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2021

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### Recommended Citation

Lindell, M., Daniels, J., & Michener, M. (2021). The Lived Experience of College Students with Intellectual Disabilities. *Journal of the International Association of Special Education*, 21(1), 34-45.

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# The Lived Experience of College Students with Intellectual Disabilities

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## Abstract

*Within a private university in the United States, BUILD is a two-year program for individuals with intellectual disabilities. BUILD provides inclusive opportunities in coursework, employment, residential, and social activities with traditional students, as well as life skills and career training in courses specific to BUILD students.*

*This empirical phenomenological research study explored the lived experience of students with intellectual disabilities enrolled in the BUILD program. From interviews with six participants, the themes of social experience, independence, safety, and belonging emerged. The findings of this research indicate that the opportunity-rich environment, a network of support, and a community of belonging contributed to the participants' growth in self-determination. Therefore, innovative college programs can be used as an intervention to improve or enhance the self-determination of individuals with intellectual disabilities and these findings offer intervention components to consider in designing and implementing future programming.*

Keywords: *intellectual disabilities, post-secondary education, self-determination, diversity, inclusion*

## INTRODUCTION

Within a private, faith-based university in the United States, BUILD is a residential two-year program for individuals with intellectual disabilities (ID). BUILD represents one university's attempt to increase post-secondary educational access for students with ID. Simultaneously, BUILD is a pathway toward improved quality of life for individuals with ID.

The purpose of this research study was to explore the lived experience of students with intellectual disabilities enrolled in the BUILD program. Through an empirical phenomenological research design, using the conceptual framework of self-determination, the self-described lived experience of young adults with intellectual disabilities who are attending an integrated residential college program were explored.

### Literature Review

Globally, people with disabilities experience poorer outcomes than people without disabilities, including health, education, economic options, and community participation outcomes (World Health Organization, 2011). For example, an increase in a wide range of health conditions and greater risk of developing secondary issues and comorbid conditions are associated with disabilities (Eide & Braathen, 2017). In many countries, children and adults with ID have been isolated within their communities and denied access to educational opportunities and development of vocational skills (Parmenter, 2011; UNESCO, 2010). Lower employment

levels for adults with ID can be linked, in part, to higher levels of isolation and lack of education (Dempsey & Ford, 2009).

Specific to the United States, outcomes for adults with disabilities in employment and independent living lag far behind their peers without disabilities. Moore and Schelling (2015) reported that in 2009 the rate of employment for young adults (ages 21–25) with ID (53%) was significantly below those without disabilities (90.2%) and those with ID earned an average hourly salary of \$7.25 compared to workers without disabilities earning \$20.90. Housing is a marker of independent living and people with ID rarely choose where or with whom they live (Stancliffe, Lakin, Larson, Engler, Taub, & Fortune, 2011) and 64% live with parents or family members as cited in the National Longitudinal Transition Survey-2 (U.S. Department of Education, n.d.).

### Intellectual Disabilities and Post-Secondary Education

In countries around the world, programs to include individuals with ID in post-secondary education (PSE) are increasing as an effort to promote inclusion, limit segregation, and improve lifelong outcomes for all people (Strnadová et al., 2018). In 1994, the World Conference on Special Needs Education adopted the principle of education for all in inclusive settings (UNESCO, 1994) and this principle was reinforced in 2000 at the World Education Forum (UNESCO, 2000). In 2006, the UN Convention on the Rights of Persons with Disabilities expanded, among other rights, the rights of

people with disabilities to have an equal opportunity to education and obligated states to provide opportunities for inclusive lifelong education for individuals with disabilities (United Nations General Assembly, 2006).

College programs have emerged in several countries, including Ireland, Canada, Iceland, Australia, and the United States, in which individuals with ID attend college with nondisabled peers (Bjornsdottir, 2017; Corby et al., 2018; Grigal et al., 2011; O'Brien et al., 2009; Plotner & May, 2019; Rillotta et al., 2020). These college and university programs provide a “normative pathway” to positive adult outcomes (Uditsky & Hughson, 2012, p. 299) and an opportunity for people with ID to lead a life similar to peers without disabilities (Corby et al., 2018). Studies have shown that students with ID who attend PSE programs have increased self-esteem, social opportunities, confidence, feelings of independence, sense of belonging, academic and living skills, employment rates, and community engagement (Bjornsdottir, 2017; Corby et al., 2018; O'Brien et al., 2009; Plotner & May, 2019; Rillotta et al., 2020).

In the United States, federal legislation mandates that public schools educate all students with disabilities, including those with ID, within the “least restrictive environment” (IDEA, 2004; PL94-142, 1975) and supports individuals with disabilities participating in PSE (Section 504 of the Rehabilitation Act of 1973; Americans with Disabilities Act, 2008n). However, while school-age students with ID participate in public education, they have not historically had opportunities to continue in PSE (Thoma et al., 2011). According to NTLS-2 data ((U.S. Department of Education, n.d.), in 2009, only 28.5% of individuals with ID reported ever having enrolled in a PSE program and none reported attending a four-year college/university.

The Higher Education Opportunity Act of 2008 (P.L. 110-315) specifically includes provisions to provide students with ID opportunities to attend institutes of higher education, contributing to an increase in inclusive college programs (Jernudd et al., 2019). Think College, a federally-funded center devoted to increasing quality inclusive higher education opportunities for students with ID, recognizes 283 PSE programs for students with ID at four-year colleges (Think College College Search Webpage, n.d.).

Although PSE programs now exist internationally and in the United States, significant variation exists among the structures, supports, and services offered (Bjornsdottir, 2017; Corby, et al., 2018; Grigal et al., 2011; O'Brien et al., 2009; Plotner & May, 2019; Rillotta et al., 2020). Regarding the curriculum, some programs

are limited to segregated special education courses and others offer only individualized versions of fully-inclusive offerings. However, the most common structure includes a mixture of both formats (Grigal et al., 2011). Further, the level of integration in the social activities and campus community also varies widely, both by the purpose of the program and the mission of the institution (e.g., a two-year college versus a four-year university). Research is limited on a mixed format integrated postsecondary education program for students with intellectual disabilities that is fully integrated and residential. The purpose of this research is to address that gap from the perspective of the students, a methodology seldom found in studies about people with ID, thus exploring the self-described lived experience of young adults with intellectual disabilities who attend an integrated residential college program.

### **One Post-Secondary Education Model for Students with Intellectual Disabilities**

This research study was conducted at a private, faith-based liberal arts institution located in the United States. The student population of approximately 5,000 is evenly distributed between traditional undergraduate and post-traditional (adult undergraduate, graduate, and seminary students). The majority of the traditional undergraduate students are residential.

Within this institutional context, the BUILD program is a fully residential two-year program for young adults with ID. BUILD students earn an Applied Skills Certificate, while focusing on five benchmarks: self-care, home care, relationships, academics, and employment. BUILD is a mixed program (Harrison et al., 2019), providing inclusive opportunities in coursework, employment, residential, and social activities with traditional students, as well as life skills and career training in courses specific to BUILD students. The BUILD program is housed in the University's Center for Access and Integration and employs eight full-time staff, along with traditional students who serve as mentors for BUILD students in academics, employment, and residential life.

### **Conceptual Framework**

The conceptual framework of self-determination was used to explore the lived experience of students with ID attending an integrated residential college program. Self-determination is an important component of individual quality of life (Lachapelle et al., 2005; Wang et al., 2010; Wehmeyer & Schalock, 2001) and a criterion used to evaluate programs supportive of individuals with ID (Schalock & Verdugo, 2002).

Wehmeyer's causal agency theory of self-determination centers on the dispositional characteristics of individuals to possess and exercise volition to act intentionally and with causal agency (Shogren et al., 2015; Shogren et al., 2008). According to Shogren et al. (2008), self-determination is a personal characteristic that empowers individuals to exercise intention to maintain or improve one's life or circumstances and to make conscious choices based on personal will. Self-determination is not limited to a distinct list of skills but rather encompasses any behavior that furthers a person's ability to impact, direct, or cause events, and to have causal agency.

The social-ecological approach to self-determination considers how the environment influences the development and exercise of self-determination (Walker et al., 2011, Wehmeyer et al., 2003). This approach emphasizes that developing and exercising self-determination occurs in a social context. If self-determination is limited, it is often the result of human factors in the environment; for example, someone else is exerting personal will and controlling the environment. This interpretation recognizes that marginalized people (e.g., people with ID) have fewer opportunities to act intentionally to impact their lives, as minimal opportunities to make choices can limit an individual's development of self-determination.

According to Martin and colleagues (2003), self-determined learning occurs when an individual faces an obstacle to attaining a goal and they attempt to control the event by modifying their response. The individual learns as they alter their thinking, beliefs, and behaviors, while adjusting to the obstacle. In meeting and overcoming challenging circumstances, individuals impact the situation and self-determination grows (Shogren et al., 2008).

## METHODS

An empirical phenomenological research design was used to explore the following research question: What are the lived student experiences of students with intellectual disabilities enrolled in a residential mixed program at a private university located in the United States? Empirical phenomenology was appropriate for the study given the dual commitments to represent the participants' unique and authentic perspectives in the analysis and to attend to pre-existing theory and research in contextualization (Aspers, 2009).

## Site and Participants

This research study was conducted at a private, faith-based liberal arts institution located in the United States. Having obtained Institutional Review Board approval for the study, all second-year BUILD students, with the approval of their parents/guardians (if applicable), were invited by email to participate in the research.

Of the 12 BUILD students invited, six students agreed to be interviewed. As required by the BUILD program, all of the student participants lived on campus. All participants were second-year BUILD students, ensuring that they had nearly two years of university experience. Four participants were female and two were male, all were between 20 and 25 years of age, and all identified as White. The (required) internships and (optional) co-curricular involvement of the students varied significantly.

Due to ethical, methodological, and logistical concerns, limited research exists in which people with ID are the participants (Iacono, 2006; National Disability Authority, 2009). Thus, in this study the researchers made accommodations to hear the authentic lived experiences directly from the participants (Corby et al., 2015). The researchers were particularly sensitive to the participant's ability to provide informed consent (and if applicable, the need for guardian consent), the language and structure of the interview protocol, and the tone and impact of the interview.

## Data Collection

Data for this research study were collected through semi-structured individual interviews (Merriam & Tisdell, 2016) with six BUILD students and guardian/parents, if applicable (Appendix A). The interviews were conducted by three researchers with terminal degrees in related educational fields, two with qualitative methodology expertise and two with education, special education, and/or intellectual disability expertise. The interviews were recorded virtually through Google Hangout and lasted from 35 to 95 minutes.

Each participant responded orally to the semi-structured interview questions, although the communication style and ability varied significantly among the participants. Some participant responses were concrete, bare, and literal, while others were loquacious and detailed. In order to account for this variation, two researchers conducted each interview, to better engage with the participants, hear their answers, and observe and interpret physical and non-verbal responses to the interview questions. Further, the option of interview follow-up

prompts and responding to the interview questions in writing were used to attempt to obtain as much description as possible. After the oral interviews, one participant also responded to the questions in writing.

In a few of these video calls, the researchers observed the participants' parents and/or guardians in proximity to the participant during the interview. Occasionally, participants looked to the parent for clarification; however, parents primarily remained available but unengaged. However, one parent was intrusive to the interview and did not allow the participant to self-describe their lived experience without regular interference. This participant provided further and more differentiated written responses to the interview questions.

### **Analysis and Procedures**

In this research study, the phenomenon being researched was the lived experiences of students with ID enrolled in a residential two-year mixed program at a private university located in the United States. All student participants and their parents/guardians (if appropriate) reviewed their interview transcripts and three modified and/or expanded upon their initial responses. Three researchers analyzed the interview transcripts, individually coded words and phrases, then collaboratively negotiated and developed themes, and ultimately constructed meaning of the phenomenon (Moustakas, 1994). The researchers then used existing theory and literature to contextualize the phenomenon while staying true to the experience of the participants (Aspers, 2009).

Particularly due to the vulnerability of the study participants, the trustworthiness of this research process was paramount. The variety of academic discipline and personal backgrounds represented among the researchers reinforced the process of bracketing and enriched the inter-rater reliability of the collaborative coding process. Theoretical triangulation was achieved through the use of two interviewers, member checking, and a collaborative coding and analysis process, as described above (Aspers, 2009; Morse et al., 2002; Thurmond, 2001).

## **RESULTS**

From the student interviews and written responses, three primary themes emerged: *social experience*, *independence*, and *safety and belonging*. Although the communication style and ability varied significantly among the students, these themes were clearly emphasized by the respondents as definitive of their student experience.

### **Social Experience**

The social aspect of the student experience was emphasized by all of the participants. Although the expectations, needs, and preferences for interaction and activity varied, all participants referenced relationships and co-curricular activity as significant to their time on campus. Although the participant responses were overwhelmingly positive, conflict among roommates and friends was also described.

### **Relationships**

According to the interview, relationships were a defining component of the BUILD student experience. The connections described included relationships with BUILD students, traditional student BUILD mentors, traditional students, and BUILD staff.

Most student participants highlighted time spent and relationships with friends. As stated in one interview, "Well, most of the time, pretty much every single day... I would spend a lot of time with my [BUILD] friend group." Multiple respondents, un-prompted, named their friends, seemingly proud of the number and network. Interview participants described "doing fun things together and learning new things every day together."

In particular, roommates seemed to be central to the relationship matrix. One respondent stated, "I think with my roommates, they were really like sisters to me." Most participants described spending time with their roommates, including listening to music, playing video games, and "just talking."

However, according to the interviews, there were also important friendships with non-BUILD traditional students. One participant described meeting traditional students who lived in the residence hall, explaining that they "sometimes invited us into their rooms to talk" and another shared that she "still keeps in contact with them." In the interviews, respondents also described developing relationships with non-BUILD traditional students around shared experiences or interests, such as sports, classes, or activities.

The traditional student BUILD mentors seemed to serve an interconnected friendship and support relationships role. The BUILD program included academic, housing, and internship mentors. According to the interviews, these BUILD mentors provided guidance and assistance. For example, participants shared that the housing mentors enforced living and social norms, with one student stating, "They explained...I learned...you can't just walk into someone's room; you would have to knock on their door, and there was some rules about

doing that.” Another described the onsite internship mentor as explaining protocols and providing ongoing reminders. The participants indicated that mentors also assisted with necessary tasks, such as waking up, doing laundry, and getting back into their room when they locked themselves out. Another student emphasized the academic support that his mentor provided, stating, “They helped me when things are tough in class. If I had tests or something, they always helped me read. Because I’m a little harder reading a little bit.” Other participants seemed to receive the mentors as friends who explained campus jokes, planned fun activities, or accompanied them to sporting events. Simply the accessibility of the mentors seemed to be an important and reassuring relational support for BUILD students.

### ***Co-curricular Activities***

In addition to relationships, the student participants seemed to enjoy participating in or attending co-curricular activities. In the interviews, respondents referenced university events, student activities, and BUILD student-specific programming. For some participants, meals, both in the cafeteria and in their apartments, were also social activities.

Some participants were involved in or attended university-wide co-curricular activities, such as choir or vespers (a student-led worship service). Several participants referenced sporting events. One respondent was particularly enthusiastic about games, stating, “I loved sports...hockey, football...hockey is my favorite...” According to the interviews, the traditional student BUILD mentors seemed to facilitate and encourage this engagement.

Other participants seemed more interested in the student and BUILD-specific programming, such as karaoke nights, bowling, residence hall parties, and coordinated shopping runs. One participant even described planning her own party, stating, “It was a Valentine party because no one was doing anything... I was like, ‘I’m a single woman and don’t really like Valentine’s Day because I don’t have any significant other to spend it with.’ I had sugar, I had lemonade, and I had all appropriate things.”

### ***Conflict***

Although less frequent in the interviews, a few participants did reference conflict with their roommates and/or other BUILD students. Some of the conflict appeared to be related to basic personality differences. For example, one participant stated, “Sometimes I would clash with their personalities, if I was in a bad mood,”

or another stated, “She was very quiet and I’m very in-your-face; I’m an extrovert.” In contrast, a more significant conflict appeared to involve roommates, with a confrontation resulting in a room change; the participant explained, “we [were] fighting a lot. She always told me what to do.”

### ***Independence***

Student participants were explicit about the theme of independence motivating and defining their student experience, seeming to perceive this opportunity to attend college to be an act of independence. According to the interviews, the participants navigated the daily requirements and demands of living on their own at college and indicated that the college experience enriched and improved their experiences of living on their own.

### ***Independent Living***

Participants indicated that one of the primary reasons they enrolled in BUILD was to become more independent. Some indicated general longings for independence, wanting “to learn how to be independent,” or “live my life independently,” while another referenced specific skills stating, “so I can learn stuff about cleaning and then laundry.” Student participants also described the act of living independently on campus and managing their own affairs, including daily routines. One participant stated, “we went on our school iPads. We looked at our calendars to see what class was first and we [would] go to that classroom.” Another student included her love of coffee in her morning routine, “then I would make a quick stop at [a local coffee shop]. I really like coffee, so I’ll get some coffee. I’ll get something for breakfast as well. And then I go to class.” Others confessed that it was hard to get up and arrive on time for early classes.

The interviews indicated that students took advantage of many decision-making opportunities to exercise their independence. Participants made choices about eating in the dining center alone or with friends, cooking favorite things to eat, and “choos(ing) the right decisions” regarding exercise and healthy eating. One student explained splitting time between eating in the dining center and eating in the apartment “because I wanted to have like a really good balance.” Respondents made choices about how to spend free time, such as attending certain sporting events, hanging out and listening to music, or spending time in the library. One participant reported going to the residence hall common area to “see what was going on... if nothing was happening, I would just go back to my dorm.” Another student chose not to go bowling because it was “until midnight.” One

participant summarized the experience: “I would just choose to execute my decisions wisely and just make good decisions.”

### ***Learning Independent Living Skills***

Students reported learning “different stuff about what to do on your own.” They learned “independent life skills and how to manage college life” in classes like independent living skills class and math class where students “learned to use money.” Participants shared learning numerous skills in jobs and employment class, including “how to act in an interview, what do you wear in an interview,” “job etiquette,” and “you can’t lie on a resume.” Mentors supported participants in gaining independent living skills, “helping me doing stuff about cleaning. And then, I always ask them for help if I needed it.” Participants learned skills in cleaning, cooking (e.g., “making a souffle and pesto”), folding clothes, washing dishes, and doing laundry, and they reported confidence in being able to perform these skills on their own after college

### ***Hopes for an Independent Future***

Interviews revealed that BUILD students are excited to maintain or increase their independence in the future. Most have a goal to live independently in an apartment either alone or with a friend and plans to work in areas of interest, such as working with children or at a church or hospital. Some are actively looking for work by applying at specific employers or utilizing an online job search platform. Participants described working with a government agency and a nonprofit organization to meet their independent living and employment goals. One student hoped for “a good life” that includes “watching different sports on TV, cook foods and work in the kitchen in an apartment.” Another student is “really looking forward to what the future holds.”

### ***Safety and Belonging***

The theme of safety and belonging emerged from a wide range of responses, but with the consistent emphasis on safety within spaces and a sense of belonging created through known campus community. While aspects of this theme intersect with the themes of *social experience* and *independence*, respondents used language that suggested that safety and belonging was foundational to their lived student experience.

### ***Safe Spaces***

Most participants emphasized their residence hall room or apartment as an important space that offered a sense of safety. In the interviews, many students

seemed to find security and belonging through having their own designated living space, exemplified by one participant stating, “I had my own kitchen and I had my own living room and I shared my bedroom with my other roommate and then I had my own bathroom, too.” Another respondent explicitly used the word “safe” to describe her apartment.

Aligned with the relationships referenced in the *social experience* theme and the independent living emphasis of the *independence* theme, participants expressed sentiments of ownership around their living space. Respondents used phrases such as “inviting (a friend) in” or “making them a meal” that demonstrated their sense of confidence in their full belonging in that space. Some participants even referenced “appropriate boundaries” around living spaces, seemingly desiring that their own space was respected, and respecting the space of others.

However, students also highlighted alternative spaces that offered them a sense of safety and belonging. For example, one participant stated, “a lot of the time I would go to the library at the University because I love the library and it was just so peaceful and it was just really calming and the aura of the atmosphere was just really calm.” Another student referenced the university auditorium, in which the first few rows of seats were informally reserved for BUILD students, due to the frequency of their usage.

According to the interviews, navigating the physical campus was initially “scary,” “big,” and caused some anxiety. One participant referenced “memorizing” where the dining center and classrooms were located. A sense of safety and belonging appeared to develop as students learned the campus layout and/or asked for directions.

### ***Sense of Belonging***

A sense of belonging seemed to emerge through the integration of the lived student experience. Phrases referencing campus as “home” and “where I want to be” suggest a feeling of belonging. Words such as “helping,” “supportive,” and “understanding” indicate confidence in the ability to access necessary assistance. One participant stated simply, “I really appreciated just like how the University was so supportive and understanding.”

Aligned with the theme of *social experience*, relationship and participating in community activities reinforced the participant’s sense of belonging. Respondents used words such as “safe,” “relaxing,” “accepting,” and “connection,” indicating belonging was

created amidst those connections. One stated, “Whenever I was feeling different like afraid. If I was feeling like I needed to be with my friends, I would contact [them] and I would just kind of go off base from how my emotions were feeling.” Another stated, “everyone was really accepting and kind.”

A sense of belonging on campus, physically and relationally, seemed particularly important, considering the challenge of leaving the known comfort and safety of home. As one participant stated, “The scary part was leaving my family.” However, the student continued, “I think when my parents left, I felt ok with really cool roommates...They were like sisters to me.” Another student concluded, “I decided it was a really great fit. I really love the community.”

Additionally, being involved in a shared faith community and participating in worship activities was highlighted in respondents’ lived experience. These events included the broader campus, expanding community beyond the BUILD group. Attending chapel and vespers seemed to develop a sense of belonging through “singing songs about God” and “learning about Jesus.” One student stated he, “went all the time. It was cool.” Students appeared to identify a connection to God and others during these experiences, which deepened their community.

The enthusiasm expressed by participants regarding their lived experience seemed to emanate from a sense of feeling safe and belonging to a community. This theme was summarized as students shared what they loved most about their BUILD experience and what they would tell new BUILD students. Respondents stated they, “loved being a part of the community and experiencing everything.” They would tell incoming students to “have fun,” “make friends,” “talk to mentors and teachers,” and “be kind to one another.” Lastly, the participants stated they did not want their BUILD experience to end. They wished for a third year.

## DISCUSSION

The themes of *social experience*, *independence*, and *safety and belonging* illuminated how students with intellectual disabilities grew in self-determination through attending an integrated residential college program. Although the findings align with existing research and theory, new insights were also found as to how support and a strong sense of belonging contributed to the participants’ increased self-determination.

Beginning with their recollections of wanting to enroll in the BUILD program to become more independent and live on their own, the participants described

experience with setting and attaining goals and decision making. In this decision process, students demonstrated their inclinations to be self-directed, suggesting that they were already developing what Wehmeyer et al. framed as “causal agency” (2000). The college experience provided an innovative environment or intervention with a context that positively impacted the self-determination of individuals with ID (Walker et al., 2011). Key components of the college environment/intervention were opportunities to act with autonomy, appropriate supports, and a community of belonging.

### Opportunity-Rich Environment

Self-determination is impacted by the environments in which people with ID live and work (Vincente et al., 2019) and the level of autonomy offered (Walker et al., 2011). According to Chambers et al. (2007), the development of self-determination depends more on the environment or context than cognitive abilities and individuals with ID who accessed community settings (to live and work) demonstrated higher levels of self-determination than those in more segregated settings. Historically, individuals with ID have experienced segregated settings with few opportunities to practice causal agency (Wehmeyer & Metzler, 1995). In contrast, BUILD students set and managed their daily routines, chose how to spend free time and with whom, advocated for themselves in relationships, and negotiated solutions to personal or group issues. Participants described navigating the social, practical, academic, and personal aspects of their lived student experience, the decisions they made, and what they learned about themselves.

The myriad of opportunities offered in the college campus environment allowed students to develop elements of self-determination outlined by Burke and colleagues (2020), including choice making, decision making, problem solving, goal setting and attainment, planning, self-advocacy, self-awareness, and self-knowledge. In this environment, participants were empowered to act in ways that made a “real” difference in their lives, to be causal agents (Wehmeyer, 2014). Exemplifying Martin and colleagues’ self-determined theory (2003), being a college student also required participants to engage in new roles, adjust their responses based on their engagement in these new roles, and learn from the adjustment process. The opportunity-rich environment provided by the BUILD program and the broader university setting provided opportunities for students to develop and demonstrate greater self-determination.



## Network of Support

The participants experienced a network of interconnected supports within the BUILD program and the broader university context, including BUILD specific coursework and designated mentor support. Classes and mentor support were designed to help students learn and practice independent living skills (e.g., cooking, laundry, employment skills, money skills). Participants expressed pride in developing independent living skills and enthusiasm to continue performing these important skills of daily living after college.

Skill-building has been viewed as an important avenue to developing greater self-determination; however, specific skill development is of secondary importance to acting in a self-determined way (Wehmeyer, 2014). Yet participants' confidence in their independent living skills seems to have increased their feelings of being prepared to live independently; they indicated that their plans to continue living independently after college were shaped by their college experiences. This finding aligns with O'Brien and colleagues' research (2009), that individuals with ID who attended a college program began to see themselves differently and as more capable to live independently after college and perceived that others (i.e., people without disabilities) also viewed them as more capable than before they attended the college program. Uditsky and Hughson (2012) also found that college students with ID assumed a new family position as their competence, confidence, and autonomy grew.

Participants viewed student mentors as helpful to problem-solve (e.g., help with getting to class on time or with coursework), operationalize their choices (e.g., go to a sporting event), and guide them to maintain college living norms and expectations. The mentor role is similar to Uditsky and Hughson's (2012) facilitator role "to engage the student in campus life, interpret both student and environment when necessary, and remain in the background as much as possible" (p. 301) and Rillotta and colleagues' peer mentor (2020). Students with ID benefitted from the support of mentors to ease the transition to college life, facilitate academic learning, and provide employment coaching.

The BUILD program provides a "normative pathway" (Uditsky & Hughson, 2012, p. 299) toward positive adult outcomes for people with ID in a college environment that is similar to the pathway of individuals without disabilities. In this integrated experience, students with ID and students without disabilities live and learn together, in contrast to an environment where

students with ID live separately from traditional students or learn skills in isolation. Within this typical college setting, assistance is provided to students with ID, varies depending on individual student characteristics, and fluctuates based on skill areas such as academic, social, vocational, residential living, and independent living within a typical college setting.

## Community of Belonging

According to research, a student's sense of belonging, or their feelings of acceptance and connectedness, significantly impact their student experience (Strayhorn, 2012). Mahar and colleagues (2013) defined "sense of belonging... as a subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs or personal characteristics" (p. 6). In this study, participants embraced community life at college and reported a sense of belonging that included feeling safe, assuming ownership, building relationships, and sharing a faith experience.

Students linked their sense of safety and ownership. They discussed concrete ways in which they felt safe within their dorm or apartment, exercised boundaries related to ownership, and invited others into their space. Beyond their specific residence, participants claimed other spaces on campus as safe and expressed satisfaction that they had learned to navigate the entire campus which suggests they were making the campus their own. This finding is similar to Strnadová and colleagues (2018) belonging-in-relation-to-space findings, which highlight the importance of being in a place where one can be oneself and decide what to do, who to be with, and how to express oneself.

Participants described connections to other students with ID, mentors, and traditional students, and these relationships facilitated a sense of belonging. Similarly, Power (2013) confirmed that meaningful engagement and reciprocal relationships are essential to belonging. Finally, students' sense of belonging was seemingly enhanced by their participation in activities that aligned with their expressions of faith, reflecting Mahar et al.'s "shared beliefs" (2013).

A sense of belonging and community are linked to developing and exercising self-determination (Bjornsdottir, 2017; Mahar et al., 2013). Individuals with ID have often been marginalized and may not have experienced opportunities to exercise agency over their situations and may feel powerless to belong to a group or community (Mahar et al., 2013). However, participants demonstrated self-determination in that they exercised choice

and had power to develop satisfying relationships and a sense of belonging that defined their student experience.

### LIMITATIONS AND FUTURE RESEARCH

Consistent with the inherent limitations of a qualitative research design, the findings of this study are not directly generalizable to other students with intellectual disabilities or university programs, particularly given the comprehensiveness of the BUILD program. Acknowledging the distinctiveness of the participant population, and the unique cognitive and communication patterns of these students with ID, it is difficult to determine if the accommodations that were made in order to conduct this research were effective. Additionally, further research, potentially through a longitudinal quantitative study, is needed to better understand the impact of the BUILD program on the participants' ongoing life skills and independent living.

### CONCLUSION

This empirical phenomenological research explored the lived experiences of students with intellectual disabilities who attend a mixed program at a four-year residential university in the United States. BUILD represents one university's attempt to increase post-secondary educational access for students with ID. Simultaneously, BUILD is a pathway toward improved quality of life for individuals with ID. From interviews with six participants, the themes of social experience, independence, and safety and belonging emerged. The findings of this research indicate that the opportunity-rich environment of independent living on campus, the network of support provided by the BUILD program and the university, and the community of belonging that the BUILD students experienced contributed to the participants' growth in self-determination. The findings of this study align with previous research on self-determination and also provide new interpretations and applications. This suggests that innovative college programs can be used as an intervention to improve or enhance the self-determination (Walker et al., 2011) of students with intellectual disabilities. Further, these findings offer intervention components to consider in designing and implementing future initiatives for individuals with disabilities across international contexts, including public policy, government and private support systems, and residential and school programs.

### REFERENCES

- Americans with Disabilities Act Amendments Act, Pub. L. 110-325 (2008). <https://www.ada.gov/pubs/adastatute08.pdf>
- Aspers, P. (2009). Empirical phenomenology: A qualitative research approach (The Cologne Seminars). *Indo-Pacific Journal of Phenomenology*, 9(2), 1–12.
- Bjornsdottir, K. (2017). Belonging to higher education: Inclusive education for students with intellectual disabilities. *European Journal of Special Needs Education*, 32(1), 125–126.
- Burke, K. M., Raley, S. K., Shogren, K. A., Hagiwara, M., Mumbardó-Adam, C., Uyanik, H., & Behrens, S. (2020). A meta-analysis of interventions to promote self-determination for students with disabilities. *Remedial and Special Education*, 41(3), 176–188.
- Chaffee, E. E., & Tierney, W. G. (1988). *Collegiate culture and leadership strategies*. Macmillan.
- Chambers, C. R., Wehmeyer, M. L., Saito, Y., Kerry, M., Lida, K. M., Lee, Y., & Singh, V. (2007). Self-determination: What do we know? Where do we go? *Exceptionality*, 15(1), 3–15. <https://doi.org/10.1080/09362830709336922>
- Corby, D., Taggart, L., & Cousins, W. (2015). People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection. *Research in Developmental Disabilities*, 47, 451–465.
- Corby, D., Taggart, L., & Cousins, W. (2018). The lived experience of people with intellectual disabilities in post-secondary or higher education. *Journal of Intellectual Disabilities*. <https://doi.org/10.1177/1744629518805603>
- Dempsey, I., & Ford, J. (2009). Employment for people with an intellectual disability in Australia and the United Kingdom. *Journal of Disability Policy Studies*, 19(4), 233–243.
- Eide, A. H., & Braathen, S. H. (2017). Disability and equity in public health. *Tidsskriftet den Norske Lægeforening*, 137(21). <https://tidsskriftet.no/en/2017/11/global-helse/disability-and-equity-global-health#ref1>
- Education for All Handicapped Children Act, Pub. L. 94-142 (1975). <https://www.govinfo.gov/content/pkg/STATUTE-89/pdf/STATUTE-89-Pg773.pdf>

- Grigal, M., Hart, D., & Weir, C. (2011). Framing the future: A standards-based conceptual framework for research and practice in inclusive higher education. *Think College Insight Brief*, 10, 1–3.
- Harrison, A. J., Bisson, J. B., & Law, C. B. (2019). Impact of an inclusive postsecondary education program on implicit and explicit attitudes toward intellectual disability. *Intellectual and Developmental Disabilities*, 57(4), 323–336.
- Higher Education Opportunity Act, Pub. L. No. 110-315 § 122 STAT. 3078 (2008). <https://www.congress.gov/bill/110th-congress/house-bill/4137>
- Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability*, 31(3), 173–179.
- Individuals with Disability Education Improvement Act, 20 U.S.C. § 1400 (2004). <https://www.congress.gov/bill/108th-congress/house-bill/1350>
- Jernudd, I., Nagaraj, S., Mueller, S., & Rozell, D. (2019). State policy actions supporting higher education for students with intellectual and developmental disabilities. *Think College Insight Brief*, 42. University of Massachusetts Boston, Institute for Community Inclusion.
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M.-C., Courbois, Y., Keith, K. D., Schalock, R., Verdugo, M. A., & Walsh, P. N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research*, 49(10), 740–744.
- Mahar, A. L., Cobigo, V., & Stuart, H. (2013). Conceptualizing belonging. *Disability and Rehabilitation*, 35(12), 1026–1032.
- Martin, J. E., Mithaug, D. E., Cox, P., Peterson, L. Y., Van Dycke, J. L., & Cash, M. E. (2003). Increasing self-determination: Teaching students to plan, work, evaluate, and adjust. *Exceptional Children*, 69(4), 431–446.
- Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation*. Jossey-Bass.
- Moore, E. J., & Schelling, A. (2015). Postsecondary inclusion for individuals with an intellectual disability and its effects on employment. *Journal of Intellectual Disabilities*, 19(2), 130–148.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1, 1–19.
- Moustakas, C. (1994). *Phenomenological research methods*. Sage.
- National Disability Authority. (2009). *Ethical guidance for research with people with disabilities*. (Disability Research Series No. 13).
- O'Brien, P., Shevlin, M., O'Keefe, M., Fitzgerald, S., Curtis, S., & Kenny, M. (2009). Opening up a whole new world for students with intellectual disabilities within a third level setting. *British Journal of Learning Disabilities*, 37(4), 285–292.
- Parmenter, T. (2011). *Promoting training and employment opportunities for people with intellectual disabilities: International experience* (Employment Working Paper No. 103). International Labour Organization.
- Plotner, A. J., & May, C. (2019). A comparison of the college experience for students with and without disabilities. *Journal of Intellectual Disabilities*, 23(1), 57–77.
- Power, A., Lord, J. E., & DeFranco, A. S. (2013). *Active citizenship and disability implementing the personalisation of support*. Cambridge University Press.
- Rillotta, F., Hutchinson, C., Arthur, J., & Raghavendra, P. (2020). Inclusive university experience in Australia: Perspectives of students with intellectual disabilities and their mentors. *Journal of Intellectual Disabilities*, 24(1), 102–117.
- Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, 31(2), 181–190.
- Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. American Association on Mental Retardation.

Section 504 of the Rehabilitation Act, as amended, 29 U. S. C. § 794. (1973). <https://www2.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html>

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A., Little, T., & Lopez, S. (2015). Causal agency theory: Reconceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities, 50*(3), 251–263.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T. D., Garner, N., & Lawrence, M. (2008). Understanding the construct of self-determination: Examining the relationship between the Arc's Self-Determination Scale and the American Institutes for Research Self-Determination Scale. *Assessment for Effective Intervention, 33*(2), 94–107.

Stancliffe, R. J., Lakin, K. C., Larson, S., Engler, J., Taub, S., & Fortune, J. (2011). Choice of living arrangements. *Journal of Intellectual Disability Research, 55*(8), 746–762.

Strnadová, I., Johnson, K., & Walmsley, J. (2018). "... but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*(6), 1091–1102.

Strayhorn, T. L. (2012). *College students' sense of belonging: A key to educational success for all students*. Routledge.

Think College Webpage. (n.d.). *College Search*. <https://thinkcollege.net/college-search>

Thoma, C. A., Lakin, K. C., Carlson, D., Domzal, C., Austin, K., & Boyd, K. (2011). Participation in postsecondary education for students with intellectual disabilities: A review of the literature 2001–2010. *Journal of Postsecondary Education and Disability, 24*(3), 175–191.

Thurmond, V. (2001). The point of triangulation. *Journal of Nursing Scholarship, 33*, 253–258.

Uditsky, B., & Hughson, E. (2012). Inclusive postsecondary education—An evidence-based moral imperative. *Journal of Policy and Practice in Intellectual Disabilities, 9*(4), 298–302.

UNESCO. (1994). *The Salamanca world conference on special education: Access and quality*. UNESCO and the French Ministry of Education.

UNESCO. (2000). *Education for all: Meeting our collective commitments, World Education Forum; The Dakar Framework for Action*. UNESCO

UNESCO. (2010). *Reaching the marginalized* (EFA Global Monitoring Report, 2010). Oxford University Press. <http://unesdoc.unesco.org/imag-es/0018/001866/186606e.pdf>

United Nations General Assembly. (2006). *Convention on the rights of persons with disabilities*. United Nations.

U.S. Department of Education. Institute of Education Sciences, National Center for Education Statistics. (n.d.). *National Longitudinal Transition Study-2*. <https://ies.ed.gov/ncser/projects/nlts2/>

Vicente, E., Verdugo, M. A., Gómez-Vela, M., Fernández-Pulido, R., Wehmeyer, M. L., & Guillén, V. M. (2019). Personal characteristics and school contextual variables associated with student self-determination in Spanish context. *Journal of Intellectual & Developmental Disability, 44*(1), 23–34.

Walker, H. M., Calkins, C., Wehmeyer, M. L., Walker, L., Bacon, A., Palmer, S. B., Jesien, G. S., Nygren, M. A., Heller, T., Gotto, G. S., Abery, B. H., & Johnson, D. R. (2011). A social-ecological approach to promote self-determination. *Exceptionality, 19*(1), 6–18.

Wang, M., Schalock, R. L., Verdugo, M. A., & Jenaro, C. (2010). Examining the factor structure and hierarchical nature of the quality of life construct. *American Journal on Intellectual and Developmental Disabilities, 115*(3), 218–233.

Wehmeyer, M. (2014). Disability in the 21st century: Seeking a future of equity and full participation. In M. Agran, F. Brown, C. Hughes, C. Quirk, & D. Ryndak (Eds.), *Equity and full participation for individuals with severe disabilities* (pp. 3–24). Paul H. Brooks.

Wehmeyer, M. L., Abery, B. H., Mithaug, D. E., & Stancliffe, R. J. (2003). *Theory in self-determination: Foundations for educational practice*. Charles C. Thomas.

Wehmeyer, M. L., & Metzler, C. A. (1995). *How self-determined are people with mental retardation?* The National Consumer Survey.

Wehmeyer, M. L., Palmer, S. B., Agran, M., Mithaug, D. E., & Martin, J. E. (2000). Promoting causal agency: The self-determined learning model of instruction. *Exceptional Children, 66*(4), 439–453.

Wehmeyer, M. L., & Schalock, R. L. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children, 33*(8), 1–16.

Wilson, N. J., Jaques, H., Johnson, A., & Brotherton, M. L. (2016). From social exclusion to supported inclusion: Adults with intellectual disability discuss their lived experiences of a structured social group. *Journal of Applied Research in Intellectual Disabilities, 30*(5), 847–858. doi:10.1111/jar.12275

World Health Organization. (2011). *World report on disability*. Author. <https://www.refworld.org/pdfid/50854a322.pdf>

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## Appendix A

1. Why did you come to Bethel? What did you think it would be like?
2. What is your day like at Bethel?
  - a. How do you spend your free time?
  - b. Where do you live? What's it like in the dorms/apartments?
3. Who do you spend time with?
  - a. Who do you spend your time with at Bethel?
  - b. Student mentors?
  - c. Other BUILD students?
  - d. Other students?
4. What makes you happy at Bethel?
5. What has been hard about being at Bethel? Challenges.
  - a. Classes?
  - b. Internships/Jobs?
  - c. Other students?
  - d. Managing time?
6. What have you learned and how have you changed since being at Bethel?
  - a. Classes?
  - b. Teachers?
  - c. Student Mentors?
  - d. Internships/Jobs?
7. How do you see your future after you leave here? Is that different than before you came?