I Can Identify Saturn but I Can't Brush My Teeth: What Happens When the Curricular Focus for Students with Severe **Disabilities Shifts**

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Abstract: Determining the most effective curricula for students with severe disabilities requires increased attention as legislation and curricular changes are being made in the field of special education. This article a) reviews the legislation mandates from the 2004 Individuals with Disabilities Education Improvement Act (IDEIA) and the 2001 No Child Left Behind Act (NCLB), b) discusses evidence-based practices for a standards-based curriculum and functional curriculum, and c) examines longitudinal outcomes for students with severe disabilities. The research suggests that students working on functional skills provided through a meaningful curriculum leads to a more independent life. Recommendations for future research and discussion are also presented.

Developing curriculum for students with severe disabilities has been a topic that has been widely addressed since the inception of the field of special education. 'What' and 'how' to teach are topics that are addressed regularly in the literature (Dymond & Orelove, 2001). Over time, those topics have cycled through selecting from the broad categories of developmentally appropriate curricula, functional curricula, and currently, general education standards-based curricula (Bricker, Siebert, & Casuso, 1980; Brown et al., 1979; Hitchcock, Meyer, Rose, & Jackson, 2002; Wehmeyer, Lattin, & Agran, 2001). Currently, a focus on functional curriculum for students with severe disabilities is being reexamined and to a large extent altered if not abandoned in favor of a more general education or standards-based curriculum. Standards-based curriculum has an outcome of grade-level achievement that may or may not lead to more independent

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functioning. Functional curriculum has outcomes of improving a student's independent functioning in their current and future environments (Snell & Brown, 2006; Westling & Fox, 2004). These two curricula approaches are not and should not be exclusive, however, current prioritizing of standards-based curricula seems to set them up as such.

Evidence presented in this article suggests that students with severe disabilities can learn objectives related to grade-level standards. The question of whether or not students can learn standards is not the question we seek to answer-we know they can. The imperative question to be answered is 'at what cost do they learn these standards?' Will these skills help the students get a job? Choose where to live? Actively participate in their community? All educators should have high expectations for their students and seek to challenge their students at appropriate levels, but learning fragments of higher level academic skills should not be achieved at the cost of learning how to function independently in society. One of the authors, while seated in an IEP meeting as a consultant witnessed a frustrated parent of a child with severe intellectual disabilities say "My son can identify Saturn but he still can't request a snack or even wipe his ass." This is the quintessential point that begs discussion by the entire field of severe disabilities. At what point does working toward fragmented, watered down academic standards become less important than working toward meaningful individualized curricula directly tied to increasing independence in identified current and future environments. It is our position to continue to increase real outcomes for students by focusing on students as individuals with specific preferences and needs resulting in meaningful curriculum for each and every student. The purpose of this paper is to examine the evidence on standards-based curricula and to examine the evidence-base supporting the achievement of functional skills for students with severe disabilities. We will also review current legislation as it applies to curricula development. By comparing these two bodies of literature, we will demonstrate the need to maintain a functional curricular approach as the priority when developing curricula for individuals with severe disabilities.

Legislation

When determining how to develop meaningful outcomes for students with severe disabilities, the field of special education is informed by several different sources. Mandates from legislation, evidence-based practices, and information on longitudinal outcomes for students should all impact the decisions we make for students with severe disabilities. This leads to our primary determinates in developing meaningful curricula for students with severe disabilities: combining what we are required to do, what we know works educationally, and what we know is a priority for students' lives after school.

IDEIA

Legislation mandates what we must do to develop meaningful outcomes from the educational programs for students with disabilities. First, the Individuals with Disabilities Education Improvement Act of 2004 continues to emphasize the connection between meaningful, individualized curriculum for students with disabilities and post-school outcomes.

IDEIA requires that students be given access to general education curriculum to the maximum extent appropriate. Access to general education is provided "in order to (i) meet developmental goals and, to the maximum extent possible, the challenging expectations that have been established for all children; and (ii) be prepared to lead productive and independent adult lives, to the maximum extent possible" (118, Stat. 2651). Lowrey, Drasgow, Renzaglia, and Chezan (2007) interpret this statement to mean that 'appropriateness' and 'meaningfulness' in a child's educational program can be measured by whether or not the educational gains of the student actually prepare that student to lead an independent and productive adult life to the maximum extent possible. IDEIA requires that educational targets be based on what students can currently do, both academically and functionally, by including a statement describing students Present Levels of Academic Achievement and Functional Performance (PLAAFP) (Yell & Drasgow, 2007). According to Yell and Drasgow, these PLAAFP statements should directly link to Individualized Education Program (IEP) goals and objectives to create a cycle of meaningful outcomes-based targets, appropriate teaching, and progress monitoring. IDEIA's focus on transition increases this connection. In addition to meaningful educational goals, meaningful transition plans are required. Transition plans are developed by "a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability" (118, Stat. 2658). The plans prepare students for postschool education, employment, independent living, and community involvement by assessing their needs, interests, preferences, and strengths in order to create objectives to help students' achieve their goals. Through transition plans, PLAAFP statements, and individualization, IDEIA provides a direct connection between a student's educational targets and a student's independence in their adult life following school. The No Child Left Behind Act of 2001 may hinder this direct connection.

NCLB

Following the passage of the No Child Left Behind Act of 2001, state education agencies (SEA) began to interpret and react to stipulations that all students' (including those with severe cognitive disabilities) educational program be tied to grade level standards (Kohl, McLaughlin, & Nagle, 2006). The No Child Left Behind Act of 2001 requires that students with severe cognitive disabilities be part of the systemic accountability measures of NCLB as well as involving them in the general education curriculum. "All students with disabilities should have access to, participate in, and make progress in, the general curriculum. Thus, all students with disabilities must be included in the measurement of AYP toward meeting the State's standards" (p. 68698). Regardless of assessment practices, this process begs the question of whether or not the curriculum for students with severe cognitive disabilities should be focused on the same topics and skills as all other students. NCLB does not require curriculum development for individuals with severe cognitive disabilities (or any disability) begin with and be limited to the standards, only that it be linked to the standards in order for students to participate and progress. Thus, the impetus for where one begins and expands educational curriculum development for students with disabilities is better informed by the provisions of IDEIA discussed above.

Although much can be made of the potential conflict between the seemingly separate aims of these two laws, we propose that indeed, students with severe disabilities can be included in generalized systemic assessment and still have individualized curriculum that leads to meaningful adult outcomes. The key component in addressing this curriculum development is the beginning point—identifying individualized needs that increase independence in the natural environment rather than looking directly at grade level academic outcomes and working backward. Because functional skills are not identified as priority skills under NCLB, they are not assessed toward AYP. Therefore, they may potentially be moved to lower instructional priority even if a teacher acknowledges the need for instruction in a functional area. We are not arguing that students with severe disabilities cannot learn some of these grade level standards in the general education curriculum. Evidence presented below suggests they can. Our concern

is on whether or not the learning of grade level standards increases independence in post-school environments thereby increasing an individual's quality of life. In a public statement at the Council for Exceptional Children national convention in Louisville, KY, 2007, a very prominent and well respected researcher in our field who was in the audience of the presentation (McDonnell, Hunt, Kleinert, & Renzaglia, 2007), publically argued that this shift is a moral and ethical shift. But on whose ethical grounds should this change be based? Unless a student's curriculum is developed using outcomes that are essential for postschool success, we argue that many of the general education standards may not be beneficial for increasing a student's quality of life as an adult. This at least follows logic and is not an ambiguous values based decision.

Findings from empirically supported practice give us much evidence to understand the pedagogy to use when teaching students with severe disabilities. In addition, that same body of research has given us many insights into skills that students can and do achieve when good pedagogy is implemented with these students. A closer examination of that literature helps us discern educational programs that are meaningful and those that are not.

Empirically Supported Practice

There are varied ways to parse research about learning. One of the simplest approaches is to separate basic research from applied research. One can do this by discriminating between those experiments that seek to identify socially important interventions and those that are pursued for the pure science of seeing what is possible (Baer, Wolf, & Risley, 1968). Both have a valid and important place in understanding how individuals learn and often, basic research is a stepping stone to applied research. By looking at both types of research, we can potentially gain better understanding of where we should head as a field. We have to be cautious though in our interpretation of this research and be sure that our decisions for our field are based on the best empiricism of applied research and how we can make differences in the lives of individuals with disabilities and their families.

Currently, the field of special education has seen several experimental studies that seek to understand the boundaries of what is possible in terms of modern instructional technology and the potential for learners with cognitive impairments (e.g. Mechling, Gast, & Krupa, 2007; Stock, Davies, Davies, & Wehmeyer, 2006; Davies, Stock, & Wehmeyer, 2001). Multiple literature reviews cite studies that demonstrate students with severe cognitive disabilities can learn academic skills in reading (Browder, Wakeman, Spooner, Ahlgrim-Delzell, & Algozzine, 2006), math (Browder, Spooner, Ahlgrim-Delzell, Harris, & Wakeman, 2008), and science (Courtade, Spooner, & Browder, 2007). Currently, much of the research has that focused on teaching gradelevel academic standards to students with severe cognitive disabilities has shown some impressive results. Jimenez, Browder, and Courtade (2008) taught three high school students with moderate intellectual disabilities how to solve an algebraic equation. But, our questions remain: Do learning these skills help individuals with severe disabilities become more independent and successful in their lives? Are teaching these standards an efficient use of instruction time? In Jimenez et al., it took one student nine sessions, another student 17 sessions, and the third student required multiple modifications throughout the intervention to achieve eight out of nine by the 31st lesson (no information was provided about how many days or weeks it required to schedule these sessions). It is also important to consider these results in the larger context of empirically supported practice. The authors rightly identify that their results need social validation. Just because students are accessing the general education standards and participating to an extent in general education classrooms, does not mean students are learning (Wehmeyer, 2006). Cihak and Foust (2008) compared using a number line and touch point strategies to teach the acquisition of solving single-digit addition problems to three elementary students with autism with IQ equivalence scores between 40 and 50. Students reached the criteria with touch points more quickly after 10 to 16 sessions, but generalization across materials or environments

was not assessed. The achievement of general education standards may be the most appropriate target for some students with severe disabilities, however, one cannot know that for certain without assessing each student's individualized needs in order to create a meaningful individualized curriculum that addresses those needs not only in the present, but in the long-term.

Functional Focus

As we shift our focus to the larger body of literature on curriculum interventions related to functional life schools, it is important to recognize that to completely summarize this literature base would require volumes. Therefore, the summary that follows will attempt to highlight only a portion of studies focused on functional or meaningful skills. Certainly, general education standards can lead students to functional outcomes. It is important to determine however, before they are chosen as a target, if indeed the outcome projected (e.g. learning the planets) is, in fact, a functional outcome. One litmus test for determining functionality of a skill that Lou Brown popularized was to ask whether someone else would have to perform a task for a student if the student themselves could not do it (Brown et al., 1979). To ultimately determine the utility of a particular skill he suggested that we ask whether or not "students could function as adults if they did not acquire the skill?" (Brown, Nietupski, & Hamre-Nietupski, 1976, p. 9). Considering the range of environments where students live and the need to provide students options so that they can make choices for themselves, the broad category of functional curriculum encompasses innumerable skills that are important for community participation. Researchers have identified a range of instructional techniques to teach these skills. Without summarizing all of the instructional techniques, and because our focus is on curriculum, it seems most appropriate to highlight some of the functional skill areas where researchers have successfully taught individuals with severe cognitive impairments to participate more independently in their environments.

Consumer skills. Beginning with shopping or consumer skills, a range of interventions have been used to teach skills such as making payments with cash (Ayres & Langone, 2002; Ayres, Langone, Boon, & Norman, 2006), making payments with debit cards (Mechling, Gast, & Barthold, 2003), locating items (Hutcherson, Langone, Ayres, & Clees, 2004; Langone, Shade, Clees, & Day, 1999; Mechling, Gast, & Langone, 2002; Mechling & Gast, 2003; Mechling, 2004), and as well as the entire process of finding an item and then paying for it (Alacantara, 1994; Bates, Cuvo, Miner, & Korbek, 2001; Haring, Breen, Weiner, Kennedy, & Bednersh, 1995; Haring, Kennedy, Adams & Pitts-Conway, 1987; Wissick, Lloyd, & Kinzie, 1992). Beyond shopping, others have successfully taught other money related skills including ordering and paying in restaurants (Donnell & Ferguson, 1988; Mechling & Cronin, 2006; Mechling, Pridgen & Cronin, 2005), using a pay phone (Collins, Stinson & Land, 1993), using a vending machine (Browder, Snell, & Wildonger, 1988), cashing a check (Branham, Collins, Schuster, & Kleinert, 1999), and using an ATM card (Alberto, Cihak, & Gama, 2005).

Other community skills. Beyond being a consumer, there are several other activities in the community in which individuals may desire to participate. Researchers have documented successful interventions for teaching a variety of office and vocational skills (Branham et al., 1999; Cihak, Alberto, Kessler, & Taber, 2004; Hillier, Fish, Cloppert, & Beversdorf, 2007; Mechling & Ortega-Hurndeon, 2007), and street crossing skills (Branham et al.; Collins et al., 1993).

Domestic and self-help skills. If an individual is going to live independently or achieve the criterion of ultimate functioning, they must know how to take care of themselves in their home. Researchers have demonstrated effective interventions for teaching multiple domestic skills including putting away groceries (Ayres & Langone, 2007; Cannella-Malone et al., 2006), preparing food (Fiscus, Schuster, Morse, & Collins, 2002; Graves, Collins, Schuster, & Kleinert, 2005; Griffen, Wolery, & Schuster, 1992; Johnson & Cuvo, 1981; Jones & Collins, 1997; Lasater & Brady, 1995; Martin, Rusch,, James, Decker, & Trtol, 1982; Norman, Collins, & Schuster, 2001; Rehfeldt, Dahman, Young, Cherry, & Davis, 2003; Robinson-Wilson, 1977; Schleien, Ash, Kiernan, & Wehman, 1981; Shipley, Benamou, Lutzker, & Taubman, 2002; Van Laarhoven & Van Laarhoven-Myers, 2006), laundry skills (Bates et al., 2001; Lasater & Brady, 1995; Morrow & Bates, 1987; Neef, Lensbower, Hockersmith, DePalma, & Gray, 1990), dressing (Norman et al.; Hughes, Schuster, & Nelson, 1993), and hygiene (Stokes, Cameron, Dorsey, & Fleming, 2004; Parrot, Schuster, Collins, & Gassaway, 2000; Snell, Lewis, & Houghton, 1989).

Functional skill summary. While the assembly of studies above is not an exhaustive accounting of empirically based interventions for teaching functional skills, it should provide ample illustration of the extant literature on teaching functional skills to students with severe developmental disabilities. These are socially significant changes if the student is able to complete the task for themselves and no longer needs to depend on others. Aside from sharing an emphasis on teaching students skills for independence, the studies above share a common element: the interventions are not "instant," they take an investment in time from the teacher as well as the student. According to IDEIA (2004) students must exit special education services by the age of 21. Services provided through IDEIA provide the most comprehensive investment of time and resources in a student with disabilities educational achievement. A student has only a finite amount of time in school to learn the critical skills that they will need to achieve the criterion of ultimate functioning (approximately 3,780 hours if attending school from age 3-21, 180 days per year, 7 hours per day). Whether the time is spent addressing academic, social or life skills, the decision needs to be individualized to the learner to reap the maximum return on the time invested. Time spent addressing the general curriculum (e.g., the solar system, Shakespeare) without prioritizing the focus to meaningful, individualized outcomes is time lost in gaining meaningful outcomes that directly improve a student's adult functioning. There is no reasonable way to integrate Chaucer or volcanoes into a community based instructional lesson related to paying for a meal at a restaurant. Addressing general education standards simply because they are the general education standard does not end in meaningful achievement towards adult outcomes for most students with severe disabilities. This is a simple zero sum formula that threatens to impinge on a student's opportunity to learn valuable life skills.

Skills in context. According to the National Transition Longitudinal Survey (Cameto, Levine, & Wagner, 2004), almost half of the students with intellectual disabilities, 57% of those with autism and 58% of those with multiple disabilities had goals related to maximizing independence. From this, one may infer that achieving the criterion of ultimate functioning (Brown et al., 1976) was important to the students and their families. Preparing students for the future requires helping them to develop the skill sets that will be needed in their future environments. Learning generalizable work skills, how to balance a checkbook, prepare a meal, and navigate public transit, are integral to meeting the criterion of ultimate functioning depending on a student's future environments. Wagner, Newman, Cameto, Gazza, and Levine (2005) reported from NTLS data that students with intellectual disabilities participate in work and work preparation activities in preparation for post-high school transition at rates lower than other disability groups and yet lack many of the skills required for independence. While one may argue that learning individual letters, differentiating types of rocks, and the order of the planets may be identified as important for some students, the reality is that many of these activities are not directly linked to increasing independence in the adult environment. It is the lack of integration or the lack of connection between the general education curriculum and the meaningful life skills that so many students with severe disabilities need that creates the problem. The standards themselves are not harmful, the lack of focus on individualized outcomes relative to meaningful individualized needs that is the problem. The data clearly show that we possess the instructional technology to teach these skills, yet we are moving toward teaching other skills that do not have as direct of a link to independence. Is this the path special education should take and if so, at what cost?

Longitudinal Outcomes

The move towards standardized general education curriculum for all students may, on the surface, seem benign. However there is a lack of empiricism on long term (post school) outcomes for students with severe cognitive disabilities whose curriculum has been focused on learning academic tasks that do not relate directly to improving post school outcomes. Absent that empiricism, there is not even a cogent, logical argument for prioritizing curriculum around skills and information that will not help students achieve greater independence. If a wholesale adoption of modified general education standards becomes the gold standard for program planning for all students, many parents of students with severe disabilities (as well as their children) will be left with out Free Appropriate Public Education. Parents have reported less satisfaction with their child's involvement in an inclusive setting and participating in the alternate assessment process as their child got older (Kasari, Freeman, Bauminger, & Alkin, 2004, Roach, 2006). Addressing 6-10 general education standards a year does not equal a functional educational program—especially if those standards are chosen outside of the context of individual student needs. Students that experience that type of educational programming will not have access to a curriculum that meets their individual needs; therefore parents will have to rely on their own ability and outside resources to provide students with the education they need and deserve.

Recommendations

We propose developing a meaningful educational curriculum that is individualized and inclusive of each student's needs (both academic and daily functioning) and interests. The research above demonstrates students with severe disabilities can make progress in all areas. Attainment of meaningful skills linked to current and future environments directly impact an individual's ability to function independently in their future housing, work, community participation, and relationships. Perceptions of mainstream society are also affected positively when students with severe disabilities

learn to operate independently in the mainstream world. This type of role valorization could lead to enhanced community opportunity. While students with severe cognitive disabilities can make progress in grade level and those standards can be taught using empirically valid teaching procedures, if those standards have not been targeted because they directly meet an established individual need, those skills may not be retained and used in everyday life. Students with severe cognitive disabilities need to learn skills that will increase their job opportunities, independent living opportunities, social integration and community independence.

Special education that abandons individualized curriculum and moves toward a single curriculum (i.e. grade level competencies) that may then be watered down to mere fragmented splinter skills, neglects a student's right to an appropriate education. While students without disabilities are being prepared to attend college, technical school, or enter the work force, students with disabilities are mandated to attend to that same curriculum that is not individually designed. These students are not being prepared for independence in the same way that students without disabilities are. Rather than looking at generalized academic standards which are in part based on the knowledge that is required for post-secondary education, curriculum designed for students with disabilities should more closely reflect the ecology of the individual environments in which these students live and will live. This would mean comprehensive local level plans to identify those skills that would provide a student with the greatest opportunities to access the least restrictive services (e.g., competitive or supported employment, independent or group living, community leisure activities). A continual focus on teaching students a curriculum that is not meaningful and helpful in their lives, such as teaching Romeo and Juliet with no preassessed identified individual targets, is about as helpful and useful as teaching a student to pay for tickets at a movie theatre when their town does not have a theatre.

In conclusion, IDEIA (2004) provides the right for every student to achieve educational progress in a curriculum that is spe-

cially designed to meet their unique learning needs (2004). Progress is not the acquisition of useless knowledge and/or skills; rather educational progress is the acquisition of knowledge and skills toward the eventual outcome of mastery. We must assess our students' progress so that we know they are learning their prioritized outcomes; so their parents can be assured that the student is getting what they have a legal right to, and so the student's educational program can continually be adjusted to meet that student's needs as they learn. A universal grade level standard does not support this definition of progress. In order to develop meaningful curriculum that supports educational progress, we must begin with a thorough assessment of individualized student needs. Once student needs are determined, those needs must be prioritized so that each student has his/her most pressing needs addressed. At this point in curriculum development, we should then review the standards for appropriate meaningful matches as well as determining what functional daily living skills are needed. By developing curricula targets in this way, we can know that students are making progress towards meaningful outcomes. If we begin with the standards, we may miss important priorities in other areas (Dymond & Orelove, 2001; McDonnell et al., 2007). When developing curriculum, we must focus on localized rather than state or national goals if we expect these students to live as independently as possible in that locale (Brown et al., 1979). Systematically, we need to hold each of these students, as well as their teachers, to high educational standards. This was the intent of NCLB 2001. However, high standards should not be interpreted directly as general education standards. Standards that are benchmarked to academic, grade level goals may not be appropriate for all students. As our technology of teaching has shown us, we have learned a tremendous amount about how to educate students with the most severe learning problems. If we aim this technology toward achieving independence and integration through targeted meaningful curriculum, we advance one step closer to helping realize a society that

values individuals for what they can do rather than what they can't.

Conclusion

Throughout the course of this paper we stand by the position that we, as special educators, should continue to increase real outcomes for students by focusing on students as individuals with specific preferences and needs resulting in a meaningful curricular development for each and every student. The purpose of this article was to examine the evidence on standards-based curricula and to examine the evidence-base supporting the achievement of functional skills for students with severe disabilities. We also reviewed current legislation as it applied to curricula development. By comparing these two bodies of literature, we demonstrated the need to maintain a functional curricular approach as the priority when developing curricula for individuals with severe disabilities. We posit that it is only through this individualized approach that students with severe disabilities will make progress towards meaningful targets that will positively affect their current and future independence in their localized environments.

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