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A REVIEW OF CURRICULAR APPROACHES AND QUALITY OF LIFE INDICATORS IN THE UNITED STATES FOR INDIVIDUALS DISPLAYING PROFOUND MULTIPLE DISABILITIES

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Abstract

During the last two decades in the United States, there has been an increase in research studies on two salient areas of interests impacting individuals with profound multiple disabilities (PMD): providing access to appropriate educational curriculums and enhancing overall quality of life. Despite this interest, attempts to link positive quality of life indicators and appropriate educational curriculum for students with PMD have not been explored. The purpose of this literature review is to identify articles related to curriculum issues, as well as those addressing the importance of skill acquisition activities that lead to an improved quality of life. Implications for establishing a potential link between quality of life assessment practices and current educational practices in the United States are addressed.

***Key words:** profound multiple disabilities, academic curriculum, functional curriculum, quality of life, happiness.*

Introduction

In the past, a relatively limited amount of research in the United States has focused on the educational and functional needs of individuals with profound multiple disabilities (PMD). Individuals with PMD are those considered to be the most significantly impaired. In public schools, this small population of students encompassed children between the ages of three and twenty-one diagnosed with a combination of disabilities including: profound cognitive disabilities, severe physical impairment, substantial sensory difficulties and/or significant medical problems (Maes, Lambrechts, Hostyn, & Petry, 2007; Nakken & Vlaskamp, 2002; 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 all core areas of functioning (e.g., communication, social skills, mobility, self-help skills; Sternberg, 1994). Historically, teachers had minimal expectations regarding academic achievement of students with PMD (Agran, Alper, & Wehmeyer, 2002) and special educators often struggle with

determining appropriate methods to encourage active participation during academic tasks. Additionally, quality of life concepts, such as happiness and self-determination, were often disregarded when considering educational focus (Schalock, 2004). Recently however, the passage of several pieces of federal legislation in the United States has served as a driving force for increasing research conducted regarding 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).

In the United States in 1997, the enactment of the Individuals with Disabilities Education Act (IDEA) Amendments 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, participate, and progress in the general education curriculum. Additionally, The No Child Left Behind Act (NCLB) of 2001, an education initiative focusing upon increasing performance for all public school children in the United States, 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; No Child Left Behind Act, 2001). To date, this was the first piece of federal legislation implemented in the United States that established the expectation that students with PMD should show progress on state standardized assessments (Browder & Spooner, 2006).

Just as the two aforementioned acts served to increase preparations and expectations for the academic achievement of students with PMD in the United States (Cushing, Clark, Carter, & Kennedy, 2005), additional federal laws laid the foundation for increasing emphasis on improving their overall quality of life. The passage of legislation such as the Developmental Disabilities Act of 2000, potentially served as an incentive to increase quality of life research in the United States for individuals, including those with PMD. Like previous legislation (e.g., IDEA, NCLB), this statute addressed the rights of persons with disabilities, particularly issues related to quality of life related concepts (Developmental Disabilities Assistance and Bill of Rights Act, 2000; Schalock, Bonham, & Verdugo, 2008). This legislation recommended that 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 is gaining prominence among several research groups, including those in the field of special education (Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005; Schalock, 2004).

Notwithstanding recent legislation, low teacher expectations and uncertainty regarding appropriate instructional strategies has remained a barrier to the exposure of students with PMD to the general education curriculum (Agran et al., 2002). Presently however, special education researchers are beginning to concentrate efforts towards determining which educational strategies provide the most appropriate access and participation in the general education curriculum while also identifying and planning for adequate quality of life opportunities, as deemed individually suitable, for students with PMD (Green, Gardner, & Reid, 1997; Lancioni et al., 2005; Petry, Maes, & Vlaskamp, 2007).

Object of review: Due to the complexity that surrounds the issue of appropriate and meaningful instruction for students with PMD in the United States, the intent of this systematic review was twofold. Primarily, in order to investigate a potential link between teaching pre-academics/academics and quality of life, special educators first must understand the history and significance of educational programming for students with PMD. Therefore, this review briefly addresses historical and emerging strategies being used with students with PMD in

order to ensure their access to the general education curriculum. Secondly, 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 is examined.

Aim of Review: To provide a brief description of the historical and current curricula for students with PMD as well as definitions and discussion of key components of quality of life (e.g., happiness, self-determination). Additionally, a discussion of the importance of the assessment of quality of life concepts and an examination of current quality of life assessment practices (e.g., proxy versus self-report; subjective measures versus objective measures) will be presented. Finally, a discussion of the implications of this body of literature will be presented. This discussion will include suggestions for future collaborative quality of life and academic interventions research in the field of PMD in the United States.

Method of Review: A thorough search of electronic resources was conducted through the following electronic databases: Education Full Text, Education: A SAGE Full-Text Collection, ASSIA: Applied Social Sciences Index and Abstracts, 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; Maes et al., 2007; 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, Maes, & Vlaskamp, 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 2011, (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 instruction related to the general education curriculum, and (d) published in English. (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 (P.L. 94-142) in the United States in 1975, which mandated free and appropriate public education for all children, special educators were confronted with the challenge to create and implement an educational curriculum that was 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 for students with PMD has been a central concern in the field of special education since its inception. Their review detailed the curricular shift in the United States from the developmental model of instruction to the functional model of instruction, as well as the implications of that curricular shift (Nietupski et al., 1997).

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 in the United States. Unfortunately, although these students were entitled to a free and appropriate public education, there were no basic guidelines in place to educate them. The initial educational services created for students with PMD were adapted from

Table 1
 Characteristics of reviewed quality of life (QOL) empirical studies

Studies	Participants (n)	Disability Label	Purpose	Outcomes
Campo, Sharpston, 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 (a) attempt to reliably observe and validate definition of happiness and unhappiness (b) demonstrate if happiness could be increased by staff	Behavioral definitions and observation system reliably identified sources of happiness/unhappiness (a) Were able to reliably observe indicators of happiness and unhappiness (b) Classroom assistants effectively increased happiness among participants
Green & Reid, 1996	6	Profound multiple disabilities		Each participant experienced an increase in overall happiness indices
Green, Gardner, & Reid, 1997	3	Profound multiple disabilities	A replication of Green & Reid, 1996	Resistance and unhappiness were decreased for participant during enriched teaching program
Green, Reid, Rollyson, & Passante, 2005	3	Profound multiple disabilities	Evaluate an enriched teaching program for reducing resistance to teaching and unhappiness	Increase in happiness indices for all participants
Ivancic, Barrett, Simonow & Kimberly, 1997	7	Profound multiple disabilities	A replication of Green & Reid, 1996	
Lancioni, Singh, O'Reilly, Sigafos, 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

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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). Examples of functional skills curricular goals included teaching currency calculation skills necessary to complete a purchase, improving capacity to follow a vocational related work-list, or increasing one's ability to interpret and utilize a public transportation schedule. Following over a decade of targeted functional skills instruction, the curricular focus for children with PMD in the United States 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).

General Education Curriculum: 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 notion of teaching these students academic (e.g., reading comprehension, mathematical calculation) 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). With the increased emphasis for students with PMD to access, participate, and progress in the general education curriculum, the shift in curricular focus has become an area of widespread and sometimes contentious debate in the field of special education in the United States (Browder et al., 2009).

Despite renewed attention, regrettably special educators are struggling to generate and implement effective educational strategies to teach academic content to students in the United States with PMD. A survey of special education teachers conducted by Agran and colleagues (2002) found teachers felt that not only access 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 stated as to why access to the general education curriculum was inappropriate.

To address uncertainty regarding pre-academic/academic instruction for students with PMD, Browder, Gibbs, and colleagues (2007) developed a list of potential benefits of this curricular focus for students with PMD. According to Browder and colleagues (2007; 2009), the potential positive results included: (a) improving post school outcomes (e.g., adult competence, independence, self-determination), (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. Additionally, it can be posited that students with PMD who are taught pre-academic and/or academic content may also experience an overall increase in self-determination and self-esteem. Consequently, these increased feelings of self-efficacy have the potential to lead to an overall enhanced quality of life (Guess, Benson, & Siegel-Causey, 2008), thereby providing a compelling rationale for pre-academic/academic skills instruction.

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 in the United States, 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 in the United States 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 positive programmatic and societal change (Schalock, 2004; Verdugo, Schalock, Keith, & Stancliffe, 2005). Although experts and researchers (Green & Reid, 1996; 1999; Maes et al., 2007; 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 disabilities research collaborated and established eight core principles that defined relevant indicators of quality of life for individuals with disabilities. These were: emotional well-being (happiness), 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). 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; Patrick, 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 on happiness as a key component 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 in the United States (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 constitutes only one unique element of the overall quality of life concept, it is a distinctive feature because 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 components, 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 positive quality of life, researchers in the United States have conducted few studies investigating the potential correlation of happiness and quality of life among individuals with PMD (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). Green and Reid (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 unable to communicate their preferences effectively (Green & Reid, 1996).

Current Quality of Life Assessment Practices

Over the past 20 years in the United States, techniques for assessing the satisfaction of people with PMD regarding various aspects of their lives have grown considerably. 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 making 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 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 capable of independently responding subjectively, for example by answering direct questions, the reliance on self-report raises a number of methodological issues.

Proxy vs. Self-Report: Traditionally, quality of life instruments have measured indicators of happiness for individuals with 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, Ferrari, Soresi, & Wehmeyer, 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). A number of 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 research findings, little rationale has been provided to support the use of proxy respondents nor 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 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). 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).

Current Quality of Life Assessment Research

Although research exploring the quality of life of students with PMD is limited (Lancioni et al., 2007; Shelly et al., 2008), there is a small, but crucial body of research pertaining to increasing happiness indices among adults with PMD. In 1996, Green and Reid introduced research concerning the measurement of displayed indices of happiness. Green and Reid 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. 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 (Davis et al., 2004). 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 and educators in the field of PMD as they create and implement strategies and interventions aimed at supporting this population.

Potential Contribution of the Current Review and Implications for Future Research

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 empirical 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 major reason to apply quality of life concepts to research in the United States 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 non-stimulating self-care routines may lead to a lessened sense of well-being and satisfaction. The resulting dilemma facing researchers in the United States is how to accurately and efficiently assess quality of life indicators in persons with PMD and utilize the resulting information to drive appropriate educational programming. 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 in the United States (Lyons, 2005; Ross & Oliver, 2003).

This systematic review may have been the first to introduce the importance of attempting to establish a link between teaching pre-academic/academic skills and increasing overall quality of life for students with PMD. As this review demonstrates, while past research on improving the quality of life for individuals with PMD has focused on teaching leisure skills or functional life skills, none to date have centered upon teaching pre-academic/academic skills. Medical and technological advances continue to benefit individuals with PMD by revolutionizing health care and intervention services (Maes et al., 2007). Consequently, the overall quality of life for these individuals is being influenced as well. As a result, quality of life, or the satisfaction one feels with his or her life, has gained increased recognition in the United States in the fields of health science, psychology research, and to a lesser degree, education.

In the past, it was assumed that since individuals with PMD displayed low levels of functioning, they must have poor quality of life (Lancioni et al., 2007; Shelly et al., 2008). Recently, research (e.g., Reiter & Schalock, 2008; Singh et al., 2004) has demonstrated that although this notion may be true in some cases, is not representative of all individuals with PMD and thus must be investigated. Additionally, there has been a paradigm shift among some experts in the field of PMD in the United States in that research now focuses on the capabilities of people with disabilities rather than their deficits (Green et al., 1997; Reiter & Schalock, 2008; Shogren, Wehmeyer, Buchanan, & Lopez, 2006). This change in outlook from a deficit perspective to a competence-based perspective, may allow for positive perceptions of the individual's overall capabilities, regardless of the severity of the individual's disabilities. This way of thinking encourages practitioners to place greater emphasis on the development of individual's strengths instead of focusing on deficit remediation (Shogren, et al., 2006). Focusing on and enhancing the strengths and capabilities of these individuals may afford them greater opportunities to have meaningful participation, community inclusion, and positive educational outcomes (Perry & Felce, 2002; Shogren, et al., 2006).

To date, there is a scarcity of quality of life assessment tools (e.g., The Life Satisfaction Matrix, Quality of Life Index, and Evaluation of Quality of Life Instrument) that are appropriate to administer to individuals with PMD (Ross & Oliver, 2003). Future research in the field of quality of life in the United States 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 between 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 attributed to gains in the areas of mental health and behavioral health for individuals with PMD (Perry & Felce, 2002; Reiter & Schalock, 2008).

Another implication for future research in the field of PMD in the United States is the dearth of research that applies quality of life concepts to educational reform. Quality of life assessments can, and should, 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). 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 (Brown, Gothelf, Guess, & Lehr, 1998; Green & Reid, 1999; Green et al., 2005; Guess et al., 2008). Using quality of life indicators could possibly increase the ability of special educators to successfully address two major factors in the lives of students with PMD, decreasing the potential unpleasantness of school while increasing skill acquisition, happiness and self-determination.

Potential Review Limitations

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).

Conclusions

1. This investigation may have been the first to explore the existence of a potential link between teaching pre-academic/academic skills and increasing overall quality of life for students with PMD in the United States.

2. Individuals with PMD represent one of the most challenging populations facing service providers attempting to assess and apply both appropriate instructional procedures and quality of life concepts (Green et al., 2005). Given limited levels of functioning, potential complex health needs, and increased dependency on others, evaluating their quality of life is an inherently complex task (Petry et al., 2007). Consequently, despite support from some researchers and experts in the field (e.g., Green & Reid, 1996; Schalock et al., 2008), the use of quality of life concepts has yet to be fully integrated into current educational practices in the field of PMD in the United States.

3. Future research demonstrating a possible link between teaching pre-academic/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 would be more valued, respected, and encouraged by educators as they strive to develop appropriate and effective educational programming in the United States for these students.

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