Critical design and co-design in autism research: a self-critical approach to combat prejudice and bias in research

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Critical design and co-design in autism research; A self-critical approach to combat prejudice and bias in research

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SUMMARY
Every researcher brings their own (implicit) values, norms and possible prejudices to the research process. This also applies to autism research. For example, the assumption that autism concerns a vulnerable minority group that needs to be helped by researchers/professionals. If a researcher does not explicitly and critically examine and analyze these and other assumptions, such harmful prejudices and misinterpretations will continue. The common characteristics of that group (autism) are then labeled as deviant and problematic compared to a dominant majority, which apparently serves as the norm group. Critical Design teaches the researcher to think independently, by increasing awareness of their own (pre)judgments, and thus initiates the debate that should stimulate action to break the prevailing status quo. This cannot be done without co-design, which refers to the active and meaningful involvement of different autistic stakeholders in the research process, and in all steps of this process. This means that researchers, practitioners and other professionals no longer talk about “the other”, but all together form a community based on equality, where no one is “granted” anything, but actions are taken to guarantee equity for everyone.

The identification of autism in Dutch and international (global north) society is growing, resulting in a huge increase in the number of diagnoses in recent years, and with it scientific research into autism. Every year, thousands of scientific studies are conducted on autism, covering a wide range of topics. On the one hand, it is good that we are trying to increase our scientific knowledge about autism. On the other hand, the question is who is conducting this research and how. Researchers bring their own norms, values and assumptions to the table, and these are often implicit, such as the assumption that knowledge about the male body is also applicable to the female body. Recently, national newspapers reported how the treatment of heart patients is often based on scientific research conducted on men, but this knowledge is often applied to female heart patients without sufficient evidence, with potentially harmful consequences.

In autism research, it is also common for certain prevailing views, norms, values, assumptions and prejudices to influence the researcher and the research (whether implicitly or not). If the research team does not critically discuss these assumptions and possible prejudices, and fails to evaluate how this way of thinking about autism influences the research and the interpretation of the results, publication of those results confirms the status quo. The prejudices and misinterpretations remain intact. This is called affirmative research. An alternative to this is the application of Critical Design in research. Critical Design challenges the status quo. It makes assumptions, values and biases explicit, questions them, and strives for innovation by formulating proposals that are critical of prevailing social norms and assumptions. The aim is to encourage independent thinking by raising awareness, exposing assumptions, stimulating debate and, of course, encouraging action to break the status quo (Dunne & Raby, 2013, p. 34).

In this essay, we first discuss the role of the researcher in the research process. Using a real-life example, we demonstrate how one's own norms and values regarding what is appropriate in society, prejudices, and stigmatization regarding autism can negatively impact the research process and its outcomes (Part I). Critical Design involves becoming aware of these common pitfalls, which should lead to a mental shift in the researcher's thinking.

In Part II, we discuss how co-design can play an important role. Co-design (sometimes also referred to as ‘participatory research’), in the present context, refers to the active and meaningful involvement of different stakeholders in the research process, including the joint formulation of the end goal of an intervention. Co-design not only contributes to the integration of diverse stakeholder needs and interdisciplinary expertise (Malinverni et al., 2017), but also has the potential to enable autistic individuals, who are traditionally treated as less ‘capable’ or less autonomous (Fletcher-Watson et al., 2019; Spiel et al., 2019), to represent their values and goals in autism research and interventions.

We would like to note that autism is a heterogeneous population, with significant individual differences in needs, abilities, and desires. Some speak, others do not; there is a wide range of gender and sexual identities, and of course, young children and older adults are rarely considered a single group—such differences impact the context in which an autistic person's daily life unfolds. But there are also similarities, based on which an individual is diagnosed with autism. In this article, we will refer to "autistic students" or "students with autism," but it is important to keep in mind that statements in this article about autism may resonate with many children, adolescents, and parents with autism, but that there will always be autistic children and adolescents for whom things are different. Such nuances can be lost in writing about autism.

In this essay, we discuss the pitfalls in autism research and possible steps to mitigate them through co-design, using very specific examples of autistic students in mainstream education. This inevitably excludes non-verbal autistic students. However, we chose to stick to a single context to convey our message

more clearly. The example could also have been a case from a social work setting or another context. However, the core message of this essay remains the same, across all autism research (and even beyond).

PART I. The researcher's distorted and biased perspective

Since the Appropriate Education Act (2014), it has been important for autistic students to integrate into the regular Dutch education system. To achieve this, it is essential that these students also feel welcome and understood at their school. In addition to attention to the structure of lessons, the school environment, and the school's facilities themselves (Rieffe & Koutamanis, 2023), informal time at school should also be a key focus. Informal school time is the time that students can spend independently, together or alone, such as during breaks. School breaks are meant for relaxing, recharging, recovering from lessons, and unwinding, so that after the break, concentration is strong enough to follow lessons. Many children are seen running around or playing together during breaks, while adolescents often hang out in groups in the schoolyard.

However, students with autism in mainstream education often stand or sit alone during breaks. A large number of scientific research publications show that these students often have fewer social contacts with their peers, are less physically active, and play less, alone or with others, compared to their non-autistic peers (Rieffe et al., 2025). The question is, is this a problem? Do these children feel at home at this school and with their peers, or would they rather be somewhere else, and does the break not help them relax and recharge for the upcoming lessons? Do autistic students perhaps feel more lonely on the school playground? Furthermore, the dropout rate among students with autism is high (Li et al., 2024). Are these factors related? What are the reasons for the high percentage of students who stay home, and what are possible solutions? These are important questions for policymakers, school boards, teachers, parents, care providers, and, above all, the students themselves. But these are also important questions for scientific researchers, because they are the ones who provide advice to all those other parties with new, scientifically based knowledge.

If we want to know more about how autistic students feel during breaks, and what we can do to help these students feel more at home in mainstream schools, we start by searching for relevant scientific research in this area: what is already known? Searching for scientific research, for example, via Google Scholar, reveals many studies focusing on play during school breaks or on playgrounds, but there are also intervention studies aimed at improving things for autistic students. However, the vast majority of these studies have one thing in common: they (almost) all assume that being alone is undesirable, and that more social contact during breaks is better, according to these researchers. This is a researcher's bias, which is not only untrue, but can even be detrimental to the well-being of autistic students and others.

First, researchers should ask autistic students themselves what they need during informal school hours. What do they need to relax? Do they indeed want more social contact, like many non-autistic students? Our own research shows, for example, that loneliness in non-autistic students is associated with fewer social contacts during breaks, but this correlation is not found in autistic children (Tsou et al., 2025). Autistic students indicate that they feel less lonely when they are accepted and liked by their fellow students. So, not that they necessarily want to spend a lot of time playing or chatting together, but it is important to know that they are welcome and have friends in the classroom. See also our previous article in WTA on loneliness (Rieffe et al., 2024). Sitting quietly next to each other can also create connection, and perhaps these are precisely the moments when autistic students can relax (Rieffe et al., 2022). In short, applying the needs of neurotypical students to autistic students (such as more social contact during school breaks is better) means that the researcher is ignoring the wishes, needs and capacities of this specific group.

Secondly, this approach also potentially implies that autistic students in mainstream education are "*different from the 'others' (the neurotypical majority)*" and may need "*help*" to meet that norm, so they can "*keep up*" with others, or so they are prepared for the demands of society later in life. This, too, fails to acknowledge the unique abilities, needs, and desires of a specific group, but instead, characteristics initially labeled ("framed") as limiting are then taken as a starting point. For a student in a wheelchair, no teacher or school psychologist will figure out how to get them to run with other students who can and may even enjoy it. Autism, on the other hand, comes with a number of characteristics that are not always clearly visible or recognized by those around them. For example, autistic children and young people are often taught to make eye contact, even though this can cause overstimulation and disrupt the autistic student's natural thought process and concentration during a conversation. When I ask adult autistic colleagues who sometimes look at me (the first author) a little too intently during a conversation, the answer I get is invariably, “my therapist (or practitioner) told me to do that.”

Teaching eye contact therefore ignores the specific disadvantages many autistic students experience when they are forced to apply it. The question is for whom this behavior actually needs to be modified, because autistic conversation partners will not need eye contact among themselves and will respect it in each other. Even non-autistic people who understand and respect autism will not have an issue with more or less eye contact. Therefore, the modification is specific to the neurotypical person who may not understand autism or condemn it as something negative. What makes this neurotypical person so special that their behavior is considered the norm, to which everyone must conform? Is this an implicit "neurotypical privilege" being imposed, or rather, a generally accepted intolerance of diversity and individual differences?

This bias in the approach to the target group also translates into the example of school breaks: for whom are more social contacts better? Does this indeed apply to all pupils, including autistic pupils? Did the researchers ask themselves this question first, or is this an assumption that could be harmful to autistic pupils if they are pushed by the results of the research to have more social contacts, which could actually make them less able to relax during breaks?

The argument that such adaptations by autistic children and adolescents to others are beneficial in preparing them for later participation in society seems plausible, stemming from concern for autistic students, but it's a fallacy. After all, not everyone needs to fit in everywhere or be able to do everything. Don't students who are good at languages choose a different curriculum than those who are passionate about science? It is precisely by cultivating qualities which they excel at and enjoy that students develop a good and strong preparation to participate in society.

Third, a researcher must be able to critically reflect on certain (unconscious) assumptions and biases that influence the research process. These can be detrimental to the development of autistic students. An example of such an (often implicit) assumption that must be critically examined is that "adapting to a dominant majority" is a form of "deficit" thinking—that is, thinking in terms of limitations with respect to autistic students. Deficit thinking touches on the so-called double empathy problem, which posits that communication problems between autistic and non-autistic individuals are mutual (Milton, 2012). In other words, individuals with autism have difficulty understanding and interpreting the communication of neurotypical people, but this also applies vice versa. What is understandable for the listener depends on the perspective one adopts. From a neurotypical perspective, autism characteristics, such as avoiding eye contact, but also hyperfocus and concentration on certain topics, or honesty in communication, are framed in a negative, non-constructive way. All these characteristics mentioned here fall under the neurotypical vocabulary of

"social awkwardness," "social communication problems," and "obsessive behavior." Just as a potential athlete is praised for their strong focus, dedication, and motivation, autistic students might also be viewed positively when it comes to autism-specific characteristics such as a hyperfocus on certain topics and a lack of interest in engaging in conversations that "go nowhere," or what non-autistics call small talk. The student with autism prefers to use their time effectively, and social bonding, like non-autistic students do during episodes of small talk, is more likely to occur for autistic students when they connect on the topic of a hyperfocus.

Finally, there's the well-intentioned assumption to offer a more "inclusive school environment," or to contribute to greater inclusivity in schools through research. Such an approach sees autistic children and young people as unequal students in a school. They fall outside the norm, for whom extra time and resources should suddenly be allocated. However, neurodiversity can also be considered a fundamental right that applies equally to every student (Rieffe et al., 2025). From this perspective, autism, as well as non-autism, can both be reformulated as forms of "neurodiversity". The problem then lies not in the abilities of the autistic student, but in the discrepancy between individual desires or needs and the opportunities offered by an environment. Social-ecological approaches aim to reduce this mismatch while preserving and valuing diversity. This shifts the problem from individual deficits to structural, cultural, and interpersonal barriers that may prevent people with physical, neurological, or mental differences from fully participating.

PART II. Co-design to ensure autistic perspectives in research

Critical design, as a research method, supports researchers by critically examining how life is influenced by assumptions, values, and ideas embedded in the designed living environment—for example, in the technologies we use—and by seriously considering the role of design in creating futures that can structurally bring us together, but also by taking structurally that role seriously (Bardzell & Bardzell, 2013). Critical design distinguishes itself by provoking, rather than recasting and repurposing, superficial norms and traditions enshrined in designs (technologies, environments, design, research) and their use (Bardzell et al., 2012). A central component of critical design is reflexivity: the researcher's reflection on their own assumptions, which stem from their cultural, political, and social background (Jamieson et al., 2023).

In short, the researcher, both as a human being and as a member of society, unintentionally and automatically brings their own perspectives and biases into the research design (Jamieson et al., 2023), which can be harmful to certain groups of people affected by the research. There is usually a power imbalance: adult researchers speak on behalf of young people, researchers from a higher socioeconomic background speak on behalf of a lower socioeconomic community, and many other power imbalances exist. One question the researcher should ask themselves in this regard is: "Where do I stand, and how can I (or not at all) engage with this topic in a respectful way? How can I carry out the project without falling into patterns of paternalism and privilege?" (Madrigal, 2020).

Co-design—the active and meaningful involvement of, among others, autistic students in the research process—can offer a blueprint for designing research that is (relatively) more immune to perpetuating of harmful biases based on power dynamics, such as a dominant non-autistic society making decisions about and for a less dominant autistic group (Nägele et al., 2018; Spiel et al., 2019). It is crucial that the researcher reports transparently on the co-design process, including with whom, at what stage, and how the research was co-designed.

Co-design, with whom and how

Co-design, in its most general form, means that various parties (autistic students, but also school boards, parents, and teachers) in the research ecosystem are actively and meaningfully involved throughout the entire research process, including formulating the

final goal. For example, researchers who want to develop an intervention for playgrounds should involve the recipients of that planned intervention well before the research questions are formulated. Without this input, the intervention's direction can be completely misguided. After all, the question "how to train more social interactions with classmates" is not a responsible research question or intervention goal to pursue if the researcher realizes that it could cause discomfort, stress, and feelings of stigmatization among autistic students.

The next point to consider is who to involve in the co-design process, and in what role. Is it sufficient to ask a teacher for feedback on a questionnaire because they know an autistic child? Is it sufficient to write an article together with an autistic person? Should everyone be involved at every step? Can a five-year-old be involved in choosing a research question? At its core, the success of co-designing research depends on effectively integrating the diverse needs of "actors" (or stakeholders) and interdisciplinary expertise (Malinverni et al., 2017; Storni, 2015).

Researchers need to identify (sometimes iteratively) who to involve at different stages of the research process, why, for what, and when. If a group, such as autistic children, is clearly most affected by a research project, but it is unclear how to actively, effectively, or meaningfully engage them, this does not mean that co-design is impossible. Rather, researchers should carefully consider whether there are ways (e.g., through caregivers or parents) to facilitate an activity that would meaningfully engage the group, or to consider the best alternatives—who are other actors who might represent the group's wishes and values? (See, for example, Frauenberger et al. 2011; 2012; Zhu et al., 2022) on practical and ethical considerations in co-designing with young autistic children.)

In doing so, the researcher must carefully and accurately address inconsistencies between different stakeholders, as they may not share the same language, goals, knowledge, opinions, or values. Putting them all together to discuss the same phase of the research process is often inappropriate. Researchers should first consider how much weight each stakeholder's contribution should carry, and for which part of the research process this is important or even possible. For example, if an architect is asked whether a light source causes discomfort to autistic children, this could lead the architect to make incorrect assumptions, even though the architect may be the right person to solve a problem involving this light source, but only after the autistic person has had the opportunity to define a desirable goal.

CONCLUSION

If Critical Design gives us the freedom to let go of the status quo and unleash our imaginations, with potential consequences for the structural design of our living environment, then this doesn't seem to be a task that should be solely the responsibility of researchers and designers. Co-design provides clear tools for doing this together, with various members of the autism community, from day one. This allows researchers, practitioners, and other professionals to stop talking about "the other" and instead form a community based on equality, where no one is "granted" anything, but instead, actions are taken to ensure equality.

It's important to note here that this shift in our thinking—from viewing autism as a "disorder," as has long been the case, to viewing it as a form of neurodiversity just as valuable as other forms, including the neurotypical form—has extended to many other areas of clinical psychology, such as ADH(D), but has its roots in the (international) autism community that has rallied around the issue (figuratively speaking) (Spiel et al., 2019). This shift has moved the emphasis from the individual to the proper fit between person and environment (Pellicano & den Houting, 2022). Consequently, it is essential to also shift our way of thinking about how scientific research is conducted in all its different phases, highlighting the importance of researchers being aware of their own norms, values, and unintended biases. Critical design and co-design require a different mindset from us researchers and a conscious investment of time and attention. It gives us the opportunity to conduct research that really matters: research in which we work together with stakeholders, including autistic children and young people, to build further coordination between neurodiverse individuals and their environment, thus contributing to the future in a sustainable way.

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REFERENCES

Bardzell, J. & Bardzell, S. (2013). What is "critical" about critical design? In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13*, 3297. https://doi.org/10.1145/2470654.2466451

Bardzell, S., Bardzell, J., Forlizzi, J., Zimmerman, J., & Antanitis, J. (2012). Critical design and critical theory: the challenge of designing for provocation. *Proceedings. DIS'12* , 288–97. https://doi.org/10.1145/2317956.2318001

Dunne, A. & Raby, F. (2013). Speculative everything: design, fiction, and social dreaming. *The MIT Press,* Cambridge, Massachusetts.

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

Frauenberger, C., Good, J., & Alcorn, A. (2012). Challenges, opportunities and future perspectives in including children with disabilities in the design of interactive technology. In Proceedings of the 11th International Conference on Interaction Design and Children (pp. 367–70). Association for Computing Machinery. https://dl.acm.org/doi/10.1145/2307096.2307171

Frauenberger, C., Good, J., & Keay-Bright, W. (2011). Designing technology for children with special needs: bridging perspectives through participatory design. *CoDesign*, *7*, 1–28. https://doi.org/10.1080/15710882.2011.587013

Jamieson, M.K., Govaart, G.H., & Pownall, M. (2023). Reflexivity in quantitative research: a rationale and beginner's guide. *Social and Personality Psychology Compass*, *17*, e12735. https://doi.org/10.1111/spc3.12735

Li, B., Heyne, D., Scheeren, A., Blijd-Hoogewys, E., & Rieffe, C. (2024). School participation of autistic youths: the influence of youth, family and school factors. *Autism, 28*, 2295-310. https://doi.org/10.1177/13623613231225490

Malinverni, L., Mora-Guiard, J., Padillo, V., Valero, L., Hervás, A., & Pares, N. (2017). An inclusive design approach for developing video games for children with autism spectrum disorder. *Computers in Human Behavior*, *71*, 535–49. https://doi.org/10.1016/j.chb.2016.01.018

Milton, D.E. (2012). On the ontological status of autism: the "double empathy problem." *Disability and Society, 27*, 883–7. https://doi.org/10.1080/09687599.2012.710008

Moreno Madrigal, K. (2020, November). The "wicked problem" of the inequalities faced by people with disabilities. Medium. https://kasmorenomadrigal.medium.com/the-wicked-problem-of-the-inequalities-faced-by-people-with-disabilities-2a9c13523605

Nägele, L. V., Ryöppy, M., & Wilde, D. (2018). PDFi: participatory design fiction with vulnerable users. *Proceedings of the 10th Nordic Conference on Human-Computer Interaction*, 819–31. https://doi.org/10.1145/3240167.3240272

Pellicano, E., den Houting, J. (2022). Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry, 63*(4):381-396. https://doi: 10.1111/jcpp.13534

Rieffe, C. Blijd-Hoogewys, E., Hoogerwerf, J., & Vermeiren, R. (2022). Vrienden als je autisme hebt; Lust of Last? *Wetenschappelijk Tijdschrift Autisme, 21*, 53-62.

Rieffe, C. & Koutamanis, A. (2023). Een autisme-vriendelijke school; architectuur als eerste stap. *Wetenschappelijk Tijdschrift Autisme, 22*, 29-39.

Rieffe, C., Tsou, T. T., Hooi, D., & Delsink, E. (2024). Eenzaamheid en autisme. *Wetenschappelijk Tijdschrift Autisme, 23*, 19-29.

Rieffe, C., Veiga, G., de Vos, M., Mohammadi, M., & Mostafa, M. (2025). Het belang van vrij spelen; hoe nodig je kinderen met autisme uit. *Wetenschappelijk Tijdschrift Autisme, 24*, 31-43.

Spiel, K., Frauenberger, C., Keyes, O., & Fitzpatrick, G. (2019). Agency of autistic children in technology research—a critical Literature review. *ACM Transactions on Computer-Human Interaction*, *26*, 1–40. https://doi.org/10.1145/3344919

Storni, C. (2015). Notes on ant for designers: ontological, methodological and epistemological turn in collaborative design. CoDesign, 11, 166–78. https://doi.org/10.1080/15710882.2015.1081242

Tsou, Y.T., Nasri, M., Li, B., Blijd-Hoogewys, E.M., Baratchi, M., Koutamanis, A., et al. (2025). Social connectedness and loneliness in school for autistic and allistic children. *Autism*, *29*, 87-101. https://doi.org/10.1177/13623613241259932

Zhu, R., Hardy, D., & Myers, T. (2022). Community led co-design of a social networking platform with adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *52*, 38–51. https://doi.org/10.1007/s10803-021-04918-9