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INTRODUCTION

The rights of people with intellectual disabilities to live an 'ordinary life' have featured in government policy (e.g. Department of Health [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% 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 & DoH, 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

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3 UK law in the Human Rights Act (HM Government, 1998), yet there has been little
4
5 research into how many people are actually in relationships (Emerson *et al.*, 2005)
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7 despite it being an important consideration for people with intellectual disability
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9 (Healy *et al.*, 2009). While there is evidence that community-based structures of
10
11 independent and supported living deliver better outcomes than institutions as long as
12
13 they are appropriately set up and managed (Mansell *et al.* 2007), there remains a
14
15 significant number of people with intellectual disabilities in institutional settings
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17 and/or residential care (Hatton, 2017).
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23 A UK based intellectual disability charity - Stay Up Late - in 2014 produced a
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25 “Manifesto for an Ordinary Life” ([https://stayuplate.org/a-manifesto-for-an-ordinary-](https://stayuplate.org/a-manifesto-for-an-ordinary-life/)
26
27 [life/](https://stayuplate.org/a-manifesto-for-an-ordinary-life/)). This featured a number of things people with intellectual disability in the UK were
28
29 consistently asking for at various workshops, forums and conferences. This concurred
30
31 with the aims of all UK intellectual disability Policy and The United Nations Convention
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33 on the Rights of Persons with Disabilities (2007) focusing on community inclusion
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35 (article 19), relationships (article 23) and work and employment (article 27), namely:
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- 40 • The right to have a proper paid job.
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- 42 • The right to have relationships and a sex life.
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- 44 • The right to choose where to live and who to live with.
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50 Indeed, the government paper “Improving The Life Chances of Disabled People”
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52 (Prime Minister Strategy Unit, 2005) stated that by 2025 disabled people in the UK
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54 would be equal members of society.
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3 This paper aims to look at progress against these three aims by examining profiles of
4 employment, marital status and housing between adults with and without intellectual
5 disability in Jersey, Channel Islands. Apart from the Capacity and Self Determination
6 (Jersey) Law (2016) and a generic Disability Strategy (2017) which focused on
7 disability in its broadest sense, Jersey does not have its own specific policy
8 concerning intellectual disability but mirrors English policy and guidance.
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21 METHOD

22 Participants and procedure

23 Jersey Context

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

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16 Data were collected between 2017 and 2018 from a total administrative sample of
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18 adults with intellectual disability known to services in Jersey. Participants were ≥ 18
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20 years of age and administratively defined as having intellectual disability (i.e. were
21
22 receiving, or had received, support from intellectual disability services in Jersey).
23
24 Participants had different levels of intellectual disability ranging from those who lived
25
26 independently to those who required wide-ranging support. In total, 217 adults with
27
28 intellectual disability were recruited (age range 18-84, Mean = 44.5, SD = 16.2),
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30 indicative of a 76% response rate (sampling frame $n = 285$). Just under 50% of
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32 participants were administratively defined as having a mild intellectual disability ($n =$
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34 108), 26% ($n = 56$) as having a moderate intellectual disability, 16% ($n = 34$) as
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36 having a severe intellectual disability and 9% ($n = 19$) as having a profound
37
38 intellectual disability. Fifty-six percent ($n=122$) were male, 44% ($n=95$) female. All
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40 information was collected by face-to-face interview and there were no missing data
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42 in this sample.
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49 General population

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52 Participants were selected using a stratified, random sampling approach. Jersey has
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54 twelve parishes, and these were divided into strata. Each parish was weighted in
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56 terms of population density reflecting the most recent population census and
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58 allowing for net inward migration (States of Jersey, 2011). Addresses were randomly
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3 drawn from the list of residential, active addresses for each parish on the Jersey
4 Land Property Index. Any household which was sampled for one of the previous
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6 Land Property Index. Any household which was sampled for one of the previous
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8 2015, 2016, or 2017 social surveys, or for the Disability Survey in 2015, was
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10 excluded. Following these exclusions, 28,000 households were eligible for inclusion
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12 in the overall sampling frame. Eight thousand surveys, weighted in terms of
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14 population density strata, were sent to households across the 12 parishes. To
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16 account for the entire adult population at random, the household member who was
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18 next to celebrate their birthday, and who was aged 18 years or over, was asked to
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20 complete the survey. A total of 2,415 surveys (30%) (age range 19 – 105, Mean =
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22 57.67, SD = 16.3) were returned with 65 of these being unusable. Sixty percent
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24 (n=1394) of the respondents were female, whilst 40% (n=941) were male. Compared
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26 to the population profile from the most recent census (States of Jersey, 2011) this
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28 represents an estimated sample over-representation of females by approximately
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30 8%. There was less than 2.5% missing data on any variable (range 0.8% - 2.3%).
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36 **Ethics**

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39 Ethical approval was granted by Lancaster University and by the Government of
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41 Jersey, Health and Community Services Ethics Committee in January and March
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43 2017. The capacity to consent process and accompanying documentation were
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45 designed using guidance from the Mental Capacity Act (2005) and the National
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47 Research Ethics Service (NRES) (<http://www.nres.nhs.uk/>). Eighty-five (39%)
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49 participants consented independently, whilst 132 (61%) participated through a
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51 personal or nominated consultee process (DoH, 2008). Full details of the consenting
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53 procedure for adults with an intellectual disability are outlined in Bowring *et al.*
54
55 (2017a) and Bowring *et al.* (2017b).
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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 1 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-Square 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 ≥ 1.22), medium ($OR < 0.54$ or ≥ 1.86) or large ($OR < 0.33$ or ≥ 3.00) (Olivier & Bell, 2013).

RESULTS

Table 1 displays employment, marital status and housing profiles for both the adult with intellectual disability and the general population samples.

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3 *** INSERT TABLE 1 Here ***
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6 **Employment**

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9 There were 19.4% of adults with intellectual disability (n=42) (proxy n=12, self-report
10 n=30) in paid employment, compared to 49.6% (n=1157) of the general population.
11 Just one adult with intellectual disability was self-employed (0.25%) (self-report n=1)
12 compared to 9.2% of the general population (n=214). Excluding retirees,
13 homemakers, individuals in full time education and other categories of employment
14 (Table 1), the prevalence of employment was 94.4% (n=1371) for the general
15 population and 23.6% (n=43) for the intellectual disability population of working aged
16 adults. People with intellectual disabilities were significantly less likely to be
17 employed than the general population ($X^2=692.19$, $df=1$, $p<0.001$) representing a
18 large effect size (OR=54.05 [95% CI: 35.93-81.29]).
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30 Of the general population, 32.9% (n=766) described themselves as retired
31 compared to 7.8% (n=17) of the intellectual disability sample (proxy n=11, self-report
32 n=6). This high retirement prevalence in the general population is reflective of the
33 age structure in Jersey. Seventy-five adults in the general population sample (3.2%)
34 described themselves as homemakers compared to 4 (1.8%) of the intellectual
35 disability sample (proxy n=1, self-report n=3). A large percentage of the intellectual
36 disability sample (35%, n=76) (proxy n=65, self-report n=11) were described as
37 unable to work because of long term sickness or disability, compared to 2.1% (n=50)
38 of the general population. Sixty-three adults with intellectual disability (29%) (proxy
39 n=34, self-report n=29) were described as unemployed, with only 20 (9.2%) (proxy
40 n=6, self-report n=14) actively looking for work.
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56 **Marital Status**

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3 There were 87.1% (n=189) (proxy n=124, self-report n=65) of adults with intellectual
4 disability who were single, compared to 16% (n=373) of the general population. Just
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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 ($X^2=315.75$, $df=1$,

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3 p<0.001) representing a large effect size (OR=24.54 [95% CI:15.03-40.06]). Despite
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5 less than 10% of people living in owner-occupied accommodation, 25% (n=55) of the
6
7 intellectual disability sample lived with family members.
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10 11 12 13 14 **DISCUSSION** 15

16
17 The employment, marital status and housing profiles of adults with intellectual
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19 disability are very different compared to the general population sample. Despite
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21 these being key priority areas for adults with intellectual disability and policy makers,
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23 the reality is that outcomes remain poor.
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27 In this sample, of working age adults, 23.5% of adults with intellectual
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29 disability were in paid or self-employment compared to 92.4% of the general
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31 population. At first glance this looks encouraging compared to the estimate of 5.7%
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33 for paid/self-employment in England (Hatton, 2018). Further analysis is required to
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35 compare what this employment looks like and the level of pay / days worked
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37 experienced by both samples. Concerningly, Hatton (2018) has suggested that paid
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39 employment rates seem to be slightly declining over time in England with a
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41 widespread variation across councils in reported paid and self-employment rates. In
42
43 this sample 67.4% of adults with intellectual disability in paid employment were male
44
45 (n=28), suggesting that employment prospects may be particularly bleak for women
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47 with intellectual disability – a common theme in the literature (Hatton, 2018). Further
48
49 research is required into why only 20 of the 63 adults with intellectual disability listed
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51 as unemployed are seeking work and why fewer adults with intellectual disability are
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53 listed as retired or are unable to work due to long term-sickness or disability. This
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55 may be linked to the earlier mortality ages this population experiences (O'Leary,
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3 Cooper and Hughes-McCormack, 2018). Regarding seeking work, it may be that
4 proxy respondents perceive that a large number of barriers across different domains
5 prohibit employment (Kocman and Weber, 2018).
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10 In this study, 9.2% of adults with intellectual disability were either married or in
11 a civil partnership or cohabiting compared to 58.1% of the general population. In a
12 previous study, only 3% of people with intellectual disability were reported to be
13 cohabiting as a couple, in comparison with 70% of the general population (Emerson
14 *et al.*, 2005). Personal relationships can bring happiness, fulfilment, companionship
15 and a greater sense of choice and control over the lives of people with intellectual
16 disability (Mencap, n.d). Nonetheless, the reality is that people with an intellectual
17 disability are seldom in relationships and a climate of risk aversion appears to exist
18 regarding supporting and maintaining relationships for people with intellectual
19 disabilities (Bates *et al.*, 2017).
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33 Whilst adults with intellectual disability may have greater support needs, their
34 housing profile is very different compared to the general population. Very few adults
35 with intellectual disability lived-in owner-occupied accommodation, which must
36 decrease the security of their accommodation. This study also suggests that a much
37 lower number of adults with intellectual disability live with their family in Jersey (52
38 adults per 100,000) compared to England (97.8 adults per 100,000), Scotland (195.1
39 adults per 100,000) and Wales (203.5 adults per 100,000) (Hatton, 2017). Whilst we
40 cannot determine the cause of this decreased prevalence in Jersey, it may mean
41 that people with intellectual disability who live with family members are potentially
42 less likely to be known to services.
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57 Notwithstanding, there is a dependence on sheltered, social or rented housing
58 potentially reflecting the lower economic status of adults with intellectual disability,
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3 possibly perpetuated by the lack of individuals in paid employment. Considering this
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5 in terms of median incomes in Jersey, it is clear that the significant majority of adults
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7 with intellectual disabilities known to services will never be able to afford to be a
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9 home owner in Jersey. This potentially prohibits cohabiting with others as it is difficult
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11 to have control when there is no ownership of your own home.
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16 There are four principal limitations to the study that should be kept in mind
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18 when considering its results. First, there is a possibility of bias in the general
19
20 population sample insofar as there is an under representation of males and the
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22 percentage of working age respondents was slightly less (59% vs 67%) when
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24 compared to the 2011 census profile (States of Jersey, 2011). However, the
25
26 corresponding unemployment rate (4.7% vs 5.6%) and marital status of both
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28 population samples (married 48% vs 51%; separated 2% vs 2.8%; widowed 10% vs
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30 10.6%) are broadly similar (States of Jersey, 2011). Second, this sample represents
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32 individuals known to intellectual disability services and does not represent the
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34 'hidden majority' (Emerson and Hatton, 2014) of adults who are not known to
35
36 services. These adults may be employed, in relationships and/or home owners.
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38 Third, there was no data collected on hours worked or history of previous
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40 employment for either population. Such data could further improve our interpretation
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42 of employment statistics for people with intellectual disabilities. Finally, we have not
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44 extended the concept of relationships to include friendships or other social networks
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46 which may be present and equally important for participants in this study. These
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48 limitations should be considered when designing future research.
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56 **Conclusion**

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3 In conclusion, this study illustrates that relatively few people with intellectual disability
4 are in paid work or in current relationships and the majority live in sheltered, social or
5 rented housing models. The reality is that, for adults with intellectual disability, life is
6 very different to that experienced by a substantial majority of the general population.
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10 Improving quality of life for persons with an intellectual disability in Jersey is a
11 critically important issue. The Government of Jersey needs to engage people with
12 intellectual disabilities and their families, along with relevant stakeholders, to ensure
13 that they have the appropriate support to be able to live a better life.
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17 Employment rates for adults with intellectual disabilities in England are lower
18 than the rates reported in this study. This may potentially impact on relationships and
19 home ownership and thus reinforces the view that these are priority areas for all
20 jurisdictions to turn policy into reality for people with intellectual disabilities. This can,
21 in part, be achieved by providing the necessary resources and support arrangements
22 to allow adults with intellectual disabilities to be employed, have relationships and
23 live in their own homes.
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30 **Acknowledgements**

31
32 The authors would like to thank all service users, their families, service providers and
33 support staff who contributed to this research. We are grateful to the following
34 research staff who contributed to data collection: Andrea Bowring, Carolann Romeril,
35 Rachel Foster, Callum Gray, Dermot Harrison, Jane Nicole and Judith Russell. We
36 are also very grateful to the Government of Jersey Health and Community Services
37 and Les Amis Services for their support to complete this research.
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Table 1 Employment, marital status and housing profiles of intellectual disability and general population samples

Variable		Intellectual Disability	General Population
Participants		n = 217	n = 2,350
Male		n = 122 (56.2%)	n = 941 (40.3%)
Female		n = 95 (43.8%)	n = 1,394 (59.7%)
Marital Status	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%)
	Missing data	n = 0 (0%)	n = 24 (1%)
Employment	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%)
Missing data	n = 0 (0%)	n = 19 (0.8%)	
Housing	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%)
	Missing data	n = 0 (0%)	n = 27 (1.1%)
Sheltered Housing	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%)
	Missing Data	n = 0 (0%)	n = 55 (2.3%)

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