Editorial:

Introduction to a new beginning for *Autism Policy & Practice*

When I took my first steps into the world of autism research, I was the typical starter for that time period: the parent of an autistic child, unsatisfied with the pejorative, unhelpful literature available. That was over 25 years ago, when what passed for autism research usually took place in rooms equipped with one-way mirrors. On one side, parents or research assistants interacted with autistic children (it was almost always children), while researchers took notes on the other side. I remember visiting one of the few such facilities in the US in the 1990s, and finding the atmosphere quite cold and clinical. Research agendas were set by non-autistic people with careers to build, and reflected what was most likely to get funding or burnish a CV.

"Cold and clinical" are good descriptive words for the research reports then issued as well. The language focused on deficits and problems (the better to prove how very important your research was) , and the results were rarely useful to, or even read by, parents, support workers or teachers. And no one even asked what autistic people thought about it all.

When human detail did creep into these research reports, it was in the form of case studies, often sensationalistic descriptions that were very much in the style of Bruno Bettelheim. Indeed, Bettelheim's shadow still loomed large over the field, whether as the source whose work had attracted a certain segment of psychologists to the field, or as the "negative role model," as TEACCH's Eric Schopler (who studied under Bettelheim at the University of Chicago) called him. The other "leading light" was O. Ivar Lovaas, the UCLA behaviourist, whose papers repelled me with their dehumanising descriptions of children and mechanistic recommendations.

The poor quality of autism research, its lack of efficacy for helping our loved ones, the poor and often harmful practices underpinned by it, drove many parents into the field. But unfortunately, the desire to be helpful was caught up with a desire to normalise, because only by normalising could parents avoid being blamed—even after Bettelheim's ghost had supposedly been thoroughly exorcised (Waltz, 2015). There is also, I suppose, the understandable parental impetus to "make things better." The question not being asked, of course, was one that only autistic people could answer: what exactly would "better" look like?

Then autism became "hot" on the heels of massive fundraising, again often driven by parents, and research career paths opened up that simply had not been there when I began. Most of the work funded concerned genetics and brain function. People with autism were recruited to take part in research, but often felt used and abused. The values of neurotypical researchers determined how results were interpreted. And although the majority of autistic people are and always were adults, the focus on children remained, leaving autistic adults to deal with issues like work, relationships, sexuality, stigma and discrimination.

Just as before, much of the research published had very little relevance to the lives of autistic people. Some not only did nothing to improve people's lives, it contributed to false narratives of "cure" or dependency, or suggested eugenic solutions.

Autism Policy & Practice exists to address this disconnect between autism research as it all too often is, and autism research as it should be. First, it is an primarily autistic-led journal, responding to community research needs and agendas. Second, as the name of the journal suggests, it focuses on real-world policies and practices, from the world of autism research itself to actions that impact on all aspects of everyday life. Third, the journal welcomes contributions from autistic researchers and allies. And so in this issue, Steven Kapp takes on the pernicious influence of deficit-based diagnostic criteria, Nick Chown looks at the concepts of "autistic traits" and the "broader autism phenotype," the team from Autism@Manchester presents guidelines for working respectfully with autistic research partners, developed in collaboration with autistic research partners. Other articles consider useful research methods and address how staff can and do handle tricky issues around sexuality and consent.

I encourage the growing community of critical autism studies researchers to contribute to *Autism Policy & Practice*, and to robustly debate the issues raised by these authors.

Dr Mitzi Waltz
Editor-in-Chief
7 September 2019

References

Waltz, M. (2015) "Mothers and autism: The evolution of a discourse of blame," *AMA Journal of Ethics*, 17(4): 353-358. doi: 10.1001/journalofethics.2015.17.4.mhst1-1504.