Avoiding the same mistakes:
What we can learn from the experiences of ageing with an intellectual disability in the USA, UK and Ireland

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Why am I here?

I was very lucky to be awarded a 2012 Churchill Fellowship to look at the issues of ageing and palliative care for people with intellectual disabilities.


Estimated total travel distance: 22,068kms.
I will be providing a very brief review of what I found in each of the locations I visited, and a description of the differences I observed.

I will finish with a series of recommendations that I have developed based upon what I think could be adapted to the Australian context.
Please ask questions or comment at any point.

I am very happy to have questions throughout the presentation – don’t feel that you have to wait until the end to ask!

Also, as a general warning, I will be discussing some issues around ageing and palliative care that could be confronting or disturbing for some individuals.
I commenced my Churchill Fellowship in the USA. I landed in late June, and after a rest-day to try and overcome the worst of the jet-lag, I started my journey in Los Angeles …..
Los Angeles

I was fortunate to be guided by the wonderful Dr Harriet Aronow from Cedars-Sinai Medical Centre. I also visited

- Bet Tzedek Legal Services;
- L.A. Care;
- Casa Colina Centers for Rehabilitation;
Chicago

In Chicago, I was hosted by Professor Tamar Heller from the Department of Disability and Human Development at the University of Illinois at Chicago.
In New York, I met with Professor Gary Stein from Yeshiva University and also visited the Overlook Medical Centre to observe their use of the POLST (Physician Orders for Life Sustaining Treatments) model to overcome legal issues that sometimes impeded dying with dignity.
Summary of USA Findings

My strongest feelings from the United States was that the system could be made to work beautifully, so long as you either had money or the right insurance to cover your specific problem.

However, there were also clearly some very positive practices, with the POLST model. Likewise, the coordination programs were assisting to overcome the often bewildering mess of legal, medical and social structures.
Ireland (Dublin)

While in Dublin, I was lucky to be supported by the excellent staff at the School of Nursing & Midwifery, Trinity College, and I also visited the Daughters of Charity Service and Down Syndrome Ireland.
Summary of Irish Findings

In what would become a recurring theme throughout Ireland and the UK, I was particularly struck by the role that the specialist Learning Disability Nurses play in the provision of support.

There was a far simpler integration of health care and social support than is evident in Australia.
Scotland (Edinburgh)

- Edinburgh City Council
- School of Health in Social Science, Edinburgh University
- Faculty of Health, Life & Social Sciences Edinburgh Napier University
- Murraypark Unit, Corstorphine Hospital
- Department of Clinical Oncology, Western General Hospital
- National Health Service Education for Scotland
- National Health Service Lothian
- Scottish Government Health Department, ID Policy and Self-Directed Support Policy Team
I took away the message that, in Australia’s move to truly person-centred support models, we need to recognise that health is not something that can simply be cordoned off to mainstream generic services. There is no point having a wonderful person-centred program if the individual is then moved to a nursing home as soon as their medical needs increase.

The integration between social and health care was much better managed than in Australia, and such coordination is desperately needed if we are to appropriately meet the needs of people with intellectual disability who are approaching end of life.
England

- Estia Centre at Maudsley Hospital
- Denis Hill Unit at Bethlem Royal Hospital
- National Development Team for Inclusion
- Norah Fry Institute at Bristol University
- British Institute of Learning Disabilities
- School of Nursing & Midwifery, Keele University
- Donna Louise Children’s Hospice Trust
- Douglas House, Oxford
- Lewisham Team for Adults with Learning Disabilities, National Health Service
- Department of Psychiatry, Cambridge University
Important Cambridge Finding

- **Quick finding no. 1** – There is an important difference between Trumpington Road and Trumpington St in Cambridge. If you are planning to visit Professor Tony Holland in Trumpington Road, don’t instead go to Trumpington St because you failed to read the directions correctly.

- **Quick finding no. 2** – It turns out that you can run from the corresponding street number in Trumpington St to Trumpington Road in around fifteen minutes and still make it to your appointment on time (just).
Summary of English Findings

- One of my main learnings specifically from England was around the environment for palliative care. The purpose-built centres that I visited worked far more effectively and were much more ‘liveable’ than many of the retro-fitted old facilities I had seen in Australia.

- The other thing that I noticed in England was the greater number of resources that were available for individuals, their families and services regarding both ageing and palliative care. Entities such as BILD and NDTI have produced excellent guides and documents that provide information and knowledge that are not as readily available in Australia.
I was struck by the fact that many of the small group homes for people with intellectual disabilities around the world that I saw could have easily been dropped into an Australian setting and I wouldn’t have batted an eyelid. There were a large number of similarities with respect to the house environment, the matching of residents, and even the attitudes of social support staff.

However, it seemed clear to me that the biggest impediment for us in Australia surrounds the management of increasing health care needs. In the USA, UK and Ireland, they had all managed, to a greater and lesser extent admittedly, to meld together the social and medical care needs of the individual into one cohesive package.
Recommendations

I have tried to collate my thoughts and observations from throughout my trip into a series of recommendations.

These recommendations are largely based around what seemed to be working effectively and efficiently within the countries I visited, and was able to be modified to an Australian context.
Recommendations 1-3

1. To greatly expand the number of specialist disability nurses employed within the Nursing and Health Care Division of the Clinical Innovation and Governance Directorate in Ageing, Disability and Home Care in NSW, and to explore similar such models within other states.

2. That current legislation surrounding ‘deaths in care’ of people with disabilities be reviewed and changes around ‘natural’ deaths versus ‘unexpected’ deaths for people with intellectual disabilities be discussed.

3. That greater cross-sector collaboration between generic health and specialist ageing, disability and palliative care services is supported, with a specific focus on providing training for all carers, both paid and unpaid.
Recommendations 4-7

4. That specific training for the provision of ‘end of life’ care is provided for disability support workers across both rural and metropolitan locations.

5. That government disability accommodation funding is made suitably flexible to actually support the concept of ‘ageing-in-place’ by recognising that individual need may increase over time.

6. That the key professional association for disability workers, the Association of Australasian Disability Practitioners (AADP), examines the feasibility of introducing specific individual accreditations for disability workers in key areas such as dementia, mental health and end-of-life care.

7. That the legislation and implementation of the new DisabilityCare model both recognises and specifically addresses responsibility for ageing and palliative care issues for people with intellectual disabilities.
Current Research

A team of researchers from the University of New England and University of Sydney have combined with non-government aged care and disability organisations across two states (NSW and Queensland) to conduct a series of studies into ageing with an intellectual disability.

The focus of this research is comparative, looking at the experiences of people ageing both with and without a lifelong intellectual disability, across rural and metropolitan locations, and in different jurisdictions. Preliminary results are going to be presented this afternoon at 2.50pm in the Beaumont Room – please come along 😊.
Future Research?

One of the goals of my Churchill Fellowship is to maintain my linkages across the USA, Ireland and the UK so that we can look at developing some collaborative research projects that examine the experiences of individuals with an intellectual disability who are either ageing or require palliative care across different countries.

From there, we can hopefully start to define exactly what is working well, and what impediments may be able to be overcome.
Any easy questions?

Full copy of report is available at

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