


SEEKING EXCELLENCE:

Clarifying the ethical boundaries between the role of applied researcher as a surrogate disability case manager

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Presentation aims

- 1) Background to the project
 - 2) Aims and structure of the research project
 - 3) Case studies from the research project
 - 4) Summary
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The Research Project

- ▶ **Title:** Transition to Retirement for Older Adults with a Chronic Disability: Increasing Community Capacity
- ▶ **Project:** part-funded by the Australian Research Council (ARC)
- ▶ **Industry partners:** part-funded by AFFORD (Sydney), St. John of God, Accord (Melbourne)



THE RESEARCH TEAM

Sydney

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Why is the research project important?

- ▶ Older people with a lifelong chronic disability face significant barriers to enjoying *active ageing* as they transition into retirement
 - ▶ Currently, older people with a lifelong chronic disability are offered no formalised support to transition into retirement
 - ▶ Due to increasing life expectancy, retirement for this group is fast becoming a major personal, practical, and policy issue for Australia
 - ▶ Research is of national significance
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The current situation

- ▶ In 2007 4,510 adults with a disability aged 50 years and over were employed in **Business Services** (Department of Families Housing Community Services and Indigenous Affairs (FaHCSIA), 2008)
- ▶ Projections suggest that by 2025 half of the entire workforce in **Business Services** will consist of people over the age of 50 (McDermott, Edwards, Abelló & Katz, 2009)

The current situation

- ▶ Disability services have a limited conceptualisation of ageing issues (Bigby, Balandin, Fyffe, McCubbery & Gordon, 2004)
 - ▶ Few national age-specific supports
 - ▶ Little funding for older people with a lifelong chronic disability
 - ▶ Disability services make ad-hoc provisions for the imminent retirement of this population (McDermott, Edwards, Abelló & Katz, 2009)
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Older people WITHOUT a chronic disability: a solution?

- ▶ What do older people WITHOUT a chronic disability do?
 - 1) *Make plans in advance of retirement*
 - 2) *Cut back to part-time work*
 - 3) *Join a community group*
 - 4) *Consider volunteering*
 - 5) Travel
 - 6) Grandchildren

- What do older people with a lifelong disability do?
 - 1) *Without support none of the above!*
 - 2) *Wait for a crisis to occur*

A model based on *Active Ageing*

- ▶ Holistic *transition to retirement plan* will identify current and future aims, goals, hopes and desires around retirement
- ▶ Central to this plan is the aim to mirror what some people WITHOUT a chronic disability do:
 - 1) Cut back day/s at work and/or day program
 - 2) Join a mainstream community or volunteer group based on INDIVIDUAL INTERESTS
- ▶ Research team to support the mainstream group over six months to engage with the person with a chronic disability

Research aim:

- ▶ **To increase social participation and engagement into retirement**

Case study 1: James

- Man in his fifties with intellectual and physical disability. Lives in an aged-care hostel following death of mother. Has few social networks. Physical disability and mobility rapidly deteriorating.
- When younger used to “tinker” with bikes – supported to join the local men’s shed as they converted old bikes into wheelchairs for developing countries.
- To make this placement happen required review of finances and local transport options which were not helped by a forced move to a hostel in another LGA.
- James’ sister, originally a regular contact, eventually admitted to me that her help to continue to solve problems specific to research had become too much for her. Sister stated issues of “change” for James had always been reactive and challenging
- James also started to ask for incidental help in other areas of his life such as: “on they way home can you”; and quite a lot of “man to man” talk about sex and access to adult stores.

JAMES: case management tasks

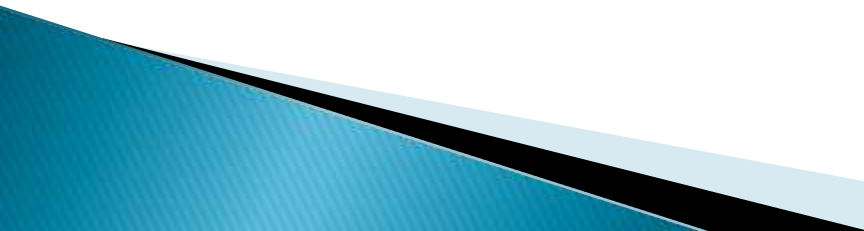
- ▶ Information session at business service
- ▶ Two visits to family to establish relationship
- ▶ Conduct planning meeting/write reports
- ▶ Identify potential group to join: “sold” research to men’s shed management
- ▶ Liaised with community transport
- ▶ Discussions with hostel: transport/finances
- ▶ Transported for introductory visits: “trial” agreed
- ▶ Conducted “access” assessment of environment: toilet, ramps, doors
- ▶ Transported each week of the 4-week trial – did not continue beyond trial
- ▶ Explored public transport options for another possible group – requires OT assessment and mobility aid review
- ▶ Waiting for move back to old hostel before possible new group start

THE RESEARCHER

- ▶ Attended planning meeting and gave a very detailed life history
- ▶ Family struggling to cope with the overall responsibility for James’ needs
- ▶ Advised what was and what was not affordable as options suggested
- ▶ Family aware project “on hold” until move back to old hostel

THE FAMILY

Case study 2: Naomi

- Naomi is in her sixties and lives in a disability-specific group home has no social networks outside home and work. Naomi sleeps for almost the entire day while at her supported employment placement
 - It took almost six months from first contact with Naomi to getting her participation in the research set up; accommodation staff were overwhelmed by the requests to support Naomi participate in research
 - Once location found – needed to provide reassurance to Naomi’s sister that placement was not putting Naomi “at risk” – this took several weeks and multiple visits to respond to
 - Now attending a senior citizens centre one regular day per week plus additional days for special events. Activities include morning tea, art, lunch, exercise afternoon tea and ping pong.
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Naomi: case management tasks

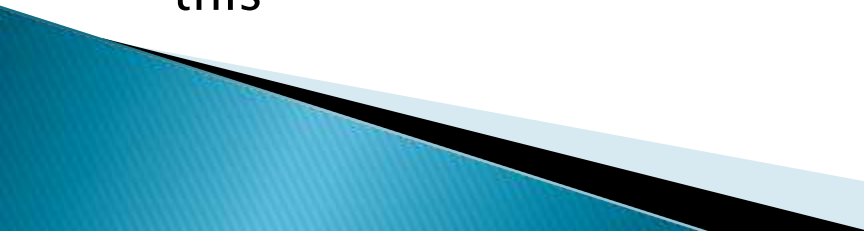
- ▶ Information session at business service
- ▶ Visits to group home to establish research relationship
- ▶ Established relationship with Naomi's sister
- ▶ Conducted planning meeting/write reports
- ▶ Identified group to join; "sold" research to senior citizens co-ordinator
- ▶ Set up intro to senior citizens centre
- ▶ Arranged medium- longer-term transport plan
- ▶ Introduced a communication book - a system to communicate about additional group activities

THE RESEARCHER

- ▶ Attended planning meeting
- ▶ Transported to intro
- ▶ Provided transport in early weeks

ACCOMMODATION SERVICE

Case study 3: Zorro

- Zorro is in his sixties and lives in a disability-specific group home
 - Was aware of retirement issues and planned to retire at the end of 2010, but had no alternatives to work planned or in place. Had a dream he was peeling vegetables in a kitchen; supported to volunteer at local community kitchen
 - Disability group home staff supported with travel training and incorporated research aims into current wider ISP-specific goals
 - Current situation: will retire at end of 2010, has learnt new bus/train routes, is building new social networks, has a plan to enjoy an active retirement
 - Potential to retain mobility allowance through 8 hours formal volunteer work per week; can increase volunteer work to achieve this
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Zorro: case management tasks

- ▶ Information session at business service
- ▶ Conducted planning meeting/write reports
- ▶ Identified group to join and “sold” research to group
- ▶ Set up and transported to intro
- ▶ Provided practical advice for Zorro to give presentation to other employees about his transition to retirement

RESEARCHER

- ▶ Attended planning meeting
- ▶ Provided travel-training from week two
- ▶ Incorporated research goals into Zorro’s overall ISP and retirement planning
- ▶ Helped Zorro write and give a powerpoint presentation about his transition to retirement

ACCOMMODATION
SERVICE

Case study 4: Jack

- Jack is in his late-sixties, lives in a large residential, works part time. Had previously retired but became bored so went back to part-time work
- For research wanted to join a group where he could “*make things and put things together*”
- Supported to join local men’s shed
- Disability service staff incorporated research aims into wider ISP goals, gradual travel training program to and from men’s shed also implemented
- Current situation: attends men’s shed each week making items such as wooden jewellery box and feral bird traps; disability service supports attendance at men’s shed independent of the research team; Jack’s retirement planning now re-structured by disability service.

Jack: case management tasks


- ▶ Information sessions at accommodation service
- ▶ Planning meeting/write reports
- ▶ Located potential group – supported introduction over 3 weeks
- ▶ Discussed emerging health issues with group co-ordinator

RESEARCHER


- ▶ Attended planning meeting
- ▶ Reviewed range of public transport options
- ▶ Is supporting graded travel training plan
- ▶ Informed research team of health issues

ACCOMMODATION
SERVICE


Discussion

- ▶ **Research design:** disability services would do the “planning”; researchers would “connect” the person to a community/volunteer group then support that group through disability-specific training
 - ▶ While all participants are clients of the same day program/business service, the “planning” required detailed negotiation with multiple accommodation services across two states
 - ▶ These disability accommodation services struggled to add the planning to their current workload; planning included review of factors such as health, mobility, finances and transport
 - ▶ For participants not living in disability service there was no one to fulfil this planning role
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Making the planning work

- ▶ Multiple meetings with layers of gatekeepers in NGO disability services; reassurance about the ethical integrity of the research project
 - ▶ Multiple meetings with family members; discussion about life history, the often crisis-driven nature of change, hitting emotional triggers, families difficulty planning for the future
 - ▶ Approached meetings with an holistic and individualised planning model in mind that disability services would be able to engage with and adopt
 - ▶ Providing the knowledge/insight/answers into how to solve problems confronted: money, transport, health, accommodation
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Summary

- ▶ Research design did not anticipate nor did it budget for the researcher doing these case-management tasks which raises 2 key questions:
 - 1) Is this a role that applied researchers should take on board?
 - 2) If not, who should?
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1) The researcher?

- ▶ Case management skills and research skills are not mutually exclusive
- BUT
- ▶ They are different roles
 - ▶ The researcher is a transient presence
 - ▶ A case manager assumes a longer-term role
 - ▶ Research funds usually offer little room for fiscal creativity
 - ▶ Competent researchers may not be competent case managers
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2) If not researcher – Who?


- ▶ Who should carry out this hypothetical role that aspires to create an individualised outcome based on active ageing?
- ▶ The day program?
- ▶ The business service?
- ▶ The accommodation service?
- ▶ Families or friends?

HOWEVER


- ▶ All these groups appear to be just coping with their current role to people with a chronic disability

Our suggestion: An ageing-specific case-manager?

BUT:

- ▶ Who should fund such a role? Federal or State Governments?
 - ▶ Should it reflect the Transition to Work program?
 - ▶ What skills are required? Social work, nursing, certificate III?
 - ▶ Where should they be located? In accommodation service, in business service/day program, in government agencies?
 - ▶ How should priority be decided? Living alone, with family, in hostel; ageing caregivers; complex health problems?
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Conclusion

- ▶ The applied researcher often has to go beyond the textbook definition of research practice to fulfil research aims
 - ▶ Where disability accommodation services actively engaged with the research aims, the process was far easier to execute
 - ▶ An ageing-specific case-manager seems to be an urgent priority for many older people with a chronic disability as they transition into retirement
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References

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- McDermott, S., Edwards, R., Abelló, D., & Klatz, I. (2009). *Ageing and Australian Disability Enterprises: Final Report*. Sydney: Social Policy Research Centre, University of New South Wales.

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