



Historical perspectives in Intellectual Disability Mental Health (IDMH) – The NSW experience

Never Stand Still

Medicine

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Background

- People with an intellectual disability (PWID) experience elevated rates of common mental disorders when compared to the general population (2-3 times higher)
(Cooper, S.A., et al., Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. British Journal of Psychiatry, 2007. 190: 27-35.)
- The mental health needs of PWID are often complex, and enduring
- Despite this, access to health care, and mental health care in particular is disproportionately poor

- Capacity, capability and sustainability of workforce has remained static over time (Mendoza, J., et al., *Obsessive Hope Disorder: Reflections on 30 years of mental health reform in Australia and visions for the future.*, 2013: Caloundra, QLD)
- Inequity in access is a direct contravention of principles set out in United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations. *Convention on the Rights of Persons with Disabilities.* 2006; Available from: <http://www.un.org/disabilities/default.asp?id=259>.)

UNCRPD

- Australia is one of the 134 States to have currently ratified the convention
- Commitment to “promoting, protecting and ensuring the full and equal enjoyment of all human rights and fundamental freedom by all persons with disabilities” .
- Article 25 – “recognise and take all appropriate actions to ensure that people with disabilities obtain the highest attainable standard of health”.
- Highlights inextricable link between health and human rights (Mann, J.M., et al., *Health and human rights*. Health and human rights, 1994: p. 6-23.)

Project

- A need to develop strategic plan for service frameworks in the field
- Tapping into the 'collective conscious' of prominent figures in the field of IDMH
- Gain a sense of the 'culture' within this workforce, and the evolution of services that exist in general

Methods

- Qualitative study
- Purposive sampling to invite participants who had significant experience in the delivery of mental health care to PWID in NSW
- 2 physicians, 5 psychiatrists, 2 psychologists, 1 developmental paediatrician, 2 advocates and 2 nurses

Methods

- Semi-structured interviews between April and August 2013 that ranged from 49 minutes to 117 minutes.
- The interviews were audio recorded and transcribed verbatim
- NVivo 10 was used to manage the data
- Thematic analysis was undertaken and data checking was completed by the research team members to facilitate the validity of data coding and analysis.

Themes with wide representation

- Deinstitutionalisation and it's impact
- Successes and failures
- Philosophies and paradigms
- Service structures
- Specialist skills
- Key motivators for working in the field
- Stigma

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Drivers of change

- Social

“looking at people as individuals and as people who have a life and family”

- Medical / overtreatment

“many of the people were on a horrendous amount of medication”

- Abuse and neglect

“very clear to us where we were sitting that the rights of people with ID was highly neglected”

“people were being treated like animals. It was shocking”

Impact

“once people were out into the community, they were more likely to be referred to mental health services... it wasn't all being prescribed to whatever their intellectual disability was”

“when it first happened there was very good discharge planning”

“amazed at the burgeoning once they've gone out into the community. You know, there are people who have developed skills and interests and social contacts”

“it's important to see people with disability in communities and I think integration in schools and in you know, out in the street and everywhere else”

Impact

“the view of holistic care was probably pushed out the window at the same time.....across the spectrum of allied health services”

“you do disability, you’re a disability team, we do mental health. You look after your disabled people and we’ll look after our mental health people”

“... there was a very strong desire to sort of have ID seen as different to mental illness which was good but I don’t think there was sufficient understanding of the complexity of the interplays”

Lost in translation

“the positive side was saying yes they have the right to this access that was fine but government saw it as a way of saving money”

“normalisation idea was sort of interpreted in a way which was just obvious denial”

“that everybody who was sick could go to the GP or, they didn’t need to have any special services”

“a false premise that they would be able to find those services in the community. They couldn’t find those services in the community, the services were not there in the community”

Governance

“People ...in group homes with minimal support, untrained carers”

“...the financial and sexual exploitation of residents happens but it’s invisible in a group home because there’s one staff and the residents”

“a culture of bullying and intimidation and that culture is hidden and staff who don’t agree with it are extruded very rapidly”

“reflective of a devolution of governance, a kind of handing down of responsibility”

Service frameworks and workforce – Implications

- **Access – Potential and Realised** (Khan, A.A. and S.M. Bhardwaj, *Access to Health Care: A Conceptual Framework and its Relevance to Health Care Planning*. Evaluation & the Health Professions, 1994. **17**(1): p. 60-76.)
- Coordinated and purpose driven data collection
- Philosophy and paradigms – Need to adopt a holistic approach (Meekosha, H. and R. Shuttleworth, *What's so'critical'about critical disability studies?* Australian Journal of Human Rights, 2009. **15**(1): p. 47; Shakespeare, T. and N. Watson, *The social model of disability: an outdated ideology?* Research in social science and disability, 2001. **2**: p. 9-28.
- Capacity building within local structures

Service frameworks and workforce – Implications – Implications

- Capacity
- Competence and skill
- Adaptable
- Responsive - Models of care – crisis-based/
triage/ parallels

Discussion

- Ideal model for service provision – Tertiary consultation Vs secondary care
- Hierarchical model – complexity/ needs based ?
- Public and private sector involvement
- Regulation

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- Date of Presentation: 14/05/2014
- Name of Conference or Forum: RANZCP Congress 2014, Perth

Thank you for your attention