Living with intellectual disabilities in the 21st century

JENNIFER CLEGG

UNIVERSITY OF NOTTINGHAM & LA TROBE UNIVERSITY

The argument

1. Examined achievements & shortcomings of current policies
   - Longitudinal cohort research on transition out of school
   - Literature review about *Dediff*: Clegg & Bigby; ASID
   - Conclude policies 50 years old & increasingly poor fit with current situation. Corrected problems of predecessors, but increasingly poor fit with current situation.
2. Society is changing (Bauman)
3. Ethics – our understanding of the right thing to do - also changing
4. **21st C ideas pushing the boundaries but… intellectual disability slow to change**

How people on ground negotiate transition Clegg Murphy Almack Pilnick

- Longitudinal cohort of 28 young people aged 18 or 19 from 2 localities
- 18 months: from 6 months before to 12 months after school-leaving
- 143 interview transcripts or other substantive pieces of data:
  - Interviews with YP where possible & notes of observations during visits
  - Parents or other family members:
    - Pre- & post-leaving audiotaped interviews
    - Notes of monthly phone calls, diaries, meetings observed
  - Transition Worker pre- & post-leaving audiotaped interviews
  - 8 audiotaped transition planning meetings

Transition for the 28

- Outcomes:
  - Good/acceptable 21
  - Undetermined 2
  - Unsatisfactory 5
- Process for parents difficult & distressing
  - *You could do with being put to sleep for the whole period*
  - *Worse than the year my husband died - I felt isolated, emotional, angry, unsupported*
- Process for transition workers highly stressful. Of initial 12:
  - 6 resigned, some after long periods of sick leave
  - 2 long term sick leave
  - Remaining 4 highly stressed

What is the problem with transition?

- High TW stress indicates not a matter of them simply needing to 'raise their game'

- Examined hidden tensions in the ideas, assumptions & moral imperatives that frame transition:

  - Inclusion

  - Risk

  - Adulthood

  - Person-centred planning

  - Choice

Policy tensions revealed by transition

- 2008: *Tensions around inclusion: reframing the moral horizon*
  - Inactivity **the** most frequently raised concern: **where** not important
- 2009: *Parental negotiations of the moral terrain of risk in relation to young people with learning disabilities.*
  - Risks & constraints underestimated;
  - Small patch of dry land between parents being seen as over- or under-protective

2011: *Constructing adulthood*

- Planning futures for young people with intellectual disabilities requires juxtaposing
  - obdurate reality of differences in capacity for autonomy & self-protection
  - resistance to objectification & infantilisation
- Decision-making enhanced when participants integrate different perspectives rather than assert one or condemn another
- Professionals will have to set aside doctrinaire assumptions that pursuit of autonomy & self-determination should trump all other considerations
- **Need genuine openness to alternative positions and respect for dissenting voices**: Such debates keep our judgements in good order

Person-centred planning

- 2010: *Questioning the answer: Questioning style, choice and self-determination in interactions with young people with Intellectual Disabilities.*

  Alec wants to join the police…

- 2011:"*Just being selfish for my own sake..*": *Balancing the views of young adults with intellectual disabilities and their carers in Transition planning.*

Services need parents to support Person-Centred Plans but parents' needs & desires not legitimated

2017 Choice

It was not a simple matter of parents and transition workers hearing about these young people's choices and facilitating what they wanted

The data raise questions about discourses of choice in ID when referring to people with severe intellectual disabilities:

➢ few 'choices' could be considered informed nor made by young people with capacity to make them

➢ interpreting some refusals as choice resulted in neglect

➢ Collectives not an option

Overarching conclusions

- Professionals need to emerge from a rule based approach to practice & moral clarity associated with asserting client empowerment as service goal

  - because

- underplays the constraints that people with ID experience

  - & because

- excludes key members of their affective community from the picture
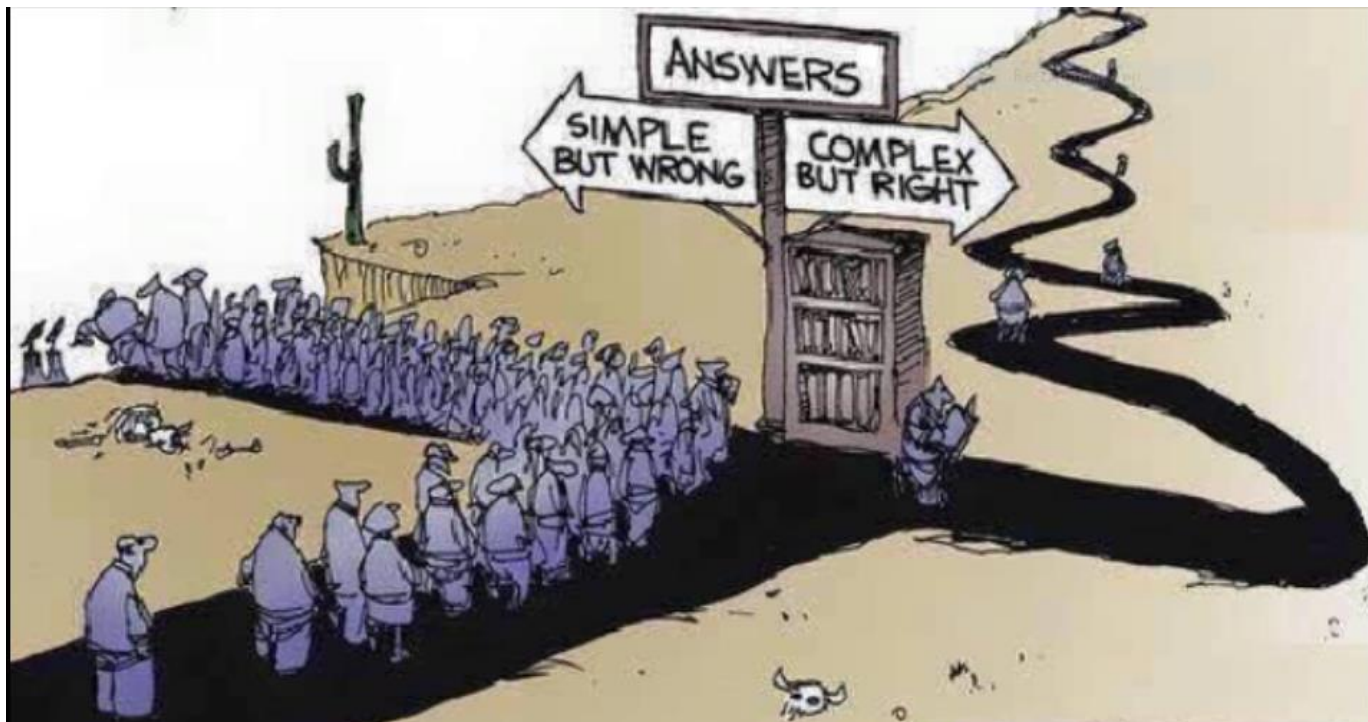
1.2 Dediff: Evidence & change

- **Debates about *dedifferentiation*: Regarding people with intellectual disability as distinct members of the disability group**

  Jennifer Clegg, University of Nottingham, UK
  Christine Bigby, La Trobe University, Australia
  2017 RAPIDD

- **Addressing the shortcomings of Dedifferentiation** ASID Position Statement

Advantages of Dedifferentiation
(ignoring 'intellectual' aspects of disability)

► **Choice** - many people with mild intellectual disabilities prefer to avoid this label.

► **Advocacy** - strengthens the collective voice of people with disability to change oppressive structures and attitudes.

► **Inclusion**. This has worked best in primary schools and child mental health services.

► **Avoids focussing on impairments and deficits**

Advantages of Differentiation
(attending to 'intellectual' aspects of disability)

- **Recognises diversity & group-specific needs** - recognises breadth of specialist knowledge & skills required

- **Acknowledges difficulties & limited success of training generic staff**

- **Avoids inaccurate or absent representations** – avoids using people with mild IDs as proxies for whole group

- **Recognises impairment-specific barriers** – beyond visible & physical barriers to cognitive and communication issues

- **Enables quality alternatives to mainstream services**

- **Avoids compounding disadvantage**

- **Enables more specific advocacy**

- **Identifies need for specific resources**

Address Dediff shortcomings

1. Design different types of services for different types of people

2. Ensure services recognise and respond to unique needs, & all staff have necessary knowledge and skills to do so

3. Provide specialist opportunities & services in segregated settings only when necessary

4. Balance service user perspectives with other diverse sources of knowledge about all people with intellectual disabilities

5. Develop new policies and support to meet high levels of physical & mental health need, amplified by social deprivation

6. Tackle social isolation

7. Negotiate a definition of a meaningful adult life so people with intellectual disability can be supported to live a life of dignity

8. Gather data that support allocation of appropriate resource to address complex needs

2. Societies are changing

- Groups, clubs, organisations are dissolving
- Greater insecurity of jobs and homes
- People move much more
- Relationships more fluid
- Achieving satisfactory recognition one of problems of the age
- Danger of pitting vulnerable groups against one another for limited resource

Bauman *Liquid Modernity*

Fine & Saad-Filho (2017) Neoliberal Individualism

- Redefined relationship between economy, state, society & individuals
- Devil-take-the-hindmost treatment of vulnerable groups (disadvantages people with ID disproportionately, Clegg & Bigby 2017)
- Dissolution of social collectives blocks political dissent & emergence of alternatives
- Different interest groups acting together can & should resist it

3. Ethics is changing

- Ethicists reject C20th dichotomies:
  - Social-medical
  - Dedifferentiated-differentiated
- Ethics of practice "less about polar right and wrong actions, but instead choosing the better action from a range of possibilities" (Sadler, van Staden, & Fulford, 2015, p. 7)
- Care Ethics highlight problem of focusing only on individuals:
  - "Must avoid humanising some lives by silencing others. Surely, people with developmental disabilities are vulnerable, but so too are the people who surround them" (Clifford-Simplican, 2015:224)

Why might ID be slow to change?

- Fully occupied juggling demands, building networks
- Fatigue: constant churn, no real change
- People defend ideas they depend on
  - *I've heard nothing new*
  - *I don't want to hear anything new*
- Politics: advocacy demands certainty

What prevents change?
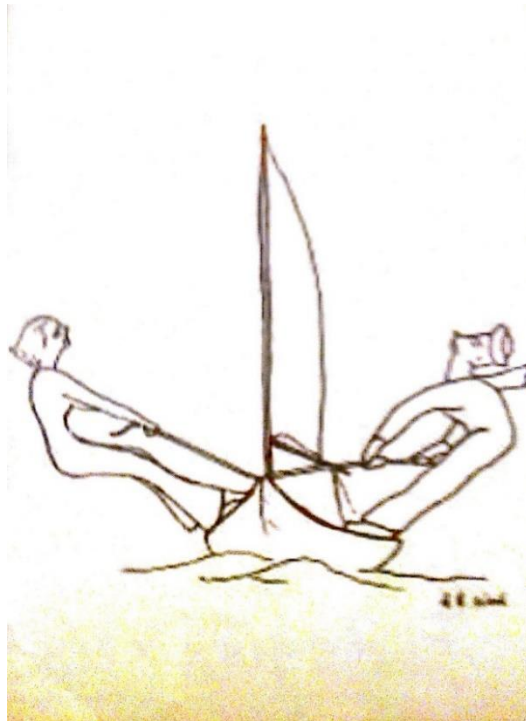
Can we push the boundaries & adopt an ethics of life?

▶ "When the essence of the individual isn't defined by their degree of impairment but instead in terms of the affective relations they are able to hold, we have an ethics that fits well with the heterogeneity of those with intellectual disabilities…. It is an ethics of life, rather than of one species, and hence is able to deal with divergent forms of life effectively." Somersby-Hall 2017

Conclusions

1. Limitations of 50 year old ideas evident in research (eg transition) & in analysis of pros & cons of dedifferentiation policy

   ▶ Can & should be addressed: upcoming ASID position statement

2. Neoliberal assumptions about good lives appears to fit well with normalisation but:

   ▶ Freeing market to find own level poor at meeting needs of vulnerable populations

   ▶ Supports financial constraints & decentralisation that together are making services worse

   ▶ Traps thought within dichotomies that exert a powerful gravitational pull

A 21st C perspective pushes the boundaries by…

   ▶ Incorporating ways that society & ethics are also changing: building alliances, being flexible

   ▶ Addressing not principles and outcomes but lives and relationships

Transition & Dediff references

- Clegg, J. & Bigby, C. (2017). Debates about dedifferentiation: Twenty-First century thinking about people with intellectual disabilities as distinct members of the disability group. Research and Practice in Intellectual and Developmental Disabilities, 4 (1): 80-97.

- Clegg, J.A. Murphy, E. Almack, K. (December 2017). Liberal individualism & Deleuzean pluralism in ID. Philosophy, Psychiatry, Psychology, 24 (4):

- Pilnick, A. Clegg, J. Murphy, E. & Almack, K. (2011). "Just being selfish for my own sake..": Balancing the views of young adults with intellectual disabilities and their carers in Transition planning. The Sociological Review, 59:2, 303-323.

- Murphy, E. Clegg, J. & Almack, K. (2011). Constructing adulthood in discussions about the futures of young people with moderate-profound intellectual disabilities. Jnl Applied Research in Intellectual Disability, 24, 61-73.

- Pilnick, A. Clegg, J. Murphy, E. & Almack, K. (2010). Questioning the answer: Questioning style, choice and self-determination in interactions with young people with Intellectual Disabilities. Sociology of Health & Illness 32 (3), 415–436.

- Almack, K. Clegg, J. & Murphy, E. (2009) Parental negotiations of the moral terrain of risk in relation to young people with learning disabilities. Journal of Community and Applied Social Psychology, 19 (4), 286-299.

- Clegg, J. Murphy, E. Almack, K. Harvey, A. (2008) Tensions around inclusion: reframing the moral horizon. Jnl Applied Research in Intellectual Disability, 21, 81-94.