The IASSID Academy on Education, Teaching and Research and the Links With Low- and Middle-Income Countries: An International Partnership

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Abstract The Academy, an arm of the International Association for the Scientific Study of Intellectual Disabilities, was formed in 2006 in order to promote clinical and academic skills in low- and middle-income countries (LAMICs) and to carry out educational activities within international events. This article describes the global context of knowledge dissemination and examples of workshops and courses led by Academy members. Discussed are reflections on the important lessons learnt from the Academy experiences to date and recommendations on better coordinating and delivering Academy-sponsored trainings and consultations in LAMICs.

Keywords: academy, education, intellectual disabilities, LAMIC, training

INTRODUCTION

New knowledge in any field—including the field of intellectual disabilities—emerges in a variety of ways. Practitioners create new interventions and new procedures for doing things that seem to fit their work conditions and seem to benefit the people they support. Scholars and legislators create philosophies and policies that set out new contexts for how the field of intellectual disabilities is practiced. Researchers generate new knowledge from systematic enquiry that focuses on specific questions, and other scholars originate new ideas and concepts through analysis and creative reasoning.

A growing concern in recent years is that these various sources do not inform one another sufficiently of their new knowledge. There is worry that research is not investigating many of the questions that are of primary concern to practitioners and policymakers and, conversely, that practitioners and policymakers are

not using new knowledge generated by research (Ademan & Taylor, n.d.). In particular, there is concern that new research knowledge, as disseminated in the traditional ways such as publication in journals, professionals magazines, books, or shared at professional conferences, is not accessed or used by practitioners or policymakers (Petrides & Nodine, 2003). This perceived concern may be especially the case in lower and middle income countries (LAMICs) where research activity is limited, and where local language and customs may make research published in more affluent countries appear less relevant.

A question that emerges from this line of thinking is how to integrate new knowledge that has emerged primarily in the more affluent countries of the world with the practices, policies, culture, and conditions of daily life experienced in LAMICs. The key here is how to encourage practitioners to take research knowledge and "make it their own" by adopting relevant and useful aspects (Tugwell, Santesso, O'Connor, & Wilson, 2007). Knowledge transfer and exchange models, although developed primarily to bridge gaps between research and practice in more affluent countries, appear to be of considerable use for this purpose. For example, a model described by Saini, Brown, and Hawser (2010) extends creation of research knowledge and traditional dissemination to alternative methods of dissemination that fit the needs of the end users, alternative methods of applying new research knowledge, and assessment of changes brought about because of its use. In the model, new knowledge (and modification of new knowledge) can occur at any stage. Models such as this appear to

be particularly apt for integrating research knowledge developed in some parts of the world to practice in other parts of the world because they allow for tailoring new information to the particular circumstances and needs of the end users.

Such a focus is particularly important when we consider that about 90% of people with intellectual disabilities worldwide live in LAMICs and face numerous problems including, among other things, lack of human rights and freedoms, social and economic disadvantages, social exclusion, ill-health, lack of formal supports and services, and high mortality rates (Lecomte & Mercier, 2008; Mercier, Saxena, Lecomte, Cumbrera, & Harnois, 2008). A problem for the field of intellectual disabilities as a whole—and indeed for all humankind—is that this is a growing population that is very often not considered a priority for scarce financial and cultural resources. It is within this context that intellectual disability scholars within the International Association for the Scientific Study of Intellectual Disabilities (IASSID) set in place the Academy to further its interest in pursuing these issues in a very practical way.

THE IASSID ACADEMY

IASSID is the largest international scientific organization concerned with research into intellectual and allied developmental disabilities. It has been in existence since 1964 (formerly called the International Association for the Scientific Study of Mental Deficiency) with a membership representing 34 countries. IASSID's mandate is to share current scientific knowledge about intellectual disability that emerges from international research, and to act as a catalyst for international linkage, partnerships, and research endeavors. A specific concern is how the application of new scientific knowledge might be shared with practitioners in LAMICs where there is little indigenous research or sharing of research knowledge from other countries. However, the importance of building on local networks, encouraging frontline organizations and parental input is a necessity in such developments.

The IASSID Academy was set up in 2006 at a meeting in Maastricht, the Netherlands, to reflect and address this new interest. Its aim was to contribute to the practical application of up-to-date research knowledge and practice around the world through workshops, courses, and consultations. It was agreed that any initiatives must be accompanied by capacity-building in the fields of health, education, and social sciences that straddle research, clinical, and practical domains. Two main challenges were recognized by the newly established Academy: (1) how IASSID could engage with local practitioners who might benefit from the proposed work of the Academy; and (2) how existing research knowledge generated by individual IASSID members and IASSID's Special Interest Research Groups (SIRGs) could be translated in ways that would be meaningful to local practitioners and would encourage development of local research.

With these purposes and challenges in mind, the Academy initiated a series of workshops and consultations around the world that were designed to explore and assess how it could best carry out its function. This article documents some of the experiences of researchers who led Academy activities in this initial stage. Sample activities are briefly explained, and lessons learned from our experiences are identified.

THE DEVELOPMENTAL STAGE OF THE ACADEMY

The first workshops and seminars began in 2007 with the aim of developing and delivering education and training to both professionals and carers or family members. An international pool of professionals drawn from volunteer IASSID members from various disciplines enables the Academy to offer a range of resources and information that address a variety of issues across the lifespan of people with intellectual disabilities and their families (Brown, 2010). The format of the Academy's activities includes free-standing workshops, courses, and consultations, as well as pre- and post- trainings at IASSID's regional or international meetings. The stand-alone events are steadily increasing in range of countries. When possible, the Academy runs orientation sessions prior to workshops with close liaison between the proposed workshop presenters and the Academy Board. Workshop application forms requiring advance completion of the details of the content are examined and discussed with the presenters. Certificates based on attendance or satisfactory performances are provided to participants, and participants provide feedback on the teaching sessions. To date, the Academy has held 39 events in 10 countries with approximately 2,000 registrants. Future objectives include the increasing involvement of the Academy members in the work of major nongovernmental organizations (NGOs), governmental entities, and research institutes and universities, among others. What follows is a brief overview of some of the Academy's early developmental activities by location in the following LAMICs: Mexico, Malaysia, China, and India.

Mexico City, Mexico

This first Academy-sponsored workshop represented a first strong collaboration between the Academy experts and the host organizing committee. It was hosted by some of the largest umbrella organizations in intellectual disabilities in México, such as: Comunidad Crecer IAP (for the rights of people with multiple disabilities), Junta de Asistencia Privada (for social problems in the country), Mexican confederation on behalf people with intellectual disabilities (CONFE), CISAME (a national mental health organization), and The National Council of People with Disabilities.

The week-long event on quality of life and people with disabilities took 7 months to design and prepare. The organizers were conscious of the need for the conference to fit in with the social and economic necessities of the country, as well as to promote and disseminate scientific work on issues of quality of life. The costs of the week were met by the hosts who recognized this event as a significant opportunity for professional development and an exchange of knowledge and training.

The broad scope was reflected in the array of participants ranging from people with a variety of disabilities, their families, community leaders, researchers, and civil servants. Colleagues from the University of Mexico hope to strengthen their contacts

with IASSID and the Academy in order to develop (1) a research program for people with disabilities; and (2) strategic plans that not only will help the population with disabilities but also increase awareness in other Latin American countries.

Ipoh, Malaysia

The Academy had run a series of workshops spaced over several weeks in association with the Yayasan Sultan Idris Shah Community Centre in Ipoh, Malaysia. The host organization invited, through personal contact with one of the authors, the Academy to conduct workshops that would benefit local practitioners in intellectual disability services. The Malaysian workshop topics included: how to conceptualize intellectual disability; making services and support person-centered and family-centered in community settings; how to apply a quality of life approach in supporting people with intellectual disabilities; ethical dilemmas faced by support workers in intellectual disability; how to manage challenging behavior; and issues of health and human biology in intellectual disability.

The hosts were extremely welcoming and offered workshop leaders accommodations in the organization's guest house as well as tours of the service and surrounding area both of which made the prospect of visiting Ipoh and learning about local services and philosophies more appealing to the workshop leaders. The local agency also planned and organized all the practical matters of the workshops such as transportation for the guest speakers, recruiting attendees, and providing space, equipment, translation of materials, and meals. The workshops were conducted by a group of colleagues, making it easier to divide tasks and benefit from one another's experience. For instance, the staging of the workshops before and after a regional conference permitted the first guest speaker to convey important information to subsequent speakers about the site and participants, which were incorporated into the later workshops.

Malaysia is a multicultural society with various ethnic and religious groups. Service provision is limited, and many families carry full responsibility of care for their relative with disability through some support from charitable organizations such as the host agency. Staff providing services also have various levels of education and experience; for many, English was a second language. The venue itself was a further challenge as Malaysia is very hot and humid, particularly in the summer months. A much higher interest in and attendance by local support workers led to an oversubscription and impacted the comfort in the room where the workshops were held, as well as on teaching methods. Although this was a challenge, it was not insurmountable and the workshop was well received. But, it left us with a "lesson learned" for future workshops—that it is important to recognize the impact of how local arrangements are organized or controlled on the overall experience of those who volunteer to lead workshops as well as those who attend.

Beijing, China

An important aspect of the Academy's work is the responding to requests by colleagues who face particular challenging issues in practicing in their own countries. As a result, the Academy has run consultative meetings relating to inclusion, deinstitutionalisation, and the development of services for older people with intellectual disabilities in China and Hong Kong. It is of interest that such consultative sessions are increasingly being requested and added to workshop and course events and are potentially the building blocks for further local action. China is an emerging economy but, as elsewhere, there is significant national variation in terms of service provision. There are significant gaps in information on intellectual disabilities, skills required in caring for them, and opportunities for work and leisure outside the home. The training needs focused on the topics of quality of life, early intervention, inclusive education, and social inclusion. At these courses and consultations, the audiences were made up of various professionals, including teachers, therapists, nurses, parents, and university lecturers. The course leaders in China, in their report to the Academy Board, highlighted the ethical development of low-cost interventions, embedded within the local cultural framework, the necessity of providing support for families, and equipping mainstream services systems such as education and health to meet the needs of persons with intellectual disabilities. A particular focus of their efforts was directed at ways in which academic institutions could promote relevant research for the benefit of the service users and their carers.

Visakhapatnam, Andra Pradesh, India

The host organizations of this workshop in aging and intellectual disabilities were the Department of Psychology at Andhra University, Visakhapatnam, the Lebenshilfe for the Mentally Handicapped, and the CareFit India Organization. The workshop experimented with using universal serial bus (USB) drives in lieu of handing out printed materials, as photocopying supports were not viable at the workshop site. The USB drives included all of the PowerPoint documents, copies of booklets and reports on aging and intellectual disabilities, as well as several aging-related educational videos that could be played at home after the workshop. This manner of providing information was well received because the audience members had ready access to home computers. The venue sponsor, the Lebenshilfe for the Mentally Handicapped used the occasion of the workshop to also organize a musical review and entertainment for parents of the adults enrolled at the center. It also used the occasion to draw in academics and government officials so as to raise consciousness on issues related to aging. The university department that was a cosponsor, also organized a significant co-timed conference that included a keynote address by one of India's past presidents. The workshop leaders were also invited to be speakers.

The practical-oriented workshop provided a review of the impact of normal aging and what it means to people with intellectual disabilities; information on understanding age-related pathologies and how they affect people with intellectual disabilities; an overview of dementia and how it affects people with intellectual disabilities; and information on alternative program models and supports for older people with intellectual disabilities. The event also involved a summative session with local parents and advocates that resulted in the establishing of a

parents' association that planned to advocate the government for more services of aging adults with intellectual disabilities.

LESSONS LEARNT

Although Academy members are highly motivated and interested in developing and enhancing links with LAMICs in applied and research partnerships, the enormity of the task should not be underestimated. Aspects of local conditions need to be carefully considered, including audience roles and number, format of lectures, local cultural and language codes, expectations of outcomes, prior familiarity with the literature, concepts of disability, and attitudes toward it. The following key considerations may enhance the training experience of future hosts, participants, and presenters:

- Volunteer presenters need to critically reflect on cultural differences and be prepared to adapt materials as required to meet needs. They should become familiar with local situations through briefing and visits with partnering organizations or professionals and advocacy groups.
- Prior to the training, there should be, wherever possible, visits to local facilities and meetings with families, if they consent to this. Insights gained can be incorporated into the training content.
- Participants and volunteer presenters should be encouraged to introduce themselves to one another, which does not always happen in cultures that place a high emphasis on expert teaching. These introductions may in turn allow participants to be more open about interacting and discussing with one another.
- A variety of teaching methods should be used incorporating local expertise and resources as a planned part of the program. Often, local researchers, organizations, managers and educators may take part in stand-alone workshops as contributors to formal discussion or events.
- Novel concepts should be made accessible, carefully explained to the participants and accompanied by case examples to illustrate their practical implications.
- There should be a balance between theory and research findings and clinical practice which may need to be adjusted depending on the participants' knowledge and level of experience.
- The presenters should be gracious and willing to learn from local custom and practices.
- Presenters need to be sensitive to the fact that local people are the ones to decide what is useful, and what they can adapt to effect in their communities.
- If workshops are held in a part of the world that does not have strong economic resources, it is important to plan them to "piggy-back" on another event to keep costs low. It is critically important that PowerPoint presentations or other documents requiring translation should be forwarded well in advance of the course. For example, the use of slides and simultaneous presentations in English and in Chinese proved very effective because many of the Chinese participants could read English but also it was a further check on accuracy of translations.

- It is extremely helpful to have an enthusiastic and helpful host organization.
- It is important to note the agency or university that the presenter comes from, as many educational institutions have research and volunteer initiatives in LAMICs and such activities are highly regarded.

Much of these points have been taken into account in one or more encounters and should be encouraged as regular practice.

CONCLUSION

Much has been accomplished in the field of intellectual disabilities since IASSID was first established 50 years ago. Changes in technologies, communications, and the world research environment have opened up new opportunities. One of these is the pressing need for dissemination of research information and findings and their applications around the world, beyond Australia/New Zealand, North America, and Europe, where IASSID has traditionally played a major role. The emerging work of the Academy has revealed a desire for education, training, and nurturing of young practitioners and researchers. The workshops that have been held by the Academy reflect the growing momentum of commitment to provide learning and capacity-building on research, application, and policy on a worldwide basis. This, however, is dependent on a cooperative partnership between host countries and the IASSID Academy. Immediate benefits of such partnerships can be seen in several cases following an event by the Academy. As a result of the course offered in India, the parents who attended mobilized and formed an official association, which is now engaged in lobbying the government for more services for their adult children and which has developed a support network for its members. Similarly, in Hong Kong, a collective planning effort has been undertaken to address the needs of their elderly population with intellectual disabilities. In China, there was a follow-up day on how to develop a service model to foster inclusion in education and measure its effectiveness.

The Academy within IASSID looks forward to working with NGOs, both international and country-based, in the development of relevant programs of education and consultation around the world. The feedback to date has been positive from outside organizations and presenters and the intention is to develop further programs to demonstrate the benefits of the Academy paradigm in strengthening the support systems around people with intellectual disabilities.

The Academy is ready to expand on other aspects of its work. The idea of both research education and teaching in the field of intellectual disabilities and research-to-practice in LAMICs is favored by the Academy Board. The links both with IASSID members, 40 of whom have presented in workshops, and contacts with the IASSID's SIRGs are expanding. Numerous SIRG leaders have been involved in teaching and training events as well as offering further support in the Academy's development. The Academy Board is an active body with members who have considerable experience working through world bodies, such as United Nations committees and organizations, including the United Nations Educational, Scientific and Cultural

Organization. Several of them have run programs and courses in a variety of countries through their organizations or as individuals in their own right. The work of the Academy is entrepreneurial and requires taking reasonable risks and forging partnerships around the world. The Academy sees itself as a joint sponsor of programs in the countries in which it works and increasingly universities or local organizations indicate their enthusiasm for equal partnership in running the workshops.

Funding the Academy's activities is central to its function, as in many instances funds are not available and registrations for courses often take place at the "last minute." Therefore, funds must be sought not just from within IASSID, but from charitable and other bodies, a development which has been encouraged and supported by members of the Academy Board. The Academy faculty is composed of experts who believe in the development of flexible services to meet the needs for quality research expansion and application in this very diverse world environment. It is a process that can, if given the freedom to do so, bring further success to IASSID.

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