

#### **4. RELATED SERVICES AND PROGRAMS FOR YOUTH WITH DISABILITIES: KEY FINDINGS**

The success that youth with disabilities achieve in school can be influenced by access to a range of services that support their education goals. The Individuals with Disabilities Education Act Amendments of 1997 (IDEA '97) require the provision of related services and supports to students with disabilities who are deemed to need them to benefit from a free appropriate public education. In this document, NLTS2 reports information from parents of secondary school students with disabilities and school staff who serve them regarding students' receipt of related services<sup>1</sup> and participation in school-based programs other than special education.<sup>2</sup> This information depicts the variation in services and supports students with disabilities receive in middle and high school, as well as some indication of the extent to which students' support needs remain unmet. Key themes are highlighted below.

##### **The Important Role of Schools in Providing Related Services and Supports**

Almost three-fourths of secondary school students with disabilities are reported by parents to receive at least one of the related services investigated in NLTS2. Importantly, parents report that several of these services are most often provided from or through their children's schools or school districts—60% of students with disabilities receive one or more related services from school sources. For example, almost all students who receive speech-language pathology services, vocational service, or occupational therapy; have a reader for the classroom; or use transportation services are provided those services through their schools. On the other hand, outside agencies or individuals are more likely to provide services that require traditionally nonacademic professionals, such as psychiatrists or psychologists, medical diagnosticians, and social workers.

In addition, schools overwhelmingly function as the primary source of information about related services for families; parents of 81% of youth with disabilities report learning about services from their children's schools. Schools also provide service coordination for four to six times as many youth with disabilities as do other professionals or family members.

Thus, parents depend on the schools to provide information and service coordination and ultimately to arrange for the services and supports included as part of their sons' and daughters' IEPs. Clearly, schools have a responsibility for students with disabilities that extends well beyond the classroom and that requires education resources and policies that are implemented effectively. Future NLTS2 reports will explore the relationships among comprehensive service provision for students with disabilities, the schools' role in this provision, student achievement, and their early postschool outcomes.

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<sup>1</sup> In IDEA '97, related services include speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreational services (including therapeutic recreation), early identification and assessment of disabilities in children, counseling services (including rehabilitation counseling), orientation and mobility services, medical services for diagnostic or evaluation purposes, school health services, social work services in schools, parent counseling and training, and transportation.

<sup>2</sup> School-based programs other than special education that have been examined in this report include the National School Lunch Program, programs for English language learners, summer school, reproductive health education or services, substance abuse prevention education or substance abuse services, conflict resolution/anger management/ violence prevention programs, and teen parenting education/services.

## **Challenges to Accessing Related Services**

### ***Service System Barriers***

Although navigating the multiple service systems involved in providing the related services needed by some youth with disabilities can be complex, 60% of students with disabilities have parents who report that finding services for their sons or daughters with disabilities took only “a little effort” or “almost no effort,” and approximately three-quarters have parents who report that the services their sons or daughters are receiving are enough to meet students’ needs. However, this generally positive report of the ability of families to traverse service systems and arrange sufficient services for their adolescent children with disabilities should not overshadow the fact that 40% of youth with disabilities have parents who report expending greater effort to obtain services, including approximately one in five who report that it required “a great deal of effort” to obtain services. Further, according to parents, more than one-fourth of youth who receive services reportedly continue to have unmet needs for more services.

Some of the effort required to arrange for services and the perceived inability to obtain sufficient services may result from barriers encountered in the process of acquiring or attempting to acquire them. A lack of information about services or the unavailability of a service itself are the barriers parents encounter most often in their efforts to obtain services for youth with disabilities; almost one-fourth of youth have parents who report these barriers to meeting their children’s service needs. Issues of time, cost, distance, and eligibility rules are reported to be barriers to service acquisition for one in six to one in eight youth with disabilities. In addition, the parents of one in five youth are unhappy with the quality of services available.

### ***The Implications of Poverty***

The fact that cost is cited as a barrier to acquiring services for some youth with disabilities hints at the important relationship between household income and service acquisition. NLTS2 findings underscore the fact that poverty poses obstacles to accessing related services for youth with disabilities and their families.

Students with disabilities living in low-income households (i.e., those with annual incomes of \$25,000 or less) are more likely than their more affluent peers (i.e., those from households with incomes of more than \$50,000) to have parents who report expending a great deal of effort to obtain services; facing barriers to access related to transportation, location, or language; and the need to go beyond the school to learn about services. Parents of low-income youth with disabilities report that their sons or daughters with disabilities are less likely to have a case manager, and when they do, they are far less likely than more affluent students to obtain this service through the school. Youth with disabilities living in low-income households are less likely to be reported by their parents as having enough related services to meet their needs. Although these unmet needs are related to individual household income, they are not related to students’ attending schools with high concentrations of low-income students.

Parents’ reports that low-income students with disabilities have fewer services than needed may reflect students’ greater need, rather than a difference in the actual rate at which students from households with different levels of income receive services. Reported receipt of most services does not differ significantly across income groups, with the exception that students with

disabilities in low-income households are less likely than students in more affluent households to receive tutoring services or assistive technology devices or services.

The more apparent difference between students of different income groups is in the significantly more prominent role of the schools as the source of services for lower-income students with disabilities. For example, although youth living in low-income households are about equally likely as their peers living in higher-income households to receive mental health/psychological services or diagnostic/medical services, lower-income youth are more likely to receive these services from or through their schools. This difference may relate to the fact that obtaining these types of services from sources other than the school often is determined by availability of medical insurance, which has been shown in previous NLTS2 reports to be less available to low-income families (Marder, Levine, Wagner, & Cardoso, 2003); thus, these families and their children may be more dependent on school resources for these types of services. Yet, other types of services, too, are more likely to be provided by schools to low-income students with disabilities than to others. For example, almost all low-income students who receive tutoring services do so through their schools, whereas only about half of students with disabilities in higher-income households receive tutoring help at school.

### ***The Challenges of Autism***

The impairments and functional challenges associated with some disabilities are particularly complex, and it may require greater effort to find and access the wide array of needed services for youth with such disabilities. For example, about half of youth with emotional disturbances, orthopedic impairments, traumatic brain injuries, or multiple disabilities have parents who report having to expend “some effort” or “a great deal of effort” to access services. This struggle appears to be most challenging for students with autism, whose parents are more likely to report investing considerable effort to obtain services, including almost one-third who report needing to spend “a lot of effort” on behalf of their children to obtain services for them. Parents of youth with autism also are more likely than those in other categories to cite most of the barriers to obtaining services for their sons or daughters. Half of parents of students with autism say the services they need for their sons or daughters are not available, and they are the most likely to report that their children with autism are ineligible for services that are available or that those services are of poor quality. Parents of youth with autism also report more often than many others that they seek information or help outside the school, and they rely more on family members, other parents, or parent groups to learn about services. They also are more likely to rely on nonschool professionals for their sons’ or daughters’ case management than parents of youth in other disability categories who have case managers. With this pattern of experience, it is not surprising that secondary school students with autism are least likely to be reported by their parents as having sufficient services. The recent rapid growth in the prevalence and identification of children and youth with autism suggests the importance of developing a greater understanding of and paying closer attention to both the academic and related service needs of these students.

## **The Implications of Disability for Receipt of Related Services**

Differences between disability categories regarding service provision can reflect in large part the functional, cognitive, academic, psychological, or social difficulties inherent in students' impairments; some services are most relevant to the functional needs of youth in particular disability categories (e.g., physical therapy for youth with orthopedic impairments). Yet some services, such as mental health counseling or tutoring, are more broadly applicable and appear in educational programs of students across all disability categories, as noted below.

### ***Widely Accessed Services***

**Psychological or mental health services or counseling.** According to parents, the most common type of related services received by secondary school students with disabilities are psychological counseling and mental health services, which are received by approximately one-third of students with disabilities nationwide. Although it would be expected that the largest share of students who receive mental health services are those with emotional disturbances (69% of whom receive them), these services also are received by 38% to 46% of students with autism, other health impairments, traumatic brain injuries, or multiple disabilities, and by about one-fourth of students in other disability categories. Overall, at least half of students who receive mental health services receive them from sources outside of school. Thus, communication between non-school-based mental health professionals and school staff regarding students' psychological needs or progress may be an important element in these students' success in school.

**Academic tutoring.** Tutoring has been shown to have beneficial effects on students' academic performance and behavior (DuPaul, Ervin, Hook, & McGoey, 1998; Franklin, Griffin, & Perry, 1994; Longwill & Kleinert, 1998). Although academic lags are a serious impediment for many youth with disabilities, according to parents, tutoring is provided to approximately one in five students with learning disabilities, hearing or other health impairments, or traumatic brain injuries. Even smaller shares of students in other disability categories receive help from tutors. Considering the current emphasis on improving achievement scores for all students, as mandated in the No Child Left Behind Act of 2001 (NCLB), and the particular challenges of meeting those expectations for students with disabilities, expanding tutoring services for them is an investment worth considering.

**Speech-language pathology or communication services** are the second most common services received by students with disabilities overall, about one-fourth of whom receive it in a given year. As expected, the majority of youth with speech or language impairments (71%) receive speech-related services, but this service also is reported to be received by from 62% to 75% of students with autism, multiple disabilities, hearing impairments, or deaf-blindness, and by 44% of students with mental retardation. As mentioned earlier in this chapter, almost all speech or language therapeutic interventions are provided through the schools.

**Medical services for diagnosis or evaluation related to a student's disability,** the third most common service type reported by parents, is used by about one-quarter of students with disabilities. More than half of youth in four disability categories (deaf-blindness, orthopedic impairment, visual impairment, and multiple disabilities) receive diagnostic medical services during a 12-month period, as do approximately 40% of youth in five other disability groups (other health impairment, autism, traumatic brain injury, hearing impairment, and emotional disturbance).

Many youth with these disabilities are characterized by various functional, sensory, or health-related impairments that require ongoing diagnostic or medical intervention. Others may need medications and maintenance checks to control aspects of their disabilities that interfere with learning or social adjustment (e.g., seizures, attention deficits, mental illness).

### ***More Disability-Focused Services***

**Physical or occupational therapies, or life skills therapy or training.** Overall, 11% of students with disabilities are reported to receive occupational therapy, and 4% receive physical therapy. However, from 6 to 10 times as many students with orthopedic impairments, multiple disabilities, or deaf-blindness as students in other disability categories receive these services; students with autism also are relatively heavy users of occupational therapy. For example, 60% of students with multiple disabilities receive occupational therapy and almost half receive physical therapy. In contrast, in five disability categories, including the largest, fewer than 15% of students receive occupational therapy, and similar percentages of students in six disability categories receive physical therapy. The school is a provider of occupational therapy for nearly all students who receive it. Nonschool sources are more frequently involved in providing physical therapy.

**Mobility and sensory enhancements.** Mobility limitations pose serious problems for many students with orthopedic impairments, multiple disabilities, deaf-blindness, or visual impairments. It follows that larger shares of students with these than with other disabilities use such services as specialized transportation, assistive technology services or devices, and orientation and mobility services to help them gain access to their schools and communities and enjoy greater independence. Some services are associated with a specific impairment; examples are audiology services or classroom readers or interpreters, which are received predominantly by students with hearing impairments (76% and 40%, respectively) or deaf-blindness (70% and 31%, respectively)—fewer than 10% of students in other disability categories are reported to use these services.

**Nursing and respite care.** These services usually are needed by the few students whose disabilities require intensive or frequent intervention or ongoing maintenance care. The physical, sensory, or neurological impairments that impede independent movement or functioning for some youth with orthopedic impairments, multiple disabilities, or deaf-blindness can require daily assistance for personal care needs. In particular, some students with severe disabilities may need nursing care to attend to intensive medical needs (e.g., feeding tubes, seizure control) at home and in school, and respite also may be necessary for families and school staff who need periodic relief from the care required for some students with severe disabilities. Although nursing care and respite care are used by fewer than 1% of students with disabilities as a whole, 10% or more of youth with orthopedic impairments, multiple disabilities, or deaf-blindness receive nursing services, and parents of one in five students report using respite care for their sons or daughters with multiple disabilities or autism.

Importantly, personal care services are the only services reported to have more families on waiting lists than are receiving them. Twice as many families are waiting for nursing care and three times as many for respite services as are receiving them. Although these personal care services are needed by a small proportion of secondary students with disabilities, the compelling nature of the services themselves implies that the long waits to obtain them could potentially impede the ability of youth who need them to succeed at school, at home, and in the community and compound the challenges already faced by their families.

## **Participation in School-Based Programs**

Students with disabilities participate in a variety of programs at school for which they are eligible for reasons other than their disabilities. Some of these are federal programs that serve all eligible students in a school and aim to reduce the limitations imposed by such factors as poverty or limited English proficiency. Others serve students who demonstrate or are at risk for behaviors often associated with negative consequences for adolescents.

### ***Participation in Schoolwide Programs***

According to school staff, 40% of secondary school students with disabilities receive free or reduced-price lunches through the National School Lunch Program. In addition, 2% participate in bilingual education or instruction specifically for English language learners, among whom poverty can be a confounding factor for many students. Participation in these programs concentrates among youth with disabilities in low-income households, three-fourths of whom receive free or reduced-price lunches and 3% of whom participate in programs for English language learners. These are rates two to five times higher than participation by students with disabilities in the next higher income group. School lunch programs also serve larger proportions of African-American and Hispanic youth with disabilities than their white peers, underscoring the association between household income and race/ethnicity. Income and racial/ethnic backgrounds are not the only demographic factors that distinguish participation in these programs. More than half of students with disabilities in seventh and eighth grades participate in the school lunch program, a proportion that declines steadily to one-third of students among high school juniors and seniors. Girls with disabilities also are 10 percentage points more likely than boys with disabilities to receive free or reduced-price lunches.

There also are differences in participation rates for these programs among youth in different disability categories, which largely reflect the differences in the distribution of poor and minority youth across categories. For example, African-Americans and students living in poverty are significantly higher proportions of students with mental retardation than of students in any other disability category; 41% live in poverty and one-third are African American, compared with 30% and 25% of students with emotional disturbances, the category with the next highest representation of these students. Therefore, it is not surprising that approximately twice the proportion of students with mental retardation as of students in most other disability categories are reported by school staff to receive free or reduced-price lunches. Students with deaf-blindness or hearing impairments are most likely to participate in bilingual or English language learner programs, suggesting that staff may be reporting students' participation in language programs that focus on communication issues as well as on English language acquisition. On the other hand, Hispanic youth also are more likely than others to be participants in programs for English language learners.

Finally, NLTS2 also investigated students' participation in summer school programs, which are designed to help students who are lagging behind academically or who desire to expand their instructional options beyond those available during the school year. NLTS2 school staff report that 12% of secondary school youth with disabilities participated in summer school programs the previous summer, with slightly more girls than boys among the participants. The summer school participation rates are from two to six times greater among youth with autism (43%), multiple disabilities (38%), or deaf-blindness (29%) than among youth in other disability categories. These

differences imply that IEP teams may be including extended-school-year services on the IEPs of these youth with disabilities as part of the provision of a free appropriate public education.

### ***Programs That Target Youth Risk Behaviors***

As noted earlier in this report, IDEA '97 requires that the IEP team, “in the case of a child whose behavior impedes his or her learning or that of others, consider, if appropriate, strategies, including positive behavioral interventions, strategies, and supports to address that behavior” [IDEA '97 Final Regulations, Section 300.346(a)(2)(i)]. According to school staff, most youth with disabilities participate in at least one program aimed at preventing or ameliorating behaviors that place students at risk for poor outcomes, ranging from about one in five students receiving teen parenting education or services to more than half receiving reproductive health education or services. School staff also perceive that approximately one-third of students with disabilities do not participate in these programs but would benefit from them. It is noteworthy that the percentages of students reported to have unmet needs for conflict resolution/anger management/violence prevention or teen parenting programs are larger than the percentages of those participating in them.

Students in every disability category participate to some extent in these programs, although participation rates vary widely across disability categories. Unlike the greater prevalence of related-service participation among students in such categories as autism or multiple disabilities, students in higher-incidence categories are more likely to participate in programs that focus on risk behaviors. For example, students with learning disabilities or emotional disturbances are reported to participate in these programs at relatively higher rates than others. Nonetheless, youth with learning disabilities or emotional disturbances also are among the students reported to have relatively high levels of unmet needs. In fact, according to school staff, youth with emotional disturbances have the highest proportions of unmet needs for each of the four risk behavior programs.

With the exception that more girls than boys with disabilities receive teen parenting education, participation rates vary little for students of different demographic characteristics. In contrast, the proportions of students with unmet needs for these programs differ by household income, race/ethnicity, and grade level. Specifically, significantly larger shares of low-income students are perceived to have unmet needs for programs that target reproductive health, teen parenting, and substance abuse. African-American and Hispanic youth also are perceived to have unmet needs for these programs in greater proportions than white students. In addition, unmet needs are reported for relatively high proportions of students at middle school grade levels, but are greatest for ninth graders. Because ninth grade marks the transition from middle to high school for most students, eighth- and ninth-grade youth with disabilities who do not have access to prevention and treatment programs aimed at risk behaviors may be headed for a difficult transition, discipline problems, and a higher likelihood of dropping out of school. School staff's perceptions of unmet needs for these programs decrease after ninth grade, perhaps reflecting an increase in the cumulative percentages of youth who have been served by these programs or, alternatively, the possibility that students with unmet needs for such programs may have dropped out.

Finally, school poverty, as measured by the proportion of the student body that are eligible for free or reduced-price lunch, is associated with some unmet programmatic needs for students with disabilities. Youth with disabilities who attend schools with smaller concentrations of low-income

students are less likely to have perceived unmet needs for programs that target high-risk behaviors than are youth with disabilities who go to schools where low-income students are a greater proportion of the student body. Thus, increased investments in such programs might well be targeted toward secondary students who attend high-poverty schools.

This report has described the receipt of related services and participation in school-based programs by secondary school students with disabilities. Findings depict the range of services and supports provided to youth, some of the challenges encountered in acquiring them, and perceptions of unmet needs, as indicated by their parents and school staff. Longitudinal analyses in subsequent waves of NLTS2 will enable a look at the effects these services, supports, and programs may have on later outcomes, as youth with disabilities transition from school to early adult life.