# Improving research about us, with us: a draft framework for inclusive autism research

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# Inclusive autism research: a draft framework

## Abstract

It is both epistemologically, as well as ethically, problematic if the autistic voice is not heard in relation to social scientific research seeking to further develop knowledge of autism. Ever since autism first emerged, it has remained medicalised and almost exclusively the preserve of non-autistic researchers. More recently autistic individuals have begun to contribute to autism research. However, the vast majority of research in autism is still undertaken *on* autistic people, rather than *with* them, and is often not concerned with improving the day-to-day lives of people with autism. We discuss the concepts of participatory research and emancipatory research before presenting a draft framework for what we regard as truly inclusive research in autism. Our proposals are firmly based on ideas developed by the members of a university-based group of autistic adults (the Asperger's Consultation Group) as well as the knowledge and experience of the other contributors.

**Keywords:** Asperger syndrome; autism; emancipatory research; participatory research; social model of disability

## Introduction

It has been argued that it is both epistemologically, as well as ethically, problematic if the autistic voice is not heard in relation to social scientific research seeking to further develop knowledge of autism (Milton and Bracher, 2013). Ever since autism emerged from the work of Asperger and Kanner (Asperger, 1944; Kanner, 1943), it has remained medicalised and almost exclusively the preserve of clinicians and non-autistic researchers. More recently autistic researchers have begun to contribute to the debates over aspects of autism, to research led by non-autistic scholars, and to the development of our understanding of autism (Arnold, 2010; Chown, 2013, 2014; Graby, 2012; Milton, 2012, 2014; Milton and Bracher, 2013; Mottron et al., 2006; Murray et al., 2005; Robertson, 2009; Yergeau, 2010). However, it

remains the case that the vast majority of research in autism is undertaken *on* autistic people[1], rather than *with* them, and is often focused on theoretical investigation into what causes autism, the search for a 'cure', and other matters not concerned with improving the day-to-day lives of autistic people (Milton and Bracher, 2013). Milton and Bracher write that 'the inclusion of autistic people as *equal participants* can help to enrich the research process (by increasing) the epistemological integrity of studies that seek to explore important questions relating to the wellbeing of autistic people' (ibid., p. 63 & 66, author's italics) by reflecting the different cognition of people with autism. The majority of the co-authors of this article are on the autism spectrum.

## Participatory research

Participatory research is research involving a partnership between academic researchers and people affected by the matter under investigation where the latter share decision-making with the academics (Boote et al., 2002; Cargo and Mercer, 2008; Jivraj et al., 2014; Macauley et al., 2011). In the context of disability this implies a partnership with individuals who have the disability under investigation (Waltz, 2006 in Arnold, 2010) and hence that autistic researchers must be involved in autism research if it is to be classified as participatory research. Despite the "Nothing about us without us" mantra of organisations *of* disabled people[2], and the increasing involvement of people with intellectual difficulties and mental health issues in research, people with autism[3] are rarely involved in research other than as subjects of it (ibid.) or, more recently, as research assistants. The very few exceptions to this, such as Michelle Dawson's partnership with Laurent Mottron at the University of Montreal in Canada, which, inter alia, led to the development of the enhanced perceptual functioning theory of autism, and Wenn Lawson's work on the monotropism hypothesis with Dinah Murray and Mike Lesser, are notable for indicating the importance of collaboration between

autistic and non-autistic academics (Mottron et al., 2006; Murray, Lesser and Lawson, 2005).

Waltz concludes that old attitudes to autism die hard so that although few people now believe

that only normalised autistic people can qualify as fully human (Lovaas, in Chance, 1974),

'all too often people with autism are still not seen as part of the diverse human family, unless

their differences can be eliminated or camouflaged' (ibid., p. 2). The remnants of this old

attitude to autism, together with its continuing medicalisation, which regards autistic people

as 'patients', may account for the rarity of truly participatory autism research, despite the

valuable contributions of autistic intellectuals such as Dawson and Lawson.


Although some authors have seen evidence of an increased emphasis on PR in autism

and other neurodevelopmental conditions covering areas such as healthcare and wellbeing,

the actual numbers of studies claiming to be participatory remains small and the number of

genuinely participatory studies smaller still (Jivraj et al., 2014). In a review of the influence

of researcher-partner involvement on the process and outcomes of participatory research in

autism and intellectual disability undertaken by Jivraj and his colleagues, only seven of 636

studies met the inclusion criteria in their carefully structured search strategy (none of these

seven studies were from the United Kingdom), and only two studies actually involved autistic

co-researchers (ibid.). Jivraj et al. called for authors to provide greater clarity on the nature

and extent of partner involvement in research studies, the ways in which decision-making

reflected partner perspectives as well as academic perspectives, and the evaluation of these

partnerships (ibid.). One study not mentioned by Jivraj et al. – possibly because the article

reporting on it was published at around the same time as theirs – is that of Martin who

reported on research she conducted with her Asperger's Consultation Group[4] comprising of

three adults with Asperger syndrome. Their study was undertaken on the basis of both

participatory and emancipatory research principles (which we discuss next), her positionality

was informed by the social model of disability (also referred to later on), and she worked with her autistic co-researchers on the enlightened and empowering basis that 'adults with Asperger's syndrome think differently rather than in an inferior way to [non-autistic people]' (Martin, 2014, p. 5). We go on to consider how, in our view, Martin's study demonstrates that PR research in autism involving autistic co-researchers produces outcomes that could not have been achieved if autism research undertaken by non-autistic scholars does not benefit from autistic perspectives on the subject matter of their investigations. Martin (2014, p. 14) writes:

> The group want to continue their work beyond this piece of research and so have been empowered to do so by the positive experience of being a part of it. The process of the group working provided a safe environment in which to explore issues of identity and share experiences. Surely, this is what emancipatory research aspires to achieve. This was achieved through the partnership of adults with Asperger's syndrome working with a neuro typical researcher. It took all the researchers together to make this research such a positive experience for us all.

But, were there specific benefits to the research project in addition to the personal gains for the autistic members of Martin's team, from this example of researchers with Asperger syndrome (AS) working alongside a predominant neurotype[5] researcher? There are plenty of such benefits. For instance, during the research design stage the section of the group's questionnaire originally entitled 'navigating the outside world' was changed to 'dealing with the outside world' because it was found that the original title was not always understood (probably because of its use of metaphor). However, the experience of this group also demonstrates that working with persons with AS may, on occasions, introduce what some may regard as limitations but we consider to reflect different ways of thinking. Perhaps the best example of this is that in the data analysis stage Martin felt that she should not encourage her autistic co-researchers to identify respondent themes that did not precisely fit the intention of the questions they were asked as 'the group was operating in a very literal manner, and this did not allow for responses that were outside the intention of the original

questions' (ibid., p. 10). She goes on to point out that 'This was not a negation of my expertise as a researcher as might be supposed, but a utilisation of my knowledge of the principles of participatory and emancipatory research and of the different way that people with Asperger's syndrome think' (ibid., pp. 10/11). Whilst it might be thought at first glance that this approach reduces the scope of the data analysis we argue that it is a more systematic approach which avoids the risk of digression and ensures the integrity of the research.

**Emancipatory research**

The distinction between participatory research and emancipatory research is not always clear. For example, whilst Waltz (2010) regards social change as an objective of emancipatory research that is not a requisite of participatory research, Stoecker and Bonacich (1992) see social change as a criterion for research to be considered to be participatory, and Cornwall and Jewkes (1995) appear to hold a similar view, stating that most participatory research leads to knowledge for action rather than for its own sake. In their discussion of community-based participatory research, Cornwall and Jewkes (ibid.) write that it involves local people controlling the research process which others regard as a feature of emancipatory research distinguishing it from participatory research. It would appear though to be generally accepted that emancipatory research extends the participatory research paradigm to include further criteria regarding the 'ownership'[6] of the research (which may be equated to the 'empowerment' that others refer to), a requirement that the research results in social change (presumably, something similar to the requirement for 'gain' mentioned by Oliver), and the accountability of the disabled researchers to the non-disabled researchers and vice versa, which we think is probably the same as the reciprocity criterion also referred to (Barnes, 2001; Barnes and Mercer, 1997; Oliver, 1992; Stone and Priestley, 1996; Zarb, 1992). We agree with Waltz (2010) that emancipatory researchers should adopt a reflexive approach to

their work, although we think that *all* researchers should do so. We do not regard reflexivity as a criterion for emancipatory research specifically but for all good research.

The renowned disability scholar Mike Oliver (1997, p.6) sets out six elements of a definition of emancipatory research which he contends will 'make a contribution to the combating of the oppression of disabled people'. Oliver's definition of emancipatory research is as follows:

1. a description of experience in the face of academics who abstract and distort the experience of disabled people;

2. a redefinition of the problem of disability;

3. a challenge to the ideology and methodology of dominant research paradigms;

4. the development of a methodology and set of techniques commensurate with the emancipatory research paradigm;

5. a description of collective experience in the face of academics who are unaware or ignore the existence of the disability movement; and

6. a monitoring and evaluation of services that are established, controlled and operated by disabled people themselves.

Stone and Priestley (1996, pp. 709/710) set out the following slightly different set of emancipatory research principles in their definition of this approach to disability research:

1. the adoption of a social model of disablement as the epistemological basis for research production

2. the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation

3. the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers

4. the evolution of control over research production to ensure full accountability to disabled people and their organizations

5. giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences

6. the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

We have compared and contrasted the Oliver and Stone and Priestley emancipatory research criteria. Oliver's requirement for a redefinition of the problem of disability appears to be reflected in Stone and Priestley's criterion requiring the adoption of a social model of disablement. In other words, a medical / individual model of disability regarding disability as being something wrong with an individual should be replaced by a social model whereby disability (as opposed to impairment) is considered to be imposed over and above impairment by societal barriers. By replacing a medical model with a social model Oliver's redefinition requirement is met. We then move on to Oliver's two ideology / methodology points. Although his requirements for a challenge to dominant research paradigms and development of emancipatory research-appropriate methodology and techniques do not mirror exactly the Stone and Priestley inclusion of a criterion requiring a willingness to adopt a plurality of methods of relevance to disability, there is clearly an intention on the part of both to require a paradigm suitable for disability research. Oliver's insistence that the individual and collective experiences of disabled people should replace academic abstraction and distortion are accurately mirrored in Stone and Priestley's criterion requiring voice to be given to the personal as political whilst 'seeking to collectivize the political commonality of individual

experiences'. Both Oliver's sixth criterion and Stone and Priestley's fourth criterion refer to the exercising of 'control' by disabled people. This brief analysis suggests that all Oliver's criteria are reflected to a greater or lesser extent in those of Stone and Priestley. However, the latter include some further criteria: overt political commitment to the emancipation of disabled people, and only undertaking research which self-empowers disabled people and/or breaks down disabling societal barriers. We have chosen to adopt the Stone and Priestley criteria as the primary basis for our draft framework as they reflect Oliver's criteria but also include emancipation, self-empowerment, and breaking down of barriers which are considered important in the context of disability.

We advocate autism research that is both participatory *and* emancipatory[7] although in the context of disability we doubt whether research could be emancipatory without also involving the participation of those with the disability being researched. We think that any study adopting the Stone and Priestley emancipatory research principles would most likely be participatory in nature. In particular, we find it difficult to see how the principles of 'full accountability' to disabled persons and of 'giving voice to the personal' could be fulfilled in the absence of participation on the part of the disabled persons concerned. Our approach avoids the need to develop precise definitions of either participatory research or emancipatory research. Because of our view that research cannot be emancipatory without also being participatory, we refer to emancipatory research only from this point onwards; in doing so we encompass what others may regard as emancipatory research *and* participatory research.

**Methodology**

Clearly, in developing methodology that we hope other researchers will make use of, it would be remiss of us not to have adopted a suitable process for developing methodology. The

process began with the inauguration of a group of autistic adults (Asperger's Consultation Group) by one of the establishments involved to begin a process of identifying the important elements of a framework for emancipatory research in the field of autism. This was followed by a widening of the team to include other universities, and independent researchers, who added to and finessed the work of the Asperger's Consultation Group. This included three separate mapping exercises. An initial mapping of the proposed elements of the framework against the stages of a research project was carried out to validate the elements and ensure that all stages of a research project were covered adequately. This was followed by mapping the framework elements against the Stone and Priestley (1996) definition of emancipatory research in the field of disability (with a focus on autism rather than disability more generally) to ensure compliance with this definition. The results of our Stone and Priestley mapping exercise are set out at Appendix 2. It will be noted that each criterion within our proposed framework maps against one or more of the elements of the definition. A final mapping exercise was carried out to check that the resulting framework was consistent with the draft Code of Practice for researchers prepared by the Shaping Autism Research project (Hampton and Fletcher-Watson, 2016). We amended various aspects of the framework following our review of the Code of Practice. The outcome of this final mapping (see Appendix 1) reassured us that the framework, based on the work of the Asperger's Consultation Group, is consistent with an important definition of emancipatory research, and with the draft Code of Practice for autism researchers. This, in turn, validates the framework sufficiently for us to present it in this article. We would want to revisit our framework if Shaping Autism Research made any significant changes to their Code of Practice.


**A framework for emancipatory research in the field of autism**

We now propose a framework for emancipatory research in the field of autism substantially based on ideas developed by the Asperger's Consultation Group working in conjunction with one of the University's predominant neurotype scholars. It is our belief that this framework is consistent with the Stone and Priestley emancipatory research principles. The various items in the framework reflect aspects of work undertaken by one of us for her PhD thesis entitled 'Participatory research with adults with Asperger's syndrome: using spatial analysis to explore how they make sense of their experience' (Robinson, 2014). Another one of us investigated the elearning experience of an autistic, mature-aged university student (Downing, 2014). Although we do not contend that either study met all the requirements to be considered emancipatory research, they were highly influential both in bringing us together and in enabling the identification of matters relevant to participation and emancipation in autism research. The identification process we adopted involved listing the stages of the research process, developing what we felt should be requirements for emancipatory research research in autism at each stage, mapping the initial set of requirements against the stages, together with reviewing and amending a draft framework over various iterations to produce the final draft at Appendix 1. We describe our proposed framework as a draft because we would be surprised if we have got it 'right first time'. It is our hope that others will find our draft of interest and work it up into something that researchers regard as a useful tool for undertaking autism research.

We propose that a framework for emancipatory research in the field of autism should encompass criteria relating to the usual stages in academic research (research design, data collection, data analysis, reporting, and publishing). In many cases items we would include in such a framework relate to all the stages of the research process; for instance, the criterion ' Understand and respect how each member of the group of researchers functions in a working

capacity and as people' clearly relates to the design, data collection, data analysis, and reporting elements of the framework. The criteria relating to the stages of the research process, all of which we believe to be self-explanatory, are set out in Appendix 1.

## General requirements

We now discuss additional requirements of a general nature, reflecting certain of the Stone and Priestley criteria, and some specific requirements designed to ensure compatibility between an emancipatory research project and those funding it.

### 1. A researcher with autism either identifies and defines the matter(s) requiring investigation or confirms the identification and definition of the problem by others[8]

This first general requirement is designed to overcome the issue that autism research is very often undertaken for interests other than that of people with autism. Because few research projects are likely to be identified and defined by an autistic researcher, we propose that one or more autistic researchers should validate the identification and definition of a research project devised by non-autistic researchers. This should help to ensure that an autistic perspective is taken into account in the initial development of a project and in applications for funding from external organisations. This requirement reflects an aspect of item 4 of the Stone and Priestley criteria for emancipatory research into disability.

### 2. Social model of disability at the heart of the project ethos

The second item is a requirement for the social model of disability to be at the heart of the project ethos. This item is designed to ensure that the project is based on a belief that the main reasons for autistic people not being able to live a fulfilling life are the barriers placed in their way by a non-autistic society, and that it is a societal responsibility to remove these barriers, not put the blame for the difficulties faced by autistic people on them as individuals.

It is essential that funding bodies believe in this principle if they are not to be in conflict with the ethos of a project identified and defined by, or validated by, one or more researchers with autism. A conflict of ethos between the funding body and researchers represents a serious conflict of interest which is likely to have damaging impacts on the project. This requirement reflects item 1 of the Stone and Priestley criteria for emancipatory research into disability.

### *3. Projects are either owned or jointly owned by representatives of the autism community*

We also consider that for research to be emancipatory research it must be 'owned' in whole or in part by members of the autism community to ensure that the research is valued by the community. This requirement reflects an aspect of item 4 of the Stone and Priestley criteria for emancipatory research into disability.

### *4. Research outcomes are focused on improving the lives of people with autism*

Finally, and perhaps most importantly of all, emancipatory research must be focused on producing outcomes with the potential to improve the lives of people with autism. It is likely that a project with this potential would be valued by the autism community, and hence be one the community would be willing to 'own'. However, we contend that overt ownership of a research project by persons with autism is an essential requirement over and above the need for outcomes that can improve autistic lives because it demonstrates the commitment of persons with autism to the project. This requirement reflects item 3 of the Stone and Priestley criteria for emancipatory research into disability.

### Funding body requirements

It is also considered that various criteria should be applied to those organisations which fund autism research if such research is to be regarded as emancipatory. We propose the following

three criteria in this regard to ensure a compatibility of ethos between a research project and an external body funding the research:

1. The research is either funded by the autism community or the ethos of an 'external' funding body is consistent with the emancipatory approach set out in this framework.

2. The funding body does not stipulate requirements as a condition of funding the research inconsistent with an emancipatory approach.

3. The funding body signs up to a suitable emancipatory research framework for the project.

**Conclusion**

Oliver (1997) asked whether emancipatory research is a realistic goal or an impossible dream. He thinks that the scope of participatory research is insufficient, and that emancipatory research is needed as a (research) game changer. His following comment makes this plain: 'Thus participatory and action approaches, it seems to me, share a limited vision of the possible. To use a game metaphor, these approaches are concerned to allow previously excluded groups to be included in the (research) game as it is whereas emancipatory strategies are concerned about both conceptualising and creating a different game, where no one is excluded in the first place' (ibid., p. 27). It is not clear whether he thinks that emancipatory research is a realistic goal though. Barnes (2002, p. 16) writes that '(eroding the forces creating and sustaining disability) is not an easy task but no one said that it would be. Nonetheless, it is a task that all of us involved in doing disability research should be aiming for. If we aren't then, for my money, there's little point in doing it'. Following Barnes, we argue there is little point in researching autism unless the forces creating and sustaining the barriers to autistic people living fulfilling lives are tackled.

To facilitate the carrying out of emancipatory research in the field of autism we have developed a framework of criteria for emancipatory research in this field based on the Stone and Priestley (1996) definition of emancipatory research and influenced by Oliver's (1997) emancipatory research criteria. Our proposed framework consists of a set of requirements relating to each of the key stages of the research process together with some general requirements, and items necessary to avoid any conflict of interest between the autism community and external bodies funding individual research projects. We put forward our ideas not as a definitive set of requirements for emancipatory research in the field of autism but as a discussion document. It is intended that publication of this draft framework will provoke a debate amongst autism researchers and thereby lead to better practice. Our framework, suitably 'translated', may also be of benefit to researchers working in other areas of disability. We echo Barnes's (2002) thoughts in arguing that all researchers of disability should be doing their utmost to erode the forces creating and sustaining disability; our aim is for the framework to make a contribution towards this erosion both in general and in relation to autism in particular. We are also hopeful that Yergeau (2010) would not regard our paper as an example of what she has described, disparagingly, as a 'typical autism essay'[9].

**Note**

1. Decisions as to which terms to use when referring to autistic individuals (or should it be persons with autism?) are always difficult and nuanced (Kenny et al., 2016). We use the identity-first language preferred by many autistic individuals (Sinclair, 2013) in addition to the person-first alternative recommended by the American Psychological Association, as avoiding one form of language would imply its superiority over the other. In taking this stance we follow Dunn and Andrews (2015) who argue that both forms should be used. Kenny at al. (2016, p. 459) conclude that 'The overriding principle for those who are unclear about appropriate terminology should … be to

inquire of the people with whom they are working or describing for clarification'. That is precisely what we did.

2. We distinguish between an organisation such as the UK's Developmental Adult Neuro-Diversity Association (DANDA) run by and for neurodiverse individuals, and organisations led by non-autistic stakeholders.

3. Autism is a developmental (social learning) disability, not an intellectual learning disability or a mental health issue. However, it may be accompanied by an intellectual learning disability and/or mental health issues.

4. The members of the Asperger's Consultation Group are Katrina Fox, Duncan MacGregor, and Laura Hickman. Asperger syndrome is an autism spectrum diagnosis under the fourth edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-IV) (APA, 1994).

5. The term "neurotypical" – short for neurologically typical – is in common use in the autism community to refer to non-autistic individuals. However, one of us introduced the term "predominant neurotype" – which focuses on autistic people being in a minority – because the "typical" in "neurotypical" was considered too close to the word "normal" for comfort (Beardon, 2008).

6. By "ownership" we mean that the overall control of a project lies with members of the autism community (although day-to-day management of the project may be delegated to others), not just that the project deliverables are for the benefit of this community.

7. For details of what the autism community regard as priorities for autism research funding please see the work of Pellicano, Dinsmore and Charman (2014). By definition, these priorities are emancipatory in nature.

8. An autism research project undertaken by one autistic researcher working alone cannot be classified as participatory even if it otherwise meets all the requirements of the proposed framework. However, such research does not *need* to be included in the framework because it is in the total control of an autistic scholar.

9. In relation to articles on autism written from a predominant neurotype perspective, Yergeau (2010, n.p., our italics) writes: 'I am loath to believe that readers of the *typical autism essay* doubt the importance of autism: it's the importance of autistics that they largely doubt'.

## Disclosure statement

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## References

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*. Washington, DC: American Psychiatric Association.

Arnold, L. (2010) The Medium is the Message. *Autism, Ethics and Society*, London: UCL.

Asperger, H. (1944). 'Autistic psychopathy' in childhood, in (Ed.) Frith, U., *Autism and Asperger Syndrome*, Cambridge: Cambridge University Press.

Balcazar, F. E., Keys, C. B., Kaplan, D. L., & Suarez-Balcazar, Y. (1998). Participatory action research and people with disabilities: Principles and challenges. *Canadian Journal of Rehabilitation*, 12, 105-112.

Barnes, C. (2002). 'Emancipatory disability research': project or process?. *Journal of Research in Special Educational Needs*, 2 (1).

Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health*, 60 (10): 854.

Beardon, L. (2008). *Asperger Syndrome and perceived offending conduct: a qualitative study*, Unpublished EdD thesis; Sheffield Hallam University, Sheffield, UK. Last accessed 14 February 2017 at: Unpublished PhD thesis; De Montfort University, Leicester, UK. Last accessed 7 September 2015 at: http://shura.shu.ac.uk/7155/1/Beardon_aspergers_-_full.pdf

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice*. *Annu. Rev. Public Health*, 29, 325-350.

Chappell, A. L. (2000). Emergence of participatory methodology in learning difficulty research: understanding the context. *British Journal of Learning Disabilities*, 28 (1): 38-43.

Chown, N. P. (2013). The mismeasure of autism: a challenge to orthodox autism theory. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1 (2).

Chown, N. (2014). More on the ontological status of autism and double empathy, *Disability & Society*, 29 (10): 1672-1676.

Cornwall, A., & Jewkes, R. (1995). What is participatory research?. *Social Science & Medicine*, 41 (12): 1667-1676.

De Martino, B., Harrison, N. A., Knafo, S., Bird, G., & Dolan, R. J. (2008). Explaining enhanced logical consistency during decision making in autism. *The Journal of Neuroscience*, 28 (42): 10746-10750.

Downing, J. (2014). Applied or Denied?: The eLearning Experience of an Autistic, Mature-Aged University Student. *International Journal of Cyber Ethics in Education (IJCEE)*, 3 (2): 1-15.

Dunn, D. S., & Andrews, E. E. (2015). Person-First and Identity-First Language: Developing Psychologists' Cultural Competence Using Disability Language, *American Psychologist*, 70 (3): 255-264.

Graby, S. (2012, June). To be or not to be disabled: autism, disablement and identity politics. In *Theorising Normalcy and the Mundane'conference, University of Chester, Chester* (Vol. 27).

Hampton, S. and Fletcher-Watson, S. (2016). *Shaping Autism Research: Code of Practice for Researchers, first draft*. Last accessed online 7 February 2017 at: http://www.shapingautismresearch.co.uk/tagged/outputs

Jivraj, J., Sacrey, L. A., Newton, A., Nicholas, D., & Zwaigenbaum, L. (2014). Assessing the influence of researcher–partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review. *Autism*, 18 (7): 782-793.

Kanner, L. (1943). Autistic disturbances of affective contact, *Nervous Child*, 2, 217-250.

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49 (1): 59.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462.

Luke, L., Clare, I. C., Ring, H., Redley, M., & Watson, P. (2012). Decision-making difficulties experienced by adults with autism spectrum conditions. *Autism*, 16 (6): 612-621.

Martin, J. A. (2014). Research with adults with Asperger's syndrome—participatory or emancipatory research?. *Qualitative Social Work*, 0 (00): 1-15.

Milton, D. E. (2012) On the ontological status of autism: the 'double empathy problem', *Disability & Society*, 27 (6): 883-887.

Milton, D. E. (2014). Autistic expertise: a critical reflection on the production of knowledge in autism studies. *Autism*, *18*(7), 794-802.

Milton, D. E., & Bracher, M. (2013). Autistics speak but are they heard?. *A Journal of the BSA MedSoc Group*, 201361.

Mottron, L., Dawson, M., Soulières, I., Hubert, B. and Burack, J. (2006) Enhanced Perceptual Functioning in Autism: An Update, and Eight Principles of Autistic Perception, *Journal of Autism and Developmental Disorders*, 36 (1): 27-43.

Murray, D., Lesser, M., & Lawson, W. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism*, 9 (2): 139-156.

Oliver, M. (1992). Changing the social relations of research production?. Disability, Handicap and Society, 7 (2): 101–114.

Oliver, M. (1997). Emancipatory research: Realistic goal or impossible dream?, in Doing Disability Research, Eds. Barnes, C. and Mercer, G., Leeds, UK: The Disability Press

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18 (7): 756-770.

Robertson, S. M. (2009). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, *30*(1).

Robinson, J. (2014). *Participatory research with adults with Asperger's syndrome: using spatial analysis to explore how they make sense of their experience*. Unpublished PhD thesis; De Montfort University, Leicester, UK. Last accessed 7 September 2015 at: http://hdl.handle.net/2086/11040

Sinclair, J. (2013). Why I dislike "person first" language, *Autonomy*, 1 (2).

Stoecker, R. (1999). Are academics irrelevant? Roles for scholars in participatory research. *American Behavioral Scientist*, 42 (5): 840-854.

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47 (4): 699-716.

Waltz, M., 2006 in Arnold, L. (2010). Participatory and emancipatory research: What's the problem, Last accessed 7 September 2015 at: http://www.science20.com/ethical_autism_research/participatory_and_emancipatory_autism_research_what%E2%80%99s_problem

Yergeau, M. (2010). Circle wars: Reshaping the typical autism essay. *Disability Studies Quarterly*, *30*(1). Last accessed 8 February 2017 at: http://dsq-sds.org/article/view/1063/1222

Zarb, G. (1992). On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap and Society*, 7 (2): 125–138.

**Appendix 1: Principles for inclusive research with adults with autism**

| Framework requirements | General | Funding body | Research design | Data collection | Data analysis | Reporting | Publishing |
|---|:---:|:---:|:---:|:---:|:---:|:---:|:---:|
| • The autism community and/or a researcher with autism either identifies and defines the matter(s) requiring investigation or confirms the identification and definition of the problem by others. | ■ | | | | | | |
| • The social model of disability is at the heart of the project ethos. | ■ | | | | | | |
| • The project is either owned or jointly owned by representatives of the autism community. | ■ | | | | | | |
| • The outcomes of the research are focused on improving the lives of people with autism. | ■ | | | | | | |
| • An advisory group of stakeholders is set up prior to any application for funding. | ■ | | | | | | |
| • The research is funded by the autism community or the ethos of an 'external' funding body is consistent with the emancipatory/participatory approach set out in this framework. | | ■ | | | | | |
| • Funding body does not make requirements inconsistent with an emancipatory/participatory approach. | | ■ | | | | | |
| • Funding body signs up to this framework in respect of the funded project. | | ■ | | | | | |
| • Understand and respect how each member of the group of researchers – both autistic and predominant neurotype[1] – functions in a working capacity and as people. | | | ■ | ■ | ■ | ■ | |
| • Agree how to work together. | | | ■ | ■ | ■ | ■ | |
| • Define functionality in the group i.e. who performs which role. | | | ■ | ■ | ■ | ■ | |
| • Agree and define the objective as a group for each stage of the analysis. | | | ■ | ■ | ■ | ■ | |
| • Meeting together as a group and discussing the data in the light of shared experiences led to a richer data analysis. | | | | | ■ | | |
| • Create an environment where all researchers feel safe to share their experiences. | | | ■ | ■ | ■ | | |
| • Respect the individuality of all researchers and allow for people to work differently. | | | ■ | ■ | ■ | | |
| • Rather than training researchers with autism on how to conduct data analysis, work with the way that the researchers think and analyse in a way that makes sense to them and use their natural skill set. | | | | | ■ | | |
| • Each researcher with autism should be allowed to be themselves, express what they want to say and use their experience as a person with autism to be creative and positive. | | | ■ | ■ | ■ | | |
| • Agree how to present the data for all researchers and this might be different for different people. | | | | | ■ | | |

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[1] From this point on all references to "researchers" encompasses both autistic and predominant neurotype researchers unless stated otherwise.

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| • Agree how the group will make sense of the data and theme it. | | | | | ▒ | | |
| • Make sense of the themes together through discussion and sharing of experience. | | | | | ▒ | | |
| • Agree how the themes relate to each other and to the question being investigated. | | | | | ▒ | | |
| • Open access publication where practical (more autism research needs to be open access as a matter of course so that the 'where practical' proviso is no longer required). | | | | | | | ▒ |
| **Participant requirements*** | | | | | | | |
| • Create a collection environment where participants feel safe to share their experiences, which avoids face-to-face contact if a participant requires, and allows sufficient time for a participant to compose their response to questions, avoiding pressure to respond more quickly. | | | | ▒ | | | |
| • Respect the individuality of all participants and allow for people to contribute differently. | | | | ▒ | | | |
| • Each participant should be allowed to be themselves, express what they want to say and use their experience as a person with autism. | | | | ▒ | | | |
| • Provide an opportunity for participants to review and comment on content relating to their contributions. | | | | | | | |
| • Where a participant disagrees with a conclusion drawn by the researchers such disagreement should be recorded in publications relating to the research project. | | | | ▒ | | | |
| • Request feedback from participants on a regular basis including at the end of the project. | | ▒ | | ▒ | | | |
| • Publish lay versions of reports for the benefit of participants. | | | | | | ▒ | |
| • Offer to hold an informal session with participants after completion of the project. | | | | ▒ | | | |
| **Researcher requirements** | | | | | | | |
| • Each researcher has different expertise and all should be respected. | | ▒ | ▒ | ▒ | | | |
| • Passion for a full inclusion of all researchers and a commitment to finding a way to make this work together with the researchers with autism. | | ▒ | ▒ | ▒ | | | |
| • Ensure that differences of opinion are handled in a respectful and supportive manner. | | ▒ | ▒ | ▒ | | | |
| • Establish Clear boundaries. | | ▒ | ▒ | ▒ | | | |
| • Communicate in a manner sensitive to the needs of each individual. | | ▒ | ▒ | ▒ | | | |
| • Respect limits. | | ▒ | ▒ | ▒ | | | |
| • Listen and allow people time to speak. | | ▒ | ▒ | ▒ | | | |
| • Allow the group to be itself and grow organically. | | ▒ | ▒ | ▒ | | | |
| • Adopt a reflexive approach to their work. | | ▒ | ▒ | ▒ | | | |

* These requirements are over-and-above the general requirements expected of all rigorous research such as obtaining informed consent.

**Appendix 2: Principles for inclusive research with adults with autism mapped against Stone and Priestley's criteria**

| Framework requirements | Social model | Commitment to emancipation | Practical benefit | Full accountability | Giving voice to the personal | Methodological flexibility |
|---|---|---|---|---|---|---|
| • The autism community and/or a researcher with autism either identifies and defines the matter(s) requiring investigation or confirms the identification and definition of the problem by others. | | | | | ▒ | |
| • The social model of disability is at the heart of the project ethos. | ▒ | | | | | |
| • The project is either owned or jointly owned by representatives of the autism community. | | | | | ▒ | |
| • The outcomes of the research are focused on improving the lives of people with autism. | | | ▒ | | | |
| • An advisory group of stakeholders is set up prior to any application for funding. | | | | ▒ | | |
| • The research is funded by the autism community or the ethos of an 'external' funding body is consistent with the emancipatory/participatory approach set out in this framework. | | ▒ | | | | |
| • Funding body does not make requirements inconsistent with an emancipatory/participatory approach. | | ▒ | | | | |
| • Funding body signs up to this framework in respect of the funded project. | | ▒ | | | | |
| • Understand and respect how each member of the group of researchers functions in a working capacity and as people. | | ▒ | | | | |
| • Agree how to work together. | | ▒ | | | | |
| • Define functionality in the group i.e. who performs which role. | | ▒ | | | | |
| • Agree and define the objective as a group for each stage of the analysis. | | ▒ | | | | |
| • Meeting together as a group and discussing the data in the light of shared experiences led to a richer data analysis. | | ▒ | | | ▒ | |
| • Create an environment where all researchers feel safe to share their experiences. | | ▒ | | | ▒ | |
| • Respect the individuality of all researchers and allow for people to work differently. | | ▒ | | | ▒ | |
| • Rather than training researchers with autism on how to conduct data analysis, work with the way that the researchers think and analyse in a way that makes sense to them and use their natural skill set. | | ▒ | | | ▒ | |
| • Each researcher with autism should be allowed to be themselves, express what they want to say and use their experience as a person with autism to be creative and positive. | | ▒ | | | ▒ | |
| • Realise that having autism is an advantage in the data analysis. | | ▒ | | | | |
| • Agree how to present the data for all researchers and this might be different for different people. | | ▒ | | | ▒ | |
| • Agree how the group will make sense of the data and theme it. | | ▒ | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| • Make sense of the themes together through discussion and sharing of experience. | ▪ | | | ▪ | | |
| • Agree how the themes relate to each other and to the question being investigated. | ▪ | | | | | |
| • Open access publication where practical (more autism research needs to be open access as a matter of course so that the 'where practical' proviso is no longer required). | ▪ | ▪ | | | | |
| **Requirements for participants** (in addition to usual good ethical practice such as informed consent) | | | | | | |
| • Create a collection environment where participants feel safe to share their experiences, which avoids face-to-face contact if a participant requires, and allows sufficient time for a participant to compose their response to questions, avoiding pressure to respond more quickly. | ▪ | | | ▪ | | |
| • Respect the individuality of all participants and allow for people to contribute differently. | ▪ | | | ▪ | | |
| • Each participant should be allowed to be themselves, express what they want to say and use their experience as a person with autism. | ▪ | | | ▪ | | |
| • Provide an opportunity for participants to review and comment on content relating to their contributions. | ▪ | | | | | |
| • Where a participant disagrees with a conclusion drawn by the researchers such disagreement should be recorded in publications relating to the research project. | ▪ | ▪ | | | | |
| • Request feedback from participants on a regular basis including at the end of the project. | | ▪ | ▪ | | | |
| • Publish lay versions of reports for the benefit of participants. | | ▪ | ▪ | | | |
| • Offer to hold an informal session with participants after completion of the project. | | ▪ | ▪ | | | |
| **Requirements for researchers** | | | | | | |
| • Each researcher has different expertise and all should be respected. | ▪ | | | | | |
| • Passion for a full inclusion of all researchers and a commitment to finding a way to make this work together with the researchers with autism. | ▪ | | | | | |
| • Challenge negative opinions. | ▪ | | | | | |
| • Establish Clear boundaries. | ▪ | | | | | |
| • Be prepared to communicate. | ▪ | | | | | |
| • Respect limits. | ▪ | | | | | |
| • Listen and allow people time to speak. | ▪ | | | | | |
| • Allow the group to be itself and grow organically. | ▪ | | | | | |
| • Adopt a reflexive approach to their work. | ▪ | | | | | |