Ethical Issues in Ageing

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In August 2016, the New South Wales division of the Australasian Society for Intellectual Disability (ASID) hosted a forum in Sydney on 'Ethical Issues in Ageing'. The forum topic arose from survey responses about preferred future events, conducted at an ASID networking event in Parramatta in 2015. Ethical Issues in Ageing was one of the top issues identified.

The 2016 Congress of the International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD) was held in Melbourne and brought together leading international figures in disability research. ASID identified this as an opportunity for State and Territory committees to host local events involving IASSIDD key note speakers.

The NSW ASID Ethical Issues in Ageing forum keynote speaker was Professor Tamar Heller from the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois, Chicago, USA. Professor Heller, who conducts leading research on ageing, health and families, provided an overview of the international perspective of ageing for people with intellectual disability related to:

• Extended life expectancy

• Ageing well

• Life-course approach.

Invited local speakers then presented four topics:

Family: Dr. Angela Dew, UNSW Australia

Health: Dr. Stuart Wark,
University of New England

Retirement: Professor Roger Stancliffe,
University of Sydney

End-of-life: Ms. Sharon Brandford,
Disability Consultant New Zealand and
Dr. Michele Wiese,
Western Sydney University.

All speakers were asked to present an overview of the topic and to identify what they saw as key ethical issues. Following the presentations, Professor Heller moderated forum discussions during which audience members raised and debated additional ethical issues with the speakers.

ASID NSW committee members collated the key issues and discussion points into a summary document to inform the ASID Ltd agenda about the importance of ethical issues in ageing for people with intellectual

Authors:

Ethical . . . Ageing

disability, their family members and formal support providers. This summary is the outcome of that process. The summary offers a background to each topic and then the ethical issues raised by each of the presenters. The forum participant discussion pertaining to these topics is included in *italic font*.

Family

Background

The overwhelming majority of people with disability receive support from family members. Family members include parents, siblings, grandparents and other extended family. Support provided by family members is often called 'informal' support to differentiate it from 'formal' support provided by paid workers. People who provide 'informal' support are often called carers. The Australian Bureau of Statistics, Disability, Ageing and Carers report (2012) estimated that 2.7 million or 12% of the Australian population identified themselves as carers, with 770,000 (3.4%) identifying as the primary carer. Primary carers indicated their reasons for caring included: family responsibility (63%), providing the best care (50%), and feeling an emotional obligation to care (41%). Twenty one percent of carers were aged between 55 and 64 years. People with disability are living longer and many require long-term services and supports throughout their lives. Ageing parent carers are concerned about who will support their adult son or daughter with intellectual disability when they are no longer able to (Llewellyn, Gething, Kendig & Cant, 2003).

Ethical Issues

What is the family versus social responsibility for providing long term services and supports?

- Should family members be paid?
- *Older parents get tired and need help with advocacy*

Who decides what voice should be heard when there is conflict within families and between the person with disability and family?

- *There is a hierarchy of influential people in decision making and this has to be navigated*

To what extent is it reasonable for a person with disability to give caregiving support to ageing parent/s?

- Is the caregiving relationship reciprocal or exploitative?

What to do when there is no obvious future planning?

- Why doesn't future planning happen more?
- *Having to tell your story over and over again is tiring and emotionally challenging*

Prof Tamar Heller

How do families navigate when the roles change after parents die?

- Siblings vs. no siblings
- *Continuity of support arrangements*
- *Circle of Support to assist with information sharing and decision making*

Is family-centred planning possible in the NDIS?

- Is family-centred planning possible in an individualised and marketised system such as the NDIS?
- *NDIS funding does not cover family-centred planning*
- *Lack of individual capacity to arrange and advocate on own behalf*

Health

Background

Individuals with an intellectual disability are more likely to have serious physical and mental health problems, and for these to occur at an earlier age, than the general population. Pioneering Australian research by Beange, McElduff and Baker (1995) indicated that: 50% of people with intellectual disabilities took prescription drugs on a daily basis, with over 30% taking more than one drug per day and over 10% of people with intellectual disabilities have a dual diagnosis with a psychiatric disability. However, despite the evidence over 20 years, people with intellectual disability still face barriers in accessing health services and screening due to low literacy levels for reading health care information, communication difficulties in speaking with health care providers, and a lack of knowledge and experience among mainstream pro-

Ethical . . . Ageing

viders about people with intellectual disability. There is still limited expertise and knowledge within both the disability and health-care sectors about how to best support people with intellectual disability with complex health-care issues, and particularly as they age.

Ethical Issues

Is (re-)institutionalisation a valid pathway to support health conditions that require nursing care?

- *Guidelines are needed to assist with ethical decision making around transitions for people e.g., moving into aged care.*

Life sustaining (health) decisions often take precedence over quality of life for people ageing with intellectual disability. Is this what we want?

- *How do we provide a holistic service that meets the needs of individuals and funding arrangements?*
- *How do we support people with intellectual disabilities to make informed decisions that are both about health and quality of life?*

Who should make health-care decisions and how do we ensure that the wishes of the individual are taken into account?

- *All the different people involved in a person's life need to be included for the best possible outcome.*
- *We need a one-page profile or an electronic record that captures the individual's wishes so they don't have to keep having the same discussion.*
- *It often falls to the family to ensure that the person's records are prepared and provided.*

Are there positive changes we can make or recommend to facilitate better support?

- *Real concern about separating out health and disability under the NDIS. NDIS funds disability not health. This is a particular issue for those who are ageing.*
- *The number of people who will fall through the gaps, exacerbated by the segregation of services and eligibility criteria. Who will be monitoring this?*
- *Risks of the continuity of service arrangements for people who are currently funded through disability services – lack of clarity around what will happen for people aged 65 or over*

Retirement

Background

Australians with long-term disability (including intellectual disability) are living longer and the workforce within Australian Disability

Prof Roger Stancliffe

Enterprises (ADE)** is ageing. Planning for retirement is something that most Australians engage in, however, the experience of this for people with intellectual disability can be very different. There are many reasons for this, including both personal and systemic issues.

In a unique Australian collaborative research project Stancliffe, Bigby, Balandin and Wilson completed the 'Transition to Retirement Project' (Bigby et al., 2014; Stancliffe et al., 2015). This project provided the opportunity for older people with disability to plan toward retirement by replacing one day a week of work with participation in a mainstream community group.

Ethical Issues

Who decides about the when and how of retirement for people with disability?

- *The concept of retirement is often meaningless or poorly understood by people with disability because it doesn't happen and isn't talked about. How do we include them in the discussion in a meaningful way?*
- *Retirement may mean the loss of social connections and opportunities that extend beyond meaningful employment/engagement. How do we replace or maintain these?*

Who is responsible for providing information, education and support?

- *Retirement traditionally happens in the mainstream around 65 years of age. If people with disability retire at the same age will retirement supports be funded through the NDIS?*
- *People with disability age at different rates. Support around individual needs can be very specific and therefore services may need to share the responsibility. How can we ensure this happens?*

** ADEs are not-for-profit organisations that provide supported employment to people with disability.

Ethical . . . Ageing

What to do when retirement opportunities are based on what is available rather than specific to the person's wants/interests?

- *How can we be truly person-centred when the opportunities are limited?*

- *In the Transition to Retirement project specific community organisations were successful. Did the values of the organisation or the fact that they were directly approached influence the inclusion? Would another person and a different organisation share the same success?*

- *It would be beneficial to have a resource/ practice guide that has easy-read fact sheets about retirement, real life stories, contacts/ organisations/referral points and options. This would need to be online and updated regularly.*

How do we know that the person is making an informed choice about retirement?

- *People may need to try multiple options before they find the fit for them. This may be an issue in terms of resources, funding and available options. How do we balance this?*

- *How do we provide enough information to help the person make an informed choice without influencing their decision? Is there a way of making information more accessible?*

End of Life

Background

Like all Australians, people with intellectual disability are living longer. This translates to increased incidence of life-limiting illness and the need for long periods of palliative care. Research about the end of life for people with intellectual disability is in its infancy. We know little about how people understand death or how they experience it - either when others they care about die, or when they themselves are dying (Wiese, Stancliffe, Read, Jeltes & Clayton, 2015). We also know little about how families, the social care, and health sectors assist people through this inevitable life phase.

Most people find it challenging to talk about or confront death. The experience of intellectual disability adds an additional challenge, as understanding this abstract construct in a society where death is somewhat taboo, means that we probably avoid the topic. Doing so, however, is unhelpful. People with intellectual disability do experience death and it cannot be avoided (McKenzie,

Brandford, Conder, & Mirfin-Veitch, 2016; Stancliffe, Wiese, Read, Jeltes & Clayton, 2016). The challenge ahead is developing ways to help people understand death, and experience it meaningfully and respectfully.

Ms Sharon Brandford

Ethical Issues

How, when and what do we tell the person who is dying?

- *Whose responsibility is it to tell the person: the person responsible/guardian, service provider, medical professionals?*

- *What is the benefit or harm of telling vs not telling?*

- *When is the right time to tell the person? What is the person's right to know? Who should be present when they are told?*

- *How to balance our own views and values with our capacity to provide impartial support?*

How can we acknowledge the experience of grief?

- *Grief is more than just about people, it extends to transitions, loss of pets and other changes in a person's life.*

- *Different people deal with grief in different ways. Grief can last for a long time and in different forms. Awareness of this is important.*

How do we know that choices the person might make are informed?

- *How can we ensure that the person understands the information?*

- *How can we make confronting/emotional information accessible?*

- *How to make abstract information about choice accessible (e.g., burial vs cremation)?*

- *What is important to a person may be very different to what we think is important. Providing the opportunity for the person to express choice.*

- *A person's ability to make informed choice may fluctuate or change based on the ageing process (including cognitive decline).*

Ethical . . . Ageing

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ability and ageing carers, this new approach may be particularly challenging to navigate. The changes may mean greater diversity and availability of services thus providing more choice. However, greater choice may also result in greater confusion and the potential for people to be "ripped off". As the service sector changes so too will the interface between services, the person with intellectual disability and families. This may mean that long term relationships between the person/family and services may diminish. For some people/families this may result in less rather than more support. It may also mean that people with disability and families use mainstream services more frequently than disability-specific services. Mainstream services will need to become more inclusive of, and responsive to, older people with intellectual disability and families.

Future Directions

- The NSW ASID committee which hosted the Ethical Issues in Ageing Forum plan to submit an abstract to conduct a World Café event at the 2017 ASID Conference to further explore the issues and keep the conversation alive.

- This summary paper will be published in the April 2017 edition of IDA.

- An ASID position paper on the ethical issues related to the ageing of people with intellectual disability will be considered.

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