Retirement and older adults with intellectual disability

Toward a transitional person-centred support model

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LIFELONG DISABILITY AND RETIREMENT: A pressing personal and national issue
Age-specific barriers to retirement

› Additional health issues due to lifelong disability
› Changes in the family; death of parents, siblings taking on role of caregiver/person responsible
› Sudden change in accommodation needs
› Changes to support needs
› A limited conceptualisation of what is possible in retirement

› HOWEVER: older men and women with intellectual disability are prepared to embrace change, but a disconnect prevails between what disability services can offer and what older people with intellectual disability want from their retirement years (Bigby, Wilson, Stancliffe and Balandin, 2011)
A demographic shift toward a greater aged population in disability services (Janicki, 2009)

By 2025, over half of the workforce in supported employment services will be over the age of 50 (McDermott et al., 2009)

Despite declining productivity and health, in the absence of alternatives older people with intellectual disability continue working

There are few, if any, funded mechanisms to support the transition to retirement

Faced with urgent changes in client support needs, disability services are forced to implement ad-hoc retirement programs

These programs tend to evolve into the “default” disability-specific day program and reflect existing service models
TOWARD A DIFFERENT WAY OF DOING THINGS
Active Mentoring

› We tested an intervention, coined Active Mentoring (Wilson, Stancliffe, Bigby, Balandin and Craig, 2010); Active Support and Co-Worker Training

› An older person with intellectual disability agreed to drop one day per week from work or day program – that day was replaced with another activity that reflected what other retirees might do

› We offered support to 30 people to join a mainstream community or volunteer group in their local community; 26 Sydney, 4 Melbourne

› Group types were determined based on the person’s stated interests; e.g. gardening groups, seniors activity groups, and Men’s Sheds. Also, groups needed to meet weekly at the same time and location

› Active Mentoring: existing group members mentored the person with a disability. We provided training and support to those mentors about how to support the person with a disability engage with and participate in that group
How did we do things differently?

› We successfully supported 27 older people to drop one day at work and join a mainstream community or volunteer group; 24 Sydney and 3 Melbourne

› BUT .....................

› HOW can these outcomes be structured into a future model for disability services to implement?
A RETIREMENT SUPPORT MODEL

FROM WORK ...... TO THIS ..........
A RETIREMENT SUPPORT MODEL

Research Aims

<table>
<thead>
<tr>
<th>What populations will the service target?</th>
<th>What strategies will accomplish this?</th>
<th>What do we want to accomplish?</th>
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<tbody>
<tr>
<td>Older people (45+) with intellectual disability who wish to cut down their days at work or day program and instead join a community or volunteer group</td>
<td>Using the technologies of Active Support and Co-worker training we will train mentors from these community or volunteer groups to support the person with intellectual disability to participate in that groups activities</td>
<td>1. Increase community capacity to enhance the social inclusion of older adults with intellectual disability 2. Enable people with disabilities to “join in” their local communities</td>
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METHOD: conceptualising the framework for a future retirement model
Conceptualising the “how”

› As we supported the 27 people to join a mainstream community or volunteer group we had to engage with many layers and gatekeepers: people with a disability, their families, disability staff and services, policies, managers, and members of mainstream groups

› We took detailed field notes about these engagements and processes; the “HOW”

› We also collected detailed notes about tasks and processes, plus a log of support hours for nine of the Sydney participants

› The field notes, task and process summaries, and log of support hours were analysed

› We developed a conceptual framework describing how to implement this model
FINDINGS: Conceptualising the framework for a future retirement model
Three key themes

› Analysis of field notes and discussion within the research team identified that there were three key themes underpinning the propositional model

› **1. Selling Retirement**

› **2. Breaking Down Barriers**

› **3. Constructing the Reality**
Theme 1. Selling Retirement

Break down retirement barriers
- Translating the notion of retirement as a positive thing
- Giving ideas of what the possibilities are in retirement

Seeking the trust of others
- Establishing strong relationships with people, their families and staff
- Exuding confidence that retirement was not setting people up to fail

Selling the Model
- Selling the idea of dropping one day at work
- An insurance policy - guaranteed right of return to work
- Provide concrete examples of group and activity types
Theme 2. Breaking Down Barriers

Getting to know local communities
- Knowing what is available in each community
- Identifying group dynamics including entry criteria (e.g., age, gender, address)
- Getting to know key leaders in seniors community

Becoming a trusted community ally
- Strong existing relationships lead to easier access to groups for people with a disability
- Two-way process of give and take
- Adapt to different subcultures (e.g., Men’s Shed, knitting group)

Breaking down disabling barriers
- Help de-mystify “disability”
- Work through previous bad experiences with people with disabilities, or disability services
- Minimise any perceived “threat” as an advocate for people with disabilities
### Theme 3. Constructing the reality – 5 stages

| 1. Planning          | • Person-centred philosophy  
|                      | • Incorporate transition to retirement into existing planning frameworks |
| 2. Finding           | • Locating possible groups of interest  
|                      | • Asking the question – “is this possible”? |
| 3. Building a new routine – 6 months | • Negotiating new routines with family and disability services  
|                      | • Travel, money, changes to work patterns, fitting in with group home rosters  
|                      | • Navigate trial periods |
| 4. Mentors           | • Identify potential mentors; recruit mentors  
|                      | • Provide training, encouragement and ongoing support to mentors |
| 5. Ongoing support   | • Create ongoing framework to monitor and support person and the group  
|                      | • Develop long-term communication pathways between key stakeholders |
CONSTRUCTING THE REALITY: tasks and processes of the 5 stages
CONSTRUCTING THE REALITY

The 5 stages; what it takes

<table>
<thead>
<tr>
<th>Process</th>
<th>TTR case manager</th>
<th>Person</th>
<th>Family</th>
<th>Accommodation service</th>
<th>Vocational service</th>
<th>Community group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Planning</strong></td>
<td>Conceptualise TTR process: &quot;what does this mean?&quot;</td>
<td>What reducing days mean</td>
<td>Communicate project goals</td>
<td>Linking with PEP processes and key worker</td>
<td>Linking with PEP processes</td>
<td>Liaise regarding dropped day</td>
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<td></td>
<td>Set up TTR meeting</td>
<td>Personal preferences leads discussion</td>
<td>Contribute to meeting and/or discussion</td>
<td>Participate and contribute to meeting</td>
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<td><strong>2. Finding</strong></td>
<td>Network in local area based on person's interests</td>
<td>Provide feedback about possibilities</td>
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<td></td>
<td>Membership rules/entry criteria</td>
</tr>
<tr>
<td></td>
<td>Visit probable group market support model</td>
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<td><strong>3. Building a new routine</strong></td>
<td>Arrange introductory visit</td>
<td>Introductory visit</td>
<td>Aware of change in routine</td>
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<td>Aware of change in routine</td>
<td>Welcome mat</td>
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<tr>
<td></td>
<td>Be prepared for first visit</td>
<td>Facilitate requirements for first visit</td>
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<td></td>
<td></td>
<td>Potential mentors</td>
</tr>
<tr>
<td></td>
<td>Travel training</td>
<td>Travel training</td>
<td>Support new travel training processes</td>
<td>Confirm new vocational timetable</td>
<td>Aware of travel arrangements</td>
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<td><strong>4. Mentors</strong></td>
<td>Mentor training</td>
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<td>Create routines and structures at group to foster participation</td>
<td>Learn new routines and tasks</td>
<td>Adapt to new routine to support person</td>
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<td><strong>5. Ongoing support</strong></td>
<td>Gradual fading of support</td>
<td>Gradual increase in independence</td>
<td>Ongoing support</td>
<td>Integrate new person-centred routines into weekly plan</td>
<td>Monitor participation and engagement</td>
<td>Communication pathways clear</td>
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*Membership rules/entry criteria*
1. Planning

› Attempt to integrate transition to retirement planning into existing person-centred plans; often a difficult task for disability services to conceptualise

› For those who still lived with parents, there was often no disability service involved so there were no formal plans; the process remained person-centred

› For those who lived alone researchers worked directly with person and any guardians/person responsible
2. Finding

› Locating possible groups was usually straightforward if the local area was well known and good networks were already developed

› Two examples of time taken to locate potential groups:

› Person with no stated interests went to three different possible groups, but none worked out – for now this participant has gone back to work
3. Building a new routine

› Facilitating new routines such as modifying work schedules, re-assessing finances, adjustment to rosters, new travel routines, and travel training

› Disability services tended to struggle to engage with these processes, often leaving the research team to drive and deliver the change

› Two participant examples of travel training in support hours:
4. Mentor Support

› Recruitment of mentors to support the person with a disability was quite straightforward

› Different groups’ wanted different types of mentoring structures, e.g. Men’s Shed wanted everyone to be a mentor

› Training occurred after a few weeks; by then mentors had already developed some of their own ideas. Often training was about refining good ideas, and supporting the group to simply use their common sense

› Training package involved “classroom style” disability awareness training followed by ongoing practical advice and support about participation

› Example from training package:
CONSTRUCTING THE REALITY

5. Ongoing support

› Ongoing process of sustaining the person’s participation and engagement in the group and their activities

› The wife of one participant died; despite a six-month established routine, significant support hours were required to re-support and re-establish a new routine

› The sole formal mentor for another participant left the group; the participant had no-one to support her participation so her engagement diminished significantly. Significant support hours were required to re-establish mentors and foster ongoing participation and engagement

› A participant who had been volunteering at the Aviation Museum suffered a significant heart problem and was hospitalised. After a 6-week gap, the previous routine, including intensive travel training, had to be re-established
Building a Program Logic: the 5 stages

1. Planning
2. Finding
3. Building New Routines
4. Mentor Support
5. Ongoing Support and Follow-up

Change for Person
Change at Community Group
Training
Consolidate
DISCUSSION: Supporting meaningful change
Change is difficult and complex

› Change at the retirement phase of one’s life means establishing new routines to replace long-standing lifelong patterns

› Disability services need novel models to support the looming demographic challenge for older people with intellectual disability

› This model uses proven technologies, what we have coined Active Mentoring, to enable community members to support the meaningful participation of people with disabilities in mainstream community or volunteer groups

› This model can work, but it requires significant up-front support for six months, with the commitment for ongoing support as needs and circumstances change
Person 1: Singing group; some travel training, person has mild ID, person can’t read so songs recorded for home practice, good communication and social skills

Person 2: Seniors activity group; no travel training, person has more severe ID and autistic traits, transported to and from by disability service, very limited communication, need for significant support by mentors to ensure participation and engagement
Toward a transition to retirement case manager

› A transition to retirement case manager role is required to replicate this model

› The skills required from a case manager to underpin this model are advanced and multi-dimensional requiring sensitivity to community sub-cultures and gender

› BUT, this role is not synonymous with the traditional disability case manager; who takes ultimate responsibility?

› The success requires input, commitment and flexibility from the person, their family, accommodation services, vocational services and mainstream community groups

› The role extends beyond disability services and into wider existing community networking

› The role is not about forcing “rights” onto others in the community; it is about creating and sustaining community allies
REFERENCES


