Getting Ready for Healthcare at the Age of Majority

Sep 4, 2015

October 2015 | Links updated, March 2017

This resource is part of the series Getting Ready for When Your Teen Reaches the Age of Majority: A Parent's Guide.



When young people with disabilities reach the "age of majority," they gain the right to manage their own affairs, including choosing their own doctor and seeing to their own healthcare needs. In most states, this happens at age 18. Legally considered as adults, they may take charge of healthcare decisions large and small. But will they be ready to make such decisions for themselves? Will they have the skills and basic information they need?

This tip sheet considers steps that you (as parents) and others (such as teachers or transition specialists) can take to help your teenager with disabilities learn what's involved in taking care of one's own health and healthcare as an adult.

Developed by:

National Secondary Transition Technical Assistance Center (NSTTAC)

National Post-School Outcomes Center (NPSO)

In collaboration with:

Center for Parent Information and Resources (CPIR)

The Importance of Starting Early

Staying healthy and making sound decisions about one's own healthcare involves many skills. Starting with the most basic, it's about:

handling cuts and bruises,

- taking medicine as prescribed,
- regularly visiting the doctor, and
- knowing when (and whom) to call for medical help.

These are skills most of us learn over time at home and at school. They provide the foundation for future learning about what it takes to see to our own physical and emotional well-being when we're adults.

For many young people with disabilities, healthcare issues are a challenge. For some, especially those with special health care needs, healthcare can be the *biggest* challenge. **That's why it's important to start early and help young people develop the skills they will need to take charge of their own health and healthcare.** Fortunately, there are many tools available that schools and families can use to help young people learn about healthcare and what's involved in managing their own (see the list of **Helpful Resources** at the end of this tip sheet). Also:

- You can use the IEP meeting to advocate that your child's IEP include goals focused on health issues, especially if he or she has special health care needs.
- Practice the skills at home, too, so that your son or daughter learns over time how to maintain good health generally and about his or her health issues in particular.

All this lays the foundation for later, when your child becomes a youth, then a young adult, then an adult who's as independent as he or she can be.

Areas of Healthcare to Consider

Think about the decisions your child may face and the skills necessary to take care of one's health. Listed below are some common health-related activities that adults engage in.

Contacting appropriate medical personnel in the event of illness or medical emergencies

Choosing and interacting with medical professionals (e.g., choosing a doctor; knowing when to provide, withhold, or withdraw medical consent)

Scheduling appointments with medical professionals

Making informed decisions about treatment options (e.g., understanding the benefits and risks of treatment options and making a responsible choice)

Managing over-the-counter and prescribed medications

Knowing when to call in prescription refills, pick up prescriptions, and contact the doctor to get prescriptions renewed

Following medical and therapeutic treatments

Maintaining medical records (e.g., requesting records, providing authorization for people to access them)

Interacting with insurance companies

Strategies for Providing Support

Now consider how to support your son or daughter (or student) in carrying out these common healthcare activities, now and in the future. Suggestions include:

Use collaborative decision making. Provide the young person with information on critical healthcare decisions, considerations, risk factors, and choices (e.g., IEP goals to learn specific decision-making skills, courses on self-determination, use of life-skills curriculum).

Let the young person gain experience in talking to medical professionals, starting when he or she goes to the pediatrician as a child.

Understand the importance of having an informal network of friends and family. Often the personal network is sufficient to provide the supports and assistance that the young adult needs. Rely on your network whenever possible.

Use technology (e.g., apps, smart phones, tablets) to support the young person in becoming and remaining independent (e.g., timers to remind when to take medication).

Use in-home care services (e.g., nurse, therapist, dietician) to provide support, ensure that medications are taken as prescribed, and that other medical needs are addressed (e.g., diabetes monitoring).

Provide needed therapy in the home (e.g., physical, occupational, speech therapy).

Use case management services to coordinate services across agencies with the aim of ensuring that the individual with a disability remains as self-sufficient as possible. Case management services may be provided by the department of human services, community mental health, or other organizations (e.g., vocational rehabilitation, advocacy organizations).

Consider using prescription delivery from community agency services to deliver prescription medications directly to the home.

Use home visit services/daily call services by having volunteers make home visits (e.g., to provide social contact, to observe how the person is faring, to obtain help if needed).

Use medical release forms (71 kb) to authorize the extent to which private medical records can be shared and with whom. Release forms do not allow others to consent on behalf of your son or daughter for actual health or medical care, and the authorization can be revoked at any time. These could be used to support collaborative decision making.

Involve agencies that offer habilitative services to increase the skills of your young person with disabilities. These services could be used to provide training on many of the areas above (e.g., selecting a physician, managing medications).

Set in place a living will/healthcare directive specifying the type of medical treatment your son or daughter wishes (or does not wish) to receive in the event that he or she is unable to communicate that information in the moment.

Appoint a surrogate decision maker in situations when a directive is not in place, and the young adult with a disability is not able to provide informed consent for medical treatment.

Use a medical power of attorney (250 kb) by having the young person provide authorization for another competent adult to also make medical decisions on his or her behalf. This does not require a court process and can be revoked at any time by the individual.

What About Guardianship?

Some parents may consider taking **guardianship** of their son or daughter as a way of protecting their child's well-being. Assuming guardianship of your son or daughter is one option for protecting his or her day-to-day safety and well-being in the future. Depending on the severity or nature of your youth's disability, it may be an option worth exploring.

However, be aware that guardianship is one of the most legally restrictive forms of support. It can also have negative effects on the individual. For instance, when a youth is denied the opportunity to make healthcare decisions or to participate in a shared decision-making process, he or she is also denied the opportunity to develop those skills. This lack of opportunity may lead to a perceived "incapacity" either by the family or by the young adult. Therefore, it is important to realize that many young people with disabilities can be adequately supported in adult life without a guardian.

Given that, consider what's involved in taking good care of oneself and in managing one's own healthcare. What will it involve for your son or daughter when he or she reaches the age of majority? Where will the challenges be? Where will supports be needed? The answers to these questions will let you know the supports to put in place for your son or daughter in adulthood. We've already mentioned quite a few of the **possible supports** you might explore.

To Learn More about the Pros and Cons of Guardianship

National Guardianship Association

http://www.guardianship.org/index.htm

An Overview of Guardianship

http://www.caregiverslibrary.org/caregivers-resources/grp-legal-matters/hsgrp-power-of-attorney-guardianship/an-overview-of-guardianship-article.aspx

National Health Care Transition Center

http://www.gottransition.org/youthfamilies/index.cfm

See in particular:

Got Transition Webinar: Understanding Guardianship and the Alternatives for Decision Making Support

In Summary

When a young adult with disabilities reaches the age of majority, he or she has the right to assume responsibility of his or her own healthcare. The issue then becomes whether young adults with disabilities are *prepared* for such responsibility.

This tip sheet highlights the importance of starting early to help your son or daughter learn health-related skills, including providing opportunities for your young person to talk to medical professionals and practice making decisions about his or her own healthcare. Build a strong system of support that your son or daughter can turn to for advice and assistance, and take advantage of the power of technology and the availability of services that can be provided in the home, such as needed therapies and medical call-in or nursing services.

Helpful Resources

Transition Health Care Checklist: Preparing for Life as an Adult | The *Transition to Health Care Checklist* is intended for youth and young adults who are preparing for the transition to life as an adult. The booklet provides a general overview of the knowledge, skills, and actions that need to be addressed as part of the fluid process of adolescent transition for youth with special health care needs.

http://www.waisman.wisc.edu/wrc/pdf/pubs/THCL.pdf (616 kb)

National Resource Center for Supported Decision-Making | The NRC-SDM provides leadership and expertise in supported decision-making, representing the interests of and receiving input from thousands of older adults and people with intellectual and developmental disabilities. The Center has applied supported decision-making in groundbreaking legal cases; developed evidence-based outcome measures; successfully advocated for changes in law, policy, and practice to increase self-determination; and shown that supported decision-making is a valid, less-restrictive alternative to guardianship.

http://supporteddecisionmaking.org/

Kids as Self Advocates (KASA) | KASA is a national, grassroots project created by youth with disabilities for youth. This webpage has real life stories told by youth and young adults with disabilities and links to other organizations and agencies that can give you information about health.

http://fvkasa.org/resources/health.php

Health Vault | Health Vault is a free online tool where people can store health and medical information, track their exercise and health conditions, and control their own level of privacy.

https://www.healthvault.com/us/en

Collaborative Care Notebook | From Utah Family Voices, this care notebook is designed to help families and young adults organize health information and forms in one centralized place. The notebook's available in PDF

and in Word, making it easy for users to edit and update their information. Available in English and Spanish. http://www.utahfamilyvoices.org/familys-coordinating-care/

Build Your Own Care Notebook | Similar to the resource above, the Care Organizer is an organizing tool for families and youth with disabilities and will help both keep track of important health-related information. Care notebooks are very personal and ideally should be customized to reflect your son or daughter's medical history and current information. Developed by the National Center for Medical Home Implementation.

https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx

Materials Used in the Development of This Tip Sheet

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http://www.pathfinder-nd.org/pdf/guardianship-handbook-12-18-08.pdf (94 kb)

Rhode Island Disability Law Center. (2008). *Guardianship and alternatives to guardianship*. Providence, RI: Author. Online

at: http://www.ridlc.org/publications/Guardianship_and_Alternatives_To_Guardianship_Booklet.pdf (224 kb)

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- National Post-School Outcomes Center (NPSO)
- Center for Parent Information and Resources (CPIR)

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Special thanks to Parent Center reviewers | Special thanks goes out to Barb Buswell, Bebe Bode, Laura Nata, and Dorie France for providing guidance throughout the project. Without their contributions, these fact sheets would not have been possible. Thank you.

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- **Center for Parent Information and Resources**, Newark, NJ (funded by Cooperative Agreement Number H328R130014) with the U. S. Department of Education.

OSEP Project Officers | Carmen Sánchez and Dr. Selete Avoke

Getting Ready for Independent Living at the Age of Majority

Sep 4, 2015



October 2015 | Links updated, March 2017

This resource is part of the series Getting Ready for When Your Teen Reaches the Age of Majority: A Parent's Guide.

When young people with disabilities reach the "age of majority," they gain the right to manage their own affairs, including where they will live and what they will do. In most states, this happens at age 18. Legally considered as adults, they may take charge of their own housing and daily-life decisions, both large and small. But will they be ready to make such decisions for themselves? Will they have the skills and basic information they need to live as independently as possible?

This tip sheet considers steps that you (as parents) and others (such as teachers or transition specialists) can take to help your young person with disabilities learn and practice the basic skills that underpin independent living, skills that will certainly come in handy in the future.

Developed by:

National Secondary Transition Technical Assistance Center (NSTTAC)

National Post-School Outcomes Center (NPSO)

In collaboration with:

Center for Parent Information and Resources (CPIR)

The Importance of Starting Early

Living independently—even with supports—involves many skills. Starting with the most basic, it's about having **daily living skills**, which include grooming and hygiene, maintaining personal safety, and knowing how

to take care of yourself. These are skills most of us learn over time at home and at school, and they provide the foundation for future learning about what it takes to live independently.

For many young people with disabilities, daily living skills can be challenging. That's why it's important to start early working on developing these skills. There are many tools available that schools and families can use to do just that (see the list of **Helpful Resources** at the end of this tip sheet). Take into consideration where your child *needs help* with daily living activities and what he or she *already knows* and can do. Also:

- Use the IEP meeting to advocate that your child's IEP include goals focused on gaining the daily living skills he or she needs.
- Practice the skills at home, too, so that your son or daughter learns over time how to do tasks such as laundry, dishes, or cleaning.

All this lays the foundation for later, when your child becomes a youth, then a young adult, then an adult who's as independent as he or she can be.

Areas of Daily Living to Consider

Daily living skills are those common activities that most adults engage in as they manage their own daily living and quality of life. These include but aren't limited to:

Using self-care skills (e.g., appropriate hygiene care, grooming, dressing, meal preparation, and laundry)

Eating, toileting, bathing, dressing

Participating in recreation and leisure activities

Demonstrating awareness of personal safety in the home

Taking medications as directed and seeking medical care when needed

Providing accurate information about one's medical condition to appropriate personnel

Making appropriate decisions concerning relationships

Understanding what is involved in managing a home

Demonstrating the ability to vote and make informed decisions

Deciding and directing the kinds of assistance or supports needed or wanted, including using assistive devices and/or technology in the home and community

Using transportation in the community as independently as possible (e.g., knowledge of community bus, taxis)

Applying for adult services and accessing services/supports necessary for success in the community (e.g., on-the-job training, employment)

Which of these (and other) daily living skills are currently challenges to your son or daughter? Which will *always* be a challenge? Which can be and need to be learned?

What About Guardianship?

Despite getting an early start learning skills that will help them live independently, many youth with disabilities (and many without!) reach the age of majority but are not yet ready for, or capable of, living entirely on their own. Some parents may consider assuming **guardianship** of their son or daughter as a way of protecting their child's well-being.

Assuming guardianship of your son or daughter is one option for protecting his or her day-to-day safety and well-being in the future. Depending on the severity or nature of your youth's disability, it may be an option worth exploring. However, be aware that **guardianship is one of the most legally restrictive forms of support**. It can also have negative effects on the individual. For instance, when a youth is denied the opportunity to make decisions about how he or she will live and where, or to participate in a shared decision-making process, he or she is also denied the opportunity to develop. This can lead to a sense of helplessness and passive dependence. Therefore, it is important to realize that **many young people with disabilities can be adequately supported in adult life without a guardian**.

Given that, consider what's involved in daily living, as well as where and with what tasks your son or daughter will need support in order to live apart from you. There are many support systems and strategies available that can help. We've listed examples in the next section.

For More Information on the Pros and Cons of Guardianship

National Guardianship Association (NGA)

http://www.guardianship.org/index.htm

An Overview of Guardianship

http://www.caregiverslibrary.org/caregivers-resources/grp-legal-matters/hsgrp-power-of-attorney-guardianship/an-overview-of-guardianship-article.aspx

Understanding Guardianship and the Alternatives for Decision Making Support

https://www.youtube.com/watch?v=0xXELClMHHE&feature=youtu.be

http://www.parentcenterhub.org/aom-series-independence/

Strategies for Providing Support

Given your son or daughter's specific needs for support in daily living activities, what types of assistance are available and appropriate? Consider, for example:

Using **supports/family** that the young adult trusts and could call or contact for guidance when needed Using **in-home care** services (e.g., nurse, therapist, dietician) for meals, medication, therapy, and to assist with your son or daughter's care needs

Using **adult service providers** who specialize in supporting adults with developmental disabilities. These agencies offer a number of group living arrangements and can hire staff to meet your son or daughter at your home or apartment to help with challenging aspects of independent living.

Using **free or reduced-price** meals, food, and prescription delivery from community agency services Using free or reduced-price **transportation services** from community agency services

Arranging daily call services with a community agency or advocacy organization to ensure your son or daughter is doing well and to obtain assistance as needed

http://www.parentcenterhub.org/aom-series-independence/

In Summary

When youth with disabilities reach the age of majority, they have the right to make independent decisions on where they would like to live and/or what they would like to do in their life. The issue then becomes whether young adults with disabilities are *prepared* for being able to live on their own.

This tip sheet highlights the **importance of starting early** when your child is young and **helping him or her learn independent living skills**, especially daily living skills in the home. It's also very important to **consider what types of support need to be put in place** (e.g., in-home care services, transportation services) to assist your son or daughter with independent living issues when he or she reaches the age of majority.

http://www.parentcenterhub.org/aom-series-independence/

Helpful Resources

Independent Living Connections.

This webpage connects you with checklists and resources on self-help and autonomy skills. You can use these resources when discussing independent living skills with your son or daughter during transition planning. http://www.parentcenterhub.org/repository/independent/

Independent Living Centers.

Independent living centers (ILCs) are nonresidential, community-based agencies that are run by people with various disabilities. ILCs help people with disabilities achieve and maintain self-sufficient lives within the community. Operated locally, ILCs serve a particular region, which means that their services vary from place to place. ILCs may charge for classes, but advocacy services are typically available at no cost. Find your local ILCs at:

http://www.ilru.org/projects/cil-net/cil-center-and-association-directory

Your state's agency for individuals with intellectual and developmental disabilities.

Get in touch with this agency, visit its website. See what community-based services are available. Find yours at: http://www.nasddds.org/state-agencies/

Your state's protection and advocacy agency.

P&A agencies have the authority to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities. Find yours at:

http://www.ndrn.org/ndrn-member-agencies.html

A Step-by-Step Guide to Training and Managing Personal Assistants:

Consumer Guide.

This guide provides information, tips and suggestions for training and managing people who provided personal assistance services (PAS). These services help people with disabilities with everyday things like bathing, dressing and running errands.

http://search.naric.com/research/rehab/download.cfm?ID=109225

National Resource Center for Supported Decision-Making | The NRC-SDM provides leadership and expertise in supported decision-making and has applied supported decision-making in groundbreaking legal cases; developed evidence-based outcome measures; successfully advocated for changes in law, policy, and practice to increase self-determination; and shown that supported decision-making is a valid, less-restrictive alternative to guardianship.

http://supporteddecisionmaking.org/

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http://www.parentcenterhub.org/aom-series-independence/

Other Tip Sheets in This Series

This tip sheet is part of a series written to support parents and youth with disabilities as youth approach the "age of majority." The series includes:

- Getting Ready for When Your Teen Reaches the Age of Majority: A Parent's Guide
- Getting Ready for Healthcare at the Age of Majority
- Getting Ready for Managing Finances at the Age of Majority
- Getting Ready for Independent Living at the Age of Majority (this tip sheet)

These tip sheets are copyright free, so please do feel free to share them with others.

http://www.parentcenterhub.org/aom-series-independence/

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OSEP Project Officers | Carmen Sánchez and Dr. Selete Avoke

Getting Ready for Managing Finances at the Age of Majority

Sep 4, 2015



October 2015 | Links updated, March 2017

This resource is part of the series Getting Ready for When Your Teen Reaches the Age of Majority: A Parent's Guide.

When young people with disabilities reach the "age of majority," they gain the right to manage their own affairs, including their money. In most states, this happens at age 18. Legally considered as adults, they may take charge of financial decisions large and small. But will they be prepared to make financial decisions for themselves? Will they have the money skills and basic understanding of finance they will need?

This tip sheet considers steps that you (as parents) and others (such as teachers or transition specialists) can take to help your young person with disabilities learn and practice basic financial management skills, skills that will certainly come in handy in the future.

Developed by:

National Secondary Transition Technical Assistance Center (NSTTAC)

National Post-School Outcomes Center (NPSO)

In collaboration with:

Center for Parent Information and Resources (CPIR)

The Importance of Starting Early

Managing money matters—even with support—involves many skills. Starting with the most basic, it's about being able to:

- recognize the value of coins and bills; and
- count money and subtract it, too.

These are skills most of us learn in school, and they provide the foundation for future learning about how to manage money.

For many young people with disabilities, money matters can be challenging. That's why it's important to start early working on developing those skills. This includes:

- Using the IEP meeting to advocate that your son or daughter's IEP include goals focused on money management.
- Practicing money skills at home and in the community—for example, let your son or daughter hand over the money to the cashier in the grocery store and count the change returned.
- Giving your young person the opportunity to decide how he or she will spend whatever allowance or gift money he or she has.

There are also many tools available that schools and families can use to teach basic math and money skills (see the list of **Helpful Resources** at the end of this tip sheet). All this lays the foundation for later, when money matters get more complicated.

http://www.parentcenterhub.org/aom-series-finance/

Areas of Financial Management to Consider

What decisions will your son or daughter face in managing money, and what skills will he or she need? Consider the common activities adults do when managing their money. Adults:

Keep a bank account, including checking and savings accounts.

Talk with the bank about their financial needs or concerns.

Make and keep to a budget that balances expenses and income.

Understand money basics, including how to pay bills, use credit or debit cards, and make money transactions.

Keep financial and money records (e.g., asking for records, keeping track of income to prevent overdrafts).

Make financial plans for the future.

http://www.parentcenterhub.org/aom-series-finance/

Strategies for Providing Support

In light of the money skills and activities just listed, you can see why it's important to **start early** developing the skills your son or daughter will need when he or she reaches the age of majority. For many youth with disabilities, it will also be important to **put supports in place** to help your son or daughter manage his or her money and financial matters as much as possible. What skills will he or she need? If any of these skills are lacking, what supports would help? Supports can include:

Using a **money management service**, where a provider can teach your son or daughter about money management and how to keep track of money.

Using direct deposit and automatic bill payments.

Using **joint checking accounts** that will help in keeping track of your son or daughter's bank account. Having family/friends/extended **family supports** in place the young adult trusts and could call or contact for guidance when needed.

Having **co-signers on bank accounts** to help your son or daughter with bill payment and money transactions. Using a **Power of Attorney** to help your son or daughter with making decisions and handling business, personal, and legal matters.

Using a **Representative Payee** to help with your son or daughter's payments.

Establishing a **legal trust** to help with the transfer of money and legal matters.

Establishing a **conservatorship** to help manage your son or daughter's assets.

http://www.parentcenterhub.org/aom-series-finance/

What About Guardianship?

Despite getting an early start on learning about money, many youth with disabilities (and many without!) reach the age of majority but are not yet ready to or capable of managing their own money wisely. Some parents may consider taking **guardianship** of their son or daughter as a way of protecting their child's financial well-being. Assuming guardianship of your son or daughter may be an option worth exploring. But it is also **one of the most legally restrictive forms of support** and can have negative effects on the individual. For instance, when a youth is denied the opportunity to make decisions about money or to participate in a shared decision-making process, he or she is also denied the opportunity to develop decision-making skills related to money. This can lead to a sense of helplessness and passive dependence. Therefore, it is important to realize that **many young people with disabilities can be adequately supported in adult life without a guardian**. This may involve managing their own finances with appropriate supports in place such as those discussed above.

To Learn More about the Pros and Cons of Guardianship

National Guardianship Association

http://www.guardianship.org/index.htm

An Overview of Guardianship

http://www.caregiverslibrary.org/caregivers-resources/grp-legal-matters/hsgrp-power-of-attorney-guardianship/an-overview-of-guardianship-article.aspx

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https://www.youtube.com/watch?v=0xXELClMHHE&feature=youtu.be

http://www.parentcenterhub.org/aom-series-finance/

In Summary

When a young adult with disabilities reaches the age of majority, he or she has the right to assume financial responsibility and manage his or her own affairs. The issue then becomes whether young adults with disabilities are *prepared* for such responsibility.

This tip sheet highlights the importance of early learning about money management, including providing opportunities for your young person to handle money in different situations and across time. It's also very important to consider what types of support need to be put in place to assist your son or daughter with financial matters when he or she reaches the age of majority.

Helpful Resources

Practical Money Skills for Life.

To help consumers and students of all ages learn the essentials of personal finance, Visa partnered with leading consumer advocates, educators, and financial institutions to develop the *Practical Money Skills* program. The link below takes you to all the free materials available.

http://www.practicalmoneyskills.com/resources/free_materials/index.php

Tools for Teaching Financial Literacy Skills.

Here are several free tools for teaching your child essential money management skills and habits.

http://lifeafterieps.com/tools-for-teaching-financial-literacy-skills/

Teaching Money Counting Skills: Using Money Is an Important Functional Skill for Independent Living.

http://specialed.about.com/od/MathematicsforSpecialEducation/a/Teaching-Money-Counting-Skills.htm

Cents and Sensibility: A Guide to Money Management for People with Disabilities.

http://www.fliconline.org/documents/patffinancialeducationbooklet-final.pdf (5.3 MB)

National Resource Center for Supported Decision-Making | The NRC-SDM provides leadership and expertise in supported decision-making and has developed evidence-based outcome measures; successfully advocated for changes in law, policy, and practice to increase self-determination; and shown that supported decision-making is a valid, less-restrictive alternative to guardianship.

http://supporteddecisionmaking.org/

Materials Used in Developing This Tip Sheet

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North Dakota Department of Human Services. (2008). *Guardianship handbook: A guide for court-appointed guardians in North Dakota*. Bismarck, ND: Author.

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OSEP Project Officers | Carmen Sánchez and Dr. Selete Avoke

Getting Ready for When Your Teen Reaches the Age of Majority: A Parent's Guide

Mar 10, 2015



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Age of majority is the age when children legally become adults. At this time, they gain the rights of adults, which include the right to vote, marry, apply for a credit card, make medical and financial decisions for themselves, sign contracts, live independently, and much more. In most states the age of majority is age 18. Developed by:

National Secondary Transition Technical Assistance Center (NSTTAC)

National Post-School Outcomes Center (NPSO)

In collaboration with:

Center for Parent Information and Resources (CPIR)

Who Decides the Age of Majority?

Each state sets the age of majority for young people in the state. In most states the age of majority is age 18. The state also decides if a parent's rights will transfer to the student when he or she reaches the age of majority.

What's the Age of Majority in Your State?

You can find out the age of majority in your state at:

http://minors.uslegal.com/age-of-majority/

What Does the Transfer of Rights Mean for Parents, Youth with Disabilities, and Schools?

Depending on your state's policies, many or all of your rights as a parent may transfer to your son or daughter at age of majority. (Read more about parental rights of children with disabilities.) If so, then at least one year *before* your son or daughter with a disability reaches the age of majority, the school must let you and your young person know about any upcoming transfer of rights.

New responsibilities | If your rights transfer to your son or daughter, he or she will have new responsibilities. These include but aren't limited to:

Participating in individualized education program (IEP) meetings (Your child *must* be invited to the IEP meeting starting at age 16, but it's a good idea to start earlier. And many states do!)

Deciding who is invited to the IEP meeting (e.g., parents, adult service providers, people who know about and understand your son or daughter's disability)

Making decisions about what IEP and post-school goals to include in the plan

Giving signed consent for re-evaluation and changes in placement

Deciding whether or not to continue his or her education

Requesting mediation or other ways to resolve disputes

These are important responsibilities. Is your son or daughter "ready" to take charge of his or her education? What about planning for life after high school? Many parents would probably answer, no, not yet! There is so much to learn still!

The bottom line | The truth of the matter is that age of majority happens whether your son or daughter is "ready" or not. And it happens whether *you*, as the parent, are ready or not! That's why it's a good idea to:

- Take advantage of your child's growing years to build skills needed in the future.
- Connect with your state's **Parent Center** and disability-related community agencies to learn about webinars or workshops they offer related to transition planning.
- Foster a team approach that involves your son or daughter.
- Lay a solid foundation through discussions, guided support and decision-making, respect, and opportunities for your son or daughter to learn the basic skills that an adult needs.

This tip sheet offers suggestions for doing just that.

Tips for Parents

• Start Early: Building confidence and decision-making skills takes time and practice.

As your child grows, let him or her make decisions appropriate to his or her age. This will help prepare your young person for making decisions in adulthood.

Lay the foundation for the coming age of majority

Over time, talk with your son or daughter about the age of majority and what it means to take on the responsibilities of an adult. Examples include:

- Paying your bills
- Getting a copy of your social security card and birth certificate
- Managing your own health care
- Living independently
- Getting from place to place (e.g., by car, bus, taxi, subway)
- Registering to vote
- Registering for the selective service (males only)
- Signing contracts (for example, to rent an apartment or to make a big purchase such as a car)

Help your young person develop self-knowledge by discussing his or her disability

No one has a greater stake in transition planning than the student with a disability. That's one reason why learning to be an effective self-advocate is a critical part of each student's transition process. **Self-advocacy skills** help young people shape their own lives and futures. Therefore, over time, explore these important topics with your son or daughter.

Talk with your child about his or her disability. Ask how the disability affects your son or daughter at school, at home, in daily life. Listen to the answers. Discuss.

Also discuss what **supports or accommodations** help your son or daughter at school, at home, and in daily life. You may be surprised at how on-target and helpful your child's perspective is!

Help your child discover his or her **preferences** and how to share that information with others. Having **good social skills** is an important personal asset, now and in the future.

Explore the **hopes and dreams** your son or daughter has for the future. Help translate these into **step-by-step goals**.

Are there things that your son or daughter will likely *not* be able to do in reality, given his or her disability? Explore these, too, in a positive and supportive way.

Talk about disability rights and responsibilities under IDEA, Section 504, and the ADA

Rights | Let your child know that he or she has rights under federal laws such as the <u>Individuals with</u>

<u>Disabilities Education Act</u> (IDEA), <u>Section 504 of the Rehabilitation Act</u> (608 kb), and the <u>Americans with</u>

<u>Disabilities Act</u>(ADA). Talk about those rights. Give concrete examples, especially related to postsecondary education, employment, and life in the community.

IEP meetings | Encourage your son or daughter to attend, <u>participate in</u>, and eventually lead the meeting where his or her IEP is written. Let your son or daughter know that he or she may invite other people to the meeting. That includes *you* when he or she reaches the age of majority!

Role-play | Role-play IEP meetings ahead of time with your son or daughter. Practice how to greet the other team members, state individual goals, offer suggestions or respectfully disagree, and thank members for their participation.

Prepare your young adult for the future by discussing adult options and choices

Explore options | Explore what options and choices we have as adults with your son or daughter over time. There are plenty of examples in daily life you can use to spark the discussion—recreation choices, driving, living independently, getting a job or going on to postsecondary education, enjoying oneself with friends. These are the kinds of choices and decisions that your son or daughter will be making now or in the future. Talking about them can be fun, too.

Team with adults | Encourage your son or daughter to develop good working relationships with adults. This includes the school staff in high school and, later, employers, fellow employees, landlords, and adult service providers.

Talk about accommodations | Let your youth know that accommodations are available in **postsecondary education** and **work settings**. Give examples and discuss. What accommodations or supports would be helpful to your son or daughter in these settings?

Disclosing the disability | Practice with your youth when and how to **disclose** the disability to an employer or a postsecondary school. Also role-play how to ask for accommodations.

Model | Model the decision-making process by "thinking aloud." State the issues and options you are considering, mull over the pros and cons of each, and allow your son or daughter to see you arrive at a decision.

Let your youth decide! Give your young person regular opportunities to make his or her own choices. As necessary, help your son or daughter walk through weighing the pros and cons of each option. Then leave the decision up to your child.

Mistakes | Allow your son or daughter to make mistakes. When it isn't a matter of health and safety, he or she can learn from poor choices, just like the rest of us have.

Concerns about Competency: IDEA's Special Rule

IDEA includes a "special rule" about transfer of parental rights when students with disabilities reach the age of majority. The special rule relates to young people:

- who do not have the ability to provide informed consent to their educational programs, but
- who have not been determined by a court to be "incompetent."

In such cases, states may adopt policies that allow parents to continue representing their son or daughter, even after the age of majority is reached. Parents would continue to represent their young person during the entire time the student is eligible for services under Part B of IDEA.

All this is to say: If you feel that your son or daughter does not have the ability to provide informed consent to his or her special education program, be sure to check your state's policies. (To find out your state's policies, contact your Parent Center.) Most states have procedures that would allow you to continue representing your son or daughter's educational interests after the age of majority. Your son or daughter can still ask that you be included in all IEP team meetings and that you help them make any decisions requiring a signature.

What about Guardianship and Other Options?

Letting children grow up and take charge of their lives is a challenge for many, many parents. It's hard to stand back, watch, and let go. When a young person has a disability that seriously affects decision-making, the challenge of "letting go" is that much greater.

Options? | For some parents, the question of assuming **guardianship** of their son or daughter will arise. There are other options to be considered as well, such as **conservatorship** or having an **educational advocate**. If these possibilities have crossed your mind, you'll need to find out more—much more—before taking action. **Guardianship as a legal matter** | Securing guardianship of your son or daughter is a legal matter that has consequences for both parents and offspring. By its very nature, guardianship is quite restrictive—for example, under guardianship, the person is typically considered "incompetent." He or she is usually stripped of the authority to make decisions that is granted to adults.

Suggestions to consider | If you feel you need to learn more about future care-taking options for your son or daughter, here are a few suggestions to get started:

Learn how **your state** defines guardianship. What guardianship options exist, and what are the laws that govern them?

Find out the **differences between** guardianship, conservatorship, and having an educational advocate. What would each mean for you and for your son or daughter?

Determine the best way to provide support to your son or daughter. What is the *least* restrictive way to provide your young person with the support he or she needs to make decisions?

Determine the **level of support** needed for your son or daughter. How much support does your son/daughter need to make sound decisions and choices? Does he or she need support, for example, in identifying *when* to make a decision? In exploring options? In coping with the consequences of choices? What *types* of supports does he or she need?

Consider the "informal" supports your son or daughter already has (e.g., a network of family or friends). Are these enough to support him or her in decision-making, or will more supports be needed?

The time to explore options for supporting your son or daughter in the future is while you are still the one responsible for making decisions about his or her education, safety, and well being. That way, you have time and opportunity on your side. You can support your son or daughter's growth and learning, build his or her capacity to make good decisions, and cultivate the team approach we mentioned earlier in this tip sheet.

To Learn More about the Pros and Cons of Guardianship

National Guardianship Association

http://www.guardianship.org/index.htm

An Overview of Guardianship

http://www.caregiverslibrary.org/caregivers-resources/grp-legal-matters/hsgrp-power-of-attorney-guardianship/an-overview-of-guardianship-article.aspx

National Health Care Transition Center

Webinar: Understanding Guardianship and the Alternatives for Decision Making Support (58 minutes)
Guardianship and Alternatives for Decision-Making Support

Definitions, Please!

Note: The following definitions contain the common elements of each term from various sources. However, specifics will vary from state to state. Therefore, it is recommended that you **refer to your state's specific definition for each term for a complete understanding** of the legal processes that will guide your choices. Terms are presented in alphabetical order.

Age of Majority | This is the age that a state sets for a minor to become an adult and assume legal responsibility for himself/herself and all decisions that accompany that (e.g., financial, medical, educational). In most states, this is age 18.

Guardianship | Guardianship is "a court-ordered arrangement in which one person is given the legal authority to make decisions on behalf of another person whom a court has deemed to be 'incapacitated.'" A guardian can be removed or replaced via a petition to the court. Guardianship can come in many forms and can apply to several areas, as shown below.

Types of Guardianship

Ad Litem | A guardian ad litem is arranged for a designated time period for a designated purpose (e.g., settling a lawsuit).

Emergency/Temporary | Emergency or temporary guardianship is arranged in situations where immediate action is necessary to protect the ward in some manner. Ninety days is a common limit to how long an emergency/temporary guardianship can be in effect.

Full/General/Plenary | Full guardianship transfers legal authority for all aspects of a ward's life to the guardian. This includes, but is not limited to, making decisions concerning the ward's "living arrangements, education, social activities, medical care, right to marry and association with others."

Limited | Limited guardianship is an arrangement in which a guardian is given legal rights to make decision only in certain areas of a ward's life (e.g., health care).

Testamentary | Testamentary guardianship is an arrangement in which a current guardian designates a successor guardian for a ward in a will. Upon the original guardian passing away, the successor guardian assumes the legal responsibility for the ward.

Incapacitation/Incompetency | An incapacitated or incompetent person is someone who the courts determine is unable to make "informed decisions" about his or her personal care or the care of his or her affairs due to a mental illness, physical illness, disability, or other condition. These decisions can include decisions about the person's finances, residence, education, vocational programs, behavioral programs, medical or dental care, or legal matters. The level of incapacitation is a threshold issue that determines what level of guardianship is granted.

Ward | The term "ward" refers to the individual who is under guardianship as a result of being deemed incapacitated or incompetent by the courts.

Resources and Helpful Connections

Growing up is natural, it's inevitable, and it's exciting. We hope that this tip sheet has helped you and your young person get ready. May all our sons and daughters go forth, make their foolish mistakes despite our warnings, enjoy their triumphs, ask for our help when they need it, and build their lives as independently and satisfyingly as possible.

Need more information? | Consult the list of resources listed below.

Your state's PTI or CPRC

Every state has at least one Parent Training and Information Center. Many states also have a Community Parent Resource Center. Both are excellent resources for parents and young adults to consult during transition planning and afterwards. There, you and your son or daughter can connect with the network of disability-related resources and agencies in your state and community, attend workshops on topics of importance, find answers to disability questions, and much more. Find your Parent Center at:

http://www.parentcenterhub.org/find-your-center/

Age of Majority | What IDEA requires and what age of majority means

http://www.parentcenterhub.org/repository/age-of-majority/

Age of Majority in Your State

http://minors.uslegal.com/age-of-majority/

Life after IEPs

http://lifeafterieps.com/age-of-majority-what-does-it-mean-for-my-child/

National Resource Center for Supported Decision-Making

http://supporteddecisionmaking.org/

Transition to Adulthood Suite

This suite is made up of 9 webpages of resources on the entire transition and postsecondary process, including transition planning in secondary school, getting students involved in writing their own IEP, independent living, finding adult services, and connections to employment and postsecondary education connections.

http://www.parentcenterhub.org/repository/transitionadult/

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