#### 4. DISABILITY PROFILES OF YOUTH WITH DISABILITIES

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NLTS2 findings thus far have examined how youth with different primary disability classifications differ from each other in ways other than disability. Their primary disability classifications result from a process of identification and eligibility determination that was completed before the formation or revision of their Individualized Education Programs (IEPs). That classification is an important component in understanding the variations in students' experiences, but it indicates only one aspect of their disabilities.

This chapter takes another step in understanding disability by addressing the variety of abilities and disabilities that parents report for secondary-school-age students.<sup>1</sup> Also discussed are the lengths of time students and families have been dealing with disability issues, as reflected in the ages at which youth first were identified as having a disability, delay, or learning problem and when they first began receiving special services from a professional. The age of students' first receipt of special services at school and their experiences with early intervention as infants and toddlers with disabilities and/or preschool special education also are discussed. Findings are presented for youth with disabilities as a whole and for those who differ in primary disability classification, age, gender, household income, and race/ethnicity.

### Parents' Reports of Youth's Disabilities

The primary disability classification assigned to students receiving special education is the result of a diagnostic process that is intended to reveal to school staff, parents, and students the one or more learning challenges that special education supports and services are designed to address. It indicates what the school believes is a student's dominant disability, from an education perspective, and is one important indicator of the disability and functional profile of students. However, a classification that is based on the educational implications of disability may not reflect the full range of academic, social, and emotional challenges students face in other areas of their lives. To obtain a broader view of students' disabilities than the primary disability classification assigned by schools, parents were asked to report the "physical, sensory, learning, or other disabilities or problems" with which students had been diagnosed.<sup>2</sup>

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<sup>&</sup>lt;sup>1</sup> Analyses similar to those reported in this chapter were conducted for elementary and middle school students as part of the Special Education Elementary Longitudinal Study (SEELS) and are reported in Wagner and Blackorby (2002).

<sup>&</sup>lt;sup>2</sup> The question wording is as follows: "{YOUTH} is included in this study because {his/her} school or school district indicated at the beginning of the 2000 school year that {he/she} may have received special education services and had an IEP (Individualized Education Plan). With what physical, sensory, learning, or other disabilities or problems has {YOUTH} been diagnosed? [PROBE: Any other disabilities or learning problems?]" Parents also were asked explicitly whether their child has attention deficit disorder or attention deficit/hyperactivity disorder if those conditions were not mentioned in response to the initial question.

#### Prevalence of Disabilities

Parents' reports of their children's disabilities are depicted in Exhibit 4-1. In addition to the disability categories set forth in the Individuals with Disabilities Education Act Amendments of 1997<sup>3</sup>, the exhibit also includes reports of attention deficit disorder (ADD) or attention deficit/hyperactivity disorder (ADHD). In interpreting the findings in Exhibit 4-1, it is important to keep in mind that parents were probed for all disabilities, not just their child's main disability.

Parents' reports reveal much about the diversity of students within the federal special education disability categories. First, it is apparent that the percentages in each column add to more than 100, indicating that parents report more than one major kind of disability for many youth. In fact, parents' reports average 1.5 different categories of disability per student. Parents of youth with speech/ language impairments report the fewest different categories of disability (1.3), and, not surprisingly, those with multiple impairments (2.2) and deaf-blindness (3.3) report the most. Parents of youth with emotional disturbances, autism, and traumatic brain injuries report an average of 1.9 disabilities.

Exhibit 4-1 PARENTS' REPORTS OF YOUTH'S DISABILITIES, BY PRIMARY DISABILITY CATEGORY

|                                 |                  |                   | Speech/             |                   | Emo-               |                    | \ C 1             | Ortho-            | Other             |                   | Trau-             | NA 101-1              | D (               |
|---------------------------------|------------------|-------------------|---------------------|-------------------|--------------------|--------------------|-------------------|-------------------|-------------------|-------------------|-------------------|-----------------------|-------------------|
|                                 | All<br>Disabili- | Dis-              | Language<br>Impair- | Mental<br>Retar-  | tional<br>Disturb- | Hearing<br>Impair- | Visual<br>Impair- | pedic<br>Impair-  | Health<br>Impair- |                   | matic<br>Brain    | Multiple<br>Disabili- | Deaf-<br>Blind-   |
|                                 | ties             | ability           | ment                | dation            | ance               | ment               | ment              | ment              | ment              | Autism            | Injury            | ties                  | ness              |
| Percentage reporting child has: |                  |                   |                     |                   |                    |                    |                   |                   |                   |                   |                   |                       |                   |
| Learning disability             | 62.1<br>(1.5)    | <b>77.8</b> (2.0) | 40.5<br>(2.4)       | 52.9<br>(2.5)     | 29.9<br>(2.3)      | 9.1<br>(1.7)       | 7.6<br>(1.8)      | 19.7<br>(2.2)     | 29.9<br>(2.2)     | 10.1<br>(1.6)     | 32.5<br>(4.3)     | 31.1<br>(2.5)         | 17.5<br>(3.7)     |
| Speech impairment               | 8.5              | 6.7<br>(1.2)      | <b>53.6</b> (2.5)   | 10.0 (1.5)        | 1.8                | 11.4               | 3.5 (1.3)         | 7.0 (1.4)         | 4.2               | 12.9 (1.8)        | 8.6<br>(2.6)      | 16.1 (2.0)            | 17.7 (3.7)        |
| Mental retardation              | 5.5<br>(.7)      | .7                | 3.0 (.9)            | <b>32.6</b> (2.3) | 1.4 (.6)           | 2.6<br>(1.0)       | 8.0<br>(1.9)      | 5.6<br>(1.3)      | 2.1               | 12.2              | 4.8<br>(2.0)      | 25.1<br>(2.3)         | 12.1 (3.2)        |
| Emotional disturbance           | 11.4<br>(1.0)    | 5.3<br>(1.1)      | 4.5<br>(1.0)        | 4.2 (1.0)         | <b>56.6</b> (2.5)  | 1.1                | 2.0<br>(1.0)      | 3.5<br>(1.0)      | 14.1<br>(1.6)     | 5.5<br>(1.2)      | 4.6<br>(1.9)      | 9.3                   | 5.6<br>(2.2)      |
| Hearing impairment              | 3.3 (.6)         | 1.9               | 3.3                 | 2.4 (.8)          | 1.6                | 100.0<br>(.0)      | .2                | 2.3               | 1.8               | 1.0               | 2.8<br>(1.5)      | 6.8 (1.3)             | 63.3 (4.7)        |
| Visual impairment               | 2.0 (.4)         | 1.1<br>(.5)       | 1.0 (.5)            | 2.2               | .6<br>(.4)         | .0<br>(0.)         | 100.0<br>(.0)     | 6.5<br>(1.3)      | 1.9<br>(.7)       | 1.4<br>(.6)       | 4.3<br>(1.9)      | 9.0<br>(1.5)          | 65.5<br>(4.6)     |
| Orthopedic impairment           | 4.8              | 2.1 (.7)          | 1.9<br>(.7)         | 8.3<br>(1.4)      | 1.7                | 3.6<br>(1.1)       | 10.2<br>(2.1)     | <b>78.1</b> (2.3) | 8.0<br>(1.3)      | 4.4<br>(1.1)      | 13.3<br>(3.1)     | 36.4<br>(2.6)         | 24.2<br>(4.2)     |
| Other health impairment         |                  | 35.1<br>(2.3)     | 22.3<br>(2.1)       | 35.2<br>(2.4)     | 64.4<br>(2.4)      | 15.3<br>(2.2)      | 17.7<br>(2.7)     | 31.9<br>(2.5)     | <b>86.3</b> (1.6) | 35.7<br>(2.5)     | 42.8<br>(4.6)     | 40.8<br>(2.6)         | 33.7 (4.6)        |
| ADD/ADHD <sup>a</sup>           | 36.4<br>(1.5)    | 32.4<br>(2.3)     | 18.7                | 28.8 (2.3)        | 63.1 (2.5)         | 11.5<br>(1.9)      | 10.8 (2.2)        | 21.9 (2.3)        | 75.8<br>(2.0)     | 32.7<br>(2.5)     | 31.1 (4.3)        | 28.3 (2.4)            | 15.0<br>(3.5)     |
| Autism                          | 1.6              | .1 (.1)           | .7 (.4)             | 2.5 (.8)          | 2.1 (.7)           | .1 (.2)            | 1.7               | 1.6               | 2.9               | <b>92.1</b> (1.4) | .8<br>(8.)        | 6.3 (1.3)             | 5.6<br>(2.2)      |
| Traumatic brain injury          | .5<br>(.2)       | .1<br>(.2)        | .1<br>(.2)          | .5<br>(.4)        | .6<br>(.4)         | .1<br>(.2)         | .5<br>(.5)        | .9<br>(.5)        | .9<br>(.4)        | .4 (.3)           | <b>58.1</b> (4.6) | 3.3                   | 1.3<br>(1.1)      |
| Deaf-blindness                  | .1 (.1)          | .0                | .0                  | .0                | .0                 | .0                 | .0                | .0                | .0                | .0                | 0.                | .0                    | <b>37.3</b> (4.7) |
| Other                           | 16.1<br>(1.2)    | 14.6<br>(1.7)     | 11.4<br>(1.6)       | 14.5<br>(1.8)     | 19.8<br>(2.0)      | 8.7<br>(1.6)       | 11.5<br>(2.2)     | 25.4<br>(2.4)     | 26.3<br>(2.1)     | 14.9<br>(1.9)     | 24.7<br>(4.0)     | 35.6<br>(2.6)         | 21.7 (4.0)        |

Source: NLTS2 Wave 1 parent interviews.

ADD/ADHD is a subset of the other health impairment category. Standard errors are in parentheses.

<sup>&</sup>lt;sup>3</sup> Definitions of these categories are presented in Appendix A.

Further, every primary disability category to which youth were assigned by schools contains youth whose parents report that they also have other types of disabilities. For example, according to parents' reports, 8% of youth classified by schools as having visual impairments have learning disabilities, 8% have mental retardation, 10% have orthopedic impairments, and 18% have other health impairments. Parents of approximately 30% of youth classified as having emotional disturbances, other health impairments, traumatic brain injuries, or multiple disabilities, and more than half of those with mental retardation, report that their children have learning disabilities. Parents of between 19% and 64% of youth whose primary disability classification is not other health impairment report that their sons or daughters have other health impairments, largely because of the prevalence of ADD/ADHD. Overall, parents report that 36% of their sons or daughters have ADD/ADHD—parents of 76% of youth whose primary disability classification is other health impairment, and parents of between 11% and 63% of youth with other primary disability classifications.

Parents' reports of disabilities are helpful in illuminating the kinds of disabilities in the "umbrella" category of multiple disabilities. Other health impairments are the most commonly reported type of disability for youth in the multiple disabilities category; 41% of them are reported to have other health impairments, including 28% with ADD/ADHD. According to parents, about one-third of youth in this category have learning disabilities, orthopedic impairments, or "other disabilities"—those not easily categorized from their label alone. One-fourth of these youth are reported to have mental retardation, and approximately 1 in 10 are reported to have emotional disturbances.

Finally, some parents of youth in every disability category do not mention that their adolescent children have the disability for which they were classified by their schools as eligible to receive special education services. For example, among youth whose school-assigned primary disability classification is learning disability, only 78% are reported by parents as having learning disabilities; 22% of parents of youth with that classification do not mention learning disabilities at all as among their diagnosed physical, sensory, or learning problems. A similar discrepancy is apparent to a lesser or greater degree for youth with every primary disability classification.

Several factors could help explain these differences in reports of students' disabilities by parents and their children's schools. It is possible that parents perceive some disabilities as more acceptable than others and thus report them more often (e.g., learning disability may be chosen as a descriptor more readily than mental retardation). Some parents also may not be familiar with the precise meaning of the disability labels used by schools and may have incorrectly described students' disabilities. Schools also may have categorized students' disabilities incorrectly. Some research has shown, for example, that schools identify boys as having dyslexia (a learning disability that affects students' reading ability) twice as often as girls, when tests of actual reading ability show that dyslexia occurs equally in boys and girls (Shaywitz & Shaywitz, 2001). It also is possible that some students' disability profiles changed over time so that the classification reported by schools when students were chosen for NLTS2 no longer accurately described the disabilities parents reported several months later. Finally, parents' perspectives of disability and students' functioning at home simply may differ from those of the schools. For example, a learning disability that is a significant enough challenge at school to qualify a student for special education may not be nearly so apparent in the less structured environment of the home, where learning educational content is not the primary expectation of youth.

### **Demographic Differences in Prevalence of Disabilities**

For the most part, age and gender do not distinguish between youth in the kinds of disabilities their parents report, with the exception of other health impairments. Parents identify boys significantly more often than girls as having other health impairments (45% vs. 30%, p<.001), largely because of differences in identifying them as having ADD/ADHD (42% vs. 26%, p<.001).

Other health impairment also is the only type of disability that parents report at different rates for youth who differ in economic status or race/ethnicity, again reflecting differences in the reported rates of those with ADD/ADHD. Specifically, the rate at which parents report that youth have ADD/ADHD is significantly higher for those from upper-income households (41% of youth from households with incomes of more than \$50,000) than for their peers from less affluent households (33% of youth from households with incomes of \$25,000 or less, p<.05). Because African American and Hispanic youth are significantly more likely than white youth to come from lower-income families, differences between racial/ethnic groups mirror those between the income groups. White youth are significantly more likely to be reported as having ADD/ADHD (41%) than African American or Hispanic youth (30% and 23%, respectively, p<.001).

Income differences also are noted regarding the rate at which parents report that youth have "other disabilities"—ones not readily classified into the primary disability categories (e.g., a genetic disorder that could manifest itself in a variety of forms of disability). Such disabilities are reported significantly more often for upper-income youth (20% of those from households with incomes of more than \$50,000) than for their lower-income peers (13% of those from households with incomes of \$25,000 or less, p < .05). Although racial/ethnic differences are few, Hispanic youth are significantly more likely than their white peers to be reported as having a learning disability (70% vs. 60%, p < .05), and rates of reported "other disabilities" are higher for white than for African American youth (18% vs. 12%, p < .05).

## **Disability Identification and Service Initiation**

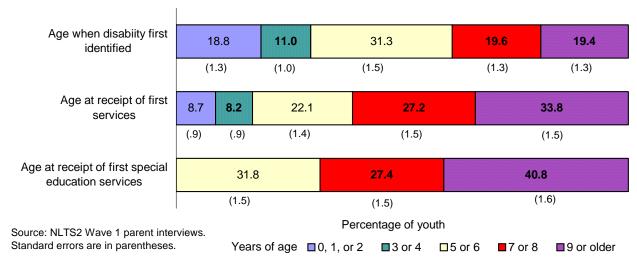
The age at which children first are recognized as having a disability or developmental delay can indicate much about the nature of their disabilities and the experiences children and families have with them. Some disabilities, such as genetic disorders and some conditions that result from premature birth, affect youth throughout their lifetimes; they and their families never experience a time when the disability is not an aspect of their relationship. Other disabilities are noticed when children reach the ages of typical developmental milestones and exhibit delays, for example, in walking or talking. Still others become apparent when children take on more sophisticated cognitive tasks, such as reading or mathematics, and demonstrate difficulty in learning. Others can result from accidents that occur at any age.

Regardless of the age at which disabilities emerge, prompt treatment can be extremely important in ameliorating their effects. The Individuals with Disabilities Education Act Amendments of 1997 mandate programs for children with disabilities that begin at birth and have outreach components to families of young children.

This section presents parents' reports of the ages at which youth first were recognized as having a disability or developmental delay. The ages at which youth first received professional services for the disability or delay and the ages at which they first received special services at school also are presented, as are findings regarding the role of parents and professionals in the identification of disabilities and initiation of services.

Approximately one in five youth have disabilities that first were recognized when they were infants or toddlers (Exhibit 4-2), and another 11% have disabilities or delays that were identified in their preschool years. More than two-thirds of youth did not have their disabilities identified until they were school age. School entry, at age 5 or 6, was when almost one-third of youth first had their disabilities identified, whereas 19% did not have their disabilities identified until they were at least 9 years old.

Exhibit 4-2
YOUTH'S AGE AT FIRST IDENTIFICATION OF DISABILITY AND FIRST
RECEIPT OF SERVICES



# Exhibit 4-3 SOURCE OF IDENTIFICATION OF YOUTH'S DISABILITIES AND REQUEST FOR SPECIAL EDUCATION SERVICES

|                                                    | Percentage | Standard Error |
|----------------------------------------------------|------------|----------------|
| Disability first identified by:                    |            |                |
| Family member                                      | 47.5       | 1.6            |
| Professional                                       | 50.5       | 1.6            |
| Other                                              | 2.1        | .5             |
| School services for disability first requested by: |            |                |
| Parent                                             | 41.3       | 1.6            |
| School staff                                       | 55.8       | 1.6            |
| Other                                              | 2.9        | .6             |
| Source: NLTS2 Wave 1 parent interviews.            |            |                |

According to parents' reports, even more youth did not begin receiving professional services for their disabilities until they reached school age. Despite the fact that 30% of youth were identified as having a disability before they were 5 years old, fewer than one in five youth received services before they were 5. An additional one in five began to receive services at the age of school entry (age 5 or 6). Approximately one-third did not receive services until they were at least 9 years old. Age of first receipt of special education services generally parallels the age of receipt of first professional services.

Approximately half of youth's disabilities first were recognized by family members, and about half were recognized by professionals; very few youth had their disabilities first recognized by others. In contrast, school staff are significantly more likely than parents to have

been the source of the request for students to receive special services at school for their disabilities (56% vs. 41%, p<.001).

### Disability Differences in Disability Identification and Service Initiation

There are dramatic differences in the ages of first identification and service among youth who differ in their primary disability classification (Exhibit 4-4). Youth with sensory or orthopedic impairments by far are the most likely to have had their disabilities identified at very young ages and to have received services as young children. For example, approximately three-fourths of youth with visual or orthopedic impairments or deaf-blindness were identified as having a disability before age 3, as were 69% of those with multiple disabilities. Youth with these types of disabilities also are the most likely to have received their first professional services as infants or toddlers (51% to 67%). Approximately 60% of students with hearing impairments or autism also had their disabilities recognized as infants or toddlers. However, 40% of those with hearing impairments received services for their disability before age 3, compared with 27% of those with autism (p<.001). Approximately 70% of students with hearing impairments and 82% of students with autism first received special education services upon school entry.

In contrast, only 11% of youth with learning disabilities and 13% of youth with emotional disturbances were identified as having a disability or delay before age 3. Approximately 45% were not identified as having a disability until age 7 or older, and almost 70% were not served until age 7 or older. School age also was the time when the majority of youth with speech or other health impairments or traumatic brain injuries first were identified as having a disability or delay. Between 77% and 81% of youth in those categories did not receive professional services for their disabilities until school age, and approximately 33% were not served until age 9 or older. Despite the fact that students with emotional disturbances tended to be identified at about the same ages as students with learning disabilities, they were more likely not to receive special education services until later; 53% of youth with emotional disturbances, compared with 44% of youth with learning disabilities, did not receive services until they were at least 9 years old.

Parents' roles in identifying students' disabilities and in requesting special services for them at school differ among the disability categories. Parents of youth with hearing impairments or autism are significantly more likely than other parents to have been the first to recognize their children's disabilities; 62% and 72% of these youth, respectively, were first recognized as having disabilities by their parents, compared with 41% to 53% of youth with other types of disabilities (p<.05). They are joined by parents of youth with visual impairments as being the most likely to have been the ones first to request services at school. Parents of youth with mental retardation are among the least likely to report having been the first to recognize their children's disabilities or to request school services for them (42% and 34%).

Exhibit 4-4
FIRST IDENTIFICATION OF AND SERVICE FOR DISABILITIES,
BY DISABILITY CATEGORY

|                                                               | Learning<br>Dis-<br>ability | Speech/<br>Language<br>Impair-<br>ment | Mental<br>Retar-<br>dation | Emotional<br>Distur-<br>bance | Hearing<br>Impair-<br>ment | Visual<br>Impair-<br>ment | Ortho-<br>pedic<br>Impair-<br>ment | Other<br>Health<br>Impair-<br>ment | Autism | Trau-<br>matic<br>Brain<br>Injury | Multiple<br>Disabili-<br>ties | Deaf-<br>Blind-<br>ness |
|---------------------------------------------------------------|-----------------------------|----------------------------------------|----------------------------|-------------------------------|----------------------------|---------------------------|------------------------------------|------------------------------------|--------|-----------------------------------|-------------------------------|-------------------------|
| Percentage with disability first identified at age:           |                             |                                        |                            |                               |                            |                           |                                    |                                    |        | 1-7                               |                               |                         |
| 0, 1, or 2 years                                              | 10.7                        | 21.7                                   | 39.3                       | 13.4                          | 60.1                       | 74.7                      | 76.9                               | 23.4                               | 61.4   | 21.9                              | 68.8                          | 77.8                    |
| o, 1, o. 2 you.o                                              | (1.6)                       | (2.1)                                  | (2.5)                      | (1.8)                         | (2.8)                      | (3.0)                     |                                    | (2.0)                              | (2.7)  | (3.7)                             | (2.5)                         | (4.3)                   |
| 3 or 4 years                                                  | 10.3                        | 14.9                                   | 10.8                       | 11.7                          | 16.3                       | 4.4                       | 7.5                                | 13.3                               | 26.1   | 13.8                              | 11.8                          | 7.6                     |
| 2 01 1 you.0                                                  | (1.5)                       | (1.8)                                  | (1.6)                      | (1.7)                         | (2.1)                      | (1.4)                     | (1.5)                              | (1.6)                              | (2.4)  | (3.1)                             | (1.8)                         | (2.8)                   |
| 5 or 6 years                                                  | 35.5                        | 27.7                                   | 23.2                       | 29.4                          | 12.8                       | 10.6                      | 7.4                                | 30.1                               | 9.3    | 16.9                              | 11.9                          | 3.3                     |
| o or o youro                                                  | (2.4)                       | (2.3)                                  | (2.2)                      | (2.4)                         | (1.9)                      | (2.2)                     | (1.5)                              | (2.2)                              | (1.6)  | (3.4)                             | (1.8)                         | (1.9)                   |
| 7 or 8 years                                                  | 22.2                        | 18.0                                   | 14.6                       | 19.5                          | 6.2                        | 4.8                       | 3.4                                | 16.9                               | 1.9    | 20.7                              | 4.6                           | 7.8                     |
| r or o youro                                                  | (2.1)                       | (2.0)                                  | (1.8)                      | (2.1)                         | (1.4)                      | (1.5)                     | (1.0)                              | (1.8)                              | (.7)   | (3.7)                             | (1.1)                         | (2.8)                   |
| 9 or 10 years                                                 | 11.4                        | 10.5                                   | 7.2                        | 12.1                          | 2.6                        | 3.2                       | 2.0                                | 9.9                                | 1.0    | 9.2                               | 1.7                           | 1.4                     |
| o or to your                                                  | (1.6)                       | (1.6)                                  | (1.4)                      | (1.7)                         | (0.9)                      | (1.2)                     | (0.8)                              | (1.4)                              | (0.5)  | (2.6)                             | (0.7)                         | (1.2)                   |
| 11 years or older                                             | 10.0                        | 7.2                                    | 4.9                        | 13.9                          | 2.0                        | 2.4                       | 2.9                                | 6.4                                | 0.4    | 17.5                              | 1.2                           | 2.1                     |
| yeare er eraer                                                | (1.5)                       | (1.3)                                  | (1.1)                      | (1.8)                         | (0.8)                      | (1.1)                     |                                    | (1.2)                              | (0.3)  | (3.4)                             | (0.6)                         | (1.5)                   |
| Percentage with first professional services at age:           | ( - /                       | ( -,                                   | ,                          | ( -,                          | ( /                        | ,                         | ()                                 | ( )                                | ( /    | (- /                              | ( /                           | ( -,                    |
| 0, 1, or 2 years                                              | 3.8                         | 6.5                                    | 20.4                       | 3.1                           | 40.1                       | 51.3                      | 60.9                               | 10.1                               | 27.3   | 12.3                              | 51.3                          | 66.6                    |
| •                                                             | (1.0)                       | (1.3)                                  | (2.1)                      | (.9)                          | (2.8)                      | (3.5)                     | (2.8)                              | (1.5)                              | (2.4)  | (3.0)                             | (2.7)                         | (5.0)                   |
| 3 or 4 years                                                  | 5.3                         | 12.4                                   | 15.8                       | 8.6                           | 20.6                       | 12.1                      | 13.2                               | 9.1                                | 40.7   | 10.9                              | 19.3                          | 11.6                    |
| •                                                             | (1.1)                       | (1.7)                                  | (1.9)                      | (1.5)                         | (2.4)                      | (2.3)                     | (1.9)                              | (1.4)                              | (2.7)  | (2.9)                             | (2.2)                         | (3.4)                   |
| 5 or 6 years                                                  | 22.0                        | 27.6                                   | 24.4                       | 21.0                          | 18.2                       | 15.2                      | 12.7                               | 23.5                               | 19.5   | 20.3                              | 16.8                          | 7.7                     |
| •                                                             | (2.1)                       | (2.3)                                  | (2.3)                      | (2.1)                         | (2.2)                      | (2.5)                     | (1.9)                              | (2.1)                              | (2.2)  | (3.7)                             | (2.0)                         | (2.8)                   |
| 7 or 8 years                                                  | 31.4                        | 21.4                                   | 18.3                       | 26.3                          | 10.7                       | 8.6                       | 4.4                                | 23.9                               | 6.0    | 23.9                              | 6.7                           | 9.8                     |
| •                                                             | (2.3)                       | (2.1)                                  | (2.0)                      | (2.3)                         | (1.8)                      | (2.0)                     | (1.2)                              | (2.1)                              | (1.3)  | (3.9)                             | (1.4)                         | (3.1)                   |
| 9 or 10 years                                                 | 19.0                        | 15.2                                   | 10.8                       | 15.5                          | 4.0                        | 7.6                       | 2.5                                | 17.1                               | 2.4    | 12.3                              | 3.3                           | 1.5                     |
| •                                                             | (2.0)                       | (1.8)                                  | (1.6)                      | (1.9)                         | (1.1)                      | (1.9)                     | (0.9)                              | (1.8)                              | (8.0)  | (3.0)                             | (1.0)                         | (1.3)                   |
| 11 years or older                                             | 18.5                        | 17.0                                   | 10.2                       | 25.6                          | 6.6                        | 5.2                       | 6.3                                | 16.3                               | 4.0    | 20.4                              | 2.6                           | 2.9                     |
|                                                               | (2.0)                       | (1.9)                                  | (1.6)                      | (2.3)                         | (1.4)                      | (1.6)                     | (1.4)                              | (1.8)                              | (1.1)  | (3.7)                             | (0.9)                         | (1.8)                   |
| Percentage first receiving special education services at age: |                             |                                        |                            |                               |                            |                           |                                    |                                    |        |                                   |                               |                         |
| 5 or 6 years                                                  | 24.2                        | 43.0                                   | 56.8                       | 22.6                          | 68.6                       | 63.6                      | 74.3                               | 29.8                               | 82.3   | 41.1                              | 81.2                          | 75.3                    |
| 5 5. 5 , 555                                                  | (2.1)                       | (2.5)                                  | (2.6)                      | (2.2)                         | (2.7)                      | (3.5)                     | (2.5)                              | (2.2)                              | (2.1)  | (4.5)                             | (2.2)                         | (4.7)                   |
| 7 or 8 years                                                  | 31.8                        | 22.2                                   | 17.0                       | 24.6                          | 14.3                       | 14.7                      | 8.9                                | 26.7                               | 7.7    | 22.8                              | 8.6                           | 9.6                     |
| ,                                                             | (2.3)                       | (2.1)                                  | (2.0)                      | (2.3)                         | (2.1)                      | (2.5)                     | (1.6)                              | (2.1)                              | (1.5)  | (3.8)                             | (1.6)                         | (3.2)                   |
| 9 or 10 years                                                 | 19.6                        | 16.7                                   | 10.7                       | 19.6                          | 7.1                        | 9.6                       | 6.5                                | 17.7                               | 5.4    | 12.6                              | 5.3                           | 8.2                     |
| ,                                                             | (2.0)                       | (1.9)                                  | (1.6)                      | (2.1)                         | (1.5)                      | (2.1)                     |                                    |                                    | (1.3)  | (3.0)                             |                               | (3.0)                   |
| 11 years or older                                             | 24.5                        | 18.1                                   | 15.6                       | 33.2                          | 10.0                       | 12.2                      | 10.3                               | 25.7                               | 4.5    | 23.4                              | 4.9                           | 6.9                     |
| ,                                                             | (2.1)                       | (2.0)                                  | (1.9)                      | (2.5)                         | (1.8)                      | (2.4)                     |                                    | (2.1)                              | (1.2)  | (3.9)                             |                               | (2.7)                   |
| Percentage with disability first identified by:               | ` ,                         | , ,                                    | ` ,                        | , ,                           | , ,                        | ` ,                       | ,                                  | , ,                                | , ,    | ,                                 | ,                             | , ,                     |
| A family member                                               | 47.9                        | 53.0                                   | 41.7                       | 46.1                          | 62.5                       | 43.3                      | 42.0                               | 49.6                               | 72.1   | 41.4                              | 49.5                          | 44.7                    |
|                                                               | (2.5)                       | (2.5)                                  | (2.5)                      | (2.6)                         | (2.8)                      | (3.5)                     | (2.8)                              | (2.4)                              | (2.4)  | (4.5)                             | (2.7)                         | (5.2)                   |
| A professional                                                | 50.2                        | 45.1                                   | 57.0                       | 51.2                          | 34.8                       | 53.9                      | 53.7                               | 47.2                               | 25.6   | 54.7                              | 48.4                          | 52.9                    |
|                                                               | (2.5)                       | (2.5)                                  | (2.5)                      | (2.6)                         | (2.7)                      | (3.5)                     | (2.8)                              | (2.4)                              | (2.3)  | (4.5)                             | (2.7)                         | (5.2)                   |
| Someone else                                                  | 1.9                         | 1.8                                    | 1.3                        | 2.7                           | 2.7                        | 2.8                       | 4.3                                | 3.2                                | 2.2    | 3.9                               | 2.1                           | 2.4                     |
|                                                               | (.7)                        | (.7)                                   | (.6)                       | (8.)                          | (.9)                       | (1.2)                     | (1.1)                              | (8.)                               | (8.)   | (1.8)                             | (8.)                          | (1.6)                   |
|                                                               |                             |                                        |                            |                               |                            |                           |                                    |                                    |        |                                   |                               |                         |

Exhibit 4-4
FIRST IDENTIFICATION OF AND SERVICE FOR DISABILITIES,
BY DISABILITY CATEGORY (CONCLUDED)

|                                                                    | Learning<br>Dis-<br>ability | Speech/<br>Language<br>Impair-<br>ment | Mental<br>Retar-<br>dation | Emotional<br>Distur-<br>bance | Hearing<br>Impair-<br>ment | Visual<br>Impair-<br>ment | Ortho-<br>pedic<br>Impair-<br>ment | Other<br>Health<br>Impair-<br>ment | Autism       | Trau-<br>matic<br>Brain<br>Injury | Multiple<br>Disabili-<br>ties | Deaf-<br>Blind-<br>ness |
|--------------------------------------------------------------------|-----------------------------|----------------------------------------|----------------------------|-------------------------------|----------------------------|---------------------------|------------------------------------|------------------------------------|--------------|-----------------------------------|-------------------------------|-------------------------|
| Percentage with school services for disability first requested by: |                             |                                        |                            |                               |                            |                           |                                    |                                    |              |                                   |                               |                         |
| A parent                                                           | 42.2                        | 42.9                                   | 33.6                       | 36.7                          | 51.1                       | 52.9                      | 47.4                               | 47.4                               | 57.5         | 48.7                              | 46.2                          | 46.3                    |
|                                                                    | (2.5)                       | (2.5)                                  | (2.5)                      | (2.6)                         | (3.0)                      | (3.6)                     | (2.9)                              | (2.5)                              | (2.8)        | (4.6)                             | (2.8)                         | (5.4)                   |
| School staff                                                       | 56.8                        | 54.1                                   | 60.7                       | 58.3                          | 39.4                       | 36.4                      | 42.0                               | 47.2                               | 32.9         | 36.2                              | 39.5                          | 40.5                    |
|                                                                    | (2.5)                       | (2.6)                                  | (2.6)                      | (2.7)                         | (2.9)                      | (3.5)                     | (2.9)                              | (2.5)                              | (2.6)        | (4.4)                             | (2.8)                         | (5.3)                   |
| Someone else                                                       | 1.0<br>(.5)                 | 3.0<br>(.9)                            | 5.7<br>(1.2)               | 4.9<br>(1.2)                  | 9.6<br>(1.8)               | 10.7<br>(2.2)             | 10.5<br>(1.8)                      | 5.4<br>(1.1)                       | 9.6<br>(1.7) | 15.1<br>(3.3)                     | 14.2<br>(2.0)                 | 13.2<br>(3.7)           |

Source: NLTS2 Wave 1 parent interviews. Standard errors are in parentheses.

### **Demographic Differences in Disability Identification and Service Initiation**

Gender does not distinguish between youth with regard to age at first identification, first service, or first receipt of special education services at school, or with regard to the role parents played in those processes. However, there are consistent differences in disability identification and service initiation for youth with different levels of household income (Exhibit 4-5). In general, youth from less affluent households are more likely to have had their disabilities identified and to have first received services for them later than youth from more affluent households. Youth from lower-income households (\$25,000 or less per year) are significantly less likely than youth from more affluent households (more than \$50,000 per year) to have been identified as having a disability at age 5 or 6 (26% vs. 37%, p<.01) and more likely to have been identified as having a disability at age 9 or 10 (37% vs. 29%, p<.05). About one-fifth of youth from the least affluent households did not receive their first professional services until at least 11 years old, compared with 14% of youth from the most affluent households (p<.05). In addition, lower-income youth tend not to receive special education services at school as early as upperincome youth; 28% of youth from the least affluent households began to receive special education services in school at age 5 or 6, compared with 37% of youth from the most affluent households (p<.05).

Lower-income youth also are significantly less likely than upper-income youth to have had their parents be the first to recognize their disabilities (43% vs. 53%, p<.05). Their parents are even less likely to have been the first to request services for them at school (30% vs. 50%, p<.001). Thus, professionals and school staff play a particularly prominent role for lower-income youth in recognizing that they have disabilities and ensuring that they receive services for them.

Exhibit 4-5
FIRST IDENTIFICATION OF AND SERVICE FOR DISABILITIES,
BY INCOME AND RACE/ETHNICITY

|                                                               | Income              |                |                  | Race/Ethnicity |                     |            |  |
|---------------------------------------------------------------|---------------------|----------------|------------------|----------------|---------------------|------------|--|
|                                                               |                     | \$25,001       | More             |                |                     |            |  |
|                                                               | \$25,000<br>or Less | to<br>\$50,000 | than<br>\$50,000 | White          | African<br>American | Hispanic   |  |
| Percentage with disability first identified at age:           |                     |                |                  |                |                     |            |  |
| 0, 1, or 2 years                                              | 19.2                | 17.8           | 20.0             | 19.2           | 16.9                | 18.4       |  |
|                                                               | (2.1)               | (2.4)          | (2.5)            | (1.6)          | (2.7)               | (3.6)      |  |
| 3 or 4 years                                                  | 10.7 (1.7)          | 11.5 (2.0)     | 10.7 (1.9)       | 11.1 (1.3)     | 9.6<br>(2.1)        | 12.1 (3.0) |  |
| 5 or 6 years                                                  | 26.3                | 32.0           | 36.6             | 34.8           | 27.0                | 23.6       |  |
|                                                               | (2.4)               | (2.9)          | (3.0)            | (2.0)          | (3.2)               | (3.9)      |  |
| 7 or 8 years                                                  | 19.9                | 19.7           | 17.6             | 18.9           | 21.5                | 21.0       |  |
|                                                               | (2.1)               | (2.5)          | (2.3)            | (1.6)          | (3.0)               | (3.8)      |  |
| 9 or 10 years                                                 | 12.0                | 12.3           | 7.2              | 9.3            | 12.1                | 12.0       |  |
|                                                               | (1.8)               | (2.1)          | (1.6)            | (1.2)          | (2.3)               | (3.0)      |  |
| 11 years or older                                             | 11/0                | 6/6            | 7.8              | 6.8            | 13.1                | 13.0       |  |
|                                                               | (1.2)               | (2.3)          | (3.0)            | (1.0)          | (2.4)               | (3.1)      |  |
| Percentage with first professional services at age:           |                     |                |                  |                |                     |            |  |
| 0, 1, or 2 years                                              | 7.8                 | 7.8            | 10.9             | 8.6            | 8.0                 | 10.2       |  |
|                                                               | (1.5)               | (1.7)          | (1.9)            | (1.2)          | (2.0)               | (2.8)      |  |
| 3 or 4 years                                                  | 6.4                 | 10.1           | 8.6              | 9.3            | 6.1                 | 6.6        |  |
|                                                               | (1.3)               | (1.9)          | (1.7)            | (1.2)          | (1.7)               | (2.3)      |  |
| 5 or 6 years                                                  | 20.1                | 20.3           | 24.3             | 24.7           | 16.1                | 18.3       |  |
|                                                               | (2.2)               | (2.5)          | (2.6)            | (1.8)          | (2.7)               | (3.6)      |  |
| 7 or 8 years                                                  | 28.4                | 26.5           | 27.3             | 27.7           | 26.9                | 23.5       |  |
|                                                               | (2.4)               | (2.8)          | (2.7)            | (1.9)          | (3.2)               | (3.9)      |  |
| 9 or 10 years                                                 | 15.8                | 16.8           | 15.2             | 14.1           | 22.7                | 19.4       |  |
|                                                               | (2.0)               | (2.3)          | (2.2)            | (1.4)          | (3.0)               | (3.6)      |  |
| 11 years or older                                             | 21.5                | 18.5           | 13.8             | 15.3           | 20.3                | 22.0       |  |
|                                                               | (2.2)               | (2.4)          | (2.1)            | (1.5)          | (2.9)               | (3.8)      |  |
| Percentage first receiving special education services at age: |                     |                |                  |                |                     |            |  |
| 5 or 6 years                                                  | 28.5                | 30.1           | 37.1             | 34.7           | 23.5                | 28.2       |  |
|                                                               | (2.4)               | (2.8)          | (3.0)            | (2.0)          | (3.1)               | (4.1)      |  |
| 7 or 8 years                                                  | 28.6                | 24.3           | 28.6             | 28.4           | 26.6                | 24.4       |  |
|                                                               | (2.4)               | (2.7)          | (2.8)            | (1.9)          | (3.2)               | (3.9)      |  |
| 9 or 10 years                                                 | 18.5                | 19.8           | 14.0             | 15.8           | 23.1                | 19.7       |  |
|                                                               | (2.1)               | (2.5)          | (2.1)            | (1.5)          | (3.0)               | (3.6)      |  |
| 11 years or older                                             | 24.4                | 25.7           | 20.3             | 21.1           | 26.7                | 27.7       |  |
|                                                               | (2.3)               | (2.7)          | (2.5)            | (1.7)          | (3.2)               | (4.1)      |  |
| Percentage with disability first identified by:               |                     |                |                  |                |                     |            |  |
| A family member                                               | 42.8                | 45.6           | 52.6             | 50.4           | 41.3                | 42.2       |  |
|                                                               | (2.6)               | (3.1)          | (3.0)            | (2.1)          | (3.5)               | (4.5)      |  |
| A professional                                                | 56.1                | 52.3           | 44.3             | 46.7           | 58.1                | 56.8       |  |
|                                                               | (2.6)               | (3.1)          | (3.0)            | (2.1)          | (3.5)               | (4.5)      |  |
| Someone else                                                  | 1.1                 | 2.0            | 3.2              | 2.9            | .5                  | 1.0        |  |
|                                                               | (.6)                | (.9)           | (1.1)            | (.7)           | (.5)                | (.9)       |  |

Exhibit 4-5
FIRST IDENTIFICATION OF AND SERVICE FOR DISABILITIES,
BY INCOME AND RACE/ETHNICITY (CONCLUDED)

|                                                                    |                     | Income                     |                          | Race/Ethnicity |                     |          |  |
|--------------------------------------------------------------------|---------------------|----------------------------|--------------------------|----------------|---------------------|----------|--|
|                                                                    | \$25,000<br>or Less | \$25,001<br>to<br>\$50,000 | More<br>than<br>\$50,000 | White          | African<br>American | Hispanic |  |
| Percentage with school services for disability first requested by: |                     |                            |                          |                |                     |          |  |
| A parent                                                           | 30.5                | 43.5                       | 50.3                     | 45.0           | 35.9                | 31.6     |  |
|                                                                    | (2.5)               | (3.1)                      | (3.1)                    | (2.1)          | (3.5)               | (4.3)    |  |
| School staff                                                       | 67.0                | 53.9                       | 46.4                     | 52.0           | 61.9                | 65.2     |  |
|                                                                    | (2.6)               | (3.1)                      | (3.1)                    | (2.1)          | (3.5)               | (4.4)    |  |
| Someone else                                                       | 2.5                 | 2.6                        | 3.3                      | 3.0            | 2.1                 | 3.2      |  |
|                                                                    | (8.)                | (1.0)                      | (1.1)                    | (.7)           | (1.0)               | (1.6)    |  |

Source: NLTS2 Wave 1 parent interviews. Standard errors are in parentheses.

Differences also are noted for youth of different racial/ethnic backgrounds, consistent in direction with those found for household income. African American and Hispanic youth, who more often are from lower-income households, are significantly more likely than white youth to have been identified as having a disability at age 9 or older (25% for both vs. 16%, p<.05) and to begin to receive services for them later (43% and 41% at age 9 or older for African American and Hispanic youth, respectively, vs. 29% for white youth, p<.05). In addition, parents of African American youth are significantly less likely than parents of white youth to report having been the first to recognize their children's disabilities (41% vs. 50%, p<.05). They, along with parents of Hispanic youth, also are less likely than parents of white youth to report having been the first to request services at school (36% and 32%, respectively, vs. 45%, p<.05).

## **Program Participation as Young Children**

Part C of the Individuals with Disabilities Education Act Amendments of 1997 authorizes funds for states to provide early intervention services for infants and toddlers. Part B of the same Act mandates that Individualized Education Programs be developed for students with disabilities ages 3 through 21. In 2001, 230,853 infants and toddlers were served under Part C, and 599,678 children ages 3 through 5 received special education and related services under Part B (Office of Special Education Programs, 2002).

As described earlier, 19% of youth with disabilities are reported to have disabilities that were identified before age 3. More than half of those youth (58%) participated in early intervention services for infants and toddlers with disabilities (Exhibit 4-6). Among the approximately 45% of youth with disabilities whose disabilities were identified before age 6, 47% received special education services in their preschool years.

# Exhibit 4-6 RECEIPT OF EARLY INTERVENTION AND PRESCHOOL SPECIAL EDUCATION, BY DISABILITY CATEGORY

|                             | Percentage<br>Receiving Early<br>Intervention<br>Services <sup>a</sup> | Percentage<br>Receiving<br>Preschool Special<br>Education <sup>b</sup> |
|-----------------------------|------------------------------------------------------------------------|------------------------------------------------------------------------|
| All youth with disabilities | 57.6<br>(3.3)                                                          | 46.8<br>(2.5)                                                          |
| Learning disability         | 41.8<br>(8.7)                                                          | 36.5<br>(4.7)                                                          |
| Speech/language impairment  | 60.7                                                                   | 47.5<br>(4.0)                                                          |
| Mental retardation          | 69.9<br>(4.4)                                                          | 66.3<br>(3.4)                                                          |
| Emotional disturbance       | 34.0<br>(8.4)                                                          | 29.9<br>(4.2)                                                          |
| Hearing impairment          | 69.0<br>(4.2)                                                          | 69.5<br>(3.0)                                                          |
| Visual impairment           | 77.3<br>(2.8)                                                          | 59.5<br>(3.7)                                                          |
| Orthopedic impairment       | 52.1<br>(5.9)                                                          | 73.3<br>(2.7)                                                          |
| Other health impairment     | 58.3<br>(3.7)                                                          | 35.9<br>(3.5)                                                          |
| Autism                      | 58.3<br>(3.7)                                                          | 71.2<br>(2.6)                                                          |
| Traumatic brain injury      | 54.8<br>(9.7)                                                          | 56.6<br>(7.4)                                                          |
| Multiple disabilities       | 81.4<br>(2.6)                                                          | 80.9<br>(2.4)                                                          |
| Deaf-blindness              | 69.8<br>(5.5)                                                          | 78.4<br>(4.6)                                                          |
|                             |                                                                        | ` '                                                                    |

Source: NLTS2 Wave 1 parent interviews.

Youth with visual impairments and multiple disabilities whose disabilities were identified before age 3 are the most likely to have received early intervention services (77% and 81%, respectively). Along with youth with hearing impairments, autism, and deaf-blindness whose disabilities were identified before age 6, they also are among the most likely to have received preschool special education (between 70% and 81%). In contrast, youth with learning disabilities or emotional disturbances whose disabilities were identified by the appropriate ages for early intervention or preschool special education services are among the least likely to have received them; approximately 42% of youth with learning disabilities and 34% of those with emotional disturbances received early intervention services, and 36% and 30% of them participated in preschool special education.

There are no significant differences in the rates at which students participated in early intervention or preschool special education for youth who differed in age, gender, household income, or racial/ethnic background.

### Summary

Information provided by parents does much to expand our understanding of the multidimensional nature of students' disabilities. Parents' reports underscore the complexity of disability, which goes well beyond the category labels used by schools. According to parents, within each primary disability classification, there are youth who also had one or more of virtually every other kind of disability.

Parents' views also may provide important insight regarding the prevalence of some kinds of disabilities. Most notably, parents of more than one-third of youth report that their children have attention deficit disorder or attention deficit/hyperactivity disorder (ADD/ADHD). This disability was mentioned by parents of 76% of youth in the other health impairment category. Although there is much debate regarding the true prevalence and appropriate diagnosis of these conditions, the rate at which parents report such diagnoses as part of students' disability profiles is telling in that reports of ADD/ADHD span all disability categories.

<sup>&</sup>lt;sup>a</sup> Of children whose disabilities were identified before age 3.

<sup>&</sup>lt;sup>b</sup> Of children whose disabilities were identified before age 6. Standard errors are in parentheses.

Information about the ages at which youth first were identified as having a disability or delay and first received services for it may point up opportunities for earlier efforts to ameliorate the effects of some kinds of disabilities. Parents of 30% of youth report that their children's disabilities were identified before age 5, but 43% of youth who were identified at those early ages did not begin to receive services until 5 or older. About 58% of 13- to 17-year-old students whose disabilities were identified before age 3 are reported to have received early intervention services; however, fewer (47%) whose disabilities were identified before age 6 participated in preschool special education programs. The majority of youth with disabilities first were served when they reached school, even when their disabilities had been identified earlier. This gap between identification and services was apparent even for such disabilities as autism and hearing impairments.

In general, disability profiles do not differ significantly for boys and girls, the exception being that parents of boys were significantly more likely than parents of girls to report that students had ADD/ADHD.

Lower-income and wealthier youth differ in their disability profiles in important ways. Upper-income youth are more likely than lower-income youth to be identified by parents as having ADD/ADHD. They also are more likely to have had their disabilities identified before school age and to have begun receiving services at younger ages when they were identified. Parents of lower-income youth are less likely to have been the first to recognize their children's disabilities or to have requested services for them in school; school staff and other professionals were most often the sources of disability identification and requests for service. However, it is encouraging to note that income limitations do not appear to pose barriers to accessing early intervention or preschool special education services; there are no differences between income groups in the rate at which children who were identified with disabilities at the appropriate ages received services for them.

Because youth with disabilities of color are much more likely than white youth to come from low-income households, racial/ethnic differences mirror those found among income groups. White youth are much more likely than youth of color to be reported as having ADD/ADHD, to have had their disabilities recognized and addressed earlier, and for their parents to have been the first to identify their disabilities and request services for them.

These findings illuminate the complexity of the concept of disability and its potential for impact on the lives of youth and their families. The next chapter moves beyond disability labels to examine the functional abilities of youth in the physical, sensory, and communication domains.