

Living with family: perceptions of health and subjective well-being of adults with an intellectual disability

J. M. Grey,¹ V. Totsika² & R. P. Hastings²

¹DECIPHer, School of Social Sciences, Cardiff University, Cardiff, UK

²Centre for Educational Development, Appraisal and Research (CEDAR), University of Warwick, Coventry, UK

Abstract

Background: Little is known about the role of living circumstances to the perception of subjective wellbeing (SWB) and health of adults with intellectual disability (ID). The aim of the present study was to examine whether living circumstances impact differently on the perception of health and SWB and whether potential differences persist after accounting for other variables (e.g. level of support needs and reporting method).

Methods: Secondary data analysis was undertaken of a large national survey of adults with an ID in England, aged 16 years and over. Participants were identified as living with family (N = 1528) or living out of home (N = 874).

Results: The results of t-test and chi-square revealed that levels of health and SWB were perceived as being higher for people living with family than those living in out-of-home settings. Multiple linear regression analyses fitted to explore factors associated with these reported differences revealed that, when controlling for other variables, living with family was highly associated with reports of better SWB. Multiple logistic regression revealed that whilst the health status of people living with families were perceived as better, this was only true when their support needs were low. Poorest health outcomes were found for people with highest support needs who lived with family.

Conclusions: On the whole, the health and well-being of adults living with family were perceived more positively than those living out of home. However, potential health disparities exist for those with high support needs who live with family. Further longitudinal research is needed to explore causes and potential solution to these inequalities.

Keywords: adults, family homes, health, intellectual disabilities, socio-economic hardship, well-being

Intellectual disability (ID) is currently the internationally recognised term for a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour (American Psychiatric Association 2013). This term will be used throughout this paper.

Environmental characteristics and living situation play an important role in people's health and subjective well-being (SWB) (Cummins et al. 2003; Stancliffe et al. 2007; Emerson et al. 2012). Living environments as potential determinants of health and SWB received much research interest during, and subsequent to, the deinstitutionalisation of adults with IDs (Emerson & Hatton 1998; Heller et al. 2002; Stancliffe et al. 2007; Perry et al. 2011; Emerson et al. 2012). In their literature review on the effects of deinstitutionalisation, Emerson & Hatton (1996) concluded that living in the community was mostly associated with improved outcomes in quality of life (QoL). Much of the research focus has, however, been on people living in community provision as an evaluative approach to service provision (Schalock et al. 2000; Cummins 2001). Less is known about the health and SWB of people who live under different residential arrangements.

Improved outcomes were evident when not only reviewing evidence from objective indicators, such as leisure or activity participation and social networks (Duvdevany 2008; Felce et al. 2011; Badia et al. 2013), but also using subjective assessments of life satisfaction (Schwartz & Rabinovitz 2003). Felce et al. (2011) used objective indicators of participation in domestic life and community integration to compare QoL of people with IDs living with family and those living out of home (staffed homes or independent living). After controlling for differences in personal characteristics (age, gender, impairments, characteristic of autism, adaptive behaviour skills and challenging behaviours), they found that living in staffed accommodation was significantly associated with greater participation in household activities and greater variety and frequency of social and community activities. Felce et al. (2011) themselves highlight that activity participation does not necessarily indicate an individual's genuine participation in activities, nor the level of satisfaction or happiness gained from activity participation. The data were also restricted to reports by carers and not adults with ID themselves.

Using subjective indicators, Emerson & Hatton (2007a, 2008) found that living in private households (mostly with family) was associated with feeling helpless, whilst living in residential care homes and supported living were associated with self-reported happiness with life and feeling confident. These associations, however, did not remain after controlling for personal characteristics (age, gender, support needs and marital status), socio-economic position and social interactions (e.g. having friends and participation in community activities – see Measures section for full details). Emerson & Hatton's (2007a, 2008) studies only included people with mild or moderate IDs who could self-report. Proxy responses were excluded from the analyses. Therefore, the identified pattern of findings may not apply to people with higher support needs.

A recent study examining racial/cultural disparities in the use of preventative health care services in the USA (Bershady et al. 2014) found an association between type of residence and receipt of preventative care regardless of ethnicity, with individuals living in institutions being most likely to receive preventive care than those living in family homes.

The impact of the UK Welfare Reform Act (2012) upon public funding of accommodation for people with IDs has resulted in priority going to those with greater support needs and a reduction in support to those with low and moderate needs (Mencap 2012). Family homes are, therefore, anticipated to remain one of the main residential options for individuals with IDs for the foreseeable future. This makes gaining an understanding of the health and SWB of people living in different residential settings ever more important. Few large-scale studies have specifically focused on adults who remain living with their families as compared with those living in other community settings.

The present study aimed to enhance our understanding of health and SWB among adults with IDs who do and do not live with their families. We used data from a large national survey of adults with IDs in England (Emerson et al. 2005). We aimed to address two research questions: (1) whether living at home is associated with different perceptions of health (rated as poor or good) and SWB compared with not living at home and (2) whether potential differences remain after accounting for participants' support needs and reporting method (i.e. independently or assisted by a carer). Whilst there are inherent difficulties in using proxy responses to evaluate subjective phenomena (Schwartz & Rabinovitz 2003), which involve self-evaluative and cognitive processes (Kahneman et al. 1999; Ryan & Deci 2001), and this study does not aim to overcome these challenges, by controlling for reporting method, we aim to explore the impact of the response method upon perceived outcomes of health and SWB. This was deemed important as evidence suggests that reports of SWB differ between proxy informants and individuals themselves (e.g. Perry & Felce 2002) and among individuals with different levels of support needs (Emerson & Hatton 2008). We drew on the same national databases as Emerson & Hatton (2007a, 2008), but unlike these earlier studies, we included information from participants of all ability levels, regardless of their reporting method.

We also paid close attention to putative control variables. Based on findings from previous studies, we expected differences in characteristics of adults with IDs based on living circumstances. Adults living with family would likely be younger (e.g. Felce et al. 2011; McConkey et al. 2011), have lower support needs (e.g. McConkey et al. 2011; Nankervis et al. 2011) and experience fewer physical health problems (Martínez-Leal et al. 2011). However, adults living out of home may have greater opportunity for participation in community activities and friendship networks (Emerson & McVilly 2004; Kozma et al. 2009), all factors associated with QoL outcomes (Felce et al. 2011).

Method

The study is based on analysis of data from the UK Department of Health commissioned English survey of adults with IDs in England 2003–2004 (Emerson et al. 2005, obtained from UK Data Services, reference number 10.5255/UKDA-SN-5293-1). The original study recruited participants through five different sampling frames: (1) weekly General Household Omnibus Surveys; (2) local government administrative records of adults with IDs living in private homes; (3) people living in registered residential care homes; (4) supported accommodation and (5) long-term National Health Service accommodation. The aim of this recruitment framework was to be as representative as possible of the English

population of adults with IDs. Full details of the sampling strategy can be found in Emerson & Hatton (2007a). The criteria for inclusion were that respondents were aged 16 (mandatory education ends and eligibility to marry and live outside the family home begins) or over and had an ID, which was defined as, ‘a difficulty with learning which has persisted since childhood and continues to make life difficult for them during their adult years’. People with dyspraxia or cerebral palsy without a concomitant ID were not included.

Experienced staff-conducted interviews using a computer-assisted personal interview method. Questions were designed at three levels of difficulty. Level 1 contained simply ‘yes/no’ questions, which were accessible to the majority of respondents with IDs. For example, ‘Do you ever feel sad or worried?’ Level 2 questions were more complex and were likely to require assistance to answer. For example, ‘Who do you live with – parents, partner/spouse, other family, friends/other residents, paid support worker, alone?’ Level 3 questions were most complex and were not included in the current study as they were not relevant to our research questions.

Flexible wording with pictorial prompts were used on the questionnaires to assist understanding of the different levels of response (e.g. Likert-type scale responses requiring an answer of how much of the time a respondent had felt a certain way; see Emerson et al. 2005, for full details). Response bias and acquiescence were assessed by four questions, three of which related to negative affect (feeling sad, left out and helpless) and one positive affect (feeling confident). Where answers seemed unlikely (i.e. affirmative answers to all four questions), participants were excluded from the original study sample. The final sample of the original survey included 2898 individuals with ID (Emerson et al. 2005).

Variables were identified within the data set in order to address the current research aims. Prior to transforming variables, the data were visually explored for errors, outliers and large cases of missing data. Errors were corrected, and variables were removed from the data set as appropriate where ambiguities or large amounts of missing data rendered them unusable (see Participants section). Listwise deletion was employed where less than 10% of data were missing (Langkamp et al. 2010).

Participants

Adults with IDs living with family were identified and included those living with (1) parents or (2) other family members. Participants in out-of-home placements included those living (1) in residential care homes, (2) supported accommodation or (3) alone. People who were living with a partner/spouse (N = 30), in a long-stay hospital (N = 83) setting or whose responses were unclear were excluded from the study (N = 495 from original study sample). The final sample of 2403 included 1423 (59.2%) men and 980 (40.8%) women, with a mean age of 33.47 (SD = 15.03; age range 16 to 89). Table 1 shows a breakdown of participant characteristics according to residential status. Participants’ support needs ranged from those requiring a high level of support with activities of daily living such as getting dressed in the morning or drinking a cup of tea (N = 30, 1.2%) to those requiring less support to accomplish these tasks (N = 44, 1.8%). The mean support needs scores for the whole study sample was 32.14 (SD 8.12) (scores ranging from 11 = high level of support needs to 44 = low support needs, see Measures section for full details). Just over a quarter of respondents were

interviewed alone (N = 611, 25.6%), with the remaining 75% being interviewed in the presence of a support person (N = 1792, 74.6%). Almost equal numbers responded independently (49%) or with assistance (50%). Level 1 questions were answered by 48% of people and level 2 questions by 33% without assistance. Of those with co-morbid physical health problems, just over 31% (N = 755) reported experiencing at least one physical health problem (see Table 1 for full details).

Table 1: The demographic characteristics of adults with IDs who lived with family and those who lived out of the family home

		Lives with family N (%), or mean (SD)	Lives outside family home N (%), or mean (SD)
		1,528 (63.6%)	874 (36.4%)
Gender	Male	943 (61.7%)	480 (54.9%)
	Female	585 (38.3%)	395 (45.1%)
Age:	16-25	774 (50.7%)	81 (9.2%)
	25-54	638 (41.8%)	502 (57.4%)
	55+	78 (5.1%)	182 (20.8%)
Mean Age		28.27 (12.31)	44.0 (14.69)
Has friends outside of family		1,186 (77.6%)	675 (77.1%)
Mean number of friends outside family		1.21 (0.41)	1.19 (0.39)
Response mode:	Unassisted	711 (46.5%)	475 (54.3%)
	Assisted/proxy reported	817 (53.5%)	400 (45.7%)
Epilepsy		232 (15.2%)	108 (12.4%)
Autism		84 (5.5%)	40 (4.6%)
Down Syndrome		18 (1.2%)	8 (0.9%)
Cerebral Palsy		29 (1.9%)	7 (0.8%)
Sensory difficulties (hearing/sight or both)		199 (13.0%)	82 (9.3%)
Health problem (physical impairment/diabetes/heart or bowel problems/other physical problems)		505 (33.0%)	251 (28.6%)
Mean number of health problems		1.40 (0.49)	1.44 (0.50)
Support needs mean scores (higher scores represent higher ability)		32.44 (8.11)	32.35 (8.16)
Socio-economic hardship (mean number of everyday items goes without due to lack of money see measures section for full list of items)		1.34 (2.21)	0.94 (1.97)
Mean frequency of community activities		4.77 (1.86)	4.89 (1.90)

Measures

Well-being/happiness with life

Five indicators of SWB, two of positive affect (rating of happiness and frequency feels confident/sure of yourself) and three of negative affect (frequency feels sad/worried, left out and helpless) were identified as outcome variables. For uniformity with the four other SWB variables (coded at three levels), 'happiness with life', originally coded at four levels (i.e. 1 = 'very happy', 2 = 'quite happy', 3 = 'sometimes happy/unhappy' and 4 = 'mostly unhappy'), was converted into a three-level variable by combining levels 1 and 2. The five indicators of SWB were then combined to create an SWB composite with scores ranging from 5 (low SWB) to 15 (high SWB). This composite measure had adequate internal consistency (Cronbach's $\alpha = 0.69$).

General health status

Participants were asked to rate their health status or that of the person they support: 1 = 'very good', 2 = 'fairly good' or 3 = 'not good'. In line with the original study, we collapsed the original three-level variable (very good and fairly good health being combined into good health) into a binary coded dichotomous variable (0 = poor health and 1 = good health) to improve conceptual clarity of the construct. Single-item questions on perceived health status have been shown to have good construct validity and reliability (DeSalvo et al. 2006).

Response mode (independently or with assistance/proxy)

Each interview section was marked to indicate whether the person with IDs answered questions alone (coded 1 = mainly person with IDs), with support (coded 2 = mixed) or by a proxy informant (coded 3 = mainly proxy). We collapsed levels 2 and 3 of this variable into a dichotomous variable (0 = 'proxy/assisted interviews' and 1 = 'person with IDs unassisted'). Over 56% of proxy respondents were parents.

Support needs

Eleven items assessed how much help individuals needed to accomplish daily living tasks: (1) getting dressed in the morning, (2) putting on a pair of shoes, (3) having a shower or bath, (4) ordering something to eat or drink in a café, (5) drinking a cup of tea, (6) washing own clothes, (7) making a sandwich, (8) completing a form (e.g. for a job application), (9) finding out what is on TV that night, (10) paying money into a bank or post office and (11) making an appointment (e.g. to see the doctor). Each item was rated on a 4-point scale (1 = 'Someone do it for you' to 4 = 'Can do it on your own'). Items were reverse coded and summed to create an index of support needs (possible scores ranged 11 to 44), with higher scores indicating lower support needs. We used the support needs index as an indicator of the severity of disability as no other adaptive skills measures were available in the survey. This index showed good levels of internal consistency for the study sample (Cronbach's $\alpha = 0.89$).

Socio-economic hardship/deprivation

Nine items derived from the Millennium Poverty and Social Exclusion Survey (Pantazis et al. 2006) assessed socio-economic hardship by counting the number of everyday items (food, new clothes and shoes, heating, telephoning friends and family, visits to the pub/cinema/club, hobby/sport and holiday) to which individuals responded ‘yes’ or ‘no’ to having to go without in the past year because of lack of money. A single indicator of hardship or deprivation was created ranging from 0 (no hardship) to 9 (maximum number of items person had to go without during the past year).

Frequency of community activities

A nine-item scale assessed the level of participation in community-based activities during the preceding month. Activities included (1) going shopping, (2) going to the pub, (3) going for a meal in a restaurant, pub/café, (4) visiting a public library, (5) playing sport/going swimming, (6) visiting friends/family, (7) going to the hairdressers, (8) watching live sport and (9) going to the cinema/a play/concerts. A single variable was created from a count of the number of activities in which a person had participated during the previous month ranging from 0 (no activities) to 9 (maximum number of activities). Similar measures of recreational and social activities have previously been used in QoL studies with individuals with ASD and co-occurring ID (e.g. Bishop-Fitzpatrick et al. 2017).

Social networks

Two variables indicating whether an individual had friends outside of the family (with and without IDs) were transformed into a single variable indicating whether or not the person had any friends with/without ID outside of his or her own family.

Co-morbid physical health conditions

Five items indicating whether participants had a specific physical health problem or physical disability: (1) physical impairment, (2) heart problem, (3) bowel problem, (4) diabetes and (5) other physical problems were combined into a single variable indicating, 0 = ‘no physical problems’ and 1 = ‘yes, at least one physical health problem’. Similarly, two separate variables indicating hearing and sight problems were combined into a single indicator of sensory impairment (0 = ‘no sensory problem’ and 1 = ‘at least one sensory problem’). The rationale for adopting a dichotomous variable for physical health was to assess the impact of the presence of a reported health problem versus the absence of at least one health problem. On average, the study population reported experiencing one physical health problem.

Table 2: Predictors of general health (multiple logistic regression) and well-being (multiple linear regression)

Model	Predictors	Health ¹ Odds Ratio	Wellbeing ² Standardised beta values
Step 1	Living with family	1.53 *	0.03
	Support needs	1.01	0.08 *
	Independent responding	0.56 ***	0.04
	Living circumstances x support needs interaction term	1.05 *	0.06
Step 2	Living with family	1.65 *	0.13 ***
	Support needs	0.98	0.10 **
	Independent responding	0.70 *	0.06 **
	Living circumstances x support needs interaction term	1.05 *	0.05
	Age	0.99	0.16 ***
	Female gender	0.82	-0.00
	Community activities	1.17 ***	0.05 *
	Hardship	0.82 ***	-0.22 ***
	Has friends outside of the family	1.47 *	0.13 ***
	Has generic illness/physical disability	0.33 ***	-0.04
	Has sensory problems	0.58 *	-0.02
	Epilepsy	0.62 **	0.02
Autism	0.66	-0.03	

*p<.05, **p<.01, ***P<.001

¹ General health status was coded 0 (poor) and 1 (good health)

² Well-being ranged from 1-15, with higher scores indicating higher well-being levels.

Bold figures indicate where there are significant associations.

Results

To address our first research question, we compared perceived health status and SWB between people with IDs living with family and those living out of home. A significant *t-test* result ($t_{(1415)} = 4.94, P < 0.001$) indicated that people living with family reported higher levels of SWB ($M = 11.44, SD = 2.50$) than those living in out-of-home settings ($M = 10.79, SD = 3.38$). An effect size of 0.23 (95% CI 0.14–0.31), estimated as a standardised mean difference (using the pooled standard deviation, $SD_{pooled} = 2.85$), indicated a small significant difference.

A significant chi-square ($\chi^2(1, N = 2379) = 8.15, P = 0.004$) indicated that more people living out of home reported poor health (16.2%) compared with people living with family (12%). An estimated odds ratio [OR 1.41, 95% confidence interval (CI) 1.11–1.79] indicated that the odds of reporting poorer health were almost one and a half times higher when living out of the family home.

To address the second research question, we fitted two multiple regression models: a multiple linear regression to identify significant associates of SWB and a multiple logistic regression for perceived health status (Table T2 2). A significant moderate correlation between support needs and response mode ($r_{pb} = 0.55, P < 0.001$) unsurprisingly suggested that people with lower support needs were more likely to report independently. This finding, in addition to previous research demonstrating little relationship between proxy and self-reports of subjective phenomena (e.g. Perry & Felce 2002) suggested we also needed to account for response mode. Research suggests an association between level of disability and residential status (e.g. Borthwick-Duffy et al. 1987; Lowe et al. 1998). We therefore accounted for the potential interaction between support needs and living circumstances (Blacher & Baker 1994; Lowe et al. 1998; Nankervis et al. 2011). Hierarchical forced entry methods were used to fit predictors, which were also grand-mean centred when continuous (i.e. age, support needs, community activities and socioeconomic hardship) to reduce the potential for multicollinearity and ease interpretation (Kraemer & Blasey 2004).

Well-being (Table 2)

At step 1, variables significantly accounted for a small percentage (2.6%) of SWB score variance ($R^2 = 0.026, F_{4, 2147} = 14.60, P < 0.001$). With the exception of support needs, which were significantly positively associated with SWB ($\beta = 0.081, P = 0.04$), indicating that those with higher ability reported more positive SWB, all other variables showed no significant association with SWB (i.e. living circumstances, main respondent and the interaction term living circumstances by support needs). The additional variables (age, gender, hardship, community activities, friendships and health) entered at step 2 significantly accounted for 13% of variance in SWB (R^2 change = 0.130, $F_{13, 2138} = 28.25, P < 0.001$). When the effects of all other variables were controlled, living with family ($\beta = 0.129, P < 0.001$) was highly positively associated with reports of SWB. Support needs remained independently positively associated with SWB, showing an increased beta value ($\beta = 0.101, P = 0.01$). Other variables positively associated with SWB were age ($\beta = 0.157, P < 0.001$), responding independently ($\beta = 0.06, P = 0.01$), having friends outside the family ($\beta = 0.129, P < 0.001$) and taking part in a greater number of community activities ($\beta = 0.05,$

$P = 0.02$). Greater levels of hardships were associated with lower SWB ($\beta = -0.221$, $P < 0.001$). No associations were found between SWB and gender, physical health problems, sensory problems, the presence of autism and epilepsy. The interaction term of living circumstances and support needs also showed no significant association with SWB.

General health (Table 2)

At step 1, the model significantly predicted perceived health status ($\chi^2_{(4, N = 1965)} = 44.35$, $P < 0.001$), with 86.8% of cases correctly classified by the model. Living circumstances and the interaction of living circumstances by support needs were significantly positively associated with perceived health status. Independent responding was negatively associated with perceived health status. This suggests that living with family was associated with perception of better health; however, self-reporting was associated with more negative reports of health. With the addition of age, gender, hardship, community activities, friendships and physical health problems at step 2, the model remained significant ($\chi^2_{(14, N = 1965)} = 244.33$, $P < 0.001$), with 88% of cases correctly classified by the model. Step 2 of the model showed that people with IDs living with family were over one and a half times more likely to report better health status than people living in other community settings, OR = 1.65 (95% CI 1.19–2.28), $P = 0.003$. Other associates of positive health status were taking part in a greater number of community activities [OR = 1.17 (95% CI 1.08–1.27), $P < 0.001$] and having friends outside of the family [OR = 1.47 (95% CI 1.06–2.03), $P = 0.02$]. Negative associates of health status were independent responding [OR = 0.70 (95% CI 0.50–0.99), $P = 0.04$], hardship [OR = 0.82 (95% CI 0.78–0.87), $P < 0.001$], having more physical health problems [OR = 0.33 (95% CI 0.25–0.44), $P < 0.001$], having sensory problems [OR = 0.58 (95% CI 0.41–0.83), $P = 0.003$] and having epilepsy [OR = 0.61 (95% CI 0.43–0.87), $P = 0.01$]. Support needs, age, gender and the presence of autism were not significantly associated with health status.

The interaction term (living circumstances by support needs) was significantly associated with positive health status [OR = 1.04 (95% CI 1.01–1.08), $P = 0.01$]. To investigate this interaction further, we recoded the support needs variable (using the mean of the original interval-level variable and one standard deviation around the mean) into a three-level ordinal variable (i.e. 0 = high support needs, 1 = moderate support needs and 2 = low support needs). Using the predicted probability of reporting good health, we plotted the three levels of support needs, to explore whether living with family and living outside family homes were differentially related to the predicted probability of reporting poor health according to level of support need (Fig. 1). People with moderate and low support needs who lived with family were more likely to report positive health outcomes than those living in other community settings. However, people with higher support needs living with family showed a greater likelihood of reporting poorer health compared with those living outside of family homes. Further simple slope analysis for the interaction terms showed a significant values for the unstandardised slopes of 0.443, $t = 2.696$ and $P = 0.01$, for lower support needs and 1.009, $t = 6.140$ and $P < 0.001$, for higher support needs (Dawson 2014).

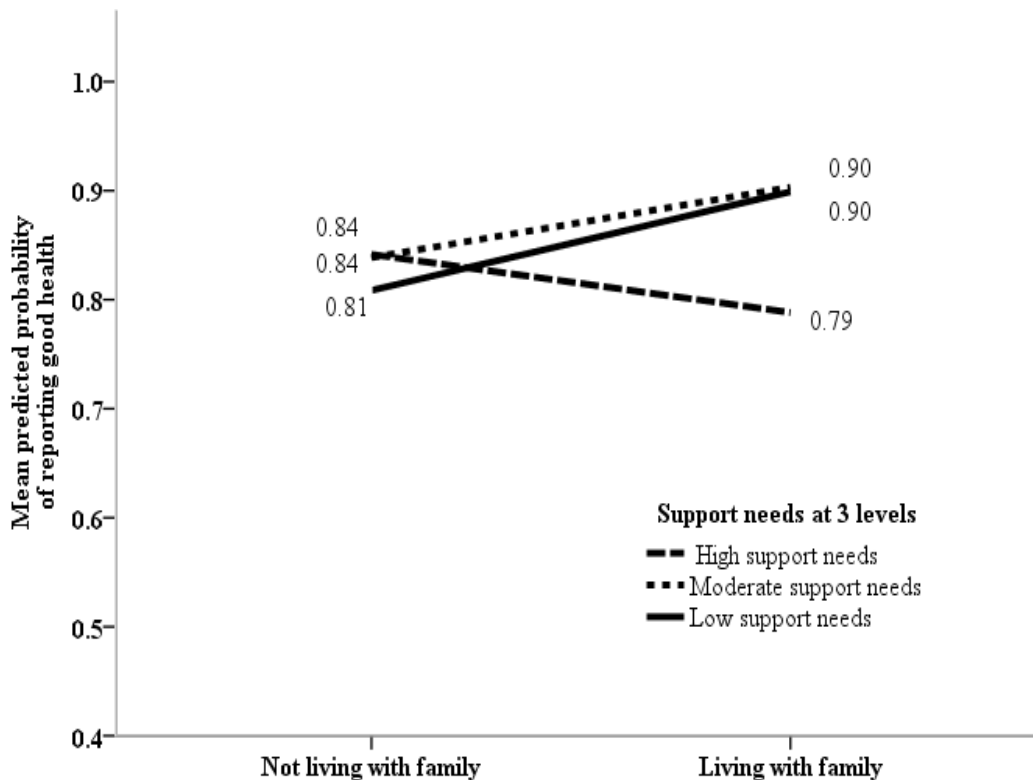


Figure 1: The probability of reporting good physical health among people with low, moderate and high support needs who live in family homes and those who live outside of home ($P < 0.001$). Simple slope analysis for the interaction terms showed a value for the unstandardised slope 0.443, $t = 2.696$, $P = 0.01$, for lower support needs and unstandardised slope of 1.009, $t = 6.140$ and $P < 0.001$, for higher support needs.

Discussion

The present study compared perceptions of health and SWB among adults with IDs who do and do not live with family. Initial between group comparisons indicated that the health and SWB of people living with family were perceived more positively than those living out of the family home. Importantly, after accounting for factors related to health and SWB, living with family was still significantly associated with better health and SWB. Interestingly, however, further investigation of the interaction between living circumstances and support needs revealed that the health of those who lived with family was only perceived as better, when their support needs were lower (Fig. 1).

The current findings support previous studies, which suggest that family homes provide living environments conducive to emotional SWB, which may be less well met in out-of-home community settings. Evidence suggests that families provide emotional as well as instrumental support to their relative (Scott et al. 2013; Seltzer et al. 1991; Seltzer & Krauss 2001). A large proportion of friendship networks for adults living out-of-home comprise paid support workers (Forrester-Jones et al. 2006; Bigby 2008). Staff turnover within residential settings is often high, resulting in inconsistent and transient friendships. The opportunity to develop emotionally supportive relationships within these settings may, therefore, be limited (Bigby 2008). The results highlight the importance of ensuring that people living in community residencies are supported to develop meaningful relationships, and, where possible, maintain contact with family. Contrary to expectation (Martínez-Leal et

al. 2011), the poorest health outcomes were found for people with the highest support needs who live with family. Obviously, the mixed reporting methods cannot be ruled out as influencing these outcomes. The limited evidence on the effect of proxy responses has demonstrated some concurrence of responses, with families' responses appearing most reliable (McVilly et al. 2000; Schwartz & Rabinovitz 2003). Therefore, proxy respondents of those living out-of-family homes may be less reliable. Individuals living with family in the current study did report the greatest hardship; therefore, associations between socio-economic position and an increased vulnerability to ill health across the life course (Emerson & Hatton 2007c) cannot be ruled out. This finding raises particular concerns for families who may be experiencing increased hardship because of radical welfare reforms such as the spare room subsidy. This finding may also suggest potential disparities experienced by those with greater support needs when accessing healthcare facilities and health promotions (Bershinsky et al. 2014; Emerson & Hatton 2007c). Further research is needed, together with a cost analysis of the impact of the welfare reforms upon the health and SWB of individuals with ID and their family carers. More flexible ways of ensuring access to health care provision, together with specialist training in understanding the needs of people with IDs and their families, are also needed for healthcare personnel (Melville et al. 2006; Mencap 2007). A whole family-centred approach to health provision, which acknowledges the role of families in identifying a relative's health needs, should also be adopted (Emerson & Baines 2010). The final regression models also identified seven predictor variables independently associated with health and five with SWB (Table 2). Consistent with previous research are the associations found between having more friends, less hardship and better general health and SWB (Emerson & Hatton 2007a, 2008; Hertzman & Boyce 2010), greater participation in community activities and better health (Felce et al. 2011), independent responding and poorer health and older age and better SWB (Emerson & Hatton 2007a, 2008).

The final regression models also identified seven predictor variables independently associated with health and five with SWB (Table 2). Consistent with previous research are the associations found between having more friends, less hardship and better general health and SWB (Emerson & Hatton 2007a, 2008; Hertzman & Boyce 2010), greater participation in community activities and better health (Felce et al. 2011), independent responding and poorer health and older age and better SWB (Emerson & Hatton 2007a, 2008).

Despite reporting better levels of health and SWB, adults living in family homes were experiencing greater hardship (Table 1). As discussed earlier, long term implications to both physical and mental health of SE hardship and potential health inequalities (Emerson 2015) should raise concerns for policymakers.

Over a third of study participants [the majority of whom (96%) lived with family] were identified as not receiving service support (e.g. housing, welfare and employment support). Much of what is known about the health and SWB of adults with IDs derives from studies focusing on people who most likely receive service support (e.g. Janicki et al. 2002). The inclusion of participants traditionally less likely to take part in research ensures a wider representation of adults with IDs and adds to the strength of the study. Previous research suggests that those who are not receiving service support have a greater propensity of experiencing hardship and social isolation and are less likely to participate in community activities, factors associated with poorer outcomes of health and SWB (Lynch et al. 1997; Pinquart & Sörensen 2000; Park et al. 2002; Emerson & Hatton 2007a,b,c, 2008; Emerson 2011).

Whilst the aim of the present study was not to overcome the difficulties related to gathering data on subjective phenomena via proxy respondents, including data from participants of all ability levels did afford an exploration of the perceived health and SWB of individuals with a range of support needs and avoid disenfranchising those with more severe ID (Hatton 1998). However, cautious interpretation of the findings is needed, as our current understanding of the effect of proxy reporting for subjective outcomes is not clear. Research has shown varying results in the effect of proxy reporting, with proxy reports from family members appearing more reliable than those of paid support staff (McVilly et al. 2000; Schwartz & Rabinovitz 2003). The results should therefore only be used as a predictor of a person's health and SWB (Schwartz & Rabinovitz 2003) until a better understanding of the cognitive processes underlying responses on subjective phenomena is known (Fujiura and the RRTC Expert Panel on Health Measurement 2012). More research exploring these factors is needed.

There are a number of limitations of the study some of which have been discussed earlier. Additionally, the cross-sectional design can only reveal associations and not causal relationships of health and SWB. Whilst the questions on SWB were based on those used in the Millennium Poverty and Social Exclusion Survey (Pantazis et al. 2006), the original survey from which data were extracted was not specifically designed to evaluate subjective SWB (Emerson et al. 2005), and therefore, analysis was undertaken on available data related to SWB. To address these limitations, further longitudinal research is needed to verify the robustness of the SWB scale and to potentially enable predictions of outcomes of subjective health and SWB for adults with IDs living with family.

A further limitation is drawing on data collected before the worldwide economic recession. The impact of the subsequent recession upon social care budgets and changes in local authorities' eligibility criteria for service support have resulted in families adopting a considerable proportion of ongoing support of a relative with ID within their homes (Learning Disability Coalition 2012). Therefore, the findings from the current study raise concerns for families who will now be coping with supporting their family member within the context of decreasing resources. Further large-scale research is urgently needed to understand the implications of social care cutbacks upon individuals with disabilities and their family carers.

Implications for research, policy and practice

From a policy and practice perspective, living with family appears to be residential model that promotes SWB among adults with ID. Strategies to raise awareness of available health interventions (e.g. annual health checks) and to increase uptake of health promotion for families who support their relatives at home should be considered. Strategies for supporting and enabling adults with IDs living in out-of-home settings to develop peer friendships and maintain contact with family should also be considered. Further research is needed to explore the first-hand experiences of adults with IDs and their family carer of health service delivery, with the aim of ensuring a service that is fit for all people with IDs. Further longitudinal research is also needed to explore causes and potential solutions to inequalities experienced by adults with IDs living with families and assess the long-term impact of these inequalities upon health and SWB.

Acknowledgements

This research was supported by the School of Psychology, Bangor University, Gwynedd, North Wales, UK, Mencap Cymru and Cartrefi Cymru. This study was funded by the Knowledge Economy Skills Scholarships (KESS), European Social Fund.

Conflict of Interest

The authors declare that there is no conflict of interest.

References

- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn. American Psychiatric Publishing, Arlington, VA.
- Badia M., Orgaz M. B., Verdugo M. Á., Ullán A. M. & Martínez M. (2013) Relationships between leisure participation and quality of life of people with developmental disabilities. *Journal of Applied Research in Intellectual Disabilities* 26, 533–45. <https://doi.org/10.1111/jar.12052>.
- Bershadsky J., Hiersteiner D., Fay M. L. & Bradley V. (2014) Race/ethnicity and the use of preventive health care among adults with intellectual and developmental disabilities. *Medical Care* 52, S25–S31. <https://doi.org/10.1097/MLR.0000000000000130>.
- Bigby C. (2008) Known well by no-one: trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability* 33, 148–57. <https://doi.org/10.1080/1366825080209>.
- Bishop-Fitzpatrick L., Smith DaWalt L., Greenberg J. S. & Mailick M. R. (2017) Participation in recreational activities buffers the impact of perceived stress on quality of life in adults with autism spectrum disorder. *Autism Research* 10, 973–82.
- Blacher J. & Baker B. L. (1994) Out-of-home placement for children with retardation: family decision making and satisfaction. *Family Relations*, 10–15 doi: <http://www.jstor.org/stable/585136>.
- Borthwick-Duffy S. A., Eyman R. K. & White J. F. (1987). Client characteristics and residential placement patterns. *American Journal of Mental Deficiency* 92, 24–30.
- Cummins R. A. (2001) Living with support in the community: predictors of satisfaction with life. *Mental Retardation and Developmental Disabilities Research Reviews* 7, 99–104.
- Cummins R. A., Eckersley R., Pallant J., Van Vugt J. & Misajon R. (2003) Developing a national index of subjective wellbeing: the Australian unity wellbeing. *Social Indicators Research* 64, 159–90.
- Dawson J. F. (2014) Moderation in management research: what, why, when and how. *Journal of Business and Psychology* 29, 1–9.
- DeSalvo K. B., Fisher W. P., Tran K., Blosner N., Merrill W. & Peabody J. (2006) Assessing measurement properties of two single-item general health measures. *Quality of Life Research* 15, 191–201. <https://doi.org/10.1007/s11136-005-0887-2>.
- Diener E. & Lucas R. E. (1999) Personality and subjective well-being. In: *Well-being: The Foundation of Hedonic Psychology*. (eds D. Kahneman, E. Diener & N. Schwarz), pp. 213–29. Russell Sage Foundation, New York.
- Duvdevany I. (2008) Do persons with intellectual disability have a social life? The Israeli reality. *Salud, Publica México* 50, 222–9. <https://doi.org/10.1590/S0036-36342008000800016>.
- Emerson E. (2011) Health status and health risks of the “hidden majority” of adults with intellectual disability. *Intellectual and Developmental Disabilities* 49, 155–65. <https://doi.org/10.1352/1934-9556-49.3.155>.
- Emerson, E., 2015. The determinants of health inequities experienced by children with learning disabilities. Public Health England.
- Emerson, E., & Baines, S., 2010. Health inequalities and people with learning disabilities in the UK: improving health & lives: learning disability observatory.
- Emerson E. & Hatton C. (1996) Deinstitutionalization in the UK and Ireland: outcomes for service users. *Journal of Intellectual and Developmental Disability* 21, 17–37. <https://doi.org/10.1080/13668259600033021>.

- Emerson E. & Hatton C. (1998) Residential provision for people with intellectual disabilities in England, Wales and Scotland. *Journal of Applied Research in Intellectual Disabilities* 11, 1–4. <https://doi.org/10.1111/j.1468-3148.1998.tb00030.x>.
- Emerson E. & Hatton C. (2007a) Socioeconomic disadvantage, social participation and networks and the self-rated health of English men and women with mild and moderate intellectual disabilities: cross sectional survey. *The European Journal of Public Health* 18, 31–7. <https://doi.org/10.1093/eurpub/ckm041>.
- Emerson E. & Hatton C. (2007b) Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. *American Journal on Mental Retardation* 112, 140–50.
- Emerson E. & Hatton C. (2007c) Poverty, socioeconomic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication. *Journal of Intellectual Disability Research* 51, 866–74. <https://doi.org/10.1111/j.1365-2788.2007.00951.x>.
- Emerson E. & Hatton C. (2008) Self-reported well-being of women and men with intellectual disabilities in England. *American Journal on Mental Retardation* 113, 143–55. [https://doi.org/10.1352/0895-8017\(2008\)113%5B143:SWOWAM%5D2.0.CO;2](https://doi.org/10.1352/0895-8017(2008)113%5B143:SWOWAM%5D2.0.CO;2).
- Emerson E., Llewellyn G., Honey A. & Kariuki M. (2012). Lower well-being of young Australian adults with self reported disability reflects their poorer living conditions rather than health issues. *Australian and New Zealand Journal of Public Health* 36, 176–82. <https://doi.org/10.1111/j.1753-6405.2011.00810.x>.
- Emerson, E., Malam, S., Davies, I., & Spencer, K., 2005. Adults with learning difficulties in England 2003/04 (available at http://www.esds.ac.uk/doc/5293/mrdoc/UKDA/UKDA_Study_5293_Information.htm)
- Emerson E. & McVilly K. (2004) Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Applied Research in Intellectual Disabilities* 17, 191–7. <https://doi.org/10.1111/j.1468-3148.2004.00198.x>.
- Felce D., Perry J. & Kerr M. (2011) A comparison of activity levels among adults with intellectual disabilities living in family homes and out-of-family placements. *Journal of Applied Research in Intellectual Disabilities* 24, 421–6. <https://doi.org/10.1111/j.1468-3148.2010.00620.x>.
- Forrester-Jones R., Carpenter J., Coolen-Schrijner P., Cambridge P., Tate A., Beecham J. et al. (2006) The social networks of people with intellectual disability living in the community 12 years after resettlement from long stay hospitals. *Journal of Applied Research in Intellectual Disabilities* 19, 285–95. <https://doi.org/10.1111/j.1468-3148.2006.00263.x>.
- Fujiura G. T. & the RRTC Expert Panel on Health Measurement (2012) Self-reported health of people with intellectual disability. *Intellectual and Developmental Disabilities* 50, 352–69. <https://doi.org/10.1352/1934-9556-50.4.352>.
- Hatton C. (1998) Whose quality of life is it anyway? Some problems with the emerging quality of life consensus. *Mental Retardation* 36, 104–5.
- Heller T., Miller A. B. & Hsieh K. (2002) Eight year follow up of the impact of environmental characteristics on wellbeing of adults with developmental disabilities. *Mental Retardation* 40, 366–78. [https://doi.org/10.1352/0047-6765\(2002\)040%3C0366:EYFUOT%3E2.0.CO;2](https://doi.org/10.1352/0047-6765(2002)040%3C0366:EYFUOT%3E2.0.CO;2).
- Hertzman C. & Boyce T. (2010) How experience gets under the skin to create gradients in developmental health. *Annual Review of Public Health* 31, 329–47. <https://doi.org/10.1146/annurev.publhealth.012809.103538>.

- Janicki M. P., Davidson P. W., Henderson C.M., McCallion P., Taets J. D., Force L. T. et al. (2002) Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research* 46, 287–98. <https://doi.org/10.1046/j.1365-2788.2002.00385.x>.
- Kozma A., Mansell J. & Beadle-Brown J. (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. *Journal of Intellectual Disability Research* 114, 193–222. <https://doi.org/10.1352/1944-7558-114.3.193>.
- Kraemer H. C. & Blasey C. M. (2004) Centring in regression analyses: a strategy to prevent errors in statistical inference. *International Journal of Methods in Psychiatric Research* 13, 141–51 <http://eduratio.be/TMP/kraemer.pdf>.
- Langkamp D. L., Lehman A. & Lemeshow S. (2010) Techniques for handling missing data in secondary analyses of large surveys. *Academic Pediatrics* 10, 205–10.
- Learning Disability Coalition (2012). *Social care in crisis – the need for reform*. Learning Disability Coalition, London.
- Lowe K., Felce D., Perry J., Baxter H. & Jones E. (1998) The characteristics and residential situations of people with severe intellectual disability and the most severe challenging behaviour in Wales. *Journal of Intellectual Disability Research* 42, 375–89. <https://doi.org/10.1046/j.1365-2788.1998.00154.x>.
- Lynch J. W., Kaplan G. A. & Shema S. J. (1997) Cumulative impact of sustained economic hardship on physical, cognitive, psychological, and social functioning. *New England Journal of Medicine* 337, 1889–95. <https://doi.org/10.1056/NEJM199712253372606>.
- Martínez-Leal R., Salvador-Carulla L., Linehan C., Walsh P., Weber G., Van Hove G. et al. (2011) The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe. *Journal of Intellectual Disability Research* 55, 858–72. <https://doi.org/10.1111/j.1365-2788.2011.01439.x>.
- McVilly K. R., Burton-Smith R. M. & Davidson J. A. (2000) Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual and Developmental Disability* 25, 19–39.
- Melville C. A., Cooper S. A., Morrison J., Finlayson J., Allan L., Robinson N. et al. (2006) The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services. *Journal of Intellectual Disability Research* 50, 11–17. <https://doi.org/10.1111/j.1365.2788.2005.007719.x>.
- Mencap, 2007. *Death by Indifference*. London: Mencap. www.mencap.org.uk/deathbyindifference (Retrieved 15/10/14).
- Mencap (2012) *Housing for People with a Learning Disability*. Mencap, London https://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report_V7.pdf (Retrieved 15/10/14).
- McConkey R., Kelly F., Mannan H. & Craig S. (2011) Moving from family care to residential and supported accommodation: national, longitudinal study of people with intellectual disabilities. *American Journal on Intellectual and Developmental Disabilities* 116, 305–14. <https://doi.org/10.1352/1944-7558-116.4.305>.
- Nankervis K., Rosewarne A. & Vassos M. (2011) Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *Journal of Intellectual Disability Research* 55, 422–33. <https://doi.org/10.1111/j.1365-2788.2011.01389.x>.
- Pantazis C., Gordon D. & Levitas R. (eds) (2006) *Poverty and Social Exclusion in Britain: The Millennium Survey*, p. 488. Policy Press, Bristol.

- Park J., Turnbull A. P. & Turnbull H. R. (2002) Impact of poverty on quality of life in families of children with disabilities. *Exceptional Children* 68, 151–70 Available from http://www.beachcenter.org/research/FullArticles/PDF/FQL1_Impacts%20of%20poverty%20on%20Quality.pdf.
- Perry J. & Felce D. (2002) Subjective and objective quality of life assessment: responsiveness, response bias, and resident: proxy concordance. *Mental Retardation* 40, 445–56. [https://doi.org/10.1352/0047-6765\(2002\)040%3C0445:SAOQOL%3E2.0.CO;2](https://doi.org/10.1352/0047-6765(2002)040%3C0445:SAOQOL%3E2.0.CO;2).
- Perry J., Felce D., Allen D. & Meek A. (2011) Resettlement outcomes for people with severe challenging behaviour moving from institutional to community living. *Journal of Applied Research in Intellectual Disabilities* 24, 1–7. <https://doi.org/10.1111/j.1468-3148.2010.00567.x>.
- Pinquart M. & Sörensen S. (2000) Influences of socioeconomic status, social networks and competence on subjective well-being in later life: a meta-analysis. *Psychology and Aging* 15, 187–224. <https://doi.org/10.1037/0882-7974.15.2.187>.
- Ryan R. M. & Deci E. L. (2001) On happiness and human potentials: a review of research on hedonic and eudaimonic well-being. *Annual Review of Psychology* 52, 141–66.
- Schalock R. L., Bonham G. S. & Marchand C. B. (2000) Consumer based quality of life assessment: a path model of perceived satisfaction. *Evaluating and Program Planning* 23, 77–87.
- Schwartz C. & Rabinovitz S. (2003) Life satisfaction of people with intellectual disability living in community residences: perceptions of the residents, their parents and staff members. *Journal of Intellectual Disability Research* 47, 75–84.
- Scott M., Foley K. R., Bourke J., Leonard H. & Girdler S. (2013) “I have a good life”: the meaning of well-being from the perspective of young adults with Down syndrome. *Disability and Rehabilitation*, 1–9. <https://doi.org/10.3109/09638288.2013.854843>.
- Seltzer G. B., Begun A., Seltzer M. M. & Krauss M. W. (1991) Adults with mental retardation and their aging mothers: impacts of siblings. *Family Relations*, 310–17.
- Seltzer M. M. & Krauss M. W. (2001) Quality of life of adults with mental retardation/developmental disabilities who live with family. *Mental Retardation and Developmental Disabilities* 7, 105–14.
- Stancliffe R. J., Lakin K. C., Doljanac R., Byun S. Y., Taub S. & Chiri G. (2007) Loneliness and living arrangements. *Intellectual and Developmental Disabilities* 45, 380–90. [https://doi.org/10.1352/1934-9556\(2007\)45%5B380:LALA%5D2.0.CO;2](https://doi.org/10.1352/1934-9556(2007)45%5B380:LALA%5D2.0.CO;2).