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Citation for the published paper:

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"Support in Housing: A Comparison Between People with Psychiatric Disabilities and People with Intellectual Disabilities"

Community Mental Health Journal, 2009, Vol. 45, Number 6, pp. 420-426

URL: <http://dx.doi.org/10.1007/s10597-009-9225-4>

Access to the published version may require subscription.

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Support in housing:

A comparison between people with psychiatric disabilities and
people with intellectual disabilities

Abstract

The primary objective of this study was to compare type of housing and support in housing in two groups (people with psychiatric disabilities and people with intellectual disabilities) typically dependent on support in everyday life. A second objective was to examine whether type of housing and support in housing were related to gender within the two groups. Information was obtained by available questionnaire reports provided by staff members. The results indicate unequal accessibility of support in housing in relation to the two groups. Moreover, the findings suggest that type of disability is a more determining factor than gender regarding support in housing.

INTRODUCTION

In the late 20th century the transition from institutional to community living for people with psychiatric disabilities and people with intellectual disabilities has been a key component of governmental policy in a number of countries. The goal is to promote equality in living conditions and full participation in the life of the community for all citizens, including people with disabilities.

The issue of community living has frequently been cited in the literature. The living conditions approach is a typically used as a monitoring tool for uncovering patterns of social inequality (Tøssebro and Kittelsaa, 2004). Housing is identified as an important dimension of living conditions for all citizens in general and for people with disabilities in particular. A relationship has been reported between quality of housing and quality of life and well-being (Baker and Douglas 1990; Browne and Courtney 2004; Nelson et al. 2007). Furthermore, housing is an important determinant of mental health for people with intellectual disabilities (McGlaughlin 2004). A number of studies have addressed the outcome of different types of housing for people with psychiatric disabilities (Hansson et al. 2002; Kyle and Dunn 2008; Nelson et al. 1998; Oliver and Mohamad 1992) and intellectual disabilities (Emerson 2004; McConkey 2007; Perry and Felce 2003; Young 2006). Studies indicate limitations in community-based housing opportunities for people with psychiatric disabilities and conclude that homelessness is all too commonly experienced by people discharged from hospital wards (Burt et al. 2007; Forchuk et al. 2006; Kuno et al. 2000; Nordentoft et al. 1997). However, to our knowledge, no studies have compared the housing situation across groups with various disabilities. People with disabilities are a heterogeneous group and it is important to study the situation of groups with different types of impairment separately.

People with disabilities in Sweden share generic social and health services with others in the population. In addition, they are eligible for complementary special services and support in everyday life as regulated in the 1994 "Act concerning support and service for persons with certain functional impairments" (SFS 1993:387). The act applies to people with severe disabilities and needing help in fundamental areas of daily life, which includes people with psychiatric disabilities and people with intellectual disabilities. The purpose is to promote equality and the possibility of people with different disabilities to live valued daily lives in the community. Support in housing is provided by staff members in sheltered homes and by personal assistance and home help service in independent living. Sheltered homes consist of a small number of apartments either in a villa or scattered in a few residential blocks. There is staff service in the vicinity. Staff also visits the private apartments when needed. Personal assistance refers to personally designed support and help with personal hygiene, meals, dressing and undressing, communicating with others or other help with basic needs that require extensive knowledge about the person with functional impairment. Personal assistance is provided by a limited number of persons. The costs are covered by municipal authorities and the social insurance system. Home help services involve both practical assistance and personal care. Practical assistance may include household duties such as cleaning and laundry, cooking or the delivery of ready-cooked meals, shopping and bank errands. Personal care may include help with eating and drinking, getting dressed and moving around, and personal hygiene. The municipal authorities charge a fee for home help services. It is commonly argued that sheltered homes and support in housing were less available for people with psychiatric disabilities than for people with intellectual disabilities. However, no studies have addressed this issue and it is therefore of vital interest to compare these two groups on the housing situation. Because of their impairment, people with psychiatric disabilities and people with intellectual disabilities are frequently in need of support in housing. Thus, it is of interest to compare these two groups regarding type of housing and support in housing.

Not until the late 20th century has research in the disability field directed attention to gender-related differences. A Swedish official report (SOU 1998:138) indicates that females with disabilities have worse living conditions and receive less help and support than males with disabilities in many respects. In contrast, Umb-Carlsson and Sonnander (2006) found few differences in living conditions between females and males with intellectual disabilities. Because role expectations differ between females and males, it is necessary to study the housing situation of females and males separately.

A recent study was done on needs of support and service in people with psychiatric disabilities (Jansson et al. 2005a). At around the same time, a study of living conditions of people with intellectual disabilities was carried out (Umb-Carlsson and Sonnander 2005, 2006). Empirical data from these studies make a comparison across two groups of mental disability possible.

Aims and hypothesis

The aim of this study was to compare type of housing and support in housing of females with psychiatric disabilities with that of females with intellectual disabilities. Furthermore, the type of housing and support in

housing of males with psychiatric disabilities was compared with that of males with intellectual disabilities. The hypothesis was that fewer females and males with psychiatric disabilities lived in sheltered housing and had support in housing compared with females and males with intellectual disabilities.

A further aim was to examine whether type of housing and support in housing were related to gender within the two groups of disability. The hypothesis was that males more frequently lived in sheltered housing and were provided more support in housing.

METHOD

Participants

The participants were recruited from two total population based studies in a Swedish county: (i) Needs of support and service in mentally disabled clients (Jansson 2005) and (ii) Living conditions of people with intellectual disabilities (Umb-Carlsson 2005).

The inclusion criteria for the people with psychiatric disabilities in this study were: (a) born between 1959 and 1974, (b) a resident of Uppsala County, (c) suffering from a mental disorder that had caused a decrease in function and significantly interfered with daily life activities for at least 6 months and (d) at least one need of support in activities of daily living, or one unmet need of service provided by the public health care or community social services sectors.

The group of people with intellectual disabilities comprises people born between 1959 and 1974 and registered at the former Board for Provision and Services for the Mentally Retarded in 1974. All persons in the study group had been assessed with intellectual disabilities in early childhood.

The Ethical Committee at the Faculty of Medicine, Uppsala University approved the studies and all participants gave their informed consent personally or through a trustee.

Instruments

The Need of Support and Service Questionnaire (NSSQ) (Jansson et al. 2005b) was used to gather information on people with psychiatric disabilities. Fourteen items were chosen for the present study. These items were selected from three domains: (a) *Socio-demographic information and present living situation* (including age, gender, housing, co-habitation, and education), (b) *Need of support in activities of daily living* (including personal hygiene, preparing a meal, buying food, cleaning and washing and handling finances) and (c) *Need of service provided by the public health and social services sector* (including sheltered housing, personal assistant, home-help service and trustee).

In order to obtain equivalent information, 14 items were selected from a questionnaire on living conditions of adults with intellectual disabilities (Umb-Carlsson and Sonnander 2005). These items corresponded to the chosen items in the NSSQ. Both questionnaires provided objective data regarding the variables included in the study (for example: Does NN manage to handle finances independently? yes/no/unknown).

Procedure and Measures

Data were obtained by questionnaire reports from key staff members having everyday contact with the person concerned. The staff member either provided information on an individual with a psychiatric disability or on an individual with an intellectual disability.

Staff in psychiatric care (mental nurses, social workers, registered nurses, physiotherapists, occupational therapists, psychologists and psychiatrists) and staff in social services (social services workers, work managers and registered nurses) provided information on people with a psychiatric disability on the NSSQ.

Information on people with intellectual disabilities was provided on a questionnaire on living conditions by staff in housing, staff in daily activities and staff offering personal counselling. In the intellectual disability group information on diagnosis was obtained by medical case records available at the Uppsala County Habilitation Service.

Statistical analysis

Since the information was on a nominal level (yes/ no, manage independently/help needed or unknown), the Chi square statistics was used for the analyses. The Student t test was used for differences in age. The statistical

software used was SPSS for Windows (Statistical Package for Social Sciences, version 16.0). All reported p-values were two-tailed and the level of statistical significance was set at $p < 0.05$.

Comparisons on housing and support in housing were calculated across (1) people with psychiatric disabilities and people with intellectual disabilities, (2) females with psychiatric disabilities and females with intellectual disabilities and (3) males with psychiatric disabilities and males with intellectual disabilities. Gender differences were calculated between (4) females with psychiatric disabilities and males with psychiatric disabilities and (5) females with intellectual disabilities and males with intellectual disabilities.

RESULTS

In all, 397 people (176 females and 221 males) in the psychiatric disability group and 110 people (43 females and 67 males) in the intellectual disability group participated in the study. The characteristics of the two groups are shown in Table 1.

Table 1. Socio-demographic characteristics of people with psychiatric disabilities and people with intellectual disabilities.

	Psychiatric disabilities				Intellectual disabilities			
	Female (n=176)		Male (n=221)		Female (n=43)		Male (n=67)	
	n	(%)	n	(%)	n	(%)	n	(%)
Age								
Mean (Sd)	34.7	(5.2)	33.5	(4.5)	34.5	(4.3)	35.1	(4.4)
Housing								
Independent living	158	(89.8)	186	(84.2)	18	(41.9) ^a	20	(29.9) ^b
Sheltered home	12	(6.8)	24	(10.8)	25	(58.1) ^a	47	(70.1) ^b
Homeless	3	(1.7)	10	(4.5)				
No information	3	(1.7)	1	(0.5)				
Co-habitation								
Living alone	100	(56.8)	167	(75.6) ^c	31	(72.1)	55	(82.1)
Living with parents	9	(5.1)	25	(11.3) ^c	11	(25.6) ^a	10	(14.9)
Living alone with a child	19	(10.8) ^a	4	(1.8) ^b				
Living with a partner	18	(10.2)	5	(2.3) ^c	1	(2.3)	1	(1.5)
Living with a partner and a child	20	(11.4) ^a	7	(3.2) ^c			1	(1.5)
Living with another adult	4	(2.3)	3	(1.3)				
No information	6	(3.4)	10	(4.5)				
Education								
Compulsory education (<10 years)	53	(30.1)	72	(32.6)	18	(41.9) ^d	28	(41.8) ^d
Upper secondary education (10-12 years)	54	(30.7)	84	(38.0)	19	(44.2) ^d	32	(47.5) ^d
Higher education (>12 years)	39	(22.2) ^a	30	(13.6) ^{bc}				
No education					2	(4.7)	3	(4.8) ^b
No information	30	(17.0)	35	(15.8)	4	(9.3)	4	(6.0) ^b

Note: ^aDifference between females with psychiatric disabilities and females with intellectual disabilities ($p < 0.05$). ^bDifference between males with psychiatric disabilities and males with intellectual disabilities ($p < 0.05$). ^cGender difference in people with psychiatric disabilities ($p < 0.05$). ^d Special education for pupils with intellectual disabilities

People with psychiatric disabilities were more frequently living independently in their own household as compared with people with intellectual disabilities. The principal DSM-IV diagnoses among people with psychiatric disabilities were schizophrenia or other psychotic disorders, $n=216$ (54.4%), mood disorder, $n=39$ (9.8%), anxiety disorder, $n=34$ (8.6%), other Axis I disorder, $n=33$ (8.3%) and personality disorder, $n=75$ (18.9%). All diagnoses were equally common among females and males. In the intellectual disability group most (58 or 52.7%) had no identified cause for their disability. Also in the intellectual disability group, there were 32 (or 29.1%) diagnosed with Down syndrome, 10 persons (9.1%) were diagnosed with autism, 4 (3.6%) with other chromosomal syndromes and 6 (5.5%) with other non-chromosomal syndromes. Diagnoses were not related to

gender. Staff estimated more females (n=23 or 53.5%) than males (n=25 or 37.3%) as having severe limitations in functioning (understanding and using language, managing to read and write, telling time and need of assistance at meals, with personal care, when dressing and when outside the home), but this difference did not reach statistical significance.

Fewer people with psychiatric disabilities were assessed as frequently having needs of support in housing in comparison with people with intellectual disabilities (Table 2). Furthermore, fewer people with psychiatric disabilities than people with intellectual disabilities were provided support in housing and support provided by a trustee (Table 3). Differences were found between females with psychiatric disabilities and females with intellectual disabilities. Females with psychiatric disabilities needed and were provided support in housing in lesser extent than females with intellectual disabilities. A similar pattern was found among males with psychiatric disabilities and males with intellectual disabilities respectively.

Analyses revealed only few gender differences within the two disability groups. In the group with psychiatric disabilities need of support in handling finances was less commonly reported among females than among males. Among people with intellectual disabilities, fewer females than males needed support in buying food (Table 2). Furthermore, more females with intellectual disabilities were provided support by personal assistant compared with males with intellectual disabilities (Table 3). Needs of people with psychiatric disabilities were reported more frequently to be unknown than for people with intellectual disabilities (Table 2).

Table 2. Need of support in housing assessed by key staff.

	Psychiatric disabilities						Intellectual disabilities					
	Female (n=176)			Male (n=221)			Female (n=43)			Male (n=67)		
	Need		Unkno wn	Need		Unknown	Need		Unkno wn	Need		Unkno wn
	n	(%)		n	(%)		n	(%)		n	(%)	
Personal hygiene	2	(13.1)	7	(4.0)	45	(20.4)	1	(2.3)	5	(76.1)	1	(1.5)
Preparing a meal	3	(17.0)	0	(0.0)	77	(34.8)	4	(93.0) ^a	1	(2.3)	7	(10.4) ^b
Buying food	4	(22.6)	1	(5.0)	60	(27.1)	1	(2.3) ^a	6	(92.5) ^b	1	(1.5) ^b
Cleaning/washing	3	(21.6)	0	(0.0)	2	(10.9)	3	(72.1) ^a	2	(2.3)	2	(3.0) ^b
Handling finances	5	(32.4)	1	(5.0)	88	(39.8)	4	(93.0) ^a	5	(88.1)	1	(1.5) ^b
	7	(40.0)	0	(0.0)	1	(0.5)	0	(0.0) ^a	9	(95.5)	1	(1.5) ^b
	6	(34.1)	1	(7.0)	10	(48.9)	4	(93.0) ^a	2	(4.6)	6	(9.0) ^b
	1	(5.7)	3	(13.6)	8	(36.4)	0	(0.0) ^a	4	(60.0)	0	(0.0)

Note: ^aDifference between females with psychiatric disabilities and females with intellectual disabilities (p<0.05). ^bDifference between males with psychiatric disabilities and males with intellectual disabilities (p<0.05). ^cGender difference in people with psychiatric disabilities (p<0.05). ^dGender difference in people with intellectual disabilities (p<0.05).

Table 3. Support provided in housing as reported by key staff.

	Psychiatric disabilities		Intellectual disabilities	
	Female (n=176)	Male (n=221)	Female (n=43)	Male (n=67)
	n (%)	n (%)	n (%)	n (%)
Personal assistant	5 (2.8)	4 (1.8)	15 (34.9) ^a	7 (10.4) ^{bc}
Home help service	25 (14.2) ^a	31 (14.0)		4 (6.0)
Sheltered home	12 (6.8)	24 (10.9)	25 (58.1) ^a	47 (70.2) ^b
Trustee	27 (15.3)	37 (16.7)	36 (83.7) ^a	59 (88.1) ^b

Note: ^aDifference between females with psychiatric disabilities and females with intellectual disabilities (p<0.05). ^bDifference between males with psychiatric disabilities and males with intellectual disabilities (p<0.05). ^cGender difference in people with intellectual disabilities (p<0.05).

It may be noted that people with psychiatric disabilities were reported to have unmet needs in housing: sheltered homes (8.5% females and 18.1% males), personal assistance (2.8% females and 3.6% males), home help service (13.6% females and 20.4% males) and a trustee (5.7% females and 14.0% males). All, but one, of people with intellectual disabilities were provided support in housing.

DISCUSSION

The present study focused on two groups typically dependent on support in everyday life: people with psychiatric disabilities and people with intellectual disabilities. This study is the first study comparing these two groups on two parameters related to living accommodations (type of housing and support in housing).

There were four main findings. First, as expected, fewer people with psychiatric disabilities lived in sheltered housing and had support in housing compared with people with intellectual disabilities. People with psychiatric disabilities normally lived independently and home help service was the most common type of support in housing. For people with intellectual disabilities who lived independently, support in housing was typically provided in the form of personal assistance. National statistics in Sweden show that more hours of personal assistance are provided than hours of home help service (The Swedish National Board of Health and Welfare 2008). Thus, despite general and special legislation concentrating largely on equality in living conditions, results suggests that there is unequal accessibility of support in housing for people with different disabilities. The number of needs of support in housing that went unfulfilled in people with psychiatric disabilities indicates that support by closely related people is of vital importance to this group.

Second was the finding that the differences between the two disabilities groups regarding support provided in housing did not correspond to the extent of varying needs of support in housing. It may be hypothesized that environmental factors are more decisive than individual needs regarding support provided. Several studies have documented a high risk of homelessness among people with psychiatric disabilities (Burt et al. 2007; Forchuk et al. 2006; Herman et al. 1998; Kuno et al. 2000; Nordentoft et al. 1997). Forchuk et al. suggest that the decrease in available affordable housing have contributed to this problem. In the present study, 3% of people with psychiatric disabilities were rated as being homeless compared to none in the intellectual disabilities group. One explanation may be that people with psychiatric disabilities have limited access of sheltered homes. Whereas people with intellectual disabilities typically have a lifelong need of support in everyday life, people with psychiatric disabilities are treated in psychiatric units in local general hospitals for shorter periods. There is a possibility that mental health problems, because of their episodic nature, were not considered to imply lasting severe disability. Consequently, some people with psychiatric disabilities might be excluded from the population of people with a severe disability and thus not eligible for service and support under the Swedish special legislation (SFS 1993:387). Results indicate that there is an inequality in service and support provided people with psychiatric disabilities and people with intellectual disabilities. This finding is important and must be viewed with concern by policy makers and staff members. Appropriate housing and adequate support in housing contribute to the feeling of well-being and functioning (Baker and Douglas 1990). Absence of quality in housing is likely to be a contributory factor exacerbating mental illness (Pilisuk 2001; Rosenfield 1990).

Thirdly, results indicate that staff has limited knowledge on the needs of people with psychiatric disabilities. This hypothesis was confirmed by the finding that staff of people with psychiatric disabilities more frequently chose the response alternative "unknown" than did staff of people with intellectual disabilities. The response pattern may reflect that staff members working with people who have psychiatric disabilities are less involved in everyday matters than are staff members working with people who have intellectual disabilities. Historically, special services and support for people with intellectual disabilities have restricted the lives of the individual. It is suggested that the individual with an intellectual disability has limited influence over decisions in everyday life; they have been deprived of adult social status and responsibility (Riddell, Baron, & Wilson, 2001; Wehmeyer, & Metzler, 1995). Consequently, staff members and significant others may have superior position of control over the lives of people with intellectual disabilities whereas people with psychiatric disabilities may decline staff involvement in everyday life

The fourth main finding concerns gender related differences. Surprisingly, there were few differences between females and males within the two disability groups. However, differences were found between females with psychiatric disabilities and females with intellectual disabilities in most issues examined in this study. Likewise, differences were identified between males with psychiatric disabilities and males with intellectual disabilities. Thus, it may be hypothesised that type of disability is more decisive than gender regarding needs of support in housing and support provided. These results are in contrast to a Swedish official report (SOU 1998:138) demonstrating that more females with disabilities in general have unmet needs in everyday life compared with males with disabilities. In the present study the sample size in the intellectual disability group was small and thus sample size may have prevented the detection of gender-related differences.

In summary, despite general and special legislation aimed at equality in living conditions for people with different disabilities, our results suggest unequal accessibility of support in housing for people with psychiatric disabilities and people with intellectual disabilities. However, the knowledge on needs in housing of people with

psychiatric disabilities is often limited. This finding is important and must be viewed with concern by policy makers and staff members. The findings also suggest that gender plays a minor role with respect to staff estimation of support in housing. Because biological conditions and social role expectations differ considerably between females and males, it is necessary to make visible gender-related issues and problems. It is important to acknowledge gender in order to recognise people with disabilities as individuals with unique needs and preferences.

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