

Trends

## **Not such an ordinary life. A comparison of employment, relationship and housing profiles of adults with and without intellectual disabilities**

Martin McMahon<sup>1,3</sup>, Darren L. Bowring<sup>2,3</sup> and Chris Hatton<sup>1</sup>

<sup>1</sup> *Division of Health Research, Lancaster University, Lancaster*

<sup>2</sup> *CEDAR, University of Warwick*

<sup>3</sup> *Health and Community Services, Government of Jersey*

Correspondence: Martin McMahon, Education Centre, Peter Crill House, Gloucester Street, St Helier, Jersey, JE1 3QS [m.mcmahon2@lancaster.ac.uk](mailto:m.mcmahon2@lancaster.ac.uk)

## **Abstract**

**Purpose** – Having paid work, relationships and a choice of where to live are common policy priorities for adults with intellectual disabilities. The purpose of this paper is to compare outcomes with respect to these three priorities between adults with intellectual disability and the general population in Jersey. Design/methodology/approach – Data were collected from 217 adults with intellectual disability known to services, and 2,350 adults without intellectual disability using a stratified random sample. Data on employment, marital status and accommodation profiles were compared.

**Findings** – In sum, 87 per cent of adults with intellectual disability were currently single vs 16 per cent of adults without intellectual disability; 23 per cent of working-age adults with intellectual disability were in paid employment vs 92 per cent of working-age adults without intellectual disability; and 57 per cent of adults with intellectual disability lived-in sheltered housing vs 2 per cent of adults without intellectual disability.

**Social implications** – Very few adults with intellectual disability are in paid employment or intimate relationships, and the majority live in sheltered, supported housing, with very few owning their own home. There is a significant disconnect between policy and reality. Considerable work is required to make an ordinary life the reality for adults with intellectual disability.

**Originality/value** – This study adds to the body of evidence that suggests people with intellectual disabilities are less likely to experience an ordinary life. Furthermore, it illustrates that despite Jersey being an affluent society, the same difficulties and barriers exist there for persons with an intellectual disability as in other jurisdictions. Keywords Relationships, Employment, Housing, Intellectual disabilities, Ordinary life

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## Introduction

The rights of people with intellectual disabilities to live an “ordinary life” have featured in government policy (e.g. DoH, 2001) and are enshrined in the 1998 Human Rights Act. Over the last 50 years, different parts of the UK have targeted large-scale deinstitutionalisation to varying degrees (DoH, 1971, 2001) with the ultimate aim of improving the lives and wellbeing of this population (Hatton, 2016). Since its inception, in England, Valuing People (DoH, 2001) set out the principles of person-centred support – offering the same choices, opportunities and rights as everyone else in their communities. This policy was set within a human rights framework and reflected the influence of values movements in this field including: self-determination (Wehmeyer and Schwartz, 1998); social role valorisation (Wolfensberger, 2013) and person-centred planning (Mansell and Beadle-Brown, 2004).

The Valuing People (DoH, 2001) policy included aims for employment, relationships and housing. At this time, very few people with intellectual disability (probably less than 10 per cent, according to DoH, 2001) were in paid employment and an increased target was set. Nearly 20 years on, there is continuing, strong English Government commitment to increasing the number of people with intellectual disability in paid work (Parkin et al., 2018); however, the reality is that employment rates remain low (Department of Work and Pensions and The Department of Health, 2017) and employment in the broadest sense is precarious for people with intellectual disability (Emerson et al., 2018).

Objectives were set to enable people with intellectual disability to live fulfilling lives which included developing relationships. The rights of people with intellectual disability to have relationships (World Health Organisation, 2006) are enshrined in UK law in the Human Rights Act (Human Rights Act, 1998), yet there has been little research into how many people are actually in relationships (Emerson et al., 2005) despite it being an important consideration for people with intellectual disability (Healy et al., 2009). While there is evidence that community-based structures of independent and supported living deliver better outcomes than institutions as long as they are appropriately set up and managed (Mansell et al., 2007), there remains a significant number of people with intellectual disabilities in institutional settings and/or residential care (Hatton, 2017).

In 2014, a UK-based intellectual disability charity – Stay Up Late – in 2014 produced a “Manifesto for an Ordinary Life” (<https://stayuplate.org/a-manifesto-for-an-ordinary-life/>). This featured a number of things people with intellectual disability in the UK were consistently asking for at various workshops, forums and conferences. This concurred with the aims of all

UK intellectual disability Policy and the United Nations (2007) Convention on the Rights of Persons with Disabilities focussing on community inclusion (article 19), relationships (article 23) and work and employment (article 27), namely:

- the right to have a proper paid job;
- the right to have relationships and a sex life; and
- the right to choose where to live and who to live with.

Indeed, the government paper, “Improving The Life Chances of Disabled People” (Prime Minister’s Strategy Unit, 2005), stated that, by 2025, disabled people in the UK would be equal members of society.

This paper aims to look at progress against these three aims by examining profiles of employment, marital status and housing between adults with and without intellectual disability in Jersey, Channel Islands. Apart from the Capacity and Self Determination (Jersey) Law (2016) and a generic Disability Strategy for Jersey (2017) which focussed on disability in its broadest sense, Jersey does not have its own specific policy concerning intellectual disability but mirrors English policy and guidance.

## **Method**

### **Participants and procedure**

Jersey context: The resident population of Jersey is estimated as 105,500 (Government of Jersey, 2018). A recent study by Bowring et al. (2017a) identified a 0.4 per cent administrative prevalence rate of intellectual disability in Jersey based on figures obtained from the 2011 census. This administrative prevalence is broadly similar to other jurisdictions (0.33–0.48 per cent: Jones et al., 2008; Lundqvist, 2013). In terms of employment, less than 5 per cent of working-age adults are unemployed and the median weekly salary for full-time employees is currently £590 per week – with average income estimated at £440 per week for hotel/restaurant and bar work and at £1,020 for financial and legal work (Government of Jersey, 2019a, b). Since 2002, home ownership has become less attainable with the mean household income unable to service a mortgage on the purchase of a median price residence. It should also be noted that housing legislation in Jersey prohibits individuals who are not native to Jersey or essentially employed to purchase or rent certain types of property, e.g. there are some restrictions limiting people to renting lodging or tourist accommodation if they have not lived-in Jersey for five years. No existing evidence exists

with regard to the prevalence of employment or home ownership for adults with intellectual disability in Jersey.

Intellectual disability sample: Data were collected between 2017 and 2018 from a total administrative sample of adults with intellectual disability known to services in Jersey. Participants were  $\geq 18$  years of age and administratively defined as having intellectual disability (i.e. were receiving, or had received, support from intellectual disability services in Jersey). Participants had different levels of intellectual disability ranging from those who lived independently to those who required wide-ranging support. In total, 217 adults with intellectual disability were recruited (age range 18-84, Mean = 44.5, SD = 16.2), indicative of a 76% response rate (sampling frame  $n = 285$ ). Just under 50% of participants were administratively defined as having a mild intellectual disability ( $n = 108$ ), 26% ( $n = 56$ ) as having a moderate intellectual disability, 16% ( $n = 34$ ) as having a severe intellectual disability and 9% ( $n = 19$ ) as having a profound intellectual disability. Fifty-six percent ( $n=122$ ) were male, 44% ( $n=95$ ) female. All information was collected by face-to-face interview and there were no missing data in this sample.

Participants were selected using a stratified, random sampling approach. Jersey has twelve parishes, and these were divided into strata. Each parish was weighted in terms of population density reflecting the most recent population census and allowing for net inward migration (States of Jersey, 2011). Addresses were randomly drawn from the list of residential, active addresses for each parish on the Jersey Land Property Index. Any household which was sampled for one of the previous 2015, 2016, or 2017 social surveys, or for the Disability Survey in 2015, was excluded. Following these exclusions, 28,000 households were eligible for inclusion in the overall sampling frame. Eight thousand surveys, weighted in terms of population density strata, were sent to households across the 12 parishes. To account for the entire adult population at random, the household member who was next to celebrate their birthday, and who was aged 18 years or over, was asked to complete the survey. A total of 2,415 surveys (30%) (age range 19 – 105, Mean = 57.67, SD = 16.3) were returned with 65 of these being unusable. In sum 60% ( $n=1394$ ) of the respondents were female, whilst 40% ( $n=941$ ) were male. Compared to the population profile from the most recent census (States of Jersey, 2011) this represents an estimated sample over-representation of females by approximately 8%. There was less than 2.5% missing data on any variable (range 0.8% - 2.3%).

## **Ethics**

Ethical approval was granted by Lancaster University and by the Government of Jersey, Health and Community Services Ethics Committee in January and March 2017. The capacity to consent process and accompanying documentation were designed using guidance from the Mental Capacity Act (2005) and the National Research Ethics Service ([www.nres.nhs.uk/](http://www.nres.nhs.uk/)). In sum, 85 (39 per cent) participants consented independently, whilst 132 (61 per cent) participated through a personal or nominated consultee process (DoH,

2008). Full details of the consenting procedure for adults with an intellectual disability are outlined in Bowring et al. (2017a, b).

## Measures

The instruments used in this study were extracted from the Jersey Opinions and Lifestyle Survey (States of Jersey, 2017) as these are general measures covering demographics, economic activity and household structure that are aligned to Jersey census variables for annual monitoring.

## Data analysis

Data were analysed using the Statistical Package for the Social Sciences Version 25 (SPSS, Inc., Chicago, IL, USA). Congruent with the paper's aim and to provide a detailed description of employment, marital status and housing activities, descriptive statistics using frequency counts were calculated. The employment, marital status and housing categories in Table I were condensed and binary variables were created to represent: employed (working for an employer, self-employed, employing others, self-employed, not employing others) vs unemployed (unable to work because of long-term sickness/disability, unemployed, looking for work, unemployed, not looking for work); single (single) vs in a current relationship (married/civil partnership and cohabiting (includes same sex couples)); and home owner (owner occupied) vs non-home owner (staff/service accommodation, social housing, registered lodging, lodger paying rent in private household, private qualified rent, other non-qualified accommodation). Supplementary Pearson  $\chi^2$  statistics and Odds Ratios were undertaken to determine potential differences between people with and without intellectual disabilities. Effect size categories for Odds Ratios for 2x2 comparisons were interpreted as small (OR  $\leq 0.82$  or  $\geq 1.22$ ), medium (OR  $\leq 0.54$  or  $\geq 1.86$ ) or large (OR  $\leq 0.33$  or  $\geq 3.00$ ) (Olivier and Bell, 2013).

## Results

Table I displays employment, marital status and housing profiles for both the adult with intellectual disability and the general population samples.

++++++ Insert Table 1 here ++++++

## Employment

There were 19.4% of adults with intellectual disability (n=42) (proxy n=12, self-report n=30) in paid employment, compared to 49.6% (n=1157) of the general population. Just one adult with intellectual disability was self-employed (0.25%) (self-report n=1) compared to 9.2% of the general population (n=214). Excluding retirees, homemakers, individuals in full time education and other categories of employment (Table 1), the prevalence of employment was 94.4% (n=1371) for the general population and 23.6% (n=43) for the intellectual disability population of working aged adults. People with intellectual disabilities were significantly less likely to be employed than the general population ( $X^2=692.19$ ,  $df=1$ ,  $p<0.001$ ) representing a large effect size (OR=54.05 [95% CI: 35.93-81.29]).

Of the general population, 32.9% (n=766) described themselves as retired compared to 7.8% (n=17) of the intellectual disability sample (proxy n=11, self-report n=6). This high retirement prevalence in the general population is reflective of the age structure in Jersey. Seventy-five adults in the general population sample (3.2%) described themselves as homemakers compared to 4 (1.8%) of the intellectual disability sample (proxy n=1, self-report n=3). A large percentage of the intellectual disability sample (35%, n=76) (proxy n=65, self-report n=11) were described as unable to work because of long term sickness or disability, compared to 2.1% (n=50) of the general population. Sixty-three adults with intellectual disability (29%) (proxy n=34, self-report n=29) were described as unemployed, with only 20 (9.2%) (proxy n=6, self-report n=14) actively looking for work.

## **Marital status**

There were 87.1% (n=189) (proxy n=124, self-report n=65) of adults with intellectual disability who were single, compared to 16% (n=373) of the general population. Just 12 adults with intellectual disability (5.5%) (proxy n=1, self-report n=11) were married / in a civil partnership, compared to 51.2% (n=1192) of the general population. There were 3.7% (n=8) (proxy n=1, self-report n=7) adults with intellectual disability cohabiting compared to 6.9% (n=160) of the general population. People with intellectual disabilities were significantly more likely to be single (than married/in a civil partnership/cohabiting) than the general population ( $X^2=428.13$ ,  $df=1$ ,  $p<0.001$ ) representing a large effect size (OR= 34.49 (95% CI: 21.28-55.56)).

## **Housing**

The majority of adults with intellectual disability (56.7%, n=123) (proxy n=98, self-report n=25) lived in sheltered or housing for the disabled, compared to 2.4% (n=54) of the general population, a statistically significant difference ( $X^2=887.01$ ,  $df=1$ ,  $p<0.001$  [OR=52.83 95% CI: 37.04-76.92]) representing a large effect size. Sheltered or disabled housing was defined as residential or nursing care where the person was in receipt of paid care in their usual place of abode. A large number of adults with intellectual disability (35.9%, n=78) (proxy n=31, self-report n=47) lived in social housing or accessed the private rental market (49.3%, n=107) (proxy n=82, self-report n=25). In the general

population fewer people lived in social housing (8.7%, n=202) or rented accommodation (15.2%, n=353). Furthermore, very few adults with intellectual disability lived-in owner-occupied accommodation (8.3%, n=18) (proxy n=12, self-report n=6), with 17 of these living in the home owned by their family. In the general population, 69% (n=1604) of people lived-in owner-occupied accommodation. Overall, people with intellectual disabilities were statistically less likely to live-in owner-occupied accommodation ( $\chi^2=315.75$ ,  $df=1$ ,  $p<0.001$ ) representing a large effect size (OR=24.54 [95% CI:15.03-40.06]). Despite less than 10% of people living in owner-occupied accommodation, 25% (n=55) of the intellectual disability sample lived with family members.

## **Discussion**

The employment, marital status and housing profiles of adults with intellectual disability are very different compared to the general population sample. Despite these being key priority areas for adults with intellectual disability and policy makers, the reality is that outcomes remain poor. In this sample, of working-age adults, 23.5 per cent of adults with intellectual disability were in paid or self-employment compared to 92.4 per cent of the general population. At the first glance, this looks encouraging compared to the estimate of 5.7 per cent for paid/self-employment in England (Hatton, 2018). Further analysis is required to compare what this employment looks like and the level of pay/days worked experienced by both samples. Concerningly, Hatton (2018) suggested that paid employment rates seem to be slightly declining over time in England with a widespread variation across councils in reported paid and self-employment rates. In this sample, 67.4 per cent of adults with intellectual disability in paid employment were male (n 1/4 28), suggesting that employment prospects may be particularly bleak for women with intellectual disability – a common theme in the literature (Hatton, 2018). Further research is required into why only 20 of the 63 adults with intellectual disability listed as unemployed are seeking work and why fewer adults with intellectual disability are listed as retired or are unable to work due to long-term sickness or disability. This may be linked to the earlier mortality ages this population experiences (O’Leary et al., 2018). Regarding seeking work, it may be that proxy respondents perceive that a large number of barriers across different domains prohibit employment (Kocman et al., 2018).

In this study, 9.2 per cent of adults with intellectual disability were either married or in a civil partnership or cohabiting compared to 58.1 per cent of the general population. In a previous study, only 3 per cent of people with intellectual disability were reported to be cohabiting as a couple, in comparison with 70 per cent of the general population (Emerson et al., 2005). Personal relationships can bring happiness, fulfilment, companionship and a greater sense of choice and control over the lives of people with intellectual disability



(Mencap, n.d.). Nonetheless, the reality is that people with an intellectual disability are seldom in relationships and a climate of risk aversion appears to exist regarding supporting and maintaining relationships for people with intellectual disabilities (Bates et al., 2017).

Whilst adults with intellectual disability may have greater support needs, their housing profile is very different compared to the general population. Very few adults with intellectual disability lived-in owner-occupied accommodation, which must decrease the security of their accommodation. This study also suggests that a much lower number of adults with intellectual disability live with their family in Jersey (52 adults per 100,000) compared to England (97.8 adults per 100,000), Scotland (195.1 adults per 100,000) and Wales (203.5 adults per 100,000) (Hatton, 2017). Whilst we cannot determine the cause of this decreased prevalence in Jersey, it may mean that people with intellectual disability who live with family members are potentially less likely to be known to services.

Notwithstanding, there is a dependence on sheltered, social or rented housing potentially reflecting the lower economic status of adults with intellectual disability, possibly perpetuated by the lack of individuals in paid employment. Considering this in terms of median incomes in Jersey, it is clear that the significant majority of adults with intellectual disabilities known to services will never be able to afford to be a home owner in Jersey. This potentially prohibits cohabiting with others as it is difficult to have control when there is no ownership of your own home.

There are four principal limitations to the study that should be kept in mind when considering its results. First, there is a possibility of bias in the general population sample insofar as there is an under representation of males and the percentage of working-age respondents was slightly less (59 vs 67 per cent) when compared to the 2011 census profile (States of Jersey, 2011). However, the corresponding unemployment rate (4.7 vs 5.6 per cent) and marital status of both population samples (married 48 vs 51 per cent; separated 2 vs 2.8 per cent; widowed 10 vs 10.6 per cent) are broadly similar (States of Jersey, 2011). Second, this sample represents individuals known to intellectual disability services and does not represent the “hidden majority” (Emerson and Hatton, 2014) of adults who are not known to services. These adults may be employed, in relationships and/or home owners. Third, there were no data collected on hours worked or history of previous employment for either population. Such data could further improve our interpretation of employment statistics for people with intellectual disabilities. Finally, we have not extended the concept of relationships to include friendships or other social networks which may be present and

equally important for participants in this study. These limitations should be considered when designing future research.

## **Conclusion**

In conclusion, this study illustrates that relatively few people with intellectual disability are in paid work or in current relationships and the majority live in sheltered, social or rented housing models. The reality is that, for adults with intellectual disability, life is very different to that experienced by a substantial majority of the general population.

Improving quality of life for persons with an intellectual disability in Jersey is a critically important issue. The Government of Jersey needs to engage people with intellectual disabilities and their families, along with relevant stakeholders, to ensure that they have the appropriate support to be able to live a better life.

Employment rates for adults with intellectual disabilities in England are lower than the rates reported in this study. This may potentially impact on relationships and home ownership and thus reinforces the view that these are priority areas for all jurisdictions to turn policy into reality for people with intellectual disabilities. This can, in part, be achieved by providing the necessary resources and support arrangements to allow adults with intellectual disabilities to be employed, have relationships and live in their own homes.

## **Acknowledgements**

The authors would like to thank all service users, their families, service providers and support staff who contributed to this research, and also the following research staff who contributed to data collection: Andrea Bowring, Carolann Romeril, Rachel Foster, Callum Gray, Dermot Harrison, Jane Nicole, Judith Russell and Helen Sands. The authors are also very grateful to the Government of Jersey Health and Community Services and Les Amis Services for their support to complete this research.

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**Table 1. Employment, relationship and housing profiles of adults with ID and the general population sample without ID**

| Variable                 |   | Intellectual Disability | General Population   |
|--------------------------|---|-------------------------|----------------------|
| <b>Participants</b>      |   | n = 217                 | n = 2,350            |
| <b>Male</b>              |   | n = 122 (56.2%)         | n = 941 (40.3%)      |
| <b>Female</b>            |   | n = 95 (43.8%)          | n = 1,394 (59.7%)    |
| <b>Relationships</b>     | Single  | n = 189 (87.1%)         | n = 373 (16%)        |
|                          | Married / Civil Partnership                             | n = 12 (5.5%)           | n = 1,192 (51.2%)    |
|                          | Cohabiting (includes same sex couples)                  | n = 8 (3.7%)            | n = 160 (6.9%)       |
|                          | Separated (includes same sex couples)                   | n = 3 (1.4%)            | n = 64 (2.8%)        |
|                          | Divorced  | n = 2 (0.9%)            | n = 291 (12.5%)      |
|                          | Widowed   | n = 3 (1.4%)            | n = 246 (10.6%)      |
|                          | <i>Missing data</i>                                     | <i>n = 0 (0%)</i>       | <i>n = 24 (1%)</i>   |
| <b>Employment</b>        | Working for an employer                                 | n = 42 (19.4%)          | n = 1,157 (49.6%)    |
|                          | Self-employed, employing others                         | n = 0 (0%)              | n = 105 (4.5%)       |
|                          | Self-employed, not employing others                     | n = 1 (0.5%)            | n = 109 (4.7%)       |
|                          | Retired   | n = 17 (7.8%)           | n = 766 (32.9%)      |
|                          | Unable to work because of long-term sickness/disability | n = 76 (35%)            | n = 50 (2.1%)        |
|                          | Unemployed, looking for work                            | n = 20 (9.2%)           | n = 24 (1%)          |
|                          | Unemployed, not looking for work                        | n = 43 (19.8%)          | n = 8 (0.3%)         |
|                          | In full-time education                                  | n = 3 (1.4%)            | n = 10 (0.4%)        |
|                          | A homemaker   | n = 4 (1.8%)            | n = 75 (3.2%)        |
|                          | Other   | n = 11 (5.1%)           | n = 27 (1.2%)        |
|                          | <i>Missing data</i>                                     | <i>n = 0 (0%)</i>       | <i>n = 19 (0.8%)</i> |
| <b>Housing</b>           | Owner occupied  | n = 18* (8.3%)          | n = 1,604 (69%)      |
|                          | Staff/ service accommodation                            | n = 5 (2.3%)            | n = 35 (1.5%)        |
|                          | Social housing  | n = 78 (35.9%)          | n = 202 (8.7%)       |
|                          | Registered lodging                                      | n = 7 (3.2%)            | n = 45 (1.9%)        |
|                          | Lodger paying rent in private household                 | n = 1 (0.5%)            | n = 44 (1.9%)        |
|                          | Private qualified rent                                  | n = 107 (49.3%)         | n = 353 (15.2%)      |
|                          | Other non-qualified accommodation                       | n = 1 (0.5%)            | n = 40 (1.7%)        |
|                          | <i>Missing data</i>                                     | <i>n = 0 (0%)</i>       | <i>n = 27 (1.1%)</i> |
| <b>Sheltered Housing</b> | Sheltered / disabled Housing - Yes                      | n = 123 (56.7%)         | n = 54 (2.4%)        |
|                          | Sheltered / disabled Housing - No                       | n = 94 (43.3%)          | n = 2,240 (97.6%)    |
|                          | <i>Missing Data</i>                                     | <i>n = 0 (0%)</i>       | <i>n = 55 (2.3%)</i> |

\*Of the 18 people reporting that they owned the property they currently lived in, 17 were living in a family home.