

Factors Influencing the Research Participation of Adults with Autism Spectrum Disorders

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Abstract Recruiting adults with autism spectrum disorders (ASD) into research poses particular difficulties; longitudinal studies face additional challenges. This paper reports on a mixed methods study to identify factors influencing the participation in longitudinal autism research of adults with ASD, including those with an intellectual disability, and their carers. Common and differentiating factors influencing the research participation of participants are identified and discussed. Factors influencing participation were found to differ both between and within participant categories. We propose a dichotomy whereby factors influencing research participation can be classified as those arising from a participant's values, which act as either a motivator or a deterrent; and those based on convenience, which act as either an enabler or inhibitor. These findings are applicable to research studies that seek to recruit adults with ASD as participants.

Keywords Autism · Asperger syndrome · Incentive · Longitudinal studies · Motivation · Research recruitment · Research participation

Introduction

Achieving a representative sample is vital to the validity of social research findings, particularly when findings are used as evidence to inform social policies and programs, and autism researchers face particular challenges in recruiting participants. The unique social-communicative profile associated with the autism spectrum (Howlin 2005) can contribute to the reluctance of some adults with autism spectrum disorders (ASD) to be involved with new people and experiences or to disclose personal information, and thus influence their willingness to participate in research, to the extent that adults with ASD can be considered as a 'hard-to reach' population (Beadle-Brown et al. 2012).

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Diagnostic-related assumptions about people with ASD can also lead researchers to develop strategies that exclude or restrict rather than maximise the research participation of people with ASD (Harrington et al. 2014). An informed understanding of the factors influencing the likelihood that adults with ASD will participate in research is an essential basis from which researchers can devise and deploy recruitment and retention strategies to optimise participation across the full spectrum of people with ASD.

Recent research has recognised that motivations for participating in research can be defined as either personal or social (e.g., Clark 2010; Mapstone et al. 2007). Hunter et al. (2012, p. 84) concluded that: “while altruism motivates participation in medical research, for many potential participants, the opportunity to benefit directly was the primary, and sometimes the only motive to participate.” Mein et al. (2012) observed that rather than being motivated solely by altruism, participants in a longitudinal health study were also motivated by personal benefits including medical information and care received and the sense of loyalty and membership associated with belonging to the study, which the authors term ‘conditional altruism’.

This is consistent with Fry’s (2008, p. 44) observation that: “... participant motivation is a multi-dimensional construction...” and “... the relative salience of these types of research participation incentives and barriers varies across participant group, research focus and setting ...” a view shared by others in this field (e.g., Tishler and Bartholomae 2002). Asserting that: “In spite of this variability ... there is notable consistency in the self-reported reasons for research participation where a number of core themes emerge independently of the type of research in which people are participating” (Fry 2008, p. 44), he categorised these core themes as either factors that can motivate participation (e.g., information access, financial gain, altruism, expected therapeutic benefit) or factors that can discourage participation (e.g., inconvenience, risk, discomfort).

Nicholson et al. (2013) categorised factors influencing participant recruitment in intellectual disability research into seven themes: participant attributes, research process, researcher’s standing and style as perceived by the participant, impact of participant’s previous experience with research, attitudes of participant’s family and carer(s), use of an ‘active’ recruitment approach and motivators. Similarly, Robinson et al. (2007) compared 368 retention strategies from 21 varying health-related studies and classified these retention strategies into 12 themes: community involvement, study identity, study personnel, study description, contact and scheduling methods, reminders, visit characteristics, study’s benefits, financial incentives, reimbursement, non-financial incentives and special tracking methods. Noting this diversity of themes, three

systematic reviews of recruitment and/or retention strategies (Beadle-Brown et al. 2012; Mapstone et al. 2007; Robinson et al. 2007) have recommended that to optimise participant retention, researchers should combine a greater number of retention strategies from across a wider variety of such themes.

Individual personality traits could also influence participation in research. Marcus and Schütz (2005) observed that research volunteers were more extraverted, more open to experience and more narcissistic than non-volunteers.

An additional factor is the participant-researcher relationship. Beadle-Brown et al. (2012) concluded that researchers’ conventional views about what data should look like, assumptions about the efficacy or validity of including particular types of people and stereotyped views about people outside the ‘mainstream’ can significantly influence research design and result in excluding certain groups of people.

Table 1 summarises commonly-identified motivators and barriers to participation in longitudinal research projects, as found in the literature.

Recruitment and Retention of Participants with an Intellectual Disability

Studies exploring how to improve the research participation of people with an intellectual disability provide useful insights for autism research. Stigma engendered by negative public attitudes to disability and the resultant low self-esteem and reluctance of people living with disability to identify with a particular condition (such as autism) have been found likely to discourage research participation for people with an intellectual disability (Thompson and Phillips 2007). Approaches found to produce higher participation rates in intellectual disability research include enabling investigators to have direct access to participants, using non-invasive data collection methods and requiring consent from substitute decision makers only (Cleaver et al. 2010). Lennox et al. (2005) concluded that recruitment for intellectual disability research was best achieved through direct contact from a service provider staff member to the adult with an intellectual disability and their caregivers. Gatekeepers of people with an intellectual disability, such as doctors, care managers, support workers, carers and parents can potentially act as a barrier when these third parties either select potential participants or seek to ‘protect’ these participants (Beadle-Brown et al. 2012).

These findings support those of Ouellette-Kuntz et al. (2013) that recruitment of participants with an intellectual disability was most successful where: there was an established relationship between the participant and a research team member; and when a third party assisted recruitment, it was made clear to the participant, their family and carers

Table 1 Commonly-identified incentives and disincentives for participation in longitudinal research

Incentives
<i>Intrinsic incentives</i>
Desire to help others and contribute to valued research (Bell 2013; Brodaty et al. 2013; Marcantonio et al. 2008)
Gain information and personal insight gained about self (Hunter et al. 2012; Mein et al. 2012)
Voice and share experiences and concerns (Bell 2013)
Participation as therapy (Bell 2013)
Belonging to a community (Mein et al. 2012; Robinson et al. 2007)
<i>Extrinsic incentives</i>
Monetary payments and gifts (Leonard et al. 2003; Marcantonio et al. 2008; Tishler and Bartholomae 2002)
Tell-a-friend rewards (Bonk 2010)
Birthday cards (Bonk 2010; Leonard et al. 2003)
Annual drinks reception to report results (Bonk 2010)
<i>Procedural incentives</i>
Reminders (Leonard et al. 2003; Robinson et al. 2007)
Choice of how and when to participate (Marcantonio et al. 2008; Mein et al. 2012)
Manner and perceived credibility of researchers (Nicholson et al. 2013; Robinson et al. 2007)
Project updates/newsletters (Leonard et al. 2003)
Disincentives
<i>Intrinsic disincentives</i>
Lack of faith in researcher (Marcantonio et al. 2008)
Suspicion or anxiety about the study (Bonk 2010; Lennox et al. 2005; Nicholson et al. 2013)
<i>Extrinsic disincentives</i>
Lack of time (Brodaty et al. 2013; Nicholson et al. 2013)
Travel (Beadle-Brown et al. 2012; Marcantonio et al. 2008)
Time required (Bonk 2010)
<i>Procedural disincentives</i>
Excessive paperwork (Brodaty et al. 2013)
Inadequate explanation of research (Beadle-Brown et al. 2012; Brodaty et al. 2013; Nicholson et al. 2013; Robinson et al. 2007)
Concerns re privacy of personal data (Kirkland et al. 2009)

which person(s) and which organisation was conducting the research. It was least successful in those cases where either the study relied on a third party for recruitment; or there was a considerable time lag between the participant's expression of interest and their engagement in the research; or data collection relied on face-to-face interviews. They also found that participation rates in intellectual/developmental disability research were positively influenced by financial incentives, though the most effective type of financial incentive was unclear.

Engaging Adults with ASD in Longitudinal Research

Magiati et al. (2014) conducted a systematic review of 25 longitudinal studies that have investigated the cognitive, language and social behavioural outcomes for adults with ASD. Each of the studies recruited participants as children and thus offer no insights into techniques for recruiting adults with ASD. Similarly, of the 18 peer-reviewed papers identified by this study as reporting on results from longitudinal studies of adults with ASD, 15 of the studies drew on data from participants recruited in childhood. The remaining three studies recruited adult participants, however none reported on the effectiveness of the recruitment approaches used or factors influencing participation (Cedrlund et al. 2008; Gerber et al. 2011; Madriaga 2010).

Two other studies involving adults with ASD have commented on engaging participants. Balfe and Tantam (2010) noted that techniques which could be effective in recruiting younger children are not necessarily suitable for the recruitment of adults and school leavers because "... adults and older adolescents are not 'captive populations' in the same way that children are." (Balfe and Tantam 2010, p. 2). MacLeod et al. (2014) concluded that a participatory research methodology could alleviate barriers to research participation faced by higher education students with ASD in dealing with a neuro-typical world. They reported that these participants had a keen interest in autism research, demonstrated commitment to the project, viewed themselves as "potential agents of change" and expressed the wish to improve the understanding of autism and help others (MacLeod et al. 2014, p. 47).

The limited scope of these insights from the literature indicates that the factors influencing participation in research for adults with ASD have not been identified or examined in any depth. This paper addresses this by reporting results for adults with ASD and their carers from a larger study identifying factors that influence the participation of adults in autism research (Haas et al. 2014).

Methods

A mixed methods design was chosen as the most appropriate for this study, with quantitative data providing an initial indication of the comparative strength of the views of different groups of participants and qualitative enquiry used to further investigate and explain the participants' rationale for these differences. Thus, each research instrument was designed and used to sequentially collect both quantitative and qualitative data. These qualitative and quantitative elements were then combined in data analysis

and in reporting of results to give the reader a single comprehensive interpretation of the study's findings.

Participants

Researchers recruited 167 participants for the study, mainly from four major Australian cities (Sydney, Melbourne, Brisbane and Perth). As shown in Table 2, participants were recruited in four categories: adults diagnosed with high functioning autism/Asperger's syndrome (HFA/AS); adults diagnosed with an ASD and an intellectual disability (ASD + ID); carers of ASD + ID adults (Carers); and neuro-typical adults (NT). No participants withdrew from the study. This report focuses on the individuals with ASD and their carers.

Instruments

In focus groups and interviews, researchers mixed the collection of both qualitative data using a card sort exercise and a written questionnaire (see Appendix 1 of supplementary material), which were completed by each participant. This yielded both quantitative and qualitative data on participants' attitudes to research, preferences for modes of participating in research and the likelihood of certain factors motivating, enabling or inhibiting participants' involvement in autism research. The topics canvassed and questions used in the card sort exercise and questionnaire were generated from the commonly-identified incentives and disincentives for participation in longitudinal research

listed in Table 1. To enable participation of those who may prefer an online environment, all items from the questionnaire and card sort exercise were incorporated into an online survey, generated via Qualtrix® software. Prompts were included to allow online participants to add open-ended written comments to their responses to quantitative items, yielding additional qualitative data. Complete versions of the card sort exercise, questionnaire and discussion points are available in Haas et al. (2014).

Ethics

Ethics approval to conduct the study was obtained from La Trobe University, The University of Queensland, Curtin University and Autism Spectrum Australia.

Procedure

Recruitment

Various methods were used to recruit participants including posting on social media (Twitter, Facebook) and websites via autism service providers, autism community networks and autism support groups and autism research groups, centres and networks. Flyers were distributed to autism-related organisations and to community and university-based disability support services, autism-related social groups, psychologists specialising in autism-related services and carer networks, for display at their premises.

Table 2 Total number of participants, by mode of participation, participant category, gender and age

	No. male	No. female	Not specified	No. transgender	Total no. of participants	Age range	Mean age
<i>Focus group participants</i>							
HFA	34	19	0	0	53	18–78	37
ASD + ID	13	1	0	0	14	18–38	23
CARERS	3	12	0	0	15	25–63	44
NT	22	24	0	1	47	19–62	30
Sub-total	72	56	0	1	129	18–78	33.5
<i>Online participants</i>							
HFA	5	4	0	0	9	22–51	32
ASD + ID	0	1	0	0	1	58	58
CARERS	0	0	2	0	2	–	–
NT	0	11	15	0	26	24–60	41
Sub-total	5	16	17	0	38	22–60	43
<i>All participants</i>							
HFA	39	23	0	0	62	18–78	36
ASD + ID	13	2	0	0	15	18–58	25
CARERS	3	12	2	0	17	25–63	44
NT	22	35	15	1	73	19–62	32
Total	77	72	17	1	167	18–78	34

–, no data on age or gender for 15 cases

Potential participants were also approached personally and through social media by those individuals already recruited to the study who were active, well-connected and well-known as advocates in the autism/Asperger's community. Researchers gave presentations about the study to autism and disability support groups. Information about the study was also distributed to individuals on research participant registries held by study partner organisations. In some cases, information was distributed by personal contacts to participants in previous autism-related studies.

Each participant was screened for study inclusion based on place of residence (Australia only); age (18+ years only); self- or proxy-reported diagnosis of ASD (and intellectual disability as applicable); and carer responsibilities.

A completed consent form was required from all participants prior to participation. Carer/guardian written consent was also required for participants with an intellectual disability and from those carers who accompanied other ASD participants to a focus group or interview.

Data Collection

Focus Groups and Interviews

Seventeen focus groups and 17 interviews were conducted from May to July 2014 with a total of 129 participants. The focus groups involved 110 participants and ranged in size from three to 12 participants, with a median size of six. Interviews were conducted with 21 participants where the participant indicated that they were unable to or did not wish to attend a focus group or the researcher in consultation with the participant's carer judged that due to the limited verbal capacity of the participant, an interview would be more effective than a focus group in eliciting meaningful responses. Both the focus groups and the interviews were conducted by trained social science researchers with honours or postgraduate qualifications in psychology, social work or behavioural science.

In focus groups and interviews, participants first individually completed the card sort exercise then the questionnaire. Based on their responses as tallied by the researcher, a discussion was then facilitated by the researcher. This yielded qualitative data on participants' attitudes, reasoning, motivations and preferences about factors likely to influence their participation in autism research.

Focus groups and interviews were approximately 1.5 to 2 h. All focus group and interview participants were provided with a \$20 shopping voucher at the end of the session. Participants who travelled more than 20 km to attend a focus group or interview received partial reimbursement for travel costs.

Online Survey

Following feedback received from participants during the initial recruitment process that limiting data collection to focus groups and interviews was potentially only appealing to those willing to engage in social interactions, an online survey was incorporated into the study. Recruitment into the online survey was via posts on social media pages of autism community groups, and by emailing a direct link for the online survey to those participants who indicated to the researchers that they wished to participate but were unable or did not wish to attend either a focus group or an interview. Over a two-week period in June 2014 a total of 38 participants across all categories completed the online survey.

Data Analysis

Quantitative Analysis

The quantitative data from the card sort exercise, questionnaire and online survey were collated and tabulated. A frequency analysis was produced for each question, cross tabulated by participant category and mode of participation.

Qualitative Analysis

Participants' commentaries in focus groups and interviews and the open-ended responses given by online participants yielded the qualitative data for analysis, providing in-depth explanations as to the participants' rationales for their quantitative responses that they gave in the card sort exercise and the questionnaire (or the online versions of these instruments). Participants' commentaries in focus groups and interviews were fully transcribed from audio recordings and the extended written responses were extracted from the online survey data. Thematic analysis was applied to the entire qualitative data set using grounded theory method (Charmaz 2006; Guest et al. 2011) using the following method: first, the entire set of qualitative data was hand-coded, with initial coding open to allow for themes to emerge from the data itself; next, codes were iteratively re-grouped, merged, re-coded and sub-coded to identify and categorise main and sub-themes. Final coding of all qualitative data was checked by the primary coder and sections of data coding were checked and verified by an independent coder who was not associated with the project but experienced in autism research, to ensure alignment between raw data and final coding.

Mixed-Method Analysis

The quantitative and qualitative analyses were then mixed in the reporting of the results to provide a comprehensive

picture of respondents' views on participation in autism research.

Results

The data analysis showed that the factors that influenced the likelihood of participating in autism research could be categorised into those factors that arose from participant values, which were observed to act as either a motivator or a deterrent; and those factors that were based on participant convenience, which acted as either an enabler or an inhibitor¹ of participation. (This is addressed in the Discussion section).

The results indicate that some motivators, deterrents, enablers and inhibitors of participation were common to all participants while other motivators, deterrents, inhibitors and enablers differed markedly between different types of participants. In addition, some factors identified as motivators or deterrents for certain participants were found to be either inhibitors or enablers for others.

Common Motivators and Deterrents

A Brighter Future

Most participants were primarily motivated to engage with autism research as a way to help improve the lives of people with ASD. Eighty-five percent of HFA/AS participants, 73 % of ASD + ID participants and 94 % of Carers said they would be more likely to participate if the research was likely to benefit other people, especially those with ASD. In supporting autism research, participants voiced strong support for research focused on producing practical programs to improve opportunities for adults with ASD to engage in all aspects of life in meaningful and rewarding ways, to be adequately recognised for their abilities and contributions, and to enable greater acceptance and understanding of them by the wider community.

While helping others was found to be a key motivator, 59 % of HFA participants, 60 % of ASD + ID participants and 59 % of Carers agreed that if they were going to take part in a research project, they wanted to know that they would personally benefit from the research. What participants considered a 'personal benefit' differed between participant categories. For adults with ASD, 'personal benefit' was viewed through the lens of their individual preferences and needs and their desire for improved opportunities to engage in all aspects of life in meaningful and rewarding ways. HFA/AS participants were most keen to have their voices heard and understood, while some also

sought opportunities for social engagement, particularly with others similar to them. For most ASD + ID participants, receiving acceptance was a key motivator. Some also sought recognition and appreciated extrinsic rewards, such as gifts and cards. Carers of adults with ASD interpreted 'personal benefit' in terms of benefit to their child rather than to themselves.

Personal learning and development was a notable 'personal' benefit valued by participants. Seventy-four percent of HFA/AS participants and 71 % of Carers said they would be more likely to participate if the research would help them learn more about autism and/or themselves. HFA/AS participants commented that information they received via group discussions, project communications and interactions with the project team would assist their personal learning and development. Similarly, Carers commented that the opportunity for their adult child to learn more about themselves and autism would benefit their child's personal development and self-awareness, including 33 % of Carers who expressed an interest in their adult child working 'behind the scenes' to assist with the administration and conduct of a research project. Some HFA/AS participants (48 %) were also keen for any opportunity to work 'behind the scenes', with those HFA/AS participants in focus groups (55 %) showing much more interest than those responding via online survey (11 %).

The desire of participants with ASD to support research was tempered by some (26 %) who were suspicious about the motives behind large-scale research projects.

Belonging in a Caring Community

Participants indicated a desire to draw comfort, a sense of worth and inspiration from belonging to a research project community. For example, 66 % of HFA/AS participants, 60 % of ASD + ID participants and 71 % of Carers indicated they would use a project website where they could ask questions, give feedback and engage in online discussions with the research team and other study participants. Common reasons that participants valued such a website were the flexibility to engage in an online community as it suits the individual, the opportunity to form and engage in relationships online, the facility to exchange helpful information, and the reassuring support of a community of people with similar interests. Project communication was also found to be an important part of engendering this sense of belonging.

Being Informed and Updated

Most participants were keen to receive project communications, including newsletters (66 %), website (71 %), and

¹ Inhibitors can also be properly described as 'barriers'.

outcome reports (82 %). Participants indicated they valued receiving ongoing and updated information about the project and its progress, about how their input had contributed to outcomes and being able to see and compare others' responses and contributions.

(In)sensitivity

HFA/AS participants noted that adults on the autism spectrum will be deterred from engaging in research if autism researchers do not clearly demonstrate in their research design and the conduct of their studies, from recruitment through to data collection and reporting, in a way that they both understand and that is sensitive to particular and individual cognitive and communication styles, behaviours and sensory needs of people on the autism spectrum. This ensures that participants can make meaningful contributions and engage in the research to their full capacity. Insensitivity to the particular needs of adults on the autism spectrum also manifested as an inhibitor to participation as indicated in the sections that follow.

Common Inhibitors

Travel and Time

Some HFA/AS participants (34 %) and Carers (41 %) considered any significant amount of travel (over 50 km round trip) would be a barrier, citing cost, inconvenience and anxiety associated with travel. However, 76 % of HFA/AS participants and 88 % of Carers said reimbursement for travel costs would encourage their participation.

Carers (65 %) and ASD + ID participants (60 %) were concerned to have adequate time to complete surveys. Boredom and shorter concentration were also issues for ASD + ID participants when completing surveys. Comments from ASD + ID participants and Carers highlighted that such tasks need to be broken into smaller sections to be completed over a longer time period.

Mental and Physical Health

A notable proportion of ASD + ID participants (47 %), HFA/AS participants (38 %) and Carers (29 %) said their mental health might be a barrier to participation or were unsure if it might be. Some HFA/AS participants at focus groups (33 %) and ASD + ID participants at focus groups (27 %) said their physical health might be a barrier but this was not a concern for either Carers or HFA/AS participants in the online survey, though some (22 and 18 % respectively) were unsure about this.

Inaccessibility

Participants expressed the need for data collection methods that account for the particular and individual cognitive and communication styles, behaviours and sensory needs of people across the autism spectrum. This included providing opportunities for participants to clarify the meaning of questions or provide explanations to researchers about the participant's responses to questions, and carefully choosing venues that accommodated the sensory needs of adults on the autism spectrum. Suggestions included convenient locations, quiet acoustics, a private venue, and a relaxed, informal setting. Some HFA/AS participants commented that to support their difficulties with executive functioning, they would need reminders to undertake activities. In conducting this study it was also found that visual aids assisted in project communication and data collection with ASD + ID participants. Some HFA and ASD + ID participants requested that a carer or companion accompany them in a focus group or interview for reassurance and in some cases, for assistance with concepts and communication.

Common Enablers

Choice

Maximising choice for all aspects of project involvement was seen as a vital enabler of participation, because it allows for the breadth and idiosyncratic nature of the personal preferences and needs of individuals across the autism spectrum. Most HFA/AS participants (76 %), ASD + ID participants (79 %) and Carers (82 %) said a choice of how to participate would make them more likely to participate. HFA/AS participants expressed that they did not want to be "boxed in" to any pre-conceived notions of what might appeal to them or not. They commonly expressed that they would appreciate the choice to accept or decline anything offered to them, whether extrinsic rewards (e.g., gift, voucher, cash), project communications (e.g., newsletters, reports, reminders) or event invitations. HFA/AS participants suggested being given an option as to whether they wished to receive any particular communication, their preferred format for each communication (e.g., digital or print), and the option to receive a summary or a plain language version of any report or a face-to-face session explaining the project outcomes. The flexibility of cash payments (as reward for participation) was generally preferred to receiving a voucher.

Access to Researchers

Most HFA/AS participants (61 %) and Carers (71 %) and some ASD + ID participants (47 %) said they would be

more likely to participate if they could contact the research team directly at any time by telephone or email. Access to researchers was either a common motivator or enabler for reasons that differed between participant categories. For HFA/AS participants, a key reason was the opportunity to either clarify a survey question or to explain the participant's response to a survey question. Carers expressed two key reasons: for many, it would enable them to make practical arrangements with the researchers to facilitate their child's participation in the research study, while other Carers and some HFA/AS participants were keen to be able to readily contact researchers for information or advice concerning autism related issues.

Differentiators

Extrinsic Rewards

While participants welcomed any acknowledgement of the time and effort that they contribute, the results show that using financial and other extrinsic rewards is likely to be problematic as a means of encouraging people to participate in autism research. For some these rewards were an enabler of participation, for others they were an inhibitor.

Within the HFA/AS participants, 53 % said they would be more likely to participate if they received cash payments or vouchers as thanks for their participation, while 34 % indicated that such rewards would make no difference to their likelihood to participate. HFA/AS participants generally considered extrinsic rewards to be less meaningful and relevant as motivators of their participation than the intrinsic benefits they might gain, and for those willing to accept extrinsic rewards, such incentives were not the key motivator of their participation. Of those HFA/AS participants who said they would be less likely to participate if they received cash payments or vouchers, many expressed distaste for or disapproval of such incentives.

Over half of HFA/AS participants (53 %) said receiving a birthday card from the research team would make no difference to their participation, while 27 % indicated it would discourage their participation. Similarly, 44 % said receiving a small gift, three times a year would make no difference and 19 % said it would discourage their participation. Support within the HFA/AS group for receiving a 'tell-a-friend' reward for enlisting others into the study was lower: only 31 % said it would encourage their participation, 50 % said it would make no difference and for 19 % it would discourage their participation. Instead, HFA/AS participants expressed that extrinsic rewards were valued as recompense for expenses such as time, travel and child-minding.

Most ASD + ID participants were happy to receive extrinsic rewards. About half of ASD + ID participants

said receiving acknowledgment and recognition, such as an article about them in the project newsletter (53 %) or a birthday card (47 %) would encourage their participation. Many said receiving vouchers or cash (67 %) would encourage their participation. Gifts were somewhat problematic for this group: 43 % of ASD + ID participants responded that gifts would encourage their participation, however an equal proportion (43 %) said it would make no difference, with the remaining 14 % indicating that gifts would discourage their participation.

Consistent with their primary focus on others and their children, Carers showed little or no interest in receiving any exposure or recognition for themselves.

Social Interaction

Preferences about social interaction produced divergent responses about activities requiring participants to be with other people.

Some participants with ASD, including those with HFA/AS and those with an intellectual disability, expressed that they did not enjoy or were fearful of social interaction, or were concerned about mixing in large groups and preferred engaging within smaller groups. For others, the opportunity for social interaction, particularly with others similar to themselves, was a prime motivator and their preferred mode for participation in research. This divergence was consistent across both HFA/AS and ASD + ID participants.

Most HFA/AS participants at focus groups highly valued the opportunity for interaction with others who were similar to them and enthusiastically engaged in these interactions. Most said meeting and sharing experiences with others at events such as discussion groups (72 %) or drinks receptions (59 %) would increase the likelihood of their participation. Of prime importance for these participants was the lively and free exchange of views, in an environment of mutual understanding and acceptance of differences where much that is particular to them does not need any explanation. This sharing of opinion and experiences was valued for the supportive contact, learning and self-development it affords.

Others expressed a preference for face-to-face communication because it lessens the chance for ambiguity and misunderstandings and prompts them for contributions. Some HFA/AS participants also viewed such events as opportunities to meet researchers, either to exchange views, learn more about autism or query the researcher's approach to autism research. For other HFA/AS participants at focus groups, the social aspect was either less important or not relevant to them. Instead, they valued the opportunity to contribute and exchange opinions around a specified topic of interest to them while undertaking a purposeful task in a structured format (and this in part

ameliorated their distaste for or anxiety about the social setting).

Over one-third of HFA/AS participants responding via online survey said meeting and sharing experiences with others at events such as a discussion group (44 %) or a drinks reception (33 %) would decrease the likelihood of their participation.

ASD + ID participants also divided into those who would enjoy activities with social interaction, particularly interactions with others similar to them, and those who did not seek or enjoy social interaction. Sixty per cent said meeting and sharing experiences with others at a discussion group would increase the likelihood of their participation; 40 % said it would discourage their participation. Fewer (47 %) were enthusiastic about attending a drink reception; an additional 33 % were unsure about such an event.

Most Carers said meeting and sharing experiences with others at events such as discussion groups (53 %) or drinks receptions (71 %) would increase the likelihood of their participation. Some were reticent to participate in a forum where negative aspects of caring for an ASD + ID child might dominate the discussion.

Preferred Modes of Data Collection

Preferences about modes of participation also produced divergent responses between and within the participant categories (Table 3).

Most ASD + ID participants said they would not enjoy telephone and paper surveys or were unsure about them. Carers commented that paper or online surveys would be more manageable and effective for their adult child than telephone surveys or interviews. Internet or telephone access was not identified as a significant barrier to participation for HFA/AS or ASD + ID participants, but a notable minority of Carers did not have regular access to either the internet (18 %) or a telephone (12 %).

Participation by a Friend or Family Member

Most HFA/AS participants perceived participation in research as an individual, personal engagement. Participation by a friend or family member was likely to encourage 31 % of HFA/AS participants to take part in research and 60 % of ASD + ID participants. The full support of carers of ASD + ID participants was in almost all cases essential to organise, enable and facilitate the participant's involvement and expression of their views in this study.

Recruitment Strategies

A 'broad brush' method was least effective in recruiting for each of the participant categories; it was more effective to

tailor the networks, methods, channels and messages to appeal to each specific participant category.

Effective methods of recruiting HFA/AS participants included: via social media of autism support networks, support groups and service providers; assistance from active, high-profile and well-connected advocates in the HFA/AS community (as this provided credentialed and trusted access to participants) and snowballing, by encouraging neuro-typical participants already recruited to the study to enlist relatives and friends with ASD to also join.

ASD + ID participants were the most challenging to recruit. It was essential to first recruit carers as co-participants, because carers generally acted as the 'gatekeeper' and conduit for communications and consent.

Carers were most effectively reached through disability networks rather than via the autism community. While a small proportion were recruited via social media, most Carers were found with the assistance of disability carer network organisations and disability service providers who enabled credentialed and trusted access.

Discussion

Classifying Motivators, Deterrents, Enablers and Inhibitors

Previous studies of factors influencing research participation have commonly divided factors into two simple categories, being those with either a positive or negative impact (e.g. Mapstone et al. 2007; Fry 2008). However, our analysis indicated that our understanding of participant behaviour can be furthered by distinguishing between those factors arising from participant values, which act as either a motivator or a deterrent; and those factors based on convenience, which act as either enablers or inhibitors. Value-based outcomes that participants with ASD sought, such as altruism, access to information and sense of community, were found to be motivators of their research participation. Tokenism and perceived insensitivity to the individual's needs were deterrents to research participation, as these outcomes did not align with participants' expressed values. Convenience-based factors that influenced the research participation of people with ASD included maximising choice, which acted as an enabler (as distinct from a motivator); and the cost and time of travel, which acted as an inhibitor.

Common Factors

This study adds to the existing knowledge about research recruitment and retention by identifying factors influencing

Table 3 How do you feel about this way of collecting information from you?

	Would enjoy (%)	Not sure (%)	Would not enjoy (%)
<i>ASD + ID participants</i>			
Face-to-face interview	46.7	26.7	26.7
Focus group	46.7	26.7	26.7
Online survey	46.7	26.7	26.7
Telephone interview	40.0	33.3	26.7
Paper survey	13.3	20.0	66.7
Telephone survey	6.7	26.7	66.7
<i>HFA/AS participants</i>			
Face-to-face interview	76.7	18.3	5.0
Focus group	68.9	21.3	9.8
Online survey	70.5	21.3	8.2
Paper survey	45.9	31.1	23.0
Telephone interview	32.8	41.0	26.2
Telephone survey	26.2	27.9	45.9
<i>Carer participants</i>			
Face-to-face interview	76.5	17.6	5.9
Focus group	76.5	23.5	0.0
Online survey	64.7	5.9	29.4
Paper survey	52.9	35.3	11.8
Telephone interview	58.8	5.9	35.3
Telephone survey	52.9	0.0	47.1
<i>Neurotypical participants</i>			
Face-to-face interview	68.5	24.7	6.8
Focus group	63.0	23.3	13.7
Online survey	86.1	8.3	5.6
Paper survey	56.2	21.9	21.9
Telephone interview	57.5	27.4	15.1
Telephone survey	50.7	24.7	24.7

research participation that are particularly relevant to the lived experience of adults with ASD. For example, factors found to be vital enablers of research participation by people with ASD (and inhibitors when absent) were the sensitivity shown to each individual's personal needs and preferences for engaging with the world and others; and related to this, maximising the choices available for participants across all aspects of their involvement in the research. This finding is consistent with the findings of MacLeod et al. (2014). Broadly, the desire for maximum choice and sensitivity to individual needs reflects the self-focus of people with ASD (Baron-Cohen 2000) together with the diversity of cognitive functioning and skills, behaviours, lifestyles and personal preferences that is observed across the autism spectrum (Mazefsky and White 2014).

Some factors we found influencing the research participation of adults with ASD are similar to those identified in the literature for neuro-typical people and people with an intellectual disability. The motivators for participation were found to be both social and personal in nature (as

reported by Barton et al. 2012; Clark 2010; Hunter et al. 2012; Kirkland et al. 2009; Mapstone et al. 2007; Mein et al. 2012). Travel and time were common inhibitors to participation (e.g., Barton et al. 2012; Beadle-Brown et al. 2012; Bonk 2010; Brodaty et al. 2013; Marcantonio et al. 2008; Nicholson et al. 2013) while information access (Barton et al. 2012; Hunter et al. 2012; Leonard et al. 2003; Mein et al. 2012) and belonging to a research community (Mein et al. 2012; Robinson et al. 2007) were motivators of participation.

The results also indicate that, in contrast with the results of previous studies involving neuro-typical participants only (Leonard et al. 2003; Marcantonio et al. 2008; Tishler and Bartholomae 2002), offering extrinsic rewards as an incentive for participation could be problematic in research involving people with ASD, because such rewards act as an enabler for some and an inhibitor for others; they did not act as a motivator for any of our participants. Again this is indicative of the diversity of presentations encompassed within the autism spectrum (Mazefsky and White 2014). It

also reflects the rejection of tokenism and paternalism by the HFA/AS participants.

Differentiating Factors

While some findings were applicable to all participants, the responses of each participant category displayed a number of unique themes.

HFA/AS participants wanted to be heard and understood as equal and valued partners in research in order to both improve community understanding of ASD and to participate in the wider community. They rejected tokenism and were generally not interested in extrinsic rewards for research participation; rather they wanted respect for themselves and their point of view. Furthermore some individuals wanted to be key decision makers in research, based on concerns that their views are commonly misrepresented, misinterpreted and misused by the wider community, especially neuro-typical researchers. This view is consistent with the “Nothing about us without us” catchcry of the Autistic Self Advocacy Network (ASAN; <http://autisticadvocacy.org/>) and is a view that is strongly held and that we must strive to actively respect. To engage with this group we must be actively collaborative and be inclusive.

For ASD + ID participants, belonging and acceptance, wanting to know ‘what was happening’ and what others were doing, especially people known to them were key motivators for research participation. Involvement in research required flexibility in the mode of participation, relationships of trust with researchers, the capacity to fit the research activities into the participant’s normal daily routine, and a sense of security, safety and calm in the research environment. This finding aligns closely with those of MacLeod et al. (2014). Many ASD + ID participants expressed a liking for extrinsic rewards and any public recognition of their research participation provided a much-appreciated boost to their self-esteem and public profile.

The responses of Carers were characterised by a balance of altruism and pragmatism. The key focus of Carers was the development of practical knowledge and solutions about ASD to improve their adult child’s well-being and life choices. This is similar to parents of children with ASD who express a desire for information relevant to them and their child and to promote independence and child autonomy (Derguy et al. 2015). Carers were not unconcerned about obtaining ‘personal’ benefits, but these were interpreted from the perspective of their carer role. Thus, they were vitally concerned to protect their child and their child’s privacy, but were unconcerned about disclosure of their own personal information. Carer’s desire, willingness and capacity to contribute were balanced by their need to manage the daily practicalities of caring for an adult with a

disability. A pragmatic concern was how they would facilitate their child’s participation in research, such as organising and funding travel, communicating with the research team and finding appropriate modes of participation for their child.

Limitations

While a range of methods was used to engage as broad a spectrum of participants as possible, the reach of the study is limited by the effectiveness of the recruitment communications, the time period for recruitment (particularly for the online survey) and the modes of participation offered. We did not examine reasons for non-participation. Although we sought to gather data from a representative sample of the population based on age and gender, we have not examined the impact of any socio-demographic factors. The participants in the focus groups and the online survey were not identified individually and therefore not coded for age or gender; and the card sort exercise was completed as an anonymous exercise and was also not coded for gender or age. Nevertheless the relatively large sample size (62) and wide age range for the HFA/AS group provides some confidence for the findings for this demographic.

There were key differences between our two ASD groups both with regard to sample size and age, which must be considered when reflecting on our findings. The HFA/AS group was four times larger, over 10 years older on average, with almost three times as many females than the ASD + ID group. The ASD + ID group was primarily recruited via carers, and it is likely that older individuals with ID may no longer be living with elderly parents, or their parents may have died, consequently this age group may be less accessible. Thus, the research participation views of younger individuals with ASD + ID may not reflect those of individuals who are middle-aged or older. The small sample size for the ASD + ID group may only reflect the opinions of people with ASD and an ID who are able to articulate their opinions and concerns and may not reflect the feelings of people with ASD and more severe communication difficulties. Finally, over a third of the HFA/AS group was female, which is not representative of the typical male/female ratio reported in ASD (APA 2013).

The carer sample was small, and as is typical in carer research, was predominantly female. Middle aged or older individuals with ASD + ID may no longer have family members who act as carers, but may be living in group homes, while older individuals with HFA/AS may be living independently. Nevertheless the small sample size limits the generalizability of our carers’ information.

Finally for all three groups, these were people who were already willing to participate in research as evidenced by their entering this study and providing their opinions. We

cannot know how well these findings may translate to individuals with ASD and their carers who are more reluctant to be involved in research. This will always be a conundrum.

Conclusions

The results of this study indicate that the factors that either motivate, inhibit, deter or enable the research participation of adults with ASD differ markedly between those with high-functioning autism or Asperger syndrome, those with an intellectual disability; and their Carers, and also between individuals within these categories. Thus, a ‘one size fits-all’ approach will not be effective in optimising the research participation of adults with ASD. Instead, choice, flexibility and sensitivity are likely to be key elements in a successful strategy to engage adults with ASD in research.

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Compliance with Ethical Standards

Conflict of interest The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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