COMMENTARY

A Global Public Health Strategy for Autism Spectrum Disorders

Simon Wallace, Deborah Fein, Michael Rosanoff, Geraldine Dawson, Saima Hossain, Lynn Brennan, Ariel Como, and Andy Shih

In recent years, there has been increasing awareness about autism spectrum disorders (ASD) around the world, including in low and middle income countries. Unlike countries in Western Europe and North America where infrastructure and capacity are available to help meet some of the needs of individuals with ASD, little expertise or capacity exists in most of the developing world. In 2008 Autism Speaks launched the Global Autism Public Health (GAPH) Initiative to facilitate the development of systematic and sustainable solutions for enhancing global autism awareness, research, training and service delivery. In the last 3 years Autism Speaks has established collaboration with stakeholders from over 20 countries who are working alongside dedicated local and international stakeholders to effect change. In this article, the GAPH framework is described, along with a few brief case examples that illustrate how the framework for implementation of the model can occur. GAPH is still in its infancy but has the potential to have significant impact through inclusive collaboration with local and international stakeholders to develop effective and sustainable public health solutions for disseminating best practices and delivering tangible benefits to individuals with ASD and their families. ***Autism Res** 2012, 5: 211–217.* © 2012 International Society for Autism Research, Wiley Periodicals, Inc.

Keywords: epidemiology; behavioral intervention; parent training; clinical psychiatry

Introduction

Although many economically developed countries like those in North America and West Europe now benefit from improved autism awareness, identification, services and research, most low and middle income countries (LMIC) have only recently begun to recognize and diagnose autism spectrum disorders (ASD). Autism research in LMIC dates back over 30 years, including research conducted in Africa [Lotter, 1978, 1980] and India [see Daley, 2004]. Researchers in such countries were optimistic about the potential for increasing capacity for research and service development in LMIC.

Recently, there has been an increase in LMIC-related autism research [for reviews see Daley, 2002; Elsabbagh et al., 2012; Hastings, Robertson, & Yasamy, 2012]. Challenges clearly exist when conducting this type of research, but given the significant needs in many of these countries, it is crucial that both the quantity and quality of research and development efforts continue to improve.

Epidemiologic findings from the United States [Kogan et al., 2009] and the UK [Baird et al., 2006] suggest that approximately 1% of children have an ASD, although methodological differences across studies and a dearth of epidemiological studies in LMIC counties make it hard to extrapolate these estimates to a "true" global prevalence of ASD. Prevalence figures vary among countries but there is generally good consistency in the estimates from one continent to the next [see Elsabbagh et al., 2012]. In 2011, researchers reported that 2.64% of a general population sample of school-aged children in South Korea had ASD, and that two-thirds of those children had been unrecognized prior to the study [Kim et al., 2011]. This research suggests that ASD may be underdiagnosed in many parts of the world, including the United States, with individuals going undetected and without treatment.

Benefits of conducting epidemiological studies of autism include increased community awareness and an improved understanding of the scale and impact of ASD on society. Many families in LMIC struggle with the stigma of having a child with disability, including ASD, which can lead to increased levels of parental stress and barriers to employment [Wang, Michaels, & Day, 2011]. A lack of knowledge and training among professionals [Bakare et al., 2009; Daley, 2002] can result in parents investing significant amounts of their resources in interventions

From the Autism Speaks, New York (S.W., M.R., G.D., A.S.); Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford, UK (S.W.); Department of Psychology, University of Connecticut, Storrs, Connecticut (D.F.); Department of Psychiatry, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina (G.D.); Chair, National Advisory Committee for GAPH-Bangladesh, Ontario, Canada (S.H.); an independent Applied Behavior Analysis (ABA) consultant, Stow, Massachusetts (L.B.); Child and Adolescent Psychiatry Service, Tirana University School of Medicine, Tirana, Albania (A.C.); Albanian Children Foundation, Tirana, Albania (A.C.)

Received December 21, 2011; accepted for publication April 11, 2012

Address for correspondence and reprints: Andy Shih, Autism Speaks, 1 East 33rd Street, New York, NY 10016, USA. E-mail: ashih@autismspeaks.org

Published online 17 May 2012 in Wiley Online Library (wileyonlinelibrary.com)
DOI: 10.1002/aur.1236

that have no demonstrated effectiveness for improving short- or long-term outcomes for their children [Xiong et al., 2011]. The limitations in professional knowledge and service delivery in LMIC may be partly due to a lack of professional training but also to the small number of research studies exploring the evidence base of interventions delivered in LMIC. A recent review by Hastings, Robertson and Yasamy [2012] was able to identify only four published studies examining the efficacy of interventions in LMIC. Although the authors of this review were unable to make any firm conclusions or recommendations about evidence-based practices in these settings, they did argue for the importance of professional training for primary and secondary health-care workers and the crucial role of parents in the delivery of interventions. The authors made a clear call for researchers to fill the gap in our knowledge for adapting existing models of early intervention and professional training to low resource settings.

The acknowledgment that ASD is an emerging public health issue by the United Nations (http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/62/139) and the World Health Organization (WHO; http://www.who.int/mental_health/evidence/mhGAP_intervention_guide/en/index.html) demands an immediate and organized response. ASD is part of the mental health portfolio at the WHO, and as part of the 2007 *Lancet* series on the global impact of mental health, Saraceno et al. [2007] identified five major barriers to increasing mental health services in LMIC: (a) absence of financial resources and government commitment; (b) an overcentralized health system; (c) failure to integrate mental health services into the primary health-care system; (d) a lack of professional training; and (e) poor knowledge among mental health leadership. In order for the goal of increased awareness, early detection and early intervention to be achieved on a global scale, a coordinated approach is needed involving the delivery of immediate, tangible benefits to individuals with ASD and their families, while continuing to support broader systemic changes to enable sustainable solutions for the community.

Global Autism Public Health (GAPH) Initiative

Launched in 2008, Autism Speaks' GAPH Initiative is an international science and advocacy effort focused on the development of public health policies and effective programs for autism awareness, research and service delivery. Collaborations with partners in more than 20 countries across six continents have been established to date. The GAPH model involves several components. First, local leadership is typically identified by convening a National Advisory Committee (NAC), which is typically comprised of advocacy leaders, government officials, representatives of professional communities, international content experts and Autism Speaks staff. The NAC is responsible for identifying shared community priorities, establishing a set of programmatic opportunities and developing a strategic plan, including consideration of resources needed to implement the plan.

Second, an awareness campaign is launched, which focused on recognizing the signs and symptoms of ASD, and reducing stigma and misinformation surrounding autism. The process for developing an effective autism awareness campaign involves due diligence and informal research to determine the attitudes of the general public related to ASD. Coordination of awareness activities with research and service development is critical for success, as increased awareness is likely to increase demand for services.

Third, to assist in planning the public health infrastructure and programs that will be needed to support families and professionals, data pertaining to the needs of the community are usually collected. This may include designing and implementing a national or regional autism screening study through existing health clinics or a full-scale prevalence study conducted by an autism epidemiologist. This often involves the adaptation and translation of standardized screening and diagnostic instruments for cultural relevance and sensitivity, or the development of new clinical tools that are validated against the gold standard.

Fourth, in parallel with conducting research is the building of capacity for delivery of evidence-based clinical and educational services. Effective treatments involve close collaboration between professionals and families, and require sensitivity to cultural perspectives and values. The GAPH training model builds capacity for services by providing professional education and development and ongoing technical assistance offered by external and local experts. It is driven by approaches that facilitate sustainability, such as those involving "train-the-trainer" [Orfaly et al., 2005], which allow the local community to maintain and build capacity after the departure of external trainers.

Fifth, in addition to sustainability, solutions that are provided through the GAPH initiative must be compatible with the sociopolitical context of the community being served. By working with families, NGOs and government departments, the NAC guides the development of a public health and legislative framework that is technically and financially sustainable, informed by the best available knowledge, and will be responsive to the changing needs of the ASD population.

National Case Study: Albania

Pre-GAPH Status of Autism Activities in Albania

In Albania, autism awareness has been high over the last 4 years because of campaigns run by the Albanian

Children Foundation (ACF), an NGO historically focused on child health and welfare issues. There is a strong history of child and adolescent psychiatric expertise and a network of pediatricians who manage the primary health-care needs of children. There was a need for increased professional training specifically on autism and for assessment tools and textbooks to be translated into Albanian. Interventions for children with ASD were largely lacking. Most children with ASD were either sent to a school for children with a range of disabilities where autism-specific intervention was lacking, or to a general education classroom. If they could not be taught in the general education classroom, they were sent home, where they received no intervention other than medication when deemed necessary and appropriate.

Initiation of GAPH Albania

The ACF and Autism Speaks made contact in 2008 and this was followed by a planning meeting that involved both outside experts in early intervention and psychiatry, representatives of the ACF, government agencies (Ministries of Health, Education, and Diversity) and other NGOs to assess the current status of autism services and establish consensus priorities for improving services for individuals with ASD in Albania. The visit ended with a signed collaborative agreement on priority projects, which included the establishment of an ACF library on autism, translation and adaptation of educational resources and research instruments into Albanian, planning for an academic conference in October 2009, the initiation of pilot projects on screening, therapist training and planning for an epidemiology study. Finally, in 2009, ACF opened the Fly for Life (FFL) Center in Tirana as the first early intervention center for children with ASD in Albania.

Initial Activities

The Modified Checklist for Autism in Toddlers [M-CHAT; Robins, Fein, Barton, & Green, 2001], a well-known screener for autism in children aged 16–30 months, as well as its follow-up interview, was translated into Albanian, back-translated and approved by the authors. With advice from the authors and consulting American pediatricians, training was then provided to five pediatricians on administering the M-CHAT, and 300 children were screened; those who screened positive received a follow-up diagnostic assessment. The gold standard diagnostic instrument for autism in young children, the Autism Diagnostic Observation Schedule—Generic [ADOS-G; Lord, Rutter, DiLavore, & Risi, 2002], was next translated into Albanian, and training in its administration will begin in 2012. An additional screening instrument for older children, the Social Communication Questionnaire [Rutter, Bailey, & Lord, 2003], was also translated.

Two practical textbooks (*Autism in Your Classroom* [Fein & Dunn, 2007] and *Autism: A Parent's Guide* [Powers, 2000]) were translated into Albanian. Several hundred books about autism in English, covering all aspects of the syndrome, were donated by academics in the United States and the UK, forming a core library for the ACF. Awareness campaigns built on the success of the ACF's ongoing public communications and included televised videos for World Autism Awareness Day and two professional conferences. In 2010 the Albanian Ministry of Health signed a pledge to write a national strategy on autism, the data for which is currently being collected.

Increasing Capacity for Evidence-Based Services in Albania

A pilot effort aimed at building capacity for evidence-based serviced focused on training professionals to deliver empirically validated early intervention, based on applied behavior analysis. Two Board Certified Behavior Analysts from the United States conducted didactic training for five clinicians whose English skills allowed them to access the didactic material. A training curriculum was designed to provide, within the year of training, the necessary skills to deliver a behaviorally oriented intervention for selected children at the center.

An important adaptation of the intervention to the Albanian context was to determine the number of hours of intervention that could be delivered to each child. Given the increasing number of children enrolled at the center and restrictions over cost, a maximum of 20 hours per week could be delivered. The involvement of parents is not only considered a key component of evidence-based early intervention programs [Dawson et al., 2010] but would also allow for increased number of intervention hours provided to each child. Both therapists and parents were provided training covering basic intervention techniques, such as shaping and chaining, activity schedules, incidental and natural environment teaching strategies, programming for generalization, Picture Exchange Communication System and decreasing problem behavior. A special workshop targeted at parents was given, about toileting, sleeping and eating difficulties. Therapists with good English were made available to parents who needed translation from English to Albanian.

In 2011, additional workshops for therapists and parents were held on teaching joint attention, increasing eye contact and social engagement in the natural environment, reading emotional states in others and more complex perspective taking skills. To maintain this intervention training in the longer term, a basic package of training materials was created, translated in Albanian and back-translated by the FFL Center therapists into English.

In the long run, it will be important that the trained professionals offer training to others to build broader capacity in Albania.

Pilot data on the acceptability of the training materials and the therapy and on changes in child behavior were collected. Therapist and parent ratings of the effectiveness of the training and the therapy, using a standardized measure, were very strong. Therapist skill acquisition was measured with quizzes in addition to the ongoing supervision, and all therapists passed the quizzes with over 80% correct. Children's skill gains were assessed with the Assessment of Basic Language and Learning Skills [Partington & Sundberg, 1998]. All five children targeted for work with the trainees made excellent progress in a wide range of skill acquisition as well as in cooperation with adult directives.

National Case Study: Bangladesh

Pre-GAPH Status of Autism Activities in Bangladesh

Like many developing South Asian countries, Bangladesh is poor, heavily populated and agrarian. In 1999, the National Foundation for Development of the Disabled Persons (NFDDP) was founded to ensure persons with disabilities received some financial support and social services. The NFDDP has since allocated loans, grants and other services free of cost to persons with disabilities.

In June of 2010, The Center for Neurodevelopment and Autism in Children (CNAC) at the Bangabandhu Sheikh Mujib Medical University was inaugurated. It is the first autism-specific government initiative linked to a medical university. The center aims not only to provide training to parents, teachers, therapists and all medical professionals, but also to engage in the comprehensive management of services and research on autism and other neurodevelopmental disorders.

Clearly, the Bangladesh government has taken steps in recent years to develop programs to meet the needs of the autism and developmental disability community, but the persistent lack of expertise, capacity, infrastructure, resources and systematic coordination across agencies and programs has limited the impact of these efforts.

Initiation of GAPH-Bangladesh and the Formation of South Asian Autism Network (SAAN)

GAPH-Bangladesh was formally launched on July 25, 2011 at an international conference entitled *Autism Spectrum Disorders and Developmental Disabilities in Bangladesh and South Asia*. The conference was copresented by the Government of Bangladesh, CNAC, WHO, The South East Asian Regional Office of the WHO and Autism Speaks. Three days of training were held in conjunction with the conference to provide both parents and professionals working with children with ASD opportunities to be introduced to relevant information and skills. After the conference, the NAC for GAPH-Bangladesh was convened and began to develop consensus community priorities. The GAPH-Bangladesh NAC will publish their recommended program of work in the first quarter of 2012.

The Bangladesh conference was also attended by experts and government representatives from India, Thailand, Bhutan, Maldives, Sri Lanka, Indonesia, Myanmar, Nepal, Jordan and UAE. Given the similar needs across these countries, conference participants unanimously adopted the Dhaka Declaration on Autism Spectrum Disorders and Developmental Disabilities [see Conference on Autism Spectrum Disorders and Developmental Disabilities in Bangladesh and South Asia, 2011] calling for more support and assistance from the international community. Thus, the first steps toward increasing services for persons with ASD in Bangladesh were made.

While Albania and Bangladesh face similar challenges to progress such as capacity and resources, the path taken by each community is the result of a unique collaborative process by key stakeholders and reflects the local reality that each community needs to navigate. Regardless, it is expected that more local leadership and ownership in project planning and implementation in general will translate into enhanced feasibility and sustainability.

Challenges Facing Global Autism Public Health Research

Although many clinical features of ASD are universal and many of the evidence-based approaches developed in North America and Europe can be adapted to new countries, there are important sociocultural differences that need to be carefully considered before undertaking decisions about public health programs for ASD. One example is in the appropriateness of recommending the use of screening and diagnostic tools that have been developed in high income countries. The ADOS-G [Lord et al., 2002] was initially designed and tested for clinics in the United States and Europe where content such as having a pretend birthday party may be relevant but this may not be appropriate content to use in all cultures. Screening in the context of a well-baby check-up is not feasible in most developing countries. In addition, there are differences in the recommendations on screening for autism among different countries [e.g. Matson et al., 2011] so care should be taken when advising countries about screening efforts.

When therapist training was implemented as part of GAPH-Albania, there was considerable discussion among the local and international members of the project team about the cultural factors that affected the training process, as well as how parents would feel about being

included in the therapy. Broadly speaking, although therapists were unfamiliar with both the terms and the concepts of the therapy being taught, they were extremely energetic, dedicated to the children, and had relatively few preconceptions about therapy. Family structure in Albania more often includes multigenerational households than in high income countries, and these generations often lack consistency in their attitudes and practices toward behavior management. This was addressed by including extended family members in family training workshops and enlisting their support and alliance.

Language issues also present significant challenges. Trainers can find that the language and terminology more than the concepts themselves are barriers to learning. Assessing language of a child from another culture may be difficult for nonnationals who may find it challenging to judge a child with autism's vocabulary, prosody or articulation. The overall improvement in communication and understanding between therapists and trainers in Albania was accomplished by using multiple modalities. First, several Albanian therapists spoke enough English to communicate well with the trainers and to translate for their colleagues. Second, it was important for the trainers to spend the 3 weeks in Albania for face-to-face teaching, supervision and demonstrations in order to build a foundation for the subsequent distance supervision. Third, using Skype and e-mail meant that the project team could stay in touch and continue to transfer knowledge across the 12 months training.

A final challenge is the large-scale global need and the limited capacity to meet that need. As awareness of autism increases, through activities like the United Nations World Autism Awareness Day, so does the demand for support and guidance. The International Society for Autism Research has supported professionals from LMIC in the last years through a travel fellowship that allows LMIC professionals to attend the International Meeting for Autism Research. Through their mental health Gap Action Programme (mhGAP) the WHO have made progress in terms of highlighting awareness about the needs of individuals with developmental disabilities and possible services that could be effective in low-resourced settings (http://www.who.int/mental_health/evidence/mhGAP_intervention_guide/en/index.html). In particular, mhGAP's emphasis on "task-shifting," or the engagement of paraprofessionals or lay members of the community, including parents, to deliver evidence-based practices promises new ways of addressing the capacity barrier.

Future Directions

In spite of some progress made in recent years, in many countries, autism awareness remains low and access to quality services remains scarce. GAPH initiatives have begun to build a foundation for developing solutions by assisting in the translation of materials, helping to launch research and awareness campaigns, providing technical assistance, and facilitating the development of national support and strategic efforts to build and sustain efforts to improve services. Future efforts will benefit from new knowledge gleaned from dissemination and implementation science that takes into account cultural attitudes, so that future awareness efforts can be more targeted. For example, studies have shown that Chinese fathers become less involved with their child with ASD, take less of the burden of care [McCabe, 2008] and may abuse substances as a coping strategy [Wang et al., 2011]. In this context, an awareness campaign targeted at fathers may be a necessary focus.

There is also a need for research to improve our understanding of the influence of sociocultural differences on the early manifestation of ASD in different parts of the world [Daley, 2002; Matson et al., 2011]. Decisions for each GAPH program about the appropriateness of screening and diagnostic tools will be made based on the collection of data and in consultation with stakeholders in the local community. In some cases, a better solution will be for a region to develop its own instruments for screening and diagnosis. In India, for instance, the GAPH initiative is supporting the development of a novel screening tool for neurodevelopmental disabilities that is currently undergoing validation in the field. This is a vital step in terms of producing culturally relevant tools, since these new assessment measures may be more economical and efficient than those currently used in high income countries, making their broader dissemination more feasible. Collection of data on the costs and benefits of establishing a formal screening program in LMIC will be an important part of the process.

To date, most GAPH programs have focused on urban settings and as highlighted in previous studies [Daley, 2004; Lotter, 1978; Sun & Allison, 2011], there may be variations from urban to rural environments when planning a public health program in LMIC. Daley [2004] reported that some families in her study had taken days to travel thousands of kilometers to attend clinical meetings. There is a clear need to decentralize some of the programmatic activities in LMIC to maximize coverage by enabling services at primary care settings. As described earlier, there are plans in Albania to adopt an innovative approach of disseminating information on autism through regional libraries. This will include strategies to create parent groups and train primary health-care workers in basic intervention approaches. Data will be collected as part of this project to explore differences in rural and urban settings, which will help guide future efforts in other Southeast European countries. Telemedicine and other web-based training strategies will help

with the decentralization of services and reduce the travel burden on families and professionals [Kobak, Stone, Ousley, & Swanson, 2011a; Kobak et al., 2011b].

There has been a call from a number of studies in LMIC settings [Hastings et al., 2012; McCabe, 2008; Wang, 2008; Wang et al., 2011; Yanqing, 2006] for greater parent involvement in intervention delivery as a cost-effective way of providing services as well as to help manage levels of stress [Wang et al., 2011] and increase parental knowledge and responsibility [McCabe, 2008]. However, as highlighted by Hastings et al. [2012], there remains a need to collect data on the effectiveness of parent-mediated intervention approaches that have been developed in high income countries and then adapted for use in LMIC settings. Furthermore, parental burden is already very high in many LMIC and the expectations on parents who are centrally involved in delivering the intervention may add to that burden.

Clearly, data collection in the context of disseminating best practices from developed countries to developing countries will facilitate the evaluation and future enhancement of the development program, especially in regard to its feasibility, effectiveness and sustainability. It is important to note that lessons learned from these efforts will also inform and ease dissemination and implementation activities in developed countries, where similar lack of infrastructure and capacity or difference in language and culture present barriers to optimum care, such as rural and minority communities.

In conclusion, although we are encouraged by the success of the beginning steps toward increasing awareness and services for individuals with ASD in developing countries, a tremendous challenge in addressing the diverse and large needs of individuals with ASD in LMIC lies ahead of us. By funding research on innovative strategies for improving early detection and access to services, advocating for more local resources and collaborating with parents, persons with ASD, professionals and government agencies, we hope to witness steady and sustainable progress in the future.

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