

Friendships and Relationships

Themes include: friendships; social interaction; social network; relationships; loneliness; friendship activities

1

Title:

A Question of Friendship: Community Care and the Relationships of People with Learning Difficulties

Author:

Chappell A.L.

Source: [Disability & Society](#), Volume 9, Number 4, January 1994, pp. 419-434(16)

Abstract:

There is evidence that a number of people with learning difficulties living in the community do not enjoy a range of satisfactory social relationships. This paper will examine the way that the issue of the apparent loneliness of people with learning difficulties has been approached in the community care literature. I will argue that there is a clear assumption in much of the literature that friendships between disabled and non-disabled people are of greater value than those relationships between disabled people. The low value accorded to friendships between disabled people is very damaging to their individual self-esteem, as well as to the possibility of political action based on a sense of solidarity. The paper will point also to the constraints that many people with learning difficulties face which render it difficult for them to form friendships and, therefore, reinforce their isolation.

2

Title:

Friendships, relationships and the management of rejection and loneliness by people with learning disabilities

Authors:

K. Nunkoosing

M. John

Source:

Journal of Intellectual Disabilities, Vol. 1, No. 1, 10-18 (1997)

Abstract:

Fifteen people with learning disabilities participated in this qualitative study which was concerned with enabling the participants to tell their own stories and experiences of friendships and relationships through several interviews. Analyses of the responses identified factors that both enhanced and hindered the development of friendship and relationship for people with learning disabilities. Whilst friendship was facilitated by mutuality and acceptance, poverty, limited transport and the absence of physical and emotional support prevented the development of friendships and led to the experience of loneliness. Participants also managed their experiences of rejection and loneliness through the development of coping skills and positive self-image.

3**Title:**

The dialectic of friendship for people with psychiatric disabilities

Authors:

Katherine M Boydell,
Brenda M Gladstone,
Elaine Stasiulis Crawford

Source:

Psychiatric Rehabilitation Journal, Fall 2002, Vol. 26, No. 2, pgs 123-131

Keywords:

Friendship; social networks; mental illness

Abstract:

In the psychiatric literature, the meaning and importance of friendship has remained largely unexplored, subsumed under the rubric of social support or viewed as a component of community integration. Twenty-one qualitative interviews were conducted with individuals suffering from psychiatric disabilities focusing on the meaning of friendship as they described it. Analysis revealed the contrasts, contradiction and paradox of friendship for this group of people. The ongoing struggles of people with psychiatric disabilities regarding the need to connect with others and have friends, and conversely, the need to be alone and to withdraw from others, was highlighted.

4

Title:

Increasing Social Interactions for People with More Severe Learning Disabilities Who Have Difficulty Developing Personal Relationships

Authors:

R. Whitehouse
P. Chamberlain
A. O'Brien

Source:

Journal of Intellectual Disabilities, Vol. 5, No. 3, 209-220 (2001)

Key Words:

Friendships • interactions • learning disability • opportunities • support

Abstract:

This article is based on the findings from a social contact group set up for four men with severe learning disabilities. The formation of friendships and relationships is an area where little improvement has occurred following the closure of large institutions. The reasons why people with learning disabilities find friendship formation difficult can include social skill deficits, the severity of their learning disability and the lack of supportive opportunities. The current study suggests that in order to facilitate friendships between people with more severe learning disabilities, the physical opportunity to meet others in a supportive environment is much more important than the severity of their learning disabilities and how socially skilled they are.

5

Title:

Social Networks of People with Mental Retardation in Residential Settings

Authors:

Janet Robertson
Eric Emerson
Nicky Gregory
Chris Hatton
Sophia Kessissoglou
Angela Hallam
Christine Linehan

Source:

Mental Retardation: 2001, Vol. 39, No. 3, pp. 201–214.

Abstract:

Information was collected on the social networks of 500 adults with mental retardation

receiving different types of residential supports. Results indicated that (a) the reported median size of participants' social networks (excluding staff) was 2 people; (b) 83% of participants were reported to have a staff member; 72%, a member of their family; 54%, another person with mental retardation; and 30%, a person who did not fit into any of these categories in their social network; (c) variation in the size and composition of participants' social networks was associated with a range of variables, including the personal characteristics of residents (age, autism, ability, and challenging behavior), the type of previous and current accommodation, staffing ratios, institutional climate, and the implementation of "active support."

6

Title:

Understanding friendship: Young adults with Down syndrome exploring relationships

Authors:

Anne Jobling
Karen B. Moni
Andrew Nolan

Source:

Journal of Intellectual and Developmental Disability 2000, Vol. 25, No. 3, Pages 235-245

Keywords:

Young adults, down syndrome, friendship

Abstract:

Having friends and being a friend defines us as human beings. Friends can play many roles in our lives, and without friends, life can become increasingly lonely. For young people, friends often take a counseling role in times of emotional stress, so loneliness or a life without friends who can understand the emotional contexts of friendships and "counsel" may affect a person's psychosocial quality of life. This paper describes a six session program that was designed to help a group of young adults with Down syndrome understand friendships better. The Down Syndrome Research Program LATCH-ON staff at the University of Queensland developed the program in conjunction with the Queensland Family Planning Association. During the sessions, the students explored and discussed various types of friendships and the emotions associated with them, using the students' own experiences and videos in conjunction with structured materials such as The Circle Concept (Smith, 1987) and Network Hand (Birch & Higgs, 1996). Some reflections from the authors' experiences with the program are provided. Future research directions are suggested.

7

Title:

The Meanings of Close Friendship: the Views of Four People with Intellectual Disabilities

Authors:

Marie Knox
Fay Hickson

Source:

Journal of Applied Research in Intellectual Disabilities 2001 Volume 14 Issue 3, Pages 276 - 291

Keywords:

Man-woman relationships; quality of life; intellect- deterioration

Abstract:

The present study examined the views of four people with intellectual disabilities (IDs) on the relationships in their lives which they described as close friendships. A participatory approach was adopted in this study, whereby the participants were seen as experts on their own close friendship experiences and the researchers as marshallers of this expertise. To this end, two in-depth interviews were conducted with each participant. They shared their individual expertise on the close friendships in their lives. The participants delineated two distinctive types of close friendships: the 'good mate' and the girlfriend/boyfriend. The factors mediating each of these friendship types are discussed. Avenues for further research and consideration are given. These include the significance of friendships with people with IDs, intimate relationships, the impact of environmental factors on friendship enactment and friendships with older people who have IDs. Finally, the present paper argues for the value of adopting participatory approaches to research with people who have IDs.

8

Title:

Friendship Activities of Adults with Intellectual Disabilities in Supported Accommodation in Northern England

Authors:

Eric Emerson
Keith McVilly

Source:

Journal of Applied Research in Intellectual Disabilities 2004 Volume 17 Issue 3, Pages 191 - 197

Keywords:

Friendships • relationships • social networks • supported accommodation

Abstract:

Background Despite there being considerable evidence to suggest that friendships are central to health and well-being, relatively little attention had been paid to the friendships of people with intellectual disabilities.

Methods Friendship activities involving people with and without intellectual disabilities were measured over the preceding month in a sample of 1542 adults with intellectual disabilities receiving supported accommodation in nine geographical localities in Northern England.

Results The results of the study indicate: (1) low levels of friendship activities among people with intellectual disabilities in supported accommodation; (2) people with intellectual disabilities are more likely to be involved in activities with friends who also have intellectual disabilities than with friends who do not have intellectual disabilities; (3) most friendship activities take place in the public domain rather than in more private settings (e.g. at home); (4) the setting in which a person lives is a more significant determinant of the form and content of activities with their friends than the characteristics of participants.

Conclusions Further attention needs to be given to research and practice initiatives aimed at increasing the levels of friendship activities of people with intellectual disabilities.

9

Title:

'I Get by with a Little Help from my Friends': Adults with Intellectual Disability Discuss Loneliness

Authors:

McVilly, Keith R.

Stancliffe, Roger J.

Parmenter, Trevor R.

Burton-Smith, Rosanne M.

Source:

[Journal of Applied Research in Intellectual Disabilities](#), Volume 19, Number 2, June 2006 , pp. 191-203(13)

Keywords: [friendship](#); [intellectual disability](#); [loneliness](#); [qualitative analysis](#); [quality of life](#); [relationships](#)

Abstract:

Background: This study explored 'loneliness' as experienced by adults with intellectual disability, with 'intermittent' to 'limited' support needs.

Method: A measure of loneliness was piloted, and qualitative techniques used to develop a greater understanding of the participants' experience.

Results: The Loneliness Scale proved valid and reliable and the participants reported loneliness in ways comparable with the general population.

Conclusions: The findings demonstrate the effectiveness of combining quantitative and qualitative techniques to enhance understanding of people's perspective when developing

support systems to promote their quality of life. Based on participant perspectives, recommendations are made concerning the issues and types of support families and professionals could consider when seeking to assist people with intellectual disability address loneliness. Further investigation of the effects of differing educational and vocational opportunities on people's post-school social networks appears warranted.

10

Title:

Social skills and the stability of social relationships between individuals with intellectual disabilities and other community members

Authors:

J. Stephen Newton
Deborah Olson
Robert H. Horner
William R. Ard, Jr.

Source:

[Research in Developmental Disabilities](#) [Volume 17, Issue 1](#), January-February 1996, Pages 15-26

Abstract:

Stability of social relationships may be an important indicator of lifestyle quality. Fifteen individuals with intellectual disabilities participated in an analysis of the relationship between their social skills (as measured via the Scales of Independent Behavior and the Assessment of Social Competence) and the stability of the social relationships they experienced with other community members, who were neither paid staff nor family members, across the course of 94 consecutive weeks. A participant's social skills did a moderately good job of predicting the average social stability achieved by all of his or her social network members, but a poorer job of predicting the average social stability achieved by the participant's three most stable social network members. The findings suggest that the stability of a participant's most stable social network members is based not on the participant's social skills, but rather on other factors.

11

Title:

Measuring relationship strength in roommates with MR/DD: the development of the Roommate Friendship

Author:

James Wiltz

Source:

[Research in Developmental Disabilities](#) [Volume 24, Issue 5](#), September-October 2003, Pages 359-367

Abstract

Most people with mental retardation who live in government-funded housing have roommates. Roommate relationships are significant determinants of quality of life, but current methods of roommate selection generally do not prioritize roommate compatibility. One problem is that inadequate research has been conducted on roommate relationships. In order to improve the process of roommate selection, research is needed. The purpose of this investigation was to identify an important and neglected study topic and to facilitate new research by developing a scale to measure the strength of roommate relationships. The Roommate Friendship Scale (RFS) has a stable internal structure, is reliable, and has demonstrated the ability to differentiate between compatible and incompatible roommates. The scale items are included in this report.

12**Title:**

Social interactions of persons with developmental disabilities living independently in the community

Authors:

Alan Ralph
Erica Usher

Source:

[Research in Developmental Disabilities](#) [Volume 16, Issue 3](#), May-June 1995, Pages 149-163

Abstract

Fifty-four adults with developmental disabilities living independently in three different communities were interviewed about their social interactions during seven consecutive days. Results indicated that most interactions were with other persons with disabilities, and almost half of those interviewed reported no interactions with persons without disabilities. Those living in an outer suburban setting had fewer interactions with persons without disabilities. Those who had lived previously in supervised group residences had more interactions than those lacking this experience, but these were mostly accounted for by interactions with other persons with disabilities. The main conclusion of the study was that integration of persons with developmental disabilities was not occurring at a satisfactory level, when judged by their interactions with persons without disabilities.

13

Title:

Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community.

Author:

[Bigby, Christine](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Jun2008, Vol. 33 Issue 2, p148-157

Abstract:

Informal relationships are central to conceptualisations of quality of life. Deinstitutionalisation studies consistently suggest a trend of increased contact with family and friends by people with intellectual disability (ID) following relocation from an institution to the community. In this study, changes in the nature of the informal relationships of residents 5 years after leaving an institution were examined. Method A sample of 24 participants was randomly selected from a group of 55 residents who moved to the community. Data were collected prior to leaving the institution, and 1, 3 and 5 years after the move, through interviews with staff, a telephone survey with 20 family members, and intensive case studies undertaken with a small purposive sub-sample of 11 residents. Results Data indicated that: (i) residents did not form new relationships after relocation, (ii) the number of residents in regular touch with a family member decreased, and (iii) patterns of contact changed as residents aged. Some 62% of residents had no-one outside the service system who knew them well or monitored their well-being. Conclusion Services must take a more active role in supporting the development of relationships between individuals with ID, particularly those who are middle-aged or older, and people outside the service system, and in adapting to the changing capacity of ageing families.

14

Title:

An exploration of loneliness: Communication and the social networks of older people with cerebral palsy.

Authors:

[Ballin, Liora](#)

[Balandin, Susan](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Dec2007, Vol. 32 Issue 4, p315-326

Abstract:

There is a large body of research focusing on the experiences of loneliness of older adults, yet little is known about the loneliness experiences of older adults with lifelong disability. In this paper, the authors present some findings from a larger qualitative study on the loneliness

experiences of older people with cerebral palsy. Method Seven older adults with cerebral palsy participated in in-depth interviews. Analysis of the interviews identified overarching themes and recurrent topics in the data. These topics were coded and then grouped under the overarching themes. Results Six themes were identified. All participants agreed that the themes of communication and social networks are most important when considering loneliness. In this paper, the participants' discussion of these two themes and their related topics are presented. Conclusions The results demonstrate the need to provide support and training in communication to older people with cerebral palsy who experience communication difficulty, as well as to their communication partners. They also indicate the need for policy development to assist older adults with cerebral palsy to develop and maintain their social networks and form relationships that are rewarding and enriching.

15

Title:

Social relationships and friendships of children with developmental disabilities: Implications for inclusive settings. A systematic review.

Authors:

[Webster, Amanda A.](#)

[Carter, Mark](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Sep2007, Vol. 32 Issue 3, p200-213

Abstract:

The engagement of children with developmental disabilities (DD) in social relationships with typically developing peers has become increasingly important as inclusive practices have become more the norm than the exception. This paper provides an overview of the research on social relationships between these two groups. Method Studies were included if they provided a naturalistic examination of the relationships between children with DD (from the age of 3 years to school exit) and peers they have met in school or in age-appropriate educational settings. Results A total of 36 studies are reviewed, providing a framework for analysis of the relevant research, with a particular focus on implications for inclusive settings. Three specific areas are addressed: (a) features of social relationships; (b) types of social relationships and roles assumed by the individuals involved; and (c) the existence and nature of friendship within these relationships. Conclusion Research on relationships between children with DD and their peers in inclusive settings is patchy, limited in context, and non-linear in its development. Directions for future research are discussed, together with a range of methodological issues that should be considered.

16

Title:

Friendship quality among children in three educational settings.

Author:

[Heiman, Tali](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Mar2000, Vol. 25 Issue 1, p1-12

Abstract:

This study investigates the quality of friendship as reported by adolescents with mild intellectual disabilities in different educational settings, compared with similar reports by students without disabilities. Participants included 121 students with intellectual disability in special education schools, 189 students with intellectual disability in self-contained mainstreamed schools and 265 students without disability. Results indicated significant differences between these groups in their perception of friendship. Students with intellectual disability in special schools tended to have fewer friends than students with intellectual disability within mainstreamed schools, most of them meeting friends at school only. The students in special education schools responded more passively, and felt lonelier, than students in the other groups.

17

Title:

From biscuits to boyfriends: the ramifications of choice for people with learning disabilities.

Authors:

[Smyth, Catherine M.](#)

[Bell, Dorothy](#)

Source:

[British Journal of Learning Disabilities](#); Dec2006, Vol. 34 Issue 4, p227-236

Abstract:

Accessible summary • Choosing can be easy, such as when deciding what biscuit to eat. • Sometimes it is hard to choose, such as deciding on who to have as a boyfriend or girlfriend. • Sometimes even choosing a biscuit can be hard if your doctor says it is not healthy for you. • There are lots of reasons why we choose to do things. • Everyone needs to think about these reasons to help people with learning disabilities make good choices. Choice plays an important role in a person's quality of life. This paper looks at the issue of choice for people with learning disabilities. It considers the extent to which people with learning disabilities are able to choose and are provided with real choices. It also covers the extent to which true choice may or may not be advantageous for some people with learning disabilities. By concentrating particularly on the issue of choice about food and diet, this paper indicates how seemingly simplistic choices, such as decisions over food consumed, can cause major health

problems for the decision-maker and hence be a more complex and vital decision than at times it is perceived to be. Additionally, this paper focuses on important factors surrounding choice for people with learning disabilities that previous research may have overlooked. One such factor is how past experience affects the decision-making process. Another, is the issue of the range of choice that is possible, relative to a person's cognitive ability to be fully aware of this range. In particular, this paper emphasizes the important role of the carer. It addresses the impact which the carer's own, perhaps unconscious personal choices, beliefs and ideologies may have on the 'choices' made by people with learning disabilities, and more worryingly, on the 'choices' offered to them. This paper highlights problems with current research into the area of choice for people with learning disabilities and provides suggestions for future study.

18

Title:

Friendship formation in adults with learning disabilities: peer-mediated approaches to social skills development.

Authors:

[Moore, Tracey](#)

[Carey, Louise](#)

Source:

[British Journal of Learning Disabilities](#); Mar2005, Vol. 33 Issue 1, p23-26

Abstract:

Studies have indicated that people with learning disabilities have few friends. Making friends requires both opportunities and skills. This paper focuses on the development of skills in order to facilitate friendship; an area that has received limited attention in the literature. Traditional social skills approaches are considered briefly, before moving on to discuss peer-mediated approaches. Peer-mediated approaches appear promising, with positive changes in the social behaviour of children with disabilities reported. It appears few studies have directly investigated maintenance, and evidence of generalization is limited. Factors that may improve generalization and maintenance are discussed. Finally, consideration is given to whether peer-mediated approaches actually facilitate friendship, rather than simply increasing interaction.

19

Title:

Good practice in befriending services for people with learning difficulties.

Author:

[Heslop, Pauline](#)

Source:

[British Journal of Learning Disabilities](#); Mar2005, Vol. 33 Issue 1, p27-33

Abstract:

Despite the growing trend for the development of befriending services, there is a paucity of research about the views of people involved with these services and the effectiveness of service provision. This article describes some of the views and experiences of paid workers, volunteer befrienders, service users (befriended) and family carers involved with seven befriending services for children and/or adults with learning difficulties in England. Although each of the befriending services shared the broad purpose of increasing the friendship circles of the befriended, their aims and the ways in which they worked, differed considerably. The focus of the article is on some of the key issues that the befriending services faced, factors that were found to contribute to good practice within befriending services and recommendations for good practice.

20

Title:

Love and Loving Relationships in People with Learning Disabilities: A Scientific Approach

Author:

Raquel Morentin

Benito Arias

Cristina Jenaro

J Manuel Rodríguez-Mayoral

Michelle McCarthy

Source:

[Tizard Learning Disability Review, Volume 13, Number 2 / August 2008](#)

Abstract:

Love has been a recurring theme through history and literature, and its relevance to health, well-being and quality of life has been widely acknowledged. However, the scientific study of love has not yet reached people with learning disabilities. The study reported here was based on research with 376 people with learning disabilities in Spain, and aimed to analyse their appraisal of love, loving relationships and related issues (global evaluation, satisfaction, role of the family and self-determination). A Likert-type measure was developed, and the outcomes indicate that the measures have satisfactory psychometric characteristics. It is also evident that the theoretical model of love for people without disabilities can be applied to

individuals with disabilities, and includes three key factors ('commitment, stability and idealisation', 'passion and physiological arousal' and 'intimacy and romanticism'). It also indicates that the perceptions of love in people with learning disabilities are relatively idealised and influenced by context, and interference from family and self-determination are key issues.

21

Title:

The friendships of people with a learning disability.

Authors:

[Brackenridge, Rachel](#)

[McKenzie, Karen](#)

Source:

[Learning Disability Practice](#); Jun2005, Vol. 8 Issue 5, p12-17

Abstract:

Describes a study designed to explore the qualities that individuals look for in their friends. Meaning of friendships to people with learning disabilities; Importance of social relationships; Introduction of person-centered planning; Factors that made people popular as friends or unpopular; Use of grounded theory.

22

Title:

A Good Friend is Hard to Find: Friendship Among Adolescents with Disabilities

Authors:

Matheson, Catherine

Olsen, Rebecca J.

Wesiner, Thomas

Source:

American Journal on Mental Retardation v. 112 no. 5 (September 2007) p. 319-29

Abstract:

We asked 27 Euro American teens ages 16 to 17 with developmental disabilities in Los Angeles to describe friendships. Eleven characteristics of friendship reported in the research literature (similarity, proximity, transcending context, companionship, reciprocity, mutuality, intimacy, support, trust/loyalty, conflict management, and stability) were mentioned by at least some teens. However, most teens focused on companionship, doing activities across contexts, similarity in interests/personality, sheer proximity, and stability. Gender did not influence number or types of themes reported. Teens with higher IQ/Vineland Communication scores mentioned more friendship themes and were less positive about their friendships. Most teens reported some satisfying friendships, and friendships between peers with

developmental disability usually were more stable and positive than friendships with typically developing peers. Reprinted by permission of the publisher.

23

Title:

Friendships Between Persons With and Without Developmental Disabilities.

Authors:

Pottie, C.

Sumarah, J.

Source:

[Mental Retardation](#); Feb2004, Vol. 42 Issue 1, p55-66, 12p

Abstract:

Interpersonal connections, friendships, and belonging play important roles in a person's emotional and physical well-being. However, recent studies reveal that persons with developmental disabilities often live with few connections and friendships within unwelcoming communities. Through this qualitative study, we enter this relatively unexplored area of friendships between persons with and without developmental disabilities by interviewing four existing friendship dyads in the intentional community of L'Arche. In this research these friendships are described, factors that foster or inhibit their development are identified, and communal influences on the relationships are discussed.

24

Title:

Developing Friendships and social integration through Leisure for People with Moderate, Severe and Profound Learning Disabilities Transferred from Hospital to Community Care

Authors:

Srivastava, A.K.

Source:

Tizard Learning Disability Review, Volume 6, Number 4/ October 2001

Abstract:

This paper looks at the quality and value of leisure and friendships that people with learning disabilities experience in the community. It provides an overview of the problems in developing friendships for people with moderate, severe and profound learning disabilities transferred from hospital to community care and identifies recommendations for commissioners, providers, staff and carers for the development of friendships through leisure in the community.

25

Title:

A Multisource Exploration of the Friendship Patterns of Children With and Without Learning Disabilities.

Authors:

[Wiener, Judith](#)

[Schneider, Barry H.](#)

Source:

[Journal of Abnormal Child Psychology](#); Apr2002, Vol. 30 Issue 2, p127, 15p

Abstract:

Compares the friendship patterns of children with and without learning disabilities. Ability of the learning disabled to have mutual friends; Predominance of conflicts, lower levels of validation among social bonded children with the condition; Quality of friendship of children without learning disabilities.

26

Title:

Self-advocates have the last say on friendship.

Authors:

[McVilly, Keith R.](#)

[Stancliffe, Roger J.](#)

[Parmenter, Trevor R.](#)

[Burton-Smith, Rosanne M.](#)

Source:

[Disability & Society](#); Dec2006, Vol. 21 Issue 7, p693-708

Abstract:

This study reports the friendship experiences and aspirations of adults with intellectual disabilities. The findings of a larger study were reviewed by an expert group of self-advocates with intellectual disability. The expert group confirmed some of the interpretation of the original data and expanded on issues. Friendship is established as an issue of concern among adults with intellectual disability. Consequently, policy-makers and service providers need to be intentional about providing support for friendships. Participants asserted a positive self-identity of being a person with intellectual disability and how this could be a basis for friendship. Also, people with intellectual disability demonstrated how they should be considered experts in their own life experience and how they can be effectively included in the formulation, implementation, analysis and review of research. †In memory of our dear friend Allison J. Dewing-Moore, died 3 November 2005.

Staff Supports

Themes include: staff support; residential services; staff: resident interactions; measuring levels of support.

1

Title:

The social networks of older people with learning disabilities living in staffed community based homes.

Authors:

Dave Dagnan
Lorraine Ruddick

Source:

The British Journal of Developmental Disabilities, Vol. XLIII, Part 1, January, 1997, No. 84

Abstract:

This article reports on the social networks of 52 older people with learning disabilities living in community-based, staffed homes. We report the number of people in the networks, who they are and the frequency and type of support they offer with particular emphasis upon support in leisure activities. The relationship of age, sex and disability with the number of contacts with people in the social network was explored. The only significant relationship indicates that older people have fewer contacts with their families.

2

Title:

Factors associated with staff support and resident lifestyle in services for people with multiple disabilities: a path analytic approach

Authors:

C. Hatton
E. Emerson
J. Robertson
D. Henderson
J. Cooper

Source:

Journal of Intellectual Disability Research, 1996, 40, 466-477

Keywords:

Community • mental retardation • residential services • sensory impairment • staff support

Abstract:

The quality and costs of residential services for 40 adults with severe learning disabilities and sensory impairments across four different service models were evaluated. A path analytic approach was used to calculate factors associated with four indicators of service quality: (1) assistance received by residents from staff; (2) positive contact received by residents from staff; (3) resident engagement in constructive activity; and (4) the level of physical integration of residents. The path analyses accounted for between 50 and 77% of the variance in the indicators. Factors found to be commonly associated with all four indicators included a community location, a specialized service orientation, the cognitive abilities of residents and a high level of scheduled activity. Service resources in the form of costs or staff ratios were not associated with any indicator of service quality. The findings strongly suggest an inverse system of care in that residents with greater skills receive more staff support. The implications of these and other findings for further research and service practice are discussed.

3**Title:**

The determinants of staff and resident activity in residential services for people with severe intellectual disability: Moving beyond size, building design, location and number of staff

Authors:

David Felce

Source:

[Journal of Intellectual and Developmental Disability](#) 1998, Vol. 23, No. 2, Pages 103-119

Abstract:

The replacement of institutional residential services for people with severe intellectual disability with community-based alternatives has progressed similarly in many of the countries of the developed world. In the first wave of reform, the idea of reversing institutional conditions provided a design brief for the alternative services which emphasised various structural characteristics of the settings: smallness of scale, typical housing design, homelike equipment, furnishings and decor, community location in typical residential areas, autonomy over household management and increased staff support. As the poor quality of existing services was widely seen as due to "institutionalisation", there was an equally wide-spread belief that such reforms would lead automatically to high quality outcome. However, expectations for improved quality from the initial reforms, while partially met, were far from fully confirmed by research evidence. A decent, homelike, well located, reasonably staffed environment may be a necessary condition for good outcome, but these factors are not sufficient to guarantee it. The existing metaphor of institutionalisation needs further elaboration if it is to be useful, and the design brief for the alternative service requires expansion to include factors such as the orientation of staff and their working methods and training, which are shown by the research literature on the micro-organisation of settings to make a difference. Based on a review of the literature which inevitably but not exclusively favours British research on community alternatives to institutional care, the paper shows how

the quality of staff and resident activity is dependent on an interaction between the structure, orientation and procedures followed within the setting.

4

Title:

The extent of support for ordinary living provided in staffed housing: The relationship between staffing levels, resident characteristics, staff: resident interactions and resident activity patterns

Authors:

David Felce
Jonathan Perry

Source:

[Social Science & Medicine](#) *Volume 40, Issue 6*, March 1995, Pages 799-810

Keywords:

Staffing; staff behaviour; resident behaviour

Abstract

Staffed housing has become an accepted alternative to institutional residential services for people with learning disabilities on the expectation that such provision will promote 'ordinary' patterns of living. Information on staffing levels and the behavioural characteristics of residents together with direct observational data on staff: resident interactions and resident engagement in activity were collected on 15 housing services in South Wales and analysed to explore the interrelationship between these key input and outcome variables. Staffing levels were found to be related to resident characteristics in general but not consistently so. The extent of staff: resident interaction per staff was related to resident characteristics, with staff in services for more able residents spending more time with them. The level of staff support given to residents with more substantial disabilities, slightly higher than that given to more able residents, reflected high staffing input. Resident engagement in activity was strongly related to ability. Participation in household activity was virtually non-existent among residents with the greatest disabilities. The results were compared to similar data from earlier studies on a range of residential services. The relative benefits of small, community-based housing services over institutional and larger community settings were confirmed by the Welsh data. However, comparison to other housing services, which had a particular emphasis on staff helping residents become involved in domestic activity, supports the conclusion that 'ordinary living' for people with severe or profound learning disabilities depends not only on the provision of ordinary environments but also on the orientation and working methods adopted.

5

Title:

The Reliability, Validity and Practical Utility of Measuring Supports using the I-CAN Instrument: Part II.

Authors:

[Riches, Vivienne C.](#)
[Parmenter, Trevor R.](#)
[Llewellyn, Gwynnyth](#)
[Hindmarsh, Gabrielle](#)
[Chan, Jeff](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); Jul2009, Vol. 22 Issue 4, p340-353, 14p

Abstract:

Background There is an urgent need for developing reliable, valid and practical instruments that assess and classify the support needed by persons with disability to function in their chosen living, working and social environments. I-CAN is an instrument that addresses the frequency and level of support needed (not individual skills or deficits) for each individual with a disability. Method Studies were conducted to assess the test–retest reliability and inter-rater reliability. Concurrent validity was investigated by exploring the relationship between the I-CAN domain scales and the Inventory for Client and Agency Planning (ICAP) (Bruininks et al. 1986) and the Quality of Life Questionnaire (QOL-Q) (Schalock & Keith 1993). Predictive validity studies were undertaken using day- and night-time support hours. Regression analyses were run using these measures with I-CAN domain scales. Two independent studies were also conducted to ascertain the practical utility of the instrument. Results The I-CAN instrument demonstrated excellent inter-rater and test–retest reliability in the Activities and Participation domains. Low-to-moderate test–retest results in Physical Health, Mental Emotional Health and Behaviour domains were tracked to actual change in support needs in these areas. Validity proved acceptable. The relationships between I-CAN domain scales and adaptive behaviour were mixed but in the expected direction. Low-to-moderate correlation coefficients were evident between the I-CAN scales and the QOL-Q Total, but greater support needed in certain domains was associated with less empowerment and independence, and less community integration and social belonging. Attempts to explain current support hours against the I-CAN scales were disappointing and suggest that a number of other factors apart from individual support need to play a significant role. There was general satisfaction with the assessment process from stakeholders and participant groups. Conclusions I-CAN is a reliable, valid and user-friendly instrument for assessing the support needs of people with disabilities. It uses a process that involves the persons with disability, their family and friends and staff as appropriate. It is also apparent that the current provision of paid support hours by agencies is a complex phenomenon that is not based solely on individual support needs. Further research is warranted on the influence of the environment and the perceptions of need for support based on negotiable and non-negotiable support needs.

6

Title:

What characteristics do service users with intellectual disability value in direct support staff within residential forensic services?

Authors:

[Clarkson, Rachael](#)

[Murphy, Glynis H](#)

[Coldwell, Jon B.](#)

[Dawson, David L.](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Dec2009, Vol. 34 Issue 4, p283-289, 7p

Abstract:

This study explores the perceptions of a group of adults with intellectual disability regarding direct support staff. Method Semi-structured interviews relating to experiences of direct support staff were developed from two focus groups. These interviews were conducted with 11 adults with intellectual disability residing within a forensic inpatient service. Results Interpretative Phenomenological Analysis (IPA) revealed two superordinate themes; namely, staff relationship factors and positive and negative attributes of staff. The participants valued relationships with staff based on qualities such as honesty, trust, and a caring, nurturing manner that enabled individuals to feel safe. Staff characteristics such as immaturity, inexperience, and a short temper appeared to lead to feelings of discontentment amongst the participants. Conclusions The implications of the findings are discussed in relation to clinical practice, staff recruitment, and training.

7

Title:

Rekindling commitment: reflections from a pastoral educator enmeshed in direct support professional workforce development and person centered supports.

Authors:

[Gaventa, W. C.](#)

Source:

[Journal of Intellectual Disability Research](#); Jul2008, Vol. 52 Issue 7, p598-607

Abstract:

Background Services with people with intellectual disabilities (ID) are increasingly structured by regulations, policies and licensing standards by public funding entities. The key responsibility for direct care staff often becomes that of compliance with all the rules and regulations. Method The impact of an increasing focus on compliance with regulations in the systems of services and supports for people with ID is explored along with the absence of focus on professional commitment and relationships. This exploration is done through a

review of literature and also anecdotes and observations from 30 years of professional experience in working with direct care staff. Results Whether the source for enhanced regulation is concern about health and safety, honouring rights, meeting laws and/or an underlying fear that we cannot rely on the caregivers because of the turnover or lack of skill; we end up building a system based more and more on compliance, on regulations, programme and behavioural plans and competencies, without the same kind of concern or attention for people who are doing the caring, their motivation and what they need. One of the hypotheses and conclusions of this article is that the focus on compliance diminishes professional competence and commitment, and contributes both to staff disillusionment and to the rapid turnover. Conclusions As recruitment and turnover in the direct support professional workforce become ever more difficult problems, the newer focus on person-centred planning, self-directed supports and workforce development have both possibilities and problems in enhancing staff commitment in relationships with people they support. The importance of enhancing and supporting commitment also calls for new forms of professional identity and education that recapture the language and habits of commitment while also providing opportunities for staff to reflect on the values, visions and commitments that support their work.

8

Title:

Friendship or Facilitation: People with Learning Disabilities and Their Paid Carers

Author:

Pockney, R

Source:

Sociological Research Online, 2006 Volume 11, Issue 3

Abstract:

This article compares the composition and characteristics of the social networks of 14 people with learning disabilities with those of 24 of their paid support staff. In doing so the article not only establishes the differences in the diversity, durability and density of each group's social set, but highlights the disparity in perspective that the service users and the support staff have about their shared relationships. This is followed by a sociological discussion of why those with learning disabilities perceive their support staff as friends, while the support staff seldom consider the service users in this way, preferring to view themselves as facilitators to these individuals' friendships. The article concludes by discussing the consequences of the staff and service users' differing perspectives about their relationships, in terms of the tensions it generates in staff about their caring role and the effect it may have upon those with learning disabilities' broader social inclusion.

Sexuality

Themes include: staff attitudes; sex education; homosexuality; caregiver perceptions; sexual knowledge; sexuality and rights.

Sexual abuse perpetrated by people with learning disabilities is beyond the remit of this reading list but it does include some interesting journal articles regarding the need to support relationships for people with learning disabilities who sexually offend or who have 'difficult sexual behaviour'.

1

Title:

An Evaluation of Staff Attitudes towards the Sexual Activity of People with Learning Disabilities

Author:

Holmes, Maria

Source:

[The British Journal of Occupational Therapy](#), Volume 61, Number 3, March 1998, pp. 111-115(5)

Abstract:

This article presents part of a study which aimed to evaluate staff attitudes towards the sexual activity of people with learning disabilities. The need for such a study is clarified, drawing upon the development of societal attitude change, normalisation and community care. Previous research in this area is reviewed and the potential change in hospital policy at the research site, which is a medium secure unit, is considered. The first part of the research is presented, which involved 69 questionnaires containing a 20-item attitude rating scale and open and closed questions being sent to both clinical and non-clinical staff. The data from the 46 (67%) returned questionnaires are analysed. Although some conservative attitudes remain, the results highlight a liberal trend in attitudes. Many staff identified a need to change hospital policy, provide more staff training and improve condom availability. Methodological issues are also discussed.

2

Title:

Sexual relationships in adults with intellectual disabilities: understanding the law.

Authors:

[O'Callaghan, A. C.](#)

[Murphy, G. H.](#)

Source:

[Journal of Intellectual Disability Research](#); Mar2007, Vol. 51 Issue 3, p197-206, 10p

Keywords:

People with mental disabilities; developmentally disabled; adulthood; sex crimes; education; law; sex; intellect; sex offenders

Abstract:

Adults with intellectual disabilities (IDs) are known to be very vulnerable to sexual abuse. This may result partly from their lack of sexual knowledge and their powerless position in society. It could also be exacerbated by an ignorance of the law. This study investigates their understanding of the law relating to sexuality. Method Understanding of the law regarding sexual relationships, consent and abuse was assessed in 60 adults with IDs (mean age 37.6 years) and 60 young people aged 16–18 years (deemed in law capable of consenting to a sexual relationship). Questions were wide ranging, including general laws around sexuality and abuse, as well as the law relating to sexual relationships and ID. Results There were significant differences between the two groups: adults with IDs had a very limited understanding of the general laws relating to sexuality (e.g. age of consent, incest, abuse), as well as the law relating to sexuality and IDs (e.g. whether they could have sexual relationships, whether they were allowed to marry, what protection they should expect from the law). Young people without disabilities showed a better understanding, both for general laws and for those relating specifically to adults with IDs. Conclusions These findings show that there is a need to educate people with IDs about the laws relating to sexuality. It is important for people to understand the law and, given the high rates of sexual abuse perpetrated against people with ID, it is essential for them to benefit from the protection the law affords. The new law in England (Sexual Offences Act 2003) post-dated this study. It will be interesting to see whether the new legislation is easier for people with and without disabilities to understand.

3**Title:**

The sexuality of people with mild intellectual disability: Perceptions of clients and caregivers

Authors:

Agnes A. Szollos
Marita P. McCabe

Source:

[Journal of Intellectual and Developmental Disability](#), 1995, Vol. 20, No. 3, Pages 205-222

Abstract:

The sexuality of people with mild intellectual disability was assessed via administration of the Measure to Assess Sexual and Relational Knowledge, Experience, Feelings and Needs (Sex Ken-ID), an instrument developed to enable direct and comprehensive assessment of these areas preliminary to designing appropriate sex education programs. This paper reports on a study where data on the sexuality of a group of people with mild intellectual disability were obtained by interviewing them directly, and then comparing their responses with the perceptions of their caregivers, as well as to data collected from a group of people without

intellectual disability. A broad range of sexual areas was studied, and subjects were questioned about their knowledge, experience, feelings and needs in each of these areas. Care staff consistently overestimated the responses of their clients, whom they perceived to be more knowledgeable and experienced, have more positive feelings and a greater need to know, than was indicated by the clients themselves. The group without intellectual disability demonstrated a higher level of sex knowledge and reported greater interactive sexual experience than the people with intellectual disability. The exceptions to this were that the latter group had experienced higher levels of sexual abuse, and reported equal frequencies of same-sex experiences. The implications of these findings with regard to sex education programs are discussed.

4

Title:

Not Such an 'Ordinary' Relationship: the role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour

Authors:

David Thompson
Isabel Clare
Hilary Brown

Source:

[Disability & Society](#), Volume 12, Number 4, 1 September 1997 , pp. 573-592(20)

Keywords:

Man-woman relationships; women-sexual behavior; employees; learning disabilities; nymphomania entertaining

Abstract:

This paper brings together some preliminary data on the management of men with learning disabilities who have unacceptable/abusive sexual behaviour patterns with a small pilot study which specifically explores the roles of women support workers in relation to difficult sexual behaviour. A specific focus on the behaviour of men with learning disabilities is justified because of consistent evidence that it is men, rather than women, service users who challenge services in this way. The studies explore with staff the boundaries of what is considered acceptable sexual behaviour and how breaches of these are responded to within services. One issue which we have chosen to highlight is the frequent exposure of women staff to the men's sexual behaviour, sometimes precipitated by the unusual relationship that exists between the two parties, and exacerbated by the lack of clear management guidance within the gendered hierarchies found in service agencies.

5

Title:

Sexuality and People Living with Physical or Developmental Disabilities: A Review of Key Issues

Author:

Gina Di Giulio

Source:

[Canadian Journal of Human Sexuality](#); 2003, Vol. 12 Issue 1, p53-68, 16p

Keywords:

People with disabilities; developmental disabilities; sex; sex therapy; sex instruction; sexual behavior

Abstract:

People with disabilities often face obstacles to maximizing their potential as fully sexual human beings. People with disabilities may internalize negative societal assumptions and attitudes regarding the sexuality of people with disabilities. This paper examines key issues related to sexuality within the disabled population. It begins with an examination of how the traditional model of sexual response (i.e. Masters & Johnson) often does not apply well to people with physical disabilities. Societal, parental, and staff attitudes towards the sexuality of people with developmental disabilities are critically examined. Sexuality related obstacles and systemic barriers to sexual health faced by people with physical and developmental disabilities are reviewed (increased HIV/AIDS risk, vulnerability to sexual exploitation and abuse, reduced access to sexuality education for disabled youth, reduced access to privacy, sexuality related information and health care, and sexual partners). Recommendations for providing sexuality education and sex therapy to the disabled are provided.

6

Title:

Perception of Sex Education for Individuals with Developmental and Cognitive Disability: A Four Cohort Study.

Author:

[Swango-Wilson, Amy](#)

Source:

[Sexuality & Disability](#); Dec2009, Vol. 27 Issue 4, p223-228, 6p

Keywords:

Developmental disabilities; people with disabilities- sexual behavior; sex instruction; medical care; sex crimes

Abstract:

Individuals with developmental disabilities/cognitive disabilities (DD/CD) may lack experience and skills necessary to build relationships and define their sexuality boundaries. This lack of experience makes them particularly vulnerable to sexual abuse and exploitation. The short-term goal of this study was to discover the expectations for a sex education program as described by individuals with DD/CD, parents of individuals with DD/CD, professionals who work with individuals with DD/CD, and health care professionals who come into contact with these individuals. The long term goal is to gain information that will be helpful in the development of an appropriate **sex** education program for individuals with DD/CD.

7**Title:**

A Study on Sexuality with the Parents of Adolescents with Intellectual Disability.

Authors:

[Isler, Aysegul](#)

[Beytut, Dilek](#)

[Tas, Fatma](#)

[Conk, Zeynep](#)

Source:

[Sexuality & Disability](#); Dec2009, Vol. 27 Issue 4, p229-237, 9p

Keywords:

People with disabilities; sex instruction; guardian and ward; adolescent psychology

Abstract:

The objective of this study was to determine the knowledge, opinions, attitudes and concerns of the parents regarding sexuality of their children with intellectual disabilities. Forty parents who have children with intellectual disabilities formed this study's sample from Turkey. The children had mild to moderate intellectual disabilities aged between 15 and 21 years in an occupational school. The data taken from questionnaires was evaluated with SPSS 13.0 package program. 87.5% of the parents consisted of mothers and 12.5% consisted of fathers. Seventy five percent of the parents had not received any professional education on sexuality and 32.5% never talked on sexuality with their children. Fifty-five percent of the parents thought that sexual education should start during elementary school years. While 45% of the parents acknowledged their children engaging in masturbation, more than half had false opinions on masturbation. 57.5% of the parents stated that they inform their children on the physical characteristics of the adolescence period and 27.5% of them provide information to their children on subjects like the reproductive organs. In addition, a large majority of the parents (72.5%) had concerns regarding the future of their children. The parents of the adolescents with intellectual disabilities had not received any professional education on sexual development. It is very crucial that parents with children who have special needs be informed by health care professionals.

8

Title:

The Invisibility of Young Homosexual Women and Men with Intellectual Disabilities.

Author:

[Löfgren-Mårtenson, Lotta](#)

Source:

[Sexuality & Disability](#); Mar2009, Vol. 27 Issue 1, p21-26, 6p

Keywords:

Interpersonal relations; sexual orientation; mental retardation; homosexuality; bisexuality; sex; social aspects

Abstract:

The aim of the article is to identify, describe and understand the opportunities and hindrances for young people with intellectual disabilities (ID) in expressing a variety of sexual expressions, such as homosexuality and bisexuality. The method is qualitative interviews with people with ID in the age of 16–27, staff members and parents. The study found young gay people with ID to be an invisible group, and that the possibilities to show a variety of sexual expressions are depending on the surroundings attitudes and behaviors toward them. Therefore it is important to teach about different sexualities in the sex education at special schools and also to do more research concerning homosexuality and bisexuality and intellectual disability, without having the heterosexual norm as a starting point.

9

Title:

Sexuality in Adolescents with Intellectual Disabilities.

Authors:

[Isler, Aysegul](#)

[Tas, Fatma](#)

[Beytut, Dilek](#)

[Conk, Zeynep](#)

Source:

[Sexuality & Disability](#); Mar2009, Vol. 27 Issue 1, p27-34, 8p

Keywords:

Sex; generative organs; interpersonal relations; students with disabilities; developmental disabilities; developmental biology; adolescent with intellectual disabilities; sexuality; Turkey

Abstract:

Purpose This study aims to characterize adolescent development and knowledge, opinions, and attitudes toward sexuality in adolescents with intellectual disabilities. Methods Sixty

students in occupational school with mild to moderate intellectual disabilities, aged between 15 and 20 years, formed this study's sample from Turkey. The data taken from questionnaires was evaluated with the SPSS 13.0 package program. Results These results demonstrate that 51.7% of adolescents have not been educated professionally with regard to sexuality. In addition, 46.7% of them have never talked about sex with their parents. The level of knowledge among adolescents of both sexes is quite low. Most adolescents do not know the male and female differences in reproductive organs. While more than half of adolescents describe sex as kissing and intimate touching, about half of them think only married couples have sex. Conclusion Adolescents with intellectual disabilities in this study have very low levels of correct information about sex and the characteristics of the adolescent stages of development.

10

Title:

Sexuality of 15/16-Year-Old Girls and Boys With and Without Modest Disabilities.

Authors:

[Brunnberg, Elinor](#)

[Boström, M. Lindén](#)

[Berglund, Mats](#)

Source:

[Sexuality & Disability](#); Sep2009, Vol. 27 Issue 3, p139-153, 15p

Keywords:

Children with disabilities; sex; teenagers-sexual behavior; mental health; psychology; adolescents; disability; gender; sexual debut; substance abuse; Sweden

Abstract:

Girls and boys with disabilities, 15–16 years of age, report a significantly higher rate of sexual debut than adolescents with no disabilities. In a society where a young person with a disability often is considered to have an essentially asexual status, there can be several fronts for adolescents to fight. The survey Life and Health—Young People 2005 was completed by 3,084 adolescents attending mainstream schools in Sweden. In this study the sexual debut in girls and boys with and without disabilities is related to mental health, school exposure and substance use. Our findings might be explained by a mechanism of identity construction from the adolescents' ideas of normality and by a battle for acceptance and confirmation of life. The ideas of normality can be erroneous but still influence the adolescents' sexual activity. Multivariate analyses also showed that the relationship between sex and substance use is strong among all adolescents.

11

Title:

Judging the Acceptability of Sexual Intercourse Among People with Learning Disabilities: French Laypeople's Viewpoint.

Authors:

[Esterle, Mélanie](#)

[Muñoz Sastre, Maria Teresa](#)

[Mullet, Etienne](#)

Source:

[Sexuality & Disability](#); Dec2008, Vol. 26 Issue 4, p219-227, 9p

Keywords:

Learning disabled; judgment (ethics); sexual intercourse; autonomy in youth; public opinion; sexual behavior; moral and ethical aspects; France; learning disability; parenting; sexual intercourse

Title:

The importance of different situational factors that may alter acceptability judgments (i.e., gender, etiology of the disability, person's present level of autonomy, use of contraceptive devices, and partner's age and possible handicap) with regards to the sexuality of people with learning disability was examined. Participants were members of the community in France, aged 19–70. They were presented with several concrete cases in which a young person with a learning disability is having sexual intercourse. The participants' main concerns were centered on the consequences of the sexual relationships, and not on the relationships per se. Relationships that could lead to procreation were judged not acceptable, even if the child could be cared for by a non-handicapped parent. They were judged moderately acceptable in the cases when the person is autonomous, the partner is of the same age and is also handicapped, and the relationship is a protected one.

12

Title:

Caregiver Perception of Sexual Behaviors of Individuals with Intellectual Disabilities.

Author:

[Swango-Wilson, Amy](#)

Source:

[Sexuality & Disability](#); Jun2008, Vol. 26 Issue 2, p75-81, 7p, 3 Charts

Keywords:

Caregivers; perception; sex; mental illness; intellectuals; people with disabilities; caregiver; individuals with intellectual disabilities; individuals with intellectual disorders; intellectually disabled; perception; sexuality

Abstract:

Sexuality defines how we interact with others, what relationships we develop, how we love and show affection, and how we feel about our bodies. Individuals afflicted with intellectual disabilities often lack skills to make sensible decisions regarding their safety and well being. Caregivers are in the position to provide social skills and experiences needed to develop exploration of sexuality and awareness of self protection skills. The purpose of this descriptive survey study was to determine the perception of caregivers toward the sexuality of individuals with intellectual disabilities. The Perception of Sexuality scale was used to measure caregiver attitude toward sexual behaviors of individuals with intellectual disability. The survey format was sent to 160 caregivers and yielded responses from 87 participants. Inferential statistics was used to determine basic characteristics of the responses.

13**Title:**

Training in Sexuality and Relationships: An Australian Model.

Authors:

[Chivers, Jane](#)

[Mathieson, Sue](#)

Source:

[Sexuality & Disability](#); Mar2000, Vol. 18 Issue 1, p73, 8p

Keywords:

Sex; people with mental disabilities; bureaucracy; Australia; curriculum development; disability; discourses; sexuality; staff training;

Abstract:

This article examines some of the dominant discourses which impacted on the process of developing a curriculum for staff working with people with an intellectual disability in the area of relationships and sexuality within a medium sized Government bureaucracy providing services to people with a disability. Constructions of sexuality as being solely a biological function, sex as dangerous and sex as penetration are challenged as are some of the dominant discourses of learning.

14

Title:

Final report of the Bawnmore personal development programme: Staff attitudes and sexuality programme development in an Irish service organisation for people with mental handicap

Author:

John F. Toomey

Source:

[Research in Developmental Disabilities Volume 14, Issue 2](#), March-April 1993, Pages 129-144

Abstract

In this paper, issues on sexuality and mental handicap are reviewed, and recognition of the growing importance of sex education to integration is noted. The development of a sex education programme and staff training provided within a service organisation, with some involvement from other services within an Irish setting, are described, and their evaluation is reported. Attitudes towards involvement prove of particular interest, and factors influencing continuation or discontinuation are identified. The need for attitude change among staff and administration towards the priority given to sex education is highlighted, and a need for structural change in staffing arrangements to facilitate such education is indicated. Failure to recognise sexuality as a research issue in evaluating the success of integration efforts is noted, and such research is recommended as a top priority for the future.

15

Title:

Construction and psychometric properties of sexuality scales: sex knowledge, experience, and needs scales for people with intellectual disabilities (SexKen-ID), people with physical disabilities (SexKen-PD), and the general population (SexKen-GP)

Authors:

Marita P. McCabe
Robert A. Cummins
Amanda A. Deeks

Source:

[Research in Developmental Disabilities Volume 20, Issue 4](#), 8 July 1999, Pages 241-254

Keywords:

Sexuality; intellectual impairment; physical disability

Abstract

This study reports on the development and assessment of the psychometric properties of three measures to assess sexual knowledge, experience, feelings, and needs. The first was designed to assess the Sexual Knowledge, Experience, Feelings, and Needs of people with

mild intellectual disabilities (SexKen-ID). The two parallel measures were designed to assess the same areas of sexuality among people with physical disabilities (SexKen-PD) and among the general population (SexKen-GP). The areas of sexuality included in the scales were Friendship, Dating and Intimacy, Marriage, Body Part Identification, Sex and Sex Education, Menstruation, Sexual Interaction, Contraception, Pregnancy, Abortion and Childbirth, Sexually Transmitted Diseases, Masturbation, and Homosexuality. Generation of the items in these scales is described in Studies 1–3. Study 4 describes the evaluation of the psychometric properties of the scales. Sixty-six people with intellectual disabilities, 54 people with physical disabilities, and 100 people from the general population completed the scales. Test-retest reliabilities were also calculated with 30 people with intellectual disabilities, 30 people with physical disabilities, and 30 people from the general population. These data demonstrate the good psychometric properties of the scales and so their suitability for assessing the sexual knowledge, experience, feelings, and needs of people with disability.

16

Title:

Attitudes of Social Service Providers towards the Sexuality of Individuals with Intellectual Disability.

Authors:

[Bazzo, Giuseppe](#)

[Nota, Laura](#)

[Soresi, Salvatore](#)

[Ferrari, Lea](#)

[Minnes, Patricia](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); Mar2007, Vol. 20 Issue 2, p110-115

Abstract:

The sexual lives of people with intellectual disability is made complex by the involvement and influence of social service providers, whose beliefs and values have a great impact on the support they provide. We hypothesized that social service providers' role, educational level and service in which they worked could affect attitudes towards the sexual behaviour of individuals with intellectual disability. Materials and methods The current study describes attitudes of social service providers towards the sexuality of individuals with disability measured by 20 items of Sexuality and Mental Retardation Attitudes Inventory (SMRAI). This instrument was devised by Brantlinger [Mental Retardation (1983) Vol. 21, pp. 17–22] to assess the attitudes of the staff employed by organizations that supplied services to individuals with intellectual disability. Specifically, analysis of variance (type of service × professional role × education) was performed on participants' scores. Results Results suggested that the social service providers participating in this research study tended to have moderately liberal attitudes. Educational level and role carried out did not produce differences in their attitudes. A significant difference emerged between those who operated in different services. It was especially the staff of the outpatient treatment services who revealed the

most liberal and positive attitudes towards the sexuality of individuals with intellectual disability. Conclusions The data reported in the present study seem to underline some differences between the data collected from the Italian and the Anglo-Saxon social service providers. Failure to record influences associated with the role carried out and previous training could be related to the different contextual differences. Results suggest that particular attention should be paid to the training of those who hold managerial posts in Italian residential services.

17

Title:

Still Off-Limits? Staff Views on Supporting Gay, Lesbian and Bisexual People with Intellectual Disabilities to Develop Sexual and Intimate Relationships?

Authors:

[Abbott, David](#)

[Howarth, Joyce](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); Mar2007, Vol. 20 Issue 2

Abstract:

Background In the UK and elsewhere, there is a growing policy and legislative imperative to ensure that people with intellectual disabilities are supported to develop relationships, including sexual ones. However, gay, lesbian and bisexual people with intellectual disabilities may have additional needs or face particular barriers in this area of their lives. They may require particular kinds of support from the staff who work with them. But how able, or willing, are staff in services to address these issues? Method As part of empirical, qualitative research, the authors carried out interviews with 71 staff in 20 intellectual disability services across the UK about their views and experiences of working with people with intellectual disabilities who were, or may have been, gay, lesbian or bisexual. Results The majority of staff interviewed said that they did not feel confident working in this area. A number of barriers to doing the work were identified including a lack of policy and training as well as the prejudice of staff and parents/carers. Conclusions The reticence of staff to engage with these issues needs addressing especially in the light of the emerging human rights of people with intellectual disabilities to develop sexual and intimate relationships.

18

Title:

Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability): Scale development and community norms.

Authors:

[Cuskelly, Monica](#)

[Gilmore, Linda](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Sep2007, Vol. 32 Issue 3, p214-221

Abstract:

Attitudes to the sexual expression of adults with an intellectual disability (ID) are one reflection of the inclusiveness of a community. Our capacity to measure attitudes towards this important aspect of adult life is limited by the lack of an appropriate instrument. The aim of this study was to continue the development of a recently published questionnaire and to establish normative data. Method The Attitudes to Sexuality Questionnaire (Individuals with an Intellectual Disability) (ASQ-ID: Cuskelly & Bryde, 2004) was modified slightly and questions about hypothesised stereotypical views of sexuality were added. A community sample of 261 adults completed this modified questionnaire, as well as a shorter version of the questionnaire about attitudes to sexual expression in typically developing adults. Results Factor analysis revealed one general factor associated with sexual rights, plus three other factors related to parenting, non-reproductive sexual behaviour, and self-control. There were few differences in attitudes towards male and female sexuality, and attitudes were only slightly less positive for individuals with an ID than for those without a disability. Views about parenting by people with an ID were more cautious than for other aspects of sexuality. Conclusions The present study established the factor structure of an instrument for measuring attitudes towards the sexual expression of adults with an ID and provided normative data. Community attitudes towards the sexual rights of adults with an ID are generally quite positive.

19**Title:**

Quality of life and relationships in sex offenders with intellectual disability.

Authors:

[Steptoe, Lesley](#)
[Lindsay, William](#)
[Forrest, Diane](#)
[Power, Mick](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Mar2006, Vol. 31 Issue 1, p13-19

Abstract:

Hayes (1991) and Day (1994) have developed hypotheses about the importance of social and developmental variables in the aetiology of sexual offences in offenders with intellectual disability. The present study is the first of its kind to investigate the perceived quality of life and relationships of sex offenders in comparison to an appropriate control group. Method A group of 28 sex offenders with intellectual disability (ID) were compared with 28 members of a control group of individuals with ID. All participants completed the Significant Others Scale (SOS) which assesses self-perceptions of potential and ideal support from significant others in the individual's life, and the Life Experience Checklist (LEC) which assesses experiences

and opportunities across 5 living domains: home, leisure, freedom, relationships and opportunities. Results There were no differences between the groups on age and IQ. On the SOS there were no differences between the groups on the number of times each significant other was reported. Actual and ideal levels of support from both mother and father were lower for sex offenders than the control group. On the LEC, sex offenders reported lower scores on the relationships and leisure sections. Conclusions Poorer relationships and little indication of any wish to change that state of affairs suggests lower levels of integration and identification with society for sex offenders compared with the control group.

20

Title:

The assessment of sexual knowledge in people with intellectual disability.

Authors:

[Galea, Jennifer](#)

[Butler, Jenny](#)

[Iacono, Teresa](#)

[Leighton, Daniel](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Dec2004, Vol. 29 Issue 4, p350-365

Abstract:

The aims of this study were to evaluate components of a new tool, the Assessment of Sexual Knowledge (ASK), and to use it to assess the sexual knowledge of adults with intellectual disability. The ASK consists of a Knowledge Section, an Attitudes Section, a Quick Knowledge Quiz and a Problematic Socio-Sexual Behaviours Checklist. A sample of 96 adults with intellectual disability participated in the study. The Knowledge Section was administered twice (with a one to two week interval between testing) to examine its test-retest reliability. Inter-rater reliability was determined by having a second scorer for approximately a third of participants. The Quick Knowledge Quiz (QKQ) was also administered to examine its relationship with the Knowledge Section. The results of this study suggest that the ASK is a tool that is reliable across examiners and will also elicit responses that are stable over time. The relationship between the Knowledge Section and the QKQ indicated that the QKQ is a predictor of knowledge scores in the ASK. In terms of people with intellectual disability's knowledge, the results demonstrated their poor overall knowledge of sexuality, particularly in the areas of sexually transmitted infections, sexual health, safer sex practices, legal issues and contraception.

21

Title:

Attitudes towards the sexuality of adults with an intellectual disability: parents, support staff, and a community sample.

Authors:

[Cuskelly, Monica](#)

[Bryde, Rachel](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Sep2004, Vol. 29 Issue 3, p255-264

Abstract:

Attitudes toward the sexuality of adults with intellectual disability were assessed in parents and carers of adults with intellectual disability and in a community sample. An instrument that contained items relating to eight aspects of sexuality (sexual feelings, sex education, masturbation, personal relationships, sexual intercourse, sterilisation, marriage, and parenthood) was developed and found to have good internal consistency and test-retest reliability. Age was associated with attitudes, with those aged 60 and above holding more conservative attitudes. Parents and staff differed in their attitudes, with parents holding more conservative attitudes. This difference was the product of age differences between the groups; nevertheless it may produce some confusion for adults with intellectual disability unless it is addressed appropriately. Both parent and staff groups were less positive about parenthood than about other aspects of sexuality, however the community group did not differ in their views when attitudes towards parenthood were compared with the remaining items of the scale.

22

Title:

Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'.

Authors:

[Kelly, Grace](#)

[Crowley, Helen](#)

[Hamilton, Carol](#)

Source:

[British Journal of Learning Disabilities](#); Dec2009, Vol. 37 Issue 4, p308-315

Abstract:

Accessible summary • This paper talks about what a group of people with intellectual disabilities in Ireland had to say about their experiences of relationships and sexuality, and the type of support they might like in this area of their lives. • Many people did not get enough information about sexuality. There were lots of things they did not understand properly and they wanted more information. • Many people wanted to have boyfriend and girlfriend

relationships, but relationships were not allowed in their service. Some people had to have relationships in secret. • In Ireland it is against the law to have a sexual relationship with a person who cannot live without support, or protect themselves from abuse, unless you are married. • The law needs to be changed because some people with intellectual disabilities who need support in their lives are still capable of having sexual relationships and protecting themselves from abuse. • People with intellectual disabilities need better sexual information and need support to have their voices heard by government. How to translate the right of people with intellectual disabilities to a full sexual and intimate life into proactive support remains a challenge for disabilities services in Ireland. Little formal research has been undertaken in this country into what people with intellectual disabilities think about these issues and what they would like to see happen in this area of their lives. This paper presents a preliminary analysis of the first author's PhD research into the views and experiences of a small group of Irish people with intellectual disabilities in the area of sexuality and relationships. Initial findings suggest that people with intellectual disabilities are getting insufficient sex education and that changes are needed at a disabilities service level to ensure that people with intellectual disabilities can express their sexuality in an open and supportive climate. At a government level, changes will need to be made to Irish legislation concerning the sexuality of vulnerable adults so that this country is meeting its obligations under the UN Convention on the Rights of Persons with Disabilities (2006). The authors argue that people with intellectual disabilities' views must come first in all debates concerning their sexuality.

23

Title:

'A Right to Know'. Facilitating a relationship and sexuality programme for adults with intellectual disabilities in Donegal.

Authors:

[Gardiner, Tina](#)

[Braddon, Eileen](#)

Source:

[British Journal of Learning Disabilities](#); Dec2009, Vol. 37 Issue 4, p327-329, 3p

Abstract:

Accessible summary • It is often hard for people with intellectual disabilities to learn about sexuality and relationships. • It is also often hard for workers to talk about this issue with them. • We set up an education program so that people with intellectual disabilities could learn more about sexuality and relationships. • People found it useful although they said that sometimes it was embarrassing. • We found it was important to give parents and carers training too to support people with intellectual disabilities

24

Title:

'May we please have sex tonight?'– People with learning difficulties pursuing privacy in residential group settings.

Author:

[Hollomotz, Andrea](#)

Source:

[British Journal of Learning Disabilities](#); Jun2009, Vol. 37 Issue 2, p91-97

Abstract:

Accessible summary • Everyone has the right to privacy and relationships. • Some people who live in group homes are not allowed to be private with their partner. • We will explain how this makes us feel. • We will say what should change. • Parts written in 'bold' font are in plain English. Read them to find out more. Many residential group settings for people with learning difficulties do not provide individuals with the private space in which they can explore their sexual relationships in a safe and dignified manner. Lack of agreed private spaces seriously infringes the individual's human rights. Many people with learning difficulties who lack privacy have no other option but to escape to isolated public or semi-private spaces to be sexually active. This places individuals at risk. It is suggested that self-advocacy driven policy guidance must be developed which must require residential services to review their practice to ensure that they accommodate residents' need for privacy, whilst supporting them to lead safe sexual relationships.

25

Title:

Staff attitudes towards the sexuality of people with learning disabilities: a comparison of different professional groups and residential facilities.

Authors:

[Grieve, Alan](#)

[McLaren, Shona](#)

[Lindsay, William](#)

[Culling, Ewan](#)

Source:

[British Journal of Learning Disabilities](#); Mar2009, Vol. 37 Issue 1, p76-84

Abstract:

Accessible summary This study asked 188 nurses and care staff what they thought about people with learning disabilities having relationships. Other studies found that care staff often think that it is not okay for people with learning disabilities to have relationships. Studies have also found that staff do not think that it is okay for men to have relationships with other men.

This study found that: • Staff in the community were more likely than nursing home staff to think that it was okay for people with learning disabilities to have relationships. • Staff with more training were likely to think that it was okay for people with learning disabilities to have relationships. • Nursing home staff were less likely to think that it was okay for men with learning disabilities to have relationships with other men. The role of care staff is invaluable in the day to day living of many people with learning disabilities. Consequently, care staff can often have substantial influence, although this may not always serve the best interests of the individual. Previous studies have shown significant levels of stigma towards people with learning disabilities, both from other members of the community and from carers. This is especially the case in relation to the sexuality of people with learning disabilities. Standardised measures of attitudes towards the sexuality of people with learning disabilities (Mitchell et al. 1978) were completed by qualified nurses and other care staff (n = 188). Place of employment was a main variable and it was found that nursing home staff held significantly more conservative attitudes when compared with community care staff. This was the case with attitudes towards homosexuality, and attitudes towards the sexuality of people with mild, moderate and severe/profound learning disabilities. Levels of training emerged as a significant factor. These findings suggest that training and education on issues relating to the sexuality of people with learning disabilities may benefit all care staff, and especially those who work in nursing homes. Training may help to change their attitudes and develop an awareness of the ways in which people with learning disabilities form loving and personal relationships.

26

Title:

An evaluation of research and training resources for the sex education of people with moderate to severe learning disabilities.

Authors:

[Grieve, Alan](#)

[McLaren, Shona](#)

[Lindsay, William R.](#)

Source:

[British Journal of Learning Disabilities](#); Mar2007, Vol. 35 Issue 1, p30-37

Abstract:

To review the literature on issues surrounding the sexuality of people with moderate to severe learning disability (SLD), and evaluate available assessment and training methods. This research arose from an increasing number of referrals for clinical intervention in the training and education of appropriate social and sexual behaviour in people with moderate to SLD. What became apparent was the lack of suitable materials and assessments, which is significant as a large number of persons with SLD have problems with language, and so require tools and programmes which have enhanced levels of pictorial support. This research was necessary as people with SLD are vulnerable and have been open to emotional and sexual abuse [Ment Handicap Res 16 (1993) 193]. Also, the present study was also required

to help keep clients safe and reduce their vulnerability. It has been proposed that this should be achieved through providing educative input. An extensive review of the literature revealed that the research on sexuality in SLD was limited. Furthermore, where research had been conducted, poor methodology or validation issues were common, and materials appeared overly complicated for clients with moderate to SLD. Further research into the development and validation of assessment tools and training programmes which increase appropriate sexual behaviours is urgently required.

27

Title:

The sexual lives of men with mild learning disability: a qualitative study.

Authors:

[Yacoub, Evan](#)

[Hall, Ian](#)

Source:

[British Journal of Learning Disabilities](#); Mar2009, Vol. 37 Issue 1, p5-11

Abstract:

Accessible summary • We talked to some men with learning disability about sex and relationships. Some people lived in the community, and some people lived in hospital. • The men knew quite a lot about sex. Most people said they got good support from their keyworkers. • Some people were asked for sex when they did not want it. Some people were made to have sex that was not safe. • We have some ideas about how men with learning disabilities can speak up for themselves about sex and relationships. We aimed to explore in detail the sexual lives and behaviour of men with mild learning disabilities living both in community and in secure hospital settings. We wanted to generate hypotheses about them and identify potential unmet needs. We used a narrative interview that focused on areas such as relationships, sex education, contraception and the attitudes of others towards the participants' sexual lives and orientation. We used the constant comparative method to analyse transcribed interviews. Several clients reported engaging in unsafe practices despite being aware of the risks. Participants generally felt that services had shifted from a paternalistic to a more supportive approach towards their sexual lives and orientation. Experiences with other men were commonly reported. Several participants reported being pressurised into sex as adults. In our sample, sexual knowledge did not lead to safe sexual practices. The good rapport with services reported by the participants may be utilised to provide further education and empowerment to improve the safety of sexual practices in this group. Other ways of improved service delivery are suggested.

28

Title:

An investigation of students' with mild learning disabilities reactions to participating in sexuality research.

Authors:

[Thomas, Gail](#)

[Kroese, Biza Stenfert](#)

Source:

[British Journal of Learning Disabilities](#); Sep2005, Vol. 33 Issue 3, p113-119

Abstract:

This study investigates 35 students' with mild learning disabilities reactions to participating in a research project exploring their sexual knowledge, attitudes and behaviour. Students completed an informed consent procedure prior to their participation in the sexuality research and all were interviewed using a confidential interview procedure. During the research interviews, each student's reaction to participation was observed and recorded by their interviewer. Following the interviews, each student's reaction to participation was observed and recorded by their college tutor. Researchers observed that although some students were embarrassed discussing certain sexual topics, none chose to stop their interviews when invited. Ten students requested additional information from their interviewers about the issues discussed. Tutors reported that no students appeared anxious or distressed following their interviews and that no inappropriate sexualized behaviour, or talk, were observed. Tutors also reported that several students appeared to have been positively affected by their participation. No tutors expressed concern about their students participating in similar research in the future. It is concluded that a number of methodological and participant factors may have accounted for the positive outcomes reported. The implications of these findings and recommendations for future research are discussed.

29

Title:

The assessment of the sexual knowledge of a person with a severe learning disability and a severe communication disorder.

Authors:

[Bell, Dorothy M.](#)

[Cameron, Lois](#)

Source:

[British Journal of Learning Disabilities](#); Sep2003, Vol. 31 Issue 3, p123

Abstract:

Summary This paper arose as a consequence of joint working between therapists of two different disciplines – clinical psychology and speech and language therapy – on a case involving a young woman who required an assessment of her sexual knowledge and attitudes. It explains how the recent development of a method of communication for those with a severe communication disorder (Talking Mats) has meant that it has become possible to work with those who have a severe learning disability and poor communication. In the past, clients with both severe learning disability with poor communication may have been excluded from traditional and cognitive therapy, which was dependent to a large extent on verbal communication. This paper, therefore, is of value in extending the range of methods for assessment and intervention that may be used by a range of disciplines with people showing severe learning disabilities and severe communication disorder.

30**Title:**

Ethically managing sexual activity in long-term care

Authors:

Everett, B.

Source:

Sexuality & Disability, 2007, Vol 25, Issue 1, p21-27

Abstract:

Although care providers in almost every long-term care facility face daily challenges involving issues related to residents' sexual lives, guidelines for the ethical, legal and socially responsible management of sexual activity are rare and ubiquitously inadequate. In this essay, I argue that ethically and legally, care providers should only interfere in residents' sexual activity in restricted ways and for limited reasons. I utilize Joel Feinberg's philosophical works, which address the limits of power that can be legitimately exercised by society over the individual, to derive an ethical framework for determining how and when care providers should intervene in residents' sexual activity.

31**Title:**

Training in sexuality and relationships: An Australian model

Authors:

Chivers, J.

Mathieson, S.

Source:

Sexuality & Disability, Vol18, Issue 1, p.73-80

Abstract:

This article examines some of the dominant discourses which impacted on the process of developing a curriculum for staff working with people with an intellectual disability in the area of relationships and sexuality within a medium sized Government bureaucracy providing services to people with a disability. Constructions of sexuality as being solely a biological function, sex as dangerous and sex as penetration are challenged as are some of the dominant discourses of learning.

32**Title:**

Staff values regarding the sexual expression of women with developmental disabilities

Authors:

Christian, L.
Stinson, J.
Dotson, L.A.

Source:

Sexuality & Disability, 2001, Vol.19, Issue 4, p.283-291

Abstract:

Women with developmental disabilities face a myriad of barriers that prevent sexual expression. These include, but are not limited to, inadequate access to health care, limited choices regarding reproductive issues, and lack of sex education. The values and beliefs of support staff also represent potential barriers. A survey was conducted to determine the attitudes and knowledge of support staff at an agency serving individuals with developmental disabilities. Findings indicated that a majority of staff felt comfortable supporting women in expressing their sexuality, but few were trained to do so. Results also suggested that staff were guided more by their personal views than by agency policy.

33**Title:**

Attitudes towards sexuality: A pilot study in Ireland

Authors:

Drummond, E.

Source:

Learning Disability Practice, 2006, Vol 9, Issue 4, p.28-34

Abstract:

The article presents information related to a study designed to ascertain what a group of caregivers and parents thought about issues relating to sexuality in people with learning

disabilities. The study reveals that people with intellectual disability have the same needs and desires in terms of their sexuality as everyone else in society. It also reveals that many primary caregivers believe that people with intellectual disability lack the capacity to make informed decisions about their sexuality or about having more intimate sexual relationships.

34

Title:

Enhancing capacity to make sexuality-related decisions in people with an intellectual disability

Authors:

Dukes, E.

McGuire, B. E.

Source:

Journal of intellectual disability research, 2009, Vol. 53, Issue 8, p.727-734

Abstract:

AIM: The aim of the study was to apply an intervention to the area of sexual knowledge in order to determine if capacity to make sexuality-related decisions could be improved. **METHOD:** The study adopted a single subject design using multiple baseline method with four adults with a moderate intellectual disability. The intervention consisted of individually tailored sex education adapted from Living Your Life (Bustard 2003). Treatment was offered to each participant twice weekly for a 10-week period on a one-to-one basis. The Sexual Consent and Education Assessment (SCEA, Kennedy 1993) was used for measurement purposes. The SCEA K-Scale (knowledge) and the S-Scale (safety practices) were administered weekly throughout the baseline, treatment and post-treatment phases of the study. Staff concerns were also assessed using the SCEA Inappropriate Sexual Behaviour Scale. **RESULTS:** All four participants improved their decision-making capacity in all targeted areas as measured by improvements in K-Scale and S-Scale scores. Staff concerns were not increased as indicated by results on the Inappropriate Sexual Behaviour Scale. Six-month follow-up data for three of the participants showed maintenance of scores on the S-Scale and some decay in scores on the K-Scale from post-intervention performance. **CONCLUSION:** The results demonstrate that tailored sexuality education can improve capacity to make sexuality-related decisions.

35

Title:

Sexuality and personal relationships for people with an intellectual disability. Part II: staff and family carer perspectives

Authors:

Evans, D. S.

McGuire, B.E.

Healy, E.
Carley, S.N.

Source:

Journal of intellectual disability research, 2009, Vol. 53, Issue 11, p.913-921

Abstract:

BACKGROUND: Recent ideological shifts in service provision promote appropriate sexual expression for people with an intellectual disability (ID), although there is little evidence that such advances in ideology are matched by current service provision. Part II of the current two-part study assessed the attitudes of staff and family carers to the sexuality of people with an ID. **METHOD:** A questionnaire survey which included case scenarios was carried out with family (n = 155) and staff carers (n = 153) of people with an ID in the west of Ireland. **RESULTS:** In general, staff carers were more inclined than family carers to openly discuss issues of sexuality with service users, and to suggest environmental, rather than service-user characteristics, as impediments to such discussions. Attitudinal differences emerged with significant differences between staff and family carers and between younger and older carers. Staff carers were more likely to support service-user engagement in intimate and non-intimate relationships whereas the majority of family carers (80%) showed a preference for low levels of intimacy in service-user relationships. **CONCLUSION:** When compared with the attitudes of family carers towards the sexuality of people with ID, the attitudes of staff carers more closely match those promoted by ideological developments. However, differences in attitudes between carer groups may lead to inconsistent approaches to the management of sexuality. As a consequence, we conclude that there is continued need to provide staff and family carers with opportunities for dialogue and an ongoing need for training in the area of sexuality.

36

Title:

Sexuality training, education and therapy in the health care environment: Taboo, avoidance, discomfort or ignorance?

Authors:

Gill, K.M.
Hough, S.

Source:

Sexuality & Disability, 2007, Vol. 25, Issue 2, p.73-76

Abstract:

Multiple sources of resistance are present in the healthcare environment to comprehensive assessment and intervention efforts in regard to sexuality. The authors survey both the diversity of needs and values presented by consumers, and encourage providers to equip themselves educationally, emotionally and ethically so that they can deliver relevant, holistic services to consumers.

37

Title:

"Now I'd like to sleep with Rachel": Researching sexuality support in a service agency group home

Authors:

Hamilton, C

Source:

Disability & Society, 2009, Vol. 24, Issue 3, p.303-315

Abstract:

Many intellectually disabled people living in agency services require significant forms of support to live safe and satisfying sexual lives. Research reveals that despite support personnel working in service systems now holding largely positive attitudes towards sexuality assistance, proactive practice is rarely initiated. This article probes what might lie within this attitude/assistance gap. This investigation reveals a complex picture of practices that rely on intellectually disabled people showing conformation to a 'couple doing normal' ideal, so as to be judged capable of being supported. It examines how wider social locations of meaning related to 'intellectual disability' and 'sexuality' might substantiate these judgement calls. The degree to which it can be said that worker's own attitudes and values underpin their reluctance to provide support is then explored. Finally, why researchers and practitioners might need to reappraise the complex interactions that shape worker's practice in this area is discussed.

38

Title:

Sexuality and personal relationships for people with an intellectual disability. Part 1: service-user perspectives

Authors:

Healy, E.
McGuire, B.E.
Evans, D.S.
Carley, S.N.

Source:

Journal of intellectual disability research, 2009, Vol. 53, Issue 11, p.905-912

Abstract:

BACKGROUND: Despite a recent ideological shift towards the recognition of sexual autonomy for people with an intellectual disability (ID), there are continuing social and cultural barriers to sexual expression. Part I of the current two-part study assessed the sexual knowledge, experiences and aspirations of service users through focus groups and also examined their perceptions of impediments to achieving sexual autonomy. **METHOD:** Thirty-

two participants (20 male, 12 female) attending an ID service participated in focus groups delineated by gender and age group (13-17 years; 18-30 years; 31+ years). RESULTS: Analysis of the focus groups showed that service users, especially those over the age of 18 years, had an understanding of their sexual rights but also identified a number of social and cultural barriers that they felt prevent them from achieving sexual autonomy. Those under the age of 18 years had only rudimentary knowledge of sexuality issues, for example pregnancy and sexual anatomy, but aspired to relationships and marriage similar to those over the age of 18 years. Family and staff attitudes appeared to be very influential in the views of respondents. All service users had received some form of sex education, although the benefits of such education appeared most enduring for those over 18 years. CONCLUSION: Service users had an understanding of their sexual rights and the social and environmental barriers that prevent them from fulfilling their rights. The provision of sex education training and promotion of positive attitudes towards appropriate sexual expression is critical to the realization of sexual autonomy for people with an ID.

39

Title:

Level of knowledge about sexuality of people with mental disabilities

Authors:

Leutar, Z.

Mihokovic, M

Source:

Sexuality & Disability, 2007, Vol 25, Issue 3, p.93-109

Abstract:

The paper examines the level of knowledge about sexuality of people with mental disabilities. The research also presents differences resulting from sex and the level of mental retardation. The sample included 24 persons with mental disabilities, who the author of this paper knew very well due to the time spent with them during a summer camp at a club in Vjeverica. Data was collected through direct interviews. Two types of questionnaires on sexuality of people with mental disabilities were used during these interviews. Results indicate that the level of knowledge about sexuality is not sufficient. Specifically low knowledge was shown in the area of the protection of sexual health such as sexually transmitted diseases and methods of protection. A relatively good level of knowledge was shown by the respondents in distinguishing between appropriate and inappropriate ways of sexual behaviour and social understanding of certain situational norms. Differences regarding sex and the level of disability were found. The results indicate the need for additional education on sexuality of both people with mental disabilities and their parents, along with support. Despite the fact that the research was conducted on a small occasional sample, it indicates that further research on this subject is needed.

40

Title:

“May I?” About sexuality and love in the new generation with intellectual disabilities

Authors:

Lofgren-Martenson, L.

Source:

Sexuality and Disability, 2004, Vol 22, Issue 3, p.197-207

Abstract:

The aim of the article is to identify, describe and understand the opportunities and hindrances for young people with intellectual disabilities (ID) in forming relationships and expressing sexuality and love. The methods are participant observations at dances geared towards youths with ID and qualitative interviews with youngsters, staff members and parents. The results show a big variation of sexual conduct, where intercourse seems to be quite unusual. The study also shows that staff and parents feel responsibility for the youngsters' sexuality and often act disciplinary as 'new institutional walls', while the youngsters develop different social strategies to cope with the surroundings. It seems clear that staffs need more guidance and education about sexuality and disability in their social interaction with a new generation of people with ID.

41

Title:

Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability

Authors:

McConkey, R.
Ryan, D.

Source:

Journal of Intellectual Disability Research, 2001, Vol 45, Issue 1, p.83-87

Abstract:

Previous studies have focused on staff attitudes to sexuality rather than their experience of dealing with sexual incidents. A self-completion questionnaire was devised in which seven scenarios were proposed relating to client sexuality (e.g. public masturbation and accusation of sexual abuse). Staff noted whether or not they had encountered this type of incident, and if so, how confident they felt (or would feel) in dealing with it, and whether or not they would enlist the help of colleagues. Questionnaires were sent to all statutory, voluntary and private service providers (including schools) within one community health and social services trust area in Northern Ireland, and 150 staff responded. Around two-thirds of staff reported having dealt with at least one of the seven incidents listed. Staff with previous experience of the incident listed, felt that they could deal with it more confidently in future, as did staff working in

residential services rather than day services. The latter group of staff were more likely to enlist the help of colleagues than were residential staff. Nearly 50% of staff identified more training and clear policy guidelines as the two means of increasing their confidence in dealing with issues of client sexuality. These results highlight the need for staff training that spans agencies and results in common approaches to client sexuality. Suggestions for further research are noted.

42

Title:

The myth of asexuality: A survey of social and empirical evidence

Authors:

Milligan, M.S.

Neufeldt, A.H.

Source:

Sexuality and Disability, 2001, Vol 7, Issue 2, p.195-196

Abstract:

Self-advocacy groups and individual authors have increasingly expressed concern that persons with disabilities (PWD) are sexually disenfranchised by a society that inaccurately perceives them as asexual beings. The purpose of this paper is to evaluate the social and empirical foundations for the contention that PWD are indeed viewed as asexual and examine whether there is cause for ongoing concern and intervention. This review includes a consideration of the implications for both clinical practice and future research as well. It is concluded that despite significant gains in our biological and psychosocial understanding of sexuality in the context of disability, there remains much to be accomplished to effect needed change in the areas of professional practice, research, societal attitudes, and most importantly, in the lives of PWD.

43

Title:

Attitudes toward acceptable socio-sexual behaviours for persons with mental retardation: Implications for normalization and community integration

Authors:

Oliver, M.N.

Anthony, A.

Leimkuhl, T.T.

Skillman, G.D.

Source:

Education and Training in Mental Retardation and Developmental Disabilities, 2002, Vol 37, Issue 2, p.193-201

Abstract:

This study evaluated attitudinal discrepancies among non-disabled community members regarding the acceptability of socio-sexual expression for persons with and without mental retardation. Overall, discrepancies between adults with and without mental retardation primarily concern attitudes toward marriage and parenthood. Older adults, both non-disabled and disabled, were more conservative in their attitudes toward socio-sexual behavior.

44**Title:**

Capacity of adults with intellectual disabilities to consent to sexual relationships

Authors:

Murphy, G.H.

O Callaghan, A.

Source:

Psychological Medicine, 2004, Vol 34, Issue 7, p.1347-1357

Abstract:

Background. For people with intellectual disabilities there is a difficult balance to be struck between empowering people to claim their sexual rights and protecting them from abuse. Hypothetically, services should be guided by whether a particular person with intellectual disabilities has the capacity to consent to sexual relationships. However, there has been little agreement on how to define such capacity. This study examines the issue of capacity to consent to sexual relationships using a functional approach.

Method. Adults with intellectual disabilities ($n=60$) and young people presumed in law able to consent ($n=60$) were assessed for their sexual knowledge and vulnerability to abuse.

Results. Adults with intellectual disabilities were significantly less knowledgeable about almost all aspects of sex and appeared significantly more vulnerable to abuse, having difficulty at times distinguishing abusive from consenting relationships. Nevertheless, some adults with intellectual disabilities scored highly on all measures, especially if they had relatively high IQs and had had sex education.

Conclusions. The reasons for the poorer knowledge and increased vulnerability of people with intellectual disabilities are discussed and it is recommended that they should have on-going access to sex education. Implications of the findings for definitions of capacity to consent to sexual relationships are considered.

45

Title:

Sexual health care in persons with intellectual disabilities

Authors:

Servais, L.

Source:

Mental Retardation and Developmental Disabilities Research Reviews, 2006, Vol 12, Issue 1, p.48-56

Abstract:

In the past, preventive health concerning sexuality of people with intellectual disabilities was addressed through surgical sterilization as part of nationwide eugenic programs in many countries. For more than 30 years now, it has come progressively to light in the scientific literature that, besides major ethical and legal problems, these programs also failed to assess many of the individual's needs in sexual health. The fact that an increasing number of people with intellectual disabilities live in the community rather than in institutions has heightened public awareness that these individuals have sexual expectancies, desires, and needs that must be supported through both education and health services. The emergence of AIDS, including descriptions of cases among people with intellectual disabilities, has further demonstrated that surgical sterilization cannot be considered a global option to achieve preventive sexual health. The aim of this paper is to review scientific studies that have assessed the expectancies and support needs of persons with intellectual disabilities in terms of sexual health. These needs vary widely from one individual to another, according to life milieu, level of disability, and potential comorbidity. From this review, it appears that hygiene management, global gynecological care, and prevention of unplanned pregnancy, sexually transmitted diseases, and abuse have been frequently identified as areas in which the presence of intellectual disability dictates specific support needs. Different approaches that have been evaluated to address these issues will also be discussed.

46

Title:

Current issues in sexuality and the disability movement

Authors:

Waxman Fiduccia, B.

Source:

Sexuality & Disability, 2000, Vol 18, Issue 3, p.88-95

Abstract:

The theme of this plenary speech is an account of the lessons learned by the author's putting her efforts into sexual and reproductive rights policy in the lives of disabled people. She offers some strategies to use disability rights law to correct inequities such as: marriage penalties,

child custody, sex education, and the right to privacy. These examples can provide the disability community with a framework with which to infuse sexual and reproductive rights into the larger disability rights agenda.

47

Title:

Sex, sexuality and relationships for young people with learning disabilities

Authors:

Wheatley, H.

Source:

Current Paediatrics, 2005, Vol 15, Issue 3, p.195-199

Abstract:

Learning about sex, sexuality and relationships is a significant part of growing up for all young people. Access to good quality information and advice on sexual health, relationships, sexuality and related issues is an important part of this learning. Children and young people with learning disabilities are less likely than others to have access to this. This is common and occurs for a range of reasons including a lack of appropriate resources, professionals not knowing where to find information and societal attitudes to disability and sexuality.

48

Title:

Sex education for students with disabilities: An evaluation guide

Authors:

Wolfe, P.S.

Blanchett, W.J.

Source:

Teaching Exceptional Children, 2003, Vol 36, Issue 1, p.46-51

Abstract:

This article discusses the development of the Sexuality Education Protocol and a set of questions designed to assist educators in reviewing sexuality curricula for their students with disabilities. The questions address whether the curriculum reflects the values of students' families and if it is appropriate for students' ages and ability level.

49

Title:

The influence of personal values on issues of sexuality and disability

Authors:

Wolfe, P.S.

Source:

Sexuality & Disability, 1997, Vol 15, Issue 2, p.69-90

Abstract:

Issues of sexuality and disability have traditionally been value-laden areas. Using quantitative and qualitative methodology, attitudes toward sexual practices and relationships of individuals with disabilities were examined. Responses of teachers and administrators were differentiated on the variable of level of disability (moderate and severe disabilities). Results of the study indicated that teachers and administrators differentiated between individuals with moderate and severe disabilities on issues of sexual practices, types of relationships deemed appropriate, and the right to have children. The potential effects of trainer values on sexuality issues of individuals with disabilities are discussed.

Quality of Life and Community Integration/Socialization

The following journal articles outline themes that impact on the capacity of people with learning disabilities to develop friendships and relationships such as: lived experiences; social inclusion and exclusion; community integration and participation; quality of life; family networks; parents' perception; quality of choice; economic restraints.

1

Title:

How we live: participatory research with six people with learning difficulties

Author:

Richardson M.

Source:

[Journal of Advanced Nursing](#), Volume 32, Number 6, December 2000 , pp. 1383-1395(13)

Keywords:

[learning disabilities](#); [participatory research](#); [social model](#); [nursing](#); [power](#); [community living](#)

Abstract:

Drawing from the Social Model of disability, six people with learning difficulties participated over 18 months in researching their own lived experiences. The method involved weekly group discussions supplemented by participant observation. The study's value stems from in-depth inquiry, which included the participants in the data collection, analysis, dissemination and consequences that they found meaningful. The participants lived in nurse managed community homes. They described how they had faced social and economic exclusion, for example, concerning marriage, child rearing and decently paid employment. With the assistance of nursing staff, the participants had overcome many other social barriers and were enjoying a wide range of activities and choices. Consequently, the participants lived varied lives which they described as interesting and worthwhile. Contemporary models of nursing had successfully directed nursing staff to support 'ordinary living'. However, some disabling assumptions were evident within contemporary nursing. Hence, models of nursing and service delivery were helping both to create lifestyles that the participants valued, whilst simultaneously contributing to their disempowerment.

2

Title:

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

Authors:

Suzanne Abbott

Roy Mcconkey

Source:

Journal of Intellectual Disabilities, Vol. 10, No. 3, 275-287 (2006)

Key Words:

intellectual disability • learning disability • residential accommodation • social inclusion • supported living

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.

3**Title:**

Social exclusion and young disabled people with high levels of support needs

Author:

Jenny Morris

Source:

Critical Social Policy, Vol. 21, No. 2, 161-183 (2001)

Keywords:

Dependency • disability • human rights • social inclusion • welfare

Abstract:

There are significant differences between the concept of social exclusion adopted by the mainstream policy agenda and what social exclusion means to young disabled people, particularly those with high levels of support needs. Currently, the experiences and concerns of this group are not being heard in the arenas where policies are developed. The silence about their experiences masks an assumption that, to have high levels of support needs, means dependency and exclusion are inevitable. It is unlikely, therefore, that current initiatives to tackle social exclusion will address the experiences of these young disabled people as they grow into adulthood. In contrast, a human rights agenda offers greater opportunities to challenge the way young disabled people with high levels of support needs are 'shut out' from society.

4

Title:

Embracing quality of life in times of spending restraint

Author:

Ivan Brown

Source:

[Journal of Intellectual and Developmental Disability](#) 1999, Vol. 24, No. 4, Pages 299-308

Abstract:

Quality of life has emerged as an important trend in recent years in the field of intellectual disabilities. At the same time, spending restraints in developed countries have placed strains on services. This paper explores the relationship between these two seemingly opposing trends. Quality of life is seen as the goal toward which we strive, and also the degree to which we have achieved that goal. It is proposed that we “reframe” to quality of life. Reframing to quality of life is based on the principle that every person with intellectual disabilities has the right to lead a life of quality, and presents us with three service goals, namely, to maintain or improve 1) good conditions of life, 2) each person's happiness, and 3) the ways people have of becoming enabled to lead fulfilling lives of their own choosing. It is suggested that we need to reframe to quality of life in times of spending restraint to ensure adequate service standards, to use our resources in ways that are most beneficial to people with intellectual disabilities, and to save resources that are not wanted. It is concluded that there can be a mutually beneficial relationship between quality of life and spending restraint, if approached wisely. Containing service costs can be a positive force if used to help us focus our costs on things that make people's lives better. Improving people's quality of life can lead us to identify the most important places to use our resources, and ways to use them to help people have better lives.

5

Title:

Personal lifestyle preferences of people with an intellectual disability

Authors:

Robert Neumayer

Michael Bleasdale

Source:

[Journal of Intellectual and Developmental Disability](#) 1996, Vol. 21, No. 2, Pages 91-114

Abstract:

There is a great deal of input into the programming of lifestyles for people with an intellectual disability. Service providers, academics, practitioners, policy makers and other professionals all have their personal values, beliefs and views on how services should be delivered for people with an intellectual disability. This research was an attempt to understand the preferences, viewpoints and values people with intellectual disability may have regarding

certain aspects of their lives, and how their perceptions relate to service policy and delivery. Semistructured interviews were conducted with 30 people with an intellectual disability. The intent of the qualitative interviews was to obtain the values, views and preferences of the participants in regard to four major areas of their lives, being divided into home, work, leisure and relationships. Results of the interviews showed that some of the lifestyle conditions and preferences of people with an intellectual disability were not being fully met or addressed in relation to the principles and values of some programming philosophies adopted by various professional service provider organisations.

6

Title:

How central and connected am I in my family?: Family-based social capital of individuals with intellectual disability

Authors:

E.D. Widmer
N. Kempf-Constantin
C. Robert-Tissot
F. Lanzi
G. Galli Carminati

Source:

[Research in Developmental Disabilities](#) *Volume 29, Issue 2*, March-April 2008, Pages 176-187

Keywords: Adult; Intellectual disability; Psychiatric disorders; Social capital; Family relationships; Family network method (FNM)

Abstract

Using social network methods, this article explores the ways in which individuals with intellectual disability (ID) perceive their family contexts and the social capital that they provide. Based on a subsample of 24 individuals with ID, a subsample of 24 individuals with ID and psychiatric disorders, and a control sample of 24 pre-graduate and postgraduate students matched to the clinical respondents for age and sex, we found that family networks of clinical individuals are distinct both in terms of composition and in terms of social capital made available to them by their family ties. Individuals with ID perceive themselves as less central in their own family; their family networks are perceived as less dense, less centralized, and more disconnected. Individuals with intellectual disabilities and psychiatric disorders have less family-based social capital than individuals with intellectual disabilities only. The composition of their family is also distinct as spouses or partners and children are missing. We discuss the importance of those findings for research on family relationships of individuals with ID.

7

Title:

Increasing community integration and inclusion for people with intellectual disabilities

Authors:

Shannon H. Thorn
Amanda Pittman
Rachel E. Myers
Connie Slaughter

Source:

[Research in Developmental Disabilities](#) [Volume 30, Issue 5](#), September-October 2009, Pages 891-901

Keywords:

Community integrated activities; Community presence; Community participation; Therapeutic milieu; Community integration; Community inclusion; Intellectual disability

Abstract:

Historically residential facilities for individuals with intellectual disabilities have served the role of segregation and congregation with no real focus on integration into the community. More recently the focus has been to get people out of residential institutions and into community-based living settings. This work examines an approach to changing the systems and culture at a large residential facility to create higher rates of transitions to community-based living settings. A multi-phased systematic implementation approach is discussed in which each successive phase builds upon the previous phase. This approach creates opportunities for community integrated activities and then utilizes these community contexts as functional learning opportunities. Results are evaluated in the areas of community presence, community participation, community integration and community inclusion. Data indicate significant increases in each of these areas based on changing the facility focus, simplifying the intrusive accountability systems, aligning resources and teaching staff how to utilize support plans more efficiently to teach skills in functionally appropriate community integrated activities.

8

Title:

Community involvement and socialization among individuals with mental retardation

Authors:

Amy L. Kampert
Anthony J. Goreczny

Source:

[Research in Developmental Disabilities](#) [Volume 28, Issue 3](#), May-June 2007, Pages 278-286

Keywords:

Mental retardation; Quality of life; Socialization; Community involvement; Self-determination

Abstract

Mental retardation, a condition characterized by significantly lower than average intellectual ability and adaptive behavior deficits, currently affects between 2% and 3% of the population. Individuals with mental retardation experience many difficulties throughout their lives, with one such difficulty being that they have few opportunities for community involvement and often have few social relationships. To determine if increased community involvement and increased socialization are among the most common desires expressed by individuals with mental retardation, we conducted a study examining pre-existing data of 1348 individuals. The study focused on specific desires expressed by individuals with mental retardation—including, but not limited to, increased community involvement and increased socialization. Although these individuals expressed a wide variety of desires, they expressed a desire for increased community involvement most frequently. Individuals also frequently expressed a desire for increased socialization, change of residence, work-related changes, increased personal belongings, and increased personal activities. We discuss the importance of community involvement and socialization, the link between the two, interactions that could potentially exist among other expressed desires, and ways of increasing community involvement while addressing other desires that individuals with mental retardation expressed.

9**Title:**

Breaking Out of a Distinct Social Space: Reflections on Supporting Community Participation for People with Severe and Profound Intellectual Disability.

Authors:

[Clement, Tim](#)

[Bigby, Christine](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); May2009, Vol. 22 Issue 3, p264-275

Abstract:

Background Typically people with intellectual disability have small, highly restricted social networks characterized by interactions with other people with intellectual disabilities, family members, and paid workers. The goal of 'inclusion' has been central to policies that have shaped services over the past 30 years. It is an ill defined concept with disagreement about its meaning, the problems it seeks to overcome and how it should be realized. Method Ethnographic and action research methods were used to support and collect data on the implementation of a programme, known as the Community Inclusion Framework, in a group home for five adults with severe intellectual disabilities in Victoria, Australia. Results and Conclusions A pattern of service delivery based on community presence rather than

participation evolved and endured over 16 months. The findings show that most staff attached a different meaning to inclusion from that proposed in the Community Inclusion Framework, disagreed with the proposed meaning or felt these residents were too different for it to be meaningful. This suggests that priority will only be accorded to activities that lead to inclusion if staff are convinced of the veracity of this and given strong and consistent direction and support.

10

Title:

Quality of life for young adults with severe intellectual disability: mothers' thoughts and reflections.

Authors:

[McIntyne, Laura Lee](#)

[Kraemer, Bonnie R.](#)

[Blacher, Jan](#)

[Simmerman, Susan](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Jun2004, Vol. 29 Issue 2, p131-146

Abstract:

Thirty mothers of transition-aged young adults (18-24 years) with severe intellectual disability were interviewed regarding their son or daughter's quality of life. All mothers completed the standardised Quality of Life Questionnaire and responded to several open-ended questions to further delineate quality of life for their child. Mothers were asked to describe quality of life for their young adult child and to evaluate their child's quality of life. Most mothers (73%) mentioned recreation, activities, and hobbies as important components of their young adult child's quality of life. Other common responses included having their son or daughter's basic needs met (53%), having their son or daughter belong to a social network (40%), and having their son or daughter be happy or content (37%). Less common responses included work (7%) for their son or daughter, communication capabilities (10%), health (13%), and consistency (17%) in their son or daughter's life. Mothers' visions for their sons and daughters, environmental and social supports for family members, and family quality of life issues are explored. Discussion focuses on contributions of this study to the burgeoning quality of life literature.

11

Title:

Reflections on social integration for people with intellectual disability: Does interdependence have a role?

Author:

[Carnaby, Steven](#)

Source:

[Journal of Intellectual & Developmental Disability](#); Sep98, Vol. 23 Issue 3, p219

Abstract:

Examines issues concerning the social integration of people with intellectual disability into the community, while considering the concept of independence in theory and practice. Possible problems which will be experienced as a result of this measure; Information on the social life of persons with disabilities; Presentation of a model of independence of persons with intellectual disabilities.

12

Title:

Translating quality of life into service action: use of personal outcome measures in the Republic of Ireland.

Authors:

[McCormack, Bob](#)

[Farrell, Margaret](#)

Source:

[British Journal of Learning Disabilities](#); Dec2009, Vol. 37 Issue 4, p300-307

Abstract:

Accessible summary • Two-hundred-and-fifty-six people with intellectual disabilities in Ireland were asked about their lives. What is important to them? Do they get the help they need from staff? • We found that very few people exercised their rights. Very few people choose the work they do. Very few people live, work and have fun in ordinary places. People said they want to choose their own goals. • People want to choose the work they do. People want to take part in their own community. People with severe communication difficulties can be supported to say what is important to them. • This report tells staff about things people want help with. A growing consensus exists regarding Quality of Life measures and their use to support person-centred planning and organisational development. A survey designed to assess current Quality of Life of 256 adults with intellectual disabilities was conducted across a range of 22 service providers in the Republic of Ireland using Personal Outcome Measures (Council on Quality & Leadership 2000). The aim of the survey was to gauge whether

organisational processes are in place to support the achievement of personal outcomes of people with intellectual disabilities and to identify people's unmet priority outcomes. Results reveal that, on average, participants had less than half their personal outcomes fully present at the time of the survey. However, the number of personal outcomes present varied with the severity of the disability. Findings highlight the need to develop more integrated services, to maintain people in their local communities rather than remove them into special settings and develop more reciprocal relationships with communities. The results provide a baseline for Irish services against which to benchmark further progress. Newer models of service such as individualised service design, supported employment and supported living offer this potential.

13

Title:

Social inclusion, social networks and ethnicity: the development of the Social Inclusion Interview Schedule for young people with learning disabilities.

Authors:

[Pawson, Nicole](#)
[Raghavan, Raghu](#)
[Small, Neil](#)
[Craig, Sue](#)
[Spencer, Marion](#)

Source:

[British Journal of Learning Disabilities](#); Mar2005, Vol. 33 Issue 1, p15-22

Abstract:

The paper reports on the development and piloting of the Social Inclusion Interview Schedule (SIIS). This uses pictures to explore social networks and feelings of social inclusion. The background, conceptual framework and development of the interview schedule are discussed and interim findings are highlighted. The challenge of not just identifying the constituents of a social network but also attributing some measure of intensity to the relationships and activities identified will be considered. The study site is Bradford in the UK and the study population are young people with learning disabilities and their carers. There is a specific focus on people from the South Asian community resident in the city.

14

Title:

Community participation of people with an intellectual disability: a review of empirical findings.

Authors:

Verdonschot, M. M. L.

De Witte, L.P.

Reichrath, E.

Buntinx, W. H. E.

Curfs, L. M. G.

Source:

Journal of Intellectual Disability Research; 53(4):303-318

Keywords:

Social life; mental retardation; community involvement; sheltered workshops; social networks; professional services; interpersonal relationship; research methodology; employment; disabilities; comparative analysis.

Abstract:

Study design: A systematic review of the literature. Objectives: To investigate community participation of persons with an intellectual disability (ID) as reported in empirical research studies. Method: A systematic literature search was conducted for the period of 1996-2006 on PubMed, CINAHL and PSYCINFO. Search terms were derived from the International Classification of Functioning, Disability and Health. Three investigators assessed the relevance of the initially identified studies using predefined content and methodological selection criteria. Included domains of community participation were: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, civic and social life. Results: Of 2936 initial hits, 23 quantitative studies eventually met the selection criteria and were included in the study. Only two studies are based on a theoretical framework. Research instruments were various and were most often "ad hoc" and not validated. The average number of persons in the social network of people with ID appears to be 3.1, one of them usually being a professional service staff member. People with ID are 3-4 times less employed than non-disabled peers; they are less likely to be employed competitively and are more likely to work in sheltered workshops or in segregated settings than those with other disabilities. People with ID are less likely to be involved in community groups, and leisure activities are mostly solitary and passive in nature. Most of the people with ID had been accompanied in an activity by training/therapeutic staff. Conclusion: It can be concluded that on the basis of empirical evidence, within the time frame of this literature search, little is known about community participation of people with ID. Many researchers did not clearly define community participation and were concerned with limited areas of community participation; research is seldom based on a theoretical framework. Most studies focus on people with mild ID, and there are few reports of the subjects' sample. However, one conclusion can consistently be drawn from the review: people with ID living in community settings participate more than people living in a segregated setting, but their participation level is still much lower than non-disabled and other disability groups.

15

Title:

Active Negotiation: Mothers with Intellectual Disabilities Creating Their Social Support Networks.

Authors:

[Mayes, Rachel](#)

[Llewellyn, Gwynnyth](#)

[McConnell, David](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); Jul2008, Vol. 21 Issue 4, p341-350

Abstract:

Background The support networks of mothers with intellectual disabilities play an important role in caring for children. Understanding the support provided by the network is therefore vital in understanding the capacity of a mother to care for her child. Nevertheless, how these important networks came into existence is yet to be explored. Furthermore, the other functions support networks may serve are poorly understood, apart from assistance with child care. **Materials and Methods** This paper reports some findings from a phenomenological study into becoming a mother for women with intellectual disabilities. Semi-structured interviews were conducted with 17 expectant mothers with intellectual disabilities. One part of the phenomenon, 'negotiating a support network for me and my baby' is described. **Results** Expectant mothers strategically negotiated support networks prior to the baby's birth. They sought practical assistance for the tasks of mothering from those who acknowledged them as the most important person in their baby's life. **Conclusions** The findings have implications for the practitioners engaged in supporting mothers and their children, particularly those who are a part of the lives of women with intellectual disabilities and their children due to a court order.

16

Title:

Breaking Out of a Distinct Social Space: Reflections on Supporting Community Participation for People with Severe and Profound Intellectual Disability.

Authors:

[Clement, Tim](#)

[Bigby, Christine](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); May2009, Vol. 22 Issue 3, p264-275

Abstract:

Background Typically people with intellectual disability have small, highly restricted social networks characterized by interactions with other people with intellectual disabilities, family members, and paid workers. The goal of 'inclusion' has been central to policies that have

shaped services over the past 30 years. It is an ill defined concept with disagreement about its meaning, the problems it seeks to overcome and how it should be realized. Method Ethnographic and action research methods were used to support and collect data on the implementation of a programme, known as the Community Inclusion Framework, in a group home for five adults with severe intellectual disabilities in Victoria, Australia. Results and Conclusions A pattern of service delivery based on community presence rather than participation evolved and endured over 16 months. The findings show that most staff attached a different meaning to inclusion from that proposed in the Community Inclusion Framework, disagreed with the proposed meaning or felt these residents were too different for it to be meaningful. This suggests that priority will only be accorded to activities that lead to inclusion if staff are convinced of the veracity of this and given strong and consistent direction and support.

17

Title:

Outcomes Important to People With Intellectual Disabilities.

Authors:

[Miller, Emma](#)

[Cooper, Sally-Ann](#)

[Cook, Ailsa](#)

[Petch, Alison](#)

Source:

[Journal of Policy & Practice in Intellectual Disabilities](#); Sep2008, Vol. 5 Issue 3, p150-158

Abstract:

An emphasis on the outcomes of health and social care services has become increasingly apparent within public policy in the United Kingdom. Alongside this, working in partnership has been a key theme, despite a relatively underdeveloped evidence base. Of central importance, however, must be whether directives toward partnership working are delivering improved outcomes, and in particular, the outcomes that are valued by service users. The authors describe a project that sought to identify the outcomes important to people with intellectual disabilities, and where possible, whether partnerships delivered these outcomes. The research was primarily based on interviews with service users and carers, and involved people with intellectual disabilities as both researchers and research subjects. The project categorized key outcomes in two categories (quality of life and process) and identified ways in which health and social care partnerships can deliver the outcomes service users want. If agencies are to deliver good outcomes to users, as increasingly emphasized in policy, this focus should accurately reflect the outcomes that users themselves define as important.

18

Title:

Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability.

Authors:

[Lippold, T.](#)

[Burns, J.](#)

Source:

[Journal of Intellectual Disability Research](#); May2009, Vol. 53 Issue 5, p463-473

Abstract:

Background Social support has been identified as a major protective factor in preventing mental health problems and also as a major contributor to quality of life. People with intellectual disabilities (ID) have been identified as having limited social support structures. Interventions have been focused on promoting their social presence and integration. However, previous studies have shown that this does not always lead to the formation of social relationships. To date few studies have looked at how having an ID leads to impoverished social networks. This study aimed to do this by contrasting the social relationships of people with physical disabilities (PD) and people with ID. Methods Two groups of participants were recruited; 30 people with mild ID and 17 people with PD. Social and functional support networks were assessed, in addition to life experiences. Between and within group differences were then explored statistically. Results Adults with ID had more restricted social networks than PD, despite being involved in more activities. Social support for adults with ID was mainly provided by family and carers and few relationships with non-disabled people were identified. In contrast adults with PD had larger social networks than had been reported in the mainstream literature and had a balance of relationships with disabled and non-disabled people. Conclusions The results suggest that there are additional processes attached to having an ID, which lead to continued impoverished lifestyles. The findings also endorse other work that suggests being physically integrated and engaged in a wide range of activities does not guarantee good social and emotional support.

19

Title:

Predictors of life satisfaction in individuals with intellectual disabilities.

Authors:

[Miller, S. M.](#)

[Chan, F.](#)

Source:

[Journal of Intellectual Disability Research](#); Dec2008, Vol. 52 Issue 12, p1039-1047

Abstract:

Background The purpose of this study was to examine factors that predict life satisfaction in individuals with intellectual disabilities (ID). Two groups of variables were studied: life skills (interpersonal, instrumental and leisure) and higher-order predictors (social support, self-determination and productivity). Method Fifty-six participants with ID were recruited from two community agencies in Wisconsin. Data were collected using both a self-report inventory, which was administered to each individual in an interview format, and a behaviour rating scale, which was completed by a knowledgeable staff member. Hierarchical regression was used to analyse the data. Results Both sets of variables were found to explain a significant amount of the variance in life satisfaction. Within the sets, social support and interpersonal skills were individually significantly associated with life satisfaction. Conclusion It is hoped that the results of this study will help support providers organise services in such a way that maximises the life satisfaction of the consumers that they serve.

20**Title:**

Starting a New Job: The Social and Emotional Experience of People with Intellectual Disabilities.

Authors:

[Jahoda, Andrew](#)

[Banks, Pauline](#)

[Dagnan, Dave](#)

[Kemp, Jeremy](#)

[Kerr, Wendy](#)

[Williams, Victoria](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); Sep2009, Vol. 22 Issue 5, p421-425

Abstract:

Background Employment is viewed by policy makers as both a human right and as a means of changing the marginalized status of people with intellectual disabilities, with important social and emotional benefits. However, there has been little longitudinal research examining the experience of people with intellectual disabilities in the workplace. Methods Thirty-five individuals with mild to borderline intellectual disabilities participated in this study. They were recruited from supported employment agencies in Scotland. A longitudinal approach was adopted, with the participants being interviewed around the time of starting their jobs, and again 9–12 months later. Results The content analyses of the semi-structured interviews indicated that the participants perceived continuing benefits from entering mainstream employment, including more purposeful lives and increased social status. However, over the follow-up period the participants reported few social opportunities that extended beyond the workplace, and an anxiety about their competence to meet employers' demands remained a concern for some. Conclusions The discussion addresses the importance of understanding work in relation to the participants' wider lives, along with the longer-term role for supported

employment agencies to help people achieve their social and emotional goals in a vocational context.

21

Title:

People with an intellectual disability living in an intentional community.

Authors:

[Randell, M.](#)

[Cumella, S.](#)

Source:

[Journal of Intellectual Disability Research](#); Aug2009, Vol. 53 Issue 8, p716-726

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.

22

Title:

Leisure activities, friendships, and quality of life of persons with intellectual disability: foster homes vs community residential settings.

Authors:

Duvdevany, I.
Arar, E.

Source:

International Journal of Rehabilitation Research

Abstract:

Living in the community does not, in itself, guarantee social integration and inclusion for persons with intellectual disability. Friendships and leisure participation can indicate the beginning of such a process and their impact on quality of life. The present study investigated the quality of life, friendships and leisure activities of persons with intellectual disability who live in community settings or in foster families. Three hypotheses were examined: 1. Persons with intellectual disability who live in foster families have more friends than do those who live in community residential settings. 2. Persons with intellectual disability who live in community residential settings participate in more leisure activities than those who live in foster families. 3. The more friendships and leisure activities in which one is involved, the higher the quality of one's life. The sample consisted of 85 adults with intellectual disability, ranging in age from 18 to 55 years. Forty-five live in community residential settings and 40 live in foster families in Israel. Five questionnaires were used: 1) a demographic questionnaire; 2) Quality of Life Questionnaire, 1990); 3) the Revised UCLA Loneliness Scale; 4) Social Relationships List; and 5) Leisure Activities List. The main findings show no significant differences between the two groups in the number of friendships or feelings of loneliness. Foster residents were more involved and more independent in their leisure activities than were those who live in community residences. An association between friendships, leisure activities and quality of life was partly confirmed. The need for intervention programs and leisure education programs is discussed.

23

Title:

The Social Networks of People with Intellectual Disability Living in the Community 12 Years after Resettlement from Long-Stay Hospitals.

Authors:

[Forrester-Jones, Rachel](#)

[Carpenter, John](#)

[Coolen-Schrijner, Pauline](#)

[Cambridge, Paul](#)

[Tate, Alison](#)

[Beecham, Jennifer](#)

[Hallam, Angela](#)

[Knapp, Martin](#)

[Wooff, David](#)

Source:

[Journal of Applied Research in Intellectual Disabilities](#); Dec2006, Vol. 19 Issue 4, p285-295

Abstract:

Background The social inclusion of people with intellectual disabilities presents a major challenge to services. As part of a 12-year follow up of people resettled from long-stay hospitals, the size of 213 individuals' social networks and the types of social support they received were investigated, as viewed by people with intellectual disabilities themselves. The types of support received in four different kinds of community accommodation were compared. Method Individuals were interviewed and their social support networks mapped using a Social Network Guide developed for the study. Descriptive statistics were generated and comparisons made using generalized linear modelling. Results The sample comprised 117 men (average age 51 years) and 96 women (average age 56 years). All but seven were White British, 92% were single and they had in general, mild to moderate intellectual disabilities. The average network size was 22 members (range 3–51). The mean density was 0.5. A quarter of all network members were other service users with intellectual disabilities and a further 43% were staff. Only a third of the members were unrelated to learning disability services. In general, the main providers of both emotional and practical support were staff, although these relationships were less likely to be described as reciprocal. Other people with intellectual disabilities were the second most frequent providers of all types of support. People in small group homes, hostels and supported accommodation were significantly more likely to report close and companionable relationships than those in residential and nursing homes, but they also reported a greater proportion of critical behaviour. Conclusions The social networks revealed in this study are considerably larger than those of previous studies which have relied on staff reports, but findings about the generally limited social integration of people with intellectual disabilities are similar. A clearer policy and practice focus on the desirability of a range of different social contexts from which to derive potentially supportive network members is required so that people do not remain segregated in one area of life.

24

Title:

Social Networks of People with Mental Retardation in Residential Settings.

Authors:

[Robertson, Janet](#)

[Emerson, Eric](#)

[Gregory, Nicky](#)

[Hatton, Chris](#)

[Kessissoglou, Sophia](#)

[Hallam, Angela](#)

[Linehan, Christine](#)

Source:

[Mental Retardation](#); Jun2001, Vol. 39 Issue 3, p201, 14p, 5 Charts

Abstract:

Explores the social networks of adults with mental retardation in village communities, National Health Services residential campuses, and community-based residential supports.

Characteristics of the institutional residences; Issues regarding the social networks of people with mental retardation receiving residential supports; Factors that affect social networks.

25

Title:

The good life for citizens with intellectual disability

Authors:

Reinders, J.S.

Source:

Journal of Intellectual Disability Research, 2002, Vol 46 part 1, pp 1-5