Using 'Inclusive Practices for Neurodevelopmental Research' (Fletcher-Watson *et al.*, 2021) as an Ethical Framework for Eliciting the School Experiences of Autistic Girls

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Abstract

Traditionally, research on the topic of autism was primarily carried out on, about or for autistic individuals (Chown et al., 2017). However, there has been a gradual shift away from this approach in recent times with momentum for inclusive and neurodiversity affirming research growing (Pellicano and Stears, 2011). Encouraging steps have been made in autism research in terms of establishing research priorities and engaging autistic people and their families in research. Despite this, research with autistic young people remains scant (Eilis, 2017). Inclusive research must take place with members of the relevant community (Fletcher-Watson et al., 2021). Furthermore, thorough reflection on the ethical considerations is required when working with vulnerable populations to ensure inclusive research practice. The current study aimed to amplify the voices of autistic girls and provide them with the opportunity to share their experiences of mainstream education provision. Participatory research has been identified as a transformative approach to truly ethical and inclusive research, however, Pickard et al. (2022) highlight that early career researchers are often limited in their capacity to facilitate truly participatory research practices, as a result of time, funding and support. This paper details how the researcher adopted the Inclusive Practices for Neurodevelopmental Research model as a framework to attend to the ethical considerations for including autistic girls in the current study. Fletcher-Watson et al. (2021) appreciate different degrees of inclusion depending on the resources available, the scale of the research and the probable impact. Six key pillars are identified as essential in the delivery of inclusive research within this model. Each of the six pillars will be introduced and detail provided on how the researcher responded to the pillar in terms of its practical implementation. This paper will have implications for future researchers in terms of learning from the actions of the current project and continuing to improve practice when engaging with inclusive research.

Keywords: *Inclusive Research, Ethics, Ethical Practice, Autism, Neurodiversity, Participation*

1. Introduction

Defined within a clinical context, autism is a neurodevelopmental condition characterised by differences in social interaction and communication and restricted, repetitive patterns of behaviour, interests and activities, including differences in sensory processing [1]. However, from a neurodiversity lens, autism is better understood as a natural variation of neurology [2] associated with a different style of processing [3].

The historical grounding of autism within a medical model of disability [2] meant that autism research in the past prioritised an intervention focus with research conducted *on, about,* or *for* autistic individuals [4,5]. Furthermore, the autistic community were traditionally perceived as harder to engage in research due to the characteristics associated with their diagnosis [6], resulting in the persistent exclusion of autistic individuals from engagement in knowledge production [5]. However, recent developments in autism research have seen a renewed effort to include autistic individuals and those in their immediate microsystem in the identification of research priorities [4] and engagement in research more broadly [7]. Despite the increase in the inclusion of autistic voices in research [8, 9], autistic children and young people remain underrepresented [10], and similar to autism research more generally, samples are often male-biased [11], emphasising the importance of continued efforts to detail processes and promote the inclusion of autistic children and young people in research.

Participatory research has been recognised as a potentially transformative approach to support the inclusion of marginalised voices in research [12,13]. Despite this, the enactment and conceptual understanding of participatory research is varied [14]. Furthermore, it has been acknowledged that

facilitating truly participatory research (participation across all research stages) can be impeded by several factors such as academic environments that are inconsistent with participatory research, support, time and funding [15]. It is also argued that there is a need for flexibility within participatory research to ensure it is not rudimentary in nature [15,16]. In response to this, Fletcher-Watson *et al.* [16] put forth the idea of Inclusive Practices for Neurodevelopmental Research, a model centred around six key pillars for supporting inclusive research.

The current paper aims to delineate how the 'Inclusive Practices for Neurodevelopmental Research' model proposed by Fletcher-Watson et al. [16] was used as an ethical framework for eliciting the school experiences of autistic girls to ensure an inclusive approach to research. The research context within which the framework was operationalised is first presented. Following this, the six pillars of the 'Inclusive Practices for Neurodevelopmental Reseach' are introduced and their application examined in the context of the current study.

2. Research Context

Much of the research exploring mainstream educational inclusion for autistic individuals is explored through the adult stakeholder lens or limited by male-dominated samples. A systematic review of research conducted with autistic individuals suggests that their needs are often not supported in mainstream provision [17]. Furthermore, evidence suggests that due to differences in presentation, autistic girls often go unrecognised and unsupported [18,19] and, as a result face unique systemic barriers to inclusion [20]. In light of this, it is understood that they can have qualitatively different school experiences to autistic boys [21]. There is currently no published research known to the researcher that looks at the experiences of autistic girls in schools in the Irish education context, situating the current research as timely.

The research underpinning this paper is the author's PhD research and is a mixed-methods, multi-informant study to better understanding the educational experiences of autistic girls. The primary research study aim is to explore the experiences of autistic girls attending mainstream education provision at post-primary level in the Republic of Ireland. Underpinned by Interpretative Phenomenological Analysis (IPA), the research seeks to elicit the lived experience of being autistic and attending mainstream education provision and amplify the voices of those historically left out of knowledge production.

3. Inclusive Practices for Neurodevelopmental Research (200)

The 'Inclusive Practices for Neurodevelopmental Research' was developed by Fletcher-Watson *et al.* [16] as a mechanism for embedding inclusive practices within research, across all levels of the continuum of participation [22]. This model places responsibility on researchers to embed inclusive practices within the research process to facilitate research *with* members of the relevant community [23,16]. It promotes the idea that those with 'lived experience of the neurotype being researched' should be provided with 'meaningful and accessible opportunities' to share their experiences [16]. It is argued that community engagement is necessary to ensure the research has a positive impact in terms of its outcomes [24]. The model proposed by Fletcher-Watson *et al.* [16] identifies 6 key pillars that aim to provide guidance for researchers on how to embed inclusive practices within their research. The six key pillars include; *the who and how of inclusive research, setting expectations, community specific inclusion measures, inclusion and intersectionality, the role of empowerment* and *knowledge exchange for inclusion* (**Fig. 1**). The following subheadings present each principle in turn and provide examples of how it was considered in the context of the research.

Figure 1: 6 Key Pillars of 'Inclusive Practices for Neurodevelopmental Research' (Fletcher-Watson *et al.*, 2021)

3.1 The Who and How of Inclusive Research

Inclusive research demands that the voices of those with lived experience are prioritised [16]. Traditionally, adult stakeholders, e.g. parents and teachers, were recruited as proxies in research concerning the experiences of autistic young people [4], however, it is argued that researchers must find ways to facilitate the participation of children and young people in the research process [16], particularly where the research focus is pertinent to their lives. Successful inclusion must be considered from the outset in terms of planning and design and may require adaptations to the research processes. In the current project, autistic girls were central to the process and IPA was selected as an approach suitable for amplifying their voices [25]. In IPA, participants are deemed 'experts-by-experience' [25], an understanding extremely appropriate when seeking to elicit the lived experience of a different neurotype [16]. In addition, While the inclusion of autistic voice is critical, it is also acknowledged that other stakeholders' contributions can develop understanding of a phenomenon and add rigor to the data [16]. Therefore, consistent with IPA research, this study adopted a multi-perspectival approach through the use of dyadic research design with autistic girls and their parents/guardians forming research dyads [26].

3.2 Setting Expectations

The setting of clear expectations is deemed essential in inclusive research to promote transparency in the research process [16]. The researcher and the participants should have a shared understanding in terms of the expectations, roles and responsibilities within the process. Guided by the Participatory Autism Research Starter Pack [27], the researcher ensured that the goals, procedures and outcomes, as well as information on how participant data would be used was detailed to participants in a coherent manner using plain language. The researcher created a private webpage that hosted a suite of resources to support clarity around the research process. These resources included a text-based biography and photograph of the researcher, an animation introducing the concept of research, a video of the researcher introducing the research and explaining the research process, a child-friendly information sheet, a parent/guardian information sheet, an infographic detailing a step-by-step guide of the research process, as well as an option to express their interest in participating or to request

contact from the researcher. The multi-modal approach to information sharing was praised by parents/guardians as useful in initiating discussion on the research with their daughters and for preparing them for the first meeting with the researcher.

3.3 Community Specific Inclusion Measures

In adopting a neurodiversity affirming perspective, it is of critical importance to acknowledge the differences experienced by autistic individuals within the context of a neurotypically-dominated society in order to make provisions for support. The constellation of autistic traits and differences in processing can mean that some autistic individuals may experience difficulties with some of the more commonly adopted research practices [16]. It is the responsibility of the researcher(s) to make adaptations to the research process as necessary to minimise and, where possible, eliminate barriers to participation [16]. Cascio *et al.* [28] advocate for individualised adaptations in four key areas of which will now be discussed in the context of the project.

3.3.1 Consent Procedures: The researcher designed an accessible age-appropriate assent form for the autistic girls that used clear, concise language. The researcher explained the concept of consent to the girls upon initial meeting and discussed the content of the assent form. Following this discussion, the girls were given the opportunity to provide written assent indicating their desire to participate in the research. However, in line with the literature on consent procedures with children and young people [30], *process* consent was employed throughout the study as a way to support safeguarding within research [31]. Assent to engage was reassessed at the start of the second session but was also informally monitored throughout data collection sessions through observation of reactions, engagement and body language. In addition to this, in their wellbeing plan completed in advance of data collection, participants were asked to detail how the researcher would know if they were becoming distressed or wanted a break. This alerted the researcher of signs to look out for. Furthermore, visual cue cards were also incorporated into the session, enabling the girls to control the research in terms of stopping, pausing or continuing, requesting a break or asking a question.

3.3.2 Research Design and Data Collection: Considering design and data collection procedures is integral to inclusive research, with partnership participatory research which situates participants as co-researchers identified as best-practice [32]. However, due to the nature of the current study in terms of its scope, timeline and a pre-accepted research proposal for funding, the researcher was somewhat limited in terms of changes that could be made to the research design. Despite this, inclusivity was a core focus in the selection and use of data collection methods. Recognising the importance of trust and security, a two-session approach to data collection was utilised with the option for participants to request additional informal Teams meetings. Moreover, acknowledging that traditional methods of data collection may not be suitable for autistic individuals [24], a variety of methods were used to accommodate diversity [33]. Firstly, a walk-and-talk session [34] in the girls' schools was selected as a way to empower the girls as experts within the environment. The second session took the form of an 'interrupted' interview [35] to allow for a series of activities to be embedded in the session as prompts for discussion. A side-by-side approach was adopted within the interview to reduce anxiety with diamond ranking, picture as stimulus and metaphor elicitation using illustrated cards incorporated as multimodal activities. In addition to the above, a topic guide was provided to participants in advance of the sessions and flexible options to engage were offered. All participants engaged with the two sessions in a face-to-face capacity with the exception of one participant who completed the second session in an adapted written format.

3.3.3 Support for Participants during the Study: This action point refers to supporting the unique needs of participants. In an effort to facilitate individualised support, a well-being plan was developed and sent to participants in advance of data collection. This endeavoured to elicit pertinent information such as sensory needs, distress signs and identification of support personnel. As previously mentioned, visual cue cards were incorporated into the session to afford individual control to the participants. Participants were offered the option of having a familiar adult present. The researcher ensured the provision of adequate 'wait' time in the data collection sessions and clarification or rephrasing of questions was offered if required. Data collection sessions were undeniably supported by the researcher's personal experience working as a teacher and a research fieldworker.

3.3.4 Tailoring of language to reflect individual preferences: Participants were asked to select their preferred terms (autistic individual / individual with autism / other / no preference) in their wellbeing plan. The participants of the current research did not express specific preferences.

3.4 Inclusion and Intersectionality

Intersectionality acknowledges the various intersecting identities of individuals and proposes that those with various minoritised identities will experience life in a different way to those who share one or some of those identities [36,37]. Autism researchers have emphasised the importance of recognising that the participant's diagnosis is not their sole identity [16,24] and that the other identities may either empower them or place them at a further disadvantage. There is evidence to suggest that the intersection of the non-dominant gender with disability can have a negative impact on life outcomes [38] with autistic females identified as one such cohort at risk [39]. As mentioned previously, autistic females are significantly underrepresented in research [11] and it is only by eliciting the voices of those with lived experience can authentic understanding of their experiences be garnered. The current research responded to a call from researchers to include autistic females in research to better understand the intersections of gender and autism [24,37]. In order to support the selection of a gendered sample, intersectional feminism was used as a theoretical lens within the conceptual framework of the research.

3.5 The Role of Empowerment

Inclusive research emphasises the importance of community members playing an active role in the research process [16]. Therefore, regardless of the level of participation, measures to facilitate empowerment can and should be implemented [16]. Despite not adopting a full participatory approach in this research, the researcher endeavoured to empower participants. Firstly, consistent with Fletcher-Watson *et al.* [16] that 'payment explicitly values expertise by lived experience' and in line with other researchers [40,41], the participants did receive a small reimbursement in the form of a gift voucher. Acknowledging the argument that reimbursement could increase the risk of inducement, it was not advertised on the recruitment call and instead was offered at the end of the process as an expression of appreciation for the time invested and the contribution to the research process [31]. Secondly, Pellicano *et al.* [4] reported that autistic individuals are often not informed of the results of research, despite having shared their views. While the findings of the current study have not yet been finalised, it is intended they will be communicated to the participants. The researcher has indicated to the participants that they will receive a summary of the findings and a copy of any papers published pertaining to the findings. It is hoped that a summary document alongside an infographic and/or brief animation will be developed to present the findings using multimodal means to ensure access for all.

3.6 Knowledge Exchange for Inclusion

The final pillar seeks to highlight how individuals can be disadvantaged in the research process and face barriers to participation in terms of 'technical language' and 'specialist knowledge' [16]. As discussed previously, a number of measures were incorporated into the research to ensure information about the research and the data collection sessions were accessible to participants. Furthermore, to ensure the research project was 'culturally and contextually appropriate' to autistic individuals [24], all materials were reviewed by an autistic individual. In addition to this, the researchers ensured that an open line of communication was maintained during the process and encouraged participants to contact her if they had any questions or wished to discuss anything further [28]. The researcher also drew on her experience working with children and young people and her knowledge and skills garnered from on-going engagement with continuous professional development to support the adoption and embedding of inclusive practices throughout the research.

4. Conclusion

This paper has responded to a call for researchers to provide detail on the measures embedded in research to demonstrate inclusive practices in action [16]. Furthermore, the study used to contextualise this paper has responded to a call to include autistic females in research [37] and has engaged autistic female students to better understand their experiences of mainstream education provision at post-primary level in the Republic of Ireland. It is hoped that this paper has provided some insight into how the work of Fletcher-Watson *et al.* [16] and the model of 'Inclusive Practices for Neurodevelopmental Research' can be adopted to support the meaningful engagement of autistic individuals in research. The researcher hopes that this paper provide opportunity for reflection, adds to

the emerging body of literature in this area and continues to promote dialogue and communication in relation to inclusive research.

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