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Education and Training in Developmental Disabilities

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Manuscripts Accepted for Future Publication in Education and Training in Developmental Disabilities

September 2007

Use of adapted bicycles on the learning of conventional cycling by children with mental retardation. Tammy L. Burt, David L. Porretta, and Richard E. Klein, Department of Kinesiology & Health Education, Campus Box 1126, Southern Illinois University Edwardsville, Edwardsville, IL 62026.


Assistive technology as a self-management tool for prompting students with intellectual disabilities to initiate and complete daily tasks: A literature review. Linda C. Mechling, University of North Carolina Wilmington, Department of Curricular Studies, Donald R. Watson School of Education, 601 South College Road, Wilmington, NC 28403-5940.

Review of recent treatment acceptability research. Stacy L. Carter, 4518 20th St., Lubbock, TX 79407.

Examining the career paths and transition services of students with disabilities exiting high school. Robert M. Baer, Robert W. Flexer, and Lawrence Dennis, Center for Innovation in Transition and Employment, Kent State University, 202 White Hall, Kent, OH 44242.

Assessing work tasks preferences among persons with intellectual disabilities: An integrative review of literature. Virginie Cobigo, Diane Morin, and Yves Lachapelle, 2966 A rue Fendall, Montreal (QC), H3T 1N1, CANADA.

“Am I supposed to understand this stuff?” Youth with special health care needs readiness for transition. Tanis Bryan, Nora Stiles, Karen Burstein, Cevriye Ergul, and Pen-Chiang Chao, Southwest Institute for Families and Children with Special Needs, 5111 North Scottsdale Road, Suite 105, Scottsdale, AZ 85250.

Attitudes of preservice teachers enrolled in an infusion preparation program regarding planning and making adaptations for included students with mental retardation. David L. Cameron and Bryan G. Cook, Faculty of Education, Agder University College, Service Box 422, 4604 Kristiansand, NORWAY.

Training paraeducators to promote the use of augmentative and alternative communication by students with significant disabilities. Mary Anna Bingham, Fred Spooner, and Diane Browder The University of North Carolina at Charlotte, Department of Special Education and Child Development, College of Education, 9201 University City Blvd., Charlotte, NC 28223.
"I Never Put it Together": The Disconnect Between Self-Determination and Guardianship - Implications for Practice

Dorothy Squatrito Millar
Saginaw Valley State University

Abstract: IDEA mandates that students be responsible for their educational programming once they reach the age of majority, and are considered competent. Guardianship is often raised when student competence is questioned. Six focus groups were conducted to gather information regarding the extent to which participants understood guardianship and its alternatives, and how these related to self-determination. Two groups consisted of young adults with disabilities; Group 1 had legal guardians. Parents were also focus group participants; the last two groups consisted of special educators. Data suggested that the majority of participants (a) perceived they exhibited/promoted self-determination; (b) did not recognize a disconnect between self-determination and guardianship; and (c) had limited understanding of guardianship and its alternatives. Implications for practice are discussed.

In the recently reauthorized Individuals with Disabilities Education Act several changes from the 1997 amendments with regard to the transition from school to adulthood were presented. Changes include (a) procedures for reevaluations [614(a)(2)], (b) requirements for summary of performances for students whose eligibility under IDEA terminates due to graduation or has exceeded the age for free public schooling under state law [614(c)(5)(B)], and (c) a switch as to when transition services must be addressed, which is now age 16 as opposed to 14 [614(d)(1)(A)VII]. One area that did not see a change was the section in relation to the transfer of parental rights at the age of majority [614(d)(1)(A)VII]. Specifically, IDEA states that when a student reaches the age of majority under State law, all rights accorded to parents are to transfer to students. The special rule under Section 615 (m) procedural safeguards states that this right of transfer is to occur for all students with disabilities, unless the student is determined to be incompetent by State law, or has not been determined incompetent by State law, but considered unable to provide informed consent with respect to educational programming. In these cases, the State is to establish procedures for appointing the parent, or some individual, to represent the educational interests of the student when the student is eligible to receive services under IDEA, section B [614(d)(1)(A)VIII].

To date, no known comprehensive or small study has investigated how States and local schools districts are responding to this mandate. Michigan, as an example, has addressed the mandate on the Individualized Educational Program (IEP) form by including an item such as "Parental Rights and Age of Majority (check all applicable): (a) if the student will be age 17 during this IEP, the student was informed of parental rights that will transfer to him or her at age 18; (b) if the student has turned age 18 the student and parent were informed of the parental rights that transferred to the student at age 18 including the right to invite a support person(s) such as parents, other family members, advocate, or friend; (c) the student has turned age 18 and there is a guardian established by court order. The guardian is ___; and (d) the student has turned age 18 and has appointed a legally designated representative (e.g., power-of-attorney, trustee). The representative is ___" (Michigan Department of Education, Section 1-2, 2005). Furthermore, the
State’s IEP manual presents “Guardianship issues (e.g., independence, decision-making, partial guardianships as appropriate) can be addressed in the student’s secondary education career in the IEP under Transition services (e.g., Courses of study, Adult living. Daily living)” (Michigan Department of Education, Section 1-2). Although an IEP manual may suggest that ‘age of majority’ should be an ongoing educational topic for the student well before the student becomes of legal age (Michigan Department of Education, Section 1-2), statements such as this may be interpreted that guardian appointments should be considered.

Briefly, guardianship is a legal process, governed by individual state law as opposed to unifying federal law, by which a court appoints someone (a guardian) to have the authority to make decisions for another (a ward or respondent) who has been determined to be either totally or partially incompetent (Leary, 1997; Lisi, Burns, & Lussendend, 1994). As a result, the ward may lose many legal and civil rights. The potential ramifications of a guardian appointment can be enormous, therefore, it has been argued that alternatives should be explored (Iris, 1986; Lisi et al.). Alternatives to guardianship include youth and young adults collaborating with (a) family and friends; (b) representative payees; and (c) agency case managers (Lisi et al.; Sullivan, 1986). Trusts, specialized checking accounts, power of attorney and protective orders are additional guardianship alternatives that can be explored (Lisi et al.; Pierangelo & Giuliani, 2004; Sullivan). Table 1 presents more information on guardianship alternatives.

Interestingly, guardianship has been in existence for hundreds of years (Lisi et al., 1994), however, research on the topic and its related issues are sparse. Two recent studies are considered to be the first that investigated guardianship in relation to young adults who have developmental disabilities. By reviewing over 220 guardianship court files, Millar and Renzaglia (2002) and Millar (2003) found that main reasons why guardians were appointed included that young adults were perceived as having limited or no ability to make decisions, and youth were reaching the age of majority. More interesting, it was revealed that guardianship appointments did not necessarily resolve the areas of concern presented to the courts. Although information regarding alternatives used prior to the filing of a petition was hoped for, such information obtained from the files was limited as no specific questions regarding the use of alternatives were found on guardianship petitions. These two studies, like the few others that examined guardianship in relation to the elderly (Iris, 1989; Lisi et al.) raised questions about the views of members of the judicial system, community service organizations, and family members with respect to alternatives. Importantly, it was pointed out that there is a need for research that includes formal participatory research methods in which key stakeholders provide in-depth experience-based perspectives.

This study is a response to this call as it includes perspectives from three key stakeholders: (a) young adults with disabilities who either have or do not have a legal, court appointed guardian; (b) parents of young adults who have disabilities; and (c) educators who work with young adults and their parents. It is the first known study that explores issues surrounding the age of majority, transfer of rights, self-determination, guardianship decisions, and guardianship alternatives. Focus groups were used as little is known about these areas. In addition, an aim of this investigation was to develop interest into and direction for future research. With the growing trend of encouraging students to be self-determined, it is crucial that educators, families and agency personnel understand what guardianship entails. Specifically, they need to examine the extent to which self-determination efforts are potentially being undermined by guardian appointments.

Method

Participants and District

Participant selection was purposeful such that six homogenous groups could be created. A mid-west regional school district, from which participants were selected, had a reputation at the state and local level for providing quality school-to-adulthood transition services. The district, comprised of a diverse student population, in addition to having several high schools, had a regional facility (transition/vocational center) such that students with disabilities, aged 18 and older, could continue their education and focus on transition issues. Participants were nomi-
nated by the district special education coordinator or high school department chair. Criteria for participation of young adults included that they:
(a) had the same special education eligibility label of “moderately cognitively impaired” based on results from IQ assessments, adaptive behavior scores, and onset of the disability; (b) reached the age of majority (18 years old); (c) were eligible for agency support (e.g., vocational rehabilitation, social security income, Medicaid, department of mental health - services of people with developmental disabilities); (d) had high level of parental involvement; and (e) were able to verbally communicate in an interview forum. The goal was to have at least 10 students nominated for participation who were to be their own legal guardian, having a letter of intent from parents that guardian appointments would not occur; and at least 10 students where parents were appointed as their legal guardians. Parents of these individuals also had to be willing to participate in focus groups. Finally, special educators who worked with students aged 17 and older and were considered by district standards to be well versed in transition services, were selected for participation.

In total, six focus groups were conducted. Focus Group 1 was comprised of six young adults with moderate cognitive developmental disabilities who had legal guardians (a parent) appointed by the courts. Within this group: (a) three students were male and three were female; (b) three were Caucasian, one was Black, one was Hispanic and one was Indian from India; and (c) their ages ranged between 19 and 22. The second group consisted of seven young adults with developmental disabilities who did not have a court appointed

### TABLE 1

<table>
<thead>
<tr>
<th>Overview of Guardianship Alternatives</th>
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<tr>
<td><strong>Family and friends</strong></td>
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<tr>
<td><strong>Trust funds</strong></td>
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<tr>
<td><strong>Specialized bank account</strong></td>
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<tr>
<td><strong>Power of attorney</strong></td>
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<tr>
<td><strong>Representative payee</strong></td>
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<td><strong>Case management services</strong></td>
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*Note.* Adapted from Pierangelo and Giuliani (2004), Sullivan (1986), and Wood et al. (1991).
Of these seven: (a) three were male and four were female; (b) four were Caucasian, two were Black, and one was Hispanic; and (c) ages ranged between 20 and 22. Groups 3 and 4 consisted of parents, five (one father and four mothers) and six (one father and five mothers) respectively, of the young adults in Groups 1 and 2. Group 3 parents were also plenary (full) guardians of the adult children in Group 1. For each parent group, one parent of the student groups was unable to attend the focus group meetings. The final two Groups, 5 and 6, were comprised of special educators who had taught special education for at least five years. Group 5 educators, seven in total (five females and 2 males), worked at the transition/vocational center with young adults 18+ years of age; Group 6, ten (eight females and two males), were special educators at high school settings.

It is important to note that the author relied on self-reporting, supported by the special education coordinator or department chair, on determining the group formation. Interestingly, this participant selection was an enlightening process. For example, regarding the composition of Group 1, 10 parents believed that they were their child’s legal guardian. Four of these individuals, however, did not have the proper documentation. One of these parents stated “He is disabled—I’m his parent—I don’t need a judge to tell me I’m his guardian.” Three other parents had similar responses and were surprised to learn from the director that guardianship is a legal, court, process. These parents and their adult children did not participate in the focus groups.

Procedure

Focus groups, commonly used in the business and marketing arenas, were selected for this educational study as they provided an avenue to obtain comprehensive, in-depth diverse perspectives from key stakeholders in areas not previously investigated, guardianship and self-determination issues. In this study, the key stakeholders were young adults with disabilities who reached the age of majority, their parents and educators. As with most focus groups, the aim in this study was to form groups comprised of individuals who shared a common experience, and learn from them (Vaughn, Schumm, & Sinagub, 1996). Although it is difficult to generalize the findings of focus groups, the method was selected so that complete and in-depth understanding of perceptions from multiple viewpoints could be obtained (Vaughn et al.), and perhaps more importantly, launch interest into and direction of future research.

Prior to each focus group, every participant received consent forms (and for Group 1 assent forms) and a list of the focus group questions. The intent of presenting the questions ahead of time was to establish a sense of trust between investigator and participants. All focus groups were held in a district administration conference room, a central location to all participants. The author of the study facilitated each focus group and an assistant recorded responses. At the beginning of each session, ground rules for the focus group were presented. Main rules included that (a) there were no right or wrong answers, (b) what was said was to stay among the participants, and (c) everyone was encouraged to speak freely such that each question could be comfortably and adequately discussed. The school administrator stayed with each group to ensure everyone felt at ease, then left once the ground rules were established. Each meeting lasted between 60-90 minutes and sample questions posed to each group can be found in Table 2. Following the focus groups, each participant was offered a gift certificate of $25 as a way to acknowledge their participation. All meetings were audio-taped and then completely transcribed.

Coding

Transcribed information was analyzed in two phases. Phase 1 occurred once the focus group meeting tapes were transcribed. As a foundation for determining themes, data were categorized using the focus group questions as an outline. That is, data for students (Groups 1 and 2), parents (Groups 3 and 4), and educators (Groups 5 and 6) were sorted by group make-up, under each focus group question. Per each group session, at least 25% of the transcripts, randomly selected passages, were coded by two individuals, the author and an assistant. When inter-coder reliability was established at 85% (or higher) the remaining...
transcripts were coded by the author. Discrepancies were discussed between coders until 100% agreement could be reached. Phase 2 of the analysis was performed by the author. In this phase, a content analysis was completed such that issues and concerns were sorted into main and sub-themes that went beyond the focus group questions. Key words, sentence sections, and complete sentences from the focus groups were used as units of analysis, which were sorted and grouped. Once all main and sub-themes were coded, data were organized to allow for comparisons between groups, as well as to previous research findings. Unique responses are presented as they are considered to be new contributions to the literature.

Results

Interestingly, findings revealed that there were more common responses and issues across the three groups (students, parents and educators) than differences. Therefore, common results across the three groups are presented first, followed by unique group findings. Regarding student responses, it has been cautioned that the validity of responses by individuals with cognitive impairments during interviews may be threatened by a number of biases (Heal & Sigelmann, 1995), including acquiescence, the disposition to agree or answer “yes” regardless of the question asked. Therefore, the validity of an interview response from persons with cognitive impairments is dependent on how they are asked, and/or the format of the question. With this knowledge, questions were carefully phrased during student focus groups to circumvent potential acquiescence bias.

Common Findings Across Groups

Guardian defined. When asked “What is the first thing that comes to mind when you hear the term guardian?” Six students, five parents and seven educators reported that they saw a guardian as someone who “protects” or “takes care of” another. One of these educators stated “I view a guardian as someone who is legally and morally bound to seek and ensure the best interests of another person.” On the other hand, five students, six parents and four educators envisioned “someone who takes over” or “is in charge of” someone. Three teachers indicated that they thought of someone who is responsible for children (under 18) who may or may not be a biological parent; two said “someone who assists someone” and one person said “not really sure.”

When asked whether differences existed between parents and guardians for adults, students with guardians, their parents and a supermajority of educators thought there were no differences. Seven educators, however, thought the motivation may be different as suggested in this statement: “Both parent and guardian should be doing everything possible to ensure that the needs of another person are met; however, a parent usually does so out of love for their child and a guardian doesn’t necessarily have to love their charge.” In response, one educator added:

When a student is of legal age, their parent relinquishes the power to make decisions for them. Legal age adults have the legal right to make their own decisions that will affect their future. The term “guardian” implies that the legal age adult is unable to make decisions and therefore is unable to. Their guardian will determine whether or not they seek employment, where to live, and even whether or not they might seek additional education or training.”

TABLE 2

Focus Group Questions

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<th>Common key questions across focus groups.</th>
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<tr>
<td>1) What is the first thing that comes to mind when you hear the term guardian?</td>
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<tr>
<td>2) How does someone 18 years of age and older get a guardian?</td>
</tr>
<tr>
<td>3) What are your experiences, if any, with someone who is of legal age and has a guardian?</td>
</tr>
<tr>
<td>4) What, if any, guardianship alternatives are you aware of, and how did they work?</td>
</tr>
<tr>
<td>5) What type of curriculum does your school emphasize? (academics, life-skills, self-determination skills)</td>
</tr>
<tr>
<td>6) Where did you first learn about guardianship as it relates to adults?</td>
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The remaining students stated that parents might be “bossier than a guardian” but they, like their parents, thought parents would be there to help out when needed.

Guardianship process. When asked, “How does someone get a guardian if they are of legal age?”, all students and their parents knew that it involved the courts. Six of the 17 educators stated “I don’t (really) know.” The other educators stated that the court or a judge is involved, but only four educators seemed to fully grasp the legal process. One educator stated “Typically, if a parent feels that a student is unable to make their own decisions, then that parent would petition the court requesting that power be granted to them so that they may remain making decisions for that student.” In response, another educator added:

Someone has to petition the court and the court assigns one. I’m assuming there is a process, but do not know for sure what process if any investigates how fit the guardian is to serve. I believe if the parent wants some say in the process or expects one will be needed, it should be started before the 18th birthday. A person who is of legal age automatically becomes their own guardian unless someone petitions the court, regardless of competence. Information must be provided by the petitioner to the court, like medical documentation that show incompetence, like doctor’s statements and medical or psychiatric information. A probate judge is who decides and assigns a guardian if one is needed.

One of the six educators unsure of the guardianship process exclaimed, “Wow, I’m learning so much from being here [in the focus group].” In response, another educator said “I didn’t realize until now how much I didn’t know.”

Guardianship alternatives. Some groups (Groups 1, 3, 5, and 6) had limited awareness of alternatives to guardian appointments. These individuals did not recognize that instead of guardianship, family and friends could be consulted for advice when decisions needed to be made. In Groups 3, 5 and 6 many participants openly wondered whether they may have acted differently, regarding the IEP section which discusses age of majority, had they known then all the information that was being discussed during the focus group. Groups 2 and 4 were aware of several alternatives, the main being family and friends, power of attorneys and representative payees. Five of the seven students in Group 2 had specialized checking accounts. Two of these five students shared “I can’t write checks. My mom writes it out for me. It is in both of our names – we both have to sign the check,” and “My sister can help me too when we go shopping, she writes the check and has me sign it at the bottom.” Another student from this group said “I believe my mom is my power of attorney. That means she’ll help me make money decisions-doctor, dentist, school decisions, things like that. Yeh, I am pretty sure my mom is my power of attorney.” The mother of this student confirmed that she did have power of attorney to make medical decisions, but stated she has not needed to use it.

District curriculum emphasis. All groups of participants were asked what they perceived to be the district’s emphasis on the transition process, teaching life-skills, in addition to self-determination and self-advocacy skills. Here, the majority of teachers indicated that as a whole, the district did not emphasize these areas, rather they perceived that specific teachers at specific grade levels (secondary) were emphasizing them. Not surprisingly, 100% of the educators in Group 5 stated their school was dedicated to the transition process, teaching life, and self-determination skills. They also had a curriculum that focused on students’ abilities to make choices, set goals, and engage in problem-solving. The district, all 17 educators stated, had its main emphasis on academics and high test scores on the state assessment. Only the educators in Group 5 indicated that they addressed guardianship to a limited extent, and the others all stated that this was not addressed beyond the checklist item found on the IEP.

All students in the two groups stated that they were involved in their educational program planning (including the IEP), and received year long self-determination skills training. To check for student understanding of self-determination, students were requested to give examples of how they were self-determined. One student shared that “We talk about human rights and
legal rights – I voted.” “Yeh” another student stated “They teach us to say what we want – but they don’t always listen.” Finally, one student said, “We get to talk at our IEPs if we want – tell them what we want and stuff.” Essentially, the students all perceived that they exhibited self-determination, and parents and educators perceived they promoted students doing this. All groups, however, did not view guardianship as being in opposition to self-determination. No one recognized the disconnect. One educator shared “I never put it together—until now.” Another teacher said, “I just saw the IEP check area, ‘a guardian has been appointed by law’, responded, and moved on to the next part of the IEP.”

Final thoughts. The advice offered by all three groups was similar: be involved, be informed, stay current, listen, collaborate, and encourage children/students to advocate for themselves. One parent, who was a guardian of a student in Group 1 shared “Students can still make mistakes, even when they have a guardian; for parents, guardianship is more of an assurance that we still have a say in our child’s life.” Another parent in the group stated “Some students get taken advantage of and a guardian may help, not sure.” Interestingly, two teachers shared that even though they want their students to self-advocate, “students aren’t really allowed to make choices and are taught helplessness.” Students on the other hand said “We are adults. They need to accept that,” “they need to listen,” and “they [teachers and parents] should put themselves in our shoes sometime.”

Unique Group Findings

Students with guardians. The students in Group 1 first learned about guardianship at an IEP. A teacher at their IEP meeting said “Do you have a guardian?” From that point forward, their parents went to the court to file a guardianship petition. “I think my mom told me we had to go to court and there was paper work and stuff we had to fill out.” All students relayed that going to court was “scary” as they had no prior experience with the court system. One student shared that the judge said she needed a guardian because “maybe you could make the wrong decision and they [the guardians] will try to guide you where to go. Like that’s not a good decision-try to make another one. Maybe they’ll help you with how to dress. Like that’s got a spot on it, or that’s wrinkled, go take it off, and put another one on. Things like that.” Another student added that having a guardian means “You have to do this thing they say and sometimes you don’t feel like doing it. I always listen to her [the guardian]- sometimes I don’t want to listen . . .Like she said you have to study now and I say no I don’t want to study, but I do anyway.” Another student stated that she and her guardian (her father) “Sometimes have disagreements but work it out.”

Parents. Across both groups of parents, it was clear that they had great concern for their adult children. They reported that they constantly worried about the decisions their children made or that they would be taken advantage of. Sample transcripts that reflect their concerns included: “He is just so trusting – I think he’d give his shirt away” and “I hate to say this, but I don’t want the schools to pull a fast one.” Their death, the parents’, was also a common concern across both groups. One person shared “the transition stuff – the schools basically are all gloom, doom, I’m gonna die soon – it is scary – who is gonna take care of my son when I’m gone?”

Interestingly, all five of the guardians in Group 3 stated that they obtained guardianship because, as one parent shared, “I thought I was supposed to do it.” Guardianship related information was sparse, and all five indicated that they did not believe they were really informed about the process until they went through it. All parents in this group found it difficult or “devastating” to say their child was either totally or partially incompetent. Even during the focus group, they questioned the need for guardian appointments, as they did not perceive they needed to “use the power” other than signing permission slips or IEP forms. Parents in Group 4 essentially had the attitude that “just because my daughter is slower than her brothers and sisters doesn’t mean she shouldn’t take responsibility for her actions or that she can’t decide things on her own.” And another parent from this group added “We all make mistakes, and we all need help sometime – but that doesn’t mean we need guardians.”
When asked how they learned about guardianship, most educators that had knowledge about guardianship, reported that they learned about it on-the-job. Some did, however, have personal family experiences. Two had learned about the issues from previous jobs (nursing home assistant). On-the-job training, however, was limited to the evening presentations created for families. Teachers could attend if they wanted. Of the teachers in the focus groups, two attended such presentations, but these were also the two who had an understanding of the process. In terms of formal teacher preparation, it was found that a supermajority (70% or more) learned about the transition process, strategies for teaching students self-determination and self-advocacy skills throughout their teacher preparation program. That is, the issues were discussed briefly across all of their special education courses. Guardianship and its alternatives, however, were not addressed for over 60% of educators. For those where guardianship was addressed, it occurred for no longer than 45 minutes in one class of one 15 week course. Lack of preparation was clear. Some educators speculated that the lack of preparation was due to the professors’ limited knowledge, or concern that they would be perceived as giving out legal advice, hence guardianship was a topic best left un-discussed.

When asked about their experiences with guardians, the following situations were shared by teachers:

Doing permission slips – it is usually a big deal to get a permission slip signed if they are not their legal guardian - whereas other students are 18 and can sign it themselves.

This past year, I had a student who was almost 20 years old and her mother was her appointed guardian. Her mother made all, and I do mean all, decisions for her. My co-workers and I were so disturbed by the relationship. I had known the student for years and felt that she had extremely regressed in all aspects. The young lady that I was working with had always expressed a desire to pursue her education. Sadly, I know that my ex-student is continuing to remain at home with no tangible future in sight. I truly believe that it is her mother that is unable to function independently of the student; not the other way around!

When a father came to visit our school for the first time he was under the impression that he was the guardian because his child had a disability. So at that point when we asked him for guardianship papers he was like - well what do you mean? I don’t know what those are; I’m his guardian though. So immediately he wanted to know how to get guardianship. A lot of parents don’t know the advantages and disadvantages of guardianship. They want a resource where they can contact and find out if they really want guardianship. I think a lot of them don’t know much about it - they don’t know they need to go to court, they don’t know if they should or shouldn’t.

Discussion and Implications

By using focus groups, this study is the first to examine the perspectives from three key stake-holders: (a) young adults with disabilities who either have or do not have a legal, court appointed guardian, (b) parents of young adults who have disabilities, and (c) educators who work with young adults and their parents regarding issues surrounding age of majority, transfer of rights, self-determination, guardianship decisions and alternatives. With the trend of encouraging students to be self-determined, it is crucial that educators and families examine the extent to which self-determination efforts are potentially being undermined by guardian appointments. Major findings from this study revealed that the majority of participants (a) perceived that they exhibited/promoted self-determination; (b) did not recognize a disconnect between self-determination and guardianship; and (c) had limited understanding of guardianship and its alternatives. As noted earlier, focus group findings should be considered more as discovery than conclusion (Vaughn et al., 1996). With this in mind, it is believed that the results of this study provide useful information for educators and families, and important implications for practice.

On-going transition awareness. This study worked with families in a district considered to have quality transition services. Even with this
reputation, findings from this study are consistent with those where parents believed they lacked the knowledge with respect to post-school issues (Chambers, Hughes, & Carter, 2004). While it was believed that the district worked with in this study had exemplary transition services in place, confusion, lack of information and disconnects were observed. This was evident during the selection of focus group participants, as several parents did not realize they were not legal guardians of their adult children. Parents and educators who did participate in the study also seemed to have questions, which may have occurred for variety of reasons – lack of preparation, fear of being sued if perceived as giving legal advice, fear of harm coming to students, or simple ignorance. The findings in this study are similar to those of Thorin, Yovanoff, and Irvine (1996). That is, the transition to adulthood is a challenging time for families of youth, including those who have disabilities. The parents of both groups in this study struggled with wanting to create opportunities for child’s independence, while at the same time had concerns for their child’s health and welfare (Thorin et al). Similarly, they had concerns that their child’s life could include potential exploitation.

Educators and families must be offered a variety of approaches to discuss guardianship and its alternatives. Some individuals may prefer to receive newsletters (electronic or paper), whereas others may prefer to attend workshops. Other means for providing guardianship/alternatives information could include (a) providing workshops/presentations on transition issues for both families and educators, (b) connecting families with other families who have elected to go through the guardianship process and maybe more importantly with families who did not, and used alternatives, (c) arranging visitations with members of the judiciary such that differing worlds can learn from one another, (d) creating training videos and modules for people to check out, and (e) encouraging the use of person-centered planning, alternative exploration and mediation. Resources need to be available, and not just presented in one three hour class or workshop. Educator preparation programs may need to consider how much emphasis has been place on self-determination, guardianship and its alternatives.

Examining emphasis on self-determination. Self-determination has been (a) viewed as an educational outcome, (b) defined in relation to behaviors exhibited by an individual, and (c) realized by individuals throughout life-long learning, opportunities, and experiences (Wehmeyer, 1996). Much of the research that has been done on self-determination, however, has been directed toward students participating in their IEPs. In the group of students who participated in the focus groups, all students reported they had major roles at their meetings. Teachers and parents also verified this and stated that they encouraged student involvement. These findings differ from those of Katsyannis, Zhang, Woodruff, and Dixon (2005) who studied data from the National Longitudinal Transition Study 2 (NLTS2), where professionals and educators did not necessarily act on their beliefs.

When the section on age of majority and transfer of rights on the IEP form was discussed, however, focus group participants failed to recognize that guardianship contradicted their efforts to promote self-determination. Unlike findings by Wehmeyer, Agran, and Hughes (2000), teachers in this study were familiar with self-determination and felt it was important to teach. Wehmeyer et al. found teachers in their study questioned whether students would benefit from instruction and a minority of teachers they surveyed indicated that self-determination issues were addressed on IEPs. The teachers in this study, however, took the Wehmeyer et al. quote to heart “The fact that someone may not become completely independent in his or her decision-making does not mean that he or she cannot become less dependent or more involved in decisions that impact his or her life.” (p. 65). These teachers and parents, as verified by students, also invested heavily in preparing students for participation in the transition process across the students’ life-span, instead of simply preparing students for one or two school meetings. Similar investment was not found in other studies such as the one conducted by Thoma, Rogan, and Baker (2001). In this work, individuals often sought to ensure that self-determination efforts were
sustained beyond the confines of the IEP. Even with this, however, they did not fully appreciate the disconnect between self-determination and guardianship.

**Considering mediation.** In addition to the alternatives presented in Table 1, mediation is a form of intervention that may help an individual with disabilities remain autonomous and prevent unnecessary guardian appointments (Special Committee on Aging, United States Senate, 1993; Wood, Dooley, & Karp, 1991). Mediation is a process that involves communication and negotiation between parties such that options can be discussed and mutually acceptable plans for action can be established. It is also a time where people can learn from one another on topics that may not ordinarily be addressed in educational planning (Devlieger & Trach, 1999; Mueller, Engiles, & Peter, 2003). IDEA requires that states offer mediation whenever due process hearings are requested in an effort to resolve disagreements about educational programming. Not only are parents involved in mediation, but it has been suggested that students should fully participate in mediations regarding the educational services they receive (Mueller et al., 2003). Application of mediation for young adults with developmental disabilities in relation to transfer of rights, guardianship and use of alternatives, however, has not been previously presented. Prior to the student reaching the age of majority, it is possible that mediation regarding guardianship would be beneficial. Benefits to students could include (a) maintaining their legal and civil rights, (b) learning how to address issues in a constructive manner, (c) appreciating that people can have differing points of view, and (d) exhibiting their self-determination skills. Should it be determined that mediation would assist with guardianship decisions, it is essential that a mediator be found who has the skills and knowledge regarding the judicial system, disability and collaboration. The mediation process is time consuming and at this time, there are no data available suggesting whether mediation has helped a situation with regard to young adults with disabilities and guardianship issues indefinitely, or if the petitioner went to court following the mediation activities. Mediation, however, is a viable option for not only guardian prevention, but for other life issues as well (Special Committee on Aging, United States Senate; Wood et al.).

**Limitations**

Although this study provides important new information, its format presents many limitations. For example, in the selection of participants for the focus groups it is possible that the participants were not truly representative, hence restricting the ability to generalize these findings to other families and teachers. Future research should include a larger number of individuals to minimize the influence of factors unique to these participants. Another concern is that information was gained from participants based on self-reporting. Although confirmation of perceptions were somewhat addressed by asking similar questions to all three groups of participants, direct observation to determine the extent to which responses could be confirmed would have made the results more credible.

**Future Research**

One purpose of focus groups is to develop directions for future research. Based on the results of these focus groups, major findings included that the majority of participants (a) perceived that they exhibited/promoted self-determination; (b) did not recognize a disconnect between self-determination and guardianship; and (c) had limited understanding of guardianship and its alternatives. Hence, more research in these areas is needed. Perhaps a nationwide longitudinal study could add questions about how guardianship and its alternatives are being handled as there is no comprehensive data base that addresses these issues. A related area to investigate is the extent to which IDEA and IEP forms are being interpreted as promoting guardian appointments. We also must learn what school personnel are saying, if anything, to families about these areas.

**Summary**

Involvement of students in the transition process is critical, as is the collaboration between families and school personnel. By determining the student’s and family’s expectations,
knowledge, and concerns, transition services can be better aligned with their values and needs. Although there is merit to discussing transition-to-adulthood issues such as employment goals, residential living situations and recreation/social options during educational planning meetings, guardianship and its alternatives also need to be discussed. Such information should be given well before a student reaches the age of majority. In order to effectively deliver transition services, all parties involved need to have information about guardianship and, perhaps more importantly, its alternatives. Communication and collaboration are key to helping youth become and remain autonomous adults.

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Description of the Support Needs of People with Profound Multiple Disabilities Using the 2002 AAMR System: An Overview of Literature

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Abstract: This paper gives a description of the support needs of people with profound multiple disabilities (PMD), based on the five basic dimensions of the 2002 AAMR System, being intellectual abilities, adaptive behavior, participation, interaction and social roles, health and context. It is based on a study of the literature concerning the target group. The overview shows that people with PMD have the same needs as other people, with regard to participation, relationships, choices, resources and physical and socio-emotional well-being. Nevertheless, it becomes apparent that the needs of people with PMD require specific support. In order to meet these special needs, a relational perspective on support as well as specific characteristics of the support staff and of the support context are necessary.

Anna is a five-year-old girl with congenital brain damage. Her diagnosis is spastic quadriplegia with epilepsy and cortical blindness. Her motor, cognitive and verbal skills are developed to a limited extent. She cannot move. Despite her limitations, Anna is a cheerful girl. She loves physical contact and individual attention from familiar people. She expresses herself by means of her smile and facial expression. She recognizes certain people by their voice, in particular her mother and her brother. In a few weeks Anna will visit a day centre for the first time.

Anna is an individual with profound multiple disabilities (PMD). The expression ‘profound multiple disabilities’ refers to people with severe cognitive as well as severe motor disabilities (Nakken & Vlaskamp, 2002). These disabilities may be the consequence of genetic defects, congenital brain damage, degenerative disorders, disorders of the metabolism or problems during pregnancy or birth. It concerns an extremely heterogeneous group in terms of functional abilities. Due to their limitations in many areas and the combination of limitations, people with PMD need specific support. In order to offer this specific support, a description of their support needs is necessary.

Nevertheless, describing the support needs of people with PMD is not easy. According to Zijlstra and Penning (2004) this has to do with the fact that there is still a lack of psychometrically sound assessment instruments for this target group. However, a description of the support needs is of great benefit for practice as well as for research. According to Nakken (2004, in Zijlstra & Penning) an accurate description can: (1) prevent misinterpretations of research results and of descriptions of ‘good practices’, and result in a more effective use of support strategies, (2) contribute to the discussion that strategies developed for people with visual and intellectual disabilities are not automatically applicable to people with PMD and (3) evaluate the consequences of new developments for the target group.

In this paper we attempt to make a contribution to the description of the support needs of people with PMD. By means of a literature review we explored what is known in international research about the needs of this target group.
Research Design

Framework

The framework that we used in this study is the 2002 System’s theoretical model of the AAMR (Luckasson et al., 2002). According to this model, which is presented in Figure 1, the functioning of people with intellectual disabilities can be understood from the interaction of factors on five dimensions. The concept ‘interaction’ implies that these dimensions are not independent, but that limitations in one dimension should always be seen in connection with other dimensions (Buntinx, 2003). This 2002 AAMR System offers a framework for categorizing and describing the capabilities, the limitations and the support needs of people with intellectual disabilities in several areas. By adopting this framework in describing the needs of people with PMD we come to meet the plea of Nakken (2004, in Zijlstra & Penning, 2004) for a multidimensional description of (the needs of) people with PMD.

For a concise description of the five dimensions, we based ourselves on Buntinx (2003, p. 10–12) and Schalock and Luckasson (2004, p. 139–142):

(1) ‘Intellectual abilities’ or ‘intelligence’ refers to “a general mental ability that includes reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience” (Luckasson et al., 2002, p. 51).

(2) ‘Adaptive behavior’ is the “collection of conceptual, social and practical adaptive skills that have been learned by people in order to function in their everyday lives” (Luckasson et al., 2002, p. 73).

(3) The third dimension is the dimension of ‘participation, interaction and social roles’. ‘Participation’ and ‘interaction’ must be determined by directly observing one’s engagement in everyday activities and asking whether the individual is actively engaged with (attending to, interacting with, participating in) his or her environment. ‘Social roles’ refer to a set of valued activities normal for a specific age group.
The dimension of ‘health’ comprises a state of complete physical, mental and social well-being and the way in which it influences functioning.

‘Context’ describes the interrelated conditions within which people live their everyday lives and includes the immediate social setting, including the person, family, and/or advocates; the neighbourhood, community, or organization providing education or habilitation services or supports; and the overarching patterns of culture, society, larger populations, country, or sociopolitical influences (Schalock & Luckasson).

Method

We searched literature using four bibliographical databases: ERIC, Medline, PsycINFO and Social Sciences Citation Index. The search strategy existed in combining search terms for the target group (e.g., profound multiple disabilities, profound multiple handicaps, profound mental retardation, profound learning disabilities) with search terms regarding the dimensions of the AAMR-framework (e.g., cognition, adaptive behaviour, health, participation, interaction, social roles, context). We completed the literature, which was mainly in English, with available Dutch literature on the target group. In selecting publications we laid down following criteria:

- Published between 1995 and 2005;
- Empirical research or a review of empirical studies;
- Target group is people with PMD.

Next, publications that met these criteria were categorized per dimension. If for a certain dimension the search strategy yielded very few or no hits, at first the time span was broadened and at a later stage more general publications on this dimension in relation to the target group were included. If a lot of similar studies were available on a certain topic, we only refer to the most recent publications.

Description of the Support Needs

Intellectual Abilities

The level of cognitive functioning of people with PMD is very low. Their IQ is generally under 20 to 25 or their mental age is below 24 months (Ware, 1994). In Piaget’s framework following domains of knowledge are considered to be important for this group: object permanence, (verbal and gestural) imitation, operational causality, object relations in space and cognitive schemes (Kerssies, Rensen, Opppenheimer, & Molenaar, 1989). Through an integration of sensory perceptions and physical movements and through the frequent repetition of actions that bring about certain effects, sensory-motor action schemes are developed, that are the foundation of single problem solving behavior.

Remington (1996) also describes the different fundamental learning processes that take place in people with PMD. One of these processes is habituation, which relates to the effect of repeatedly presenting a stimulus (e.g., a person, who always uses a green spoon, will keep looking for it when some day he/she cannot find it in the cutlery tray). By means of associative learning, people learn to see the association between two stimuli or situations on the basis of repeated experiences, routines and rituals in daily living conditions. This insight enables them to predict events and to anticipate them (e.g., the person has undergone painful tests in hospital, when driving into the hospital’s parking he or she already has a panic reaction). They also learn to become aware of the association between a certain behavior and its effect. When a certain behavior has a positive effect, that behavior will be displayed more often in the future (e.g., the person learns that tapping its cup on the table is followed by filling up the cup, because of this positive effect the person will display the same behavior once more in order to reach the same objective). Research has shown that people with PMD are aware of or can be made aware of such contingencies (Lancioni et al., 2003; Saunders et al., 2003). Learning contingencies enables the individual to have control over his/her environment. Finally, people with PMD learn by means of observation and imitation.

Adaptive Behavior

People with PMD need support and stimulation to acquire social adaptation skills (Aird,
These skills include:

- Conceptual and communicative skills such as demanding something, indicating yes or no, making eye contact and listening to stories.
- Social and emotional skills such as expressing and understanding emotions, taking turns, playing together, learning rules, making choices, taking initiative and task orientation.
- Practical skills such as toilet-training, eating and drinking and getting dressed.

Learning and developing these skills is only possible for people with PMD in an intensive relation with direct support staff and a constructive interaction with their environment (Nind & Hewett, 2001). Therefore, it is necessary to adequately organize the environment and to actively support people with PMD so that they can accomplish interaction and participation (Felce, Jones, & Lowe, 2002).

The learning process has to be dealt with in an active and systematic manner (Choi, Meeuwsen, French, Sherrill, & McCabe, 2001; Lancerini, O’Reilly, Campodonico, & Mantini, 2002; O’Neill & Heathfield, 2004; Reid, Phillips, & Green, 1991; Remington, 1996). This regards breaking up skills into small sub-steps that are gradually taught in the person’s tempo, offering effective forms of support and systematically using reinforcers. Additionally, the person’s self-control and his/her own contribution to the learning process must be preserved. The motivation and engagement of people with PMD is furthered by relating to their initiatives and perception of the environment, by creating challenging situations and by introducing variation in the learning process. The importance of positive expectations and gaining successful experiences with this is stressed.

In the learning process technical aids can also be used (Davis, Young, Cherry, Dahman, & Rehfeldt, 2004; Murphy, Saunders, Saunders, & Olswang, 2004; Smith, Gast, Logan, & Jacobs, 2001). When selecting learning aids the individual’s cognitive and sensory-motor limitations and capabilities should be taken into account. Preferences for sensory perception of specific stimuli and materials should also be assessed in order to adequately shape the learning process.

An important focus of attention in the learning process is the alertness and attention of people with PMD. In research, these characteristics are put forward as an essential basis for learning and developing (Arthur, 2003, 2004; Foreman, Arthur-Kelly, Pascoe, & King, 2004; Guess, Roberts, & Rues, 2002). ‘Behavioral state assessment’ comprises the systematic observation of behavioral expressions of alertness in people with PMD. Research has shown that variables on the level of the individual (e.g., health status) as well on the level of the context (e.g., an active, interactive and social learning environment) influence the level of alertness of the individual (Arthur, 2003, 2004; Vlaskamp, de Geeter, Huismans, & Smit, 2003).

Even though people with PMD can acquire social adaptation skills, they need support in almost all daily life activities such as dressing, washing, eating, going to the toilet and so on (Nakken & Vlaskamp, 2002). Personal and intimate care therefore takes up a lot of time and it is important to pay attention to its quality (Carnaby & Cambridge, 2002).

Because communication plays a crucial part in the lives of people with PMD, we will look into this domain of adaptive behavior more closely. People with PMD rarely use spoken language, instead they express their wishes and feeling by way of pre- or protosymbolic communication such as facial expressions, movements, sounds, posture and muscle tension (Vlaskamp & Oxener, 2002). They send out unconventional and mostly idiosyncratic and context-bound signals that are often difficult to interpret. As such, a thorough knowledge of the person and the context is necessary to attach an adequate and consistent meaning to the person’s signals (Grove, Bunning, Porter, & Olsson, 1999). It is also very important that the team of professional staff and the parents confer on this matter and share experiences. For research demonstrates that direct support staff often only slightly agree with each other when it comes to interpreting affective expressions (Hogg, Reeves, Roberts, & Mudford, 2001).

Several studies deal with the question on how to support the communication of people with PMD in daily living situations (Daelman,
First, it is very important to regard the person as an active partner in communication. Analyzing videotaped interactions may offer support staff a clearer view of the person’s contribution and initiatives in the interaction and may help interpreting the person’s communication more adequately. As such, support staff becomes more able to attune to the person’s communicative abilities and to respond in a responsive and contingent manner to the person’s behavior. At first, many of the person’s signals have no conscious meaning but support staff attaches meaning to them by overinterpretation. Through shared attention towards objects and familiar rituals, both partners in communication build up shared meanings to which they may refer afterwards. As such, the person’s communicative behavior becomes more direct and goal-oriented and the person gets the opportunity to comment on actions and objects (protodeclaratives) or to ask something (protoimperatives). Reciprocity is encouraged by taking turns and by immediate or delayed imitation.

This process can be supported by technical aids, which include systems that play pre-recorded verbal messages when a button is pushed (e.g., Big Mack) and concrete objects (or parts) that refer to certain situations or activities (e.g., beaker: drink) (Jones, Pring, & Grove, 2003). Graphic-visual representations in the form of communication boards or communication books (e.g., pictos, photos) are also utilized. When selecting communication aids, the capabilities and preferences of the person must be taken into account. Other relevant criteria are age adequacy, availability and user-friendliness of the communication aids.

**Participation, Interaction and Social Roles**

It is important that people with PMD can participate actively in a variety of activities geared to their abilities and limitations and to their interests and preferences. Their perception of the environment is mostly orientated at their own body (Fröhlich, 1995). Therefore, sensory perception (by way of hearing, sight, taste, smell and touch) and perception of movement (by way of somatic, vestibular and vibratory stimuli) take on a central place in setting up activities.

Activities play an essential role in the personal development of people with PMD, as it is important that they enjoy being active, whether or not together with other people (Nilsson & Nyberg, 2003; Petry, Maes, & De Muynck, 2004; Wiersma, Beumer, Koedoot, & Vlaskamp, 2002). The activities should furthermore be sufficiently stimulating and challenging. For one of the objectives is to make people with PMD aware of their own capabilities and of their environment. They are encouraged to move, (re)act, manipulate and explore materials. In this way they obtain certain knowledge and insights and expand their options for action. In addition, activities are a way of building up contacts with support staff and group members.

Several authors stress the positive significance of social interactions with peers without a disability (Downing, 2001; Foreman & Arthur, 2004; De Muynck et al., 2004; Logan et al., 1998). The latter turn out to be responsive partners who, when supported, interpret the person’s communicative signals adequately and use effective strategies to build up positive interactions. The person with PMD gets the opportunity to participate, to enjoy interactions with others and to enlarge its social network. Therefore, currently, it is stressed that having people with PMD participate in regular class and leisure time activities may develop their sense of being part of the community.

Every person with PMD is an individual who has his own character and temperament. The challenge therefore is to discern and to take into account each person’s individuality in daily contacts and activities (Petry, Maes, & Vlaskamp, 2005). Esteem of and respect for their individuality is essential for people with PMD (Fröhlich, 1995). Moreover, it is important that support staff perceives, confirms and positively appreciates the person’s capabilities. As such, a feeling of positive self esteem can grow.

The positive self esteem that people with PMD feel is also linked to the degree of self determination they have. It is of great importance for people with PMD to feel that they influence and control their life and environment and that they can make choices. Research has demonstrated that people with
PMD are able to make choices (Lancioni, O’Reilly, & Emerson, 1996; Saunders et al., 2005). Support staff is expected to adequately build in options in the daily context and to contingently take into account a person’s preferences (Browder, Cooper, & Lim, 1998; Cannella, O’Reilly, & Lancioni, 2005; Green, Middleton, & Reid, 2000). As a result of the opportunity to make choices the person takes more initiatives and is more actively involved in activities (Cannella et al.; Cole & Levinson, 2002; Lancioni et al., 1996) and problem behavior is reduced (Cannella et al.; Lohrmann-O’Rourke & Yurman, 2001).

Several studies illustrate how to systematically examine the preferences of people with PMD (Hagopian, Long, & Rush, 2004; Hatton, 2004; Lancioni et al., 1996; Logan & Gast, 2001). These preferences can be investigated in an indirect manner (e.g., interviewing proxies) as well as in a direct manner. In the latter, the person is given (one after the other or in pairs) several alternatives (e.g., food, personal things, toys, sensory stimuli) and one observes if the person turns towards the stimuli or aside and how long the person focuses on certain stimuli. It is also possible to put the person in different situations in order to determine preferences for certain postures, interactions or activities. The stimuli, objects or activities for which the person has expressed a certain preference, can subsequently be built into the curriculum or used as reinforcers in a learning process. However, these preferences must be repeatedly retested, for they may change over time. Reid and Green (2002) have observed that there is but little agreement on the preferences of people with PMD between the results of a systematic investigation on the one hand and a questionnaire for support staff on the other hand.

Material aids may help the person to express certain choices (Lancioni, O’Reilly, & Basili, 2001). The person himself/herself may activate pleasant stimuli (light, music, toys) by using switches by hands, feet or head (Lancioni, O’Reilly, Singh, Oliva, & Groeneweg, 2002; Singh et al., 2003). Speech output systems make it possible for the person to turn a non-verbal question into a verbal message, e.g., by pushing a button or by touching on a board the photo of a favourite object or activity.

Health

Sensory motor functions. People with PMD often face problems with regard to their motor system such as spastic tetra- or quadriplegia, scoliosis, deformities, malformations, fragile bones and muscular lengthening. As a consequence, many people cannot sit, stand or move without support and they cannot use their hands and/or arms or only to a restricted extent. As such, they cannot move freely and their activities are extremely hindered (Nakken & Vlaskamp, 2002).

Measures need to be taken to prevent, compensate and/or treat the motor limitations. Furthermore, it is important to pay attention to a good posture. Regularly changing the person’s posture allows him/her to observe the environment from diverse angles, increases his/her bodily comfort and improves his/her social-communicative interactions (McEwan, 1992). Moreover, a good posture that maximizes movements of hand, arm and head is an important condition for learning (Smith et al., 2001). In order to make these changes of posture possible, adequate aids are used (e.g., positioning systems, supine board). Moving aids allow people with profound motor limitations to participate in activities in their immediate environment and to increase their freedom of movement (Nilsson & Nyberg, 2003). Finally, sensory-motor skills such as using arms and hands to manipulate objects, eye-hand coordination, posture control, mobility and orientation can be taught through goal-orientated activities.

An estimated 90% of people with PMD have profound, mostly cerebral, visual disorders and 25% have auditory limitations (Evenhuis & Nagtzaam, 1999; Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; van den Broek, Janssen, van Ramhorst, & Deen, 2004). Moreover, other senses, such as taste, smell and touch, are often damaged. It is obvious that these limitations affect the way people with PMD process the stimuli that are offered to them. Therefore, it is essential that sensory abilities and limitations are charted and taken into account when offering activities, making the environment recognizable and looking for adequate forms of communication.
Physical health. Physical well-being is for people with PMD no commonplace. They encounter several physical problems, e.g., regarding the bronchial tubes, the digestive system or urinary tract system (Veugelers, Benninga, Penning, & Evenhuis, 2004; Zijlstra, Vlaskamp, & Fonteine, 2004). Epilepsy also frequently occurs and has a large impact on the person’s alertness. Regular observation and registration of the person’s health status are therefore advisable. Physical problems can be registered and if possible their cause may be discerned and adequate medical treatment can be given. At the same time aggravations of existing health problems or complications can be avoided. Attention also has to be paid to signals that indicate pain and to pain control (Zwakhalen, van Dongen, Hamers, & Abu-Saad, 2001). Because of these medical problems many people with PMD take medication, which must be carefully monitored, adjusted and if possible cut down. For medication may cause a number of side effects such as reduced alertness or habituation and resistance. In addition, it is important to have an eye for the impact of health problems on the daily support of the target group (Zijlstra et al., 2004).

Feeding problems are a frequently occurring health problem. Research has shown that about 70% of the people with PMD suffer from gastro-oesophageal reflux (Böhmer et al., 1999). This results in oesophageal complaints, breathing complaints and behavioral problems. In addition to gastro-oesophageal reflux, other problems such as phlegm, bad digestion or swallowing and chewing problems make feeding difficult (Rouse, Herrington, Assey, Baker, & Golden, 2002). About 16% of people with PMD are tube fed (Inspectie voor de Gezondheidszorg, 2000). Support from nutritionists and speech therapists are necessary and meaningful in order to find adequate forms of support for people with feeding problems.

Mental health status. Behavioral problems seem to increase in proportion to the person’s cognitive and other disabilities (Emerson, 2001). Kiernan and Kiernan (1994) find a prevalence of 22% children with problem behavior (e.g., aggressive behavior, outbursts of anger, self injuring behavior, destructive behavior, rebellious behavior, stereotypic behavior) in a sample of schools for children with severe intellectual disabilities. These behavioral problems may impede the personal growth and development, relations with others and participation in the environment. Behavioral problems are often analyzed and treated from a multimodal point of view (Emerson, 2001). Behavioral problems may be related to the person’s genetic syndromes, neurological disorders or physical state of health (e.g., pain, fatigue) or may be an expression of fear, uncertainty, traumatic experience or psychiatric disorders such as depression or psychosis (Tsiouris, 2001). As a consequence, more and more attention is paid to preventing mood disorders in people with PMD (Phillip & Hogg, 2004; Ross & Oliver, 2002; Oliver, 2004). However, interpreting the emotional state of mind of people with PMD remains a difficult matter (Ross & Oliver, 2003). Limitations in the field of learning, social relations and communication furthermore make these children especially vulnerable. Not only individual factors may elicit problem behavior, but also interactional factors (e.g., lack of positive attention, expectations that are too high or too low, lack of own contribution, lack of control, negative interactions with group members) and contextual factors (e.g., group pressure, lack of adequate activities, difficult situations of transition). In many cases problem behavior persists because of a learning process of positive or negative reinforcement. Therefore, Emerson (2001) concludes that a clear understanding of problem behavior is only possible on the basis of a model directed at the interface between developmental, learning, neurobiological, psychiatric and ecologic processes.

Context
To give people with PMD adequate support the context has to meet certain requirements. We successively go more deeply into the relational support perspective, the characteristics of support staff and the characteristics of the environment.

A relational support perspective. People with PMD need other people who have an eye for the subtle way they express their needs and wishes and who are able and willing to respond to these needs and wishes (Vlaskamp & Verkerk, 2000). This relational dependence is
the core of the support process. However, dependence must not be regarded as a notion with a negative meaning, but rather as a means to develop one’s existence and as an essential condition for quality of life. The life of people with PMD is imbedded in relations with other people that give meaning to their existence. They can have meaningful living and learning experiences only when there are other people who support them.

The well-being of people with PMD is closely connected to establishing a safe attachment relation with familiar support staff (Petry et al., 2004; Petry et al., 2005; Vlaskamp, 1999). Such a relation is characterized by support staff making the person feel safe by their availability and sensitive responsiveness. The latter implies that support staff perceives the person’s signals, accurately interprets their meaning, selects adequate answers and reacts in such a way that the person’s needs are met (Clausen & Crittenden, 2000; Petry, Maes, & Vlaskamp, in press). As such, a feeling of basic safety and security evolves which enables the person to optimally develop his/her abilities, to feel competent and to explore the environment. This feeling of safety is also enhanced by making the environment surveyable, recognizable and predictable. People with PMD can better follow and understand what is happening in the environment when support staff adapt to their pace, announce what is going to happen, avoid sudden transitions and give them time to get used to (new) situations. Regularly recurring behavior patterns and routines, familiar support staff, permanent structures and a recognizable organization are things they can hold onto and which make their environment comprehensible and predictable. People with PMD can better follow and understand what is happening in the environment when support staff adapt to their pace, announce what is going to happen, avoid sudden transitions and give them time to get used to (new) situations.

Characteristics of support staff. In accordance with the relational support perspective, the importance of the relational skills of support staff is strongly stressed (Petry et al., in press). Support staff is expected to believe in the (developmental) capabilities of people with PMD, who need to be approached as competent persons who are able to enter into relations and to have control over their environment (Vlaskamp, 1999).

To be able to discern the needs of people with PMD, support staff needs to be attentive and committed. An attitude of receptivity is essential in order to check whether the person experiences support as it was intended to be. In a dialogue with the person support staff creates opportunities for the person to make his/her own contribution and actively gear their actions to his/her needs, wishes and preferences.

Working with people with PMD requires a great deal of motivation and commitment. Support staff is expected to critically reflect on their own beliefs, values and expectations, behavior and attitude (Maeckelberghe, 2004).

To be able to attune one’s actions to the above-mentioned support needs, support staff requires specialist knowledge and skills. High quality instruction and permanent training that is specifically oriented towards working with this target group may contribute to this. In research, a description is given of training programs that are directed at giving options to persons with PMD (Salmento & Bambara, 2000), at offering support in a well-considered and reflexive manner (Singh et al., 2003), at actively and adequately supporting them to participate in activities (Jones et al., 2001) and to improve mutual communication and interaction (Bloomberg, West, & Iacono, 2003; Dobson, Upadhyaya, & Stanley, 2002; Realon, Bligen, La Force, Helsel, & Goldman, 2002; Roemer & Van Dam, 2004).

Characteristics of the support environment. Supporting people with PMD involves many people who must cooperate intensively (Petry et al., in press; Vlaskamp, 1999; Zijlstra, 2003). This presupposes a shared responsibility and a full partnership between parents and professional support staff. Parents have acquired very important expertise with regard to their child, which is why it is important that their experience and expertise is exchanged with professional support staff and that it is taken seriously. It is necessary that parents and professional support staff pass on information to each other because of the person’s limited communicative abilities. In addition, parents want to have a say in the support process and to participate in deciding which objectives will
be worked on and what shape and content will be given to their child’s support. Finally, sound communication between parents and professional support staff is essential for tuning the context of family, school and support in to one another and for enriching the parent’s and professional support staff’s competence in giving sensitive support to the person with PMD (Owen, Ware, & Barfoot, 2000).

The same is required of the cooperation between members of professional support staff (Orelove & Sobsey, 1996; Petry et al., in press; Rainforth & York-Barr, 1997; Smith et al., 2001; Vlaskamp, 1999; Zijlstra, 2003). It is essential that the work of all disciplines concerned with supporting people with PMD, is integrated. Together they decide which objectives they want to achieve and which approach best fits in with the person’s needs, wishes and capabilities. They are experts in their own discipline, but they can also learn from other disciplines. It may for instance be desirable that the physiotherapist teaches the other team members how to further the child’s posture. Good teamwork is characterized by an open communication and consultation between disciplines.

For people with PMD, continuity in support is essential (Zijlstra, Vlaskamp, & Buntinx, 2001). They need a stable environment with familiar people in whose company they feel safe and understood. Employing temporary workers and applying a shift system make it more difficult to build up or sustain a relationship. People with PMD not only need permanent support staff, but also a sufficient number of support as well as medico-therapeutic staff. Tøssebro (1995) demonstrated that support staff in groups of one to five people paid more attention to their individual wishes and reacted better to their communicative signals than in larger groups.

Finally, supporting people with PMD must be goal-oriented and methodical (Petry et al., in press; Zijlstra, 2003). More specifically, this implies that in an individual support plan or educational programme knowledge is systematically collected on the person’s capabilities, limitations, wishes and preferences. Concurrently, an analysis is made of the resources and limitations of the family and of other contexts that are relevant for the person. Furthermore, all parties concerned discuss how support can be optimally geared. Together they determine objectives and steps that are to be taken in order to realize them. They also regularly check whether the planned objectives have been realized and whether one has proceeded as agreed upon. Objectives and content has to be geared to the person’s individual learning and developmental capabilities. For each person must be able to follow his/her own life and learning track that answers to his/her capabilities, needs and interests.

Discussion

At the beginning of this paper we introduced Anna, a girl with PMD. A description of Anna using the 2002 AAMR System (Luckasson et al., 2002) would without a doubt have rendered a richer, more complete and more balanced picture. The multidimensionality of the model makes a broader characterization possible with the description of a person’s functioning on different dimensions. Within each of these dimensions attention is paid to the person’s capabilities, limitations and needs. It is a functional system in which the functioning of people in daily situations takes a central place with an eye for an individual’s capabilities and not only for his/her limitations (Buntinx, 2003). A description of the target group according to the 2002 AAMR System invites us to focus not only on the person with PMD but also on the context that can have an impeding or stimulating influence on the person’s functioning and offer adequate support. Another important aspect in the 2002 AAMR System is the attention for the interaction between the dimensions. The complex interaction between the capabilities and limitations of people with PMD on several domains is very decisive for their functioning. A final advantage of the 2002 AAMR System is that the different dimensions are not typical for describing people with (intellectual) disabilities, but have a universal validity (WHO-FIC, 2002 in Buntinx). As such, people with PMD are not isolated as a separate group. Throughout the description it becomes clear that people with PMD have the same needs as other people with regard to participation, relations, choices, competences and physical and socio-emotional well-being. It also becomes appar-
ent that on each of the dimensions the needs of the target group require specific support.

Nevertheless, using the 2002 AAMR System to describe the support needs of people with PMD, has also some disadvantages. Certain aspects that are important in the functioning of the target group fit difficultly into the model or are interpreted too limited in it. An example is communication. In the 2002 AAMR System there is only room for a description of the person’s communicative skills whereas for people with PMD communication is best looked at more broadly as a communicative process between the person with PMD and support staff. The communicative and relational aspect takes on such a central place in people with PMD that it influences all other aspects of functioning. As a result, the theme of relation, interaction and communication repeatedly recurs in the description of the support needs using the 2002 AAMR System. The interdependent character of support, that forms a thread throughout all dimensions of functioning of people with PMD, fits difficultly into one dimension of the model. Other authors also pointed out this neglect of the relational perspective in support (Buntinx, 2003; Reinders, 2000; Vlaskamp & Verkerk, 2000).

A description of the support needs of people with PMD using the 2002 AAMR System can in several areas offer a surplus value for practice and research as well as for policy. In practice, the AAMR framework is usable for the characterization of individual clients. The description presented in this paper can be operationalized in concrete topics and items that give direction in assessment of this target group. The presented support needs on each dimension offer guidelines for interventions and activities and they can function as a starting point for determining and evaluating the range of support that is offered to people with PMD. In research, an accurate description of the target group has the advantage of spotting gaps in research. The overview of literature shows that the attention of researchers for this target group has increased substantially during the last years. Nevertheless, an expansion and deepening of the research on all domains remains necessary. Moreover, a clear delineation of the target group promotes an unambiguous interpretation of research on the (needs of the) target group and on the place where and the manner in which they are supported. Finally, policy benefits from an accurate description of the support needs of this target group. It offers an insight in the problems of people with PMD and aids the making of adequate policy. Additionally, evaluating and assessing the extent to which new policy developments are geared to the support needs of the target group becomes easier.

This overview of literature presents the state of the art of research on the support needs of people with PMD. Nevertheless, we do not pretend to give a complete overview. For instance, some specific intervention studies were not included although they could yield useful information on the support needs of the target group. An overview of literature on intervention strategies and their effectiveness would therefore be a useful addition to this overview on the support needs of children with PMD.

References


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Abstract: The development of self-determination skills in individuals with developmental disabilities is a primary focus of curriculum development in the field. Research over the last decade has identified the components of self-determination and provided an analysis of individuals' acquisition of skills in this area. A key concern that has been less addressed is the ethical considerations of instruction in self-determination. Using a model developed by Bredberg and Davidson (1999), four foundational elements in ethics are explored with reference to self-determination: justice, respect for economy, beneficence, and non-malfeasance. After a discussion of these four prongs, implications for the development of curriculum in this area are explored.

Self-determination has become a core concern in the field of special education, particularly for adolescents with developmental disabilities. It implies a set of skills and behaviors, that a student possesses, characterized by descriptors such as self-regulatory, goal-oriented, and independent (Karvonen, Test, Wood, Browder, & Algozzine, 2004). The importance of self-determination has been affirmed in research, practice, and the number of articles written on this subject. There has been, however, limited attention given to the connection between what are deemed ethical teaching practices and the focus on self-determination. This article is an attempt to help bridge this gap.

Four components of self-determination have been identified in the literature. These components are: the ability to act autonomously; the capacity to self-regulate behaviors; the ability to act in an empowered way; and being able to act in a self-realizing manner (Bremer, Kachgal, & Schoeller, 2003; Palmer & Wehmeyer, 1998; Stancliffe, Abern, Spring-
ning. If special educators do not realize that self-determination instruction needs to begin early and do not carefully plan for making self-determination an integral part of a student’s transition services, the implications can be grave.

The purpose of this paper is to examine self-determination as an issue in the lives of persons with developmental disabilities in terms of ethics. The first question that must be addressed is the impact of self-determination on the lives of these individuals. If self-determination is a significant life issue, what is taught and how it is taught is clearly an ethical issue. Second, this paper will consider how to determine what is ethical in teaching self-determination by using a four-prong test identified in the literature on ethics and instruction [i.e., justice, respect for autonomy, beneficence, and non-maleficence (Bredberg & Davidson, 1999)]. After identifying the components of ethical behavior, attention then focuses on key ethical issues for teachers when addressing self-determination. Finally, the paper focuses on the components of ethical self-determination education based on current research as well as the four-prong ethical test in order to provide a clearer sense of key issues that teachers need to address when dealing with self-determination in an ethical manner.

Self-Determination in the Lives of Persons with Developmental Disabilities

Wehmeyer and Palmer (2003) researched the impact of self-determination on the lives of students with disabilities three years after they had graduated from high school. They sampled 94 students from seven states who were identified by IDEA definitions as having a learning disability or mental retardation. At the time of the students’ graduation, Wehmeyer and Palmer had the students complete an initial survey in which they collected self-determination data.

Wehmeyer and Palmer (2003) then followed up with the students after one year and again after three years. They reported that students with higher levels of self-determination at the time of graduation had better financial independence, including things like being able to maintain a checkbook and being able to pay for groceries at the times of follow-up. The persons identified as having high self-determination also were able to access jobs, which allowed them to gain benefits like sick leave, medical insurance, and vacation. Additionally, looking at the sample three years past graduation, the high self-determination group was also more likely to be living independently (Wehmeyer & Palmer, 2003). While some of the variances correlated with level of intelligence (e.g., those with lower IQ scores were more likely to have lower self-determination scores), these researchers hypothesized that the greater impact on better life outcomes came from self-determination skills rather than intellectual level.

Wehmeyer and Schwartz (1998) also studied the relationship between self-determination and quality of life in fifty adults with mental retardation who were living in a group home situation. Participants were given the Quality of Life Questionnaire developed by Schalock and Keith (1993). The questionnaire is a 40 item, widely used questionnaire. They reported a modest correlation (i.e., $r = .25, p = .04$) between self-determination scores and quality of life scores. Interestingly, they had previously found that persons in a group home setting had quality of life scores that were lower than those in a more independent setting. Although there was an expectation that the quality of life scores of the persons living in the more restricted environment would be lower, the researchers found that self-determination scores were still related to more positive quality of life outcomes despite the more restricted environments.

Another aspect of self-determination was explored by Palmer and Wehmeyer (1998) when they evaluated the impact of hopelessness on self-determination. In this study, 429 students who ranged in age from 10 to 19, and who had cognitive disabilities, were surveyed. This study was based on a model developed by Zimmerman (Palmer & Wehmeyer). One characteristic of self-determination is empowerment and, in the model, Zimmerman linked feelings of hopelessness to a lower level of empowerment. They surveyed the students and found that those who were identified as mentally retarded had the highest hopelessness scores. Palmer and Wehmeyer noted several reasons why it was more likely that these particular students had the lowest scores. Rea-
sons cited included the lack of choice they had to exercise in their lives and their restricted learning environment (mostly in self-contained classrooms).

Stancliffe et al. (2000) examined self-determination and personal control levels in decision-making of persons with mental retardation. They evaluated the degree of decision-making and personal control of the respondents based on the type of guardian that each person had been appointed. Respondents were all from residential facilities and they either had a conservator or a guardian, or they had been making their own decisions. They found that the persons without any type of court-appointed conservator or who did not have a guardian exerted the most control over their own lives. Persons with a court-appointed conservator were next in terms of exerting control in their lives. Those with guardians expressed the lowest levels of control. Stancliffe et al. also noted that they had evaluated the level of disability, and that it had less effect than did the type of guardian on the control scores. Persons who had guardians and conservators making decisions for them may not have needed the level of care being provided as evidenced by the differential scores. The researchers point out, one key characteristic of self-determination is the ability to exert control over one’s own life. They were able to demonstrate that it may be possible for persons with mental retardation to handle more significant decision-making tasks than originally expected because the disability was not the decisive characteristic in this study. The amount of decision-making exerted by each respondent was impacted more by the type of guardian than by the extent of disability.

Self-determination is an important characteristic and skill that persons with developmental disabilities need to attain. Clearly the model development work and research in this area support the fact that self-determination is a critical skill that persons must be taught. Consequently a persuasive argument has been made for the importance of self-determination training and education for persons with developmental disabilities. The focus thus becomes how do we make ethical choices concerning self-determination?

Making Ethical Choices

Determining how to measure what is to be considered ethical behavior in any context is a difficult task. In considering the literature on ethics, there are a variety of ways that this term is defined and evaluated. Greer (1988) examined ways to look at ethics that have been applied to special education. For example, some individuals use an ethical construct that is based on the notion that there is a universal law that must be upheld. Greer noted problems with this perspective because many societies and cultures do not subscribe to a universal sense of right and wrong.

A second way to make ethical arguments is to look at ethics as a moral code (Greer, 1988). The goal is to do the “right thing”. The difficulty in this case, as pointed out by Greer, however, is that this type of ethical formula becomes problematic when the issues become complex and varied like many of those associated with the field of special education and concerning people with disabilities.

A third way to make ethical decisions discussed by Greer (1988) is to make them based on relationships with people. In other words, the primary focus should always be on putting people first and never treating a person as a means to an end. The difficulty with this argument however, is that it tends to fall into the world of relativism and people sometimes associate a person’s best interests with their own wishes, a dilemma often experienced in the world of special education.

Paul, French, and Cranston-Gingras (2001) also discussed ethics and special education. They noted that the field of special education historically has been under attack on an ethical front as related to accountability and its ability to demonstrate clear benefits for students. Several examples in the history of special education of questionable ethical practices have included institutionalization, the use of biased testing and assessment practices, and the disproportional representation of minorities and children and youth from lower SES homes in special education (Paul et al.). Paul and colleagues note that it is vital to look at such issues and to realize that ethics not only needs to be discussed but that special educators need to come to a firm understand-
ing that ethics involves responsibility and responsible decision making.

Greer (1988) reaffirmed the code of ethics as it was developed by the Council for Exceptional Children. First, special educators are to be professionals who are, “committed to developing the highest educational and quality of life potential of exceptional individuals” (Greer, p. 393). Additionally, the code of ethics states that, “special education professionals exercise objective professional judgment in the practice of their profession” (p. 393).

For the purposes of this paper, the subjective concept of ethics will be considered within the context of a reasonably objective standard. In normative ethics, there is a four prong test that has been used to assess what is ethical and what is not. These four prongs are justice, respect for autonomy, beneficence, and non-maleficence (Bredberg & Davidson, 1999). These four concepts are foundational elements when making an ethical argument and seem to address the concerns raised by Greer and reflected on other traditional models of ethics and generally encompasses the ideas addressed by Paul et al. (2001) as noted above.

To best understand their applicability, the four prongs must first be defined. Justice is a term that refers to “fairness” (Bredberg & Davidson, 1999). This term concerns the assumption that one group will not be either advantaged or disadvantaged relative to another group. The second term is respect for autonomy, which refers to a respect for the independent personhood of another. The third term is beneficence, which refers to working for the benefit of another. In terms of teaching, this term refers to working for the benefit of a student. The final term is non-maleficence - that is, not causing harm to a person. Based on this four prong test, ethical behaviors should rise to a standard of being fair, respectful, beneficent, and not harmful.

Self-Determination: Application of an Ethical Model

Teaching and assessing self-determination as a part of the transition process for persons with developmental disabilities is an ethical responsibility, first and foremost. Following the framework of Bredberg and Davidson (1999), the initial issue to be explored is justice. Is it fair to not teach and help students to become self-determined? Clearly, from the extant research in this domain (e.g., Myers & Eisenman, 2005; Palmer & Wehmeyer, 1998 Stanciliffe et. al, 2000; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998), self-determination can improve adult outcomes (e.g., salary, benefits, and overall quality of life). The sense of justice reflects Bredberg and Davidson’s (1999) focus, as reflected by teachers of students with disabilities. They concluded from their research that, “a child’s right to participate in schooling was not subject to qualification or differentiation. It was not earned, nor was it bestowed as an act of charity. It was objectively a right, situated in the child’s person. The teacher did not regard the child’s placement as within a hierarchy educational entitlement; she worked at realizing an entitlement” (p. 6).

The second prong of the test is respect for autonomy. Self-determination, as previously established, is about an individual having some say in his or her own life. Clearly teaching self-determination skills that enable a person to be more in control of one’s own life is in line with the second part of the test of ethical considerations. At the same time, the question of autonomy always creates some challenges for teachers and, at times, for families. As Bredberg and Davidson (1999) noted “teachers were not unaware of the potential conflicts between their recognition of students’ autonomy and concerns for their best interests . . . They recognized the obligation of responsible adults to make decisions in children’s interest, even if those decisions went against the immediate wishes of the child” (p. 7). Thus, the decision to teach self-determination may be made by a responsible adult but the outcome of the instruction should enable individuals to make choices for themselves in a future context. Teachers and families need to appreciate this goal.

The third prong in the test is beneficence. Bredberg and Davidson (1999) indicated that beneficence was the primary ethical principle governing the actions of teachers of individuals with more significant disabilities. As they noted from their research with teachers, “the obligation to choose the best course of action to serve the child’s best interest is not . . . an
individual disposition but a mandate to be shared by everyone involved with a child’s care and which demands the achievement of consensus among them” (p. 5). Does teaching self-determination benefit the person? Clearly, as previously discussed, not only does self-determination improve the likelihood of everyone being treated more equally in society, it also enhances many other adult outcomes.

Finally, the last prong in the ethical test (i.e., non-malfeasance) addresses whether or not teaching self-determination does no harm. The emphasis on non-malfeasance has received less attention as teachers have considered self-determination programs for students with disabilities. However, as Smilansky (1997) has noted, we should not overlook the fact that a critical ethical principle is that of ensuring that no harm comes to the individual for whom we are providing instruction. Clearly, the research again indicates that self-determination improves life outcomes for all persons and ultimately for their families as well. Thus using the four-prong test, there is a strong ethical basis for positing that self-determination skills must be taught to all students with disabilities. Failing to teach these skills can not only cause harm, but it also increases the chances for injustice. It could potentially lead to a person with a disability being denied or losing his or her personal freedom.

Despite clear evidence that self-determination can and must be taught, Karvonen et al. (2004) reported from a review of the literature that while 75% of teachers at the middle and secondary levels rated self-determination skills as important, only 55% could attest to those goals actually being included in IEPs. Additionally, when Wehmeyer and Schwartz (1998) examined 895 IEPs, they found that none included self-determination skills in transition goals. Additionally, Mason, Field, and Savilowsky (2004) polled teachers and administrators and found that only 8% reported that they were satisfactorily addressing self-determination goals with students in their IEPs. These results may be explained in part by the fact that self-determination skills are seldom assessed as part of the IEP or transition process.

Curricular Considerations

There is clearly a foundation for making the ethical argument that teachers should include self-determination skills within the curriculum when teaching persons with developmental disabilities. Beyond this assertion, however, there is evidence that teachers are given limited preparation and guidance on how and when to assess and include these skills and what should be included in the curriculum. The next challenge, therefore, is to determine what should be included in a teacher’s preparation program that can guide them in behaving ethically regarding self-determination for their students. Wehmeyer (2002) composed a list of essential skills and knowledge that a person must obtain in order to be self-determined. These skills include: learning to set personal goals; learning to solve problems; learning to set personal goals; learning to solve problems; learning to make good choices that acknowledge personal interests and preferences; learning to participate in decisions that impact on a person’s life; learning to advocate for himself or herself; learning to create a plan to achieve goals; and learning to self-regulate daily actions.

Wehmeyer (2002) identified a list of age-appropriate activities that can be used to guide the curriculum for persons with developmental disabilities regarding self-determination. He stated that these skills can be infused into the curriculum even in the early elementary grades with activities that provide opportunities for choice making and allow the child to exert control. Along with choice making, Wehmeyer indicated that the choices needed to have natural consequences so that students can learn to see the link between actions and their consequences. He also encouraged teachers to include the use of modeling via a think aloud approach to problem solving. Students should then be encouraged to use this technique for themselves. At this level, he also encouraged teachers to let students begin to self-evaluate their choices based on standards. At the upper elementary level and into the middle school grades, Wehmeyer encouraged decision making, but he indicated that this should now include the added component of analyzing options and the benefits and drawbacks of each choice. He
also encouraged teachers to enable students to examine past behavior to achieve insight from history. At the middle school level, students should also be encouraged to set personal goals, including educational goals. Once these goals are established, of course, steps to achieve those goals should be established. Also at the middle school age, students should not only be looking to evaluate their work based on a model but also identifying ways to improve their performance. At the high school level, Wehmeyer stated that students should be making day-to-day decisions as well as setting their own academic and post-school goals. One key aspect that is particularly stressed at the high school level is the connection between day-to-day activities and long-term outcomes.

Karvonen et al. (2004) reviewed the literature on self-determination to determine the kinds of programs that are available to teach these skills and to assess outcomes. Ethically, given the four prong test, self-determination should be taught in a way that preserves justice and autonomy as well as creating benefit without harm. They found 411 journal articles written on this topic and 61 different curricula. Of those articles, however, the studies tended not to be longitudinal and few actually explored adult outcomes (Karvonen et al.).

Karvonen et al. (2004) further considered those practices that held the most promise and showed the greatest chance of enhancing self-determination. Generally speaking the programs that were the most successful had an explicit self-determination curriculum. They also used teaching methods that helped students to be involved in their own educational planning. Finally, the sites with the most success clearly encouraged students to make their own choices outside the instructional environment.

One of the first places that students can begin to utilize self-determination skills is in the IEP process. Karvonen et al. (2004) identified lack of student involvement in the IEP process as a potential hindrance to self-determination. There are a variety of methods to enhance student participation in the IEP process. In sites that had programs where self-determination could be measured, all had strategies for keeping students involved in their own educational planning (Karvonen et al.). The amount of planning and coaching varied by school and program, but it was always a part of the program. Some schools even had students using person first language and ultimately writing their own IEPs.

Bassett and Lehman (2002) have developed a practical resource that provides teachers with ways to include students in a variety of conferences that affect their lives and require key self-determination skills. These practical ideas focus on student-led conferences, student-centered planning sessions, and student-directed meetings. Their suggestions underscore the need to provide these experiences at an early age and to teach students to be true participants.

Myers and Eisenman (2005) explored the idea of having student-led IEP meetings. In order for a student to lead his or her own IEP meeting, he or she must: have a clear idea of what he or she wants in life; take responsibility for educational and life choices; and serve as an advocate for himself or herself. Clearly the idea of having a student-lead IEP is in line with the ethical arguments being raised for self-determination education. There is, however, one area of caution. If children are unable to represent their ideas or use poor judgment to harm themselves, the teacher and IEP team must make sure that the meeting does not result in detriment to the child. The idea is to provide opportunities for students to become more self-determined—not simply give them freedoms that they are unable to manage and cause them to flounder. Of successful programs, Karvonen et al. (2004) noted that they began with students in middle school not only talking about self-awareness, strengths and weaknesses, but also how to behave in IEP meeting.

There are a number of options available for the design of self-determination curricula. As previously noted, however, many have not been studied and do not have longitudinal data to show that the skills being taught are generalized beyond the classroom experience and several years out (Karvonen et al., 2004). From an ethical standpoint, and consistent with the four-prong test, beneficence seems to be at issue with untested programs. An ethical program is one that is clearly beneficial to the student. Ethical programs, therefore, must have empirical research to support their use.
Some of the curricula that were explored in Karvonen’s et al. (2004) study and were proving to be successful included the Self-Advocacy Strategy, the Become Your Own Expert, and the Choicemaker program. Some schools had even used a program they had designed with university assistance. Based on Algozzine, Browder, Karvonen, Test, and Wood’s (2001) previous meta-analysis of self-determination programs, they determined that, of the programs that had been used extensively enough to evaluate, all produced a positive change in the students, in comparison to those that did not have access to such programs. As research on self-determination curricula continues, those programs with the highest levels of efficacy are increasingly likely to be identified from the programs available.

One area that has largely been overlooked in the discussion on self-determination instruction is the assessment component that identifies areas needing attention. A number of informal instruments have been developed that teachers can use to identify skill areas (see Clark, Patton, & Moulton, 2000). As previously noted, self-determination must be a key piece of the transition process. Noting that a comprehensive assessment of transition needs should be conducted in the early stages of the formal transition process, Clark and Patton (2006) included “self-determination” as a major transition domain in their transition instrument (Transition Planning Inventory). The intent of including this area was to ensure, as much as possible, that this important transition area was not overlooked during the assessment and planning phases of the process.

A key characteristic of successful self-determination programs is that they encourage students to make their own choices and decisions beyond the instructional environment. In the sites with the most effective programs, students were taught about decision-making and then immediately put them into practice (Karvonen et al., 2004). Factors that researchers saw in successful programs were: teachers making sure students made informed choices; students being given a range of options; and teachers occasionally disagreeing with their choices—forcing the students to think for themselves.

Discussion

The extant literature supports the notion that educators need to assess and teach self-determination because it makes a significant difference in the lives of persons with disabilities. Skills implicit in the domain of self-determination are clearly among the critical foci for special education, especially at the secondary level and with regard to transition services (Johnson, Stodden, Emanuel, Luecking, & Mack, 2002). Given that it is vital, the discussion in this paper has focused on to how to determine the ethics of teaching self-determination. For the purposes of this article, a four-prong test of justice, respect for autonomy, beneficence, and non-malfeasance was used as the test to determine if a program has an ethical foundation.

Based on contemporary research, a teacher has an ethical responsibility to teach self-determination and encourage its development in students with disabilities. Beyond establishing that self-determination should be taught, a determination has to be made on how to decide on an ethical basis for teaching this skill. Certainly any choice made needs to be fair, show respect for the humanity of the student, benefit the student, and not cause harm. Since self-determination instructional programs are relatively new, it is sometimes difficult to determine what will benefit a person with a disability. Research on several programs that have proven to be successful suggest that the best practices include programs with a well-defined curriculum, programs that involve students in their educational planning, and finally programs that make students take responsibility for choice-making in and out of the instructional environment.

While this is a good place to begin thinking about ethics and the teaching of self-determination, further research is needed especially to investigate longitudinal outcomes of self-determination programs. Do the skills being taught translate into higher self-determination scores outside of the classroom and, in turn, do they lead to better outcomes for students in their lives outside the school environment?

Outcomes for students with disabilities can be improved by identifying the self-determination needs of students and by implementing
self-determination teaching strategies. When this evidence is presented not only as empirically validated but also as an ethical responsibility, it can assist teachers in examining their current teaching practices to make sure that these skills are being taught in an ethical manner. Morris’ (2001) statement about “care” can be generalized to education, “if it does not enable people ‘to state an opinion’, ‘to participate in decisions which effect their lives’, and ‘to share fully in the social life of their community’, then it will be unethical” (p. 15).

References


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Comparison of Engagement Patterns of Young Children with Developmental Disabilities between Structured and Free Play

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Abstract: Children with developmental disabilities are slower to develop skills at intentional and symbolic communication than typically developing children, and may rely on atypical patterns of preintentional behaviors to support more complex communication development. The present study compared complex gaze engagement behaviors elicited by 25 preintentional children with developmental disabilities during two interactive contexts: structured object-based play with an examiner and free play with parents that included social play. Children with developmental disabilities demonstrated more onlooking and complex engagement behaviors (i.e., coordinated joint and combined joint), and less unengagement in structured play than in free play. The degree of change in engagement behaviors between play settings was not significantly associated with children’s receptive language, motor, or overall developmental scores. Clinical implications for adapting play and partner behaviors to support more complex engagement behaviors in this population are discussed.

Early gaze behaviors during shared attention contribute significantly to children’s development of complex attention and language skills (Baldwin, 1995). Joint or shared attention is defined as a state in which the attention of a caregiver and child are focused on the same object or activity (Bakeman & Adamson, 1984). Bakeman and Adamson reported a developmental continuum of infant gaze behaviors during shared attention, which increase in complexity from gaze at a person or object to coordinated 3-point gaze shifts between people and objects. Dyadic measures of gaze, vocalization, and smiling at 6 months were all correlated with language measures at 6 and 12 months (D’Entremont & Iype, 2002). More complex attention behaviors in the second year, particularly parent-supported incorporation of symbols into shared attention, predicted children’s language at 30 months (Adamson, Bakeman, & Deckner, 2004). Gaze following in infants as young as 6 months was significantly associated with later language outcomes in typically developing children in their second year (Morales, Mundy, & Rojas, 1998) and cocaine-exposed infants in their third year (Neal & Block, 2001).

Research supports the importance of frequent shifts in gaze for early development of complex attention behaviors. At five months, infants who looked relatively longer at stimuli tended to have difficulty disengaging from the look, and did not sample novel visual information as readily as short lookers (Jankowski, Rose, & Feldman, 2001). Dynamic stimuli (red lights flashing) that systematically drew infant attention to relevant information improved novelty behaviors of long lookers to the levels of short lookers. In interaction, infants needed dynamic rather than static cues to follow adult gaze direction if they did not already show spontaneous joint visual attention (Moore, Angelopoulos, & Bennett,
Without active intervention, infant looking patterns are stable across time in early development; children who were distractible or long lookers at nine months continued to be so at 31 months (Kannass, 2001).

Infants increase complexity of their gaze behaviors under some interactive circumstances more often than others. Parent nonverbal behaviors (i.e., touch, gestures) elicited infants’ gaze toward the mother’s face in typically developing 22 week-old infants (Stack & Arnold, 1998). Typically developing newborns exposed to interactive parental behaviors looked more at their mother’s faces than newborns exposed to parental behaviors that were not interactive (Wendland-Carro, Piccinini, & Millar, 1999). Five-month old infants gazed longer at toys that a mother was holding if the mother used nonverbal attention behaviors such as shaking, waving, tapping, or pointing to toys (Leiba & Stack, 2002). At 12 months, mothers decreased their use of direct strategies (physically assisting or touching objects with the infant), and increased indirect toy demonstration strategies. Children’s skills at 3-point gaze shifts at 12 months were related to infant temperament (smiling/fear) and amount of eye contact, as well as caregiver demonstration with toys at nine months (Vaughn & Block, 2001). Parent strategies that maintained a 10-month-old infant’s attention to an object were associated with better infant focused attention at 18 months, but strategies that redirected attention were negatively correlated with later infant attention (Bono & Stifter, 2003).

Specific early gaze behaviors that are delayed in children with developmental disabilities are particularly important for the complex gaze shifts that support symbolic communication development. Looking at parents before and after an unexpected event in 6 month-old infants was associated with skills at 3-point gaze shifts (looking back and forth between parent and toy) at 12 months (D’Entremont & Iype, 2002). In contrast, looking only at the parent was negatively correlated with 3-point gaze shift development, interpreted as difficulty in children disengaging their social engagement to shift gaze focus. Prelinguistic children with developmental disabilities who showed relatively more person-only engagement (e.g., look and smile to adult) developed significantly fewer intentional requesting behaviors than children who engaged reciprocally with objects and people (Yoder, Warren, & Hull, 1995). Preintentional infants with Down syndrome (six months) engaged less frequently with toys and shifted less often to toy gaze at mother’s prompts than matched high-risk preterm infants, even though both groups of children had no severe sensory or physical impairments (Landry & Chapieski, 1990). Children with Down syndrome showed greater difficulty shifting attention between toy and person referents in a cognitively challenging task than mental-age peers, and children with better language and cognitive skills spent more object-focused time than person-only time (Kasari, Freeman, Mundy, & Sigman, 1995). Preintentional children with developmental and neurological disabilities had relatively high rates of person-only gaze and fewer 3-point gaze shifts, compared to those reported for developmental peers (Arens, Cress, & Marvin, 2005; Cress et al., 1999). Difficulty in object-focused or shared attention for children with neurological impairments has been related to physical impairments (Wasserman, Allen, & Solomon, 1985) and neurosensory issues such as abnormal reflexes and unfocused gaze patterns (Yoder & Farran, 1986).

Interactions that increase complex gaze with young infants with disabilities involve active partner cueing that follows infant attention within shared object-based activities (e.g., Harris, Kasari, & Sigman, 1996), whether or not the interventions specifically target gaze behaviors. For parent dyads with either typically developing or disabled children, coordinated attention was demonstrated most consistently in play episodes of repetitive game-like sequences (Yoder & Farran, 1986). Children with developmental disabilities took a more active role and initiated more communicative behaviors during structured play with experimenters than unstructured play (Iacono, Waring, & Chan, 1996; Salmon, Rowan, & Mitchell, 1998). An intervention designed to increase prelinguistic requests (Prelinguistic Milieu Teaching) also increased coordinated gaze shifts and vocalizations for joint attention in children with developmental disabilities (Yoder & Warren, 2001). Nonspeaking persons with severe disabilities who
learned symbolic communication during communication intervention also increased the number and complexity of their attention shifts significantly more than nonlearners (Abrahamsen, Romski, & Sevcik, 1989).

Even children at risk for motor impairments can effectively develop complex attention behaviors under conditions conducive to shared attention. Infants with cerebral palsy initiated less eye contact and fewer referential gazes than children with typical development (Hanzlik, 1990). Similarly, children with neurologic and developmental disabilities with greater motor impairment showed lower rates of object gaze and supported joint attention (Arens et al., 2005). However, high-risk preterm infants responded to parent attention prompts as well as children at low motoric risk when parents noticed and followed children’s attention; high-risk children only decreased motorically complex attention behaviors when parents attempted to redirect child attention (Landry, 1995). Arens et al. noted anecdotal improvement in object gaze and gaze shifts when parents actively structured toy play to elicit communicative behaviors. Specific effects of structured play on attention behaviors of children with specific motor risks have not yet been established.

Children with disabilities may not respond as readily to partner prompts for attention as expected for typical or high-risk peers. Infants with Down syndrome required more specific interactive prompts (e.g., giving toys and attention-directing gestures) than preterm infants, and did not improve attention in toy play as well with general demonstration prompts that required independent child responses (Landry & Chapieski, 1989). Typically developing children could shift from onlooking to joint attention behaviors during peer play, but children with Down syndrome showed this increase in attention complexity less often and only with parent structured object play (Legerstee & Weintraub, 1997).

Recognizing and maintaining infant attention can be difficult for parents of preintentional children with developmental disabilities in free play, particularly if those disabilities include motor and/or sensory impairments. Adult viewers were more accurate and confident in recognizing referential looks by children without disabilities than looks by children with developmental delays or Down syndrome (Walden, Blackford, & Carpenter, 1997). Parent responsiveness increased significantly with the development of intentional communication in prelinguistic children with developmental disabilities (Yoder & Warren, 2001), attributable in part to the difficulty of recognizing and responding consistently to preintentional signaling behaviors in children with disabilities (Iacono, Carter, & Hook, 1988). Preterm children withdrew their attention from shared toy interaction more often than full-term infants, and did not spontaneously stay engaged in activities as long as their parents (Landry, 1986). Parents of infants with motor impairments showed less frequent and shorter looks at their infants and shared toys than developmentally matched controls, even when infant gaze was not significantly different less than children without disabilities (Karns & Romero, 1997). The authors proposed that parents of children with motor impairments were providing less attention and gaze stimulation than the infants were capable of utilizing during interaction. When children’s communication modes differ from parents (e.g. deaf children of hearing parents), parents may spontaneously engage child attention to toys with general strategies such as object movement, but are less likely to produce focused attention cues used by deaf parents (such as tapping objects or waving) without parent coaching and support (Waxman & Spencer, 1997).

The present study addressed whether children with developmental disabilities at risk for being nonspeaking produce more complex gaze behaviors in structured than unstructured communicative interactions. If children with developmental disabilities engage in structured play focused on communicative intentionality with toys, will they also increase the complexity of their object-related gaze behaviors, over what they produce in unstructured free play with parents? Second, will children with developmental disabilities who demonstrate improvement in complex gaze behaviors in structured play have higher overall developmental, motor, or language scores?
Method

Participants

Data were collected from 25 infant participants with a mean corrected age of 17.2 months (corrected for prematurity), who were part of a 50-participant longitudinal study of communication development for children with developmental disabilities at risk for being nonspeaking (Cress, 1995) (See Table 1). The 25 participants were selected due to their limited use of intentional communication, such that none of them demonstrated sufficient coordinated joint attention or intentional communication acts during free play to justify administering the Communication and Symbolic Behavior Scale (Wetherby & Prizant, 1993). Participants had the following physical or oral/motor conditions, with additional risk factors for being nonspeaking (McDonald, 1980): cerebral palsy (n = 11), acquired brain injury/illness (n = 7, e.g., meningitis, encephalitis, or traumatic brain injury), congenital conditions (n = 1, e.g., microcephaly), syndromes (n = 3), or unknown diagnosis (n = 3). Nine of the 25 participants were female, and 36% were from racial minority groups. By parent report, 40% of parents had high school degree or less, 60% completed some college courses, and 20% had college degrees. Ranked occupation scores of parents averaged 37.2, suggesting skilled manual labor positions, below the international midpoint score of 40 (Ganzeboom & Treiman, 1996). One single parent was a student, considered not codeable for occupation.

On the Battelle Developmental Inventory (Newborg, Stock, Wnek, Guidibaldi, & Swinicki, 1984), the 25 participants in this study had a mean developmental age of 6 months (range 2–12 months), a mean motor age of 4.5 months (range 2–9 months), a mean receptive communication age of 9.6 months (range 4–20 months), and a mean expressive communication age of 6.8 months (range 1-16 months). On these subtests, each child scored at least one standard deviation below the mean for the corrected age. Participants exhibited adequate hearing abilities for communication judged by criterion-level responses to calibrated noisemakers (Hearkit: BAM World Markets, 1991). On the Functional Vision Assessment (Vision Associates, 1996), each child provided expected visual responses to environmental information. Despite participants demonstrating at least a minimum of functional vision, 28% displayed visual processing difficulties, 8% displayed acuity problems only, and 16% presented both processing and acuity difficulties. In preferential looking to LEA grating acuity cards, seven children demonstrated visual acuity values that were either untestable or below normal limits of their mental age (Baby Screen Kit: Vision Associates). Although three children wore glasses, they had no other visual concerns.

Procedure

Data collection. Data were collected as part of a longitudinal study involving communication development in young children with developmental disabilities who were at risk for being nonspeaking (Cress, 1995). All children and their parents took part in a total of six sessions in the families’ homes lasting approximately two hours, every three months for eighteen months. During these sessions, the examiner (first author) interviewed the child’s parents and assessed the child’s communicative and cognitive development over time using a variety of formal and informal measures. The present study addresses the first home session, comparing data from examiner and child structured play interactions, with data reported in Arens et al. (2005) on free play interactions between the same 25 participants and their parents.

Structured play. Structured play activities were comparable to preintentional enhancement strategies of Enhanced Natural Gestures (Calculator, 2002) and Joint Action Routines (Snyder-McLean, Solomonson, McLean, & Sack, 1984). These behaviors included establishing routines with the child, responding to child initiations as if they were intentional communication, feedback and input regarding child behaviors, and creating options for children to make communicative expressions. For example, the examiner paused in a joint social routine or activation of a toy that elicited child preference behaviors such as vocalization, and continued the play routine with touch feedback if the child repeated the preference signal. Because the goal of the inter-
<table>
<thead>
<tr>
<th>Subjects</th>
<th>Age (mos)</th>
<th>Gender</th>
<th>Developmental Overall Development</th>
<th>Age Scores (months)</th>
<th>Motor Skills</th>
<th>Vision Status</th>
<th>Visual Acuity Grating (cpcm)</th>
<th>Diagnosis</th>
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<td>Adequate</td>
<td>4.0</td>
<td>Cerebral Palsy</td>
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</tbody>
</table>

Mean 17.2 mos. 6.5 mos. 9.6 mos. 6.8 mos. 4.4 mos. 4.2 cpcm

a Age in months as reported from the Battelle Developmental Inventory
b VI-P = visual impairments - processing problems
c VI-A = visual impairments - acuity problems
d Adequate with corrected vision
cpcm - cycles or lines per centimeter of the testing surface. Each cycle corresponds to one degree of visual angle. For instance, at two cycles per centimeter at optimal viewing distance there are four lines or two cycles in each degree of the child’s visual angle. There is no way of converting the grating acuity values to optotype acuity such as 20/20 vision.
** Vision acuity either impossible to score (NA = not available) or below normal limits for mental age.
vention was to detect and respond meaningfully to children’s interpretable behaviors, structured play activities also naturally followed and reinforced child attention (Bono & Stifter, 2003). Most of the children’s behaviors were not yet intentional communication as scored by the Communication and Symbolic Behavior Scale (Wetherby & Prizant, 1993), and not produced by the child with deliberate directiveness toward the adult. Children’s recognizable communication signals that were interpreted systematically by parents were identified in extensive probes and discussion with parents during interaction and recorded in Communication Signal Inventories (Siegel & Cress, 2002).

The following principles were guiding strategies and goals for structured play:

a) Elicit interpretable spontaneous behaviors or signals from infants during toy play, particularly preference and nonpreference signals,

b) respond contingently to infant signals with touch, vocal, and/or play behaviors - repeat the play event and directly reinforce specific behavior with touch,

c) repeat partner and task behaviors that elicited the signal to increase child consistency and awareness of the communicative impact of the behavior.

Structured play occurred at naturally occurring opportunities during the two hour assessment period, usually in brief intervals following an interpretable child behavior. Beyond the specific goals of structured play described above, it was not possible to standardize types of play behaviors across children or contexts because of high variability in types of infant signals and play events that elicited them. The immediate goal of structured play events was to elicit more consistent or conventional production of behaviors that parents judged as conveying interpretable signals (e.g., preference, interest, discomfort). Play was not specifically targeted at increasing gaze behaviors, although gaze could be one of many interpretable behaviors that parents considered to be signaling behaviors of preference (e.g., looking longer at lighted than unlighted toys).

Data coding. Each session was videotaped with a Panasonic AG 456 video camera using S-VHS tapes. Structured play coding segments from these videotapes were selected for the presence of one of the following experimenter behaviors: presenting a communicative temptation, prompting for a spontaneous or intentional child behavior, or providing specific vocal or touch feedback to a child’s interpretable behaviors. Types and amount of cues or temptations were individualized to each child and play interaction, and by necessity differed between children and contexts. In some cases, the experimenter might be attempting to interact with the child even if the child did not respond with interpretable behaviors.

Segments that included structured play between the experimenter and child were dubbed onto coding tapes with an average of 9.8 minutes (range 1.0–32.5) of structured play activity. Because of differing responses and interest level for the experimenter’s structured play probes, the children did not have equal interaction times with the experimenter. A few participants had relatively short interaction times, due to reluctance to interact directly with the experimenter. One child in particular exhibited distress after approximately one minute of structured play with the experimenter, and further parent-mediated structured play was not included in the analysis for this child. Relatively short structured interaction periods are necessary for preintentional children to minimize fatigue, and 2-minute intervals were sufficient to demonstrate joint attention behavior patterns in infants with Down syndrome (Landry & Chapieski, 1990).

The video segments of examiner-child structured play interaction were viewed in S-VHS format on a Panasonic SVHS videocassette recorder AG-1980 Desktop Editor with a 27” JVC monitor. The frequency of children’s various engagement behaviors were scored from videotapes, and the rate of each engagement behavior per minute was calculated (total frequency of each engagement behavior divided by time). To account for the amount of time each child spent in any given attention behavior, the specific engagement behavior rate per minute was then divided by the overall rate of total engagement behaviors per minute to determine the percent of time spent in each specific engagement behavior.
For example, if a child had 16 unengaged engagement behaviors in a 16.8 minute period, this would result in a rate of .95 unengaged engagement behaviors per minute. The child could have also had other engagement behaviors during the same time period, which account for an additional 4.59 engagement behaviors per minute for a total of 5.54 engagement behaviors per minute. Therefore, the child spent .95 divided by 5.54 or 17% of the time being unengaged.

**Data scoring.** A coding scheme, adapted in Arens et al. (2005) from Bakeman and Adamson (1984), looked at seven categories of child engagement including unengaged, onlooking, with persons, with objects, and three types of joint attention, passive joint, two-point gaze shifts, and coordinated three-point gaze shifts. See Table 2 for operational definitions of these terms. As in Arens et al. the present study used three categories for joint attention instead of the two proposed by Bakeman and Adamson (1984) (passive joint and coordinated 3-point joint). The extra category of combined coordinated joint (3-point plus 2-point gaze shifts) was included to allow for limitations of head/trunk movement and eye control that pre-intentional children with developmental disabilities might show. Two-point gaze shifts, in which the child shifted gaze briefly to or from adults during toy play, were similar to gaze behaviors of 6 month infant gazes (D’Entremont & Iype, 2002) and proposed to be transitional behaviors that facilitate and potentially substitute for more conventional 3-point gazes in children with physical impairments (Arens et al.).

Coding was completed in 15-second intervals and the target engagement behaviors had to occur for at least three seconds in order to be coded. Exceptions included the two- and three-point gaze shift categories where every instance of the behavior that occurred was coded. Behaviors were not coded from any video segments in which the face of the child was off camera or was obstructed from view. For example, if the child could be heard playing off camera or if an object was obstructing

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**TABLE 2**

**Child Engagement Coding Scheme Definitions**

<table>
<thead>
<tr>
<th>Definitions</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unengaged: The child is not engaged in anything, looking off into space.</td>
<td>Child’s eyes are not fixated on any one thing.</td>
</tr>
<tr>
<td>Onlooking: Child is looking but not taking part in the activity</td>
<td>Child may be looking at what the adult is doing but is not actively involved.</td>
</tr>
<tr>
<td>Objects: The child is attending to only the object the child is involved with.</td>
<td>Infant is engaged in a toy and is not looking to the adult.</td>
</tr>
<tr>
<td>Persons: The child is engaged with the person, social play.</td>
<td>Adult may be making silly faces at child and child is responding to them.</td>
</tr>
<tr>
<td>Passive joint attention: Infant and adult are involved with the same object, but child does not look at adult.</td>
<td>Adult is interacting with the object the child is attending to, but the child is not looking at the adult.</td>
</tr>
<tr>
<td>Two-point gaze shift: The infant looks from person to object but doesn’t look back to person or vice versa. This needs to be a clear attention shift.</td>
<td>Child is looking at an object and then looks to the adult or vice versa. The child does not make the third transition.</td>
</tr>
<tr>
<td>Three-point gaze shift: Three-point attention shift between object-person-object and vice versa. This has to be a clear attention shift.</td>
<td>The child looks at the adult then the object and back at the adult.</td>
</tr>
<tr>
<td>Face not visible: This occurs when the child’s face is not visible.</td>
<td></td>
</tr>
<tr>
<td>Off Camera: This occurs when the child is off camera.</td>
<td></td>
</tr>
</tbody>
</table>

Coding scheme from Arens et al. (2005), adapted from Bakeman and Adamson (1984).
the view of the child, then no target behaviors were coded.

Interobserver agreement. The second and third authors completed the primary coding and interobserver agreement coding. These coders were trained to use the coding scheme by rating the engagement behaviors of pilot children of children with developmental disabilities from the Cress (1995) database that were not included in this study. During the training period, these authors discussed examples of what was considered an engagement behavior and how it should be coded to increase consistency. Videotaped segments were viewed and coded independently by the second author until interobserver agreement exceeded 80% on three different children. After coding the video segments for the research participants, interobserver agreement was established using a random sample of 20%. Overall agreement of the coding was 87.6% (range = 76%–93%). This was calculated by dividing the number of agreements by the total number of agreements plus disagreements. A Cohen’s Kappa of .89 was also calculated.

Results

Means and standard deviations for the percentages of time that children spent in each engagement behavior are provided in Table 3. Data for free play are recorded from Arens et al. (2005). These free play engagement behaviors were scored from parent/child episodes during the same 2–3 hour sessions as the present study, using the same participants, coders and coding scheme. All computer-based analyses of results were completed on a Macintosh computer using StatView 4.0 (Abacus Concepts, 1992).

A Wilcoxon Signed Rank test compared the percent of total time spent in specific engagement behaviors of children with developmental disabilities when participating in parent free play (from Arens et al., 2005) versus experimenter structured play (Table 4). Results indicated that children spent significantly greater time during structured play in the following behaviors than during free play: onlooking, coordinated triadic joint, and total coordinated joint (dyadic plus triadic). Children produced significantly less unengaged behavior during structured play than free play. No significant differences were found between free and structured play for the engagement behavior categories of objects, persons, and passive joint.

Computer-based z-test correlations were calculated using the difference in rate between free and structured play for each engagement behavior. Correlations between developmental characteristics and the difference in rate of engagement behaviors between free and structured play are presented in Table 5. No significant differences were found between developmental characteristics (developmental age, motor age, receptive age) and the change in engagement behaviors across play type.
TABLE 4
Wilcoxon Signed Rank Test of Engagement Behaviors during Structured Play vs. Parent Free Play (Arens et al., 2005) in Children with Developmental Disabilities (n = 25)

<table>
<thead>
<tr>
<th>Engagement Behavior</th>
<th>z-value</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unengaged</td>
<td>-3.296</td>
<td>.001</td>
</tr>
<tr>
<td>Onlooking</td>
<td>4.345</td>
<td>.0001</td>
</tr>
<tr>
<td>Objects</td>
<td>1.369</td>
<td>.171</td>
</tr>
<tr>
<td>Persons</td>
<td>-1.825</td>
<td>.068</td>
</tr>
<tr>
<td>Passive Joint</td>
<td>-1.444</td>
<td>.149</td>
</tr>
<tr>
<td>Coordinated Joint (3-point shifts)</td>
<td>1.955</td>
<td>.05</td>
</tr>
<tr>
<td>Combined Coordinated Joint (2-point + 3-point shifts)</td>
<td>3.045</td>
<td>.002</td>
</tr>
</tbody>
</table>

* Significant at p < .05

Discussion

It was hypothesized the children with developmental disabilities when engaged in structured play would demonstrate an increase in complex engagement behaviors (i.e., passive joint, coordinated dyadic, coordinated triadic) and a decrease in less complex engagement behaviors (i.e., unengaged, onlooking, persons). Results indicated that during structured play, children with developmental disabilities spent significantly more time in the most complex engagement categories of coordinated triadic joint and total coordinated joint than during free play. Therefore, when engaged in structured play, children with developmental disabilities can demonstrate more complex engagement behaviors, even when demonstrating primarily preintentional communication signals.

Children also showed significantly more onlooking behaviors and fewer unengaged behaviors during structured play than in free play. Within the structured environment the examiner introduced more objects than the parents did during free play. The examiner also was positioned to facilitate the child’s ability to observe and interact with the object presented. This type of structured environment provided more opportunities for children to watch partner play with objects, and had greater potential to elicit the two- and three-point gaze shifts that involve objects than the types of social free play typically noted from parents in Arens et al. (2005). It is interesting that the structured play did not elicit significantly more object-focused or fewer person-focused behaviors than free play. The children engaged more in observing object-based play but did not increase their own engagement behaviors with the toys by themselves. Instead, the structured interactions increased child gaze shift behaviors that integrated person and object information critical for developing perceived intentionality of partner behavior.

TABLE 5
Correlations Between Developmental Scores and Engagement Behaviors for Children with Developmental Disabilities (n = 25)

| Engagement Behavior                      | Overall Development | | Motor | | Receptive Language | | |
|------------------------------------------|---------------------|---------|-------|-------------------|---------|
|                                          | R²                  | (p)     | R²    | (p)              | R²      | (p) |
| Unengaged                                | .349 (.087)         | .157 (.458) | .233 (.266) |
| Onlooking                                | -.092 (.665)        | -.094 (.660) | .114 (.590) |
| Persons                                  | -.156 (.461)        | -.151 (.475) | .019 (.929) |
| Objects                                  | -.005 (.981)        | .149 (.481) | -.288 (.164) |
| Passive Joint                            | -.201 (.340)        | -.199 (.345) | -.243 (.244) |
| Coordinated Joint (3-point shifts)       | .112 (.597)         | -.043 (.840) | -.068 (.751) |
| Combined Coordinated Joint (2-point + 3-point shifts) | .185 (.380) | .047 (.824) | .100 (.637) |

All correlations were not significant at p < .05
These results are consistent with research that suggests responsivity of communication partners increases the child’s engagement behaviors (Wilcox, Bacon, & Shannon, 1995). Kaiser, Ostrosky, and Alpert (1993) emphasize the importance of setting up an environment to support language to help children with disabilities to be symbolic communicators. The examiner’s responsIVENESS during the structured play may have facilitated the dyadic and triadic gaze shift behaviors of the children with developmental disabilities. In a structured environment with an appropriate amount of scaffolding, the children with developmental disabilities increased the complexity of their engagement behaviors.

A second research question addressed whether or not children with developmental disabilities who demonstrate greater improvement in complex engagement behaviors in structured versus free play will have higher overall developmental, motor, and/or visual skills. The correlation did not reveal any significant relationships between the difference in rate of engagement behaviors between free and structured play and children’s developmental characteristics. The developmental abilities of the children with developmental disabilities did not relate to the increases in complex engagement behaviors observed during structured play as compared to free play. This suggests that children with poorer developmental skills are no less likely to benefit from structured interaction than children with higher skills, among preintentional children. A moderate trend was found between increases in participants’ receptive language ages and greater two-point gaze shifts. This would be consistent with the expectation that children produce more complex gaze behaviors as they begin to understand intentional communication (Wetherby & Prizant, 1993). These trend observations suggest directions for further investigation but should be viewed with caution because they are not statistically significant.

Results of the present study indicate that children with developmental disabilities can demonstrate more complex engagement behaviors when provided an appropriate level of scaffolding and environmental support. These results are similar to results of studies discussing the importance of Prelinguistic Mileu Teaching (Yoder & Warren, 2001) and responsivity training of parents (Wilcox et al., 1995). Children’s engagement behaviors benefit from feedback from the communication partner, environmental structuring to support interaction and turntaking, and communication partner-child interaction focusing on child selected objects. Complex engagement behaviors provide children with developmental disabilities a foundation on which to build future symbolic communication. The child has the opportunity to perceive that sharing attention with the communication partner will result in shared interpretation of the child’s communicative intent. The present study extends principles from prelinguistic intervention studies to children who have more severe physical disabilities and fewer intentional behaviors than previously studied.

**Future Research**

Future research could compare the relative success of specific parent and/or experimenter behaviors in eliciting more complex engagement behaviors. The Arens et al. (2005) study did not analyze the extent to which parents produced similar types of prompting behaviors as in the present study. It is also important to identify whether structured play over an extended period of time leads to generalization of complex engagement behaviors with the absence of structured play. The present results do not indicate which aspects of structured play were most effective at eliciting child engagement behaviors, since the types and amount of play varied across children and contexts.

Future research is also necessary to determine the validity of two-point gaze shifts as a developmentally meaningful skill for coordinated joint attention both in children with typical development and children with developmental disabilities. It is not possible from the present data to determine whether the two-point shifts demonstrate equivalent association between object and person for children with developmental disabilities, as three-point shifts do for typically developing children. Further longitudinal data could determine whether children with developmental disabilities produce two-point gaze shifts for an extended period of time, or reduce their
frequency as three-point shifts develop, and whether these simpler gaze shifts remain prevalent in disabled children who demonstrate intentional communication.

**Clinical Implications**

Results of this study suggest that children with developmental disabilities will benefit from a structured play environment in improving engagement behaviors. In this type of environment, children with developmental disabilities demonstrate more onlooking and complex engagement behaviors (i.e., coordinated joint and combined joint), and less unengagement. Parents as well as interventionists can incorporate structured play into natural interactions. For instance, parents can position themselves and objects in a visually appropriate location to encourage the child to interact, as well as introduce a variety of objects.

Parents can also reinforce communicative behaviors by responding to the child’s actions. This includes providing the child with verbal, visual and tactile cues in response to their actions, and helps children associate their engagement behaviors with responses from the environment. Parents can establish routines that respond to their child’s engagement signals so that the child can begin to anticipate and perceive what occurs during meaningful communicative interactions. These types of reinforcement facilitate the development of the child’s joint attention skills, thus providing a foundation for further communicative and symbolic development.

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Keys to Play: A Strategy to Increase the Social Interactions of Young Children with Autism and their Typically Developing Peers

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Abstract: Crucial to the successful inclusion of young children with disabilities is the premise that benefit occurs when children socialize with peers and are actively involved in preschool activities including play. Playgroups are often primary to learning in typical preschool classrooms since it is within playgroups that preschool-age children learn both preacademic and social skills. However, this critical avenue of learning is often closed to young children with autism who may have difficulty initiating play interactions with other children. This study examined the effects of a visual intervention strategy on the play initiations of four young children with autism in inclusive preschool classes.

The strategy was successful in increasing the play initiations of the participating young children with autism. At the same time, the children’s engagement time within playgroups concomitantly increased, as did the sophistication level of their play.

Central to the successful inclusion of young children with disabilities in preschool classes is the premise that benefit occurs when children are in proximity to peers, socialize with them, and actively engage in typical preschool activities including play (Harris & Handlerman, 1997; Kellogrew, 1995; Koegel, Koegel, Harrower, & Carter, 1999; McGee, Morrimer, & Daly, 2001; McWilliam, Trivette, & Dunst, 1985; Rogers, Hall, Osaki, Reaven, & Herbinson, 2001; Strain, 1983). Unfortunately, skills that facilitate such behaviors are frequently impaired in young children with autism. Social interactions are often fundamentally different from those of typically developing children because they may not exhibit joint attention to play activities and may fail to respond when other children seek their attention and interest (Carpenter & Tomasello, 2000; Wetherby, Prizant, & Schuler, 2000). Children with autism may be able to talk, but unable to initiate conversation and interaction (Layton & Watson, 1995; Quill, 1995a). Young children with autism may produce few, if any, social initiations and may exhibit stimulus selectivity in which they fail to respond to multiple environmental cues (Koegel et al.). In addition to such difficulties with social initiations and responses, children with autism frequently engage in stereotypic, self-stimulatory and other undesirable behaviors that serve to further isolate them from typically developing peers (Simpson, 1999).

Young children acquire social knowledge and skills in play (Bruner, 1986; Parten, 1932). It is within play that they learn to coordinate interpersonal skills such as turn-taking and reciprocity and learn the strategies necessary for collaborative and symbolic pretend play (Schuler & Wolfberg, 2000; Wolfberg, 1995). Through social play, children learn and practice social skills such as asking to enter into peer or play groups and inviting others to play (Dodge, Schlundt, Schocken, & Delugach, 1983). The play of young children with autism...
is frequently impoverished in both form and content. They may engage in a single play sequence for hours or months and may manipulate play objects in a stereotypic manner. Pretend play may be nonexistent or extremely limited in variety (Wolfberg, 1995). In addition, children with autism often have difficulty conveying a desire to play or join in activities and they may fail to respond to invitations of others to play. As a result, they are often found outside of peer play groups (Wolfberg, 1995).

Visual cues or symbols have been identified as one strategy that can assist in the provision of support for social communication (Bondy & Frost, 1994; Hodgdon, 2000; Jolly, Test, & Spooner, 1993; Krantz & McClannahan, 1993; Quill, 1995a, 2000; Wolfberg & Schuler, 1993; Zanolli, Daggett, & Adams, 1996).

Visual-graphic symbols include pictographic symbols, printed words, and pictures that may be used for both receptive and expressive purposes. They have been widely used with children with autism because they are usually iconic and capitalize on the relative strengths of individuals with autism in the areas of visual-spatial skills, rote memory, cued recall, and associative learning (Mirenda & Ericson, 2000; Prior & Chin, 1976; Quill, 1997, 1998; Sigman, Dissanayake, Arbelle, & Ruskin, 1997). Visual cues are static and allow the child to focus on a cue as long as necessary and revisit it as needed (Schuler, 1995). Visual communication tools are gestalt by nature, concrete and specific in appearance, and convey broad concepts or ideas rather than specific language structures (Quill, 1995b, 1997). Furthermore, recent research suggests that the use of visual strategies for communicative purposes promotes the use of oral language in children with autism (Bondy & Frost, 1994; Schwartz, Garfinkle, & Bauer, 1998).

The current study used peer-mediated instruction that was embedded within ongoing preschool activities to teach the use of a visual strategy for initiation. Embedded instruction is at the core of many naturalistic intervention strategies (Horn, Lieber, Scouming, Sandall, & Schwartz, 2000). It involves the systematic and normalized expansion, modification, or adaptation of activities in order to maximize opportunities for the child to practice specific goals (Bricker, Pretti-Frontczak, & McComas, 1998). Embedded instruction and practice within preschool activities has enjoyed widespread support in the field of early childhood special education (Hemmeter, 2000; Sandall, McLean, & Smith, 2000; Sandall et al., 2002); however, there have been few studies examining actual efficacy in preschool classrooms (Daugherty, Grisham-Brown, & Hemmeter, 2001). Peer-mediated strategies in preschool classrooms often involve prompting peers to interact with children with disabilities and peer modeling (Kohler & Strain, 1997). Such strategies have been shown to increase the interactions among children with and without disabilities in preschool classrooms (e.g., Goldstein, Kaczmarek, Pennington, & Shafer, 1992; Odom & Strain, 1984).

In summary, few empirical studies have examined effective strategies for teaching social skills to young children with autism within the routines of inclusive preschools. Several studies have been completed that examined the effectiveness of various applications of peer-mediated intervention with children with autism, but few studies have looked at naturalistic or embedded strategies or have empirically examined the combination of naturalistic and peer-mediated intervention strategies for use with young children with autism in preschool classes. In the same vein, while visual strategies offer much promise for the remediation for the specific deficits seen in children with autism and their use is rapidly increasing (Hodgdon, 2000), the research base as to their actual effectiveness as well as their impact on speech development in young children with autism is very limited.

The Keys to Play intervention package utilized an embedded instruction, class-wide, peer-mediated teaching strategy to promote the use of a laminated paper key that was shown to peers to initiate play. The study examined the effectiveness of the Keys to Play intervention package in increasing initiations and responses of children with autism in inclusive preschool classrooms. The specific research questions were: (a) Does the Keys to Play intervention package increase the play initiations of young children with autism? (b) Does the Keys to Play intervention package increase the time young children with autism spend engaged in playgroups? (c) Does the Keys to Play intervention package affect the
child with autism’s concomitant or singular use of another communication strategy such as speech, sign language, or manipulation of play materials to enter playgroups? and (d) How do classroom staff and family members rate the acceptability and perceived effectiveness of the Keys to Play intervention package for children with autism?

Method

Participants and Settings

The four participants were children identified as meeting the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorder (1994) criteria for autism (with or without the presence of other disabilities) by agencies not connected with this research. Each participant attended different preschool programs, including two Head Start classes, a community preschool class, and an integrated special education class in which the majority of children were typically developing. Participating children were identified through observations by research staff and by their classroom teachers as appearing to have an interest in the play of other children or in classroom activities, but also as having difficulty with social-communication initiations and responses.

Participant 1, “Emerson,” was a 4 year 5 month (53 month) old Caucasian boy who attended an urban Head Start classroom five days per week. Results from the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner) indicated that he had severe autism. According to the Achenbach Child Behavior Checklist (Achenbach, 1991), Emerson was in the clinically significant range on the withdrawal scale. Observations in the classroom environment revealed that during free-play or learning center time, Emerson primarily moved around the periphery of the room holding small objects such as a piece of straw up to his eye and putting inedible objects such as staples in his mouth. He engaged in brief onlooker behavior to a few select activities but made no attempt to interact with the children in the groups. He often went alone into the book area. He did, however, display some onlooker behavior of peer play groups. His teacher and mother reported that Emerson could speak in four or five word sentences but rarely did so outside of the home.

Participant 2, “Aaron,” was a 4 year 1 month (49 month) Caucasian boy who two mornings per week attended an integrated special education preschool class in which the majority of the children were typically developing. Aaron scored as having mild to moderate autism on the CARS (Schopler et al., 1988), the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2000) and the Gilliam Autism Rating Scale (GARS; Gilliam, 1995). Both the classroom teacher and school district psychologist reported that Aaron had verbal language but much of it was echolalic. He had pronoun confusion and referred to himself by name rather than as “I.” He had a lack of social timing and reciprocity, difficulty with pragmatic language and exhibited impairments in his ability to initiate or sustain conversations. Aaron appeared interested in the play of his peers, but in classroom observations frequently engaged in onlooker behavior and his attention to any one play activity was brief. He initiated interactions with adults and occasionally with peers, but many of his initiations to peers were ignored and were thus unsuccessful.

Participant 3, “Enrique,” was a 3 year 9 month (45 month) old boy of Latino and African American heritage who attended an urban Head Start class three mornings per week. Enrique presented as having mild to moderate autism on the CARS (Schopler et al., 1988). His score on the Preschool Language Scale (PLS-3 Zimmerman, Steiner, & Pond, 1991) was three standard deviations below the norm. He was described by the diagnosing agency as having no language, making little eye contact, and “playing in his own world.” In classroom observations, Enrique walked around the periphery of the room holding small objects such as a piece of straw up to his eye and putting inedible objects such as staples in his mouth. He engaged in brief onlooker behavior to a few select activities but made no attempt to interact with the children in the groups. Spanish was the predominant language spoken in his home, and although both English and Spanish were spoken in the classroom, English predominated. Enrique was observed to respond to some requests in either English or Spanish and would occasionally clearly repeat words heard in either language although most of his vocalizations were unintelligible.
Participant 4, “Daniel,” was a 4 year 3 month (51 month) old Caucasian boy who attended an inclusive community preschool class in a suburban setting three mornings per week. Daniel scored in the severe autism range on both the CARS (Schopler et al., 1988) and the ADOS (Lord et al., 2000). He was below the standard scales on the Mullen Scales of Early Learning (Mullen, 1995). Daniel had some limited verbal language but used it infrequently. During classroom observations, Daniel frequently went to the book area and chose books. He turned the pages rapidly without stopping to look at the pictures. He did not appear interested in the books other children were looking at and did not attempt to obtain joint attention to his selected books. Occasionally, Daniel approached play groups and watched children for brief periods of time.

Measurement

Dependent measures were the percentage of opportunities that a child (a) used the Keys to Play successfully to enter a playgroup, or (b) used another strategy such as words, sign language, or parallel manipulation of objects to enter a playgroup. Amount of time spent engaged in playgroup activities was also measured. Duration of engaged time with peers was cumulatively totaled throughout each session. Engaged time in a playgroup was defined as time spent in proximity (within 2 feet) of one or more peers and either manipulating play or learning materials in a similar manner as the other children in the group, or interacting with peers. Acting-out behaviors such as hitting, crying, or having tantrums were not counted as engaged time. An opportunity for use of the Keys to Play was said to occur when the target child (a) was not engaged in a playgroup or other learning center activity for a period of three minutes, and/or (b) looked at and approached a peer or play group (within 3 feet). The interventionist ensured that there were between five and 10 opportunities for initiation per session. A play group was defined as two or more children (including the target child) interacting with play or child-selected learning materials in a similar manner within three feet of each other. A summary of the definitions used is contained in Table 1.

Baseline. Opportunities and initiations by the target child to join playgroups were counted during learning center time. Up to 10 initiations were recorded if they occurred anytime during a given session. The cumulative time spent engaged in playgroups during each session was also recorded. Additional information gathered included the mode of communication used for the initiation, if the initiation was to a child or an adult, if the opportunity was natural or created, the types of errors made (e.g., no response, aggression, hovering, or moving away), if, and how, the target child responded to play initiations by peers (e.g., affirm, refuse, ignore), and what type of play the child used within the playgroup. The researcher collected baseline data on a probe basis of one day per week with more frequent probes taken just before the onset of the intervention phase.

Intervention. During intervention, the same information was collected with the addition of data regarding the type of prompt used to encourage initiation (e.g., establishment of joint attention, model, indirect verbal or gestural prompt, direct verbal or gestural prompt, partial physical or full physical prompt). The percentage of correct and successful initiations of play out of available opportunities was counted throughout the learning center time. Intervention sessions occurred between two and four days per week depending on how frequently each child attended preschool and excluded holidays or other special events within the preschools.

Maintenance. The same information collected in baseline and intervention was collected on a weekly basis during the maintenance condition. The maintenance phase began when the target child achieved a stable rate of 75% unprompted initiations in the classroom and continued for up to four weeks. The school year ended before the last two children achieved a stable rate of unprompted initiations.

PDA-based data collection system. A Personal Digital Assistant (PDA)-based data collection system asked the following questions and stamped the time when each answer was entered: (a) Is there an opportunity? (b) Is the opportunity for initiation or responding? (c)
Table 1

Keys to Play Definitions

**Engaged time:** Time spent in proximity (within 2 feet) of peers and manipulating play or learning materials or interacting with peers. Acting-out behaviors such as hitting, having tantrums, or crying are not counted as engaged time.

**Opportunity to initiate:** The target child is not engaged in a playgroup or other learning center activity for a period of 3 minutes and/or looks at and approaches (within 3 feet) a peer or play group.

**Interventionist created opportunity:** If target child is not engaged in playgroup for a period of 3 minutes and does not look at and approach a playgroup, the interventionist will create an opportunity by verbally and gesturally directing a child’s attention toward an activity that the child has engaged with in the past. The interventionist will pause 5 seconds and if there is no response, will deliver a full physical prompt leading the child to the activity. The interventionist may also assist classroom staff to add motivating materials or activities if none are available that are of interest to the child.

**Play group:** 2 or more children (including the target child) interacting in a similar fashion with play or child selected learning materials that are the same or belong together and are within 3 feet of each other.

**Intervention sequence:**
1. Comment on interest and natural cues
2. Five second time delay
3. Model use of key
4. Verbal prompt “You can use your key to say you want to play”
5. Full physical prompt
6. Prompt will decrease to partial physical from wrist or elbow when child reaches 90% level

**Categories of Play (adapted from Parton, 1932)**
1. **Solitary:** Child plays alone and independently with toys that are different from those used by other children who are within speaking distance. Child does not reference what other children are doing.
2. **Onlooker:** Child spends most of the time watching other children play. He may talk to children whom he is observing or give suggestions but does not overtly enter the play. The child stands or sits within speaking distance of the group.
3. **Parallel:** The child plays independently, but the activity he chooses naturally brings him among other children. He plays with toys that are like those which the children around him are using but he plays with the toy as he sees fit and does not try to modify or influence the activity of the other children. He plays beside rather than with the other children and does not attempt to control the coming or going of children in the group.
4. **Associative play:** The child plays with other children. The conversation concerns the common activity and there is a borrowing and loaning of play material. All members engage in similar if not identical activity but there is no division of labor and no organization of the activity among the children around any goal or product. Each child acts as he wishes.
5. **Cooperative play:** The child plays in a group that is organized for the purpose of making some material product or striving to obtain some competitive goal, or of dramatizing situations of adult and group life, or of playing formal games. There is a division of labor, the taking of different roles by various group members, and the organization or activity so that the efforts of one child are supplemented by those of another.

**Possible child initiation errors:**
1. **Aggression:** The child either uses verbal aggression such as a shout or physical aggression such as hitting, kicking, or grabbing or destroying play materials.
2. **Move away:** The child moves away from the play group
3. **Hover:** The child stays in proximity of the group but does not initiate play-instead seems to hover around the group
4. **Move closer:** The child moves closer to the group, but does not initiate play or use the play materials
5. **No response:** There is no identifiable response to either the play or the intervention sequence.

**Communication Form**
1. **Key:** The child lifts the key and directs it toward another person
2. **Verbal:** The child uses a verbalization such as “I want to play” to indicate a desire to play
3. **Key plus verbal:** Child uses the key as above in addition to a vocalization such as “I want to play”
4. **Gesture:** Child uses a gesture such as pointing to indicate a desire to play
5. **Sign:** Child uses a formal sign to request play
6. **Picture:** The child uses a picture symbol (could also be an object symbol) other than the key and either points at it or gives it to a peer or adult to request play.
7. **Positional:** The child stands or sits beside (within 1 foot) a child or adult playing
8. **Object or toy:** The child picks up or manipulates an object or toy that is being used within the play group. The object or toy is one that is actually part of the play rather than a representation or a toy,
If there is an opportunity for initiation, did the child initiate? When the answer was yes, choices of communication modes were then presented and a question regarding whom the child initiated to (child or adult) appeared. When the answer was no, choices of possible errors were presented; (d) when the opportunity was for the child to respond to an invitation, three choices (ignore, affirm, deny) appeared on the screen; (e) each time yes was answered for opportunity, a question also appeared asking for level of adult prompt, (f) when a child entered a play group, the data collector pushed an icon that activated a timer to record engagement time; and (g) a final question appeared that asked for the level of play primarily used by the child as per the Parten Scale (Parten, 1932). Categories used in the Parten Scale include unoccupied play, solitary play, onlooker behavior, parallel play, associative play, and cooperative play.

Interobserver Agreement

The first author of the study conducted training on data collection methods and teaching strategies for the use of the Keys to Play and practice with the PDA data collection system with the interventionist, the research assistant, and the secondary data collector. The data collectors (first and second authors) reached 90% or better point-by-point agreement on all behavior categories during an on-site observation of a preschool program with children other than the target children and on one observation of each target child before formal data collection began.

The primary and secondary data collectors collected data simultaneously during 20 to 25% of sessions across all phases (baseline, intervention and maintenance) per child. The point-by-point formula used was agreement divided by agreement plus disagreement multiplied by 100 (Kazdin, 1982). A tolerance of plus or minus five seconds was set as an acceptable level of agreement for each event. The time-stamping feature of the PDA data collection system allowed for point-by-point comparison. Agreement of engagement time was calculated by comparing agreement on each period of engagement. Mean agreement for Emerson was 98% across phases (all scores were 99% during baseline and ranged from 92 - 99% during intervention and maintenance). Mean agreement for Aaron was 97% across phases (range = 98 - 99% during baseline, and 93 - 98% during intervention and maintenance). For Enrique, mean agreement was 96% across phases (range = 98 -100% during baseline and 93 - 96% during intervention), and for Daniel, mean agreement was 99% (range = 98 -100% during baseline and 99% during intervention).

A research assistant (a university student in special education) observed the interventionist to monitor fidelity to teaching procedures one time per week during the intervention phase across children. This was accomplished through the use of a checklist of the intervention procedures including prompting sequences and error correction. Fidelity data were calculated by dividing the number of interventionist behaviors exhibited by the number of planned interventionist behaviors during completed opportunities and multiplying by 100. Data indicated that the interventionist correctly performed the planned behaviors during completed opportunities with a mean of 96% accuracy (range of 92% to 100%).

Design

A multiple-baseline probe (Tawney & Gast, 1984) design across children and settings was used to evaluate the effectiveness of the Keys to Play visual strategy for young children with autism. Each child experienced a baseline phase and an intervention phase. Two of the children experienced the maintenance phase before the school year ended.

Procedure

The visual strategy, Keys to Play, consisted of 4-inch long, gold colored laminated paper keys that were either worn around the neck or attached at the hip with Velcro. All children and adults in the preschool programs were given instruction in the use of the Keys to Play visual strategy and were given the option of wearing and using them during learning center time. The Keys to Play use was taught, prompted, and measured within learning center time (approximately 30 minutes per day) in preschool classrooms. The interventionist
was a research assistant trained in special education who was constant across children to ensure fidelity to the prescribed teaching sequence.

**Baseline.** During the baseline condition, the children with autism were given the Keys to Play to wear, but no instructions, training, or prompting on their use was provided. Classroom routines and procedures were not altered during this phase except that the interventionist was stationed in the same learning center as the target child. Baseline probes were taken weekly with three probes in succession taken before moving to the intervention phase. The baseline phase was continued until data were stable.

**Intervention.** Typically developing peers in the classroom initially received instruction in the use of the Keys to Play within the large group activity that preceded learning center time. Adults in the classroom modeled the use of the keys during learning center time. Typically developing peers were prompted by the adults in the classroom to show their keys to the target child in the class and either verbally ask him/her to play or show the child play materials. They were told to continue showing the key to the target child until they got a response or the child left.

Target children received training on the use of and response to the keys through an incidental-teaching, peer mediated intervention model (McGee, Morrimer, & Daly, 1999; Prizant, Wetherby, & Rydell, 2000). The interventionist first ensured play activities were available that were motivating to the target child. Preference was given to delivering intervention within ongoing learning center activities but when activities did not provide a high level of motivation, the interventionist added materials to ensure that motivating activities were available across all children. When the child was not engaged in a play group and showed an interest in a play activity by directing attention and approaching the activity, the interventionist commented on the child’s interest in the activity and the natural cues that would indicate to a child to ask to play and paused for 5 seconds to allow the child time to initiate entry into the play. If the child did not initiate, the interventionist went over to the playgroup and modeled use of the key combined with the verbal phrase “I want to play.”

The interventionist again paused for 5 seconds to allow the target child an opportunity to initiate play. If the child did not initiate play, either through key use or other symbolic communication means, the interventionist prompted the child by using a verbal prompt, “You can use your key to say you want to play.” If still no response, the interventionist delivered a full physical prompt. The prompting level decreased to a partial physical prompt from either the elbow or wrist as success reached the 90% level. All correct responses were verbally reinforced and the natural consequence of getting to play was emphasized. If the target child was not engaged in a playgroup for a period of 3 minutes and did not look at and approach a playgroup, the interventionist created an opportunity by verbally and gesturally directing the child’s attention toward an activity that the child had engaged with in the past. The interventionist then paused 5 seconds and if the child did not respond, a full physical prompt was delivered leading the child to the activity. This level of opportunity creation was noted on the PDA data collection system. The interventionist ensured that there were between five and 10 opportunities to initiate play in each 30-minute period.

**Maintenance.** This condition began when the child reached a stable rate of 75% or higher unprompted initiations as defined by three initiations at or above this level. Initiations continued to be reinforced by the classroom teacher on an intermittent basis. Data were collected once a week for up to four weeks to assess whether the behaviors were continuing.

**Data Analysis**

The dependent variable was plotted on a multiple baseline graph for the participating children (see Figure 1). Data were examined by visual analysis for changes in level, the latency of change between phases, and changes in trend within phases. Other information such as mode of communication, prompts needed, and type of errors made is reported through descriptive statistics using mean scores. Results of the social validity survey were analyzed using descriptive statistics for ordinal data (median and mode) for each question.
Figure 1. Percentage of correct and successful initiations across participants
Results

Data presented in this section examine the dependent variables of (a) successful initiation of playgroup entry, (b) percentage of time spent engaged in playgroups, and (c) communication forms utilized in play initiations. In addition, social validity data provided by teachers, teaching assistants, and parents are presented.

Impact on Successful Play Initiations

Data pertaining to the dependent variable of correct initiation of successful playgroup entry have been summarized as the percentage of opportunities for initiation. There were between five and ten such opportunities in each session. Figure 1 presents summarized daily data for the baseline, intervention, and maintenance conditions for all the participating children. In order to be counted as correct, play initiations had to result in successful playgroup entry. Correct initiation forms included use of the Key to Play, verbal behavior, gestures, and nonverbal strategies such as parallel play. The solid line in Figure 1 reflects the total number of successful prompted initiations for each child. The dotted line reflects successful initiations that were unprompted.

During baseline, play initiations were, for the most part, consistently low for each of the four children. However, Aaron and Enrique had a spike of higher initiation when a particularly favored learning center was introduced (sand for Aaron and bubbles for Enrique). The general trend or slope for all of the participants in the intervention phase was upward.

Impact on Engagement Time

The daily percentage of learning center time that each child spent engaged in playgroups across the conditions of the study was examined. Engaged time in a playgroup was defined as time spent in proximity (within 2 feet) of one or more peers and manipulating play or learning materials in a similar manner as the other children in the group, or interacting with peers. The mean rate of engagement for each of the children rose substantially across the conditions. The total increase in Emerson’s mean engaged time was 66.3% as it rose from a mean of 1.7% in baseline (range = 0 - 6.48%) to 48.3% in intervention (range = 13.4 - 83.8%), and finally, 68% in maintenance (range = 21.2 - 93.5%). Aaron’s mean length of engagement increased by 35.4% as it rose from 26.8% in baseline (range = 0 - 62.7%) to 59.5% in intervention (range = 41.1 - 86.5%) and 62.2% in maintenance (range = 48.1 - 88.8%). Enrique had not met the criterion for unprompted initiations and so he did not experience the maintenance condition, however, his mean length of time spent engaged in play groups increased by 34% as it rose from 8.7% in baseline (range = 0 - 34.1%) to 42.7% in intervention (range = 19 - 88.2%). Daniel’s intervention phase was short in duration, yet the rise in his rate of engagement was substantial. His mean percentage of engagement time rose 47.4% over the baseline mean of 3.1% (range = 0 - 21.5%). His mean rate of engagement during intervention was 50.7% (range = 32.6 - 70.4%).

Impact of the Strategy on Communication Forms used for Initiation

In order to determine the impact of the Keys to Play strategy on communication forms used for initiation, the communicative form used for each play initiation was recorded. Initiations that were counted as correct included (a) verbal, (b) gestural, (c) positional (e.g., standing or sitting in or by a playgroup), (d) parallel manipulation of play objects or materials, (e) the Keys to Play, and (f) the Keys to Play paired with verbal language. Data collection on the use of sign language and picturegraphic symbol use other than the Key to Play was planned; however these communicative forms were not used by any of the children during the study. Figure 2 represents the percentage of correct unprompted or prompted by comment only initiations by form used across participants and across the baseline, intervention, and maintenance conditions of the study. The forms are represented as a percentage of opportunities that were either unprompted or prompted by comment only and that were initiated correctly. Therefore, the number of opportunities in baseline for
Figure 2. Mean percentage of communication forms used in play initiations across participants.
Figure 2. Continued

Enrique

Percent Communication Form Used

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Baseline</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key</td>
<td>20</td>
<td>60</td>
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<tr>
<td>Verbal</td>
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<td>10</td>
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<tr>
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<td>18</td>
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<tr>
<td>Gesture</td>
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<td>9</td>
</tr>
<tr>
<td>Position</td>
<td>14</td>
<td>36</td>
</tr>
<tr>
<td>Object Play</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Daniel

Percent Communication Form Used

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Baseline</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Verbal</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Key + Verbal</td>
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<td>80</td>
</tr>
<tr>
<td>Gesture</td>
<td>32</td>
<td>37</td>
</tr>
<tr>
<td>Position</td>
<td>16</td>
<td>0</td>
</tr>
<tr>
<td>Object Play</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Figure 2. Continued
some of the children is very low and the percentages may not be representative.

As illustrated by Figure 2, the verbal language of all of the children increased across conditions. Manipulation of play materials also increased as an initiation form of choice or remained relatively stable for all of the children except Daniel. All of the children used the Keys to Play either alone or in combination with verbal language during the intervention condition. The two children who experienced the maintenance condition, Emerson and Aaron, either rarely used the visual strategy of the Keys to Play or did not use it at all during maintenance.

Social Validity

Education team survey. At the conclusion of the study, classroom teachers and teaching assistants (N = 10) in the involved classrooms independently and anonymously completed surveys regarding the significance, effectiveness, and utility of the study. All of those surveyed reported that it is either important or very important for children to use symbolic communication to express a desire to play with other children. With regard to the effectiveness of the strategy, 30% said that the strategy was very useful in helping the child with autism successfully play with peers, 40% said it was useful, and 30% said it was somewhat useful. Fifty percent indicated that the child with autism would be likely to continue to use the Keys to Play strategy in the future. In looking at the utility of the strategy, 60% said the strategy did not disrupt the activities and routines of the classroom and 40% said it was a little disruptive. Those who reported that it was a little disruptive indicated that the number of adults involved in the research was at times, overwhelming. A majority (60%) thought the strategy would be easy to implement, 30% somewhat easy, and 10% somewhat difficult (n = 1). Ninety percent of the teaching staff thought it would not be difficult to implement the strategy and still meet the needs of the other children in the classroom while 10% thought it would be a little difficult. Furthermore, 90% of the respondents indicated that the time required to implement the strategy was worth the observed benefits, and 80% plan to continue to use the strategy in the future.

Discussion

Keys to Play Package Can Increase the Play Initiations of Children with Autism

Results of the study suggest that the intervention package was successful in teaching preschool aged children with autism to initiate entry into playgroups. All children in the study exhibited increases in initiations of play over the course of the study. However, the dependent variable of using the Keys to Play or another communication form to successfully initiate play is multifaceted and as such includes at least three major components. The first is learning to use the Key or another communicative strategy such as the words, “I want to play;” the second is viewing children playing in playgroups as possible opportunities to initiate play; and the third is actually using a communicative strategy to successfully gain entry into a playgroup. Day by day data gathered through use of the PDA showed that three of the four children (Emerson, Aaron, and Daniel) demonstrated an understanding of how to use the Keys to Play and/or how to say “I want to play” by the second day of intervention and showed an increase in unprompted or minimally prompted initiations by that time. The fourth child, Enrique, only began to demonstrate an understanding of the communicative properties of the Keys to Play and the words, “I want to Play” during the last 10 days of intervention. Demonstrating an interest in the play of others and actually using the Keys to Play strategy or another strategy to initiate entry into playgroups varied across the children and was often dependent on their interest in activity materials.

Keys to Play Package Can Result in Increased Time Spent Engaged in Playgroups and Increased Level of Play

During the baseline condition, the play interests of all of the children were narrow and each spent a high percentage of learning center time engaged in solitary activities on the periphery of the centers. By the end of intervention, all of the children showed significant
gains in time spent engaged in playgroups. As engagement time went up, other play benefits were also noted. Both Emerson and Aaron, the only two children to complete the intervention condition and experience maintenance, generally sampled most of the available playgroups; however Emerson continued to avoid centers that involved fine motor activities. During the maintenance phase, Emerson and Aaron also engaged frequently in pretend play which supports the literature base demonstrating that increased play leads to more symbolic and pretend play (Schuler & Wolfberg, 2000; Wolfberg, 1995). In addition, the levels of play as delineated by Parten (1932) also evolved concomitantly with the increased time spent in playgroups (see Figure 3). For example, both Daniel and Enrique demonstrated increases in parallel play and decreases in onlooker and solitary play as their time engaged in playgroups increased. Therefore, although the study made no claim on what would happen once children successfully initiated play and entered playgroups, results indicate that an increased number of playgroup entries results in increased engagement time within playgroups and consequent increases in play skills for the participating children.

**Keys to Play Package May Promote the Use of Verbal Language for Initiation Purposes**

Consistent with previous findings that visual supports may promote the use of verbal language in young children with autism (Bondy & Frost, 1994; Johnston, Nelson, Evans, & Palazolo, 2003; Schwartz et al., 1998), the data in this study point to increases in verbal initiations across children. As noted by Johnston et al. (2003), the choice of communication form might be explained by the tenets of matching theory that hold that when given a choice between two or more responses, individuals will select the form that is perceived as most efficient (Mace & Roberts, 1993). Aaron had verbal skills that were easily understandable at the beginning of the study and so might have perceived continued use of such skills as most efficient. Emerson had verbal skills, but at the beginning of the study rarely used them, and may have not found them to be efficient until later in the study when they...
were more practiced and thus more readily reinforced. Daniel had limited verbal skills and may have perceived the combination of the visual support and verbal language as most efficient. Enrique, however, did not have consistently understandable verbal language and still chose to use it over the visual support of the Key.

Although verbal in both the baseline condition and beginning intervention, Aaron consistently referred to himself in the third person as “Aaron” rather than using a personal pronoun. A serendipitous effect of the intervention appeared during intervention as Aaron began to use the pronoun “I” that he used in the “I want to play” portion of the strategy. Interesting too, was the evolution of Emerson’s verbal initiations as they expanded beyond the practiced phrase of “I want to play” in both late intervention and maintenance conditions. Such initiations began to included phrases such as, “Hey, I want to play too, where’s a chair for me?” and “I’m going to get some paint so I can play too.”

It is important to note that consistent with the literature regarding play initiations of typically developing children (Cosaro, 1979, 1995; Craig & Washington, 1993), manipulation of play materials continued to play a large role in the initiations of all of the children in the study except Daniel, who had limited intervention time. The frequency of usage of this communication form occurred regardless of symbolic communication use. Furthermore, as the number of playgroup entries increased, the sophistication and acceptance of the nonsymbolic communications increased as children moved from hovering behaviors to more sophisticated manipulation of materials.

**Limitations**

There are some limitations associated with the study that could affect the extent to which results of the study can be generalized to other settings or children. In order to ensure that the intervention was constant across settings, an interventionist who was not a member of the classroom teaching staff was used. Therefore, it is not known if the same results could be obtained by classroom staff. However, in a similar study (Johnston et al., 2003), the classroom teacher did fulfill the role of the interventionist and was able to effect change in the dependent variable of increased symbolic initiations through the use of a visual strategy.

Although four separate sites were utilized in the study, without systematic replication it is difficult to say that these sites are representative of inclusive preschool programs. In the same vein, it is not known if the four participating children are representative of the population of children with autism. Also, only two of the four children completed the intervention portion of the study and experienced the maintenance condition before the end of the school year. Therefore, it is unknown if gains made by the other two children would have maintained without intervention support.

**Implications for Further Research**

Several studies have demonstrated that visual strategies have the potential to increase initiative behaviors in young children with autism or Autism Spectrum Disorder (e.g., Johnston et al., 2003; Jolly et al., 1993; Shabani et al., 2001; Wolfberg & Schuler, 1993; Zanolli et al., 1996) and results of this study lend themselves to several future research activities in this area. In order to discover the relative importance of each component of the intervention package in increasing play initiations, future research should systematically examine the impact of each variable (e.g., the visual strategy, the least to most intensive prompting sequence, the creation of opportunities, and the non-exclusion rule) on intervention outcomes. Also of interest would be a comparison of the relative effectiveness of embedded teaching of the initiative skill versus priming of the strategy prior to the activity. Effects of the addition of a zero-delay condition on the efficiency of obtaining unprompted initiations would also be of interest to the field.

Although the existing research base is promising, more inquiry is needed into the impact of visual strategies on verbal language in children with autism as well as children who are typically developing. At the same time, given the importance of the nonsymbolic strategy of parallel manipulation of play materials, research examining strategies to help young children with autism make effective and salient use of such naturally occurring
nonsymbolic strategies is also warranted. Results of this study suggesting that increased initiations of play can lead to increased engagement time as well as increases in play skills need further investigation. Of specific importance would be inquiries into the respective roles played by the provision of increased time within playgroups and the increased use of symbolic communication by children on their subsequent gains in play skills. Finally, comments made by the parents of the participating children suggested that the strategy resulted in play initiations in settings outside of school (e.g., daycare, church, and neighborhood). An inquiry into such generalization could inform the field of the efficacy of such a visual strategy in impacting the social interactions of young children with autism across settings.

Implications for Practice

The outcomes of this study, while not definitive, offer several implications for practitioners in early childhood classrooms. First, during the baseline period, all four children with autism were allowed to participate or not participate in classroom activities as they chose. Both initiations of play and time spent engaged in the playgroups were very low. A major component of the Keys to Play intervention involved prompting children to enter playgroups when they displayed interest in a playgroup or when they were not engaged for three minutes. Results of this study provide impetus for more structured intervention than free-choice of activities dictates. It would appear that free-choice in a structure to assist children with autism to engage in activities is associated with isolation and low engagement within playgroups. Second, the inclusion of specific materials in learning centers that attracted the interest of the children with autism also appeared to increase play initiations and result in a concomitant increase in engaged time. Finally, results support previous research demonstrating that use of a visual strategy for the purpose of initiation can provide a socially valid way to increase both verbal and nonverbal play initiations in children with autism.

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Ratings of Communication Competence by Siblings of Persons with Down Syndrome
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Southern Connecticut State University

Abstract: This study surveyed 25 siblings of persons with Down Syndrome to gain an ecological perspective about important communication competence indicators. Siblings favorably described persons with Down Syndrome as “effective” and “good” communicators who “communicate to potential.” Siblings regarded social communication skills as especially important, i.e., being able to communicate without fear, being able to express wants, needs, opinions, and feelings, being able to ask questions, and alerting partners to communication breakdowns. Siblings also regarded language comprehension as an important skill. Favorable descriptive labels were often applied to adult-aged persons with mild ID and normal hearing. Clinical implications are discussed focused on functional communication planning and implementation that takes into account the perspectives of family members, teachers, and rehabilitation personnel.

Speech-language pathologists are professionals who are concerned with speech, language, hearing, and swallowing. Although speech-language pathologists are well trained in identifying communication disorders, they are also interested in the nature and type of supports that assist people in achieving effective social communication during daily routines. Effective or competent communication depends on the communication context, including the expectations of communication partners, and the degree to which the person meets the interpersonal demands of a given situation, despite having a communication disorder (Ball, Beukelman, & Pattee, 2002; Cascella, 1999; Hustad & Gearhart, 2004; McCarthy & Light, in press; Pavitt & Haight, 1985; Spitzberg & Hecht, 1984). For example, Ferguson (1994) argued that individuals with significant disabilities could be relatively effective communicators only when their communication partners respect, value, and see the individual as a competent communicator. In other words, even people with the most severe developmental disabilities should be encouraged and provided with opportunities to communicate so as to meaningfully affect daily routines (Cascella & McNamara, 2004; National Joint Commission for the Communication Needs of Persons with Severe Disabilities, 2004).

Communication competence is difficult to measure, in part, because of the subtle differences and expectations that might exist in specific situations, cultures, and learning contexts. However, it can be estimated by speech intelligibility, non-verbal skills, developmental speech-language milestones (i.e., vocabulary, grammar, syntax, morphology), listening skills, hearing ability, and language comprehension (Andrews, 1993; Burbules, 1993; Carroll, Willmington, & Clay, 1998; Doll, Sands, Wehmeyer, & Palmer, 1996; Ferguson, 1994; Hustad & Beukelman, 2001; Kent et al., 1992; Kleinman, 2003; Light, 1989; Payne-Johnson, 1986; Ralph, 1998; Spitzberg, 1983; Sprague & Stuart, 1996; Yorkston & Beukelman, 1978). Competent communicators convey messages efficiently and without anxiety or fear (Light; Ralph; Spitzberg & Hecht, 1984). In the American culture, ratings of communication competence influence employment, self-esteem, community access, interpersonal relationships, and social success (Daly & McCroskey, 1984; McDowell, 1997; Smythe & Powers, 1978). When an individual is regarded as less
communicatively competent, fewer choices may be available for community involvement, employment, and self-determination.

When a speech-language pathologist attempts to estimate communication competence, it is helpful to interview family members and significant others of the person with the communication disorder. For example, the speech-language pathologist might assess communication in the home situation to learn about real-life communication opportunities (Rini & Hindenlang, 2007). In a school setting, it is important to ask the teacher how the communication disorder impacts peer relationships and the child’s access to the educational curriculum. Family or caregiver report is a useful tool for estimating communication because it helps establish ecological validity, especially among individuals with severe intellectual disability (Cascella, 2005; McLean, Brady, & McLean, 1996). To date, no reports have examined communication from the sibling’s perspective among persons with developmental or intellectual disabilities.

This paper examines communication competence among individuals with Down Syndrome by considering the opinions of their siblings. Family members, particularly siblings, are often affected when a child is born with Down Syndrome. Several reports have documented the social, academic, emotional, and developmental impact on siblings of persons with Down Syndrome (Baumann, Dyches, & Braddick, 2005; Cuskelly, Hayes, & Chant, 1998; Cuskelly & Gunn, 2003; Van Riper, 2000). Few reports have examined the nature of communication between siblings when one has Down Syndrome. Siblings may view the communication needs of persons with Down Syndrome differently than professionals, peers, or teachers and thus offer insights that can be utilized to enhance functional communication programming. If particular communication factors are regarded as especially important to siblings, then the speech-language pathologist might want to assess and intervene on these points. Therefore, this study examined how typically developing siblings of individuals with Down Syndrome rated communication competence indicators.

Method

Participants and their Siblings with Down Syndrome

Participants for this study were an available sample of 25 individuals without intellectual disability (ID) whose siblings had Down Syndrome. Participants and their siblings had a current or prior affiliation with community resource agencies in Connecticut, including, the Down Syndrome Congress, the Center for Communication Disorders at Southern Connecticut State University, public schools, and private human services agencies. Thirty siblings were invited to participate, yielding a return rate of 84%. Participants were 10 to 64 years in age. Fifteen (60%) of the participants were 18 years of age or older, while 10 (40%) were under the age of 18. Eight (32%) of the participants were male and 17 (68%) were female. Fourteen (56%) of the participants lived with the sibling with Down Syndrome. Among these 14 participants, 4 (28.6%) were adults (> 18 years) and 10 (71.4%) were children (≤ 18 years).

Participants for this study had siblings with Down Syndrome between the ages of 8 to 51. Thirteen (52%) of the siblings with Down Syndrome were children (≤ age 18) and 12 (48%) were adults (> age 18). Fifteen (60%) of the siblings with Down Syndrome were male and 8 (32%) were female. Two participants did not indicate their siblings’ sex. These siblings had different degrees of ID, including mild (n = 8), moderate (n = 6), and severe to profound (n = 5). One sibling did not have ID and 5 participants did not report their siblings’ degree of ID. In addition, 9 of the siblings with Down Syndrome were reported to have a hearing loss. A majority of the siblings (76%) with Down syndrome were reported to be verbal communicators who used conversational speech or short phrases as their primary means of communication. In addition, 12% vocalized via sounds and noises, 4% used body language, and 4% used sign language. None of the individuals with Down syndrome used a voice output communication device.
As already noted, many researchers have defined communication competence. Along with demographic information, each participant rated three yes/no descriptive questions about whether his/her sibling with Down Syndrome “communicates to his/her potential”, was an “effective communicator” and was a “good communicator.” Then, participants were asked to rate 16 communication competence indicators culled from the professional literature (see Table 1). Participants rated each of the 16 items by degree of importance: very important, important, somewhat important, not important, or not applicable.

The survey was developed in four forms, adjusted for age and gender (e.g., male child siblings, female child siblings, male adult siblings, female adult siblings). Table 1 provides the survey items for the child and adult male siblings. As part of survey development, six nationally certified speech-language pathologists reviewed the survey instrument, offered suggestions for wording of the items, and made comments about content validity. Two children, ages 6 and 13, reviewed the child version and identified words and concepts that were confusing.

Survey Completion

All participants received a cover letter, survey, and return self-addressed envelope. There was a child version and an adult version of the cover letter. The cover letter stated the purpose of the study and talked about voluntary participation and confidentiality. Participants were given three weeks to complete and return the survey. A second mailing did not occur. Twenty-one participants (84%) reported that they independently filled out the survey, while four child participants (16%) reported assistance with survey completion. Of those who had assistance, two were assisted by a mother, one by a father, and one by a cousin.

Data Analysis and Results

Descriptive Ratings of Communication

Among all of the participants, a majority favorably rated the communication of their siblings with Down Syndrome; 79.1% rated the sibling as an “effective communicator”, 83.3% rated the sibling as a “good communicator”, and 84.1% rated the sibling as able to communicate to his/her potential. Results further suggest that degree of ID influenced how participants rated their siblings’ communication on the descriptive statements. Siblings with mild to moderate ID were rated higher than those with severe/profound ID (Table 2).

Communication Competence Indicators

A majority of the participants (92%) answered all or nearly all of the 16 communication competence survey items. Among the 16 competence indicators, 14 (87.5%) were rated as important or very important by a majority of the participants. Table 3 shows the indicators rated from most to least important. This list suggests that communicating without fear, being able to express wants, needs, opinions, and feelings, and being able to ask questions were rated the highest, along with alerting partners to communication breakdowns and language comprehension. In contrast, two indicators were rated especially low, use of correct verb tenses and speech that was not too wordy.

Further analysis indicated that degree of ID was a factor for the rating of communication competence indicators. Participants most often rated communication competence indicators as “important” or “very important” among siblings with mild ID (81.1%) or moderate ID (73.5%), versus those with severe/profound ID (53.1%). These results are generally consistent with the descriptive statements already discussed.

Communication Competence Indicators Based on Hearing Loss

An analysis of the 16 communication competence indicators was completed based on hearing status since nine of the participants were reported to have a concomitant hearing loss.
<table>
<thead>
<tr>
<th>Communication Competence Indicator</th>
<th>Child Survey Question</th>
<th>Adult Survey Question</th>
<th>References</th>
</tr>
</thead>
</table>
| Speech clarity among familiar listeners | How important is it that your brother speaks clearly when he talks to you? | How important is it that your brother’s speech sounds clear to you and your family members? | *Yorkston & Beukelman (1978)*  
*Hustad & Beukelman (2001)*  
*Payne-Johnson (1986)*  
*Kent et al. (1992)* |
| Speech clarity among naïve listeners | How important is it that your brother speaks clearly to new friends? | If your brother speaks, how important is it that his speech sounds clear to strangers, new people, and unfamiliar listeners? | *Yorkston & Beukelman (1978)*  
*Hustad & Beukelman (2001)*  
*Payne-Johnson (1989)*  
*Kent et al. (1992)* |
| Communication breakdowns | How important is it that your brother lets people know when he does not understand what someone says to him? | How important is it that your brother lets people know when he does not understand what the other person is saying? | *Light (1989)*  
*Savignon (1983)* |
| Communicating without fear or anxiety | How important is it that your brother is not afraid or nervous about talking? | How important is it that your brother communicates without feeling fear or anxiety? | *Burbules (1993)*  
*Spitzberg & Hecht (1984)* |
| Asking questions to obtain information | How important is it that your brother can ask questions to get information? | How important is it that your brother asks questions when he needs information? | *Andrews (1993)* |
| Comprehension of oral directions | How important is it that your brother understands what someone else is telling him? | Same | *Carrell & Wilmington (1998)*  
*Wilmington & Steinbrecher (1995)* |
| Being able to justify an opinion | How important is it that your brother lets people know what he thinks and how he feels? | How important is it that your brother communicates his opinion? | *Spitzberg & Hecht (1984)* |
| Being able to state needs | How important is it that your brother lets people know what he needs and wants? | How important is it that your brother conveys what he wants or needs? | *Light (1989)*  
*Kleinman (2003)* |
| Being an efficient communicator | If your brother speaks, how important is it that his speech is direct and not too wordy? | Same | *Ralph (1998)*  
*Light (1989)* |
| Being able to communicate on the telephone | How important is it that your brother communicates using the telephone? | Same | *Lomas et al. (1989)* |
| Being able to interpret non-verbal communication | How important is it that your brother understands what people are feeling by the look on their face or the sound of their voice? | How important is it that your brother understands people’s body language, for example: facial expression, tone of voice, and use of gestures? | *Ralph (1998)*  
*Dolls, Sands, Wehmeyer, & Palmer (1996)* |
| Adequate writing skills | How important is it that your brother can write? | How important is it that your brother can communicate by writing? | *Payne-Johnson (1986)*  
*Kleinman (2003)* |
| Being able to communicate with friends in a socially competent way | How important is it that your brother is able to share ideas and feelings with his friends? | How important is it that your brother is able to effectively communicate with his friends? | *Sprague & Stuart (1996)*  
*Hazen & Black (1989)*  
*Chaney, Medina, O’Connell, & Tobar (1995)* |
| Being able to stay on topic | How important is it that your brother is able to stay on topic when he talks? | How important is it that your brother is able to stay on topic? | *Light (1980)*  
*Kleinman (2003)* |
| Correct use of verb tenses | How important is it that your brother uses verb tenses correctly? | Same | *Burbules (1993)*  
*Light (1989)* |
| Being able to code switch and use communication appropriate to the setting | How important is it that your brother knows how to talk in a restaurant or a place of worship? | How important is it that your brother communicates differently for different situations, for example: at home vs. in a restaurant vs. at a place of worship | *Spitzberg (1983)*  
*Bernstein & Tiegelman-Farber (2002)* |
Siblings with Down syndrome and a hearing loss were consistently rated lower on effective communication, good communication, and meeting their communication potential (Table 4) and a slightly higher number of communication competence indicators were rated as “very important” or “important” among siblings with a hearing loss (74.8%) than siblings without a hearing loss (69.3%).

Communication Competence Ratings Based on Age of the Siblings with Down Syndrome

All of the child participants rated a sibling who was younger than 18 years of age, and all but one of the adult participants rated an adult-aged sibling. On the three descriptive ratings, children with Down Syndrome were less often rated as good communicators (63.6%), effective communicators (71.4%) or those that communicated to potential (54.5%) than adult siblings (85.7%, 81.8%, and 92.9% respectively). In contrast, a relatively comparable number of communication competence indicators were rated as “very important” or “important” for child (72.6%) and adult (69.0%) siblings with Down Syndrome.

Discussion

Major Findings

Results of this study suggest that a majority of individuals with Down Syndrome were favor-
ably regarded as “effective” and “good” communicators who “communicate to potential” as reported by their siblings. Among the 16 communication competence indicators amassed from the professional literature, 14 were judged to be important for persons with Down Syndrome. The favorable descriptive labels and communication competence indicators were most often used to describe individuals with Down Syndrome who had mild to moderate ID (versus severe), normal hearing (versus hearing impaired), and who were adults (versus children). Certain communication competence indicators were rated as the most important, i.e., being able to communicate without fear, being able to express wants, needs, opinions, and feelings, being able to ask questions, alerting partners to communication breakdowns, and language comprehension. In contrast, correct use of verb tenses and using speech that was not too wordy were rated the lowest.

Clinical Implications

This study yielded three particularly interesting findings about communication competence and persons with Down Syndrome. First, the finding that participants placed great importance on their siblings’ ability to communicate without fear or anxiety was interesting and unexpected. Communicating without fear or anxiety is seldom directly targeted in speech-language assessment protocols or therapy for individuals with developmental or intellectual disabilities. Speech-language pathologists might need to more directly ask a question about how the person with Down Syndrome feels about communicating and whether or not fear or anxiety impacts the person’s ability to communicate in home, school, and community settings. Intervention strategies may need to target helping the person with Down Syndrome feel more confident about communication abilities.

A second interesting finding was that the participants placed more importance on social communication skills (i.e., stating wants, needs, opinions, and feelings; communication breakdowns) than the mechanics of communication (i.e., verb tenses, direct speech, and writing). Here, it appears that the participants rated communication functions as more important than communication forms. This lends support to speech-language pathologists whose programmatic decisions aim to work on pragmatic skills more so than vocabulary and grammar. Since half of the siblings rated adult-aged persons with Down Syndrome, it is not remarkable that they rated social communication abilities as more important than developmental skills. Not surprisingly, the participants consistently rated communication abilities lower among siblings with Down Syndrome who had a hearing loss. This reminds speech-language pathologists that the hearing status of persons with Down Syndrome needs to be consistently and aggressively managed, so as to prevent the impact of hearing loss on the person’s overall communication abilities.

Finally, speech-language pathologists, educators, and rehabilitation personnel might choose to use this communication competence scale among other individuals with developmental or intellectual disabilities. Professionals might consider using the rubric so as to rate whether particular communication competence indicators are important to other primary communication partners (parents, teachers, and peers) and whether each skill pertains to the person’s home, school, and community. By completing a scale like this, professionals can further evaluate communication in real life situations and develop functional communication objectives that are individualized to the person’s unique life circumstances.

Concluding Comments

It is important to note that these findings represent the opinions, not the behavior, of

<table>
<thead>
<tr>
<th>Communication Descriptors</th>
<th>Hearing Impaired</th>
<th>Normal Hearing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective Communicator</td>
<td>62.5%</td>
<td>87.5%</td>
</tr>
<tr>
<td>Good Communicator</td>
<td>62.5%</td>
<td>93.3%</td>
</tr>
<tr>
<td>Communicates to Potential</td>
<td>50.0%</td>
<td>93.8%</td>
</tr>
</tbody>
</table>
people who have a sibling with Down Syndrome. For example, the participants’ reports may not reflect how they interact with their siblings. It is also important to note that it is difficult to generalize these results to a larger sample of siblings of persons with Down Syndrome since the number of participants was relatively low and the accuracy of their reported information (i.e., intelligence and hearing status) was not confirmed by other sources. A participant could have incorrectly rated his/her sibling’s hearing loss or level of ID.

Although this study has provided some useful information about how individuals rate their siblings, it did not give an opportunity for siblings to expand on why they chose their selected ratings. Conducting interviews with the participants would have been helpful for gaining further insight into communication competence. Future research should include information about family culture, such as communication opportunities, expectations, and family views of disability. In addition, it would be very valuable to consider how people with Down Syndrome rate their own communication, along with ratings by siblings, parents, teachers, and peers, so as to see the variation in how these different groups of people view communication competence. This information would provide deeper insight into the intervention planning and implementation process.

References


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Ratings of Communication Competence / 189
A Beginning Communication Intervention Protocol:  
In-Service Training of Health Workers

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Abstract: Primary health care nurses are frequently overlooked when delivering services to children with developmental disabilities, despite the fact that they are often the first contact many primary caregivers have with rehabilitation professionals and usually remain the bridge between caregivers and professionals. A time series one group design with withdrawal was used to evaluate an in-service training programme for primary health care workers aimed at facilitating beginning communication skills between primary caregivers and their children with developmental disabilities. Training employed adult learning principles and was one week long, followed by three follow-ups that were conducted in situ (at two weeks, six weeks and five months post-training). Multiple measurements were used to evaluate the knowledge and skills acquired after training, namely questionnaires, structured interviews, skill demonstrations (which were video recorded and rated by the researcher and an independent rater) and a focus group. Results indicated that the particular in-service training programme was relevant in bringing about a significant change in the targeted domains, namely knowledge and skills.
they are viewed as sensitised professionals who have the skills to observe behavioural patterns and environmental concerns enabling them to make recommendations where necessary. Nurses are also expected to function as expert generalists because of the diverse skills they need when working with individuals across the lifespan with diverse health conditions, including disability (Clark, 1996; Hamell-Bissell, 1992; Tiffany & Hourigan, 1992). In addition they need to be independent and self-reliant since they make on-site decisions at clinics that can be some distance from support (Thobaben & Biteman, 1999).

However, when attempting to include primary health care nurses as part of the intervention, two major stumbling blocks exist. The first being the fact that nurses receive very little training in service delivery to people with disability and the second being the paucity in available material. The vast majority of available materials have a strong American and/or European emphasis, which is not applicable to developing country contexts as life experiences differ, language issues are paramount, and differences in developmental norms and expectations exist (Lynch & Hanson, 1988). Thus, when attempting to train nurses in developing country contexts, appropriate materials and methods for assessment and intervention that are ecologically valid and culturally sensitive should be a high priority.

As a result of this, an in-service training programme, the Beginning Communication Intervention Protocol (BCIP) was developed, with the explicit goal of providing nurses who work in primary health care settings with knowledge and skills about beginning communication skills (i.e. informational and social communication functions using aided and/or unaided communication means) (Bornman, 2001). This training was intended to assist nurses to function as true trans-disciplinary professionals when training primary caregivers of beginning communicators to facilitate interaction with their children.

This in-service training comprised three major phases, namely the needs analysis phase followed by the course development phase and finally the training phase. The needs analysis indicated that primary health care nurses felt inadequate about the way in which they were able to provide services to beginning communicators and their primary caregivers and that they required knowledge and skills that in turn would impact positively on their attitudes towards this population (Bornman & Alant, 2002). It was also evident that nurses were well aware of the problems experienced by these children and their primary caregivers and that they are trusted by these caregivers regarding discussions of their personal problems. This makes the nurses ideally suited to provide training to the primary caregivers of beginning communicators, enabling them to stimulate their own children, which is in line with current thinking about family-focussed intervention (Shonkoff & Meissels, 2000). In addition, this would imply that these children can remain in the community and that they do not have to move away, which reflects current thinking about inclusion and equalization (Tøssebro & Kittelsaa, 2004). The needs analysis therefore recommended that a specific in-service training programme should be developed to meet these identified needs by equipping community nurses with the knowledge and skills to provide training and support to the primary caregivers of beginning communicators, so that the rehabilitation process can begin (Bornman & Alant, 2002).

The needs analysis resulted then in the development of the BCIP. The first step in the development of the BCIP was to provide a theoretical framework for understanding the pivotal role of primary health care nurses in providing services to caregivers of beginning communicators (Bornman & Uys, 2005). It was important to place the BCIP training within the realm of current nursing practice, so that nurses would be able to integrate newly gained knowledge and skills with existing ones. Research results indicated that many of the skills required by nurses when providing services to children with developmental disabilities and their caregivers could be easily integrated into traditional nursing roles and tasks, such as raising awareness and providing information, referring, providing feedback and follow-up, prevention, early identification and screening and finally service delivery (Bornman, Alant, & Lloyd, 2004).

The third and final phase included the in-service training, and addressed the following dimensions: the target group, goals, form,
content and the time frame. A brief summary of these dimensions is included in Table 1.

As previously discussed the specific target group is primary health care nurses, as the in-service training will aim to equip them with the knowledge and skills to function as trans-disciplinary professionals. The goals of in-service training can be analysed into the type of goal and the target of the change. Any effective training programme aimed at making a difference in current practices should assist with the transfer-of-learning (applying new knowledge in their own work context) (Caffarella, 1994). For this particular in-service training the desired effect would be increased skills in delivering services to primary caregivers of beginning communicators. However, skills should be based on knowledge and not only theoretical knowledge but also applied knowledge, in other words the extent to which they were able to apply the theoretical knowledge to a specific case.

Several literature reviews have reported that the form of training is strongly related to the outcomes of training (Caffarella, 1994; Granlund & Björck-Åkesson, 2000; Jarvis, 1995; Jarvis & Gibson, 1997). In addition, the form and content of any in-service training programme needs to be adjusted to the actual working situation of the target group (in this case nurses) (Granlund & Björck-Åkesson, 1996). Practical applications of course content (e.g. through the use of case studies) are important for the maintenance of change in skills (Blackman, 1995), while theoretical knowledge seems to be important for the generalization of skills to new, but related contexts (Granlund & Björck-Åkesson, 2000). Therefore, different forms of training were combined in the BCIP training. In order to counteract fatigue, sessions between tea or lunch breaks were never longer than 1½ hour. These sessions were usually made up of theoretical discussions (lasting approximately 20–30 minutes) followed by short video clips, interactive workshops and role-play sessions of 60 minutes in line with adult training principles (Jarvis & Gibson, 1997). Firstly a problem-based approach was used, which included the use of case studies based on real life experiences as well as traditional lectures to transfer specific knowledge (Givens-King, Sebastian, Stanhope, & Hickman, 1997; Savin-Baden, 1997). Care was taken to ensure authenticity of the case studies used in the BCIP and they were compiled after focus groups had been conducted with nurses, primary caregivers of typically developing children and primary caregivers of children with developmental disabilities in the particular district. Case studies shown on video ensured that all participants understood concepts in exactly the same way.

### Table 1

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Application to BCIP training</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Target group</strong></td>
<td>Single professional group, namely primary health care nurses</td>
</tr>
<tr>
<td><strong>Goals of training</strong></td>
<td>• Gaining knowledge (theoretical knowledge and applied knowledge) and skills</td>
</tr>
<tr>
<td>• Type of goal</td>
<td>• Participants</td>
</tr>
<tr>
<td>• Target</td>
<td>• Participants</td>
</tr>
<tr>
<td><strong>Form of training</strong></td>
<td>Problem-based learning using authentic case studies and traditional lectures, Interactivity (e.g. group discussions, role play in small groups, video observations and discussions), Repetition and review</td>
</tr>
<tr>
<td><strong>Content of training</strong></td>
<td>• Beginning communication skills, including communication means, functions and the deliberate creation of communication opportunities</td>
</tr>
<tr>
<td>• Topic</td>
<td>• Knowledge related to specific cases (e.g. applied knowledge)</td>
</tr>
<tr>
<td>• Focus</td>
<td>• Specific methodology in terms of handling beginning communicators and their primary care-givers</td>
</tr>
<tr>
<td>• Process</td>
<td>• Specific methodology in terms of handling beginning communicators and their primary care-givers</td>
</tr>
<tr>
<td><strong>Time frame</strong></td>
<td>One week intensive training followed by three in-situ follow-ups</td>
</tr>
</tbody>
</table>

(This table is based on Granlund and Björck-Åkesson, 2000).
(e.g. the various manifestations of the concept “beginning communicator”), forming common ground and facilitating insightful understanding of the particular concept. The use of case studies and problem-based learning assist participants in applying new knowledge and skills to real life situations (Blackman, 1995). Secondly, an emphasis was placed on interactivity by including specific strategies, e.g. the use of group discussions to facilitate the acquisition of knowledge and applied knowledge and using role-play in small groups of three, providing each nurse with the opportunity to take on the role of the nurse, the primary caregiver and the beginning communicator. This type of role-play requires the active involvement of each participant to fulfill a particular role during the activity (Caffarella, 1994). In addition, video observations with critical group discussions were used, enhancing nurse’s observation skills and their ability to make appropriate recommendations. Another strategy that was incorporated to ensure interactivity, relates to the relationship between the trainer and participants (nurses). This process was characterised by facilitation and co-operation rather than control (Maehl, 2000), and the trainer attempted to provide positive reinforcement throughout (Heimlich & Norland, 1994). Finally, the logistical arrangements also facilitated interactivity. A positive climate for learning was created from the moment the participants arrived with training orientation and appropriate introductions (Heimlich & Norland, 1994). All participants wore name labels on the first and second days to facilitate interaction, after which it was no longer necessary as everybody was on first-name terms. Thirdly repetition and review was included by providing complete handouts each morning during the weeklong training and starting each day with a review of the most important concepts discussed the previous day (Appendix). To maintain the effects of in-service training over extended period of time, training needs to be supplemented in a manner that supports the desired change. In the BCIP training, the new training content was integrated with current nursing practices, which assisted with the internalization of the knowledge.

The content of the training varies along the three dimensions of topic, focus and process. The topic of the BCIP training was specific and related to communication means, functions and the deliberate creation of communication opportunities within three specific activities of daily living. This knowledge was combined with specific application to case studies in an attempt to contextualise the content for the nurses. However, despite the fact that the knowledge was specific in nature, it also covered some generic concepts related to disability, particularly on the first day of training (Table 1). This generic knowledge helped nurses in understanding where disability fits into their current nursing practices. Likewise, the training process needs to fit with the specific context. Therefore, a focus was placed on identifying current communication means and functions throughout, explaining the importance of communication means and functions to primary caregivers, deciding on which means and functions should be stimulated and how opportunities can be created to do this, by implementing the BCIP steps.

Finally, the time frame for the in-service training should be highlighted. This varies along two dimensions, namely the time period for training and the intensity of training (Granlund & Björck-Åkesson, 2000). Due to the specific logistical arrangements in the primary health care clinics, a model of an intensive weeklong training coupled with three in-situ follow-up visits was decided upon. It was convenient for the nurses to rather be away from their respective clinics for a week than being away at various intervals and also because the training follows the principle of total immersion to introduce nurses to these new and unfamiliar concepts. The consecutive training also limited the possibility of forgetting new information as adults forget 50% of what they learn after two hours and an additional 20% after two days (Rosenthal, 1991). In addition to the intensive weeklong training, three follow-up visits were conducted at respectively 2-weeks, 6-weeks and 5-months post-training. These follow-ups provided interactive hands-on skills and practise opportunities, optimising learning. During the follow-ups, difficult cases were problem-solved, which served as an opportunity to review knowledge and skills, providing nurses with the opportunity to practise new knowledge and skills whilst also acting as an independent trigger.
for review (e.g. after the follow-ups some of the nurses reported that they started reading on the subject). It has been reported that if training does not include follow-up, the outcomes are probably not optimal (Granlund & Björck-Åkesson, 2000).

The aim of this study was therefore to evaluate the application of a communication intervention protocol aimed at facilitating beginning communication skills between primary caregivers and children with developmental disability through in-service training of primary health care nurses in South Africa.

Method

Research Design and Phases

A quasi-experimental time series one group design O₁-X-O₂-O₃-O₄-O₅ with withdrawal was used. All subjects acted as their own control, providing a strong indication that the independent variable (BCIP training) could be responsible for the observed change in the dependent variables (knowledge and skills). O₁ represents the skills of the nurses before training, X the BCIP training and O₂ the nurses’ skill post-training. Three in-situ follow-ups were conducted, the first one two weeks post training (O₃), the second one six weeks post training (O₄) and the third one after a withdrawal period of five months (O₅).

Participants

Two non-probability sampling techniques were used. Firstly purposeful sampling was done by the Assistant Director of Health in the particular health district (Moretele, a rural area outside Pretoria, South Africa) who selected nurses who were eager to receive further training, following the needs analysis (Bornman & Alant, 2002). As this was the first BCIP training it was felt that nurses who were keen to receive training in disability would be useful in refining the programme. A convenience sample was then taken from this list to ensure that two nurses from the same clinic were not selected (as this could hamper service delivery) and not selecting nurses who were due for leave, time off or night duty. Although these sampling techniques had many advantages for the present research, the sampling bias that limits the generalisability of the results should not be overlooked (Babbie & Mouton, 2001; Brink, 1999).

This process resulted in the inclusion of twenty primary health care nurses. Except for one, all nurses were female and none of them had received any prior training in service delivery to children with developmental disability. Two of the participants had a relative with a disability, namely a sister with polio (that had resulted in a deformed left leg) and a sister whose daughter had hydrocephaly. The nurses’ ages ranged from 28 to 54 years and they tended to be older, with the majority (13) being between 41 and 45 years of age. This highlights the fact that this is a group of mature learners and that adult learning styles had to be taken into consideration with the BCIP training. Qualifications covered a broad spectrum, including eight with no formal training after school (Grade 10 or Grade 12), nine with nursing diplomas and three with nursing degrees. Regarding their nursing status, the majority (13) were professional nurses (including senior professional and chief professional nurses). In addition, there were three senior auxiliary nurses as well as four staff nurses who were receiving additional in-service training by the National Department of Health to equip them with the skills to become professional nurses.

Materials

The study involved two main types of materials: three different measuring instruments and the training programme (BCIP and handouts). All materials were tested in a pilot study, resulting in changes and refinement.

Measuring instruments. Three different instruments were used. Response Form I was a structured interview which dealt primarily with the nurses’ skills and applied knowledge, and was administered during all 5 research periods. It is based on four comparable case studies (the same case study was used for phases O₁ and O₅ as it was assumed that nurses would not remember the exact details of the particular case study after the long time lapse during which time they were exposed to three other cases). It consists of three main sections namely the applied knowledge about the current abilities of the particular case
study, applied knowledge about recommendations, and practical skill demonstration in using the BCIP with the particular case (Bornman, 2001).

Response Form II also had three main sections, namely biographic information, prior knowledge about disability and communication and self-evaluation) but was only administered during three research periods, namely O1, O2 and O5. A mixture of open-ended and close-ended questions (e.g. with true-false format or Likert scales) was used. Finally, Response Form III, a short two-page questionnaire that dealt with the evaluation of training was included. This was only administered during 2 research periods, namely O2 (directly post-training) and during O5 (at the five month withdrawal period).

Training programme. Equipping nurses with the knowledge and skills to provide services to primary caregivers of beginning communicators constitutes the primary aim of this research. The BCIP (Table 2) with its accompanying handouts and training (Table 3) represents a method through which this can be achieved. The training makes use of the multi-skilling principle as it facilitates change on the knowledge and skill levels.

Procedure

After permission had been obtained from the local authorities to conduct the research, the study commenced with the identification of community nurses’ knowledge and skills (O1). This was done by means of completing Response Form I and II on the first day of the weeklong training, before the formal training commenced. Six interviewers, who assisted in conducting the structured interviews and completing Response Form I, were trained beforehand. In order to heighten the reliability of the data, the structured interviews were video recorded and an external rater viewed all. After all the structured interviews were completed, nurses assembled in the training venue and completed Response Form II. This was followed by a tea break after which the BCIP training commenced.

This in-service training in the application of the BCIP (Phase X) was conducted over five consecutive days (Table 3) where after the same procedures as described for O1 were repeated for O2, with the addition of Response Form III (training evaluation) after Response Form II had been completed. Random selections were made, implying that nurses were not necessarily interviewed by the same interviewer pre- and post-training. This was followed by the presentation of certificates of attendance, which served as reward, and made nurses feel positive about their newly acquired skills and eager to learn in future (Jarvis, 1995).

Training was followed by an in situ follow-up two weeks after the initial training (O3) and lasted three days. This was necessitated by the fact that vast distances between the various clinics had to be covered, making it impossible to conduct this over a shorter time. Blackman (1995) reported that the quality of training is enhanced if it is followed by a training session during which the participants have the opportunity to interact individually with the trainer. These follow-ups were conducted in situ for logistical reasons (nurses did not have to take time off from work and consequently service delivery was only slightly disrupted) as well as the fact that the advantages of in situ training are documented (Bornman & Alant, 1999). The researcher then conducted the structured interviews and completed Response Form I. All interviews were video recorded by the fieldworker. The external rater then viewed the recordings and completed Response Form I independently. These sessions concluded with the researcher addressing issues with which the particular nurse still had difficulty (e.g. the implementation of the communication board) and by answering all possible questions. The date for the next follow-up was confirmed. Each session lasted approximately 50 minutes.

The second follow-up (O4) was conducted six weeks post training and followed the exact same format as described for O3. Some of the nurses had arranged for caregivers and the beginning communicators to be present and the researcher demonstrated some of the principles of the BCIP on these children. In addition, each nurse received five PCS symbols that could be placed on the 4-option digital speaker. In order to allow for some flexibility they received five symbols despite the fact that they only needed a maximum of
### TABLE 2
Summary of BCIP Elements for One Context, Namely Mealtime

<table>
<thead>
<tr>
<th>Communication functions</th>
<th>Communication means</th>
<th>Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Providing choices of Objects:</strong> Spoon, plate, cup, food</td>
<td><strong>Before starting to feed, ask the child “Do you want your porridge or your milk?” Hold up both options so that child can see. Emphasise the particular one by holding it slightly more to the front.</strong> (material)</td>
<td></td>
</tr>
<tr>
<td><strong>● Materials</strong></td>
<td><strong>●</strong> Before starting to feed, ask the child “Do you want your porridge or your milk?” Hold up both options so that child can see. Emphasise the particular one by holding it slightly more to the front.** (material)</td>
<td></td>
</tr>
<tr>
<td><strong>● Tasks</strong></td>
<td><strong>●</strong> Before starting to feed, ask the child “Do you want your porridge or your milk?” Hold up both options so that child can see. Emphasise the particular one by holding it slightly more to the front.** (material)</td>
<td></td>
</tr>
<tr>
<td><strong>● Partners</strong></td>
<td><strong>●</strong> Before starting to feed, ask the child “Do you want your porridge or your milk?” Hold up both options so that child can see. Emphasise the particular one by holding it slightly more to the front.** (material)</td>
<td></td>
</tr>
<tr>
<td><strong>This teaches labelling &amp; choice-making</strong></td>
<td><strong>This teaches labelling &amp; choice-making</strong></td>
<td></td>
</tr>
<tr>
<td><strong>I, grandmother, eat, drink</strong></td>
<td><strong>I, grandmother, eat, drink</strong></td>
<td></td>
</tr>
<tr>
<td><strong>PCS Communication board</strong></td>
<td><strong>PCS Communication board</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Easy Talk 4 Option</strong></td>
<td><strong>Easy Talk 4 Option</strong></td>
<td></td>
</tr>
<tr>
<td><strong>2. Making desired items inaccessible</strong></td>
<td><strong>Object: Cup</strong></td>
<td><strong>●</strong> Place food in see-through container that the child cannot open independently.</td>
</tr>
<tr>
<td></td>
<td><strong>Pictures: Cup, help, want</strong></td>
<td><strong>●</strong> Place cup on top of cupboard (out of reach but in sight)</td>
</tr>
<tr>
<td></td>
<td><strong>Signs: Cup, want, help</strong></td>
<td><strong>●</strong> Place food out of reach.</td>
</tr>
<tr>
<td><strong>This teaches the concept of requesting “help”</strong></td>
<td><strong>This teaches the concept of requesting “help”</strong></td>
<td></td>
</tr>
<tr>
<td><strong>PCS Communication board</strong></td>
<td><strong>PCS Communication board</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Easy Talk 4 Option</strong></td>
<td><strong>Easy Talk 4 Option</strong></td>
<td></td>
</tr>
<tr>
<td><strong>3. Providing small portions/brief turns</strong></td>
<td><strong>Objects: Cup, spoon, plate</strong></td>
<td><strong>●</strong> Pour only one mouthful of water into the child’s cup</td>
</tr>
<tr>
<td></td>
<td><strong>Pictures: Cup, spoon, plate</strong></td>
<td><strong>●</strong> Feed one mouthful, and take plate away. If child feeds himself, follow same procedure.</td>
</tr>
<tr>
<td></td>
<td><strong>Signs: More, want, help, eat, drink</strong></td>
<td><strong>●</strong> Pour only one mouthful of water into the child’s cup</td>
</tr>
<tr>
<td><strong>This teaches the concept of requesting “more”</strong></td>
<td><strong>This teaches the concept of requesting “more”</strong></td>
<td></td>
</tr>
<tr>
<td><strong>PCS Communication board</strong></td>
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<td></td>
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<tr>
<td><strong>Easy Talk 4 Option</strong></td>
<td><strong>Easy Talk 4 Option</strong></td>
<td></td>
</tr>
<tr>
<td><strong>4. Selecting materials that require assistance</strong></td>
<td><strong>Objects: Cup, jug, mango</strong></td>
<td><strong>●</strong> Put water in jug that closes very tightly, so that child has to ask for assistance.</td>
</tr>
<tr>
<td></td>
<td><strong>Pictures: Cup</strong></td>
<td><strong>●</strong> Close tap tightly, so that child cannot open it independently.</td>
</tr>
<tr>
<td></td>
<td><strong>Signs: Cup, jug, want, help, drink</strong></td>
<td><strong>●</strong> Put a fruit in a see-through container that the child cannot open independently.</td>
</tr>
<tr>
<td><strong>This teaches the concept of requesting “help”</strong></td>
<td><strong>This teaches the concept of requesting “help”</strong></td>
<td></td>
</tr>
<tr>
<td><strong>PCS Communication board</strong></td>
<td><strong>PCS Communication board</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Easy Talk 4 Option</strong></td>
<td><strong>Easy Talk 4 Option</strong></td>
<td></td>
</tr>
<tr>
<td><strong>5. Withholding attention</strong></td>
<td><strong>Objects: Cup, jug, mango</strong></td>
<td><strong>●</strong> When setting the table, or when giving food to the siblings, pretend to “forget” the CSD. When he signals his presence, immediately react, and say “I’m sorry I forgot about you I’m silly”</td>
</tr>
<tr>
<td></td>
<td><strong>Pictures: Cup, mango</strong></td>
<td><strong>●</strong> When setting the table, or when giving food to the siblings, pretend to “forget” the CSD. When he signals his presence, immediately react, and say “I’m sorry I forgot about you I’m silly”</td>
</tr>
<tr>
<td></td>
<td><strong>Signs: Cup, jug, want, help, drink</strong></td>
<td><strong>●</strong> When setting the table, or when giving food to the siblings, pretend to “forget” the CSD. When he signals his presence, immediately react, and say “I’m sorry I forgot about you I’m silly”</td>
</tr>
<tr>
<td><strong>This teaches the child to draw attention to himself and to signal his presence.</strong></td>
<td><strong>This teaches the child to draw attention to himself and to signal his presence.</strong></td>
<td></td>
</tr>
<tr>
<td><strong>PCS Communication board</strong></td>
<td><strong>PCS Communication board</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Easy Talk 4 Option</strong></td>
<td><strong>Easy Talk 4 Option</strong></td>
<td></td>
</tr>
</tbody>
</table>
The data collection procedure for O₅, the third follow-up conducted five months post training was exactly the same as for the previous two (O₃ and O₄). After all the follow-ups had been conducted, nurses gathered in the initial training venue on the fourth day. The purpose of this meeting was to determine what each nurse felt that she had gained from the training (and if not – why not) and to hear her recommendations regarding the training. This day commenced with nurses completing Response Form II in order to determine their knowledge after having been involved in the training programme for five months. A focus group was then conducted to obtain qualitative information on benefits and recommendations. Finally, nurses were asked to complete Response Form III (training evaluation) taking the whole five months into consideration (implying the initial weeklong training and three follow-ups). Data from the focus groups and Response Form III will not be described as it falls beyond the scope of this paper.

**Reliability**

In order to heighten reliability, certain precautions were built into the measuring instruments and the methodology followed. As mentioned, structured interviews (used to obtain the data for Response Form I) were video-recorded in order to ascertain if data were collected and recorded consistently and accurately. Both inter-rater and intra-rater reliability measurement were included. To address the former, two raters (the researcher and an independent rater) independently scored Response Form I for all twenty participants for all five periods. Inter-rater agreement scores for the different research periods were as follows: O¹/H₁ = 98%; O₂/H₂ = 95%; O₃/H₃ = 96%; O₄/H₄ = 93%; O₅/H₅ = 97% with an average of 96% indicating high inter-rater reliability. To address the latter and evaluate the stability of judgments made by the same rater, Rater 1 re-administered Response Form I five months later. The videos of five participants (20%) were randomly selected for this purpose. The rater watched the videos and scored all 86 items. An intra-rater score of 96% across all items was obtained.

### Results and Discussion

Primary outcomes are described in terms of knowledge (including prior and applied knowledge) and skills of participants after having completed the BCIP training. In Figure 1 knowledge and skills are expressed relative to the measures obtained during pre-training, which implies that the pre-training average for both constructs was zero and that knowledge increased with an average of 1.5 and skills with

<table>
<thead>
<tr>
<th>Communication functions</th>
<th>Communication means</th>
<th>Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Offering non-preferred items</td>
<td>Objects: Water, mango, lemon Pictures: Mango, lemon Signs: Like, yuck, no</td>
<td>● If you know that the child wants a mango, give him a lemon instead and see if he will reject it. ● If child wants milk, give water.</td>
</tr>
<tr>
<td>This teaches protesting and the concept of “no”.</td>
<td>PCS Communication board EasyTalk 4 Option</td>
<td>● If child wants to eat, first give a drink.</td>
</tr>
<tr>
<td>7. Violating expectations</td>
<td>Objects: Cup, spoon, plate Pictures: Cup, spoon, plate Signs: No, funny, mine</td>
<td>● When feeding the child, do something totally unexpected like eating a mouthful yourself! ● When feeding the child, hold the spoon the wrong way round or upside down. ● Instead of giving the child something to eat, give him something else, e.g. a stone</td>
</tr>
<tr>
<td>This teaches protesting as well as surprise and humour.</td>
<td>PCS Communication board EasyTalk 4 Option</td>
<td></td>
</tr>
<tr>
<td>#</td>
<td>Aims</td>
<td>Learning outcomes</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>1</td>
<td>Contextualise training within Primary Health Care and human rights of children with developmental disability</td>
<td>Demonstrate knowledge about human rights of children with developmental disability, the importance of communication for these children, the concepts &quot;developmental disability&quot; and &quot;multi-skilling&quot; as well as their role in training beginning communication skills</td>
</tr>
<tr>
<td>2</td>
<td>Highlight the importance of communication</td>
<td>Describe 3 communication areas</td>
</tr>
<tr>
<td>3</td>
<td>Explain &quot;developmental disability&quot; and their role in training beginning communicators</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Discuss &quot;multi-skilling&quot; and their role in training beginning communicators</td>
<td></td>
</tr>
</tbody>
</table>

198 / Education and Training in Developmental Disabilities-June 2007
<table>
<thead>
<tr>
<th>#</th>
<th>Aims</th>
<th>Learning outcomes</th>
<th>Teaching material &amp; styles</th>
<th>Theoretical discussion</th>
<th>Practical session</th>
</tr>
</thead>
</table>
| 3.1 | Revisit 3 communication areas                                       | Demonstrate knowledge of aided and unaided communication means included in the BCIP | • Overhead projector  
• Transparencies  
• Video recorder  
• Videos  
• Handouts: Day 3  
• BCIP  
• Lecture  
• Object & PCS communication boards  
• SASL dictionary  
• Case study  
• Small group discussion  
• Feedback | Revise 3 communication areas, highlighting means. Discuss the concept “AAC” and demonstrate aided and unaided strategies included in the BCIP. Unaided strategies included gestures (e.g. pointing, yes/no headshake, facial expressions and natural gestures) and sign language (SASL). Aided strategies include real objects, colour photographs, PCS and a 4-option digital speaker. Provide culturally sensitive PCS communication boards in all 11 official languages. Discuss advantages and disadvantages of aided and unaided strategies. | Practise various aided and unaided strategies in the BCIP. These were first practised in isolation (e.g. “Make the gesture for “open”). Secondly had to incorporate this with skills of the previous day (e.g. use a gesture to provide a choice). Small groups provided opportunities for nurse to take the role of a beginning communicator, a caregiver and a nurse. Skills were then applied to a specific case. |
| 2   | Discuss aided and unaided communication means                        | Demonstrate skills in implementing aided and unaided strategies in the BCIP        | • Overhead projector  
• Transparencies  
• Video recorder  
• Videos  
• Handouts: Day 3  
• BCIP  
• Lecture  
• Object & PCS communication boards  
• SASL dictionary  
• Case study  
• Small group discussion  
• Feedback | Revise 3 communication areas covered by BCIP, highlighting the importance of the communication context (environment) by discussions, demonstrations and videos. BCIP focuses on 3 contexts, i.e. bath time, mealtime and dressing/undressing. Discuss and demonstrate general intervention principles, e.g. the importance of a “give-and-take balance”, role of praise. | Practise implementation of 3 contexts provided by the BCIP in small groups, with integration of general intervention principles. Finally role play of recommendations for specific case, e.g. “Nomusa is 7-years old and spends her days with her 90-year old grandmother who doesn’t want her to attend school. Her only toy is a broom that she pushes around aimlessly”. |
| 3   | Facilitate skills related to the implementation of aided and unaided communication strategies | Demonstrate knowledge of the importance of including different communication environments in intervention as well as general intervention principles | • Overhead projector  
• Transparencies  
• Video recorder  
• Videos  
• Handouts: Day 4  
• BCIP  
• Lecture  
• Case study  
• Small group discussion  
• Feedback | Revise 3 communication areas covered by BCIP, highlighting the importance of the communication context (environment) by discussions, demonstrations and videos. BCIP focuses on 3 contexts, i.e. bath time, mealtime and dressing/undressing. Discuss and demonstrate general intervention principles, e.g. the importance of a “give-and-take balance”, role of praise. | Practise implementation of 3 contexts provided by the BCIP in small groups, with integration of general intervention principles. Finally role play of recommendations for specific case, e.g. “Nomusa is 7-years old and spends her days with her 90-year old grandmother who doesn’t want her to attend school. Her only toy is a broom that she pushes around aimlessly”. |
| 4.1 | Revisit 3 communication areas                                       | Demonstrate knowledge of the importance of including different communication environments in intervention as well as general intervention principles | • Overhead projector  
• Transparencies  
• Video recorder  
• Videos  
• Handouts: Day 4  
• BCIP  
• Lecture  
• Case study  
• Small group discussion  
• Feedback | Revise 3 communication areas covered by BCIP, highlighting the importance of the communication context (environment) by discussions, demonstrations and videos. BCIP focuses on 3 contexts, i.e. bath time, mealtime and dressing/undressing. Discuss and demonstrate general intervention principles, e.g. the importance of a “give-and-take balance”, role of praise. | Practise implementation of 3 contexts provided by the BCIP in small groups, with integration of general intervention principles. Finally role play of recommendations for specific case, e.g. “Nomusa is 7-years old and spends her days with her 90-year old grandmother who doesn’t want her to attend school. Her only toy is a broom that she pushes around aimlessly”. |
an average of 1.7. It should be mentioned that knowledge was only measured at three different periods, whilst skills were measured at all five periods. It is noticeable that skills increased at a higher rate than knowledge, which could possibly be ascribed to the particular focus of the training on skills and the fact that skills were measured and emphasised more regularly than knowledge during the follow-ups. In addition, as the in-service training had stopped, it is understandable that knowledge didn’t continue to increase. However, as nurses had opportunities to practice their skills in implementing the BCIP, skills continued to increase.

Knowledge

The knowledge dimension was divided into two sections, namely prior knowledge and applied knowledge. The prior knowledge sec-

![Figure 1. Global increase in knowledge and skills post-training.](image-url)
tion included a set of 25 questions, comprising 15 true-false questions and 10 multiple-choice questions. Data were obtained by using Response Form II, which was administered at three different intervals (pre- and post-training and post-withdrawal). Applied knowledge on the other hand, was obtained from data recorded in Response Form I and comprised three sections, the first dealing with applied knowledge about the current abilities of the case study in terms of communication means and functions, the second with applied knowledge about general advice and specific advice about communication means, functions, opportunities and finally a skill demonstration regarding the implementation of the BCIP.

The last measurement not only focused on the practical skills, but also evaluated the amount of prompting required and the general level of confidence in using the BCIP. Data were collected at five different intervals.

Prior knowledge. A Friedman test was used to determine whether the change in prior knowledge was statistically significant over time. A $p$-value of 0.0001 was noted ($p < 0.05$) implying a statistical significant difference. The pair wise comparisons showed a statistical significant increase in prior knowledge at the 1% confidence level between the pre-training score ($R_1$) ($M = 13.5$) and the post-training score ($R_2$) ($M = 19.5$) and the post-withdrawal scores ($R_3$) ($M = 17.9$) respectively.

Regarding the 15 true-false questions, it was noted that the aspects that were highlighted during the follow-ups resulted in knowledge increasing in seven of the 15 areas (e.g., “Withholding attention is an example of a deliberate communication opportunity”, which increased from seven to 20, 20 over the three periods, and “Dressing does not provide many communication opportunities” which had frequency scores of 12, 18 and 19 over the three periods and “The EasyTalk is an example of a voice output communication device”, with scores of 14, 18 and 20). Two of the items showed that some information was maintained (namely the meaning of the acronym AAC and the definition of “unaided systems”). Aspects not addressed during the follow-ups resulted in post-withdrawal knowledge declining, although the decline was mostly slight (e.g., the World Health Organizations definition of disability with scores of 10, 13 and 11 and the definition of multi-skilling with scores of two, nine and five). One specific question related to rubella as a possible cause for disability, initially indicated no change but a small gain was noted at the post-withdrawal (from 18 to 19). This might be due to the fact that such a high number of nurses had it correct pre-training, due to the fact that this concept was probably familiar. The greatest knowledge improvement in this section was seen in the question that dealt with the deliberate creation of communication opportunities (with scores of seven, 20 and 20 during the three periods). This improvement was sustained over the 5-months post-withdrawal period, which might be due to the fact that this is a new concept, which was highlighted during training.

A similar investigation into the multiple questions was made. Results indicated that with four of the eight items nurses performed better post-training (namely requesting interaction, requesting objects, and both of the communication temptations); with two items no change was noted (pointing and crying) and with two items they performed, interestingly enough, poorer post-training (vocalizations and indicating thirsty). The lower post-training score for vocalisations is similar to a general tendency which is often noted directly after individuals had received training in the use of augmentative and alternative communication (AAC) strategies as they become so engrossed in the different AAC strategies that they tend to “forget” about speech as a means of communication (Bornman & Alant, 1999; Bornman, Alant, & Meiring, 2001). At the 5-month withdrawal period, this score increased but not to the pre-training level. This might be indicative of the fact that the focus is beginning to move towards including both speech (vocalisations) and AAC strategies when viewing communication means. Likewise, nurses performed poorer in the communication function category of “indicating thirsty” during the post-training and post-withdrawal periods, which might be due to the fact that this aspect was not emphasised to the same extent during training as the other two functions that are mentioned. It is therefore not surprising to note that major increases in knowledge are to be seen regarding communication functions as nurses became much more aware that “requesting interaction” and “requesting
objects” were communication functions post training.

In the prior knowledge section, communication temptations remained the most difficult to answer. It might be due to the fact that this concept was novel to nurses and that more training regarding this aspect was required. Pre-training none could identify “creative stupidity,” and only five could identify “providing small portions.” These two concepts were practised at great length during training, consequently 18 could correctly identify “providing small portions” and eight could identify “creative stupidity” post-training. Although a decline was seen during post-withdrawal, it was never to the pre-training level. It is interesting to note that these two items were trained to the same extent, but that the one yielded better results. This could possibly be because the term “creative stupidity” is more difficult (in spite of the fact the term was used during training) and the fact that “providing small portions” was trained first. In addition, “providing small portions” is very similar to its counterpart “providing brief turns” which in effect implies that nurses practised this strategy (albeit adapted) twice as much as they did “creative stupidity”.

Applied knowledge. The second component of knowledge comprised applied knowledge. This section is particularly relevant to the present research as the nature of training was problem-based and thus directly impacted on the nurses’ ability to apply knowledge to a particular case study. A Friedman test was employed to determine whether the change in combined applied knowledge was statistically significant over time (Table 4). A p-value of 0.0001 was noted (p < 0.05) implying a statistical significant difference. The pair wise comparisons showed a statistically significant increase for all the constructs that made up applied knowledge at the 1% confidence level between the pre-training score (R₁) and the post-training score (R₂), the two-week follow-up (R₃), the six-week follow-up (R₄) and the post-withdrawal scores (R₅). However, the construct specific advice about communication opportunities not only showed this pattern, but in addition it also showed a statistical significant increase between the post-training score (R₆) and the post-withdrawal score (R₅).

The identification of current communication means as well as specific advice in this regard, yielded interesting results. The total number of current communication means used by the individual described in the case study that was correctly identified by the nurses, increased from 52 (pre-training), to 67 (post-training), 72 (2-week follow-up) 73 (6-week follow-up) and 79 (post-withdrawal). In addition, the BCIP training increased awareness of the different communication means, as nurses were not aware of that pointing, using objects and vocalizations could be used for communication pre-training. They mostly identified manual signs and speech as the major means of communication.

This heightened awareness is also seen in their answers regarding specific advice about which different communication means the particular child in the case study could still learn. The different communication means that were recommended increased from 46 to 121. It is also evident that pre-training the focus was on better-known unaided strategies (speech and manual signs). A few aided strategies were mentioned, with the emphasis on drawing and writing. Post-training a wider distribution of different means was noted. Drawing and writing (aided communication means) decreased from nine pre-training to between one and two at the different post-training phases. This was possibly due to the fact that nurses became aware of the fact that these means are not appropriate for begin-
ning communicators as a primary means of interaction.

Regarding the nurses’ identification of communication functions, it was noted that post training, the number of “don’t know” answers disappeared, the number of incorrect answers decreased and the number of correct answers increased. The number of communication functions that nurses could identify increased from 42 (pre-training) to 74 (post-withdrawal), and regarding specific advice related to communication functions scores increased from 31 to 118. The fact that the total scores continued to increase could be possibly be attributed to the fact that communication functions were addressed throughout the BCIP training (including the follow-ups), and that nurses continually provided themselves with opportunities to practice their skills every time they implemented the BCIP. Nurses also became much more aware of the range of communication functions. Some functions, e.g. requesting help, requesting more, making choices and protesting, which were stressed during training, continued to increase. Some functions, e.g. greetings, expressing basic needs and expressing pain decreased despite the fact that they were correct. The most noticeable difference was seen in “requesting more” which changed from 0 to 19. Scores obtained during the post-training ($O_2$) and the 2-week follow-up ($O_3$) period correlate closely (there was an interval of two weeks between them). There was a noticeable increase between the 2-week follow-up 1 ($O_3$) and the 6-week follow-up 2 ($O_4$) (with an interval of four weeks), which was maintained over the five-month withdrawal ($O_5$).

As with all the other applied knowledge constructs, nurses’ knowledge regarding the specific advice they would give to provide deliberate communication opportunities to the particular case study, increased. A shift had taken place from generalised statements that were provided pre-training to more specific answers post-training. It is also interesting to note that as nurses had the opportunity to practise using the BCIP (during the follow-up and post-withdrawal phases) their knowledge regarding the creation of deliberate communication opportunities through the use of communication temptations, continued to increase. Although all the communication opportunities addressed during the BCIP training were mentioned by participants, this was not done to the same extent. Some strategies were mentioned more frequently during all the phases (e.g. “providing small portions” and “making items inaccessible”). This might possibly be due to the fact that nurses could identify

### TABLE 4

#### Friedman Test of Different Applied Knowledge Constructs

<table>
<thead>
<tr>
<th>Construct</th>
<th>$R_1$ Pre-training</th>
<th>$R_2$ Post training</th>
<th>$R_3$ 2-week follow-up</th>
<th>$R_4$ 6-week follow-up</th>
<th>$R_5$ Post-withdrawal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combined applied knowledge</td>
<td>$M = 15.90$</td>
<td>$M = 29.6$</td>
<td>$M = 30.95$</td>
<td>$M = 32.95$</td>
<td>$M = 33.05$</td>
</tr>
<tr>
<td>Current abilities in terms of communication means</td>
<td>$M = 2.55$</td>
<td>$M = 3.35$</td>
<td>$M = 3.60$</td>
<td>$M = 3.65$</td>
<td>$M = 3.95$</td>
</tr>
<tr>
<td>Current abilities in terms of communication functions</td>
<td>$M = 2.00$</td>
<td>$M = 2.90$</td>
<td>$M = 3.20$</td>
<td>$M = 3.70$</td>
<td>$M = 3.40$</td>
</tr>
<tr>
<td>General advice</td>
<td>$M = 0.95$</td>
<td>$M = 15.60$</td>
<td>$M = 16.75$</td>
<td>$M = 17.80$</td>
<td>$M = 18.20$</td>
</tr>
<tr>
<td>Specific advice about communication means</td>
<td>$M = 2.25$</td>
<td>$M = 4.20$</td>
<td>$M = 4.70$</td>
<td>$M = 4.90$</td>
<td>$M = 4.85$</td>
</tr>
<tr>
<td>Specific advice about communication functions</td>
<td>$M = 1.30$</td>
<td>$M = 3.95$</td>
<td>$M = 4.25$</td>
<td>$M = 4.55$</td>
<td>$M = 4.50$</td>
</tr>
<tr>
<td>Specific advice about communication opportunities</td>
<td>$M = 0.00$</td>
<td>$M = 2.95$</td>
<td>$M = 4.40$</td>
<td>$M = 4.45$</td>
<td>$M = 4.50$</td>
</tr>
</tbody>
</table>
better with these strategies, while others (e.g. “deliberately withholding attention”) were more difficult.

**Skills**

Results for this section were obtained from data recorded on the third section of Response Form I, which was also administered at five different intervals, and was scored by two independent raters throughout with high inter-rater reliability. A Friedman test was employed to determine whether the change in skills was statistically significant over time. A p-value of 0.0001 was noted (p < 0.05) implying a statistical significant difference (Table 5).

The pair wise comparisons showed a statistical significant increase of combined skills at the 1% confidence level between the pre-training score (R1), the post-training score (R2), the two-week follow-up (R3) and the six-week follow-up (R4) and the post-withdrawal scores (R5), respectively. This implies that skills increased statistically significantly during the follow-up phases when compared to pre-training and post-training. This emphasises the importance of follow-ups in skills development. Each of the skills aspects will now be described in detail.

**Table 5**

**Friedman Test of Different Skill Constructs**

<table>
<thead>
<tr>
<th>Construct</th>
<th>R1 Pre-training</th>
<th>R2 Post training</th>
<th>R3 2-week follow-up</th>
<th>R4 6-week follow-up</th>
<th>R5 Post-withdrawal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combined skill areas</td>
<td>M = 32.80</td>
<td>M = 58.65</td>
<td>M = 62.15</td>
<td>M = 70.80</td>
<td>M = 70.95</td>
</tr>
<tr>
<td>Skill in using objects for communication</td>
<td>M = 7.75</td>
<td>M = 12.95</td>
<td>M = 13.55</td>
<td>M = 13.85</td>
<td>M = 13.80</td>
</tr>
<tr>
<td>Skill in using photographs for communication</td>
<td>M = 2.00</td>
<td>M = 2.90</td>
<td>M = 3.20</td>
<td>M = 3.70</td>
<td>M = 3.40</td>
</tr>
<tr>
<td>Skill in using communication boards</td>
<td>M = 5.65</td>
<td>M = 9.15</td>
<td>M = 8.70</td>
<td>12.2</td>
<td>12.25</td>
</tr>
<tr>
<td>Skill in using manual signs for communication</td>
<td>M = 00</td>
<td>M = 10.15</td>
<td>M = 11.55</td>
<td>M = 13.35</td>
<td>M = 14.00</td>
</tr>
<tr>
<td>Skill in using the Easy Talk 4 Option digital speaker for communication</td>
<td>M = 5.10</td>
<td>M = 10.35</td>
<td>12.50</td>
<td>13.80</td>
<td>13.65</td>
</tr>
</tbody>
</table>

The pair wise comparisons showed a statistical significant increase of combined skills at the 1% confidence level between the pre-training score (R1), the two-week follow-up (R3) and the six-week follow-up (R4) and the post-withdrawal scores (R5), respectively. This implies that skills increased statistically significantly during the follow-up phases when compared to pre-training and post-training. This emphasises the importance of follow-ups in skills development. Each of the skills aspects will now be described in detail.

Table 5 indicates a statistical significant increase in skills in using communication boards, between the pre-training score (R1), the six-week follow-up (R4) and the post-withdrawal score (R5), and also between the post-training score (R2) and the two-week follow-up (R3), the six-week follow-up (R4) and the post-withdrawal scores (R5), respectively. For skills in using manual signs, a statistically significant increase between the pre-training score (R1), the six-week follow-up (R4) and the post-withdrawal scores (R5), respectively were seen and also between the post-training score (R2) and the post-withdrawal scores (R5). Finally, a statistically significant increase in using the EasyTalk 4 Option digital speaker for communication was noted between the pre-training score (R1), the two-week follow-up (R3), the...
six-week follow-up (R_4) and the post-withdrawal scores (R_5), respectively.

**Dependence on prompts.** A Friedman test was employed to determine whether the frequency of prompts given to nurses changed statistically significantly over time. A p-value of 0.076 was noted (p < 0.05) indicating no statistically significance. This implies that the number of prompts remained consistent over time despite the initial hypothesis that the number of prompts will be reduced as nurses’ skills increased. It would thus appear that they were dependant on prompts in order to demonstrate their skills. On the other hand, it is also reassuring to note that the increase in skills that was noted was not due to an increase in prompts.

**Confidence in facilitating communication.** A Friedman test was employed to determine whether the change in the nurses’ confidence in facilitating beginning communication skills was statistically significant over time. A p-value of 0.0154 was noted (p < 0.05) implying that multiple comparisons were required to test the nature of the significance. The Friedman test showed a statistically significant increase in confidence at the 5% confidence level between the pre-training score (R_1) (M = 1.79) and the post-withdrawal score (R_5) (M = 2.53). This implies that the nurses’ confidence continued to increase over time as their knowledge and skills increased.

The statistically significant increase in the nurses’ skills together with a description of their confidence in demonstrating these skills and the amount of prompting required to demonstrate these skills, is shown in Figure 2.

It is clear from Figure 2 that the nurses’ skills initially increased noticeably and then remained consistent during the last two phases. After the noticeable first increase in confidence, the next increases were more gradual. A plateau was not reached, indicating that as skills continued to increase confidence also continued to increase. Regarding the amount of prompting that was initially required; nurses became less dependent on prompts. For the second follow-up, however, they required slightly more prompts than during the first follow-up but this declined again during the post-withdrawal period. During the pre-training phase nurses’ dependence on prompts was higher than their confidence and skills, this changed post-training.

**Conclusions**

Results of this study indicate that in-service training of one single professional group (primary health care nurses) has a significant impact on their knowledge (both theoretical and applied) as well as on their skills. In the introduction it was argued that in many developing countries, children with developmental disability and their families often live in remote rural areas where primary health care nurses are often the only persons available to provide...
services (Downs & Walker, 1996), and that they should therefore be included as part of the service delivery team.

In this training, the goals were focused on increasing knowledge and skills. There was a global increase in both of these aspects following the training, which continued to increase even after training had ended. When looking at knowledge specifically, it can be seen that prior knowledge regarding disability and communication increased over time. It also became evident that nurses were able to apply their knowledge to specific case studies. Applied knowledge was related to the identification of current abilities in terms of communication means and communication functions as well as to general and specific advice they would provide in an attempt to increase beginning communication skills. With all these aspects it became clear that there was not only an increase in the frequency of responses (indicating that nurses identified these aspects easier and more regularly) but there was also an expansion of the range of all of the aspects they identified.

However, in the primary health care context, knowledge should be intertwined with skills. As expressed so aptly by Bruner “It matters not what we have learned. What we can do with what we have learned...” (cited in Brewer, 1985, p. 3). During training the nurses received hands-on instruction in the utilization of the BCIP. Results indicated that statistically significant changes were obtained in their skills between the pre-training measurement and all the following research phases. Skills in the use of all the different BCIP elements in providing the particular child described in the case study increased statistically significantly over time. This included elements such as using photographs for communication, communication boards, manual signs and skill in using the EasyTalk 4 Option digital speaker.

It is also important to note that despite the increase in skills, nurses did not become more dependent on prompts and the number of prompts required remained fairly consistent over time. Results also indicated that the nurses’ confidence increased over time, as there was a statistically significant improvement in confidence between the pre-training measurement and the post-withdrawal period on the 5% level. This indicates that confidence continued to increase over time as nurses became more familiar and skilled in using the BCIP.

These results are not surprising when the form of training is considered. Problem-based learning and interactivity in the teaching-learning process (e.g. by means of role play and modeling) are known to be more effective in teaching than merely using lectures (Granlund, 1993; Jarvis & Gibson, 1997). However, as new theoretical constructs had to be explained, e.g. the concepts “developmental disability” and “beginning communicators” traditional lectures were also included, but video clips and/or interactive workshops always followed them.

Another factor that could have impacted positively on the increase in knowledge and skills that was seen might be related to the specific content of the training. The content (including the topic, focus and process) resulted from a needs analysis that had been conducted previously (Bornman & Alant, 2002). Therefore, in-service training was not viewed by nurses as something externally that was forced on them, but was rather seen as something that would make their work easier and enhance job satisfaction, as they would be better equipped to deliver services to beginning communicators and their primary caregivers. In addition, the concepts were not trained in a fragmented way emphasising newness, but were related to existing knowledge. All information was also contextualised by means of case studies and therefore nurses could relate to the information. In this training, the emphasis was placed on integrating the BCIP principles with existing nursing tasks and roles (Bornman et al., 2004) and therefore it was overt to nurses from the beginning what was expected of them, and how this related to their existing nursing practice.

Finally, the time frame is of importance. This in-service training programme proved to be cost effective, when considering the length of training. The above discussed increase in knowledge and skills were achieved with only a week of intensive training, followed by three in-situ follow-ups. The importance of the follow-up sessions should not be underestimated, as feedback and joint problem solving has been shown to yield positive results in training (Bornman & Alant, 1999; Granlund, 1993).
Limitations and Future Directions

The comprehensive approach used in the BCIP in-service training aimed at equipping primary health care nurses with skills outside their specific discipline boundaries. This could lead to insecurity about their primary roles and responsibilities, which, to a large extent could impact on job satisfaction and motivation. The relationship between this type of in-service training and job satisfaction, and between this type of in-service training and motivation to work with children with developmental disabilities and their primary caregivers should be further investigated. The focus of the present evaluation was based on an external evaluation by the researcher and could be broadened to include more opportunities for self-evaluation. A self-evaluation after each of the research phases would promote a reflection on practice and would guide participants to keep track of their own development. It could also enhance their awareness of the elements of the BCIP and the skills required to provide services to primary caregivers of beginning communicators. Self-assessment is also in line with using a problem-based approach as it advocates that participants should provide information about their ability to solve problems, to retrieve information, to find new solutions to problems and to be creative.

A comparison between the present methodology that was followed (e.g. interactivity, a problem-based format, creative repetition and revision) and distance training will yield interesting results. In evaluating the training, 80% of the nurses commented that the presence of real cases would have further enhanced the quality of training. This aspect should be explored further and alternatives investigated. Nurses could possibly be exposed to real cases on the final day of the formal training after having had ample opportunity for role-play. Another alternative would be to make it compulsory for nurses to have a primary caregiver and a beginning communicator available on the days of the follow-up visits to demonstrate their skills and for the trainer/researcher to assist with problem-solving certain aspects.

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Using Picture Activity Schedule Books to Increase On-Schedule and On-Task Behaviors

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Abstract: The purpose of this study was to evaluate the effectiveness of using picture activity schedule books to increase on-schedule and on-task behaviors of children with moderate intellectual disabilities. Four students enrolled in a self-contained classroom participated in the study. Graduated guidance, system of least prompts, and verbal prompting were used to teach students how to use the picture schedules. Percentage of on-schedule steps completed and percentage of intervals on-task were evaluated within the context of an A-BC-B-A-B withdrawal design. Stimulus generalization was assessed with novel activities in a different location and at different times during the academic day. Results showed increases in on-schedule and on-task behavior only when using the picture activity schedules. Students’ on-schedule and on-task behavior generalized to novel activities, settings, and times when using the picture activity schedule books.

While independent functioning is the ultimate goal for the education of students with intellectual disabilities, one cannot ethically ignore that some students will not learn to independently perform certain activities, routines, or skills. It is more beneficial for students with intellectual disabilities to live, function, and participate in the community with support and/or adaptations rather than depending on someone else for total assistance (Wolery, Ault, & Doyle, 1992). Frequently, students with intellectual disabilities have difficulty managing their behaviors independently without the use of external controls (Mechling & Gast, 1997). If educators can provide these students with effective supports, students may decrease their reliance on caregivers and, thus, live more autonomous lives.

In school situations, students frequently move through class periods following some sort of schedule or routine with changes or progression signaled by a teacher or a school bell. Considering this structure, if students do not independently progress from one activity to the next, not only will they have to rely on peers or teachers to assist them, but they may also miss instructional time and opportunities to engage socially with peers. Picture based activity schedules are one way to increase the independence of these students. Further, picture based schedules are not too distant a departure from more traditional supports used by many people without disabilities (e.g. day planners, personal digital assistants).

Visual prompts could take several forms from concrete realistic photographs to cartoons and line drawings. Researchers have used visual prompts presented in forms of line drawings or pictures to teach vocational task completion (Lancioni, O’Reilly, Seedhouse, Furniss, & Cuhuna, 2000), sight word reading (Rivera, Koorland, & Fueyo, 2002), initiating conversation (Spohn, Timko, & Sainato, 1999), and on-task behavior (Bryan & Gast, 2000; MacDuff, Krantz, & McClannahan, 1993). Using photographs, researchers have taught daily living skills (Mechling & Gast, 1997), shopping for groceries (Morse & Schuster, 2000), independent performance of vocational tasks (Copeland & Hughes, 2000), participation in family activities (Krantz, MacDuff, & McClannahan, 1993), task engagement (Hall, McClannahan, & Krantz, 1995; Massey & Wheeler, 2000), task engagement, and activity completion (Bevill, Gast, Maguire, & Vail, 2001). The current study attempts to
build on the earlier foundations established by the research related to on-task behavior and activity engagement.

Massey and Wheeler (2000) used a combination of a system of least prompts and graduated guidance to teach a four-year-old child with autism to use a photographic activity schedule to remain on-task. Once the student attained a targeted level of task engagement, the researchers introduced the photographic schedule during another activity. The student maintained high levels of task engagement once the photographic activity schedules were introduced and his aberrant behaviors decreased. Copeland and Hughes (2000) also evaluated a photographic picture prompt intervention. They used the photographic prompts to improve the task initiation and task completion of two high school aged students with intellectual disabilities who were working on vocational tasks. Students were to look at individual photos in a photo album prior to initiating a task. After they finished the task, they were taught to turn the page of the album to look at the next photo. They learned to use the photo album and improved their task initiation and completion.

Bryan and Gast (2000) expanded on this literature. They examined the use of graduated guidance and picture activity schedules to increase on-task and on-schedule behavior of elementary aged students with autism. Students used photo albums containing line drawings of classroom activities. They were taught to follow the sequence of pictures in the album. All students improved on-schedule and on-task behavior and generalized this to novel activities. The current study was an attempt to further extend the knowledge of picture activity schedules by integrating them into picture activity schedule (PAS) books for middle school aged students with intellectual disabilities. Although there is research showing their effectiveness with other populations, no studies have evaluated the use of picture activity schedules with this population of children. If effective, the findings may encourage use by teachers in middle and high school settings as a means for addressing student’s independence across the school day.

As a systematic replication, the current study differs from Bryan and Gast (2000) in the following ways: (a) ages, functioning levels, and diagnosis of participants; (b) investigator; (c) setting of the study; (d) form of the picture prompts; (e) methods used to teach the use of the picture schedules; and (f) activities completed during the centers. The studies were similar in regards to the dependent variables. The purpose of the current study was to answer the following questions: (a) Will children with moderate intellectual disabilities increase their on-schedule behaviors when using the picture schedules?; (b) Will on-schedule behaviors increase the percentage of time on-task for middle school students with moderate intellectual disabilities?; (c) Will students with moderate intellectual disabilities generalize on-schedule and on-task behaviors using PAS books to novel settings and times of day?

Method

Participants

Four students with moderate intellectual disabilities, ranging in age from 12 years 7 months to 13 years 8 months, participated in this study. All participants received the majority of their special education services in a self-contained classroom and participated independently in a general education homeroom. They received adaptive P. E. and speech/language services on a weekly basis.

Individual students were chosen for this study based on their inability to transition on-schedule independently within the self-contained classroom and their high rates of off-task behavior. All four students demonstrated the ability to identify pictures depicting centers around the room. This was assessed prior to the study by showing each student a picture and having her state what the picture was showing. All four students correctly identified all eight pictures. All students could also perform all the tasks required at each center. All students had limited experience with visual activity schedules at the onset of the study. None of the students previously had formal instruction using graduated guidance or system of least prompts. Table 1 displays psychometric assessment data for each student to supplement the behavioral descriptions below.

Mary was 13 years 0 months old and was in
the eighth grade. She was diagnosed with Attention Deficit Hyperactivity Disorder and took Ativan once a day during the duration of the study. Academically, Mary had a relative strength in sight word reading and reading comprehension but struggled with math topics like money, addition, and time. Her social skills were less mature than other students in the class and she often drew attention to herself. She obsessed over routines in the classroom and worked best with a rigid schedule. Staff reported that Mary liked to know what was expected of her.

Cindy, a 13 year 2 month old female, was in the sixth grade. Cindy had strengths in several math skills and listening comprehension. She had difficulty reading sight words. She was a very social student who was eager to please. She made friends easily, and was very influential over her peers (this influence was not always positive). Cindy often lied to peers about her activities outside of school (drinking, smoking, being pregnant). She frequently complained about being sick and hurt even though there was nothing medically wrong.

Holly was 12 years 7 months old and was in the sixth grade. She had a medical diagnosis of Williams Syndrome and was not taking any medication during the study. Holly was a pleasant student with strengths in social skills. She was well liked by her peers and made friends easily. She would engage in overly dramatic behavior that occasionally disrupted the class. She was easily influenced by others, and, in a group, her feelings were hurt anytime she felt that she did not belong.

Jennifer was a seventh grader who was 13 years 5 months old. Jennifer was an affectionate student who had a strong desire to be accepted. On occasion, she had a tactile obsession with things like newspapers, books, construction paper, etc. She worked hard on school work but became easily frustrated. If she failed to complete a task or felt the teacher was disappointed, she would stop talking and sometimes cry.
The acquisition phase of the study took place in students’ self-contained classroom during a 45-minute block of time where students rotated through independent work activities. Generalization testing took place in the adjacent self-contained classroom, during a different block of time. The classrooms, measuring approximately 10 m x 10 m, were set up to include center-based instruction with tables, desks and chairs, computers and available floor space. Student desks were arranged in a “U” shape in the middle of the classroom facing the front of the room. Students had individual boxes located on a three-tier shelf in the front of the room. The computers were located on two computer tables in the front corner. Math and spelling centers were arranged on small tables near the back of the room, on opposite sides.

Work areas. Four work areas were set up around the classroom: (a) spelling center, (b) computer center, (c) math center, and (d) individual skill center. Each center was labeled with a sign hanging from the ceiling. The spelling center was made up of a round table with 4 chairs. The table was placed toward the back of the room so that it was easily accessible from every side. Materials for the center were located on the table and a large piece of construction paper in the middle of the table displayed the spelling words for the week. The computer center consisted of two IBM student computers located together near the front of the room. The math center was located at a rectangular table near the math manipulative shelf. Math materials for the day were available on the table. The individual skill center was located in the front of the room and consisted of a three-tier shelf with individual boxes labeled with students’ names. Each box contained individualized work for students. Most of this work was vocational in nature (sorting, counting, manipulating money, telling time, etc.). Each location was familiar to students and each center was used in every session. During generalization sessions, the center areas were set up in the same manner, spread around the room and labeled.

After the teacher gave initial instructions, one of the classroom paraprofessionals monitored students’ behaviors and answered questions from students regarding assigned tasks. The other classroom paraprofessional monitored all non-participants. The classroom teacher, trained in the data collection and behavior observation methods, sat in an unobtrusive corner of the room collecting data. The students independently moved around the room among centers.

Materials and Equipment

PAS books. Each student had a PAS book displayed in a 10 cm x 15 cm inch plastic photo album. Four black and white “Board Maker” pictures (5 cm x 5 cm) depicting center activities were inserted, one per page, into the transparent plastic pages in the order to be completed. The last page in the photo album had a card marked “finished” in it. The teacher placed the PAS books on each student’s desk prior to each session. The pictures used during generalization conditions had identical features, with different activities pictured. Students were familiar with all of the pictures.

Center areas and materials. Centers were arranged to accommodate daily activities. The teacher determined the content of the centers based on students’ current Individualized Education Plans (IEPs), present levels of performance, and classroom observations. Center-based materials and equipment reflected daily activities (i.e. math worksheets, manipulatives, computers and computer programs, books, etc.). Specific materials reflected skills that had been acquired by students but required maintenance. All materials used in center areas were materials found in and around the classroom or school library. Materials that students manipulated in the spelling center included, for example: Edmark Level 1 Basic Sight Words, blank printer paper, colored construction paper, and foam letter stamps. Some of the materials used at the computer center included: two Windows computers, Microsoft Word 2000, The Functional Literacy System software: Survival Signs and Words, and Attainment’s software: Dollars Cents Series. The math center materials contained a range of materials including: basic math facts worksheets, Aurora DT 342 calculators, Match Me: Telling Time cards, Money Coin-U-Lator,
Money Station: classroom money tray, and the Clock.O.Dial. Materials located in students’ individual boxes depended on the students’ needs. Some of the materials included: LDA Language Cards: Why? Because; Word Wise cards; and Real Life Reading cards. Materials used during generalization settings included: puzzles ranging from 25 pieces to 100 pieces, books on tape checked out from the school’s library, and teacher-made file folder games copied from *Day-By-Day Math Mats* (Rosenberg, 2002).

Reinforcers. The classroom used a token economy. Students earned the same tokens during the study that they earned during their routine school day. After completing a session, students received tokens based on the amount of work completed. Students exchanged tokens on Wednesdays and Fridays for back-up reinforcers that the teacher identified based on previous experience with these students and the token economy.

**Response Definitions and Recording Procedures**

The dependent variables and definitions were the same as those used by Bryan and Gast (2000, p. 556).

**On-Schedule.** Students performed the following task analyzed behaviors in chronological order: (a) remove the current picture activity card from their book; (b) move to the appropriate center; (c) begin work within 10 s; (d) put away center materials when finished with the activity; and (e) put the completed activity card into the “finished” sleeve in the schedule book. A nonoccurrence was recorded if a student failed to complete one of the specified steps within 10 s or made an error while trying to complete one of the steps.

**On-Task.** Students were considered on task if they: (a) maintained visual attention to scheduled material; (b) properly manipulated the scheduled activity materials; (c) looked at their schedules; (d) transitioned from one scheduled activity to another; (e) placed a card in the “finished” sleeve in their book; or (f) put their materials away when they completed the activity. A nonoccurrence was recorded if students: (a) attended to non-scheduled activities; (b) used materials improperly; (c) manipulated materials but did not look at the materials; (d) engaged in inappropriate behaviors (e.g. aggression, tantrums, refusals); (e) put their materials away prior to completing the activity; or (f) did not engage in activities or using materials.

**Recording procedure.** An observer recorded occurrence/non-occurrence of on-schedule behavior during the 40 min activity sessions (see response definition above). A variable time sample recording system was used during activity sessions to record on-task behaviors. Intervals varied from 1 to 5 min. Percentages of on-schedule behaviors and time on-task were calculated for each child during each observational period.

Event recording was used to tally the number of adult delivered prompts necessary to maintain a student’s engagement in on-task and on-schedule behaviors during the 40-minute period. The observer recorded six prompt levels: (a) light touches; (b) orienting a student’s body toward material; (c) hand-over-hand physical assistance; (d) gestures; (e) modeling; and (f) verbal prompts. The number of teacher delivered prompts was totaled for each child at the end of each session. These responses were recorded across all conditions.

**General Procedure**

The study spanned five different phases (not including replication of phases): Generalization Pre-Test, No Book (NB), Schedule Instruction, Book Only (BO), and Generalization Post-Test. In each phase, observation sessions occurred daily during students’ scheduled center time (2:40 PM – 3:25 PM). Each session lasted approximately 40 min, with the first 5 min used for giving directions. One activity per center was pre-selected for each session based on students’ current IEP goals and objectives. The order of the selected activities was determined randomly across sessions and participants. All sessions began by the teacher having students return to their desks and then look up at her. The teacher then made the statement, “It is time to begin centers now”; followed by individual center instructions. After each 10 min center period, a timer sounded and the teacher stated, “It is time to change,” without designating where they were to go. This protocol was followed
across all conditions. The teacher and para-
professionals ignored student approaches and
inappropriate behaviors, except for aggressive
behaviors if they were to occur, throughout
the study. The teacher gave descriptive verbal
praise for appropriate behaviors at the end of
all sessions and gave students tokens based
upon their task completion. This routine was
used across all conditions.

**Generalization Assessment Procedure**

Generalization assessments took place prior to
the first NB or baseline phase and after the
last BO phase. The generalization assessments
were designed to evaluate stimulus generaliza-
tion across activities and times. Generalization
sessions were identical to the BO conditions.
The only variations from the BO phase were
that the PAS books included novel pictures
and the sessions occurred at different times
during the academic day (11:30 AM – 12:15
PM) in a different, but similar classroom. The
novel center activities used during this session
included: (a) puzzle center, (b) listening cen-
ter, (c) reading center, and (d) folders center.
The generalization phase continued for four
consecutive sessions.

**No Book Baseline (NB) Procedure**

The purpose of the NB phase was to assess
student performance of on-schedule and on-
task behaviors when not using the PAS books.
After the teacher announced that it was time
for centers and provided instructions for the
day’s centers, students transitioned independ-
ently among centers within the classroom.
Activity variation and sequence varied across
students and across days for each student by
picking activities from a box. Correct transi-
tions and on-task behavior were verbally
praised at the end of the 40 min. Tokens were
also given to reward completed work. Student
approaches and incorrect/inappropriate be-
behavior were ignored. These baseline proce-
dures were implemented daily for four con-
secutive sessions.

**Schedule Instruction Procedure**

The purpose of the Schedule Instruction
phase was to teach students how to use their
PAS books to transition between centers
within the classroom. Centers were prepared
prior to the beginning of the session. Each
activity was randomly assigned (drawn from a
box) to a new position in the activity schedule
to avoid satiation and/or memorization of
routine. Graduated guidance was used during
the first session of Schedule Instruction. Fol-
lowing the delivery of instructions for the ac-
tivity center, the paraprofessional waited 10 s
for students to stand and move to their PAS
book. If a student did not stand within 10 s,
the paraprofessional put her hand on the stu-
dent’s shoulder and guided her to her PAS
book. A graduated guidance technique, where
moment-to-moment decisions were made as
to what prompt level a student needed, was
used to help students complete the sequence
of activities in their picture schedules. To de-
crease prompt dependence and avoid provid-
ing reinforcement through adult attention,
physical prompts were given from behind.

Following the same routine sequence to be-
in centers, a system of least prompts was used
during the second session of Schedule Instruc-
tion. After the specific activity instructions
were given, the paraprofessional waited 10 s
for students to locate and remove the first
picture in their schedules. If a student did not
open their picture schedule within 10 s, the
paraprofessional would gesture toward the
student’s PAS book. The paraprofessional
would then wait 10 s to allow the student to
locate and remove the picture from the book.
The paraprofessional would continue through
the prompt hierarchy until the student lo-
cated and removed the first picture in their
activity schedule. Prompts that were available
during this session included: (a) gesture, (b)
model, (c) direct verbal, (d) orienting student
toward the material, (e) light touches, and (f)
hand-over-hand physical assistance. This sys-
tem of least prompts procedure was used to
guide the students through each step in the
task analysis, giving each student 10 s to initi-
te each step, beginning with gestures and
increasing a level until the step was com-
pleted. After using system of least prompts
during the second session, all prompts except
verbal were removed. The sessions continued
in the same manner, with verbal prompts serv-
ing as the controlling prompt.

Throughout Schedule Instruction, students
were observed for the 40 min duration scheduled for centers. A timer signaled the end of a 10 min period along with the teacher statement, “It is time to change.” Appropriate on-schedule and on-task behaviors were verbally praised at the end of the 40 min session. Incorrect and/or inappropriate behaviors were ignored. Schedule Instruction continued until students consistently performed on-task and on-schedule behaviors independently for at least three days at 90% or above.

Book Only (BO) Procedure

The purpose of this condition was to evaluate the effects of using the PAS book to increase independence when transitioning between centers within the self-contained classroom. The picture schedules served as the only prompt during this condition (i.e. no prompting from the paraprofessional as in the Schedule Instruction procedures). The teacher initiated center time in the same way as in other conditions. Sessions lasted 40 min with a timer sounding after each 10 min period and the teacher stating, “It is time to change.” The classroom paraprofessional was available to answer questions regarding assigned work. The teacher provided descriptive verbal praise at the end of the session for on-schedule and on-task behaviors. Incorrect and/or inappropriate behaviors were ignored. These conditions continued until 90% or better on-schedule and on-task behaviors were observed for at least three consecutive days.

Experimental Design

A single-subject A-BC-A-B withdrawal design (Tawney & Gast, 1984) was used to evaluate the effectiveness of picture schedules in keeping students on-schedule and on-task during independent centers. The withdrawal design evaluates experimental control by replicating effects through the repeated introduction and withdrawal of the independent variable (Book Only) with a single participant. If the data trends during intervention conditions (B₁ and B₂) increased and decreased under baseline conditions (A₁ and A₂) a functional relationship would be demonstrated between the independent and dependent variables. The conditions in this study occurred in the same order as Bryan and Gast (2000): (a) Generalization Assessment Pre-Test, (b) NB (Baseline), (c) Schedule Instruction to teach picture-activity schedule use, (d) BO (Intervention), (e) NB, (f) BO, and (g) Generalization Assessment Post-Test. This design allowed the evaluation of history and maturation threats to internal validity. If there were no history or maturation effects during the study, student performance would return to baseline (A₁) levels during the second baseline (A₂). External validity was demonstrated to the extent to which these participants differed from one another and from participants in previous studies, and the independent variable was effective across participants.

Reliability

Inter-observer agreement data on student’s behaviors were independently collected by a classroom paraprofessional previously trained on data collection procedures. Specific behavioral definitions and responses, direct observational recording, and specific condition requirements were reviewed prior to each condition with the investigator. Reliability data were collected during 24.3% of all sessions, with at least one observation per condition. Inter-observer agreement estimates were calculated by using the point-by-point method in which the number of agreements were divided by the number of agreements plus disagreements and then multiplied by 100. At least 90% agreement was required in each condition to continue the study without retraining.

Procedural reliability data on teacher behaviors were collected by a paraprofessional previously trained in condition procedures. Procedural reliability checks were made during 21.6% of all sessions, with at least one observation per condition. Procedural reliability estimates were calculated by dividing the number of behaviors emitted by the number of planned teacher behaviors and multiplying by 100 (Billingsley, White, & Munson, 1980). Teacher behaviors that were monitored included: (a) having students come to their seats; (b) gaining students’ attention; (c) providing the instructional cue; (d) providing instructions on each center to be completed; (e) prompting students through each step, if
necessary; (f) setting the timer for 10-minutes so the students knew when to change centers; (g) only providing reinforcement at the end of the 40-minute session; and (h) providing tokens at the end of the session. During each observation, the reliability observer recorded occurrences or non-occurrences of teacher behaviors listed on the procedural plan. The percentage agreement was reported for each teacher behavior listed. At least 90% agreement was required to continue the study without retraining.

**Social Validity**

Social validity data were collected using a survey with a Likert scale. Professionals who worked directly with participants provided feedback on the use of the PAS books. These professionals included a self-contained teacher, self-contained paraprofessionals, Speech and Language Pathologist, Occupational Therapist, and the students’ general education teachers. Each of these individuals had observed a NB and a BO condition prior to completing the survey. Data were collected after the last Generalization Post-test session. Mean scores on the questions are reported along with anecdotal comments.

**Results**

**Reliability**

Mean inter-observer agreement for on-schedule behaviors across all participants and conditions was 99%. Mean agreement for on-task behaviors across all students and conditions was 98%. Mean procedural reliability was 99.85% during all phases, i.e. one procedural error was observed during one session during the duration of the study.

**Effectiveness of Procedures**

**On-Schedule data.** Graphic displays of the percentages of steps completed on-schedule for each participant appear in Figures 1 – 4 (open squares). Direct intra-subject and inter-subject replications were obtained. The withdrawal design allows demonstration of experimental control by the replication of effects via repeated introduction and withdrawal of the PAS book. Student on-task behavior increased during BO phases (B<sub>1</sub> and B<sub>2</sub>), and was low or decreased during NB phases (A<sub>1</sub> and A<sub>2</sub>). There was 0% overlap between BO and NB phase data for all participants.

Mary’s on-schedule data depicted in Figure 1 shows her performance at low levels of on-schedule behavior during both the first NB (baseline) and second NB (return to baseline) phases. Mean performance during both NB phases was 1.25%, with a range from 0% to 5%. After introduction of Schedule Instruction (BC) and the BO Condition, Mary’s data showed an immediate change in level with an accelerating trend that stabilized at or above 90% during four consecutive sessions. Her on schedule performance during the seven sessions of Schedule Instruction was 82.14%, ranging from 40% to 100%. Mary maintained high levels of on-schedule behaviors during both BO phases, with means of 96.25% (range 90% to 100%) during the first BO condition and 98.75% (range 95% to 100%) during the second BO phase.

Figure 2 shows Cindy’s on-schedule data. During the first NB phase, Cindy showed variable performance ranging from 0% to 30% with a mean percentage of 8.75%. Upon introduction of Schedule Instruction, there was an immediate change in level to 85% with an accelerating trend stabilizing at 100% for three consecutive sessions. The mean percentage of steps completed during the five sessions of the Schedule Instruction phase was 96% (range 85 to 100%). Cindy maintained her mean percentage of steps completed at 98.75% (range 95% to 100%) during the first BO phase over four consecutive sessions. Re-introduction of NB resulted in an immediate change in level with the mean percentage of steps completed correctly at 8.75% (range 0% to 20%). Upon reintroduction of BO, Cindy’s on-schedule mean rose to and maintained at 100%.

Holly’s on-schedule data are illustrated in Figure 3. Her mean percentage of on-schedule behavior during the first NB phase was 0%. Upon introduction of Schedule Instruction, there was an immediate change in level to 65%. During this 12-session condition, Holly’s data ranged from 65% to 100% with a variable accelerating trend that eventually stabilized above 90% for four consecutive ses-
sions. During the first BO phase, Holly’s level of on-schedule behavior maintained at or above 90%, with a mean of 96.25%. Upon returning to the NB condition, the mean percentage of steps completed correctly dropped to 1.25% (range 0% to 5%) over four continuous sessions. When the BO phase was reinstated, the mean level of steps completed correctly on-schedule returned to 94%, ranging from 85% to 100% over five consecutive sessions.

Jennifer’s on-schedule data are presented in Figure 4. The mean percentage of steps Jennifer completed correctly on-schedule during the first NB condition was 3.75% (range 0% to 10%) over four consecutive sessions. During Schedule Instruction an immediate change in level occurred with a variable accelerating trend that stabilized above 90% over four consecutive sessions. During the 10 sessions in this condition, the data ranged from 40% to 100%, with a mean of 86%. During the first BO condition, Jennifer’s data maintained at or above 90% for five consecutive sessions, ranging from 90% to 100%. Upon return to baseline, the level dropped and stabilized at 0% over four consecutive sessions. When Jennifer returned to the BO condition, an increase in level to 80% occurred with an accelerating trend that stabilized over 90% for four consecutive sessions. The mean percentage of steps completed correctly during the five sessions in the second BO condition was 93%. There was 0% overlap between the baseline and intervention conditions.

On-Task data. Graphic displays of the percentage of intervals on-task with scheduled materials also appear in Figures 1-4 (closed diamonds). Replication of effects is evidenced through the A-BC-B-A-B design. Data trends during BO conditions (B1 and B2) increased and then decreased under NB (A1 and A2), for all students. Mary (Figure 1) performed at low levels during both NB conditions with means of 1.25% and 4% intervals on task (range 0% to 16%), respectively. Upon introduction of Schedule Instruction (BC), Mary’s performance increased and the trend accelerated until stabilizing at 94% over three consecutive sessions. Her mean percentage of on

Figure 1. Mary’s on-task and on-schedule behavior
task intervals with scheduled materials was 75.28% with a range from 31% to 94%. During the first BO condition, Mary’s on-task behavior remained at or above 94%, with a mean of 97.25% (range 94% to 100%). The second BO condition generated a mean of 98.5% over five sessions, ranging from 94% to 100%.

Cindy (Figure 2) also exhibited low levels of on-task behavior during NB phases with a mean percent intervals on-task of 14% during the first NB phase (range 0% to 31%); during the second NB phase, her mean percent intervals on-task was 20% (range 0% to 53%). When Schedule Instruction was introduced, Cindy’s percentage of intervals on-task rose to 100% and stabilized between 94% and 100% over five consecutive sessions, with a mean of 97%. During the first BO phase, Cindy’s percentage of intervals on-task remained high, with a mean of 98.5% (range 94% to 100%). Similar high levels of performance were recorded during the second BO phase, when Cindy maintained 100% intervals on-task over four sessions.

Holly’s (Figure 3) percentage of intervals on-task maintained at 0% during the first NB phase. Under Schedule Instruction, her on-task behavior immediately increased and stabilized at or above 94% for four consecutive sessions. Her mean percent intervals on-task during this condition was 86.25% (range 59% to 100%). During the first BO phase, Holly showed high levels of on-task behavior with a mean of 98.5% (range 94% to 100%). During the second NB phase, she returned to 0% intervals on-task. Her mean percent intervals on- in the second NB phase was 2.75% (range 0% to 11%). Her level immediately increased to 76% under the second BO phase, where the trend accelerated and stabilized at or above 93%. Holly’s mean percentage of inter-
vals on-task during the second BO condition was 91.4% (range 76% to 100%).

Jennifer’s (Figure 4) on-task data replicate Holly’s data, with decreases in performance during NB phases and increases in performance during the BO phases. During the first and second NB conditions, Jennifer was on-task of 8% (range 0% to 19%) and 0% of intervals, respectively. Introduction of the Schedule Instruction resulted in an immediate increase in level that stabilized at or above 90%. Her mean percent intervals on-task during this phase was 88.1% (range 53% to 100%). During the first BO phase, Jennifer’s on-task behavior remained high, with a mean of 95.4% (range 88% to 100%). The second BO condition yielded similar results, with a mean percent intervals on-task at 92.8% (range 82% to 100%).

In summary, the effectiveness of using the PAS books to increase on-schedule and on-task behaviors was replicated across all four students. Along with inter-subject replication, intra-subject replication was demonstrated with both dependent variables. Clear distinctions are evident between the NB and BO phase. There was 0% overlap between the NB and BO conditions for all four students for both dependent variables.

**Generalization Data**

During the Generalization Pre-test condition, the mean steps completed correctly on-schedule was 7.8% for all students with a range of 2.5% to 13.75% (see Figures 1-4). During the Generalization Post-test condition, the mean steps completed correctly on-schedule was 96.25%, with a range from 95% to 98.75%. Student performance of on-task behavior yielded similar results. The mean percent of intervals on-task during the Generalization Pre-test condition was 14.3%, ranging from 3.25% to 18.75% across the four students. During the Generalization Post-test condition, the mean percentage of intervals on-task was 96.875% with a range from 95.25% to 98.5%.

In summary, inter-subject replication was
demonstrated across participants showing that the effects of using PAS books generalized to novel settings and activity schedules, and that the use of PAS books was not restricted to the activities scheduled during training.

Social Validity

Table 2 presents the mean score for each question, for each participant. Questions were scored using a Likert scale format ranging from 1 (strongly disagree) to 5 (strongly agree). The first question indicated a mixed response from raters that the students really learned academic skills using the picture schedules (mean = 3.47). All raters strongly agreed that students became more independent while using the picture schedules (mean = 5). Most raters agreed that implementing a picture activity schedule in their own classrooms would be feasible (mean = 4.3) and that all children could use these schedules (mean = 4.4). All raters strongly agreed that picture schedules were a useful management tools (mean = 5) and that participants in the study seemed to accomplish more during center-time when they were using the picture schedules, as opposed to when they were not using them (mean = 5). The raters agreed that the picture schedules were responsible for student learning (mean = 4.07). Most raters also agreed that their opinions changed once they observed the participants using the PAS books (mean 4.42).

Discussion

The purpose of this study was to evaluate the effects of using picture activity schedule books on student on-schedule and on-task behaviors. In replicating Bryan and Gast (2000), which was a systematic replication of MacDuff et al. (1993), the current study expands the research on picture activity schedules to middle school students with moderate intellectual disabilities. Although the population in the current study was different from previous studies, the current results were similar in six ways: (a)
students quickly learned the mechanics of the picture schedules; (b) teacher prompting was easily faded; (c) students maintained high levels of independent on-schedule and on-task behaviors with the picture schedule; (d) increase in on-task behavior with appropriate scheduled materials correlated with a decrease in non-scheduled behaviors; (e) sessions to criterion were low; and (f) students generalized the use of the picture schedules to novel activities, settings, and times of day.

Several differences exist between the current study and previously published research. First, MacDuff et al. (1993) evaluated picture schedules with males who had low functioning autism, ages 9 to 14; the participants in the Bryan and Gast (2000) study were children with high functioning autism, ages 7 to 8. Female students aged 12-13 with moderate intellectual disabilities participated in the current study. The current study took place in the students’ local school (similar to Bryan & Gast, except in this case the school was a middle school rather than an elementary school); this contrasts with MacDuff et al. where the researchers conducted the study in a group home. MacDuff et al. focused on using picture schedules during homework and leisure skills whereas Bryan and Gast used picture schedules during literacy-based centers. The current study also targeted center-based skills but included a broader range of activities: math, spelling, independent vocational skills, and computers. These differences help expand the database that exists on picture activity schedules.

Another finding from the current study that other researchers have not noted is student dependence on the picture activity schedules during the second NB condition. Jennifer wandered around the classroom asking, “Where are our books?” Likewise, during the second NB condition, Cindy told the investigator, “I can’t do it without the book, so don’t

### TABLE 2
Social Validity Questionnaire: Mean Score and Range Per Question

| (number of respondents) Question | Mary 10 | Mary 10 | Cindy 10 | Cindy 10 | Holly 10 | Holly 10 | Jennifer 10 | Jennifer 10 | Mean Range | Mean Range | Mean Range | Mean Range | Mean Range | Mean Range |
|----------------------------------|---------|---------|----------|----------|----------|----------|-------------|-------------|------------|------------|------------|------------|------------|------------|------------|
| 1. This child really learned academic skills using the picture schedules. | 3.6 2-5 | 3.5 2-5 | 3.6 2-5 | 3.2 1-5 | 3.475 |
| 2. This child became more independent while using the picture schedules. | 5 | 5 | 5 | 5 | 5 |
| 3. Implementing a picture activity schedule in my classroom would be feasible | 4.3 3-5 | 4.4 3-5 | 4.3 3-5 | 4.2 2-5 | 4.3 |
| 4. This child can only learn if they have a one on one teacher. | 1.6 1-3 | 1.5 1-3 | 1.6 1-3 | 1.7 1-4 | 1.6 |
| 5. Picture schedules can be used for all children. | 4.4 3-5 | 4.4 3-5 | 4.4 3-5 | 4.4 3.5 | 4.4 |
| 6. Picture schedules are a useful management tool. | 5 | 5 | 5 | 5 | 5 |
| 7. The picture schedule is responsible for student learning. | 4.1 3-5 | 4 | 3-5 | 4.1 3-5 | 4.1 3-5 | 4.075 |
| 8. The students seem to accomplish more during center-time when using the picture activity books. | 5 | 5 | 5 | 5 | 5 |
| 9. My opinions have changes since I have observed this child using a schedule | 4.4 3-5 | 4.5 3-5 | 4.4 3-5 | 4.4 3-5 | 4.4 3-5 | 4.425 |
Both students’ remarks were ignored by the teacher but student reliance on these supports was noted. It was interesting to see Cindy change centers and appropriately manipulate materials even though she was off-schedule. She kept looking at the investigator to see if she was being watched. Jennifer and Cindy appeared more comfortable using the picture books than not. Future research on the dependence of the picture activity schedules and how they can be faded while maintaining high rates of on-task behavior is worthy of investigation.

An additional result of the current investigation worthy of mentioning is that like participants in the Bryan and Gast (2000) study, the students’ on-task behaviors with scheduled materials increased during both BO conditions. The difference between the two studies occurred during the NB conditions. In the Bryan and Gast study, participants had low on-task behaviors with scheduled materials but a high occurrence of on-task behaviors with non-scheduled materials. While some on-task behavior occurred with non-scheduled materials in the current study, levels were low.

Some procedural differences between the two previous studies and the current study need attention. The main difference between the Bryan and Gast (2000) study and the current investigation was the procedure used to teach the use of the picture activity books. Systematic replication of the graduated guidance procedures used by Bryan and Gast to teach students how to use the picture schedules was intended. Graduated guidance techniques were planned to help students complete the sequence of activities in their picture schedule books with manual prompts delivered from behind students to decrease dependence on adult assistance and to avoid providing reinforcement through teacher attention. No gestural or verbal prompts were planned. Initially, graduated guidance techniques were to be used until the students acquired the skills necessary to independently use their picture schedules, however, after using graduated guidance for one session, the investigator decided to withdraw the use of graduated guidance based on student responses to the procedure. All four students resisted hand-over-hand assistance, a technique not used on a regular basis in their classroom. Jennifer pulled away, with force, and appeared nervous every time hand-over-hand assistance was provided. Cindy pulled away and laughed, saying, “What are you doing? Are you crazy?”. Mary and Holly also resisted the touches, but were not as obvious as Jennifer and Cindy. After consulting with the classroom paraprofessional, who also observed these behaviors, it was decided that using a system of least prompts procedure would be less intrusive for students.

During the second session of the Schedule Instruction phase, the system of least prompts procedure was implemented. All four students imitated the gestures modeled by the teacher (i.e. pointing to the book) at every step where gestures were required. All four students just stared at the models or if the teacher opened their book and closed it, they would open their book and close it. Verbal prompts were eventually sufficient. This procedural change proved effective in teaching students how to use their picture schedules. The number of teacher delivered prompts decreased over trial and all four students appeared less tense during instruction after the change to the system of least prompts procedure.

Future research could explore the three aforementioned suggestions: (a) how dependence on the books effects generalization and/or student performance in other settings when the book is not present, (b) observational learning regarding the use of picture schedules, and (c) results of giving verbal instructions of how to use the books with no further teacher prompting. Other areas of future research might focus on finding an effective and efficient way to teach students how to use picture schedules in a systematic, replicable way. Maintenance of these skills over periods of time (i.e. summer vacation) and generalization of these skills to areas in the community (i.e. church, stores, and job sites) could be a vital source of information for future research. Since the database is limited with respect to picture schedules and middle school students with moderate intellectual disabilities, further investigation would benefit classroom teachers trying to increase independent functioning with their students.
References


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Educator Perceptions and Ratings of Pain in School-Age Children with Mental Retardation and Developmental Disabilities

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Abstract: Educator perceptions and ratings of pain between school age children with and without mental retardation were investigated using written vignettes of three different pain types (acute/procedural; accidental; chronic). Diagnostic/functional information (i.e., mental retardation) was randomized across raters (N = 95). Raters were asked to consider whether the child experienced any pain (yes/no) and if so to rate its intensity on a standardized numeric rating scale. There were no significant differences between groups for the perception of pain or the rating of pain intensity by diagnostic/functioning information. Additional analyses showed that participants rated pain differently across pain types (p < .05) suggesting that the written vignettes had face validity (i.e., represented different types/sources of pain). Secondary analyses between licensed special education teachers and prospective pre-licensure special education teachers found significant differences (p < .05) between ratings for acute/procedural pain. These results suggest that more experienced (i.e., licensed) teachers may be better ‘detectors’ of pain/discomfort in children with or without mental retardation than less experienced teachers. Implications of this finding are discussed. Considering the limited research in the area of pain, disability, and education further work appears warranted.

A long standing assumption suggests that individuals with mental retardation and related developmental disabilities are insensitive or indifferent to pain or discomfort (Oberlander, Symons, van Dongen, & Abu-Saad, 2003). Emerging evidence shows, however, that children with mental retardation have more frequent daily incidents associated with pain than similar aged children without mental retardation (Breau, Camfield, McGrath, & Finley, 2003), pain thresholds may actually be lower among individuals with mental retardation (Defrin, Pick, Peretz, & Carmeli, 2004) and the emotional expression of pain, at least in some conditions associated with mental retardation, is intact (Oberlander, Gilbert, Chambers, O’Donnell, & Craig, 1999). Given the likelihood that the sensation and expression of pain may be preserved among individuals with mental retardation, there are a number of pressing issues related to pain recognition, measurement, and management (LaChapelle, Hadjistavropoulos, & Craig, 1999).

Pain in children with mental retardation may be under-recognized because of issues around the definition of pain and difficulty assessing and measuring pain. The International Association for the Study of Pain (IASP) defines pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (Merskey & Bogduk, 1994). A further clause suggests that the inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment. Despite this additional clause, the core definition promotes self-report of individuals as the ‘gold standard’ in terms of communicating the location, type, and source of pain. Consequently, the cognitive and communicative impairments associ-
ated with mental retardation and related conditions can create considerable ambiguity in the ability of care providers to recognize conventional signs or symptoms of pain or measure pain reliably (Oberlander et al., 2003).

It remains a relatively open question of whether and how pain among individuals with mental retardation is routinely detected and measured among health care and related providers. There is a growing interest in examining bias about pain in other populations and groups including studies of race and ethnicity (Bonham, 2001) gender and sex (Hoffman & Tarzian, 2001) and gender and race (Weisse, Sorum, & Dominquez, 2003). Overall, findings from this line of inquiry using vignettes of clinical pain scenarios suggest that physicians’ pain management decisions are influenced, in part, by patient demographic characteristics (e.g., less aggressive treatment decisions were made for black female patients versus black males and white male patients versus white females for treating kidney stone pain).

In the first work of its kind, Oberlander and O’Donnell (2001) conducted a qualitative survey on beliefs about pain among health-care professionals working with children with significant neurologic impairment and associated mental retardation. Results from their survey suggested that only 20% of the professionals believed that pain was adequately expressed and/or accurately located among children with mental retardation. Oberlander and O’Donnell also reported that more than two thirds (69%) of the professionals did not often or always perform an accurate assessment of pain even when they thought pain was present. These results suggest that pain in children with significant neurologic impairment is poorly communicated, located, and most likely inadequately treated.

There has been no similar line of inquiry among educational professionals in terms of their perceptions and ratings of pain among school-age children with mental retardation. Although direct decisions about pain and its management are outside the professional scope of teachers and allied education professionals (i.e., paraprofessionals, speech language pathologists, etc.), educators are often the initial frontline ‘detectors’ of health conditions and advocates for the students they serve. The purpose of this preliminary study was to examine teacher and allied educator perceptions and ratings of pain for children with and without mental retardation on numerical pain rating scales using written vignettes of three different pain types/sources (acute/procedural; accidental; chronic).

Method

Participants

Following Institutional Review Board approval, a convenience sample was formed with ninety-five students enrolled in a master of education program in a special education program recruited as initial participants. Seventy-six participants were female (80%). The average time spent in the field of education as a professional was 15 years (Range 1 – 30). In terms of professional categories, twenty-seven participants were pre-licensure prospective special education teachers (28%), twenty-six were licensed special education teachers (27%), nineteen were paraprofessionals (20%), six were regular education teachers (6%), four were early childhood teachers (4%), three were educational administrators (3%), one was a speech-language pathologist (1%), and nine were unknown (9%). All earned extra class credits for participating in this study.

Materials and Measures

Participants were provided with written vignettes describing scenarios of school-age children experiencing acute/procedural pain, accidental pain, and chronic pain. Each scenario presented a fictitious name of a child, gender, age, type of pain source, and description of pain the child experienced. To measure pain, participants rated each scenario by answering a question about whether the child was experiencing pain (yes/no) and rating the pain from 0 (no pain) to 10 (unbearable pain) on a numerical rating scale. The written vignettes of each type of pain were as follows.

Acute/procedural pain

Sam is a 10-year-old boy attending Lincoln Elementary School. Today is the school’s vaccination day. Sam does not like to get
needles and has to get vaccinated. In the line to see the school nurse, he appears very anxious, rocking back and forth on his feet. During the injection, Sam closes his eyes tightly, winces, and clenches his hands into fists. After the injection, Sam relaxes and the nurse tells him he was very brave and gives him a lollipop.

**Accidental pain**

Nancy is a 14-year-old girl at Washington Middle School. During a class change while walking down a hallway with a friend, Nancy was knocked down, lost her balance, and hit her face against the floor. Her face was red and a bruised. She started crying, but stopped soon after, and she was helped up by her friend. They then walked to see the school nurse. The nurse did a routine examination to ensure that there were no serious consequences associated with the fall. The nurse called Nancy’s mother and father to tell them what had happened but that she was fine.

**Chronic pain**

Dan is a 17-year-old boy attending Jackson High School. He also suffers from juvenile arthritis in his wrists and hands. The pain in his hands has been coming and going for more than six months. When his arthritis flares up, Dan often winces, holds his breath, and stops what he is doing. When it passes, he resumes his ongoing activity. His parents have told the school nurse that they think that Dan is often uncomfortable and this arthritis limits his ability to interact with routine activities associated with home and school.

Half of the vignettes included diagnostic/functioning information of the child in the form of an additional second sentence that read ‘Sam/Nancy/Dan is nonverbal and functions in the severe range of mental retardation’. 

**Procedure**

At the beginning of scheduled class time, packets of the vignettes were provided to participants in an alternating format to randomize diagnostic/functional information. The packet consisted of a consent form, an instruction sheet, a practice pain vignette, and the three pain study vignettes. Each vignette consisted of a paragraph describing a child and a pain scenario. On the same page, directly below the scenario, was a question of whether the child had experienced any pain (yes/no) and below that was a numeric rating scale anchored with 0 (no pain) and 10 (unbearable pain) with a written instruction to rate the amount of pain experienced by the child if the child was in pain. After vignette distribution and to increase participant understanding of the procedure, the first author stood at the front of the classroom and read aloud the example scenario to participants and asked them to answer the question about the presence/absence of pain by circling yes or no and then to rate the pain that the child experienced on the numeric rating scale. Any questions about procedure were answered. Participants were then asked to independently read the vignettes and complete the activity.

**Design and Analysis**

This study used an experimental design with the presence/absence of diagnostic/functional information of mental retardation manipulated through written vignettes. Distribution of packets of vignettes was randomized. Descriptive analyses were used to characterize the responses between groups with and without diagnostic/functional information of mental retardation (MR) and across pain types. T-tests were used to examine differences in pain rating between diagnostic/functional label (MR, non MR) and pain types/sources (acute/procedural, accidental, chronic) for each vignette. T-tests were also used to compare ratings by pre-service and already licensed special education teachers.

**Results**

There were no significant between group differences (MR, non MR) by pain type (acute/procedural, accidental, chronic) for the initial rating of the presence or absence of pain for each vignette. Across raters, 92% indicated the child experienced pain for the acute/procedural pain vignette; 99% indicated the child experienced pain for the accidental pain vignette; and 97% indicated the child experi-
enced pain for the chronic pain vignette. There were no significant between group (MR, non MR) rating differences for pain intensity for each pain type (acute/procedural, accidental, and chronic) (Table 1).

To test the face validity of the vignettes (i.e., whether pain type/source was rated differently), paired $t$-tests were used to test overall differences in average pain rating across the three pain types, independent of diagnostic information. Participants reliably rated pain differently with significant differences for pain types; acute/procedural pain, accidental pain, and chronic pain (Table 2).

To test for specific differences in ratings by teachers, analyses were conducted to examine relations between pain ratings for participants with special education teaching licenses ($N=26$) and prospective special education teachers ($N=27$). There was a significant difference in pain ratings for acute/procedural pain between licensed special education teachers ($M = 3.92$) and pre-licensure special education teachers ($M = 2.33$), $t = 3.59$, $p = .02$, independent of diagnostic/functional status of the child.

TABLE 1
Mean Ratings by Presence of Mental Retardation (MR) in Vignettes

<table>
<thead>
<tr>
<th>Vignette</th>
<th>MR</th>
<th>Non-MR</th>
<th>$t$ (93 df)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vignette 1</td>
<td>3.36</td>
<td>2.98</td>
<td>.98</td>
</tr>
<tr>
<td>Vignette 2</td>
<td>4.78</td>
<td>4.55</td>
<td>.62</td>
</tr>
<tr>
<td>Vignette 3</td>
<td>6.04</td>
<td>6.00</td>
<td>.11</td>
</tr>
</tbody>
</table>

Vignette 1 - Acute/procedural pain; Vignette 2 - Accidental pain; Vignette 3 - Chronic pain

TABLE 2
Mean Differences in Pain Rating on Different Pain Types

<table>
<thead>
<tr>
<th>Pair</th>
<th>Mean Difference</th>
<th>SD</th>
<th>$t$ (93 df)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vignette 1 &amp; 2</td>
<td>-1.50</td>
<td>2.15</td>
<td>-6.77*</td>
</tr>
<tr>
<td>Vignette 1 &amp; 3</td>
<td>-2.86</td>
<td>2.54</td>
<td>-10.91*</td>
</tr>
<tr>
<td>Vignette 2 &amp; 3</td>
<td>-1.36</td>
<td>2.20</td>
<td>-5.90*</td>
</tr>
</tbody>
</table>

Vignette 1 - Acute/procedural pain; Vignette 2 - Accidental pain; Vignette 3 - Chronic pain

* $p < .05$

Discussion
This preliminary study was designed to examine whether education professionals rated pain differently for school-age children with and without mental retardation for three different pain types/sources. Although the study was exploratory not confirmatory, the results did not provide any evidence of bias by educators toward children with mental retardation experiencing pain. In other words, the ratings of pain perception and intensity did not differ by the described diagnostic/functional status of the child.

Results did, however, indicate that pain was rated differently by the type/source of pain. This finding suggests at least some degree of face validity that the different vignettes as written contained enough information specific to different types/sources of pain and that raters made this discrimination (chronic pain rated > accidental pain rated > acute/procedural pain). This may also suggest that information about types/sources of pain in written vignettes was more powerful than the written description of the presence of mental retardation.

Secondary analyses specific to special education teachers revealed significant differences between licensed and pre-licensure special education teachers ratings of acute/procedural pain suggesting that special education teachers may be more sensitive to (i.e., better ‘detectors’ of) the possibility of pain in school-aged children under acute or procedural circumstances. Although this might be an expected outcome and seems consistent with conventional wisdom (i.e., more experience, more sensitive), the effect could certainly go the other way (i.e., more experience, less sensitive). Thus, further investigation is required for this notion be more fully substantiated.

Although emerging findings from other similar lines of work suggest health care professionals (i.e. physicians) may be influenced by race and ethnicity (Bonham, 2001), gender (Hoffman & Tarzian, 2001), and gender and race (Weisse et al., 2003) in their judgment of pain, the findings from this study suggest that mental retardation did not similarly influence
Given the considerable heterogeneity of the study sample, however, and the single line manipulation of cognitive status, there may have been other factors overshadowing the ratings.

In terms of specific study limitations, there are several points worth making. The sample was one of convenience thus limiting the overall generality of the findings. There was considerable heterogeneity among the sample, which led to small cell sizes for some of the education professional categories thereby limiting the range of analyses possible. Although we were interested most directly in teachers and their ratings, future work could address sample heterogeneity by increasing the sample size and capitalize on the variability inherent in the heterogeneity. Although the written vignettes enabled participants to reliably rate pain differently across three pain types/sources, there is the possibility that using a different format for the vignettes (i.e., visual/video vs. written) may have led to different findings. Similarly, because each vignette differed on the child’s age and gender across pain conditions, this precluded comparing ratings across all conditions simultaneously and led to $t$-tests for each pain condition. Thus, it may be worth considering a next study that directly compares vignette format across raters using identical scales with comparable information.

Overall, it seems that further work investigating the influence of intellectual and functional status in relation to pain among school age children and the responses of educators...
may be warranted. It is an open question, for example, whether school-age children with more or less severe impairments may be rated differently for pain. Considering the role of teachers and paraprofessionals as ‘front line’ health detectors in addition to their other professional capacities, the issue and impact of pain in children with mental retardation and associated cognitive and communication impairments should be considered in educational contexts.

References


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Usefulness of a Perceived Exertion Scale for Monitoring Exercise Intensity in Adults with Intellectual Disabilities

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Abstract: In order to gain physical fitness and health, exercise must be performed at a sufficient level of intensity. Exercise intensity can be monitored with rated perceived exertion (RPE) scales to promote safe and effective programming. The usefulness of the Children’s OMNI Scale as a subjective measure of intensity for adults with intellectual disabilities (ID) was examined. Heart rate, workload, and RPE were monitored during a progressive walking protocol on a motorized treadmill in 18 adults with ID. Statistical analyses on individual data revealed that significant positive relationships among RPE, heart rate, and workload existed in most participants. However, results were highly variable. Results imply that some individuals with ID are able to provide a subjective estimate of exercise intensity while others may not be able to report accurately. The findings have significant practical implications for exercise programming in this population.

Considerable research has indicated that people with intellectual disabilities (ID) have low levels of physical fitness (Graham & Reid, 2000; Fernhall & Pitetti, 2001; Pitetti, Yarmer, & Fernhall, 2001), which likely contribute to the poor health status observed in this segment of the population (Draheim, McCubbin, & Williams, 2002; Janicki et al., 2002; Rimmer, Braddock, & Marks, 1995). Exercise training is critical to increase fitness and to improve overall health in people with ID. In order to be effective, exercise needs to be performed at a minimum frequency, intensity, and duration. Safe and effective exercise prescription is dependent upon accurately monitoring these specific components. While frequency (i.e., bouts per week) and duration (i.e., minutes per bout) are relatively easy to monitor, exercise intensity can be more complicated. There are various methods used to estimate exercise intensity with heart rate monitoring being the most common in the general population. Monitoring exercise intensity may be challenging for individuals with ID due to compromised cognitive functioning. Specifically, heart rate monitoring could be difficult since it involves precision as well as rapid counting. Identifying the exact location (i.e., carotid or radial artery) to palpate requires considerable practice as does applying the appropriate pressure and counting beats. Further, exercising at a safe, age-appropriate target heart rate may be problematic for individuals who have ID since it requires ongoing comparisons to published charts and/or tables. Rated perceived exertion (RPE) scales may be a useful alternative for individuals with ID because they allow a person to simply, and subjectively, express how they feel during exercise. The principle underlying RPE scales is that values selected should have a positive linear correlation with a person’s heart rate (i.e., physical effort) and the exercise workload (i.e., intensity) (American College of Sports Medicine, 2000). Simply stated, as exercise becomes harder an individual’s heart rate increases and they should perceive that added exertion. Accordingly, they should select a num-

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ber or descriptor on the RPE scale that corresponds to the greater workload.

Rated perceived exertion is a reliable indicator of an individual’s exercise tolerance (American College of Sports Medicine, 2000). Since RPE is highly correlated with exercise heart rate and workload, RPE scales are frequently used by practitioners during exercise tests and for exercise prescription. Borg’s RPE Scale is one of the most widely used of the existing scales and was developed as a subjective measure of feelings during exercise that takes into account fitness level, the environment, and fatigue (Borg, 1970; 1998). Rated perceived exertion scales are especially valuable as an indicator of exercise intensity for individuals who have difficulty palpating heart rate or who have limited experience engaging in exercise. The scales have been used with various populations including older adults (Shigematsu, Ueno, Nakagaichi, Nho, & Tanaka, 2004), children (Tenenbaum, Falk, & Bar Or, 2002), and individuals with disabilities (Birk & Mossing, 1988; Holland, Bouffard, & Wagner, 1992; Ward, Bar-Or, Longmuir, & Smith, 1995) as a means of allowing people to express feelings of fatigue and exertion while engaging in physical activity.

Two published studies have examined perceived exertion during exercise in adults with ID. Arnhold, Ng, and Pechar (1992) studied the relationship of heart rate, workload, and RPE in 10 adults with ID and a nondisabled comparison group. The authors used the Borg Scale (Borg, 1970) to rate perceived exertion during treadmill walking. Heart rate and RPE were positively correlated ($r = .65$), as were workload and RPE ($r = .81$). The relationships among variables were not significantly different from the nondisabled comparison group. The authors concluded that the ability of adults with ID to accurately perceive physical exertion during submaximal exercise was equivalent to their nondisabled peers. In addition, they reported that the Borg Scale was a useful measurement tool for people with ID. Downing and Keating (2003) examined the effect of verbal encouragement on performance and RPE during a graded exercise test in 16 adults with developmental disabilities. The authors used the Children’s OMNI Scale of Perceived Exertion to gather information. It was found that verbal encouragement led to longer times to exhaustion and greater peak heart rates than no verbal encouragement. However, RPE was not influenced by verbal encouragement during submaximal exercise. Participants without Down syndrome (DS) had longer times to exhaustion but no differences in peak heart rates were found. Since the publication was an abstract and contained only limited details of the study, no information was presented on differences in RPE among genders or people with and without DS.

Due to the limited published work, it remains unclear whether or not individuals with ID are able to accurately rate perceived exertion. In order to determine if RPE scales are useful for monitoring exercise intensity in people with ID, more work is required. The importance of examining RPE in this population segment is further supported by evidence that adults with ID generally accumulate a reasonable volume of daily physical activity (specifically walking) but the intensity of the activity is thought to be low and inadequate to achieve health benefits (Stanish & Draheim, in press; Temple & Walkley, 2003). If it is demonstrated that RPE scales are effective for monitoring exercise intensity in adults with ID, then they may be useful for increasing the intensity levels of existing physical activities.

The intent of this study is to build upon previous work by further examining the usefulness of the Children’s OMNI Scale of Perceived Exertion as well as examining potential differences between males and females, and individuals with and without DS in regards to RPE. Since differences in maximal heart rate of people with DS have been documented (Fernhall et al., 2001), it seems important to examine individuals with that diagnosis independently. Therefore, the main purpose of this study was to determine the usefulness of the Children’s OMNI Scale of Perceived Exertion for monitoring exercise intensity in adults with ID through examining relationships among heart rate, workload, and RPE during a graded walking test.

**Method**

**Participants**

Eighteen adults (10 males, 8 females) with mild-moderate ID and a mean age of 34.7 ± 12.3 years volunteered to participate in the study.
The sample included five participants with DS (2 males, 3 females). Participants were recruited through a local employment workshop and a residential agency that provide services to people with ID. All participants either provided consent or a parent/guardian provided consent on their behalf. All procedures were approved by a University Research Ethics Board prior to data collection.

**Familiarization Session**

Familiarization is useful for people with ID to become comfortable with the testing environment and equipment (Fernhall & Tymeson, 1987; Pitetti, Rimmer, & Fernhall, 1993). Exposure to the testing environment may reduce anxiety during actual testing and may promote accuracy of results. Participants were brought into the exercise laboratory in groups of three or four for approximately 45 minutes, 3-5 days prior to testing. Instructions and orientation procedures were standardized as much as possible for all participants. However, some participants required more instruction than others and an effort was made to accommodate all intellectual levels. Instructions for the Children’s OMNI walk/run Scale that were published in a validation study were used (Utter, Robertson, Nieman, & Kang, 2002) and were repeated or simplified as needed. Participants were introduced to the investigators and oriented to the equipment involved in the study. Specifically, participants tried on heart rate monitors and walked on the treadmill at 1.5 mph, which was the speed for the testing protocol. Extensive instruction was provided on the RPE scale in order to ensure, as best possible, that participants understood how to use the scale. Simple language was used when providing instruction as well as demonstrations and repetition. Each participant practiced rating their exertion while walking on the treadmill at various inclines until they verbally confirmed that they were comfortable with the protocol and understood the scale. Any questions or concerns were addressed by the investigators during the familiarization session.

**Procedure**

Participants wore heart rate monitors for the duration of the walking protocol. The Children’s OMNI-walk/run Scale was used to rate perceived exertion (Figure 1). Robertson et al. (2000) developed the Children’s OMNI-cycling Scale of Perceived Exertion in response to limitations of traditional RPE scales to accurately assess children. A version of the original cycling scale was modified for rating perceived exertion during walking and running (Utter et al., 2002). The Children’s OMNI-walk/run Scale (i.e., OMNI Scale) has a numerical range of 0-10 and also includes pictorial and simple verbal descriptors. Although the OMNI Scale has not been validated in persons with ID, it has been used in a previous study on this population (Downing & Keating, 2003). Due to the cognitive limitations of adults with ID, it seemed logical that the simplicity of the OMNI Scale would make it an appropriate measurement tool for this population. Pictures on the OMNI Scale eliminate the need to read. The traditional Borg Scale is reasonably complex with a numeric range from 6-20 and verbal descriptors such as “fairly” and “somewhat.” The Borg Scale could be challenging for a person with ID despite its use in previous work (Arnhold et al., 1992).

A Trackmaster TMX 425 CP model treadmill was used to perform a graded walking protocol. The walking protocol was initially intended to replicate that of Arnhold et al. (1992). However, following the familiarization session it was evident that the speed of the treadmill had to be reduced for our participants. The treadmill speed started at 0.5 mph and increased by 0.5 mph each minute until 1.5 mph was reached. During the test, the speed was held constant at 1.5 mph while treadmill incline increased by 2% every two minutes until the walking protocol was completed (11 stages; 0% – 20% incline). Completion of the walking protocol involved achieving a 20% incline for two minutes. Participants loosely held the handrails at all times while walking on the treadmill for safety purposes. In addition, participants were verbally encouraged while walking to promote staying on the treadmill as long as possible. A previous study showed that verbal encouragement did not affect RPE values reported by people with ID (Downing & Keating, 2003). The test was concluded if any of the following conditions were presented: (a) participant’s heart rate reached 85% of age predicted max-
imum, (b) participant completed two minutes of walking at 20% incline (i.e. entire walking protocol was completed), or (c) participant indicated that they were too tired and/or did not want to continue. During the last 15 seconds of each two minute workload participants were asked to select a number, either verbally or by pointing, on the OMNI Scale that corresponded to their perception of exertion. Specifically, each participant was asked the following question: “Which number or picture best tells me how tired your whole body is from walking right now?” Once the participant selected a number or picture, they were asked the following question: “Are you sure that is the number/picture that best tells me how tired your whole body is from walking?” Questions were based on the terminology used in the development and validation studies of the OMNI Scales (Robertson et al., 2000; Robertson et al., 2002; Utter et al., 2002). The final response and the heart rate were then recorded.

Statistical Analysis

Statistical analyses were conducted on an individual level to best represent the ability of each participant to rate perceived exertion during exercise. Spearman rank-order correlation coefficients (rho) were calculated for all participants to examine the specific relationships among RPE and heart rate, and RPE and workload. Regression analyses were performed on individual data to determine the variance in RPE that could be accounted for by changes in heart rate and workload. It was of interest to examine both heart rate and workload to better understand the contribution of each variable to RPE.

Results

Physical descriptors organized by gender and diagnosis of DS are presented in Table 1. Males were significantly taller and heavier than the females but there were no other gender differences. Participants without DS were significantly taller than participants with DS but there were no other differences between the groups.

Nine participants completed all 11 stages (20% incline) of the walking protocol. Two participants discontinued walking after completing four stages (6% incline) and the re-
mainder of the participants completed various stages in between. As a whole, participants reported RPE values on the OMNI Scale ranging from the minimum of 1 to the maximum of 10. Half of the participants reported a maximum RPE value of 10 on the OMNI Scale at some point during the walking protocol while only two reached 85% of their age-predicted maximum heart rate.

Table 2 presents individual statistics to describe the relationship between RPE and heart rate including Spearman’s rho, R-squared ($R^2$), beta variable, and $p$-value. A significant positive relationship existed between RPE and heart rate for 10 participants while the values for seven participants were not significantly related. Participants #3 and #16 each selected the same RPE value for every workload during the walking protocol so a correlation coefficient could not be calculated for their data; hence, they were included among the seven with no significant relationship. A significant inverse relationship was present for one participant.

### Table 1

**Physical Descriptors of Participants by Gender and by Down Syndrome Diagnosis**

<table>
<thead>
<tr>
<th></th>
<th>Males (N = 10)</th>
<th>Females (N = 8)</th>
<th>Down Syndrome (N = 5)</th>
<th>Non-Down Syndrome (N = 13)</th>
<th>All Participants (N = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>32.6 ± 13.2</td>
<td>37.4 ± 11.3</td>
<td>30.2 ± 11.6</td>
<td>36.5 ± 12.5</td>
<td>34.7 ± 12.3</td>
</tr>
<tr>
<td>Height (cm)</td>
<td>165.7 ± 12.2**</td>
<td>150.1 ± 10.1</td>
<td>150.2 ± 6.0</td>
<td>162.1 ± 14.3*</td>
<td>158.8 ± 13.5</td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>80.0 ± 14.9**</td>
<td>56.6 ± 13.2</td>
<td>67.0 ± 25.0</td>
<td>70.6 ± 16.1</td>
<td>69.6 ± 18.2</td>
</tr>
<tr>
<td>BMI (kg/m²)</td>
<td>29.5 ± 7.4</td>
<td>24.8 ± 2.9</td>
<td>29.6 ± 11.1</td>
<td>26.6 ± 3.1</td>
<td>27.2 ± 6.2</td>
</tr>
<tr>
<td>RHR (bpm)</td>
<td>80.6 ± 11.4</td>
<td>83.6 ± 7.4</td>
<td>82.8 ± 7.7</td>
<td>81.6 ± 10.6</td>
<td>81.9 ± 9.7</td>
</tr>
</tbody>
</table>

Note. $M \pm SD$, * $p<.05$, ** $p<.01$

### Table 2

**Individual Statistics for RPE vs. Heart Rate**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Spearman’s rho</th>
<th>R-squared</th>
<th>Beta variable</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (male, NDS)</td>
<td>−0.91**</td>
<td>0.86</td>
<td>−0.93</td>
<td>0.00</td>
</tr>
<tr>
<td>2 (male, NDS)</td>
<td>0.98**</td>
<td>0.94</td>
<td>0.97</td>
<td>0.00</td>
</tr>
<tr>
<td>3 (female, NDS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 (female, NDS)</td>
<td>0.47</td>
<td>0.22</td>
<td>0.47</td>
<td>0.15</td>
</tr>
<tr>
<td>5 (male, NDS)</td>
<td>0.86**</td>
<td>0.71</td>
<td>0.84</td>
<td>0.00</td>
</tr>
<tr>
<td>6 (male, DS)</td>
<td>0.92**</td>
<td>0.67</td>
<td>0.82</td>
<td>0.00</td>
</tr>
<tr>
<td>7 (male, NDS)</td>
<td>0.68*</td>
<td>0.52</td>
<td>0.72</td>
<td>0.03</td>
</tr>
<tr>
<td>8 (female, NDS)</td>
<td>0.78*</td>
<td>0.63</td>
<td>0.80</td>
<td>0.02</td>
</tr>
<tr>
<td>9 (male, DS)</td>
<td>0.69</td>
<td>0.62</td>
<td>0.79</td>
<td>0.06</td>
</tr>
<tr>
<td>10 (male, NDS)</td>
<td>0.98**</td>
<td>0.81</td>
<td>0.90</td>
<td>0.00</td>
</tr>
<tr>
<td>11 (female, DS)</td>
<td>0.15</td>
<td>0.01</td>
<td>0.08</td>
<td>0.90</td>
</tr>
<tr>
<td>12 (female, NDS)</td>
<td>0.84*</td>
<td>0.39</td>
<td>0.62</td>
<td>0.14</td>
</tr>
<tr>
<td>13 (male, NDS)</td>
<td>0.44</td>
<td>0.29</td>
<td>0.54</td>
<td>0.09</td>
</tr>
<tr>
<td>14 (female, DS)</td>
<td>0.69*</td>
<td>0.43</td>
<td>0.65</td>
<td>0.03</td>
</tr>
<tr>
<td>15 (male, DS)</td>
<td>0.83**</td>
<td>0.61</td>
<td>0.78</td>
<td>0.01</td>
</tr>
<tr>
<td>16 (male, DS)</td>
<td>0.57</td>
<td>0.44</td>
<td>0.66</td>
<td>0.15</td>
</tr>
<tr>
<td>17 (female, NDS)</td>
<td>0.81*</td>
<td>0.53</td>
<td>0.73</td>
<td>0.10</td>
</tr>
</tbody>
</table>

Note. * $p<.05$, ** $p<.01$
The $R^2$ values between heart rate and RPE ranged from .01 - .94.

Table 3 presents individual statistics to describe the relationship between RPE and workload. A significant positive relationship existed between RPE and workload data for 11 participants while the values for six participants were not significantly related. Again, statistics could not be calculated for participants #3 and #16 so no relationship existed for RPE and workload. A significant inverse relationship was present for one participant (#1). The $R^2$ values between workload and RPE ranged from .08 - .98.

Figures 2 and 3 plot mean RPE versus mean heart rate and workload, respectively, to provide a visual representation of linearity.

Discussion

This study examined the ability of adults with ID to rate perceived exertion during a graded walking test on a motorized treadmill. Insight into the ability of adults with ID to monitor exercise intensity is important for developing safe and effective exercise interventions. The positive associations observed among RPE, heart rate, and workload provide some evidence that the Children’s OMNI Scale of Perceived Exertion is an effective tool for adults with mild-moderate ID to subjectively estimate exercise intensity.

Results of this study are somewhat consistent with the one other study that aimed to examine the relationship of RPE to heart rate and workload in adults with ID (Arnhold et al., 1992). In the previous study, correlation coefficients provided evidence that RPE was positively and significantly related to heart rate and workload. Results indicated that adults with ID were able to accurately perceive physical exertion at submaximal levels using the Borg Scale. Findings of the present study support the use of RPE scales for some adults with ID and specifically the OMNI Scale. The significant positive values for Spearman’s rho indicate that over half of the participants selected higher RPE values as heart rate and workload increased. This implies that most participants could perceive, and report, an increase in exercise intensity. Further, Figures 2 and 3 depict positive linear relationships for RPE values vs. mean heart rate and vs. workload, which implies that, on average, the
group selected higher RPE values as the walking became more physically demanding. However, the relationships among RPE and heart rate and workload were variable. This finding is also consistent with the previous work. One participant exhibited a significant inverse relationship (i.e., RPE values decreased as heart rate and workload increased) and two participants selected the same RPE value throughout the walking test. The variability between participants suggests that some individuals were able to more effectively rate perceived exertion using the OMNI scale while walking on a treadmill.

Accordingly, the regression analyses revealed that the percent of variance in RPE...
explained by changes in heart rate and workload differed greatly among participants. In some cases, almost 100% of the variance in RPE could be accounted for by heart rate or workload while in others very little variance was explained.

It is possible that an individual’s level of cognitive functioning could influence their ability to select an RPE value that is reflective of physical exertion. Individuals with higher IQ scores might be able to more accurately rate perceived exertion and/or better understand the instrument. However, an examination of our results revealed that the participants who functioned at a higher cognitive level (based on adaptive skills not IQ scores) did not necessarily display stronger relationships among RPE, heart rate, and workload. Gender also did not contribute to the variability among participants in reporting RPE. Since no previous study has examined gender differences in RPE in adults with ID, it is not possible to determine if our findings represent a trend or are unique to this sample. However, there is no reason to expect that males and females with ID would differ in their ability to subjectively estimate exercise intensity.

There were no significant differences in the ability of adults with and without DS to rate perceived exertion. Although it is known that individuals with DS have variations in maximal heart rate (Fernhall et al., 2001), it seems that they have a similar ability to rate perceived exertion as other adults with ID. These results must be interpreted with caution since only five participants in the study had DS.

It is interesting to note that nine participants reported a maximum RPE value of 10 at some point during the walking protocol. This finding suggests that half of the participants perceived that they were working at a maximal level although the walking protocol was designed to be submaximal. Only two of those participants reached even 85% of their age predicted maximal heart rate. This finding is consistent with Arnhold et al. (1992) who also had participants report a maximal value of 20 on the Borg Scale during submaximal exercise. So, even though the objective measure of intensity did not suggest a maximal effort, participants perceived that they were exercising at that level. This result is very important considering many tests of physical fitness require a maximal attempt for accurate scoring. Researchers have expressed concern over fitness scores of people with ID for this very reason, a reduced ability to interpret maximal exertion (Lavay, Reid, & Cressler-Chaviz, 1990). However, it must be noted that age is not always a sound predictor of maximal heart rate in people with ID (Fernhall et al., 2001). It is important to consider that the participants may have been working closer to maximal capacity than their heart rates indicated.

Results of this study have considerable practical implications. Since monitoring heart rate during exercise may be challenging for individuals with ID, a subjective measure of exercise intensity may be an appropriate alternative to facilitate independent engagement in physical activity. Walking was selected as the mode of activity for the present study because it is the most commonly reported physical activity by adults with ID (Draheim, Williams, & McCubbin, 2002; Stanish & Draheim, 2005; Temple, Anderson, & Walkley, 2000). Authors have suspected that walking intensity is typically low in people with ID and have proposed that intensity should be the focus of interventions (Stanish, 2004; Stanish & Draheim, in press; Temple et al., 2000). Rated perceived exertion may be a simple tool that can be used to increase walking intensity. Specifically, encouraging adults with ID to walk at a level on the OMNI Scale that would represent moderate to vigorous intensity physical activity may be a useful programming strategy.

The limitations of this study should be considered. First, the presence of the tester may have had some influence on motivation and could potentially influence RPE values. Second, without IQ scores it is impossible to determine if cognitive ability per se is related to RPE. Third, it is not clear how reliably adults with ID can rate their perceived exertion using the OMNI Scale. Since each participant was only tested once, it is not possible to comment on the consistency with which they rated their exertion. Future studies may look to examine the repeatability of the RPE and workload relationship.

It can be concluded that the Children’s OMNI Scale of Perceived Exertion could be useful for estimating exercise intensity in adults with ID. Since the relationship of RPE
to heart rate and workload was highly variable among participants in the present study, additional work is required before making a clear statement about the effectiveness of RPE scales for this population segment. The OMNI scale is simple and offers both verbal descriptors as well as pictures to assist a person in expressing how tired they are from exercising. Since exercise intensity is a critical component of safe and effective programming, the information derived from this study could be useful for practitioners who provide physical activity opportunities for individuals with ID.

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