

Practicing Epistemic Collaboration in Transformative Inclusive Research with Students with ASD

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1. Objectives or purposes

The inclusion of people with Autism Spectrum Disorders (ASD) and neurodevelopmental disorders in traditionally inclusive research poses challenges in terms of epistemological assumptions and methodological choices (Atherton et al., 2023). For example, students with ASD are often identified as deviating from what is culturally considered ‘normal’ or ‘neurotypical’ ways of interacting with the world. Despite significant progress in the participation of people with neurodivergence in social research, barriers to social equality, equal opportunity and independent living continue to exist (Embregts et al., 2018). Too often, the notion of 'remediation' has been generalised to remedial approaches to teaching and learning, mis-locating deficits in individuals with ASD and school systems, rather than critically examining institutions, policies and educational strategies (Najeeb & Quadt, 2024). In addition, research with people with ASD shows the complexity of inquiring about the implications of culturally situated representations of neurodevelopmental conditions (Atherton et al., 2023).

With this in mind, this paper presents the qualitative step of a mixed methods study that aims to further interrogate the discussion about challenging and transforming bias based on a remedial approach to research with people with ASD. The study, entitled “ALL Inclusive”¹, was carried out by the team of the University of Siena, Italy, with high school students with autism and neurodevelopmental disorders in 2023-2024. The aim of the study was to explore which internal and situational factors influence the students' vocational adaptability and work expectations (Cottini, 2024).

In the Italian context, students with ASD in secondary school are accompanied by support teachers as part of an individual education plan (Cottini, 2024). These individualised supports

¹ <https://allinclusive.unisi.it/en/home-en/>

may not be present in the workplace, where the type of support is usually based on physical accommodation and assistive technologies. Based on these challenges, the purpose of the study was to explore which internal and situational factors influence students' vocational adaptability and work expectations, and which educational pathways can support students with ASD in their transition to the labour market.

Therefore, the findings provide key elements that are useful for designing collective pathways that support students with ASD to access the labour market, reducing the risk of reproducing medicalization or stigmatization (Bagatell, 2010). In doing so, it also provides greater insight into how to avoid the risk of using remedial and reparative approaches in inclusive transformative research with people with autism and neurodivergence (Izuno-Garcia et al., 2023).

2. Perspective(s) or theoretical framework

Our theoretical framework is a unique combination of theoretical and methodological approaches to transformative research with people with autism (Embregts et al., 2018). The theoretical framework includes transformative research in disability studies (Kofke, 2018; Kofke, 2020) combined with intersectional perspectives in research with people with ASD (Cottini, 2024). This complex theoretical framework considers key axes of power, inequality, and injustice in society, as well as research and all sites of knowledge production that produce oppression (Hanson & Fletcher, 2021). It addresses the limitation of “epistemic poverty” (Paul, 2016) we are currently facing, when inclusive research is being carried out in more traditional ways (Bottema-Beutel et al., 2021). In contrast, the approach we suggest utilizes the different epistemic perspectives through a participatory transformative research paradigm. This framework highlights how the social constructions of the notion of 'ability' are intertwined with gender, race, neurotypical assumptions and academic achievement,

particularly as they relate to students with ASD (Izuno-Garcia et al., 2023)). It recognises the material and psychological impact of being labelled as a student with ASD, which exacerbates the levels of systemic oppression, racism and ableism they experience in their educational contexts and in accessing the labour market (Atherton et al., 2023). Stigmatization, specifically regarding a lack of understanding and overt acceptance of autism in workplaces, is a condition that students with neurodivergence frequently express (Lindsay et al, 2021).

3. Methods, techniques, or modes of inquiry

The “ALL Inclusive” project adopts a mixed methods intervention design that incorporates a convergent design (Hirose & Crewswell, 2022). The research has been conducted with groups of young adult males and females with autism (ASD) and neurodevelopmental disorders. The research aims to develop training programmes to support adults in accessing the labour market and developing their vocational identity. The research team included people with non-binary gender identity, diagnosed neurodiversity and non-western ethnic backgrounds. This heterogeneity was the first criterion to ensure that a plurality of intersecting dimensions of diversity were represented in the research team. Figure 1 portrays the design used in the research.

Convergent Research Design

Exploratory mixed-methods research design

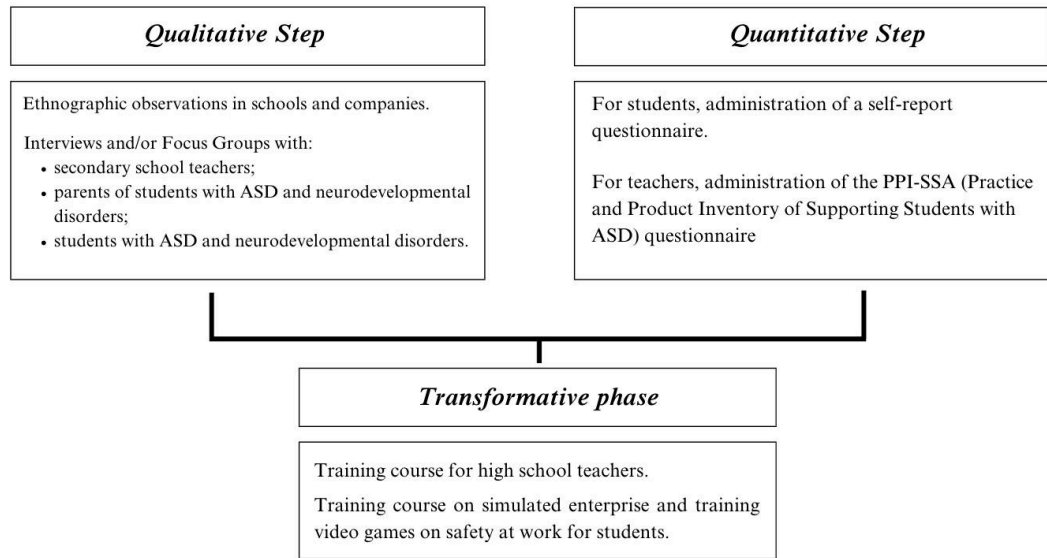


Table 1 displays an overview of the methodology of the “ALL Inclusive” Project.

Table 1. Research Design of the “ALL Inclusive” Project

<i>Research design</i>	Exploratory <i>mixed-methods</i> research design (Hirose, & Creswell, 2022)
<i>Qualitative Step</i>	<ul style="list-style-type: none"> • Ethnographic observations in schools and companies; • Interviews and Focus Groups with 36 secondary school teachers, such as support teachers and PCTO (Orientation to Work Individual Plan) representatives; • Interviews with 12 parents of students with ASD and neurodevelopmental disorders; • Interviews with 20 employers and HR managers; • Interviews with 10 workers with ASD and neurodevelopmental disorders with employment contracts; • 12 Focus Groups with students with ASD and neurodevelopmental disorders; • Adoption of reflective self-inquiry techniques, such as Critical Incident Analysis (Brookfield, 2015; Fabbri, & Romano, 2017) and the Autoethnographic Case Study (Tisdell, 2022; Romano, 2022) with groups of secondary school teachers.
<i>Quantitative Step</i>	<p>For students, administration of a self-report questionnaire consisting of four scales (Yang, Pang, & Sing, 2022):</p> <ul style="list-style-type: none"> • Adaptability Scale • Job Expectations Scale • Security Perception Scale • Work Orientation Scale <p>For teachers, administration of the PPI-SSA (Practice and Product Inventory of Supporting Students with ASD) questionnaire (Yang, Pang, & Sin, 2022) to 365 secondary school teachers.</p>
<i>Transformative phase: designing the training intervention</i>	Development of a simulated enterprise training course and training video games in Simulated Intelligence to support the transition into the world of work (https://allinclusive.unisi.it/video-scenari/)
<i>Participants</i>	<p>N = 160 students with autism and neurodevelopmental disorders from 3rd, 4th and 5th grade high schools.</p> <p>N = 365 high school teachers.</p> <p>N = 12 parents of students with ASD and neurodevelopmental disorders.</p> <p>N = 20 Human Resource Managers, CEOs, HR Heads.</p>

The data collection process and findings from the qualitative exploratory step are elaborated as follows: Participants were recruited from five secondary schools in three school districts in the Tuscany region in the centre of Italy. Qualitative data were collected from school ethnographic field observations and interviews conducted with: i. 12 parents (8 mothers and four fathers) of students with ASD; ii. 36 secondary school teachers who have the function of support teachers, job advisors and job consultants in their schools; iii. 20 professionals from the labour market who are leaders/managers/human resources directors of private and public companies where people with autism and intellectual disabilities are hired.

In addition, to ensure the epistemic centrality of people with autism in the research (Romano & Torres-Corona, 2024), 12 focus groups were conducted with secondary school students with ASD and 10 in-depth interviews were conducted with professionals with disabilities already employed with full-time or long-term contracts. All the interviews and focus groups were video recorded and transcribed verbatim.

4. Results and/or substantiated conclusions or warrants for arguments/point of view

By presenting the findings, we would address the current and ongoing challenges of conducting rigorous and robust studies with people with neurodevelopmental disorders and generate relevant evidence to inform transformative interventions.

Qualitative content analysis (Hirose & Creswell, 2022) was carried out immediately upon completion of data collection. In the first step, the researchers independently and inductively analysed the transcriptions of the interviews and focus groups, searching for *in vivo* categories representing conceptual themes. In the second stage, all inductive analyses were discussed by the whole research team. Validation checks by participants were conducted at every stage of data analysis.

Students with Autism identify a number of contextual and organisational resources that they consider important for creating inclusive pathways for their transition from school to the labour market. They prioritise work-related learning experiences, both in the classroom and in enterprises, as the most effective support pathways for strengthening connections with enterprises and acquiring the organisational skills needed to access the labour market (Romano & Torres-Corona, 2024).

In Table 1, the key elements identified to support the transition of students with autism into the labour market are summarised in four categories, i.e. (1) *building a collaborative inter-institutional network*, (2) *adjusting job environments to students' needs*, (3) *co-creating*

digital tools for students' work-related learning, and (4) constructing training pathways for the development of adaptive skills.

Table 2. Four contextual and organizational resources for orientation to work

Categories	Descriptors
1. <i>Building a collaborative inter-institutional network</i>	<ul style="list-style-type: none"> - Reinforcing formal collaborations between schools, job agency, and small and medium enterprises through formal conventions, meetings and events - Increasing the opportunity for students with ASD to spend time in workplaces under the guidance of a job mentor and educational personnel
2. <i>Adjusting job environments to students' needs</i>	<ul style="list-style-type: none"> - Adjusting working spaces, time and pace to students' needs and instances - Creating technical and formative supports for the development of adaptability skills of students with ASD
3. <i>Cocreating digital tools for students' work-related learning</i>	<ul style="list-style-type: none"> - Co-creating digital and formative supports for the development of adaptability skills of students with ASD - Designing digital games and virtual scenarios to help students with ASD learn how to move, behave and work in real-life workplaces
4. <i>Constructing training pathways for the development of adaptive skills</i>	<ul style="list-style-type: none"> - Enhancing training paths based on work-related learning as integrated and parallel activities for the school curriculum - Engaging students with ASD, families and job mentors in the training paths based on work-related learning

5. Confronting the implications of researcher's epistemic limitations

The importance of getting the perspectives of people with ASD, whose interests the educational system is supposed to serve, is self-evident. Paul (2016) helps us understand why this perspective is crucial and necessarily presupposes the participation of students with ASD in this research project. Paul's (2016) work on *transformative experiences* highlights the epistemic limitation one might have regarding certain experiences. Following her, *transformative experiences* include fundamental and deep processes of change on an epistemic and a personal level. Such an experience teaches us something we can not know without having it; there is an epistemic inaccessibility of what it is like to have that

experience. Paul (2016, p. 10) uses the term *epistemic poverty*; we are unable to grasp crucial information about the nature of an experience. This is also true of our perspective as researchers, trying to grasp an understanding of someone's experiences and perspectives that are fundamentally different from our own lived experiences and understanding of the world. The researchers' epistemic access to the participants' lived experience remains inaccessible or, at best, very limited. Therefore we - as researchers - are forced to confront and work with the implications of our epistemic limitations. One way to address this epistemic poverty is to choose a collaborative research approach in order to develop such training programmes. It helps us confront the existential implications of our epistemic limitations when working in a team with researchers from various backgrounds, including neurodiversity.

6. Scientific or scholarly significance of the study

Through the example of the qualitative research presented, the paper raises critical questions about the '*by whom*' and '*for whom*' of transformative inclusive research with people with autism (Romano & Torres-Corona, 2024). We agree with the assumption that research settings are never *neutral* and present a unique combination of power relations, hierarchical relationships, ambiguity and so on, in which participants occupy and move between different positions (Rautio et al., 2022). Therefore, research with students with autism requires researchers to be reflexive about the structural ableist oppressions perpetrated by the remedial, medicalised and reparative approaches that are implicitly assumed when studying the experiences of people with autism.

What is the '*on, to, for, with or by*' space that inclusive research can leave for participants with ASD? Expanding multiple pathways of participation for students with autism could increase the unpredictability of the research design intended by researchers and bring more situated perspectives on the impact of research findings on material changes in individuals' lives. In the research described in the paper, the perceptions of students with autism were seen as crucial to a more practical and equitable approach to supporting their transition to adulthood and independent living. Inviting and incorporating the voices of individuals with ASD is a necessary practice to foster agentic engagement among participants. This practice is a crucial component of promoting a sense of belonging (Kramlich & Gilpin-Jackson, 20; Othering and Belonging Institute, 2021) and allows participants to be recognized on their own terms, according to their needs, granting them

greater recognition from others--something even more essential for those from marginalized and misunderstood communities. (Fleming, 2011; Romano, 2023).

We see '*inclusion*' and '*participation*' of people with ASD in research as a non-innocent practice: it is crucial to interrogate these practices by asking on whose terms people with ASD participate in transformative inclusive research and to challenge situations in which participation may not be in their interests. In this regard, the first critical question points to the importance of including people with ASD as producers of knowledge (rather than sources of data) on their own terms and confronting our own epistemic limitations. The second question has implications for the range of participants and the construction of a more equitable and inclusive research methodology for transformative impacts (Johnson-Bailey, 2012).

There are still few approaches in which people with ASD are represented as active co-researchers, involved in the consideration of research designs, the selection of methods and the refinement of research questions. This conversation is now needed to radically question remedial approaches that are still practiced in inclusive research and education, and how they can be overcome when we conduct research on autism.

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