RUNNING HEAD: Community attitudes to early autism research

Attitudes of the autism community to early autism research

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Abstract

Investigation into the earliest signs of autism in infants has become a significant sub-field of autism research. This work invokes specific ethical concerns such as: use of 'at-risk' language; communicating study findings to parents; and the future perspective of enrolled infants when they reach adulthood. The current study aimed to ground this research field in an understanding of the perspectives of members of the autism community. Following focus groups to identify topics, an online survey was distributed to autistic adults, parents of children with autism, and practitioners in health and education settings across eleven European countries. Survey respondents (n=2317) were positively disposed towards early autism research and there was significant overlap in their priorities for the field, and preferred language to describe infant research participants. However there were also differences including overall less favourable endorsement of early autism research by autistic adults relative to other groups and a dislike of the phrase 'at-risk' to describe infant participants, in all groups except healthcare practitioners. The findings overall indicate that the autism community in Europe is supportive of early autism research. Researchers should endeavour to maintain this by continuing to take community perspectives into account.

Keywords

Autism spectrum disorder; development; infancy; public engagement; ethics

Attitudes of the autism community to early autism research

Abstract

Investigation into the earliest signs of autism in infants has become a significant sub-field of autism research. This work invokes specific ethical concerns such as: use of 'at-risk' language; communicating study findings to parents; and the future perspective of enrolled infants when they reach adulthood. The current study aimed to ground this research field in an understanding of the perspectives of members of the autism community. Following focus groups to identify topics, an online survey was distributed to autistic adults, parents of children with autism, and practitioners in health and education settings across eleven European countries. Survey respondents (n=2317) were positively disposed towards early autism research and there was significant overlap in their priorities for the field, and preferred language to describe infant research participants. However there were also differences including overall less favourable endorsement of early autism research by autistic adults relative to other groups and a dislike of the phrase 'at-risk' to describe infant participants, in all groups except healthcare practitioners. The findings overall indicate that the autism community in Europe is supportive of early autism research. Researchers should endeavour to maintain this by continuing to take community perspectives into account.

Keywords

Introduction

Autism spectrum disorder is not often diagnosed before the age of 3 years old (Boyd et al., 2010). A recent review reported mean age of diagnosis to range from 3 – 10 years depending on factors such as symptom severity but also socio-economic status (Daniels and Mandell, 2013). In a large European sample, mean age of diagnosis was 3.5 years (42 months) and varied with language ability and gender (Salomone et al., 2015a). This is despite the fact that the presence of features in the early developmental period is a criterion for diagnosis (APA, 2013) and that ASD is largely determined by a combination of genetic and environmental factors, the latter group believed to act primarily on the developing brain in the pre-natal period (Gardener et al., 2011; Geschwind and State). While many tools exist to screen for signs of autism in infancy and early childhood (Charman and Gotham, 2013), these are not necessarily widely available outside English-speaking countries (García-Primo et al., 2014). Worldwide, reliable clinical diagnosis at less than 2 years old therefore remains elusive, and at the time of writing diagnosis in infancy or pre-natally is impossible.

A significant focus of current research endeavour focuses on description of the earliest signs of ASD (Elsabbagh and Johnson, 2007; Jones et al., 2014). This work tracing the development of ASD in the developmentally-sensitive period from birth to three years aims to provide reliable early diagnosis and identify targets for early intervention (Dawson, 2010; Webb et al., 2014). In addition, many theoretical models attribute the roots of the social communication difficulties, restricted interests and sensory behaviours, which characterise ASD, to this early life stage (Johnson et al., 2015). Thus precise accounts of the early features of ASD have the potential to elucidate our understanding of social and cognitive development in typical populations as well (Johnson et al., 2009).

Prospective longitudinal studies have the greatest potential to detect these early features. However, because ASD is present in not more than 1% of the population (Elsabbagh et al., 2012), recruitment from a general population sample at birth would require 1000 infants to

yield a final group of just 10 children with an ASD diagnosis. Mass population screening could produce larger sample, but is expensive and may be ethically complex, in part due to high rates of false-positive results (Ross, 2015; Stenberg et al., 2014). Thus many early autism researchers have chosen to adopt a practical solution, focusing their attention on so-called 'at risk' groups. These are normally the infant siblings of children who already have an ASD diagnosis (Elsabbagh and Johnson, 2009), often known as 'ASD-siblings', of whom about 20% later receive an ASD diagnosis (Ozonoff et al., 2011). In addition, children born very preterm have begun to be a focus of early autism studies due to their enhanced likelihood of later ASD diagnosis (Kuzniewicz et al., 2014). Key findings from studies employing ASD-sibling designs include identification of atypicalities during infancy, in social responding (Bedford et al., 2012; Jones and Klin, 2013; Ozonoff et al., 2010), attention (Elsabbagh et al., 2013), language (Landa et al., 2012) and structural and functional connectivity (Wolff et al., 2012; Orekhova et al., 2014). However, few of these findings have yet been unequivocally corroborated, with the exception of early attention switching atypicalities (Elsabbagh et al., 2013; Zwaigenbaum et al., 2005; Elison et al., 2013). Further study is needed to identify early markers with adequate specificity and sensitivity to act as individual level predictors for later ASD (Jones et al., 2014).

Early autism research, particularly work employing longitudinal designs with infant siblings, entails a series of ethical concerns (Yudell et al., 2012; Zwaigenbaum et al., 2007). The relationship between participating families and research teams is complex and requires careful management. Participants are asked to commit to a long research study incorporating multiple data collection points, and where, in most cases, all of the assessments focus on their new baby and not on their older child, already known to have ASD. This attention to the younger child, for whom the most likely outcome is still typical development, may affect parenting and family dynamics and certainly fails to address what might be the most present concern for most parents – their older child with ASD. Most longitudinal designs are principally descriptive and, in Europe, not necessarily linked with clinical services (Bolte et

al., 2013) Therefore intervention will not be offered, even if early signs of autism are detected, (though exceptions where longitudinal studies incorporate intervention include Green et al., 2015; Rogers et al., 2014). In fact, researchers are not always permitted by their ethical oversight body to share early concerns with parents. And indeed the fact that these early signs are not yet reliable markers presents research teams with a dilemma.

For the autism community more broadly there are additional ethical concerns. One is regarding the use of the phrase 'at-risk' to describe infant groups such as ASD-siblings or infants born preterm, who also have a higher-than-usual likelihood of receiving an ASD diagnosis (as well as other atypical outcomes, cf. Moore et al., 2012). This language necessarily defines ASD diagnosis as a negative outcome, though it is not perceived that way by many autistic people (Bachelor and Wolbring, 2014).

There is an increasing expectation that researchers should, wherever possible, formulate questions, design studies and interpret and share findings in partnership with stakeholder groups (Tarpey and Bite, 2014). This is particularly pressing in a field such as early autism research where ethical concerns abound. Accordingly, the perspectives of members of the autism community (encompassing autistic individuals, their family members and supporters, and professionals who work with them) have begun to be sought more systematically by research teams (Pellicano et al., 2013; Pellicano et al., 2014; Elsabbagh et al., 2014). These projects have often revealed differences between the opinions of different groups within the autism community. In particular, the rise of an autistic self-advocacy movement has highlighted how autistic people may disagree with other stakeholders, such as parents of children with autism (Kenny et al., 2015). Further, it remains unclear whether or how the opinions of autistic adults with intellectual disability, including individuals who are minimally-verbal, might differ from those of autistic self-advocates without such barriers to voicing their thoughts.

The current study aims to collect the opinions of autism community members in order to provide a foundation for early autism researchers wishing to engage with stakeholder groups. We ask what are the opinions of the autism community on early autism research? In particular, we address four categories of stakeholders whose perspectives we consider to be of importance: autistic adults, parents of children with autism, healthcare practitioners and education practitioners. Parents of children with autism have an obvious investment in early autism research: they may be invited to participate in such studies and the eventual outputs from the field (early diagnosis, early intervention) will directly impact on the experience of similar parents in future generations. Autistic adults were consulted for two main reasons. The first is that, in line with the *nothing about us without us* disability rights movement (Carlson, 2013; Shakespeare, 2013), it is appropriate to gather the views of autistic people on any topic relating to autism (Pellicano et al., 2011). More specifically however, we must also try to consider how the current generation of children enrolled in early autism studies may subsequently feel about their participation when they reach adulthood. Even before that, researchers will have to secure consent from child participants as they reach a suitable age (e.g. 16 years old). Healthcare and education practitioners also have a key role to play in this kind of survey as they will normally be involved in referral, diagnosis and post-diagnostic support. To the extent that the early autism research field aims to produce outputs of practical relevance, it is practitioners in healthcare and education who will be expected to respond to, and enact these findings.

We used focus groups to develop an online survey suitable for all stakeholder groups, probing attitudes to early autism research. Our goal was to answer the following key research questions:

- Is early autism research supported by stakeholder groups?

- What do stakeholders think should be the goals of early autism research?

- Are there differences in attitudes towards early autism research between stakeholder groups?

- Are there differences in the preferred language used to describe early autism research participant groups between stakeholder groups?

- What factors influence attitudes to early autism research?

Methods

Survey development

Prior to the main survey study, five focus groups were held in three European countries (Italy, Portugal and the UK) to ascertain the principal topic areas that should be addressed in the survey. The goal was to ensure that the topic areas were meaningful and relevant to stakeholders. Focus groups included parents of children with autism, autistic adults and practitioners from healthcare, education and social support settings. The groups ranged in size from n=8 to n=24 individuals. Each focus group was lead by a facilitator and another researcher who was present took notes.

Each group started with a brief introduction to the topic: research into early autism, especially longitudinal studies with infant siblings and other relevant groups (e.g. premature infants). Facilitators started with general questions (e.g. *"What do you think about this kind of research?"*) but also asked more specific questions depending on what issues were raised spontaneously (e.g. *"One of the foundations of this research is to strive for earlier diagnosis of autism – do you think this is a good goal for research?"*). Facilitators then independently reviewed the themes covered in their focus group. Next the researchers met to identify common themes across the groups. A summary of the themes raised in each focus group is provided in Table 1. This clearly indicates a high level of consistency in themes raised across countries and stakeholder groups. There were three themes that were raised by every group:

the use of 'at-risk' language; intervention in early autism research; and the issue of transparency between research participants and researchers.

[insert table 1 about here]

Following identification of themes in the focus group data, a survey was scripted and developed iteratively with input from researchers across Europe[1]. Themes were incorporated into the survey in three possible ways. First, we asked questions directly pertaining to a theme – for example in a section specifically asking for opinions on the use of "at-risk" language. Second, we targeted participant groups based on themes raised in focus groups – for example we recruited adults with autism and also included items on autism diagnostic status for parents in order to capture data from autistic adults, relevant to the theme *"perspective of baby-sibs when they grow up".* Third, we attempted directly to address some of the themes raised in the focus groups – such as *transparency between researchers and participants* in the way we collected data and shared our findings with participants.

Next, the survey was piloted in the UK with a handful of autistic adults (n=2), practitioners (n=3) and parents (n=3). The survey had four sections. In the first section, all respondents provided basic information about their gender, age, country of residence and birth. In the second section, all participants were asked to identify themselves in one stakeholder category. These were: autistic adult; parent; healthcare practitioner (e.g. medic, therapist); education practitioner (e.g. teacher, learning support assistant); other. For simplicity, healthcare practitioners are referred to in the analysis as Practitioners, and education practitioners are referred to as Teachers.

In the third section, depending on the category chosen, participants were asked to provide further background information. For example, the two different practitioner categories were asked about professional qualifications and techniques regularly used in their practice, while parents were asked for information about their children including diagnostic information for

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[1] A copy of the English-language survey can be downloaded at www.dart.ed.ac.uk/ear-project

the (youngest, if more than one) child with autism. Parents were also asked if they had, or suspected they should have, an autism diagnosis and likewise autistic adults were asked whether they were parents. In addition, all stakeholder groups (except 'Other') were asked to rate the quality of their local autism services and whether these were available as a public service or privately.

The fourth section was prefaced with a short introduction to the field of early autism research in order to ensure a shared basic level of knowledge among respondents. Subsequently participants were asked questions about their attitudes to early autism research in five domains inspired by the focus group data: 1) reasons for doing research; 2) involvement in research projects; 3) measurement in research projects; 4) intervention; 5) 'at-risk' language. Finally, participants had the opportunity to add further comments in a final text box.

The survey was translated from English into 10 other languages for circulation across Europe (see Table 2). Translations from English into their native language were carried out by researchers who were fluent in English. Where available, another native speaker checked translations for accuracy. These researcher teams were also responsible for adapting vocabulary to the local circumstances (e.g. listing appropriate job titles as examples within the 'education practitioner' respondent category).

Recruitment Procedure

The survey was made available online and distributed by researchers affiliated to the [REMOVED FOR BLIND PEER REVIEW] network in eleven European countries: Czech Republic; Finland; France; Italy; Israel; Macedonia; Norway; Poland; Portugal; Spain; and the UK. Recruitment routes were largely via parents' associations, advocacy groups for autistic adults, and professional bodies. In addition the survey was advertised through a variety of social media and directed to the professional networks of the authors. In Italy and the UK recruitment included circulation of the survey to participants who had previously taken part in

early autism research studies (i.e. parents of children with autism), either directly through a register of former participants or indirectly via social media associated with a research group.

Analysis

Responses were collected and re-aligned in a single English language database for analysis. The design of the questions minimised the need for translation as respondents were asked to select from pre-set options in most cases. Where open-ended responses were permitted, native speakers of the original language – normally the same individuals who had translated the original survey - translated the responses into English.

Participants were excluded from the final sample if they did not complete the majority of the section four questions that probed attitudes to autism, and if they were not resident in one of the countries in which recruitment took place. In addition, most participants who had classified themselves as 'Other' were re-categorised into one of the four stakeholder groups. For example, speech and language therapists were classified as healthcare practitioners, and people working as learning support assistants in schools or as nursery staff, were added to the education participant group. In total, 160 respondents were re-assigned in this way. In addition, the small number (n=26) of other relatives of autistic people who responded (e.g. siblings, grandparents) were added to the Parent group (still called Parent as parents constituted 97.5% of this group). The number of participants remaining in the Other category was now very small relative to the other groups (n=37, 1.6%). In addition, some respondents skipped the 'respondent type' answer altogether (n=59, 2.5%). These two latter groups were combined into a new Other category, and included in analysis involving the whole sample, but not in comparisons between stakeholder groups.

Our analyses are in three distinct phases. First we provide descriptive accounts of the overall responses of the whole sample. In many cases respondents were asked to rank items in order of importance (e.g. *What are the most important reasons for doing autism research?)*. In each case lower scores represent a higher priority ranking (i.e. number 1 = top priority,

etc.). We present these data using a combination of means and modal rankings to illustrate the issues that were most important to the sample.

The second stage examines differences between stakeholder groups (excluding the Other category). We used chi-square analysis to investigate the influence of respondent type on overall attitude to early autism research. For ranking data, we used chi-square analyses to compare the distribution of responses in each possible category (ranking position 1 – 7) for each group, against expected counts. We focused only on differences in the top two possible rankings, since each ranking choice constrains other choices and thus significant differences in one ranking inevitably lead to differences in others. Where a significant chi-square results indicated differences between participant groups in the distribution of responses, z-tests with Bonferroni corrections were then employed to examine the source of these significant differences.

Finally we probed for demographic and circumstantial influences by using logistic regression to predict attitudes to early autism research. In each case we employed binary logistic regression using the Enter method. As in the previous section comparing stakeholder attitudes, we included data only from the four principal stakeholder categories (Parent, Practitioner, Teacher, Autistic Adult) and not from participants who were in the new Other category.

Results

Sample Characteristics

The final sample is described in Table 2 and 3. In total 2681 individuals started the survey, and we received data adequate for analysis from 2317 respondents across 11 European countries. Of these the largest group (44.9%) were Parents (including other family members). However each group was robustly represented, including 101 adults with autism (4.4%). In total, 152 people categorised themselves as both Parents and Autistic Adults by selecting

one respondent category at the start of the survey and then subsequently additionally reporting that they had a diagnosis / had children (see Table 3).

[insert table 2 about here]

Responses from section 3 of the survey are described in Table 3. The participant groups have similar mean ages and are mostly female, including the Autistic Adult sample. Among the two practitioner groups, about half of education practitioners and close to two-thirds of healthcare practitioners report having more than five years' worth of experience working in an autism setting. Additionally more than half of education practitioners report having autism-specific training. Self-rated knowledge of autism is average to good but all groups are less confident about their knowledge of early autism specifically. Note that we did not ask Autistic Adults to rate their knowledge of autism because it didn't seem a suitable question for a group with personal experience of having the diagnosis.

[insert Table 3 about here]

Parents were asked to provide some information about their children, in particular focusing on diagnosis. Children with autism ranged in age from 1 year to 41 years old. Age of diagnosis also ranged widely from 1 – 28 years old with 25 parents reporting that their child was currently awaiting diagnosis. More than half the sample reported raising concerns about their child when they were younger than 2-years-old, and 91% of the sample had raised concerns when their child was less than four years old. This contrasts with an average age of diagnosis of 4.75 years in this sample. Three quarters (76%) of parents reported that the first person to raise concerns was themselves, or another family member, rather than a professional.

Whole sample attitudes

The first item in Section 4 of the survey, probing attitudes to early autism research, was *Do you think research into the early signs of autism should be done?* Whole sample responses

are illustrated in Table 3 (and Supplement Figure 1) and demonstrate overwhelmingly favourable attitudes.

[insert figure 1 about here]

Mean ranks for each question are shown in Figures 1a-1c, where the response items for each question are listed in order of their modal ranking value. When asked *What are the most important questions scientists should be asking about early autism?* participants ranked questions about the genetic basis of ASD and the early signs of autism in infants as the most important. Further to this we asked what should be the goals of early autism research. Stakeholder priorities were: early identification, better clinical knowledge of early signs and (for some stakeholders) provision of help to develop skills, which prevent children from later receiving an autism diagnosis. We also asked participants specifically about the language used to describe infant groups who participate in early autism research. The preferred options were *infants with high autism likelihood* and *infants with higher chance of developing autism.*

Differences between stakeholders

These analyses include a sample of n=2222 participants across the four respondent groups (excluding 'Other'). We first explored group differences in overall attitudes to whether early autism research should be done. A chi-square analysis ($\chi2 = 43.22$, p<.001) demonstrated significant differences between the attitudes of each group. Post-hoc z-tests with Bonferroni corrections showed that the source of this significant effect was a lower proportion of Autistic Adults responding *Yes, definitely* and a higher proportion of Autistic Adults responding *Yes, probably* relative to all other groups (see Table 4).

[insert figure 2 and Table 4 about here]

Figure 2a illustrates the mean rankings provided by each stakeholder group for the reasons why early autism research should be conducted, with items exhibiting significant differences

between two or more stakeholder groups marked (chi square, p<.005). Autistic Adults more often differ in their mean rankings than the other three respondent categories. The same process was repeated for the rankings of the main goals of early autism research, illustrated in Figure 2b. Once again we can see clearly that the Autistic Adults deviate from the rest of the groups on a number of items. Post-hoc z-testing (see Supplement) shows that their rankings of *environmental factors* and *unique development* are significantly lower (i.e. more important), while *early identification* is less of a priority. In addition, parents consider *quick* diagnosis to be a higher priority than do practitioners. Finally the same process was repeated to compare stakeholder rankings of the preferred language to describe infants involved in early autism research.   These are illustrated in Figure 2c, where the only significant differences found in post-hoc z-tests were between practitioners versus other groups. They ranked *at-risk* language more favourably and *pre-autistic* less favourably than other respondents. In each case detailed results of the analysis are provided in the Supplement, Tables 1-3.

Differences between Countries

To explore national influences on attitudes to early autism research a new dependent variable was created from participant responses to the questionnaire item *Do you think research into the early signs of autism should be done?* Data were classified dichotomously as either Definite (responding 'Yes, definitely') or Not Definite (responding in any other category) in their level of support. This was because the number of participants responding in each category apart from '*Yes, definitely*' was very low and in particular very few participants responded in the negative categories (respondents selecting '*probably not*' or '*definitely not'*, total n = 31, 1.4% of whole sample; see Figure 1 and Table 3).

[insert figure 3 about here]

The distributions of respondents by country, falling into each overall attitude category are illustrated in Figure 3. As we have described already, attitudes are largely very positive. The

highest proportions of Not Definite attitudes are found in the UK, Finland and the Czech Republic. All three of these countries also had the largest numbers of respondents in the Autistic Adults category (see Table 1)

An alternate reason for national differences in attitudes to early autism research could be differences in the reported quality of service provision. Countries with poorer quality, or fewer services might induce a positive attitude to research as a way to secure additional support for an individual family, or to promote much-needed service development. Participants had been asked to estimate the usefulness of their local autism services in three categories: support, intervention and education. Ratings on a scale of 1 – 4 were moderate to positive. Since these ratings were highly correlated (all Pearson's r > .65, all p<.001) a single variable for 'service provision' was created by summing scores across the three original categories.

Logistic regression revealed that quality of service provision was a significant predictor of attitudes, Wald $\chi2$ = 4.32, p=.038, OR = .810. To further explore this effect we compared the service provision ratings of respondents within the Definite and Not Definite attitude categories, across all countries collapsed together. These data are illustrated in Figure 4, and show that people with definitely supportive attitudes to early autism research also rated the quality of regional services more favourably, perhaps indicating an overlap of attitude to both service providers and the research community. Student's t-tests (equal variances not assumed after Levene's test) indicate that the differences in mean rating of intervention and support services are statistically significant: Intervention, t(203.6) = 2.93, p=.004, 95% CI 0.08 – 0.39; Support, t(200.3) = 2.01, p=.046, 95% CI 0.002 - .332.

[insert figure 4 about here]

Discussion

The goal of this study was to examine the attitudes on early autism research of stakeholder groups in the autism community, in order to provide an evidenced foundation for researchers

wishing to engage with and incorporate the perspectives of these groups. The stakeholder groups targeted in the online survey were autistic adults, parents of children with autism, healthcare practitioners and education practitioners (both working with autistic client groups). In response to a direct attitude question, we found evidence of overall support for early autism research across all stakeholder groups. In fact the very small numbers of respondents with negative attitudes to research in the entire sample made some analyses challenging.

Goals and reasons for research that were categorised as being of highest importance clustered around the description of the earliest signs of autism. Combining survey data with focus group discussions, and information on mean age of diagnosis in this sample, we interpret this focus as reflecting a desire to achieve earlier diagnosis of autism. Understanding the genetic basis of autism was also a highly-ranked motivation for research in the field. This latest finding conflicts with a previous report in which genetic research did not emerge as a priority for stakeholder groups in the UK (Pellicano et al., 2014). This discrepancy may be attributed to our focus on early autism research rather than autism research generally. Prioritising the genetic basis of autism might seem more relevant in this sub-field than to autism research generally because identifying a genetic foundation would be the most effective way of achieving early diagnosis.

Differences in attitudes between autistic adults and other groups

As in previous reports (Pellicano et al., 2014) one of the most striking findings from these data is a considerable consistency of opinion among stakeholder groups. While differences were found, it could be easy to overstate the practical significance of these. For example, statistically significant differences between groups in the mean rankings given to a particular item do not necessarily reflect radically different sets of priorities, and visual inspection of the data reveals more correspondence than divergence. In this way, we feel these data present a positive picture of stakeholder attitudes to research, that suggests it may be possible to carry out research which corresponds with the priorities of the majority of those invested in

the research. Importantly, we are optimistic that when infants currently participating in early autism research studies grow up and look back, they will be reassured by the fact that this research was considered important by a variety of stakeholder groups at the time.

The group most likely to produce responses that did differ statistically from the others was autistic adults. These stakeholders were less likely to endorse early autism research at the most positive level, and also had somewhat different priorities for the field. One possibility, which we have not been able fully to explore with these data, is that there are differences of opinion within the autistic adult community with regard to research. The higher rate of "Yes probably" endorsements of early autism research in this group may, for example, reflect a degree of uncertainty about the goals of the field and potential impact of findings on autistic individuals. One way to address this uncertainty is to build effective knowledge exchange partnerships with community members to guide research endeavour, and online resources are available to provide guidance on this[2].

One difference of particular interest was the finding that autistic adults were more likely to rate the study of environmental factors as an important reason to do early autism research. It is possible that this item was interpreted differently by different respondents. The original wording was a question: *"What are the most important questions scientists should be asking about early autism?* and response item "*What aspects of the environment (i.e. things we can change) contribute to autism?".* Environmental influences could be interpreted as 'toxins' having a causal role in the onset of autism. For example, concerns are still present in the community about early vaccination, despite conclusive evidence to the contrary (Taylor et al., 2014). However another interpretation of this item is apparent in the open-ended responses of autistic adults at the end of the survey. One autistic participant comments that:

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[2] http://www.shapingautismresearch.co.uk/

This research must be done in order to improve the lives of autistics to make them empowered and happy, and not in order to stigmatize them. To get a diagnosis is essential, but to offer a support adapted to each is equally important.

While another says:

I hope that some day this research will give us all ASD people respect and a feeling of dignity together with the "neuronormal" people and make them understand that we have all come down from the same tree and created this civilization with the help of our common ancestors.

Thus, some survey respondents may have interpreted the role of the environment as a reference to the disability rights movement which emphasises the societal source of disability: i.e. disability is not a constant within the individual, rather their environment causes disability by failing to provide appropriate support and access. This alternative interpretation may underpin the difference in importance assigned to this item by autistic adults versus the rest of the sample.

When ranking goals of autism research, autistic adults also felt early identification was less important and showed an interest instead in *understanding the unique development of autistic children.* Likewise, although this difference was not statistically significant, patterns observed in the data indicate that autistic adults are also less concerned with the development of skills in very young children who are otherwise likely to receive a diagnosis. As highlighted above, this may reflect a fundamentally distinct approach to autism, which is founded on a personal and positive conceptualisation of the diagnosis.

As we interpret the ways in which autistic adult responses differ from those of other stakeholder groups, it is essential to acknowledge that the individuals responding to this questionnaire most likely do not have any significant intellectual disability. Differences between their point of view and that of the parents and professionals who took part may be attributable not just to having a different disposition towards autism (and by extension

towards autism research) but also to having a different experience of what autism is, or entails. In our sample, almost 60% of parents reported that their child with autism also had an intellectual disability. Their children's need for diagnosis, intervention, support and research may be very different to the needs of the adult sample in a study such as this one. At the same time, it should be noted that it is challenging to determine, in the absence of an opportunity to speak for themselves, who should most legitimately speak on behalf of autistic individuals with a profound intellectual disability: the parents and professionals who care for them? Or autistic adults, who share an autism diagnosis, but are much more cognitively able?

Differences in attitudes between parents and practitioners in health and education

When probing the preferred language used to describe infants recruited to early autism studies, healthcare practitioners deviated from other groups, most notably in their relatively higher endorsement of the phrase *infants at-risk of autism.* This phrase is very current in a research context, and it is likely that the healthcare practitioners surveyed would be most familiar, and therefore comfortable, with its use. However the preference of all groups for more neutral phrases using *chance* and *likelihood* to make the association between early developmental factors and later diagnosis indicates that researchers should consider varying their usual language if they wish to engage effectively with stakeholders.

Parents ranked the quest for earlier diagnosis more highly than did any other respondent type. This is unsurprising, in the light of our finding that average age of diagnosis of the autistic children of parents in this sample was almost five years. The large majority of parents also reported that they first raised concerns at less than four years, with more than half stating that these concerns were raised when their child was aged under two years old. Furthermore, three-quarters of the parent sample reported that concerns were first identified by themselves or another family member – not a professional. It is therefore logical that

parents in our study felt that early diagnosis was a preferred outcome from early autism research.

Other factors influencing attitudes to early autism research

These data were collected from eleven countries in Europe to provide a broad and international perspective on stakeholder attitudes. When examining all stakeholder groups together, there were differences between countries in the degree of positive support for early autism research. One possible explanation may be that the distribution of stakeholder groups was different for each nation surveyed, and so apparent country-level differences in fact are recapitulations of differences between stakeholders. For example, the highest proportions of respondents with less-enthusiastic attitudes to early autism research were found in those countries that also had the highest numbers of autistic adults responding to the survey (UK, Finland and Czech Republic).

Another possibility is that national differences reflect differences in the availability and quality of regional autism services. Service quality ratings were predictive of research attitudes in a regression, and respondents with a positive attitude to early autism research also rated their regional services as higher quality. We had expected that low quality services would promote a positive attitude to research as a way to secure additional support for the family (by enrolment in studies) and as a route to improving local services. Instead individuals with a poor opinion of local services may have extended the same negative perspective to research. This may be related to work showing that parents may be likely to seek 'alternative treatments' outside of evidence-based practice in countries where quality research evidence is not disseminated effectively (Salomone et al., 2015b).

Limitations

The study used a convenience sampling method, employing social media, personal and professional networks, parent support organisations and so on to reach a large and diverse

sample of members of the autism community. This limitations of this method mean that the final sample may not be representative of the wider community (Salomone et al., 2015c). In particular, due to the self-selecting nature of the sample, it is possible that the very positive attitudes to research observed would not be shared by a sample from a less research-engaged background (though we did not ask directly about experiences of taking part in research nor about baseline attitudes to research in general). On the other hand, it is notable that the highest proportion of respondents with less positive attitudes were from the UK, also one of only two countries (with Italy) who recruited from existing communities of participants involved in early autism research. While we do not know how many survey respondents definitely had been involved in early autism studies before, it seems likely that personal experience of research is not a guarantee of highly positive attitudes.

Another potential sampling limitation derives from the substantial quantity of missing data in this survey. There were 364 participants who started the survey but did not complete it and it is not possible to ascertain the reason for this. However it is plausible that the respondents who managed to complete the survey were among the more able and adequately resourced individuals eligible to take part and to this extent may not have been representative of the wider autism community.

Data reported in this survey derive largely from closed-response question formats, which constrain participant responses. This was necessary given the international nature of the survey and the absence of the considerable resources needed for accurate translation and back-translation of open-ended responses. As a result, analyses of influences on attitudes to early autism research rely on responses to a single survey item as the outcome variable. While this survey design choice limits participant responses, it also means that we were able to recruit a large number of participants in order to capture an overview of community opinion relating to early autism research. We hope that this work will provide the basis for more in-depth examinations of some of the issues raised in this study which will allow for better capture of individual differences and nuances of opinion.

Implications of the study

This paper reports a number of differences between stakeholder perspectives and on national lines. In particular autistic adults often had priorities and opinions, which deviated from the other stakeholder groups. However when considering the data set as a whole, and especially the practical consequences of this study, we are struck by the high levels of consistency between groups and by the powerful endorsement of early autism research provided by this very large, diverse sample. This is in contrast to recent data from the USA indicating wide divergence between attitudes and understanding of parents and scientists (Fischbach et al., 2015). The priorities of the sample surveyed correspond with what we understand to be the priorities of the scientific community: to enhance our understanding of the earliest signs of autism (including the genetic basis) in order to facilitate early diagnosis and intervention. The research community should take note of one particular finding, which is that some stakeholders may prefer alternatives to the phrase *at-risk* when describing infant groups who are more likely to later receive an autism diagnosis. However, overall the powerful endorsement of the goals of the scientific community portrayed by these data indicates that the future of early autism research has a secure foundation in the support of stakeholder groups.

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Attitudes of the autism community to early autism research: supplementary information

<u>Supplement Figure 1:</u> *Should early autism research be done?*

Legend:
- Yes definitely
- Yes probably
- No probably not
- No, definitely not
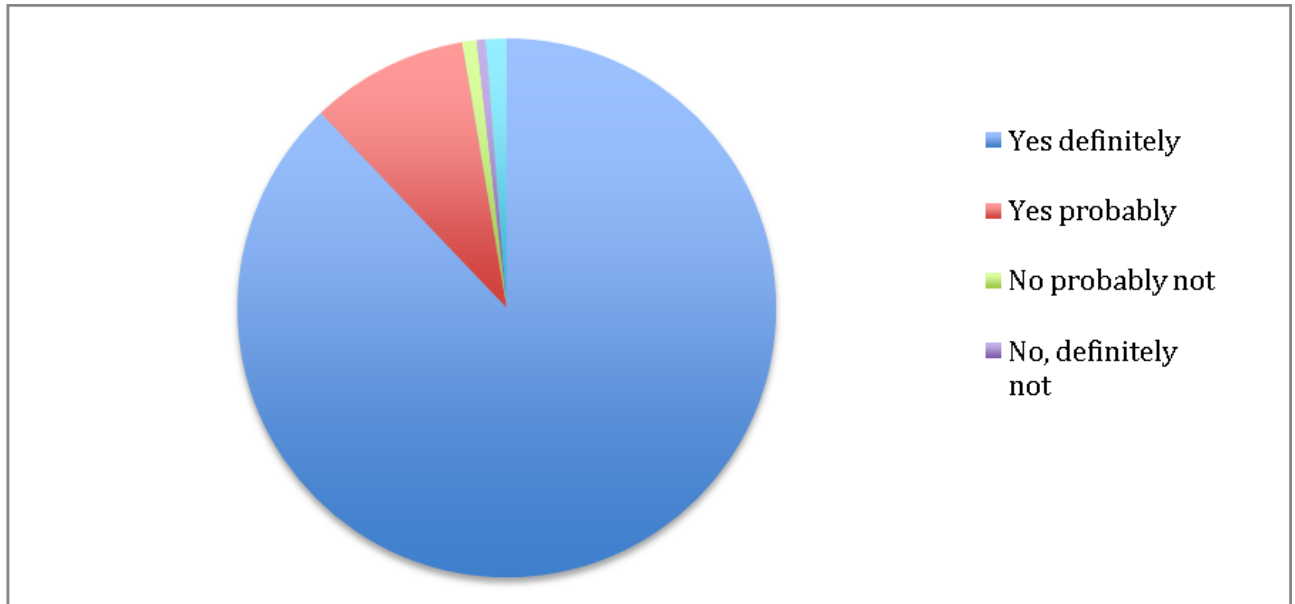
<u>Supplement Table 1: What are the most important questions scientists should be asking about early autism?</u>
Summary of chi-square results for item rankings

Item	Chi-square	z-test results summary, with Bonferroni correction
Genetic basis	χ2 = 40.00, p=.002	No significant differences in top two rankings
Present before birth	p=.473	
How develops	p=.379	
Signs in babies	χ2 = 42.52, p=.001	No significant differences in top two rankings
Environment factors	χ2 = 36.87, p=.005	Autistic Adult more likely to rank highly than Practitioner & Teacher (rank 1 only)
When does it start	p=.099	
Are infants all alike	p=.173	

<u>Supplement Table 2: What are the main goals of early autism research? Summary of chi-square results for item rankings</u>

Item	Chi-square	z-test results summary, with Bonferroni correction
Identify earlier	χ2 = 82.69, p<.001	Autistic Adult less likely to rank highly than all others (rank 1 only)
Help develop skills	χ2 = 55.60, p<.001	No significant differences in top two rankings
Early signs	p=.384	
Quick diagnosis	χ2 = 32.85, p<.017	Parent more likely to rank highly than Practitioner (rank 1 only)
Design intervention	χ2 = 44.19, p=.001	No significant differences in top two rankings
Unique development	χ2 = 69.32, p<.001	Autistic Adult more likely to rank highly than all others (rank 1 only)
Provide services	p=.053	

Supplement Table 3: What is the preferred language for early autism research? Summary of chi-square results for item rankings

Item	Chi-square	z-test results summary, with Bonferroni correction
Higher chance	p=.329	
Infants at risk	$\chi2 = 49.90$, p<.001	Practitioner more likely to rank highly than all others (ranks 1 & 2)
High likelihood	p=.342	
Increased susceptibility	$\chi2 = 35.16$ p=.009	No significant differences in top two rankings
Susceptible	$\chi2 = 29.85$, p=.039	No significant differences in top two rankings
Special groups	p=.183	
Pre-autistic	$\chi2 = 30.51$, p=.033	Practitioner less likely to rank highly than all Teacher and Parent (ranks 1 only)

Attitudes of the autism community to early autism research

Table 1: Themes raised in each focus group

	Groups who covered these themes				
	1. UK parents	2. UK practitioner	3. UK autistic	4. Portugal parent	5. Italy mixed
Themes identified					
At-risk language	X	X	X	X	X
Understanding genetic risk		X		X	X
Effects on parents and parenting	X		X		X
Effect of BAP among parents		X	X		
Communicating diagnosis or concern	X	X	X	X	
Measurement: what's appropriate	X	X		X	
Using DNA samples	X			X	
Intervention	X	X	X	X	X
Whole family support		X		X	X
Perspective of baby-sibs when they grow up	X		X		
Transparency between researchers and participants	X	X	X	X	X
Integrating research and clinical practice		X		X	X
Ways to share information		X			
Need for earlier diagnosis		X	X	X	
Communicating research findings to the community		X		X	

Table 2: Sample sizes by country and respondent category

	Practitioner	Parent	Teacher	Autistic Adult	Other / Missing	Total n	%
Czech Rep	31	122	42	9	-	204	8.8
Finland	50	97	43	38	-	228	9.8
France	37	99	7	2	1	146	6.3
Italy	71	40	9	1	5	126	5.4
Israel	20	10	15	-	-	45	1.9
Macedonia	6	10	-	-	-	16	0.7
Norway	59	91	46	8	11	215	9.3
Poland	138	103	37	4	2	284	12.3
Portugal	124	76	182	3	34	419	18.1
Spain	53	225	45	6	34	363	15.7
UK	50	167	16	30	8	271	11.7
Total n	639	1040	442	101	97	2317	
%	27.6	44.9	19.1	4.3	4.1		

Table 3: Sample characteristics by respondent type

	Practitioner	Parent	Teacher	Autistic Adult
Age in years *Mean (SD)*	39 (10.9)	41 (8.4)	42 (10.8)	36.7 (12.3)
Gender *Percentage male*	12.5%	14%	9.3%	30.7%
Years of experience in autism setting *No. (%) of sample over 5 years*	297 (63.1%)	---	101 (47.9%)	---
Rated knowledge of autism *some: average: good*	3%: 30%: 67%	5%: 30%: 65%	15%: 43%: 42%	---
Rated knowledge of early autism *some: average: good*	14%: 40%: 46%	20%: 37%: 43%	41%: 33%: 26%	---
Do you have autism training *No. (%) saying Yes*	---	---	69 (57.5%)	---
*Quality of support services	2.91 (0.80)	2.51 (0.99)	2.84 (0.85)	---
*Quality of intervention services	3.03 (0.75)	2.52 (0.99)	2.90 (0.82)	---
*Quality of education services	3.00 (0.80)	2.67 (1.01)	3.03 (0.88)	---
Age in years at leaving education *Mean (SD)*	---	22.5 (5.7)	---	24.7 (6.3)
Do you have autism? *No. (%) saying Yes*	---	138 (19%)	---	---^
Age of diagnosis (autistic adult) *Mean (SD)*	---	---	---	14.0 (18.4)
Age child diagnosed (years) *Mean (SD)*	---	4.75 (3.81)	---	---
Child age now *Mean (SD)*	---	10.3 (6.61)	---	---
Child gender *Percentage male*	---	81%	---	---
Does your child have ID? *Number (percentage) saying yes*	---	427 (59%)	---	---
Age first concerns raised *< 2 years: 2 – 4: > 4 years*	---	55%: 36%: 9%	---	---
Concerns raised by whom? *No. (%) saying "self" or "family"*	---	515 (76%)	---	---
Do you have children? *No. (%) saying Yes*	---	---	---	17 (35%)

*mean rating on a scale from 1 – 4: not very useful / a little bit useful / useful / very useful
^ participants in this category were not asked this question as they had already declared their diagnostic status by selecting the category 'adult with autism' at the start of the survey
NB: all percentages are valid percentages, excluding missing values

Table 4: Should early autism research be done? Numbers and (valid percentages)

	Practitioner	Teacher	Parent	Autistic Adult
Yes, definitely	576 (90.6%)	384 (87.7%)	910 (88%)	69 (68.3%) *
Yes, probably	43 (6.8%)	42 (9.5%)	99 (9.6%)	26 (25.7%) *
Probably not	5 (0.8%)	6 (1.4%)	7 (0.7%)	2 (2%)
Definitely not	2 (0.3%)	2 (0.5%)	6 (0.6%)	1 (1%)
Not sure	10 (1.6%)	4 (0.9%)	12 (1.2%)	3 (3%)

Figure 1: Stakeholder attitudes to early autism research

Fig 1a: Reasons for doing early autism research

- What is the genetic basis of autism?
- What are the signs of autism in babies?
- How does autism develop in early life?
- What aspects of the envrionment contribute to autism?
- Is autism present before birth?
- Whan does autism "start"?
- Are all infants who later get an autism diagnosis alike?

Mean ranking value

Fig 1b: The main goals of early autism research

- To identify autism earlier in life
- Help children [not] ... get a diagnosis*
- Help clinicians better understand early signs
- Help parents get a quick diagnosis
- Help design intervention programmes
- Understand the unique development of autistic children
- Help provide services for children at higher likelihood of autism

Mean ranking value

Fig 1c: Preferred language to describe infant participants

- Infants with higher chance of developing autism
- Infants at risk of autism
- Infants with high autism likelihood
- Infants with increased susceptibility for autism
- Infants susceptible to autism
- Special infant groups
- Pre-autistic infants

Mean ranking value

NB: lower scores indicate higher importance. Items are listed in order of their modal ranking, but values are mean rankings.
*the original item was *help children develop skills so they don't later get a diagnosis*

Figure 2: Difference in attitude rankings, by stakeholder group

Figure 2a: Reasons for doing autism research

* What is the genetic basis of autism?
* What are the signs of autism in babies?
How does autism develop in early life?
* What aspects of the envrionment contribute to autism?
Is autism present before birth?
Whan does autism "start"?
Are all infants who later get an autism diagnosis alike?

Figure 2b: Goals of early autism research

* To identify autism earlier in life
* Help children develop skills so they don't later get a diagnosis
Help clinicians better understand early signs
* Help parents get a quick diagnosis
* Help design intervention programmes
* Understand the unique development of autistic children
Help provide services for children at higher likelihood of autism

Figure 2c: Preferred language

Infants with higher chance of developing autism
* Infants at risk of autism
Infants with high autism likelihood
* Infants with increased susceptibility for autism
* Infants susceptible to autism
Special infant groups
* Pre-autistic infants

■ Autistic Adult   ■ Parent   ■ Teacher   ■ Practitioner

Figure 3: Percentage of respondents showing a Definite, or Not Definite, level of support for early autism research, organised by country.
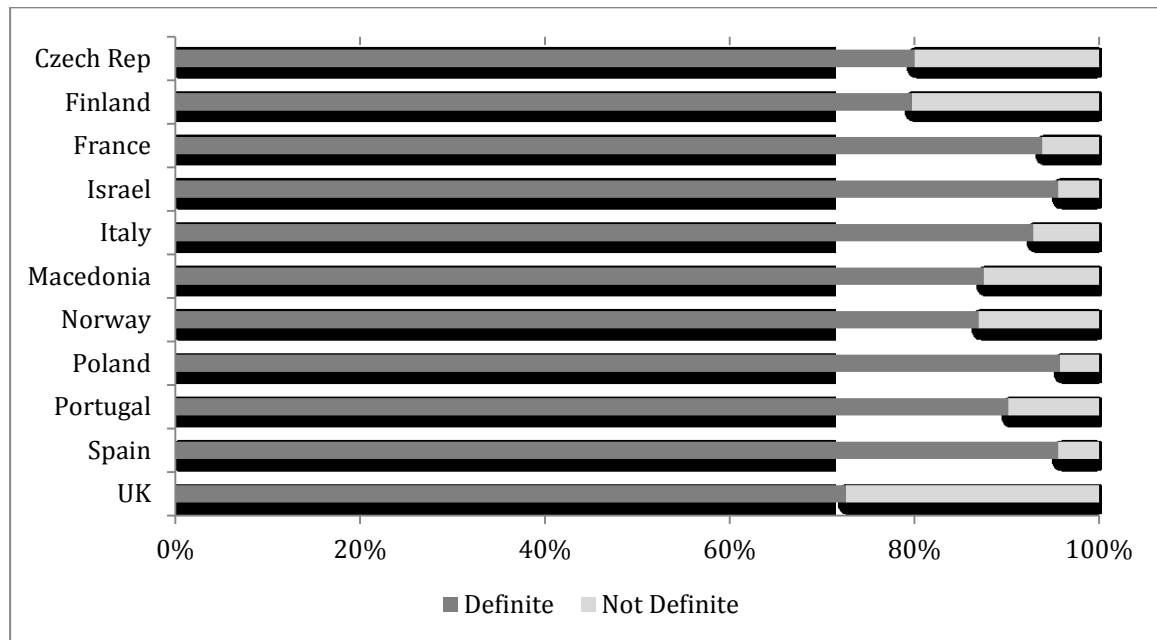
Figure 4: Ratings of the quality of regional autism services by attitude group