Community Living and Quality of Life Outcomes for People with Intellectual Disability: What Makes a Difference.

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Choice, Outcomes and Evidence.

Choice problematic - opportunities, options, experience, knowledge – for people with more severe intellectual disability – ascertaining preferences and making substituted judgment - who and how?

Choice is one of elements embedded in UNDRP along with 'full inclusion and participation in the community'

Should choice be mediated by evidence about outcomes? (using public money)

Clearly this is so for everyone in many areas of life – medical procedures, medication, therapeutic services

Why not housing and support services?

Yet in disability there is dominance of opinion often driven by strong beliefs

Damnation of those who are not directly involved – disregard of research

What researcher/s can offer - knowledge and synthesis of the literature – original contributions to knowledge - contribute to policy making

Overview research – what types of housing and support achieve best outcomes – focus people with pervasive support needs – severe and profound impairment

Institutions

Design

- large establishments serving tens, hundreds or even thousands of people.
- physically and socially segregated from the wider society.
- residents were not easily able to leave them to live elsewhere.
- material conditions of life worse than for most people in the wider society.

Working practices

- depersonalisation (removal signs and symbols of individuality and humanity)
- rigidity of routine (fixed timetables irrespective of preferences or needs)
- block treatment (processing people in groups without privacy or individuality)
- social distance (symbolising the different status of staff and residents) (King, Raynes and Tizard, 1971).

Outcomes

- social exclusion – abuse – loss of individuality/humanity - lack choice, personal development (Blatt, 1966)

Deinstitutionlisation

Condemnation of institutions from 1970s driven by scandal and normalisation

"While the reasons for deinstitutionalisation are complex and vary across political contexts, one common factor is the embrace of the concept of normalisation and the rejection of segregation of people with intellectual disabilities from the rest of society. Institutions became both the symbol and the instrument of separation and consequent stigmatisation of people with an intellectual disability." (Bradley, 1994)

Deinstitutionlisation more than closure

- Requires both significant individualised support as well as societal change (Bigby & Fyffe, 2006)

the process of supporting persons on an individual basis and providing tools necessary for them to create a presence and a life within the community… The success or failure of deinstitutionalization will rest with our ability, collectively, to prepare our communities to accept persons with (intellectual) disabilities as valued and contributing members of our society. (Gallant, 1994, cited Bigby & Fyffe, 2006)

Main strategy - however accommodation support

Australia 1-6 bed supported accommodation (group homes) and larger hostel facilities

UK small supported accommodation and campus cluster style accommodation small units on same site

Research Findings: Deinstitutionalisation

There can be no doubt, in general, that people with an intellectual disability benefited from deinstitutionalisation (Mansell & Ericsson, 1996).

- More choice making opportunities
- Larger social networks and more friends
- Access to mainstream community facilities
- Participation in community life
- Chances to develop and maintain skills
- More contact from staff and more engagement in ongoing activities
- A better material standard of living
- Increased acceptance from the community.

Less clear advantages -challenging behavior, psychotropic medication, health

(Emerson & Hatton, 1996 & Kozma, Mansell & Beadle Brown, 2009)

Recent Victorian studies similar (Bigby, 2006, Bigby & Clement, 2011, Clement & Bigby (2010, 2011)

Research Findings: Variability

- UK demonstration programs - community living is possible for everyone – even people with severe challenging behavior and high complex support needs
- Raising our Sights - Jim Mansell
  http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Variation

Best institutions better than the worse supported accommodation (staffed individual or small group)

Best supported accommodation exceeds best institutions

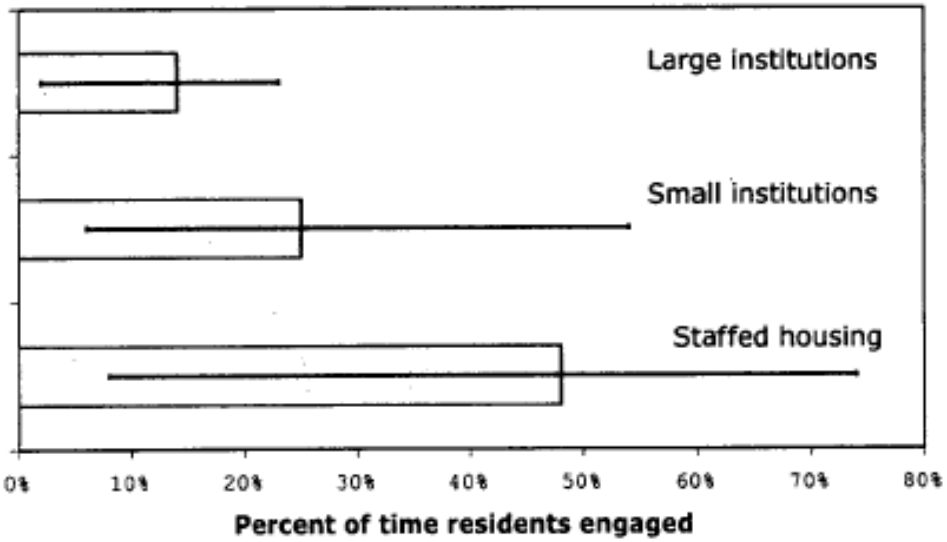
Low engagement of clients in meaningful activities has persisted in community houses (Mansell, 1996)

Closing institutions does not guarantee against the re-emergence of "institutional" practices or ensure improved client outcomes (Felce, 1996; Mansell & Ericsson, 1996).

Community living requires careful and sustained implementation and monitoring strategies.

Variability most apparent on QoL domains of community participation, social networks and self determination

Variability in performance in residential settings in England and Wales for engagement in meaningful activity



Mean = 13.7% Range = 2 - 23%

Mean = 24.7% Range = 6 - 54%

Mean = 47.7% Range = 8 - 74%

Mansell (2006)

Post Deinstitutionlisation Research

Why variability – why best institutions cannot match

Realist review – 60 variables and 53 outcome clusters (Clement et al.,2010)

Degree of impairment major predictor

Complex interactions 6 main elements (see diagram)

Necessary but Not Sufficient Conditions –

Resources & Design

•**Size** 1-6 stepped rather than gradual (Tossebro, 1995)

• **Type** ordinary and dispersed (Emerson et al.; Janssen et al., 1999; Mansell & Beadle Brown, 2009) - small body of literature - Some definitions

- •Dispersed – small supported accommodation 1-6 (housing and support) or supported living 1-3 (separation housing and support)
- •Cluster – 'number of living units forming a separate community from the surrounding population'
  - • residential campus's often inst sites some shared services (UK primarily)(refurbished inst units KRS)
  - •cluster housing – housing same site, or cul de sac (Plenty, QLD new clusters)
  - •Intentional villages – separate site, shared facilities – unpaid life sharing – strong [illegible] (Camphill) some failed attempts with staff in OZ Redlands

Good quality of life outcomes when.....

Necessary but not sufficient conditions
- Adequate resources
- Size & Type

Service user characteristics
Organisational and staff practices that compensate as far as possible for inherently disadvantageous characteristics of residents

Coherence of organisational values and policies of a mission that puts quality of life of service-users at the core of all its actions
- Organisational leadership policies and procedures
- Service characteristics
- Staff training
- Staff characteristics

Staff and managerial working practices that reflect organisational values and policies and the principles of active support

An informal culture that is congruent with and supports the formal mission of the organisation

An external environment that is congruent and reinforces the mission and values of the organisation

Design Type: Research Findings

Mansell & Beadle Brown (2009) review 19 papers 10 studies, UK, Oz, Netherlands, Ireland – most large robust studies

'Dispersed housing is superior to cluster housing on the majority of quality indicators'

Cluster housing has poorer outcomes on domains of Social Inclusion, Material Well-Being, Self-Determination, Personal Development, and Rights

On Most sub domains dispersed housing has better or no different outcomes (see table)

Only exception Physical Well-Being villages or clustered settings primarily villages not cluster

No studies reporting benefits of clustered settings.

No evidence cheaper

Young's (2006) Australian study better outcomes: choice, domestic skills, frequency and variety of community activities wellbeing - no difference on interpersonal relationships or material well being

No evidence for contention that residents in cluster setting are more connected to community of people with intellectual disability

No evidence that residents are safer in cluster settings

Quality of life domains	Dispersed Better	No difference	Cluster /village better
Social inclusion	x	-	-
Access to local neighbourhood	x	-	-
Use of community facilities	-	xx	-
Number of community amenities visited	x	-	-
Community activities and opportunities	xxx	x	-
Residential well-being	x	-	-
Interpersonal Relations	xx	xx	-
Sexual activity	-	x	-
Relationships with family, carers, others	x	x	-
Number of people in network	xxx	x	-
Composition of network	-	x	-
Contact with family/family members in network	-	xxxx	x
People with ID in network	x	xx	-
Local people in network	x	x	-
Contact with friends	x	x	x
Contact with neighbours	-	x	-
Observed contact from others	-	x	-
Stayed away/guest to stay	-	x	-
Vistors to home	x	-	x
Material Well-Being	x	xx	-
Emotional Well-Being	-	x	-
Challenging behaviour/stereotypy	x	xx	-
Satisfaction in all areas except friendships/relationships	-	x	-
Satisfaction friendships/relationships	-	-	x
	x	-	-

Quality of life domains	Dispersed Better	No difference	Cluster /village better
Self Determination	xxxxxx	xxxx	-
Personal Development	-	x	-
Scheduled activity	x	xx	-
Constructive activity	-	x	-
Opportunities to learn new skills	x	-	-
Change in adaptive behaviour over time	-	x	-
Change in domestic activity and in responsibility	x	-	-
Life achievements and changes	x	-	-
Education/employment	x	-	-
Work experience/adult education/day centre activities	-	x	-
Rights	-	-	-
Privacy	x	-	-
Access/adapted environment	-	x	-
Freedom	x	-	-
Exclusion/restraint, sedation used for challenging behaviour	x	-	-

Size, Type, Resources - Necessary but Not Sufficient

Small Dispersed Supported Accommodation

Better for the people concerned. In well-organised community services, people can lead lives that are richer, more varied and more stimulating. They can experience more independence, more choice and more contact with family, friends and neighbours'.

Sometimes do not achieve these things, especially for people with more complex needs. But the point is that only in community services can the best outcomes be realised.

Other conditions for good outcomes.

Working practices – what staff do

- Organisational – policies, working procedures, staff recruitment, training
- Front line leadership - practice leadership, modeling, coaching , monitoring, supervising

External Environment –other aspects of deinstitutionalisation

- Attitudes - lower expectations, families, staff, b'crats, policy makers (Bigby et al., 2009)
  - 'they are not like us' – 'it's pretty hard for our ones'
- Create conditions for attitudes change not reinforce and construct infrastructure that separates and congregate
- Reduces risks 'people are more visible, more connected and therefore better protected."

Arrangement for Structuring Housing and Support

Should Mean

Partnership between formal and informal supporters, without undue burden before access to formal support can be gained;

People able to live alone or share a household with others with whom they have a common interest, life pattern, or friendship;

Forms of housing that are the same as those available in the general community;

Decisions about housing and support that are interdependent and ensure coordination of support around the individual;

Opportunity for changes to daily life patterns;

Opportunity to use local services, public spaces and be included in the social, economic, and spiritual life of the local community;

Sustained involvement of at least one person from outside the service system who can help raise issues of concern and give voice to their interests and involvement in the everyday running of their household;

Resources allocation that is proportional to support needs.

Should Not Mean

People with the highest support needs experience the worst, most restrictive, most outdated, or most unstable housing and support arrangements;

People live in congregate living arrangements or facilities;

People are required to move as their support needs change;

Residential aged care (large congregate care for older people, generally known as ‘‘nursing homes’’) is the default solution for people with increasing support needs;

People live with others with whom they have nothing in common.

(Bigby & Fyffe, 2009, Bigby & Fyffe, 2007)

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