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The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe

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Abstract

Background—Despite progress in the process of deinstitutionalisation, very little is known about the health conditions of people with intellectual disability (PWID) who live in large institutions and PWID living in small residential services, family homes or independent living within the community. Furthermore, there are no international comparison studies at European level of the health status and health risk factors of PWID living in fully staffed residential services with formal support and care compared with those living in unstaffed family homes or independent houses with no formal support.

Methods—A total of 1269 persons with ID and/or their proxy respondents were recruited and face-to-face interviewed in 14 EU countries with the P15, a multinational assessment battery for collecting data on health indicators relevant to PWID. Participants were grouped according to their living arrangements, availability of formal support and stage of deinstitutionalisation.

Results—Obesity and sedentary lifestyle along with a number of illnesses such as epilepsy, mental disorders, allergies or constipation were highly prevalent among PWID. A significantly higher presence of myocardial infarctions, chronic bronchitis, osteoporosis and gastric or duodenal ulcers was found among participants in countries considered to be at the early stage of deinstitutionalisation. Regardless of deinstitutionalisation stage, important deficits in variables

related to such medical health promotion measures as vaccinations, cancer screenings and medical checks were found in family homes and independent living arrangements. Age, number of people living in the same home or number of places in residential services, presence of affective symptoms and obesity require further attention as they seem to be related to an increase in the number of illnesses suffered by PWID.

Discussion—Particular illnesses were found to be highly prevalent in PWID. There were important differences between different living arrangements depending on the level of formal support available and the stage of deinstitutionalisation. PWID are in need of tailored primary health programs that guarantee their access to quality health and health promotion and the preventative health actions of vaccination programs, systematic health checks, specific screenings and nutritional controls. Extensive national health surveys and epidemiological studies of PWID in the EC member states are urgently needed in order to reduce increased morbidity rates among this population.

Keywords

deinstitutionalisation; health; health indicators; intellectual disability; living arrangements

Introduction

Intellectual disability (ID) has been underrepresented in health care and health research. Furthermore, in most countries a large divide exists between availability of services and the health needs of persons with intellectual disability (PWID) (Salvador-Carulla & Saxena 2009). This disparity between services and need is worrying, as PWID have higher levels of health needs than the general population and these are often unrecognised and unmet (Cooper *et al.* 2004). In this context, some authors have proposed that a key public health function should be to address health disparities and the social determinants of health, specifically as they relate to disability (Drum *et al.* 2009).

Persons with ID as a group show a disparity of health profiles compared with the general population (Havercamp *et al.* 2004; Krahn *et al.* 2006). PWID report increased morbidity, poorer health status and a reduced participation in health promotion activities (Lennox & Kerr 1997; Havercamp *et al.* 2004; van Schroyen Lantman-de Valk & Walsh 2008). PWID also present with higher rates of obesity, mental health disorders, and lower rates of cardiovascular fitness, vaccination levels, and preventive health screenings (Walsh *et al.* 2003). It is broadly accepted that PWID show poorer health and greater difficulty accessing primary health care services than the general population (Whitfield *et al.* 1996; Alborz *et al.* 2005). These problems have been recognised at a European level (Walsh *et al.* 2003; Freyhoff *et al.* 2004; Gustavson *et al.* 2005; Barron *et al.* 2008; Directorate General for Employment, S. A. a. E. O. 2009; Linehan *et al.* 2009) and health targets and indicators are being developed for PWID (Whitfield *et al.* 1996; Davidson *et al.* 2004; Jansen *et al.* 2006; van Schroyen Lantman-de Valk *et al.* 2007; Scholte 2008; Krahn *et al.* 2010).

Residential supports for PWID in Europe

The impact of different forms of residential supports on the quality of life of PWID has attracted considerable attention (Kozma *et al.* 2009). In Europe, there is a determined movement towards deinstitutionalisation of intellectually disabled people, although the stage and the policies related to this process vary from country to country and show a heterogeneous picture (European Coalition for Community Living 2006). In countries such as Sweden and Norway, residential institutions for PWID have been completely closed and no one with IDs lives in institutional settings anymore (Beadle-Brown *et al.* 2007). In the UK the process of deinstitutionalisation is well advanced (Mansell & Beadle-Brown 2010)

and the number of places in large institutions has been decreasing in a constant way in recent years (Mansell 2006). In countries such as Belgium, The Netherlands, Germany, Spain, Greece, Italy and Portugal there is still a varying pattern of institutional care (Beadle-Brown *et al.* 2007) even though the number of people in large residential institutions is also decreasing (Mansell *et al.* 2008). On the other hand, in countries such as France, Hungary, Poland, Romania, Czech Republic and in general, Central and Eastern Europe, large institutional settings are the predominant place for care. Although it has proved to produce poor outcome results for residents (Freyhoff *et al.* 2004; Mansell *et al.* 2004), in some Member States institutional care still accounts for more than half of public care expenditure (Mansell *et al.* 2008).

Benefits of moving from institutions to community are well established in the available literature. Since 1980, over 170 studies have found consistent improvements in adaptive behaviour, competence and personal growth, community participation, engagement in meaningful activities, contact from staff, client satisfaction, contact with family and friends, social networks and friendships, interactions with staff, parent satisfaction, self-determination and choice and quality of life (Emerson & Hatton 1994; Young *et al.* 1998; Kim *et al.* 2001; Kozma *et al.* 2009).

Health status as a function of residential setting

Despite progress in the process of deinstitutionalisation, very little is known about the health conditions of residents living in large institutions and people living in small residential settings, family homes or independent living within the community. However, both health surveys and clinical studies show high unmet care needs in PWID living in the community. These unmet needs include physical ill health misinterpreted as part of the mental health problem or ID (causally referred to as diagnostic overshadowing) (Ali & Hassiotis 2008), untreated common and severe diseases (Baxter *et al.* 2006; van Schrojenstein Lantman-de Valk & Walsh 2008), difficulty accessing primary health service and reduced participation in health promotion activities. (Alborz *et al.* 2005) Deinstitutionalisation may also be associated with higher non-specialised care, as in many cases, professionals without specialised knowledge of the health needs of adults with ID are asked to provide care (Sullivan *et al.* 2006). Therefore, moving out of institutions may be identified as a necessary but not a sufficient condition to improve health status unless quality health services for PWID are implemented and provided in the community.

Rationale for the present study

To the authors' knowledge, there are no international comparison studies at European level of the health status and health risk factors of PWID living in residential services with formal support and care compared with those living in family homes or independent houses with no formal support or care. Furthermore, to our knowledge the stage of deinstitutionalisation has not been compared before in relation to the health status of PWID living in different EU countries. Informed evidence towards deinstitutionalisation and related policies in Europe can be difficult to achieve without previously mapping the current care system and the health status of these population groups in different European countries, which show different policies and are at different stages of the deinstitutionalisation process.

This paper presents findings from an initial application of a health survey tool that was carried out within a convenience sample of $n = 1269$ persons with ID resident in 14 European countries. The paper explores the health status of these residents as a function of the level of formal support they receive, and of the stage of deinstitutionalisation of their country of residence.

Method

This paper is part of the European POMONA-II project ‘Health Indicators for People with Intellectual Disabilities in Europe: Applying an indicator set’ (2005–2008), where a previously developed health indicator set (Walsh *et al.* 2003; van Schrojenstein Lantman-de Valk *et al.* 2007) was implemented in 14 European countries. The main aim of the POMONA-II project was to apply and to test the indicator set at European level. The project was not intended to be an epidemiological study; consequently, the results presented here should be considered with caution.

Sample

A total of 1269 persons with ID were recruited and face-to-face interviewed in 14 European countries; however, 12 participants had missing data for type of living arrangement, therefore the final sample was reduced to 1257. If participants were unable to answer given their level of ID, then the interview was conducted with a proxy person, either a friend, family relative or staff who knew the participant.

Samples were neither random, nor representative of the countries from which they were drawn. However, within the local health administration areas selected in each country, efforts were made to ensure samples were broadly representative of the typical living circumstances, ages and ability levels of the administrative population of adults with ID.

Project partners in each country were asked to select a geographical area that could provide a representation of typical living circumstances for PWID, identify available services and interview at least 80 PWID in different residential and outpatient health and social services. In all countries residential service providers were contacted to identify PWIDs living in residential settings. To include people in family/individual housing, generally the service providers’ registers were used as a suitable frame to identify potential participants living independently or with their families. Partners aimed to avoid selecting participants by their health or disease, for example, by diagnosis, medical records or hospital stay.

Where possible, participants provided written informed consent. In case of greater ID or legal incapacity to provide informed consent, their legal guardian or carer consented or assented for them. In each country, the study was approved by the local or national research ethical committees as required.

Extensive information about the sampling procedures and about the process of informed consent has been published elsewhere. (The Pomona Group 2008; Veenstra *et al.* 2010)

Groups of participants were formed depending on the intensity of formal support provided and the living arrangement (staffed residences vs. unstaffed homes) and the stage of deinstitutionalisation of their countries (advanced stage of deinstitutionalisation vs. early stage of deinstitutionalisation). Staffed residences differed from unstaffed homes as they were offered and managed by service providers and had some degree of paid staff support available. The staffed residences group ranged from typical small community group homes with 3–4 residents to large institutionalised type settings including acute settings such as nursing homes, psychiatric facilities and other intensive placements with special requirements. Unstaffed homes included participants living in their family homes or in independent and semi-independent residences even if they had some degree of floating supports. Floating supports were considered when a maximum of 2 h of daily supervision (alone or with others) or on call support were available.

According to recent reports and studies (Svab & Tomori 2002; Juodkaite 2005; Mansell *et al.* 2008; The Pomona Group 2008; Directorate General for Employment, S. A. a. E. O. 2009; Friedman 2009; Knapp *et al.* 2009; Veenstra *et al.* 2010) the countries that participated in the POMONA-II project were categorised into two groups: the first group of countries was named 'Countries with an advanced stage of deinstitutionalisation' (AD) and the second one 'Countries with an early stage of deinstitutionalisation' (ED). The existence of a national mental health policy, a national policy for deinstitutionalisation, the availability of community care, the additional injection of resources into community care and the evolution of psychiatric beds among other factors, were taken into consideration to decide if a country was in one or another stage of deinstitutionalisation (Medeiros *et al.* 2010).

In a first stage of the analysis, two groups were formed: staffed residences vs. unstaffed homes. In a second stage of the analysis four groups were formed as follows: unstaffed homes in a country with an advanced stage of deinstitutionalisation (UH-AD), staffed residences in a country with an advanced stage of deinstitutionalisation (SR-AD), unstaffed homes in a country with an early stage of deinstitutionalisation (UH-ED) and staffed residences in a country with an early stage of deinstitutionalisation (SR-ED). 584 participants were recruited in community day services as day centres, workshops, non-profit associations, etc., and all lived in family homes and independent or semi-independent houses. 474 out of these participants were living in unstaffed homes in advanced deinstitutionalisation countries and 110 in unstaffed homes in early deinstitutionalisation countries. Six hundred and seventy-three participants were recruited in staffed residential services such as hospitals, psychiatric hospitals and supported residences; 568 were living in advanced deinstitutionalisation countries and 105 in early deinstitutionalisation countries (see Table 1). Groups were compared according to the parameters established by the POMONA set of health indicators.

Materials

The POMONA P-15 is a multinational assessment battery for collecting data on health indicators relevant to PWIDs. It comprises items related to demographic characteristics of respondents, health status, health determinants and health systems: service utilisation, training, etc. The interview includes the PAS-ADD (Psychiatric Assessment Schedule for Adults with Developmental Disability) (Moss *et al.* 1997, 1998), which is an ID-specific measure of symptoms associated with mental problems, and the Aberrant Behaviour Checklist (ABC) (Aman *et al.* 1985), which is an ID-specific measure of challenging behaviour.

Variables

Socio and demographical variables included: age, sex, urban/rural location, living arrangements, daily occupation and capacity to economically afford basic necessities and activities. Health status comprised epilepsy, oral pain, body mass index (BMI), mental health disorders, sensory and mobility difficulties, ID level, etc. Smoking, alcohol consumption and behaviour disorders were considered as health determinants. Information about medical checks, utilisation of health services, vaccinations and cancer screenings among others were also collected. Variables examining capacity to economically afford basic necessities and activities, number of support needs or independency as measured with the Support Needs Scale (SNS) (Emerson 2005), total number of diseases suffered by the participant, number of difficulties for exercise practice, number of difficulties in day living activities, number of stressing life events, total PAS-ADD rates and total ABC rates were calculated and extracted from the Pomona P15 interview.

Statistical analysis

Descriptive analysis, chi-squared tests and analysis of variance (One-way anova) were used for comparison between groups of dichotomic and continuous single items. One-way anova with Tukey HDS *post hoc* analysis was used for comparison of data between groups.

A univariant general linear model was designed comprising total number of illnesses as dependent variable. ID level (mild, moderate, severe and profound), number of people in family/independent homes or number of places in residential settings, BMI category (underweight, normal, overweight, obese), subject grouping (unstaffed homes vs. staffed residences vs. advanced deinstitutionalisation vs. early deinstitutionalisation), type of activity (sedentary vs. active vs. sportive) and affective symptoms were considered as fixed factors according to previous analysis. Age and gender were considered as co-variables. Odds ratios for presence of illness were calculated for significant or near-signification variables using an adjusted logistic binary regression model. Statistical analysis used the spss v. 15.0.1 software. The significance level was considered at $\alpha = 0.05$

Results

The sample was formed by four different groups according to the place of residence, the level of formal support and the stage of deinstitutionalisation: unstaffed homes in AD ($n = 474$), staffed residences in AD ($n = 568$), unstaffed homes in ED ($n = 110$) and staffed residences in ED ($n = 105$). The average number of people per home was 2.99 (SD 1.54) in unstaffed homes in AD and 3.58 (SD 1.85) in unstaffed homes in ED. Average number of places per living arrangement was 12.38 (SD 14.62) in staffed residences in AD and 42.66 (SD 27.42) in staffed residences in ED. Social and demographic, health status and other clinical data are presented in Table 2. When comparing the total sample in family homes and independent living and the total sample in staffed residences statistically significant differences arose, as shown below.

Staffed residences vs. unstaffed homes

Participants living in staffed residences presented a higher mean age $F(56.003)$; $P < 0.001$, a lower presence of paid employment ($\chi^2 = 22.879$; $P < 0.001$), a higher number of cases of epilepsy with more epileptic seizures in the last 5 years ($\chi^2 = 8.151$; $P < 0.005$), a higher number of participants in the underweight BMI category ($\chi^2 = 8.561$; $P < 0.003$) and a lower number of participants in the obese BMI category ($\chi^2 = 21.071$; $P < 0.001$). For sensory and mobility disability indicators, the group living in staffed residences presented a lower number of participants with difficulties seeing >4 m ($\chi^2 = 24.985$; $P < 0.001$) and a higher number of participants with mobility problems ($\chi^2 = 9780$; $P < 0.002$). According to ID level, the group living in staffed residences presented a higher number of people with severe ($\chi^2 = 23.124$; $P < 0.001$) and profound ($\chi^2 = 10.156$; $P < 0.001$) ID level. There were no significant statistical differences about the presence of organic ($\chi^2 = 0.148$; $P < 0.754$), affective/ neurotic ($\chi^2 = 0.050$; $P < 0.905$) or psychotic ($\chi^2 = 1.554$; $P < 0.254$) disorders but behaviour disorders were higher in staffed residences samples [$F(27.61)$; $P < 0.001$].

Unstaffed homes in advanced and early deinstitutionalised countries

Comparison of participants living in unstaffed homes in AD and ED countries yielded the following results. Family homes and independent living samples in ED presented a lower mean age [$F(7.493)$, $P < 0.006$], a lower proportion of men ($\chi^2 = 5.035$; $P < 0.026$), a considerably lower number of people living in unstaffed with partial or floating support ($\chi^2 = 38.844$; $P < 0.001$) and people in paid employment ($\chi^2 = 88.383$; $P < 0.001$). Regarding health status, there was a higher number of participants who complained about 'mouth pain' ($\chi^2 = 7.751$; $P < 0.008$) in ED countries but there were not significant differences in epilepsy

diagnosis, number of seizures in the last 5 years, or BMI categories (see Table 1). A higher number of participants with problems seeing >4 m ($\chi^2 = 41.741$; $P < 0.001$) was also found. According to ID level and presence of disorders, the unstaffed homes sample in ED countries had a higher number of participants with moderate ($\chi^2 = 7.382$; $P < 0.007$) and profound ($\chi^2 = 8.557$; $P < 0.006$) ID level and a higher number of organic disorders ($\chi^2 = 30.480$; $P < 0.001$) and affective/neurotic disorders ($\chi^2 = 19.946$; $P < 0.001$). There were significant differences regarding behaviour disorders, with rates being higher in unstaffed homes ED samples [$F(33.490)$; $P < 0.001$].

Staffed residences in advanced and early deinstitutionalised countries

Considering the samples living in staffed residences in AD and ED countries we found that participants living in staffed residences in ED countries presented a lower mean age [$F(25.039)$; $P < 0.001$] a lower rate of urban/rural living location ($\chi^2 = 60.868$; $P < 0.001$) and a lower number of participants in paid employment ($\chi^2 = 109.034$; $P < 0.001$). Higher number of seizures in the last 5 years ($\chi^2 = 7.987$; $P < 0.008$), and a higher proportion of participants in the under-weight ($\chi^2 = 10.555$; $P < 0.002$) and normal weight ($\chi^2 = 7.509$; $P < 0.008$) categories of the BMI were found in the group of participants living in staffed residences in an ED country. Higher proportions of participants with mobility problems were found in staffed residences in ED countries ($\chi^2 = 4.722$; $P < 0.037$). Regarding level of ID, the sample living in staffed residences in ED countries presented lower number of participants with mild ID level ($\chi^2 = 20.720$; $P < 0.001$) and higher number of participants with profound ID level ($\chi^2 = 7.335$; $P < 0.009$).

Results in Table 3 refer to four blocks: health-related habits, illnesses suffered by the participants, health services use and a number of variables related to medical prevention measures. In the block of health habits, the total sample living in unstaffed homes presented a higher number of participants drinking alcohol at least once per month ($\chi^2 = 7.662$; $P < 0.007$) and sedentary lifestyle was higher in both the group of participants living in unstaffed homes ($\chi^2 = 30.248$; $P < 0.001$) and in staffed residences ($\chi^2 = 6.548$; $P < 0.011$) in countries with an early stage of deinstitutionalisation. Cataracts ($\chi^2 = 4.712$; $P < 0.033$), osteoporosis ($\chi^2 = 7.171$; $P < 0.008$) and constipation ($\chi^2 = 28.781$; $P < 0.001$) were more prevalent in the group living in staffed residences. Chronic obstructive pulmonary disease and gastric or duodenal ulcer were more prevalent in ED samples independently of the type of living arrangement. For health services use, in all cases the sample living in staffed residences consumed a higher proportion of services than sample living in unstaffed homes. In general, indicators that can be related to prevention and promotion measures (vaccinations, screenings, etc.) benefited the group living in staffed residences although for countries with an early stage of deinstitutionalisation, almost all the indicators were negative (see Table 3). Finally, medication consumption was significantly higher in the sample living in a staffed residence [$F(144.319)$, $P < 0.001$].

Participants living in AD countries showed a higher economic capacity to cover basic necessities and activities than participants living in ED countries independently if they were living in unstaffed homes (MD = 4.89; $P < 0.001$) or in staffed residences (MD = 5.53; $P < 0.001$). Participants living in unstaffed homes in AD countries had a significant lower number of needs for support than participants living in AD (MD = -3.24; $P < 0.001$) or ED (MD = 5.61; $P < 0.001$) staffed residences. There were no significant differences for total number of illnesses suffered by the participants in the different groups. Participants living in AD countries seem to have fewer difficulties in taking part in exercise practice than participants living in ED either in unstaffed homes (MD = -1.02; $P < 0.001$) or in staffed residences (MD = -1.22; $P < 0.001$). The number of difficulties in day living activities was significantly higher in staffed residences in AD countries (MD = -0.60; $P < 0.001$), unstaffed homes in ED countries (MD = -0.65; $P < 0.011$) and staffed residences in ED

countries (MD = -0.90; $P < 0.001$) than in unstaffed homes in AD countries. The same pattern was true for Number of Life Events (see Table 4). Regarding total PAS-ADD rates, unstaffed homes in AD countries had lower rates than the rest of the groups. Unstaffed homes in advanced deinstitutionalisation countries also presented lower ABC rates than the rest of the groups (see Table 5).

The univariant general linear model showed a significant effect in the dependent variable number of illnesses for the factors age [$F(9.732)$; $P < 0.002$]; higher numbers of people living in family or independent homes or higher numbers of places in staffed residences [$F = (1.543)$; $P < 0.028$]; presence of affective symptoms [$F = (6.224)$; $P < 0.013$] and higher BMIs [$F = (3.422)$; $P < 0.018$]. Subject grouping interacted with the number of people living in community homes or number of places in residential settings [$F = (2.074)$; $P < 0.009$]. According to this, the participants in living arrangements in ED countries with higher number of persons at home or higher number of places in residences, presented a higher number of illnesses.

The logistic regression model, predicting the presence or absence of illness as outcome variable, showed good fit (goodness-of-fit test, $\chi^2 = 11.764$, d.f. = 8, $P < 0.162$) and a Nagelkerke approximation of $R^2 = 0.115$. Age presented significant adjusted odds ratios for presence of illness but with a very small effect (OR = 1.029; $P < 0.001$; CI = 1.013– 1.045).

Discussion

Main findings

A significantly higher presence of myocardial infarctions, chronic bronchitis, osteoporosis and gastric or duodenal ulcers was found among participants in countries considered to be at the early stage of deinstitutionalisation. Regardless of deinstitutionalisation stage, important deficits in variables related to medical health promotion measures such as vaccinations, cancer screenings and medical checks were found in family homes and independent living arrangements.

Living arrangements, stage of deinstitutionalisation, gender, ID level, sedentary lifestyle or disrupting behaviours do not seem to have any effect *per se* in the number of illnesses presented by the participants. However, age, higher number of people living in the same home or higher number of places in staffed residences, presence of affective symptoms and obesity require further attention as they seem to be related to an increase in the number of illnesses suffered by the participants. A higher number of people living in the same residence was related to an increase in the number of illnesses suffered by PWID even if they were living in their own family homes.

In this study the main predictor of the presence and the number of illnesses in PWID was age. The odds that an older individual has an illness increase 2.90% over that of a younger individual with each year of age.

Strengths and limitations

The strengths of this study include the application of a multinational assessment battery for collecting data on health indicators in 14 European countries, the analysis of the samples considering age, sex, living arrangements, deinstitutionalisation stage, intensity of formal support received, level of ID and the ascertainment of a number of potential confounding factors as mental illness, behaviour disorders, BMI, physical activity level and sensory difficulties among others. On the other hand, the main aim of the study was to test the utility of the P15 rather than the data it yielded *per se*, and the current sample was not intended to be representative of the administrative population from which it was drawn. Therefore, the

conclusions of the present paper should be considered with caution and further research is needed in this area.

The data collection instrument was limited by the fact that the questionnaires were subjectively answered by participants or proxy respondents. Inclusion of systematic reviews of clinical medical files or measures as clinical laboratory reports could have improved the quality and reliability of the data and a complete medical check could have resolved the problem of diagnostic overshadowing, but this was beyond the resources of the study. The POMONA (P15) health indicators set does not include some illnesses that have proven to be more prevalent in PWID than in general population such as HIV and sexual transmission illnesses (Servais 2006; Rohleder & Swartz 2009), gastrointestinal reflux (Bohmer *et al.* 1999, 2000; de Veer *et al.* 2008) dementia (Cooper 1997; Kirk *et al.* 2006; Torr & Davis 2007), gastrointestinal cancer (Kitchens *et al.* 2007), diseases of the genitourinary system, cerebral palsy or genetic syndromes (Gustavson *et al.* 2005; Tyrer *et al.* 2007; Tyrer & McGrother 2009). Finally, although the total sample reached more than 1100 subjects, the great number of categorical variables including subject grouping, BMI, type of activity, ID level, etc., did not allow more sophisticated statistical analysis.

Comparison with other studies

To the best of our knowledge, this is the first study that compares the health status of PWID across the EU member states using the same survey protocol.

Comparative studies about health in PWID and living location have mostly focused on relocation and have been very scarce; moreover, half of them have been conducted only in English-speaking countries. Therefore, data about the situation in Europe as a whole are almost non-existent. Available data pointed to differences in health status and health risk factors when moving from residential institutions to community. A recent review (Kozma *et al.* 2009) found that as a group the prevalence of health risk factors such as inactivity and obesity among PWID was high and that less restrictive living arrangements increased the probability of smoking, poor diet and obesity but at the same time, relocation decreased the probability of inactivity. These findings are in line with our results although both studies are not entirely comparable. We found a higher prevalence of obesity in PWID living in arrangements that could be considered as less restrictive, like family homes or independently than in staffed residences, the prevalence being higher in advanced deinstitutionalisation countries. In contrast, sedentary lifestyle was higher in staffed residences and in early deinstitutionalised countries. Regarding health status we found higher rates of epilepsy, cataracts, osteoporosis and constipation in staffed residences and higher rates of migraines and headaches in unstaffed homes. Significant differences were found between AD and ED countries samples in cataracts, heart attack, chronic obstructive pulmonary disease, osteoporosis, gastric or duodenal ulcer and thyroid dysfunction.

Different studies agreed about insufficient participation and involvement of PWID living in the community, carers and general practitioners in health promotion activities (Lennox & Kerr 1997; Haverkamp *et al.* 2004; Alborz *et al.* 2005). Our results support this finding to some extent as we found higher percentages of vaccination, cancer screenings and medical checks in PWID living with some degree of formal support in staffed residences than in family homes or independently living samples.

Size of institutional residences has been traditionally proposed as an important factor in service provision quality and poor outcomes in large residential settings (Beadle-Brown *et al.* 2007). Our study supported this finding although we found that a higher number of people living with the PWID was related with an increase in the number of illnesses suffered

by the PWID independently of the type of living arrangement and the intensity of the formal support available.

As regards to the role of age as the main predictor for the presence of illness and for the number of different illnesses suffered by a PWID, our results supported the main findings of a recent report written by the POMONA II Group (Haveman *et al.* 2011).

In conclusion, obesity and sedentary lifestyle along with a number of chronic illnesses such as epilepsy, mental disorders, allergies or constipation are highly prevalent among PWID. There are important differences between PWID living in unstaffed homes and PWID living in staffed residences and between advanced and early deinstitutionalisation countries. PWID are in need of tailored primary health programs that guarantee their access to quality health, health promotion and preventative health actions such as vaccination programs, systematic health checks, specific screenings and nutritional controls. In countries with an early level of deinstitutionalisation, measures need to be taken to prevent people living in unstaffed living arrangements from being excluded from primary health care services during and after the deinstitutionalisation process, and to improve the health care offered in their staffed residences. Extensive national health surveys and epidemiological studies for PWID in the EC member states are urgently needed in order to reduce increased morbidity rates among this population.

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Table 1

Sampling groups according to living arrangements, level of support available and stage of deinstitutionalisation

	Advanced stage of Deinstitutionalisation AD	Early stage of Deinstitutionalisation ED
Unstaffed homes	474	110
Staffed residences	568	105

Table 2

Comparisons of sociodemographic variables and variables related to health indicators and clinical factors by level of formal support and stage of deinstitutionalisation

	Total (n = 1257)			Unstaffed homes (n = 584)			Staffed residences (n = 673)		
	Unstaffed homes (UH)	Staffed residences (SR)	Sig	Advanced Deinstt.	Early Deinstt.	Sig	Advanced Deinstt.	Early Deinstt.	Sig
n	584	673		474	110		568	105	
Age years, mean (SD)	38.14 (13.74)	44.27 (15.03)	F(56.003); P < 0.001***	38.89 (14.10)	34.93 (11.58)	F(7.493); P < 0.006**	45.49 (14.53)	37.57 (16.04)	F(25.039); P < 0.001***
Sex, male/female, n	311/273	324/349	$\chi^2 = 3.267$; P < 0.080	263/211	48/62	$\chi^2 = 5.035$; P < 0.026	268/300	56/49	$\chi^2 = 1.343$; P < 0.288
Rural/Urban	205/373	241/429	$\chi^2 = 0.034$; P < 0.859	171/297	34/76	$\chi^2 = 1.233$; P < 0.319	168/397	73/32	$\chi^2 = 60.865$; P < 0.001***
Employed	327 (56%)	348 (52%)	$\chi^2 = 1.966$; P < 0.171	309 (65%)	18 (16%)	$\chi^2 = 88.383$; P < 0.001***	342 (60.2%)	6 (6%)	$\chi^2 = 109.034$; P < 0.001***
Paid employment	198 (65%)	149 (46%)	$\chi^2 = 22.879$; P < 0.001***	185 (40%)	13 (12%)	$\chi^2 = 1.932$; P < 0.190	147 (25.9%)	2 (2%)	$\chi^2 = 0.514$; P < 0.597
Epilepsy	131 (23%)	212 (32%)	$\chi^2 = 12.593$; P < 0.001***	107 (23%)	24 (23%)	$\chi^2 = 0.001$; P < 1.000	170 (29.9%)	42 (40%)	$\chi^2 = 3.962$; P < 0.052
Seizure in last 5 years	98 (17%)	155 (24%)	$\chi^2 = 8.151$; P < 0.005**	75 (16%)	23 (21%)	$\chi^2 = 1.485$; P < 0.258	119 (21%)	36 (34%)	$\chi^2 = 7.987$; P < 0.008**
Oral pain	118 (21%)	130 (22%)	$\chi^2 = 0.108$; P < 0.775	85 (18%)	33 (31%)	$\chi^2 = 7.751$; P < 0.008**	105 (20.8%)	25 (26%)	$\chi^2 = 1.214$; P < 0.282
Underweight BMI	49 (12%)	94 (19%)	$\chi^2 = 8.561$; P < 0.003**	37 (11%)	12 (17%)	$\chi^2 = 2.135$; P < 0.158	68 (16.3)	26 (32%)	$\chi^2 = 10.555$; P < 0.002**
Normal BMI	130 (31%)	177 (35%)	$\chi^2 = 1.804$; P < 0.182	105 (22%)	25 (35%)	$\chi^2 = 0.601$; P < 0.483	137 (32.9%)	40 (49%)	$\chi^2 = 7.509$; P < 0.008**
Overweight BMI	114 (27%)	144 (29%)	$\chi^2 = 0.233$; P < 0.685	97 (28%)	17 (24%)	$\chi^2 = 0.535$; P < 0.559	134 (32.2%)	10 (12%)	$\chi^2 = 13.352$; P < 0.001***
Obese BMI	122 (29%)	83 (17%)	$\chi^2 = 21.071$; P < 0.001***	105 (30%)	17 (24%)	$\chi^2 = 1.228$; P < 0.317	77 (18.5%)	6 (7%)	$\chi^2 = 6.178$; P < 0.014
Organic disorder	21 (4%)	21 (3%)	$\chi^2 = 0.148$; P < 0.754	7 (2%)	14 (13%)	$\chi^2 = 30.480$; P < 0.001***	17 (3.2%)	4 (4%)	$\chi^2 = 0.097$; P < 0.765
Affective disorder	35 (6%)	41 (7%)	$\chi^2 = 0.050$; P < 0.905	18 (4%)	17 (16%)	$\chi^2 = 19.946$; P < 0.001***	34 (6.8%)	7 (7%)	$\chi^2 = 0.008$; P < 1.000

	Total (n = 1257)			Unstaffed homes (n = 584)			Staffed residences (n = 673)		
	Unstaffed homes (UH)	Staffed residences (SR)	Sig	Advanced Deinst.	Early Deinst.	Sig	Advanced Deinst.	Early Deinst.	Sig
Total ABC mean (SD)	9.88 (16.39)	15.38 (18.85)	F(27.61); P < 0.001***	8.30 (13.54)	14.36 (18.11)	F(33.490); P < 0.001***	16.44 (23.93)	22.06 (22.07)	F(2.70); P < 0.102
Difficulty seeing >4 m	281 (50%)	214 (36%)	$\chi^2 = 24.985$; P < 0.001***	199 (44%)	82 (79%)	$\chi^2 = 41.741$; P < 0.001***	176 (31%)	38 (40%)	$\chi^2 = 0.898$; P < 0.352
Difficulty with mobility	128 (22%)	200 (30%)	$\chi^2 = 9.780$; P < 0.002**	94 (20%)	34 (31%)	$\chi^2 = 6.200$; P < 0.015**	159 (28.4%)	41 (39%)	$\chi^2 = 4.722$; P < 0.037
Mild ID	163 (35%)	111 (20%)	$\chi^2 = 28.193$; P < 0.001***	155 (42%)	8 (9%)	$\chi^2 = 34.464$; P < 0.001***	107 (24.2%)	4 (4%)	$\chi^2 = 20.725$; P < 0.001***
Moderate ID	168 (36%)	170 (31%)	$\chi^2 = 3.030$; P < 0.094	124 (33%)	44 (49%)	$\chi^2 = 7.382$; P < 0.007**	139 (31.4%)	31 (31%)	$\chi^2 = 0.022$; P < 0.906
Severe ID	81 (18%)	167 (31%)	$\chi^2 = 23.124$; P < 0.001***	60 (16%)	21 (23%)	$\chi^2 = 2.527$; P < 0.123	128 (29%)	39 (39%)	$\chi^2 = 3.598$; P < 0.073
Profound ID	48 (10%)	95 (17%)	$\chi^2 = 10.156$; P < 0.001***	31 (8%)	17 (19%)	$\chi^2 = 8.557$; P < 0.006**	68 (15.4%)	27 (27%)	$\chi^2 = 7.335$; P < 0.009**

* P < 0.05;

** P < 0.01;

*** P < 0.001.

One-way ANOVAS and Chi-squared tests comparisons by level of formal support and stage of deinstitutionalisation.

Percentages exclude missing data. Data were missing for less than 3% of subjects for all variables except 'pain inside mouth' (7%), 'BMI category' (27%), 'difficulty seeing small print' (12%), 'difficulty seeing >4 m' (8%), 'difficulty hearing' (7%), 'level of ID' (20%), 'behaviour disorder' (8%) and 'mental disorders' (11%).

Table 3

Comparisons of variables related to health habits, type of regular activity, presence of different illnesses, health services utilisation, medication consumption and variables related to promotion of health and preventative measures by level of formal support and stage of deinstitutionalisation

	Total (n = 1257)			Unstaffed homes (n = 584)			Staffed residences (n = 673)		
	Unstaffed homes	Staffed residences	Sig	Advanced Deinstt.	Early Deinstt.	Sig	Advanced Deinstt.	Early Deinstt.	Sig
Drinks once per month	126 (13%)	103 (16%)	$\chi^2 = 7.662; P < 0.007^{**}$	109 (23%)	17 (16%)	$\chi^2 = 2.930; P < 0.094$	98 (17.6%)	5 (4.8%)	$\chi^2 = 10.892; P < 0.001^{***}$
Sedentary	273 (51%)	321 (52%)	$\chi^2 = 0.301; P < 0.594$	201 (45%)	72 (77%)	$\chi^2 = 30.248; P < 0.001^{***}$	257 (50.2%)	63 (64.3%)	$\chi^2 = 6.548; P < 0.011^*$
Active	220 (41%)	257 (48%)	$\chi^2 = 0.159; P < 0.719$	199 (45%)	21 (22%)	$\chi^2 = 16.349; P < 0.001^{***}$	224 (43.8%)	33 (33.7%)	$\chi^2 = 3.426; P < 0.074$
Sportive	44 (8%)	33 (7%)	$\chi^2 = 3.534; P < 0.076$	43 (10%)	1 (1%)	$\chi^2 = 7.700; P < 0.003^{**}$	31 (6.1%)	2 (2.0%)	$\chi^2 = 2.590; P < 0.142$
Cataracts?	26 (5%)	51 (8%)	$\chi^2 = 4.712; P < 0.033$	23 (5%)	3 (3%)	$\chi^2 = 1.034; P < 0.445$	48 (8.6%)	3 (2.9%)	$\chi^2 = 4.123; P < 0.045^*$
Heart attack?	11 (2%)	11 (2%)	$\chi^2 = 0.167; P < 0.830$	6 (1%)	5 (4%)	$\chi^2 = 4.980; P < 0.041$	7 (1.3%)	4 (3.8%)	$\chi^2 = 3.523; P < 0.081$
Chronic bronchitis, emphysema [†]	49 (9%)	41 (6%)	$\chi^2 = 2.999; P < 0.099$	32 (7%)	17 (16%)	$\chi^2 = 8.300; P < 0.007^{**}$	25 (4.5%)	16 (5.2%)	$\chi^2 = 17.572; P < 0.001^{***}$
Osteoporosis?	20 (4%)	47 (7%)	$\chi^2 = 7.171; P < 0.008^{**}$	15 (3%)	5 (4%)	$\chi^2 = 0.448; P < 0.561$	28 (5.0%)	19 (18.1%)	$\chi^2 = 22.875; P < 0.001^{***}$
Gastric or duodenal ulcer?	25 (4%)	37 (6%)	$\chi^2 = 0.759; P < 0.433$	13 (3%)	12 (11%)	$\chi^2 = 13.979; P < 0.001^{***}$	26 (4.7%)	11 (10.5%)	$\chi^2 = 5.648; P < 0.033^*$
Migraine and frequent headache?	121 (22%)	77 (12%)	$\chi^2 = 22.646; P < 0.001^{***}$	100 (22%)	21 (20%)	$\chi^2 = 0.343; P < 0.604$	62 (11.1%)	15 (14.3%)	$\chi^2 = 0.855; P < 0.406$
Constipation?	111 (20%)	223 (34%)	$\chi^2 = 28.781; P < 0.001^{***}$	95 (21%)	16 (15%)	$\chi^2 = 2.054; P < 0.178$	188 (33.8%)	35 (33.3%)	$\chi^2 = 0.007; P < 1.001$
Hypo/Hyperthyroidism?	48 (9%)	49 (7%)	$\chi^2 = 0.610; P < 0.458$	40 (9%)	8 (7%)	$\chi^2 = 0.219; P < 0.848$	48 (8.6%)	1 (1.0%)	$\chi^2 = 7.573; P < 0.004^{**}$
Had to stay at the Hospital [‡]	81 (14%)	126 (19%)	$\chi^2 = 5.252; P < 0.022^*$	61 (13%)	20 (19%)	$\chi^2 = 2.510; P < 0.122$	102 (18.1%)	24 (23.1%)	$\chi^2 = 1.409; P < 0.275$
Been admitted but not stayed overnight [‡]	73 (13%)	116 (17%)	$\chi^2 = 5.342; P < 0.022^*$	63 (13%)	10 (10%)	$\chi^2 = 1.176; P < 0.332$	107 (19.2%)	9 (8.8%)	$\chi^2 = 6.412; P < 0.011^*$
Emergencies [‡]	70 (12%)	112 (17%)	$\chi^2 = 5.520; P < 0.020^*$	65 (14%)	5 (5%)	$\chi^2 = 6.918; P < 0.008^{**}$	101 (18%)	11 (10.9%)	$\chi^2 = 3.080; P < 0.085$

	Total (n = 1257)			Unstaffed homes (n = 584)			Staffed residences (n = 673)		
	Unstaffed homes	Staffed residences	Sig	Advanced Deinstt.	Early Deinstt.	Sig	Advanced Deinstt.	Early Deinstt.	Sig
Admitted because of epilepsy [‡]	14 (2%)	34 (5%)	$\chi^2 = 6.027; P < 0.017^*$	11 (2%)	3 (3%)	$\chi^2 = 0.060; P < 0.735$	31 (5.5%)	3 (2.9%)	$\chi^2 = 1.223; P < 0.338$
Visited a doctor for a full medical	308 (56%)	445 (71%)	$\chi^2 = 27.236; P < 0.001^{***}$	232 (52%)	76 (71%)	$\chi^2 = 12.176; P < 0.001^{***}$	356 (67.4%)	89 (87.3%)	$\chi^2 = 16.208; P < 0.001^{***}$
Influenza vaccination [§]	234 (42%)	449 (69%)	$\chi^2 = 88.421; P < 0.001^{***}$	192 (43%)	42 (40%)	$\chi^2 = 0.368; P < 0.585$	363 (66.7%)	86 (81.9%)	$\chi^2 = 9.509; P < 0.002^{**}$
Tetanus vaccination [§]	236 (47%)	341 (60%)	$\chi^2 = 18.191; P < 0.001^{***}$	221 (55%)	15 (14%)	$\chi^2 = 53.632; P < 0.001^{***}$	300 (64.2%)	41 (40.6%)	$\chi^2 = 19.351; P < 0.001^{***}$
Hepatitis B vaccination [§]	107 (22%)	242 (41%)	$\chi^2 = 44.789; P < 0.001^{***}$	106 (27%)	1 (1%)	$\chi^2 = 32.936; P < 0.001^{***}$	220 (44.6%)	22 (21.8%)	$\chi^2 = 18.117; P < 0.001^{***}$
Blood pressure checked [¶]	908 (84%)	577 (93%)	$\chi^2 = 25.856; P < 0.001^{***}$	402 (88%)	506 (93%)	$\chi^2 = 29.921; P < 0.001^{***}$	506 (92.7%)	71 (66.4%)	$\chi^2 = 0.900; P < 0.408$
Cholesterol checked [¶]	292 (56%)	381 (63%)	$\chi^2 = 5.747; P < 0.017^*$	258 (62%)	34 (32%)	$\chi^2 = 30.199; P < 0.001^{***}$	347 (69.5%)	34 (32.7%)	$\chi^2 = 50.231; P < 0.001^{***}$
Did not have a breast examination [¶]	199 (24%)	179 (46%)	$\chi^2 = 31.986; P < 0.001^{***}$	147 (73%)	52 (87%)	$\chi^2 = 4.672; P < 0.037^*$	139 (48.8%)	40 (83.3%)	$\chi^2 = 19.740; P < 0.001^{***}$
Never had a mammogram	197 (78%)	210 (65%)	$\chi^2 = 11.101; P < 0.001^{***}$	143 (73%)	54 (93%)	$\chi^2 = 10.435; P < 0.001^{***}$	167 (60.3%)	43 (91.5%)	$\chi^2 = 17.152; P < 0.001^{***}$
Did not have a cervical screening [¶]	177 (70%)	219 (69%)	$\chi^2 = 0.124; P < 0.784$	127 (66%)	50 (84%)	$\chi^2 = 7.756; P < 0.005^{**}$	178 (65.7%)	41 (87.2%)	$\chi^2 = 8.677; P < 0.003^{**}$
Did not have a testicular cancer ^{††}	258 (92%)	253 (89%)	$\chi^2 = 1.264; P < 0.309$	211 (91%)	47 (100%)	$\chi^2 = 4.816; P < 0.032^*$	199 (86.9%)	54 (100%)	$\chi^2 = 7.913; P < 0.002^{**}$
Access to dentist	475 (84%)	585 (90%)	$\chi^2 = 9.189; P < 0.003^{**}$	396 (87%)	79 (75%)	$\chi^2 = 8.502; P < 0.007^{**}$	501 (91.8%)	84 (82.4%)	$\chi^2 = 8.662; P < 0.006^{**}$
Medication consumption mean(SD)	1.21 (1.38)	2.26 (1.68)	$F(144,319); P < 0.001^{***}$	1.37 (1.40)	0.50 (1.03)	$F(37,688); P < 0.001^{***}$	2.25 (1.70)	2.35 (1.58)	$F(0.306); P < 0.581$

* $P < 0.05$;

** $P < 0.01$;

*** $P < 0.001$.

Chi-squared tests comparisons by level of formal support and stage of deinstitutionalisation.

One way ANOVA on medication consumption by level of formal support and stage of deinstitutionalisation.

Percentages exclude missing data. Data were missing for less than 3% of subjects for all variables except 'type of activity' (9%), 'visited a doctor for a full medical check' (7%), 'influenza vaccination' (5%), 'tetanus vaccination' (15%), 'hepatitis B vaccination' (14%), 'blood pressure checked' (4%) and 'cholesterol checked' (11%).

[†] Excluding allergy asthma.

[‡] During the last 12 months.

[§] During the last 10 years.

[¶] During the last 5 years.

^{††} During the last 3 years.

Table 4

Comparisons on number of difficulties in day living activities, number of life events, mental health and behaviour disorders by level of formal support and stage of deinstitutionalisation

Variable	Group 1	Group 2	Mean difference	Sig.
Number of difficulties in day living activities	Unstaffed AD	Staffed AD	-0.60	$P < 0.001$ ***
		Unstaffed ED	-0.65	$P < 0.011$ *
	Staffed AD	Staffed ED	-0.90	$P < 0.001$ ***
		Unstaffed ED	-0.04	$P < 0.997$
		Staffed ED	-0.29	$P < 0.477$
		Unstaffed ED	Staffed ED	-0.25
Number of life events	Unstaffed AD	Staffed AD	0.18	$P < 0.051$
		Unstaffed ED	0.65	$P < 0.001$ ***
	Staffed AD	Staffed ED	0.76	$P < 0.001$ ***
		Unstaffed ED	0.47	$P < 0.001$ ***
		Staffed ED	0.58	$P < 0.001$ ***
		Unstaffed ED	Staffed ED	0.10
Total pass add rates	Unstaffed AD	Staffed AD	-0.77	$P < 0.011$ **
		Unstaffed ED	-2.07	$P < 0.001$ ***
	Staffed AD	Staffed ED	-1.03	$P < 0.065$
		Unstaffed ED	-1.29	$P < 0.007$ **
		Staffed ED	-0.25	$P < 0.924$
		Unstaffed ED	Staffed ED	1.03
Total ABC rates	Unstaffed AD	Staffed AD	-6.06	$P < 0.001$ ***
		Unstaffed ED	-8.13	$P < 0.001$ ***
	Staffed AD	Staffed ED	-13.75	$P < 0.001$ ***
		Unstaffed ED	-2.07	$P < 0.680$
		Staffed ED	-7.69	$P < 0.001$ ***
		Unstaffed ED	Staffed ED	-5.61

* $P < 0.05$;

** $P < 0.01$;

*** $P < 0.001$.

One-way ANOVA test with Tukey pairwise comparisons (95% CI).

Table 5

Comparisons on economic capacity to afford basic necessities and services, needs level, number of illnesses and number of difficulties for exercise practice by level of formal support and stage of deinstitutionalisation

Variable	Group 1	Group 2	Mean difference	Sig.
Capacity to afford basic necessities and services	Unstaffed AD	Staffed AD	-0.27	$P < 0.535$
		Community ED	4.89	$P < 0.001^{***}$
		Staffed ED	5.53	$P < 0.001^{***}$
	Staffed AD	Community ED	5.16	$P < 0.001^{***}$
		Staffed ED	5.80	$P < 0.001^{***}$
		Unstaffed ED	0.63	$P < 0.491$
Needs level	Unstaffed AD	Staffed AD	-3.24	$P < 0.001^{***}$
		Community ED	-0.86	$P < 0.576$
		Staffed ED	-5.61	$P < 0.001^{***}$
	Staffed AD	Community ED	2.38	$P < 0.002^{**}$
		Staffed ED	-2.37	$P < 0.002^{**}$
		Unstaffed ED	-4.75	$P < 0.001^{***}$
Sum of all illnesses	Unstaffed AD	Staffed AD	-0.04	$P < 0.980$
		Community ED	-0.05	$P < 0.989$
		Staffed ED	0.02	$P < 0.999$
	Staffed AD	Community ED	-0.01	$P < 1.000$
		Staffed ED	-0.06	$P < 0.985$
		Unstaffed ED	0.08	$P < 0.986$
Number of difficulties for exercise practice	Unstaffed AD	Staffed AD	-0.30	$P < 0.125$
		Unstaffed ED	-1.02	$P < 0.001^{***}$
		Staffed ED	-1.22	$P < 0.001^{***}$
	Staffed AD	Unstaffed ED	-0.71	$P < 0.010$
		Staffed ED	-0.92	$P < 0.001^{***}$
		Unstaffed ED	-0.20	$P < 0.906$

* $P < 0.05$;

** $P < 0.01$;

*** $P < 0.001$.

One-way anova test with Tukey pairwise comparisons (95% CI).