# Intellectual and Developmental Disabilities College Students with Intellectual and Developmental Disabilities' Experiences, Conception, and Development of Emotional Wellness --Manuscript Draft--

Manuscript Number:	IDD-D-22-00073R3			
Article Type:	Research			
Keywords:	emotional wellness; wellness; college students; intellectual and developmental disabilities; consensual qualitative research			
Corresponding Author:	Alexander M. Fields, Ph.D. University of Nebraska Omaha Omaha, NE UNITED STATES			
First Author:	Alexander M. Fields, PhD			
Order of Authors:	Alexander M. Fields, PhD			
	Olivia Lewis, PhD			
	Madeline Saunders, MEd			
	Rebecca B. Smith-Hill, PhD, MSW			
	Chelsea V. Stinnett, PhD			
Manuscript Region of Origin:	UNITED STATES			
Abstract:	This study aimed to understand the ways in which college students with intellectual and developmental disabilities (IDD) experience and develop their understanding of emotions and emotional wellness. Semi-structured interviews with college students with IDD were conducted. The research team utilized consensual qualitative research (CQR) to analyze interviews and came to consensus in generating domains, core ideas, and a cross-analysis to answer the research question, "What are the experiences of college students with IDD in developing an understanding of emotions and emotional wellness?" Findings suggest college students with IDD have experience developing and maintaining their emotional wellness, though they may experience barriers prior to and during college enrollment. Limitations and implications for future research are discussed.			

College Students with Intellectual and Developmental Disabilities' Experiences,

## **Conception, and Development of Emotional Wellness**

Author

Institution

## **Author Note**

Author

We have no known conflict of interest to disclose.

Correspondence concerning this article should be addressed to Author

1

1

## IDD AND EMOTIONAL WELLNESS DEVELOPMENT

## Abstract

This study aimed to understand the ways in which college students with intellectual and developmental disabilities (IDD) experience and develop their understanding of emotions and emotional wellness. Semi-structured interviews with college students with IDD were conducted. The research team utilized consensual qualitative research (CQR) to analyze interviews and came to consensus in generating domains, core ideas, and a cross-analysis to answer the research question, *"What are the experiences of college students with IDD in developing an understanding of emotions and emotional wellness?"*. Findings suggest college students with IDD have experience developing and maintaining their emotional wellness, though they may experience barriers prior to and during college enrollment. Limitations and implications for future research are discussed.

*Keywords*: emotional wellness, wellness, college students, intellectual and developmental disabilities, consensual qualitative research

#### **College Students with Intellectual and Developmental Disabilities' Experiences,**

#### **Conception, and Development of Emotional Wellness**

The Center for Disease Control (CDC, 2020) estimates that one in four Americans live with a disability, and that intellectual and developmental disabilities (IDD) were the most common in young adults (Okoro et al., 2018). The Diagnostic and Statistical Manual of Mental Disorders fifth edition-text revision (DSM-5-TR) classified IDD as a deficit in intellectual abilities (e.g., abstract thinking, learning, understanding cause and effect, and problem solving) that results in impaired functioning to meet independence and social responsibility in one or more areas of the individual's daily life (American Psychiatric Association, 2022). Individuals with IDD may require support with self-care, social communication and relationships, understanding and reciprocating or responding to social cues, and independently understanding risks and consequences (Zisman-Ilani, 2022). While the diagnosis of IDD can be made between birth and late adolescence (age 18 years), individual support needs can vary widely from person to person depending on contextual factors. Research has suggested that young adults with IDD are less likely than young adults without disability to be employed, enrolled in postsecondary education, or live independently after high school (Newman, et al., 2011). There is evidence that individuals with intellectual disability specifically are also at an increased risk for anxiety and depression (Whitney et al., 2019). Researchers posit that lower access to community resources, lower rates of employment, and fewer social connections that individuals with IDD often experience are likely contributors to this increased risk (Whitney et al, 2019). All of these conditions are associated with difficulties experiencing and expressing emotions.

The benefits of providing holistic support options to enhance students with IDD's postsecondary development have a documented impact (Becht et al., 2020), yet there is limited

literature to identify this population's mental health needs, specifically, their emotional wellness needs (Brown et al., 2013). Although mental health and emotional wellness appear together in literature, there are notable differences. Through a wellness perspective, an individual is viewed through a prevention and holistic lens to achieve optimal health in their natural environment (Ohrt et al., 2019). Ohrt and colleagues outlined five domains of wellness, with emotional wellness describing how an individual develops, identifies, regulates, expresses, and responds to their emotions within an interpersonal and intrapersonal context. Each domain of wellness is critical to understanding an individual and contributes to the development of someone's holistic health and well-being. Therefore, emotional wellness is a contributing factor to the development and maintenance of mental health. For individuals diagnosed with IDD, the development of emotional wellness may differ from peers without disabilities (Milroy et al., 2021) and is viewed as a gap in special education services delivered through K-12 settings (Ziomet-Diagle, 2015). Coduti et al. (2016) noted that higher education staff and faculty's lack of understanding for the needs of college students with disabilities may contribute to factors that inhibit emotional wellness and create added stress during their college experience.

#### **College Students with IDD**

With the advent of inclusive postsecondary education (IPSE) programs in the past two decades, college has recently become an option for students with IDD. These programs are embedded on college campuses and give students with IDD access to academic courses, life skill courses, and campus membership including social access and dorm-living. Three hundred and fourteen IPSE programs exist across the United States at the time of this report (Think College, 2022). While each IPSE program is unique, programs vary widely in terms of degree of inclusive campus engagement and type of support options offered to students (Plotner & Marshall, 2015).

This includes a varying level of support and access to mental health services and coaching, despite knowing that targeted interventions through education, prevention, and direct support can promote emotional wellness in college students with IDD.

There is a relative dearth of research investigating health and wellness needs of college students with IDD. A systematic literature review of peer-reviewed articles related to health of college students with IDD resulted in only seven articles fitting that criterion (Oakes et al., 2020b). Oakes and colleagues (2020a) conducted interviews with seniors and recent program graduates using photo elicitation and a Q-sorting exercise. Findings from eight student interviews at Oakes et al.'s 4-year IPSE program, similar in description to the program used in the current study, included a theme of "coping with stress and anxiety," among others. McKnight-Lizotte et al. (2021) most recently surveyed 33 IPSE directors nationwide to assess the mental health needs of students with IDD attending their programs. They found that directors were most frequently reporting anxiety and depression among students, and of note was the fact that many directors reported that referrals to campus mental health resources at times were not occurring due to wait lists or university mental health professionals were unskilled at working with students with IDD (McKnight-Lizotte et al., 2021).

Recent research efforts focused on identifying barriers that prevent a student with disabilities from accessing campus resources (Carroll et al., 2020), but it is difficult to describe these barriers without understanding the lived experiences of the students. In addition to the systems-imposed barriers, Carroll and colleagues noted that a student with a mental disability such as DD is less likely than their neurotypical peers to self-advocate for their emotional wellness needs. As such, this study aims to explore the lived experiences of college students diagnosed with IDD to better understand how they define, develop, and experience emotional

wellness. The research team aims to inform educators, families, mental health staff, administrators, and other support staff involved with all levels of programming (e.g., K-12 systems, centers for independent living, IPSE programs) in supporting college students with IDD in developing their emotional wellness. The guiding research question behind this study is: *"What are the experiences of college students with IDD in developing an understanding of emotions and emotional wellness?"* 

#### Methodology

For the purposes of our study, we used consensual qualitative research (CQR; Hill e al., 2021), which allowed us to systematically explore college students with IDD and their experiences surrounding emotional wellness. The four main components of CQR that allow for a rigorous design and enhance trustworthiness of the data include: (a) utilizing a semi structured interview protocol that consists of open-ended questions; (b) multiple researchers coming to consensus on the meaning of participant answers; (c) implementing external and internal auditors feedback throughout the research process; and (d) identifying the domains, core ideas, and categories through cross analysis (Hill et al., 2021).

#### **Participants**

Participants included in this study were college students with IDD, actively enrolled in a large southeastern, research-intensive university's IPSE program. This IPSE program is a fouryear certificate granting program that provides holistic support options with the goal for students to be competitively employed and live how and where they would like upon graduation. There are currently 25 students enrolled in this IPSE program. Participants were recruited through purposive sampling procedures (Glesne, 2016) through our institution's IPSE program. Following the recruitment and semi-structured interview process, 14 participants were included.

Our final participant count meets the Hill et al. (2021) recommended 13 minimum participants in a CQR study for a thorough cross-analysis. Participants in our study consisted of students enrolled in various levels of schooling (e.g., freshman, sophomore, junior, senior), age ranges (i.e., 18 to 26), race and ethnicity (i.e., White, African American, Latino, Asian American/Pacific Islander), gender (e.g., male and female), and disability identity. A more detailed description of each participant can be found in Table 1.

## **Research Team**

The research team is made up of five scholars, whose primary commonality is that we all work or have worked for the IPSE through which we recruited our participants. The first author is a doctoral candidate in Counselor Education and Supervision and has provided counseling services for two separate IPSE programs, with over three years working with people with IDD. Our second author is a clinical assistant professor in Counselor Education with over three years experience working with populations with IDD. Third author is a doctoral candidate in Counselor Education and Supervision and has worked for two separate ISPE programs, and has over three years experience providing counseling services to college students with IDD. The final two authors have a combined 28 years working with students and young adults with disabilities in educational settings and have doctoral degrees in Special Education.

#### **Positionality and Trustworthiness**

As employees of the IPSE program through which we recruited our study participants, all researchers had prior relationships with all participants to varying degrees. Due to the nature of our program's support teaming model, all researchers were at least minimally familiar, and some were very familiar with each participant and their individualized support needs prior to this study. In order to address any possible issues of transference or researcher bias related to prior

professional experiences with a study participant, one-on-one participant interviews were executed by a researcher from our team who had minimal experience with that participant prior to the current study.

To enhance data trustworthiness, each interviewer conducted member-checks using the interview transcript with the participant following each one-on-one interview to ensure accuracy and to gain participant feedback and clarification if needed (Glesne, 2016). Our four-person data analysis team coded interview data in multiple rounds, which included hours of individual analysis based on the team's determined domains and categories, followed by additional hours of group triangulation of theories and codes from multiple investigator perspectives over the course of several weeks. Throughout the methodical CQR data analysis process, all researchers reflected upon their subjectivities by revisiting the reflexive notes kept throughout the interview process (Glesne, 2016; Lincoln & Guba, 1985). The fifth author on this manuscript served as an external auditor for the study to enhance the study's reliability and confirmability (Lincoln & Guba, 1986; Hill et al., 2021), offering multiple rounds of feedback on domain and category creation during the data analysis phase.

#### **Data Collection**

After obtaining Institutional Review Board (IRB) approval, participants were contacted via in-person strategies and provided with information on informed consent in plain language. Data collection started in the Spring 2022 semester. A coach employed by the IPSE program read the informed consent aloud to each prospective participant. Interested students were encouraged to email the first author. All consenting study participants were their own guardians. Prior to the interview, participants verbally provided demographic information. The interview protocol was semi-structured, consisting of nine open-ended questions guided by Ohrt and

7

colleagues' (2019) conceptualization of emotional wellness, along with additional probes for each in order to obtain an in-depth discussion (Glesne, 2016). Furthermore, participants were provided alternative phrasing and visual prompts when necessary. Due to implications of the COVID-19 pandemic, participants were offered face-to-face or virtual interviews.

### **Data Analysis**

The data analysis followed Hill et al.'s (2021) CQR process. Hill and colleagues described the CQR analysis as a multi-step process involving: (a) development of domains; (b) summarizing participant core ideas; and (c) comparing reports among the cases through a cross-analysis. We began by coding data in each interview into domains, which represented larger themes. Interview transcripts were randomized for their order of analysis. Following the creation of the domains and separating data, we developed core ideas by summarizing the essence of each participant statement. This process paralleled in vivo coding procedures (Glesne, 2016). Lastly, the core ideas were placed into categories based on similar themes and were compared across the 14 cases.

#### Domains

As suggested by Hill et al. (2021), the process of creating domains started with the core research team coding Dillon's interview together and coming to a consensus on the start domain list. The start domain list consisted of 11 domains. Our research team elected not to create a domain list prior to data analysis to limit potential biases (Hill et al., 2021). Max's interview was coded independently by each member of the research team using the initial domain list and then we met to reach consensus. Our domains were provided to the external auditor and their feedback was incorporated into our domain development. For example, the external auditor suggested that the "lack of emotional education" domain did not consider potential education

that was received and not retained and suggested a more strengths-based domain. After creating the expanded domain list, the research team evenly split the remaining interviews to code independently. Each member coded their assigned interviews and an additional member of the research team acted as an internal auditor. Following the independent coding process, we refined our domains and collapsed or removed domains through the CQR consensus process (Hill et al., 2021). All domains were provided to the external auditor for an additional review to which the external auditor suggested minor feedback on strengthening the domains.

#### Core Ideas

Following the development of the domains, core ideas were the next step in our data analysis process. According to Hill et al. (2021), core ideas highlight the essence of what each participant is saying, in a more succinct and comprehensive fashion. We worked individually to code the core ideas for two to three interviews. Then, a member of the research team served as an internal auditor for each core idea and a consensus process was used throughout. Once core ideas were developed for each line of the raw data, we started the cross analysis.

#### **Cross Analysis**

During cross analysis, we began by analyzing one domain together and creating categories through a consensus process. Categories reflect themes and consistencies among the core ideas and across domains (Hill et al., 2021). We individually looked at two to three domains and coded core ideas to identify categories and subcategories. Following independent work, we internally audited each other's domains and came to consensus on the final categories. Many categories and subcategories were collapsed, or the wording was changed to fully encompass the participants' experiences. The final categories and subcategories are outlined in Table 2. Following the finalization of the domain names and categories, the research team coded the

categories and subcategories for frequency (Hill et al., 2021). As recommended by Hill and colleagues (2021) for 14 cases, the category frequency fell between variant (3-7 cases), typical (8-12 cases), general (13+ cases). An external auditor reviewed our categories and core ideas, and their feedback was considered prior to assigning a frequency.

#### Results

The results of our study are reported through the Hill et al. (2021) analysis procedures: outlining domains (i.e., general participant themes) and categories (i.e., themes developed through participant core ideas) that detail the cross analysis. Domains were considered finalized when they were strong enough in relevance to the research question and differentiation between other domains and categories. The final seven domains are: (a) emotional intelligence; (b) emotion education; (c) emotion regulation skills; (d) communication; (e) familial and societal norms; (f) acknowledged lack of understanding of emotions; and (g) barriers. In addition to the domains, 18 categories were developed to enhance the abstraction. There were two domains that did not have a category because the data were not diverse enough to support the abstraction. There were five categories described as general, 10 as typical, and seven as variant. The cross analysis is represented in Table 2.

#### **Domain I: Emotional Intelligence**

A large proportion of participant responses were categorized under the emotional intelligence domain. Participant data was coded under this domain if it was related to their cognitive understanding of the meaning of emotions or the connection of emotions to outside influences. Additionally, when participants showed a deeper discernment of emotional implications, purpose, or origination, the data was assigned to a category within this domain. The categories are (a) connected thoughts, emotions, and behaviors; (b) recognized situational

influences on emotions; (c) demonstrated abstract thinking; (d) recognized that emotions are complicated and ephemeral; and (e) demonstrated empathetic responses.

### Emotional Intelligence Category 1: Connected Thoughts, Emotions, and Behaviors

This general category had participant statements that included a combination of observations about their bodily connection to emotions as well as connections they saw in other people's behaviors to their emotions. Some data included connections between bodily sensations and emotions. Other data included connections between other's outward body language and facial expressions and emotions: "...their movement, or the facial expression, I mean, I can just tell how they are [feeling] by looking at their movement...like nonverbal cues." Also coded in this category were participant declarations of emotional connection to thoughts and the understanding that emotions are tied to explicit feelings in the body (i.e., stress or nervousness).

## **Emotional Intelligence Category 2: Demonstrated Empathetic Responses**

Participant statements coded under this category included recognition of emotions in other people, as well as specific reactions based on that recognition. Although this was coded as variant, participants made assertions they could recognize when someone was sad and either reflected that emotion back to the person in empathy or made some other gesture of recognition. Mason offered this: "gonna try and walk, walking in their shoes, the same; that way we understand" as their show of empathy for someone who may be displaying sad emotions.

#### **Emotional Intelligence Category 3: Recognized Situational Influences on Emotions**

Many participants observed that their emotions are connected to outward influences including other people, situations, specific places and settings, and major life events. This category was coded as general. Examples of situational influences on emotions mentioned by participants include feeling sad at the death of a family member, acknowledging that transitions

evoke feelings of nervousness, and connecting happiness to a beloved sports team winning a game.

#### Emotional Intelligence Category 4: Demonstrated Abstract Thinking

This typical category represented participants connecting emotions to a deeper cognitive understanding of self or an understanding of the purpose or meaning of emotions. Some participants made statements related to how they process strong emotions. Others declared their understanding of the ways in which their thoughts and emotions were connected and how they felt that contributed to their lives. When asked what purpose she thought emotions served in her life, Dillon shrewdly replied: "Sometimes they make me see me."

# Emotional Intelligence Category 5: Recognized that Emotions are Complicated and Ephemeral

This category captured participant statements reflecting their recognition that emotions are messy, complicated, and ever-changing and was coded as typical. One example that more than one student asserted is the fact that they could feel more than one emotion at the same time. Felix described his complicated feelings about being at college: "I feel kind of in the middle about being happy and frustrated most of the time in college because it's a new environment for me." Another astute recognition of the complicated nature of emotions was one participant's recognition that their emotions and their bodily reactions may not always align. Participant acknowledgements that emotions change over time and that emotions can be unpredictable are other examples of data coded in this category.

#### **Domain II: Education**

Education was another common discussion amongst participants. In this domain, participants identified instances of learning emotional wellness through structured educational

settings, experiences through interpersonal relationships, and independent curiosities. Within this domain, the following categories are presented: (a) postsecondary education; (b) lessons from family; (c) lessons from peers, and (d) independent exploration.

## **Education Category 1: Post-Secondary Education**

The first category encompasses all participant experiences with emotional wellness as it relates to their experiences on a university campus. This category was endorsed as general by participants. Within this category, the data revealed shared participant experiences in prompting their emotional wellness through both IPSE program-specific and university administered coursework and supports. Regarding IPSE program education, participants described the ability to obtain individualized understandings of emotions through program-specific coursework, supports, and connections made with staff members. In describing their experience in an IPSE program course, Mackenzie shared, "The Healthy Relationships class that I took this semester kind of helped me. I knew a little bit and they helped me build more." Participants additionally described the overall structure of their IPSE program as a means to enhance understanding of emotions itself; in that it allows them to build upon knowledge gained in previous semesters and utilize familiar staff when presented with challenges to their wellness. Subsequently, participants reflected on experiences in which university coursework, faculty relationships and their instructional strategies (e.g., daily check-ins, infusion of media/videos into course content), resources or supports, involvement on campus, and financial aid (e.g., Vocational Rehabilitation) promoted their holistic understanding of emotional wellness while in college. For instance, three participants identified university courses that contributed to their emotional wellness understanding (e.g., Civil Rights Movement, Sports Psychology, and Women's Health). **Education Category 2: Lessons from Family** 

The second category is typical and describes instances of participants having received emotional education through their family members. This includes direct teaching about emotions, modeling emotional support and care for participants' wellness, and learning through their family's engagement and behavior with others. For example, Kyle stated "my parents said, like, if you have frustration or anger problems, you need to breathe and go outside to walk around because that helps you calm yourself down and go for another angle."

## **Education Category 3: Lessons from Peers**

Within this typical category, participants identified peer relationships as an opportunity to expand their knowledge on emotional wellness. From directly learning coping skills through interpersonal relationships and attending functions or events with peers (e.g., summer camp, organizations). These accounts included peers with and without disabilities, and primarily included accounts of peer support since being in college. Colby shared, "A friend of mine told me if you're feeling stressed out or sad, just count backwards from 10 to 1 and you should be calm and collected." Additionally, participants who identified peer support as a key aspect to their understanding of emotions spoke to the value they place on these relationships in their daily lives.

#### **Education Category 4: Independent Exploration**

The final category within the education domain reflects participant descriptions of opportunities utilized to independently explore the concept of emotional wellness and was labeled as variant. For instance, participants described independently furthering knowledge on skills, utilizing pre-established skills while at college, and expanding on concepts from university coursework in an effort to further their understanding of emotions. Elliot described three forms of media utilized to explore emotional wellness concepts (e.g., movies, television shows, and video games) while Mackenzie described reading as an opportunity to independently learn more about her emotions.

#### **Domain III: Emotion Regulation Skills (ERS)**

This domain encompasses participant responses to their maintenance of emotional wellness. Participants described their use of various coping strategies, both interpersonal (e.g., talking to someone) and intrapersonal (e.g., deep breathing). Furthermore, participants reported engaging in positive activities such as hobbies allows emotions to return to a baseline. The following categories emerged from the data: (a) coping skills; and (b) engaging in positive activities.

## ERS Category 1: Coping Skills

Coping skills was the second category in the emotion regulation domain and had a frequency of typical. Participants coded in this category discussed various skills they use to work through strong emotions. Examples include walking outside, listening to music, journaling, taking deep breaths, counting backwards, as well as distraction techniques such as watching tv, playing video games, and looking up funny videos. Steve stated sitting by himself and recognizing his emotions was helpful in calming down. Additionally, Erica stated, "I'll go to the bathroom to regroup myself where I'll just be like, "hey, like it's okay". Or if I'll step outside for a second and just walk around, especially outside, or just sit on one of the benches or something. And just like, cool down, take a little breather."

## **Category 2: Engaging in Positive Activities**

With a variant frequency, participants express that engaging in positive activities and hobbies allows them to reset and regulate their emotions in a healthier way. Participants talk about attending football games, spending time with friends, playing board games, and watching

internet videos as ways in which they engage with their hobbies to experience positive emotions. Kyle stated, "I like going to the football games because, like football games make everyone happy because you can talk to new people. Like watching funny videos, or bloopers that are funny [also help]."

## **Domain IV: Communication**

Many participants identify the role communication has played in their ability to express, understand, identify, learn, and support others with their emotions. Participants identified communication of emotions through both verbal and non verbal avenues in addition to how they display their own emotions to the world around them. Participants describe how their own experiences with emotions has shaped how they are able to support others who are communicating a strong emotion. Three categories emerged from the data: (a) sharing emotions; (b) showing emotions; and (c) supporting others.

## **Communication Category 1: Sharing Emotions**

The sharing emotions category is split into two subcategories of verbal communication (typical frequency) and nonverbal communication (variant frequency). Throughout the interviews, participants discussed methods of communication in a verbal context by using words to express feelings, or in a nonverbal context in which participants used facial expression and body language.

**Sharing Emotions Subcategory 1a: Verbal Communication**. Participants express that telling others how they feel is their way of expressing and understanding emotions. Two participants state that "I" statements are helpful in communicating emotions, along with being able to process a situation with a friend in order to understand what their emotions are. For example, Felix stated, "I express my emotions sometimes. I do that every Sunday, which is when

my grandparents give me a call, they always check and see how I was doing." Participants also discuss sharing their emotions with friends, family members, staff in their IPSE program, and outside supports (e.g., counselor) to assist in the regulation and understanding of their emotions. Tyler stated, "When I feel something like that, I usually talk with my brother. It helps. Like, just tell him the situation and he helps me. Tell him like the problems I have. Or my teachers are helpful to talk to."

Sharing Emotions Subcategory 1b: Nonverbal Communication. Participants state they communicate their feelings outwardly through facial expressions, hand movements, and body language. Facial expressions mentioned include smiling and raising eyebrows and body language discussed includes crossing arms, putting your head down, or turning your back. Steve mentions, "I identify my emotions by like what I'm expressing. I got this, like this smile. And you can see like, see hand movements and all I can do and if I'm sad you can just also look at my face and body expressions."

## **Communication Category 2: Showing Emotions**

The showing emotions category is of variant frequency and encompassess the expression of emotion through creative, non-traditional sources. For example, Felix states they show their emotions through music and the type of music they listen to that day. Additionally, Ryan remarked they show their happiness to others by showing people personal items they are proud of. He stated, "I showed my family said hey, here's my new car. And well, they were all like thrilled and I showed it, and I took a video and pictures I showed my friends and they loved it. And they were happy for me and I was happy." Finally, another participant states they display happiness by talking to new people and making friends.

## **Communication Category 3: Supporting Others**

The supporting others category was typical and represents how participants communicate with others (i.e., peers and family members with and without disabilities) to support them in their emotional journey. Participant responses range from checking in with friends, asking others how they can help, problem solving, perspective taking, and validation of others emotions. Mason stated, "If that's like, a sad emotion, like if they're sad, I tell them like I'm here for them. I can figure out a way to help them." Max also mentioned, "…And I told him that I got that same feeling before so I knew what to do. So I say, you can call, me text me anytime you need to. Or you can call me and hang out if you want to just talk about it."

## **Domain V: Familial and Societal Norms**

Participants identified family and society as contributors to their emotional wellness understanding. This connection was identified through the research team's review of participant disclosure of learned behaviors, both positive and negative examples of expressing emotions, and the practice of adopting worldviews and beliefs through family and or society. This domain also represents implicit messages that participants have adopted into their understanding of emotional wellness. For example, Charlie disclosed his worldview of gender norms as it applies to emotional expression in saying, "Men always keep things (to themselves) to figure out their own problems." Another participant, Erica, expressed frustration with family through their disregard of and lack of acknowledgement or respect for their own emotions since being in college. This domain is represented as a typical frequency and differentiation between core ideas to support independent categories.

#### **Domain VI: Acknowledged Support in Understanding of Emotions**

The acknowledged support in understanding of emotions domain emerged after the first round of domain coding. This domain represents participants recognizing that there are aspects

of emotions they do not understand and self-reported the need to learn more about their emotions. Participants responses for this domain were originally coded as a barrier, however the research team came to a consensus that recognizing that there is more to learn more about emotions involves insight and self-advocacy. Furthermore, this domain evolved through the domain coding process. Originally, this domain was titled, "acknowledged lack of understanding of emotions," but was renamed with "support" to reflect a strength-based perspective. The new domain name represents that aspects of emotional wellness may not have been readily available for our participants and encourages college students with IDD and their educators to advocate for additional opportunities to better understand emotional wellness development for this population. For example, Elliot stated, "I am not sure. I need to learn more about that," when asked about the role of emotions. Participants also reported that they did not always have the vocabulary to express their emotions. Furthermore, some participants endorsed that they have previously learned about emotions in silos (i.e., at one point in time and with little review) and topics not pertaining to their personal experience with emotions. This domain does not have categories as the core ideas did not have a high enough level of abstraction. This domain was labeled as typical.

#### **Domain VII: Barriers**

The data in this domain describe the barriers participants experience as they develop and experience emotional wellness. This domain was originally coded throughout the domains with the notion it would appear as a category in different domains, however the research team reached consensus that it should stand alone because experiencing barriers was a common experience for participants as they develop and maintain their emotional wellness. Furthermore, this domain had the most ranging responses, which is represented in having the highest category count. Data was

coded in this domain if the participant explicitly described a barrier, provided a response that did not match the interview question, described a maladaptive regulation skill, or reported that they have an unhealthy relationship with emotions. Dillon described their barrier as, "I was homeschooled for about 18 years. So there was really no one to express emotions to besides my mom. So it's kinda difficult because you know, it's my mom." These categories detail the barriers: (a) previous education; (b) equating positive behaviors to positive emotions; (c) stigma; and (d) maladaptive regulation skills.

#### **Barriers Category 1: Previous Education**

The previous education category describes the barriers participants experience as they receive education on emotional wellness and is labeled as general. Specifically, their reports of not receiving education or describing their desire to have additional education across different educational settings. Most participants reported a gap in the education they received in K-12 settings. Erica commented on this gap and said, "I guess, like I don't really think I learned anything, like emotion-wise during when I was in school, especially for like kindergarten through 12th grade." In addition to K-12 education, a few participants remarked that they did not receive education on emotional wellness in postsecondary settings. This includes their IPSE program, traditional college courses, and individual supports they receive. For example, when asked if he had learned anything about emotions in college, Blake, a senior, responded, "Not that I can think of."

## **Barriers Category 2: Equating Positive Behaviors to Positive Emotions**

Category two in the barriers domain includes statements or ideas from participants that equate a positive behavior or an enjoyable activity to a positive emotion, and was given a variant frequency. Researchers categorized these statements under barriers because while the

participants may be making appropriate connections between doing something well or something that they enjoy to the emotion of happiness, it was clear the participants also may have been socially conditioned to believe that "good behavior" or a fortuitous occurrence automatically resulted in concurrent positive emotion. Max equated a new skill he had acquired and was now performing well to happiness: "Some of the stuff...I do my laundry. Pretty good doing that." While the participant may have consequently experienced happiness because of his new capacity for doing laundry on his own, aligning doing things well to happiness per se is missing the level of abstraction and understanding connecting the behavior to emotion explicitly. Another example is Steven's response to the researcher probe: "How do you know when you're feeling happy?" The participant responded: "Something good is happening to me." This connection made between a good experience or occurrence and the emotion of happiness signifies the participant's awareness of the broader underpinnings of the emotion, but a probable lack of depth in understanding the directional relationship between the occurrence and the resulting feeling of happiness.

#### **Barrier Category 3: Stigma**

Although the stigma category was reported as variant, participant data from this category reinforces that there is a stigma associated with emotional wellness amongst college students. Participants that endorsed this category reflected on their experiences hiding their emotions from others. A variety of factors contributed to stigma, such as fear of judgment or being perceived as weak if they expressed their emotions. When asked about their level of comfort in sharing their emotions, Max stated, "Maybe people wouldn't be able to tell but I'd be nervous to kind of tell them." Additionally, data in this category reflects the notion that emotions are a weakness. For example, Elliot reported, "I try to hide back my tears. I don't like to cry. It shows weakness."

## **Barriers Category 4: Regulation Skills**

The regulation skills category includes participant data reflecting concerns with how they regulate their emotions. This category appeared as variant with ranging data amongst participants. Participants noted a variety of regulation skills that create barriers to emotional wellness, such as expressing uncomfortable emotions as another emotion (e.g., anger), exhibiting unhealthy behaviors for self-regulation, avoidance of their emotions, and general uncertainty on how they regulate their emotions. When asked about how they manage their uncomfortable emotions, Tyler responded, "I usually just lose control of my emotions. Even my excitement emotions."

#### Discussion

Our results support that emotional wellness education is a potential gap in K-12 education (Ziomek-Daigle, 2015). Additionally, results from our study highlighted mixed reports of emotional wellness education received in postsecondary settings. Although participants reported that there were concepts of emotional wellness not introduced in their coursework, postsecondary education settings were the only settings that participants perceived they received structured education. This serves as an implication for both K-12 and postsecondary professionals. K-12 educators and school counselors may consider structured lessons specifically for students with IDD and assist these students in a baseline understanding of emotional wellness. Furthermore, postsecondary professionals should consider additional opportunities and topics to assist college students with IDD in their emotional wellness understanding. Examples include more structured support in an IPSE program, resources for the college student (e.g., feelings wheel, see https://feelingswheel.com for reference), additional resources or training

within their counseling offices, training for their faculty and staff on this population, and workshops offered within their disability services office.

Francis et al. (2020) suggested that students in IPSE programs report learning life lessons through familial and social norms, which is supported by implicit messages developed in the familial and societal norms domain, as well as the explicit messages developed in the lessons from peers and lessons from family categories. Therefore, parents and guardians of individuals with IDD should understand their influence on childhood and adolescent emotional wellness development and consider exploring these concepts during formative years. For example, discussing or modeling appropriate coping skills or ways to manage stress would be helpful for parents to engage their children with in order to facilitate prosocial skill development.

In addition to aspects of emotional wellness development, our data resulted in themes on how college students with IDD experience their emotions and emotional wellness. Participants recounted how they use communication (verbal and nonverbal) as strategies for relationship building and emotional regulation. Brown et al. (2013) reported that aspects of communication have holistic quality of life benefits for individuals with IDD, including a correlation with aspects of emotional wellness. Our data corroborates this report and suggests that college students with IDD that engage in healthy interpersonal communication strategies make connections to their emotional wellness. This may involve seeking out support from postsecondary staff, family, or friends. However, Oakes et al. (2020) noted that college students with IDD have greater difficulties engaging in healthy interpersonal communication compared to their peers without disabilities, thus additional opportunities to learn and practice these skills may support continued emotional wellness maintenance. Beyond communication, our participants reported intrapersonal strategies to maintain their emotional wellness. Participants in

this study explained coping strategies they use to manage uncomfortable emotions, such as listening to music, mindfulness (e.g., deep breathing), watching their favorite TV show or movie, playing video games, and creative art strategies. McKnight-Lizotte et al. (2021) concluded that college students with IDD have unique considerations for supporting their emotional needs, such as ensuring the strategy is developmental appropriate, and staff members young adults with IDD should be prepared to explore a variety of options with the student.

The acknowledged support in understanding of emotions domain represents the first step a college student with IDD can take to develop a plan to address their emotions. As opposed to viewing a student's acknowledgment as a barrier, it can be viewed as strength to promote continued education. Coduti et al. (2016) concluded that college students with disabilities are less likely to advocate for their emotional wellness needs as compared to their peers without disabilities, and acknowledgment can be seen as an opportunity to validate an advocacy effort. Additionally, the barriers domain can be viewed as the precursor to the acknowledged gap in understanding of emotions domain. The barriers domain highlights common obstacles the participants face as they develop and maintain their emotional wellness. As supported by literature, barriers can occur across the individual's lifespan (Ziomek-Daigle, 2015) and there may be multiple barriers experienced by the college student with IDD. Furthermore, educators and other helping professionals serving college students with IDD should assist the student in identifying their barriers. Following the identified barriers, the educator or helping professional can incorporate strategies endorsed through the other domains and categories (e.g., coping skills, setting boundaries, and making connections) to address the barriers.

## Limitations

24

It is vital to review limitations experienced for transparency and future research. First, Hill et al. (2021) reported that a disadvantage of CQR is the potential of researcher bias. Through processes of bracketing (Glesne, 2016) and consensus (Hill et al., 2021) we attempted to limit the influence of our prior biases (e.g., blinding interviews, assigning researchers with a minimal relationship with participants in interviews). Second, the majority of our participants identified as male. The disproportionate gender differences may have influenced the data analysis process. Third, each IPSE program operates from a unique philosophy and model of support (Plotner & Marshall, 2015), thus influencing participant biases and reports. For example, students in this IPSE program are offered targeted services for their holistic wellness development and collected data may reflect a bias towards prior education and value of emotional wellness.

## **Implications for Future Research**

Our study resulted in a variety of future research implications to strengthen our understanding of college students with IDDs' emotional wellness development. Starting in formative years, future research could focus on replicable training interventions to provide K-12 educators and school counselors a curriculum to educate their students with IDD on emotional wellness. As participants in our study frequently reported they did not receive emotional wellness education in K-12 settings; empirical investigations could meet the gap in emotional education literature (Ziomek-Daigle, 2015). Moreover, empirical investigations at the college or university level could also produce replicable training interventions to provide educators strategies to help college students with IDD further conceive of emotions and ultimately emotional wellness. Alternatively, accommodations to provide better access to existing services and supports for emotional wellness should be explored. A greater representation of longitudinal studies could demonstrate retention of emotional knowledge and skills across elementary,

middle, high, and postsecondary education. Next, future research could investigate college students with disabilities who are receiving education outside of an IPSE program setting. Results could be compared to this study to capture a holistic view of the college experience and the level of emotional knowledge and understanding of those living with a disability. Additionally, research should investigate the experiences of college students with IDD navigating barriers to their emotional wellness. Beyond emotional wellness, future studies could also investigate additional aspects of wellness development such as social, physical, or spiritual wellness.

#### Conclusion

This study sought to explore the lived experiences of how college students with IDD understand and conceptualize their emotional wellness. The findings suggest college students with IDD may have a basic understanding of concepts related to emotional wellness, such as how their thoughts connect to their emotions and healthy coping strategies. In addition, natural supports (e.g., family and friends) and postsecondary staff and faculty commonly model emotional wellness through implicit and explicit messages. Unfortunately, college students with IDD experience unique barriers to receive support for their emotional wellness. Moving forward, research is needed to further examine strategies to address these barriers, as well as emotional wellness curricula for college students with IDD. The domains and categories from our study could guide the continued investigation of emotional wellness for students with IDD in postsecondary settings.

#### References

- American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders: DSM-5-TR (Vol. 5 Text Revision). Washington, DC: American Psychiatric Association.
- Becht, K., Blades, C., Agarwal, R., & Burke, S. (2020). Academic access and progress for students with intellectual disability in inclusive postsecondary education: A systematic review of research. *Inclusion*, 8(2), 90-104. https://doi.org/10.1352/2326-6988-8.2.90
- Brown, I., Hatton, C., & Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities*, 51(5), 316-332. <u>https://doi.org/10.1352/1934-9556-51.5.316</u>
- Remley, T. P, & Shaw, B. M. (2017) College counseling and student affairs. In Capuzzi, D., & Gross, D. R. (Eds.). *Introduction to the counseling profession*. New York: Routledge.
- Carroll, J. M., Pattison, E., Muller, C., & Sutton, A. (2020). Barriers to bachelor's degree completion among college students with a disability. *Sociological Perspectives*, 0731121420908896. <u>https://doi.org/10.1177/0731121420908896</u>
- Centers for Disease Control and Prevention. (2020). Disability impacts all of us. Centers for Disease Control and Prevention. Retrieved from

https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all

- Coduti, W. A., Hayes, J. A., Locke, B. D., & Youn, S. J. (2016). Mental health and professional help-seeking among college students with disabilities. *Rehabilitation Psychology*, *61*(3), 288.
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual*

and Developmental Disability 36(2), 137-143.

https://doi.org/10.1080/13668250.2011.572548

Francis, G. L., Reed, A. S., & Howard, M. E. (2020). Interactions with and between families and professionals in college: Perspectives of young adults with intellectual and developmental disabilities. *Inclusion*, 8(2), 163–179. https://doi.org/10.1352/2326-6988-8.2.163

Glesne, C. (2016). Becoming qualitative researchers: An introduction. (5th Ed.) Pearson.

Harrison, A. J., Bisson, J. B., & Laws, 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.

https://doi.org/10.1352/1934-9556-57.4.323

- Hill, C. E., & Knox, S. (2021). Essentials of consensual qualitative research. American Psychological Association.
- Lincoln, Y. S. & Guba, E. G. (1985). Naturalistic Inquiry. SAGE.
- Lincoln, Y. S. & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Evaluation 30*, 73-84.
- McKnight-Lizotte, M., Dimond, E., Landon, T. J. Gerald, M., & Reeves, S. M. (2021). Mental health needs for students enrolled in inclusive postsecondary education programs. *Journal of Inclusive Postsecondary Education 3*(1).

https://doi.org/10.13021/jipe.2021.2925

Milroy, J. J., Oakes, L. R., & Hickerson, B. D. (2021). Design Thinking: Assessing the health needs of college students with intellectual and/or developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 34(6), 1408-1420.
https://doi.org/10.1111/jar.12882

- Newman, L., Wagner, M., Knokey, A-M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2). *National Center for Special Education Research*, NCSER 2011-3005.
- Oakes, L., Hickerson, B., & Milroy, J. J. (2020). Let's talk about health: Engaging college students with intellectual and/or developmental disabilities and support staff in conversations about health and wellness needs. *Journal of Inclusive Postsecondary Education* 2(1), 1-22. <u>https://doi.org/10.13021/jipe.2020.2476</u>
- Oakes, L., Milroy, J. J., & Hickerson, B. (2020). Health disparities and health promotion needs of college students with intellectual and/or developmental disabilities: A systematic literature review. *Journal of American College Health* 68(7), 742-753.

https://doi.org/10.1080/07448481.2019.1615495

- Ohrt, J. H., Clarke, P. B., & Conley, A. H. (2019). Wellness counseling: A holistic approach to prevention and intervention.
- Okoro, C. A., Hollis, N. D., Cyrus, A. C., & Griffin-Blake, S. (2018). Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016. *Morbidity and Mortality Weekly Report*, 67(32), 882.

https://doi.org/10.15585/mmwr.mm6732a3

Plotner, A.J. & Marshall, K. (2015). Postsecondary education programs for students with an intellectual disability: Facilitators and barriers to implementation. *Intellectual and Developmental Disabilities 53*, 58-69. <u>https://doi.org/10.1352/1934-9556-53.1.58</u>
Think College. (2022). College Search. <u>https://thinkcollege.net/college-search</u>

- Whitney, D. G., Shapiro, D. N., Peterson, M. D., Warschausky, S. A. (2019). Factors associated with depression and anxiety in children with intellectual disability. *Journal of Intellectual Disability Research* 63(5), 408-417. <u>https://doi.org/10.1111/jir.12583</u>
- Woo, H., Goo, M., & Lee, M. (2016). A content analysis of research on disability: American Counseling Association journals between 2003 and 2013. *Journal of Multicultural Counseling and Development*, 44(4), 228-244. <u>https://doi.org/10.1002/jmcd.12051</u>
- Ziomek-Daigle, J. (Ed.). (2015). *School counseling classroom guidance: Prevention, accountability, and outcomes.* Sage Publications. <u>https://doi.org/10.4135/9781071801123</u>
- Zisman-Ilani, Y. (2022). The mental health crisis of individuals with intellectual and developmental disabilities. *Psychiatric Services* 73(3), 245-246.

https://doi.org/10.1176/appi.ps.202200022

# Table 1

Participant pseudonyms and demographics

Participant	Disability Identity	Race	Gender	High School Diploma	Academic Standing
Dillon*	IDD, Cerebral Palsy	White	Male	No	Freshman
Max	IDD, Deaf and Hard of Hearing	Mixed Race	Male	No	Freshman
Elliot	ASD	Mixed Race	Male	No	Sophomore
Colby	ASD	White	Male	No	Sophomore
Felix	ASD	White	Male	No	Freshman
Mason	ASD	Black	Male	No	Junior
Charlie	ASD	Black	Male	No	Senior
Erica	IDD	White	Female	Yes	Junior
Steve	IDD, ADHD	Black	Male	Yes	Junior
Tyler	IDD	White	Male	No	Senior
Ryan	ASD, Speech/Language Impairment	White	Male	No	Senior
Blake	ASD	White	Male	No	Senior
Kyle	IDD, Speech/Language Impairment	Filipino	Male	No	Sophomore
Mackenzie	IDD	Black	Female	No	Junior

\* indicates piloted interview participant

*Note: IDD* = *intellectual and developmental disability, ASD* = *autism spectrum disorder, and ADHD* = *attention-deficit / hyperactivity disorder* 

# Table 2

Domain	Category	Frequency
I: Emotional	1. Connected, Thoughts, Emotions and Behaviors	General
Intelligence	2. Demonstrated Empathic Responses	Variant
	3. Recognized Situational Influences on Emotions	General
	4. Demonstrated Abstract Thinking	Typical
	5. Recognized that Emotions are Complicated and Ephemeral	Typical
II: Emotion Education	1. Postsecondary Education	General
	2. Lessons from Family	Typical
	3. Lessons from Peers	Typical
	4. Independent Exploration	Variant
III: Emotion	1. Coping Skills	General
Regulation Skills	2. Engaging in Positive Activities	Variant
IV: Communication	1. Sharing Emotions	
	Subcategory 1a. Verbal Communication	Typical
	Subcategory 1b. Nonverbal Communication	Variant
	2. Making Connections	Variant
	3. Supporting Others	Typical
V: Familial and Societal Norms		Typical
VI: Acknowledged Support for Understanding of Emotions		Typical
VII: Barriers to	1. Previous Education	General
Emotional Wellness	2. Equating Positive Behaviors to Positive Emotions	Variant
	3. Stigma	Variant
	4. Regulation Skills	Variant

Results of the final domains, categories, and cross analyses.

*Note*: The frequency of participant statements were represented through a cross analysis. A

category was determined to be general if there were 13 or more cases, typical if there were 8-12

cases, and *variant* if there were 3-7 cases.