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EXPLORATION OF ATTITUDES TOWARD INDIVIDUALS WITH
INTELLECTUAL DISABILITIES

by

STEPHANIE CHOPKO, PHD

A DISSERTATION

Submitted to the graduate faculty of The University of Alabama at Birmingham,
in partial fulfillment for the requirements for the degree of
Doctor of Philosophy in Medical (Clinical) Psychology

BIRMINGHAM, ALABAMA

2011

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EXPLORATION OF ATTITUDES TOWARD INDIVIDUALS WITH INTELLECTUAL DISABILITIES

STEPHANIE CHOPKO

MEDICAL/CLINICAL PSYCHOLOGY

ABSTRACT

Individuals with disabilities, and with intellectual disabilities/mental retardation (ID/MR) in particular, have a long history of being overlooked in many different areas, including research, service provision, health care, education, and treatment. Recent research has suggested that the attitudes that are held by individuals in the general population toward individuals with ID/MR has not changed significantly over the past 50 years, both nationally and internationally. Attitudes can be powerful. Social psychologists have documented how the perception or attitude that an individual holds about another can lead to confirmation of that perception, even if it is not valid, by means of the self-fulfilling prophecy or behavioral confirmation.

This study attempted to evaluate a measure designed to assess the perceptions or attitudes that people hold toward individuals with ID/MR and their potential for independence. Participants were asked to complete two short surveys, the Community Living Attitudes Scale – Mental Retardation and a newly developed Independence Scale, in order to provide a range of perceptions. Participants included undergraduate students enrolled in a large urban campus setting, direct care staff working with individuals with ID/MR, and a community sample. Principal components analysis revealed three separate factors or components for the Independence Scale, similar to previous results suggesting the presence of difference subscales based on qualitative analyses. Factors from this

analysis were labeled Adaptive, Personal, and Privacy. Overall, there were no differences revealed between the three groups on the Independence Scale. On the previously established CLAS-MR scale, some group differences were revealed on two of the subscales. Notably, participants who worked in direct care settings appeared to describe individuals with ID/MR as less in need of sheltering or protection, and individuals from the community appeared to describe individuals with ID/MR as more similar to themselves when compared to psychology undergraduates or the direct care staff.

While in the recent past there have been a number of studies published which have evaluated attitudes toward individuals with ID/MR in other countries (e.g., Japan, Australia), there has been little recent research in the United States. Measures which specifically evaluate the attitudes held toward independence for individuals with ID/MR are lacking in the literature. Thus, this study attempted to contribute to filling in the void in the research literature and providing a description of the perceptions held by a range of participants about independence for individuals with ID/MR.

DEDICATION

This is dedicated to my aunt, Karen Swann. Karen has always been my inspiration and remains a huge part of who I am and what I do every single day. She taught me more than I could ever hope to learn in graduate school.

ACKNOWLEDGEMENTS

As always I am so grateful for my family. They have always been a huge support and help, and without their support and assistance I would not be where I am today. My parents always placed an emphasis on education and were willing to sacrifice so that all of their children could pursue educational opportunities. Their emotional, physical, and financial support has been wonderful and will always be appreciated. My grandparents have been tireless supporters and had undying faith in my ability to do anything, even earn a doctoral degree. My sisters and brothers-in-law have also been so supportive and have provided endless encouragement, assistance and support.

My number one fan and the person who truly has helped to shape me into the person I have become was and always will be my aunt, Karen Swann (#5). She is the reason I entered graduate school and every day she is the reason I continue to do what I do. Her perseverance and dedication, along with her quiet love and support for those around her, made her the best role model I could ever hope for. Karen taught me that family matters more than anything else and truly believed that I could accomplish anything, even if I was not always convinced myself. Her faith and belief in me means more than I could ever hope to express and she is missed every single day.

I also owe a huge debt to Fred Biasini, my advisor and mentor throughout my graduate school career. Fred has extended endless amounts of patience, wisdom, guidance, and understanding over the years. My graduate school career was also supported through the years by many others, including faculty and fellow students/Sparks trainees. All of them have provided laughter, support and assistance and I am forever grateful.

This project could not have been completed without several individuals who gave generously of their time and effort. Kelli Netson provided statistical assistance. The assistance of staff at the direct care sites was invaluable and their help made this possible. The assistance of other individuals and offices in the community who allowed me to recruit for participants was also appreciated. I also would like to acknowledge my committee members current and past, who provided support, encouragement, and valuable insight and advice throughout the very long process: Karen Dixon, Kristi Guest, Maria Hopkins, Snehal Khatri, Elizabeth Griffith, and David Vance. Their patience and support has been tremendous.

Finally, I would like to thank all of those individuals who participated in this study and took time out of their schedules to complete the surveys. Without them this project truly would not have been possible. Supporting individuals and families with ID/MR has always been a passion of mine, as this is a population that has long been overlooked. Finding individuals who were willing to support this goal in a small way by completing the surveys was wonderful and I am forever indebted to them for their participation.

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LIST OF ABBREVIATIONS

AAIDD	American Association on Intellectual and Developmental Disabilities
AAMR	American Association on Mental Retardation
ANOVA	analysis of variance
CLAS-MR	Community Living Attitudes Scale – Mental Retardation
COM	community group
DCS	direct care staff group
DSM-IV-TR	Diagnostic and Statistical Manual, Fourth Edition, Text Revision
F	Fisher's F ratio
ID/MR	intellectual disabilities/mental retardation
LSD	Least Significant Difference
MR	mental retardation
n	number in a subsample
N	total number in a sample
p	probability
PCA	principal components analysis
PSY	psychology undergraduate group
WHO	World Health Organization

INTRODUCTION

Individuals with intellectual disabilities/mental retardation (ID/MR) represent a population with a long history of being overlooked or forgotten. As far back as 1552 B.C. there were written references in Egypt to problems of the mind or body due to damage to the brain. In ancient Greece and Rome, infanticide was common for those infants who were determined to somehow be inferior. Individuals with mental or physical disabilities were also sold for amusement or entertainment purposes. It was not until the 15th century that a movement to care for individuals with mental disabilities was begun. The idea that individuals with ID/MR are capable of training, learning, and living among the general population unfortunately took centuries longer to become common practice (Biasini, Grupe, Huffman, & Bray, 1999).

To this day, individuals with ID/MR are still overlooked in many settings – education, community living, and in treatment of both medical and psychological ailments. Healthy People 2010, a statement of the National Institutes of Health (NIH) health objectives, identified individuals with disabilities in general as being a “potentially underserved population” even though individuals with ID/MR were not specifically included since there were limited data for this population available at the time the objectives were set. A report from the President’s Committee for People with Intellectual Disabilities (formerly President’s Committee on Mental Retardation) also described the conditions faced by many individuals with ID/MR currently (President’s Committee for

People with Intellectual Disabilities, 2004), and called for action on the part of federal, state, and local governments to ensure change takes place. A study commissioned by Special Olympics, the Multinational Study of Attitudes Toward Individuals with Intellectual Disabilities (2003), revealed that the attitudes held by the general public toward individuals with ID/MR have not changed significantly in the past 50 years, despite the many advances that have taken place in the areas of education, access to services and health care, access to employment, etc.

Defining Intellectual Disability/Mental Retardation and Prevalence Rates

The definition of “mental retardation” has been changed throughout the years. First attempts to classify functioning of individuals with ID/MR focused on social adaptation to the environment or medical/clinical factors. It was not until the rise of intelligence testing that a system was developed to classify individuals by intellectual capabilities (AAIDD, 2010; AAMR, 2002). In 1959, the American Association on Mental Deficiency (AAMD) issued their first attempt to define mental retardation using both intellectual capabilities as well as what would become known as adaptive behavior (skills in the areas of communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety). The definition also noted that the age of onset (e.g., the developmental period, or prior to the age of 18 years) was important. Since this time, these three elements – intellectual functioning, adaptive behavior, and early onset – have consistently remained part of the definitions of ID/MR (AAIDD, 2010; AAMR, 2002). In 1959, the classification system instituted labels to correspond to the different levels of ID/MR: Profound, Severe,

Moderate, Mild, and Borderline. Although the IQ ranges associated with the different levels have changed slightly, these labels are still in use today. A brief exception was during the period between 1992 and 2002, when an attempt was made to change to a definition that focused more on the level of supports required as opposed to the level of impairment observed.

The most current definition of ID/MR was published in 2010 by the American Association on Intellectual and Developmental Disabilities (AAIDD, formerly American Association on Mental Retardation) and states:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. The following five assumptions are essential to the application of this definition:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve.

(AAIDD, 2010, p. 1)

The Diagnostic and Statistical Manual, Fourth Edition, Text Revision (DSM-IV-TR) definition of ID/MR is closer to previous AAIDD definitions in the way it discusses adaptive functioning. Current levels of ID/MR based on the DSM-IV-TR include Profound (for IQ measured below 20 or 25), Severe (for IQ measured between 20-25 and 35-40), Moderate (for IQ measured between 35-40 and 50-55), and Mild (for IQ measured between 50-55 to approximately 70) (APA, 2000).

Prevalence rates for ID/MR range from 2.5-3% of the general population, which in the United States translates into about 6.2 to 7.5 million people. Given the multiple factors which can impact prevalence rates, including accuracy of diagnosis, it is likely that these estimates are somewhat conservative (AAMR, 2002; Batshaw, 2002; Rimmer, Braddock, & Marks, 1995). ID/MR impacts individuals across socioeconomic status, gender, and race. As a condition, it is 10 times more common than cerebral palsy, 28 times more common than neural tube defects and 25 times more common than blindness. One out of 10 families in this country is directly impacted by ID/MR (ARC, 2003).

Attitudes and Beliefs

Social psychology has a long history of exploring different attitudes, beliefs, and stereotypes individuals hold regarding other groups: how they are formed and perpetuated, how they change, what influences them, and what the behavioral outcomes of those stereotypes or attitudes look like. It has been documented that in some cases an attitude or stereotype can be socially pragmatic (Fiske, 1998). Reasoned action theory suggests that behaviors are often consistent with beliefs (Tak-fai Lau & Cheung, 1999). However, attitudes or stereotypes can also impact the behavior of both the person who holds the

belief and the person the belief is about, via behavioral confirmation or self-fulfilling prophecy. For example, if one person holds the attitude that individuals with ID/MR are aloof and remain distant much of the time, their actions are likely to be consistent with their beliefs (e.g., they may act distant or reserved when meeting someone with ID/MR). By acting in such a manner, they are likely to elicit similar behaviors from the individual with ID/MR, and thus their attitude or belief is confirmed.

One concern arises when the attitudes being held are negative about a group (e.g., individuals with ID/MR). By nature, humans have a tendency to compare themselves and their behaviors to those around them (social validation, see Cialdini & Trost, 1998; Darley & Latane, 1970; Hornstein, Fisch & Holmes, 1968) and then make a decision about how to act on the basis of what they have seen others do in similar situations. This principle was explained several years ago by Festinger, with his Social Comparison Theory. In part, Social Comparison Theory states that when there is not independent or objective evidence to use, individuals will use social comparison to make decisions about how to act. Cialdini & Trost (1998) stated that “when the goal is to evaluate the correctness of an opinion or action, research has generally supported Festinger’s theory (p. 172).”

The concept of social influence states that the behaviors we observe others engaging in provide a basis for our own actions in similar situations. This idea of social influence, that the behaviors we observe others engaging in then provide the basis for our own actions in similar situations, means that attitudes and behaviors which are negative can be rather easily spread. As an example, think of individuals at a theme park or large festival dropping their trash on the ground – those who might never do so otherwise may actually engage in the behavior if they witness enough other people doing it. When examining

research with individuals with ID/MR, Antonak & Livench (2000) noted that negative attitudes toward people with disabilities can actually serve to impede them from reaching goals.

One line of research into this area has examined the attitudes physicians hold regarding certain patients. Patient characteristics such as race and SES are believed to impact physician perceptions and behavior during office encounters (e.g., van Ryn & Burke, 2000; Ventres & Gordon, 1990). For example, one study looked at the physicians treating individuals with HIV who were also injection drug users, and evaluated the quality of care and types of medications the patients were receiving (Ding et al., 2005). In a cross-sectional study, the authors found that while overall quality of care was not associated with physicians' attitudes and beliefs about injection drug use, patients who used injection drugs and whose physicians had more negative attitudes toward the use were only half as likely as other patients to have received highly active antiretroviral therapy. Another study examined physicians' beliefs about their patients with obesity, and suggested that negative attitudes held by physicians could impact their interest in treating the patients' obesity or recommending newer techniques (Foster et al., 2003).

Attitudes Toward Individuals with ID/MR

In recent years, the number of research studies examining attitudes toward individuals with ID/MR appears to be slowly increasing, at least internationally. Relatively fewer studies focusing on this area were found in the United States, with many based in research labs in Australia (Lennox), Japan (Tachibana), and the United Kingdom (Hastings).

In 2004, Yazbeck and colleagues conducted a large study in Australia examining the attitudes toward ID/MR held by students, disability services professionals, and the general population. In general, more positive attitudes toward individuals with ID/MR were found among students and service professionals than among the general population. In addition, there were differences found by age, educational level, and prior experience with ID/MR – specifically, those who were younger, more educated, and had more prior experience were also more likely to demonstrate positive attitudes. Similar findings were obtained by Henry and colleagues (2004) in a study comparing staff working with individuals with ID/MR in both Israel and the United States.

The perceptions of teachers towards individuals with ID/MR and inclusion in the classroom has also been evaluated, given that a positive teacher attitude is considered necessary for the success of inclusion programs. Prucher & Langfeldt (2002) performed content analysis of a qualitative measure examining the perceptions teachers in Germany held regarding students with ID/MR. Hastings & Oakford (2003) found that a group of student teachers in fact held more negative attitudes about inclusion for children with behavioral and emotional problems than they did for those with ID/MR alone. Interestingly, Hastings found that the teachers' training had little impact on their attitudes, a finding which may initially appear somewhat contradictory to conventional beliefs in addition to social contact theory. However, their definition of training did not appear to include specialized training courses or workshops focusing on individuals with ID/MR (see below).

Another line of research has examined ways of creating more favorable attitudes toward individuals with ID/MR. Consistent with the “contact hypothesis” (Stephan, 1987),

findings generally indicate that more experience is often associated with more favorable attitudes. For example, in the UK, Robertson found that more positive attitudes toward ID/MR were associated with those who had more contact with individuals with ID/MR (e.g., neighbors of group homes). One way to create “more experience” is to participate in additional training. Studies that have examined perceptions following specialized training have generally resulted in more favorable attitudes (Adler et al., 2005; Bailey, Barr & Bunting, 2001; Haslam & Milner, 1992; MacDonald & MacIntyre, 1999; Oullette-Kuntz et al., 2003).

Specific Aims of the Current Study

The overall goal for this study was to examine perceptions that participants hold regarding individuals with ID/MR and the importance of independence in this population. To that end, there were a number of specific aims for this study. The first aim was to explore potential group differences among participants completing two different measures: the already established CLAS-MR and the newly established Independence Scale. The hypothesis associated with this aim was that based on social contact theory, direct care staff, who likely have the most contact with individuals with ID/MR, will endorse more positive attitudes toward independence than other groups.

The second aim for this study was to evaluate the newly developed Independence Scale to learn more about the psychometric properties and assist in development. To assist in this aim, a principal components analysis will be conducted to determine if there are different subscales as suggested by previous qualitative analyses. Responses across the groups were also compared.

METHODS

Participants

Participants were recruited from three groups: upper-level undergraduate students enrolled in one of two psychology classes at the university, a group recruited from the community, and direct care staff working in group homes and institutions for individuals with ID/MR. The final number of participants was 177. Inclusion criteria for the entire sample included being 19 years and older as well as being able to read English.

Psychology students

Upper-level undergraduate students enrolled in one of two psychology classes at the University of Alabama at Birmingham (UAB) comprised the first group of participants. It was decided to include students from “upper-level” psychology courses instead of the usual Psychology 101 pool for two reasons. The first was that one of the exclusion criteria was based on age: anyone under the age of 19 years was not eligible to participate. The second reason for using “upper-level” psychology courses was that these were less likely to be students who were taking an introductory class simply to fulfill a requirement of the educational curriculum, and more likely to be students who had an interest in, and perhaps some more experience with, psychology.

Psychology undergraduate students were recruited with the permission of the class instructors and the primary investigator attended one class meeting to recruit. Students

were approached in two separate classes: PY212 – Developmental Psychology and PY319 – Psychopathology and Culture. They were asked as a group if they were interested in participating in the project. They were then provided with copies of the questionnaire, which they completed and returned to the principal investigator, collected in a pile at the front of the class, or handed to their instructor. From the first class, a total of 63 surveys were returned, of which 51 were usable (defined for these purposes as missing no more than 3 of the items, excluding the demographic and the open-ended questions). From the second class, a total of 71 surveys were returned, of which 68 were usable. This resulted in a total of 119 participants in the psychology undergraduate group. The response rate for this group (calculated as the number of returned surveys divided by the number of surveys given out) was 95.7%.

Community sample

The second group consisted of a group of individuals from the community. These participants were recruited primarily by the use of flyers being placed in different locations in and around the cities of Philadelphia, Pennsylvania and Wilmington, Delaware. Permission was sought and received to place flyers in a storefront location, offices in and around the two cities, and professional meetings in Philadelphia. These participants were given the survey and either returned it directly to the principal investigator or were given the option to use a stamped, addressed envelope to mail their completed survey to the principal investigator. Of these participants, a total of 37 surveys were returned and able to be used. The response rate for the community sample was 72.5%.

Direct care staff

The third group participating in the study was direct care staff. Staff members were recruited from multiple locations in the Philadelphia area suburbs. All participants were identified by their supervisors or administrators as having direct, daily contact with individuals of various ages with ID/MR. For this group, each administrator or supervisor at the particular site, in conjunction with the principal investigator, decided upon the best method of administration for their site. So as to not interfere with staff day-to-day responsibilities, surveys were provided to the administrator/supervisor to give to staff members and then were collected later. Overall, a total of 21 usable surveys were collected from two different sites. The overall response rate from the direct care staff group was 70%.

Procedures

As described above, participants were recruited through their classes, via flyers, or through their workplace. As each completed survey was returned, they were coded with a unique subject identification number, which included a three letter code to identify group membership (e.g., COM for community, PSY for psychology undergraduate, and DCS for direct care staff). Data was analyzed using SPSS, version 16.0.1. As a reliability check for data entry, 41 of the surveys (23%) were checked by an independent investigator.

Agreement was calculated as a percentage of items that the two raters agreed and was calculated as 99.97%. Any disagreements were discussed until a consensus was reached. Any data that was observed to be missing was entered into SPSS as “99.”

Measures

Questionnaires provided to participants consisted of three parts: a short demographic questionnaire, the Community Living Attitudes Scale – Mental Retardation (1990), and the Independence Scale.

The demographics page for this study was included as the first page each participant completed. It included basic, non-identifying information such as year of birth, race, gender, state in which the participant currently resides, where they were born, educational attainment, and employment status. Each of these questions was asked in an open-ended format such that the participant had to write in their answer. In order to obtain some limited information about each participant's history and experience with individuals with ID/MR, they were asked three questions: if they had any experience at all with individuals with ID/MR (followed up by "for how long and in what capacity"), if they ever worked with individuals with ID/MR (again followed up by "for how long and in what capacity"), and if they have or ever had a relative diagnosed with ID/MR. Finally, the demographic page concluded with a multiple-choice format question designed to assess the participant's perception of their own level of experience and comfort in interacting with individuals with ID/MR. They were provided with four choices and asked to choose one that best describes themselves: 1) expert; 2) ok, but not an expert; 3) very little experience; and 4) not at all experienced. A copy of the demographic questionnaire used is attached to the appendix of this document.

The Community Living Attitudes Scale – Mental Retardation (CLAS-MR) was developed by David Henry and colleagues in 1990 to evaluate attitudes held about

individuals with ID/MR. According to Henry, Keys, Jopp and Balcazar (1996), the CLAS-MR was developed with input from self-advocates to look at four aspects of attitudes toward individuals with ID/MR: beliefs about empowerment, exclusion from community life, sheltering of individuals with ID/MR from harm in communities, and “beliefs regarding the extent to which people with disabilities share a common humanity with other persons in society” (Henry, Keys & Jopp, 1999, p. 3). This measure consists of 40 statements, and respondents are asked to rate each on a 6-point scale from “Disagree strongly” to “Agree strongly.” There are four separate subscales for the CLAS-MR: Empowerment, Exclusion, Similarity, and Sheltering. According to Henry, items that fall on the Empowerment scale were designed to assess the perception that individuals who have been diagnosed with ID/MR should be allowed and encouraged to share their opinions in situations that will impact them (e.g., policies). The Exclusion scale includes items that suggest the need or wish to separate or segregate individuals with ID/MR from the rest of society. Items that fall on the Sheltering subscale, as described by Henry, are designed to assess the belief that individuals with ID/MR are in need of supervision and protection in their day to day activities or when in the community. Although it should be noted that these items may be perceived as similar to the ones on the Exclusion scale, Henry et al. describe these items less negative in tone than those on the Exclusion scale. Finally, the items on the Similarity subscale assess the degree to which individuals with ID/MR are perceived to be similar to the respondent and others in the community without ID/MR (Henry, Keys, Jopp, & Balcazar, 1996). The CLAS-MR has been used in a handful of studies since development (Henry, Duvdeyany, Keys, & Balcazar, 2004; Jones,

Ouellette-Kuntz, Vilela, & Brown, 2008; Ruedrich, Schwartz, Dunn, & Nordgren, 2008; Schwartz & Armony-Sivan, 2001; Scior, Kan, McLoughlin, & Sheridan, 2010).

The Independence Scale was also developed to evaluate attitudes about individuals with ID/MR. However, it was developed primarily to explore attitudes about the importance of everyday independent living activities. It begins with a scenario about “Bill,” a 29-year-old male with ID/MR living in a group home. The respondent reads the scenario, and then reads a series of statements asking how important various everyday independent living activities are for Bill (e.g., “How important is it for Bill to eat what he wants?”). Respondents are asked to rate how important each activity is for Bill on a 6-point Likert scale, ranging from “not at all important” to “very important.” A version of the Independence Scale was used in a pilot study (Chopko, Rector, Partridge, and Biasini, 2004) comparing responses on the measure given by professionals in an assessment/treatment center and those given by direct care staff working in group homes for individuals with ID/MR. In that study, qualitative categories were established and multivariate analysis of variance resulted in significant differences between the groups on multiple categories (social involvement, involvement in the community, medication, life choices) as well as the overall average score. In addition, follow-up analyses determined that the scale demonstrated good internal consistency (e.g., Cronbach’s $\alpha = 0.892$). In addition to the Likert-scale items, the Independence Scale also includes a number of open-ended questions. For example, as the first item, the participant is provided with a quote from the World Health Organization (WHO) definition of “health” which reads: “The World Health Organization (WHO) defines health as: *a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*” The respondent

is then asked “Can an individual with mental retardation ever truly be considered ‘healthy’ in the sense of this definition? Why or why not?” Additional open-ended questions occur after the respondent has rated the importance of different items for “Bill” and ask if the respondent would recommend anything else specifically for Bill “in order to better his life.” The final question asks if the respondent would consider “anything else to be essential for the overall health and well-being of individuals with intellectual disabilities/mental retardation.”

Data Analysis

Preliminary Analyses

As a preliminary step, information collected via the demographic questionnaire was evaluated. Across the groups, the average age of a participant in this study was 28.87 (range 19-80, $N = 176$). Average years of education for participants was 15.03 (range 12-29, $N = 163$). Additional demographic information for the entire sample of participants is presented in Table 1 below. Information regarding the geographic location of the entire sample is presented pictorially in Figure 1. Basic demographic information is also presented for each group separately in Table 2.

Table 1. Demographic Characteristics of the Entire Sample

	<i>N</i>	Percentage
Gender		
Male	49	27.7
Female	127	71.8
Not reported/missing	1	0.5
Ethnicity		
Caucasian	127	71.8
African-American	40	22.6
Hispanic/Latino	3	1.7
Other	5	2.8
Not reported/missing	2	1.1
Highest degree attained		
Ph.D.	1	0.5
Ph.D./MD	1	0.5
J.D.	6	3.4
Masters	14	7.9
Bachelor	22	12.4
Associates	20	11.3
High school diploma	91	51.4
Not reported/missing	22	12.4
Nationality		
United States	155	87.5
Outside of the US	19	10.7
Not reported/missing	3	1.7
State of residence (at survey)		
AL	115	64.6
PA	41	23.0
NJ	8	4.5
DE	5	2.8
KS	3	1.7
MD	1	0.6
MO	1	0.6
GA	1	0.6
Toronto	1	0.6
Not reported/missing	1	0.6

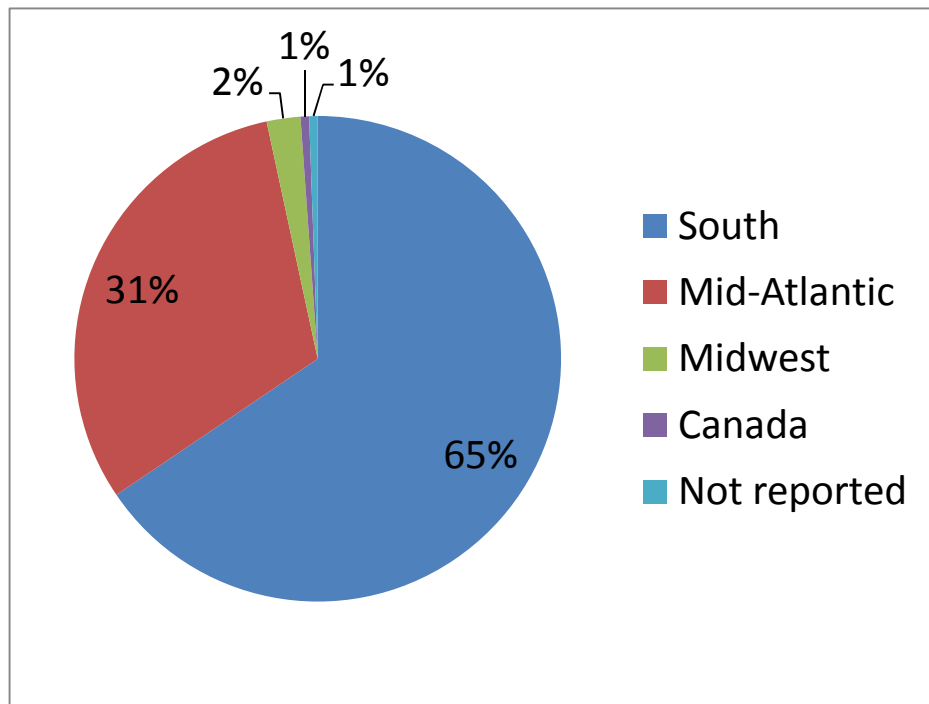


Figure 1. Graph of Current Geographic Location of Residence for Participants (N = 176)

Table 2. Basic Demographic Information by Group

	Gender		Ethnicity/Race			Age
	Male	Female	Cauc	Afr-Am	Other	
Psychology undergraduate (n = 119)	28.6%	71.4%	72.8%	21.2%	2.5%	21yr
Community sample (n = 37)	19%	80.5%	89.2%	8.1%	2.7%	47yr
Direct care staff (n = 21)	38.1%	61.9%	40%	60%	0	37yr

Note. Cauc = Caucasian, Afr-Am = African-American; Participants in the direct care staff group all identified themselves as either Caucasian or African American and therefore the percentage of the Other group was 0.

In order to compare the different groups on some of the continuous variables collected via the demographics page, an analysis of variance (ANOVA) was conducted using the variables age, years of school, how long the participant had experience with individuals with ID/MR, how long the participant worked with individuals with ID/MR, and how long the participant had been in their current position.

To evaluate the categorical variables included in the demographic information collected from participants, chi square analyses were performed. Categorical variables included gender, ethnicity/race, degree, experience with individuals with ID/MR (not limited to work experience), past work with individuals with ID/MR, nationality, and having a relative with ID/MR.

Principal Components Analysis

Another goal of this study was to further evaluate the Independence Scale and determine if items were related to the concept of independence as well as determine if there are subscales that occur in the measure. Previous use of the early version of the Independence Scale had explored some qualitative analyses to determine if there were subscales and suggested that items could be divided into a number of different categories. One of the purposes of this study was to evaluate this early finding more closely and determine if there was statistical support for these categories or subscales. A principal components analysis using varimax rotation was performed. Results from this analysis are presented and discussed below.

Group Differences

Potential group differences between the three different subject groups were evaluated using analysis of variance (ANOVA) to compare the different summary measures for the CLAS-MR. Subscales on the CLAS-MR include Empowerment, Sheltering, Exclusion, and Similarity. Per Henry et al. (1996; 1999), the subscale scores are calculated by first reverse scoring items # 2, 3, 4, 6, 8, 11, 12, 13, 17, 20, 27, and 30. Using SPSS, items were reverse scored in the database and the new variables were included in the creation of the summary scores. Subscale scores are created by taking the average of all responses to the items in the subscale. Once created, these subscale scores were compared across groups using a one-way analysis of variance (ANOVA) procedure.

For the Independence Scale, a total score was created by summing the responses given. In addition, based on the results of the principal components analysis, three separate subscale scores were also compared across the groups. Findings and results from these analyses are presented and discussed below.

RESULTS

Analysis of Demographic Information

Results are presented first for the analysis of demographic information provided by the participants. In order to evaluate the categorical information provided by participants on the demographics page, chi square analyses were used. Significant differences were found between the groups for race/ethnicity, nationality, educational level (categorized for this analysis as graduate level, bachelors degree, or less than bachelors degree), experience with ID/MR (not limited to work experience), previous work with ID/MR, and how the participant described their own level of experience and/or comfort with ID/MR. No differences were found for gender or whether or not the participant had a relative with ID/MR. Results from the chi square analyses are presented in Table 3.

Table 3. Chi Square Analyses for Ethnicity/Race, Gender, Nationality, Degree, Experience with ID/MR, Work with ID/MR, Relative with ID/MR, and Self-described Experience Level with ID/MR Comparing the Three Participant Groups

Variable (n)	Pearson Chi-Square	df	Significance
Ethnicity/Race (175)	22.211	6	0.001
Nationality (174)	20.544	2	0.000
Education (154)*	64.710	4	0.000
Experience (176)**	15.357	2	0.000
Previous work (176)	32.018	2	0.000
Experience level (176)	31.347	6	0.000
Gender (176)	2.394	2	0.302
Relative (172)	4.234	2	0.120

* Education: Self-reported degree was separated into three categories: graduate, bachelors, or less than bachelors.

** Experience: Participants were asked if they had any previous experience with individuals with ID/MR, not limited to work experience (yes/no format). Experience level: Participants were asked to rate their own level of comfort and expertise with individuals with ID/MR.

In order to compare the groups on the continuous variables provided by the participants on the demographics sheet, analysis of variance procedures (ANOVA) was conducted using the following variables: age, years of education, length of time on their current job (months), length of time they had experience with individuals with ID/MR (months), and length of time they had previously worked with individuals with ID/MR (months). All comparisons were found to be statistically significant and are presented in Table 4.

To investigate these differences more closely, post-hoc analyses used the Least Significant Difference (LSD) method to compare the means between the groups. These results are included in Table 5 below. For the variables age and work with ID/MR (mos), which was the number of months the participant reported having previous work experience with individuals with ID/MR, the significant differences reported in the ANOVA above appear

Table 4. Analysis of Variance for Continuous Demographic Variables

	Source	Sum of Squares	df	Mean Square	F	Sig
Age	Between Groups	19840.485	2	9920.242	139.421	.000
	Within Groups	12309.510	173	71.153		
	Total	32149.994	175			
Years of school	Between Groups	127.875	2	63.938	13.282	.000
	Within Groups	770.189	160	4.814		
	Total	898.064	162			
Time at job (mos)	Between Groups	251348.367	2	125674.183	21.933	.000
	Within Groups	590183.492	103	5729.937		
	Total	841531.858	105			
Experience with ID/MR (mos)	Between Groups	103109.438	2	51554.719	10.692	.000
	Within Groups	838999.206	174	4821.835		
	Total	942108.644	176			
Work with ID/MR (mos)	Between Groups	185271.282	2	92635.641	11.332	.000
	Within Groups	474147.701	58	8174.960		
	Total	659418.984	60			

Note. mos = months.

to be driven by the comparisons between all three groups; that is, participants in the each group responded differently to the questions when compared to participants in the other two groups. For the remaining variables years of school (number of years the participant reported being in formal education), time at job (number of months the participant reported being employed in their current position), and experience with ID/MR (number of months the participant reported having experience with individuals with ID/MR – not limited to employment experience), the significant differences reported in the ANOVA above appear to be driven by two separate comparisons: the comparison between the psychology undergraduates (group 1) and the community sample (group 2) and the comparison between the community sample (group 2) and the direct care staff (group 3). Comparisons between the psychology undergraduates (group 1) and direct care staff (group 3) were not significant, suggesting that these two groups described themselves as more similar when responding to these questions.

Table 5. Differences Between the Groups on the Categorical Variables of Age, Years of education, Time at Job (mos), Experience with ID/MR (mos) and Work with ID/MR (mos)

	Group	Group	Mean Diff	Std Error	Sig
Age	1	2	-25.40586	1.58776	.000*
		3	-15.59370	2.03853	.000*
	2	1	25.40586	1.58776	.000*
		3	9.81216	2.34109	.000*
	3	1	15.59370	2.03853	.000*
		2	-9.81216	2.34109	.000*
Years of education	1	2	-2.15706	.42273	.000
		3	-.16262	.53448	.761
	2	1	2.15706	.42273	.000
		3	1.99444	.61188	.001
	3	1	.16262	.53448	.761
		2	-1.99444	.61188	.001

Time at job (mos)	1	2	-110.44118	16.75945	.000
		3	-31.93277	19.62666	.107
	2	1	110.44118	16.75945	.000
		3	78.50840	21.00909	.000
	3	1	31.93277	19.62666	.107
		2	-78.50840	21.00909	.000
Experience ID/MR	1	2	-59.838	13.071	.000
		3	-3.669	16.436	.824
	2	1	59.838	13.071	.000
		3	56.169	18.972	.003
	3	1	3.669	16.436	.824
		2	-56.169	18.972	.003
Work with ID/MR	1	2	-134.548	28.729	.000
		3	-72.607	27.289	.010
	2	1	134.548	28.729	.000
		3	61.941	30.679	.048
	3	1	72.607	27.289	.010
		2	-61.941	30.679	.048

Principal Components Analysis of the Independence Scale

Results from the principal components analysis (PCA) of the Independence Scale, conducted to determine if items were related and if there were indeed subscales within the measure are presented in the table below. The PCA was conducted using IBM SPSS Statistics version 19. Sample size for this analysis was 173 and any cases with missing data were excluded. Initial analyses revealed that item correlations were acceptable and ranged from low to moderate, with many falling into the .3 to .5 range.

The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.874 (per Field, 2009, this value should be greater than 0.5 if the sample is adequate) and Bartlett's test of sphericity was significant ($X^2 = 2383.948$, $p < .05$), which indicates that correlations between items were acceptable for PCA. Both indicate that factor analysis was appropriate for this data. Communalities were all greater than .3, ranging from .552 to .799, indicating

that all of the items shared variance. All of these measures suggest that factor analysis, specifically a PCA, was appropriate for this data.

A principal components analysis with an orthogonal rotation (varimax) was used to determine if there were underlying subscales or factors included in the Independence Scale and provide support for the earlier qualitative findings. Results revealed seven total components with initial eigen values greater than Kaiser's criterion of 1. Combined, these seven components explained 65.79% of the variance. The first component explained by far the largest amount of variance at 34.57%. The remaining components accounted for 8.63% (second component), 5.56% (third component), 4.98% (fourth component), 4.46% (fifth component), 3.99% (sixth component), and 3.60% (seventh component) of the variance. Given the large number of potential factors based on this solution, the scree plot was examined. Support for a three factor solution, which explained a total of 49.89 percent of the variance, was revealed based on the point of inflexion and therefore the PCA was re-run using a criterion of retaining only three factors (as opposed to the initial analysis which retained all factors with eigen values greater than 1).

The three factor solution resulted in communalities all greater than .3, with three exceptions for items number 8 (How important is it for Bill to do his own laundry), 12 (How important is it for Bill to have a communication system that makes it easy for him to talk to strangers on the street), and 20 (How important is it for Bill to receive as little medication to control his behavior as possible). The communalities for these three items were .292, .211, and .292, respectively. In addition, item number 12 (communication system) did not load onto any of the three factors and therefore may be excluded from further analyses. Therefore, after rounding the communalities for items numbers 8 and 20

(both .292) up to .3, it was decided to eliminate item number 12 from the analyses for this study. The resulting 27 items were again run through principal components analysis as a final step and the rotated component matrix and factor loadings are presented in Table 6.

Table 6. Factor loadings and communalities based on principal components analysis with orthogonal rotation (varimax) for 27 items of the Independence Scale ($N = 173$)

Item (#)	Component 1	Component 2	Component 3
Learn new skills (28)	.811		
Be a part of the neighborhood in which he lives (26)	.757		
Have a friend (24)	.737		
See relatives on regular basis (27)	.705		
Interact with non-disabled peers who are not family/staff (17)	.676		
Spend time away from work with friends (29)	.667		
Have a paying job (13)	.647		
Go on outings in the community (16)	.642		
Learn how to cook for himself (14)	.609		
Make a decision about how to use his free time (18)	.568		.456
Receive as little medication to control his behavior as possible (20)	.511		
Have a say in where he lives (25)	.499	.475	
Learn to manage his behavior without medication (21)	.492		
Be able to make his own choices and decisions (19)	.476	.407	.447
Retire at the appropriate age (15)	.469	.468	
Attend religious services of his choice if he wants (11)	.459		
Do his own laundry (8)	.418		
Eat when he wants (2)		.652	
Eat what he wants (3)		.607	
Be in control of his own money (9)		.558	
Live within the community (7)		.551	
Have a checking and/or savings account (10)		.524	
Engage in organized leisure activities within the community (6)	.416	.516	
Be able to take a vacation day when he chooses (23)	.422	.500	

Have privacy in his bedroom (4)	.778
Have privacy in the bathroom (5)	.767
Have his own room (1)	.645

Note. Factor loadings < .4 are suppressed

The first factor, which by far contained the greatest number of items loading, appeared to include items related to living independently, similar to adaptive behavior tasks. Sample items included having a paying job, doing laundry, and learning to cook independently. This first factor was labeled Adaptive.

The second factor was comprised of items that were related to personal well-being and independence. This factor included items that with strong loadings like numbers two and three (How important is it for Bill to eat when he wants, How important is it for Bill to eat what he wants). The other items that loaded strongly included managing money independently (How important is it for Bill to be in control of his own money, How important is it for Bill to have a checking and/or savings account). This second factor was labeled Personal.

The third and final factor contained the fewest number of items. These items appeared to be related to the idea of privacy and included items asking about privacy in the bedroom and privacy in the bathroom. The label for this factor, then, was Privacy.

Reliability

Reliability of the Independence Scale and the three new subscales was also checked as part of the overall analyses. Cronbach's alpha was used as it provides a good estimate of split-half reliability. Both the overall scale as well as the three subscales were determined to

have good reliability, e.g., above the commonly accepted value of .7 to .8 (Fields, 1999).

These values are presented in Table 7 below.

Table 7. Reliability Ratings for Independence Scale and 3 subscales

	Cronbach's α	Number of items
Independence Scale	.919	27
Privacy	.789	5
Personal	.825	10
Adaptive	.917	19

Group Comparisons

The primary aim of this study was to compare and contrast group responses on the two self-report measures administered, the CLAS-MR and the new Independence Scale. In order to compare the responses on the CLAS-MR, the four composite or subscale scores were used. Results are presented in Table 8 below.

Table 8. Comparing Subscales of CLAS-MR

	Source	Sum of Squares	df	Mean Square	F	Sig
Empowerment	Between Groups	3.431	2	1.716	2.754	.067
	Within Groups	101.521	163	.623		
	Total	104.952	165			
Sheltering	Between Groups	4.971	2	2.485	4.851	.009
	Within Groups	87.089	170	.512		
	Total	92.060	172			
Exclusion	Between Groups	.039	2	.019	.053	.949
	Within Groups	63.676	172	.370		
	Total	63.715	174			
Similarity	Between Groups	1.509	2	.755	3.048	.050
	Within Groups	41.590	168	.248		
	Total	43.099	170			

As presented in the table, statistically significant differences were obtained for the Sheltering and Similarity subscales, and the Empowerment subscale approached statistical significance, indicating that there were differences in the responses provided to these items by the three groups. To further examine these differences, post-hoc analyses were conducted using the follow-up method of Least Significant Difference (LSD), which uses a pairwise comparison of the means to further examine group differences when significant results are found in an ANOVA. Results are presented in Table 9 below. The significant differences observed in the ANOVA appear to have resulted from the comparisons between the psychology students (group 1) and the direct care staff (group 3) as well as the comparison between the community sample (group 2) and direct care staff (group 3) on the Sheltering subscale. For the Similarity subscale, differences appear to have resulted from the comparison between the community sample (group 2) and direct care staff (group 3).

Table 9. Differences Between Groups on Sheltering and Similarity CLAS-MR Subscales

Scale	Group	Group	Mean Diff	Std Error	Sig
Sheltering	1	2	-.11891	.13655	.385
		3	-.52651	.16974	.002*
	2	1	.11891	.13655	.385
		3	-.40760	.19653	.040*
	3	1	.52651	.16974	.002*
		2	.40760	.19653	.040*
Similarity	1	2	-.13793	.09384	.144
		3	.21912	.12914	.092
	2	1	.13793	.09384	.144
		3	.35705	.14579	.015*
	3	1	-.21912	.12914	.092
		2	-.35705	.14579	.015*

Note. Group 1 = Psychology undergraduates, Group 2 = Community sample, Group 3 = Direct care staff.

* Differences significant at the .05 level.

In order to explore potential differences between the groups on the Independence Scale, another ANOVA was conducted. The three groups were compared on four separate scores: the overall score for the Independence Scale as well as the three scores for the subscales. Results were not statistically significant when comparing the three groups on these four scores, although the comparison between the groups on the subscale of Privacy approached significance, $F(2,174) = 2.840, p = .061$.

As another group comparison, the responses on the subscales and overall score of the Independence Scale and the four subscales from the CLAS-MR were compared for participants across all three groups who identified themselves as having a relative diagnosed with ID/MR and those who did not identify themselves as having a relative with ID/MR. No significant differences were found on any of the subscales for the CLAS-MR or the Independence Scale.

Finally, as a post-hoc analysis, responses on the subscales of both the Independence Scale and the CLAS-MR were compared for participants across all three groups with varying levels of education: graduate level, bachelor's degree, and less than bachelor's degree. No significant differences were found on any of the subscales for the CLAS-MR or the Independence Scale.

Open-ended Responses

The World Health Organization (WHO) defines health as: a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. Can an

individual with mental retardation ever truly be considered “healthy” in the sense of this definition? Why or why not?

This question was posed as an open-ended question and was placed between the CLAS-MR and the Independence Scale. The majority of participants did not respond to this question, with only 26% (n = 46) providing an answer. It is not clear whether participants did not see this question, or if they made an active choice to not respond to it. Certainly by nature of the question being open-ended it is more difficult for participants to answer, when compared with the likert-scale questions on the rest of the surveys. Of those participants who did respond to the question, 45% (n = 21) believed that a person with MR can indeed be considered healthy, while 54% (n = 25) stated that people with MR cannot truly be considered healthy. Responses from the participants were varied and samples are presented below.

Yes, people with disabilities are not all helpless and not able to function. The ones that can can be an asset to society and have that right to be.

Because the WHO adds “mental well-being” to their definition then I suppose they’re not completely healthy.

Yes, because people can be happy and physically healthy and socially productive even if they have an infirmity.

No, by this definition an individual with mental retardation can be “healthy” in some aspects of this definition, but not all. I don’t agree with the entirety of this definition.

Yes, especially with support of family, friends, organizations, employers, etc. Some of this is dependent on severity of mental retardation as well, because there are sometimes physical limitations.

No, they cannot because they are usually not thought of as having

mental and social well-being

Yes – define “well being.” Mental well-being is contentment, happiness, acceptance, adjustment – mental retardation does not exclude those feelings for the individual

No, mental retardation is a permanent disability.

Yes, even though a person has mental retardation they can still have a sense of mental and social well-being.

No because their mental well-being will never be considered normal in comparison to the general public.

DISCUSSION

There were a number of specific aims included in this study. The first goal was to evaluate potential differences in attitudes or perceptions about individuals who have been diagnosed with ID/MR. To this aim, participants were asked to complete two different surveys, the CLAS-MR and an instrument that is in development, the Independence Scale. While the CLAS-MR was designed to evaluate perceptions of individuals with ID/MR in general, the Independence Scale hopes to more specifically evaluate the perceptions participants hold regarding the importance for individuals with ID/MR to be independent in various day-to-day activities. Potential differences in the responses the participants in each group provided were compared.

The second goal for this study was to evaluate the Independence Scale and assist in the development process. Individuals with ID/MR have a long history of being overlooked as a population in general. Several large scale studies have recently determined that the attitudes held by the general population regarding individuals with ID/MR have not changed significantly in recent years. With the growing body of research about how attitudes can impact behavior towards a group, it seems important to find a way to more carefully evaluate attitudes for constructs which will be important for the future of individuals with ID/MR. Therefore, a measure was developed with the intent of measuring attitudes towards the independence in everyday activities for individuals with ID/MR. This new measure has been used only once in a small-scale pilot study. The current study

allowed for a larger sample of responses which will be important in the continued process of developing the measure.

Sample Characteristics

In the total sample of 177 participants, two thirds were students enrolled in a psychology undergraduate class. The remaining one third consisted of individuals recruited from the community and individuals who have direct daily contact with individuals with ID/MR. Based on these different types of participants, one would expect to find significant differences on demographic variables such as age, degree, years of education, and therefore the results presented above describing the differences found were expected.

There were no differences between groups based on gender nor were there differences in whether participants from the different groups reported having a relative (either current or previously) who had been diagnosed with ID/MR. In relationship to the general public, the sample was overwhelmingly female (about 71%), which was expected given the populations being sampled. Psychology and human service industries have a trend to include more females than males.

Regarding the question as to whether or not the participant has (or had) a relative diagnosed with ID/MR, our overall sample is likely biased somewhat towards being more likely to describe themselves as having had a relative with ID/MR than those in the general population. According to the American Association of Intellectual and Developmental Disabilities (AAIDD, formerly AAMR), nearly 1 in 10 families in the United States are impacted by ID/MR. In our sample, just over 28% of participants endorsed having a

relative who is (or was) diagnosed with ID/MR. It is possible that individuals in psychology, who work as direct care staff, or even those who are willing to take the time to complete a survey about individuals with ID/MR are more likely to do so because they have had experience with, or a relative diagnosed with, ID/MR. Based on social contact theory, this could be a logical conclusion, although we do not have the evidence to support such a conclusion on the basis of this study.

There is also a possibility that the way the question was worded may have resulted in over-reporting on the part of some participants. The question states “Do you have (or did you have in the past) a relative diagnosed with mental retardation/intellectual disabilities?” In addition to the fact that some participants may have included an individual who was rather far back in their family line (e.g., mother’s sister’s cousin twice removed), the use of the term “intellectual disabilities” may have resulted in some over-reporting. The term “intellectual disabilities” is a new development in the history of ID/MR and advocacy groups and clients alike are hoping to have it replace the term “mental retardation” which has developed a very negative stigma. However, the use of the term has the potential to be somewhat confusing to people who are not professionals or who work in the field but whose agency has not adopted the term yet. The term “intellectual disabilities” may result in participants thinking that diagnoses such as ADHD or Asperger Disorder (without accompanying intellectual deficits) would be included. It would be interesting in future studies to examine what individuals believe is meant by the term “intellectual disabilities.” The term “mental retardation,” while it had the negative stigma attached, did not necessarily have the potential for confusion given its long history. Regardless of the reason for why participants may have identified themselves as having a relative with ID/MR, it

does not appear that their endorsement influenced their responses in any significant way as comparisons across the groups were not statistically significant.

Regarding other sample characteristics, the educational attainment of participants may be somewhat lower than the usual estimates for the United States, which are generally that one third of the population is believed to have achieved a bachelor's degree or higher. However, given that two of the groups being sampled were specifically expected to not have completed at least a bachelor's degree (psychology undergraduates and direct care staff), the fact that 23% of the population had a bachelor's degree or higher may be more appropriate for the purposes of this study. The participants in the study were currently living in a variety of different states and the sample was not limited to one particular city or geographic area of the country. In addition, 10.9% of the overall sample was born outside of the United States, and individuals reported coming from a number of different locations, ranging from New Zealand to countries in West Africa (where a large percentage of the direct care staff reported being from). While the numbers are likely too small to produce any statistical significance for this study, further studies may investigate the perspectives reported by individuals who were born in the US and those who were born elsewhere.

Another characteristic of the sample as a whole was that the population came from multiple different geographic areas. The two major areas represented included a mid-sized city in the Southeast and a large city (and surrounding suburbs) in the Mid-Atlantic region of the United States. While recruiting from the two different locations was necessary in order to increase the overall sample size, this type of sample brings with it both positives and negatives. One might argue that inclusion of participants from different parts of the country may result in increased ability to generalize the findings of this study. On the other

hand, the argument could also be made that there are regional differences in the treatment and perception of individuals with ID/MR and that these differences may have impacted the answers provided by the participants. Another factor influencing this is that the differences were also likely occurring along group lines, with the psychology undergraduates being from the Southeast and the community and direct care staff coming from the Mid-Atlantic. When examining the results, we find that there were no obtained differences on the Independence Scale between the groups, which could lead to the hypothesis that the regional differences did not impact responses on this measure. The evidence is less clear for the CLAS-MR scale, as differences between the groups were obtained on this measure for two of the scales (Sheltering and Similarity). As a post-hoc analysis, the different summary measures for the CLAS-MR and the Independence Scale were compared using the participant's self-reported residence as a predictor. The only significant comparison was for the Sheltering subscale of the CLAS-MR: $F(2,169) = 3.836$, $p = .023$. Follow-up analyses revealed that this significant difference was due to individuals from the Mid-Atlantic scoring higher on the Sheltering subscale than individuals from the South. While the ability to make any generalizations from this data is severely limited by the sample size and confound of original group membership (e.g., community versus psychology undergraduates), it will be important for future research to follow-up on these findings and assist in determining if they are due in part to regional differences in the perception of individuals with ID/MR.

Overall, the current sample, when compared to the general population, appears to be less likely to have achieved a bachelor's degree, more female, and somewhat more likely to describe themselves as having had a relative with ID/MR. Again, given the

populations we were sampling, these results are not surprising. However, they do provide a reminder that a note of caution would need to be applied when interpreting these results and attempting to generalize our findings to the general population.

Principal Components Analysis of the Independence Scale

To more carefully examine the Independence Scale and assist in the instrument development process, principal components analysis was used. A goal of this study was to examine the Independence Scale and determine if there was any statistical support for the idea of different subscales within the overall measure, as previously some categories had been suggested using qualitative methods. The results of the PCA yielded three separate factors or components. The first factor or subscale was by far the largest and included mostly items designed to assess adaptive behavior types of tasks that are generally associated with living independently, such as having a paying job, doing laundry, and learning to cook independently. The second factor contained items relating to personal well-being and making independent decisions, such as making decisions about when and where to eat and managing money independently. The final factor or subscale contained the fewest number of items and they mostly related to the idea of privacy – for example, having privacy in the bathroom or bedroom, and having a room of one's own. Follow-up analyses did not reveal differences between the three groups on any of the three subscales nor the overall total score for the Independence Scale, although the comparison for the Privacy subscale approached statistical significance. It is important to note that our ability to discuss findings and results from this PCA may be somewhat limited due to the relatively smaller sample size for this analysis. It would be interesting in the future to

repeat the study with a larger sample and determine if there is still support for a three-factor solution. It is also important to note that one item in particular, #12 (How important is it for Bill to have a communication system that makes it easy for him to talk to strangers on the street) did not load onto any of the three factors. Further studies should evaluate this more carefully and determine if this result is replicated.

Group Comparisons

A final aim of this study was to evaluate any potential differences between the three groups included on the self-report measures they completed. ANOVA and follow-up least significant difference testing revealed that for the CLAS-MR, there were some differences detected in the way that the different groups answered certain questions. Specifically, while both the psychology undergraduates and the community sample appeared to respond to items on the Sheltering subscale in a similar manner, the direct care staff tended to answer these questions less strongly. Interpreting this result suggests that the direct care staff perceive individuals with ID/MR as less in need of sheltering or protection than do those participants from the community sample or the undergraduate sample. On the Similarity subscale, the significant differences appear to have been driven by the comparison between the community and the direct care staff groups, with the community participants responding that they perceived individuals with ID/MR as more similar to themselves.

Although there were some group differences in the way participants answered questions for the CLAS-MR, there did not appear to be statistically significant differences in the way that participants in the different groups responded to the items on the

Independence Scale. This could in part be due to the fact that the items on the Independence Scale appear to have a high degree of face validity, or it could be due to the smaller sample size. It would be helpful to determine if these results were replicated with a larger sample size in the future.

Limitations

There were a number of limitations to the current study. As mentioned above, analyses and findings were likely hampered by the relatively small sample size. Specifically, the principal components analysis is one of the analyses that may have produced greater results had the overall sample been greater than 300. In addition to the overall small sample size, there were large size differences between the groups, with nearly two thirds of the sample coming from psychology undergraduate classes and the remaining one third being split between direct care staff and a community sample. As mentioned previously, the fact that the sample was not limited to one specific geographic region of the country or city may have increased the diversity of the overall sample, but it also opens the door to questions regarding any potential cultural differences that may exist in the attitudes toward and beliefs surrounding the care and potential for individuals with ID/MR. In order to increase the sample size for the direct care staff, multiple sites were contacted and there are likely different cultures within those different sites. Any potential differences of this nature may have been slightly abated by the fact that all of the participating sites were part of the Archdiocese of Philadelphia, a Catholic organization. In addition, the fact that this was to some extent a sample of convenience and there were no tangible incentives for participation may have led to some differences and limitations to generalizability of these

results in the future. While the psychology undergraduates received some time away from their class, they were not specifically given class credit for participation, and the direct care staff and community sample groups were not given incentives at all.

Another potential limitation lies in the fact that psychology undergraduates enrolled in upper-level classes are likely more “research savvy” than individuals in the community and direct care staff, some of whom have not attended college. While this is likely true in this case as it is for many different studies, one must also weigh the potential input they can provide merely for the fact that they have chosen to pursue psychology (many of them were majors) versus the input/interest to an average person enrolled in a non-psychology related field.

Finally, another limitation includes the fact that neither of these measures had been used in very large scale research projects thus far. While the CLAS-MR has been used in some research studies, it appears that the majority of the published research using it occurs in studies that do not have tremendously large sample sizes. The Independence Scale was used in one previous study. Both of these measures would benefit from being used in future research studies to increase the overall sample size and gather additional information regarding response patterns from different groups.

Future Directions

In the future, it would be helpful for research to focus on increasing the sample size with measures such as the CLAS-MR and the Independence Scale to assist in the ability to generalize findings and uncover significant results. It is important to note that any potential group differences may be more apparent in the future with larger sample sizes.

While the sample sizes in this study were not very different from some of the other research in this area, in order to gain a better understanding a larger sample would be needed.

The use of online methods, such as surveymonkey.com, will likely assist in these efforts. Increasing the sample size may also assist researchers in discovering whether there truly are statistically useful categories that can be applied to the Independence Scale. As mentioned previously, future research projects should also consider examining participants' beliefs regarding the importance of being independent for individuals diagnosed with ID/MR and the ability of individuals with ID/MR to be independent.

Conclusions

In conclusion, the current study found limited differences on the two measures, CLAS-MR and Independence Scale, when comparing responses from a group of psychology undergraduates, a community sample, and a group of direct care staff. When compared with the other two groups, the direct care staff tended to describe individuals with ID/MR as less in need of protection and sheltering from the outside environment. Participants from the community sample endorsed items suggesting they perceive individuals with ID/MR as more similar to themselves than did the other two groups. This finding was somewhat surprising, as participants from the community were no more likely to have had more contact with individuals with ID/MR, at least on the basis of the demographic questions asked as part of this study. If true, this finding would not necessarily be in support of the contact theory; however, additional research in the future

should examine this finding more carefully with larger sample sizes to determine if the effect can be replicated.

Previous studies in this area have examined attitudes in the hypothetical. One of the most consistent comments heard by the principal investigator from participants and one of the comments often written on the form itself was that the first questions (the CLAS-MR) were “too vague” and an often-given answer was “well, it depends on the level of mental retardation.” There is likely a vast difference of opinion as to what an individual with ID/MR looks and acts like across the general population. In addition, many of the participants were savvy enough to realize that there is a vast range of ID/MR, and commented accordingly. The use of the Independence Scale avoided these difficulties by providing a hypothetical scenario for respondents to keep in mind as they answered the questions. We believe that the use of the hypothetical situation, while it could limit some responses, helps ground the ideas that participants have and helps provide a point of perspective for their responses. This avoids any confusion or the “it depends” type of responses so often given on the CLAS-MR.

Regardless of the limitations, this study represents a potentially important area of research. Individuals with ID/MR are living in community settings more and more, and attitudes towards their independence will be important in such settings. Previous studies have examined general attitudes towards individuals with ID/MR in school settings, in health care offices, and in community living. Fewer have touched on the topic of independence and the importance of independence for individuals with ID/MR. The concept of independence and the importance of working towards being more independent is an important one and will likely become more important as long as individuals with

ID/MR continue to live in community settings. Examination of attitudes toward independence as well as beliefs about the importance of independence could have significant impacts in many different areas, including planning for services for the future, funding decisions, and training of staff and professionals. Therefore, it will be important for researchers to continue to evaluate these types of topics for individuals with ID/MR in the future.

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APPENDIX A

QUESTIONNAIRE ABOUT INDIVIDUALS WITH MENTAL
RETARDATION/INTELLECTUAL DISABILITIES

Questionnaire About Individuals with Mental Retardation/Intellectual Disabilities

Dear potential participant,

Attached are two surveys that will ask you for your ideas about individuals with mental retardation/intellectual disabilities. We are hoping to learn more about what people think about individuals with mental retardation/intellectual disabilities. If you decide to participate, it is estimated that completing these surveys should take you anywhere from 5 to 10 minutes.

Purpose

The purpose of this study is to learn more about the perceptions different people hold regarding individuals with mental retardation/intellectual disabilities. We are hoping to learn more about your ideas and thoughts about individuals with disabilities living in the community. We hope that by conducting this study, in the future we will soon be able to provide more effective services to individuals with disabilities.

Research Participation

This study is being conducted as part of a research project. Your participation in this research is entirely voluntary. If you decide to participate, any data collected will be combined into one large database. No single individual will be able to be identified. You may withdraw your consent to participate at any time without fear of penalty or bias.

If you are a UAB student, you may choose not to be in the study or you may withdraw from (stop participating in) the study at any time before it is over. This will not affect your class standing or grades at UAB. You will not be offered or receive any special consideration if you take part in this research.

If you have any questions about this survey or the research project, please feel free to contact the primary investigator, Stephanie Chopko, Ph.D. (email: schopko@gmail.com; phone: 205-914-6368). You may also contact Fred Biasini, Ph.D. at 205-934-9465.

If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact Ms. Sheila Moore. Ms. Moore is the Director of the Office of the Institutional Review Board for Human Use (OIRB) at the University of Alabama at Birmingham (UAB). Ms. Moore may be reached at (205) 934-3789 or 1-800-822-8816. If calling the toll-free number, press the option for "all other calls" or for an operator/attendant and ask for extension 4-3789. Regular hours for the Office of the IRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.

When finished with the survey, please place it in the envelope/container provided or hand it back to the investigator. If you wish to complete the survey at home, you may request a stamped, addressed envelope from the investigator.

Thank you so much for completing these questionnaires and helping with this research project! Your assistance is greatly appreciated!

Information about you:

- 1) **Year** you were born: _____ 2) Race: _____ 3) Gender: _____
- 4) State in which you **currently** reside: _____ 5) Where were you born? _____
- 6) Number of years you went to school: _____ 7) Highest degree obtained: _____
- 8) Current job: _____ 9) Length of time in current position: _____
- 10) Do you have any experience at all with individuals with mental retardation/intellectual disabilities (e.g., school, neighbor, church, etc.)? Y N
- 10b) If so, for how long and in what capacity? _____
- 11) Have you ever worked with individuals with mental retardation/intellectual disabilities? Y N
- 11b) If so, for how long and in what capacity? _____
- 12) Do you have (or did you have in the past) a relative diagnosed with mental retardation/intellectual disabilities? Y N
- 13) In terms of your experience and comfort level in interacting with individuals with mental retardation/intellectual disabilities, would you describe yourself as:
- _____ Expert – I've had lots of formal or informal experience
- _____ Ok, but not an expert – I've had some experience but not as much as others
- _____ Very little experience – I've had one or two interactions with someone with mental retardation/intellectual disabilities, and seen some movies like Rain Man, but otherwise that's about it
- _____ Not at all experienced – I really haven't had any experience with individuals with mental retardation/intellectual disabilities

Community Living Attitudes Scale
Form A
(Henry & Keys, 1990)

Directions: Indicate the extent to which you agree with the following statements according to this scale:

1 = Disagree strongly	4 = Agree somewhat
2 = Disagree moderately	5 = Agree moderately
3 = Disagree somewhat	6 = Agree strongly

1. People with mental retardation are happier when they live and work with others like them.
1.....2.....3.....4.....5.....6
2. People with mental retardation trying to help each other is like "the blind leading the blind".
1.....2.....3.....4.....5.....6
3. People with mental retardation should not be allowed to marry and have children.
1.....2.....3.....4.....5.....6
4. A person would be foolish to marry a person with mental retardation.
1.....2.....3.....4.....5.....6
5. People with mental retardation should be guaranteed the same rights in society as other persons.
1.....2.....3.....4.....5.....6
6. People with mental retardation do not want to work.
1.....2.....3.....4.....5.....6
7. People with mental retardation need someone to plan their activities for them.
1.....2.....3.....4.....5.....6
8. People with mental retardation should not hold public office.
1.....2.....3.....4.....5.....6
9. People with mental retardation should not be given any responsibility.
1.....2.....3.....4.....5.....6
10. People with mental retardation can organize and speak for themselves.
1.....2.....3.....4.....5.....6

11. People with mental retardation do not care about advancement in their jobs.

1.....2.....3.....4.....5.....6

12. People with mental retardation do not need to make choices about the things they will do each day.

1.....2.....3.....4.....5.....6

13. People with mental retardation should not be allowed to drive.

1.....2.....3.....4.....5.....6

14. People with mental retardation can be productive members of society.

1.....2.....3.....4.....5.....6

15. People with mental retardation have goals for their lives like other people.

1.....2.....3.....4.....5.....6

16. I would trust a person with mental retardation to be a baby sitter for one of my children.

1.....2.....3.....4.....5.....6

17. People with mental retardation cannot exercise control over their lives like other people.

1.....2.....3.....4.....5.....6

18. People with mental retardation can have close personal relationships just like everyone else.

1.....2.....3.....4.....5.....6

19. I would not want to live next door to people with mental retardation.

1.....2.....3.....4.....5.....6

20. People with mental retardation are usually too limited to be sensitive to the needs and feelings of others.

1.....2.....3.....4.....5.....6

21. People with mental retardation should live in sheltered facilities because of the dangers of life in the community.

1.....2.....3.....4.....5.....6

22. People with mental retardation should be encouraged to lobby legislators on their own.

1.....2.....3.....4.....5.....6

23. People with mental retardation are the best people to give advice and counsel to others who wish to move into community living.

1.....2.....3.....4.....5.....6

24. The opinion of a person with mental retardation should carry more weight than those of family members and professionals in decisions affecting that person.

1.....2.....3.....4.....5.....6

25. People with mental retardation can plan meetings and conferences without assistance from others.

1.....2.....3.....4.....5.....6

26. People with mental retardation can be trusted to handle money responsibly.

1.....2.....3.....4.....5.....6

27. Residents have nothing to fear from people with mental retardation living and working in their neighborhoods.

1.....2.....3.....4.....5.....6

28. People with mental retardation usually should be in group homes or other facilities where they can have the help and support of staff.

1.....2.....3.....4.....5.....6

29. Sheltered workshops for people with mental retardation are essential.

1.....2.....3.....4.....5.....6

30. The best care for people with mental retardation is to be part of normal life in the community.

1.....2.....3.....4.....5.....6

31. Most people with mental retardation prefer to work in a sheltered setting that is more sensitive to their needs.

1.....2.....3.....4.....5.....6

32. Without some control and supervision, people with mental retardation could get in real trouble out in the community.

1.....2.....3.....4.....5.....6

33. The rights of people with mental retardation are more important than professional concerns about their problems.

1.....2.....3.....4.....5.....6

34. Agencies that serve people with mental retardation should have them on their boards.

1.....2.....3.....4.....5.....6

35. The best way to handle people with mental retardation is to keep them in institutions.

1.....2.....3.....4.....5.....6

36. Homes and services for people with mental retardation should be kept out of residential neighborhoods.

1.....2.....3.....4.....5.....6

37. Increased spending on programs for people with mental retardation is a waste of tax dollars.

1.....2.....3.....4.....5.....6

38. Homes and services for people with mental retardation downgrade the neighborhoods they are in.

1.....2.....3.....4.....5.....6

39. Professionals should not make decisions for people with mental retardation unless absolutely necessary.

1.....2.....3.....4.....5.....6

40. People with mental retardation are a burden on society.

1.....2.....3.....4.....5.....6

Questionnaire About Intellectual Disabilities/Mental Retardation

The World Health Organization (WHO) defines health as: *a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*. Can an individual with mental retardation ever truly be considered “healthy” in the sense of this definition? Why or why not?

When answering the following questions, please keep in mind this individual:

Bill is a 29-year-old male who has been diagnosed with intellectual disabilities/mental retardation (ID/MR). He received special education services all throughout his school career, and left the public school system at the age of 21. He lived with his parents until he was 23 when his father died and his mother transitioned him into a local group home. His mother tries to visit him every other week and he usually goes home on holidays. Bill's cognitive abilities were last tested thirteen years ago, when he was 16. At that time, his Full Scale IQ score fell within the upper end of the range of Moderate Mental Retardation (IQ score was 50). He appears to enjoy interacting with other residents at his home, but gets into some physical altercations about once a week. He is easily provoked by other residents and sometimes accuses them of stealing his belongings. He also has a tendency to try and boss other residents around. Bill currently attends a sheltered workshop program for individuals with mental retardation in the community, where he works on tasks such as sorting small items and packaging. Every other week, he receives a small check based on how much work he completes. He has trouble remaining on task at the workshop and often spends most days getting up from his seat and going to the bathroom, hanging out around the staff members, or going outside to smoke cigarettes. Staff at his group home report that he does not complain of any major medical problems at this time. His speech is slow and contains many articulation errors, and it is often difficult for strangers to understand him, but staff who have worked with him can usually determine what he means. He often has trouble finding the right words to use, and can become frustrated if people are impatient or cannot understand him.

Please rate the following on a six point scale, with 1 being not at all important and 6 being very important. Please circle the number that corresponds to your choice.

How important is it for Bill to....

1) have his own room?

1.....2.....3.....4.....5.....6
not at all very important
important

2) eat when he wants?

1.....2.....3.....4.....5.....6
not at all very important
important

3) eat what he wants?

1.....2.....3.....4.....5.....6
not at all very important
important

4) have privacy in his bedroom?

1.....2.....3.....4.....5.....6
not at all very important
important

5) have privacy in the bathroom?

1.....2.....3.....4.....5.....6
not at all very important
important

6) engage in organized leisure activities within the community?

1.....2.....3.....4.....5.....6
not at all very important
important

7) live within the community?

1.....2.....3.....4.....5.....6
not at all very important
important

8) do his own laundry?

1.....2.....3.....4.....5.....6
not at all very important
important

9) be in control of his own money?

1.....2.....3.....4.....5.....6
not at all very important
important

10) have a checking and/or savings account?

1.....2.....3.....4.....5.....6
not at all very important
important

11) attend religious services of his choice if he wants?

1.....2.....3.....4.....5.....6
not at all very important
important

12) have a communication system that makes it easy for him to talk to strangers on the street?

1.....2.....3.....4.....5.....6
not at all very important
important

13) have a paying job?

1.....2.....3.....4.....5.....6
not at all very important
important

14) have the opportunity to learn how to cook for himself?

1.....2.....3.....4.....5.....6
not at all very important
important

15) retire at the appropriate age?

1.....2.....3.....4.....5.....6
not at all very important
important

16) go on outings within the community?

1.....2.....3.....4.....5.....6
not at all very important
important

17) interact with non-disabled peers who are not part of his family or staff members?

1.....2.....3.....4.....5.....6
not at all very important
important

18) be able to make a decision about how to use his free time?

1.....2.....3.....4.....5.....6
not at all very important
important

19) be able to make his own choices and decisions?

1.....2.....3.....4.....5.....6
not at all very important
important

20) receive as little medication to control his behavior as possible?

1.....2.....3.....4.....5.....6
not at all very important
important

21) learn to manage his behavior without medication?

1.....2.....3.....4.....5.....6
not at all very important
important

22) be able to engage in sexual behavior of his choosing (as long as it doesn't harm another person)?

1.....2.....3.....4.....5.....6
not at all very important
important

23) be able to take a vacation day/personal holiday when he chooses?

1.....2.....3.....4.....5.....6
not at all very important
important

24) have a friend?

1.....2.....3.....4.....5.....6
not at all very important
important

25) have a say in where he lives?

1.....2.....3.....4.....5.....6
not at all very important
important

26) be a part of the neighborhood in which he lives?

1.....2.....3.....4.....5.....6
not at all very important
important

27) see his relatives on a regular basis?

1.....2.....3.....4.....5.....6
not at all very important
important

28) spend time learning new things/skills?

1.....2.....3.....4.....5.....6
not at all very important
important

29) spend time outside of work/day programs/school with friends?

1.....2.....3.....4.....5.....6
not at all very important
important

If you could recommend anything at all for Bill, in order to better his life, what would you recommend?

1)

2)

3)

4)

Do you consider anything else to be essential for the overall health and well-being of individuals with intellectual disabilities/mental retardation?

Any other comments?

APPENDIX B
IRB APPROVAL FORM



Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on September 29, 2013. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: CHOPKO, STEPHANIE

Co-Investigator(s):

Protocol Number: **X100923013**

Protocol Title: *Evaluating Perceptions of Independence for Individuals with Intellectual Disabilities/Mental Retardation*

The IRB reviewed and approved the above named project on 10/19/10. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 10-19-10

Date IRB Approval Issued: 10/19/10

Marilyn Doss, M.A.

Vice Chair of the Institutional Review
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

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