Title: The factors associated with care-related Quality of Life of adults with Intellectual Disabilities in England: Implications for Policy and Practice

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Abstract

Over the last three decades, quality of life (QoL) has been advocated as an indicator of social care outcomes for adults with intellectual disabilities. In England, the Adult Social Care Survey (ASCS) is conducted annually by local authorities to contribute to the evidence base of the care-related QoL of people receiving publicly-funded adult social care. This study explores relationships between QoL and non-care related factors to identify relationships that could inform social care policy and practice. Cross-sectional data collected from 13,642 adults who participated in the 2011 and 2012 ASCS were analysed using regression to explore the factors associated with QoL measured using the Adult Social Care Outcomes Toolkit (ASCOT). Self-rated health, rating of the suitability of home design and anxiety/depression were all found to be significantly associated with ASCOT. Other individual and survey completion factors were also found to have weak significant relationships with ASCOT. The models also indicate that there was an increase in overall ASCOT-QoL and in five of the eight ASCOT domains (*Personal comfort and cleanliness, Safety, Social participation, Occupation* and *Dignity*) between 2011 and 2012. These findings demonstrate the potential value of QoL data for informing policy for people with intellectual disabilities by identifying key factors associated with QoL, the characteristics of those at risk of lower QoL, and QoL domains that could be targeted for improvement over time. Future research should establish causal relationships and explore the risk-adjustment of scores to account for variation outside of the control of social care support.

Key Words: learning disabilities; intellectual disabilities; quality of life; adult learning disability services; Community Care and Learning Disabilities

What is known about the topic?

- Quality of life (QoL) has been advocated as an indicator to assess social care for adults with intellectual disabilities.
- Variation in QoL is associated with individual, environmental or survey-related factors that are unrelated to the effect of social care.
- Interpreting and applying QoL data to improve policy and practice would be supported by an understanding of the associations between QoL and these non-care-related factors.

What this paper adds

- After controlling for other factors, there is evidence for an improvement over time in five of the eight domains of care-related QoL.
- Health-related variables are key predictors of care-related QoL.
- Associations between individual characteristics and QoL identify areas for further exploration of causal relationships.

Introduction

Over the last three decades, quality of life (QoL) has been advocated as an indicator of the quality and effectiveness of social care policy and practice for adults with intellectual disabilities (ID) (Schalock *et al.* 2002, Schalock, 2004, Schalock *et al*. 2008, Verdugo and Schalock, 2009). The measurement of QoL has been advanced to enable those who use social care services to have a voice in defining the quality of care, driving provider-level change and shaping policy strategy (Schalock et al., 2002, Schalock, 2004, Brown & Brown, 2005, Verdugo & Schalock, 2009, Verdugo et al., 2012). This trend is situated within the wider movement towards outcomes-based performance management across the public sector (Heinrich, 2003, Bovaird, 2012).

The UK has been at the forefront of this outcomes-based approach (Bovaird, 2012) and has developed an 'outcomes framework' for the adult social care sector in England, known as the 'Adult Social Care Outcomes Framework' (ASCOF) (Department of Health, 2011). Within the ASCOF, the Adult Social Care Outcomes Toolkit (ASCOT) provides a measure of care-related QoL (Netten et al., 2011, Netten et al., 2012, Malley et al., 2012). Social care in England includes a range of support services designed to enable individuals to undertake everyday activities: for example, personal hygiene and social participation. The intention is that the indicators within ASCOF are used to provide a social care evidence base to support local and central policy-making, as well as to improve the quality of services by guiding local management decisions and to increase transparency of performance in each locality (Department of Health, 2012a, Department of Health, 2013). The inclusion of the ASCOT measure in the ASCOF aims to ensure that the voice of service users is at the heart of policy decisions and innovations designed to improve social care policy and practice (Department of Health, 2011).

Although there are strong arguments in favour of using QoL to inform policy and drive systems-level and organisational change (Schalock et al., 2002, Schalock et al., 2008, Verdugo & Schalock, 2009, Verdugo et al., 2012, van Loon et al., 2013), there are measurement challenges associated with measuring individual QoL, for example, response bias and potential exclusion of people with severe ID (Hatton, 1998, Perry & Felce, 2002, Janssen et al., 2005, Schmidt et al., 2010). There is also the 'attribution problem' of how to determine the impact of social care on QoL to the exclusion of other (non-care-related) influences. The attribution problem is particularly important when considering how to use cross-sectional survey-based outcome data. Without some understanding of the part that social care services play in determining individual QoL, we cannot hope to identify ways of improving QoL through the provision of social care support and services (Malley & Fernández, 2010). Indeed, understanding the impact of services on QoL was one of the areas that organisations struggle with when trying to find ways to use the ASCOT measure to improve services (Heath et al., 2015).

This production of welfare framework is useful for exploring the influence of various factors in determining outcomes for service users (Davies & Knapp, 1981, Malley & Fernández, 2010). This framework posits that the final outcome of social care (i.e. care-related QoL) is causally influenced by a range of 'non-resource inputs' including socio-demographic and environmental characteristics. Many non-resource inputs can be considered 'non-care-related' factors outside of the direct control of social care. Studies have shown the importance of non-resource inputs in predicting final outcomes in social care (Forder et al., 2014, Malley & Fernandez, 2014), but, to our knowledge, few studies have specifically explored the relationship between these factors and QoL outcomes in people with ID.

One such study compared the effects of various care-related and non-care-related characteristics on QoL of adults with ID in the Netherlands (Claes et al., 2012) and found that social care directly accounted for only 10% of the variance. By contrast, 44% of the variance was accounted for by personal characteristics and a further 8% was associated with environmental factors that were beyond the direct control of services (Claes et al., 2012). Although this particular study did not explore survey-related factors, such as the effect of help to complete questions, these are also known to influence self-reported care-related QoL (van Leeuwen et al., 2014). The relatively small contribution of social care to QoL found in the Dutch sample highlights the importance of developing a better understanding of the relationship between non-care-related factors and QoL to support the interpretation and application of QoL to policy and practice in the English and other contexts.

As the outcomes-based approach is adopted by organisations and governments, it seems likely that QoL measures will play an ever more important role in informing quality and performance improvement. Very little research has looked specifically at how governments can foster the use of QoL data for this purpose (Razik & Beecham, 2014). The current literature has, however, identified that, alongside organisational change, a factor promoting the adoption of QoL data for performance improvement is detailed analysis of the relationship between various factors and QoL (Razik & Beecham, 2014). Given the limited evidence about the relationship between ASCOT-QoL and other factors, a more complete understanding of the association between survey-related factors and individual or environmental characteristics on QoL would seem to be a first step towards applying the outcomes evidence to drive systems- or organisational-level improvement.

In this paper, we use data from the 2011 and 2012 Adult Social Care Survey (ASCS) to explore the factors that affect overall and individual domain scores of ASCOT-QoL for adults with ID who use publicly-funded community-based social care services in England. Our choice of independent variables is driven by the theoretical framework we have outlined and the availability of data. The aim of this analysis is to support the interpretation and use of the ASCS data to inform local and national policy and practice by adding to the evidence-base around the factors associated with the QoL of adults with ID. Furthermore, as a case study, it will add to the emerging evidence on how organisations may use QoL data to drive systems and organisational-level improvement.

Methods

The Adult Social Care Survey (ASCS)

In England, ASCOF data are collected and reported at the level of local authorities (LAs), since it is these organisations who commission (and in some cases provide) local social care services. A number of the outcome measures in the ASCOF are collected from a sample of users of publicly-funded social care in the annual Adult Social Care Survey (ASCS). The ASCS was first introduced in 2011 and is conducted by LAs according to guidance set by the Health and Social Care Information Centre (HSCIC) on sampling, data collection and management processes (HSCIC, 2010, HSCIC, 2011). For this study, we use the data collected in 2011 and 2012.

The ASCS questionnaire includes the ASCOT measure of care-related QoL (Netten et al., 2011, Netten et al., 2012, Malley et al., 2012), which is a self-report instrument with one item for each of eight QoL domains (see Table 1). An easy-read version of the questionnaire was developed by the Personal Social Services Research Unit and the Tizard Centre at the University of Kent (Caiels et al., 2010a, Malley et al., 2010). The development, construct validity and internal reliability of the easy-read version of the ASCOT instrument are reported elsewhere (Caiels et al., 2010b, Rand, 2014).

Each QoL attribute is measured by a single item with four response options that correspond to: the ideal state, which is the preferred situation for the respondent; no needs, where the individual's needs are met but not to the desired level; some needs, where the needs do not have immediate or longer-term health implications; and, high-level needs, where the individual's needs have immediate or longer-term health implications. Each item is scored as either the ideal state (3), no needs (2), some needs (1) or high-level needs (0) and combined to create a continuous scale score from 0 to 24. Although utility weights are available for ASCOT (Potoglou et al., 2011, Netten et al., 2012), we do not apply these here because the weights have not been developed for the easy-read version and the ASCOF reports the equally-weighted rather than the utility-weighted score.

INSERT TABLE 1

The ASCS also includes items to capture factors identified as being theoretically important in determining QoL to support the interpretation of ASCOT-QoL; these items were selected based on insights from the production of welfare model (Davies & Knapp, 1981, Malley & Fernández, 2010) and discussions with practitioners from the field of adult social care. These items include socio-demographics, health status (self-rated health on a 5-point scale, pain/discomfort and anxiety/depression on 3-point scales), disability (difficulty with eight activities of daily living (ADLs) or instrumental activities of daily living (IADLs)) and appropriateness of the design of the home for the individual's needs on a 4-point scale. Data were also collected on receipt of informal help from someone inside or outside of the household and payments for additional social care support. There are also items capturing whether the questions were completed with assistance from someone else, as well as the source and type of assistance. The survey guidance and questionnaires are available online (HSCIC, 2010, HSCIC, 2011).

Ethical approval for the ASCS was obtained from the Social Care Research Ethics Committee (REC) in England. This is a REC outside of the UK National Health Service responsible for reviewing adult social care research involving sites in England and another UK country.

Sampling

The survey sample was drawn from adults who receive publicly-funded social care stratified by client group and age. For this study, a sub-sample was extracted from the dataset using the following inclusion criteria: individuals whose social care records have ID as their primary or secondary client group, who were sent an easy-read version of the ASCS questionnaire, and were not in residential or nursing care at the time of the survey. Of the 32,395 people sampled with these characteristics, 13,642 (42.1%) completed the questionnaire and were included in the sample analysed in this article. This excludes cases where the primary and secondary client groups (n=19), the response status (n=1) or residential status (n=2) were missing.

Statistical modelling

The data were analysed using Stata version 12. Multivariable regression was used to explore the individual characteristics and survey completion factors associated with QoL whilst controlling for LA-level variation. The dependent variables are overall ASCOT-QoL score (treated as a continuous variable) and the score for each of the eight ASCOT domains (treated as categorical variables). The predictor variables were selected from those available in the ASCS (see Table 2). These were considered according to the theoretical framework provided by the Production of Welfare model (Davies & Knapp, 1981), which has been further developed to provide a theoretical basis for understanding the factors that influence social care outcomes other than the quality or quantity of social care support (Malley & Fernández, 2010, Forder et al., 2014, Malley & Fernandez, 2014). Since survey administration factors have been found to affect responses among older adults with physical and sensory impairment (van Leeuwen et al., 2014) these were also considered. Dummy variables for the survey year and local authorities were included to capture changes by geographical location or over time.

Including both home design and the number of I/ADLs completed with difficulty meant that the relationship between I/ADLs and QoL was positive. This relationship suggests that I/ADL with difficulty variable, when included with home design, was potentially capturing the effect of social care support, which we would expect to have a positive relationship with QoL. This scenario is plausible since social care support in England is allocated on the basis of social care need, which is partly determined according ability to undertake I/ADLs (Department of Health, 2010a). Since the primary aim of this analysis was to explore the non-care-related factors associated with QoL, it was decided to omit the I/ADL variable from the models.

INSERT TABLE 2

The overall ASCOT-QoL score was modelled using OLS estimation. Ordered logit (ologit) regression was initially employed for the models with the eight ASCOT domains as the outcome variables. For these analyses, the responses for the lowest two response categories (0, 1) were collapsed into a single category (1) due to the small proportion of responses in the ‘high needs’ category (see Table 3). Only those variables significant at the 1% level were retained in the final OLS and ologit models.

Due to relatively high rates of missingness (see Table 2), which can cause issues such as a loss of precision in regression models or nonresponse bias, multiple imputation using chained equations (ICE) was applied using MI Impute Chained to generate an imputed dataset (van Buuren et al., 1999, Statacorp, 2011). The analysis of the imputed dataset generated results similar to the complete case data; therefore, the analyses presented in the article are based on the complete case analysis only.

Results

The sample characteristics are reported in Table 2. 54.9% of the respondents were male, 8.1% aged 65 years or older, and 89.7% self-reported ethnicity as white British or another white background. Of the cases included in the analysis, 10.3% were completed by proxy. The ASCOT-QoL responses by domain are shown in Table 3. The mean ASCOT-QoL score was 20.76 (2.87 SD). The Shapiro-Wilks test of normality ($p<0.001$) indicates that the ASCOT-QoL score was not statistically normal; this was confirmed by visual inspection of the distribution, which was negatively skewed.

INSERT TABLE 3

The OLS model with equally-weighed ASCOT-QoL score as the dependent variable is shown in Table 4. The model failed diagnostic tests for homoscedasticity, so we report robust standard errors using the Huber-White sandwich estimators (Huber, 1967, White, 1980). The OLS model also failed the Ramsey RESET test (Ramsey, 1969) and Pregibon’s link test (Pregibon, 1980), which indicates possible model specification error and omitted variable bias. Since the ASCOT score was negatively skewed, which is typical of multi-dimensional health-related QoL measures (Austin, 2002, Basu & Manca, 2012, Pullenayegum et al., 2012), we explored forms such as beta regression (Ferrari & Cribari-Neto, 2004) with transformation of the dependent variable at 0 and 1 (Smithson & Verkuilen, 2006) and fractional response models (Papke & Wooldridge, 1996, Baum, 2008) in an attempt to improve the fit of the model. However, the results were similar to those from the OLS and did not improve model fit statistics, so are not presented here.

The results of the eight models with the rating of QoL in each ASCOT domain as the dependent variable are shown in Table 5. The models were initially calculated using ordered logistic regression. The assumption of parallel regression, which was tested for using the user-written *omodel* Stata command (Wolfe & Gould, 1998), was found to fail for all eight models. Generalized ordered logit (gologit) models, which do not assume parallel regression (Fu, 1998), were therefore estimated using the user-written gologit2 command (Williams, 2006). The gologit models can be interpreted as two logistic regression models: response option 1 (some/high needs) versus response option 2/3 (no needs/ideal state), and response option 1/2 (some/high or no needs) versus response option 3 (ideal state). For parsimony, we used a partial proportional odds model and, where warranted, constrained some independent variables to meet the parallel regression assumption.

Three of the four variables capturing underlying health condition-related and environmental characteristics (self-perceived health, rating of anxiety/depression, and rating of the suitability of the home design) had both a strong negative relationship with QoL score in the OLS model and across all eight gologit models. Those with poorer self-reported health, worse rating of home design or higher levels of anxiety/depression are more likely to report lower QoL. In instances where the parallel lines assumption was violated, the coefficient was more negative for the 1 vs. 2, 3 contrast than for the 1, 2 vs. 3 contrast. This indicates that those who reported poorer health, less adequate home design for their needs and higher levels of anxiety and depression are especially likely to report poor QoL. The remaining health-related variable (self-reported pain) did not reach significance in the OLS model (Table 4) and was only found to be significantly negatively associated with QoL in the gologit model with *Personal safety* as the outcome variable (Table 5).

INSERT TABLES 4 & 5

The socio-demographic variables had weak associations with overall ASCOT-QoL (Table 4). Being male was associated with lower QoL, whereas being aged 65 years and over, or from a white ethnic background were associated with higher QoL. These variables only had significant associations with some of the QoL domains, although the direction of the relationship was consistent across the gologit and OLS models (see Table 5).

Receipt of practical help from someone inside the household, which is taken as an indicator of unpaid care by a partner or relative, was found to have a significant positive association with overall ASCOT score in the OLS model (Table 4). Those who reported that they had practical help from someone inside of the household were more likely to report higher QoL for *Dignity*. Likewise, there were significant positive relationships between practical help from someone inside the household and *Accommodation* and *Social participation*; the coefficients indicate that those who received practical help from someone in the home were less likely to report the lowest QoL states. There was also a significant positive coefficient for the 1 vs. 2, 3 contrast in the model with feeling clean and comfortable (*Personal cleanliness*) as the outcome variable, which suggests that those who received practical help from someone in the same household were less likely to rate their QoL as poor in this domain. Unlike the other five domains, where significant positive coefficients were observed, there was a significant negative coefficient for the 1, 2 vs. 3 contrast for *Control over daily life*; those who received help from someone inside the household were less likely to rate their QoL at the top level (‘ideal state’).

Practical help from someone outside of the household did not meet the inclusion criteria in the OLS model. It was, however, included in the gologit model with *Social participation* as the outcome variable. A significant positive association between receipt of help and QoL was observed with a larger coefficient for the 1 vs. 2, 3 than for the 1, 2 vs. 3 contrast. Respondents who received help from outside of the household were less likely to rate their QoL as poor for *Social participation*.

Completion of the survey by proxy was positively associated, and help to complete the survey from a care worker was negatively associated with, overall QoL in the OLS model (Table 4). In the gologit models, responses by proxy were more likely to report worse QoL for *Occupation* and *Control over daily life*, but had a significantly increased likelihood of reporting better QoL for *Accommodation, Personal safety* and *Social participation*. The negative association with overall ASCOT score observed in the OLS model is likely due to the comparatively large effect size for proxy response in the *Control over daily life* domain. Help to complete the survey from a care worker had both significant positive associations (*Food and drink, Accommodation, Personal safety* and *Dignity*) and negative associations (*Social participation* and *Control over daily life*) with QoL score across the gologit models. The significant positive relationship in the OLS model is likely to be due to the moderate-large effect size in the *Dignity* domain. Varying associations, some of different sign, were also observed in the other survey completion variables included only in the gologit models (see Table 5).

The dummy variable for survey year with 2011 as the base category was found to have a significant positive association with overall ASCOT-QoL score in the OLS model. This variable was also included in five of the gologit models with the following ASCOT domains as the outcome variables: *Personal cleanliness, Personal safety, Social participation, Occupation* and *Dignity.* In all five models it was found that those who completed the survey in the 2012 data collection were more likely to rate their QoL as better than those who completed the 2011 survey. The survey year variable only failed the parallel regression assumption in one model (*Social participation*), where the coefficient for the 1,2 vs. 3 is smaller than the 1 vs. 2, 3 contrast. This suggests that respondents were less likely to report low QoL for *Social participation* in the 2012 survey.

Discussion

This study explores the individual, environmental and survey-related characteristics associated with QoL of people with ID who access publicly-funded social care in England using the Adult Social Care Survey (ASCS) data. The ASCS aims to capture the service users' perspective of the outcome of LAs' activities as commissioners (and in some cases providers) of services, as well as strategic managers of the availability and diversity of social care provision through local policy (Department of Health, 2012b). To this end, it is difficult to disentangle the role of LAs and formal social care from other influences on the QoL of people with ID and, although the analysis presented here does not solve the attribution problem, it does establish the associations between individual, environmental and survey-related factors that could support the interpretation and use of the ASCS data to inform local and national policy and practice.

An important finding is that, after controlling for a range of variables that capture individual-level and survey completion factors that may explain variation in ASCOT-QoL scores, three health-related variables evaluated in this study are found to be strongly associated with QoL. This is consistent with previous studies that have found a relationship between health and QoL (Schalock et al., 1994, Schalock, 2004, Lehmann et al., 2012). This is not surprising; health conditions may contribute to social care needs, and indeed many measures of QoL include physical and/or psychological health as a domain (Townsend-White et al., 2012). The suitability of the design of the home for an individual's needs may not only capture health and social care need (as evidenced by the relationship with I/ADLs), but also the quality of housing or the home environment in relation to those needs. Housing quality has been found in previous research to be an important indicator associated with QoL; well-designed housing enables individuals to live in a comfortable, safe and accessible environment (Evans et al., 2002, Wahl et al., 2009). These strong associations between QoL and overall health, psychological health, and home design, provide tentative support for a policy strategy that recognizes the interrelationships between health, social care and housing needs and outcomes.

The findings could be used to identify broad groups who may be at risk of lower QoL or may benefit from strategically-targeted support at the local or national level. To illustrate this we draw on two examples. First, the finding that informal care from a co-resident carer is associated with higher QoL in five of the eight ASCOT domains supports the premise of the carers' strategy in England

(Department of Health, 2010b, Department of Health, 2014) that unpaid caregiving, particularly by co-resident carers, helps to support the QoL of the people they care for. However, the negative relationship with practical help from a co-resident informal carer and *Control over daily life,* particularly at the ‘ideal state’, does raise the question of whether there may be scope for social care to work alongside unpaid carers to promote independence and increased control over everyday choices. Second, the association between non-white ethnic backgrounds and worse ratings of *Control over daily life* and *Occupation* highlight areas of QoL that could be targeted by policy or practice interventions for non-white groups. Further research is, however, warranted to understand causal relationships and the effectiveness of such interventions.

The ASCS data collection could also be used to evaluate and drive systems-level change in QoL over time. After controlling for individual characteristics and survey administration factors there was a small significant increase in aggregate user-reported QoL from 2011 to 2012 in five of the eight ASCOT-QoL domains, particularly at the ‘ideal state’ for *Social participation* and *Occupation* domains. This provides tentative evidence for an increase in the QoL of users of publicly-funded social care services over time. It should, however, be noted that there has been a 0.2% real term reduction in spending on publicly-funded social care for adults under the age of 65 in England between 2010/11 and 2012/13 that has meant a reduction in the availability of publicly-funded care (National Audit Office, 2014). Due to the nature of the ASCS sample, it is not possible to draw conclusions about the QoL of the wider population of adults with ID in England, or for those individuals who may have lost access to publicly-funded services as a result of a reduction in public spending over this period.

A key requirement for outcomes data to drive systems- or organisational-level change is that the data are routinely applied to create an organisation or system that targets resources to maximise positive effects (Schalock et al., 2002). Such outcomes-based organisational change is a complex process with various steps at which there may be challenges or facilitators (schalock & Verdugo, 2012, Razik, 2014 #556). In the English context, a considerable challenge is the limited availability of resources at the local level to conduct in-depth analysis of outcomes data to inform managerial and organisational practice (Heath et al., 2015). If local authorities are to use QoL to drive change there is a need for investment to support them in their analysis, interpretation and use of data.

Alongside the use of QoL data to inform outcomes-based strategy, for example, through the identification of 'at risk' groups and targeting of particular areas of QoL for improvement, the development of a risk-adjusted QoL indicator would allow a fairer comparison of QoL scores between councils in England or over time to evaluate the impact of social policy strategy and local interventions as intended by policymakers (Department of Health, 2011, Department of Health, 2013) and practiced by LAs (Heath et al., 2015). Indeed, the analysis presented in this article resembles the types of models used for 'risk adjustment' (Iezonni, 2013) and could form the basis of a risk-adjusted indicator for the outcomes framework. Further work would be needed to explore other relevant factors, and to decide whether to exclude some factors on theoretical grounds. For example, it could be argued that ethnicity and home design should be excluded from risk adjustment because of difficulty determining, in the former's case, whether differences are due to disparities in survey administration or reporting rather than experience (Gray et al., 2014) and, in the latter's, its plausible designation as a factor that could be within the control of social care services through the delivery of equipment and adaptations. Our findings also raise the question of whether risk adjustment should be carried out by QoL domain rather than on the overall QoL scale-level due to the differences in the pattern of relationships between some of the variables explored here (particularly the survey completion variables) and the different ASCOT-QoL domains (Ara et al., 2011).

Limitations

There are some limitations to this study. First, due to the cross-sectional data collection, the associations cannot be interpreted as causal relationships. Evidence of causality would further support the interpretation and application of these findings (Bovaird, 2012). Second, the analysis was limited to those variables available in the ASCS dataset and the Ramsey RESET test (Ramsey, 1969) and Pregibon's link test (Pregibon, 1980) indicated omitted variable bias. One potential source of bias is the omission of service intensity and type of service in the analysis due to a lack of good quality data of the care received by each individual in the sample. As LAs allocate publicly-funded social care support to individuals on the basis of social care need, which includes assessment of health conditions, ability to perform activities of daily life and availability of informal care (Department of Health, 2010a), the omission of intensity may mean the regression coefficients for indicators of social care need in the model, such as the health, home design and practical help variables, are underestimated where the sign is negative and overestimated where positive. Furthermore, due to the relatively modest response rate of 42.1%, some caution is required in application of conclusions to the wider population of publicly-funded social care service users. Finally, the analysis only focuses on the estimated 13% of adults with ID who receive publicly-funded community-based social care services (Emerson et al., 2012). It does not include individuals who do not meet the eligibility criteria for publicly-funded social care, who only purchase social care support privately, or adults who are in residential or nursing care homes.

Despite these limitations, the analysis presented in this article is based on a large, national, randomly-selected sample. It provides results with good generalizability to the population of people who use publicly-funded adult social care support in England that should be of particular interest to local and national policy-makers, and as a study of some of the measurement challenges inherent in an outcomes-based approach to policy and planning.

Conclusion

This study demonstrates the potential value of the ASCS to inform and evaluate local and national policy and practice in England. Health, psychological wellbeing and the design of an individual's home are all possible targets for further research to establish causal relationships and potential targets for local and national policymakers to improve outcomes for people with ID. This analysis has also highlighted groups of adults with ID who may be at risk of lower QoL, and identified particular domains of QoL that could be strategically targeted to improve the QoL of users of publicly-funded social care support. There is also the potential to use these data to compare local policy and practice. This study has identified potential factors that could be considered to generate a risk-adjusted ASCOT-QoL measure for such a purpose, although further development of the models proposed here is required.

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Table 1. Definition of ASCOT QoL domains

ASCOT Domain	**Definition**
Control	Being able to choose what to do and when to do it, having control over daily life and activities.
Personal cleanliness	Feeling clean and comfortable, looking presentable, and being dressed in a way that reflects personal preferences.
Food and drink	Having a nutritious, varied and culturally appropriate diet with enough food and drink at regular and timely intervals.
Accommodation	Feeling that the home environment is clean and comfortable.
Personal safety	Feeling safe and secure. This means being free from fear of abuse, falling or other physical harm, and fear of being attacked or robbed.
Social participation	Being content with social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends and family, and feeling involved or part of a community.
Occupation	Being sufficiently occupied in a range of meaningful activities, whether formal employment, unpaid work, caring for others or leisure activities.
Dignity	The negative and positive psychological impact of support and care on the individual’s personal sense of significance.

Table 2. Predictor variables considered in regression models (n=13,642)

[Please note that this table continues onto the next page, p.23]

Variable	Definition	Obs.	Mean†	Std. Dev.	Min/Max	% Missing Values
Personal characteristics						
Male	Female (0), male (1).	13,639	0.549	0.498	0/1	<0.1%
over 65 years	Dummy variable with aged under 65 years as the base category. Under 65 years (0), 65+ years (1).	13,639	0.081	0.273	0/1	<0.1%
White	Ethnicity rated as white (1), mixed (2), Asian (3), black (4), other (5). Recoded as a dummy variable with ‘not white’ (2-5) as the base category.	13,479	0.897	0.304	0/1	1.2%
Practical help, inside household	Receipt of help from friends or family, someone inside the household. No (0), Yes (1).	13,054	0.584	0.493	0/1	4.3%
Practical help, outside household	Receipt of help from friends, family or neighbours, someone outside the household. No (0), Yes (1).	13,054	0.333	0.471	0/1	4.3%
Private Own	Does the respondent pay for extra social care support? No (0), Yes (1).	12,766	0.227	0.419	0/1	6.4%
Private Family	Does the respondent’s family pay for extra social care support? No (0), Yes (1).	12,766	0.100	0.300	0/1	6.4%
Underlying health conditions						
Number of I/ADLs with difficulty	Katz Activities of Daily Living or ‘ADLs’ (Katz et al., 1970) (get in/out of chair/bed, feed self, use WC/toilet, wash all over using bath/shower, get dressed/undressed) ††, plus two further ADLs (ability to get around indoors, wash face and hands) and the Instrumental Activity of Daily Living (IADL) ‘manage paperwork and finances’. Each ADL was rated as ‘I can do this by myself’, ‘I can do this with difficulty’ or ‘I cannot do this myself’. These ratings were used as a scale from 0 to 8 of the number of I/ADLs that the respondent has difficulty to complete on their own or is unable to complete without help.	12,700	2.344	2.170	0/8	6.9%
Self-perceived health	Self-perceived health rated as very good (1), good (2), fair (3), bad (4), very bad (5).	13,314	2.071	0.998	1/5	2.4%
Pain	Pain item rated as none (1), moderate (2) and extreme (3).	13,102	1.454	0.596	1/3	4.0%
Anxiety/depression	Anxiety/depression item rated as none (1), moderate (2) and extreme (3).	13,109	1.578	0.558	1/3	3.9%
Environmental characteristics						
Home design	Rating of the suitability of design of home in terms of ease of mobility and ability to reach things rated as: my home meets my needs very well (1), my home meets most of my needs (2), my home meets some of my needs (3) and my home is totally inappropriate for my needs (4).	13,160	1.406	0.705	1/4	3.5%
Other factors: geographical differences (local authority) and time (survey year)						
Survey year 2012	ASCS year of 2011 (0) or 2012 (1).	13,642	0.568	0.495	0/1	0.0%
Local authority dummies	Dummy code for each of the 152 local authorities in England with adult social care responsibilities.	13,642	N/A	N/A	N/A	0.0%
Other factors: survey administration						
Proxy	Whether help was given to complete the questionnaire – Answered by proxy. No (0), Yes (1).	13,044	0.103	0.305	0/1	4.4%
Read	Whether help was given to complete the questionnaire – Read out questions. No (0), Yes (1).	13,044	0.565	0.496	0/1	4.4%

Variable	Definition	Obs.	Mean†	Std. Dev.	Min/Max	% Missing Values
Explain	Whether help was given to complete the questionnaire – Explain questions. No (0), Yes (1).	13,044	0.580	0.494	0/1	4.4%
Write	Whether help was given to complete the questionnaire - Write answers. No (0), Yes (1).	13,044	0.459	0.498	0/1	4.4%
Discuss	Whether help was given to complete the questionnaire – Discuss answers. No (0), Yes (1).	13,044	0.263	0.441	0/1	4.4%
Survey help, inside household	Help to complete the questionnaire from someone in the household. No (0), Yes (1).	12,907	0.266	0.442	0/1	5.4%
Survey help, outside household	Help to complete the questionnaire from someone outside the household. No (0), Yes (1).	12,907	0.166	0.372	0/1	5.4%
Survey help, care worker	Help to complete the questionnaire from a care worker. No (0), Yes (1).	12,907	0.354	0.478	0/1	5.4%

† For the following dummy variables, the mean multiplied by 100 represents the percentage of the sample: Male, Over65years, White, Practical help In, Practical help Out, Private Own, Private Family, Year 2012, Proxy, Read, Explain, Write, Discuss, Help in, Help out and Help CW. For example, for the variable 'Male', the mean of 0.549 indicates that 54.9% of the sample are male.

†† We were unable to ask about continence in the context of a self-completion questionnaire for ethical reasons.

Table 3. Responses to the ASCOT (Easy Read community-based version from the 2011 and 2012 ASCS) by QoL domain (n=13,642)

	Frequency (%)
Control over daily life	
Ideal state: I make all the choices I want	5,149 (37.74%)
No needs: I make some choices, not all, but that is OK	6,916 (50.71%)
Some needs: I make some choices but not enough	834 (6.11%)
High-level needs: I not get to make any choices	377 (2.76%)
Missing values	366 (2.68%)
Personal cleanliness and comfort	
Ideal state: I feel clean and I like the way I look	9,856 (72.25%)
No needs: I quite like the way I feel and look, it's OK	2,968 (21.76%)
Some needs: I feel a bit clean and tidy, but not enough	461 (3.38%)
High-level needs I do not feel at all clean or tidy	47 (0.34%)
Missing values	310 (2.27%)
Food and drink	
Ideal state: I get all the food and drink I like when I want it	9,486 (69.54%)
No needs: I get enough food and drink	3547 (25.99%)
Some needs: I do not get all the food and drink I want, but I do not think I will get ill because of it	230 (1.69%)
High-level needs I do not get all the food and drink I need, and I think this might make me ill	84 (0.62%)
Missing values	295 (2.16%)
Accommodation	
Ideal state: My home is as clean and nice as I want	10,374 (76.04%)
No needs: My home is quite clean and nice, it's OK	2,714 (19.89%)
Some needs: My home is not clean or nice enough	191 (1.41%)
High-level needs My home is not at all clean or nice	45 (0.33%)
Missing values	318 (2.33%)
Personal safety	
Ideal state: I feel very safe	9,894 (72.53%)
No needs: I feel quite safe, but not as safe as I would like	2,820 (20.67%)
Some needs: I do not feel safe enough	433 (3.17%)
High-level needs I do not feel safe at all	135 (0.99%)
Missing values	360 (2.64%)
Social participation and involvement	
Ideal state: I see my friends and family as much I want	8,058 (59.07%)
No needs: I see my friends and family sometimes, it's OK	3,596 (26.36%)
Some needs: I do see friends and family, but not enough	1,208 (8.86%)
High-level needs I feel lonely because I do not see my friends and family very much or at all	411 (3.01%)
Missing values	369 (2.70%)
Occupation	
Ideal state: I spend my time as I want, doing the things I like	7,880 (57.76%)
No needs: I can do quite a lot of the things I like. It's OK	3,954 (28.98%)
Some needs: I can do some of the things I like but not enough	1,305 (9.57%)
High-level needs I do not do any things I like	103 (0.76%)
Missing values	400 (2.93%)
Dignity	
Ideal state: The way I am helped makes me feel better about myself	9,679 (70.95%)
No needs: The way I am helped does not change the way I feel about myself	2,877 (21.09%)
Some needs: The way I am helped sometimes makes me feel a bit bad about myself	461 (3.38%)
High-level needs The way I am helped makes me feel very bad about myself	82 (0.60%)
Missing values	543 (3.98%)

Table 4. Multiple regression (OLS) with ASCOT quality of life score as the outcome variable[1]

	Unstandardised Coefficient (B)	*95% C.I.*
Proxy	-0.339***	-0.510 to -0.168
Survey help, care worker	0.403***	0.301 to 0.505
Self-perceived health	-0.816***	-0.871 to -0.761
Anxiety/depression	-1.208***	-1.302 to -1.114
Home design	-0.758***	-0.844 to -0.672
Practical help, inside household	0.375***	0.277 to 0.473
Male	-0.289***	-0.379 to -0.199
Over 65 years	0.299***	0.134 to 0.464
White	0.287**	0.101 to 0.473
Survey year 2012	0.272***	0.176 to 0.368
Constant	25.206***	24.755 to 25.657
Local authority dummies	Yes	-
Model statistics		
N		11,056
F		20.38***
AIC		50,928
R^2		0.304

Legend: ** p<.01, ***p<.001

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[1] For further detail on the independent variables, please refer to Table 2.

Table 5. Estimation results from the GOLOGIT models by ASCOT domain [2] [3]

Outcome Variable:	Control over daily life		Personal cleanliness		Food and drink		Accommodation		Personal safety		Social participation		Occupation		Dignity	
Coefficients:	**1 vs. 2, 3** [4]	**1, 2 vs. 3** [5]	**1 vs. 2, 3**	**1, 2 vs. 3**	**1 vs. 2, 3**	**1, 2 vs. 3**	**1 vs. 2, 3**	**1, 2 vs. 3**	**1 vs. 2, 3**	**1, 2 vs. 3**	**1 vs. 2, 3**	**1, 2 vs. 3**	**1 vs. 2, 3**	**1, 2 vs. 3**	**1 vs. 2, 3**	**1, 2 vs. 3**
Proxy	-1.251***	-2.276***					0.680***		0.511***		0.406**	0.161*	-0.470***	-0.737***		
Read	0.235***								-0.143**							
Explain			0.159**													
Write	-0.024	-0.230***	0.390***	0.110*			0.216***									
Discuss													-0.118*			
Survey help, inside household	-0.044	-1.560***	-0.294***				1.021***	0.478***					-0.130	-0.482***		
Survey help, outside household	-0.109	-0.849***	-0.376***		-0.199	0.300***							-0.408***	-0.196**		
Survey help, care worker	0.166	-0.459***			-0.019	0.349***	0.200**		0.342***		-0.265***				0.431***	
Self-perceived health	-0.366***	-0.253***	-0.758***	-0.533***	-0.596***	-0.289***	-0.787***	-0.410***	-0.481***	-0.319***	-0.363***		-0.577***	-0.337***	-0.315***	
Pain									-0.255***							
Anxiety/depression	-0.633***	-0.425***	-0.759***	-0.508***	-0.755***	-0.245***	-0.380***		-1.377***	-1.024***	-0.821***	-0.539***	-0.906***	-0.547***	-1.387***	-0.535***
Home design	-0.443***	-0.279***	-0.239***		-0.452***	-0.306***	-0.440***		-0.247***		-0.271***		-0.532***	-0.391***	-0.120***	
Practical help, inside household	0.003	-0.249***	0.548***	0.096			0.796***	0.395***	0.367***		0.899***	0.645***			0.174***	
Practical help, outside household											0.511***	0.371***				
Male			-0.403***		-0.129**		-0.334***									
Private Own																
Private Family											0.200**		-0.206**			
Over 65 years	0.269***		0.701*	0.251**	0.265**		0.297**		0.275**						0.843**	0.214*
White	0.504***	0.212*											0.528***	0.187*		
Survey year 2012			0.166***						0.210***		0.325***	0.174***	0.233***		0.160***	
Local authority dummies	Yes		Yes		Yes		Yes		Yes		Yes		Yes		Yes	
Model statistics																
N	11,641		11,809		12,127		11,809		11,667		11,378		11,464		11,735	
X^2	2,770***		1,724***		990***		1,556***		2,138***		1,848***		2,274***		1,220***	
McFadden's Pseudo R^2	0.130		0.107		0.060		0.112		0.133		0.089		0.109		0.075	

Legend: * p<.05, ** p<.01, ***p<.001

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[2] The coefficients that do not vary by threshold are presented as a single coefficient under the column labelled '1 vs. 2, 3'. For coefficients that vary between the ideal-state to no needs threshold and the no needs to some/high needs threshold, the two coefficients are reported separately under the columns labelled '1 vs. 2, 3' and '1, 2 vs. 3'.

[3] For further detail on the independent variables, please refer to Table 2.

[4] Contrast between Some/High needs (recoded as 0) and No needs with the Ideal state (recoded as 1), or coefficients not varying by threshold

[5] Contrast between Some/High needs with No needs (recoded as 0) and the Ideal state (recoded as 1)