Self-Determination for Persons with Developmental Disabilities: Ethical Considerations for Teachers

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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, Abery, Springborg, & Elkin, 2000; Wehmeyer, Field, Doren, & Mason, 2004; Wehmeyer, Kelchner, & Richards 1996; Wehmeyer & Schwartz, 1998). Collectively these behaviors that constitute self-determination result in a person being able to make personal choices that best benefit his or her own life course. Research has repeatedly confirmed, however, that persons with developmental disabilities tend to lack skills in this area (Wehmeyer & Palmer, 2003).

Research on self-determination blossomed in part as a result of federal grants targeting this domain as well as the prior reauthorization of IDEA that emphasized post-secondary outcomes (Wehmeyer & Palmer, 2003), with self-determination skills studied as a part of this emphasis. Implications for persons who do not develop these skills, however, are far more than just a question for research. Rather, there are broad implications for the lives of persons with developmental disabilities, and self-determination has paralleling ethical implications as well. While all persons who have professional or personal relationships with individuals with disabilities have a responsibility to uphold and encourage self-determination, special education teachers have a unique role. They plan instruction as well as often leading the IEP team, which drives both instruction and transition plan-
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 Stanley 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 Sawilowsky (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 that could prevent a person from reaching their goals; making 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. At the middle 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 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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