Variables Within a Household That Influence Quality-of-Life Outcomes for Individuals With Intellectual and Developmental Disabilities Living in the Community: Discovering the Gaps

Grace Lucille Francis¹, Martha Blue-Banning¹, and Rud Turnbull¹

Abstract

Individuals with intellectual and developmental disabilities (IDD) and their families face many important decisions as the individuals with IDD enter adulthood, including where to live. Although there are numerous housing options for individuals with IDD outside of institutions, there is a paucity of information available to inform them about how various characteristics of these settings can affect their quality of life. The purpose of this study was to determine key variables within a household that influence individual quality of life (QOL) of people with IDD living in community settings, thereby enabling these individuals and their families to make informed decisions regarding housing options available to them.

Keywords

community housing, quality of life, intellectual and developmental disability, de-institutionalization

Research demonstrates that individuals with intellectual and developmental disabilities (IDD) living in the community experience greater quality of life (QOL) compared with individuals living in segregated institutional settings (Golding, Emerson, & Thornton, 2005; Lerman, Apgar, & Jordan, 2005; McConkey, McConaghie, Mezza, & Wilson, 2003; O’Brien, 2001; Schalock & Alonso, 2002; Young, 2001). The authors of this manuscript conducted a review of literature on individual QOL and community housing published between 2000 and 2012 to explore QOL outcomes for individuals with IDD living in various types of community housing. The results of this review concluded that (a) researchers reported positive QOL outcomes for each type of housing studied, (b) variables within a household directly influenced QOL (in some cases, more than the type of housing) and can be generalized (for the most part) across settings, and (c) no studies in the review focused intently on the influence of these variables. These findings warranted a deeper investigation into the variables within a household that influence QOL across community settings. Information on these variables could provide individuals with IDD tools needed to identify a home that best aligns with their individual characteristics, wants, and needs. This study investigated the following research question:

Research Question 1: What variables within a household does literature on community housing indicate influence QOL outcomes for individuals with IDD?

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De-Institutionalization and Down-Sizing

The de-institutionalization movement, initiated in the early 1970s, focused on changing the nature of institutions, limiting access to them, and transferring individuals out of them and into community residences. More recently, the enactment of the Americans With Disabilities Act (ADA; 42 U.S.C. Secs. 12101 et seq., 1990) and the Supreme Court’s interpretation of its “integration mandate” in *Olmstead v. L.C.* (1999) held that unwarranted institutionalization violates the ADA and required states to develop community-based residences as presumptively appropriate placements. This led to the widespread adoption of the Home and Community-Based Services (HCBS) Medicaid waiver option, which promotes community residences and supports for individuals who otherwise would receive institutional services.

As a result of these significant policy and program changes, multitudes of individuals with IDD have exited institutions and many states are closing their institutions (Cooper & O’Hara, 2002; Smith, Lakin, Larson, & Salmi, 2011). In fact, “between 1988 and 2008 the number of people with intellectual and developmental disabilities living in residential settings with 6 or fewer residents increased 311%,” while individuals living in institutions “decreased rapidly” (Salmi, Scott, Webster, Larson, & Lakin, 2010, p. 168). Furthermore, as of 2009, nearly one million individuals with disabilities used services from HCBS waivers. This reflects a 57% overall increase of individuals with disabilities receiving residential supports in the community (2010).

De-institutionalization, ADA, *Olmstead*, and HCBS initiatives reflect a movement seeking to increase QOL of individuals with IDD. Schalock and Alonso (2002) contend that there is a general agreement in the field on the definition of QOL and the associated QOL domains and indicators. Put simply, QOL is the degree to which an individual is satisfied with his or her life or perceives his or her life as “good.” We use Schalock’s conceptualization of QOL because it is heavily researched and used in the disability field, especially among individuals with IDD. Schalock’s conceptualization of QOL used in this study is measured by eight domains: Social Inclusion, Physical Well-Being, Interpersonal Relations, Material Well-Being, Emotional Well-Being, Self-Determination, Personal Development, and Rights (Schalock, 1996). It appears that various types of community residences contribute to enhanced QOL outcomes (Felce & Perry, 2007) and yield numerous benefits, including enhanced: interpersonal relations, material well-being, productivity, adaptive behavior, community access, support networks, participation in daily activities, and general satisfaction (Schalock & Alonso, 2002).

Although research indicates heightened QOL for individuals with IDD living in the community, there is little information that indicates what variables within a household influence QOL outcomes. An exploration of these variables would allow people with IDD and their families to better evaluate housing options available to them and make a more informed decision on where to live.

Method

We conducted a literature review to determine what variables within a household influence QOL outcomes.

Search

We obtained documents for this review through (a) a comprehensive literature search and (b) conversations with experts in the field. Together these procedures resulted in 92 documents.

Literature search. We began the literature search by gathering information about how various types of housing and QOL indicators are labeled and defined from sources such as The Arc, PACER, and Schalock and Alonso’s (2002) quality of life work. From these sources, we extracted 71 frequently reoccurring terms (e.g., planned residential community, supported living, group home, co-housing, safety, spirituality) related to housing and QOL. These 71 terms were used to search for current, relevant literature published in English between 2000 and 2012 in four academic databases: GoogleScholar, WilsonWeb, Academic Search Premier, and ProQuest.

This method resulted in thousands of articles. We took several steps to select articles from the database search. First, we sorted the documents by relevance by using the “sort by relevance” search tool within each
database, which ranks manuscripts by several criteria including the prominence of the author, journal, and the number of times the articles has been cited. Next, we read through titles, selecting those that appeared most relevant based on title terminology and phrasing that reflected the purpose of this study. We continued to read through titles until 10 consecutive titles were irrelevant (e.g., the title was not related to QOL, community housing, or people with IDD), a point we found that relevant titles stopped occurring. We then read the abstracts of each of the articles with seemingly relevant titles to determine if the content of the article applied to this study. This process narrowed our results to 58 documents. We then conducted ancestral searches of literature cited in the 58 documents to obtain additional relevant literature and recover definitions of key variables. This process yielded an additional 19 sources, resulting in a total of 77 sources.

**Conversations with experts.** We also gathered information through email and phone conversations with scholars and professionals who study community housing and/or quality of life for individuals with IDD from: the University of South Carolina School of Medicine, Cardiff University, University of Chicago, the National Association of Sate Directors of Developmental Disabilities (NASDDDS), the Tizard Centre at the University of Kent, and the Bazelon Center for Mental Health Law. We selected these individuals based on their work and research in community housing, and also from recommendations from other professionals. These individuals represented two of the areas (the United States and the United Kingdom) in which the majority of studies included in this review occurred. During these conversations, we asked for references and additional sources of data or information. These conversations resulted in references to documents and data sources such as the National Core Indicators. In total, we collected 15 documents from these contacts.

The literature search and conversations with experts collectively yielded a total of 92 documents about housing and QOL for individuals with IDD from several nations. These documents included 70 peer-reviewed publications (4 literature reviews, 63 research studies, and 3 commentary pieces), 5 national reports, 5 resource databases from national organizations (e.g., the Urban Institute), 4 national surveys/databases, 2 handbooks, 2 books, 2 PowerPoint presentations, 1 white paper, and 1 doctoral dissertation.

**Procedure**

We used four steps to determine which of the 92 documents were relevant to this study and narrow our focus. Our first step involved eliminating documents that (a) reported data from individuals living in institutional settings, (b) did not describe the settings where participants lived, or (c) combined several housing types together (e.g., small group homes, clustered settings, institutional settings). We did this by examining abstracts and methods sections. In Step 2, we conducted a more thorough reading of the documents and began the iterative process of extracting meaningful information related to the labels and definitions of influencing variables, and placing the content into tables organized by themes (e.g., QOL domains, QOL findings). For Step 3, we continued to re-read the documents and refine the themes. We used constant comparison analysis (Glaser & Strauss, 1967) to define the influencing variables, which we describe in the results section.

The analysis of all 92 documents indicated that many were (a) irrelevant to this study (e.g., residents lived in institutional settings, study did not report the influence of key variables), (b) irrelevant for purposes of this literature review (e.g., findings were unrelated to QOL and/or housing), or (c) inaccessible (e.g., restricted access to national databases, an inability to recover documents from ancestral searches). This left 18 relevant documents included in this study, included on Table 1. In the name of brevity, we refer to these documents by the number assigned to them on the table in the remainder of this article.

**Results**

The purpose of this study was to review literature on community housing to determine what variables within a household influence QOL outcomes for individuals with IDD. Our analysis indicated that the literature consistently reported four variables within a household that influence QOL for people with IDD living in community settings: (a) residents, (b) culture, (c) staff, and (d) size of a household. In addition to
Influencing Variables

The most frequently reported influencing variable was residents \((n = 39)\), followed by culture \((n = 16)\), staff \((n = 10)\), and finally size \((n = 6)\). We discuss findings related to these variables.

Residents. “Residents” refers to the characteristics of individuals that live in a setting (e.g., age, gender, needs, strengths). The most frequently documented influencing resident characteristic was resident adaptive and/or challenging behavior (residents with greater adaptive behavior and less challenging behaviors experienced greater QOL outcomes; 1; 4; 5; 6; 7; 8; 10; 12; 13; 17). The literature also indicated that resident’s (a) socioeconomic status or income, (b) sex, and (c) age influenced QOL. Residents with greater financial means (9) and females (10; 11) were more likely to experience greater QOL outcomes. Furthermore, younger residents (13; 18) were more likely than others to experience greater QOL outcomes. On the other hand, two studies indicated that older residents experienced greater opportunities for choice making, compared with younger residents (17; 18).

Culture. “Culture” describes the degree to which the physical setting, staff, and daily routines and procedures of a residence reflect those typical of an “institutional” setting (e.g., rigid daily schedule and/or procedures, low expectations from staff, minimal autonomy), or a “normalized” setting (e.g., individualized and flexible daily activities/procedures, positive staff perceptions of residents, high levels of autonomy). Residences that maintained a “normalized culture” positively influenced QOL (13; 14; 15; 18).

Staff. “Staff” refers to the workplace behavior and professional qualifications of residential staff. Generally, knowledgeable staff members, with high expectations, who interacted constructively with the residents, positively influenced QOL (12; 17; 18). For example, residents who received attention (not necessarily

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Table 1. Documents Included in the Literature Review.

<table>
<thead>
<tr>
<th>Number</th>
<th>Author</th>
<th>Year</th>
<th>Location</th>
<th>Type of document</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Baker</td>
<td>2007</td>
<td>The United Kingdom</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>2.</td>
<td>Chou, Lin, Pu, Lee, and Chang</td>
<td>2008</td>
<td>Taiwan</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>3.</td>
<td>Emerson et al.</td>
<td>2001</td>
<td>The United Kingdom</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>4.</td>
<td>Emerson et al.</td>
<td>2000</td>
<td>The United Kingdom</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>5.</td>
<td>Fahey, Walsh, Emerson, and Guerin</td>
<td>2010</td>
<td>Ireland</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>6.</td>
<td>Felce, Lowe, Beecham, and Hallam</td>
<td>2000</td>
<td>Wales</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>7.</td>
<td>Felce, Lowe, and Jones</td>
<td>2002a</td>
<td>Wales</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>8.</td>
<td>Felce, Lowe, and Jones</td>
<td>2002b</td>
<td>Wales</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>10.</td>
<td>McConkey, Abbott, Walsh, Linehan, and Emerson</td>
<td>2007</td>
<td>Ireland</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>11.</td>
<td>Perry and Felce</td>
<td>2003</td>
<td>The United Kingdom/Wales</td>
<td>Peer-reviewed research</td>
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<tr>
<td>12.</td>
<td>Perry and Felce</td>
<td>2005</td>
<td>Wales</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>13.</td>
<td>Robertson et al.</td>
<td>2001</td>
<td>The United Kingdom</td>
<td>Peer-reviewed research</td>
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<tr>
<td>15.</td>
<td>Stancliffe, Abery, and Smith</td>
<td>2000</td>
<td>The United States</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>16.</td>
<td>Stancliffe, Lakin, Taub, Chiri, and Byun</td>
<td>2009</td>
<td>The United States</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>17.</td>
<td>Young and Ashman</td>
<td>2004a</td>
<td>Australia</td>
<td>Peer-reviewed research</td>
</tr>
<tr>
<td>18.</td>
<td>Young and Ashman</td>
<td>2004b</td>
<td>Australia</td>
<td>Peer-reviewed research</td>
</tr>
</tbody>
</table>

Note. Documents are arranged in accordance with the American Psychological Association (APA) formatting for a reference list.
assistance) from staff experienced more choice, enhanced social engagement, and increased participation in community and purposeful activities (12). Furthermore, residents benefited from staff that appropriately modeled adaptive skills (18).

**Size.** “Size” of a household refers to the number of residents living in a single residential unit. Smaller residences were found to facilitate better QOL outcomes (3; 6; 13; 15). For example, residents living in homes with three or fewer residents were found to experience greater instances of personalized support and safety (3), and enhanced social networks (3; 13). Individuals living in homes with four or fewer residents experienced enhanced personal control (15).

**Methodological Issues and Gaps**

We identified a number of methodological concerns and gaps in the literature we reviewed, which makes it difficult to compare findings across research studies or types of community settings. These methodological issues and gaps included (a) failure to define key terms, (b) underuse of qualitative methods, (c) use of proxy raters, and (d) consideration of variables.

**Failure to define key terms.** The terminology and definitions reported for community housing varied widely in the literature. For example, although the terms “group home” and “supported living” are frequently reported in the literature and often used synonymously, they were not consistently defined in the same way. Of the literature reviewed, we extracted 107 labels and definitions for community housing. Furthermore, the literature on community housing also frequently combined community housing types (e.g., own homes, group homes) into a single category (e.g., “dispersed housing”). These limitations of research on community housing make it difficult to confidently attribute a specific QOL outcome(s) to any one particular category of housing or compare outcomes across settings. As a result, we did not report or compare QOL outcomes across housing types as a part of our findings.

**Underuse of qualitative methods.** Every study analyzed in this review used quantitative instruments (e.g., scales, surveys) to measure QOL. However, 72% of studies in this review also incorporated an interview to inform the instrument. While quantitative measurement tools provide valuable information, they often do not account for cultural differences (e.g., residents’ language or socioeconomic statuses) or experiences (e.g., life stories; 9), even when they are completed via interviews.

**Use of proxy raters.** Half of the studies analyzed in this review relied entirely on staff members as proxy raters to report QOL outcomes on behalf of residents. One study in this review collected data from family and staff. None of the studies reported data from individuals with IDD alone, but 39% retrieved data from individuals with IDD, in addition to their families and/or support staff. Not surprisingly, the reliance on proxy raters was especially prevalent when residents experienced moderate to severe disabilities. Although Schalock and Alonso (2002) endorse the use of proxy raters when individuals are unable to respond for themselves, reliance on proxies raises a concern regarding the validity of the findings (9).

**Consideration of variables.** Many studies on community housing did not consider influencing variables as part of the research (of the 92 documents originally recovered, only 18 reported information about these variables in the results section). The literature also frequently only took certain variables into account (e.g., adaptive behavior), ignoring other variables (e.g., geographical location, employment, romantic relationships) that could potentially influence QOL. Furthermore, researchers who did include influencing variables as a part of their study often did not include them as a focus of the study or provide rich information or discussion related to the variables.

Researchers also frequently “control for” many variables at once as part of a regression analysis, making it impossible to determine their influence on resident outcomes or generalize findings (Cummins & Lau, 2004). Likewise, researchers frequently fail to include matched comparison groups in their studies.
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(Cummins & Lau, 2004) and residents are not randomly assigned to settings, resulting in compromised internal validity. Future research should address these methodological issues and gaps in the literature.

Future Research

Our literature review revealed four influencing variables within a household found to affect QOL: resident characteristics, culture, staff, and size. However, we also discovered multiple limitations and gaps in the literature that future research should address. Using the information derived from this review, we offer recommendations for future research on QOL and community housing.

Types of Housing

Future research should mitigate the inconsistencies in language regarding community housing in the literature. Many documents included in this study described the types of housing studied in limited detail, or in some cases, not at all. Future research should describe the various elements of the housing in detail (including size, structure, location, staff, residents, values, and culture). Researchers should use matched comparison groups to conduct comparative studies across housing settings. Another area of need is research on QOL and community housing in the United States. The majority of studies \((n = 15)\) in this analysis were conducted outside of the United States.

Influencing Variables and QOL Domains

No studies focused intently on the influence of these variables or took other variables such as opportunities for or existing employment, transportation, or romantic relationships of residents with IDD into account. Considering their influence and generalizability, future researchers should specifically identify the components and indicators of these variables and then investigate how these components and indicators relate to QOL outcomes. Our review also revealed two understudied QOL domains: Emotional Well-Being and Rights. Only one study reported on the domain of Emotional Well-Being (16), and no studies reported on Rights or Material Well-Being.

Another area understudied in research on QOL and community housing is choice about where to live. Individuals with IDD who choose where and with whom they live experience greater QOL than individuals who do not (16). However, individuals with IDD are oftentimes not provided the opportunity to make this decision (2; Emerson, Malam, Davies, & Spencer, 2005). Research on the influence of roommate and housing-type choices on QOL (in addition to or in spite of type of housing/other variables) could influence policies designed to provide individuals with IDD more choice and control.

Future research should also carefully investigate and consider the influence of values undergirding specific housing schemes as an element of culture. To illustrate this point, one study included in this review reported information from Camphill village communities from the United Kingdom (5). Camphill maintains a particular value set and mission, making findings from those studies not easily comparable with other types of village communities and certainly not to other types of housing, such as group homes. Similarly, different communities, housing agencies, and families are likely to hold varying perceptions of QOL, provide different types of services/supports, and hold different expectations for individuals with IDD, which would affect QOL, regardless of housing type.

Conclusion

Over the past two decades, research has consistently shown that living in the community is superior to living in institutions (Golding et al., 2005; Lerman et al., 2005; McConkey et al., 2003; O’Brien, 2001; Schalock & Alonso, 2002; Young, 2001). While the type of housing undoubtedly affects QOL, variables such as the characteristics of residents in a specific setting, the culture of a residence, the staff employed within a residence, and the size of the residential setting may have an even greater influence. Furthermore, although the
purpose of this review was to determine what variables within the household influenced QOL outcomes across many community housing setting, we also discovered an unexpected finding related to methodological issues and gaps in the literature. These issues make it difficult to attribute QOL outcomes to a specific type of housing or compare QOL outcomes across housing types. However, the influencing variables uncovered in this review are relatively generalizable across settings, and therefore may assist individuals with IDD and their families in decision making as they explore and evaluate community housing.

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