



Autism Community Research Priorities: The Potential of Future Research to Benefit Autistics

Nick Chown¹ & Luke Beardson² & Shona Louise Murphy³ & Elsa Suckle⁴ & Joanna Baker-Rogers⁵

¹London South Bank University, UK

^{2,3}Sheffield Hallam University, UK

^{4,5}Independent Scholar, UK

Correspondence: Nick Chown, London South Bank University, UK

Email: chownn@lsbu.ac.uk

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Abstract

Despite the enormous amounts of money spent on autism research, there has been little focus to date on what members of the autistic community believe should be prioritised by autism researchers. Our systematic review of the literature identified three published studies that had developed wide-ranging autism research priority sets. We undertook an in-depth analysis of these priorities sets to determine whether research focused on each priority had the potential to benefit the well-being of and/or emancipate autistic individuals. For this purpose, we used published ‘inclusive research’ criteria. We also compared the three sets of autism research priorities in the context of autistic well-being and emancipation. Our findings demonstrated substantial differences between the priorities in the studies in terms of whether they might benefit and/or be emancipatory for autistic people. Autistic people were a small minority of participants in studies where participant numbers had been recorded. There has yet to be a study focused solely on understanding the autism research priorities of autistic adults.

Keywords: Autism Research Priorities, Emancipatory Research, Participatory Research, Wellbeing

Introduction

Autistic adults are usually not involved in the co-production of research that informs future practice or research priority development (Benevides et al., 2020), let alone in leading their own research into autistic prioritisation of future research topics. Most research in autism is still undertaken on autistic people rather than with them and is often unconcerned with improving their day-to-day lives (Chown et al., 2017). Leadbitter et al. (2021, p. 3) rightly point out that researchers ‘should not assume that the things that make a good neurotypical life are identical to autistic priorities.’ There is a huge volume of publications about autism with many of these making recommendations for future research.

However, only a small handful of studies have sought to identify a cluster of top priorities for autism research generally rather than to specific autism research topics. Our objective, as a group of autistic autism researchersⁱ, was to identify studies that had developed a set of general autism research priorities, analyse the priorities in each of the studies against the criteria for ‘inclusive’ autism researchⁱⁱ we had developed earlier (Chown et al., 2017), and compare the studies from the perspective of these priorities. We searched the English language literature over the period 2012 to 2022 for studies that had developed sets of general autism research priorities. After removing two duplications from the 26 studies identified by our review, we noted that eight studies focused on funding analysis/statistics, and statistical approaches to determining equitable distribution of public funding and priority ratings; whilst another seven studies focused on specific issues (applied behaviour analysis (ABA), chemical links to autism, co-occurring anxiety, mental health, sexuality and intimate relationships, suicide prevention, and transition to adulthood and employment). One item had actually been published prior to our publication date search criterion and there was a brief encyclopaedia entry. Roche, Adams & Clark (2021) had undertaken a systemic review of priority studies. All the publications included in this systematic review were included in our review except for an investigation into the earliest signs of autism in infants by Fletcher-Watson et al. (2017) and a study by Shattuck et al. (2018) which focused on the transition of autistic youth into adulthood. As both these studies were investigations into specific aspects of autism rather than the general autism prioritisation we focused on, no additions to our study were required.

Six studies had developed relevant autism research priority sets, two from Australia (Clark & Adams, 2020; Gatfield et al., 2016), two from the UK (Pellicano, Dinsmore & Charman, 2014; Warner, Cooper & Cusack, 2019), one US study (Frazier et al., 2018), and one study was undertaken by Australian and Singaporean researchers (Simpson et al., 2022). The Simpson et al. (2022, p. 1) study was limited to the staff of one Singaporean company and is unlikely to have included any autistic participants so was excluded from our study. The Clark and Adams study was focused on parental perspectives on autism research and was also considered too narrowly focused for inclusion in our evaluation exercise.

Pellicano, Dinsmore and Charman (2013; 2014) study had been commissioned by the UK charity Research Autism. The Warner, Cooper & Cusack (2019) research was undertaken on behalf of Autistica. Frazier et al. (2018) had been commissioned by Autism Speaks. Further searching of literature citing items included in our analysis identified one study – Gotham et al. (2015) – which had used the research priority set developed by the Pellicano-led team. The study led by Gatfield for the Australian Autism Research Council had been updated in 2021 (AARC, 2021). The first author (Chown, 2019) had undertaken a preliminary review of Pellicano, Dinsmore and Charman (2014) and Warner, Cooper and Cusack (2019).

The Gatfield et al. (2016) priorities study was funded by the Cooperative Research Centre for Living with Autism (Autism CRC) which was established under the Cooperative Research Centre Program of the Government of Australia. Their survey was based on the Warner, Cooper and Cusack (2019) research priorities. The Gotham et al. (2015) priorities study was funded by Autism Speaks, the Simons Foundation, the US National Institutes of Health, and the Vanderbilt Institute for Clinical and Translational Research. This study replicated the Pellicano, Dinsmore & Charman (2014) study priorities. As we evaluated the Warner, Cooper and Cusack (2019) and Pellicano, Dinsmore & Charman (2014) priorities there was no need to evaluate the Gatfield et al. (2016) or Gotham et al. (2015) priorities. We now describe the three studies which had developed general autism research priority sets:

- (1) Frazier et al. (2018)
- (2) Pellicano, Dinsmore and Charman (2014), and
- (3) Warner, Cooper and Cusack (2019).

Frazier et al. (2018, p. 3966) undertook an online survey of ‘community stakeholder’ⁱⁱⁱ views about autism research priorities, ‘conducted ... as part of a strategic planning process for Autism Speaks’. Their survey was ‘intended to reach autism stakeholders as broadly as possible through the multiple channels by which the survey link was published’, with special mention for Autism Speaks’ website and social media platforms, and an Interagency Autism Coordinating Committee meeting. There was insufficient detail in the brief report from Frazier et al. (2018) to enable a judgement as to how diverse the stakeholders they contacted were, although they refer to the ‘broader autism community’. Over 96% of respondents were from either the USA or Canada. The authors reported that the most highly rated research topics were co-occurring conditions; health and well-being; adult transition; and lifespan issues. The report stressed the importance of including autistic people and their families in the process of developing priorities for autism research funding, and of considering the wide range of autistic needs when setting priorities and in designing and delivering studies.

The article by Pellicano, Dinsmore & Charman (2014, p. 756) reported the results of a study which ‘sought to establish whether the pattern of current UK autism research funding maps on to the concerns of the autism community’. Their approach was to compare actual UK autism research funding against views on research priorities obtained through an online survey, interviews, and focus groups, involving autistic adults, family members, practitioners, and researchers. These authors concluded that there was a clear disparity between UK autism research funding and the priorities identified by the majority of their participants. Major findings included a general consensus that future priorities should focus more on matters that make a difference to people’s day-to-day lives, and that the autism community should be more involved in the setting of priorities, and in research more

generally, to ensure that resources are focused on areas of highest need. The term ‘autism community’ is not defined, however the participation of families, practitioners, and researchers, in addition to autistic people, suggests that the authors drew this term at least as widely as Frazier et al. (2018). Pellicano, Dinsmore and Charman (2013, p. 18) developed a taxonomy of six research areas ‘which drew heavily on the research questions from the US’s 2011 IACC [Interagency Autism Coordinating Committee] *Strategic Plan for Autism Spectrum Disorder Research*’. These researchers derived 13 research questions (RQs) from the six key research areas – presumably RQs they felt more appropriate for the UK than the IACC US-focused RQs – and asked their participants to rate the relative importance of the 13 RQs. They reported ‘Overall, ... broad agreement across all four stakeholder groups [autistics, parents, people working with autistics, and researchers] that all 13 research questions were of value, each obtaining a rating of at least ‘moderately important’ (ibid., p. 29).

Warner, Cooper & Cusack (2019, p. 2) produced a report on autism research funding for the UK autism body Autistica, the objective of which was to ‘highlight gaps in autism research and neglected topics or groups, so in the future we can prioritise underfunded areas and make sure research has a focus on community priorities’. This study was a similar strategic funding initiative to that undertaken by Frazier et al. (2018) for Autism Speaks. It was also said to ‘provide a springboard to track annual funding trends’. The study focused on funding grants made in 2016 which went to 17 universities and NHS Trusts across the UK. The authors calculated that 27% of autism research funding in the UK was spent on the top ten community priorities as identified by over 1,000 participants, ranked ‘by the community’ and then ‘sorted into a top ten list in a final workshop attended by autistic people, parents and professionals’ (p. 16). It is not clear how the participants were recruited, what ranking ‘by the community’ means, or why this ranking would not have produced a ‘top ten’ priority list without the need for a workshop. The finding that ‘animal research represented 44% of total UK autism research funding in 2016’ (p. 18) is clear indication that UK grants were heavily focused on genetic studies rather than research to benefit autistic people. Survey participation in the three studies we evaluated are summarised in Table 1.

Table 1: Participation in the three autism research prioritisation studies

<i>Study</i>	<i>Participation</i>
Frazier et al. (2018)	Autism stakeholders as broadly as possible including autistic people, family members, researchers, clinician/educators and ‘others’
Pellicano, Dinsmore & Charman (2014)	Autistic people, immediate family members, professionals, and researchers
Warner, Cooper & Cusack (2019)	Autistic people and their families, caregivers, clinicians, and professionals

The percentage of responses in these studies from autistic adults where participant numbers had been recorded were less than 10%. It is noteworthy and disappointing that the great majority of responses to these surveys were not from those with lived experience of autism, indeed the autistic viewpoint in some of the studies appeared almost incidental. In preliminary work for this study, Chown (2019) reviewed 129 studies covering the period 1997 to 2016, to identify whether they were (i) linked to the priority set developed by Pellicano, Dinsmore and Charman (2014), and (ii) compliant with the criteria for 'inclusive autism research' proposed by The Independent Autism Research Group, of which the first, second, third, and fifth authors are founding members (Chown et al., 2017). Of the 37 studies which involved either autistic adults or parents of autistic individuals, only four (11%) were linked with one of the priorities developed by Pellicano, Dinsmore and Charman (2014), which was just 3% of the complete dataset. Only one study from the 37 was even partially compliant with the criteria for 'inclusive autism research' (Chown et al., 2017). Although difficulties associated with being a sole, self-funded researcher prevented drawing any firm conclusions, the findings that only 3% of the studies reviewed were linked with a UK autism community research priority, and that only 1% could be classified as partly 'inclusive' (no study was fully compliant), are indicative of the challenge facing those who argue that autism research should improve autistic lived experience. The difference between the 3% reported by Chown (2019) and the 27% reported by Warner, Cooper and Cusack (2019) is immediately obvious. It is possible that this discrepancy might reflect at least some movement in the focus of autism research towards the priorities of autistic people, as the Chown (2019) review encompassed the two decades prior to the year (2016) studied by Warner, Cooper & Cusack. However, in the absence of research transparency, there is a high risk of misunderstandings. Such transparency is essential 'to ensure that autism research priority studies ... are meaningful and replicable' (Chown, 2019, p. 95). Without it, no conclusions regarding a shift in focus towards the priorities of autistic people can yet be drawn.

There appears to be no reliable source of annual data for country comparison purposes. However, of the vast sums spent in the US on autism research in 2008, only 5% went on lifespan issues and 1% on services for autistic people (Pellicano, Dinsmore & Charman, 2014). Similarly, only 5% of UK research funding between 2007 and 2011 was focused on identification of services for autistic individuals and their families (ibid). It appears that the powerful influence of stakeholders seeking prevention/cure of autism has, for a long time, been skewing the focus of autism research to the profound detriment of autistic people, with nothing to suggest that this situation has changed to any significant extent since these figures were published. For example, it has been reported by Roche, Adams and Clark (2020, p. 21) that across all the studies included in their systematic review of key autism stakeholder perspectives, 'applied research foci were prioritised over research targeting basic science, despite this [basic science] being one of the areas to have

received the greatest funding to date'. Cervantes et al. (2020), reporting on trends in US National Institutes of Health (NIH) funding for autism services research over the period 2008-2018, identified that aetiology remains the overriding priority for US research funding. The IACC 2016-2017 strategic plan (IACC, 2016) called for more research to improve services for autistic people, alongside a recommendation to double autism research spending from the 2015 level. Despite the calls for change, Cervantes and her colleagues found that, even when there are clear recommendations to funding bodies based on identified priorities, these recommendations are not always followed. It appears that those seeking funds for applied research priorities are, in effect, competing for crumbs. The primary objective of the current study was to carry out an in-depth analysis of the three major studies into autism research priorities, to determine the extent to which the priorities presented by each study had the potential to benefit the well-being of autistic people, and the extent to which the priorities could be regarded as potentially emancipatory for autistics. We also compared the research priority sets to determine whether there were any significant differences between them from the perspectives of well-being and emancipation.

Methods

We have mapped each priority proposed by the four studies introduced earlier against the following two research questions (RQs):

- (1) Will research focused on the priority be of potential benefit to the well-being of autistics?
- (2) Will research focused on the priority have the potential to be emancipatory for autistics?

There is as yet no definitive understanding of autistic wellbeing. For research question (1) each member of the team took an individual view as to whether or not research in respect of each priority could/would benefit autistics' wellbeing, in terms of such indicators as: enhanced satisfaction in the quality of their lives; increased life opportunities; greater opportunities for the realisation of their potential; and more positive mental health outcomes. In relation to research question (2) we adopted the 'inclusive autism research' framework from Chown et al. (2017), which combines participatory and emancipatory approaches based on ideas developed by the members of a university-based group of autistic adults.

Phase 1 involved all members of the team evaluating the priorities against the two RQs and providing feedback to the team. This qualitative evaluation was based on our team's expertise in autism, by lived experience, through working with autistic people, and as researchers. In Phase 2, the first author reviewed and amalgamated all the feedback from the team members. This was then shared with the members of the team for ratification. There was a large degree of agreement, about whether or not research under each priority

could potentially benefit autistics and/or be emancipatory for them at both stages. A similar degree of consistency existed between the team members in relation to both RQs, which suggested that the absence of a framework for RQ (1) was not a significant issue. Differences of opinion were discussed amongst the team and a majority view adopted. Although coding of priorities, in relation to their potential to benefit autistics and be emancipatory for autistics, was based on individual judgement, all members of the team are autism specialists, and the majority of us are autistic. We therefore feel qualified to exercise such judgement.

Results of the Mapping Exercises

We now set out our mapping of the priorities in the three analysed studies against our RQs in tables 4, 5 and 6. Priorities are considered to have the potential to benefit and/or emancipate autistics if research complies with the criteria set out in Chown et al. (2017) in addition to standard research criteria (reproducibility, rigor, transparency etc.). We focus on matters with the potential to improve well-being and be emancipatory simply because we do not believe that research can, in and of itself, achieve either of these goals. By the phrase '*if deployed appropriately*', we mean research undertaken to facilitate positive outcomes for autistics, e.g., through appropriate support, empowerment, or greater understanding (of self and by others), rather than to bring about any change that might harm them, e.g., attempts at normalisation. The results of the mapping of the priorities against the RQs are shown in Table 2 (Pellicano, Dinsmore & Charman (2014)), Table 3 (Autistica (Warner et al., 2019)) and Table 4 (Autism Speaks (Frazier et al., 2018)).

Table 2: Results of mapping the Pellicano, Dinsmore & Charman (2014) priorities against the RQs

Research priorities	Potential benefits for autistics?	Potentially emancipatory for autistics?
(a) How can we better recognise the signs and symptoms of autism?	Yes	If deployed appropriately
(b) Are there different types of autism?	If deployed appropriately	If deployed appropriately
(c) How common is autism?	If deployed appropriately	If deployed appropriately
(d) How do autistic people think and learn?	Yes	If deployed appropriately
(e) How are autistic people's brains different from the brains of non-autistic people?	If deployed appropriately	If deployed appropriately
(f) To what extent is autism caused by environmental factors?	No ^{iv}	No
(g) To what extent is autism caused by genetic factors?	No	No
(h) What are the best ways to treat the core symptoms of autism?	No, unless social or bio-psycho-social (BPS) model adopted and deployed appropriately	No, unless social or BPS model adopted and deployed appropriately
(i) How can public services best meet the needs of autistic people?	Yes	Yes
(j) What is the place of autistic people in society today?	No	No
(k) What are the best ways to improve the life skills of autistic people?	Yes	If deployed appropriately
(l) What does the future hold for autistic adults?	No	No
(m) Why do autistic people appear to be more at risk from some medical conditions than non-autistic people?	Yes	If deployed appropriately
N.B. Study participants rated the priorities on a Likert scale (from 'not-so-important' to 'very important'). We evaluated the priorities for potential benefit for autistics and potential for the emancipation of autistics.		

Table 3: Results of mapping the Autistica (Warner et al., 2019) priorities against the RQs

Research priorities	Potential benefits for autistics?	Potentially emancipatory for autistics?
(a) Which interventions improve mental health or reduce mental health problems in autistic people?	Yes	If deployed appropriately
(b) Which interventions are effective in the development and communication/language skills in autism?	Yes	If deployed appropriately
(c) What are the most effective ways to support/provide social care for autistic adults?	Yes	Yes
(d) Which interventions reduce anxiety in autistic people?	Yes	If deployed appropriately
(e) Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?	Yes	Yes
(f) How can parents and family members be supported/educated to care for and better understand an autistic relative?	Yes	Yes
(g) How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?	Yes	Yes
(h) How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?	If deployed appropriately	If deployed appropriately
(i) How can sensory processing in autism be better understood?	If deployed appropriately	If deployed appropriately
(j) How should service delivery for autistic people be improved and adapted in order to meet their needs?	Yes	No, but would be 'yes' if all services are offered according to universal design principles and the neurodiversity model – so if deployed appropriately

Table 4: Results of mapping the Autism Speaks (Frazier et al., 2018) priorities against the RQs

Priority research areas	Potential benefits for autistics?	Potentially emancipatory for autistics?
(a) Genetics	No	No
(b) Other molecular studies	No	No
(c) Cellular studies	No	No
(d) Animal models	No	No
(e) Environmental risk and protective factors	Yes	No
(f) Neural systems	No	No
(g) Biomarkers/measures	Some areas ^v	No
(h) Immunity and inflammation	Some areas	No
(i) Metabolic and mitochondrial	Some areas	No
(j) Screening and identification	Yes	If deployed appropriately
(k) Understanding co-occurring conditions	Yes	If deployed appropriately
(l) Diet and nutrition	Yes	If deployed appropriately
(m) Developmental and behavioural interventions	If deployed appropriately	If deployed appropriately
(n) Medical interventions	No	No
(o) Devices and other technology	Only if social or BPS model adopted and deployed appropriately	Only if social or BPS model adopted and deployed appropriately
(p) Adult transition	Yes	Only if social or BPS model adopted and deployed appropriately
(q) Lifespan issues	Yes	Only if social or BPS model adopted and deployed appropriately
(r) Health and well-being	Yes	Yes

Comparison of the Three Priority Sets

We compared the results of the evaluation of the three priority sets as shown in Table 5.

Table 5: Results of comparing the priority sets as a whole

Study	Percentage of autistic participants	Number of priorities	Potential benefits for autistics?		Potentially emancipatory for autistics?	
			As is	If all deployed appropriately	As is	If all deployed appropriately
Pellicano, Dinsmore & Charman	9%	13	5 (38%)	9 (69%)	1 (8%)	9 (69%)
Autistica	Not recorded	10	8 (80%)	10 (100%)	4 (40%)	10 (100%)
Autism Speaks	7%	18	7 (39%)	9 (50%)	1 (6%)	8 (44%)
N.B. The figures in the 'If all deployed appropriately' columns are the sum of the 'As is' figure and the number of additional priorities that would potentially benefit/emancipate if deployed appropriately.						

Of the 13 Pellicano, Dinsmore & Charman (2014) priorities, five are considered to have the potential to be beneficial to autistics and an additional four priorities could potentially be beneficial if deployed appropriately. Only one priority could potentially be emancipatory as it is, although eight others have the potential to be emancipatory if the research is deployed appropriately. The 10 Autistica priorities include eight with the potential to be beneficial with the other two having the potential to be beneficial if deployed appropriately. Four Autistica priorities are considered to have emancipatory potential as they are, and six others have the potential to be emancipatory if the research is deployed appropriately. Seven of the 18 Autism Speaks priorities have the potential to benefit autistic people and two others could potentially be beneficial if deployed appropriately. Only one of the Autism Speaks priorities has the potential to be emancipatory as is, but eight could potentially be emancipatory if the research is deployed appropriately.

Discussion

Of the three evaluated studies, Autistica came out on top as regards priorities we felt could be beneficial to autistic people with 80% (8 of 10) of their priorities being of potential benefit as they stand, increasing to 100% if the research is deployed appropriately. The percentages for Pellicano, Dinsmore & Charman (2014) were 38% (5 of 13), increasing to 69% (9 of 13), and for Autism Speaks were 39% (7 of 18) increasing to 50% (9 of 18). As regards research priorities considered to have emancipatory potential for autistic people, Autistica again came out on top with 40% (4 of 10), increasing to 100% if the research is deployed appropriately. The percentages for Pellicano, Dinsmore & Charman (2014) and Autism Speaks were 8% (1 of 13) and 6% (1 of 18) respectively, although considerably more of the priorities identified by Pellicano, Dinsmore & Charman (2014) were potentially capable of being emancipatory, if deployed appropriately, than those identified by Autism Speaks (69% and 44% respectively). In summary, future research focused on any of the ten Autistica priorities has the potential to benefit and be emancipatory for autistics if it is deployed appropriately in comparison to almost 70% of the priorities developed by Pellicano, Dinsmore & Charman (2014) and fewer than half (47%) of the Autism Speaks priorities. It is clear that there are substantial differences between the potential of research focused on the priorities identified in these studies to benefit and/or emancipate autistic people.

Autism Speaks states that it 'is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families'. However, this organisation's clear medical model focus, search for medical treatments, and involvement with the 'world's largest genomic database', might indicate why only just over one third of their priorities were considered relevant to benefitting the lived experiences of autistic people, and only one was considered to be emancipatory.

Although Autistica was originally an offshoot from Autism Speaks, it is our understanding that there has not been a formal relationship between these organisations for many years. Despite the reference in the Autistica vision to medical research, there is a clear difference in the Autistica rhetoric from that used by Autism Speaks, as the former refer specifically to the importance of ensuring that autistic people achieve long, healthy, happy lives. It is possible that Autistica's priorities were impacted by the fact that its lead researcher is autistic, that autistic people were involved in the research priorities project, and the agenda-setting process was autistic-led. This may have encouraged trust, participation and openness on the part of research participants, leading to results that better reflected autistic community priorities. The inclusion of autistic people at all stages of the Autistica project (although it is not known exactly how many) might explain our finding that a much higher percentage of their identified priorities could result in research with the

potential to benefit and emancipate autistics than those of the Pellicano-led and Autism Speaks studies.

The priorities identified by the Pellicano, Dinsmore & Charman (2014) study fall midway between those of the Autism Speaks and Autistica studies in terms of both benefit and emancipation. We were surprised that only 1 (8%) of the priorities developed by Pellicano and her colleagues (2014) were considered to have emancipatory potential as they stand, although, if deployed appropriately, this figure rises to 9 (69%). It is of interest to compare this finding with the Pellicano, Dinsmore and Charman (2013, p. 29) finding that 'Overall, there was broad agreement across all four stakeholder groups that all 13 research questions were of value, each obtaining a rating of at least 'moderately important'. Despite differences in the potential benefit, and emancipatory capacity, of research focusing on the individual priority sets in the studies evaluated, a consensus existed across all the conclusions regarding where future autism research should focus its efforts. All these studies call for a focus on matters that make a positive difference to autistic people's daily lives, including health and wellbeing, societal education, and a shift away from the negative aspects of autism. Including autistic people and their families in the process of developing priorities for autism research funding, in designing and delivering studies, and taking account of the wide range of autistic needs when setting priorities, was advocated by all. The percentages of autistic participants in the two studies where this could be calculated were only 7% and 9%. There has yet to be an English-language study investigating the research priorities of autistic adults which represents a yawning gap in the literature.

There are inherent conflicts in autism research priority-setting. Given that the majority of the authors of this report are autistic, it will not surprise readers to learn that we believe that autism research should be both beneficial to autistics and emancipatory, and that we desire a shift in research focus from aetiology, cure, and prevention to better lived lives. However, for non-autistic parents of autistic children (widely included in the priority setting studies) there can be a tension between the desire for research to improve their child's lives and research that might improve their own lives. This is not necessarily problematic, as parental wellbeing and support is an important factor in the lives of all children, but it is imperative that the measures taken to help parents do not inherently harm autistics. For many non-autistic researchers, as the Autism Speaks priority list in particular highlights, career considerations can take a primary role in the setting of research agendas. Funding for autism research in the USA, for example, has been a bonanza for researchers seeking a way to fund basic brain research or to assemble tools, such as large genetic databases, in order to do genetic or genomic research. As a result, much of this research has only been incidentally about autism, with autism providing a pretext for researchers to investigate other fundamental issues. Unfortunately, for those of us who wish to see a shift in autism research priorities towards those with the potential to benefit and emancipate

autistics, research actually on autism is still far more often focused on preventing/curing autism than on improving autistic lives. We agree with Bovell (2020, p. 52) who writes as follows about preventing/curing autism:

prevention and/or cure [of autism] as a desirable general goal is neither clinically/scientifically coherent nor morally legitimate. To talk in approving terms about prevention and cure implies that a world where there are no more autistic people would be a better world. Aside from how offensive this is to some, it is wildly simplistic. To persist in justifying prevention and cure as broad goals means to persist in believing ... that such a future world would be a better place.

We recognise that our findings are unlikely to influence those research funders who support research with the long-term aim of preventing/curing autism. This is largely due to what the first author refers to as the *autism worldview dilemma*, which expresses the impossibility of reconciling the different perspectives (worldviews) on autism which range from wanting to remove autism from the human genome to viewing autism as natural human difference. However, for those funding bodies which fund autism research without necessarily adopting a particular perspective on autism, our comparative study demonstrates that autism research priority setting reflects the wide range of worldviews on autism. If a funding body wishes to finance research of value to autistic people – research with the potential to improve the lives of autistics – they should take note of the worldview on autism of the priority setting body. In particular, they should determine whether the research they are thinking about funding has potential to emancipate autistics. For autism research to be of maximum benefit to autistic people it should at least be participatory but ideally it should be autistic-led, as research led by autistics will almost always have the potential to be emancipatory or lead to an increase in emancipatory research. In their paper proposing a framework for participatory and emancipatory autism research, Chown et al. (2017) proposed emancipatory criteria for ensuring a compatibility of ethos between a research project and an external body funding the research as follows:

- (1) ... 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.

Funding bodies which seek to finance autism research which is both participatory and emancipatory could incorporate the following specific criteria within their funding application guidance as set out by Chown et al. (2017):

- (1) [An autistic researcher] either identifies and defines the matter(s) requiring investigation or confirms the identification and definition of the problem by others
- (2) Social model of disability at the heart of the project ethos
- (3) Projects are either owned or jointly owned by representatives of the autism community
- (4) Research outcomes are focused on improving the lives of [autistic people].

Limitations

Although we used the ‘inclusive autism research framework developed by Chown et al. (2017) in relation to RQ (2), we were unable to find a suitable framework for RQ (1).

Whilst great care was taken to ensure that our findings represent the views of us all, they are the result of individual assessments. As the first author undertook much of the Phase 2 work, the results could have been overly influenced by him. However, all members of the team have reviewed the first author’s work and support the results reported here. All our evaluation work is inevitably subjective assessment as is the case for all qualitative research. In combination, the members of the team have expertise in autism by lived experience, through working with autistic people, and as researchers. With priorities of a medical nature, we sought specialist advice from an expert member of Autistic Doctors International, a peer support and advocacy group for medical doctors identifying as autistic.

It is necessary to examine bias in the procedural determination of research priorities (Roche et al., 2020). Our group is not representative of the autistic community as all our autistic members are so-called ‘high functioning’ individuals (like most scholars of course).

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ⁱ We are members of the Independent Autism Research Group which, in addition to developing criteria for what we call ‘inclusive’ autism research, have undertaken studies of support for autistic students in higher education and published a range of articles on subjects of relevance to autistic adults. Most of us are autistic.

ⁱⁱ Inclusive autism research is research that is both participatory and emancipatory.

ⁱⁱⁱ Frazier et al. state that ‘the online survey was intended to reach autism stakeholders as broadly as possible’ (2018, p. 3966). The reference to ‘community stakeholders’ appears to include anyone with an interest in autism i.e., in this case the term “stakeholder” seems to be a synonym for “participant”.

^{iv} Whilst we consider research to identify and enable the removal of environmental factors that may cause autism, such as possible hazards from exposure to chemicals and medication, to be justifiable such research is of no benefit to autistic lived experience.

^v Generally speaking, genomics research has great potential for healthcare benefits. If biomedical research is to benefit autistic people, it will also be in the area of healthcare, not in community stratification. Adding to basic science will lead to genetic tests including pre-natal tests. But this is not openly acknowledged or addressed in the consent process for biomedical research projects. One often reads that “There are no anticipated harms associated with participating”. Whilst this may well be true for individual participants, the potential harm to the autistic community is ignored (Doherty, 2022).