

Opinions and Perspectives

Why Are Conferences “Sometimes About Us, Without Us?”

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“If they are serious they should be including us in all parts of the conference, giving papers, going to the conference with everyone else and having a say in how they are ran” (Research participant)

One of the three authors of this paper, Heather Forsyth, is a self advocate and a seasoned participant in the Australasian Society for the Study of Intellectual Disability (ASSID) national conferences. ASSID promotes research and practice development in the area of intellectual disability and each year holds a National Conference. Heather’s continued frustration with the inaccessibility of these conferences to people with intellectual disability together with our perception of the inherent contradictions between the practice of conferences and the value base of organisations such as ASSID prompted us to question how concepts such as “accessible” and “inclusive” are applied to conferences about intellectual disability. Our aim in tackling this issue was to consider whether ‘inclusiveness’ and the values of equality, self determination and participation that have come to underpin policy and practice in the field of intellectual disability can be achieved in the environment of conferences that have historically and primarily been exclusive? Is “Nothing about us without us” achievable or when it comes to conferences is it “Sometimes about us without us”?

The authors felt that this issue was important enough to seek the views of conference organisers, self advocate participants and office bearers of ASSID, to gain a fuller understanding of how ‘inclusiveness’ and ‘accessibility’ has been addressed by ASSID. We asked the broad question “are ASSID conferences inclusive”? We ran a focus group with eleven self advocates who had attended conferences, conducted phone interviews with past conference organisers and reviewed ASSID conference programs for

the ten years from 1994-2004. Based on information gathered through this process, our own reflections and the discussion generated from a symposium held at the ASSID 2005 conference we identified the following issues and make some suggestions for a way for ASSID to move forward on this issue.

Planning for inclusive and accessible conferences

A number of key challenges arise in combining inclusive principles and practices in an exclusive environment which by definition focuses on knowledge and knowledge sharing. Over the past ten years many and varied attempts have been made by conference organisers to address issues of inclusion and access. Planning for inclusion however has lacked consistency and does not seem to be based on a framework of principles or learnings from previous years. An ad-hoc approach has characterised each conference, with the degree of attention and effort given to inclusion dependent on a “champion” driving and supporting the process. Not all conference organising committees have had such a champion, which has been a limiting factor.

One consistent inclusive practice has been the demarcation of papers by their level of accessibility. In several instances papers were presented in different formats at two sessions; one in formal academic language and one in plain English. Few guidelines however, have been available to assist presenters to develop accessible papers or presentations. They are generally asked to self select the level of their paper. Neither has monitoring occurred to ensure papers meet expectations or standards of access. Without a set of principles for organising committees and clear guidelines for presenters, inclusion and access are likely to remain optional and a minor consideration in conference planning,

Programming for inclusive and accessible conferences

A variety of programming strategies have been used to support inclusion of participants with an intellectual disability. The most common has been a “consumer or self advocate” strand in the program during which accessible papers are delivered to an exclusive audience of people with an intellectual disability and / or additional papers or workshops are held in formats that support more opportunities for questions and more time for discussion. One conference added to this strategy a lunchtime roundtable that brought together delegates to talk about the morning presentations. A variation on the consumer strands has been a “consumer or self advocate” day, where for one day of the conference a room is set aside for plain English presentations and exclusive activities and workshops are run for and by people with an intellectual disability. A small minority of conferences have adopted a fully integrated approach that has been characterised by at least one keynote speaker being a person with intellectual disability, co presentations of research by research teams comprised of people with and without intellectual disability and integrated workshops run by local self advocacy groups and keynote speakers (usually academics).

The effectiveness of these various approaches has not been systematically evaluated. We found a consensus among conference organisers and ASSID office holders that it was not feasible to have a fully integrated program at conferences such as those run by ASSID. An alternative approach is to run a separate parallel program for people with intellectual disability with one day where the two programs merge. This type of format would also enable cross-stream presentations during the conference, where people with an intellectual disability can present in the general program and academics/service providers present in the self advocate program. Although this approach seems to support the “sometimes about us without us” view it does so with a commitment to access and sharing of resources and ideas. It also enables all delegates to benefit from hearing national and international speakers.

Views of people with intellectual disability

People with intellectual disability who have attended conferences were unsure about the best way to achieve inclusion and access. They thought that conferences should aim to bring people with an intellectual disability, researchers, academics and service providers without intellectual disability together to learn from each other, and share knowledge and experiences. They had some very clear ideas about what was needed to work towards an inclusive and accessible experience for all.

As a starting point they stressed that conferences needed to be affordable and support from grants and scholarships for people with an intellectual disability was needed. They acknowledged that funds are sometimes available from ASSID branches and State organising committees to support registration and travel expenses for delegates with an intellectual disability. Such provision is limited however to only a few people, it not advertised and requires considerable effort to obtain. It is sorely in need of expansion and systematisation. One participant noted that the Victorian State Government provided scholarships and travel grants to workers in the field and wondered if this could be extended to include people with an intellectual disability.

People with intellectual disability pointed to the need for the program itself and presentations to be in plain or easy English. They suggested that although papers were often advertised as being in plain English few actually were. In relation to support for participation, a key issue was the need to have facilitators, support workers and note takers available to ensure people got the most out of the conference. One participant noted that skills were required for such positions by saying, “they need to be good at what they do”. Being a part of the program as key note speakers, presenters and co-presenters to all delegates was also highlighted. Finally, people with an intellectual disability wanted conferences to be interesting and use a variety of presentation modes to assist with

inclusion and access; breaking into groups to talk about what has been presented, having extra time to talk and feedback thoughts and questions and having slides and presentations that can be read, understood and enjoyed.

Some ideas for a way forward

Should conferences be inclusive or exclusive? Can they meet the aims of inclusion and access and also be forums for the meaningful presentation and sharing of knowledge that delegates without intellectual disabilities expect? It is difficult to answer these questions conclusively but we do think it is time that associations like ASSID began to debate the notion of inclusive conferences and reach an agreed position on conference programming and planning that is supported by policy and guidelines. These must have sufficient flexibility to reflect the local community strengths and alliances. The way forward should acknowledge the disadvantageous financial position of people with intellectual disability and self advocacy organisations. Formal partnerships between ASSID and organisations of people with an intellectual disability could address this by making a commitment to share conference infrastructure, and thus support an annual national forum for people with an intellectual disability in parallel with the ASSID national conference. Some people have argued against inclusive conferences noting that self-advocacy holds its own conferences at a state, national and international level. While this might be so, it is important to recognise that not all people with an intellectual disability are connected to self advocacy and most self advocacy groups are not funded to participate in self advocacy conferences or to attend national or international conferences. Self advocacy conferences that are held rarely bring together researchers and people with an intellectual disability and often focus more on service type issues and social activities than research. In our view organisations like ASSID have an important role in supporting self advocacy conferences, and the existence of separate forums should not exclude the

possibility of inclusive conferences where people with an intellectual disability can engage in the rigorous, knowledge sharing environment that may lead to better policy and practice in the field.

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