

The transition to adulthood for youth with ID/DD: A review of research, policy and next steps

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Introduction

More than a third of youth with special health care needs* have been diagnosed with a developmental, emotional, or behavioral disability or condition.¹

Youth with developmental disabilities face numerous challenges with regard to maintaining effective and continuous health care as they reach adulthood. First, they must ensure that they maintain access to health coverage, either through public insurance programs (e.g., Medicaid) or through private insurance. Second, as legal adults, they must take on responsibility for managing their own health care, with appropriate supports. Third, they must secure age-appropriate health care and must transition from pediatric health care providers to adult-oriented providers or, in the context of family medicine, transition from a pediatric model of health care to an adult model of health care.

Background

Youth aging out of public benefits and private health insurance must secure alternate sources of coverage.

According to the 2009-2010 National Survey on Children with Special Health Care Needs, the vast majority of youth with special health care needs are insured.² Coverage, however, is usually subject to age-related cutoffs and may therefore expire in young adulthood. Youth who have health care coverage through their parents' private health insurance plans must obtain independent coverage by the age of 26.³ Youth enrolled in the Children's Health Insurance Program (CHIP) become ineligible for coverage at age 19.⁴ Youth who are enrolled in Medicaid typically lose coverage at the age of 18 unless they qualify for Medicaid as adults, although some states extend Medicaid coverage until the age of 21 for full-time students.⁸ Although Medicaid is typically available to all children who meet income eligibility criteria, in most states adults are eligible for Medicaid only if they meet additional criteria in addition to income, such as parenting or eligibility for Supplemental Security Income (SSI).¹⁰

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* The Maternal and Child Health Bureau defines children with special health care needs as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." (Gleason, et al., 2009).

These age-based eligibility requirements have historically contributed to widespread loss of insurance when youth reach adulthood, regardless of disability. The Commonwealth Fund Survey of Young Adults in 2009 found that 30% of previously insured young adults became uninsured upon graduating from high school. This is in addition to the 15% who were required to transition to a new source of coverage, nearly half of whom experienced a gap in coverage. The majority of those gaps lasted one year or more.¹³ A separate study in 2007 found that nearly 30% of all individuals between the ages of 18 and 24 years of age were uninsured, compared to only 12% of children under the age of 18.¹⁴

Although young adults with disabilities experience loss of insurance at similar rates to the general population, they may be at additional risk of experiencing gaps in coverage.¹⁶ Youth of color and youth in rural areas who are in need of public health benefits may also be at particular risk of losing coverage.¹⁸

As with all young adults, lack of coverage leads to poor health outcomes for young adults with developmental disabilities. Overall, 76% of uninsured young adults have reported forgoing necessary medical care because of cost.¹⁹ Young adults who lack access to health insurance are also less likely to obtain preventative care and may suffer from uncoordinated and disjointed care.²⁰ Uninsured children with autism spectrum diagnoses are similarly at an increased risk for unmet health needs.²²

The Affordable Care Act will increase the number of young adults with developmental disabilities eligible for continued insurance coverage.

The Patient Protection and Affordable Care Act of 2010 (ACA) includes provisions regarding public and private insurance that may, if properly implemented, smooth the transition to adulthood for youth with developmental disabilities. As of 2010, private insurance plans that include dependent coverage must now extend that coverage to dependents until they reach the age of 26. Beginning in 2014, young adults with disabilities will be able to purchase affordable health insurance through statewide exchanges even if their employers do not provide health insurance. Young adults with incomes up to 400% of the poverty line may be eligible for subsidized premiums for insurance they purchase through exchanges. Moreover, youth with developmental disabilities will be able to obtain insurance despite their pre-existing diagnoses, as health insurance providers may not refuse coverage or charge higher rates based on pre-existing conditions.²⁶

The ACA also expands Medicaid benchmark plan coverage to childless adults with incomes below 133% of the poverty line. In 2012, the Supreme Court ruled that this eligibility expansion is not mandatory and that states may elect not to offer coverage to this population.²⁷ Nevertheless, in those states that do elect to expand coverage, youth who previously enjoyed Medicaid coverage based on family income qualifications may be able to retain at least some health coverage even if they do not qualify for SSI or have not yet successfully completed the process of applying for SSI. Moreover, although states are permitted to offer only limited “benchmark” plans to adults earning less than 133% of the poverty line, individuals with disabilities that prevent them from performing one or more “activities of daily living” may be eligible for full Medicaid benefits even if they are not eligible for SSI.²⁸

As a result of the ACA’s expansions of Medicaid and private insurance eligibility for young adults, the vast majority of youth need not experience a loss of coverage upon reaching adulthood.³⁰

The Affordable Care Act includes provisions regarding public and private insurance that may, if properly implemented, smooth the transition to adulthood for youth with developmental disabilities.

Increased rates of eligibility for coverage may not translate into increased rates of coverage.

Ensuring continued coverage may require careful advance planning. Youth who rely on Medicaid benefits, especially those who qualified for Medicaid as children based solely on family income, are in particular need of benefits planning. These youth typically “age out” of their previous source of health insurance after the age of 18 or 21, many years before their privately insured counterparts who may remain covered under their parents’ health plans until the age of 26. Moreover, young adults with disabilities are at high risk of unemployment or underemployment, and as a result may experience significant difficulty obtaining employer-based health insurance.^{31, *}

Young adults who live in states that have rejected the Medicaid expansion, or who rely on Medicaid services not available through benchmark plans, may be required to apply for SSI in order to receive Medicaid. This process may be lengthy, and youth should be advised to begin collecting medical records and preparing application materials in advance of their 18th birthday so that they may apply as soon as they become eligible for adult SSI. Young adults may also need to arrange for interim coverage while their application for adult benefits is pending.

Young adults who are not eligible for Medicaid may also need counseling in order to ensure that they are aware of insurance options such as statewide exchanges and Medicaid buy-in programs. Lack of awareness of the Medicaid buy-in option has led to low historical enrollment rates.³²

Youth who will remain eligible for coverage through their parents’ insurance will also need benefits counseling. Youth who do not anticipate employment may elect to apply for SSI well in advance of the age of 26, both for the purpose of receiving income supplementation and for the purpose of obtaining coverage through Medicaid, which may provide a broader range of independent living and home health services than that available through private insurance. Youth who anticipate employment that may include health insurance benefits should also receive services to plan for transition, including advice regarding locating employers with comprehensive health plans and selecting a provider.³³

Adults with developmental disabilities must transition to self-directed care.

When youth transition to adulthood, it is typically assumed that they will begin taking responsibility for their own health care, including making doctor’s appointments and managing their own treatment regimens. Moreover, as legal adults, they are typically entitled to make their own treatment decisions and enjoy privacy with respect to their medical appointments and records.³⁴

Young adults with developmental and intellectual disabilities must not be an exception to this rule. The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine have stated that, “[a]fter the age of majority, all youth deserve to be treated as adults and to experience an adult model of care,” even when they require decision-making support or are under legal guardianship.³⁵ Nevertheless, young adults with developmental

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* For example, among participants in a recent Social Security Administration Youth Transition Demonstration Project, only 10.8% were able to find employment with health insurance, and only 24.2% found employment without health insurance. (Fraker, et al., 2011, p. 88).

disabilities may need support in order to manage these responsibilities. Inadequate preparation for these responsibilities and inadequate planning for supports may lead to unmet health care needs and unnecessary guardianship proceedings that may limit young adults' autonomy and privacy.³⁷

The transition to self-directed care is often difficult for youth with developmental disabilities. Youth with autism spectrum diagnoses were only two-thirds as likely as other youth with special health care needs to be encouraged to take on responsibility for their own health care needs as adults.³⁸ Youth with other emotional, behavioral, or developmental disabilities are also less likely to receive transition counseling than youth with other special health care needs.³⁹

Stereotypes about developmental disabilities are a barrier to young adults' transition to self-directed care.

Difficulties transitioning to self-directed care may stem in part from perceptions that youth with developmental disabilities are not capable of making their own health care decisions. Perceptions of an individual's cognitive abilities also influence parents' and providers' attitudes toward transition to adult-oriented health care providers and self-directed care, especially when the young adult needs continued support from family members to manage his or her health care.⁴⁰ Although one study found that parents' perceptions of their children's abilities appear not to influence their children's receipt of health care transition services,⁴¹ another has suggested that youth whose parents perceive them as having more significant impairments are significantly less likely to receive transition counseling.⁴²

Young adults with developmental disabilities may need preparation, assistance and accommodations in order to transition to self-directed health care.

Other difficulties may stem from adult-oriented providers' failure to provide supports that young adults need in order to communicate with doctors, set up appointments, and make health care decisions. Youth may need preparation or accommodation in order to begin scheduling their own medical appointments, fill prescriptions, engage in one-on-one conversations with medical providers, and provide information about their own medical histories.⁴³

Providers, however, may be unwilling to work with adult patients to determine how their families or other support networks can support them in meeting their health care needs.⁴⁴ Lack of access to support with managing health conditions may lead to serious adverse health outcomes, especially for young adults with complex medical needs.⁴⁶

Adults with developmental disabilities have changing health care needs.

Like all youth, youth with developmental disabilities are likely to have evolving health care needs as they transition from adolescence to adulthood. They must transition from pediatric to adult-oriented primary care providers and medical subspecialists.⁴⁷ In the context of a family practice, they may continue seeing the same primary care provider, but must nonetheless discuss their evolving health care needs, transition to an adult model of care, and transition to adult-oriented subspecialists.⁴⁹

Lack of access to support with managing health conditions may lead to serious adverse health outcomes, especially for young adults with complex medical needs.

Youth with developmental disabilities and other special health care needs may experience difficulties finding adult-oriented health care providers. In some areas, there are few adult health care providers who are familiar with the needs of adults with developmental disabilities.^{50*} Physicians may also lack specific training in caring for youth with behavioral or communication challenges.⁵² In addition, presumption of incompetence and stereotypes about disability may prevent adults with developmental disabilities from receiving care for adult health issues. For example, some providers are reluctant to discuss sexual health with adolescents and adults with disabilities.⁵³

Youth with disabilities and their families may also be hesitant to leave familiar pediatric providers and transition to adult-oriented care. Youth with disabilities may also find the more “disease-centered, quick and dirty” approach of adult-oriented care “disorganized and impersonal” in comparison with the more collaborative, psychosocial approach they experienced in the pediatric health care system.⁵⁴ Youth and their families may be reluctant to “start all over again” and educate the new adult provider about their medical condition.”⁵⁵

When young adults do transition to adult-oriented providers, proper communication between the referring pediatric provider and the receiving adult-oriented provider is crucial. Adults with disabilities may have communication support needs that make it difficult for them to explain their health history to a new physician without the assistance of their previous primary care provider. Even in the absence of a communication impairment, adult-oriented health care providers often experience difficulty caring for young adults when the referring pediatric physician has provided only “minimal information about the youth and/or his or her condition.”⁵⁶

Youth with developmental disabilities require health care transition support services in order to transition successfully to adulthood.

Health care transition support services help to ensure that youth maintain continuous access to health care, are empowered to take control of their own care as adults, and transition successfully to adult providers. The American Academy of Pediatrics, American Academy of Family Practice, and the American College of Physicians-American Society of Internal Medicine have stated that health care transition services are essential in order to support youth with special health care needs as they reach adulthood.⁵⁷ In addition, the U.S. Department of Health and Human Services’ Maternal and Child Health Bureau (MCHB) has named transition services as one of the core performance outcomes to promote the system of services for children with special health care needs.⁶⁰ Expanding provision of health care transition services to youth with special health care needs is one of the goals of Healthy People 2020.⁶¹

Necessary elements of transition support services

Transition services should touch on a range of topics likely to influence an individual’s successful transition to adulthood. At a minimum, health providers should discuss (1) transitioning to an adult primary care physician (or, in the case of a family provider, an

*It should be noted, however, that individuals with developmental disabilities may often have health care needs that do not require the services of a provider who specializes in developmental disabilities. With the possible exception of care that is specific to developmental disability – such as neuropsychological testing or speech therapy – adult-oriented health care providers should not turn down prospective patients with developmental disabilities on the sole basis that they do not specialize in developmental disabilities.

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adult model of care); (2) changes in the individual's health care needs as an adult; (3) ensuring health insurance coverage as an adult; and (4) transitioning to self-directed care as the individual reaches adulthood.⁶³ Other important topics may include discussion of continuing education, employment, and independent living needs.⁶⁶ When the individual reaches legal adulthood, providers should also explain their adult consent and confidentiality policies.⁶⁷

Providers should begin discussing transition with the youth and family when the youth reaches 12 and should increase yearly as the individual reaches adulthood.⁶⁸ Youth with developmental disabilities or other special health care needs in particular must begin discussing transition in early adolescence so that the health care team may identify potential barriers to successful transition. Actual planning for transition should begin when the youth reaches the age of 14. As the youth nears adulthood, he or she may benefit from visits with potential adult providers in advance of the transition from pediatric to adult-oriented care.⁷¹ In addition, the medical team should prepare a "portable medical summary" and care plan, which will be transmitted to the adult-oriented provider and the patient at the time of transfer.⁷² The care plan should include emergency treatment plans, the patient's health education history, and, for individuals with communication support needs, the patient's preferred mode of communication and necessary accommodations.⁷³

Most youth with developmental disabilities lack adequate transition support services

Although youth with special health care needs, including developmental disability, may require extensive preparation and support in order to maintain coverage and transition to adult-oriented, self-directed care, only 40% of youth with special health care needs met the MCHB's transition planning outcome.⁷⁴ This statistic may, in fact, overestimate the rate at which youth receive transition planning because youth are counted as not meeting the outcome only when families are aware of a need for transition planning.⁷⁷ Data from the National Survey of Children with Special Health Care Needs (NS-CSHCN) indicates that, according to caregiver reports, only 23% of youth with special health care needs aged 12-18 had a discussion with a health care provider about maintaining insurance and only 21% discussed transition to an adult provider.⁷⁸ Moreover, efforts over the past several years have resulted in only limited, if any, improvements in the rate at which individuals with special health care needs receive transition planning services.⁷⁹

Youth with developmental disabilities, including autism spectrum diagnoses, receive fewer health care transition planning services than other youth with special health care needs.⁸³ Youth with public health coverage or who are uninsured are less likely to receive care meeting the core transition outcomes outlined in the NS-CSHCN than their privately insured peers.⁸⁵ Youth of color with developmental disabilities are also less likely to receive transition support services; for example, Hispanic youth with ASD are significantly less likely to receive health care transition services than non-Hispanic youth.⁸⁶ As in other health care contexts, language barriers may pose a significant obstacle to successful transition, especially when providers attempt to rely on the youth as an interpreter when speaking to the youth's family about transition.⁸⁷

Paradoxically, the presence of complex medical needs, in addition to developmental disability, can make transition planning both more important and less likely to take place. For example, although many youth with autism spectrum disorder also have

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significant psychiatric and medical health care needs,⁸⁸ existence of other serious health conditions or another developmental disability (such as Down Syndrome or cerebral palsy) in addition to ASD made youth far *less* likely to receive health care transition services.⁸⁹

The “medical home” model increases access to comprehensive transition support services

The past several years have seen increased focus on the “medical home” model of care for individuals with special health care needs.⁹⁰ The medical home is not a physical location at which health care services are delivered but rather a health care delivery model involving a personal physician who leads a coordinated team of providers who collaborate to meet patients’ individual health care needs.⁹¹ The medical home model must include three “distinct but interrelated processes: preventative care; acute illness management; and chronic condition management (CCM).⁹² Chronic condition management involves active coordination of care based on a written care plan.⁹³

Youth who receive care through medical homes are more likely to receive transition preparation services.⁹⁴ The coordination and active planning inherent in the medical home model may facilitate delivery of transition support services,⁹⁵ and medical homes may address many of the barriers to timely provision of transition support services, which include limited training and lack of an identified individual responsible for transition planning.⁹⁷ After young adults transfer to adult-oriented health care providers, additional medical home services, such as active care coordination and chronic condition management, may also assist them in the transition to self-directed care.⁹⁸

Despite the benefits of the medical home model, fewer than half of all youth with special health care needs receive medical home service, even though over 95% have some form of health care coverage. Reimbursement policies are a significant barrier to provision of adequate transition coordination and medical home services.¹⁰⁰ Physicians also lack education on the importance of transition planning and training in best practices.¹⁰²

Summary of Recommendations

Expand funding for medical “homes” and transition services

The Patient Protection and Affordable Care Act permits states to provide “health home” services to individuals with chronic health conditions enrolled in Medicaid.¹⁰³ States may reimburse either a designated health provider or team of providers for provision of health home services, including care management, care coordination, referral to community services, and use of information technology to link services.¹⁰⁴ As of 2011, seventeen states had already begun to explore use of Medicaid incentive payments to primary care practitioners to encourage compliance with medical home standards.¹⁰⁵

The evidence shows that medical home model increases access to transition coordination and planning for youth and young adults. Youth enrolled in Medicaid are in particular need of transition support and are less likely to receive this support from their privately insured counterparts.

As a result, we recommend that more states amend their State Plans to include reimbursement for “health home” services. In addition, both states and CMS should clarify

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that health home services include care management, referral to community services, patient support, and use of information technology for the specific purpose of facilitating the transition to adulthood. For example, health home services should include benefits planning, preparation and planning for self-directed care, and planning for transition to adult-oriented health care providers.

States must follow the ACA’s direction to expand Medicaid eligibility to adults with incomes below 133% of the Federal Poverty Line

Youth with developmental disabilities face loss of coverage or gaps in coverage when they age out of child-focused health benefits programs such as Medicaid and CHIP. Even when they are eligible for continued Medicaid coverage through SSI, they may face gaps in coverage as a result of the lengthy application process for SSI. Expansion of Medicaid eligibility to all adults with incomes below 133% of the Federal Poverty Line will dramatically reduce the rate at which youth with developmental disabilities experience gaps in coverage or loss of coverage when they reach the age of 18. Moreover, under the Medicaid expansion, individuals with disabilities that prevent them from performing one or more activities of daily living” are—even if they are not eligible for SSI—entitled to “full” Medicaid coverage despite the ACA’s provision that states may provide only “benchmark” coverage to the expansion population.¹⁰⁷ As a result, individuals with disabilities who are newly eligible for Medicaid through the Medicaid expansion will be entitled to full Medicaid benefits.

Expand education and outreach on transition planning

Research to date shows that parents and physicians are often unaware of the importance of health care transition planning, especially for young adolescents and adolescents with cognitive or developmental disabilities.¹⁰⁹ Physicians are also in need of education on best practices for supporting young adults transitioning to adulthood, including young adults with developmental or intellectual disabilities and young adults with special health care needs.¹¹¹ Educational efforts to date have not been sufficient to produce widespread improvements in transition support services.¹¹²

A major barrier to transition for young adults with developmental and intellectual disabilities is parents’ and providers’ perception that this population is not capable of transitioning to self-directed care. Educational outreach to parents and physicians should emphasize the importance of transitioning to an adult model of care for all young adults, including those with cognitive impairments and decision-making support needs. Providers should receive training in providing adult models of care to individuals who may be in need of decision-making, communication, or other supports.¹¹³

In addition, outreach efforts should focus on groups of youth with developmental and intellectual disabilities who are at heightened risk for not receiving transition services, including youth with behavioral disabilities, youth of color, youth who live in homes in which English is not the primary language, and low-income youth.¹¹⁴

Youth with developmental disabilities face loss of coverage or gaps in coverage when they age out of child-focused health benefits programs such as Medicaid and CHIP.

Further research on outcomes of transition support programs

Outcome-focused research

We recommend increased research on transition outcomes, especially for youth with developmental and cognitive disabilities. Despite increasing awareness of the importance of transition planning, research to date has typically focused on the rates of transition support services delivery rather than on the effects those services have on health outcomes such as retention of coverage and long-term effects on health status.¹¹⁵

Research on the specific needs of youth and young adults with developmental and intellectual disabilities

There is a particular need for research that focuses on transition outcomes for youth with developmental and intellectual disabilities. Much of the research on transition supports to date has focused on individuals with special health care needs as a whole.¹¹⁶ Youth with developmental and intellectual disabilities, especially those with cognitive or communication support needs, may have unique needs for accommodations, preparation, and support in order to transition successfully to self-directed, adult-oriented care when they reach adulthood. Research is necessary in order to determine the best practices for supporting this population of youth as they reach adulthood.

Research on the experiences of youth and young adults with developmental and intellectual disabilities

We recommend increased collection of data reflecting the views and experiences of youth and young adults with disabilities. Studies to date have typically focused on the reports of parents of youth and young adults with disabilities, as opposed to the youths and young adults themselves.¹²¹ Many of these studies rely on data from the National Survey on Children with Special Health Care Needs, which collects data exclusively from parents and caregivers.¹²² Because youth and young adults have unique and valuable perspectives on their own care, we recommend that the National Survey on Children with Special Health Care Needs expand its survey population to include older adolescents and adults with special health care needs.

Research on additional transition support services, including nutritional and sexual health

We recommend increased research on provision of transition services that have until now not been the focus of research, including advanced care planning, sexual health counseling, and nutritional counseling for individuals with disabilities and special health care needs. When surveyed, a significant percentage of parents of children with special health care needs have reported a need for such services.¹²³

There is a particular need for research that focuses on transition outcomes for youth with developmental and intellectual disabilities.

Research on health care transition support through non-medical providers

Insufficient research exists on the delivery of health care transition services through sources other than medical providers, such as schools or other systems that support adolescents.

The Commonwealth Fund Survey of Young Adults in 2009 found that 19% of all youth aged 19-29 lacked health coverage while in high school.¹²⁴ Because they lack coverage, they may be less likely to have access to transition planning provided through the health care system. Other systems designed to support youth, including public schools and child welfare programs, should incorporate health care transition planning into their overall transition plans. The IDEA, for example, requires public schools to offer transition planning services to youth and young adults with disabilities until the age of 21.¹²⁵ Even when a high school student with special health care needs is receiving health care transition support from a regular health care provider, collaboration with the student's Individualized Education Plan (IEP) team may be valuable.¹²⁶

Other systems designed to support youth, including public schools and child welfare programs, should incorporate health care transition planning into their overall transition plans.

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Endnotes

- 1 McManus, et al., 2013.
- 2 Id. Among young adults as a whole, according to the 2009 Commonwealth Survey of young adults, of 61% of all young adults were insured through their parents' employer during high school, 10% were insured through Medicaid, and 5% were insured through individual insurance plans which may have included plans obtained through CHIP. Collins & Nicholson, 2010, p. 19 Table 1.
- 3 PPACA, sec. 2714, 42 U.S.C. § 300gg-14; Collins & Nicholson, 2010.
- 6 Gleason, et al., 2009; Collins & Nicholson, 2010.
- 8 Gleason, et al., 2009; Collins & Nicholson, 2010.
- 10 Collins & Nicholson, 2010.
- 13 Id.
- 14 Gleason, et al., 2009.
- 16 Lotstein, et al., 2010; Lotstein et al., 2008.
- 17 Pullman, Heflinger, & Mayberry, 2010; Lotstein, et al., 2010.
- 19 Collins & Nicholson, 2010.
- 20 Szilagyi, 2012; Lotstein, Kuo, Strickland, & Tait, 2010.
- 22 Kogan, et al., 2008.
- 26 Collins & Nicholson, 2010.
- 27 National Federation of Independent Business v. Sebelius, 567 U.S. ___, 132 S. Ct. 2566 (2012).
- 28 Final Rule: Medicaid Program; State Flexibility for Medicaid Benefit Packages, 2010 ("Exempt Individuals," (§ 440.315)); National Council for Community Behavioral Healthcare, 2010.
- 30 Collins & Nicholson, 2010.
- 31 US Dep't of Labor, Office of Disability Employment Policy, 2013.
- 32 Wang & Grembowski, 2010.
- 33 American Academy of Pediatrics, et al., 2011.
- 34 Id.
- 35 Id.
- 37 Id., p. 183; TASH, 2003.
- 38 Cheak-Zamora, et al., 2013.
- 39 McManus, et al., 2013.
- 40 Reiss, Gibson, & Walker, 2005.
- 41 Cheak-Zamora, et al., 2013.
- 42 McManus, et al., 2013.
- 43 American Academy of Pediatrics, et al., 2011.
- 44 Osgood, Foster, & Courtney, 2010; Reiss, Gibson, & Walker, 2005, pp. 27-28.
- 46 Cheak-Zamora, et al., 2013, p. 116.
- 47 Id.; Gleason, et al., 2009.
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