Exceptional Teachers Teaching Exceptional Children

NASET
SPECIAL EDUCATOR E-JOURNAL

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Special Education Legal Alert

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This month's update identifies court decisions that address current issues for students with disabilities, including dyslexia identification/ interventions and masking policies. For various related articles, special supplements, and earlier monthly updates, see **perryzirkel.com**.

On January 12, 2022 in *Crofts v. Issaquah School District No. 411*, the Ninth Circuit Court of Appeals addressed the evaluation of and successive IEPs for a student with dyslexia. In the summer before the student started grade 2, the parents obtained an independent educational evaluation (IEE) that concluded that the student presented with "the classic profile of the specific learning disability of dyslexia." Providing the report to the district, the parents requested an eligibility evaluation under the IDEA. The district's evaluation determined that the student was eligible under the classification of specific learning disabilities (SLD). The resulting IEP provided for 40 minutes of reading and writing instruction per day in a special-education resource room as well as several accommodations in the general education classroom. At the end of grade 2, the student progressed toward but did not meet the goals in the IEP. The IEP team revised the goals and increased the special-education instructional time to 60 minutes per day. In grades 2 and 3, the IEP team rejected the parents' respective requests for (a) the Orton Gillingham reading program and (b) the specific classification of dyslexia and an IEE at public expense. The resulting due process hearing and federal district court decisions were in favor of the district, and the parents appealed to the Ninth Circuit.

For the evaluation, rejecting the parents' arguments based on the IDEA requirements for a comprehensive evaluation that assesses "all areas of suspected disability," the Ninth Circuit ruled that "the District did not procedurally violate the IDEA when it found [the student] eligible for language-related services under the [SLD] category rather than using the term 'dyslexia.'"	Careful reading of the court's rationale provides potentially mixed signals. The use of "procedural" in the ruling suggests that the parents faced the additional hurdle of showing resulting harm for denial of FAPE. On the other hand, the court narrowly reasoned that (a) the district's evaluation in this case incorporated the original IEE's dyslexia assessment and (b) the parents had neither identified any additional testing needed for this purpose nor shown that the student's educational difficulties were so different from SLD to require this specific label.
For the IEPs in grades 2 and 3, sidestepping the parents' contention that the student would have obtained more progress with Orton Gillingham, the Ninth Circuit ruled that the district met the substantive standard under *Endrew F.* without providing for this specific approach.	Although citing the traditional judicial deference to district's methodological discretion in the provisions and implementation of this aspect of IEPs, the Ninth Circuit recognized the exception for preponderant proof that a particular approach was necessary for the requisite progress. Similarly mixed in potential application, the court reasoned that the *Endrew F.* standard does not require meeting "all" IEP goals or grade-level expectations.
The bottom line is to continue individualized evaluation and FAPE determinations with due consideration for, but not overreliance on, particular diagnoses, such as dyslexia; methodological brands, such as Orton-Gillingham; or stilted interpretations of *Endrew F*.	
In response to the COVID-19 pandemic, various states have adopted policies that prohibit school districts from requiring masking of students and staff. The result has been litigation in several federal courts in which parents of medically vulnerable students with IEPs or 504 plans have claimed that such bans violate their rights under Section 504 of the Rehabilitation Act (§ 504) and the Americans with Disabilities Act (ADA). Although the challenged state policies are not all identical in their rigor and the pandemic context is similarly fluid, most of the federal district courts resulted in	

preliminary injunctions in favor of the plaintiff-students. However, four of these cases have resulted in federal appeals court decisions that reveal the unsettled state of the case law, with further judicial developments on the horizon.	
On November 19 in *G.S. v. Lee* and December 20, 2021 in *M.B. v. Lee*, the Sixth Circuit Court of Appeals denied Tennessee's motion for a stay of the lower courts' preliminary injunctions against the governor's order banning school district mask mandates.	The Sixth Circuit relied on the defendant's failure to show alternative reasonable accommodations under § 504/ADA beyond universal masking but pointed out that "there are significant arguments in favor of both sides of this case" for the various factors applicable for preliminary injunctive relief.
On December 1, 2021 in *E.T. v. Paxton*, the Fifth Circuit Court of Appeals granted Texas' motion for an emergency stay of the lower court's injunction prohibiting enforcement of the governor's ban, pending an ultimate appellate decision on the merits.	The Fifth Circuit alternatively relied on the plaintiff-parents lack of standing, their failure to exhaust due process hearings under the IDEA, and their failure to show that universal masking, as compared with other mitigation measures, such as social distancing and voluntary masking, was the requisite reasonable § 504/ADA accommodation.
On January 25, 2022 in *Disability Rights South Carolina v. McMaster*, the Fourth Circuit Court of Appeals vacated the lower court's preliminary injunction against the legislature's ban, but it only applied to the two of the original more widespread group of defendants who appealed—the governor and the state's attorney	The Fourth Circuit relied on its conclusion that the plaintiffs had not shown the requisite elements for standing. However, the decision was split 2-to-1, with the blistering dissent in the plaintiffs' favor, and, more importantly, the majority relied on a state supreme court ruling that the ban did not apply to school districts' use of funds beyond the 2021-22 appropriation act.

<table>
<tr><td>general.</td><td></td></tr>
<tr><td>On the same day in 2022 in *ARC of Iowa v. Reynolds*, the Eighth Circuit Court of Appeals rejected the defendants’ arguments based on standing and exhaustion but modified the lower courts’ injunction to apply only to the schools that the plaintiff-students attended.</td><td>This decision was also 2-to-1, with the dissent relying on the IDEA’s exhaustion provision, but the majority concluded that requiring at least some staff and students to wear masks (presumably those who posed direct risk to the plaintiff students) was the requisite reasonable accommodation under § 504/ADA.</td></tr>
<tr><td colspan="2">These four decisions reveal not only the lack of a prevailing judicial view with regard to masking policies in schools in relation to medically vulnerable students with disabilities but also the complex litigation issues, including the prerequisites of standing and exhaustion and the ultimate contours of reasonable accommodations under § 504/ADA. Moreover, these rulings are only at the preliminary stage in the ponderous process of judicial decision-making, and they do not address other challenging issues, such as the § 504/ADA rights of students who have disability-related difficulties with mask wearing. In these polarized political times, the ultimate challenge for educators, parents, and other stakeholders is to find solutions that are a rational, effective, and harmonizing compromise among various competing interests and views.</td></tr>
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Buzz from the Hub

All articles below can be accessed through the following links:

https://www.parentcenterhub.org/buzz-feb2022-issue1/

https://www.parentcenterhub.org/buzz-jan2022-issue2/

https://www.parentcenterhub.org/buzz-jan2022-issue1/

https://www.parentcenterhub.org/buzz-nov2021-issues1-2/

Sharing Info about State Assessments with Families

(Also available in Spanish) Riches, indeed, are shared in this Febrary 11th CPIR webinar, which focuses on NCEO's new (and quite amazing!) resource, the *Participation Communications Toolkit*. You'll love the toolkit; it's designed for stakeholders of all stripes to use in discussing and making decisions about how children with disabilities will participate in state assessments. The webinar highlights the role that Parent Centers in particular can play in supporting the family's role as one of the primary decision makers about their child's participation.

Return to School | Child Find and Early Intervention Services

(Also available in Spanish) This February 2nd webinar features presenters from OSEP as they elaborate on two of OSEP's recent *Return to School Roadmaps*, both focused on Part C: (1) Child Find, Referral, and Eligibility; and (2) Provision of Early Intervention Services. Both roadmaps are also available in Spanish, as is this webinar.

Introduction to the Vocational Rehabilitation Program

(Also available in Spanish) Want to learn more about the services available from the vocational rehabilitation system for people with disabilities? Check out this January 24th webinar from the RAISE Center. It covers eligibility, developing the Individualized Plan for Employment, available services, and financial factors to consider. Links to the captioned English and Spanish versions are given at the bottom of the page linked above.

Honoring Black History Month: Unsung Heroes of the Disability Rights Movement

The month of February is dedicated to honoring the long history of Black Americans and their many contributions to society. In this article, NCLD (National Center for Learning Disabilities) highlights the stories of Black heroes whose vision, commitment, and activism helped advance progress for people with disabilities.

Plain Language Made It Easy

(Also available in Spanish) | The RAISE Center and PEATC (Virginia's PTI) collaborated to develop this resource guide and video in English and Spanish to assist people in making their documents accessible to everyone.

Return to School Roadmaps now available in Spanish

The U.S. Department of Education released its series of *Return to School Roadmaps* in the summer and fall of 2021. Now it has posted Spanish versions of each roadmap in the series– which we are pleased to list below.

Letter to Special Education and Early Intervention Partners [**English** | **Español**]

Child Find, Referral, and Eligibility Under Part C [**English** | **Español**]

Provision of Early Intervention Services for Infants and Toddlers with Disabilities and their Families [**English** | **Español**]

Child Find Under Part B of IDEA [**English** | **Español**]

Development and Implementation of IEPs in the LRE [**English** | **Español**]

Federal Funding Support Specifics

In March 2021, the American Rescue Plan (ARP) Act was signed into law. It included $122 billion for states and school districts to help safely reopen and operate schools and address the impact of the pandemic on students. Want to know more about ARP funding for your state? How about what your state proposed to do with those funds? Find out at the link above, posted by the Office of Elementary and Secondary Education at the U.S. Department of Education.

The Department's January 2022 press release on the approval of all state plans and the distribution of funds to states highlights what SEAs and school districts are doing to address the urgent needs of their schools with ventilation improvements, staff hiring and retention, mental health services, high-dosage tutoring programs, after-school and summer learning partnerships, and more.

Support for COVID-19 Screening Testing in Schools

Heard of the ELC at the CDC? In April 2021, it awarded $10 billion from the ARP on behalf of CDC to 62 recipients to support COVID-19 screening testing and other mitigation activities in K–12 schools for teachers, staff, and students. Use the USA map to find out about the screening programs and plans in your state. Funding is available through July 31, 2022.

Competitive Integrated Employment (CIE) Toolkit

This toolkit is a resource for educational and vocational rehabilitation agencies in improving post-school employment outcomes for students with disabilities. It's meant to facilitate the collaboration necessary to implement secondary transition services across agencies at the state, community, and student levels and increase the use of evidence-based practices (EBPs). From NTACT, the National Technical Assistance Center on Transition.

Pros and Cons of Disclosing a Disability to Employers

*(Also available in Spanish: **Ventajas y desventajas de revelar a los empleadores que tiene una discapacidad**)*

Starting a new job can make teens and young adults feel excited, independent, and maybe nervous. They're expected to learn new skills and routines, interact with new people, and make decisions. One of the biggest decisions is whether to tell their employer about any learning and thinking differences.

Getting Ready for the 2021-22 School Year: FAQs About Testing Children with Disabilities

As children return to school, it is critical that states and districts gather information on what children with disabilities have learned and where they need more support to meet their learning goals. This FAQ from NCEO addresses some common questions and provides links to useful resources.

Questions Often Asked by Parents about Special Education Services

This CPIR resource includes answers to 26 questions. To zoom in to those pertaining to evaluation, go to Questions 5 and 6.

The School Evaluation Process: What to Expect

(Also available in Spanish: ***El proceso de evaluación escolar: En qué consiste****)*

From understood.org, this article is well suited for parents new to the evaluation process, as is the next resource in this list.

Understanding Evaluation Results and Next Steps

(Also available in Spanish: Entender los resultados de la evaluación y los siguientes pasos)

How to Understand your Child's IEP Evaluations | Preparing for an IEP Eligibility Meeting

Definitely well suited for families new to the special education process and for all who are understandably baffled by the meaning of the data! Includes a 38-minute video.

Many of the students returning to school this year come from homes where English is not the primary or native language. How to ensure that these families can understand and fully participate in revisiting their child's IEP or existing evaluation data? Consult these 2 resources.

Information for LEP Parents and Guardians and for Schools and School Districts that Communicate with Them

This fact sheet answers common questions about the rights of parents and guardians who do not speak, listen, read, or write English proficiently. Jointly issued by the U.S. Departments of Justice and Education.

Civil Rights Protect Language Access for Parent Participation in Child's Education

Under state and federal law, all parents have the right to information about their child's education in a language they can understand. This information is translated on handouts in multiple languages from Washington State's Office of Superintendent of Public Instruction (OSPI).

Facing Fears, Supporting Students

(Also available in Spanish: De vuelta a la escuela 2021)

This back-to-school toolkit comes from Mental Health America (MHA) and aims to help students, parents, and school personnel recognize how feeling unsafe can impact mental health and school performance, and what can be done to help young people who are struggling with their mental health.

Updated CDC Guidance for Operating Early Care and Education/Child Care Programs

*(Also available in **Spanish** and other languages, via the Languages drop-down menu)*

Updated as of November 10th, this guidance starts by identifying what key changes the CDC has made to its earlier guidance to early care programs.

In Case You Missed It: **Webinar on Development and Implementation of IEPs**

In late October, CPIR hosted an info-rich webinar with presenters from OSEP explaining and elaborating upon **OSEP's guidance** on this crucial topic. It's online for your viewing, as are the presentation slides and a transcript of what presenters had to say. (BTW, it was a fantastic webinar!)

How Parent Support Groups Can Help

(Also available in Spanish: Cómo pueden ayudar los grupos de apoyo para padres)

When a child's challenges first emerge, parents often find themselves feeling not only confused but alone. This is where special-needs communities can become key. By finding other parents who are facing, or have faced, the same issues, many parents feel better able to navigate a path they never envisioned.

p.s. Another useful resource for parents when they learn that their child has a disability: **You are Not Alone** *(In Spanish: Ud. no está solo)*.

Special Needs Trusts and ABLE Accounts: How Are They Different?

(Also available in Spanish: Fideicomisos Para Necesidades Especiales y Cuentas ABLE: ¿En

qué se diferencian?)

Do parents know the differences between a special needs trust and an ABLE account? This video can help them decide which is right for their family.

Development and Implementation of the IEP in the LRE

In late September the Office of Special Education Programs (OSEP) released a 40-page **guidance** describing how many children with disabilities will have a range of new or additional needs resulting from the pandemic that schools and IEP teams must address as students return to school. In late October, CPIR hosted a webinar on the same subject, with OSEP taking Parent Centers through the salient points raised in its guidance. The link above will take you to the archive of the webinar, where you can connect with the video recording, the slides OSEP used, a transcript of what presenters said, and the written guidance that inspired the gathering.

Behavior Challenges: Conversation Starters to Use with Your Child's Teacher *(good to share with families)*

*(Also available in Spanish: **Problemas de conducta: Cómo iniciar la conversación con el maestro de su hijo**)*

When a child has behavior challenges, it can be hard for parents to talk about them with teachers. Having these conversations can help parents get support for their child at school, even if learning is happening at home. Parents can use these sample conversation starters to help themselves plan what to say when they talk with their child's teacher.

Cutting and Other Self-Injury *(good for sharing with families)*

*(Also available in Spanish: **Cortes y otro tipo de autolesiones: Cómo ayudar**)*

When kids intentionally hurt themselves, often by cutting or scratching their skin, it's often as a way to manage difficult emotions. This Child Mind offering discusses self-injurious behavior as part of answering 3 questions: *Why do kids cut or hurt themselves? What are signs of self-injury?* and *How can parents help?*

Part C Finance Glossary

Download this glossary of terms relevant to **finance** for IDEA Part C and Part B, Section 619 programs (e.g., blending and braiding funds, pass-through-funding, and supplant). Terms include references to IDEA and other related federal fiscal requirements and those specific to billing public and private insurance for IDEA services. The glossary was developed collaboratively by Infant Toddler Coordinators Association (ITCA), ECTA, the DaSy Center, and Center for IDEA Fiscal Reporting (CIFR).

Supporting and Protecting the Rights of Students at Risk of Self-Harm

From the U.S. Department of Education's Office for Civil Rights (OCR) and the U.S. Department of Justice, this joint 3-page fact sheet can help support students with mental health disabilities, their families, and their schools in the era of COVID-19. OCR also released a **letter to educators** highlighting the civil rights obligations of schools and postsecondary institutions to students with mental health disabilities.

Connect to Care

From the Child Mind Institute come several on-point mental health resources for families and professionals alike.

- Its new **Family Resource Center**, which features over 700 resources on kids' mental health, learning disorders, and common parenting challenges — all in English and Spanish.
- Its **latest newsletter**, which connects you with stand-alone articles in English and Spanish, such as "*Should I get care for my child?*" and "*How to find a children's mental health professional.*"
- The **2021 Children's Mental Health Report** (also available in ***Spanish***), which focuses on the effects of the COVID-19 pandemic on children's mental health.

For Parents of Children Who Were Just Diagnosed With a Health Condition

Having your child diagnosed with a health condition can be downright frightening. Here are 5 gentle reminders for anyone whose child was just diagnosed with a disability or chronic illness.

Update from the U.S. Department of Education

U.S. Department of Education Invites Applicants for Javits Gifted and Talented Program

The U.S. Department of Education (Department) released the FY 2022 notice inviting applications (NIA) for the Jacob K. Javits Gifted and Talented Students Education Program (Javits). The program will award up to $6.6 million in new grants for five-year projects that support evidence-based research, demonstration projects, innovative strategies, and similar activities that enhance elementary and secondary schools' capacity to identify gifted and talented students and meet their unique educational needs.

Supporting all students, including gifted and talented students, with accelerated learning opportunities is critical to addressing the impacts of lost instructional time and supporting positive academic outcomes for all children. Accelerated learning opportunities can help to ensure students excel and thrive.

"Expanding access to gifted and talented programs is one important way that we can ensure all students—particularly those who are underserved—have the opportunity to engage in rich, rigorous learning experiences that open doors for them to discover new passions and reach their potential," said U.S. Secretary of Education Miguel Cardona. "This work is perhaps more important now than ever before, when we must support students through our nation's continued recovery from the pandemic and boldly address opportunity gaps in our education system."

The Department strives to ensure that the educational needs of underserved children and youth, including those with disabilities who are gifted and talented, are met. Addressing and closing educational opportunity gaps in underserved communities—before and after the pandemic—are one of the top priorities of the Biden-Harris Administration. A major emphasis of the Javits program is to identify and serve students underrepresented in gifted and talented programs, to include the training of personnel in the identification and education of gifted and talented students and in the use, where appropriate, of gifted and talented services, materials, and methods, for all students.

The FY 2022 Javits program competition focuses on students who are underserved and underrepresented in gifted and talented programs by including an absolute priority that applicants must address to be eligible for review. This year's application requires applicants to develop "new information that assists schools in the identification of, and provision of services to, gifted and talented students (including economically disadvantaged individuals, individuals who are multilingual learners, and children with disabilities) who may not be identified and served through traditional assessment methods."

Eligible applicants include state educational agencies; local educational agencies, the Bureau of Indian Education; institutions of higher education; other public agencies; or other private agencies or organizations.

Applications are due on April 4, 2022. Successful applicants will be selected through a competitive peer review process, and awards will be made by August 2022. A pre-application webinar will be held for potential applicants on Feb. 24, 2022, from 1 – 4 p.m. ET, via MS Teams. Information about the pre-application meeting will be posted here.

https://www.ed.gov/news/press-releases/us-department-education-invites-applicants-javits-gifted-and-talented-program

New Updates to College Scorecard Make Tool More Useful for Students and Families With Data About College Costs, Graduation Rates, and Post-College Earnings

The U.S. Department of Education released updates to the College Scorecard that make the tool more useful for students and families weighing college options. The tool also includes new and updated information that may be beneficial to school counselors, college access providers, researchers, and other critical stakeholders. The Department has improved the College Scorecard interactive web tool, in addition to restoring several metrics that help students gauge how their prospective institution compares to other colleges across costs, graduation rates, post-college earnings, and other metrics. The changes reflect the Department's priority of supporting and encouraging inclusive, affordable postsecondary programs that provide strong career outcomes for students.

U.S. Secretary of Education Miguel Cardona will highlight these new updates to the College Scorecard today, during the 2022 Community College National Legislative Summit, an event that brings together hundreds of community college leaders from across the country.

"For so many students and families, the college search process can be overwhelming. But easily accessible, high-quality information about higher education institutions can help students determine which college or university is the best fit for them," said U.S. Secretary of Education Miguel Cardona. "The updated and enhanced College Scorecard shines a spotlight on affordability, inclusivity, and outcomes, over exclusivity and colleges that leave students without good jobs and with mountains of debt. This update reflects the Biden-Harris administration's commitment to ensuring students remain at the heart of the Department's work."

Updates to the College Scorecard also include an annual refresh of the cumulative loan debt of student borrowers at both the institution-level and by field of study within each institution, as well as federal student loan repayment rates for the institution.

For the first time since 2018, the Department is publishing—both in the data files and on the consumer site—institution-level earnings data, which provide an overall sense of the career outcomes for alumni of the institution. The Scorecard also includes additional information about graduates who are better off for having gone to the college, by showing the percentage of those earning more than the typical worker with only a high school diploma.

College Scorecard data provide essential details for students and prospective students across all colleges, helping them to make informed decisions about their postsecondary education plans. The data also shine a spotlight on accessible colleges that are serving their students well, including by closing gaps in the completion rates among students of color compared with white students and by ensuring programs lead to positive career outcomes with manageable levels of debt. Examples include:

- University of Baltimore, a Predominantly Black Institution in Maryland, enrolls Black students as nearly half of its enrollment, charges much lower tuition than most four-year institutions, and saw median post-college earnings of more than $58,000.
- Valencia College, a community college in Florida, enrolls three in four of its undergraduate population as students of color and has narrowed its college completion rate gaps; today, 45% of white students and 41% of Hispanic students graduate from the program.

The College Scorecard includes many other examples of institutions that are inclusive, often under-resourced, and are working to improve their students' outcomes.

The College Scorecard builds on efforts by the Biden-Harris Administration to address barriers to college completion, particularly for students from low-income backgrounds and students of color, and increase accountability for institutions of higher education. Secretary Cardona discussed these efforts as part of his vision for education from early childhood education through higher education and career pathways, which he laid out earlier this year. These efforts include:

- Launching the Institutional and Programmatic Eligibility negotiated rulemaking committee to develop strong rules to ensure career training programs lead to valuable credentials for their graduates;
- Establishing an Office of Enforcement within the office of Federal Student Aid to identify and address major problems across institutions that pose widespread risks to students and taxpayers;
- Providing billions in federal COVID relief funding for institutions that serve high populations of students of color and students from low-income backgrounds;
- Cancelling more than $15 billion in student loan debt for 675,000 borrowers across the country; and
- Proposing expanded access through more funding for Pell Grants for students.

https://www.ed.gov/news/press-releases/new-updates-college-scorecard-make-tool-more-useful-students-and-families-data-about-college-costs-graduation-rates-and-post-college-earnings

Getting Ready for Healthcare at the Age of Majority

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.

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

Guardianship and 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

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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 (*this* tip sheet)
- Getting Ready for Managing Finances at the Age of Majority
- Getting Ready for Independent Living at the Age of Majority

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

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Financial Planning Guide for Parents of a Child with Special Needs

This article from eParent.com discusses a topic of great importance of parents of a child with disabilities. As *A Financial Planning Guide for Parents of a Child with Special Needs* states, "Raising a child with special needs can be one of the richest experiences life has to offer, but it is also one of the most costly." Depending on the nature and severity of the child's disability, the costs can be quite staggering. Should something happen to the parents, the financial security of the child (even as an adult) can be devastated. This is why it's crucial for parents to start long-term financial planning as early as possible. This guide from eParent.com can help parents plan for the best possible future for their son or daughter.

The guide is divided into sections, beginning with 5 steps important to defining the parents' future goals. The guide discusses:

- early intervention services for very young children;
- different kinds of federal benefits and what's involved in applying for them;
- non-profit grants and scholarships for students with disabilitie:
- what special-needs trusts are (did you know there are several different kinds?) and how to fund such trusts for the future security of the person with the disability;
- types of life insurance policies; and
- the role that transition planning (for adulthood) can play in reassessing and establishing a sound financial plan for the child's future.

The guide is available online, at:
http://www.eparent.com/money-uncategorized/a-financial-planning-guide-for-parents-of-a-child-with-special-needs/?amp=1

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