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DEVELOPMENT OF THE SECONDARY CONDITIONS
AMONG ADOLESCENTS WITH DISABILITIES (SCAAD) INSTRUMENT:
AN EXPLORATORY STUDY

By

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The purpose of this study was to develop a measure of secondary conditions, explore the reliability and validity of the measure, and explore the relationship between secondary conditions and participation among adolescents with disabilities. This research collected ratings of limitation due to secondary conditions, and ratings of participation for 24 adolescents with Intellectual/Developmental Disability. Data show that the participants experience an average of 11 secondary conditions during a three-month period as reported by families. The inter-rater agreement between parents and Family Support Specialists was .73 on a point-by-point comparison, and .85 when comparing whether or not limitation was a concern. Data collected from the participation measure demonstrated that participants in this sample participate in an average of 23 activities in a four-month period as reported by families. Data showed no statistically significant correlation between secondary condition limitation and participation in this sample.
Development of the Secondary Conditions

Among Adolescents with Disabilities (SCAAD) Instrument:

An Exploratory Study

Research on the developmental time period of adolescence is abundant. Since the establishment of the 1990 Americans with Disabilities Act, research focusing specifically on adolescents with intellectual and developmental disabilities has increased. Nevertheless, such research has not yet tapped into a number of areas concerning the development of adolescents with disabilities. This study aimed to explore the health and participation among adolescents with disabilities. Using a convenience sample of adolescents between the ages of 13 and 21 years with intellectual or developmental disabilities (I/DD), data regarding disability, secondary conditions and participation was collected and analyzed. Results may provide needed information for future development of health promotion and intervention programs for the targeted population, as well as serve as a stepping-stone to further research in the area of adolescents with disabilities.

Disability in America

Disability, in general, can be “defined as a limitation in performing certain roles and tasks that society expects of an individual” (Institute of Medicine, 1997, p. 5). Disability manifests itself when there is an imbalance between an individual’s competence or capabilities and the demands placed on that individual by the environment. The interaction between the individual and the environment has been a focus of research for a very long time. In 1936, Kurt Lewin conceptualized the person and environment interaction with the use of the equation \( B = f(P, E) \) wherein behavior \( B \) is a function \( f \) of both the person \( P \) and the environment \( E \). This formulation suggested that it is necessary to take into account both the individual and the environment in which that individual is placed in order to more fully understand behavior as well as development. This concept applies especially when considering individuals with disabilities. The behavior that is expressed by
individuals with disabilities must be considered within the context of their environments. Additionally, it is important to consider the abilities of the individuals given the limitations they may develop secondary to disability.

Models of Disability.

Historically, there have been many views of disability, including a variety of disability models. One specific disability model, published in the 1950s by Saad Nagi, stated that there are four major components to the disabling process: pathology, impairment, functional limitation, and disability (Institute of Medicine, 1997). The Institute of Medicine (1997) describes this model as follows:

1. **Pathology** refers to molecular, cellular, or tissue changes caused by disease, infection, trauma, congenital conditions, or other factors. An example is the death of spinal cord neurons following injury.
2. **Impairment** occurs at the organ or organ systems level and results in an individual’s loss of a mental, physiological, or biochemical functional, or abnormalities in these function.
3. **Functional limitation** is an inability or hampered ability to perform a specific task, such as climb a flight of stairs.
4. **Disability** component of the model refers to “a limitation in performing certain roles and task that society expects of an individual” (p. 5).

The International Classification of Functioning, Disability and Health (ICF, 2000) also established a model of disability. The ICF, established by the World Health Organization (WHO), “offers an international, scientific tool for understanding human functioning and disability for clinical, research, policy development and a range of other public health uses” (Üstün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003, p. 565). The WHO, and in turn the ICF, view disability
as having a universal nature. That is to say, disability is viewed as an integrated part of the life of individuals. The WHO and the ICF aim to describe disability in terms of a health perspective as opposed to a disease perspective (Lollar & Simeonsson, 2005). The ICF model of disability indicates that disability is often related to an altered or compromised function (Lollar & Simeonsson, 2005). Furthermore, the ICF emphasizes that disability does not equate with illness. Rather, it suggests that human functioning is based on a number of different dimensions. These dimensions include the ongoing influence of environmental factors, personal factors and contextual factors. Environmental factors might include such things as access to buildings, activities, participation, and discrimination. Personal factors include such aspects as age and education. Contextual factors include such aspects as socioeconomic status (Lollar & Simeonsson, 2005).

The models of disability put forth by Nagi and the ICF have parallels with several models of human development. Both disability models make reference to the individual as an active participant in his or her development. For example, Nagi includes the individual on a very biological level. Precursors to disability, according to Nagi, fall on the molecular to the organ systems level, and ultimately to the level of the individual’s inability or hampered ability to function in his or her environment. Additionally, the ICF notes the importance of both the individual and the environment. Both models emphasize the importance of not only the individual, but the environment as well. The affect of the dynamic interaction of individual and his or her environment are readily found in a number of human development models as well.

Most modern viewpoints of development recognize that both the environment and the individual are significant factors in the course of human development. Lewin’s 1936 construction of the individual and environment interaction, as previously discussed, is one such developmental model that incorporates aspects of the environment and the individual. The contextualistic worldview of development is a paradigm in which the individual and the environment are in
dynamic interaction at all times (Parke, Ornstein, Rieser, & Zahn-Waxler, 1994). Without the context, or the environment, the individual is unable to develop. In turn, the individual readily affects the surrounding environment (Kuczynski, 2003). This two way processes illustrated by Bell (1968) and Kuczynski (2003) in the context of child development suggests that children are curious and want to understand as well as explore the world around them. This curiosity and exploration result in socialization with others. The socialization between children and others is influential in both directions. Children influence the actions of others, while others influence the actions of children. This dynamic, unfolding process of interaction serves as a contributing factor of the developmental process.

In summary, models of disability and models of human development share an emphasis on the importance of both the environment and the individual. A commonality of these models is that both disability and development are produced by the dynamic interaction between the individual and the environment. Understanding disability, like understanding development, involves appreciating the roles played by factors outside of the individual as well as those within the individual.

Demographics of Disability

According to the United States Census (2007) approximately 51.2 million people (or 18 percent of the population) have some level of disability. An estimated 32.5 million (11.5 percent of the population) reported having a severe disability. While determining the prevalence rates of disability among Americans of a specific age group is difficult, the August 2002 DD Data Brief has estimated that 3,258,817 of the school-age population (ages 6-17 years) have one or more disabilities (Anderson, Larons, Lakin, & Kwak, 2002). This statistic includes children with developmental disabilities, intellectual disabilities, developmental and intellectual disabilities, and other disabling conditions or impairments. This number makes up approximately 7.1% of the school-age population. It is necessary to keep in mind that this figure includes children with a variety of
disabilities, including learning disabilities, emotional conditions (i.e., behavior disorders, depression, anxiety) as well as those with intellectual and developmental disabilities.

More specifically, of the 3.2 million children with disabilities, 1.9 million are children between the ages of 6-12, and 1.3 million are children ranging from 13-17 years of age (Anderson, et al., 2002). Although these statistics include children with a variety of disabilities, the fact remains that there is a rather sizable population of children with disabilities. Understanding these children and the environments in which they reside will aid in better understanding how to design health promotion and intervention programs for children with disabilities.

**Intellectual and Developmental Disabilities**

Intellectual and developmental disability, or I/DD, is a term used to cover a wide range of impairments. Broadly speaking, the term developmental disability refers to chronic conditions resulting from mental or physical impairments (http://www.cdc.gov/ncbddd/dd/ddl.htm). Developmental disabilities range from mild to severe (Pope, 1992). The Center for Disease Control states that developmental disability describes a condition of one or more mental or physical impairments that begin at an early age and will likely continue indefinitely (http://www.cdc.gov/niosh/wdd-back.html). Furthermore, individuals with developmental disabilities may have problems with activities such as language, mobility, learning, self-help, and living independently. Generally, developmental disabilities have an onset anytime during development (up to 22 years of age) and usually continue throughout the entire lifetime. Examples of intellectual and developmental disabilities include cognitive impairments (i.e., as mental retardation), sensory impairments (i.e., as blindness), neurological disorders (i.e., cerebral palsy), and genetic disorders (i.e., as Down syndrome) (http://www.cdc.gov/niosh/wdd-back.html).

Disability research terminology tends to focus on the phrases intellectual disability and/or developmental disabilities. Intellectual disability most commonly refers to mental retardation.
Developmental disability refers to mental retardation in addition to other disabilities such as cerebral palsy, muscular dystrophy, or Down syndrome. For purposes of this paper, intellectual and developmental disabilities will be presented in the format of I/DD.

Mental Retardation. Mental retardation is the most common intellectual disability. According to the American Association of Intellectual and Development Disability (AAIDD) formerly known as the American Association of Mental Retardation (AAMR) mental retardation involves intellectual and adaptive behavior limitations (http://www.aamr.org/Policies/faq_mental_retardation.shtml).

The disability of mental retardation originates before age 18. The age of onset of mental retardation before the age of 18 is similar to the Center for Disease Control and Prevention’s indication that developmental disabilities originate at any point in development before the age of 22 years.

Furthermore, the AAIDD suggests that there are five assumptions essential to the application of the definition of mental retardation. These assumptions include:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.

2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.

3. Within an individual, limitations often coexist with strengths.

4. An important purpose of describing limitations is to develop a profile of needed support.

5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve. (AAMR, 2002).

The American Psychiatric Associations defines mental retardation, or significant limitations in intellectual function, as an IQ of 70 or less (Orto & Marinelli, 1995). Mild mental retardation is
considered when an individual has an IQ ranging from 55 to 69. An individual with moderate mental retardation has an IQ of 40 to 45; severe mental retardation IQ ranges from 25 to 39, and an IQ of 24 or less is indicative of profound mental retardation (Orto & Marinelli, 1995). In general, mild mental retardation has been accepted to refer to individuals with IQs ranging from 50 to 70.

Although the biological causes of mental retardation are numerous, in a large number of cases (30 to 40%) the cause of mental retardation is unknown (Papalia, Olds, & Feldman, 2006). The known causes of mental retardation include prenatal development problems (i.e., the effects of teratogens), mental disorders, environmental factors (i.e., lack of stimulation), birth trauma, and medical or hereditary conditions (APA, 1994).

Secondary Conditions

In recent years, disability research has begun to focus on secondary conditions as a factor that can limit participation in everyday life (Marge, 1988). The WHO and ICF have instituted resolutions focusing on the nature of disability and its effect on participation. Just has Lewin suggested the interaction between the person and the environment creates behavior, WHO and ICF consider this behavior as participation. Secondary conditions have recently come to the forefront as elements limiting the participation in everyday life for individuals with disabilities. Secondary conditions are defined as “preventable health problems that are experienced by an individual after he or she has a primary impairment” (Seekins, Traci, Bainbridge, & Humphries, 2005, p. 326) and limit participation. Individuals with disabilities are at risk for secondary conditions. Secondary conditions result directly or indirectly from the primary disability (Kinne, Patrick, & Doyle, 2004).

Secondary conditions play a rather prominent role in the lives of those with disabilities. Kinne and her colleagues (2004), reporting data compiled from over 2,000 randomly selected adult respondents from Washington, suggested that 87% of those
respondents with disabilities reported at least one secondary condition. Simeonsson, McMillen, and Huntington (2002) suggest that when an individual has a primary disability, various complications are often associated with the disability, and have come to be defined as secondary conditions.

Simeonsson, McMillen, and Huntington (2002) have elaborated on the definition of secondary conditions by stating four basic criteria necessary for a condition to be considered a secondary condition. First, secondary conditions are a direct or indirect consequence of the primary conditions and are preventable. Second, such conditions "reflect the effects of person-environment interactions in which the primary condition constitutes a risk factor, but is not sufficient to account for the expression of secondary conditions" (p. 199). Third, there may be factors relating to why a person manifests a secondary condition. Such factors may include an individual's age or stage of development. Fourth, personal traits and characteristics serve a mediating role in individual differences seen in the expression of secondary conditions.

Secondary conditions in adults with disabilities have been well documented in the literature (e.g., Traci, Seekins, Szalda-Petree, & Ravesloot, 2002; Kinne, et al., 2004; Simeonsson, et al., 2002). Secondary conditions in adults include, but are not limited to: urinary tract infections, depression, obesity, dental problems, and self-injurious behaviors. In addition to the documentation of secondary conditions in adults with disabilities, research has focused on the prevalence and prevention of secondary conditions. What appears to be lacking in current literature is a well-defined set of secondary conditions experienced by children and adolescents under the age of 21 years, and a method for assessing those conditions. Even less is known of the effects that secondary conditions have on the developing adolescent. Understanding the secondary conditions experienced by adolescents
with disabilities is one of the first steps on the path to understanding the influence of secondary conditions on development.

Secondary Conditions and Medical Costs.

Frequently, individuals with disabilities will experience limited access to health and medical care. These individuals are considered at risk for secondary conditions such as depression, anxiety, or joint and muscle pain due to their primary disabling conditions (Edwards, Patrick, & Topolski, 2003; see also Healthy People 2010; Pope 1992). Zajicek-Farber (1998) suggest that in order for adolescents to experience the benefits of adult life, it is important that they not only establish autonomy, but also have good health. Even with the needs of autonomy and good health for adolescents pronounced as important, the U.S. Department of Health and Human Services has not provided appropriate resources for the promotion of health for adolescents with disabilities (Zajicek-Farber, 1998; see also Lipkin, 1996; Lollar, 1994).

Good health, for the general population “has been defined as both the absence of illness, injury, and disability and the presence of the ability to achieve greater choice and control in life” (Zijicek-Farber, 1998, p. 204). For adolescents with I/DD, good health tends to refer to the cognitive, emotional, or physical limitations or restrictions that limit the ability to function. The focus of physical deficits being indicative of good or poor health for adolescents with disabilities is contradictory to the focus of good health for the general population that includes the concepts of choice and control. Lollar (1994) stresses the importance of good health as it relates to a sense of personal well-being. Personal well-being is related to a sense of satisfaction in a number of areas of life such as relationships, education, community, and perceived stress. Rather than focusing solely on the physical deficits that might limit adolescents with disabilities, it is necessary to incorporate social strengths including an individuals ability to make decisions about personal care, education, relationships and job choices (Zijicek-Farber, 1998).
Rice and Turpin (1996) report the medical expenditures accounted for by people with disabilities. While people with disabilities constitutes approximately 19% of the population of the United States, this 19% accounts for 47% of total medical expenditures. Traci and her colleagues (2002) report that on average, the medical expenses of individuals with disabilities are four times more than those of individuals without disabilities. Identification and measurement of secondary conditions experienced by individuals with disabilities could contribute intervention programs to reduce the deficits imposed by secondary conditions and in turn reduce some of the medical costs associated with disability. Because secondary conditions are preventable, identification is necessary to implement any type of effective intervention and health promotion programs.

Disability, the Family, and Peers

Disability affects not only the individual with the disability, but those who relate to the individual such as parents, siblings, and peers. Research investigating the parents of children with I/DD has focused on parental reactions, stress and coping, and parental behavior (Kerig, 2006). Additional research focusing on peers and friendships among children with disabilities has centered on acceptance among peer groups and social cognition (e.g., Siperstein, 1996).

Family relations

Parent-child relationships are affected when a child has a disability such as mental retardation. When a child is born with a disability, parental reactions are often described as being depressed or grief-like in response to the child being different or atypical (for example, Travis, 2004; see also Lewis & McLean, 1982). I/DD has been regarded as an added stressor to the family system and exploration of coping techniques is of importance (Shaffer & Kipp, 2007). The characteristics of the disabled child play a role in the parent-child relationship as well. Children with disabilities can behave differently, and this behavior will in turn affect parental behavior.
Internal and external factors are also related to parental ability to cope with a child with a
disability. Kerig (2006) and Hodapp, Dykens, and Masino (1997) suggest that affluent parents cope
better than those who are less affluent, two-parent families cope better than single parent families,
and mothers in marriage they perceive to be happy cope better than those who perceive their
marriages as unhappy. Furthermore, Hodapp, Dykens, and Masino (1997) suggests that mothers
with more social-emotional support are the most effective at coping with a child with a disability,
whereas fathers tend to be more worried about the financial costs of raising the child. Both mothers
and fathers of children with disabilities find social support necessary for coping.

Peer relations

Nabors (1997) reports that children with disabilities are often not fully accepted by peers
without disabilities. Rather than children with disabilities experiencing outright rejection by typically
developing peers, they are more often simply ignored. As children with disabilities develop into
preadolescence and adolescence, their friendship patterns also differ from their nondisabled peers.
Siperstein, Leffert, and Wenz-Gross (1997) conclude that high levels of engagement,
communication, decision-making, and sharing of emotions mark the typical preadolescent
friendship. For the preadolescent or adolescent with a disability, engaging in the markers of the
typical age-appropriate relationship may be difficult due to the conditions of the disability. As such,
adolescents with disabilities may not be readily included into peer groups. Rather the adolescents
with disabilities will look more like acquaintances than friends (Siperstein, Leffert, & Wenz-Gross,
1997).

For children with disabilities, the marker of their difficulties in engaging in peer relationships
seems to lie with a low level of social competence. Social competence involves social cognition, or
the ability to think about people and attempt to make sense of people’s behavior as it relates to how
they think and feel (Fabes & Martin, 2003; see also Hala 1997). Research evidence suggests that
children with disabilities, especially those with mental retardation, have more difficulty with perspective-taking, interpreting social skills, and dealing with problem situations (Leffert & Siperstein, 1996). This fact may explain the difficulty those with disabilities, especially during the preadolescent and adolescent years, have fitting in socially with peers.

Disability and the Developmental Course: A Brief Summary

With one criterion of I/DD being an onset of impairment prior to age 18, it is understandable that disability will play a role in the developmental course. Kerig (2006) reports that the developmental course of mental retardation includes understanding that an individual's functioning may wax and wane over time in regards to the level and type of retardation. Understanding the stability and change patterns of the nature of I/DD may help to understand its role in development, and its relation to health and participation.

Infancy

During infancy (0 to 2 years of age), the major tasks include attachment, self-regulation, and exploration of the environment (see Sachs & Barrett, 2000, for a complete description). Disability, such as mental retardation and associated disorders, may result in disruption of the mastery of these developmental tasks (Sachs & Barrett, 2000). For example, the formation of attachment can be affected by disability in a number of ways. First, an inability to respond vocally and with eye contact with an attachment figure will impede attachment. Second, uncertainty about the prognosis or survival of an infant with a disability can influence normal attachment development. Third, parental reactions of anger, denial, sorrow or grief may interfere with the attachment process. Additionally, the inability to achieve milestones when expected may lead parents to feel they lack appropriate skills and become frustrated with the parenting process which can also affect attachment.
complex thinking. It is not uncommon for children with mental retardation to fall behind in school which only emphasizes their differences from peers. I/DD in middle childhood may also interfere with the ability to engage in socializing events such as extracurricular activities and sports (Kerig, 2006) which may only serve to further separate those with disabilities from those without. Middle childhood is a time of vast developmental progress; for a child with I/DD this development may be impeded in a number of ways by the disability. The development in infancy, early, and middle childhood pave the way for entrance into adolescence. Experiences and skills learned up to this point are vital to the transition into a new stage of development.

Disability and Adolescent Development

The life of the adolescent, a typical adolescent or one with a disability, is complicated. Adolescents are faced with a number of developmental tasks. Adolescence is linked to the future. It is a time period when children develop into adults and become prepared for or rebel against taking over the responsibilities of adulthood. (Larson, 2007). It is during this important time period that one strives for independence, reinforces self-esteem, creates an identity, and becomes preoccupied with social awareness. Familial and friend relationships are of utmost important to the adolescent and are necessary for the adolescent to achieve his or her goals as an adolescent.

Navigating the social environment by forming friendships, learning to choose suitable attire, exploring sexual roles and behaviors, developing a sense of identity and a sense of autonomy requires the development of new coping skills and ways of being in this rapidly changing developmental phase of life. Achievement of these developmental milestones is difficult even for the typically developing adolescent. For an adolescent with a disability, these tasks are additionally challenging as the disability, as well as the health and environmental conditions that accompany the disability may influence the ability to
successfully engage in the development of these tasks. Achievement of adolescent
developmental tasks may be more difficult for the adolescent for a variety of reasons. For
instance, poor social skills and lack of attention may lead to peer rejection. Physical
appearance during adolescents is an important component to peer acceptance, and any
differences may result in difficulties in peer relationships. Developmental disabilities that are
accompanied by behavior problems might also serve to isolate and impede attainment of
milestones. Furthermore, as other adolescent children begin to achieve their developmental
milestones, adolescents with disabilities may be left behind socially, intellectually, and
physically. In addition, for adolescents with disabilities who also have the cognitive capacity
to understand that their peers are becoming more autonomous, it may become an
increasingly difficult time as they are reminded of their inability to separate from caregivers
and become like their typical developing peers (Nickel & Desch, 2000).

During a developmental period in which complex social relationships are the norm,
it can be difficult to keep up. Adolescents with disabilities may, indeed, have a very difficult
time keeping up with their developmentally typical peers (Sachs & Barrett, 2000).
Additionally, during a time of experimenting with independence and autonomy, adolescents
with disabilities may find it frustrating to realize they may be unable to achieve certain status
symbols such as driving or having a “cool” job. Adolescents with disabilities may respond to
these new challenges and stressors with depression and withdrawal (Sachs & Barrett, 2000).

In summary, adolescence is a period of vast developmental change. For adolescents with
I/DD this challenging developmental stage may prove to be even more difficult than for nondisabled
peers. Understanding the experiences adolescents have, not only with their disabilities, but with the
conditions that accompany disability may lead to future development of health promotion and
Development of the Secondary  18

prevention programs which can alleviate some of the additional difficulties of adolescent development.

Adolescence and Participation

For adolescents, the school environment plays an important role for both education and socialization (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). Research examining the role and outcome of participation in school activities has suggested that the more involved a student is in activities, the greater the positive outcomes (Simeonsson, et al, 2002). These positive outcomes include lower rates of dropping out of school, better academic achievement, and a more long term effect of greater social participation in early adulthood (Elkstrom, Goertz, Pollack, & Rock, 1986; Berliner, 1990; Greenwood, and Lindsay, 1984). Research has further suggested the social experiences students have at school are related to patterns of drug use, challenging behaviors, and how students learn. (Patton et al., 2006).

The Individuals with Disabilities Education Act (IDEA) promotes the importance of inclusion of students with disabilities in a regular educational environment. Furthermore, there is an emphasis on the inclusion of students with disabilities in the full range of activities that entail total participation in the life of the school. Although IDEA is in place, students with disabilities are not always fully included in the mainstream educational experience. Simple physical inclusion in a regular classroom environment is not enough. Social and education integration includes more than just including students with disabilities in the instruction of core subjects. (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001, p. 50).

Evidence supports the notion that inclusion in a wide number of activities, in school or out of school, is beneficial for those involved. Participation in school activities is positively related to higher quality of life ratings (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). Social inclusion has been related to lower rates of substance abuse, antisocial behavior, emotional
difficulties, and risky behavior among adolescents (Patton, et al., 2006). Conditions such as I/DD have been considered major factors in activity limitation among persons of all ages (LaPlante, 1989). Research examining secondary conditions in adults has readily demonstrated that such conditions can result in limitations in participation and activity (see Pope, 1992; Institute of Medicine, 1991). Given the current state of the literature and the limited information that is available on secondary conditions and adolescents, it unknown how secondary conditions are affecting the ability to participate among adolescents. Disabilities and secondary conditions can impede the participation rates for adults. Further research must define if this true for adolescents as well.

Rationale and Specific Aims

The prevalence rate of disabilities among Americans makes any research focusing on this population group of importance. Understanding how disability interacts with a variety of life aspects such as health, development, and participation is key to the development of appropriate health promotion and intervention programs for the portion of the population with disabilities. One component of understanding disabilities lies in understanding the secondary conditions experienced by those with disabilities. Secondary conditions are a relatively new area of research and exploration. Simeonsson, McMillen, and Huntington (2002) report that

With the relative newness of secondary conditions as an area of inquiry, a number of research directions need to be pursued. One direction is to continue research to establish baselines on the prevalence of secondary conditions and the person-environment interactions that are associated with their manifestations...further research of this type is needed to document the nature and distribution of secondary conditions across groups defined by age, impairment condition or minority status (p. 204).
A portion of this project addressed what Simeonsson and his colleagues suggest – explore secondary conditions across varying age groups, specifically the adolescent age group.

In order to more fully understand adolescent development, and more specifically the development of adolescents with disabilities, it is important to explore not only secondary conditions, but the ways in which secondary conditions influence rates of participation. Understanding these concepts individually, and in the aggregate, will aid in future creation of health promotion and prevention programs for adolescents with disabilities. Furthermore, this may contribute to facilitating successful achievement of developmental milestones. The specific aims of this study are to:

1. Develop a secondary conditions assessment instrument for adolescents with intellectual and developmental disabilities.
2. Explore reliability of a secondary conditions assessment instrument for adolescents with intellectual and developmental disabilities.
3. Explore validity of a secondary conditions assessment instrument for adolescents with intellectual and developmental disabilities.
4. Explore the relationship between secondary conditions and participation among adolescents with intellectual and developmental disabilities.

Method

Setting

This research took place in Missoula and Kalispell, Montana through an organization known as the Child Development Center (CDC). The Child Development Center provides services to children and adolescents with developmental delay. CDC’s primary mission is to promote the development and well-being of individuals with developmental disabilities through strengthening families. CDC serves Federal and state funds allow for approximately 325 children from birth to 22
years of age on a monthly basis. Five home-based intervention service options are available. Table 1 outlines the service options, ages served, eligibility requirements, and numbers served during March 2008.

<table>
<thead>
<tr>
<th>Service</th>
<th>Ages Served</th>
<th>Eligibility Requirement</th>
<th>Service Description</th>
<th>Number Served in March 2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Education and Support (FES)</td>
<td>6-21</td>
<td>Diagnosed developmental disability</td>
<td>Provides home-based intervention services designed to help parents learn the skills necessary to teach their child. Provides support for families as they become aware of the unique needs and opportunities for their child and assists in identifying and locating resources and support. This service includes a minimum of 2 home visits per month with a Family Support Specialist.</td>
<td>101</td>
</tr>
<tr>
<td>Part C Infant and Toddler Program (Part C)</td>
<td>Birth to 3</td>
<td>Diagnosed physical or medical condition that has a high probability for developmental delay, or who are experiencing significant delays in cognition, gross and fine motor skills, communication, social-emotional development or self-help abilities</td>
<td>Provides family education and support services for children birth to age three who have a. This service includes a minimum of 2 home visits per month with a Family Support Specialist.</td>
<td>133</td>
</tr>
<tr>
<td>Intensive Family Education and Support (IFES)</td>
<td>Birth to 21</td>
<td>Extraordinary needs and a developmental disability</td>
<td>In addition to providing all services included in FES services, IFES is a Medicaid Waiver program that provides case management, parent coaching, respite, specialized instruction, and access to a variety of other applicable resources and supports for children ages who. This service includes a minimum of 2 home visits per month with a Family Support Specialist</td>
<td>83</td>
</tr>
<tr>
<td>Limited Respite</td>
<td>Any age</td>
<td>Diagnosed developmental disability</td>
<td>Offers respite funding and limited support services. Families on this service are required to have one annual visit with a Family Support Specialist and are eligible for three additional contacts if desired.</td>
<td>3 (approximately 60 individuals utilize this service annually)</td>
</tr>
<tr>
<td>Follow-Along</td>
<td>Birth to 21</td>
<td>At risk for delays in development or have a diagnosed developmental disability</td>
<td>Provides resource services. This service includes up to four home visits per year with a Family Support Specialist.</td>
<td>3</td>
</tr>
</tbody>
</table>
Staff at CDC uses psychological diagnostic instruments and procedures to determine eligibility for services. In order to be served by CDC, children must meet the criteria for a person with a developmental disability according to the state of Montana. Eligibility criteria for FES and IFES programs include individuals who have one or more of the following characteristics:

1) severe/profound mental retardation, including extreme deficiencies in self-care and daily living skills as compared to age peers;
2) Significant maladaptive social and/or interpersonal behavior patterns that require an ongoing supervised program of intervention; or Severe medical or health-related problems such as sensory or physical deficits requiring substantial care (CDC, n.d.).

Participants

A convenience sample of participants from the Child Development Center (CDC) of Missoula and Kalispell, Montana was recruited. At the time this study was conducted, 323 children were being served through all programs at CDC; 133 children were being served under Part C (birth to 3 years of age) services. These children were excluded from the sample because of age. One hundred and eighty-four children were being served under the FES and IFES programs. Of the 184 children (ages 6 to 21 years) those meeting the age criteria (13 to 21 years of age) were asked to participate in the study. Of the 184 children, 51 children fell between the ages of 13 to 21 years of age (see Figure 1). Of those 51 children, 24 responded to the request to be involved in this project.

Eleven female and 13 male adolescents between the ages of 12 and 19 years (mean age = 17 years) with I/DD participated in this study (see Appendix A for a list of diagnoses). Participation was completely voluntary. All participants who responded were served under the FES or the IFES service options. Since staff working with those children receiving Limited Respite and Follow-Along services had limited contact with the families (a maximum of 4 times per year), and would have
difficulty answering questions about these clients, those families were excluded from the sample. As such, 47% (24 out of 51) of the children between the ages 13 and 21 being served by FES and IFES service options participated in this study.

The majority of the adolescents selected for this study were unable to complete the questionnaires independently. Therefore, parents and support staff were asked to complete the surveys on behalf of the adolescents. Proxy ratings were given by family members (generally the primary caregiver) as well as the Family Support Specialist (FSS) working with that adolescent. Fourteen Family Support Specialists served as proxy raters for the twenty-four adolescent participants (see Appendix A for a list of how long staff have worked with each participant). Several Family Support Specialists work with a number of adolescents falling in the age range of this study.
and therefore filled out surveys for several participants. A family member, primarily mothers, served as the second proxy rater in this study.

The use of proxy rater was necessary due to the severity of the disabilities the participants experience. Proxy ratings have been a source of interest in research in terms of the accuracy of the ratings. Research focusing on proxy ratings is often related to quality of life studies. A systematic review done by Eisner and Morse (2001) of children’s quality of life ratings by proxy raters (parents) suggests agreement between parents and chronically sick children is better when compared with parents and their healthy children. This review reported that no effects were found based upon age or gender of the child. Thus, the systematic review suggests that whenever possible it is best to obtain information from both parents and children. In some cases, such as this particular study, obtaining information from the adolescents was not possible due to the level of their disability. Therefore, it became necessary to rely upon the ratings of parents and support staff. Table 2 includes information about each participant. Participants, for purpose of this study, were given participant numbers. Diagnoses for each participant as well as the length of time Family Support Specialists have worked with them are noted in the table. Information marked as “unknown” was due to Family Support Specialists not reporting back to this researcher when information was requested.

Materials

Two survey instruments were used in this study. The Secondary Conditions Among Adolescents with Disabilities (SCAAD) assessed limitations from secondary conditions (see Appendix A). The SCAAD was developed through modification of a previously established measure, the Health and Secondary Conditions Instrument for Adults with Developmental Disabilities (HSCIADD). Secondly, the Children’s Assessment of Participation and Enjoyment (CAPE) assessed participation. (See Appendix B).
Table 2: Participant diagnoses and length of relationship with Family Support Specialists

<table>
<thead>
<tr>
<th>Participant</th>
<th>Diagnosis or developmental disability/concerns</th>
<th>Amount of time FSS has worked with participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cognitive delay – moderate to severe</td>
<td>3 months</td>
</tr>
<tr>
<td>2</td>
<td>Cognitive delay – moderate</td>
<td>5 months</td>
</tr>
<tr>
<td>3</td>
<td>Autism</td>
<td>6 months</td>
</tr>
<tr>
<td>4</td>
<td>Autism</td>
<td>6 months</td>
</tr>
<tr>
<td>5</td>
<td>Rhett’s syndrome</td>
<td>6 months</td>
</tr>
<tr>
<td>6</td>
<td>Unknown</td>
<td>9 months</td>
</tr>
<tr>
<td>7</td>
<td>Autism, childhood on-set schizophrenia</td>
<td>9 months</td>
</tr>
<tr>
<td>8</td>
<td>Autism</td>
<td>11 months</td>
</tr>
<tr>
<td>9</td>
<td>Down syndrome</td>
<td>1 year</td>
</tr>
<tr>
<td>10</td>
<td>Cognitive delay – moderate</td>
<td>1½ years</td>
</tr>
<tr>
<td>11</td>
<td>Autism, Oppositional Defiant Disorder</td>
<td>2 years</td>
</tr>
<tr>
<td>12</td>
<td>Cerebral Palsy, Microencephaly</td>
<td>2 years</td>
</tr>
<tr>
<td>13</td>
<td>Tuberous Sclerosis, seizure disorder, Obsessive Compulsive Disorder</td>
<td>2 years</td>
</tr>
<tr>
<td>14</td>
<td>Fetal Alcohol Syndrome</td>
<td>3 years</td>
</tr>
<tr>
<td>15</td>
<td>Cognitive delays – frontal lobe damage; oppositional defiant disorder</td>
<td>7 years</td>
</tr>
<tr>
<td>16</td>
<td>Seizure disorder, epilepsy, non-verbal, severe global delays, severe behavioral challenges</td>
<td>7 years</td>
</tr>
<tr>
<td>17</td>
<td>Angelman syndrome</td>
<td>8 years</td>
</tr>
<tr>
<td>18</td>
<td>Spastic dysplasia</td>
<td>7 years</td>
</tr>
<tr>
<td>19</td>
<td>Leber’s Congenital Aumorosis, Autism</td>
<td>10 years</td>
</tr>
<tr>
<td>20</td>
<td>Seizure disorder, agenesis of the corpus collosum, epilepsy, Mowat Wilson syndrome</td>
<td>10 ½ years</td>
</tr>
<tr>
<td>21</td>
<td>Microcephaly, seizure disorder, cerebral palsy</td>
<td>10 ½ years</td>
</tr>
<tr>
<td>22</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>23</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>24</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

*Development of the Secondary Conditions Among Adolescents with Disabilities (SCAAD)*.

Development of the SCAAD occurred by modifying an existing instrument entitled the Health and Secondary Conditions Instrument for Adults with Developmental Disabilities (HSCIADD). The HSCIADD was originally developed to “assess the prevalence and extent of limitation due to secondary conditions among adults receiving services from community-based developmental disabilities providers” (Traci, Seekins, Szalda-Petree, & Ravesloot, 2002, p. 124). Furthermore, data gathered from the HSCIADD “might be used to improve systems of services and supports to enhance the health and participation of adults with developmental disabilities in community life” (p. 119). The original HSCIADD assessed 34 potential secondary conditions as they relate to limitation within the adult sample population. These 34 secondary conditions went through a process of factor
Development of the Secondary

analysis (Traci, Brod, Seekins, Bainbridge, Ravesloot, & Humphries, in preparation), which resulted in the retention of 25 secondary conditions in seven factors. Table 3 illustrates the initial listing of the 34 secondary conditions investigated, followed by the 25 secondary conditions retained in the factor analysis as well as the seven factors that were established.

Table 3: HSCIADD Factor Analysis Results

<table>
<thead>
<tr>
<th>Original HSCIADD Secondary Condition List</th>
<th>Post Factor Analysis Secondary Condition List</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment failures</td>
<td>Equipment failures</td>
<td></td>
</tr>
<tr>
<td>Equipment related injuries to others</td>
<td>Equipment related injuries to others</td>
<td></td>
</tr>
<tr>
<td>Access problems</td>
<td>Access problems</td>
<td></td>
</tr>
<tr>
<td>Care-related injuries to others</td>
<td>Care-related injuries to others</td>
<td></td>
</tr>
<tr>
<td>Care related injuries to consumer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with mobility</td>
<td>Problems with mobility</td>
<td></td>
</tr>
<tr>
<td>Contractures</td>
<td>Contractures</td>
<td></td>
</tr>
<tr>
<td>Communication difficulties</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep problems/disturbances</td>
<td>Sleep problems/disturbances</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Self inflicted injuries or abuse</td>
<td>Self inflicted injuries or abuse</td>
<td></td>
</tr>
<tr>
<td>Persistence problems/low frustration</td>
<td>Persistence problems/low frustration</td>
<td></td>
</tr>
<tr>
<td>tolerance</td>
<td>tolerance</td>
<td></td>
</tr>
<tr>
<td>Side effects from medication</td>
<td>Side effects from medication</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>Fatigue</td>
<td></td>
</tr>
<tr>
<td>Balance problems/dizziness</td>
<td>Balance problems/dizziness</td>
<td></td>
</tr>
<tr>
<td>Injuries due to accidents or seizures</td>
<td>Injuries due to accidents or seizures</td>
<td></td>
</tr>
<tr>
<td>Respiratory problems</td>
<td>Respiratory problems</td>
<td></td>
</tr>
<tr>
<td>Weight problems</td>
<td>Weight problems</td>
<td></td>
</tr>
<tr>
<td>Physical fitness and conditioning problems</td>
<td>Physical fitness and conditions problems</td>
<td></td>
</tr>
<tr>
<td>Cardiovascular/circulatory problems</td>
<td>Cardiovascular/circulatory problems</td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>Arthritis</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>Osteoporosis</td>
<td></td>
</tr>
<tr>
<td>Joint and muscle pain</td>
<td>Joint and muscle pain</td>
<td></td>
</tr>
<tr>
<td>Eating problems/gastrointestinal dysfunction*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over-/under-nourishment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergies and allergic reactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel dysfunction</td>
<td>Bowel dysfunction</td>
<td></td>
</tr>
<tr>
<td>Bladder dysfunction</td>
<td>Bladder dysfunction</td>
<td></td>
</tr>
<tr>
<td>Personal hygiene/appearance</td>
<td>Personal hygiene/appearance</td>
<td></td>
</tr>
<tr>
<td>Dental/oral hygiene problems</td>
<td>Dental/oral hygiene problems</td>
<td></td>
</tr>
<tr>
<td>Vision problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing problems</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Physical Fitness Conditions

Orientation Related Conditions

Psychological Conditions

Mobility Conditions

Pain Related Conditions

Elimination Conditions

Hygiene Conditions
Although the HSCIADD was designed for use with adults with developmental disabilities, it has served as a useful framework for developing an instrument to gather information regarding secondary conditions with adolescents with developmental disabilities. The HSCIADD was modified in terms of wording and definitions in order to be more age-appropriate for adolescents. Several items on the original HSCIADD were removed from the SCAAD based on expert review feedback and purported irrelevance to the adolescent population.

The development and revision of the SCAAD from the HSCIADD occurred in four steps. Step one involved examination of the original 34 secondary conditions of the HSCIADD. Step two involved a review by the Research Unit of the Rural Institute on Disability (including this researcher, Tom Seekins, and Catherine Ipsen) of the 25 secondary conditions of the HSCIADD factor analysis, and a literature review related to secondary conditions and adolescents. The review resulted in 32 secondary conditions selected for expert review. These 32 conditions were taken from the original HSCAIADD and reworded to be more adolescent age-appropriate and to more clearly explain the condition. Once the rewording was completed, the revised HSCIADD was distributed to five expert reviewers for the third step in the process. Table 4 outlines the expert reviewers, their professional affiliations and expertise in the area of disability.

<table>
<thead>
<tr>
<th>Name</th>
<th>Professional Affiliation</th>
<th>Area of Expertise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jeff McCubbin, Ph.D.</td>
<td>Oregon State University, Associate Dean and Distinguished Professor of Exercise Science</td>
<td>Improving and reducing the complications of disability through physical activity programs</td>
</tr>
<tr>
<td>Meg Ann Traci, Ph.D.</td>
<td>Rural Institute on Disabilities at the University of Montana</td>
<td>Program director, original researchers involved in the development of the HSCIADD</td>
</tr>
<tr>
<td>Darcie Mersereau, M.P.H.</td>
<td>Special Olympics</td>
<td>Administration role within Special Olympics</td>
</tr>
<tr>
<td>Susan Kinne, Ph.D.</td>
<td>University of Washington, Department of Health Services</td>
<td>Quality of life and people with disabilities, secondary conditions</td>
</tr>
<tr>
<td>Tamar Heller, Ph.D.</td>
<td>University of Illinois at Chicago, Head of the Department of Disability and Human Development</td>
<td>Intervention for individuals with disabilities and their families, and women with disabilities</td>
</tr>
</tbody>
</table>
The expert reviewers were asked to rate each secondary condition in terms of its relevancy to the health and wellness of adolescents with intellectual and developmental disabilities. Relevancy ratings were given on a scale of 0 to 3 in which 0 indicated not relevant and 3 indicated very relevant. In addition to relevancy ratings, the expert reviewers were asked to comment on the clarity of the health condition labels and descriptions, as well as provide feedback on items that should be omitted or added to the instrument. Feedback from the expert review resulted in the elimination of two secondary conditions (access problems and osteoporosis) due to irrelevancy to the target population. The remaining secondary conditions were given ratings of 2 or 3 with regards to relevancy to the targeted population by each of the expert reviewers. Therefore, the revised HSCAIDDD became the SCAAD measuring the limiting effects of 30 secondary conditions. Table 5 illustrates the revision process from the 34 original HSCAIDDD secondary conditions to the 30 secondary conditions included on the SCAAD.

Based on the previously described procedure, the SCAAD was developed to assess limitations posed by secondary conditions. Thirty secondary conditions were identified and included in the instrument. To complete the SCAAD, raters indicate the level of limitation each secondary condition has posed within the past three months. Limitation ratings are presented on a scale of 0 to 3 in which 0 indicates the secondary condition does not pose any limitation and 3 indicates the secondary condition limits activity by 11 or more hours per week. Each secondary condition is given a label followed by an example or description of the condition. For example, the first secondary condition in question is labeled “Physical Fitness/Conditioning Problems” followed by the description “I can’t do some activities because I am not in good enough shape or my muscles just won’t let me.” Respondents are then asked to rate the level of limitation on the 0 to 3 scale.
### Table 5: HSCIADD Revisions to Final SCAAD Instrument

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Fitness/Conditioning Problems</td>
<td>Physical Fitness/Conditioning Problems</td>
<td>Physical Fitness/Conditioning Problems</td>
<td>Physical Fitness/Conditioning Problems</td>
</tr>
<tr>
<td>Eating problems/Gastrointestinal Dysfunction</td>
<td>Eating or Weight Problems</td>
<td>Eating or Weight Problems</td>
<td>Eating or Weight Problems</td>
</tr>
<tr>
<td>Over-/Under-Nourishment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight Problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular/Circulatory Problems</td>
<td>Cardiovascular (Heart) Problems</td>
<td>Cardiovascular (Heart) Problems</td>
<td>Cardiovascular (Heart) Problems</td>
</tr>
<tr>
<td>Respiratory Problems</td>
<td>Circulatory Problems</td>
<td>Circulatory Problems</td>
<td>Circulatory Problems</td>
</tr>
<tr>
<td>Allergies and Allergic Reactions</td>
<td>Respiratory Problems</td>
<td>Respiratory Problems</td>
<td>Respiratory Problems</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Fatigue</td>
<td>Fatigue</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Depression</td>
<td>Depression</td>
<td>Depression</td>
<td>Depression</td>
</tr>
<tr>
<td>Sleep Problems/Disturbances</td>
<td>Sleep Problems/Disturbances</td>
<td>Sleep Problems/Disturbances</td>
<td>Sleep Problems/Disturbances</td>
</tr>
<tr>
<td>Perseverance Problems/Low Tolerance or Frustration</td>
<td>Low Tolerance or Frustration</td>
<td>Low Tolerance or Frustration</td>
<td>Low Tolerance or Frustration</td>
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<tr>
<td>Self-Inflicted Injuries or Abuse</td>
<td>Self-Inflicted Injuries or Abuse</td>
<td>Self-Inflicted Injuries or Abuse</td>
<td>Self-Inflicted Injuries or Abuse</td>
</tr>
<tr>
<td>Bladder Dysfunction</td>
<td>Bladder Dysfunction</td>
<td>Bladder Dysfunction</td>
<td>Bladder Dysfunction</td>
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<td>Bowel Dysfunction</td>
<td>Bowel Dysfunction</td>
<td>Bowel Dysfunction</td>
<td>Bowel Dysfunction</td>
</tr>
<tr>
<td>Personal Hygiene Problems</td>
<td>Urinary Tract Infections</td>
<td>Urinary Tract Infections</td>
<td>Urinary Tract Infections</td>
</tr>
<tr>
<td>Dental/Oral Hygiene Problems</td>
<td>Personal Hygiene Problems</td>
<td>Personal Hygiene Problems</td>
<td>Personal Hygiene Problems</td>
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<tr>
<td>Problems</td>
<td>Dental/Oral Hygiene Problems</td>
<td>Dental/Oral Hygiene Problems</td>
<td>Dental/Oral Hygiene Problems</td>
</tr>
<tr>
<td>Injuries Due to Accidents or Seizures</td>
<td>Injuries Due to Accidents</td>
<td>Injuries Due to Accidents</td>
<td>Injuries Due to Accidents</td>
</tr>
<tr>
<td>Problems with Mobility</td>
<td>Problems with Mobility</td>
<td>Problems with Mobility</td>
<td>Problems with Mobility</td>
</tr>
<tr>
<td>Equipment Failures</td>
<td>Equipment Failures</td>
<td>Equipment Failures</td>
<td>Equipment Failures</td>
</tr>
<tr>
<td>Equipment Related Injuries to Self</td>
<td>Equipment Related Injuries to Self</td>
<td>Equipment Related Injuries to Self</td>
<td>Equipment Related Injuries to Self</td>
</tr>
<tr>
<td>Injuries Due to Loss of Sensation</td>
<td>Injuries Due to Loss of Sensation</td>
<td>Injuries Due to Loss of Sensation</td>
<td>Injuries Due to Loss of Sensation</td>
</tr>
<tr>
<td>Contractures</td>
<td>Contractures</td>
<td>Contractures</td>
<td>Contractures</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>Osteoporosis</td>
<td>Osteoporosis</td>
<td>Osteoporosis</td>
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<tr>
<td>Arthritis</td>
<td>Arthritis</td>
<td>Arthritis</td>
<td>Arthritis</td>
</tr>
<tr>
<td>Joint and Muscle Pain</td>
<td>Joint and Muscle Pain</td>
<td>Joint and Muscle Pain</td>
<td>Joint and Muscle Pain</td>
</tr>
<tr>
<td>Care-Related Injuries to Others</td>
<td>Care-Related Injuries to Others</td>
<td>Care-Related Injuries to Others</td>
<td>Care-Related Injuries to Others</td>
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<td>Osteoporosis</td>
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<td>Arthritis</td>
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<tr>
<td>Joint and Muscle Pain</td>
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<td></td>
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<tr>
<td>Contractures</td>
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<tr>
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<tr>
<td>Arthritis</td>
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<td></td>
<td></td>
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<tr>
<td>Joint and Muscle Pain</td>
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</tr>
</tbody>
</table>
The Children’s Assessment of Participation and Enjoyment (CAPE) is a measure developed to assess the types of activities children participate in outside of mandatory school activities. The CAPE has been used for children with and without disabilities. (King, King, Rosenbaum, Kertoy, Law, Hurley, Hannah, & Young, 2004). The CAPE includes 55-items in a variety of categories of activities in which adolescents might participate. The CAPE asks about participation in the following categories:

1. Hobbies, crafts, and games (such as, puzzles and video games)
2. Social activities (for example, going to a party and visiting others)
3. Quiet recreation (for example, pretend play and playing with toys)
4. Organized sports (team and individual)
5. Other skill-based activities (such as, learning to sing or playing a musical instrument)
6. Clubs, groups, and organization (for example, school clubs and religious activities)
7. Active physical recreation (dancing, snow sports)
8. Entertainment and education (going to the movies, watching TV, going to a live event)
9. Jobs, chores, and employment (including volunteer and paid jobs)

In addition to examining whether or not a participant engages in activities, the CAPE also gathers information about the frequency of the activity (on a scale of 1 to 7 with 1 indicating one
time in the past four months and 7 indicating one time a day or more); with whom the activity is done (alone, with family, with other relatives, with friends, or with others); where the activity occurs (at home, a relative’s home, in the neighborhood, at school, in the community, and beyond the community); as well as the enjoyment of the activity (from 1 indicating not at all to 5 indicating a love of the activity). The CAPE is a child-friendly measure with pictures to indicate each of the activities as well as a scale of faces (from very unhappy to very happy) to indicate enjoyment. The CAPE generates overall scores that reflect the overall nature of participation including the frequency and intensity of participation, the level of sociability, and where activities occur.

The CAPE has been established as a reliable and valid measure through a number of statistical procedures. The reliability of the CAPE was examined by way of internal consistency and test-retest reliability. Cronbach’s coefficient alpha was used as a measure of reliability with reported coefficients of .78 and .84 at two different times of measurement. Giving the same participants the same test at two different intervals produced test-retest reliability. Sufficient test-retest reliability scores ranging from .64 to .86 were found. Evidence of validity was found by way of content validity. The developers of the CAPE established content validity through review of current literature on participation, expert review, and pilot work.

Procedure

Once the measures had been selected for this particular research project and Institutional Review Board approval obtained (see Appendix C), the following occurred. A meeting was held between this researcher and the director of Intensive Family Education and Support at CDC. This meeting resulted in an invitation for the researcher to attend an upcoming staff meeting at the Missoula CDC office in order to present the research proposal to staff, the Family Support Specialist (FSS), working directly with families being served by CDC.
At the staff meeting, the researcher presented the research project. The presentation included the rationale for the project, age criteria of participants, a brief overview of the IRB process including the consent and assent forms, as well as a brief summary of the measurement instruments. Staff agreed to participate in the study and were then further educated on the procedures of the project, including survey administration and consent procedures. Staff was given a brief training on how to complete both measures for this project. They were provided with information about the Likert scale on the SCAAD and given examples of the levels of limitation for each of the number choices on the scale. For example, for the secondary condition of physical fitness or conditions problems staff was trained that a 0 would indicate no limitation such that the child is able to participate in any activities he or she is interested in participated in. Limitation of a 1 might manifest itself in the child being unable to do one or two activities (such as going the entire distance of a hike or an inability to ride his or her bike for as long as the individual would like because their fitness does not allow). Limitation of a 2 might be chosen if the child is unable to do a number of activities because of his or her fitness. Finally, limitation of a 3 would manifest itself such that the child is unable to participate in nearly all activities due to fitness conditioning. This child might be unable to walk very far without getting short of breath.

The CAPE includes directions that were reviewed. Staff was asked to relay the instructions to the parents they work with who would be completing the surveys. Upon completion of the explanation process, staff was given packets that included an introductory letter for parents to explain the project, consent/assent forms, two copies each of the SCAAD and the CAPE (one for parents to complete, one for the FSS to complete). The Family Support Specialists were asked to present the study and ask for participation from families who fit the criteria for the study. Additionally, staff members were asked to serve as proxy raters and complete the surveys on behalf of those adolescents who volunteered to participate in the study. A stipend of $20 was offered to
each FSS and family who participated and turned in a survey packet. The FSSs were then given approximately one month to meet with families and complete the measures.

After approximately one month, this researcher met with the director of IFES to collect the completed survey packets. During this meeting, the director suggested a few other potential participants and the Family Support Specialists were contacted in person about the inclusion of suggested participants. Several other participants were included based on these in person requests. Approximately two more weeks were given for all Family Support Specialists to facilitate the completion of the survey packets. At this time, it became apparent that the study needed to be expanded to the Kalispell area due to a lower than expected response rate (n=15) of participants in the Missoula area.

At this point in time, this researcher held a phone conference with the Family Support Specialists in Kalispell to explain the procedure and ask for volunteers to participate in the study. Those working in Kalispell agreed to invite families to join the study. The same packets were given to the Kalispell office as were given to those in Missoula. The Kalispell Family Support Specialists were given one month to complete their survey packets. One week prior to the deadline given, an email was sent out reminding the FSSs of the deadline.

After approximately three months of data collection opportunities a final count of 24 packets were collected. Families and support staff were each given a $20 stipend and a thank you letter for their participation in the study. Family Support Specialists who completed more than one survey for more than one child were given $20 for each survey completed. Stipends were given to all families and FSSs who returned surveys whether they were completed or not.

Data Analysis

Proxy rating by parents or family members was used as primary data for analyses. Rates of limitation due to secondary conditions on the SCAAD was analyzed by calculating sums,
Development of the Secondary

frequencies, and averages. SCAAD inter-rater agreement was calculated by giving parents and staff the same survey to complete and then comparing results for agreement. The results were then examined, item-by-item, to determine the level of agreement of the raters. To determine inter-rater reliability on an item-by-item basis the following formula was used (Jackson, 2008):

\[
\text{Inter-Rater Reliability} = \frac{\text{Agreements}}{\text{Agreements} + \text{Disagreements}} \times 100
\]

This formula was used to calculate inter-rater agreement by looking first at exact level of agreement in which parents and staff reported exact numbers of limitation for each item as well as partial agreement in which parents and staff reported some level of limitation existed although it may not have been an exact match (for example, parents may have reported the limitation a 1 whereas staff reported the limitation a 2).

Cronbach’s alpha calculations were analyzed to further explore the reliability of the SCAAD by looking at the seven factors established from the factor analysis of the HSCIADD.

The CAPE was examined by exploring the frequencies for each sub domain as well as the inter-rater agreement between family and staff by using the above stated formula. Pearson’s r correlations were calculated to examine the potential relationship between the overall limitation on the SCAAD and the findings from the CAPE as reported by parents.

Results

Secondary Conditions

General summative findings of the SCAAD suggest that the sample population experienced a number of limitations based on secondary conditions. Each secondary condition presented in the SCAAD poses some level of limitation to members of the sample population as reported by families. An average of 11 secondary conditions was found based upon family report. According to
family responses on the SCAAD, the psychological factors of isolation, low tolerance or frustration, and fatigue create the greatest level of limitation. Table 5 presents the sum limitations for each condition as well as the number of participants reporting the limitation.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number reporting limitation n=24</th>
<th>Total Limitation</th>
<th>Average Limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation</td>
<td>20</td>
<td>52</td>
<td>2.60</td>
</tr>
<tr>
<td>Low Tolerance or Frustration</td>
<td>21</td>
<td>45</td>
<td>2.14</td>
</tr>
<tr>
<td>Fatigue</td>
<td>19</td>
<td>40</td>
<td>2.10</td>
</tr>
<tr>
<td>Physical Fitness/Conditioning Problems</td>
<td>17</td>
<td>35</td>
<td>2.06</td>
</tr>
<tr>
<td>Anger</td>
<td>16</td>
<td>34</td>
<td>2.13</td>
</tr>
<tr>
<td>Balance Problems/Dizziness</td>
<td>14</td>
<td>31</td>
<td>2.21</td>
</tr>
<tr>
<td>Weight Problems</td>
<td>14</td>
<td>30</td>
<td>2.14</td>
</tr>
<tr>
<td>Sleep Problems/Disturbances</td>
<td>16</td>
<td>30</td>
<td>1.88</td>
</tr>
<tr>
<td>Medication Side Effects</td>
<td>14</td>
<td>26</td>
<td>1.86</td>
</tr>
<tr>
<td>Bladder Dysfunction</td>
<td>11</td>
<td>25</td>
<td>2.27</td>
</tr>
<tr>
<td>Bowel Dysfunction</td>
<td>12</td>
<td>23</td>
<td>1.92</td>
</tr>
<tr>
<td>Problems with Mobility</td>
<td>9</td>
<td>23</td>
<td>2.56</td>
</tr>
<tr>
<td>Depression</td>
<td>14</td>
<td>20</td>
<td>1.43</td>
</tr>
<tr>
<td>Dental/Oral Hygiene Problems</td>
<td>14</td>
<td>20</td>
<td>1.43</td>
</tr>
<tr>
<td>Personal Hygiene Problems</td>
<td>16</td>
<td>19</td>
<td>1.19</td>
</tr>
<tr>
<td>Contractures</td>
<td>9</td>
<td>17</td>
<td>1.89</td>
</tr>
<tr>
<td>Joint and Muscle Pain</td>
<td>10</td>
<td>16</td>
<td>1.60</td>
</tr>
<tr>
<td>Self-Inflicted Injuries or Self-Abuse</td>
<td>8</td>
<td>14</td>
<td>1.75</td>
</tr>
<tr>
<td>Injuries Due to Accidents</td>
<td>10</td>
<td>14</td>
<td>1.40</td>
</tr>
<tr>
<td>Cardiovascular (Heart) Problems</td>
<td>6</td>
<td>12</td>
<td>2.00</td>
</tr>
<tr>
<td>Circulatory Problems</td>
<td>6</td>
<td>12</td>
<td>2.00</td>
</tr>
<tr>
<td>Respiratory Problems</td>
<td>5</td>
<td>11</td>
<td>2.20</td>
</tr>
<tr>
<td>Allergies</td>
<td>7</td>
<td>11</td>
<td>1.57</td>
</tr>
<tr>
<td>Injuries Due to Loss of Sensation</td>
<td>7</td>
<td>11</td>
<td>1.57</td>
</tr>
<tr>
<td>Urinary Tract Infections</td>
<td>4</td>
<td>8</td>
<td>2.00</td>
</tr>
<tr>
<td>Equipment Failures</td>
<td>4</td>
<td>8</td>
<td>2.00</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>3</td>
<td>7</td>
<td>2.33</td>
</tr>
<tr>
<td>Equipment Related Injuries to Others</td>
<td>3</td>
<td>7</td>
<td>2.33</td>
</tr>
<tr>
<td>Equipment Related Injuries to Self</td>
<td>4</td>
<td>5</td>
<td>1.25</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1</td>
<td>3</td>
<td>3.00</td>
</tr>
</tbody>
</table>

When summations of the levels of limitation from each secondary condition were calculated, there were similarities between parents and families. Summations of the level of limitation for each item were calculated. Table 6 presents the top five secondary conditions and the average
number of respondent for each choice on the 4-point likert scale. This table is representative of the responses given by family members.

Table 6: Number of Responses for each Level of Limitation as Reported by Family

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number of Respondents Reporting 0 (not limiting)</th>
<th>Number of Respondents Reporting 1 (limits a little)</th>
<th>Number of Respondents Reporting 2 (limits some)</th>
<th>Number of Respondents Reporting 3 (limits a lot)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation</td>
<td>4</td>
<td>2</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Low Tolerance for Frustration</td>
<td>3</td>
<td>6</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Fatigue</td>
<td>5</td>
<td>6</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Physical Fitness/Conditioning Problems</td>
<td>7</td>
<td>7</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Anger</td>
<td>8</td>
<td>3</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 7 presents severity of limitation from greatest to least based upon family report and staff report.

Findings from the summation of limitation from secondary conditions suggest that families and staff have similar views of the secondary conditions of major concern to the adolescents in this sample. For instance, the first six secondary conditions are ranked similarly in severity between staff and parents. Isolation, low tolerance or frustration, anger, fatigue, physical fitness/condition problems, and balance problems/dizziness ranked among the most severely limiting of all secondary conditions. These findings, when coupled with the developmental stage of adolescents, provide a telling picture into the secondary conditions that may need to be more closely examined and eventually addressed when working with this population. Again, further discussion is to follow.

**SCAAD Reliability.**

This formula of number agreements divided by number of agreements plus number of disagreements multiplied by 100 was used to calculate the inter-rater agreement of the 30 secondary conditions assessed on the SCAAD based upon responses given by parents and responses given by Family Support Specialists working directly with the adolescent participants. All 24 participants were included in this analysis.
### Table 7: Comparison of Staff and Family Report of Secondary Conditions

<table>
<thead>
<tr>
<th>CONDITION</th>
<th>TOTAL LIMITATION AS REPORTED BY STAFF</th>
<th>CONDITION</th>
<th>TOTAL LIMITATION AS REPORTED BY FAMILY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation</td>
<td>47</td>
<td>Isolation</td>
<td>52</td>
</tr>
<tr>
<td>Low Tolerance or Frustration</td>
<td>42</td>
<td>Low Tolerance or Frustration</td>
<td>45</td>
</tr>
<tr>
<td>Anger</td>
<td>36</td>
<td>Fatigue</td>
<td>40</td>
</tr>
<tr>
<td>Physical Fitness/Conditioning</td>
<td>35</td>
<td>Problems</td>
<td>35</td>
</tr>
<tr>
<td>Problems</td>
<td>30</td>
<td>Anger</td>
<td>34</td>
</tr>
<tr>
<td>Balance Problems/Dizziness</td>
<td>27</td>
<td>Balance Problems/Dizziness</td>
<td>31</td>
</tr>
<tr>
<td>Problems with Mobility</td>
<td>25</td>
<td>Weight Problems</td>
<td>30</td>
</tr>
<tr>
<td>Weight Problems</td>
<td>24</td>
<td>Sleep Problems/Disturbances</td>
<td>30</td>
</tr>
<tr>
<td>Medication Side Effects</td>
<td>22</td>
<td>Medication Side Effects</td>
<td>26</td>
</tr>
<tr>
<td>Sleep Problems/Disturbances</td>
<td>21</td>
<td>Bladder Dysfunction</td>
<td>25</td>
</tr>
<tr>
<td>Bladder Dysfunction</td>
<td>21</td>
<td>Bowel Dysfunction</td>
<td>23</td>
</tr>
<tr>
<td>Dental/Oral Hygiene Problems</td>
<td>20</td>
<td>Problems with Mobility</td>
<td>23</td>
</tr>
<tr>
<td>Personal Hygiene Problems</td>
<td>17</td>
<td>Depression</td>
<td>20</td>
</tr>
<tr>
<td>Depression</td>
<td>16</td>
<td>Personal Hygiene Problems</td>
<td>19</td>
</tr>
<tr>
<td>Contractures</td>
<td>16</td>
<td>Contractures</td>
<td>17</td>
</tr>
<tr>
<td>Joint and Muscle Pain</td>
<td>15</td>
<td>Joint and Muscle Pain</td>
<td>16</td>
</tr>
<tr>
<td>Bowel Dysfunction</td>
<td>13</td>
<td>Self-Inflicted Injuries or Self-Abuse</td>
<td>14</td>
</tr>
<tr>
<td>Self-Inflicted Injuries or Self-Abuse</td>
<td>13</td>
<td>Injuries Due to Accidents</td>
<td>14</td>
</tr>
<tr>
<td>Injuries Due to Accidents</td>
<td>11</td>
<td>Cardiovascular (Heart) Problems</td>
<td>12</td>
</tr>
<tr>
<td>Allergies</td>
<td>9</td>
<td>Circulatory Problems</td>
<td>12</td>
</tr>
<tr>
<td>Respiratory Problems</td>
<td>9</td>
<td>Respiratory Problems</td>
<td>11</td>
</tr>
<tr>
<td>Urinary Tract Infections</td>
<td>9</td>
<td>Allergies</td>
<td>11</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>8</td>
<td>Injuries Due to Loss of Sensation</td>
<td>11</td>
</tr>
<tr>
<td>Cardiovascular (Heart) Problems</td>
<td>8</td>
<td>Urinary Tract Infections</td>
<td>8</td>
</tr>
<tr>
<td>Circulatory Problems</td>
<td>8</td>
<td>Equipment Failures</td>
<td>8</td>
</tr>
<tr>
<td>Equipment Related Injuries to Others</td>
<td>7</td>
<td>Injuries Due to Loss of Sensation</td>
<td>5</td>
</tr>
<tr>
<td>Injuries Due to Loss of Sensation</td>
<td>5</td>
<td>Scoliosis</td>
<td>7</td>
</tr>
<tr>
<td>Equipment Failures</td>
<td>4</td>
<td>Equipment Related Injuries to Others</td>
<td>7</td>
</tr>
<tr>
<td>Arthritis</td>
<td>3</td>
<td>Equipment Related Injuries to Self</td>
<td>5</td>
</tr>
<tr>
<td>Equipment Related Injuries to Self</td>
<td>2</td>
<td>Arthritis</td>
<td>3</td>
</tr>
</tbody>
</table>

Inter-rater reliability analysis involved assessing the response given for each item for each participant by the parent and by the Family Support Specialist. Two analyses were conducted. First, item-by-item inter-rater agreement percentages were established. This analysis involved comparing family responses to staff responses and determining if an agreement took place. For the first calculation, an agreement was considered to have occurred if both family and staff reported the
exact same level of limitation for the item. Overall inter-rater agreement for exact agreement resulted in a moderate inter-rater agreement of .73, with individual items scores ranging from .46 to .92.

Second, partial inter-rater agreement percentages were calculated. Again, this involved comparing family responses to staff responses and determining if agreement took place. In this case, agreement was considered to have occurred if both family and staff reported that there was some level (or no level) of limitation for the item. Overall inter-rater reliability for partial agreement resulted in a higher inter-rater reliability agreement of .85, with scores ranging from .67 to .92. Table 8 illustrates item-by-item inter-rater agreement as well as overall inter-rater reliability agreement.

The overall exact inter-rater reliability score (.73) is moderate, the overall partial inter-rater reliability score (.85) falls within the moderately high to high range. This level of agreement between the partial agreements suggests that there is acknowledgement between family and staff that there are limitations on activity due to secondary conditions. Further information will be provided in the discussion section below.

Table 8: Exact and Partial Inter-Rater Reliability Results

<table>
<thead>
<tr>
<th>CONDITION</th>
<th>Number of EXACT Agreements Between Staff and Family on Limitation</th>
<th>Number of PARTIAL Agreements Between Staff and Family on Limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Fitness/Conditioning Problems</td>
<td>14</td>
<td>.58</td>
</tr>
<tr>
<td>Weight Problems</td>
<td>16</td>
<td>.67</td>
</tr>
<tr>
<td>Cardiovascular (Heart) Problems</td>
<td>21</td>
<td>.88</td>
</tr>
<tr>
<td>Circulatory Problems</td>
<td>22</td>
<td>.92</td>
</tr>
<tr>
<td>Respiratory Problems</td>
<td>20</td>
<td>.83</td>
</tr>
<tr>
<td>Allergies</td>
<td>20</td>
<td>.83</td>
</tr>
<tr>
<td>Fatigue</td>
<td>15</td>
<td>.63</td>
</tr>
<tr>
<td>Depression</td>
<td>15</td>
<td>.63</td>
</tr>
<tr>
<td>Sleep Problems/Disturbances</td>
<td>16</td>
<td>.67</td>
</tr>
<tr>
<td>Medication Side Effects</td>
<td>17</td>
<td>.71</td>
</tr>
<tr>
<td>Self-Inflicted Injuries or Self-Abuse</td>
<td>18</td>
<td>.75</td>
</tr>
<tr>
<td>Condition</td>
<td>Family</td>
<td>Staff</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>--------</td>
<td>-------</td>
</tr>
<tr>
<td>Bladder Dysfunction</td>
<td>17</td>
<td>.71</td>
</tr>
<tr>
<td>Bowel Dysfunction</td>
<td>16</td>
<td>.67</td>
</tr>
<tr>
<td>Urinary Tract Infections</td>
<td>22</td>
<td>.92</td>
</tr>
<tr>
<td>Personal Hygiene Problems</td>
<td>12</td>
<td>.50</td>
</tr>
<tr>
<td>Dental/Oral Hygiene Problems</td>
<td>12</td>
<td>.50</td>
</tr>
<tr>
<td>Balance Problems/Dizziness</td>
<td>18</td>
<td>.75</td>
</tr>
<tr>
<td>Injuries Due to Loss of Sensation</td>
<td>18</td>
<td>.75</td>
</tr>
<tr>
<td>Contractures</td>
<td>15</td>
<td>.63</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>22</td>
<td>.92</td>
</tr>
<tr>
<td>Arthritis</td>
<td>22</td>
<td>.92</td>
</tr>
<tr>
<td>Joint and Muscle Pain</td>
<td>22</td>
<td>.92</td>
</tr>
<tr>
<td>Anger</td>
<td>12</td>
<td>.50</td>
</tr>
<tr>
<td>Isolation</td>
<td>13</td>
<td>.54</td>
</tr>
<tr>
<td>Low Tolerance or Frustration</td>
<td>11</td>
<td>.46</td>
</tr>
<tr>
<td>Injuries Due to Accidents</td>
<td>15</td>
<td>.63</td>
</tr>
<tr>
<td>Problems with Mobility</td>
<td>17</td>
<td>.71</td>
</tr>
<tr>
<td>Equipment Failures</td>
<td>22</td>
<td>.92</td>
</tr>
<tr>
<td>Equipment Related Injuries to Self</td>
<td>22</td>
<td>.92</td>
</tr>
<tr>
<td>Equipment Related Injuries to Others</td>
<td>20</td>
<td>.83</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>522</td>
<td>.73</td>
</tr>
</tbody>
</table>

A Pearson’s Product Correlation analysis was conducted on the overall scores of limitation as reported by both family and staff in order to better understand the properties of chance for the reported results of the SCAAD. A correlation of \( .777, p < .01 \) was found. This suggests a modest positive correlation between the overall score of the SCAAD as reported by family when compared with the overall score reported by staff. This correlation coefficient suggests that the inter-rater reliability scores found on the SCAAD are likely not due to chance and are due to actual perceived agreement on limitation by family and staff working with the participants. Figure 2 provides a scatterplot representation of the Pearson Product Correlation.

**SCAAD Internal Consistency.** Cronbach’s alpha analyses were explored to further assess the reliability of the SCAAD and the responses given by the twenty-four families (see Table 9). Cronbach’s alpha measures how well as set of variables measures a single construct. Because the original HS CA IDD had been factor analyzed, the SCAAD was readily set up for analysis via Cronbach’s alpha. The seven factors from the factor analysis were used as the single construct, and the secondary conditions falling within each of the factors were used as the set of...
variables. For example, to explore the consistency between items associated with the “mobility conditions” factor, the secondary conditions related to that factor were analyzed. These factors were equipment failures, equipment related injuries to others, equipment related injuries to self, scoliosis, problems with mobility, and contractures. Cronbach’s alpha scores ranged from a high of .746 for physical fitness conditions to a low of .271 for pain related conditions. Table 6 indicates the Cronbach’s calculations for the seven factors and the secondary conditions included in each factor. The relatively modest Cronbach’s alpha scores are consistent with the inter-rater reliability scores. The SCAAD is a relatively brief assessment of health conditions and Cronbach’s alpha scores generally increase as the number of items increase. Increasing the number of secondary conditions assessed is one potential way of increasing the internal consistency of the SCAAD, especially in those areas where Cronbach’s alpha scores are very low.
Table 9: Cronbach’s Alpha for Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>Secondary Conditions Included</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility Conditions</td>
<td>Equipment failures&lt;br&gt;Equipment related injuries to others&lt;br&gt;Equipment related injuries to self&lt;br&gt;Scoliosis&lt;br&gt;Problems with mobility&lt;br&gt;Contractures&lt;br&gt;Sleep problems/disturbances&lt;br&gt;Depression&lt;br&gt;Self inflicted injuries or abuse&lt;br&gt;Persistence problems/low frustration tolerance&lt;br&gt;Side effects from medication&lt;br&gt;Fatigue&lt;br&gt;Anger&lt;br&gt;Isolation</td>
<td>.701</td>
</tr>
<tr>
<td>Psychological Conditions</td>
<td>Balance problems/dizziness&lt;br&gt;Injuries due to accidents&lt;br&gt;Respiratory problems&lt;br&gt;Weight problems&lt;br&gt;Physical fitness/conditioning problems&lt;br/Cardiovascular problems&lt;br/Circulatory problems</td>
<td>.544</td>
</tr>
<tr>
<td>Orientation Related Conditions</td>
<td></td>
<td>.682</td>
</tr>
<tr>
<td>Physical Fitness Conditions</td>
<td></td>
<td>.746</td>
</tr>
<tr>
<td>Pain Related Conditions</td>
<td>Arthritis&lt;br&gt;Joint and muscle pain&lt;br&gt;Injuries due to loss of sensation</td>
<td>.271</td>
</tr>
<tr>
<td>Elimination Conditions</td>
<td>Bowel dysfunction&lt;br&gt;Bladder dysfunction&lt;br&gt;Urnary tract infections</td>
<td>.692</td>
</tr>
<tr>
<td>Hygiene Conditions</td>
<td>Personal hygiene problems&lt;br&gt;Dental/oral hygiene problems</td>
<td>.522</td>
</tr>
</tbody>
</table>

Participation

**Primary CAPE Findings.** The Children’s Assessment of Participation and Enjoyment (CAPE) assesses five areas of participation. First, the CAPE examines the diversity of activities in which children engage. Fifty-five items are presented, and participants are asked whether or not they have engaged in the activity in the past four months. Second, the CAPE examines the frequency in which children participate in activities. Third, the CAPE examines with whom the children engage in the
activities. Fourth, the CAPE examines where the activities occur. Lastly, the CAPE examines how much the children enjoy doing each activity in which they participate. Families were asked to rate each of these items for the activities in which the participants engage. For each sub domain higher scores are indicative of greater levels of participation. For example, higher scores in the “with whom” category indicate that the participant is engaging in the activity with others, rather than in isolation. Table 10 illustrates summative responses given for each of the sub domains presented from most commonly engaged activity to least commonly engage.

### Table 10: Summative CAPE Sub Domain Responses

<table>
<thead>
<tr>
<th>Activity</th>
<th>Diversity n= 22</th>
<th>Frequency</th>
<th>With Whom</th>
<th>Where</th>
<th>Enjoyment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listening to music</td>
<td>20</td>
<td>120</td>
<td>50</td>
<td>38</td>
<td>88</td>
</tr>
<tr>
<td>Shopping</td>
<td>20</td>
<td>89</td>
<td>58</td>
<td>97</td>
<td>82</td>
</tr>
<tr>
<td>Visiting</td>
<td>19</td>
<td>91</td>
<td>69</td>
<td>65</td>
<td>73</td>
</tr>
<tr>
<td>Watching TV or a rented movie</td>
<td>19</td>
<td>125</td>
<td>49</td>
<td>30</td>
<td>90</td>
</tr>
<tr>
<td>Doing a chore</td>
<td>18</td>
<td>102</td>
<td>48</td>
<td>24</td>
<td>46</td>
</tr>
<tr>
<td>Doing crafts, drawing or coloring</td>
<td>17</td>
<td>84</td>
<td>66</td>
<td>56</td>
<td>65</td>
</tr>
<tr>
<td>Talking on the phone</td>
<td>17</td>
<td>84</td>
<td>41</td>
<td>25</td>
<td>66</td>
</tr>
<tr>
<td>Going for a walk or a hike</td>
<td>17</td>
<td>88</td>
<td>63</td>
<td>74</td>
<td>70</td>
</tr>
<tr>
<td>Playing with pets</td>
<td>16</td>
<td>108</td>
<td>37</td>
<td>28</td>
<td>67</td>
</tr>
<tr>
<td>Playing computer or video games</td>
<td>15</td>
<td>80</td>
<td>41</td>
<td>39</td>
<td>63</td>
</tr>
<tr>
<td>Hanging out</td>
<td>15</td>
<td>89</td>
<td>61</td>
<td>61</td>
<td>64</td>
</tr>
<tr>
<td>Playing with things or toys</td>
<td>15</td>
<td>101</td>
<td>39</td>
<td>35</td>
<td>67</td>
</tr>
<tr>
<td>Playing board or card games</td>
<td>14</td>
<td>62</td>
<td>45</td>
<td>33</td>
<td>52</td>
</tr>
<tr>
<td>Reading</td>
<td>14</td>
<td>89</td>
<td>56</td>
<td>45</td>
<td>50</td>
</tr>
<tr>
<td>Making food</td>
<td>14</td>
<td>69</td>
<td>37</td>
<td>23</td>
<td>51</td>
</tr>
<tr>
<td>Going to a party</td>
<td>12</td>
<td>25</td>
<td>38</td>
<td>55</td>
<td>48</td>
</tr>
<tr>
<td>Doing pretend or imaginary play</td>
<td>12</td>
<td>67</td>
<td>21</td>
<td>18</td>
<td>45</td>
</tr>
<tr>
<td>Swimming</td>
<td>12</td>
<td>27</td>
<td>48</td>
<td>58</td>
<td>62</td>
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<tr>
<td>Playing games</td>
<td>11</td>
<td>38</td>
<td>51</td>
<td>48</td>
<td>43</td>
</tr>
<tr>
<td>Doing individual physical activities</td>
<td>10</td>
<td>57</td>
<td>46</td>
<td>42</td>
<td>33</td>
</tr>
<tr>
<td>Going to the public library</td>
<td>10</td>
<td>32</td>
<td>42</td>
<td>49</td>
<td>37</td>
</tr>
<tr>
<td>Going to a live event</td>
<td>10</td>
<td>21</td>
<td>30</td>
<td>51</td>
<td>38</td>
</tr>
<tr>
<td>Taking care of a pet</td>
<td>10</td>
<td>53</td>
<td>18</td>
<td>15</td>
<td>32</td>
</tr>
<tr>
<td>Collecting things</td>
<td>9</td>
<td>49</td>
<td>25</td>
<td>24</td>
<td>37</td>
</tr>
<tr>
<td>Doing team sports</td>
<td>9</td>
<td>47</td>
<td>47</td>
<td>46</td>
<td>38</td>
</tr>
<tr>
<td>Doing a religious activity</td>
<td>9</td>
<td>33</td>
<td>25</td>
<td>43</td>
<td>31</td>
</tr>
<tr>
<td>Dancing</td>
<td>9</td>
<td>43</td>
<td>28</td>
<td>21</td>
<td>41</td>
</tr>
<tr>
<td>Going on a full-day outing</td>
<td>9</td>
<td>25</td>
<td>30</td>
<td>46</td>
<td>32</td>
</tr>
<tr>
<td>Doing a paid job</td>
<td>9</td>
<td>40</td>
<td>36</td>
<td>44</td>
<td>32</td>
</tr>
<tr>
<td>Writing letters</td>
<td>8</td>
<td>25</td>
<td>16</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Going to the movies</td>
<td>8</td>
<td>27</td>
<td>24</td>
<td>38</td>
<td>34</td>
</tr>
<tr>
<td>Playing a musical instrument</td>
<td>7</td>
<td>34</td>
<td>19</td>
<td>17</td>
<td>32</td>
</tr>
<tr>
<td>Doing snow sports</td>
<td>7</td>
<td>29</td>
<td>32</td>
<td>35</td>
<td>27</td>
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<tr>
<td>Activity</td>
<td>Family</td>
<td>Staff</td>
<td>Agreement</td>
<td>Score</td>
<td></td>
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<td>--------</td>
<td>-------</td>
<td>-----------</td>
<td>-------</td>
<td></td>
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<tr>
<td>Doing homework</td>
<td>7</td>
<td>29</td>
<td>18</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td>Doing puzzles</td>
<td>6</td>
<td>26</td>
<td>21</td>
<td>14</td>
<td>27</td>
</tr>
<tr>
<td>Entertaining others</td>
<td>6</td>
<td>27</td>
<td>21</td>
<td>19</td>
<td>27</td>
</tr>
<tr>
<td>Getting extra help for schoolwork from a tutor</td>
<td>6</td>
<td>35</td>
<td>22</td>
<td>26</td>
<td>20</td>
</tr>
<tr>
<td>Participating in community organizations</td>
<td>5</td>
<td>24</td>
<td>20</td>
<td>21</td>
<td>21</td>
</tr>
<tr>
<td>Bicycling, in-line skating, or skateboarding</td>
<td>5</td>
<td>20</td>
<td>9</td>
<td>21</td>
<td>23</td>
</tr>
<tr>
<td>Doing volunteer work</td>
<td>5</td>
<td>26</td>
<td>21</td>
<td>24</td>
<td>17</td>
</tr>
<tr>
<td>Horseback riding</td>
<td>4</td>
<td>14</td>
<td>16</td>
<td>19</td>
<td>17</td>
</tr>
<tr>
<td>Learning to sing</td>
<td>4</td>
<td>16</td>
<td>20</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td>Taking art lessons</td>
<td>4</td>
<td>16</td>
<td>19</td>
<td>17</td>
<td>12</td>
</tr>
<tr>
<td>Learning to dance</td>
<td>4</td>
<td>12</td>
<td>12</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>Playing on equipment</td>
<td>4</td>
<td>19</td>
<td>18</td>
<td>14</td>
<td>14</td>
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<tr>
<td>Gardening</td>
<td>4</td>
<td>15</td>
<td>14</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Playing non-team sports</td>
<td>4</td>
<td>16</td>
<td>13</td>
<td>21</td>
<td>16</td>
</tr>
<tr>
<td>Racing or track and field</td>
<td>3</td>
<td>11</td>
<td>15</td>
<td>16</td>
<td>11</td>
</tr>
<tr>
<td>Taking music lessons</td>
<td>3</td>
<td>15</td>
<td>11</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Fishing</td>
<td>3</td>
<td>9</td>
<td>6</td>
<td>18</td>
<td>13</td>
</tr>
<tr>
<td>Writing a story</td>
<td>2</td>
<td>16</td>
<td>3</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
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<td>2</td>
<td>8</td>
<td>9</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Doing martial arts</td>
<td>1</td>
<td>7</td>
<td>5</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Doing gymnastics</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Doing water sports</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>6</td>
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</tbody>
</table>

**CAPE Inter-Rater Reliability.**

Inter-rater reliability for the CAPE was calculated initially by looking at the level of agreement between family and staff for each activity presented (diversity). Twenty-two of the twenty-four participants were analyzed at this point. One was not included because the family did not fill out the participation survey. Another was not analyzed as the staff working with this individual was not yet familiar enough with the participant to accurately provide information. Inter-rater reliability was calculated by using the same formula as presented previously. Whether or not the participant engaged in the activity was analyzed by looking at the responses by staff and by families. Responses were either a yes or no for this category. An overall moderate inter-rater reliability score of .79 was found. Individual inter-rater reliability scores ranged from .68 to .95. Table 11 outlines the agreement numbers between staff and families as well as the inter-rater reliability score for each item.
<table>
<thead>
<tr>
<th>Activity</th>
<th># of EXACT Agreements Between Staff and Family on Diversity</th>
<th>Inter-Rater Reliability Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doing puzzles</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Playing board or card games</td>
<td>16</td>
<td>.72</td>
</tr>
<tr>
<td>Doing crafts, drawing or coloring</td>
<td>15</td>
<td>.68</td>
</tr>
<tr>
<td>Collecting things</td>
<td>15</td>
<td>.68</td>
</tr>
<tr>
<td>Playing computer or video games</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Talking on the phone</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Going to a party</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Hanging out</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Visiting</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Writing letters</td>
<td>15</td>
<td>.68</td>
</tr>
<tr>
<td>Entertaining others</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Playing with pets</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Writing a story</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Doing pretend or imaginary play</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Playing with things or toys</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Doing martial arts</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Swimming</td>
<td>15</td>
<td>.68</td>
</tr>
<tr>
<td>Doing gymnastics</td>
<td>20</td>
<td>.91</td>
</tr>
<tr>
<td>Horseback riding</td>
<td>18</td>
<td>.82</td>
</tr>
<tr>
<td>Racing or track and field</td>
<td>20</td>
<td>.91</td>
</tr>
<tr>
<td>Doing team sports</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Learning to sing</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Taking art lessons</td>
<td>18</td>
<td>.82</td>
</tr>
<tr>
<td>Learning to dance</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Getting extra help for schoolwork from a tutor</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Playing a musical instrument</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Taking music lessons</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Participating in community organizations</td>
<td>16</td>
<td>.72</td>
</tr>
<tr>
<td>Doing a religious activity</td>
<td>16</td>
<td>.72</td>
</tr>
<tr>
<td>Participating in school clubs</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Dancing</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Going for a walk or a hike</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Bicycling, in-line skating, or skateboarding</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Doing water sports</td>
<td>18</td>
<td>.82</td>
</tr>
<tr>
<td>Doing snow sports</td>
<td>20</td>
<td>.91</td>
</tr>
<tr>
<td>Playing on equipment</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Playing games</td>
<td>14</td>
<td>.64</td>
</tr>
<tr>
<td>Gardening</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Fishing</td>
<td>20</td>
<td>.91</td>
</tr>
<tr>
<td>Doing individual physical activities</td>
<td>13</td>
<td>.59</td>
</tr>
<tr>
<td>Playing non-team sports</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Going to the movies</td>
<td>14</td>
<td>.64</td>
</tr>
<tr>
<td>Going to the public library</td>
<td>15</td>
<td>.68</td>
</tr>
<tr>
<td>Watching TV or a rented movie</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Going to a live event</td>
<td>18</td>
<td>.82</td>
</tr>
<tr>
<td>Going on a full-day outing</td>
<td>16</td>
<td>.73</td>
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</table>
Development of the Secondary

<table>
<thead>
<tr>
<th>Activity</th>
<th>Limitation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Listening to music</td>
<td>19</td>
<td>.86</td>
</tr>
<tr>
<td>Doing volunteer work</td>
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<td>.77</td>
</tr>
<tr>
<td>Doing a chore</td>
<td>20</td>
<td>.91</td>
</tr>
<tr>
<td>Doing a paid job</td>
<td>18</td>
<td>.82</td>
</tr>
<tr>
<td>Making food</td>
<td>17</td>
<td>.77</td>
</tr>
<tr>
<td>Doing homework</td>
<td>16</td>
<td>.73</td>
</tr>
<tr>
<td>Shopping</td>
<td>21</td>
<td>.95</td>
</tr>
<tr>
<td>Taking care of a pet</td>
<td>16</td>
<td>.73</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>957</strong></td>
<td><strong>.79</strong></td>
</tr>
</tbody>
</table>

**Secondary Conditions and Participation**

Pearson’s r correlations were calculated to explore the relationship between overall limitation as reported by parents on the SCAAD and each of the sub domains on the CAPE. Table 12 outlines the findings from the Pearson’s r correlation calculations. While no significant correlations were found in relation to reported SCAAD limitation and CAPE sub domains, small sample size may play a role.

Table 12: Pearson’s r Correlations for SCAAD and CAPE

<table>
<thead>
<tr>
<th></th>
<th>Total SCAAD Limitation</th>
<th>Total Diversity</th>
<th>Total Intensity</th>
<th>Total With Whom</th>
<th>Total Where</th>
<th>Total Enjoyment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total SCAAD Limitation</td>
<td>1</td>
<td>.144</td>
<td>.123</td>
<td>.290</td>
<td>.167</td>
<td>.194</td>
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<tr>
<td>Total Diversity</td>
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<td>.924**</td>
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<td>.751**</td>
<td>.890**</td>
<td>.936**</td>
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<td>Total Intensity</td>
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<td>.806**</td>
<td>.831**</td>
<td>.901**</td>
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<tr>
<td>Total With Whom</td>
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<td>.806**</td>
<td>.831**</td>
<td>.901**</td>
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<td>Total Where Score</td>
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<td>.858**</td>
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<tr>
<td>Total Enjoyment</td>
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<td>.858**</td>
<td>.694**</td>
<td>.936**</td>
<td></td>
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</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).

**Discussion**

The purpose of this study was to develop a measure of secondary conditions, explore the reliability and validity of the measure and explore the relationship between secondary conditions and participation among adolescents with disabilities. This research collected ratings of limitation due to secondary conditions and ratings of participation of adolescents with I/DD. Ratings were collected from parents and Family Support Specialists. Data show that the participants experience an average of 11 secondary conditions during a three month period as reported by families. The inter-rater agreement between parents and Family Support Specialists was .73 on a point-by-point comparison,
and .85 when comparing whether or not limitation was an issue. Furthermore, data collected from the participation measure show that the participants in this sample participate in an average of 23 activities in a four month period as reported by families. Collected data show no statistically significant correlation between secondary condition limitation and participation in this sample.

The exploratory nature of this study allowed for examination of several topics related to adolescents with disabilities. Exploration of the validity and reliability of a secondary conditions measure occurred, as well as the relationship between secondary conditions and adolescent’s participation in a variety of activities. This small study was an introduction to the area of adolescents with disabilities, and can serve as a stepping-stone for programmatic implementation for service providers working with this population.

Overall findings from this project suggest that the adolescents in the sample population do experience limitation from secondary conditions. Family report suggests that a relatively high number of participants in the sample experience limitation from conditions such as isolation (n = 20, or 83% of the sample population), low tolerance or frustration (n = 21, 88%), fatigue (n = 19, 80%), and physical fitness/conditioning problems (n = 17, 71%). Relatively high percentages of participants in this sample report experiencing limitation due to preventable and treatable secondary conditions. This project has brought to light those secondary conditions that are most limiting to the sample. With this knowledge, service providers and families to begin can address areas of limitation.

When looking at staff and family response of the overall limitation posed by secondary conditions in this sample, there is agreement that psychological and physical fitness concerns are the most limiting. This level of agreement is indicative of families and staff working together and seeing the same kinds of limitations. Consequently, parents and staff are more likely to work together to address these concerns because they are seeing the same concerns. Additionally, the agreement between staff and parents on the secondary conditions measure points towards a reliable means of
assessing secondary conditions among adolescents with I/DD. Certainly more extensive study is warranted due to the lower exact agreement score (.73). Findings from the current study of agreement between staff and families are somewhat lower than those reported in a preliminary study conducted with the original HSCIADD. Szalda-Petree and Traci (1999) reported that an 89% agreement rate was found on the HSCIADD when completed by two individuals very familiar with the participant in question.

For the current study, a larger sample size and assessing the level of knowledge staff has of the adolescents with whom they are working may boost the reliability of the SCAAD to more acceptable levels of agreement. Additional items added to the measure in each of the factors may address the relatively low level of internal consistency found within the measure. Further research could also focus on the readability and wording of the SCAAD. Additionally, use of proxy raters, while necessary for the majority of the participants in this sample, may also affect the outcome due to an inability to fully understand the limitation experienced by the individual.

The participation data collected suggest that within this sample population there are a number of activities in which the majority of the adolescents engage. The top five activities engaged in by the majority of the participants are listening to music (n = 20, or 91%), shopping, (n = 20, 91%), visiting (n = 19, 86%), watching TV or a rented movie (n = 19, 86%), and doing a chore (n = 18, 82%). These results have prompted questions for the researcher about the activities of typical developing peers and whether or not similar results would appear in terms of the top activities in which adolescents engage in if typically developing peers were polled. It is possible that that there are several activities that the sample population engages in less frequently than their typical developing counterparts. For example, 32% of the sample population (n = 7) indicate that they have done homework at least once in the past four months, 23% (n = 5) indicate they have participated in community organizations in the last four months, and 10% (n = 2) report participating in school
clubs. While a population of typical developing peers was not surveyed, it is possible that there are differences between rates of participation in some activities, such as those just mentioned, among adolescents with disabilities and their typical developing counterparts. Further investigation looking at a sample of children without disabilities might shed light on the types of activities in which they engage and potential reasons that the percentages are low in the sample used in this study. It is possible that the nature of the primary disability does not allow for the participation in some activities. It may also be that accommodations are not readily available to help the adolescents with disabilities engage in those activities in which their same aged peers without disabilities engage.

The correlational analyses conducted for this study did not find any significant relationship between overall limitation due to secondary conditions as measured by the SCAAD and participation. A limitation of this study is the small sample size. It is possible that a stronger correlational relationship between secondary condition limitation and participation could be noted with an increase in sample size. While this study did not directly support a correlational relationship between secondary conditions and participation, it is still possible that a relationship exists. Further exploration and research into this area is necessary.

When looking at varying populations of individuals with disabilities, this study provides comparative findings for the prevalence and limitations put forth by secondary conditions. A 2004 study by Santiago and Coyle, looking at secondary conditions among women with physical disabilities, found that highest ranked secondary conditions were physical fitness/conditions problems and isolation. Both of these secondary conditions influenced the women’s ability to engage in participation in desired activities. Kinne, Patrick, and Doyle (2004) reported that some of the highest ranked secondary conditions among adults with disabilities included chronic pain, fatigue, weight problems, periods of depression, and feelings of being isolated. Findings from previous research with women with physical disabilities and adults with disabilities suggest that the current
study is on a similar track; secondary conditions found among this sample population of adolescents with disabilities is somewhat comparable to other sample populations.

Understanding the relationship between the effects of secondary conditions and participation is an important aspect in understanding development. Adolescents face the developmental task of creating and establishing their identity. Adolescence is a vital period in which the future seems bright and the exploration of the world at large becomes possible. Understanding this time period and especially understanding how this development occurs in adolescents with disabilities is important. This understanding can ultimately help organizations, such as CDC, and families foster independence and identity development in adolescents with disabilities and set them on a path towards productive adulthood. This study is a first step in understanding the developmental domain of disability and its effect on adolescents. Further research is warranted to create a bigger picture within which to work.

One potential outcome of this particular study is directly related to the service provided at the Child Development Center. This study has identified a number of secondary conditions that are affecting a subset of the population served by CDC. With this information in hand, it is possible that staff and families can be provided with education and training about the needs of adolescents associated with CDC. In particular, the prevalence rates of psychological and physical fitness conditions in this population could be addressed by creating specific training for staff to better understand, identify, and manage these types of conditions. Staff at CDC works closely with occupational and physical therapists as well as psychologists, all of whom work as a team to provide the best service possible to the children and adolescents at CDC. The information from this study can be shared with the service providers working at CDC and changes in service can be made to better address the limiting conditions of the adolescents being served.
Implications for Treatment.

The CAPE was designed for use in both clinical and research areas. Clinically, the results of the CAPE can help staff better understand the differing aspects of activities in which the participants engage. For instance, knowledge of the variety, frequency, location, and enjoyment of activities clients participate in might guide program development by way of creating a picture of client’s interests, abilities, and current level of participating. The CAPE has uses as a research tool in terms of its ability to examine “changes in children’s participation or the effectiveness of interventions over time” (King, King, et al., 2004, p. 14). Both clinically and in research, the CAPE may serve as an effective tool for the sample population and the organization from which the sample was taken.

On a case-by-case basis, the results of the SCAAD and CAPE could be used to implement appropriate programs and interventions for the families involved with a service such as the Child Development Center. Through qualitative analyses, a picture of health, limitation, and participation could be created for children and families associated with CDC and programming could be put in place. For illustrative purposes, the stories of two participants are outlined below; names have been changed for confidentiality.

Sarah. Sarah is a 14-year-old girl who currently attends a local middle school. Sarah was born prematurely and has been diagnosed with moderate cognitive delay. Sarah is a very small and thin girl. She reportedly experiences a lot of oral-motor defensiveness (i.e., will only eat liquids or pureed foods) and a number of dental-related issues, and is therefore limited in what she can eat. Sarah receives special education services at school where she is rarely mainstreamed with her typical developing peers. Sarah has recently begun services with CDC after being on the waitlist for a short period of time. Sarah’s family heard about CDC services through a peer of Sarah’s who is on services and often talks of his work with his habilitation aide.
Sarah and her family completed both the SCAAD and the CAPE for this project. Sarah’s family reported mild limitations related to physical fitness/conditioning problems, weight problems, and personal hygiene problems. The family reported major limitation due to isolation and low tolerance or frustration. Sarah’s CAPE scores indicate moderate levels of participation in activities (31 out of 55 activities) with a good portion of the activities occurring at home and in isolation.

From these findings, services through CDC could be directed toward the areas of most concern. At this point, Sarah’s family reported concerns related to Sarah’s psychological well-being (high levels of limitation due to isolation and low tolerance) as well as Sarah’s physical fitness. With this knowledge, the Family Support Specialist can work directly with Sarah and her family to address some of these concerns. In this particular case, a habilitation aide has been hired to work with Sarah for several hours everyday after school. With the habilitation aide, Sarah is learning to do daily chores and engaging in an academic activity such as reading or writing a story. The habilitation aide works directly with Sarah during these tasks and is implementing programs to address Sarah’s low tolerance for frustration. For example, the habilitation aide works with Sarah on the steps involved in each task and discusses with Sarah how to problem solve and prepare for the next steps. Sarah’s high levels of isolation are addressed by the habilitation aide as well. Sarah is now engaging in social activities on a daily basis with the aide. Furthermore, CDC helps coordinate social activities for children with aides to get together for activities such as bowling, eating out, and going to the mall.

Sarah’s Family Support Specialist is working directly with the family to coordinate occupational therapy sessions to address some of Sarah’s oral motor defensiveness which will in turn address some of her physical fitness concerns.

Peter: Peter is an 18-year-old senior in high school. Peter has been diagnosed with a cognitive delay. Peter lives with his parents and older siblings. All of Peter’s siblings have been on services with CDC during their childhoods. Peter is currently in the process of transitioning from child
services to adult services with the goals of graduating high school, getting a job, and moving to his own place. Peter was able to fill out the majority of the survey on his own. He indicated mild levels of limitation due to fatigue, depression, medication side effects, bladder dysfunction, personal and oral hygiene problems, anger, and low frustration or tolerance. Peter indicated a moderate level of limitation due to bowel dysfunction. Peter’s CAPE scores indicate a modest level of participation in activities (24 out of 55), a relatively high level of frequency in which he engages in these activities, and a high level of solitary participation.

Peter’s SCAAD and CAPE results provide an insight into the health conditions Peter finds troubling (especially bowel dysfunction) as well as the activities he currently engages in. Through understanding Peter and the responses given on the measures, his Family Support Specialist can work with him to better address some of the concerns he experiences and potentially alleviate some of his limiting factors. For example, Peter’s Family Support Specialist can help Peter advocate for medical attention to address his bowel and bladder dysfunction. He can also receive support and education regarding treatment for depression. Furthermore, CDC can work with Peter to bring him out into the community and to engage in activities with others by inviting him to activities held for peers his age or hiring a habilitation aide to work with him one-on-one.

Conclusion.

This exploratory study is only the beginning of research necessary to better understand and implement appropriate intervention and prevention programming for adolescents with disabilities. Further research is necessary with larger sample sizes, more diverse methods of measurement, and deeper degrees of analysis. Not only could future studies could address prevalence rates of secondary conditions and relationships between secondary conditions and participation as this study did, they could also explore the nature of effectiveness of special education services in school and its
relationship to health and participation, and the relationship between participation opportunities and being linked with a service organization.

From information gained in this exploratory study, the next steps involve educating staff at CDC about the rates of secondary conditions in the sample population, how these secondary conditions can be identified and treated, and implementing appropriate programs to better address the health conditions within the population served by CDC. While on a greater scale this study may not change the world, it is possible that it might influence and possibly change the world for a few adolescents in Montana who are working with staff at CDC to strengthen and improve their well-being.
References


Berliner, D. C. What's all the fuss about instructional time? In M. Ben-Peretz, & R. Bromme (eds.), The nature of time in schools: Theoretical concepts, practitioner perceptions (pp. 3-35), New York: Teachers College.


Research and training Center on Community Living, Institute on Community Integration. *DD Data Brief: Children with disabilities: social roles and family impacts in the NHIS-D.* Minneapolis, MN: Author.


## Appendix A

### Secondary Conditions Among Adolescents with Disabilities (SCAAD)

<table>
<thead>
<tr>
<th>Appendix Conditions</th>
<th>Descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Injuries</td>
<td>Description of injuries and limitations caused by physical injuries.</td>
</tr>
<tr>
<td>Severe Motor Problems</td>
<td>Description of severe motor problems and their impacts.</td>
</tr>
<tr>
<td>Severe Coordination Problems</td>
<td>Description of severe coordination problems and their impacts.</td>
</tr>
<tr>
<td>Severe Emotional Problems</td>
<td>Description of severe emotional problems and their impacts.</td>
</tr>
<tr>
<td>Severe Learning Disabilities</td>
<td>Description of severe learning disabilities and their impacts.</td>
</tr>
<tr>
<td>Severe Physical Disabilities</td>
<td>Description of severe physical disabilities and their impacts.</td>
</tr>
<tr>
<td>Severe Emotional Disabilities</td>
<td>Description of severe emotional disabilities and their impacts.</td>
</tr>
<tr>
<td>Severe Social Disabilities</td>
<td>Description of severe social disabilities and their impacts.</td>
</tr>
</tbody>
</table>

Please refer to the following table for a detailed description of each condition.
Secondary Conditions Among Adolescents with Disabilities (SCAAD)

Please rate how much each of the following conditions have affected your activity and independence in the last three months. If you have not experienced the condition in the last three months, or if it is an insignificant problem for you, please circle "0". Please refer to the following rating scale in making your ratings.

0 = not limiting or does not affect me  
1 = limits my activity a little (1 to 5 hours per week)  
2 = limits my activity some (6 to 10 hours per week)  
3 = limits my activity a lot (11 or more hours per week)

<table>
<thead>
<tr>
<th>Rating</th>
<th>Condition</th>
<th>Example or Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3</td>
<td>Physical Fitness / Conditioning Problems</td>
<td>I can’t do some activities because I am not in good enough shape or my muscles just won’t let me.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Weight Problems</td>
<td>I have a hard time keeping my weight where it needs to be for me to be healthy</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Cardiovascular (Heart) Problems</td>
<td>A doctor has told me that I have problems with my heart, such as high or low blood pressure or an irregular heartbeat.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Circulatory Problems</td>
<td>My veins or feet swell or I have had too blood clots or my blood won’t clot as it should. My blood doesn’t have enough iron or oxygen.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Respiratory Problems</td>
<td>I have difficulty breathing, I get more respiratory infections than other people my age, or I cough up phlegm.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Allergies</td>
<td>I often have allergic reactions such as rashes, puffy red eyes, runny nose, or other severe allergic reactions.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Fatigue</td>
<td>I get a very tired (though not necessarily sleepy) feeling after minimal exertion.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Depression</td>
<td>I feel very sad most of the time. I have felt this way for a long time. For example, I don’t enjoy doing my favorite things or I have a hard time sleeping.</td>
</tr>
<tr>
<td>Rating</td>
<td>Condition</td>
<td>Example or Description</td>
</tr>
<tr>
<td>--------</td>
<td>-----------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Sleep Problems/ Disturbances</td>
<td>I have a hard time falling asleep, staying asleep, or staying awake during the day</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Medication side effects</td>
<td>I am on medications that cause side effects, such as dry mouth, trembling or dizziness.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Self-inflicted injuries or Self-Abuse</td>
<td>I sometimes hurt myself on purpose. I might cut, burn, or bite myself to cause injury.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Bladder Dysfunction</td>
<td>I can't always get to the bathroom when I need to and sometimes have urinary “accidents” or I have bladder or kidney stones.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Bowel Dysfunction</td>
<td>I have problems such as diarrhea, constipation, or bowel &quot;accidents.&quot;</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Urinary tract infections</td>
<td>Sometimes when I urinate I have pain, burning, or my urine is bloody or cloudy.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Personal Hygiene Problems</td>
<td>Sometimes my hands, face, and teeth are not as clean as they should be because I do not shower, use deodorant, or do things to take care of my body and how I look very often.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Dental/Oral Hygiene</td>
<td>I have problems with my teeth, gums, or breath because I do not problems brush my teeth often enough.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Balance Problems/Dizziness</td>
<td>I have a hard time keeping my balance. I sometimes feel dizzy, am clumsy, or have a hard time moving the way I want to.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Injuries Due to Loss of Sensation</td>
<td>Parts of my body (especially my hand and feet) get hurt because I can't feel things like extreme cold, extreme heat, or sharp objects.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Contractures</td>
<td>I have a hard time moving my joints (such as my knees, hips, elbows) because the tissue around them is really tight.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Scoliosis</td>
<td>My spine has a curve in it. This curve causes me pain or problems with mobility and balance.</td>
</tr>
<tr>
<td>Rating</td>
<td>Condition</td>
<td>Example or Description</td>
</tr>
<tr>
<td>--------</td>
<td>----------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Arthritis</td>
<td>There is a lot of swelling in my joints that make it painful and hard to move or a doctor has told me that I have arthritis.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Joint and Muscle Pain</td>
<td>I have pain in my joints and muscles.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Anger</td>
<td>I get really mad in some situations or at some people and it is hard to get over being so mad.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Isolation</td>
<td>I spend a lot of time by myself. I don't hang out with friends or other people very often except for my parents, support staff, or aides.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Low Tolerance or Frustration</td>
<td>I often get so frustrated when I am trying to complete tasks that I give up.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Injuries Due to Accidents</td>
<td>I get hurt in accidents that happen because I have a hard time getting around or learning new things.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Problems with Mobility</td>
<td>I have a hard time moving my body where I want it to go because I don't have enough strength or muscle control.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Equipment Failures</td>
<td>I have problems with my equipment. Sometimes a walker, brace, hearing aid, or communication device doesn't work right.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Equipment Related Injuries to Self</td>
<td>I sometimes get hurt because my equipment (such as a wheelchair or crutches) doesn't fit me very well or is difficult for me to operate safely.</td>
</tr>
<tr>
<td>0 1 2 3</td>
<td>Equipment Related Injuries to Others</td>
<td>Other people have gotten hurt when they have tried to lift or move my equipment, such as my wheelchair.</td>
</tr>
</tbody>
</table>
Appendix B

Children’s Assessment of Participation and Enjoyment (CAPE)

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**Record Form**

Child's name ____________________________

Age _________  ☐ Male  ☐ Female  Date ____________

Did the child require assistance to complete the CAPE? ☐ Yes  ☐ No

Name of person who assisted the child in completing the CAPE: ______________________________

Relationship to child: ________________________________________________

**Directions**

1. Review each of the activities shown in the CAPE by looking at the picture and reading the description of the activity provided.

2. For each activity, ask the child if he or she has done the activity in the past four months. It may be helpful for the child to think of an activity or event that happened approximately four months ago (e.g., a birthday, holiday, spring break, start or end of the school year, or a cultural or religious event celebrated by the child's family) or to look at a calendar.

3. If the child has not done the activity in the last four months, check No and go on to the next item.

4. If the child has done the activity in the last four months, check Yes and complete the rest of the questions for that item. Circle the scores associated with the child's responses.

Always let the child answer first, before offering any assistance. Remind the child that there are no right or wrong answers to the questions.
Here is an example of a completed item to show the child.

1. Ask the child if he or she has brushed his or her teeth in the past four months.

2. Ask the child how often he or she brushes his or her teeth.

3. Next, ask the child with whom he or she does this activity.
   - Note: If the child does an activity with two types of people, circle the type with the highest score. For example, if he or she went to a party with siblings and friends, circle 4. With Friends. If he or she does an activity with three or more types of people, for example, does an activity with family, other relatives, and friends, circle the score of 5. With Others.

4. Next, ask the child where he or she does this activity.
   - Note: If the child does the activity at school, it must be outside of regular classes, such as before or after school, at recess, or as part of a school club. Neighborhood and Community was needed to be defined for the child based on the type of community (urban or rural) in which he or she lives.

5. Ask the child how much he or she likes doing the activity.
Hobbies, Crafts, and Games

Items 1-5

These drawings show kids doing hobbies, crafts, or games. Think about any hobbies, crafts, or games that you have done in the past four months outside of school.

1. Doing puzzles

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

How often?

- 1 time or less a week
- 2 times a week
- 3 times a week
- 4-5 times a week
- 6-7 times a week
- More than 7 times a week

With whom do you do this most often?

- Alone
- With Family
  (Parents, Brothers, Sisters)
- With Other Relatives
  (Grandparents, Aunts, Uncles, Cousins)
- With Friends
- With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

- At Home
- At a Relative's Home
- In Your Neighborhood
- At School (but not during classes)
- In Your Community
- Beyond Your Community

How much do you like or enjoy doing this activity?

- Not at all
- Somewhat
- Pretty much
- Very much
- Love it
### Hobbies, Crafts, and Games (continued)

#### Playing board or card games

**Have you done this activity in the past four months?**
- □ No (go to the next item)
- □ Yes (complete each of the questions below)

<table>
<thead>
<tr>
<th>How often?</th>
<th>1 2 3 4 5</th>
<th>1 2 3 4 5</th>
<th>1 2 3 4 5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Once a day</td>
<td>Once a week</td>
<td>Once a month</td>
</tr>
</tbody>
</table>

**With whom do you do this most often?**
- □ Alone
- □ With Family (Parents, Brothers, Sisters)
- □ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
- □ With Instructors (Parents, Brothers, Sisters)
- □ With Other individuals, or Multiple types of people

**Where do you do this most often?**
- □ At Home
- □ At a Relative’s Home
- □ At School (but not during classes)
- □ In Your Neighborhood
- □ In Your Community
- □ Beyond Your Community

**How much do you like or enjoy doing this activity?**

![Rating scale](image)

#### Doing crafts, drawing, or coloring

**Have you done this activity in the past four months?**
- □ No (go to the next item)
- □ Yes (complete each of the questions below)

<table>
<thead>
<tr>
<th>How often?</th>
<th>1 2 3 4 5</th>
<th>1 2 3 4 5</th>
<th>1 2 3 4 5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Once a day</td>
<td>Once a week</td>
<td>Once a month</td>
</tr>
</tbody>
</table>

**With whom do you do this most often?**
- □ Alone
- □ With Family (Parents, Brothers, Sisters)
- □ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
- □ With Instructors (Parents, Brothers, Sisters)
- □ With Other individuals, or Multiple types of people

**Where do you do this most often?**
- □ At Home
- □ At a Relative’s Home
- □ At School (but not during classes)
- □ In Your Neighborhood
- □ In Your Community
- □ Beyond Your Community

**How much do you like or enjoy doing this activity?**

![Rating scale](image)
**Hobbies, Crafts, and Games (continued)**

## Collecting things

### Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

#### How often?

- 1 time in the past 4 months
- 2-3 times in the past 4 months
- 1 time a week
- 2-3 times a week
- 1 time a day of more

#### With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

#### Where do you do this most often?

1. At Home
2. At a Relative’s Home
3. In Your Neighborhood

#### How much do you like or enjoy doing this activity?

![Emoji icons representing different levels of enjoyment]

1. Not at all
2. Complacent, Sort of
3. Pretty much
4. Very much
5. Love it

## Playing computer or video games

### Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

#### How often?

- 1 time in the past 4 months
- 2-3 times in the past 4 months
- 1 time a week
- 2-3 times a week
- 1 time a day of more

#### With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Individuals (Instructors, Other individuals, or Multiple types of people)

#### Where do you do this most often?

1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. In Your Community
5. Beyond Your Community

#### How much do you like or enjoy doing this activity?

![Emoji icons representing different levels of enjoyment]

1. Not at all
2. Complacent, Sort of
3. Pretty much
4. Very much
5. Love it
Social Activities

Items 6-11

The next drawings show kids doing things with other people. Think about the activities that you have done with other people in the past four months outside of school.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Have you done this activity in the past four months?</th>
<th>How often?</th>
<th>With whom do you do this most often?</th>
<th>Where do you do this most often?</th>
<th>How much do you like or enjoy doing this activity?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking on the phone</td>
<td>Yes (complete each of the questions below)</td>
<td>1-2 times a month</td>
<td>Alone</td>
<td>At Home</td>
<td>Love it</td>
</tr>
<tr>
<td></td>
<td>No (go to the next item)</td>
<td>3-4 times a month</td>
<td>With Family (Parents, Brothers, Others)</td>
<td>At a Relative's Home</td>
<td>Preferable</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5-6 times a month</td>
<td>With Other Relatives (Grandparents, Aunts, Uncles, Cousins)</td>
<td>In Your Neighborhood</td>
<td>Probably</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7-8 times a month</td>
<td>With Other (Instructors, Other individuals, or Multiple types of people)</td>
<td>At School (but not during classes)</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td></td>
<td>More than once a week</td>
<td></td>
<td>Beyond Your Community</td>
<td>Somewhat</td>
</tr>
</tbody>
</table>

Note: This activity involves talking on the phone, and the questions ask about the frequency, with whom, and where the activity is done, as well as how much the person enjoys it.
Social Activities (continued)

7. Going to a party

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?
1. Once or twice a month
2. Once a month
3. Twice a month
4. Twice a month
5. Three to four times a month
6. Once a week
7. More than once a week

With whom do you do this most often?
1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it

8. Hanging out

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?
1. Once or twice a month
2. Once a month
3. Twice a month
4. Twice a month
5. Three to four times a month
6. Once a week
7. More than once a week

With whom do you do this most often?
1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it
### Social Activities

#### Visiting

Have you done this activity in the past four months?
- □ No (go to the next item)
- □ Yes (complete each of the questions below)

**How often?**

- □ 1 time in the past 4 months
- □ 2-3 times in the past 4 months
- □ 4-5 times in the past 4 months
- □ 6+ times in the past 4 months
- □ Never or less than once a month
- □ Once a month
- □ Twice a month
- □ Three times a month
- □ Four times a month
- □ Five times a month
- □ Six times a month
- □ More than six times a month

**With whom do you do this most often?**

- □ Alone
- □ With Friends
- □ With Family (Parents, Brothers, Sisters)
- □ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
- □ With Others (Instructors, Other individuals, or Multiple types of people)

**Where do you do this most often?**

- □ At Home
- □ At a Relative’s Home
- □ At School (but not during classes)
- □ At School (but not during classes)
- □ In Your Community
- □ In Your Neighborhood
- □ Beyond Your Community

How much do you like or enjoy doing this activity?

- □ Not at all
- □ Somewhat
- □ Pretty much
- □ Very much
- □ Love it

#### Writing letters

Have you done this activity in the past four months?
- □ No (go to the next item)
- □ Yes (complete each of the questions below)

**How often?**

- □ 1 time in the past 4 months
- □ 2-3 times in the past 4 months
- □ 4-5 times in the past 4 months
- □ 6+ times in the past 4 months
- □ Never or less than once a month
- □ Once a month
- □ Twice a month
- □ Three times a month
- □ Four times a month
- □ Five times a month
- □ Six times a month
- □ More than six times a month

**With whom do you do this most often?**

- □ Alone
- □ With Friends
- □ With Family (Parents, Brothers, Sisters)
- □ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
- □ With Others (Instructors, Other individuals, or Multiple types of people)

**Where do you do this most often?**

- □ At Home
- □ At a Relative’s Home
- □ At School (but not during classes)
- □ In Your Community
- □ In Your Neighborhood
- □ Beyond Your Community

How much do you like or enjoy doing this activity?

- □ Not at all
- □ Somewhat
- □ Pretty much
- □ Very much
- □ Love it
Entertaining others

Have you done this activity in the past four months?

☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1. Never
2. Once or twice a month
3. Once a month
4. Twice a month
5. Almost every week
6. More than once a week
7. Once a day
8. More than once a day

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Hate it
2. Dislike it
3. Dislike it
4. Like it
5. Love it
Quiet Recreation

Items 12-15

These drawings show kids doing quiet activities. Think about quiet activities that you have done in the past four months outside of school.

Playing with pets

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

How often?
1. 1 time in the past 4 months
2. 2 times in the past 4 months
3. 1 time a month
4. 2-3 times a month
5. 1 time a week
6. 2-3 times a week
7. 1 time a day or more

With whom do you do this most often?
1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Hate it!
2. Complained
3. Sort of
4. Pretty much
5. Yeah, much
6. Love it!
Quiet Recreation (continued)

12. Writing a story

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

- Every day
- 2 times a week
- 1 time a week
- 2-3 times a month
- 1 time a month
- 2-3 times a year
- 1 time a year
- More than once a year
- Rarely
- Never

With whom do you do this most often?

- Alone
- With Family
  (Parents, Brothers, Sisters)
- With Friends
- With Other (Instructors, Other types of people)
- With Other Relatives
  (Grandparents, Uncles, Cousins)

Where do you do this most often?

- At Home
- At a Relative’s Home
- At School (but not during classes)
- In Your Neighborhood
- In Your Community
- Beyond Your Community
- School (during classes)
- Travel

How much do you like or enjoy doing this activity?

- Not at all
- Somewhat
- Pretty much
- Very much
- Love it

13. Doing pretend or imaginary play

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

- Every day
- 2 times a week
- 1 time a week
- 2-3 times a month
- 1 time a month
- 2-3 times a year
- 1 time a year
- More than once a year
- Rarely
- Never

With whom do you do this most often?

- Alone
- With Family
  (Parents, Brothers, Sisters)
- With Friends
- With Other (Instructors, Other types of people)
- With Other Relatives
  (Grandparents, Uncles, Cousins)

Where do you do this most often?

- At Home
- At a Relative’s Home
- At School (but not during classes)
- In Your Neighborhood
- In Your Community
- Beyond Your Community
- School (during classes)
- Travel

How much do you like or enjoy doing this activity?

- Not at all
- Somewhat
- Pretty much
- Very much
- Love it
113 Playing with things or toys

Have you done this activity in the past four months?

☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1 time in the past 6 months 2 times in the past 4 months 1 time a month 2-3 times a month 1 time a week 2-3 times a week 1 time a day or more

With whom do you do this most often?

1 Alone
2 With Family (Parents, Brothers, Sisters)
3 With Other Relations (Grandparents, Aunts, Uncles, Cousins)
4 With Friends
5 With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1 At Home
2 At a Relative’s Home
3 In Your Neighborhood
4 At School (but not during classes)
5 In Your Community
6 Beyond Your Community

How much do you like or enjoy doing this activity?

1 Not at all
2 Somewhat
3 Pretty much
4 Very much
5 Love it
Items 16-21

In the next group of drawings, you will see kids playing different kinds of sports. The kids playing these sports are usually on sports teams and may play games against other teams. Sometimes these kids will have lessons or practices to get better at their sport. Think about any sports lessons, practices, or games that you have done in the past four months outside of school.

53 Doing martial arts

Have you done this activity in the past four months?

☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1. Every week
2. 2-3 times a week
3. Once a week
4. 2-3 times a month
5. Once a month
6. Several times a year

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. In School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Not at all
2. Somewhat
3. Partly
4. Very much
5. Love it

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Organized Sports (continued)

57. Swimming

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

How often?
- 1 time in the past 4 months
- 2-4 times in the past 4 months
- 1 time a month
- 2-4 times a month
- 1 time a week
- 2-4 times a week
- I have done it daily

With whom do you do this most often?
1. Alone
2. With Friends
3. With Others (Instructors, Other individuals, or Multiple types of people)
4. With Family (Parents, Brothers, Sisters)
5. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Dislike
3. Pretty much
4. Very much
5. Love it

---

58. Doing gymnastics

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

How often?
- 1 time in the past 4 months
- 2-4 times in the past 4 months
- 1 time a month
- 2-4 times a month
- 1 time a week
- 2-4 times a week
- I have done it daily

With whom do you do this most often?
1. Alone
2. With Friends
3. With Others (Instructors, Other individuals, or Multiple types of people)
4. With Family (Parents, Brothers, Sisters)
5. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Dislike
3. Pretty much
4. Very much
5. Love it
Organized Sports

Horseback riding

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1. Never
2. Less than a month
3. Once a month
4. Twice a month
5. Three times a month
6. Four times a month
7. More than four times a month

With whom do you do this most often?
1. Alone
2. With Family
   (Parents, Brothers, Sisters)
3. With Other Relatives
   (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others
   (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it

Racing or track and field

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1. Never
2. Less than a month
3. Once a month
4. Twice a month
5. Three times a month
6. Four times a month
7. More than four times a month

With whom do you do this most often?
1. Alone
2. With Family
   (Parents, Brothers, Sisters)
3. With Other Relatives
   (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others
   (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At School (but not during classes)
2. At School (but not during classes)
3. In Your Community
4. In Your Community
5. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it
# Organized Sports (continued)

**Doing team sports**

<table>
<thead>
<tr>
<th>Have you done this activity in the past four months?</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ No (go to the next item)</td>
</tr>
<tr>
<td>☐ Yes (complete each of the questions below)</td>
</tr>
</tbody>
</table>

**How often?**

- 1 time in the past 4 months
- 2-3 times a month
- 2-3 times a week
- More than once a week

**With whom do you do this most often?**

- 1 Alone
- 2 With Family (Parents, Brothers, Sisters)
- 3 With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
- 4 With Friends
- 5 With Others (Instructors, Other individuals, or Multiple types of people)

**Where do you do this most often?**

- 1 At Home
- 2 At a Relative’s Home
- 3 In Your Neighborhood
- 4 At School (but not during classes)
- 5 In Your Community
- 6 Beyond Your Community

**How much do you like or enjoy doing this activity?**

- 1 Not at all
- 2 Dislike
- 3 Pretty much
- 4 Very much
- 5 Love it
Other Skill-Based Activities

Items 22-27

The next group of drawings shows kids taking lessons with an instructor or a tutor. The kids in these drawings are trying to get better at a skill or learn a new skill. These activities also include practices or rehearsals as well as performances such as recitals. Think about any lessons, practices, or performances that you have done in the past four months outside of school.

Learning to sing (choir or individual lessons)

Have you done this activity in the past four months?

□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

□ 1 time in the past 4 months □ 2 times in the past 4 months □ 1 time a month □ 2-3 times a month □ 1 time a week □ 2-3 times a week □ 1 time a day or more

With whom do you do this most often?

□ Alone □ With Family □ With Friends □ With Others (Instructors, Other individuals, or Multiple types of people)
□ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?

□ At Home □ At a Relative's Home □ In Your Neighborhood □ At School (but not during classes) □ In Your Community □ Beyond Your Community

How much do you like or enjoy doing this activity?

□ Not at all □ Somewhat □ Pretty much □ Very much □ Love it!
Other Skill-Based Activities (continued)

3. Taking art lessons

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (please complete each of the questions below)

How often?

1. Never
2. Once a month
3. 2-3 times a month
4. Once a week
5. 2-3 times a week
6. Once a day or more
7. Other

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)
6. Other

Where do you most often?

1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community
7. Other

How much do you like or enjoy doing this activity?

1. Not at all
2. Because
3. Pretty much
4. Very much
5. Love it

4. Learning to dance

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (please complete each of the questions below)

How often?

1. Never
2. Once a month
3. 2-3 times a month
4. Once a week
5. 2-3 times a week
6. Once a day or more
7. Other

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)
6. Other

Where do you most often?

1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community
7. Other

How much do you like or enjoy doing this activity?

1. Not at all
2. Because
3. Pretty much
4. Very much
5. Love it
Other Skill-Based Activities (continued)

Getting extra help for schoolwork from a tutor

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

1. Once in the past 4 months
2. 2-3 times a month
3. Once a week
4. Twice a week
5. Every day or more

With whom do you do this most often?
1. Alone
2. With Family (Parent, Brother, Sister)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or multiple types of people)
6. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
1. At Home
2. At School (but not during classes)
3. At a Relative’s Home
4. In Your Community
5. In Your Neighborhood
6. Beyond Your Community

How much do you like or enjoy doing this activity?

□ Not at all
□ Somewhat
□ Pretty much
□ Very much
□ Love it

Playing a musical instrument

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

1. Once in the past 4 months
2. 2-3 times a month
3. Once a week
4. Twice a week
5. Every day or more

With whom do you do this most often?
1. Alone
2. With Family (Parent, Brother, Sister)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or multiple types of people)
6. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
1. At Home
2. At School (but not during classes)
3. At a Relative’s Home
4. In Your Community
5. In Your Neighborhood
6. Beyond Your Community

How much do you like or enjoy doing this activity?

□ Not at all
□ Somewhat
□ Pretty much
□ Very much
□ Love it
Taking music lessons

Have you done this activity in the past four months?

☐ No (go to the next item)

☐ Yes (complete each of the questions below)

How often?

1 time in the past 6 months
2 times in the past 6 months
3 times in the past 6 months
4 times a week
5 times a week
6 times a week
7 times a week or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative’s Home
3. At School (but not during classes)
4. In Your Neighborhood
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Hate it
2. Dislike it
3. Neutral
4. Like it
5. Love it
### Doing a religious activity

**Have you done this activity in the past four months?**
- [ ] No (go to the next item)
- [ ] Yes (complete each of the questions below)

**How often?**
- [ ] 1 time in the past 4 months
- [ ] 2-3 times in the past 4 months
- [ ] 4-6 times in the past 4 months
- [ ] 7-9 times in the past 4 months
- [ ] More than a day or more

**With whom do you do this most often?**
- [ ] Alone
- [ ] With Family (Parents, Brothers, Sisters)
- [ ] With Other Relatives (Grandparents, Aunt, Uncle, Cousins)
- [ ] With Friends
- [ ] With Others (Instructors, Other individuals or Multiple types of people)

**Where do you do this most often?**
- [ ] At Home
- [ ] At a Relative's Home
- [ ] In Your Neighborhood
- [ ] At School (but not during classes)
- [ ] In Your Community
- [ ] Beyond Your Community

**How much do you like or enjoy doing this activity?**
- [ ] Not at all
- [ ] Somewhat
- [ ] Pretty much
- [ ] Very much
- [ ] Love it

### Participating in school clubs

**Have you done this activity in the past four months?**
- [ ] No (go to the next item)
- [ ] Yes (complete each of the questions below)

**How often?**
- [ ] 1 time in the past 4 months
- [ ] 2-3 times in the past 4 months
- [ ] 4-6 times in the past 4 months
- [ ] 7-9 times in the past 4 months
- [ ] More than a day or more

**With whom do you do this most often?**
- [ ] Alone
- [ ] With Family (Parents, Brothers, Sisters)
- [ ] With Other Relatives (Grandparents, Aunt, Uncle, Cousins)
- [ ] With Friends
- [ ] With Others (Instructors, Other individuals or Multiple types of people)

**Where do you do this most often?**
- [ ] At Home
- [ ] At a Relative's Home
- [ ] In Your Neighborhood
- [ ] At School (but not during classes)
- [ ] In Your Community
- [ ] Beyond Your Community

**How much do you like or enjoy doing this activity?**
- [ ] Not at all
- [ ] Somewhat
- [ ] Pretty much
- [ ] Very much
- [ ] Love it
Active Physical Recreation

Items 31-41

These drawings show kids doing physical recreation activities. Some of the activities are sports that you would play, but these are not organized or team sports. Think about the physical recreation activities that you have done in the past four months outside of school.

Dancing

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

How often?

- Once in the past 4 months
- 2 times in the past 4 months
- 1 time a month
- 2-3 times a month
- 1 time a week
- 2-3 times a week
- 1 time a day or more

With whom do you do this most often?
- Alone
- With Family (Parents, Brothers, Sisters)
- With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
- With Friends
- With Others (Instructors, Other individual, or Multiple types of people)

Where do you do this most often?
- At Home
- At a Relative's Home
- In Your Neighborhood
- In Your Community
- At School (but not during classes)
- Beyond Your Community

How much do you like or enjoy doing this activity?
- Not at all
- Somewhat
- Pretty much
- Very much
- Like it
Active Physical Recreation (continued)

33. Going for a walk or a hike

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

□ 1 time in the past 4 months □ 2 times in the past 4 months □ 3 times in the past 4 months □ 4 times in the past 4 months □ 5 times in the past 4 months □ 6 times in the past 4 months □ 7 times in the past 4 months □ 8 times in the past 4 months □ 9 times in the past 4 months □ 10 times in the past 4 months □ More than 10 times in the past 4 months

With whom do you do this most often?

□ Alone □ With Friends □ With Family (Parents, Brothers, Sisters) □ With Other Relatives (Grandparents, Aunts, Uncles, Cousins) □ With Other Individuals, or Multiple types of people

Where do you do this most often?

□ At Home □ At a Relative’s Home □ In Your Neighborhood □ At School (but not during classes) □ In Your Community □ Beyond Your Community

How much do you like or enjoy doing this activity?

□ Not at all □ Somewhat □ Sort of □ Pretty much □ Very much □ Love it

34. Bicycling, in-line skating, or skateboarding

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

□ 1 time in the past 4 months □ 2 times in the past 4 months □ 3 times in the past 4 months □ 4 times in the past 4 months □ 5 times in the past 4 months □ 6 times in the past 4 months □ 7 times in the past 4 months □ 8 times in the past 4 months □ 9 times in the past 4 months □ 10 times in the past 4 months □ More than 10 times in the past 4 months

With whom do you do this most often?

□ Alone □ With Friends □ With Family (Parents, Brothers, Sisters) □ With Other Relatives (Grandparents, Aunts, Uncles, Cousins) □ With Other Individuals, or Multiple types of people

Where do you do this most often?

□ At Home □ At a Relative’s Home □ In Your Neighborhood □ At School (but not during classes) □ In Your Community □ Beyond Your Community

How much do you like or enjoy doing this activity?

□ Not at all □ Somewhat □ Sort of □ Pretty much □ Very much □ Love it
Active Physical Recreation (continued)

44. Doing water sports

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

1. Once a day or more
2. 2-3 times a week
3. 1 time a week
4. 2-3 times a month
5. 1 time a month
6. 2-3 times a year
7. 1 time a year
8. Never

With whom do you do this most often?
1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it

45. Doing snow sports

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

1. Once a day or more
2. 2-3 times a week
3. 1 time a week
4. 2-3 times a month
5. 1 time a month
6. 2-3 times a year
7. 1 time a year
8. Never

With whom do you do this most often?
1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it
Active Physical Recreation (continued)

Playing on equipment

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?
1. Never
2. 1 time in the past 4 months
3. 2-3 times a month
4. 1 time a week
5. 2-3 times a week
6. 1 time a day or more

With whom do you do this most often?
1. Alone
2. With Family
   (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other Individuals, or Multiple Types of People)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it

Playing games

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?
1. Never
2. 1 time in the past 4 months
3. 2-3 times a month
4. 1 time a week
5. 2-3 times a week
6. 1 time a day or more

With whom do you do this most often?
1. Alone
2. With Friends
3. With Family
   (Parents, Brothers, Sisters)
4. With Other Types of People
5. With Others (Instructors, Other Individuals, or Multiple Types of People)
6. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
1. At Home
2. At School (but not during classes)
3. At a Relative's Home
4. In Your Neighborhood
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it
Active Physical Recreation (continued)

Gardening

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1 1 1 1
1 time a week 2 times a week 1 time a month 2 times a month

With whom do you do this most often?
☐ Alone
☐ With Family (Parents, Brothers, Sisters)
☐ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
☐ At Home
☐ At a Relative’s Home
☐ In Your Neighborhood
☐ At School (but not during classes)
☐ In Your Community
☐ Beyond Your Community

How much do you like or enjoy doing this activity?

Not at all
Somewhat
Pretty much
Very much
Love it

Fishing

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1 1 1 1
1 time a week 2 times a week 1 time a month 2 times a month

With whom do you do this most often?
☐ Alone
☐ With Family (Parents, Brothers, Sisters)
☐ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
☐ At Home
☐ At a Relative’s Home
☐ In Your Neighborhood
☐ At School (but not during classes)
☐ In Your Community
☐ Beyond Your Community

How much do you like or enjoy doing this activity?

Not at all
Somewhat
Pretty much
Very much
Love it
Active Physical Recreation (continued)

43. Doing individual physical activities

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?
1. Never
2. Once in the past 4 months
3. 2-3 times a month
4. Once a week
5. 2-3 times a week
6. Once a day or more

With whom do you do this most often?
1. Alone
2. With Friends
3. With Others (Instructors, Other individuals, or Multiple types of people)
4. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Quite a bit
4. Very much
5. Love it

44. Playing non-team sports

Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?
1. Never
2. Once in the past 4 months
3. 2-3 times a month
4. Once a week
5. 2-3 times a week
6. Once a day or more

With whom do you do this most often?
1. Alone
2. With Friends
3. With Family (Parents, Brothers, Sisters)
4. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

Where do you do this most often?
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?
1. Not at all
2. Somewhat
3. Quite a bit
4. Very much
5. Love it
Entertainment and Education

Items 42-48

The next group of drawings shows kids who are being entertained or learning new things. These activities do not include field trips that are taken with school. Think about activities you have done in the past four months where you were entertained or you learned something new outside of school.

Going to the movies

Have you done this activity in the past four months?

☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

1 2 3 4 5

1-3 times in the past 4 months
3-6 times in the past 4 months
6 or more times in the past 4 months
1-3 times a month
3-6 times a month
6 or more times a month
1-3 times a week
3-6 times a week
6 or more times a week

How much do you like or enjoy doing this activity?

□ Not at all
□ Occasionally
□ Pretty much
□ Very much
□ Love it

With whom do you do this most often?

☐ Alone
☐ With Friends
☐ With Family (Parents, Brothers, Sisters)
☐ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
☐ With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

☐ At Home
☐ At a Relative’s Home
☐ In Your Neighborhood
☐ At School (but not during classes)
☐ In Your Community
☐ Beyond Your Community

Think about activities you have done in the past four months where you were entertained or you learned something new outside of school.
Entertainment and Education (continued)

423 Going to the public library
Have you done this activity in the past four months?
□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

[Diagram showing frequency options: Never, Once a month, Twice a month, 2-3 times a month, Once a year, Less than once a year]

With whom do you do this most often?
1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
1. At Home
2. At a Relative’s Home
3. At School (but not during classes)
4. Beyond Your Community
5. In Your Neighborhood
6. In Your Community

How much do you like or enjoy doing this activity?

[Scale from 1 to 5: Not at all, Somewhat, Pretty much, Very much, Love it]
Going to a live event

Have you done this activity in the past four months?

□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

- 1 time in the past 4 months
- 2 times in the past 4 months
- 3 times a month
- 4 times a month
- 5 times a week
- 6 times a week
- 7 times a day

With whom do you do this most often?

1. Alone
2. With Family
   (Parents, Brothers, Sisters)
3. With Other Relatives
   (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Not at all
2. Dislike
3. Pretty much
4. Nor much
5. Love it

Going on a full-day outing

Have you done this activity in the past four months?

□ No (go to the next item)
□ Yes (complete each of the questions below)

How often?

- 1 time in the past 4 months
- 2 times in the past 4 months
- 3 times a month
- 4 times a month
- 5 times a week
- 6 times a week
- 7 times a day

With whom do you do this most often?

1. Alone
2. With Friends
3. With Family
   (Parents, Brothers, Sisters)
4. With Other Relatives
   (Grandparents, Aunts, Uncles, Cousins)
5. With Other (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. At School (but not during classes)
5. In Your Community
6. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Not at all
2. Dislike
3. Pretty much
4. Nor much
5. Love it
Entertainment and Education (continued)

**Reading**

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

**How often?**

1. Never in the past 4 months
2. 1 month
3. 2-3 months
4. 1-2 times a week
5. 2-3 times a week
6. 1 time a day or more
7. More than a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative’s Home
3. In Your Neighborhood
4. In Your Community
5. Beyond Your Community

How much do you like or enjoy doing this activity?

1. Not at all
2. Disappointed
3. Sort of
4. Pretty much
5. Love it

**Listening to music**

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

**How often?**

1. Never in the past 4 months
2. 1 month
3. 2-3 months
4. 1-2 times a week
5. 2-3 times a week
6. 1 time a day or more
7. More than a day or more

With whom do you do this most often?

1. Alone
2. With Family (Parents, Brothers, Sisters)
3. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
4. With Friends
5. With Others (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?

1. At Home
2. At a Relative’s Home
3. At School (but not during classes)
4. In Your Community
5. In Your Neighborhood

How much do you like or enjoy doing this activity?

1. Not at all
2. Disappointed
3. Sort of
4. Pretty much
5. Love it
These activities are things kids do, like helping out at home. Think about any jobs or chores that you have done in the past four months outside of school.

**Items 49-55**

**49. Doing volunteer work**

Have you done this activity in the past four months?
- [ ] No (go to the next item)
- [ ] Yes (complete each of the questions below)

**How often?**

[ ] 0 times in the past 4 months
[ ] 1 time in the past 4 months
[ ] 2 times in the past 4 months
[ ] 3-5 times in the past 4 months
[ ] 6-9 times in the past 4 months
[ ] 10 or more times in the past 4 months

**With whom do you do this most often?**

[ ] Alone
[ ] With Family (Parents, Brothers, Sisters)
[ ] With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
[ ] With Friends
[ ] With Others (Instructors, Other individuals, or Multiple types of people)

**Where do you do this most often?**

[ ] At Home
[ ] At a Relative's Home
[ ] In Your Neighborhood
[ ] In Your Community
[ ] At School (but not during classes)
[ ] Beyond Your Community

**How much do you like or enjoy doing this activity?**

[ ] Not at all
[ ] Somewhat
[ ] Pretty much
[ ] Very much
[ ] Love it
Jobs, Chores, and Employment (continued)

Doing a chore

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

How often?

1. Once in the past 4 months
2. Twice a week
3. Every other week
4. 2-3 times a month
5. 1 time a month
6. 1 time a day or more

With whom do you do this most often?
- Alone
- With Friends
- With Family (Parents, Brothers, Sisters)
- With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
- With Other Individuals (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
- At Home
- At a Relative’s Home
- In Your Neighborhood
- At School (but not during classes)
- In Your Community
- Beyond Your Community

How much do you like or enjoy doing this activity?
- Not at all
- Somewhat
- Pretty much
- Very much
- Love it

Doing a paid job

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

How often?

1. Once in the past 4 months
2. Twice a week
3. Every other week
4. 2-3 times a month
5. 1 time a month
6. 1 time a day or more

With whom do you do this most often?
- Alone
- With Friends
- With Family (Parents, Brothers, Sisters)
- With Other Individuals (Instructors, Other individuals, or Multiple types of people)

Where do you do this most often?
- At Home
- At a Relative’s Home
- In Your Neighborhood
- At School (but not during classes)
- In Your Community
- Beyond Your Community

How much do you like or enjoy doing this activity?
- Not at all
- Somewhat
- Pretty much
- Very much
- Love it
Making food

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

□ 1 time in the past 4 months
□ 2 times in the past 4 months
□ 3 times in the past 4 months
□ 4 times in the past 4 months
□ More than 4 times in the past 4 months

With whom do you do this most often?
☐ Alone
☐ With Friends
☐ With Others (instructors, other individuals, or multiple types of people)
☐ With Family
☐ With Family (Parents, Brothers, Sisters)
☐ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
☐ With Others (instructors, other individuals, or multiple types of people)

Where do you do this most often?
☐ At Home
☐ At a Relative's Home
☐ In Your Neighborhood
☐ At School (but not during classes)
☐ In Your Community
☐ Beyond Your Community

How much do you like or enjoy doing this activity?

Not at all
Somewhat
Quite a lot
Very much
Love it

Doing homework

Have you done this activity in the past four months?
☐ No (go to the next item)
☐ Yes (complete each of the questions below)

How often?

□ 1 time in the past 4 months
□ 2 times in the past 4 months
□ 3 times in the past 4 months
□ 4 times in the past 4 months
□ More than 4 times in the past 4 months

With whom do you do this most often?
☐ Alone
☐ With Friends
☐ With Others (instructors, other individuals, or multiple types of people)
☐ With Family
☐ With Family (Parents, Brothers, Sisters)
☐ With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
☐ With Others (instructors, other individuals, or multiple types of people)

Where do you do this most often?
☐ At Home
☐ At a Relative's Home
☐ In Your Neighborhood
☐ At School (but not during classes)
☐ In Your Community
☐ Beyond Your Community

How much do you like or enjoy doing this activity?

Not at all
Somewhat
Quite a lot
Very much
Love it
Jobs, Chores, and Employment (continued)

**Shopping**

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

**How often?**
1. Never
2. 1-2 times in the past 6 months
3. 2-3 times a month
4. 1 time a week
5. 2-3 times a week
6. 1 time a day or more

**With whom do you do this most often?**
1. Alone
2. With Friends
3. With Family
4. With Others (Instructors, Other individuals, or Multiple types of people)
5. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)
6. Other

**Where do you do this most often?**
1. At Home
2. At a Relative's Home
3. In Your Neighborhood
4. In Your Community
5. Beyond Your Community

**How much you like or enjoy doing this activity?**
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it

**Taking care of a pet**

Have you done this activity in the past four months?
- No (go to the next item)
- Yes (complete each of the questions below)

**How often?**
1. Never
2. 1-2 times in the past 6 months
3. 2-3 times a month
4. 1 time a week
5. 2-3 times a week
6. 1 time a day or more

**With whom do you do this most often?**
1. Alone
2. With Friends
3. With Family
4. With Others (Instructors, Other individuals, or Multiple types of people)
5. With Other Relatives (Grandparents, Aunts, Uncles, Cousins)

**Where do you do this most often?**
1. At Home
2. At School (but not during classes)
3. In Your Community
4. In Your Neighborhood
5. Beyond Your Community

**How much you like or enjoy doing this activity?**
1. Not at all
2. Somewhat
3. Pretty much
4. Very much
5. Love it

**Other Activities**

Are there any other activities outside of school that we have not talked about? This is an opportunity to add in any other activities you have done in the last four months that we have not asked you about.

_____________________________________________________

36