



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

ACHIEVING SOCIAL INCLUSION THROUGH PERSONALISED LIVING AND SUPPORT

Edurne Garcia Iriarte*, Kaitlin Stober*, Rachel Kidd* & Roy McConkey**

*Trinity College Dublin, The University of Dublin

**The University of Ulster

3rd International Disability Studies Conference
“The Art of Belonging”
Disability Studies in Nederland
1st-2nd December 2017

Content

- Background to the study
 - Policy
 - Literature review
- Aims
- Methodology
- Findings on social inclusion
- Conclusions

Background to the study

Global: 1% of the population live with intellectual disability (WHO & World Bank, 2011)



Europe: 1 million people lived in institutions in 2007 (Mansell et al., 2007)

Ireland: 27,863 people in receipt of services

- 68.7% in home settings (parent, siblings, relatives) (NIDD, 2016)
- 7,612 (27.3%) receive full-time residential services (more people in group homes than residential services)
- 4.3% live in independent settings

Convention on the Rights of persons with Disabilities

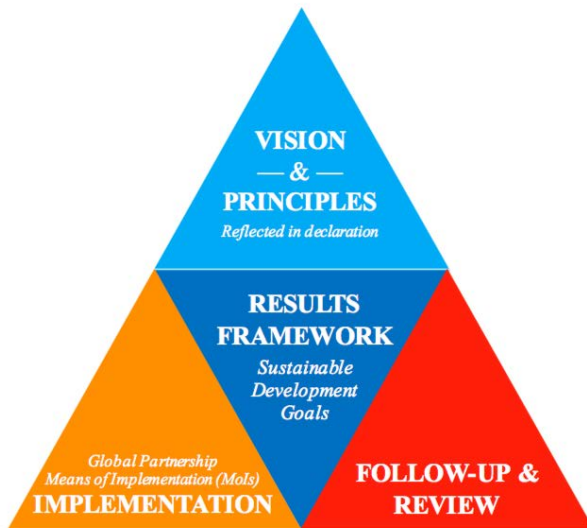
Article 19: Living independently and being included in the community

- Right to choose:
 - Where to live and
 - With whom
- Access to services:
 - Disability specific and
 - Mainstream services

Article 24: Education; Article 27: Employment



Sustainable Development Goals & Disability



Goal 4: Education

Equal and accessible education, inclusive learning environments and assistance for persons with disabilities

Goal 8: Employment

Inclusive economic growth, full and productive employment, full access to the job market

Goal 10: Reduce inequality

Social, economic and political inclusion

Goal 11: Human settlements inclusive, safe and sustainable

Accessible cities and water resources, affordable, accessible and sustainable transport systems, universal access to safe, inclusive, accessible and green public spaces.

<http://www.un.org/sustainabledevelopment/sustainable-development-goals/>

Policy context in Ireland



- Transforming lives: Supporting Person-centred disability services (HSE, 2016)
 - Support people with disabilities to live lives of their choosing in the community
- National Housing Strategy for People with a Disability 2011-2016 (Environment, Community and Local Government; Department of Health, 2012)
 - To facilitate access, for people with disabilities, to the appropriate range of housing and related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living.
- Value for Money and Policy Review of Disability Services in Ireland (Department of Health, 2012)
 - no new congregated settings to be opened; no new admissions to be made to existing congregated settings; a new model of community-based supports to be put in place for persons moving from congregated settings.
- New Directions: Personal Support Services for Adults with Disabilities (HSE, 2012)
 - Widest possible choices and options for people with disabilities
- Congregated settings report (HSE, 2011)
 - All housing arrangements for people moving from congregated settings should be in ordinary neighbourhoods (dispersed housing in the community), with individualised supports (supported living) designed to meet their individual needs and wishes.

Literature review findings

Has de-institutionalisation come at the cost of social inclusion? (Duggan & Linehan, 2013)

Families

- Social isolation of young adults – more support on developing relationships (Issacson, Cocks, & Netto, 2014)
- Concerns about community opposition (O’Doherty et al., 2016)
- Gaps: inclusion in the community (Jones et al., 2016)

Personalised supports

- Strategies: community supports and relationships; staying away from facility-based settings (Cocks & Boaden, 2011)

Community involvement

- Requires a move away from services and the incorporation of individualised forms of funding (personal budgets, direct payments) (Power, 2013)

Literature review findings

Choice

- Most people with ID do not choose where or who they live with
- Those with more severe ID have less choice (Stancliffe et al., 2011; Smith et al., 2005)
- People with ID need to build confidence in themselves as decision makers through peer support and joint decisions with trusted others (Williams & Porter, 2015)

Literature review findings (Ireland)

Personalised vs group homes vs residential institutions

- Rented accommodation: younger and fewer support needs, more control over their lives, and better personal relationships (McConkey et al., 2016)

Social relationships

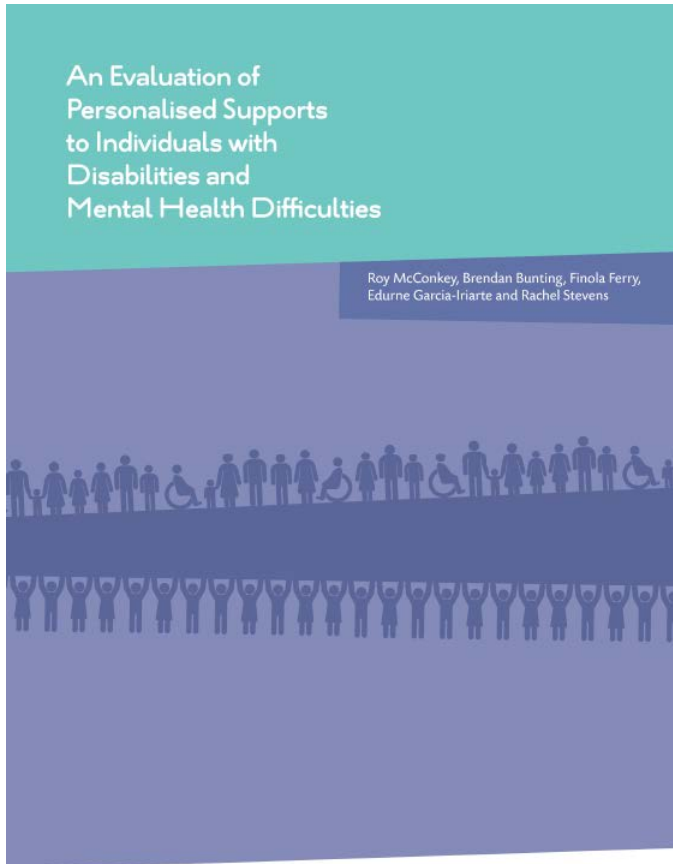
- Only one in five persons increased their social relationships as a result of changes in their accommodation, particularly persons with an intellectual disability and high support needs (McConkey et al., 2017)

Role of support staff

- Care tasks versus social inclusion: more priority to social inclusion in personalised living arrangements vs residential settings (McConkey & Collins, 2010)
- Helped people moved to personalised living arrangements BUT limited opportunities for building relationships and need for further training for both staff and persons with intellectual disabilities to foster community inclusion (Garcia Iriarte et al., 2016)
- Goal setting as a way to promoting social inclusion (McConkey & Collins, 2010b)

It is not a matter of dispassionately working on redesigning structures, independent of the relationships, practices, emotions, and mental models of the managers, professionals, families, and people with developmental disabilities creating the change (Meissner, 2011).

Evaluation Research Conducted in Ireland on Personalised Supports



- Longitudinal evaluation (2011-2013)
- 197 persons receiving individualised support (MH:64, ID:116, PD:17)
- Structured interviews with person supported, key workers and relatives

<https://www.genio.ie/multimedia/publications/research-reports/full-report-an-evaluation-of-personalised-supports-to>

Aim of the study

To explore social inclusion for people who have moved to personalised living arrangements in the community.

Social Inclusion

Access to public good and services, enjoying positive relationships, living supported, independent life, experience valued social roles of one's choosing based on age, gender and culture, be recognised as a competent individual and trusted to perform social roles, belonging to a social network within which one receives and contributes support, working or having a circle of support in the community (Cobigo et al., 2012)

Personalised living arrangements:

Rented accommodation in ordinary houses or apartments with people either living alone or with a partner of their choosing. The tenants often chose the property and location as well as deciding on furnishings. They had support staff visiting their home at agreed days and times for a set number of hours per week in accordance with their needs (McConkey et al., 2013)

Methodology

Data collection: individual semi-structured interviews

- Support worker (n=31); Tenants (n=21); Relatives (n=13).
- Conducted in the tenant's home two years after persons had moved (i.e., to rented accommodation in town settings, with support staff for a number of hours per day).
- Interviews were audio-recorded and were transcribed word by word.

Data analysis: thematic analysis

- 2 authors analysed a selection of transcripts
- Discussion of emerging themes and sub-themes with the other two authors to develop shared meaning
- Themes were triangulated across the three informant groups.

Main findings: Personalised living had resulted in greater community participation and a widening of tenants' social networks

He spends a lot of his time in the library in [town]; so through that he's met an awful lot of people in the community. I think just, he goes down the town to do his bits during the day, and through that he's got to know an awful lot of people. Because I know even when I started working with him, if you were going for a cup of coffee, everybody seemed to know [Rory] in the coffee shop. (Key worker, Rory)

I like living here and I like the.. the neighbours. (Alana)

Yeah. And they've given me a good bit of social activities outside of the job. With bowling and going to [city] and going to different places like that. (Ryan)

Because she has grown and she has integrated into the community. Now [service organisation] and myself have worked hard to integrate her insofar as I feel that no matter how good and sharp they are they need guidance the whole way, they need to learn how to mix, how to converse with people, so it has been very successful and the whole community, the fact that she works in [supermarket chain] here is great, they all kind of look out for her. (Family, Margaret)

Main findings: support workers' role in helping tenants to reconnect with their family and with the community whom they had known previously.

Has benefited ten folds, she would have been in the institution previously (...), she actually has her own home (...) she's also involved in many different like groups, and she made a lot of connections in her hometown where she lived, and she's switched connected with her family again, which was one of the most important things for her. // She's in two social groups, she has a knitting group, she's in the church group cleaning committee. She has a busier social life than many people have. (Key worker, Sonya)

Well, firstly they, [support person] took Marie under her wing and started to encourage her to be more out in the community here in [town], mix more in the community. And she found her little part time jobs, so that she was eventually (...) able to leave her day centre. That was the first thing that she did, and she just gave her a lot more confidence by encouraging her to do things on her own. She also encouraged us as a family to treat her more as an adult rather than a child. (Family, Marie)

No quotes found from persons supported

Main findings: Friends and social life

She'd have freedom to come and go as she pleases. And I suppose she gets to organise her life around her own choices. And she's probably nearer to everybody else as well and she's able to access the community better. (Key worker, Sinead)

Her own social life opened up a bit more as well, she got involved with [organisation] with her support workers, and she was on [the organisation] committee and they had meetings in her apartment. And so that she was able to socialise (Family, Marie)

Would you be happy to stay on in this place?

I would, yeah. Near my neighbours and all, you know. Because they watch out for you.

And you watch out for them too?

I do, yes. (Alex)

To see [Jessica] more often. She's my new best friend now. I never had a friend like [Jessica] before. (...) Means a lot to me. We had a sleep over, we did. It was great. (Mairead)

Main findings: Hardly any romantic relationship developing or people working

Now that she is in her own house ahm her boyfriend comes to visit her more often, ahm and we kind of help to assist her to do that ahm. (Key worker, Aoife)

I'd like to get a job now; do you know what I mean. I think (...) cleaning [an] office or something like that, you know. I would [get] a few pound, you know. (Alex)

With [Laura] I can't... She says she would like a partner but it's not a major thing in her life at the moment. I think that for someone to share her house with her would be her biggest goal, whether it be a partner or just a friend. (Key worker, Laura)

I would like to see her being happy, and having a partner to live with. I mean in an ideal world it would be great, if she had somebody who was compatible, I think that is one of the big things really. (Family, Margaret)

[Sonya] is being supported by their business, her jam making business, which is in five outlets now and is selling regularly. Her furniture is starting to sell as well, she restores furniture. (Key worker, Sonya)

Main findings: Hardly any romantic relationship developing or people working

I think that because he's lonely, he needs to some sort of maybe a course or maybe a little job or try and get him his confidence enough to go out there and do – it doesn't have to be every day of the week, but definitely needs to be encouraged more and maybe supported in getting something like that, to get him out of himself and to meet new people so that he won't be as lonely. (Family, Thomas)

Main findings: Isolation and sustainability of support

I think em maybe in the future she might need a bit of support around her relationships, friendships, which seems to be the biggest stressor. (Key worker, Alana)

Are support staff different to the support staff in [previous home]?

I can't say they have changed much

They're just different people

I will say they're a little different but not a lot (...) which I'm delighted much about. I love them all I'm happy to say they're all still my best friends. (Linda)

And would you like support in?

I would, people would come in and out to see me.

Support people or friends?

Friends. Where are you from Doctor? (Mark)

We're very restricted here and staff constraints you know like it's very hard for her to get to bring her out to social events at night there you know, it's hard. Linda loves to socialise and goes to all these parties but it's with the shortage of staff it's very hard to do these things. (Key worker, Linda)

Main findings: Isolation and sustainability of support

So she has an awful lot of time on her hand and it's a bit difficult. That's another problem; she's no one to go on holidays with, she doesn't want to go on holidays with us anymore. But yeah, if we could have another fifteen hours it would be fantastic, she needs a lot more support, she's a lot of time on her own. (Family, Marie)

Changes in the self-rated well-being of people who move from congregated settings to personalized arrangements and group home placements

Roy McConkey
Ulster University, UK

Fiona Keogh
Genio Ltd, Ireland

Brendan Bunting
Ulster University, UK

Eduarne Garcia Iriarte
Trinity College, Ireland



Journal of Intellectual Disabilities
1–12
© The Author(s) 2016
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1744629516674086
joid.sagepub.com

Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalized arrangements and group home placements

Roy McConkey
University of Ulster, UK

Fiona Keogh
Genio Trust, Ireland

Brendan Bunting
University of Ulster, UK

Eduarne Garcia Iriarte
University of Dublin, Ireland

Sheelah Flatman Watson
University of Ulster, UK



Journal of Intellectual Disabilities
1–12
© The Author(s) 2016
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1744629516624639
joid.sagepub.com

The impact on social relationships of moving from congregated settings to personalized accommodation

Roy McConkey
Ulster University, Ireland

Brendan Bunting
Ulster University, Ireland

Fiona Keogh
Genio Ltd., Ireland

Eduarne Garcia Iriarte
Trinity College, Ireland



Journal of Intellectual Disabilities
1–11
© The Author(s) 2017
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1744629517716546
journals.sagepub.com/home/jid

The role of support staff as people move from congregated settings to group homes and personalized arrangements in Ireland

Eduarne García Iriarte
Trinity College Dublin, Ireland

Janine Stockdale
Ulster University, UK

Roy McConkey
Ulster University, UK

Fiona Keogh
The Genio Trust, Ireland



Journal of Intellectual Disabilities
1–13
© The Author(s) 2016
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1744629516633966
joid.sagepub.com

Conclusions

Has de-institutionalisation come at the cost of social inclusion? (Duggan & Linehan, 2013)

The study findings indicate:

- Greater community participation and widening of social networks
- Connection with the family and the community
- Opportunities for friendships and social life
- Few examples of romantic relationships and employment
- Challenges remaining: isolation and sustainability of support



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Thank you, Dank je wel!

iriartee@tcd.ie

References

- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our Conceptualization of Social Inclusion. *Stigma Research and Action, 2*(2), 75-84. doi:DOI 10.5463/SRA.v1i1.10
- Cocks, E, & Boaden, R (2011). A quality framework for personalised residential supports for adults with developmental disabilities. *Journal Of Intellectual Disability Research, 55, 8*, pp. 720-731.
- Department of Health (2012). Value for Money and Policy Review of Disability Services in Ireland.
- Doyle, A., Hourigan, S., & Fanagan, S. (2016). Annual Report of the National Intellectual Disability Database Committee 2016: Main Findings. HRB Statistics Series 33. Available from http://www.hrb.ie/uploads/tx_hrbpublications/NIDD_2016_Annual_Report.pdf.
- Duggan, C, & Linehan, C (2013). The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature. *British Journal Of Learning Disabilities, 41, 3*, pp. 199-207.
- Environment, Community and Local Government; Department of Health (2012). National Housing Strategy for People with a Disability 2011-2016.
- García Iriarte, E, Stockdale, J, McConkey, R, & Keogh, F (2016). The role of support staff as people move from congregated settings to group homes and personalized arrangements in Ireland. *Journal Of Intellectual Disabilities, 20, 2*, pp. 152-164.
- Health Service Executive (2016). Transforming lives: Supporting Person-centred disability services.

References

Health Service Executive (2012). *New Directions: Personal Support Services for Adults with Disabilities*.

Health Service Executive (2011). *Congregated settings report*.

Isaacson, N, Cocks, E, & Netto, J (2014). Launching: The experiences of two young adults with intellectual disability and their families in transition to individual supported living. *Journal Of Intellectual And Developmental Disability*, 39, 3, pp. 270-281.

Jones, J., Gallus, K. et al., (2016). *Research and Practice for Persons with Severe Disabilities* 41(2), pp. 116-131

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.

McConkey, R., Bunting, B., Ferry, F., Garcia Iriarte, E., Stevens, R. (2013). *An evaluation of personalised supports to individuals with disabilities and Mental Health Difficulties*. Available from <https://www.genio.ie/multimedia/publications/research-reports/full-report-an-evaluation-of-personalised-supports-to>.

References

- McConkey, R, & Collins, S (2010). Using personal goal setting to promote the social inclusion of people with intellectual disability living in supported accommodation. *Journal Of Intellectual Disability Research*, 54, 2, pp. 135-143.
- McConkey, R, & Collins, S (2010b). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal Of Intellectual Disability Research*, 54, 8, pp. 691-700.
- McConkey, R, Keogh, F, Bunting, B, Garcia Iriarte, E, & Watson, S (2016). Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalized arrangements and group home placements. *Journal Of Intellectual Disabilities*, 20, 2, pp. 109-120.
- McConkey, R, Keogh, F, Bunting, B, & Garcia Iriarte, E. (2016). Changes in the self-rated well-being of people who move from congregated settings to personalised arrangements and group home placements. *Journal Of Intellectual Disabilities*.
- McConkey, R, Bunting, B., Keogh, F., & Garcia Iriarte, E. (2017). The impact on social relationships of moving from congregated settings to personalised accommodation. *Journal Of Intellectual Disabilities*.
- Meissner, H (2011). How the shift to individualize supports gets stuck and the first step out of gridlock. *Intellectual And Developmental Disabilities*, 49, 5, pp. 383-387.

References

- O'Doherty, S, Linehan, C, Tatlow-Golden, M, Craig, S, Kerr, M, Lynch, C, & Staines, A (2016). Perspectives of family members of people with an intellectual disability to a major reconfiguration of living arrangements for people with intellectual disability in Ireland', *Journal Of Intellectual Disabilities*, 20, 2, pp. 137-151.
- Power, Andrew (2013). Making space for belonging: Critical reflections on the implementation of personalised adult social care under the veil of meaningful inclusion. *Social Science & Medicine*, 88, 68-75.
- Stancliffe, R, Lakin, K, Larson, S, Engler, J, Taub, S, & Fortune, J (2011). Choice of living arrangements. *Journal Of Intellectual Disability Research*, 55, 8, pp. 746-762.
- Smith, R., Burton, M., Morgan, M. and Davidson, J., (2005). Does the daily choice making of adults with intellectual disability meet the Normalisation principle? *Journal of Intellectual and Developmental Disability* 30(4), pp.226-235.
- United Nations (2015). Sustainable Development Goals. Available from <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>.
- United Nations (2006). Convention on the Rights of Persons with Disabilities. Preamble. Available from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/preamble.html>.
- Williams, V, & Porter, S (2015). The meaning of 'choice and control' for people with intellectual disabilities who are planning their social care and support. *Journal Of Applied Research In Intellectual Disabilities*.
- World Health Organisation and World Bank. (2011). World Report on Disability. Chapter 2, Disability – A Global Picture. (pp. 39-45). Available from http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.