



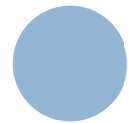
# LATE-LIFE DISABILITY AND EXPERIENCES OF LIMINALITY

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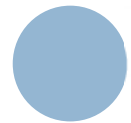
# THE AGE OF SUPPORTED INDEPENDENCE

- a stage in later life characterised by frailty and increasing dependence on formal and informal care while remaining at home



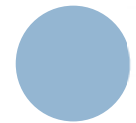
# THE TRANSITION INTO THIS STAGE OF LIFE

- The transition as a rite of passage
- Three stages:
  - Separation
  - Liminality
  - Reconnection



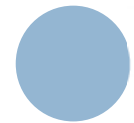
# SEPARATION EXPERIENCES

- Interactions in the assessment process are accompanied by feelings of confusion, anxiety and anguish:
  - 'I wasn't sure what was going on',
- 'Excruciating'
- 'Strong resistance to accepting being in need of ... help.'



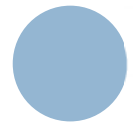
# THE EXPERIENCE OF ASSESSMENT

- 'Somebody came whilst I was in hospital and asked me what I had at home and so they bundled me up into an ambulance and took me home to see what I could do and what I couldn't do. ... They put rails up for me and rails in the bathroom and in my bedroom beside my bed so that I could pull myself up. And they supplied me with boxes to put my chair up a bit higher. ... I got terribly depressed, I'm sorry I just -- I can't cry, I have no tears. And sometimes I wanted -- I felt if only I could have a damn good howl I'd feel better, but I can't.'



# THE EXPERIENCE OF ASSESSMENT

- Who are you really? You become a set of ticks in boxes.
- 'Bundles of expertly defined needs'
- Together these experiences constitute a significant 'biographical disruption'



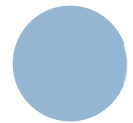
# EXPERIENCES OF LIMINALITY: SPATIAL DISRUPTIONS

- Home arrangements express identity
- New spaces are created to house ageing bodies
- When 'home' becomes a site of service delivery, it challenges these meanings we attach to 'home'



# EXPERIENCES OF LIMINALITY: TEMPORAL DISRUPTIONS

- Biographical disruption
- Time identities
- Formal care introduces multiple time-scapes into the home challenging the rhythms of daily life



# EXPERIENCES OF LIMINALITY: RELATIONAL DISRUPTIONS

- New relationships, new rules, new social roles and new obligations
- A social limbo
- Socially invisible



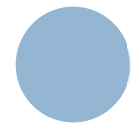
# LIMINARS

- Victor Turner (1969): liminars pass through a cultural realm that has few or none of the attributes of the past or of the coming state
- Robert Murphy (1987): the individual [becomes] alienated from his old carefully nurtured and closely guarded sense of self by a new foreign and unwelcome identity (p.109)



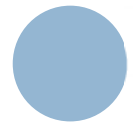
## RESPONSES TO THE LIMINAL

- It is precisely when the individual begins to experience the erosion of freedom and agency that often comes with impairment and frailty that public policies should be designed to provide the resources needed to resist the loss of agency and allow the individual to exercise as much autonomy as possible under conditions of impairment (Polivka and Longino jnr 2004p. 5, and Tulle 2004, p. 185).



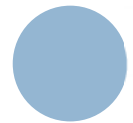
# SUGGESTIONS?

- Policies?
- Practice?
- Formal support?
- Informal?
- A mixture – and how to combine?



# POLICIES AND PRACTICE

- Home careworkers as guides
- Continuing to address broader exclusionary social processes which have older people on the periphery
- Age-relevant reflections



# HOME CARE

- Workers as 'guides' / instructors through the transition
- Social/emotional care to assist in reconnections to a 'preferred identity' (Charmaz 1987)
- Assistance towards a socially valued role for older individuals



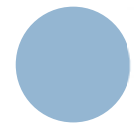
## HOW?

- Allow people to tell their stories
- To 'express who they are and to preserve their identities as something other than sick, declining persons' (Stone 2005, p.283)
- Like grief, liminality needs attention (Sacks 1991:77)



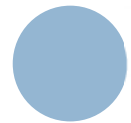
## CARE FOR/CARE OF/CARE ABOUT?

- 'Will they really care about me, or are they just there for the work?' (Hale,2006:186)
- ...excellent care in terms of good practical skills is less appreciated by recipients than poorer physical care from more compatible workers' (Eustis & Fisher, 1991:283)
- The conversations which envelop the practical, physical tasks of caring that 'give clients their lives back and make a difference – which is more important to them than say giving a bath or a meal.' (Eustis & Fisher, p.283)



## OUTSIDE HOME: COMMUNITY

- Older people with disabilities need to be visible:  
To become accepted, and to accept.
- Is there a role here for creating and maintaining sustainable communities for older people with disabilities?



# INDIVIDUAL

- Opportunities and support for personal reflection:
  - A community of understanding, and of sharing knowledge
  - Facilitating opportunities for spiritual growth through sharing with others

