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## "I Knew She'd Get It, and Get Me": Participants' Perspectives of a Participatory Autism Research Project

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### Abstract

**Introduction:** Autistic advocates and their supporters have long argued that conventional research practices provide too few opportunities for genuine engagement with autistic people, contributing to social disenfranchisement among autistic people. We recently described one attempt to develop and implement a participatory study in which a team of autistic and nonautistic researchers worked together to gather life histories from late-diagnosed autistic people. In the current study, we sought to understand the impact of this participatory approach on the participants themselves.

**Methods:** We spoke to 25 Australian late-diagnosed autistic adults (aged 45–72 years), who had been interviewed by an autistic researcher using an oral history approach. We asked them about their experience of being involved in that project and the research process more broadly. We thematically analyzed participants' interviews.

**Results:** Participants responded overwhelmingly positively to the opportunity to tell their life history, considering it illuminating and empowering. While recounting their life history was often described as "exhausting" and "draining," participants also reported feeling "supported all the way" and agreed "it was made easier because I had an autistic researcher interviewing me." One participant went so far as to say that they "probably would have dropped out [of the project] if it was run by people who weren't autistic."

**Conclusions:** These findings demonstrate that the benefits of coproduction to researchers and community partners extend to study participants and to the quality of the research itself. Involving autistic partners in the research process, especially in its implementation, can play a crucial role in enhancing autism research.

**Keywords:** coproduction, community involvement, research impact

### Community Brief

#### *Why is this an important issue?*

Autistic people are often left out of decisions that affect them, including in research. We wanted to change that. We, a group of autistic and nonautistic researchers, worked together to come up with a research project. In that project, we wanted to know more about autistic people who were diagnosed late in their lives.

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**What was the purpose of this study?**

We wanted to know about their experiences of taking part in the research. We also wanted to understand what it was like for our study participants to tell their life story to another autistic person.

**What did we do?**

We spoke to 25 autistic people about their experiences of telling their life history. We asked questions like, “Can you tell me a bit about why you wanted to share your life history?” and “What was your overall experience of taking part in this research project?” We interviewed participants for about 25 minutes.

**What were the results of the study?**

We found that participants felt good about taking part in this project. They felt supported and were pleased that the project was being run by autistic people. They also told us that telling their story was often painful. However, it was made easier because they had an autistic researcher interviewing them. They also felt that they could share more with this person than with someone who was not an autistic person.

**What do these findings add to what was already known?**

This study shows that research that is done together by autistic and nonautistic researchers has a positive effect on participants.

**What are the potential weaknesses in the study?**

Most of our participants were well educated, White, and were in some form of work. We do not know if participants' positive experiences would also happen with other autistic people, including those from different cultural groups. This study was also unusual because it allowed participants to tell their own stories in their own way. That might have made participants more positive about it.

**How will these findings help autistic adults now or in the future?**

These findings show how important it is to include autistic people in research. It makes a real difference to the participants and to the quality of the research.

## Introduction

RESEARCHERS, FUNDING ORGANIZATIONS, and the broader public are increasingly aware of the significant disconnect between the health-related research that gets done and the impact that it has on people's everyday lives. This disconnect is especially true in the field of autism. In the last two decades, international investment in autism science has grown extensively<sup>1–3</sup> and the number of articles published on autism has increased 10-fold.<sup>4</sup> Yet, recent research demonstrates that across the world autistic people, their families, educators, and clinicians feel that autism science generally fails to describe the nature of autistic life experiences.<sup>5</sup> They also feel it fails to make a significant contribution to autistic people's quality of life or to the range of opportunities open to them, which often appear to remain extremely constrained.<sup>6</sup>

One potential way to address this concern, and thus increase the value of research,<sup>7</sup> is by ensuring that autistic people and their allies are directly engaged in the research process, as full partners.<sup>8–10</sup> Community-based participatory, codesigned, and coproduced research, where decision-making power is shared between researchers and community members,<sup>11</sup> has a long history outside autism research—most notably with regard to HIV<sup>12,13</sup> and First Nations communities.<sup>14</sup> It is currently having widespread effects on other scientific areas, including agricultural and environmental science.<sup>15</sup>

There appear to be clear substantive *scientific* reasons for involving autistic people in the design and conduct of the research. Put simply, we might get more effective autism science if we actively involve community members who can direct attention to aspects of autistic experience that are routinely missed without such input.<sup>16–18</sup> There are also clear *ethical* reasons for autistic involvement in research. Marginalized communities, including the autistic community, are often not involved in making decisions that affect them, and feel disenfranchised as a result.<sup>19,20</sup> Thus, and consistent with the disability rights mantra, “nothing about us, without us,” autistic people should be able to contribute to research that could in some way affect their lives.<sup>21</sup> Yet, genuine (nontokenistic) power-sharing research collaborations between nonautistic researchers and autistic partners remain rare,<sup>22</sup> despite repeated calls from autistic advocates for increased community involvement in research,<sup>23–25</sup> and some compelling efforts to engage.<sup>9,26</sup>

One way to encourage researchers to adopt participatory research methods is to demonstrate the impact of such research—on the research itself and on the researchers and community partners involved. Systematic reviews outside the field of autism have repeatedly demonstrated that participatory research yields mutual benefits for researchers and community partners.<sup>27–29</sup> They report the valuable contribution of community partners to the research process, including on setting the research agenda, study recruitment and retention rates, research design and

measurement selection, and on securing funding. They also describe the impact on community partners, including gains in confidence, leadership and research-related skills, and greater trust in research. Such research also can be challenging, however. It can have an impact on time, resources, and funding.<sup>27,30</sup> It also has the potential to place community partners at risk when it is poorly executed or tokenistic,<sup>21</sup> for example, by involving community partners in the research process, but not listening to, or acting on, their input. These impacts—both positive and negative—have been echoed in the few studies and commentaries exploring researcher and autistic partners' experiences of being involved in participatory autism research.<sup>31–34</sup>

Despite all these benefits, there is a paucity of work directly examining the impact of participatory research on study participants themselves, that is, those participating in, rather than making decisions about, the research. One such study in the field of nursing examined the perspectives of low-income women who had participated in a community-based participatory research study designed to test the efficacy of a health-screening tool. The women reported that they were highly motivated to participate in a focus group because the research centered on an unmet health need; that they had the opportunity to speak to, and help, other women in similar situations; and they had their voices heard.<sup>35</sup> Other studies have examined the impact of “peer interviewers.” For example, Bengtsson-Tops and Svensson<sup>36</sup> elicited the views of mental health service users about being interviewed by another service user. Participants described how feelings of solidarity and mutual understanding created a relaxed interview atmosphere in which they felt able to share deeply personal experiences (see also Jørgensen et al.<sup>37</sup>). Despite this sense of empowerment, these same participants also sometimes questioned the interviewers’ competence, especially when interviewers “took over” the interview or offered too much personal information of their own, which disrupted the “commission of trust” of the interview situation.<sup>34</sup>

To our knowledge, no study has examined study participants’ experiences of taking part in participatory autism research. Here, we addressed this issue within the context of the Hidden Histories project.<sup>38,39</sup> In this project, autistic and nonautistic researchers worked together to gather the untold histories of Australian adults diagnosed with autism late in life, using an oral history approach. All autistic partners, including Autistic Advisory Group members, actively participated in making decisions throughout the research process. This involvement included two late-diagnosed autistic researchers, who corresponded with participants and guided them through the process, including conducting at least two initial interviews plus the main oral history interview.

The Hidden Histories participants also took part in a fourth, and final, follow-up interview to share their reflections on taking part in the project. Here, we analyze these data, specifically to understand (1) participants’ experiences of the research process and (2) the perceived impact of participating in an intentionally participatory study.

## Method

### Participants

The majority ( $n=25$ ; 89%) of the Hidden Histories participants agreed to participate in an additional interview. They ranged in age from 45 to 72 years ( $M=52.2$  years,

$SD=6.0$ ) and had received their autism ( $n=20$ ) or Asperger’s ( $n=5$ ) diagnosis, on average, at the age of 48 years ( $SD=5.9$ ; range =40–62). Fifteen people identified as female (60%), eight as male (32%) and one as nonbinary (4%) (one preferred not to say). They came from diverse parts of Australia, with most ( $n=16$ ; 64%) living in cities and the remainder living in inner regional ( $n=8$ ; 32%) or remote ( $n=1$ ; 4%) communities. All reported being of White European ethnic background and one person also identified as Aboriginal. Most were highly educated, with 21 participants (84%) having at least an undergraduate degree. Nineteen (76%) were also employed at the time of participation.

### Procedure

Ethical approval for the study was obtained from Macquarie University’s Human Research Ethics Committee (Ref. no: 52019556310562). All interviewees provided written informed consent before participation. Throughout both the recruitment and research phases, the codesigned nature of the project was repeatedly noted in written and oral communications with participants (see supplementary materials in Pellicano et al.<sup>38</sup>).

Participating in the broader Hidden Histories project involved four separate sessions (see Pellicano et al.<sup>38</sup> for full details). In Session 1 (~60 minutes), participants met with the interviewer to establish rapport, provide informed consent to take part in the study, and discuss their involvement and the main interview questions. In Session 2 (~1–3 hours), participants met with the interviewer once again for the main, digitally recorded oral history interview. Approximately one month later, the participant took part in Session 3 (~30 minutes), during which they reviewed their Session 2 interview transcript and reconsented for their materials to be included in the study. These first three sessions were conducted by researchers who are themselves late-diagnosed autistic people (G.H., J.M.).

Our procedures followed Cascio et al.’s<sup>40</sup> best-practice guidance for conducting research that follows a person-oriented ethical approach. Specifically, we:

1. tailored the research process to fit the unique needs of each person by encouraging them to tell their life history in their own way, and to communicate in their preferred medium and idiom;
2. acknowledged the complexities of their “lived world” by highlighting the potential toll of telling one’s life history and encouraging them to identify a key person who could help support them outside the confines of the research (for more details, see Pellicano et al.<sup>38</sup>);
3. sought to maximize participants’ decision-making abilities throughout the research process by repeatedly taking them through, step-by-step, what the study involved, inviting them to review their interview transcript and make any changes that they wished, and asking them to reconsent for the use of their interview materials after such review;
4. demonstrated “respect for holistic personhood” by ensuring that the team and our Autistic Advisory Group (see Community Involvement section below) proactively considered and respected our participants’ preferences, needs, and priorities during the research. Central to this was the one-to-one contact between the

- participant and interviewer that helped to create a sense of familiarity and relationship that encouraged predictability, clarity, and trust; and
5. sought to address the power differentials between “the researchers” and “the researched” by having participants interviewed by another, late-diagnosed autistic person.

Finally—and the focus of the current study—we invited participants to take part in Session 4 (~20 minutes), during which they reflected on the experience of telling their life history, and on the research process itself. Participants were asked the following set of primary questions: “Can you tell me a bit about why you wanted to share your life history?” “Tell me about the main (life history) interview you did. What was it like to tell your life history?” “What was your overall experience of taking part in this research project? How does it compare with other research projects you’ve been involved in?” Additional prompt questions were used to elicit further details, if necessary. To avoid social desirability effects, where interviewees tend to answer in a way that praises the interviewer because they believe that is the socially appropriate response, a different, senior researcher (E.P., W.L.) conducted these Session 4 interviews, all via Zoom. Interviews ranged from 15 to 75 minutes (Median=22.6).

#### Data analysis

We recorded all interviews for later transcription with participants’ prior permission. We followed Braun and Clarke’s<sup>41,42</sup> method for reflexive thematic analysis, using an inductive (bottom-up) approach (i.e., without integrating the themes within any preexisting coding schemes or preconceptions of the researchers) to identify patterned meanings within the data set. Our epistemological stance fits within an essentialist framework, in which we report the experiences, meanings, and reality of the participants. Our analytic approach was informed by our training in education and psychology (E.P., W.L.), anthropology (R.L.), nursing (G.H.), history (J.M., M.Y.), and public health (M.Y.), as well as positionalities as autistic researchers and advocates (W.L., G.H., and J.M.). E.P. read and reread the transcripts, dis-

cussing potential codes with W.L., before applying codes to all transcripts. E.P. then generated a draft thematic map, before sending it to the analysis team (G.H., R.L., W.L., J.M., and E.P.) for comment and discussion. Members of this team liaised several times to review the themes and subthemes, focusing on semantic features of the data (staying close to participants’ language), resolving discrepancies, and deciding on the final descriptions of themes and subthemes. Analysis was therefore iterative and reflexive, moving backward and forward between data and analysis.

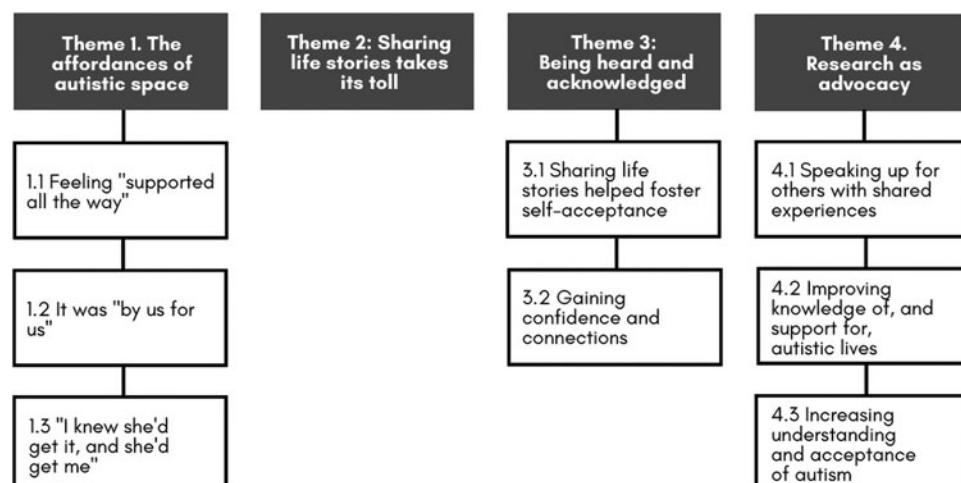
#### Community involvement

The study involved autistic scholars and advocates at every stage of the research process. The research team included three late-diagnosed autistic researchers (W.L., G.H., J.M.) who were actively involved from the beginning of the project (W.L. was a coinvestigator on the grant application), resulting in collaborative decisions that improved the relevance, clarity, and accessibility of materials, and the nature and content of the oral history interview itself. Each of our participants was interviewed by one of our paid autistic researchers (G.H., J.M.), who had received oral history interview methods’ training and supported by weekly team meetings. These weekly meetings continued as the team (R.L., W.L., G.H., J.M., and E.P.) began to analyze the data, during which team members read and reflected upon each transcript and thoroughly discussed potential codes and themes.

The project also had input and oversight from an Autistic Advisory Group comprising three autistic adults, including M.H. and H.C., who were reimbursed for their time and expertise. The Group provided detailed feedback on the participant information materials (including inclusion criteria) and data collection methods, which resulted in significant changes to all the study information documents.

#### Results

We identified four themes (Fig. 1). Below, themes are highlighted in bold and subthemes are italicized. Throughout, quotes are attributed via participant ID numbers. Readers are advised that some of this material may evoke difficult past associations.



**FIG. 1.** Participants’ experiences of taking part in a participatory, oral history study: themes and subthemes.

### *Theme 1: The affordances of autistic space\**

Overall, when participants were asked how they felt as a result of engaging in the research—from responding to the call for participants, to completing the paperwork, to being given various methods of contributing their life histories, to having their physical and emotional needs considered (breaks, interview times, support and self-care discussions, and documentation) throughout the project—they responded overwhelmingly positively. In fact, they reported feeling “supported all the way” [HH015] (subtheme 1.1) to tell their stories. They described how “it was always relaxed and very open and well communicated about what was going on and what the process was” [HH028]. They also felt that “there was lots of choice—if I needed to do it a different way, I could have” [HH023] and that they “loved all the detail… because I then knew what to do… and I felt very comfortable because I could see the things that I would be thinking about putting in there, were in there. And that made me feel much more comfortable about participating” [HH031]. Others felt “pretty reassured right from the start that everything was being done to make them feel comfortable and respect their privacy and their wishes and all that sort of thing” [HH005].

One key reason why participants felt so comfortable was because the research “was ‘by us for us’” [HH036] (subtheme 1.2). They described previous, negative experiences of research in which “sometimes we are treated like lab rats. Yesterday was a lab rat experience, whereas today it was a genuine interest in hearing my story” [HH006]. They felt that a participatory approach “ticked all the boxes” [HH032], because, usually, “we aren’t included in stuff” [HH010]. It instilled a sense of trust in the research that it would reflect autistic experience rather than the experiences of “people who aren’t autistic—neurotypical people, who have their interpretation of what it’s like to be autistic… sometimes, it’s just so far from reality it’s bizarre” [HH005]. They also felt that the research aims were consistent with their own values: “I really don’t want to get involved in things where I feel like it’s too clinically based, and people wanting to fix us. I don’t like that argument at all. Because it was a co-produced one, I was happy to participate” [HH031]. Some participants felt that the participatory nature of the research was essential to their participation. One went so far as to say that they “probably would have dropped out [of the project] if it was run by people who weren’t autistic” [HH033].

Participants further agreed that telling their stories “was made easier because I had an autistic researcher interviewing me” [HH022]. They reported feeling that the interviewer was “very, very non-judgmental and just extremely empathetic” [HH021], which meant that “it was stuff that I didn’t have to explain, she just understood” [HH018]. As a result, they felt “respected and included,” [HH032]: “I knew she’d get it, and get me” [HH005] (subtheme 1.3). One participant explained that “we feed off the interviewer having that empathy… it doesn’t have to be two people on the spectrum, but they have to be on the same wavelength” [HH006]. Another participant felt that the connection was only possible with an autistic interviewer:

The real understanding of how it feels on all levels, physically, emotionally, psychologically, I think can sadly only really be fully appreciated by another autistic person. Unless you’ve actually lived through it, it can be hard to comprehend the impact that it has on your whole being. It was wonderful to speak to somebody who completely gets that. [HH016]

The connection they felt with the interviewer and the efforts that the interviewers made to ensure that “all my physical and emotional needs were catered for” [HH036] made participants feel “relaxed” [HH014] and allowed them to “drop the filters a bit more… [to] drop the mask” [HH009]. Ultimately, this made them feel safe: “Bloody wonderful to be interviewed by Joanne. I have no objection to being interviewed by anyone that’s not autistic. But just knowing that they were set another level of safety within it. If I’m going to offer something, I’ve got to feel safe about it” [HH021]. One person described his experience of “feeling heard”:

I guess having for so long been called a freak, a spastic, a retard, and all of those things, especially through high school, knowing that there was someone there that was asking really difficult questions and exploring and probing to some extent, that there was going to be a sense of… where some people might just go, “yes, whatever, get over it. Hard nut, mate.” Where someone who’s actually had that lived experience would go, “yes, I get what you’re saying.” And it’s a certain smile or a certain nod, or yes, that just provides comfort. It allows you to keep going. Because it wasn’t easy. It’s not easy. [HH010]

Such was the level of connection between the researchers and the participants, that only one participant said that it made no difference to them whether the researcher was an autistic person. This same participant also felt their needs were overcatered for but that they also understood that the protocol required checking-in, and that while other autistic people might not be able to notice or access their own needs, this was not the case for them.

### *Theme 2: Sharing life stories takes its toll*

Despite the reassurance of being in an autistic space in which they felt “valued and can contribute” [HH002], participants reported that it was still daunting to share their stories. They found it “exhausting” [HH022], “incredibly draining” [HH016], “physically and emotionally tiring” [HH019], and “pretty intense” [HH011]. They also described it as “healing” [HH002] and “also a bit cathartic” [HH031]. They explained that the interview “does make you more aware of what you’ve been through” [HH031], and that, for some, it had “brought back a lot of stuff that I’d shut out or suppressed… a lot of stuff I’d forgotten about” [HH009]. They reported how the full effects were often felt a day or two after the interview itself, when people “slept for most of the next day” [HH005]: “I kind of wasn’t able to wind down until the next day and then, when I did, I really crashed for a while. But I was all right after that” [HH032]. Some “didn’t have any illusions about how draining it would be” [HH018], while others “didn’t make the initial connection as to why I felt so drained because I was very calm when speaking with Gabby” [HH015]. Others still were convinced that they would “be fine… but I actually really did feel quite different. And it was really nice that Gabby had forewarned me, because then when it did hit me a few days later, I was like, this is what she must have been talking about” [HH033].

\*Spaces created by, with, and for autistic people.

Some chose not to review their transcripts because revisiting the content was perceived to be “quite confronting” [HH006]. Some reported that they were “pretty drained when I read the transcript” [HH005]. Some said that “it was like reading a story about someone else” [HH034]: “I don’t know how I can describe it, they’re just facts and that’s me, you know. It’s a weird feeling” [HH021]. One person described how it took him some time to have the confidence to open the transcript: “when I finally did, it was quite confronting, because, if you have a conversation with someone, normally you don’t have the opportunity to go back and listen to it again” [HH006].

#### *Theme 3: Being heard and acknowledged*

Participants also reported that it was, nonetheless, worth this emotional and physical cost because of the broader impact that sharing their stories had on their sense of agency and well-being. They felt that *sharing their life stories helped to foster self-acceptance* (subtheme 3.1). Identifying as an autistic was a “fairly new” [HH005] experience for many, even though they appreciated that they had “been autistic all along” [HH014]. They reported that “digging a little bit deeper into my past” [HH014] and “going through the process of a structured reflection on my life” [HH005] gave them “a few more things to think about” [HH021], including things they had not yet processed, and “helped to put everything into perspective... it’s almost been like a coming out” [HH006]. Talking about their lives in this way and having someone who “was actually interested in hearing just ordinary people’s stories” [HH023] was perceived to be affirming: “I don’t think I’d ever been asked to explain myself and to actually be heard... having someone want to know my story and have that validated was actually helpful” [HH033]. In particular, they felt that being able to share their life stories with someone who is also autistic, “to acknowledge what I’ve been through” [HH016] helped with the process of acceptance, including “acceptance of things that I look back on with regret” [HH006]. As one person explained:

The more you can talk about it to people who understand, who aren’t almost questioning whether it’s valid, or aren’t we all a little bit autistic? The more I can talk about it to people who get it, the more my own acceptance is solidified. [HH005]

Participants also reported that the experience of being interviewed helped them to *gain confidence and connections* (subtheme 3.2). As one person described, “it was really nice after that interview, because I felt like it was all a bit negative about all the things that were hard. But I actually think it’s amazing to be an autistic person. I’m so proud and excited to own that” [HH033]. Others, too, reported being “excited to be part of this community” [HH007], with some feeling that the interview process had “highlighted that I need to make more friends that are in this community, and find my tribe” [HH006]. Some felt that the process was empowering:

I think I’d been so affected by the bullying and it just took me a long time to get over that... I just haven’t been able to talk about it, haven’t been able to think about it. I’ve just been an absolute wreck. This time, I was able to talk about it and I went away, and I thought actually, I think I’m also ready to do something about it... After I did the interview, I thought, no, I actually can do something. I can stand up and say something about these people. [HH023]

The apparent gains in participants’ confidence often seemed in stark contrast with their reported self-perceptions of “always feeling different” [HH034], “being ashamed of who I was for a long, long time” [HH021], and feeling “there was something wrong with me” [HH018]. As one participant described, “for 40 years, I felt bad and different but not able to put that into words” [HH007].

#### *Theme 4: Research as advocacy*

The advantages of sharing stories went beyond the personal to encompass a sense of collective advocacy and agency. As one participant described, “it was a key moment for me to stand up, actually, and be counted for a change” [HH033]. They were well aware that they belonged to an underserved—or, in the words of one participant, “forgotten” [HH021]—group of autistic people. One person commented, “it was crazy that the research community had not thought to actually latch on to people in my generation, to actually find out more about us, about how in the hell we have managed to survive and cope, some of us to a reasonable level.” They went on to explain, “that’s why I wanted to do it, it’s something that had been on my mind for quite a while. And every year that’s gone past, I thought, well it’s one year closer to us not existing” [HH018]. For this reason, our participants felt it was important for them to *speak up for others with shared experiences* (subtheme 4.1). They described wanting to share their life stories as “a way of helping other people” [HH015], so that “others can resonate with my story” [HH036]. Some felt that it was their “responsibility” [HH010]. One person described how sad she felt because “there was so much more that I could have done in my life. And that’s why I needed to do this [the interview] so badly for my own children, and for anybody else who is doubting whether it’s ok to talk about being autistic” [HH016].

One reason why participants gave “you guys the keys to our hearts” [HH010] was because they reported wanting the “differences between children and adults to be seen” [HH017]: “we’re very different—we haven’t had the level of support that many other people have had, particularly the younger generation now, who get a lot of support” [HH031]. People were aware, having been so recently diagnosed themselves, that “there was so little information for people my age, there just seems to be not very much support or resources” [HH005]. They hoped that their participation could help *improve knowledge of, and support for, autistic lives* (subtheme 4.2). They wanted to “contribute to the knowledge base around autistic adults, particularly those diagnosed later in life” [HH034], to help them gain access to better support after diagnosis, and “to create a path for others to walk to get where they need to be without falling through the gaps” [HH002].

Participants also wanted to share their stories to *increase understanding and acceptance of autism* (subtheme 4.3) in society more broadly. They felt that it was “important that our stories are recorded and told so others can understand” [HH008], to “help demonstrate better ways to relate, communicate and treat autistics” [HH002]. People spoke of wanting, in particular, to “get the understanding a bit more out there in the wider NT [neurotypical] community... to expand people’s awareness, both people on the spectrum and not on the spectrum” [HH009]. They wanted to see broader recognition of their identity, their strengths, and their struggles:

We've been among the community. Everyone says, "oh, you're not autistic, you can't possibly be autistic." Why? Because I'm holding down a job, I don't make them uncomfortable, mostly, during social interactions with them. I have a family, I've been married for 37 years. Surely, I can't possibly be autistic. But I am. It's the difficulty of conveying that. Having a study that actually opens that up is a really positive thing. [HH014]

## Discussion

This study sought to gather and understand participants' reflections on taking part in a study that was coproduced by autistic and nonautistic researchers. Despite recounting how difficult it was to share their frequently troubling life histories,<sup>39</sup> our participants were overwhelmingly positive about taking part in our study. In fact, our analysis shows that it was more than just a positive experience; participants considered it illuminating, worthwhile, and empowering.

There are several reasons for these encouraging findings. First, like the few previous studies examining the impact of a participatory approach on study participants,<sup>33</sup> our participants reported that they wanted to be involved in this study specifically because it focused on an underresearched group, namely older autistic adults. Historically, autism research has focused predominantly on understanding autism in childhood.<sup>5,43</sup> Little is known about autistic adults' lives, especially those who have grown up with a misdiagnosis or no diagnosis at all, just as our participants had done.<sup>44</sup> One purported benefit of participatory research is that research and its findings should be more meaningful, including being more relevant to the community and more consistent with their values.<sup>45,46</sup> Our findings support this claim. Our participants reported feeling included in research specifically about them, which they also felt would enhance the knowledge of, and support for, older autistic people. They were further encouraged that the research did not appear to be primarily situated within the dominant medical model, which they find deficit focused<sup>23</sup> and which is also perceived to be dehumanizing.<sup>19,20</sup>

Second, being late-diagnosed autistic people themselves, our autistic team members were aware that the process of telling one's life history was likely to be challenging, potentially reminding participants of difficult times including instances of autistic burnout<sup>47,48</sup> or masking.<sup>49</sup> The research team therefore developed and implemented processes that were respectful and that attended to our participants' welfare and well-being both during the interviews and throughout the follow-up stages, including by being aware of whether participants wished, or wished not, to read their interview transcripts at a later stage. These adjustments were fundamentally relational in nature, aligning with what Cascio and Racine<sup>50</sup> have termed "person-oriented ethics," as described earlier (see also Cascio et al.<sup>40</sup>, Ashworth et al.,<sup>51</sup> and AASET<sup>52</sup>). Participants reported feeling the positive effects of this attention to everyday, relational aspects of the research, saying they felt "catered for" and "safe." Such attention should not be limited to research adopting participatory approaches, of course. That said, the involvement of our autistic team members' experiential expertise both of being autistic people and of spending a significant portion of their adulthood not knowing they were autistic people—just like our participants—meant that addressing these person-oriented issues was an intrinsic and important part of our study.

Third, being interviewed by a late-diagnosed autistic researcher offered our participants more than just a comfortable space within which to relay their life history. It also engendered empathetic interactions, in which participants felt that they could be themselves during the research process rather than having to adopt a role or perform a task. As a result, they felt listened to and understood.<sup>36,53</sup> The positive effects of this "meeting of (autistic) minds" accords with Milton's<sup>54</sup> double-empathy problem. Milton suggests that those with similar experiences, such as being late-diagnosed autistic people, can create connections and mutual understanding more easily than those without similar experiences. Emerging empirical research has demonstrated that, akin to our participants' experiences, autistic/autistic interactions are more likely to generate a greater rapport and more effective communication than autistic/nonautistic interactions,<sup>55</sup> and also may be beneficial for autistic people's mental health and well-being.<sup>56</sup>

We suggest that "insider researchers"<sup>57</sup> (in this case, autistic researchers) are critical to enhancing the quality of research due to their unique *epistemic privilege*. That is, insider researchers are able to tap into a particular worldview and kind of knowledge—experiential expertise—that outsider (in this case, nonautistic) researchers are unable to access.<sup>57,58</sup> Our participants informed us that their open and authentic interactions with our autistic researchers meant they were more forthcoming than they might have been with a nonautistic interviewer, or at least a researcher who was not on their "wavelength"—thus providing access to insights that they may not have shared otherwise.

This does not necessarily mean that autistic researchers possess a unique access to the "true" perceptions and experiences of autistic people or that this is the only meaningful way to conduct research into autistic experience. The other particular characteristics of the interviewer, such as age, gender, and racial/ethnic background, may also impact the extent of the "shared empathy" between the interviewer and interviewee.<sup>59,60</sup> We also do not suggest that only autistic people should conduct qualitative interviews with other autistic people. Instead, we note that, as Milton<sup>61</sup> cautions us, in interactions between autistic and nonautistic people, some level of understanding can be "lost in translation" (p. 799).

This research, therefore, reminds us of how important it is to continue to bridge the epistemological divide.<sup>62</sup> Doing so entails developing a deeper appreciation for autistic people's distinctive expertise,<sup>10,61</sup> and becoming adept at combining different forms of expertise and different ways of knowing. Fostering such "epistemic fluency"<sup>63</sup> is critical for understanding complex real-world issues, which call for diverse collaborations and the combination of complementary forms of knowledge, views, and values, and approaches and levels of analysis (see Frith<sup>64</sup>). Creating greater opportunities for participatory research where autistic adults play a full role in the design and execution of the research is one crucial means to facilitate this process.

## Limitations

There are several limitations to this study. First, our main oral history study reflects the experiences of a specific group: late-diagnosed autistic adults. One important consideration is

whether and how their experiences shaped their reaction to, and feelings about, this type of participatory research. Second, our participants were predominantly of a White ethnic background, were more likely to identify as female, and more than three-quarters of the sample were currently employed. Both of these potential selection and recruitment biases make it unclear whether our participants' positive sentiments about participatory research will be applicable to other autistic adults, especially those from other cultural groups and those who were identified as autistic people in childhood. Third, oral histories allow for a multitude of points of view and give "voice" to individuals and groups who have been marginalized in conventional histories, by allowing them to tell their own stories in their own way.<sup>65</sup> It is therefore possible that the particularly positive effects of telling their stories and especially of telling them to other autistic people are due, at least in part, to the nature of the study itself.<sup>30,46</sup> Future research will need to determine whether study participants' sense of empowerment, as reported here, generalizes to other types of autism research adopting participatory approaches. Similarly, and finally, this study was dependent on the particular collaborative relationships between the autistic and non-autistic researchers comprising the overall research team, which enabled potentially contrasting perspectives on the interviews to be shared easily and effectively. Replicating these relationships and maintaining a breadth of perspectives in future studies could be difficult to achieve.

## Conclusion

Our study reveals the vital importance of deep and sustained efforts at genuine coproduction in autism research; coproduction that includes participation by autistic researchers in the design, conduct, and analysis of the research. Such work is often more time-intensive than more conventional forms of autism research and requires committed and skilled management and support throughout.<sup>9,66</sup> Here, we show that the benefits of coproduction to researchers and community partners extend to study participants and to the quality of the research itself. These findings demonstrate that involving autistic partners in the research process can play a crucial role in enhancing autism research.

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## Authorship Confirmation Statement

E.P., W.L., M.Y., and R.L. secured funding for the project. E.P., H.C., G.H., M.H., W.L., J.M., R.L., and M.Y. devised and piloted the interview content and procedures. E.P., W.L., G.H., and J.M. recruited the participants. E.P. and W.L. conducted the Session 4 interviews with participants. E.P., G.H., W.L., J.M., R.L., and M.Y. analyzed the data. E.P. drafted the article. All authors commented on and edited the article prior to submission.

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No competing financial interests exist.

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