



De-mystifying the Mysterious: Reflections from a Fellowship Year in Intellectual Disability Mental Health

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In 2016, I was fortunate to receive a fulltime Fellowship to work with people with intellectual disability (ID) and their carers. Whilst I am now nearing the end of my training in psychiatry, no textbook could have prepared me for what I was about to encounter. It has no doubt been a year of challenges, interspersed with small victories for patients and their families which seems to make it all the worthwhile. The following is a short reflection on how my year working in ID mental health has helped to de-mystify what is too often an area cloaked in misconception.

I would like to begin by pointing out that, in Australia, training posts in ID mental health are rare. Therefore going into the year, I was not sure what to expect. My prior experience was extremely limited, as if ID medicine was shrouded in mystery and belonged somewhere in the far-off land of the disability sector. At a minimum, though, I did understand that the mental health needs of people with intellectual disability were not being met. People with intellectual disability have significantly higher rates of mental illness than the general population (reference needed). Whilst almost half of this population suffers from psychiatric co-morbidity, less than 10% of those are accessing adequate mental health care (Einfeld & Tonge, 1996). Thus, with naïve enthusiasm I plunged myself into the year, with posts in busy child and adolescent, and adult outpatient clinics across a number of public hospitals in Sydney.

I quickly experienced many of the challenges that are faced by people with ID and their carers on a daily basis. The current landscape of mental health services for people with ID is a desert, with a severe lack of services catering to their complex needs. For those few services that do exist, access to and navigation of the system is difficult, and they are often severely under-resourced. Waitlists are extensive. There is also a lack of access to in-house allied health staff or care-coordinators, who would ordinarily play a vital role in providing holistic care. I became acutely aware of the stigma surrounding people with ID; local mental health services and emergency departments frequently misattribute behavioural disturbance to a disability, instead of recognising the presence of a co-morbid mental illness. This is often through no fault of the professionals, owing to the aforementioned issue of inadequate training opportunities in ID mental health. In fact, I am only able to train in the area owing to a Fellowship grant provided by the NSW Department of Ageing Disability and Home Care (ADHC), administered through the NSW Institute of Psychiatry. I am extremely grateful for the opportunity, and only saddened to learn that ADHC (and presumably this Fellowship) will also cease to exist as a government service after 2018 due to the transition to the National Disability Insurance Scheme (NDIS).

There is a significant disjunction between psychiatric, disability, government and non-government services that often left me feeling



helpless, and I could only imagine how people with ID and their families would have felt attempting to navigate this landscape themselves. With the transition to the National Disability Insurance Scheme, I have had to watch people wade through (or sometimes drown in) the complexities of the process, only to have their needs mis-identified and/or not addressed. I have therefore realised that the prescription pad, whilst central to my role, can be of secondary importance to my role in educating others and advocating for patients and families to have their needs met.

Having outlined a number of limitations, let me now turn to the sense of purpose I have developed in working with people with ID - the benefits of which certainly outweigh the systemic challenges. The Fellowship has provided me with an invaluable opportunity to develop clinical, academic and advocacy skills across the complex realms of intellectual disability and neuropsychiatry. This has been timely, particularly in view of the current paradigm shift towards the National Disability Insurance Scheme. Clinical presentations are highly varied and often extremely complex compared to general psychiatry, which lends itself to an unparalleled clinical experience. I feel I am now better able to provide clinical care for people with intellectual disability and their carers; as well as providing education and training to the health workforce at large. Collaboration with other medical specialties, allied health services and the non-government sector has been gratifying and vital for developing more comprehensive and integrated disability and health care services. In addition to clinical work, the Fellowship has enabled me to take part in conferences both nationally and internationally, and network with a cast of impressive, passionate researchers and clinicians to improve outcomes for people with ID. For registrars or psychiatrists interested in training in ID mental health, I would highly recommend pursuing the experience as a rich and rewarding field, both professionally and personally.

On a more personal level, I have been privy to the resilience of people with ID and their carers, which has been nothing short of awe-inspiring. The Fellowship has helped me to understand the complexities of ID mental health and so now it no longer feels as if it is an untouched enigma of a far-off land. However, I suspect the tireless commitment and compassion of families and



carers will remain as one of life's greatest mysteries and inspirations to me.

As the training Fellowship draws to an end, I would like to express my sincere thanks to the NSW Department of Ageing Disability and Home Care and NSW Institute of Psychiatry for administering the funding. I am thankful to each of my supervisors for sharing their wisdom to develop my foundational knowledge and skills. I would especially like to thank my greatest teachers – that is, my patients, their families and carers, for allowing me to share in snapshots of their incredible resourcefulness. I will endeavour to continue to work across health and disability, in order to continue to improve the quality of access to and raise the standard of mental health services for people with intellectual disability.

Reference

Einfeld, S. L., & Tonge, B. J. (1996). Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research*, 40(2), 99-109.