

conference keynote profile:

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What led you to start researching ID?

As an undergraduate I disliked behaviourism's neglect of emotions, but as a post-grad trainee clinical psychologist in the 1970s I found behaviourism was the only game in town. So I practiced behaviourally for 5 years in Scotland, Devon and Manchester, but became increasingly convinced that absent or unhelpful relationships are significant issues for people with ID. I then got a life-changing doctoral fellowship at the University of Nottingham that allowed me to research social relationships. It led to the position I held for the next 25 years, 50/50 in research and practice at the University of Nottingham. I won more research grants with sociologists than psychologists, many of which examined the transition from school. This moment is a pinch-point that reveals the way policies are and are not working. My return to clinical practice after the PhD was problematic: behavioural approaches not only lacked emotional sensitivity, for me they were also too individual and too powerful. I entered further training to qualify as a family therapist, which gave me rich new ways to understand and address the difficulties experienced by adults with ID, and by their parents, staff and carers. I worked alongside nurses and professionals in an assessment and treatment unit (ATU) for the very small number of acutely disturbed or distressed people who could not be supported in the community. As I came to appreciate the situation and skills of staff and families, they came to appreciate how research might enable them to better support the person with ID.

What's good about doing research?

A clinical psychologist once described his research as long, lonely, and pointless. He'd lost all interest in the topic by the time his paper came out. You do have to like your own company as you stare at blank screens, and cudgel your brain into seeing connections and expressing half-formed ideas in words. Yet there is always the hope of writing something that matters, and of provoking new ideas in others. In a small field like ID there won't be many compatible people working where you are. You have to discover what the poet e. e. cummings called 'delectable mountains' - people whose thinking is both close enough and different enough to make conversation fizz. My virtual network keeps me trying, failing, and trying again to connect research data, ideas, and practice. A career high was hosting a small international seminar, Counterpoint (reported in *Journal Intellectual Disability Research*, 2010, v54 Supplement 1). Researchers from Australia, England, Germany, Holland, Scotland, USA, & Wales presented papers that had been read beforehand so they could be fully discussed. Twenty of us took over a small country house hotel for three days, affordable because the owner waived her usual £8k fee and provided it at cost in order to support our work. In the group picture (next page) you may see two Australian Professors, Christine Bigby (front row, 3rd from left) and Brendan Gleeson (far right). That's me in the stripey dress.

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Lively conversations with researchers in Amsterdam and Brussels and a growing relationship with La Trobe University and ASID continue to energise me in retirement.

Does it change practice?

Clinically-informed research has changed practice but there are barriers to implementation. Clinicians who meet representatives of about half of the population tend to forget they know little about the other half. Research can also be misused to constrain innovation. An example is the UK's current requirement that staff implement Positive Behavioural Support (PBS), which makes service inspectors blind to new forms of intervention even when services produce research that demonstrates positive effects. It is full steam ahead for PBS despite the government's own full research review (rather than its Bowdlerised summary) which characterises the evidence base for all interventions as weak or non-existent, and their recommendations as no more than advisory.

One of the founders of practice-based research in ID, the New Zealander Jack Tizard, wrote this. 'The major impact of most research ...[is] at a local level and on the 'climate of opinion'.... It is the experience, knowledge, and way of looking at problems which research workers have, which could be of most use to ... policy What research workers have to offer government may often be by calling them as experts or consultants rather than by asking departments to commission specific pieces of research and then

attempt to assimilate directly the results of a large number of disparate enquiries.... [Researchers] if they are any good, look at their problems in a wider perspective.'(1979). Research-active services are high quality not only because their critical examinations help practice to evolve, but also because openness to people and ideas protects vulnerable people in challenging settings.

What else can ASID do to implement research effectively?

ASID's conferences have always been innovative: I first attended in 2003. It is in a good position to get proponents of different positions and modes of existence to talk to each other, so that they can identify what works well for whom. Since the World Economic Forum recently identified increased polarisation within societies as one of 5 major threats, here are some topics I would encourage working groups to discuss.

1. How to design services that address the needs of healthy people with milder ID in non-stigmatising ways, and justify and plan services that can address the needs of people with chaotic lives, severe ID, or complex needs.
2. Identifying the minimum requirements for adults with ID to live a life of dignity.
3. How can the relationship between parents and service-providers become less adversarial, more collaborative?
4. Innovation in a policy context that seeks certainty. ●