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Hidden Histories of Late-Diagnosed Autistic Adults

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The project

- Receiving a diagnosis of autism in adulthood is increasingly common for some people, who were either misdiagnosed in childhood or missed out on a diagnosis altogether.
- This qualitative study invited late-diagnosed autistic adults to share their life histories to:
  a) understand better the consequences of living without a diagnosis;
  b) elucidate what precipitates an autism diagnosis in mid-to-late adulthood; and
  c) identify the perceived impact of receiving that diagnosis.

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Two overarching approaches

This study adopted:

1. **A participatory approach.** Specifically, it was a collaboration between non-autistic academic partners, autistic co-researchers, and an Autistic Advisory Group, who all actively participated in making decisions about the research, and ensured that the methods were thorough, respectful and supportive of our autistic participants.
2. **An oral history approach.** The aim of oral histories is to record recollections of people and groups to preserve their voices and stories, and situate them within a particular time and place in history.

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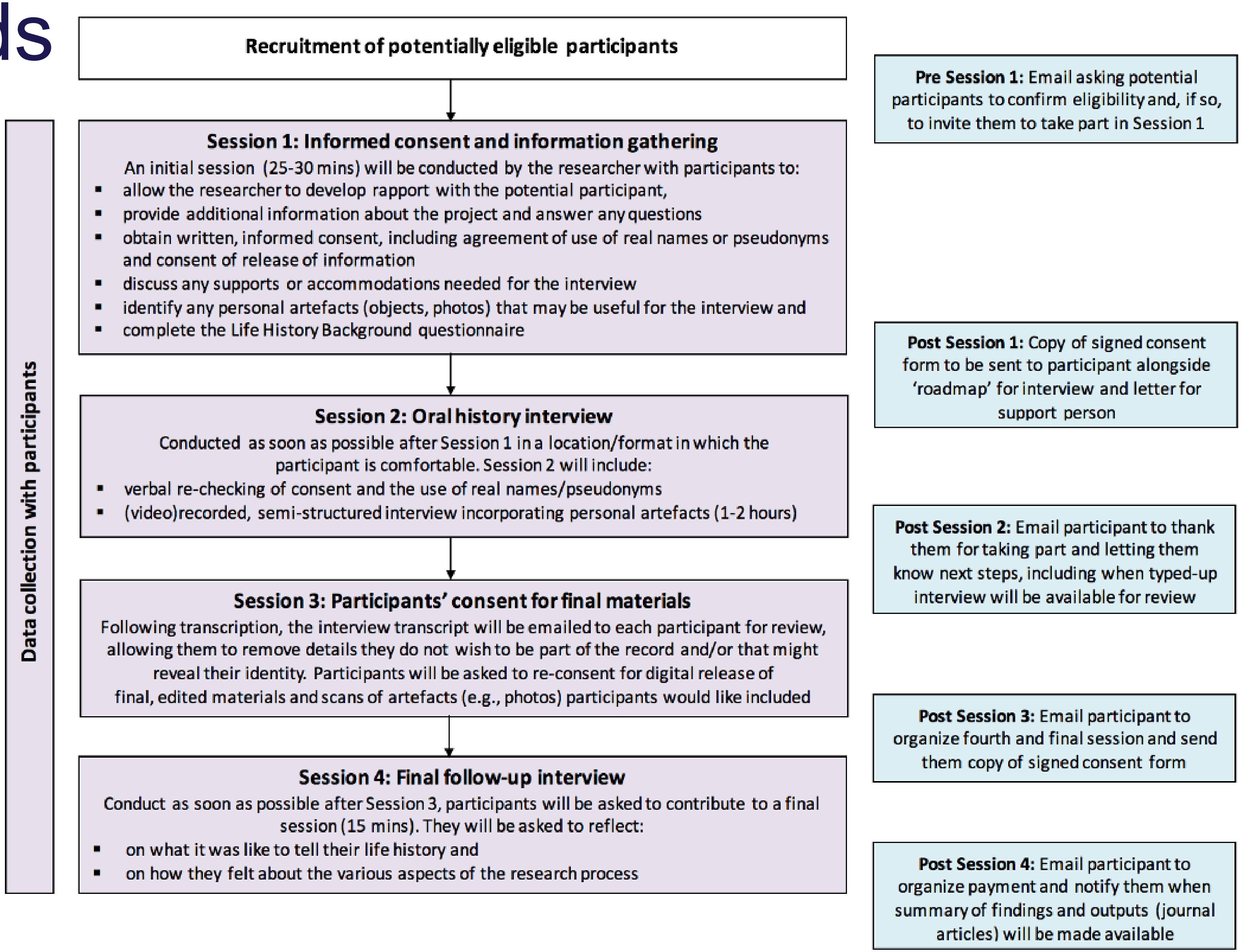
Our methods



Recruitment of potentially eligible participants

Data collection with participants

Pre Session 1: Email asking potential participants to confirm eligibility and, if so, to invite them to take part in Session 1

Session 1: Informed consent and information gathering

An initial session (25-30 mins) will be conducted by the researcher with participants to:

- allow the researcher to develop rapport with the potential participant,
- provide additional information about the project and answer any questions
- obtain written, informed consent, including agreement of use of real names or pseudonyms and consent of release of information
- discuss any supports or accommodations needed for the interview
- identify any personal artefacts (objects, photos) that may be useful for the interview and
- complete the Life History Background questionnaire

Post Session 1: Copy of signed consent form to be sent to participant alongside 'roadmap' for interview and letter for support person

Session 2: Oral history interview

Conducted as soon as possible after Session 1 in a location/format in which the participant is comfortable. Session 2 will include:

- verbal re-checking of consent and the use of real names/pseudonyms
- (video)recorded, semi-structured interview incorporating personal artefacts (1-2 hours)

Post Session 2: Email participant to thank them for taking part and letting them know next steps, including when typed-up interview will be available for review

Session 3: Participants' consent for final materials

Following transcription, the interview transcript will be emailed to each participant for review, allowing them to remove details they do not wish to be part of the record and/or that might reveal their identity. Participants will be asked to re-consent for digital release of final, edited materials and scans of artefacts (e.g., photos) participants would like included

Post Session 3: Email participant to organize fourth and final session and send them copy of signed consent form

Session 4: Final follow-up interview

Conduct as soon as possible after Session 3, participants will be asked to contribute to a final session (15 mins). They will be asked to reflect:

- on what it was like to tell their life history and
- on how they felt about the various aspects of the research process

Post Session 4: Email participant to organize payment and notify them when summary of findings and outputs (journal articles) will be made available

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Our results

… are still being analysed!

BUT the team recruited and interviewed:

- 28 late-diagnosed autistic adults (women: n=15; men: n=12; non-binary: n=1) from all around Australia
- M age = 54 years, range = 45 – 72 years

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Researchers' reflections: Methods

- Wenn's take on being a member of a team involved with co-production of a project exploring the hidden histories of late diagnosed autistic adults
- From the beginning, as we met for discussion over participant qualification through to means for locating participants to ensuring accessibility: we were all in this together. We are from varied walks of life (history buffs, autistics, researchers, professors, novice researchers & so on). Inclusion was/is at the heart of all we are doing
- We all appreciate how important the project is and are equally committed to making it a success

Researchers' reflections: Methods

- Our project aim was to sample adult experiences of a late autism identification pre- & post assessment.
- We chose 1975 as our cut off date of birth for participants because this meant they would have grown up at a time when autism was virtually unknown to clinicians and educators.
- It also meant the public awareness of autism was under-developed, but the expectation on adults (educationally/domestically) was above that of earlier times and below that of later times. We anticipated this would impact quality of life for our participants.

Researchers’ reflections: Connection

- This even meant attending a workshop in Sydney to learn how to use typical equipment (cameras, tri-pods, recorders) for recording oral history.
- Lots of ZOOM meetings to set things up and discussion over Ethics, who would do what etc.
- A weekly ZOOM meeting eventuated as a means of sharing relevant (to our study) article’s for discussion but also as a means for both debriefing and checking in on how we were all progressing. This meeting was between our two research assistants, myself and Liz.

Some participant reflections on the process

- Reasons for choosing to take part:
  - “I just hoped to be able to add to that resource, that knowledge-base of older autistic people and especially just support people that are just newly finding out for themselves”
  - “Just to get the understanding a bit more out there in the wider NT community … I thought this was another way of potentially trying to expand people's awareness, both people on the spectrum and not on the spectrum”
  - “So for me it’s wanting to make a difference so my son doesn’t have to go through what I’ve been through, and having survived I think it’s important that people know that people with autism can survive”
  - “I thought that going through that process of a structured reflection on my life might be beneficial to me”; “it helped me dig a little bit deeper into my past, and particularly my early history. And that was a really good thing”

Some participant reflections on the process

- On being interviewed by an autistic researcher:
  - “Even made it more reassuring, because I knew she’d get it, and get me”
  - “Knowing allowed me to drop the filters a bit more, if that makes sense”
  - “It just did provide an immediate sense of comfort that I could say something which would be difficult”
  - “Bloody wonderful. I have no objection to being interviewed by anyone that’s not autistic, I’m not that sort of person, 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”
  - “I just felt a lot more comfortable about it because I think there’s lots of stuff that happens where non-autistic people are making decisions about what’s best for people with autism. Once you’ve read a little bit and got your head around what’s going on, it’s quite easy to see that it can be quite insulting, really. You don’t know how my head works. You might think you do but you’re not living my life”

Some participant reflections on the process

- On taking part:
  - “I’ve found, with other people as well, the more I can talk about it to people who get it, the more my own acceptance is solidified”
  - “Well there is relief about the diagnosis but, yes, sadness in the fact that there was so much more that I could have done in my life. And that’s why I need to do this so badly for my own children, and for anybody else who is doubting whether it’s okay to talk about being autistic”
  - “The more I said it, the more I thought this is all okay. My story is normal and it’s good to tell it and there’s nothing… I think when I was a child, there were autistic behaviours that I showed, that I was made to feel ashamed of and now, I don’t”

Thank you

Questions?

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Autism CRC is the world's first national, cooperative research centre focused on autism. We are taking a whole-of-life approach to autism focusing on early years, school years and adulthood.