NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

The National Federation of Voluntary Bodies Living Options for People with Intellectual Disabilities Recommended Reading List

Title Page:

Title :

1. **Costs and outcomes of community services for people with intellectual disabilities**

Authors:
Stancliffe, Roger J., Research and Training Center on Community Living, University of Minnesota, MN, US
Lakin, K. Charlie, Research and Training Center on Community Living, University of Minnesota, MN, US

Year: 2004

Source:
Baltimore, MD, US: Paul H Brookes Publishing, 2005

ISBN:
1-55766-718-7 (paperback)

Keywords:
Intellectual disabilities; community services; costs; health policy; service provision; developmental disabilities

Abstract:

(From the cover) With many state agencies under budgetary pressure, solid information on costs and outcomes of services for people with disabilities has never been more important. Now that hard-to-find information is collected in a single volume for policy makers, advocates, service providers, and researchers. Blending original research with policy analysis, critical reviews of existing knowledge, and examples of cutting-edge programs and policies, this book demonstrates what works and helps readers make sound decisions about how to allocate resources. The highly respected contributors to this volume represent a wide range of fields--including service provision, research, evaluation, policy analysis, and administration--and contributors from the United Kingdom and Australia add an international perspective. With this volume's combined research and insights, readers will be better prepared to meet federal mandates for individualized services and improve the quality of life of people with intellectual and developmental disabilities.

Or see a review from the Tizard Centre, University of Kent in;
Agnes Kozma (2008) ‘Review’, *Tizard Learning Disability Review*, 13 (4), p.48

Link:
http://www.brookespublishing.com/store/books/stancliffe-7187/index.htm

Return to the contents page…

Title:

2. Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings.

Authors:

McConkey R; Abbott S; Walsh PN; Linehan C; Emerson E

Year: 2007

Author's Address:

Institute of Nursing Research, University of Ulster, Newtonabbey, Northern Ireland UK

Source:

Journal of Intellectual Disability Research: JIDR (2007), 51(3), pp. 207-17

Keywords:

Interpersonal Relations; Social Environment; Social Support; Intellectual disability; Epidemiology Residential Facilities; Social Isolation; Social Perception; Social Welfare; Supported Living

Abstract:

BACKGROUND: The social inclusion of tenants living in two forms of supported living schemes - those clustered on one site and those dispersed in neighbourhoods - is contrasted with more traditional provision found on the island of Ireland, namely, small group homes, residential homes and campus-style settings. METHODS: A standard pro forma based on measures used in past research was completed by the key-worker for each tenant or resident. In all, data were obtained on 620 persons, representing nearly all tenants in clustered schemes in Northern Ireland and over 40% of those in dispersed schemes. RESULTS: People in either form of supported living tended to have greater levels of social inclusion as measured by their use of community amenities and social contacts than did those in small group homes or residential homes, with participants from campus-style settings having the lowest levels of social inclusion. Moreover, multivariate analyses confirmed that the accommodation variable was a significant influence in addition to the social competence of the person. CONCLUSIONS: Although there were few differences between the two models of supported living, further research could usefully focus on decisions to place persons in either form of accommodation and their impact on wider indicators of social inclusion.

Comments:

Erratum in: JIDR (2007), 51(4):327. Abbott, S [added]; Walsh, P N [added]; Linehan, Christine [added]; Emerson, Eric [added].

Link:

http://www.ingentaconnect.com/search/article?title=Variations+in+the+social+inclusion&title_type=tka&year_from=1998&year_to=2009&database=1&pageSize=20&index=4n

Return to the contents page…

Title:

3. Attitudes of Community Developmental Services Agency Staff Toward Issues of Inclusion for Individuals With Intellectual Disabilities

Authors:
Jones, Jessica; Ouellette-Kuntz, Hélène; Vilela, Tania; Brown, Hilary

Year: 2008

Source:
Journal of Policy and Practice in Intellectual Disabilities, Volume 5, Number 4, December 2008, pp. 219-226

Publisher:
Blackwell Publishing

Abstract:

In many countries, the shift in policy surrounding intellectual disabilities (ID) from segregation to inclusion has resulted in the closure of large-scale institutions in favour of integrated community programs and living accommodations. Because the success of the community inclusion movement lies in the hands of the staff who implement these programs, it is important to determine the consistency of their attitudes with the philosophies that underlie policy directions. Using the Community Living Attitudes Scale-Mental Retardation, Short Form, the current study describes the attitudes of 241 staff working in the field of ID in Ontario, Canada, and examines demographic characteristics that are related to differences in their attitudes toward inclusion. The study found that male staff members' attitudes were less supportive of inclusion than were those of female staff. Moreover, staff members with only a high school education were less likely than those with university or college training to think that individuals with ID were similar to themselves. Finally, older staff members were more likely than younger staff to think that persons with ID should be sheltered from harm. The study showed that many community agency staff members do not hold attitudes that are entirely consistent with the inclusion philosophy and that differences in attitude are associated with their demographic characteristics. This study highlights the need for education and training targeted at particular "at-risk" staff groups in order to ensure the successful implementation of the goals of the inclusion movement.

Keywords:
Attitudes; inclusion; intellectual disabilities; staff

Link:
http://www.ingentaconnect.com/content/bsc/ppi/2008/00000005/00000004/art00001

Return to the contents page…

Title:

4. Views of People with Learning Difficulties about Current and Future Accommodation: the use of focus groups to promote discussion.

Authors: Barr, Owen; McConkey, Roy; McConaghie, Jayne

Year: 2003

Source: Disability & Society; Aug2003, Vol. 18 Issue 5, p577-597, 21p,

Subject Terms: Learning disabilities; Patients; Social networks; Social integration; Inclusive education; Privacy; Focus groups;

Abstract: There is growing emphasis on inclusion as a central philosophy in services for people with learning difficulties in the UK, Europe and the USA. Coupled with this is recognition of the need to actively involve people with learning difficulties in the research process through the use of more inclusive approaches. This paper reports the use of focus groups as a strategy for data collection from people with learning difficulties in a project that sought to review existing accommodation and support. A number of important key themes emerged relating to the importance of social networks, inclusion, reciprocal relationships, privacy and security. The implications arising from these findings for the provision of accommodation and support are considered. Furthermore, it was concluded that focus groups are potentially a valuable approach in research that seeks to actively involve people with learning difficulties.

Links: http://www.scie-socialcareonline.org.uk/profile.asp?guid=48b481b7-759d-46d0-a658-ace86c2305a2

Return to the contents page…

Title:

5. Moving from long-stay hospitals: The views of Northern Irish patients and relatives

Authors: McConkey, Roy, Ulster, Northern Ireland; McConaghie, Jayne, Ulster, Northern Ireland; Mezza, Felice, Ulster, Northern Ireland; Wilson, Jennifer, Ulster, Northern Ireland;

Year: 2003

Source: Journal of Learning Disabilities, Vol 7(1), Mar 2003. pp. 78-93.

Keywords: Long-stay hospital discharge & resettlement; nursing homes; Residential homes; Patient attitudes; Learning disabilities; Relatives; Family attitudes; Service quality;

Abstract: A cohort of 68 persons (aged 19-62 yrs) had been resettled from a long-stay hospital over a 5 year period, with over 90% moving to residential and nursing homes. Interviews were conducted with 39 residents who had learning disabilities and 34 relatives. Residents had more likes and fewer dislikes about their present accommodation than about the hospital. Nearly all were happy to have moved. A minority of families had been unhappy before the move. After the move, all families felt the residence was at least equivalent to the hospital, with most rating it as much better. Families liked the staff, the atmosphere, the buildings, and the individual rooms. They disliked the congregated living models, the failure of people to move on, and the dearth of social networks. Recommendations include increased awareness of new housing and support options, regular reviews of clients' needs and aspirations, and opportunities for access to independent advocacy services.

Link: http://jid.sagepub.com/cgi/content/abstract/7/1/78

Return to the contents page…

Title:

6. Family placement schemes for adult persons with intellectual disabilities living with elderly carers

Authors: McConkey, Roy, University of Ulster, Newtownabbey, Northern Ireland; McConaghie, Jayne, University of Ulster, Newtownabbey, Northern Ireland; Roberts, Paul, Positive Futures, Northern Ireland; King, Diana, Positive Futures, Northern Ireland

Year: 2004

Source: Journal of Learning Disabilities, Vol 8(3), Sep 2004. pp. 267-282.

Keywords: Family placement schemes; Intellectual disabilities; Elderly carers; Placement providers; Training;

Abstract: Few family placement schemes involve adult persons, and rarely have they been targeted at older carers. Twenty-five carers, aged 55 years and over, of people with intellectual disabilities using one of two placement schemes in Northern Ireland were studied, along with a further 20 carers recommended for these schemes. Semi-structured individual interviews were used to obtain the views of carers, people with intellectual disabilities and placement providers. The placement schemes were very favourably received. Carers welcomed the break and valued the relationship with the placement provider. Individuals with disability reported greater opportunities to participate in activities. Placement providers were very satisfied with the way the schemes operated: the main complaint was the low level of payments. Key factors affecting the further development of services include recruitment of male providers, registration issues, training of providers and the difficulty in meeting the needs of multiply disabled persons.

Link: http://jid.sagepub.com/cgi/content/abstract/8/3/267

Return to the contents page…

Title:

7. The features of short-break residential services valued by families who have children with multiple disabilities

Authors: McConkey R; Truesdal M; Conliffe C

Year: 2004

Source: Journal of Social Work, 2004 Apr; 4(1): 61-75

Keywords: Child with disability; Respite care; Chi square test; Child; Developmental disabilities; Funding source; Item analysis; Northern Ireland; Qualitative studies; Quantitative studies; Rural areas; Seminars and workshops; Thematic analysis; Urban areas;

Abstract: Summary: Children with physical and intellectual disabilities can place extra demands on their family carers. The need for short-break (respite) services is well documented but little research has been undertaken into the features of these services that families value. A mix of qualitative and quantitative methods was used. In the first phase, 108 parents in urban and rural areas described the features they liked about the short-break services they had received and the perceived benefits to them and their child. Their replies were validated at a consultation seminar with over 30 carers and professional workers. A pool of 47 items was then devised and in phase two, a sample of 59 families used them to rate one of three short-break services they had used.
Findings: Twelve distinguishing items were found across the three services. They were grouped into three distinct factors: characteristics of the services (eight items), benefits to the child (two items) and benefits to the carer (two items). Variations were found in carers' expectations that need further exploration.
Applications: These findings should facilitate the development of quality standards for short-break residential services and help in the commissioning of services that accord with user aspirations.

Link: http://jsw.sagepub.com/cgi/content/abstract/4/1/61

Return to the contents page…

Title:

8. Fair shares? Supporting families caring for adult persons with intellectual disabilities

Author: McConkey, Roy

Year: 2005

Source: Journal Of Intellectual Disability Research: JIDR 2005 Aug; Vol. 49 (Pt 8), pp. 600-12.

Keywords: Caregivers; Mental Retardation; Social Support; Adult; Aged; Day Care; Female; Humans; Male; Residential treatment; Respite care;

Abstract: BACKGROUND: Although the majority of adult persons with intellectual disabilities are cared for by their families, remarkably little is known of the characteristics of their carers, the support services they receive and their unmet needs. A particular concern is whether or not carers have equitable access to services. METHOD: Information was gathered from service staff who knew best the person with the disability. A standard pro forma was used with a representative sample of over 1500 family carers in Northern Ireland (26% of the estimated population). RESULTS: Nearly half of the people were being cared for by both parents, but around one third lived with lone carers and 20% with another relative. These subgroups of carers varied significantly in their personal characteristics and in terms of the person for whom they cared. However, Regression Analyses identified that their relative's higher dependency in person care was the only common variable that was predictive of carers' access to support services. A possible measure of unmet need for various support services was derived. CONCLUSIONS: Services need to pay greater attention to the characteristics of family carers so as to overcome some of the present inequities in supports offered to them. Further areas for future research are identified.

Link:
http://www.eric.ed.gov/ERICWebPortal/custom/portlets/recordDetails/detailmini.jsp?_nfpb=true&_&ERICExtSearch_SearchValue_0=EJ694261&ERICExtSearch_SearchType_0=no&accno=EJ694261

Return to the contents page…

Title:

9. Multi-agency working in support of people with intellectual disabilities

Authors:

McConkey, Roy,

Year: 2005

Source:

Journal of Intellectual Disabilities, 2005 Sep; 9(3): 193-207

Keywords:

Collaboration; Health Services; Mental Retardation; Interviews; Northern Ireland; Qualitative Studies; Questionnaires; Funding Source;

Abstract:

Although health and social services in Northern Ireland are jointly commissioned and delivered, the recent emphasis in government policy on multi-agency working for people with learning disabilities has not extended as yet to the region. A qualitative research study, with informants drawn from a range of sectors and agencies beyond health and social services, nonetheless identified at least 24 different organizations who were participating in some form of joint working. The benefits were seen to outweigh potential difficulties and respondents identified the factors that they had found facilitated joint working as well as the obstacles to it. These centred on the need to build relationships among participants, creating opportunities for partnership working to occur and increasing the capacity of individuals and organizations to work together. The need for further evaluation and research into system change and user involvement is highlighted.

Link:

http://jid.sagepub.com/cgi/content/abstract/9/3/193

Return to the contents page…

Title:

10. Views of people with intellectual disabilities of their present and future living arrangements

Authors:

McConkey, R. Sowney, M. Milligan, V. Barr, O.**Year:** 2006

Source: JOURNAL OF POLICY AND PRACTICE IN INTELLECTUAL DISABILITIES

Publisher:

United Kingdom: Blackwell Publishing.

Keywords:

Intellectual disabilities; Living arrangements; Personal perceptions; Preferences; advocacy; housing and support; intellectual disabilities; services

Abstract:

To determine personal perceptions and preferences of present and potential living arrangements, 180 adults with intellectual disabilities were recruited to participate in 20 focus groups held across Northern Ireland. About half were living with family carers and the balance in a range of other types of accommodations. Verbal probing and video clips were used to elicit views on four different living options (residential homes, small group homes, supported living, and living with a nonrelated family). Four personal preference themes emerged that were common to all participants irrespective of where they lived: having their own bedroom, participating in household activities; having access to community activities, and maintaining contact with family and friends. Adults living on their own or in supported housing valued their independence and having access to support staff, whereas adults living in residential homes spoke of the importance of relationships with co-residents and staff. Overall, most of the adults were content with their present situation, although small group homes and supported living arrangements were the most popular alternatives to living with their families. The discussion group process was useful in eliciting comments and offering participants a chance to reflect on their personal perceptions of housing options. Overall, the findings point to the need for greater consideration of personal preferences in home option choice-making by housing and services providers.

Link:
http://pi2.ingenta.com/content/bsc/ppi/2004/00000001/F0020003/art00001;jsessionid=19reo6iskjcn8.alice

Return to the contents page…

Title:

11. The barriers to social inclusion as perceived by people with intellectual disabilities

Authors:

Abbott S; McConkey R

Year: 2006

Source:

Journal of Intellectual Disabilities: 2006 Sep; Vol. 10 (3), pp. 275-87.

Keywords:

Attitude; Sick role; Social identification; Socialisation; Intellectual disability; Rehabilitation; Adult; Aged; Focus Groups; Group Homes; Middle Aged; Northern Ireland; Residential facilities;

Abstract:

Very little research has been done on social inclusion from the perspective of people with intellectual disabilities, including perceived barriers and remedies. Focus groups were held with 68 persons, mostly tenants in supported living or shared group homes. Qualitative data were obtained using a mix of workshop activities and small group discussions. Four main barriers were identified: lack of necessary knowledge and skills; role of support staff and service managers; location of house; and community factors such as lack of amenities and attitudes. Participants were able to identify a range of solutions for these barriers. Most of their proposals were in line with the aims of current government policy and good practice. These findings reinforce the contribution individuals could make to the planning of local services for themselves and others. This advocacy has been an essential element in reducing the social isolation of other marginalized groups.

Link:

http://jid.sagepub.com/cgi/content/short/10/3/275

Return to the contents page…

Title:

12. Family Carers of Adult Persons with Intellectual Disabilities on the Island of Ireland

Authors: Barron, Steve, Health Research Board, Dublin, Ireland; McConkey, Roy, School of Nursing, University of Ulster, Newtownabbey, Northern Ireland; Mulvany, Fiona, Health Research Board, Dublin, Ireland

Year: 2006

Source: Journal of Policy and Practice in Intellectual Disabilities, Vol 3(2), Jun 2006. pp. 87-94.

Publisher: United Kingdom: Blackwell Publishing.

Keywords: Family carers; Intellectual disabilities; Ireland; Northern Ireland

Abstract:

Many families provide lifelong support to their relative with an intellectual disability. However, relatively little information is available for national populations on the characteristics of the people for whom these families care and the supports they receive or need. A database of all persons in receipt of intellectual disability services has been operating in the Republic of Ireland since 1995 and records details of those living with family carers. In Northern Ireland, regional databases provide similar information. Using both sources, data were obtained on over 12,500 people living with family carers; half of whom lived with two parents, around 30% with a lone parent, and just under 20% with another relative. More people in Northern Ireland were identified as living with family carers, which was attributed mainly to less available residential alternatives. Only a minority of carers received respite breaks and domiciliary supports although higher proportions required them. The authors conclude that family care arrangements have received relatively little attention within government policy making, and hence service provision has been largely reactive. Future research should focus on the changing needs of carers over time and how they can be better supported in their role.

Link:

http://www3.interscience.wiley.com/journal/118568181/abstract

Return to the contents page…

Title:

13. Social inclusion of people with intellectual disabilities: the impact of place of residence

Authors:

McConkey R; Walsh-Gallagher D; Sinclair M

Year: 2005

Source:

Irish Journal of Psychological Medicine, 2005 Mar; 22(1): 10-4

Keywords:

Housing evaluation; Intellectual disability nursing; Quality of life; Social networks; Adolescence; Adult; Age factors; Aged; Chi square test; Data analysis software; Data analysis, statistical; Descriptive statistics; Funding Source; Logistic regression; Middle age; P-value; Questionnaires; Research instruments;

Abstract:

Objectives: People with intellectual disabilities are increasingly living in more domestic style accommodation, either in housing provided within a specialised campus setting or in ordinary houses in community settings. The main objective of the study was to determine if the extent of residents' involvement with their families and with the local community varied when they resided in campus settings (n = 55) or community housing (n = 51) and to investigate the main predictors of this involvement.

Method: With the resident's permission, their key-workers - mainly nurses - completed standard questionnaires that covered resident characteristics, contact with families and a range of life experiences.

Results: Although the type of accommodation did have a significant effect on residents' social inclusion in families and communities, the best predictor of this was the individual's level of dependency in personal self-care. Those who were more dependent tended to be more excluded.

Conclusions: Staff working with more dependent residents need to proactively promote their social inclusion although this could be harder to achieve for those living in campus style settings.

Link:

http://cat.inist.fr/?aModele=afficheN&cpsidt=16613092

Return to the contents page…

Title:

14. Residential Provision for Adult Persons with Intellectual Disabilities in Ireland

Authors:

Mulvany, Fiona; Barron, Steve; McConkey, Roy;

Year: 2006

Source:

Journal of Applied Research in Intellectual Disabilities; Mar2007, Vol. 20 Issue 2, p70-76, 7p,

Keywords:

People with mental disabilities; Interpersonal relations; Welfare economics;

Abstract: [ABSTRACT FROM AUTHOR]

Background: The type of accommodation provided for persons with an intellectual disability is a major indicator of the social policy for this client group. This is likely to vary within and across countries; hence the importance of undertaking national and international comparisons. Estimations of future need are also required to assist service planning. Method: A database of all persons in receipt of intellectual disability services has been operating in the Republic of Ireland since 1995. In Northern Ireland, regional databases were used to provide similar information. Results Around 10 000 people live in some form of residential provision: 56% in special settings, 35% in ordinary housing and 9% in hospitals. Most residents were classed as having 'severe' disabilities and were aged over 35 years. There were marked differences in the amount and type of provision provided in the two parts of the island. This was also mirrored in differences across health service areas within each country. The demand for future places was greater in Northern Ireland. Conclusions: A planning target of 3.5 places per 1000 adult population is proposed although substantial investments in services are required to achieve this. Longitudinal surveys are an important way of monitoring the impact of new policy initiatives.

Link:

http://www3.interscience.wiley.com/journal/118490133/abstract

Return to the contents page…

Title:

15. Views of family carers to the future accommodation and support needs of their relatives with intellectual disabilities

Authors: McConkey R; McConaghie J; Barr O; Roberts P

Year: 2006

Source: Irish Journal of Psychological Medicine, 2006 Dec; 23(4): 140-3, 144

Keywords: Caregivers; Psychosocial factors; Family attitudes; Health services needs and demand; Mental Retardation; Residential care; Adolescence; Adult; Aged; Chi square test; Descriptive statistics; Family; Funding source; Home environment; Interviews; Ireland; Middle Age; Patient-Family relations; Questionnaires; Random sample;

Abstract: Objectives: The demand for places in supported accommodation is likely to rise due to the increasing longevity of people with intellectual disabilities and as their parents become unavailable or unable to care for them. However few attempts have been made to ascertain carer's views on alternative accommodation.
Method: Four studies were undertaken in Northern Ireland to ascertain carer's views using three different methods. In all, 387 carers participated with the response being greatest for individual interviews conducted in the family home and least for self-completed questionnaires and attendance at group meetings.
Results: The majority of carers envisaged the person continuing to be cared for within the family. The most commonly chosen out-of-home provision was in residential or nursing homes, living with support in a house of their own and in homes for small groups of people. Few carers chose living with another family. However only small numbers of carers envisaged alternative provision being needed in the next two years and few had made any plans for alternative living arrangements.
Conclusions: The implications for service planning are noted, primarily the need for individual reviews of future needs through person-centred planning; improved information to carers about various residential options and their differential benefits, along with more services aimed at improving the quality of life of people living with family carers. These need to be underpinned by a commitment of statutory agencies to partnership working with family carers. The implications for mental health services are noted.

Link:

http://cat.inist.fr/?aModele=afficheN&cpsidt=18414640

Return to the contents page…

Title:

16. Variations in residential accommodation for adults with intellectual disabilities: the example of Northern Ireland

Author: McConkey R

Year: 2006

Source: Irish Journal of Psychological Medicine, 2006 Jun; 23(2): 68-72, 73

Keywords: Consumers; Hospitalization; Learning Disorders; Epidemiology; Nursing Homes; Residential care; Adult; Chi square test; Data analysis software; Descriptive statistics; Face validity; Funding source; Questionnaires;

Abstract: Objectives: Over the past three decades, major changes have taken place internationally in the type of residential accommodation provided for people with intellectual disabilities but these appear to be less evident in Northern Ireland.
Method: A census was undertaken of all persons in any form of residential placement using a range of existing databases to identify the population, with a short questionnaire completed for each resident.
Results: Around 440 persons lived in hospitals and 1,970 in some other form of provision but mostly in large congregated settings such as residential care homes and nursing homes. This was more marked in certain Health and Social Service Boards than in others. Most places are provided by the private sector although voluntary organisations and housing associations now manage around one-third of places. People living in hospitals reportedly had different characteristics to those in all other settings while those in nursing homes tended to require greater personal care. However the characteristics of people living in residential homes, supported living arrangements and village communities were broadly comparable. Around one in 10 persons were deemed to benefit from a move; mostly from residential homes to more independent living arrangements.
Conclusions: Compared to Britain and the Republic of Ireland there is an under-provision of residential placements in Northern Ireland. To date, funding from outside of health and social services has been the main driver for the type of accommodation provided. The implications for future policy and provision are discussed.

Link:

http://cat.inist.fr/?aModele=afficheN&cpsidt=17873681

Return to the contents page…

Title:

17. Building new systems in the community

Author:

Jim Mansell, Tizard Centre, University of Kent

Year: 2009

Source:

Tizard Learning Disability Review, 2009 Feb; 14(1): pp2-3

Keywords:

Overview of challenges, current situations and options under study and in use, community living,

Abstract:

No abstract.

Link:

No online link found. Once subscribed to the Tizard Review an online link is:

http://www.pavpub.com/pavpub/subscriptions/issues.asp?pID=16

Return to the contents page…

Title:

18. Deinstitutionalisation and community living for people with intellectual disabilities in Austria: history, policies, implementation and research.

Author:

Tobias Buchner, Lebenshilfe Academy Austria, University of Vienna

University of Innsbruck

Year: 2009

Source:

Tizard Learning Disability Review, 2009 Feb; 14(1): pp4-13

Keywords:

Community Living, deinstitutionalisation, intellectual disability, Austria

Abstract:

This article starts with a brief overview of the history of housing for people with intellectual disability in Austria. The system of care and Austrian disability policy are also examined, focusing on implementation of deinstitutionalisation and community living. The following analysis of services provided in the field of housing for people with intellectual disabilities shows that support is provided in undistinguished, generalised service packages based on a competency model. Academic research on community living is quite rare in Austria, and fails to take into account the subjective perspective of people with intellectual disabilities.

Link:

http://books.google.ie/books?id=hYSW0eYHVNQC&pg=PA11-IA2&dq=Deinstitutionalisation+and+community+living+for+people+with+intellectual+disabilities+in+Austria:+history,+policies,+implementation+and+research.

Once subscribed to the Tizard Review an online link is:

http://www.pavpub.com/pavpub/subscriptions/issues.asp?pID=16

Return to the contents page…

Title:

19. Commentary on “Deinstitutionalisation and community living for people with intellectual disabilities in Austria”

Author:

Hanna Weinbach, University of Siegen

Year: 2009

Source:

Tizard Learning Disability Review, 2009 Feb; 14(1): pp14-17

Keywords:

Community Living, deinstitutionalisation, intellectual disability, Austria

Abstract:

No Abstract

Link:

No online link found. Once subscribed to the Tizard Review an online link is:

http://www.pavpub.com/pavpub/subscriptions/issues.asp?pID=16

Return to the contents page…

Title:

20. Reflections on Deinstitutionalization in the United Kingdom

Author:

Alexandra Hamlin and Peter Oakes

Year: 2008

Source:

Journal of Policy and Practice in Intellectual Disability (2008) March 5 (1): pp.47-55

Keywords:

Deinstitutionalization; Discourses of disability; England; Intellectual disabilities; Power; Protection

Abstract:

Deinstitutionalization has been the hallmark of public policy for people with intellectual disabilities within many countries in the developed world for the past 40 years. Although within Britain deinstitutionalization is set to be completed by the end of 2008, beyond the simple closure of hospitals, the success of this initiative can at best be seen as uncertain. Although huge structural change has been achieved, the initiative's outcomes in terms of reduced distress, mainstreamed services, and enriched networks of relationships, require further examination. In order to reinstate the possibility of transformation in the lives of people with intellectual disabilities, it is necessary to return to an analysis of the relationship between people with intellectual disabilities, their supporters, formal services, and the community as a whole. One way of reflecting on these relationships is through an examination of the discourses that characterize them. The authors reflect on the themes of protection, power and humanity, and the manner in which these have survived the physical closure of long-term care hospitals. The continuation of deinstitutionalization is understood as requiring consideration of the institution in terms of the discourses that were prevalent within it. The transformation of services now depends on changes within these discourses and change now needs to be focused on relationships that challenge institutional discourses. (PsycINFO Database Record (c) 2008 APA, all rights reserved)

Link:

http://www3.interscience.wiley.com/journal/119424947/abstract?CRETRY=1&SRETRY=0

Return to the contents page…

Title:

21. “A disgrace to the nation” A turning point in the struggle to replace institutions

Author:

John O’Brien

Year: 2005

Source:

Tizard Learning Disability Review (2005) 10(1): pp.12-17

Keywords:

Institutionalised living; Review; Changing patterns; Consensus change; Recommendations;

Abstract:

No abstract

Link:

http://www.inclusion.com/disgrace.pdf

Return to the contents page…

Title:

22. Group Homes – An ordinary life? and Supported Living – A New Paradigm

Author:

Peter Kinsella

Year: 1993

Source:

NDT – Supporting Lives Series (1993)

Keywords:

Housing; Support; Choice; Control; Natural supports; Group homes;

Abstract:

No abstract.

Source:

http://www.charitynet.org/~ndt/pubs/publist.htm

Return to the contents page…

Title:

23. A Life Like Any Other? Human Rights of Adults with Learning Disabilities

Author:

House of Lords, House of Commons, Joint Committee on Human Rights.

Year: 2008

Source:

House of Commons and The Stationary Office Ltd.

Abstract:

No abstract

Link:

http://www.parliament.the-stationery-office.com/pa/jt200708/jtselect/jtrights/40/40i.pdf

Link to an easy to read summary of the document:

http://www.parliament.the-stationery-office.com/pa/jt200708/jtselect/jtrights/40/40ieasyread.pdf

Return to the contents page…

Title:

24. Issues in Creating Liveable Communities for People with Disabilities: Proceedings of the Panel *and* Creating Liveable Communities *and* Liveable Communities for Adults with Disabilities

Author:

National Council on Disability

Year: 2007

Source:

National Council on Disability (2007)

Abstract: (Extract from executive summary) P.7 of Liveable Communities for Adults with Disabilities 2004.

For the promise of full integration into the community to become a reality, people with disabilities need safe and affordable housing, access to transportation, access to the political process, and the right to enjoy whatever services, programs, and activities are offered to all members of the community at both public and private facilities.

Links:

http://www.ncd.gov/newsroom/publications/2007/pdf/livable_communities_10-01-07.pdf

http://www.ncd.gov/newsroom/publications/2006/pdf/livable_communities.pdf

http://www.ncd.gov/newsroom/publications/2004/pdf/livablecommunities.pdf

Return to the contents page…

Title:

25. Deinstitutionalisation and Community Living: Outcomes and Costs project (DECLOC)

Authors:

Jim Mansell, Martin Knapp, Julie Beadle-Brown and Jeni Beecham

Year: 2007

Source:

Mansell J, Knapp M, Beadle-Brown J and Beecham J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 1: Executive Summary. Canterbury: Tizard Centre, University of Kent.

Keywords:

Options; Control; Separation of buildings and support; Full citizens; Cost-effective transition from institutions to supported living;

Abstract:

This project aimed to bring together the available information on the number of disabled people living in residential institutions in 28 European countries, and to identify successful strategies for replacing institutions with community-based services, paying particular attention to economic issues in the transition. It is the most wide-ranging study of its kind ever undertaken. Increasingly the goal of services for people with disabilities is seen not as the provision of a particular type of building or programme, but as the provision of a flexible range of help and resources which can be assembled and adjusted as needed to enable all people with disabilities to live their lives in the way that they want but with the support and protection that they need.

Link:

http://www.ozida.gov.tr/web_english/actual/volume1.pdf

Return to the contents page…

Title:

26. Making Life Good in the Community: Building Inclusive Communities. Facilitating community participation for people with severe intellectual disabilities.

Authors:

Tim Clement and Christine Bigby

Year: 2008

Source:

La Trobe University, School of Social Work and Social Policy (2008)

Keywords:

Deinstitutionalisation; Policy; Support; Severe intellectual disabilities; Transition from a large institution to a small home;

Abstract*: (Taken from the introduction on page 10)*

This report considers issues raised by a two and a half year action research project (*Making life good in the community*) that attempted to realise the notion of an 'inclusive community' in a Department of Human Services' group home. The house, 64 Penny Lane, was a home for five men with severe intellectual disabilities who had previously lived at Kew Residential Services, a large congregate care facility which will be closed in April 2008 following a major redevelopment. The research project focused on one of the goals outlined in the State Disability Plan, that of *building inclusive communities*, a goal that is central to the government's espoused vision for the future, not only for people with disabilities, but for all Victorians.

Link:

http://www.dhs.vic.gov.au/__data/assets/pdf_file/0004/280354/kew_buldinclusivecommunity_pdf_1108.pdf

Return to the contents page…

Title:

27. ENIL Research paper on Community Living and the support of independent living for the disabled women, men and children of Europe

Author:

European Network on Independent Living (2009)

Year: 2009

Source:

European Network on Independent Living (2009)

Keywords:

Policy; Human Rights; Costs; Barriers; Quality of Life; Community Living; Institutionalisation; Personal assistance; Recommendations;

Abstract:

This paper elaborates the human rights argument for the full support of community living and independent living for all disabled people that is: living in the community independently in a place of one's own choice with financial and local support and with access to personal assistance. The paper argues that disabled people do not need to live in institutions excluded from their communities or have their human rights abused.

Link:

http://www.enil.eu/elib/app/webroot/files/ENIL%20paper_Community%20Living-1.doc

Return to the contents page…

Title:

28. Exploring Community Living Options for People with Disabilities: NDA Site Visit to USA: 5th-12th October 2008

Author(s): Mary Van Lieshout and Christine Linehan

Year: 2008

Source: NDA

Keywords: Community Living Options; People with Disabilities; USA; Host Families; Own Homes; Congregate Care Settings; Family Home Settings; Funding; Cost Effective Methods;

Abstract:

This document provides a brief outline of a recent site visit to the United States by Mary Van Lieshout, Head of Research & Standards and Christine Linehan, Senior Research Officer. The purpose of the visit was to inform an ongoing programme of work by the National Disability Authority examining independent, community-based living for people with disabilities. This site visit follows two similar visits undertaken in the United Kingdom earlier in the year. In addition to these site visits, in-house and commissioned research focusing on residential options is currently being undertaken. When concluded, this work will guide the development of a policy paper for government on this issue.

Link: Article not available.

Return to the contents page…

Title:

29. Moving to Community Living

Author(s): NDA

Year: 2008

Source: NDA

Keywords: Independent Living; Community Living; People with Intellectual Disability; Deinstitutionalisation; Civic Participation; Cost of Residential Provision; Europe;

Abstract:

This document comprises one element of a wide-ranging and ongoing body of work being undertaken by NDA in the field of Independent and Community Living for people with disabilities.

In 2005, for example, NDA commissioned a systematic review of research conducted between 1995 and 2005 examining the impact of deinstitutionalisation on residents with intellectual disabilities; specifically in terms of independence, civic participation and well-being. A publication of this review is now available on request from NDA. More recently, the NDA Research Promotion Scheme for 2009-2011 has been launched and invites researchers to apply for funding under the theme Promoting Independent and Community Living for People with Disabilities. NDA has also examined recent research literature on the process of deinstitutionalisation in Europe. NDA is also currently exploring methodologies used to determine the cost of residential provision for people with disabilities and recommendations on how such costs may be determined in future research. This document combines NDA's progress to date on examining these latter two strands of research: deinstitutionalisation in Europe and cost methodologies.

Link: Available on request from the NDA

Return to the contents page…

Title:

30. Supported Accommodation Services for People with Intellectual Disabilities: A review of models and instruments used to measure quality of life in various settings.

Author(s): NDA

Year: 2007

Source: NDA

Keywords: Supported Accommodation; Quality of Life; costs; impact of deinstitutionalisation, independence; civic participation; well-being

Abstract:

WALSH, P. N., EMERSON, E., BRADLEY, V., SCHALOCK, R. L. & MOSELEY, C. (2007) Supported Accommodation Services for People with Intellectual Disabilities. *Disability Research Series 11.* Dublin, National Disability Authority.

Link: No link

Return to the contents page…

Title:

31. Dispersed or Clustered Housing for Disabled Adults: A Systematic Review

Author(s): WALSH, P. N., EMERSON, E., BRADLEY, V., SCHALOCK, R. L. & MOSELEY, C.

Year: 2008

Source: NDA

Keywords: Clustered Accommodation; Dispersed housing; Costs; Service Planning; Review of literature;

Abstract:

The purpose of this review was (i) to find and summarise all the available research evidence on the quality and costs of dispersed community-based housing when compared with clustered housing, (ii) to assess the strength of the research and identify gaps in the evidence and (iii) to interpret the research to outline the benefits and drawbacks of each model.

Links:
http://www.nda.ie/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/292BC9700CF60D7C802575BD003C1CD4/$File/Tizard_Report.pdf

Return to the contents page…

Title:

32. Cost Effectiveness and Quality of Life Service Delivery for Persons with Dual Disability of Down Syndrome and Alzheimer's Dementia,

Author(s): McCarron, M., and McCallion, P.,

Year: (2009)

Source: School of Nursing and Midwifery, Trinity College Dublin,

Keywords: Ageing; Cost Effectiveness; Quality of Life; Dual Disability; Down Syndrome; Alzheimer's Dementia

Abstract:

Background: Providers have responded to AD among persons with DS by supporting ageing in place, creating specialized units or encouraging transfer to more restrictive settings with greater medical supports. However the question remains as to what specific care settings may be most useful in addressing and responding to dementia care needs of this increasingly at risk population in terms of both cost effectiveness and quality of life outcomes.

Method: Carers completed a battery of instruments on 92 persons with DS and AD drawn from 22 providers and served in community group homes, specialized dementia units or institutional and campus based settings. A three factor Quality of Life measure consisted of measures of confirmed dementia, functional, health and psychosocial status, and leisure participation (Factor 1), perceived difficulty in care (Factor 2) and the home environment (Factor 3). Cost of care over a three month period was also calculated. Cost and quality of life findings were then compared by type of setting.

Results: Quality of life was found to be higher in community and specialist dementia settings. Significant quality of life differences were found in the home environment. Costs were lower in institutional settings and comparable for community and specialist dementia settings.

Conclusions: All three types of settings appeared to be supporting comparable levels of need among persons with DS and AD. Historical concerns with more institutional settings remained, community settings were more challenged by changing staffing needs and specialist settings offered quality care but not dramatic improvements.

Links: http://www.cardi.ie/node/916

Return to the contents page…

Title:

33. Supporting Persons with Intellectual Disability and Advanced Dementia. Fusing the Horizons of Intellectual Disability, Palliative & Person-Centred Dementia Care Report,

Author(s): McCarron, M.,

Year: 2009

Source: School of Nursing and Midwifery, Trinity College Dublin

Keywords: Advanced Dementia; Palliative Care; Person-Centred Care,

Abstract: This study began with an effort to understand staff experiences in supporting persons with intellectual disability and advanced dementia. A cross section of intellectual disability service providers and a specialist palliative care provider in the Republic of Ireland were involved in the study. Their experiences were interpreted to gain an understanding of their education and training needs and this information was then the basis for an educational intervention which was designed, delivered and evaluated as a pilot effort with these services. A partnership approach which involved the Trinity College School of Nursing and Midwifery research team, intellectual disability service providers and a specialist palliative care service was crucial to the success of this study.

Links:
http://www.tcd.ie/Nursing_Midwifery/assets/docs/Research/Fusing_Horizons_Exec_Summary.pdf

Return to the contents page…

Title:

34. The Choice Between a “Real Home” and a Programme

Author(s): Kendrick M

Year: 1993

Source: Kendrick Consulting International

Abstract: One of the challenges agencies face when they provide housing for people with disabilities is how to create a true home for the people who live there. Too often, unless there are proper safeguards in place, there is a danger that even the most well-intended homes can become a "facility" rather than a "real home."

Links: http://www.cheshire.ie/docs/infobank/servicedesign/The%20Choice%20Between.doc

Return to the contents page…

Title:

35. At home in the community?: promoting the social inclusion of people with a learning disability living in supported accommodation: easy read version

Author(s): Roy McConkey and Suzanne Collins

Year: 2007

Source: Ballymoney: Triangle Housing Association; University of Ulster

Keywords: isolated people; learning disabilities; social exclusion; supported housing;

Abstract: This report highlights the social exclusion of people with a learning disability in Northern Ireland. This study, funded by the Big Lottery Fund, details the extent of social isolation experienced by tenants in various forms of supported accommodation provided by a range of agencies throughout Northern Ireland. Many have no friends outside of the place where they live and much of their time is spent within the home

Link: No Link

Return to the contents page…

Title:

36. Satisfaction with Living Arrangements of Older Adults with Intellectual Disability: Service Users' and Carers' Views

Author(s): Anne O'Rourke, Ian M. Grey, Ray Fuller and Brian McClean

Year: 2004

Keywords: older adults; quality of life; residential placement; service planning

Abstract: Living arrangements for older adults with intellectual disability are an important aspect of service provision. However, relatively little work has examined service users' satisfaction and dissatisfaction with where they live. Interviews were conducted with 92 service users with intellectual disability aged over 40 living in residential accommodation or with parents or guardians. A questionnaire addressing service users' living arrangements was completed by 103 carers or guardians. Service users identified physical features of living arrangements, the provision of activities, and staff as primary contributors to satisfaction. Primary contributors to dissatisfaction were staff issues such as hindering personal independence, impatience and personnel shortages. Service users living with family or guardians were more likely to report being happy but also to report loneliness than those in group homes. Carers' responses largely mirrored those provided by service users but differences emerged with respect to appropriateness of existing accommodation.

Links: http://jid.sagepub.com/cgi/content/abstract/8/1/12

Return to the contents page…

Title:

37. The Right Living Space Housing and Accommodation Needs of People with Disabilities

Author(s): A Citizens Information Board/ Disability Federation of Ireland Social Policy Report. Prepared by Michael Browne

Year: 2007

Keywords: Living Options; Accommodation; Needs; community organisations; Policy; Social Housing; Supports;

Abstract: This report is based on a joint study between the Citizens Information Board (formerly Comhairle) and Disability Federation of Ireland (DFI). The focus of the report is on the housing and accommodation needs of people with disabilities as experienced by people with disabilities and their families as well as by voluntary and community organisations working with them.

Links: http://www.disability-federation.ie/documents/Summary%20Report.pdf

Return to the contents page…

Title:

38. What is a Home? (Workshop Proceedings)

Author(s): A Citizens Information Board/ Disability Federation of Ireland Social Policy Report. Prepared by Michael Browne

Year: 2007

Keywords: Living Options; Accommodation; Needs; community organisations; Policy; Social Housing; Supports;

Abstract: This report is based on a joint study between the Citizens Information Board (formerly Comhairle) and Disability Federation of Ireland (DFI). The focus of the report is on the housing and accommodation needs of people with disabilities as experienced by people with disabilities and their families as well as by voluntary and community organisations working with them.

Links: http://www.fedvol.ie/_fileupload/NFVB%20Conference%20Report%20-%20Easy%20to%20Read.pdf

Return to the contents page…

Title:

39. Quality of life and intellectual disability: Changes over time from residential to community living.

Author(s): Egan, R., O'Neill, M and Cregg, G.

Year: 2009-06-12

Source: The Irish Psychologist (May 2009), 35(10) pp.274-280

Abstract: This study explored family members' views of the quality of life (QoL) of individuals with an intellectual disability (ID) who had moved from residential living to community living. Interviews were conducted with family members of five individuals with a moderate to severe ID who had moved to community living approximately 11 years ago. Participants were interviewed using an interview tool devised from current research on QoL indices and information from personal outcomes literature. Thematic analysis of the interview data identified eight candidate themes in relation to QoL and particularly, changes in QOL since moving to community living. The majority of participants reported that service users' overall QoL had substantially improved since moving to community living. A minority view expressed by one participant was that deinstitutionalisation was not related to perceived improvements in QoL for his/her family member. Recommendations for future research include continued evaluation of QoL for individuals with an ID and greater focus on service users' perspectives and the views of frontline staff.

Links: No link

Return to the contents page…

Title:

40. Housing Needs of the Disabled

Author(s): Dáil Debate [18259/09]

Year: 2009

Source: Tithe an Oireachtas

Background information from page 2 of the National Federation's Summer Newsletter 2007: Issue 22

National Housing Strategy for People with a Disability

The Department of the Environment, Heritage and Local Government has established a national group to develop a National Housing Strategy for people with a disability. The Strategy which is a commitment under the Partnership Agreement Towards 2016 will support the provision of tailored housing and supports to people with a disability and will have particular regard to adults with significant disabilities and people who experience mental health issues.

The Strategy will be progressed through the establishment of the National group under the aegis of the Housing Forum headed by the Department of the Environment, Heritage and Local Government and will involve the Department of Health & Children, the Health Services Executive, Social Partners and other relevant stakeholders.

The Draft Terms of Reference for the National group are as follows:

- To input into government policy on addressing the accommodation needs of people with a disability;
- To advise on the structures and supports required to effectively deliver on the accommodation needs of people with a disability including through the development of inter agency responses;
- To act as an advisory and monitoring body on the implementation of the new strategy.

The National Federation of Voluntary Bodies was invited to nominate a representative to participate on the national group and in this regard the Board of Directors approved the appointment of Paul Ledwidge, Chief Executive, St. Michael's House.
www.fedvol.ie/_fileupload/File/Newsletters/Newsletter%2022%20-%20Summer%202007.pdf

Link: http://debates.oireachtas.ie/DDebate.aspx?F=DAL20090507.xml&Node=1083#N1083

Return to the contents page…

Title:

41. Aggression, Sociability, and a Roommate Friendship: New Findings Translated Into a Resource for Self-Determined Choices

Author(s): James Wiltz and Tracy Kalnins

Year: 2008

Source: Journal of Policy and Practice in Intellectual Disabilities, 5(3), September 2008, pp.159-166.

Abstract:

Many individuals with intellectual disabilities (ID) live with others, but little is known about roommate compatibility, and there are no resources available to assist in the selection process. People with ID and those who support them need practical information in order to make more informed and therefore better choices. Self-determination also should play an increased role in this complicated choice. This American paper provides a practical, data-based resource that can be incorporated into a self-determined process of roommate selection. The authors conducted two studies, uncovered new information, and translated the findings into something that individuals and their supporters can use. The first study examined data from a community sample. In the second investigation, key findings were replicated and expanded in an institutional setting. Taken together, the findings of these studies are generalizable to a larger portion of the population. The results indicated that for the trait of sociability, similarity was the key to friendship. On the other hand, for aggressiveness, it was not similarity, but the total aggression in the pair that was (inversely) related to friendship. A practical multistep resource is provided for adults with ID and their advocates to help with the selection of a roommate who might also become a friend

Link: http://www.scie-socialcareonline.org.uk/profile.asp?guid=03116254-f5bf-4ebb-91e3-b226dee4daec

Return to the contents page…

Title:

42 Living Alone or With Others Housing and support for people with learning disabilities

Author(s): Nigel King and Maurice Harker

Year: 2000

Source: The Foundation for People with Learning Disabilities, the Mental Health Foundation

Abstract:

About half of all people with learning disabilities live with their families. They range from people who can to a large extent care for themselves in terms of daily living, through to people who require 24-hour care and support from others. For most carers, looking after their son or daughter is a positive and valued choice and a mutually rewarding experience. At the same time, many parents are aware that at some point, a move from the family home into alternative accommodation is likely to happen. The person with a learning disability may also want to leave home and move into their own accommodation (with whatever support they need). The government's aim of promoting independence One of government's national objectives is to promote the independence of adults needing support and the Department of Health recognises that most adults with severe learning disabilities will need to live other than in the family home at some point, with services planned and developed on an individual basis. This publication explores what this might mean for adults with learning disabilities.

Link:
http://www.fpld.org.uk/EasysiteWeb/getresource.axd?AssetID=14937&type=Full&servicetype=Attachment

Return to the contents page…

Title:

43 Contested Housing Landscapes? Social Inclusion, Deinstitutionalisation and Housing Policy in Australia

Author(s): Lisa Bostock and Brendan Gleeson with Ailsa McPherson and Lillian Pang

Year: 2004

Source: Australian Journal of Social Issues Vol.39 No.1

Abstract:

Deinstitutionalisation is represented as a major step toward social inclusion through the resettlement of disabled people residing in segregated large-scale institutions into community-based homes. By promoting the right to live in ordinary community residential settings, deinstitutionalisation fundamentally changes both the support services and housing arrangements of former institutional residents. In Australia, as in many western countries, debates on community care have tended to focus on the location and nature of non-housing supports for people leaving dependent care. This focus, however, overlooks the fact that deinstitutionalisation involves a radical rehousing of people in care. This paper explores the character and implications of deinstitutionalisation in Australia as a rehousing process. It is based on a recent national research project that has examined the housing futures of people with intellectual disabilities who have been, or will be, deinstitutionalised. The paper considers the increasingly divergent socio-political perspectives that have emerged in recent discussions about social inclusion, institutional reform and independent living and their implications for housing and community care policies.

Link: http://findarticles.com/p/articles/mi_hb3359/is_1_39/ai_n29080974/

Return to the contents page…

Title:

44 Community Living Research Project Canada

Author(s): Tim Stainton, Grant Charles, Cam Crawford, Rachelle Hole, Susan Powell, Carrie Yodanis, Leah Wilson, Andrea Harstone, Jonathan Brown, Tara Schoenfield, Patricia Johnston, Ashley de Regil, Colleen Evans, Laney Bryenton, Barb Goode, M Lynn Rolko, Stephen Russell, Brian Salisbury, Roberta Scott

Year: 2008

Source: Community Living Research Project, School of Social Work, The Jack Bell Building, 2080 West Mall, Vancouver, BC Canada, V6T 1Z2

Abstract:

Residential Alternatives: Both the academic literature for the past 10 years and selected programs information on residential options for adults with developmental disabilities has been explored in this document. It should be noted that cross nationals comparisons must be read with caution given differing policy, wage and funding regimes. Much of the best literature compares institutional and community options which has limited utility in jurisdictions such as British Columbia. Comparatively, literature on different community options is sparse.

Home Sharing: A discussion regarding what Home Sharing is and how it supports adults with developmental disabilities is crucial to the development of provincial standards and policies. This report is an attempt to get to the heart of Home Sharing and provide a greater overall understanding of what the trend toward Home Sharing will mean for the adults living within them.

Adult Community Living: In the late spring and summer of 2006, the Community Living Research Project conducted focus groups and interviews with 35 Self Advocates and 70 family members throughout the province of British Columbia (total participants = 105). Specifically, interviews and focus groups were held in the Lower Mainland, the Interior, Vancouver Island, the North, and Powell River. Phone interviews were also conducted to enable families in remote areas of the province to participate in the research. The goal of the focus groups and individual interviews was to elicit feedback from people with disabilities and their families and networks regarding programs and services for adults with developmental disabilities.

Link: http://www.communitylivingresearch.swfs.ubc.ca/index.php?id=11720

Return to the contents page…

Title:

45 People with an Intellectual Disability Living in an Intentional Community

Authors: **M.Randell & S. Cumella**

Year: 2009

Source: Journal of Intellectual Disability Research

Abstract:

Background Hospital closure programmes in England have generally sought to attain a fulfilling life for people with an intellectual disability by locating them in domestic-style housing in urban settings. Few have been placed in intentional or 'village' communities. Yet comparative studies of different housing types have found that intentional communities have better or similar outcomes for their residents than dispersed housing or residential clusters on former hospital sites. A possible explanation is the distinctive pattern of social relationships that exist in many intentional communities and the impact this has on the lives of their residents. This paper reports the results of research that explores the perceptions of people with an ID living in an intentional community and the meaning of their community to them. Methods The research used an ethnographic approach to interview a sample of 15 residents in a large intentional community (Botton Village), which is part of the Camphill Movement. Interviews used Makaton, pictures and symbols where required. Results Respondents included 10 men and 5 women aged between 38 and 78 years. Length of residence in Botton Village ranged from 5 to 50 years. All lived with the families of co-workers and valued these relationships. All but one (who had retired) worked in a diverse range of employment in the village. Almost all were positive about their work. Respondents reported that they took part in both individual and communal leisure activities and all but two had a network of friends. Opportunities for friendship were enhanced by proximity to other people with an ID and a sense of personal security in the village. As in many villages and communities in society in general, these advantages were balanced by some loss of privacy. Conclusions Results confirm those from earlier studies of intentional communities and suggest that positive outcomes derive from the absence of the overt subordination of residents to staff, the facilitation of friendship with other people with an ID, high levels of meaningful employment and a sense of community. These factors contrast with the experience of living in small homes funded on a contractual basis by public authorities, in which cost pressures reduce wage levels for staff resulting in difficulties in retaining suitable staff and a consequent high staff turnover.

http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=2010349035&site=ehost-live

Return to the contents page…

Title:

46 The Significance of Neighbours: views and experiences of people with intellectual disability on neighbouring

Authors: **L.M. van Alphen**

Year: 2009

Source: Journal of Intellectual Disability Research Volume 53 Issue 8 Pages 745-757

Abstract:

Background: People with intellectual disability (ID) who live in regular neighbourhoods have experiences with their neighbours, which are important to understand when studying social integration.

Method: This study describes and analyses the opinions on, and experiences with, neighbour relationships of 39 people with ID living in neighbourhood housing facilities.

Results: We found that, while the views of people with ID on 'good neighbouring' were consistent with 'neighbouring' described in sociological literature, their experiences may be influenced by an organisational context, the tendency to formalize relationships and apprehension towards meeting unfamiliar people.

Conclusion: Understanding influential factors to neighbouring for people with ID may shed light on the processes involved in social integration of people with ID at a neighbourhood level. This paper contributes to understanding the opinions of people with ID on satisfactory neighbourhood relationships, and explores opportunities to improve them.

http://www3.interscience.wiley.com/journal/122462782/abstract

Return to the contents page…

Title:

47 Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review

Authors: Agnes Kozma, Jim Mansell, Julie Beadle-Brown, University of Kent, Tizard Centre (Canterbury, Kent, United Kingdom).

Year: 2009

Source: American Association on Intellectual and Developmental Disabilities Volume 114, Number 3: 193–222 May 2009

Abstract:

Large-scale reviews of research in deinstitutionalization and community living were last conducted about 10 years ago. Here we surveyed research from 1997 to 2007. Articles were included if the researchers based the study on original research, provided information on the participants and methodology, compared residential arrangements for adults with intellectual disability, and were published in English-language peer-reviewed journals. Sixty eight articles were found. In 7 of 10 domains, the majority of studies show that community based services are superior to congregate arrangements. These studies provide more evidence of the benefits of deinstitutionalization and community living and continue to indicate variability in results, suggesting that factors other than the basic model of care are important in determining outcomes.

http://www.community-living.info/documents/Kozma%202009%20AJMR%20Residential%20outcomes.pdf

Return to the contents page…

Title:

48 Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities
ECCL - European Coalition for Community Living - FOCUS REPORT – August 2009 48

Authors: European Coalition for Community Living

Year: 2009

Source: European Coalition for Community Living

Abstract:

This Focus Report has been prepared by the European Coalition for Community Living (ECCL) as part of its work to promote the right of people with disabilities to live in the community as equal citizens. It focuses on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which provides that all people with disabilities have the right to live and participate in the community. This report seeks to provide a clear explanation of the scope and purpose of Article 19 and makes a series of recommendations designed to facilitate the effective implementation of this right.

http://www.community-living.info/documents/ECCL-Focus-Report-2009-final-WEB.pdf

Return to the contents page…