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Establishing a Connection Between Quality of Life and Pre-Academic Instruction for Students with Profound Multiple Disabilities

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ESTABLISHING A CONNECTION BETWEEN QUALITY OF LIFE AND PRE-ACADEMIC INSTRUCTION FOR STUDENTS WITH PROFOUND MULTIPLE DISABILITIES

by

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ABSTRACT

ESTABLISHING A CONNECTION BETWEEN QUALITY OF LIFE AND PRE-ACADEMIC INSTRUCTION FOR STUDENTS WITH PROFOUND MULTIPLE DISABILITIES

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The field of special education has begun to concentrate its efforts on developing objectives and procedural strategies that promote a positive quality of life for students with profound multiple disabilities, while determining which educational strategies are the most appropriate. A multi-element design was used to compare the effects of two educational conditions, pre-academic skills instruction and functional life skills instruction, on the quality of life indicators of four students with profound multiple disabilities. Results indicated that all four students demonstrated a greater number of happiness indicators while receiving pre-academic instruction. Implications for current educational practices are addressed and directions for future research are discussed.

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Establishing a Connection between Quality of Life and Pre-academic Instruction for Students with Profound Multiple Disabilities.

Historically, academic expectations for students with profound multiple disabilities (PMD) have been minimal (Agran, Alper, & Wehmeyer, 2002). However, the Individuals with Disabilities Education Act (IDEA) Amendments of 1997 required that each state create an educational framework that provided all students, including those with PMD, the opportunity to access, to participate, and to progress in the general education curriculum. In addition, the No Child Left Behind (NCLB) Act of 2001 mandated that states assess this population of learners on academic standards drawn from the general education curriculum in the content areas of reading, math, and science.

Notwithstanding recent legislation, many special educators (Agran et al., 2002) do not believe that it is appropriate for students with PMD to participate in the general education curriculum; therefore, little effort has been made to advance access to this curriculum. Agran and colleagues (2002) indicated that one of the primary reasons stated by special educators as to why access to the general education curriculum was inappropriate was the inability to determine the potential gains of this access to students with PMD. Therefore, this lack of functional assessment of the utility of student exposure to the general curriculum may be negatively influencing educators' expectations.

Over the past three decades, there has been relatively few research studies conducted in the area of educating students with PMD. These studies have addressed access to appropriate education (Browder, Wakeman, Spooner, Ahlgrin-Delzell, & Algozzine, 2006), developing self-determination (Algozzine, Browder, Karvonen, Test, & Wood, 2004), improving communication (Snell, Chen, & Hoover, 2006), and

enhancing independent functioning (Burcoff, Radogna, & Wright, 2003). Another area of recent study has been the concept of quality of life and its influence on the education of students with PMD (Helm, 2000; Petry, Maes, & Vlaskamp, 2005). Special educators have begun to concentrate efforts on developing objectives and procedural strategies that promote positive quality of life for students with PMD. As such, a central interest in this field pertains to identifying and planning for adequate quality of life opportunities for these students while determining which educational strategies are most appropriate for fostering the long term success of students with PMD (Green, Gardner, & Reid, 1997; Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005; Petry, Maes, & Vlaskamp, 2007).

The multifaceted term quality of life refers to the aspects of one's well-being (e.g., physical function), social interaction, and cognitive functioning. In addition, aspects associated with one's environment and relevant life areas contribute to overall quality of life (Schwartzman, Martin, Yu, & Whiteley, 2004; Yu et al., 2002). Many researchers (e.g., Bertelli & Brown, 2006; Lyons, 2005; Reiter & Schalock, 2008) argue that although several quality of life principles (e.g., health, happiness, contribution to society, wealth) are relevant and applicable for the majority of individuals, these principles should be translated into more concise indicators that reflect the unique needs of individuals with PMD. Specifically, various researchers (Green, Reid, Rollyson, & Passante, 2005; Lyons, 2005; Petry et al., 2005) suggest that emphasis on quality of life for these individuals should focus explicitly on measuring two key components, happiness and self-determination.

The definition of happiness established by Green and Reid (1996; 1999) is the most recognized definition in the field of PMD (Green et al., 2005; Petry et al., 2007;

Schwartzman et al., 2004). Green and Reid (1996) suggest that happiness is characterized as "any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities (e.g., smiling, laughing and yelling while smiling)" (p. 69). Additionally, specific behaviors such as clapping, hand rubbing, hopping in wheelchair, arm waving, singing, dancing, and head twirling have been considered as indicators of happiness among people with PMD (Lancioni et al., 2005; Singh et al., 2004; Yu et al., 2002). For individuals who demonstrate extremely low levels of functioning, less conventional indices of happiness have been identified. These indicators include: a change in muscle tone, increased opening of eyes, a change in arousal level, or change in physiologic measures such as heart rate (Ivancic, Barrett, Simonow, & Kimberly, 1997). Due to the multifaceted definition of happiness, in addition to the multiple components that constitute happiness (e.g., personal well-being, pleasure, and satisfaction), researchers continue to utilize this concept to describe a positive quality of life for individuals with PMD (Helm, 2000; Lancioni et al., 2005).

Overall, there has been a fundamental shift in thinking among many professionals in the field of PMD so that researchers are now focusing attention on the capabilities of people with disabilities rather than their deficits (Browder, Wakeman et al., 2007; Green et al., 1997). Therefore, quality of life measures for individuals with PMD have become an important factor to consider when educating this population. Focusing on and enhancing the strengths and capabilities of these individuals may afford them greater opportunities for meaningful participation, community inclusion, and positive educational outcomes (Clayton, Burdge, Denham, Kleinert, & Kearns, 2006).

Since the passage of the Education for All Handicapped Children Act (PL 94-142) in 1975, the challenge has been to create and implement an educational curriculum that is appropriate and effective for students with PMD. In their literature review, Nietupski and colleagues (1997) indicated the need to identify appropriate curricular content has been a central concern in the field of special education since its inception. Nietupski et al. (1997) described the elemental curricular shift for students with PMD from the developmental model, which was based on the assumption that the educational needs of students with PMD would be best served by focusing on his or her mental age, to the functional model which focused on teaching a variety of chronologically age appropriate skills deemed necessary to function successfully in domestic, community, and vocational environments (Browder & Cooper-Duffy, 2003; Burcroff, Radogna, & Wright, 2003). Currently, the curricular focus for children with PMD is shifting again (Browder & Xin, 1998), moving from a strictly functional skills approach toward one that emphasizes access to both the functional skills curriculum, as well as the pre-academic and/or academic content from the general education curriculum.

Presently, special educators continue to struggle to generate and apply effective educational strategies to teach academics to students with PMD. However, with the heightened emphasis on increasing access for students with PMD to the general education curriculum, the notion of teaching these students pre-academics and/or academic skills (e.g., pre-literacy and pre-numeracy), has received increased attention (Browder, Spooner, Wakeman, & Baker, 2006; Downing, 2006; Spooner, Dymond, Smith, & Kennedy, 2006). Reasons for this attention include improving adult competence, increasing educator's expectations, and providing instruction that combines both the

aspects of functional life skills and academic skills (Browder et al, 2009; Clayton et al., 2006). In addition to reaching higher levels of achievement and participating in meaningful social interactions, it can be posited that students with PMD who are taught pre-academic and/or academic content may also experience a greater overall quality of life.

One way to justify the teaching of pre-academic and academic content to students with PMD is to document the impact of this instruction on students. For this reason, the present study attempted to evaluate if there was a possible link between teaching pre-academics and an improvement in quality of life for students with PMD. Specifically, the following research question was investigated: What is the influence of teaching pre-academics on the quality of life of adolescent students with profound multiple disabilities as measured by established indices of student happiness?

METHOD

Participants and Setting

Four students were purposefully selected to participate in the study based on the following selection criteria: (a) an intelligence quotient that was considered unable to be calculated via traditional I.Q. assessments, therefore the student was subsequently given the diagnosis of severe/profound mental retardation (SPD) by the school program, (b) results obtained from the Battelle Developmental Inventory (Newborg, Stock, Wnek, Guidubaldi, & Svinicki, 1984) indicated an overall functioning of developmental age below 2 years, (c) non-verbal, but were able to engage in functional communication via non-traditional methods, (d) received all nourishment via gastrostomy tube, (e) fell between the ages of 13 and 21 years, and (f) had consistent attendance (e.g., absent less

than two times per month) prior to the onset of the study. All of the students selected were female, ranged in age from 13 to 21 years, and received their education in a regional public day school. In addition, all students were non-verbal, non-ambulatory, visually impaired, and suffered from seizure disorder. Demographic information for the four student participants is shown in Table 1.

----------(Insert Table 1 Here)----------

The investigation occurred in a regional public day school housed within an intermediate care facility in Southeastern Virginia. The research study was conducted during a five week summer school program that met Monday through Thursday, from 9am until 1pm. Each student received educational services in a self-contained classroom. The educational staff in each classroom consisted of one special education teacher and three paraprofessionals. Summer school instruction focused on a combination of functional skill goals derived from each student's individualized education plan (IEP) and pre-academic skill goals outlined by the Virginia Aligned Standards of Learning (ASOL) (Virginia Department of Education, 2009).

Dependent Variables and Data Collection Procedures

Dependent variables. Target behaviors were observable responses generally associated with subjective indices of happiness. The definition of happiness established by Green and Reid (1996; 1999) was utilized as a basis for determining appropriate indices of happiness for these participants. Green and Reid (1996) define happiness as "any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities (e.g., smiling, laughing and yelling while smiling)" (p. 69). Additionally, specific behaviors such as: clapping, hand wringing, hopping in

wheelchair, arm waving, singing, dancing, and head twirling are considered as indicators of happiness among people with PMD by other researchers (Lancioni et al., 2005; Singh et al., 2004; Yu et al., 2002) and, therefore, were included in the operational definition for this research.

As per annual requirements, teachers administered program specific communication assessments for each of the four participants. A summary of assessment results for each participant is shown in Table 2. According to the teachers who completed these assessments, all participants communicated enjoyment by smiling, laughing, and vocalizing. In addition, participants engaged in different target behaviors such as reaching out, maintaining eye gaze, looking toward an activity, relaxing, and rocking to indicate happiness.

----------(Insert Table 2 Here)----------

Data collection. Data were collected on the occurrence of the target behaviors described in Table 2 during a 10-min observation session. The observation recording system consisted of a 10-sec partial-interval recording procedure. Each 10-sec observation interval was separated by a 5-sec interval during which data were recorded. Data for each participant were collected in 10-min sessions which occurred six times a day (three times per classroom), four days per week. Two research assistants were employed to conduct the in-class direct observations with each observer responsible for data collection on two participants. Throughout the direct data collection period, the research assistants were unaware of the purpose of the present study.

Research Design

A single subject multi-element research design (Tawney & Gast, 1984) was used to examine the frequency of happiness indices across two instructional conditions, functional skills instruction and pre-academic skills instruction. Single subject investigations often are used in special education, specifically in the area of PMD due to the heterogeneous nature of the population (Horner et al., 2005). According to Horner and colleagues (2005), "single subject designs are organized to provide fine-grained, time-series analysis of change in a dependent variable(s) across systematic introduction or manipulations of an independent variable" (p. 172). A multi-element design generally is utilized when the investigation involves the rapid alteration of two or more conditions in order to determine a functional relationship between the condition(s) and the level of observed target behavior(s) (Kennedy, 2005). By using a multi-element design, the researchers were able to observe and collect data on "multiple direct replications of the experimental effect within a participant over a brief period of time" (Kennedy, 2005, p. 137).

Reliability, Fidelity, and Validity

Interrater reliability. Prior to the initiation of the direct observation sessions, the primary investigator and the two observers met with the classroom teachers to discuss the ways each student used to communicate happiness. The observers were trained until interobserver agreement remained consistently above 85% for each participant. Kennedy (2005) stated that when conducting single-subject research, interrater reliability above 85% is considered an acceptable level of agreement. The total number of agreements between the two observers was divided by the number of disagreements between the two

observers and the resulting quotient was multiplied by 100%. Interobserver agreement checks continued throughout the study to ensure reliability remained above 85%. As stated by Kennedy (2005), interrater reliability checks should be conducted on a minimum of 25% of total observation sessions. In the present study, interrater reliability checks were conducted on 26% of all observations, encompassing both conditions for each participant. Overall agreement for individual student happiness indices averaged 96% for each student, with some variability among participants, averaging 98%, 96%, 95%, and 96% for Student 1, Student 2, Student 3, and Student 4, respectively.

Procedural fidelity. Two times per week, the primary investigator and the school principal went into the participating classrooms to conduct procedural fidelity checks. This inspection took place to verify the nature of instruction that was occurring in the classroom during the observation session. Days and times of procedural fidelity checks varied across each classroom, with checks occurring in both the early morning and late morning and occurring at least once each day of the week over the five week period. Utilizing a checklist (see Appendix A), the primary investigator and principal independently observed the classroom activity in progress for 1-min to determine if the instruction being delivered encompassed functional life skills instruction or pre-academic skills instruction. These checklists were then compared to the instructional condition noted on each of the observer's data collection forms to ensure agreement across all parties regarding the type of instruction being delivered at that specific time. Procedural fidelity checks remained at 100% throughout the investigation.

Internal validity. To control for interaction effects between instructional condition and time of day, as well as between instructional condition and teaching staff, the

delivery and observation of both instructional conditions were counterbalanced across days, times, and teaching staff. By counterbalancing across conditions, an attempt was made to equally distribute possible interactions across both conditions. In doing so, the assumption is that any possible interaction effects that occur are the result of an uncontrolled process that emerged within the established experimental arrangement (Kennedy, 2005).

External validity. Controlling for external validity is a formable challenge when utilizing single-subject research designs. External validity can be enhanced by having a sufficient number of participants (at least three) in the study (Horner et al., 2005). This single-subject study fit this model as it incorporated four participants. In addition, external validity was demonstrated by experimental effects that were replicated across settings and participants. The investigation participants included four students from diverse age groups who received instruction in two different classrooms settings.

Procedure

Initially, the primary researcher met with the program director, assistant director, and school principal to provide basic information regarding the conduct of the investigation. With the assistance of the principal and classroom teachers, an observation schedule was established to optimize opportunities to observe and collect data during both instructional conditions. According to Kennedy (2005), this multi-element research design did not require baseline data collection since the effect of the two pre-existing instructional conditions were being observed to determine if a functional relationship existed between each condition and the participants observed indices of happiness.

Condition 1. During this condition, each participant was engaged in classroom instruction that focused primarily on pre-academic skills. For the duration of this instructional condition, students were instructed in pre-literacy skills (i.e., sight word identification, letter-sound identification), pre-numeracy skills (i.e., one-to-one correspondence, shape identification, calendar), and basic science facts (i.e., five senses, weather). Activities in which pre-academic instruction were taught included homeroom, morning report, reading circle, and math group. During these classroom activities, students participated in large group, small group, and one-on-one instruction with all three members of the teaching staff. Instruction in this condition occurred for 60 minutes, one time per day.

Condition 2. During this condition, each participant received instruction that predominantly centered on functional life skills. Throughout this instructional condition, the teaching staff focused approximately 25% of time on self-help skills (i.e., feeding, dressing), 25% of the time on motor skills (i.e., range of motion, massage), and 50% of the time independent living skills (i.e., communication, choice-making). Classroom staff delivered instruction in functional life skills during activities such as massage, homeroom, recess, reading group, and computer circle. During these activities, the teacher would provide instruction on individualized education program (IEP) goals pertaining to adaptive behavior, communication, social skills, and independent living. The majority of instruction delivered during this condition occurred via small group or one-to-one instruction. Again, all members of the teaching staff from each classroom were actively engaged in delivery of instruction which occurred for 60 minutes, one time per school day.

RESULTS

The purpose of this investigation was to evaluate a potential link between teaching pre-academics and an improvement in quality of life for students with profound multiple disabilities (PMD). Through visual analysis of the data, a difference in the level of happiness indicators demonstrated by each participant between conditions was revealed.

Instructional Condition Data

Figure 1 presents the total number of observation sessions per instructional condition for each participant. Each participant received instruction during both functional skills and pre-academic skills conditions. In addition, each participant had instructional sessions that were categorized as a missed session. A missed session was defined as one in which participants were engaged in activities unrelated to the two target instructional conditions (i.e., personal care, dozing, medical intervention) so a completed observation session could not occur. Due to the significant medical needs of the participants, missed sessions were expected.

----------(Insert Figure 1 Here)----------

Participant Data

Student 1. The observed indices of happiness for Student 1 are displayed in Figure 2. Student 1 was observed across 101 sessions, 44 (43.6%) of which occurred during functional skills instruction and 28 (27.7%) during pre-academic skills instruction. The remaining 29 (28.7%) observation sessions were classified as missed sessions. Student 1 displayed a total of 1130 behaviors defined as indicators of happiness, 651 during the functional skills instructional condition and 479 during the pre-academic skills

instructional condition. The range of happiness indices for functional skills and pre-academic skills instruction sessions were 0-31 and 0-29, respectively. Visual inspection of the Figure 2 reveals variability across the observation sessions, with a level trend for happiness indicators during functional skills instruction and a minimal decreasing trend for pre-academic skills instruction.

----------(Insert Figure 2 Here)----------

Student 2. Observed indices of happiness for Student 2 are displayed in Figure 3. Student 2 was observed across 101 sessions, 49 (48.5%) of which occurred during functional skills instruction and 32 (31.7%) occurred during pre-academic skills instruction. The remaining 20 (19.8%) observation sessions were considered missed sessions. Student 2 displayed a total of 510 behaviors defined as indicators of happiness, 246 during the functional skills instructional condition and 264 during the pre-academic skills instructional condition. The range of happiness indices per session for functional skills and pre-academic skills instructional conditions were 0-13 and 0-27, respectively. Visual inspection of the Figure 3 reveals variability across the sessions, with an increasing trend for happiness indicators during functional skills instruction and a decreasing trend for pre-academic skills instruction.

----------Insert Figure 3 Here----------

Student 3. The observed indices of happiness for Student 3 are displayed in Figure 4. During 101 sessions, Student 3 was observed during 46 (45.6%) functional skills instruction sessions and 39 (38.6%) pre-academic skills instruction sessions. Student 3 missed 16 (15.8%) instructional sessions. Student 3 displayed a total of 1054 behaviors defined as indicators of happiness, 446 during the functional skills instructional condition

and 608 during the pre-academic skills instructional condition. The range of happiness indices for functional skills and pre-academic skills instruction sessions were 1-29 and 3-39, respectively. Visual inspection of the Figure 4 reveals variability across the sessions, with a minimal increasing trend for happiness indicators during functional skills instruction and a minimal decreasing trend for pre-academic skills instruction.

----------Insert Figure 4 Here----------

Student 4. The observed indices of happiness for Student 4 are displayed in Figure 5. Student 4 was observed across 101 sessions, 52 (51.5%) of which occurred during functional skills instruction and 44 (43.6%) occurred during pre-academic skills instruction. The remaining 5 (4.9%) observation sessions were classified as missed sessions. Student 4 displayed a total of 448 behaviors defined as indicators of happiness, 183 during the functional skills instructional condition and 265 during the pre-academic skills instructional condition. The range of happiness indices for functional skills and pre-academic skills instruction sessions were 0-20 and 0-25, respectively. Visual inspection of the Figure 5 reveals variability across the sessions, with a decreasing trend noted for happiness indicators during both functional skills instruction and pre-academic skills instruction.

----------Insert Figure 5 Here----------

Total indices of happiness. Table 3 presents the mean percentage of indices of happiness per observed session for all participants. For Student 1, a comparison of happiness indices between the functional skills instructional condition and the pre-academic skills condition indicated that happiness indices were slightly higher during the pre-academic instructional condition (17.1% vs. 14.8%). A comparison of happiness

indices between the functional skills instructional condition and the pre-academic skills condition for Student 2 indicated that happiness indices were marginally higher during the pre-academic instructional condition (8.3% vs. 5.0%). For Student 3, a comparison of happiness indices between the functional skills instructional condition and the pre-academic skills condition indicated that happiness indices were considerably higher during the pre-academic instructional condition (15.9% vs. 9.7%). A comparison of happiness indices between the functional skills instructional condition and the pre-academic skills condition for Student 4 indicated that happiness indices were substantially higher during the pre-academic instructional condition (6.02% vs. 3.52%).

----------Insert Table 3 Here----------

DISCUSSION

The purpose of conducting the present study was to evaluate whether a link between teaching pre-academics skills and an improvement in the quality of life for students with profound multiple disabilities (PMD) could be established. The findings of this study demonstrated a potential relationship between pre-academic skills instruction and increased occurrence of indices of happiness. For all four participants, the mean percentage of indices of happiness for total observed sessions was higher during the pre-academic skills instruction condition than during the functional skills instruction condition. As reported in previous investigations (Davis et al., 2004; Green & Reid, 1996; 1999; Ivancic et al., 1997), instructional conditions in which the participants were exposed to preferred activities elicited greater measurable indices of happiness than sessions involving non-preferred stimuli. Results from the present study regarding the comparing of pre-academic and functional skills instruction seem to suggest that teaching

pre-academic skills results in increased indices of happiness for some students with PMD. Specifically, the results demonstrated by Students 3 and 4 may characterize the most representative results since these participants received fairly balanced instruction in both conditions. Student 3 demonstrated happiness indices of 9.7% during 46 functional skills condition observations compared to measured happiness indices of 15.9% during 39 pre-academic functional skills observation sessions. Likewise, Student 4 demonstrated happiness indices of 3.5% during 52 functional skills condition observations compared to measured happiness indices of 6.0% during 44 pre-academic functional skills observation sessions. The major reason to apply quality of life concepts to research for individuals with PMD is to determine if increasing instruction in these concept areas enhances students' satisfaction and overall well-being (Schalock et al., 2002). Because the participants in this study displayed higher indices of happiness during the pre-academic instructional condition, the results suggest that there are likely benefits for teaching pre-academic and/or academic content to students with PMD.

Presently, special educators are challenged with creating and implementing effective educational strategies to teach students with PMD. Historically, the majority of research conducted with individuals with PMD examined variables that affected skill acquisition with little attention to assessing the broader concern of the individual's quality of life (Davis et al., 2004). This study sought to establish a potential link between increased quality of life and the teaching of pre-academic/academic to students with PMD by documenting the potential positive impact of this instruction. As indicated by Agran and colleagues (2002), one of the primary reasons why special education teachers prefer not to pre-academic and/or academic content to students with PMD is the inability

to determine the potential gains of teaching this material to their students. The results of the present study suggest that some students with PMD who receive pre-academic instruction may experience more "happiness" which presents a reasonable rationale to provide this type of instruction. Besides providing positive teacher-student interactions, pre-academic instruction may also improve communication skills, increase social interactions, and increase desirable post school outcomes (Browder et al., 2007; 2009).

The outcomes of this study are consistent with results found in the literature. For example, Lyons (2005) reported that the daily routine of a child with PMD is characterized by frequent, extended periods of direct care interactions followed by shorter periods of independent activities. The majority of classroom time in the targeted classrooms used for this study focused on direct care interactions (i.e., toileting, medical intervention), functional skills instruction including self-help (i.e., feeding, dressing), range of motion activities (i.e., massage, exercising), and independent living skills (i.e., communication, choice-making). Overall classroom instruction targeting the aforementioned conditions averaged 64.6% for all participants, with some variability among participants, averaging 72.3%, 68.3%, 61.4%, and 56.4% for Student 1, Student 2, Student 3, and Student 4, respectively. The potential for many individuals with PMD to spend a substantial amount of time involved in these non-stimulating self-care routines may lead to a weakened sense of well-being and personal satisfaction. It appears that special educators should concentrate their teaching efforts on areas that enhance the quality of life of students with PMD. This new dual focus may mean balancing instructional time between pre-academic and/or academic skills instruction and functional skills instruction.

Limitations

Although the results of this investigation may be encouraging to those who consider pre-academic skills instruction useful for students with PMD, some limitations should be noted. The small sample size of the participants and the fact that all participants received instruction in self-contained classrooms housed within the same regional public day school program limits the generalizability of the findings. Secondly, due to the nature of the regional public day school summer program in which the study was conducted, the total investigation encompassed five weeks of instruction. Different outcomes, as represented by increasing and/or decreasing trends, may have occurred had the investigation been conducted over a longer period of time. A third limitation was a lack of guidance given to the teachers regarding the delivery of instruction during both conditions. This stipulation fulfilled a necessary arrangement constituted by the school program. Because of this, an uncontrolled variable could be the teacher's chosen method for delivering instruction. A fourth limitation of the study was the inability to equally observe each condition. Despite initial planning with the principal and classroom teachers regarding classroom scheduling, uncontrolled circumstances arose that altered the classroom schedule. A final limitation was the lack of subjective measures of happiness. Because of the communicative abilities of the participants, they were not able to self-report indices of happiness. Therefore, the investigation recorded only objective indices of happiness. Although some researchers (e.g., Cummins, 2001; 2002; Petry et al., 2005; Schwartz, 2005) have determined proxy reports (objective) to be valid as a means of interpreting another individual's index of happiness, it is recommended that researchers attempt to measure both subjective and objective indicators simultaneously

when assessing the quality of life of individuals with PMD when possible (Schalock et al., 2008). For example, subjective self-report measures in which individuals responded in their desired mode of communication (i.e., eye gaze, augmentative communication, picture symbols, etc.) would be supplemented with objective measures, such as direct observation or proxy report.

Implications and Recommendations for Future Research

The results of the present study suggest that students with PMD experience higher rates of happiness when they are receiving pre-academic instruction then when they receive functional life skills instruction. Assuming these findings are representative, special educators should attempt to concentrate their efforts on identifying and planning for positive quality of life opportunities for students with PMD, while determining which educational strategies provide the most appropriate access and participation in the general education curriculum as determined to be individually suitable (Green et al., 1997; Lancioni et al., 2005; Petry et al., 2007). Future research should focus on the implications of teaching all skill areas, including pre-academics skills and functional life skills with techniques such as positive interactions and allowing personal choice which have the potential to increase indices of happiness and overall quality of life. As Agran and colleagues (2002) stated, practitioners, including special educators, in the field of PMD have conflicting views regarding the potential benefits of teaching pre-academic and/or academic content to students with PMD. This study suggests that one potential benefit is that this kind of instruction has the potential to increase the happiness level of the students which could positively influence their overall quality of life. Future research should continue to address not only access to the general education curriculum for

students with PMD, but also focus on specific aspects of various instructional strategies and conditions that impact students' overall quality of life. In order to do this, special educators will need to utilize the results of effective quality of life assessment tools for students with PMD when planning and implementing appropriate instructional strategies. Finally, future research should consider the design and implementation of an educational curriculum for students with PMD that directly combines content from both pre-academic/academic curriculum and functional life skills. Rather than continuing to teach these skills in isolation, the combination of these two curricula may present a more effective teaching model as it would address both critical skill areas while potentially maintaining higher levels of engagement and interaction among students with PMD.

To date, there is a scarcity of assessment tools available to measure the quality of life of individuals with PMD (Ross & Oliver, 2003). Future research should continue to address the lack of valid measurement tools to assess the quality of life of individuals with PMD and examine other teacher friendly ways to determine if this outcome is being achieved. Additionally, in the field of PMD there is a dearth of research literature that links quality of life concepts to educational reform. Quality of life assessments can, and should, be another measure used to evaluate the effectiveness of special education programming for this population (Lancioni et al., 2007; Reiter & Schalock, 2008).

Conclusion

In recent years, perceptions have moved from a deficit to a competence-based perspective for students with PMD. Regardless of the severity of the individual's disabilities, educators are now considering an individual's overall capabilities, preferences, and engagement in activities when developing appropriate interventions.

Focusing on and enhancing the strengths and capabilities of these individuals may offer them additional opportunities to have meaningful, and pleasurable, participation in school and, in turn, more positive educational outcomes. As such, by identifying classroom activities that result in an increase in positive participation and happiness, educators may begin to adapt and design skill acquisition activities that lead to an improved quality of life for students with PMD. Finally, by using quality of life indicators when designing programs, special educators may be more likely to successfully decrease the potential unpleasantness of school while increasing skill acquisition, happiness, and self-determination.

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Table 1

Characteristics of Students

Student	Age	Disability Label	Developmental Level Battelle Developmental Inventory (Newborg et al., 1984)	Verbal	Medical Diagnosis
1	16	Profound Multiple Disabilities	1 year, 8 months	No	Anoxic enchalopathy, visually impaired, Spastic Quadriplegic Cerebral palsy, scoliosis, seizure disorder, Gastrostomy
2	13	Profound Multiple Disabilities	1 year, 1 month	No	Anoxic brain injury, visually impaired, Cerebral palsy, scoliosis, seizure disorder, Trachael Malacia, Gastrostomy
3	20	Profound Multiple Disabilities	1 year, 4 months	No	Cerebral palsy, visual impairment, hearing impairment, scoliosis, seizure disorder, Gastrostomy
4	20	Profound Multiple Disabilities	1 year, 6 months	No	Hypoxic Ischemic Encephlopathy, Visually impaired, Spastic Cerebral palsy, scoliosis, seizure disorder, Gastrostomy

Table 2

Student Indices of Happiness

Student	Classroom	Indices of Happiness
1	A	Smiling, laughing, vocalizing, reaches out with left hand, visually attends, maintains eye gaze, rocking motion
2	A	Smiling, vocalizing, relaxing, laughing, turning her head towards a person/activity while opening her mouth
3	B	Smiling, vocalizing, laughing, turning head towards person, raising her arms, remaining calm, keeping eye contact
4	B	Smiling, vocalizing, laughing, turns head towards the face of person interacting with her, relaxes extremities, opens eyes and maintains eye gaze

Table 3

Mean Percentage of Indices of Happiness

Student	Total Indices of Happiness		Total Observed Sessions			Mean Percentage of Indices of Happiness	
	Functional	Pre-academic	Functional	Pre-academic	Missed	Functional	Pre-academic
1	651	479	44	28	29	14.8%	17.1%
2	246	264	49	32	20	5.0%	8.3%
3	446	608	46	39	16	9.7%	15.9%
4	183	265	52	44	5	3.5%	6.0%

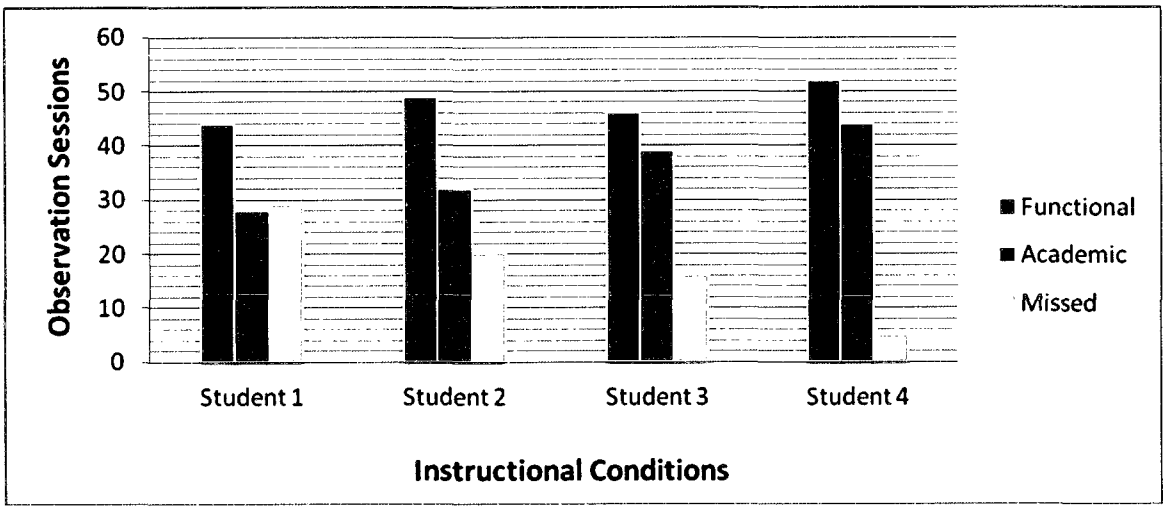

Figure 1. Total number of observation sessions for each participant.

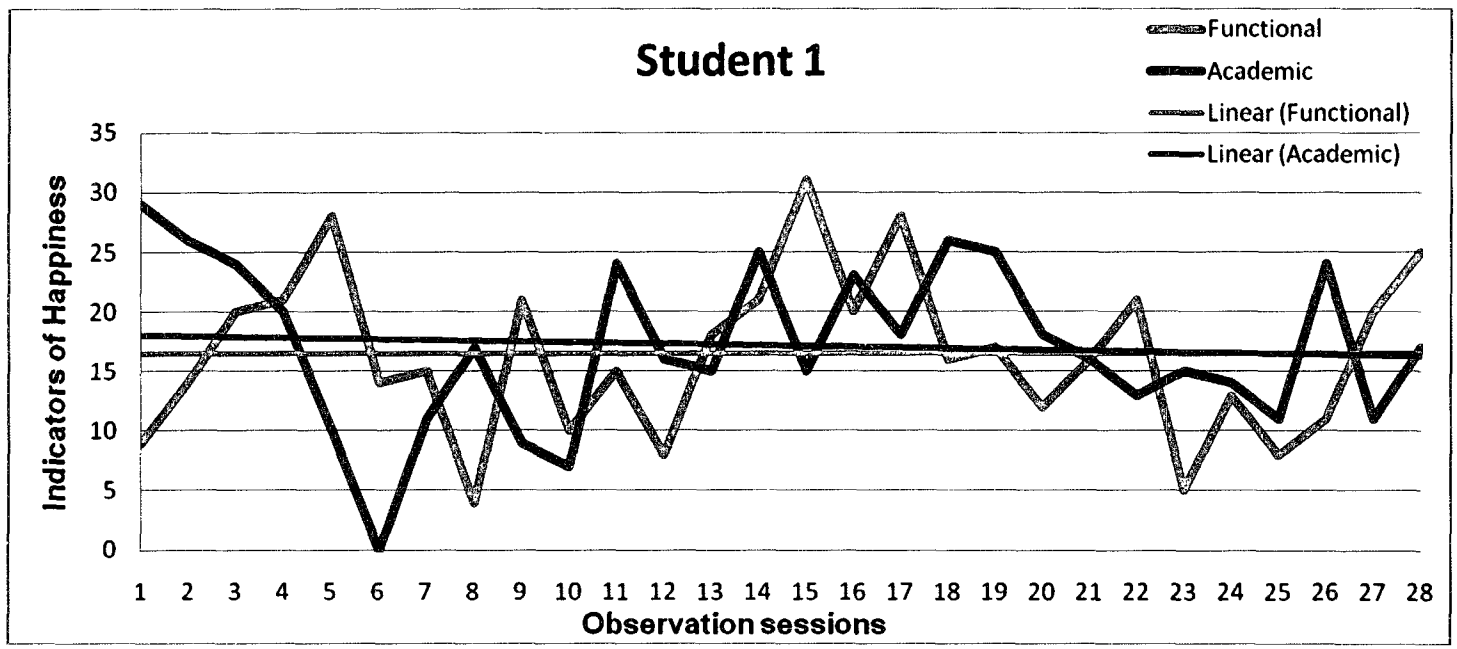

Figure 2. Total frequency of indicators of happiness per observation session for Student 1

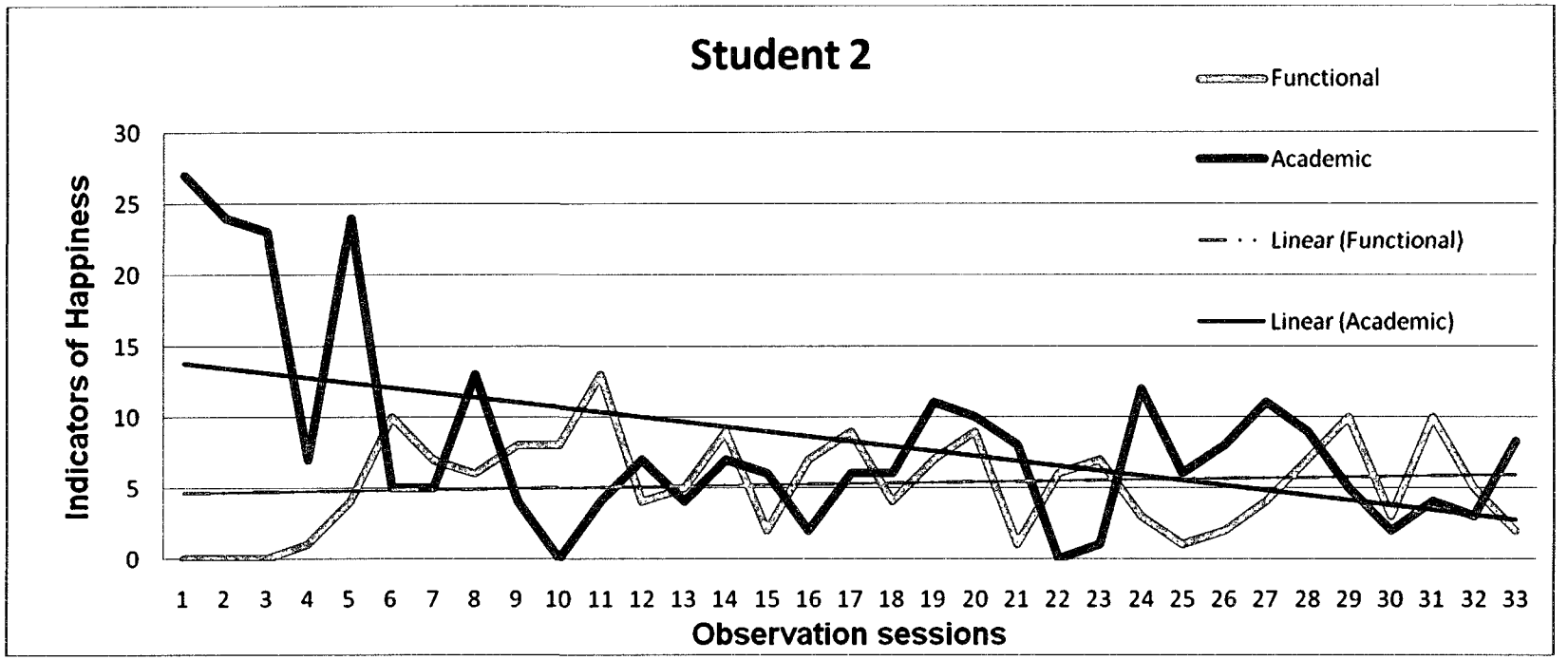

Figure 3. Total frequency of indicators of happiness per observation session for Student 2.

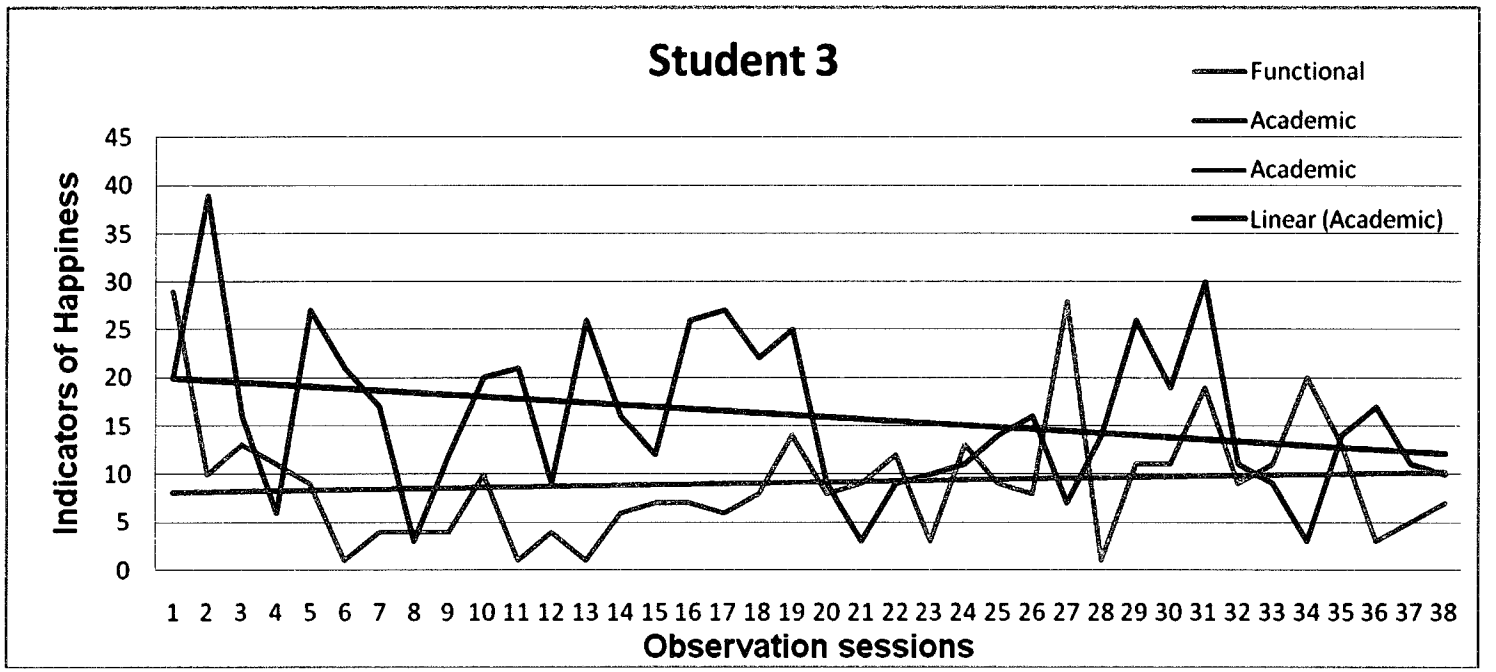

Figure 4. Total frequency of indicators of happiness per observation session for Student 3.

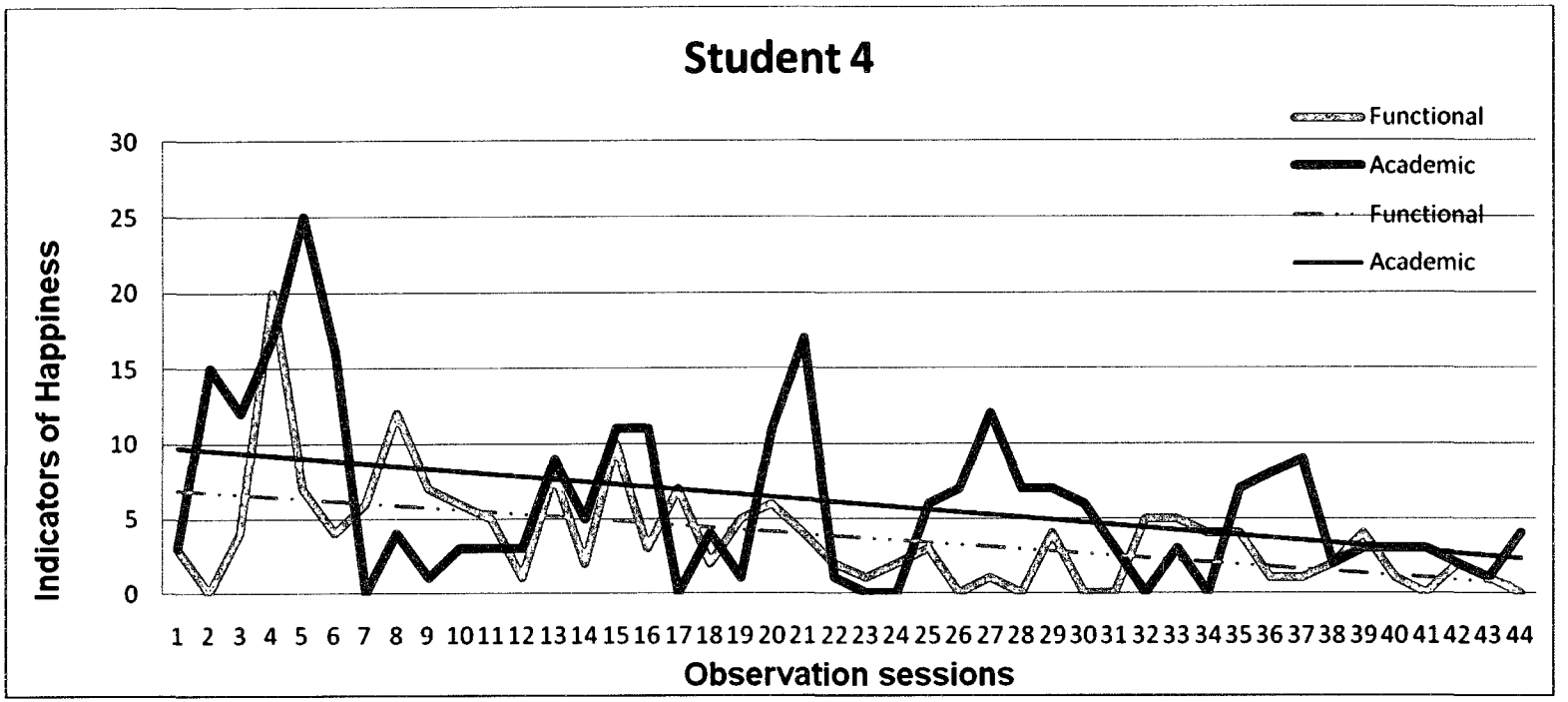

Figure 5. Total frequency of indicators of happiness per observation session for Student 4.

Appendix A

Curriculum Verification Form

Class:________________ **Time:**________________ **Date:**______________ **Current Activity Focus: Academic ☐ Functional ☐** **Signature:**____
Class:________________ **Time:**________________ **Date:**______________ **Current Activity Focus: Academic ☐ Functional ☐** **Signature:**____
Class:________________ **Time:**________________ **Date:**______________ **Current Activity Focus: Academic ☐ Functional ☐** **Signature:**____
Class:________________ **Time:**________________ **Date:**______________ **Current Activity Focus: Academic ☐ Functional ☐** **Signature:**____

CHAPTER 2: REVIEW OF THE LITERATURE

Introduction

For more than thirty years, researchers have focused on educating students with profound multiple disabilities (PMD). During the last two decades in particular, there has been an increase in research studies on two salient areas of interest: providing access for students with PMD to appropriate educational curriculums (Browder, Wakeman, Spooner, Ahlgrin-Delzell, & Algozzine, 2006; Clayton, Burge, Denham, Kleinert, & Kearns, 2006; Snell, Chen, & Hoover, 2006) and enhancing overall quality of life for these individuals (Green & Reid, 1996; Helm, 2000; Petry, Maes, & Vlaskamp, 2005). Historically, teachers had minimal expectations regarding academic achievement of students with PMD (Agran, Alper, & Wehmeyer, 2002) and quality of life concepts such as happiness and self-determination were often disregarded (Schalock, 2004). However, the recent passage of several pieces of federal legislation has served as a driving force for increasing research conducted regarding these two vital topics.

The enactment of the Individuals with Disabilities Education Act (IDEA) Amendments of 1997 instigated a change in the curricular focus for students with intellectual disabilities. IDEA (1997) required that each state create an educational framework that would provide all students, including those with PMD, the opportunity to access, to participate, and to progress in the general education curriculum. Access and participation in the general education curriculum, albeit a focal point of recent research (Browder, Wakeman, Flowers, Rickelman, Pugalee, & Karvonen, 2007; Cushing, Clark, Carter, & Kennedy, 2005), is not the only dynamic special educators must contemplate when considering meaningful instructional opportunities for students with PMD. The No

Child Left Behind Act (NCLB) of 2001 mandated that states implement assessment procedures designed to monitor the achievement of all learners on academic standards drawn from the general education curriculum in core content areas (e.g., reading, math, and science). Notwithstanding recent legislation, low teacher expectations and uncertainty regarding appropriate instructional strategies remains a barrier to the exposure of students with PMD to the general education curriculum.

While the passage of these two aforementioned acts served to increase preparations and expectations for the academic achievement of students with PMD (Cushing et al., 2005), two additional federal laws laid the foundation for emphasis on improving their overall quality of life. The passage of the Developmental Disabilities Act of 2000 and the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 has served as an incentive to increase quality of life research. Like previous legislation (e.g., IDEA, NCLB), these statutes addressed the rights of persons with PMD, particularly issues relating to quality of life related concepts (Schalock, Bonham, & Verdugo, 2008). Both pieces of legislation required quality of life domains and assessments be considered during the development of support plans for individuals with disabilities (i.e., individualized education plans and transition plans) (Schalock et al., 2008). Consequently, the concept of quality of life for persons with PMD has gained prominence among several research groups, including special educators (Lancioni, Singh, O'Reilly, Oliva, & Basill, 2005; Schalock, 2004). As such, special educators are beginning to concentrate efforts toward identifying and planning for adequate quality of life opportunities for students with PMD, while determining which educational strategies provide the most appropriate access and participation in the general education curriculum

as deemed individually suitable (Green, Gardner, & Reid, 1997; Lancioni et al., 2005; Petry, Maes, & Vlaskamp, 2007).

The purpose of this review was to examine literature that addresses quality of life concepts, the use of quality of life assessments, and application of quality of life strategies for individuals with PMD. In order to investigate a potential link between teaching pre-academics and academics and quality of life, special educators first must understand the history and significance of several concepts. Therefore, this review briefly addresses emerging strategies being used with students with PMD in order to ensure their access to the general education curriculum. Specifically, the following will be addressed: (a) a brief description of the historical and current curricula for students with PMD, (b) a definition and discussion of key components of quality of life (e.g., happiness, self-determination), (c) a discussion of the importance of the assessment of quality of life concepts, (d) an examination of current assessment practices (e.g., proxy versus self-report; subjective measures versus objective measures), and (e) a synthesis of research that addresses quality of life assessment strategies and applications. Finally, a discussion of the implications of this body of literature and suggestions for future quality of life research needed in the field of PMD will be presented.

Literature Search Procedures and Inclusion Criteria

In order to access a large body of literature, several resources were utilized. First, a thorough search of electronic resources was conducted through the following electronic databases: Education Full Text, ERIC, OVID, PSYCH Info, and Educational Research Complete. The descriptors used to identify articles were as follows: *profound multiple disabilities, significant intellectual disabilities, general curriculum, functional skills,*

academic skills, quality of life, assessment, happiness, classroom, subjective measurement, objective measurement, proxy, and self determination. In addition, the reference lists of selected literature reviews that addressed topics related to education, quality of life, and severe disabilities were reviewed in an effort to collect a broad literature base (Browder & Xin, 1998; Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Lancioni et al., 2005; Nietupski, Hamre-Nietupski, Curtin, & Shrikanth, 1997). Finally, the published results from both an expert panel (Schalock et al., 2002) and from a Delphi study of experts (Petry et al., 2007) in the field of quality of life for individuals with PMD were used.

The inclusion criteria used to determine whether a research article would be incorporated into the review involved the following: (a) published in a peer-reviewed journal between 1996 and 2008, (b) included at least one participant with the diagnosis of either severe or profound mental retardation, severe intellectual disabilities, significant cognitive impairment, or profound multiple disabilities (as defined by IDEA (2004), (c) involved some measure for assessing either quality of life in isolation, quality of life in collaboration with happiness and/or self-determination, or access to or progress in skills related to the general education curriculum, and (d) published in English. Using these selection guidelines, 17 empirical studies and/or research-to-practice articles from the field of special education, social science, and psychology were located (see Table 1 for a summary of reviewed empirical studies).

Historic and Current Curricular Focus

Following the passage of the Education for All Handicapped Children Act (PL 94-142) in 1975, special educators have been confronted with the challenge to create and

implement an educational curriculum that is both appropriate and effective for students with PMD. In 1997, Nietupski and colleagues conducted a literature review that addressed the notion that the need to identify appropriate curricular content has been a central concern in the field of PMD since its inception. Their review detailed the curricular shift from the developmental model of instruction to the functional model of instruction, as well as the implications of this shift (Nietupski et al., 1997). Currently, the curricular focus for children with PMD is shifting again, moving from a functional skills model approach toward a model that emphasizes access to the pre-academic and academic components of the general education curriculum (Browder et al., 2007).

Developmental curriculum. The enactment of P.L. 92-142 (1975) afforded all students with special needs, including those with the most severe disabilities, the right to attend public school. Students with PMD were those considered to be the most significantly impaired. This small population of students encompassed those diagnosed with a combination of disabilities including: profound mental retardation, severe physical impairment, substantial sensory difficulties and/or significant medical problems (Sternberg, 1994). These students required pervasive levels of support while in school as their level of overall development peaked at approximately two years of age in core areas of functioning (e.g., communication, social skills, mobility, self-help skills) (Sternberg, 1994). Unfortunately, although these students were entitled to a free and appropriate public education, there were no basic guidelines in place to educate them. The first educational services created for students with PMD were adapted from existing preschool curriculums (Browder et al., 2004). This curricular approach became known as the developmental model and was based on the assumption that the educational needs of

students with PMD should focus on instruction at the student's mental age as derived from developmental assessments (Browder & Spooner, 2006). During these initial years of instruction, the readiness approach guided the education of these students. This approach to learning suggested that a child with a significant level of intellectual disability cannot learn academic skills until they have mastered more fundamental life skills, such as toileting and grooming and other personal care skills (Browder & Spooner, 2006). Although there was no research to indicate that mastering life skills is a prerequisite to learning pre-academic or academic skills (Browder, Spooner, Wakeman, Trela, & Baker, 2006), this curriculum was utilized by special educators for several years until Lou Brown and colleagues (1979) challenged the special education field to concentrate on a new curricular model known as the functional curricular model.

Functional curriculum. The functional curricular model emphasized that education for students with PMD should focus on targeted skills needed by these students to function in daily life. Brown and colleagues (1979) proposed that appropriate instruction should include teaching a variety of skills that are required daily to function successfully in natural domestic, community, and vocational environments. In contrast to the developmental model, the educational goals based on the functional model were chronically age-appropriate. In addition, these age-appropriate functional skills were taught within the environment in which they naturally occurred to address generalization of the learned skills (Browder & Spooner, 2006; Burcroff, Radogna, & Wright, 2003). By the early 1980s, educators in the field of PMD were creating the first functional curricula, focusing on four skill/curricular domains: community, recreation, domestic, and vocational (Browder, Spooner, et al., 2006). For over a decade, special educators

continued to focus on teaching students with PMD according to the functional model. As the years passed, slowly the curricular focus began to shift again, this time toward access to the general education curriculum.

General education curriculum. In the early 1990s, following the introduction of inclusion, students with PMD became exposed to pre-academic and academic content as they were included in general education classrooms. Nevertheless, the priority for learning in the general education classrooms centered upon social interaction with non-disabled peers, application of functional skills in naturalistic environments, or practicing the use of expressive and receptive communication skills (Browder, Spooner et al., 2006). With the passage of IDEA (1997), the focus of learning changed as special educators were mandated to provide all students appropriate access to the general academic curriculum. The notion of access to the general education curriculum referred to adherence to "curricular standards, content and materials that are similar to those of their classmates without disabilities" (Cushing et al., 2005, p. 6). With the subsequent passage of NCLB (2001) and IDEIA (2004), the shift in curricular focus for students with PMD to access and participate in the general education curriculum has become an area widespread and sometimes contentious debate in the field of special education (Browder et al., 2009).

With the increased emphasis on access for students with PMD to the general education curriculum, the notion of teaching these students academic and/or pre-academic skills (e.g. pre-literacy and pre-numeracy) has received renewed attention (Browder, Wakeman et al., 2006; Downing, 2006; Spooner, Dymond, Smith, & Kennedy, 2006). Despite this increased emphasis, special educators are struggling to generate and

implement effective educational strategies to teach academic content to students with PMD. A survey of special education teachers conducted by Agran and colleagues (2002) found that teachers felt not only access to and participation in the general education curriculum was inappropriate, but also that students with PMD should not be held accountable to the same standards as their non-disabled peers. Furthermore, Agran et al. (2002) indicated that teacher's inability to determine the potential benefit to their students was one of the primary reasons they stated access to the general education curriculum was inappropriate. To address this uncertainty, Browder and colleagues (2007) developed a list of potential benefits of teaching pre-academic and/or academic content to students with PMD. The potential positive results included: (a) improving post school outcomes (e.g., adult competence), (b) increasing special educator's expectations of student achievement, (c) providing educational instruction opportunities that are equivalent to those offered to age-appropriate, non-disabled peers, (d) embedding functional skills instruction in pre-academic and/or academic activities drawn from the general education curriculum, and (e) increasing opportunities for social interactions with their peers without disabilities (Browder et al., 2007; 2009). In addition to reaching higher levels of achievement and participating in meaningful social interactions, it can be posited that students with PMD who are taught pre-academic and/or academic content may also experience a greater overall quality of life.

Definition of Quality of Life

The term quality of life encompasses multiple facets and can refer to the aspects of one's well-being (e.g., physical function), social interaction, and cognitive functioning. Also, quality of life can refer to aspects associated with one's environment and relevant

life areas (Green & Reid, 1996). When translated into its component parts, "quality" refers to the association of human values, such as happiness, health, and satisfaction, while "of life" refers to crucial components of human existence, such as expressing and becoming self-determined (Schalock et al., 2002; Shelly et al., 2008). Historically, the concept of quality of life was primarily utilized in the field of PMD as a sensitizing notion that guided practitioners to acknowledge what individuals with disabilities valued and desired (Schalock, 2004). At present, the term quality of life for persons with PMD is being utilized as both a unifying theme and as a social construct (Schalock et al., 2008). Quality of life indicators provide a unified foundation on which programs and services designed to enhance the well-being of individuals with PMD are built. Additionally, quality of life indicators serve as a powerful tool for eliciting programmatic and societal change (Schalock, 2004; Verdugo, Schalock, Keith, & Stancliffe, 2005). Although experts and researchers (Green & Reid, 1996; 1999; Petry et al., 2007; Schalock 2004) have posited the importance of focusing on quality of life for individuals with PMD, there continues to be debate in the field as how best to define and measure the concept of quality of life.

Recently, several experts (Petry et al., 2007; Schalock et al., 2002) in the fields of quality of life and PMD collaborated and established eight core principles that defined relevant indicators of quality of life for individuals with PMD. These were: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and human rights. The key components of these principles, based on individual choice and as much individual control as possible, are applicable to all people irrespective of gender, race, social class, or level of

disability (Reiter & Schalock, 2008; Schalock et al., 2002). These principles constitute a layered construct, comprised of both subjective and objective components. These components vary by individual and are influenced by personal factors, family life, employment, city or town of residence, education, and health (Schalock et al., 2002; Verdugo et al., 2005).

Although the same general principles associated with quality of life are viewed as important for all individuals, differences may exist in the value given to each of these principles based upon an individual's level of functioning (Campo, Sharpton, Thompson, & Sexton, 1997). Consequently, many researchers (e.g., Campo et al., 1997; Patick, 1997; Petry et al., 2005; Reiter & Schalock, 2008) argue that although the eight core quality of life principles have been found relevant and applicable for the majority of individuals, these principles should be translated into more concise indicators that reflect the unique needs of people with PMD. For example, Patrick (1997) proposed a conceptual model that emphasized environmental modification, independence, and increased opportunity as key principles for measurement of quality of life for people with PMD. Additionally, others have recommended that emphasis should focus specifically on happiness and self-determination as the two key components for measuring the quality of life of individuals with PMD (Green, Reid, Rollyson, & Passante, 2005; Lyons, 2005; Petry et al., 2005).

Happiness. The definition of happiness established by Green and Reid (1996; 1999) is the most widely accepted definition in the field of PMD (Green & Reid, 1999; Green et al., 2005; Petry et al., 2007; Schwartzman, Martin, Yu, & Whiteley, 2004). Green and Reid (1996) suggest that happiness is characterized as "any facial expression

or vocalization typically considered to be an indicator of happiness among people without disabilities (e.g., smiling, laughing and yelling while smiling)" (p. 69). Additionally, specific behaviors such as clapping, hand wringing, hopping in wheelchair, arm waving, singing, dancing, and head twirling have been considered as indicators of happiness among people with PMD by other researchers (Lancioni et al., 2005; Singh et al., 2004; Yu et al., 2002). For individuals who demonstrate extremely low levels of functioning, less conventional indices of happiness may include: a change in muscle tone, increased opening of eyes, a change in arousal level, or change in physiologic measures such as heart rate (Ivancic, Barrett, Simonow, & Kimberly, 1997). Although happiness is generally defined in an ambiguous manner, researchers in the field of PMD continue to utilize this concept as an important indicator of one's overall positive quality of life.

Although happiness constitutes only one unique element of the overall quality of life concept, it is a distinctive feature because of it is a multifaceted construct that involves various components (e.g., personal well-being, pleasure, and satisfaction) (Helm, 2000; Lancioni et al., 2005). Given that happiness elements are embedded throughout all quality of life domains, the significance of this indicator for persons with PMD cannot be diminished when assessing quality of life (Crocker, 2000; Schwartzman et al., 2004).

Despite the view that happiness is tied directly to quality of life in the field of PMD, researchers have paid little attention to the correlation of happiness and quality of life among these individuals (Green & Reid, 1999; Helm, 2000). This inattention may be due in part to the belief that although happiness is an accessible and prevalent element of quality of life for people with PMD, it is in essence a private event that may not be

amenable to direct study (Crocker, 2000; Green & Reid, 1999). As such, Green and Reid (1999) suggested that defining behaviors that represent happiness for individuals with PMD is one of the greatest challenges facing the field. Green and Reid (1996; 1999) further stated that individuals with PMD may lack sufficient communication skills to either articulate their level of happiness or to relay what stimuli exposure promotes happiness. To illustrate this logic, people with functional verbal repertoires are able to increase their level of happiness simply by requesting a desired object or stimuli. Conversely, individuals with PMD may not have access to preferred stimuli because they are not able to communicate their preferences effectively (Green & Reid, 1996). Therefore, assessing the happiness indices of persons with PMD may provide one effective method for evaluating the quality of life for this population (Ivancic et al., 1997).

Today, there is a small, but crucial body of research pertaining to increasing happiness indices among individuals with PMD. In 1996, Green and Reid introduced research concerning the measurement of displayed indices of happiness. Green and Reid (1996) conducted a single subject, alternating treatment design study regarding the use of a structured stimulation program, Funtime, on a group of adults with PMD. This program involved exposing participants to a variety of stimuli ranging from highly preferred to least preferred, as determined by systematic preference assessments. The participants were exposed to the stimuli intermittently for 1-min to 3-min during a 10-min activity session as both happiness and unhappiness indices were recorded through systematic observations. Findings from this study (Green & Reid, 1996) indicated that the stimulation sessions in which the participants were exposed to preferred stimuli elicited

greater measurable indices of happiness than sessions involving non-preferred stimuli. To further their research, Green and colleagues (1997) replicated this study utilizing a group of three adults with PMD participating in a day treatment center. Once more, the Funtime stimulation program was initiated and the results indicated that each participant demonstrated increased indices of happiness when engaged in activities encompassing predetermined preferred stimuli (Green et al., 1997).

Ivancic and colleagues (1997) conducted a similar study in which they sought to increase indices of happiness for adults with PMD. However, instead of presenting participants with items deemed favorable through preference assessments, the highly preferred stimuli items were based on the classroom staff's judgment. Using a single subject, ABAB reversal design, Ivancic et al. (1997) systematically observed seven adults with profound intellectual and motor disabilities as they engaged in staff selected activities. Results for this study were variable, in that an increase in happiness indices during activities containing highly preferred stimuli for only four of the seven participants (Ivancic et al., 1997).

Recently, Davis and associates (2004) further extended research in this area by conducting a single subject multi-element design study to determine which classroom condition produced the highest percentage of happiness indicators among three adult participants with PMD. The three conditions included: standard classroom programming, social interaction with the participant, and social interaction plus a preferred item or activity. Observers recorded happiness indices during one 10-min session, three to five days a week for each condition. Results revealed that all three participants demonstrated substantially higher indices of happiness when engaged in the social interaction/preferred

item combined condition. As the results of these studies suggest, increasing the happiness of individuals with PMD is an obtainable goal when attempting to improve one's overall quality of life. Although somewhat speculative, this knowledge might assist practitioners in the field of PMD as they create and implement strategies and interventions aimed at supporting this population.

Self-determination. Embedded within current research in the areas of disability services, special education, and quality of life, there is growing support for promoting self-determination for individuals with PMD (Wehmeyer, 2005; Wehmeyer & Schwartz, 1998). Self-determination, which can be defined as individual choice, has increased equal opportunity, individual freedom, and quality of life for people with PMD in that it is viewed as conceptually independent from the intellectual disability level of an individual (Bertelli & Brown, 2006; Wehmeyer, 2005). Although self-determination is viewed as a core principle of quality of life, it is often overlooked in individuals with PMD because they are typically unable to verbalize a preference or choice. Lancioni and colleagues (2007) suggested that this phenomenon leads to a decrease in happiness and quality of life for this population. Several experts (e.g. Green et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Petry et al., 2005) have conceptually and correlationally linked higher levels of self-determination to a more positive quality of life and better long-term outcomes for individuals with intellectual disabilities, including those with PMD. For example, Lancioni and colleagues (2007) found that utilizing microswitch programs to initiate choice-making opportunities for nine children, ages 6-18 with PMD, increased their level of self-determination. Utilizing a single subject multiple baseline study design, each student was given the opportunity to use a microswitch to select preferred activities.

All participants engaged in active choice making, thereby suggesting an increase in their individual level of self-determination. In addition, seven of the nine participants observed also demonstrated a significant increase in indices of happiness (Lancioni et al., 2007). Overall, the concepts of quality of life and self-determination can potentially be viewed as complimentary since programs or interventions that utilize quality of life applications could potentially enhance one's level of personal control, self-determination, and individual opportunity (Schalock et al., 2002; Shogren, Wehmeyer, Buchanan, & Lopez, 2006).

Importance of Quality of Life Assessments

The major reason to apply quality of life concepts to research for individuals with PMD is to determine if increasing these concepts enhances their satisfaction and overall well-being (Schalock et al., 2002). Typically, the daily routine of a person with PMD is characterized by frequent, extended periods of direct care interactions followed by shorter periods of independent activities (Lyons, 2005). These direct care interactions are primarily associated with functions of daily living and self-care routines. For children with PMD, these extended periods of direct care interactions generally occur in a school setting (Lyons, 2005). The potential for many individuals with PMD to spend a substantial amount of time involved in these non-stimulating self-care routines may lead to a lessened sense of well-being and satisfaction. Despite the possibility that these individuals experience a decreased sense of quality of life due to an apparent lack of time spent engaged in enjoyable activities, few empirical studies suggesting methods to increase the quality of life of individuals with PMD exist (Lyons, 2005; Ross & Oliver, 2003).

Historically, the majority of research conducted with individuals with PMD examined variables that affected skill acquisition with little attention to assessing the individual's quality of life (Davis et al., 2004). Bertelli and Brown (2006) stated that although some researchers (e.g., Hatton & Ager, 2002) assert that assessing persons with PMD regarding their quality of life is not possible because they lack the cognitive skills to give meaning to the concept, there is little evidence to support this claim. In actuality, even in the cases of the most severe impairments, researchers have been able to obtain information regarding emotions and feelings from individuals with significant disabilities in such a way that it allowed satisfaction in life to be perceived (Bertelli & Brown, 2006). The resulting dilemma facing researchers is how to accurately and efficiently assess and measure quality of life indicators in persons with PMD.

Current Quality of Life Assessment Practices

Over the past 20 years, techniques for assessing the satisfaction of people with PMD regarding various aspects of their lives have grown significantly. Consequentially, the role of quality of life assessment has expanded to include a "conceptual framework for measuring personal outcomes and a social construct that guides program practices and quality improvement" (Schalock et al., 2008, p. 181). Due to this increased integration of the quality of life concept into program practices, an increasing number of pediatric quality of life instruments have been developed. This plethora of measurement instruments can make it difficult for researchers and clinicians to determine which instruments or assessment techniques, if any, are the most appropriate for individuals with PMD (Davis et al., 2006; Green & Reid, 1996). Typically, quality of life assessment tools (e.g., Life Experiences Checklist, Comprehensive Quality of Life Scale) rely on an

individual's evaluation of their satisfaction and/or happiness in those areas of life that are applicable and relatively important (Bertelli & Brown, 2006). Given that individuals with PMD rarely demonstrate typical happiness indicators, it is significantly more difficult to determine the level of satisfaction and happiness of these individuals. As a result, determining which quality of life measurement approach to use with this population poses a real challenge.

Verdugo and colleagues (2005) stated that current approaches being used in the measurement of quality of life can be characterized by several key premises. Primarily, quality of life assessments are multidimensional in nature and involve investigating both core quality of life domains and individual indicators, such as happiness (Verdugo et al., 2005). Second, typical quality of life tools are methodologically plural and use both objective and subjective measures. The use of this multivariate design enables researchers to calculate the manner in which personal characteristics and environment relate to a person's quality of life (Verdugo et al., 2005). Finally, in simple quality of life assessment tools the most commonly utilized response level is a binary choice (i.e., yes/no) which, despite the simplicity of this level of response, may not be appropriate for people with PMD (Cummins, 2002). Research has revealed that the majority of people with PMD cannot reliably utilize this type of scale to complete quality of life assessments (Cummins, 2002; Verdugo et al., 2005).

In current practice with people with PMD, quality of life measures tend to be questionnaire or interview-based and are designed to be completed via self-report (Hatton & Ager, 2002). However, due to the fact that many individuals with PMD are not always capable of independently responding to direct questions, the reliance on self-report raises

a number of methodological issues. Specifically, the validity and reliability of responses by people with PMD and the validity of informant, or proxy, responses are questionable (Hatton & Ager, 2002). If the reliability and validity of quality of life interviews cannot be established for individuals with PMD due to an inability to self-report, then the utility of self-related quality of life measures used directly with this population is questionable (Hatton & Ager, 2002; Verdugo et al., 2005).

Proxy vs. Self-Report. Traditionally, quality of life instruments have measured indicators of happiness and self-determination for individuals with mild or moderate disabilities through self-report techniques (Green & Reid, 1996). When assessing the quality of life of persons who have significant communication deficits, one of the first priorities to address is how to alter the delivery method of the assessment to encourage self-report. These methods may include simplifying the questions and responses or utilizing alternative or augmentative communication devices (Verdugo et al., 2005). Despite frequent efforts to make quality of life measures accessible to all, situations remain in which utilizing self-report measures is not appropriate (Nota et al., 2007). For example, alternative data collection methods may be necessary if respondents, such as those with PMD, have impairments that significantly impact their ability to answer cognitively complex questions or if respondents have no functional communication (Nota et al., 2007). Frequently, in an attempt to include individuals with PMD, who cannot participate independently, a knowledgeable proxy is asked to respond to quality of life questions on behalf of the individual (Bonham, Basehart, & Schalock, 2004; Green et al., 1997; Lyons, 2005).

In measuring the quality of life of individuals with PMD, questions arise as to whether the use of proxy report is reliable and valid (Lyons, 2005; Perry & Felce, 2002). Several researchers (e.g., Campo et al., 1997; Perry & Felce, 2002; Petry et al., 2005) have attempted to evaluate the accuracy of proxy-participant agreements on quality of life concepts such as happiness. As a result, there are conflicting views as to the validity of utilizing proxy reports. Several researchers (e.g., Ross & Oliver, 2003; Schalock et al., 2002) maintain that since the concept of quality of life is essentially an intensely personal experience, a proxy answering on another's behalf cannot accurately convey the person's own perception of his or her life. Perry and Felce (2002) found that quality of life assessment results reported by a proxy who was familiar with a person with PMD yielded conflicting results when compared to the self-reported quality of life assessment results given by the actual individual with PMD. Conversely, a number of researchers (e.g., Cummins, 2001; 2002; Petry et al., 2005) have determined proxy reports to be valid as a means of interpreting another individual's quality of life. For example, Schwartz (2005) demonstrated evidence of consumer-proxy agreement when she compared the self-report answers obtained regarding quality of life of adults with intellectual disabilities with proxy answers obtained from the individual's parents. Due to the equivocal nature of these research findings, little rationale has been provided to support the use of proxy respondents nor have findings negated the value of proxy respondents in assessing the quality of life concepts of individuals with disabilities (Perry & Felce, 2002).

Despite the paucity of research supporting the utilization of proxy respondents, the use of this alternative method to measure quality of life continues to be employed. Since individuals with PMD often communicate through small, hard to notice behavioral

signals, the adoption of alternative methods of data collection appears to be necessary in order to include these individuals in quality of life research (Perry & Felce, 2002; Petry et al., 2005). Verdugo and colleagues (2005) stated that when necessary, quality of life data for individuals with PMD should include both proxy data about the individual, as well as self-report data that can be gathered wherever possible. The resulting data from these two sources should be analyzed separately and then tested directly to determine the degree of agreement between self-reports and proxy responses. This direct comparison would assist in determining if proxy data can be interpreted accurately (Verdugo et al., 2005). Finally, in situations where proxy respondents must relay information on behalf of an individual with a significant disability, the subjective results of such measurement techniques must be clearly identified as another person's perspective (Hatton & Ager, 2002; Schalock et al., 2002).

Subjective measurement vs. objective measurement. One of the major points of contention in current quality of life research is whether it is possible to objectively measure the quality of life of individuals with PMD or if quality of life is largely a matter of subjective appraisal (Perry & Felce, 2002). By definition, quality of life is a multi-layered construct, composed of subjective (self-report) and objective (observed) indicators; therefore, both are necessary to fully measure an individual's quality of life (Petry et al., 2005; Verdugo et al., 2005). Although subjective appraisal has been a key component of quality of life research for the general population, objective assessments have dominated quality of life research in the field of PMD (Perry & Felce, 2002).

Objective measures that are observable, such as laughing and smiling, are often used when assessing the quality of life of individuals with PMD because it is assumed

that one cannot truly ascertain the subjective feelings, or emotions, of another (Helm, 2000). However, since happiness also can be viewed as an innately private event, some behavioral studies (e.g., Perry & Felce, 2002, Campo et al., 1997) investigating people with PMD have primarily relied on subjective measures. From a behavioral perspective, subjective measures must be used because one could never reliably know another's level of happiness or what initiates feelings of happiness, unless it was relayed directly to us (Helm, 2000). Consequently, a barrier to measuring subjective quality of life of individuals with PMD is that the concept must be inferred by means other than self-report (Cummins, 2002).

Despite the difficulties that arise with regard to the measurement of quality of life for this group of individuals, several contemporary researchers (e.g., Petry et al., 2005; Schalock et al., 2002) believe the subjective experience and the resulting perceptions of that experience are extremely important and useful. Ideally, researchers should attempt to measure both subjective and objective indicators simultaneously when assessing the quality of life of individuals with PMD (Schalock et al., 2008). By measuring both subjective and objective indicators on the same item, many of the problems associated with focusing only on either subjective or objective measures, which are typically not highly correlated, are eliminated (Bertelli & Brown, 2006; Schalock et al., 2008). Therefore, one of the most pressing needs in this field of research is in the development of assessment strategies that can evaluate subjective dimensions of quality of life in addition to the more traditional, objective dimensions (Campo et al., 1997).

Potential Contribution of the Current Study

Because of the nature of this explicative literature review, there are limitations that should be noted. One possible limitation may be the omission of empirical or research-to-practice articles written prior to 1996 and works presented through non-literary methods (e.g., conference presentations, expert forums, etc.). Another possible limitation may be the exclusion of articles outside the parameters of the original ten descriptors (i.e., *long-term outcomes, unhappiness, preference, and self-report*). A final limitation is the fact that there is a dearth of research that applies quality of life concepts to educational reform. Quality of life assessments can be used as a criterion against which to evaluate the effectiveness of special education programming (Lancioni et al., 2007; Lyons et al., 2005; Reiter & Schalock, 2008).

This investigation may have been the first to explore the existence of a potential link between teaching pre-academic skills and increasing overall quality of life for students with PMD. While past research on improving the quality of life for students with PMD has focused on teaching leisure skills or functional life skills, none to date have centered upon teaching pre-academic skills. Research demonstrating a possible link between teaching pre-academic skills and improved quality of life for students with PMD has the potential to positively influence special education professionals and practitioners. As a result, the overall concept of quality of life for students with PMD will be more valued, respected, and encouraged by educators as they strive to develop appropriate and effective educational programming for these students.

Table 1

Characteristics of reviewed quality of life (QOL) empirical studies

Studies	Participants (n)	Disability Label	Purpose	Outcomes
Campo, Sharpton, Thompson, & Sexton, 1997	60	Severe or profound mental retardation	Examine variables associated with QOL of people living in Intermediate care facilities	QOL scores of participants positively related to social and staff support, and high level of integrated activities
Davis, Young, Cherry, Dahman, & Rehfeldt, 2004	3	Profound mental retardation	Effectiveness of delivering a preferred item with vs. without interaction to indicate happiness	Happiness indicators higher during presentation paired with interaction
Green & Reid, 1999	5	Profound multiple disabilities	Evaluate a means to determine sources of happiness/unhappiness within the classroom	Behavioral definitions and observation system reliably identified sources of happiness/unhappiness
Green & Reid, 1996	6	Profound multiple disabilities	(a) attempt to reliably observe and validate definition of happiness and unhappiness (b) demonstrate if happiness could be increased by staff	(a) Were able to reliably observe indicators of happiness and unhappiness (b) Classroom assistants effectively increased happiness among participants
Green, Gardner, & Reid, 1997	3	Profound multiple disabilities	A replication of Green & Reid, 1996	Each participant experienced an increase in overall happiness indices

Green, Reid, Rollyson, & Passante, 2005	3	Profound multiple disabilities	Evaluate an enriched teaching program for reducing resistance to teaching and unhappiness	Resistance and unhappiness were decreased for participant during enriched teaching program
Ivancic, Barrett, Simonow & Kimberly, 1997	7	Profound multiple disabilities	A replication of Green & Reid, 1996	Increase in happiness indices for all participants
Lancioni, Singh, O'Reilly, Sigafoos, Didden, Oliva et al., 2007	9	Profound multiple disabilities	Evaluate the effectiveness of microswitch-based programs on indices of happiness	Seven of the nine participants showed an increase in happiness indices when using the microswitch-based program
Nota, Ferrari, Soresi, & Wehmeyer, 2007	141	Intellectual disabilities	Examine relationship between personal characteristics, self-determination, social abilities, and residential status/QOL outcomes	Basic social abilities and IQ scores were greatest predictors of membership in high or low QOL group
Perry & Felce, 2002	154	Mental retardation	Examine degree of correlation between self-report responses of persons with MR vs. those of staff responding on their behalf	Proxy results were not significantly correlated with self-reported views
Petry, Maes, & Vlaskamp, 2007	45	Profound multiple disabilities	Assessed content and structure of an item pool that contained items on QOL and related supports	Experts selected relevant QOL items: physical well-being, material well-being, social/emotional well-being, development and activities
Petry , Maes, & Vlaskamp, 2005	76	Profound multiple disabilities	Considered the general validity of basic domains of QOL theoretical models in relation to this population	Supports a multi-dimensional approach as a valid way to assess QOL

Schwartz, 2005	71	Intellectual Disabilities	Examined impact of parental involvement in relocation QOL for adult children with ID	Parents perception increased the QOL of adult children with ID and made relocation easier
Schwartzman, Martin, Yu, & Whiteley, 2004	2	Severe intellectual disabilities	Determine if the provision of preferred food item resulted in increase happiness in choice	Participants showed very little happiness indices throughout study, very little effect noted
Shelly, Davis, Waters, Mackinnon, Reddihough, Boyd et al., 2008	205	Cerebral palsy	Proxy reports used to determine the strength of association between functioning and QOL domains	For proxy-parent report, all domains of QOL were significantly associated with functioning except access to services
Singh, Lancioni, Winton, Wahler, Singh, & Sage, 2004	3	Profound multiple disabilities	Determine if caregivers could increase happiness without actively focusing on contingencies of happiness	Showed very clearly that the levels of happiness were increased during preferred leisure activities
Wehmeyer & Schwartz, 1998	50	Mental retardation	Explore the contribution of self-determination to a more positive QOL and to examine relationships between QOL and self-determination	Self-determination contributes to a more positive QOL for people with MR and self-determination and QOL are correlated.

CHAPTER 3: METHOD

Participants

Following researcher obtained consent by the Institutional Review Board (IRB) at Old Dominion University in Norfolk, Virginia, four students were purposefully selected to participate in the study. In order to be eligible to participate in the study, each student met the following selection criteria: (a) had an intelligence quotient that was considered unable to be calculated via traditional I.Q. assessments, therefore subsequently given the diagnosis of severe/profound mental retardation (SPD) by the school program, (b) results achieved from the Battelle Developmental Inventory (Newborg, Stock, Wnek, Guidubaldi, & Svinicki, 1984) indicated overall functioning at a developmental age of below two years, (c) non-verbal, but were able to engage in functional communication via non-traditional methods, (d) received all nourishment via gastrostomy tube, e) fell between the ages of 13 and 21, and (f) had consistent attendance (absent less than two times per month). Parents, or legal guardians, of the anticipated participants received an informed consent form from the school program. The informed consent forms were signed and returned to the primary researcher one week prior to the start of the observation sessions.

Student 1 was a sixteen-year-old Caucasian girl who was reported to communicate functionally using vocalizations, eye gaze, and a voice output communication device (VOCA). She attended school in a regional public day school and was a student in the 5th through 8th grade classroom. According to teacher assessment, Student 1 was able to follow one-step commands and enjoyed verbal praise and adult interaction. She also enjoyed interacting with both typical peers and peers with

disabilities. Student 1's scores on the Battelle Developmental Inventory (Newborg et al., 1984) showed her developmental age to be approximately one year, eight months. At this time, her I.Q. was not considered calculable due to the severity of her disabilities. In addition to her intellectual disabilities, Student 1 had significant physical impairments, including spastic quadriplegic cerebral palsy, scoliosis, bilateral dislocated hips, Osteopenia, and visual impairment. Also, Student 1 received all of her nutrition via a gastrostomy tube and required a pervasive level of support as she was entirely dependent on others for her self-care needs.

Student 2 was a fourteen-year-old African American girl who attended school in a self-contained, 5th through 8th grade classroom housed within a regional public day school. As stated by the teacher, she communicated with teaching staff through eye gaze, vocalizations, and picture symbols. Additionally, Student 2 was able to follow one-step commands and she enjoyed sensory reinforcement such as music and massage. Her score on the Battelle Developmental Inventory (Newborg et al., 1984) assessed her developmental age to be equivalent to one year, one month. Because she was considered untestable using current I.Q. assessments, Student 2 was placed in the severe/profound range of mental retardation. She was diagnosed as having a severe seizure disorder for which a Vagus Nerve Stimulator was implanted. Due to her substantial physical disabilities, Student 2 required a pervasive level of support from classroom staff. Her physical disabilities included cerebral palsy, bilateral dislocated hips, Osteopenia, scoliosis, hypothermia, and optic atrophy. Further, she was unable to eat by mouth and she received all of her daily nutrition via a gastrostomy tube.

Student 3 was an eighteen-year-old Caucasian young women diagnosed with severe/profound mental retardation as she was considered unable to be tested using standard I.Q. assessments. She attended school in a self-contained classroom for 9th through 12th grade students in a regional public day school. Teacher reports indicated that Student 3 was typically an unsocial student and tended to ignore or turn away from adult or peer interactions. Student 3 was able to follow simple one-step directions. She was assessed using the Battelle Developmental Inventory (Newborg et al., 1984) and her scores gave her an overall developmental age of approximately one year, four months. Student 3 was considered medically fragile and had been diagnosed with a seizure disorder, cerebral palsy, bilateral dislocated hips, scoliosis, Osteopenia, spina bifida, visual and hearing impairments. Student 3 also received all of her nutrition via a gastrostomy tube and relied on others for self-care needs.

Student 4 was a member of the same class as Student 3. She was a twenty-one year-old Caucasian young woman who was preparing to transfer to an adult residential facility. As indicated by teacher reports, Student 4 enjoyed any adult and/or peer interactions, especially praise. Student 4 was social, utilized eye gaze to make choices, and communicated functionally by using eye gaze, picture symbols, or a VOCA. According to the Battelle Developmental Inventory (Newborg et al., 1984), Student 4's developmental age was approximately one year, six months old. She had an I.Q. that was considered untestable which placed her in the category of severe/profound mental retardation. Student 4 had significant physical limitations due to spastic cerebral palsy, scoliosis, osteoperosis, and optic atrophy. Finally, Student 4 suffered from a seizure

disorder, required a pervasive level of support, and she received all of her daily nutrition via a gastrostomy tube.

A summary of relevant characteristics for each participant is provided in Table 2. All of the students ranged in age from 13 to 21 years and each received her education in a regional public day school. All four participants were female and were categorized as having profound multiple disabilities (Sternberg, 1994) as it was determined they functioned developmentally below two years of age, suffered from significant physical impairments, and fell into the severe/profound range of mental retardation. In addition, all students were non-verbal, non-ambulatory, visually impaired, and suffered from seizure disorders.

Table 2

Characteristics of Students

Student	Age	Disability Label	Developmental Level Battelle Developmental Inventory (Newborg et al., 1984)	Verbal	Medical Diagnosis
1	16	Profound Multiple Disabilities	1 year, 8 months	No	Anoxic enchalopathy, visually impaired, spastic quadriplegic cerebral palsy, scoliosis, seizure disorder, gastrostomy
2	13	Profound Multiple Disabilities	1 year, 1 month	No	Anoxic brain injury, visually impaired, cerebral palsy, scoliosis, seizure disorder, Trachael Malacia, gastrostomy
3	20	Profound Multiple Disabilities	1 year, 4 months	No	Cerebral palsy, visual impairment, hearing impairment, scoliosis, seizure disorder, gastrostomy
4	20	Profound Multiple Disabilities	1 year, 6 months	No	Hypoxic ischemic encephlopathy, visually impaired, spastic cerebral palsy, scoliosis, seizure disorder, gastrostomy

Setting

The students resided in an intermediate care facility for children with severe mental and physical disabilities, as well as complex health needs located in Southeastern Virginia. Each student received educational services in a regional public day school

program housed within the residential facility. Two students received their education in a self-contained classroom for middle school students (Classroom A), while the remaining two students received their education in a high school, self-contained classroom (Classroom B). In Classroom A, the population dynamic included nine students diagnosed with severe/profound mental retardation and significant physical disabilities, and three teaching staff members. The students ranged in age from 13 to 17 years of age. Educational staff assigned to Classroom A included one special education teacher and two paraprofessionals. The special education teacher had a Master's Degree in special education, with an endorsement to teach students with severe/profound disabilities, grades K-12. Classroom B consisted of eight students, ages 17 to 21, diagnosed with severe/profound mental retardation and significant physical disabilities. Educational staff assigned to the classroom consisted of one special education teacher and three paraprofessionals. The special education teacher had a Master's Degree in special education, with endorsements in severe/profound disabilities and family life education, grades K-12. In addition to educational staff, both classrooms were regularly visited by support staff including: physical therapists, occupational therapists, speech therapists, and nursing staff.

The research study was conducted during a five week summer school program. The summer schedule of instruction began two weeks after the conclusion of the regular school year term. During the summer sessions, classes met Monday through Thursday, from 9am until 1pm. Summer school instruction centered on a combination of functional skill goals derived from each student's individualized education plan (IEP) and from pre-academic skill goals outlined by the Aligned Standards of Learning (ASOL) (Virginia

Department of Education, 2009). In Virginia, the ASOL (Virginia Department of Education, 2009) represent the standard guidelines on which pre-academic and academic instruction for students with severe or profound multiple disabilities is based. In this regional day school program, actual instructional time is spent teaching a combination of pre-academic skills and functional skills, while engaging in the delivering of self-care (e.g., feeding, positioning, grooming, etc.).

Research Design

A single subject multi-element research design (Tawney & Gast, 1984) was used to examine the frequency of happiness indices across two instructional conditions, functional skills instruction and pre-academic skills instruction. Single subject investigations are often used in special education, specifically in the area of PMD due to the heterogeneous nature of the population (Horner et al., 2005). According to Horner and colleagues (2005), "single subject designs are organized to provide fine-grained, time-series analysis of change in a dependent variable(s) across systematic introduction or manipulations of an independent variable" (p. 172). A multi-element design generally is utilized when the investigation involves the rapid alteration of two or more conditions in order to determine a functional relationship between the condition(s) and the level of observed target behavior(s) (Kennedy, 2005). By using a multi-element design, the researchers were able to observe and collect data on "multiple direct replications of the experimental effect within a participant over a brief period of time" (Kennedy, 2005, p. 137).

Independent Variables

For this multi-element research study, there were two independent variables or conditions. The first condition involved classroom instruction for students with pervasive multiple disabilities (PMD) that focused on pre-academic skills. For example, during this instructional condition, students were instructed in pre-literacy skills (i.e., sight word identification, phonics), and pre-numeracy skills (i.e., one-to-one correspondence, shape identification, calendar). Activities in which pre-academic instruction were taught included homeroom, morning report, reading circle, and math group. The second condition focused on teaching the participants skills from a functional life curriculum. During this instructional condition, teaching focused on self-help (i.e., feeding, dressing), range of motion (massage, exercising), and independent living skills (i.e., communication, choice-making). Classroom staff delivered instruction of these skills during activities such as massage, homeroom, recess, and lunchtime.

Dependent Variables and Data Collection Procedures

Dependent variables. Target behaviors were observable responses generally associated with subjective indices of happiness that are applicable across various conditions. The definition of happiness established by Green and Reid (1996; 1999) was utilized as a basis for determining appropriate indices of happiness for these participants. Green and Reid (1996) define happiness as "any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities (e.g., smiling, laughing and yelling while smiling)" (p. 69). Additionally, specific behaviors such as: clapping, hand wringing, hopping in wheelchair, arm waving, singing, dancing, and head twirling are considered as indicators of happiness among people with

PMD by other researchers (Lancioni et al., 2005; Singh et al., 2004; Yu et al., 2002) and, therefore, were included in the operational definition for this research.

As per annual requirements, teachers administered program specific communication assessments and completed student profile summaries for each of the four participants included in the study. According to the teacher completed communication assessment, Student 1 communicated that she enjoys an activity or interaction with smiles, vocalizations, and laughter. In addition, she will turn her head toward the pleasurable activity, make direct eye contact with teaching staff initiating the activity, and/or relax her upper extremities in order to participate in the activity. Student 2 communicated that she enjoyed activities or interactions with vocalizations, smiles, and laughter. In addition, she will raise her arms, and/or turn her head toward the desirable activity or interaction. According to teacher reports, Student 3 uses smiles and vocalizations to indicate that she is happy and enjoying an activity. Furthermore, she relaxes her upper extremities, opens her mouth, and/or turns her head toward a favorable person or activity. Student 4 communicates enjoyment with smiles and laughter. In addition, when she visually attends, reaches out with her left hand, and/or rocks forward and backward, she is also expressing pleasure. Table 3 contains a summary of target behaviors that were considered representative of indices of happiness for each participant as determined by teacher assessments prior to the initiation of the study.

Table 3

Student Indices of Happiness

Student	Classroom	Indices of Happiness
1	A	Smiling, laughing, vocalizing, reaches out with left hand, visually attends, maintains eye gaze, rocking motion
2	A	Smiling, vocalizing, relaxing, laughing, turning her head towards a person/activity while opening her mouth
3	B	Smiling, vocalizing, laughing, turning head towards person, raising her arms, remaining calm, keeping eye contact
4	B	Smiling, vocalizing, laughing, turns head towards the face of person interacting with her, relaxes extremities, opens eyes and maintains eye gaze

Data collection. Data were collected on the occurrence of the target behaviors described in Table 3 during the 10-min observation. The observation recording system consisted of a 10-sec partial-interval recording procedure. Each 10-sec observation interval was separated by a 5-sec interval during which data were recorded utilizing a paper and pencil data collection method. In order to minimize disruption to the classroom, each observer wore one ear plug attached to a Sony IC recorder which had been pre-recorded with a soft chime alarm to time the 15-sec intervals. Data for each participant were collected in ten minute sessions which occurred six times a day (three times per classroom), four days per week. Two research assistants were employed to conduct the in-class direct observations. Observer NK was an employee of the residential

facility as a member of the evening program staff. As such, she had extensive experience working with this population of students. Observer JF was a weekly volunteer of the residential facility and also had knowledge of the population.

Interrater Reliability and Procedural Fidelity

Interrater reliability. Prior to the initiation of the direct observation sessions, the primary investigator and the two observers met with the classroom teachers to discuss each participant. Specifically, teachers relayed information regarding the methods each student used to communicate pleasure, discomfort, and frustration. Following this meeting, the observers were trained using each student participant. Although one observer was responsible for only two participants, both observers were trained on the indices of happiness exhibited by all four participants. Primarily, observers were trained using a one minute "call-out" technique. During this training, both the observers and the primary researcher called out and recorded each occurrence of an indicator of happiness. Interrater reliability checks on the data collected by the two observers were calculated using the exact method, meaning that the records from these observations were compared point-by-point (Reinhartsen, Garfinkle, & Wolery, 2002). The total number of agreements between the two observers was divided by the number of disagreements between the two observers and the resulting quotient was multiplied by 100%. Initial reliability checks placed interobserver agreement at approximately 50%. Kennedy (2005) stated that when conducting single-subject research, interrater reliability above 85% is considered acceptable levels of agreement. Interobserver agreement checks continued throughout the study to ensure reliability remained above 85%. As stated by Kennedy (2005), interrater reliability checks should be conducted on a minimum of 25% of total

observation sessions. In the present study, interrater reliability checks were conducted on 26% of all observations, encompassing both conditions for each participant. Overall agreement for individual student happiness indices averaged at least 96% for each student, with some variability among participants, averaging 98%, 96%, 95%, and 96% for Student 1, Student 2, Student 3, and Student 4, respectively.

Procedural fidelity. Two times per week, the primary investigator and the school principal went into the participating classrooms to conduct procedural fidelity checks. This inspection took place to verify the nature of instruction that was occurring in the classroom during the observation session. Days and times of procedural fidelity checks were varied across each classroom, with checks occurring in both the morning and afternoon and occurring at least once each day of the week over the five week period. Utilizing a checklist (see Appendix A), the primary investigator and principal independently observed the classroom activity in progress for 1-min to determine if the instruction being delivered encompassed functional life skills instruction or pre-academic skills instruction. These checklists were then compared to the instructional condition noted on each of the observer's data collection forms to ensure agreement across all parties regarding the type of instruction being delivered at that specific time. Procedural fidelity checks remained at 100% throughout the investigation.

Controlling for Threats to Validity

Internal validity. Several steps were taken to ensure the internal validity of this investigation. In an attempt to minimize research effects and bias that could occur during observations and data entry, four additional individuals were employed to assist the primary investigator in data collection, interpretation, and input. Two research observers

were enlisted to conduct all direct classroom observations and data collection. Throughout the study, both data collectors were unaware of specific research question under investigation. In addition, two individuals were recruited to analyze and input all data collected on a weekly basis. Each week, the primary investigator reviewed all data entered to look for any data entry errors. Again, data entry personnel were not given information regarding the specific research question. Furthermore, participating classroom teachers were not given specific details regarding the investigation or the target behaviors being observed.

Next, the primary investigator took measures to control maturation effects and attrition. Maturation effects were monitored through careful and thorough documentation of any events and alterations that affected the student participants, teaching staff, and/or classroom environment. Attrition was not a factor since all four students attended school every day and successfully completed the entire five-week summer school program. In addition, teaching staff remained consistent in both classrooms and all personnel were present each day.

Finally, to control for interaction effects between instructional condition and time of day, as well as between instructional condition and teaching staff, the delivery and observation of both instructional conditions were counterbalanced across days, times, and teaching staff. See Appendix B for the observation and instruction schedule. By counterbalancing across conditions, the primary investigator was attempting to equally distribute possible interactions across both conditions. Therefore, the expectation is that if interaction effects arise, they are the product of an uncontrolled process that emerged within the established experimental procedure (Kennedy, 2005).

External validity. Controlling external validity is a formable challenge when utilizing single-subject research designs. External validity can be enhanced by having a sufficient number of participants (at least three) in the study (Horner et al., 2005). This single-subject study fits this model as it incorporated four participants. In addition, some external validity was demonstrated by the experimental effects that were replicated across settings and participants. The investigation participants included four students from diverse age groups who received instruction in two different classrooms settings.

Procedure

Initially, the primary researcher met with the program director, assistant director, and school principal to provide basic information regarding the execution of the investigation. Next, the primary researcher held a brief informational meeting for the classroom staff of both Classrooms A and B. Finally, with the assistance of the principal and classroom teachers, an observation schedule was established to optimize opportunities to observe and collect data during both instructional conditions. According to Kennedy (2005), this multi-element research design did not require baseline data collection since the effect of the two pre-existing instructional conditions were being observed to determine if a functional relationship existed between each condition and the participants observed indices of happiness.

Condition 1. During this condition, each participant was engaged in classroom instruction that focused primarily on pre-academic skills. For the duration of this instructional condition, students were instructed in pre-literacy skills (i.e., sight word identification, phonics), pre-numeracy skills (i.e., one-to-one correspondence, shape identification, calendar), and basic science facts (i.e., five senses, weather). Activities in

which pre-academic instruction were taught included homeroom, morning report, reading circle, and math group. During these classroom activities, each student participated in large group, small group, and one-on-one instruction with all three members of the teaching staff. Instruction in this condition lasted for 60-min, one time per school day. The pre-academic period of instruction was scheduled in Classroom A (Students 1 & 2) from 10:00 am until 11:00 am, whereas this instruction was scheduled to occur from 11:00 am to 12:00 am in Classroom B (Students 3 & 4).

Condition 2. During this condition, each participant received instruction which was predominantly centered upon functional life skills. Throughout this instructional condition, the teaching staff focused primarily on self-help (i.e., feeding, dressing), motor (i.e., range of motion, massage), and independent living skills (i.e., communication, choice-making). Classroom staff delivered instruction in functional life skills during activities such as massage, homeroom, recess, reading group, and computer circle. During these activities, the teacher would concentrate instruction on individualized education program (IEP) goals pertaining to adaptive behavior, communication, social skills, and independent living. The majority of instruction delivered during this condition occurred via small group or one-to-one instruction. As before, all members of the teaching staff from each classroom were actively engaged in delivery of instruction which occurred in a 60-min block, one time per school day. The functional life skills period of instruction was scheduled in Classroom B (Students 3 & 4) from 10:00 am until 11:00 am. In contrast, this instruction was scheduled to occur from 11:00 am to 12:00 am in Classroom A (Students 1 & 2). Appendix C provides more detailed descriptions of specific activities that occurred during both conditions.

CHAPTER 4: RESULTS

The purpose of this investigation was to evaluate a potential link between teaching pre-academics and an improvement in quality of life for students with profound multiple disabilities (PMD). Specifically, the following research question was investigated: What is the influence of teaching pre-academics on the quality of life of adolescent students with profound multiple disabilities as measured by established indices of student happiness?

Agreement

Fidelity of delivery of instructional conditions. Procedural fidelity checks for instructional condition began during the first week of direct classroom observations and they continued at a rate of two times per week throughout the five week observation period. These fidelity checks were completed by both the primary investigator and the school principal. Utilizing a checklist (see Appendix A), the primary investigator and principal observed classroom instruction as it was being delivered to determine if the instruction encompassed functional life skills instruction or pre-academic skills instruction. These checklists were then compared to the instructional condition noted on each of the observer's data collection forms to determine the occurrence of agreement across all parties regarding the type of instruction being delivered at that specific time. Results of procedural fidelity for instructional condition are presented in Table 4.

Table 4

Procedural Fidelity for Each Instructional Condition

Week	Session	Classroom	Time	Inter-rater reliability	Instructional Condition Observed
1	1	A	10:12am	100%	Pre-academic
	2	B	10:15am	100%	Functional
	3	A	11:45am	100%	Functional
	4	B	11:47am	100%	Functional
2	5	A	10:30am	100%	Pre-academic
	6	B	10:35am	100%	Pre-academic
	7	A	11:00am	100%	Functional
	8	B	11:03am	100%	Functional
3	9	A	10:05am	100%	Functional
	10	B	10:10am	100%	Functional
	11	A	11:37am	100%	Functional
	12	B	11:40am	100%	Functional
4	13	A	10:15am	100%	Pre-Academic
	14	B	10:17am	100%	Functional
	15	A	11:50am	100%	Functional
	16	B	11:53am	100%	Functional

Inter-rater reliability for student data. A total of 202, 10-min sessions were observed by the data collectors over the five week data collection period. Inter-rater reliability data was collected during 52, or 26% of observation sessions. Twenty-seven inter-rater reliability checks occurred in each classroom, with 43.1% occurring during the pre-academic skills instructional condition and 56.9% occurring during the functional skills instructional condition. To calculate inter-observer agreement, the total number or agreements between the two observers was divided by the number of disagreements between the two observers and the resulting quotient was multiplied by 100% (Reinhartsen et al., 2002). Overall agreement for individual student happiness indices ranged from 90%-100% with a mean of 96.3%. Inter-rater reliability agreement data indicated slight variability across the four participants. Inter-rater reliability for Student 1 ranged from 97%-100%, with a mean of 98.3%; Student 2 ranged from 92%-100%, with a mean of 96.8%; Student 3 ranged from 90%-100%, with a mean of 95.0%; and Student 4 ranged from 90%-100%, with a mean of 96.8%.

Instructional Condition Data

Figure 1 presents the total number of observed sessions, per instructional condition for each participant. Each participant received instruction during both functional skills and pre-academic skills instruction. In addition, each participant experienced instructional sessions that were categorized as a missed session. A missed session was defined as one in which participants were engaged in activities unrelated to the two target instructional conditions (i.e., personal care, dozing, medical intervention).

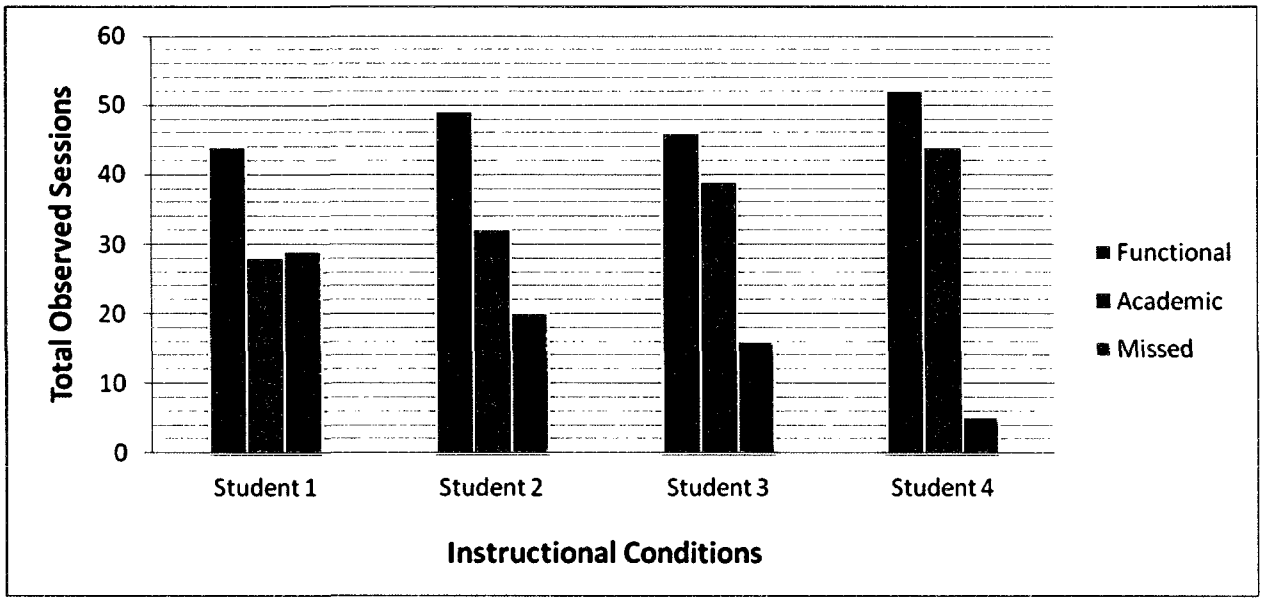

Figure 1. Total number of observation sessions for each participant.

Participant Data

Student 1. Student 1's observed indices of happiness are displayed in Figure 2. Student 1 was observed across 101 observation sessions, 44 (43.6%) of which occurred during functional skills instruction and 28 (27.7%) during pre-academic skills instruction. The remaining 29 (28.7%) of the observation sessions were excluded because the student was either engaged in personal care activities, such as toileting and medical procedure, or dozing. Student 1 displayed a total of 1130 behaviors defined as indicators of happiness, 651 during the functional skills instructional condition and 479 during the pre-academic skills instructional condition. The range of happiness indices for functional skills and pre-academic skills instruction sessions were 0-31 and 0-29, respectively. Visual inspection of Figure 2 reveals variability across the sessions, with a level trend for happiness

indicators during functional skills instruction and a minimal decreasing trend for pre-academic skills instruction

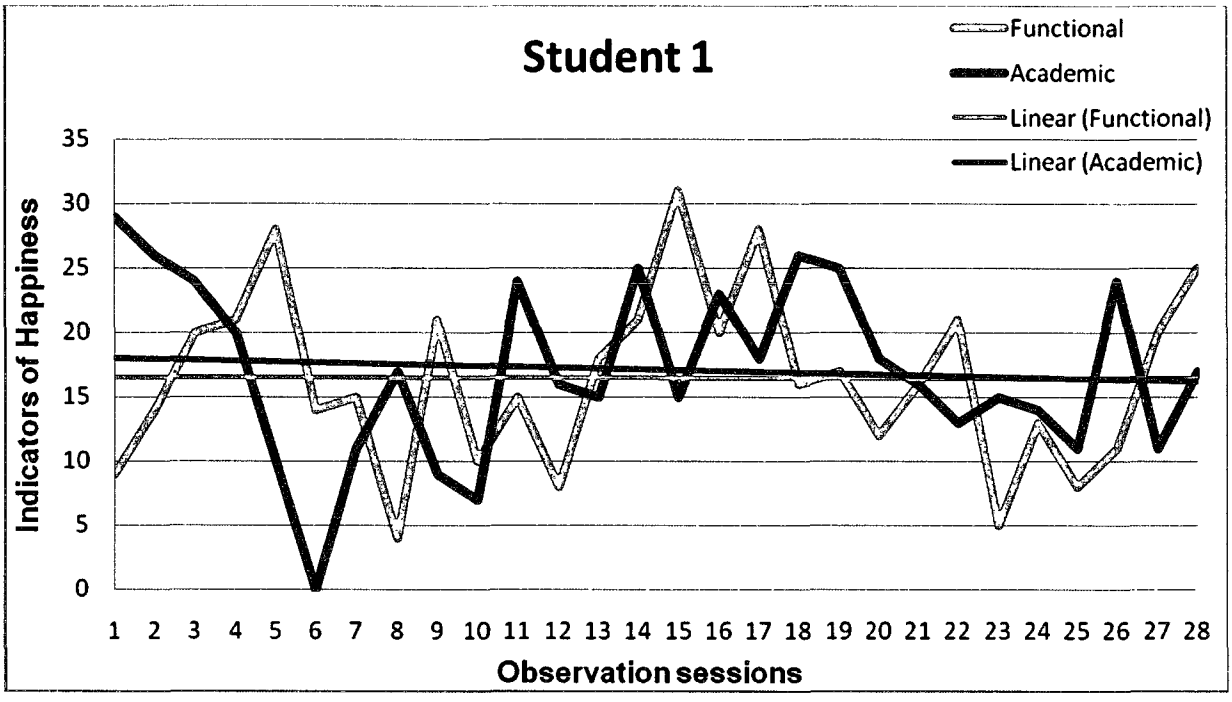

Figure 2. Total frequency of indicators of happiness per observation session for Student 1.

Student 2. Observed indices of happiness for Student 2 are displayed in Figure 3. Student 2 was observed across 101 observation sessions, 49 (48.5%) of which occurred during functional skills instruction and 32 (31.7%) occurred during pre-academic skills instruction. The remaining 20 (19.8%) of the observation sessions were considered missed opportunities because the student was either engaged in personal care activities, such as toileting and medical procedure, dozing, or receiving medical attention due to the occurrence of seizures. Student 2 displayed a total of 510 behaviors defined as indicators of happiness, 246 during the functional skills instructional condition and 264 during the pre-academic skills instructional condition. The range of happiness indices per session for

functional skills and pre-academic skills instructional conditions were 0-13 and 0-27, respectively. Visual inspection of Figure 3 reveals variability across the sessions, with an increasing trend for happiness indicators during functional skills instruction and a decreasing trend for pre-academic skills instruction.

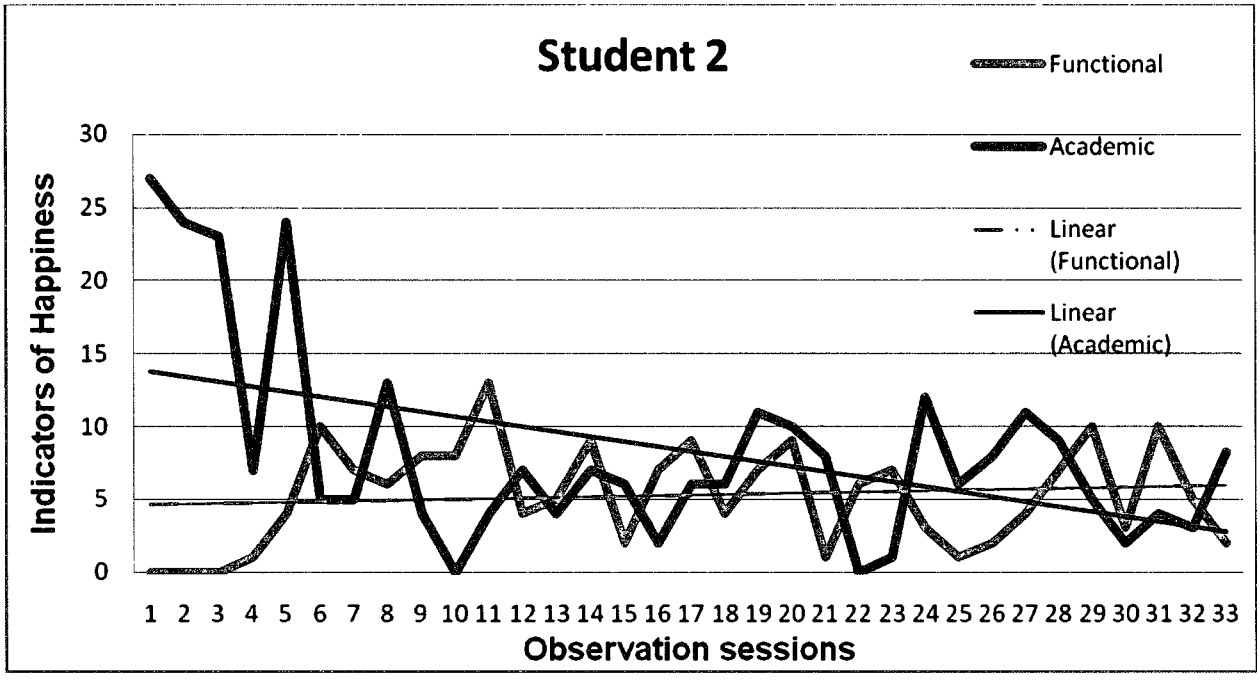

Figure 3. Total frequency of indicators of happiness per observation session for Student 2.

Student 3. The data representing the observed indices of happiness for Student 3 are displayed in Figure 4. During 101 observation sessions, Student 3 was observed during 46 (45.6%) functional skills instruction sessions and 39 (38.6%) pre-academic skills instruction sessions. Student 3 missed 16 (15.8%) instructional sessions because she was either engaged in personal care activities, such as toileting and medical procedure, or dozing. Student 3 displayed a total of 1054 behaviors defined as indicators of happiness, 446 during the functional skills instructional condition and 608 during the pre-academic skills instructional condition. The range of happiness indices for functional

skills and pre-academic skills instruction sessions were 1-29 and 3-39, respectively. Visual inspection of Figure 4 reveals variability across the sessions, with a minimal increasing trend for happiness indicators during functional skills instruction and a moderate decreasing trend for pre-academic skills instruction.

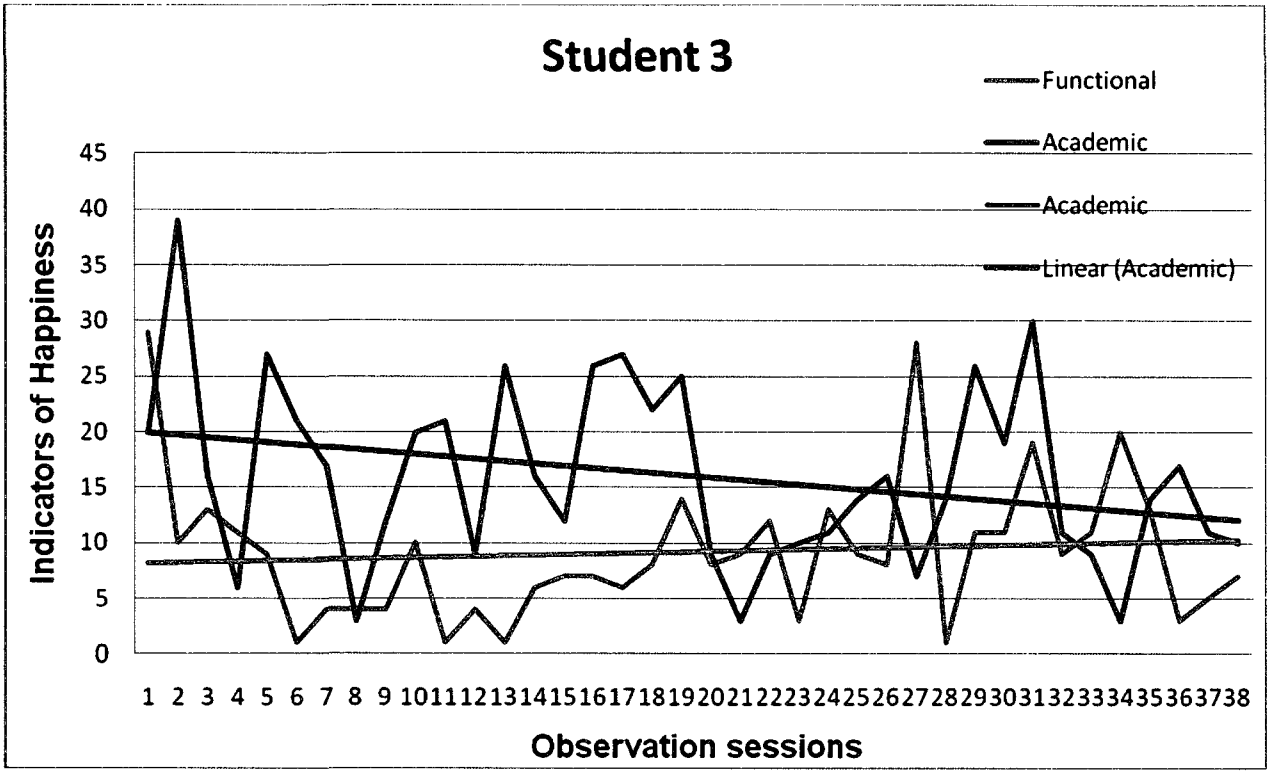

Figure 4. Total frequency of indicators of happiness per observation session for Student 3.

Student 4. Student 4 observed indices of happiness are displayed in Figure 5. Student 4 was observed across 101 observation sessions, 52 (51.5%) of which occurred during functional skills instruction and 44 (43.6%) occurred during pre-academic skills instruction. The remaining 5 (4.9%) observated sessions were excluded because the student was engaged in personal care activities such as toileting or medical procedures. Student 4 displayed a total of 448 behaviors defined as indicators of happiness, 183 during the functional skills instructional condition and 265 during the pre-academic skills

instructional condition. The range of happiness indices for functional skills and pre-academic skills instruction sessions were 0-20 and 0-25, respectively. Visual inspection of Figure 5 reveals variability across the sessions, with a decreasing trend noted for happiness indicators during both functional skills instruction and pre-academic skills instruction.

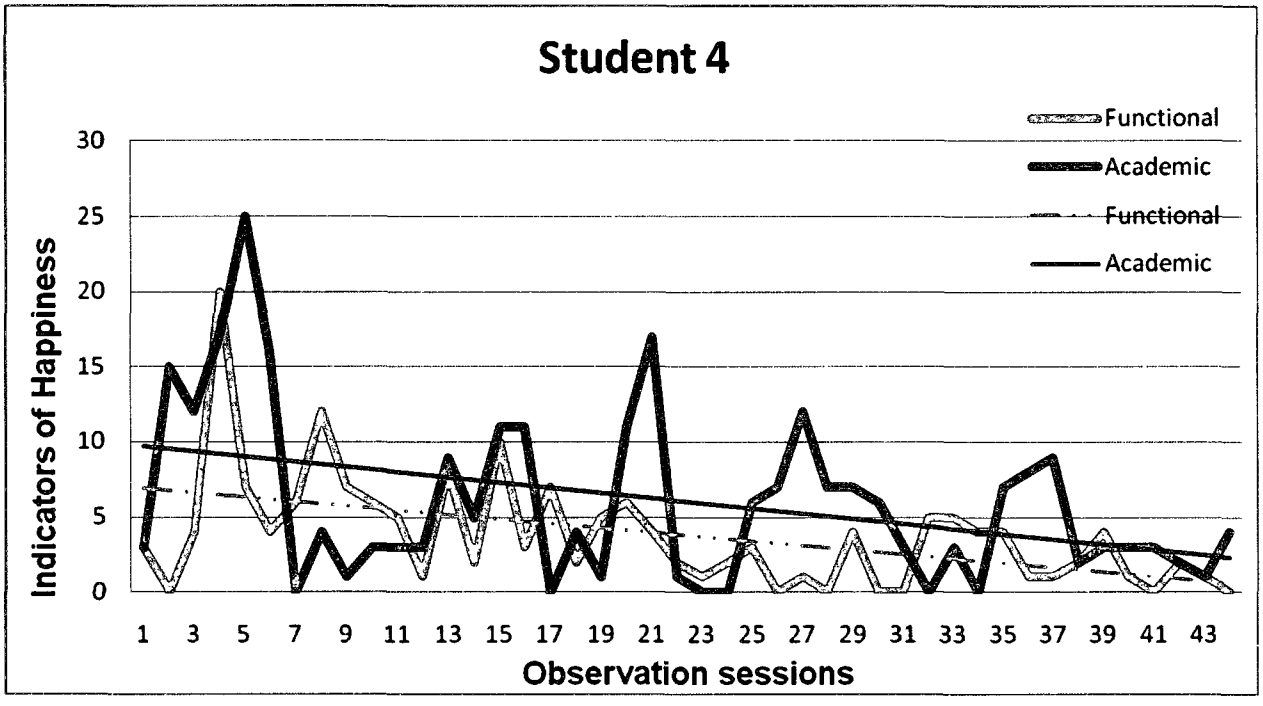

Figure 5. Total frequency of indicators of happiness per observation session for Student 4.

Total indices of happiness. Table 5 demonstrates the mean percentage of indices of happiness per observed session for all participants. For Student 1, a comparison of happiness levels between the functional skills instructional condition and the pre-academic skills condition indicated that happiness indices were slightly higher during the pre-academic instructional condition (17.1% vs. 14.8%). A comparison of happiness levels between the functional skills instructional condition and the pre-academic skills condition for Student 2 indicated that happiness indices were marginally higher during

academic skills condition indicated that happiness indices were considerably higher during the pre-academic instructional condition (15.9% vs. 9.7%). A comparison of happiness levels between the functional skills instructional condition and the pre-academic skills condition for Student 4 indicated that happiness indices were substantially higher during the pre-academic instructional condition (6.02% vs. 3.52%).

Table 5

Mean Percentage of Indices of Happiness

Student	Total Indices of Happiness		Total Observed Sessions			Mean Percentage of Indices of Happiness	
	Functional	Pre-academic	Functional	Pre-academic	Missing	Functional	Pre-academic
1	651	479	44	28	29	14.8%	17.1%
2	246	264	49	32	20	5.0%	8.3%
3	446	608	46	39	16	9.7%	15.9%
4	183	265	52	44	5	3.5%	6.0%

CHAPTER 5: DISCUSSION

Summary of Findings

The purpose of the present study was to evaluate if a link existed between teaching pre-academics skills and an increase in the quality of life for students with profound multiple disabilities (PMD). To guide the investigation, the following research question was proposed: What is the influence of teaching pre-academics on the quality of life of adolescent students with profound multiple disabilities as measured by established indices of student happiness?

In general, this study provides results that are consistent with previous studies. The findings of this study demonstrated a potential relationship between pre-academic skills instruction and increased occurrence of indices of happiness. For all four participants, the mean percentage of indices of happiness for total observed sessions was higher during the pre-academic skills instruction condition than in the functional skills instruction condition. Specifically, the results demonstrated by Students 3 and 4 may be the most representative since these participants received fairly balanced instruction in both conditions. Student 3 demonstrated happiness indices of 9.7% during 46 functional skills condition observations compared to measured happiness indices of 15.9% during 39 pre-academic functional skills observation sessions. Likewise, Student 4 demonstrated happiness indices of 3.5% during 52 functional skills condition observations compared to measured happiness indices of 6.0% during 44 pre-academic functional skills observation sessions. As reported in previous investigations (e.g., Davis et al., 2004; Green & Reid, 1996, 1999; Ivancic et al., 1997), instructional conditions in which participants were exposed to preferred activities tended to elicit greater measurable

indices of happiness than during activities that involved non-preferred stimuli. Results from the present study regarding the comparing of pre-academic and functional skills instruction seem to suggest that teaching pre-academic skills results in increased indices of happiness for some students with PMD, implying that this mode of instruction was preferred by the four participants in the present study. The major reason to apply quality of life concepts to research for individuals with PMD is to determine if increasing instruction in these concept areas enhances students' satisfaction and overall well-being (Schalock et al., 2002). Because the participants in this study displayed higher indices of happiness during the pre-academic instructional condition, the results suggest that there are likely benefits for teaching pre-academic and/or academic content to students with PMD.

Presently, special educators are challenged with creating and implementing effective educational strategies to teach students with PMD. Historically, the majority of research conducted with individuals with PMD examined variables that affected skill acquisition with little attention to assessing the broader concern of the individual's quality of life (Davis et al., 2004). This study sought to establish a potential link between increased quality of life and the teaching of pre-academic/academic to students with PMD by documenting the potential positive impact of this instruction. As indicated by Agran and colleagues (2002), one of the primary reasons why special education teachers prefer not to pre-academic and/or academic content to students with PMD was the inability to determine the potential gains of teaching this material. Although the sample size was small, the results of the present study suggest that some students with PMD who receive pre-academic instruction may experience an overall increase in quality of life, as

indicated by increased indices of happiness. As such, this study seems to suggest that one benefit of teaching pre-academic skills to students with PMD is that they enjoy it and express a higher rate of happiness during the instructional interactions with their teachers. It may be that this pleasant exchange could increase positive social interactions within the school setting, increase communication skills, and improve post school outcomes. In addition, delivering instruction in pre-academic skills may be another tool to increase the overall quality of life of students with PMD by engaging them in desired activities (Browder et al., 2007; 2009).

The results of this study are consistent with results found in the literature regarding the daily routines of individuals with PMD. For example, Lyons (2005) reported that the daily routine of a child with PMD is characterized by frequent, extended periods of direct care interactions followed by shorter periods of independent activities. This study also found that the majority of instructional time in the targeted classrooms used for this study focused on direct care interactions (i.e., toileting, medical intervention), functional skills instruction including self-help (i.e., feeding, dressing), range of motion activities (i.e., massage, exercising), and independent living skills (i.e., communication, choice-making). Despite counterbalancing both instructional conditions equally prior to the initiation of data collection, pre-academic instruction occurred in less of than 43% of observed sessions for all participants. Overall classroom instruction targeting the aforementioned conditions averaged 65% for all participants, with some variability among participants, averaging 72%, 68%, 62%, and 57% for Student 1, Student 2, Student 3, and Student 4, respectively. The potential for many individuals with PMD to spend a substantial amount of time involved in these non-stimulating self-care

routines may lead to a weakened sense of well-being and personal satisfaction. It appears that special educators should concentrate their teaching efforts on areas that enhance the quality of life of students with PMD. This new dual focus may mean balancing instructional time between pre-academic and/or academic skills instruction and functional skills instruction.

Limitations

Although the results of this investigation may be encouraging to those who consider pre-academic skills instruction useful for students with PMD, some limitations should be noted. The small sample size of the participants and the fact that all participants received instruction in self-contained classrooms housed within the same regional public day school program limits the generalizability of the findings. Horner and colleagues (2005) stated that in order to meet criteria for an evidence-based practice, the investigation should be replicated using more students of varying ages and must be completed across classroom placements. This study represents initial research in a potential body of work related to the effects of teaching pre-academic/academic skills on the quality of life of students with PMD.

Secondly, due to the nature of the regional public day school summer program in which the study was conducted, the total investigation encompassed five weeks of instruction. This time restraint made it difficult to perform maintenance probes. It would have been beneficial to continue the observations in order to determine if the indices of happiness trends demonstrated during both instructional conditions remained consistent over time.

A third limitation was a lack of guidance given to the teachers regarding the delivery of instruction during both conditions. This stipulation fulfilled a necessary arrangement constituted by the school program. The teachers were encouraged to conduct classroom activities in the methods they deemed appropriate and had used previously with the participants. For example, one teacher may have utilized small group instruction for pre-academic instruction but used one-on-one instruction for functional skills instruction. Therefore, an uncontrolled variable could be the teacher's chosen method for delivering instruction and the teaching style utilized.

A fourth limitation of the study was the inability to observe instructional conditions equally. Despite initial planning with the principal and classroom teachers regarding the classroom schedule, uncontrolled circumstances arose that altered the classroom schedule. In some cases, participants arrived late to school or medical staff removed students from the classroom for treatment. Overall, as the classroom schedule was altered, instruction in pre-academic skills was shortened resulting in more observation sessions (65%) occurring during the functional skills instruction condition.

A final limitation was the lack of subjective measures of happiness. Because of the communicative abilities of the participants, they were not able to self-report indices of happiness. Therefore, the investigation reported only objective indices of happiness. Although researchers (e.g., Cummins, 2001; 2002; Petry et al., 2005; Schwartz, 2005) have determined proxy reports (objective) to be valid as a means of interpreting another individual's level of happiness, it is recommended that researchers attempt to measure both subjective and objective indicators simultaneously when assessing the quality of life of individuals with PMD when possible (Schalock et al., 2008). For example, subjective

self-report measures in which individuals responded in their desired mode of communication (i.e., eye gaze, augmentative communication, picture symbols, etc.) would be supplemented with objective measures, such as direct observation or proxy report.

Implications and Recommendations for Future Research

The results of this study indicate that students with PMD experience higher rates of happiness when they are receiving pre-academic instruction then when they are receiving functional life skills instruction. Assuming these findings are representative, special educators should attempt to concentrate their efforts on identifying and planning for positive quality of life opportunities for students with PMD, while determining which educational strategies provide the most appropriate access and participation in the general education curriculum as determined to be individually suitable (Green et al., 1997; Lancioni et al., 2005; Petry et al., 2007). Future research should focus on the implications of teaching all skill areas, including pre-academics skills, academic skills, and functional life skills with techniques such as positive interactions and allowing personal choice which have the potential to increase indices of happiness and overall quality of life. As Agran and colleagues (2002) stated, practitioners, including special educators, in the field of PMD have conflicting views regarding the potential benefits of teaching pre-academic and/or academic content to students with PMD. This study suggests that one potential benefit is that this kind of instruction has the potential to increase the happiness level of the students which could positively influence their overall quality of life. Future research should continue to address not only access to the general education curriculum for students with PMD, but also focus on specific aspects of various instructional strategies

and conditions that impact students' overall quality of life. In order to do this, special educators will need to utilize the results of effective quality of life assessment tools for students with PMD when planning and implementing appropriate instructional strategies. Finally, future research should consider the design and implementation of an educational curriculum for students with PMD that directly combines content from both pre-academic/academic curriculum and functional life skills. Rather than continuing to teach these skills in isolation, the combination of these two curricula may present a more effective teaching model as it would address both critical skill areas while potentially maintaining higher levels of engagement and interaction among students with PMD.

To date, there is a scarcity of assessment tools available to measure the quality of life of individuals with PMD (Ross & Oliver, 2003). Future research in the field of quality of life should continue to address issues connected to the lack of valid measurement tools to assess the quality of life of individuals with PMD. The debate among researchers regarding the use of proxy versus self-report remains a key point of contention, as many feel that proxy reporting is not a reliable or valid method of collecting quality of life data (Verdugo et al., 2005). However, in order to prevent the exclusion of individuals who may not be able to self-report due to a lack of functional communication skills, the use of proxy respondents should continue for people with PMD. In addition, quality of life measurement tools must continue to utilize a multi-dimensional approach that encompasses both objective and subjective measures (Schalock, 2004). The exclusive use of one measuring method will inevitably exclude this population, thereby ignoring their views and opinions which, in the past, have

contributed to gains in the areas of mental health and behavioral health for individuals with PMD (Perry & Felce, 2002; Reiter & Schalock, 2008).

A final implication for future research in the field of PMD is the dearth of research that applies quality of life concepts to educational reform. Once effective and teacher friendly ways to assess student quality of life are developed, the results of these assessments can be used as a criterion against which to evaluate the effectiveness of special education programming (Lancioni et al., 2007; Lyons et al., 2005; Reiter & Schalock, 2008).

Conclusion

In recent years, perceptions have moved from a deficit to a competence-based perspective for students with PMD. Regardless of the severity of the individual's disabilities, educators are now considering an individual's overall capabilities, preferences, and engagement in activities when developing appropriate interventions. Focusing on and enhancing the strengths and capabilities of these individuals may offer them additional opportunities to have meaningful, and pleasurable, participation in school and, in turn, more positive educational outcomes. As such, by identifying classroom activities and procedures that result in an increase in student quality of life indicators such as happiness and self-determination, educators could begin to adapt and design skill acquisition activities to make them more enjoyable for the student. Finally, by using quality of life indicators when designing programs, special educators may be more likely to successfully decrease the potential unpleasantness of school while increasing skill acquisition, happiness, and self-determination.

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Appendix A

Curriculum Verification Form

Class:_____ **Time:**_____
Date:_____

Current Activity Focus: **Academic** ☐ **Functional** ☐

Signature:_____

Class:_____ **Time:**_____
Date:_____

Current Activity Focus: **Academic** ☐ **Functional** ☐

Signature:_____

Class:_____ **Time:**_____
Date:_____

Current Activity Focus: **Academic** ☐ **Functional** ☐

Signature:_____

Class:_____ **Time:**_____
Date:_____

Current Activity Focus: **Academic** ☐ **Functional** ☐

Signature:_____

Appendix B

Observer/Instructional Condition Schedule

Day	Classroom A= Students 1 & 2 B= Students 3 & 4	Academic skills				Functional skills	
1 6/29	A	Training				Training	
	B						
2 6/30	A	Training				Training	
	B						
3 7/1	A	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50	11:50-12:00
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50	10:50-11:00
4 7/2	A	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50	11:50-12:00
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50	10:50-11:00
5 7/6	A	10:30-10:40	10:40-10:50	10:50-11:00	11:00-11:10	11:10-11:20	11:20-11:30
	B	11:30-11:40	11:40-11:50	11:50-12:00	10:00-10:10	10:10-10:20	10:20-10:30
6 7/7	A	10:30-10:40	10:40-10:50*	10:50-11:00*	11:00-11:10	11:10-11:20	11:20-11:30
	B	11:30-11:40	11:40-11:50*	11:50-12:00*	10:00-10:10	10:10-10:20	10:20-10:30
7 7/8	A	10:30-10:40	10:40-10:50	10:50-11:00	11:00-11:10	11:10-11:20	11:20-11:30
	B	11:30-11:40	11:40-11:50	11:50-12:00	10:00-10:10	10:10-10:20	10:20-10:30
8 7/9	A	10:30-10:40	10:40-10:50	10:50-11:00	11:00-11:10	11:10-11:20*	11:20-11:30*
	B	11:30-11:40	11:40-11:50	11:50-12:00	10:00-10:10	10:10-10:20*	10:20-10:30*
9 7/13	A	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50	11:50-12:00
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50	10:50-11:00
10 7/14	A	10:00-10:10	10:10-10:20*	10:20-10:30*	11:30-11:40	11:40-11:50	11:50-12:00
	B	11:00-11:10	11:10-11:20*	11:20-11:30*	10:30-10:40	10:40-10:50	10:50-11:00
11 7/15	A	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50	11:50-12:00
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50	10:50-11:00

Day	Classroom A= Students 1 & 2 B= Students 3 & 4	Functional skills			Academic skills		
12 7/16	**A**	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50*	11:50-12:00*
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50*	10:50-11:00*
13 7/20	**A**	10:30-10:40	10:40-10:50	10:50-11:00	11:00-11:10	11:10-11:20	11:20-11:30
	B	11:30-11:40	11:40-11:50	11:50-12:00	10:00-10:10	10:10-10:20	10:20-10:30
14 7/21	**A**	10:30-10:40	10:40-10:50*	10:50-11:00*	11:00-11:10	11:10-11:20	11:20-11:30
	B	11:30-11:40	11:40-11:50*	11:50-12:00*	10:00-10:10	10:10-10:20	10:20-10:30
15 7/22	**A**	10:30-10:40	10:40-10:50	10:50-11:00	11:00-11:10	11:10-11:20	11:20-11:30
	B	11:30-11:40	11:40-11:50	11:50-12:00	10:00-10:10	10:10-10:20	10:20-10:30
16 7/23	**A**	10:30-10:40	10:40-10:50	10:50-11:00	11:00-11:10	11:10-11:20*	11:20-11:30*
	B	11:30-11:40	11:40-11:50	11:50-12:00	10:00-10:10	10:10-10:20*	10:20-10:30*
17 7/27	**A**	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50	11:50-12:00
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50	10:50-11:00
18 7/28	**A**	10:00-10:10	10:40-10:50*	10:50-11:00*	11:00-11:10	11:10-11:20	11:20-11:30
	B	11:30-11:40	11:40-11:50*	11:50-12:00*	10:00-10:10	10:10-10:20	10:20-10:30
19 7/29	**A**	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50	11:50-12:00
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50	10:50-11:00
20 7/30	**A**	10:00-10:10	10:10-10:20	10:20-10:30	11:30-11:40	11:40-11:50*	11:50-12:00*
	B	11:00-11:10	11:10-11:20	11:20-11:30	10:30-10:40	10:40-10:50*	10:50-11:00*

* = **Interrater reliability checks** (both watch same Student at same time)

Classroom	**Days**	**Academic instruction**	**Functional skills instruction**
A	1-20	10:00-11:00	11:00-12:00
B	1-20	11:00-12:00	10:00-11:00

Appendix C

Instructional Conditions Activities

Classroom Activities	Academic Focus	Functional/Leisure focus
Reading book aloud	Teaching staff questions Students regarding characters, settings, events, etc.	Teaching staff questions Students regarding enjoyment only; reading for entertainment purposes
Computer	Working with teaching staff directly, teaching staff asking questions regarding content, purpose, function, etc. of computer program	Independent leisure activity-even if it is an educational program
Viewing a movie/Television show	Teaching staff questions Students regarding characters, settings, events, etc.	Teaching staff questions Students regarding enjoyment only; Independent leisure activity-generally conducted in coordination with massage/ROM activities
Art	Coordinated activities such as identifying shapes, colors, size, etc. Art related to academic topic-ex: bugs, weather, plant, etc. that is being taught in collaboration with art project	Art completed for enjoyment only-no academic foundation skills taught
Outside activity	Walking trip with academic focus-ex: identify bugs & plants, find items that start with letter "g", etc. Activity related to academic topic	Leisure activity engaged in for enjoyment/entertainment purposes only-ex: to get fresh air, smell the flowers, etc.
Cooking	Emphasis on measuring, weighing, etc. Cooking project directly related to academic topic-ex: making American Flag cookies while discussing Independence Day	Cooking for enjoyment only-ex: making cupcakes for classmate's birthday party

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EXPERIENCE:

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July, 1999 – June, 2006:	Teacher, Students with Severe Disabilities; REACH Program: St. Mary's Home for Disabled Children; Norfolk, Virginia

July, 1996 – July, 1999: Occupational Therapy Technician; St. Mary's Home for Disabled Children; Norfolk, Virginia. (Job responsibilities included fabricating and maintaining adaptive positioning equipment, orthotics, and assistive technology devices for 88 residents living in a long-term care facility for children with severe disabilities and complex health needs).

PUBLICATIONS:

Watson, S.M., Raver, S.A., Bobzien, J., & Gear, S. (2009). Techniques for teaching young children with mild learning and behavior problems. In S.A. Raver, *Early childhood special education (0-8 years): Strategies for positive outcomes.* (pp. 225-253). Upper Saddle River, NJ: Merrill/Pearson Publishing Co.

PAPERS PRESENTED AT PROFESSIONAL MEETINGS:

Gear, S., & Bobzien, J. "Teaching Social Skills to Enhance Work Performance: Daycare Center Case Study." Poster presented at Annual Conference of the Teacher Education Division of the Council for Exceptional Children: Dallas, TX, November 7, 2008.

Gear, S., & Bobzien, J. "De-Mystify the RTI Triangle: Responsive Early Literacy Intervention." Paper presented at the Association of Teacher Educators: Washington, D.C., August 5, 2008.

Bobzien, J., & Gear, S. "Predictors of Childhood Obesity." Paper presented at Virginia Council for Exceptional Children: Charlottesville, VA, October 16, 2007.

Raver-Lampman, S. "Perceptions of Accommodations Between University Students in Ukraine and the United States." Paper presented at the Paper presented at Virginia Council for Exceptional Children: Charlottesville, VA, October 16, 2006. (Paper given by Sabra Gear and Jonna Bobzien due to Dr. Raver-Lampman's illness.)

COURSES TAUGHT:

Characteristics of Students with Autism Spectrum Disorder
Instructional Strategies for Students with Autism Spectrum Disorder
Sensorimotor Development
Fundamentals of Human Growth and Development
Foundations of Special Education: Legal Aspects and Characteristics
Problems in Education

Instructional Design II: Curriculum Procedures & IEP/Instruction/Service Delivery for Educating Students with Mild Disabilities
The Family & Child with Special Needs: Lifespan Transitions
Teaching Students with Severe Disabilities

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2006	Teacher of the Year, St. Mary's School, REACH Program; Norfolk, Virginia
2006	Nominated, District Teacher of the Year, Norfolk Public Schools; Norfolk, Virginia
2004	Who's Who Among America's Teachers
2004	Member, All City Teaching Team, Norfolk Public Schools; Norfolk, Virginia
2004	Teacher of the Year, St. Mary's School, REACH Program; Norfolk, Virginia
2004	Nominated, District Teacher of the Year, Norfolk Public Schools; Norfolk, Virginia
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2003	Outstanding Graduate Student in Special Education, Old Dominion University; Norfolk, Virginia
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2003	Wavy TV 10 Mother of the Year, Hampton Roads, Virginia (selection criteria were based on parenting skills, employment and community service)
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K-12 Special Education, Severe Disabilities
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Editorships/Reviewing:

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University Service:

2008-present	Member, Faculty Search Committee, Special Education Department, Old Dominion University; Norfolk, Virginia
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2007-present	Member, Curriculum Development Committee, Special Education Department, Old Dominion University; Norfolk, Virginia

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