org/10.1258/jhsrp.2012.011086

Szivos‐Bach, S. E. (1993). Social comparisons, stigma and mainstreaming: The self esteem of young adults with a mild mental handicap. *Mental Handicap Research*, *6*(3), 217-236. https://doi.org/10.1111/j.1468-3148.1993.tb00054.x

Toft, A., Franklin, A., & Langley, E. (2019). Young disabled and LGBT+: Negotiating identity. *Journal of LGBT Youth*, *16*(2), 157-172. https://doi.org/10.1080/19361653.2018.1544532

Toft, A., Franklin, A., & Langley, E. (2020). 'You're not sure that you are gay yet': The perpetuation of the 'phase' In the lives of young disabled LGBT+ people. *Sexualities*, *23*(4), 516-529. https://doi.org/10.1177/1363460719842135

Trimble, M., & Berkes, F. (2013). Participatory research towards co-management: Lessons from artisanal fisheries in coastal uruguay. *Journal of Environmental Management, 128*, 768-778. https://doi.org/10.1016/j.jenvman.2013.06.032

University of Kent. (2021). Playing A/Part: Project summary, aims and objectives. Accessed January 4th 2021. https://playingapartautisticgirls.org/project/

Waldock, K. E. (2019). Commentary on "Thinking differently? Autism and quality of life". *Tizard Learning Disability Review*, *24*(2), 77-81. https://doi.org/10.1108/tldr-02-2019-0006

Waldock, K. E., & Forrester-Jones, R. (2020). An Exploratory Study of Attitudes toward Autism Amongst Church-Going Christians in the South East of England, United Kingdom. *Journal of Disability & Religion*, *24*(4), 349-370. https://doi.org/10.1080/23312521.2020.1776667

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, *16*(2), 187-205. https://doi.org/10.1080/09687590120035807

Waltz, M. (2014). "Worlds of Autism: Across the Spectrum of Neurological Difference." *Disability & Society* 29(8): 1337–1338. https://doi.org/10.1080/09687599.2014.934064

Ward, K. & Trigler, J. S. (2001). Reflections on Participatory Action Research With People Who Have Developmental Disabilities. *Mental Retardation, 39*(1), 57–59. https://doi.org/10.1352/0047-6765(2001)039<0057:ROPARW>2.0.CO;2

Williams, D. (1996). *Autism – an Inside-out Approach: An Innovative Look at the Mechanics of 'autism' and Its Developmental 'cousins'*. Jessica Kingsley Publications.

Williams, G. L. (2020). Perceptual deviants: understanding autistic subjects in a (not so) predictable world In D. Milton, D. Murray, N. Martin, S. Ridout and R. Mills (Eds.), *The Neurodiversity Reader: exploring the concepts, lived experience and implications for practice* (pp.35-40). Pavilion Publishing.

Wolfensberger, W. (1972). *The Principle of Normalization in Human Services*, National Institute of Mental Retardation, Toronto.

Woods, R., & Waldock, K. E. (2020). Critical Autism Studies. J*ournal: Encyclopedia of Autism Spectrum Disorders*, 1-9. https://doi.org/10.1007/978-1-4614-6435-8_102297-2

Woods, R., Milton, D., Arnold, L., & Graby, S. (2018). Redefining Critical Autism Studies: a more inclusive interpretation. *Disability & Society, 33*(6), 974-979. https://doi.org/10.1080/09687599.2018.1454380

Young, H., Oreve, M. J., & Speranza, M. (2018). Clinical characteristics and problems diagnosing autism spectrum disorder in girls. *Archives de Pédiatrie*, *25*(6), 399-403. https://doi.org/10.1016/j.arcped.2018.06.008

---

[i] ASQoL - Autism-Specific QoL Items added to the WHOQoL-BREF (World Health Organisation's measure for QoL