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ORIGINAL PAPER

Ethical Considerations in Conducting Research on Autism Spectrum Disorders in Low and Middle Income Countries

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Abstract Autism spectrum disorder (ASD) is being identified in an ever-increasing number of countries, including many that are low or middle income (LMIC). Research conducted in these countries requires awareness of unique ethical issues. Drawing on the experience of two organizations that have been involved in conducting and collaborating in ASD research in India, we describe specific considerations in conducting epidemiological, genetic and treatment studies as well as general principles from the field of multinational clinical research as they apply to the conduct of ASD research. We argue that greater attention to ethical concerns will result in quality studies conducted in LMICs that are also of greatest relevance for families and children with ASD.

Keywords Autism spectrum disorder · Ethics · Cross-cultural · ELSI · LMIC · LAMI · Global · India

Given the rapid spread of awareness about autism spectrum disorder (ASD) around the world, the condition is being identified, and research on ASD is being conducted, in an ever-increasing number of countries classified as low or middle income (LMIC).[1] Seventy-five of approximately 120 countries in which an ASD-specific organization has been established are low or middle income (see Fig. 1). In 2011 alone, studies were published from countries as diverse as Brazil (Paula et al. 2011); China (Chan et al. 2011; Wang et al. 2012); Colombia (Talero-Gutiérrez et al. 2011); Croatia (Benjak et al. 2011); Egypt (El-baz et al. 2011a, b); India (Kishore and Basu 2011; Srivastava and Mukhopadhyay 2011); Iran (Samadi and McConkey 2011; Samadi et al. 2011); Libya (Zeglam and Maouna 2011); Nepal (Kharti et al. 2011); Nigeria (Igwe et al. 2011); Oman (Al-Farsi et al. 2011; Ali et al. 2011); and Pakistan (Rahbar et al. 2011). Moreover, there is now a dedicated source of funding for research on ASD in low and middle income countries through the Autism Speaks' GAPH initiative (Paula et al. 2011a).

This growth of autism awareness and research globally is encouraging. As discussed in previous arguments for greater examination of ASD in a cultural context (e.g., Daley 2002; Bernier et al. 2010), research that includes populations with diverse genetic, linguistic and familial backgrounds offers significant opportunities to expand our understanding of the disorder. What makes research on ASD in LMICs unique is that, in the words of ethicist Michael Yudell "autism is capturing the public imagination in a way that other disorders aren't…today autism has the stage and the potential to move the public and science in very powerful ways" (Yudell 2011). This is especially true in LMICs: Where little research has been previously conducted, the significance of each study conducted is magnified because it becomes the only or one of only a few

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[1] The terms *low and middle income country* are terms used by the World Bank to refer to countries with a Gross National Income (GNI) per capita of US $12,275 or less.

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Fig. 1 Countries in which autism activity has been identified and World Bank classification of economies[†]

Low income $1,005 or less	**Lower middle income** $1,006 - $3,975	**Upper middle income** $3,976 - $12,275	**High income** $12,276 or more
Bangladesh	Albania[†]	Algeria	Aruba
Cambodia[†]	Armenia	Argentina	Australia
Dem. Rep. of Congo[†]	Belize	Bosnia and Herzegovina	Austria
Eritrea	Bolivia[†]	Botswana[†]	Bahamas
Ethiopia	Cameroon[†]	Brazil	Bahrain
Haiti[†]	Côte d'Ivoire	Bulgaria[†]	Barbados
Kenya	Egypt	Chile	Belgium
Nepal	El Salvador	China	Bermuda
Niger	Fiji[†]	Colombia	Brunei
Tajikistan[†]	Ghana	Costa Rica	Canada
Tanzania	Guatemala	Dominican Republic[†]	Cayman Islands
Uganda[†]	Guyana	Ecuador	Croatia
	Honduras	Iran	Cyprus
	India	Jamaica	Czech Republic
	Indonesia	Jordan[†]	Denmark
	Iraq[†]	Latvia	Estonia
	Laos	Lebanon	Finland
	Morocco	Lithuania	France
	Nigeria	Macedonia	Germany
	Pakistan	Malaysia	Greece
	Paraguay	Maldives	Hong Kong
	Philippines	Mauritius	Hungary
	Sri Lanka	Mexico	Iceland
	Sudan	Namibia	Ireland
	Syria	Panama	Israel
	Ukraine	Peru[†]	Italy
	Vietnam	Romania	Japan
	Yemen[†]	Russia	Kuwait
		Serbia	Libya[†]
		South Africa	Luxembourg
		Thailand	Malta
		Tunisia[†]	Netherlands
		Turkey	New Zealand
		Uruguay	Norway
		Venezuela	Oman[†]
			Poland
			Portugal
			Qatar[†]
			Saudi Arabia
			Singapore
			Slovakia
			Slovenia[†]
			South Korea
			Spain
			Sweden
			Switzerland
			Trinidad & Tobago
			UK
			USA

[†] Darker shading and notation indicates countries in which an organization has been identified; lighter shading indicates countries in which either autism-specific services or research are available but no autism-specific organization has yet been identified. Data obtained from www.autism-india.org

studies that can be drawn upon. The confluence of increased awareness of ASD globally and increased funding opportunities specifically for research on ASD in LMICs suggests that a discussion of ethical issues in global ASD research is both timely and necessary.

In this descriptive paper, we first highlight ethical issues that may be associated with conducting genetic, epidemiology and intervention studies on ASD in LMICs, centered on one brief case example for each. We include additional observations from both our own research in India, and the relevant work of others. We then draw from global health field to describe several broad principles in conducting research with special application to ASD: How to determine research priorities, the need to establish collaborative relationships, and ensuring respect for study participants. While these are only three of numerous potential principles to guide global health research (Emanuel et al. 2004), these most closely reflect the areas in which we have seen a need for increased attention in India based on the past decade of research in the country. We conclude with a final recommendation that future research on ASD in LMICs should view the condition within the broader context of disability.

Part I: ASD Research and NGOs in India

India serves as a particularly rich backdrop for a discussion of research ethics in the area of ASD for two primary reasons. First, the quantity of research conducted on ASD in India is unparalleled among low and middle income countries. A comprehensive review has identified more than 165 published research articles from 1959 through 2010 that either used an Indian sample or appeared in an Indian journal (Daley et al. 2012). While a full examination of this literature is beyond the scope of the current paper, reports on ASD in India include virtually every type of design and focus on the health system as well as children and families. Moreover, approximately 70 % of this published literature has involved human subject participation. Of note, this published literature does not capture the true scope of research activity in India, since academic institutions produce a continual stream of masters and Ph.D. students whose research often does not result in a publication, but for whom ethical guidelines still apply.

Second, India is similar to many developing countries in its struggle to adequately monitor and review research. On the one hand, contemporary consideration of the ethical conduct of research in India dates back more than 30 years, to the creation of the Indian Council of Medical Research (ICMR) Policy Statement on Ethical Considerations Involved in Research on Human Subjects in 1980. The current ICMR guidelines, detailed in the *Ethical Guidelines for Biomedical Research on Human Subjects* (ICMR 2006) describe principles consistent with standard practice in the US, such as voluntariness, informed consent, risk minimization, and privacy of data. In addition, the mushrooming business of clinical trials in India over the past decade has forced a discussion of research ethics (Samiran et al. 2005), and led the ICMR to establish the Clinical Trial Registry-India, a system that mandates the registration of all clinical trials being conducted within the country (Tharyan and Ghersi 2008).

However, in spite of these guidelines, the concept and value of research ethics in India has been described as "still developing" and challenges have been noted regarding compliance and oversight (Mathur 2010, p. 2). According to Ahmad (2003), more than 50 % of biomedical institutions in India do not have an ethics review committee or IRB, and even those with such committees do not follow rigorous procedures. Thus, despite the high-level discussions about protection of human subjects, the current climate of ethical review of ASD research in India is likely to be similar to that in many other low and middle income countries (Schulz-Baldes et al. 2007), in that review of research does not typically take place.

This paper presents the viewpoint of two large non-governmental organizations (NGOs)[2] in India, Action For Autism (AFA) and Ummeed Child Development Centre. NGOs offer an important perspective on the ethics of conducting research on ASD because studies in low and middle income countries often rely on these sources in order to access a sample of children with ASD and their families. In India, for example, approximately 60 % of the published studies on ASD using Indian participants conducted in the past decade drew research participants from special schools; the remainder of studies drew their sample from hospitals. Because of the nature of this collaborative work, NGOs have experience working with a large number of researchers, both local and international, on studies that employ a variety of methodological approaches. Autism organizations and schools also have the most direct and sustained contact with families and individuals with autism. They therefore have a strong understanding of the issues of greatest relevance to the local community, a critical component in setting priorities for research activity in LMICs (Minkler 2005; Khandewal et al. 2010; Yasamy et al. 2011).

Action For Autism was founded in 1991, and is widely recognized as the pioneering organization for autism in South Asia. The history and activities of this organization have been described in detail elsewhere (Grinker 2007; Feinstein 2010). Across more than 10 areas of work, AFA

[2] In this paper, we use NGOs to refer to entities that are self-governing, private, and not-for-profit (Vakil 1997), which includes both organizations and schools.

serves several thousand families each year. In Delhi, AFA operates a school, an adult vocational training unit, as well as a range of clinical services. AFA is known for their training and advocacy activities, which include a two-year government accredited teacher training program; an intensive 3-month parent training program; and regular workshops by local and international speakers. AFA established an IRB in accordance with ICMR guidelines in 2009 and since this time, has directed all potential researchers through this process.

Ummeed Child Development Center is located in Mumbai, and was established in 2001. Annually Ummeed provides services to approximately 1,200 children with a range of disabilities and their families; about one third of clients are families of children with ASD. Services include different types of assessments; neuro-developmental, speech and occupational therapy; parent support groups; an early intervention center; and outreach to schools. While Ummeed does not have a formal IRB, senior staff review potential research studies to determine their appropriateness and will also utilize the IRB at the Kasturba Hospital for studies in which Ummeed collects data. A lengthier description of Ummeed has previously been published elsewhere (Krishnamurthy 2008).

AFA and Ummeed have both collaborated with researchers and conducted their own studies, with involvement in more than 45 research projects dating back to the mid 1990's. In Table 1, we provide a summary of 37 research projects conducted since 2005 by investigators at least enrolled in a Master's program; a sample of these study titles appears in Table 2 to provide a sense of the range of topics addressed. These projects represent a total of 9 different Indian academic institutions and 15 institutions from outside India, including in the US, UK, Denmark, Scotland, and France. The observations throughout this paper draw from these experiences.

Table 1 Characteristics of research projects conducted in collaboration with AFA and Ummeed, 2005–2012

Characteristics	N	%
Origin of research project		
India	19	51.4
US	9	24.3
UK	6	16.2
Denmark	1	2.7
France	1	2.7
Scotland	1	2.7
Qualifications of research investigator		
PhD	10	27.0
PhD candidate	6	16.2
MD	2	5.4
Masters candidate	19	51.4
Field of researcher		
Anthropology	2	5.4
Biological sciences	1	2.7
Child development	1	2.7
Psychology/clinical psychology	7	18.9
Cognitive and computational neurosciences	2	5.4
Food and nutrition	1	2.7
Home science	1	2.7
Human development and family science	1	2.7
Information systems	1	2.7
Marketing/business	1	2.7
Masters candidate	3	8.1
Neuroimaging	1	2.7
Neuroscience	1	2.7
Nursing	1	2.7
Occupational therapy	4	10.8
Pediatrics	2	5.4
Psychiatry	1	2.7
Public health	1	2.7
Radiological imaging and biomedical engineering	1	2.7

Part II: Specific Ethical Issues Related to ASD Research in Low and Middle Income Countries

While an extensive literature exists about ethical issues in child psychiatry research (e.g., Hoop et al. 2008; Vitiello et al. 1999), a specific focus on ethical issues in ASD research is relatively new (Walsh et al. 2011; Pellicano and Stears 2011). A recent article by Cox (2012) argues for the creation of a code of ethics and conduct to guide practice for therapeutic programs working in an interdisciplinary context, but no similar guidelines exist for research. The 2011 Strategic Plan for Autism Spectrum Disorder Research of the Interagency Autism Coordinating Committee (IACC) makes note of several ethical, legal, and social implications (ELSI) of autism research, including effective diagnosis and screening for ASD; ensuring privacy of personal information across federally funded projects that share data; appropriate communication about risk for ASD in nonaffected siblings based on genetic testing; and inclusion of individuals with ASD within the discussion of all the above topics (IACC 2011). These important areas reflect the maturity of the ASD research climate in the US. In contrast, research in many LMICs is only at the early stages, and is more descriptive. Based on the trends in our review of the research literature in India, these initial descriptive studies have been followed by genetic studies, epidemiological work, and intervention research. We therefore use a brief case example from India for each of these areas to highlight specific ethical considerations associated with these type of studies in LMICs.

Table 2 Sample titles of research projects conducted in collaboration with AFA and Ummeed, 2005–2012

Cultural aspects of parent perception of disability
Feeding problems in autistic children
Sense of well being in adolescents with Asperger's syndrome
Computing systems for people with autism
A descriptive survey to assess the psychosocial problems and quality of life of parents of children with autism with a view to develop guidelines for the parents on management of children with autism.
The effect of sensory integration therapy on attention and on task behaviors in children with autism
Effectiveness of sensory integration therapy on language in children with autism spectrum disorder
Trends in symptom recognition, diagnosis and the intervention techniques concerning the young autistic child in India
Emotional and behavioral issues in siblings of children with Autism
Developing diagnostic criteria for autism using neuroimaging techniques
Autism in India: therapeutic choice after changes to intellectual property law
Correlates of attachment security for children with autism in urban India: an exploratory study
Study of cognitive and metabolic impairment in autistic subjects
A computational analysis of language impairments in children and development of subsequent therapy
Characterization of the prenatal and perinatal risk factors of autism spectral disorder in Indian autistic population

Genetic Studies

Genetics is the area of ASD research in which ethical issues have received the greatest attention to date (e.g., McMahon et al. 2006; Walsh et al. 2011; Marchant and Robert 2009; Tabor et al. 2011). Given the prominence of genetic studies of ASD in the US, and the potential scientific opportunities provided through genetic studies on diverse samples, ASD genetics is a likely area of future work in LMICs. Indeed, in India alone, there have already been 15 published genetic studies on ASD using Indian participants (Daley et al. 2012). Regardless of the nature of genetic study undertaken, the ethical issues associated with the term "genetics" are worth noting.

> *Case example*: A workshop held by AFA was nearing its conclusion when a mother of a teenage son with autism and an unmarried, 20 year old daughter stood up to speak. About the discussion of autism having a genetic basis, she exclaimed, "I wish you people would stop talking about this!" adding, "Don't you realize that we'll never be able to get our daughters married?"

In India, as in much of the world, arranged marriages are still the norm (Georgas et al. 2006). An enormous amount of effort may be invested in selecting a groom for a daughter, and having a family member with a disability or mental illness adds complexity to the negotiation process of the marriage. Quite simply, genetic conditions reduce marriability (Ghai 2001; Kim et al. 2011). Therefore, particular weight is associated with the discovery that a family member has a known genetic disorder, and mere participation in a genetic study may create anxiety. For this reason, the World Health Organization reminds researchers and clinicians that confidentiality associated with genetic testing is critical in order to avoid stigmatization and discrimination within the community (WHO, 2009).

There are clear challenges associated with conveying accurate information about genetic studies to individuals with lower literacy skills and in LMICs (Marshall et al. 2006; deVries et al. 2011); explaining ASD in this context is even more complex. In contrast to conditions where the genetic transmission is well-known, there is a need to describe to parents the difference between genetics and heredity, given that the majority of genes identified for ASD to date have a de novo mutation. If lay understanding of autism genetics is limited in the US (e.g., Selkirk et al. 2009), it can be expected to be even lower and more varied elsewhere, especially among families with limited access to the Internet.

In our experience, a range of lay beliefs are associated with the genetics of ASD. A common reaction among newly diagnosed families is relief to learn that autism can have a genetic basis because they feel their child's ASD is therefore more amenable to medical intervention: Genetics means medical, and medical means curable. Consistent with this, we have been told by parents who provided blood samples that the "test" was helpful because taking blood means that the doctor can now provide information about what needs to be done to fix their child. At the same time, another dominant association with genetics is that it is assumed to mean that there is a problem with the mother. This mirrors research on perceived causes of intellectual disability in India by Edwardraj et al. (2010). The genetic researcher must therefore go well beyond obtaining informed consent to insure that the nontherapeutic nature of genetic research is clearly understood by participants, and that there is full disclosure of the limitations of our current knowledge about the genetics of ASD.

The unanswerable questions about the genetics of ASD blend into the ethics of prenatal detection of autism (Marchant and Robert 2009). A genetic test for ASD, if one is developed, is almost certain to find a receptive and lucrative market in India, and perhaps also in other countries where abortion does not have the same moral implications as in the US. The Indian Medical Termination of Pregnancy Act, 1971 permits abortion of a fetus up to 20 weeks when there is evidence of a congenital defect. Despite enormous attention focused on female infanticide in India, there has been comparative silence on the issue of selective abortion related to the discovery of a disability, which is perceived as an "acceptable health intervention" (Nizar 2011, p. 223). The weight of genetics in ASD is seen throughout the family life cycle: From being able to choose the best spouse for ones' daughter to determining future offspring. Thus, genetic research in LMICs should be undertaken with an understanding of the potential future ramifications for decision-making based on genetic studies.

Epidemiological Studies

Beginning with Lotter's research in Africa (1978), the question of whether autism exists throughout the world has continued to persist. In recent years, reports of prevalence have come from China (Wong and Hui 2008); Iran (Samadi et al. 2011); Korea (Kim et al. 2011); Mexico (Fombonne et al. 2012); Oman (Al-Farsi et al. 2011); Singapore (Bernard-Opitz et al. 2001); Sri Lanka (Perera et al. 2009) and Venezuela (Montiel-Nava and Peña 2008), among others. Though complicated by methodological challenges, this emerging set of studies are both contributing to global estimates of ASD and at the same time, highlighting the challenges associated with conducting such studies. Epidemiology was also the focus of the first set of projects funded under the Autism Speaks Global Autism Public Health (GAPH) initiative, and is an area of emerging work in LMICs. The ethical challenges in epidemiological work are thus becoming more clear as these studies progress.

> *Case example*: Rahul, a 9 year old with a diagnosis of ASD, was attending a second-tier private school. Although the quality of this school was much lower others his parents could have afforded, the reduced academic pressure allowed Rahul some degree of success. While Rahul had clear characteristics of ASD, he had no disruptive behaviors and in his classroom of 45 students, he generally flew under the radar: No one at the school knew of his diagnosis.

One of the primary considerations in doing epidemiological work in LMICs is whether identification of individuals with autism will cause harm to that person or his family. Because of both lower awareness of ASD and the spectrum nature of the condition, it is conceivable that many individuals who previously were not identified as having any type of disorder will be picked up through epidemiological procedures. This is, in fact, what occurred in a number of cases in the Korea epidemiological study (Kim et al. 2011). In the case of Rahul, his parents had intentionally withheld his diagnosis from his school because it carried no advantage. Unlike in the US, having a diagnosis of autism may actually *reduce* the availability of services for a child in India. We have observed schools using a diagnosis of autism as justification for removal of a child, under the rationale that they are not trained to work with children with autism. Since there is no way to know whether a new diagnosis will bring good or harm, there is a clear need for researchers to consider and resolve this issue prior to initiating an epidemiological study, particularly one in public schools, and develop procedures that minimize the possibility that the diagnosis will be discovered by others. Here, as in genetic studies, privacy and confidentiality are paramount.

A second ethical issue related to epidemiological work is the need to ensure the use of appropriate screening tools and diagnostic measures. Epidemiological work in LMICs requires true validation of tools, or else it risks inaccurately representing the magnitude of the issue. Such validation consumes considerable time and effort, and is much less common than simple translation. For example, the M-CHAT—a free tool—has been translated into over 40 languages and used in a number of countries, including China, India, Sri Lanka, Egypt, Kuwait, Jordan, Oman, Qatar, Saudi Arabia, Syria, Tunisia, and Lebanon. In Sri Lanka— where effort was made to examine the tool rather than just use it— the M-CHAT demonstrated unacceptably low specificity (Perera et al. 2009). The authors site both a lack of cultural relevance of some items, as well as a consistent pattern in which social and communication impairments were not viewed as an abnormality by the mothers. More generally, tools like the M-CHAT make assumptions about parental knowledge of child development that may not hold true in LMICs (Ertem et al. 2007). This is equally true of more complex tools that are often promoted for epidemiological work, such as the ADOS.

A third critical ethical issue in epidemiological work is identification of individuals in a context in which no services are available for the condition. Previous reports focused on early identification of disabilities in LMICs (e.g., Ertem et al. 2008; Krishnamurthy and Srinivasan 2011; McKenzie and Megson 2012; Sonnander 2000) have stressed the need to couple screening for developmental disabilities with interventions. While some studies have attempted to link a diagnosis of developmental delay or intellectual disability with simple, community based intervention services (e.g., Wirz et al. 2005), this is more

challenging in the case of ASD, which requires semi-skilled professionals. And, creating such professionals requires far more intensive training than can be delivered in a brief program.

Returning to the case example of Rahul: Although he technically already had a diagnosis of ASD, his parents chose a second rate school because there were no other viable educational options for him. In his case, identification would potentially take away the services he was receiving. While in theory, the resolution of this ethical issue would be to collaborate with service providers to ensure that there is a maximum benefit of diagnosis, in reality, such services are already scarce and a more realistic approach must be taken. The value of the data to the field must be carefully measured against the potential harm caused to individuals who are identified with ASD through epidemiological work.

Intervention Studies

The pressing need to provide services to children with ASD and their families has led to some efforts to identify effective treatments in LMICs, although these research efforts have not been well documented (Hastings et al. 2012). As alluded to above, parents of children with disabilities in LMICs often have limited access to appropriate intervention, either because it does not exist or because demand exceeds availability (Maulik and Darmstadt 2007). In a country where many children with disabilities receive no intervention at all, research on intervention must therefore start with a different set of assumptions and precautions than when undertaken in the US and other similar countries.

> *Case example:* "Recently in end of Nov. 2009 patient Amit suffering from AUTISM got treatment using Bone Marrow stem cells by SCGF center and after getting the treatment he is finding a great improvement and shown a positive result. The improved rate is 88.3 % after getting the first shot and patient says 'The use of stem cells proved to be blessing and is very promising in treating patients suffering from incurable disease like AUTISM. God bless these life affirming cures.'" (http://blog.kevaind.com/stem-cell/indian-stem-cell-company-treated-first-autism-patient/)

This description, taken directly from a site in India, illustrates one of the challenges in conducting intervention research in a climate with limited services: Parents desperate to receive services may participate in a research project, without regard to its efficacy and safety, because it is the only intervention available. Sarva Shiksha Abhiyan (SSA), India's program to achieve universal education, is far from fully implemented, especially for children with disabilities (Somaiah 2009). Estimates suggest that between 33 and 72 % of children with disabilities in India do not attend school at all (Singal 2009). Our own research is consistent with this: Based on parent calls to a national helpline, 48 % of the children with a diagnosis of ASD were not attending a school of any kind (Singhal 2010). If a parent has few intervention alternatives, it is not surprising that they may eagerly enroll in a research study on a treatment like stem cell therapy.

Parents may also have limited understanding of research and what is expected of them, as Kalyanpur and Gowramma (2007) found in their study among families in Southern India and as articulated elsewhere (e.g., Kass and Hyder 2001). Without understanding basic research principles, how can a parent of a young child with autism meaningfully provide informed consent even under a non-coercive environment? Moreover, the ubiquity of therapeutic misconception (Appelbaum et al. 1987; de Melo-Martin and Ho 2008) is a challenge that we have very much observed in our own work. Parents typically believe that an intervention *being researched* means it is known to be effective.

For intervention studies with families recruited from schools or conducted in schools, there is a related consideration for the researcher. Most children with disabilities who attend school do so in private schools (UNICEF 2003). As Jha (2010) notes, private schools are characterized by their independence in making decisions about admission, and their ability to control enrollment. Since enrollment is not guaranteed, parents of children with disabilities may fear dismissal if they irritate the school in any way—such as declining to participate in a research study. One intervention from India focused on the impact of casein and gluten free dietary interventions on children with autism. The study involved a range of procedures—anthopometric measurements, blood draws ("done with the help of a physician"), questionnaires—and then assignment to one of three dietary conditions (Nazni et al. 2008, p. 245). The lone mention of ethics in this article is that the study was approved by the ethical committee members of the researchers' institution. While we have no direct knowledge that recruitment or consent procedures were coercive in any way, there are several "risk" factors: Recruitment from a private school, blood drawn from a physician, and use of random assignment, which parents may not understand (Vitiello et al. 2005).

Similar questions could be raised about a study comparing Risperidone and Fluoxetine in forty children (Desousa 2010), in which there is no mention of how families were recruited at all, but the study involved 16 weeks of taking the medication. Pharmacological intervention studies naturally have a host of additional precautions that must

be taken. Irrespective of the type, all autism intervention studies in LMICs should establish that parents are participating without fear of retribution or jeopardizing their current services. Moreover, ensuring privacy and confidentiality of data is critical in intervention studies, Researchers conducting such autism work in LMICs have an extremely vulnerable sample pool from a research ethics perspective and should act accordingly.

Part III: Ethical Issues in Health Research in Low and Middle Income Countries: Application to ASD

In the US, the guiding principles for ethical conduct for more than 30 years have been based on the recommendations of the Belmont Report (1979), which highlight respect for participants, beneficence and justice. In contrast, global health research has been shaped by guidelines and recommendations of a number of different international committees and agencies in addition to the Belmont Report, including the Council for International Organizations of Medical Sciences (CIOMS 2002), the Declaration of Helsinki (World Medical Association 2008) and more than 90 other documents from organizations around the world (Caballero 2002). Regardless of the type of autism study undertaken, these international guidelines, as well as commentary by many ethicists (e.g., Emanuel et al. 2004; Macklin and McCall-Smith 2004; Marshall 2007) offer broad principles in that can also be applied to research on ASD. While these issues may be widely known in many fields, ASD researchers do not necessarily have any background in cross-cultural psychology, anthropology, global public health, or other relevant areas. And, training in research ethics is often absent in LMICs (Benatar 2002). From among these principles, we highlight three that most closely reflect areas that call for increased attention in India based on the past decade of research in the country.

Establishing Collaborative Partnerships

Since the early part of this decade, ASD research in the US has increasingly involved collaboration across sites (Rice et al. 2007; Singh et al. 2009). Such partnerships are singled out as the most crucial among the principles highlighted by Emanuel et al. (2004) underlying ethical global health research:

> [I]t helps to minimize the possibility of exploitation by ensuring that a developing country determines for itself whether the research is acceptable and responsive to the community's health problems. Moreover, without the engagement of researchers and host communities in the developing country, a study is unlikely to have any lasting impact, and, without the investment of makers of health policies, the research results are unlikely to influence policy making and the allocation of scarce health-care resources. A collaborative partnership also demonstrates awareness of and respect for cultural differences (Emanuel et al. 2004, p. 932).

The highly regarded bioethicist Solomon Benatar notes that a collaborative relationship must be truly "authentic, not simply pro forma," involving two-way sharing of knowledge (Benatar and Fleisher 2007, p. 620). In conducting research on ASD in low resource settings, collaboration with local organizations and researchers must be viewed as more than just a way to access the population of interest.

Collaborative relationships take time, but they offer considerable rewards, both scientific and personal. From the scientific standpoint, for example, there are a variety of ways that standard Western tools may not be culturally sensitive, having never been tested in a non-Western population of families of children with disabilities (Krishnamurthy and Srinivasan 2011). Engaging local stakeholders in conversations about the underlying constructs of the measures can result in important adjustments (Minkler 2005). In our current work on measuring empowerment as an outcome of a parent training program, selecting the "right" measures involved multiple discussions with core staff, pilot testing four different tools, conducting several validity checks, and verifying all the adjustments made to the translated tool. This type of work takes time; in our experience, researchers too often focus solely on the data collection—particularly so if they are coming from abroad. Their "collaboration" then becomes focused only on obtaining participants, rather than ensuring meaningfulness of the measures used.

An imbalance of power between a researcher entering a country, a local organization or researcher, and the participants in the study, is inherent in research collaborations with in-country partners in low and middle income countries (Marshall and Batten 2004). The power imbalance suggests the potential for pressure by external researchers. As an example of a potentially coercive approach to collaboration, one researcher provided the following email after his inability to locate participants for his project at another center:

> I am surprised and sad that although the projection for the number of people on the spectrum in India is 2 million, it is so hard to find 6–10 people/families on the spectrum willing to talk about their experiences and that too for benefitting their own community. It is very disappointing to see the amount of red tapism [sic] still prevalent in India which discourages educated people interested in coming to India to help

> increase awareness and treatment programs. I am very sought after in the field in my city and had no trouble finding families and individuals eager to participate in the study and institutions very eager and grateful to inform participants about the study. I am spending my own finances to come to India to do this study and if possible would appreciate all the support you can provide for this study.

While the frustration of the researcher is understandable, the underlying message is both accusatory ("*It is very disappointing to see the amount of red tapism still prevalent in India…*") and bullying ("*I am spending my own finances… and if possible would appreciate all the support you can provide*"). While the researcher ultimately reached his goal, we assert that coercive use of a power imbalance between local collaborators and external researchers does not constitute an ethical approach to forming collaborative relationships. The moral principle at stake here is that of balance and respect among researchers and NGO collaborators.

Setting Research Priorities

In the US, a key ethical question has focused on whether ASD funding should be used to support basic research, which tends to answer long-term questions, or on remediation research, which addresses more acute needs (Cho 2011). The significance of this issue is magnified exponentially when placed in the context of a LMIC, where there may be little research on ASD that has been conducted at all. In this situation, should new studies focus on establishing the prevalence of ASD? Examine potential risk factors? Discover genetic associations? Determine effective intervention practices? Given finite resources, the tremendous gaps in knowledge, and dramatic needs for effective strategies for parents and practitioners, researchers must grapple with the question of the true social and scientific value of a given ASD study to the participants in the culture or country where the study takes place. And, in this context, *any* study that is conducted can have a powerful impact on policy and practice, and can fundamentally shift the dialogue about ASD in that setting.

One heuristic for determining local relevance is offered by Smith (1992), based on her work with the Maori. While the underlying framework is similar to the benchmarks offered by Emanuel et al. (2004), we highlight these particular questions because of their applicability to any type of study on ASD. Smith suggests the researcher ask,

1. Who has helped define the research problem?
2. For whom is this study worthy and relevant? Who says so?
3. Which cultural group will gain new knowledge from this study?
4. To whom is the researcher accountable?
5. Who will gain the most from this study?

At the individual researcher level, if a genuinely collaborative relationship has been established prior to entering a country, these questions will generate relatively few surprises. Moreover, if a topic of relevance to the local organization is chosen, it will be easier to get buy-in and to work productively with a collaborating partner (Marshall 2007). However, in reality, the determination of a research problem is often driven by the funding source; as noted, "he who pays the piper calls the tune is true" in most instances of cross cultural research (Olweny 1994, 18). Within this constraint, we nonetheless recommend consideration of the above five questions in selecting a focus of research.

Respect for Research Participants

Respect for research participants, including appropriate informed consent, has received the most attention in global health research to date (Mandava et al. 2012). In the first section of this paper, we have touched upon the importance of ensuring informed consent in the context of genetic, epidemiological, and intervention studies. While we have observed that studies do not go far enough to ensure informed consent, an additional important and frequently overlooked aspect of respect for research participants is communication about the results of the research (Marshall 2007). The relevance of ongoing communication with participants in LMICs is that, in our experience, many parents view participation in a study very personally and may view an interview with a researcher as the beginning of a relationship. This has previously been described elsewhere, such as by Mackenzie and colleagues who note that participants complained that researchers "get their PhDs and funding from our stories and they cannot even be bothered to send us a report and a thank you letter…We give up our time and share our pain and they cannot give the time to write us a letter" (Mackenzie et al. 2007, p. 305). Given that individuals assume risks by participating, for example, exposure to others that their child has a disability, it is their right to know what was found through the research (Emanuel et al. 2004).

Publication of findings in Western scientific journals should be viewed as only one way in which findings are disseminated (Marshall and Batten 2004). Researchers in India, as in many LMICs, have limited access to most Western journals, and families who participate in projects may be completely cut off from these sources altogether. Dissemination of findings in an accessible format and

through an appropriate source is essential. One Indian researcher who collaborated with AFA published about her experience conducting research on families with autism in India in an issue of *Autism Network,* the organization's free journal that goes out to approximately 3,000 families in India and is available online (Vaidya 2006); she subsequently published her work in a scientific journal (Mehrotra and Vaidya 2008). This example provides a simple yet effective model that can be followed. As another example, in a project at Ummeed, a graduate student who collected data at the center subsequently organized a workshop for parents on issues for siblings of children with ASD, which parents found very useful. Parents who participate in research because they believe they are contributing to the larger good need to know how the questions they have spent an hour answering will help other families. When they are not given this information, they may be left feeling confused, demotivated and wondering if the time was actually put to good use.

ASD in the Context of Disability

We offer a final ethical consideration in conducting ASD research in low and middle income countries. Autism is frequently examined as a uniquely disabling condition, separate from other conditions (Waltz 2007) and the research field in the US has grown large enough that most ASD researchers have no need to situate their research in the broader context of disability. In contrast, in many LMICs, the number of children diagnosed with autism remains small compared to children with disabilities caused by malnutrition, iodine deficiencies and illness. Even with improvements in child health worldwide, these remain significant problems (Black et al. 2008; Durkin 2002; Msall and Hogan 2007). Data from the 18 low and middle income countries participating in the third round of UNICEF's Multiple Indicator Cluster Survey found positive screens for disability between 3 and 48 % for children aged 2–9 years (Gottlieb et al. 2009). Given the staggering burden of disability, many countries are challenged to make decisions about allocation of resources and implementation of programs to address the educational, health, and rehabilitation needs of all children and their families.

We strongly support and encourage the growth of ASD research globally, and believe that the particular needs of children with autism require specialized services. Given economic constraints and limited political will in many LMICs, we suggest that research on ASD in these areas can be used to shine a spotlight on particular needs of families, children and adults affected by autism *as well as* highlight the broad issues of childhood disability. We believe that autism researchers have an ethical responsibility to avoid promotion of ASD policies over those for children with other disorders. Furthermore, in light of emerging evidence of epigenetic factors in childhood developmental disability, it would be a mistake to consider autism outside the context of shared environmental and related developmental risk factors.

Summary

Compared to a decade ago, it is no longer necessary to argue for the value of conducting research on ASD in a global context. Not only has the need for such studies been persuasively articulated (e.g., Bernier et al. 2010; Grinker et al. 2011) but funding mechanisms are now in place that may support research at a level not previously seen. Such research is incrementally building a knowledge base and source for additional learning. In this paper, we have presented some examples of special issues that researchers may wish to consider when undertaking genetic, epidemiological and treatment studies in LMICs, as well as considerations related to developing research priorities, establishing collaborative partnerships, and ensuring respect for research participants. As we hope the examples in this paper have illustrated, the growth of ASD research in LMICs suggests the need to now consider both *what* kind of research to do, as well as *how* to do it.

In considering how to do ethical research in low and middle income countries, we also hope to have gone some way towards indicating an external researcher's responsibilities towards both the research population and local research collaborators. It is worth noting that these responsibilities may go beyond even the frameworks offered by Emanuel et al (2004) and others. Amartya Sen asks: "What social realizations are actually generated through the institutional base?" (Sen 2009, p. 82). In the case presented in this article, the 'institutional base' is science, with its institutionalized form of research ethics, which relies on normative assumptions of equality, justice and fairness. As Sen and others have pointed out, however, these goods must be converted into better functioning in order to be relevant to individuals, particularly in contexts where there is a lack of fair distribution of goods, and a lack of equal access to resources and opportunities. We suggest, therefore, that external researchers in LMICs should not just behave in accordance with institutionalized ethics, as codified through IRBs and ethical frameworks, but should simultaneously contribute to efforts to improve the ability of research participants and local collaborators to convert primary goods to valued resources, in the context of healthcare provision, national disability legislation, and local research capacity.

These are serious demands that require a high level of scientific and ethical commitment. We readily acknowledge that the viewpoints in this article represent a perspective that is circumscribed by both geography and the particular experiences of the two organizations included. Our intention is that the issues discussed in this paper will invite both critical discussion and empirical investigation. Through simultaneous consideration of scientific value and ethical commitments, global ASD research will more effectively examine and promote the issues of greatest significance for families, children, and local researchers in low and middle income countries.

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