Institution: University of Kent

Unit of Assessment: 22, Social Work and Social Policy

Title of case study: Empowering People with Intellectual and Developmental Disabilities: the importance of community living and Active Support.

1. Summary of the impact

This research on deinstitutionalisation and high quality community-based services has helped transform the political and public debate, informing the management of services and improving the quality of life of people with intellectual and developmental disabilities (IDD) by changing the practices and attitudes of staff. It has led to people leading more active and fulfilling lives and experiencing more choice and control. These impacts have reached far beyond the UK, extending to Ireland, Central and Eastern Europe, Australia and elsewhere.

2. Underpinning research

Over the past 15 years, research by Professor Mansell (who joined Kent in 1983 as a Lecturer and worked until 2010), **Beadle-Brown** (who joined Kent in 1995 as a Research Fellow rising to the position of Reader in 2011), and others in the Tizard Centre has produced a body of work that has provided unique insights into the factors improving the quality of life of people with disabilities, particularly those with intellectual and developmental disabilities (IDD). This case study highlights pioneering research focusing on the treatment of people with IDD in institutional environments compared with person-centred community care. The research involved collaboration with academic partners and relevant stakeholders, most notably people with intellectual disabilities themselves, their families and those supporting them. It employed a variety of methodological approaches including systematic reviews of the literature [*see references 3.2; 3.3*], collation of existing data [*ref 3.6; 3.4*] and collection of primary data on the quality of lives of people receiving services [*ref 3.5; 3.1*]. Key findings were:

- The institutionalisation of those with IDD remains widespread. In 2004, for example, there were at least 2500 institutions (with between 31 and 5700 people) across the 25 European countries studied [*ref 3.5*]. The *Deinstitutionalisation and Community Living: Outcomes and Costs* (DECLOC) project [*ref 3.6*] further collated information on the situation of 28 nations, revealing at least one million people with disabilities were still living in large, congregate settings in 2007.
- Institutionalisation of those with IDD results in reductions in quality of life. The lives of those living in large institutions were characterised by hours of inactivity, disempowerment, boredom and isolation [*ref 3.5; 3.6*].
- Small-scale, dispersed community settings provide the best quality of life for people with IDD [*ref 3.2; 3.3*]. There are few advantages, and many disadvantages to clustered settings especially for people with severe and complex needs [*ref 3.3*]. Evidence also showed that small-scale settings improve social networks and friendships; aid adaptive behaviour; improve family satisfaction and enhance person choice and autonomy. However, challenging behaviour, the use of psychotropic medication and mortality are not necessarily improved by community living.
- Being in a small ‘ordinary’ community dwelling is a necessary but not sufficient condition for improved quality of life: staff care practices are also critical [*ref 3.4*]. It was found that if staff employ an enabling style of interaction known as Person-centred Active Support, then people with IDD experience increased independence, social integration, choice and control [*ref 3.4*].

The research provided a wide-ranging assessment of the outcomes in different residential settings for people with IDD. In suggesting that community-based services provide greater benefit to adults with IDD than large residential institutions, the research has clear implications for policy and practice. Resulting publications highlight the importance of creative solutions to IDD care and advocated policies promoting inclusion rather than incarceration and institutionalisation [*ref 3.6*].

3. References to the research

3.1 – Beadle-Brown, J., Hutchinson, A. and Whelton, B. (2012) ‘Person-centred active support – increasing choice, promoting independence and reducing challenging behaviour’ *Journal of Applied Research in Intellectual Disability* 25 (4) 291-307.

3.2 - Kozma, A., Mansell, J. and Beadle-Brown, J. (2009) ‘Outcomes in different residential settings for people with intellectual disability: a systematic review’ *American Journal on Intellectual and Developmental Disabilities* 114 (3) 193-222 [*submitted to REF2, output ID SSPSSR004*].

3.3 - Mansell, J. and Beadle-Brown, J. (2009) ‘Dispersed or clustered housing for adults with intellectual disabilities: a systematic review’ *Journal of Intellectual and Developmental Disability* 34 (4) 313-323.

3.4 - Mansell, J., and Beadle-Brown, J. (2012) *Active Support: enabling and empowering people with intellectual disabilities* London: Jessica Kingsley [*submitted to REF2, output ID SSPSSR005*].

3.5 – Mansell, J., Beadle-Brown, J. and Clegg, S. (2004) ‘The situation of large residential institutions in Europe’ in Freyhoff, G., Parker, C., Coué, M. and Greig, N. (eds.) *Included in Society: Results and recommendations of the European research initiative on community-based residential alternatives for disabled people* Brussels: Inclusion Europe.

3.6 - Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study* Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

Funding

This research was funded through a series of major grants totalling nearly £1 million from 2001 onwards, with funders including the European Commission, National Disability Authority of Ireland, Office of the Senior Practitioner, Victoria, Australia, Nuffield Foundation, United Response, and Mencap. The most significant awards were as follows:

- “Comparative cost analysis: Community-based services as an alternative to institutions”, **European Commission**, Mansell, J., Knapp, M., Beadle-Brown, J., and Beecham, J. 2005-2007, €350,000.
- “Included in society: European initiative on deinstitutionalisation of disabled people”, **European Commission**, Mansell, J. and Beadle-Brown, J. 2003-2005, €72,597.
- “Costs and outcomes of skilled support for adults with complex needs in supported accommodation”, **School for Social Care Research**, Beadle-Brown, J., and Beecham, J. 2010 -2012, £287,000.
- “The role of organisation and managerial factors and training in the implementation of person-centred active support in services for people with intellectual disabilities and complex needs”, **United Response**, Beadle-Brown, J. 2008 - 2014 £75,500.
- “Implementation of ‘person-centred active support’ in residential services for people with intellectual disabilities’, **Mencap**, Mansell, J. and Beadle-Brown, J. 2003-2004, £57,342.

4. Details of the impact

The research demonstrated how the creation of supportive services and a helpful policy context might allow people with IDD to lead more included lives within the community. These insights have been embedded in practice through close working with national charities (e.g. United Response, Mencap). Impact has extended beyond the UK, to other parts of Europe and to Australia. The key impacts can be summarised as follows:

Influencing and informing policy and public debate:

The research fundamentally challenged the assumptions about the needs of those with IDD held by policy-makers and professionals. Most significantly, research on deinstitutionalisation has provided evidence supporting the argument that all people with disabilities have the same human rights as everyone else, including the right to a life in the community, free from segregation and discrimination. This helped shift the policy discourse in the UK. Notably, Mansell (CBE for services to IDD, January 2012) wrote the Department of Health's 2007 policy guidance on services for people with IDD which was acclaimed by the Parliamentary Under Secretary of State for Care Services as 'invaluable' in ensuring 'that people with additional and complex needs are appropriately cared for so that their needs are well managed and they lead fulfilling lives' [*see corroboration 5.1*]. The Mansell Report's recommendations were reiterated in the Government's policy document *Valuing People Now* [*corrob 5.2*] and, in the wake of the Winterbourne View scandal, in the Department of Health's '*Transforming Care: a National Response to Winterbourne View Hospital* [*corrob 5.3*]. The last long-stay NHS hospital for those with IDD subsequently closed in 2009. Such policy influence has been evident elsewhere. For example, the research features strongly in recent Irish reports on the use of congregate settings, leading to a new system of service provision and individualised support in Ireland [*see corrob 5.4*]. Those involved in the Health Services Executive (HSE) Congregated Settings Report in Ireland attest that the research 'has been central to the national discourse on optimal supports for people with disabilities' [*corrob. 5.5*]. This research has also had significant impact on the work of campaign groups fighting for the rights of those with IDD. The Policy Officer of the European Network on Independent Living argues the DECLOC study 'has provided crucial evidence-based policy advice which has helped make the case for transition from institutional care to community-based alternatives' [*corrob*. *5.6; 5.7*].

Impact on the management and quality of services

The research also impacts on the quality of service provision through its promotion of supportive and skilled service provision. The research suggested exemplary service systems need staff with specific skills who can enable people to access the opportunities available to them. Person-centred Active Support training materials based on these recommendations have sold more than 430 copies worldwide. Almost 100 people have been trained as trainers in Active Support in the UK and Australia, and these trainers have gone on to train staff in many other services. In addition, more than 500 front-line staff in over 25 organisations in the UK (e.g. The Avenues Group, HFT and Dimensions), Australia (e.g. Greystanes in NSW; Endeavor in Queensland; Golden City Support Services, Annecto, Jewish Care and Yooralla in Victoria), Croatia (Association for Promoting Inclusions), and Ireland (Health Service Executive and Rehab Care) have been trained in the methods recommended by this research. These organisations support thousands of people with IDD. Recent requests for training have also come from Norway and Hong Kong. Evidence of the impact of Active Support hence comes from across the world [*corrob 5.8; 5.9; 5.10; 5.11*]. Ongoing studies and feedback from organisations suggest that Active Support results in improved cost-effectiveness and value for money. Staff also report higher levels of job satisfaction. The President of the Association for Promoting Inclusion, Croatia, states 'Active Support helps our staff understand how they can be person-centered not just conceptually but also practically in the way they provide direct support' [*corrob 5.8*]. This has resulted in the adoption of a new model for care services for those with IDD, with 'the transformation methodology, staff training and resident preparation …used as models by the Croatian government to transform remaining residential institutions for people with intellectual disabilities' [*corrob 5.8*].

Impact on the quality of life of people with disabilities

Through changing policy, attitudes and staff practices, the research has contributed to a clearly-documented improvement in quality of life for people with disabilities [e.g. *corrob 5.12*]. The particular impact of Active Support on quality of life is also well documented in the research literature. However, the strongest evidence of the impact of Active Support comes from organisations and individuals who have taken it up [*corrob 5.8, 5.9, 5.10, 5.11, 5.13*]. The Managing Director of United Response reports it has allowed those with IDD 'to develop a range of relationships with other people, leading to increased wellbeing…their physical health…and emotional wellbeing has improved' [*corrob 5.9*]. In Australia, the CEO of Greystanes, who support those with the most profound disabilities, similarly confirms that 'we have seen, in the short time that we have initiated person-centred active support…enormous impact on the lives of people with disability…[it] enables participation, choice and inclusion' [*corrob 5.11*].

5. Sources to corroborate the impact (All links correct at time of submission to REF2014)

5.1 – Quote taken from Foreword to Department of Health (2007) *Services for People with Learning Difficulties and Challenging Behaviour or Mental Health Needs* London: HMSO.

5.2 - Department of Health (2009) *Valuing People Now: a new 3 year strategy for people with learning disabilities* London: Department of Health.

5.3 - Department of Health (2012*) Transforming Care: A National Response to Winterbourne View Hospital. Final Report* London: Department of Health.

5.4 – Sources demonstrating the impact of the research on Irish policy include:

1. Time to Move on from Congregated Settings
2. Advice paper to the Value for Money and Policy Review of Disability Services Programme (A Contemporary Developments in Disability Services Paper).
3. The Report of Disability Policy Review, prepared by Fiona Keogh PhD. on behalf of the Expert Reference Group on Disability Policy (Ireland).
4. Final report of the Value for Money and Policy Review of Disability Services in Ireland programme.

5.5 - Statement provided by ID 1 (Research fellow at Trinity College Dublin and Project manager for Health Services Executive Congregated Settings Report in Ireland) corroborating the impact of the research outcomes on policy development in Ireland.

5.6 – Statement provided by ID 2 (Policy Officer and Regional Teams Manager, European Network on Independent Living and Coordinator of the European Coalition for Community Living) corroborating the impact on campaign groups in Europe.

5.7 – Evidence of the citation of research in European guidelines provided by Common European Guidelines On The Transition from Institutional To Community Based Care by European Expert Group on the Transition from Institutional to Community-based Care, November 2012. Reference 3.2 cited 28 times. Reference 3.4 also cited.

5.8 – Statement provided by ID 3 (President, Association for Promoting Inclusion, Croatia), corroborating impact of DECLOC report and Active Support.

5.9 – Statement provided by ID 4 (Managing Director of United Response), corroborating impact on a national charity providing for people with intellectual disability.

5.10 - Cited in United Response Annual Review and Impact Report 2012. United Response runs 200 facilities and projects in the UK, supporting 1500 people with IDD, and has commissioned research on the merits of person-centred support, see: 'A Valued Life: Developing person-centred approaches so people can be more included'.

5.11 – Statement provided by ID 5 (CEO, Greystanes Disability Services, New South Wales, Australia). See also video on http://www.leuradayoptions.org.au demonstrating the impact of the research on IDD services in Australia.

5.12 - Documentary films charting the changes in people's lives following deinstitutionalisation in Croatia and Romania especially *New Day* and *Community not Confinement*.

5.13 – Groups which use Active Support to help people to have better lives: Avenues Group, which supports 600 people from age 10 upwards in England; Mirus, which provides individualised quality services to people with IDD in Wales and Haven, which is a leading support provider for those with learning disabilities in Plymouth and Devon.