

**ILRU Community  
Living Partnership**

National State-to-State  
Technical Assistance Center



# Youth Leadership Toolkit

## Guidebook

### PARTNERS

INDEPENDENT LIVING  
RESEARCH UTILIZATION  
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NEW HAMPSHIRE

UTAH STATE UNIVERSITY  
(CENTER FOR PERSONS  
WITH DISABILITIES)

**A Publication of Independent Living Research Utilization**

**Developed in Collaboration with Utah State University  
Center for Persons with Disabilities**

# **Youth Leadership Toolkit**

## **Guidebook**

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**A Publication of Independent Living Research Utilization**

**Developed in Collaboration with Utah State University  
Center for Persons with Disabilities**

**March 2009**

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ILRU is a program of TIRR Memorial Hermann (The Institute for Rehabilitation and Research)

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Permission is granted for duplication of any portion of this manual, providing that the authors and ILRU are credited: Hammond, M., Sheen, J., Holt, J., Romeo, A., (Authors). (2009). Youth Leadership Toolkit. Houston, Texas: ILRU.

*Substantial support for development of this publication was provided by the Centers for Medicare & Medicaid Services under Grant No. 11-P-92574/6-01. No official endorsement of the funder should be inferred. Additional funding was provided by Utah State University Center for Persons with Disabilities, Utah Regional Leadership Education and Neurodevelopmental Disabilities Program, and Utah Family Voices Health Information Center.*

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## **Acknowledgement**

We would like to express our deep appreciation to Gina Pola-Money for giving the gifts of her time and expertise to review a draft of this document and the Youth Leadership Toolkit DVD. She provided very helpful feedback and insights for both, a number of which have been incorporated into the final version.

# Youth Leadership Toolkit

## ***Introduction***

President Obama states that, "We must build a world free of unnecessary barriers, stereotypes, and discrimination.... policies must be developed, attitudes must be shaped, and buildings and organizations must be designed to ensure that everyone has a chance to get the education they need and live independently as full citizens in their communities" (White House, 2008). He further explains that one of the most important measures of any society is how well it enables each person to live up to his or her potential, and that providing the needed supports and services for individuals with disabilities to succeed goes to the heart of our nation's future (Disability Nation, 2008). President Obama's comprehensive agenda to empower individuals with disabilities includes providing the educational opportunities they need to succeed,



ending discrimination and promoting equal opportunity, increasing the employment rate of workers with disabilities, and supporting independent, community-based living (Obama, 2009). The inclusion and meaningful participation of youth with disabilities in educational, employment, social, community and leadership activities is vital to their future success and achievement of their life goals.

The involvement of youth and young adults with disabilities is also a vital component of effective service provision. There has been a concerted effort to include parents in medical care decisions, administration of services, and establishment of policies. Inclusion of both parents and young adults at all levels is an important step toward supporting the growth and independence of youth, and to ensure that services are as effective as possible.

## ***Purpose***

The target audience of this Youth Leadership Toolkit, consisting of a DVD and guidebook, is Family to Family Health Education Centers (Family Voices), parents, young adult self-advocates, healthcare providers, physicians, disability service organizations, and family members, but it may also prove useful for teachers and other individuals or organizations who work with youth with disabilities. The purpose is to increase understanding of the importance of the perspectives that youth and young adults bring and to provide information and tools that help to effectively include them in addressing the challenges of transitioning to adulthood and increased independence.

The toolkit demonstrates the importance of young adults as leaders and partners with organizations, service providers, and state and local systems. The DVD provides a means for young adult voices to be heard regarding key components

of living independently in the community. The human stories describe the impact (both potential and actual) of state and national policies and practices in health and human services.

A growing body of research has validated the importance of youth with disabilities being involved in such leadership development activities. The comprehensive positive aspects include decreasing risky behaviors and psychological problems and increasing the likelihood of:

- achieving successful transition to adulthood,
- developing deeper connections to their communities and peers,
- feeling more in control of their lives,
- achieving better academic outcomes,
- increasing self-esteem and personal identities, and
- improving life skills and decision-making (Matarese, McGinnis, & Mora, 2005; Edelman, Gill, Cornerford, Larson, & Hare, 2004).

The authors envision that family to family networks and other groups will use the DVD and guidebook as a resource for raising awareness in their communities. They might use the material with organized discussion groups, as part of formal presentations to community leaders or service providers, or for in-service trainings with youth and parents. Thus, the Youth Leadership DVD is divided into four sections for healthcare providers, families, youth, and disability organizations; this guide gives suggestions for use with each of those groups including key points, suggested discussion questions, and suitable venues. This guide also includes an additional section for teachers, and suggests how the material targeted to the other groups can be incorporated into classroom lessons, discussions or conferences. Each section of the DVD shows a number of young adults sharing their positive and negative experiences, insightful thoughts, and useful advice. The DVD demonstrates diverse examples of the strengths, skills, energy, and knowledge that young adults with disabilities bring to the table. Additional Internet resources are listed at the end of the guide.

## ***Transition***



Accomplishing real transition into adulthood – where young adults actually run their own lives - requires vision, passion, focus, flexibility, and persistence (Carol, 2006). Young adults with disabilities should expect good healthcare, and employment with benefits and independence (Noyes-Grosser, 2007). Yet youth often lack the opportunities to learn their rights, navigate services and systems, and participate in other activities necessary for building a successful adult life (Powers, Deshler, Jones, & Simon, 2006). Current post-school outcomes for many youth with disabilities are often less than optimal with

unemployment, under-education, continued dependence on parents, social isolation, and lack of involvement in youth, leadership and community activities (NCD, 2000). There is not a comprehensive national policy that effectively addresses the complexity of these issues.

Although transition outcomes have shown some recent improvement and effective support practices have been identified, there are still significant barriers that preclude full participation in critical adult life activities (Powers, Garner, Valnes, Squire, Turner, Couture, & Dertinger, 2007). Barriers to transitioning youth with disabilities include the lack of transportation, accommodations, coordinated services, accessible computers in classrooms, quality learning experiences, and employment opportunities; as well as continued stereotyping (NCD, 2000). Practices that enhance transition outcomes include student-centered transition planning, self-determination and other life-skills, family support, participation in general education and work-based learning experiences, postsecondary education, involvement in service learning, and partnerships among students and their families, schools, employers, health providers, and community organizations (Powers et al., 2006).

### ***Families and Youth***



Youth have emphasized how important it is for family members to expect them to succeed and to support their efforts (Powers et al., 2007). The support and belief of family members and peers are especially important for young adults with disabilities because they often experience low expectations, rejection, and discrimination in their daily lives. It may be difficult for young adults with disabilities not to internalize the negative attitudes they face. Low expectations and negative attitudes are major barriers for people with

disabilities to overcome in order to experience success in post-secondary education and employment settings (Dowrick, Anderson, Heyer, & Acosta, 2005). Providing a positive counter balance to these negative societal experiences is one reason why it is so critical for families, peers and providers to provide support and encouragement. Family support enables feelings of self-esteem, attachment, belonging, competence, success and independence (Peterson, 2006).

The transition from childhood to adulthood is a passage for families as well as youth with milestones, questions, needs and concerns (Agosta, Barclay, Melda, & Stenhjem, 2006). It is often a difficult adjustment for parents when their growing child starts to think and live more independently; even more so when that child has disabilities. Sometimes, parents who have been their child's strongest and most tireless advocate are understandably reluctant to put their child in challenging situations. Parents' natural protective instinct often results in trying to prevent their child from experiencing any struggle or heartache. However, the lessons that youth and young adults learn when they are on their

own, even when they sometimes fail, help them make large strides toward independence and feelings of self-worth and accomplishment. The challenge is not to discount this passage into adulthood because of the person's disability, but to embrace it and find ways to mentor young adults with disabilities to grow into strong men and women (Agosta, 2006). The support and understanding of families are vital to help youth reach beyond their current abilities, explore their dreams, and start them on the path towards attaining their goals and developing their full potential.

### ***Youth Involvement in Service Systems***

Youth and young adults with disabilities often do not have the opportunity to participate in important systems decisions that affect them. Agencies tend to operate in isolation without appropriate input, especially from young adults about what they need and how they prefer to receive their services. In a similar example, students with disabilities are often "on the sidelines" in their IEP meetings. Service and educational systems may be perceived as inconsistent, complex, and unresponsive (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004) by the young adults, further adding to their sense of powerlessness.

Yet youth and young adults are deeply affected by the decisions of agencies, and by their policies. Young adults are the ones that must live with their disabilities and the decisions that are made. Youth have first-hand knowledge of the supports they need to live independently in their communities, as well as any potential barriers (Holt, Jones, Petty, Crisp, Roth, & Galantowicz, 2007).

Ideally, young people should be involved at all levels of systems of care from planning and policy development to service provision to quality assurance. Their meaningful involvement can enhance organizational clarity and responsiveness, and facilitate the development of stronger, more diverse, creative, and effective systems (Matarese et al., 2005). Collaborative partnerships between consumers, policymakers, and program managers are an essential strategy for addressing current challenges in creating sustainable programs that maximize independence, choice, rights and inclusion of individuals with disabilities (Holt et al., 2007).

### ***Partnerships and Participation***



The DVD and guidebook will provide disability service organizations with insights that may help with creating and sustaining partnerships with young adults with disabilities. To effectively work together, each partner must learn how to communicate with, respect, and trust the other. The ultimate goal of such partnerships is an efficient, responsive service system that promotes the independence, freedom, rights, and integration of individuals with disabilities.

Full participation of young adults in home and community-based services translates into meaningful consumer involvement in all facets of program planning, implementation, and evaluation. Meaningful implies that young adults are not token representatives of the disability community, but rather have real power and authority in the decisions that are made, and that they have multiple avenues for becoming involved.

## ***Using the DVD***

If your youth group, family to family or parent organization, health care provider or disability service organization would like to use these materials as supports for discussion groups or trainings, here are some key points and questions that can be used either by your organization as discussion prompts or by the targeted groups independently as a self-study tool.

## **Youth and Young Adult Groups**

### *Possible Venues*

- Young adult groups
- Youth or young adult training events
- Viewing with parents/teachers/providers

### *Key Points*

- The DVD provides a peer-to-peer teaching/learning/sharing experience to foster leadership, advocacy, and independent living skills; and to enhance self-esteem and self-efficacy. (I did it and you can, too!)



### *Suggestions for Use*

- Use the clips from the DVD and facilitate a discussion on each topic.
- After viewing each segment, ask the youth with disabilities in your audience if they agree with the statements and if there is anything else that they would add.
- Use some or all of the suggested questions by topic area below.
- Remember that there is no right or wrong answer when discussing the questions.
- It may be helpful to have someone that is comfortable leading a small group facilitate the discussion in order to keep the group on track and focused on ideas for improvement and solutions to problem areas.
- In training sessions for youth and young adults, it may be helpful to watch about 4-6 minutes of the longer segments and break for discussions.

- For conferences or presentations with parents or professionals, it may be helpful to show a section (4-6 minutes), ask a panel of youth or young adults to share their experiences, and then take questions from the audience.

### *Discussion Questions for Young Adults by Topic*

#### Leadership

1. Why do you think it is important for people with disabilities to be on boards and in leadership positions?
2. What contributions can youth with disabilities make to disability groups and organizations?
3. How did you get motivated to become a leader?
4. What types of leadership activities are you involved in or would you like to be involved with?
5. Which disability programs and policies would you like to see changed? What can you do to make a difference?
6. Who do you think are the best people to start to make those changes?

#### Individual Education Plan

1. When did you first become involved in planning/conducting your own IEP?
2. How did you let the other people involved with your IEP know that you wanted to be in charge of or be more involved in your IEP meetings? What was their reaction?
3. Did you receive any coaching from a teacher, parent, or other person in how to conduct the meetings or develop goals?
4. What are some of the things you learned about yourself and others when you started to become more involved in the IEP process?
5. What types of things were you able to get written into your IEP that weren't included before?
6. What was the most frustrating/challenging thing about your experience with IEPs? How did you overcome your challenges?
7. What could parents and professionals do to make the IEP process better for young adults? How can they help young adults become more involved in their own IEPs?

#### Relationships

1. How does society generally treat children, youth, and adults with disabilities?
2. How do you deal with negative attitudes or responses you may get from other people?

3. What would you recommend to people who are not sure how to approach a person with a disability?
4. What steps can you take to help other people feel more comfortable talking with you?
5. Is there anything else you can do to help change attitudes?
6. How might being involved in clubs or church groups assist you in building relationships?
7. What role do friends play in your life?
8. How do you choose friends?
9. How do you set boundaries, get out of potentially bad situations, avoid being taken advantage of, etc.?

### Health and Recreation

1. What insurance and disability services do you have now?
2. Who could have done more to help you get more services? What could they have done to help?
3. What would you recommend to Medicaid, an insurance company, or an agency that provides disability services staff on how to serve you better?
4. If you could make up the rules for insurance or disability services, what would you change?
5. Is there anything you can do to improve or change your services?
6. What kind of recreational activities do you do for fun or to keep healthy?
7. What are other benefits from trying different recreational activities?
8. How could recreational activities be adapted so that you could participate?

### Self-Advocacy

1. What makes you frustrated or confused when you go to the doctor's office, visit your case worker, or get services from other places?
2. Why do healthcare professionals, policymakers and the general public need to understand what it is like to live our lives?
3. How can young adults increase their feelings of self-worth and become more assertive?
4. Can you describe a situation when you were an advocate for yourself or someone else? (For example, using public transportation).
5. Why should young adults with disabilities stand up for themselves and become self-advocates? Can they make a difference?
6. Where are some places or areas when it is important to be a self-advocate?

7. What is the best approach to take when you see something that needs to be changed, such as an inaccessible store?
8. Give an example of a time when you advocated for yourself or someone else and you were proud of yourself and/or pleased with the outcome. Were you afraid to do it? Would you do it again?

### Skills for Independence

1. What does independence mean to you?
2. Do you think independence means the same thing to all young adults with disabilities? Explain.
3. Are you living as independently as you would like? If not, what would you like to change to live more independently?
4. What do you think are the most important skills a young adult needs to develop to be independent?
5. What chores or activities do you assist with in your home that will help you be more independent?
6. How did you develop the skills that help you be independent? Did you get coaching from friends, parents, teachers, and other self-advocates?
7. How did you learn to be independent when going to see the doctor?
8. How did you learn to take your medications and find out about side effects of your medications?
9. Have you worked with any other agencies or groups like People First, Best Buddies, or a Center for Independent Living to learn skills that support independence? How did they help you gain independence?
10. What is the best thing about being as independent as you are? What is the biggest challenge?
11. What could parents, professionals and other advocates in the disability community do to help more youth live as independently as they want?
12. In what ways would you like to be more independent? Are you working towards this goal?

### Employment

1. Did you agree with the advice in the DVD for job seekers? Explain.
2. If you have applied for employment, what challenges did you face?
3. Is there anything else you would add to help job seekers?
4. Is it important to be paid for the work that you do?
5. Along with being paid a competitive wage, are there other benefits to working?

6. What are your experiences with employment?
7. What are the fun parts of your job? What are the hard parts?
8. What are your employment goals?
9. What is your dream job? What do you like about that dream job?
10. What skills or education do you need to get your dream job?

### Transportation

1. What did you think of the advice on the DVD for using transportation?
2. What would you change or add?
3. How important is accessibility to transportation?
4. Do you like to travel? How easy is it?
5. Where do you want to travel? What barriers keep you from going there?
6. What would you like to see improved to make transportation in the community, state, and country more accessible?

### **Families and Parents**

#### *Possible Venues*

- Family-to-family meetings
- Parenting groups
- Viewing with youth as a family



#### *Key Points*

- Much effort has been made to include parents in the decision-making of medical care, administration of services, and establishment of policies. This is an important step toward including the rest of the family, especially the youth/young adults, who need to be involved in these decisions to support their growth and independence as much as possible.
- Sometimes, parents who have been their child's strongest and most tireless advocate since their birth are understandably reluctant to let go or put their children in challenging situations.
- The lessons that the youth and young adults learn when they are on their own, even when they sometimes fail, help them make large strides toward independence, feelings of self-worth, and accomplishment (I did it on my own!).
- Your support and understanding are vital to help your children explore their dreams, reach beyond their current abilities, and start them on the path toward reaching their goals and attaining their full potential.

### *Suggestions for Use*

- Play the DVD section relating to parents.
- Foster a discussion around independence and self-advocacy with some or all of the suggested questions below. If using the materials to promote a group discussion, remember that there is no right or wrong answer to the questions below.
- It may be helpful to have someone that is comfortable leading a small group to facilitate the discussion in order to keep the group on track and focused.
- Play the other sections to gain additional insights on self-advocacy, leadership, independent living, healthcare, education, employment and relationships.

### *Discussion Questions*

1. Name the concerns of the young adults on the DVD.
2. What are the challenges, if any, that you face when your young adults do things on their own and live independently?
3. What are your biggest fears about your youth becoming independent?
4. What are some of the challenging situations or activities that you are reluctant to let your children participate in? How do think allowing them to experience these situations might help with their transition to adulthood?
5. How have you decided which activities to do for them and which activities they should do on their own? How has that process worked?
6. Where do you go to get support or new ideas about how to help your young adult become more independent? (Support group, counselor, friends, etc.).
7. What are some things you've done to foster independence?
8. Do you let your children make their own appointments?
9. Have you taught your children basic skills, such as how to budget, ride the bus, cook, and shop? Why or why not?
10. Do you think it's a good idea to bring youth along when you advocate for them? Do you encourage them to provide input?
11. How can you help them become a stronger self-advocate?
12. What can you do to foster more involvement and participation in leadership activities and youth groups?
13. What are some successes you've achieved with your young adult, and they've achieved on their own?
14. What barriers have been encountered in teaching your child to be independent and how did you address them?

15. How could Medicaid and Social Security rules be changed so that they do not discourage marriage and saving money?

## Physicians and Other Healthcare Providers

### *Possible Venues*

- Individual viewings
- In-service training session
- Medical home training sessions

### *Key Points*

- Your patients depend on you to provide critical medical information in a sensitive and informed manner.
- Talk to the patient, not just to their parents or caregiver.
- Ask your patients about their social lives, whether they experience depression, and what their dreams are.
- Your patients trust you and will take your advice, even when it is the same everyday advice they ignore from their parents.



### *Suggestions for Use*

- Watch the Young Adult-Doctor Interactions subsection with other doctors.
- Think about how you treat your young patients with disabilities and how you discuss medical issues with them.
- Watch the Meeting Patient Needs subsection with doctors and office staff.
- Identify other needed services that could be of benefit to the young adults you serve.
- If you are meeting with other medical providers, foster a discussion on what you might do differently to better serve the needs of young adult patients.
- Encourage your young adult patients with disabilities to watch the section and ask questions at the next visit.
- Watch the Advocating for Young Adults subsection with the medical home team.
- Play the Respecting the Young Adult Patient section at a medical home training session and invite a panel of young adults to share their thoughts.
- Play the other DVD sections, if you have time, to gain additional insights on self-advocacy, leadership, independent living, education, employment, and relationships.

### *Discussion Questions*

1. What new insights or perspectives did you get from watching the DVD?
2. Name the concerns of the young adults.
3. Do you agree with the statements of the young adults? Explain.
4. What is your approach to helping young adults learn about important considerations regarding their health?
5. What are your practices regarding explaining prognosis, and medications and other treatments you prescribe? Are they different for your patients with disabilities? If so, why?
6. Do you advocate, when needed, for your young adult patients? If so, how?
7. Are your services as efficient and responsive to the unique needs of young adults as they could be? How might you improve them?
8. What is your practice's policy for discussing sexuality with youth and allowing private time to ask questions, without parents in the exam room?
9. How could you involve youth and young adults in improving your medical home processes?
10. Are there other ways that policies and practices could be improved to better serve this population? Explain.

### **Disability Service Organizations**

#### *Possible Venues*

- Team meeting
- In-service training session
- Conferences

#### *Key Points*

- Remember that every decision (action or inaction) makes a difference in the lives of those you serve.

#### *Suggestions for Use*

- Watch the DVD section on organizations.
- Foster a discussion around the insights and perspectives that the youth provided, and the current policies of your organization and the practices of your employees.
- After determining what is occurring, discuss how your office might improve services.



- Discuss the current involvement of youth and how that could be increased in all areas.
- Remember that there is no right or wrong answer when discussing the questions below.
- It may be helpful to have someone that is comfortable leading a small group to facilitate the discussion to keep the group on track and focused.
- Play the other DVD sections to gain additional insights on self-advocacy, leadership, independent living, education, employment and relationships.
- For conferences or presentations, it may be helpful to show a section (4-6 minutes), ask a panel of youth or young adults to share their experiences, and then take questions from the audience.

### *Discussion Questions*

1. What new insights or perspectives did you get from watching the DVD?
2. How many youth with disabilities are currently involved with your organization?
3. What are some things you can do to increase meaningful youth participation in different areas, including planning, implementation, and evaluation of services?
4. What was your reaction to the comments from youth who felt they were treated as undeserving of services? Has your organization ever received feedback of that nature about your services?
5. Why do you think that teens sometimes feel devalued? How can we change that perception?
6. Do you advocate, when needed, for your clients? Give examples.
7. How can you be proactive about finding solutions when something isn't working?
8. How long does it take for most clients to receive services? Is there anything that could be done to expedite services?
9. Are your services as efficient and responsive as they could be? Why or why not? How can you improve them?
10. Are your buildings and programs as accessible as they could be? What could be better? Are all accessibility issues being addressed?
11. Are there other ways that your policies and practices could be improved?
12. How could Medicaid and Social Security rules be changed so that they do not discourage marriage and saving money?

## Teachers

### *Possible Venues*

- Classroom
- Teacher training
- Conferences



### *Key Points*

- Youth and young adults with disabilities generally will have to live with their disabilities and educational decisions for the rest of their lives.
- Teachers can help them explore their dreams, reach beyond their current abilities (what learning is all about), and start them on the path toward achieving their dreams and goals.
- Your students will always remember you, so remember to inspire them to greatness (small or large). Your students will use what you teach them to become more independent and productive members of society.
- Teachers can be powerful allies in helping educate students without disabilities about the importance of including youth with disabilities in all aspects of our communities and society.

### *Suggestions for use*

- Use the clips from the DVD in your lessons. For example, show a clip of a young adult reminding other young adults that money management, hygiene, making friends, etc. are important. The students will remember those images/videos and the teacher can refer to them during formal lessons (transition skill-building) or informal teachable moments.
- If using the materials to promote a group discussion, remember that there is no right or wrong answer when discussing the questions below.
- It may be helpful to have someone that is comfortable leading a small group facilitate the discussion in order to keep the group on track and focused on ideas for improvement and solutions to problem areas.
- Ask the students to write about their favorite clip and include why it is their favorite clip and how their lives are similar to the young adults in the clip.
- For conferences or presentations, it may be helpful to show a section (4-6 minutes), ask a panel of youth or young adults to share their experiences, and then take questions from the audience.

### *Discussion Questions*

1. Name the concerns of the young adults on the DVD.
2. Did you learn anything new or gain new insights? Describe.

3. Are IEPs being done in the best way possible? How could the process be improved? Is the student a participant in the development of their IEP?
4. Are you addressing all needed skill areas?
5. Are your students with disabilities making friends? If not, how can you foster their friendships?
6. Are they being included in school and after school activities? If not, what can you change to improve inclusion?
7. Are they being teased or ridiculed by other students? If so, what steps can you take to stop it?
8. Do you ask students about their dream jobs and why they are interested in those jobs? Do you help them develop skills for jobs that are similar to their dream jobs or meet their interests?
9. Do you always ask for student input? How do you handle that input and use it to guide planning?
10. When was the last time that your students received what they asked for?
11. How and when do you advocate for your students?
12. How can teachers and professionals provide better support and services? Why is this important?

## ***Additional Resources***

### **Disability-related Resources**

1. Disability Resources on the Internet  
Nonprofit that disseminates information about thousands of books, videos, databases, government agencies, nonprofits, hotlines and online services.  
<http://www.disabilityresources.org/>
2. Disability-related information and government programs  
Comprehensive information about disability programs, services, laws and benefits.  
<http://www.disabilityinfo.gov>
3. Family Village  
Offers thousands of online resources on disabilities, independent living, parents, aging, abuse, care-giving, siblings, mental health, state-specific resources, and much more.  
<http://www.familyvillage.wisc.edu/>
4. Information database of assistive technology devices  
Objective information about assistive technology products and rehabilitation equipment available from U.S. and international sources for consumers, organizations, families and professionals.  
<http://www.abledata.com>
5. National Dissemination Center for Children with Disabilities  
Provides information on disabilities in children and youth; IDEA; No Child Left Behind and research on educational practices.  
<http://www.nichcy.org/>
6. Online screening tool to find government benefits  
Official benefits Web site of the U.S. government with information on over

1,000 benefits and assistance programs.

<http://www.govbenefits.gov>

## **Education**

### 1. All about the IEP

This Web site article provides an overview of the IEP, and describes the contents and the composition of the team with links for more information.

<http://www.nichcy.org/EducateChildren/IEP/Pages/default.aspx>

### 2. Beyond Compliance: An Information Package on the Inclusion of People with Disabilities in Postsecondary Education

Comprehensive information on the ADA, accommodations, disability studies, peer supporters, student services, and resources.

[http://thechp.syr.edu/BCCC\\_PACKAGE.HTML](http://thechp.syr.edu/BCCC_PACKAGE.HTML)

### 3. College Preparation Resources for Students

List of resources on college preparation, college survival, accommodations, rights, financial aid, and student services.

[http://www.washington.edu/doi/Resources/college\\_prep.html](http://www.washington.edu/doi/Resources/college_prep.html)

### 4. IEP and Transition Planning

This article provides information on strategies to support students, families, and professionals in developing an IEP and transition plan.

<http://www.ncset.org/topics/ieptransition/default.asp?topic=28>

### 5. Impact Feature Issue on Achieving Secondary Education and Transition Results for Students with Disabilities

A 36 page issue describing self-determination, universal design, positive behavior supports, postsecondary access, alternative schools, success stories, cultural sensitivity, resources, and strategies for improving graduation results.

<http://ici.umn.edu/products/impact/163/163.pdf>

6. Post-secondary Education Issues for Transition-age Adolescents with Disabilities: A Guide for Teenagers and their Families

This 127 page guide covers transition preparation, selecting and applying for post-secondary programs, effective classroom strategies, conducting a job search, and retaining a job.

<http://www.hdc.lsuhsu.edu/Programs/CDP/Products/tfguide1.PDF>

## **Employment**

1. Employer Assistance and Recruiting Network

Provides comprehensive feedback from employers on the value of employees with disabilities in six areas, including return on investment, human capital, innovation, marketing, diversity and social responsibility, with links to federal, state and local resources.

<http://www.earnworks.com/businesscase/>

2. Four Strategies to Find a Good Job: Advice from Job Seekers with Disabilities

This 6 page information sheet provides strategies that 19 job seekers found useful in finding jobs that they liked.

[http://www.communityinclusion.org/article.php?article\\_id=57&typqe=topic&id=11](http://www.communityinclusion.org/article.php?article_id=57&typqe=topic&id=11)

3. Going to Work: A Guide to Social Security Benefits and Employment for Young People with Disabilities (2009)

Booklet with information about social security disability and health benefit programs, with an explanation of what happens to benefits when a young person works and how to maximize options.

[http://www.communityinclusion.org/article.php?article\\_id=211](http://www.communityinclusion.org/article.php?article_id=211)

4. Impact Feature Issue on Employment and Women with Disabilities

A 36 page issue that describes employment, profiles different women with disabilities, and offers strategies and resources.

<http://ici.umn.edu/products/impact/211/>

5. Job Accommodation Network  
Offers a variety of resources including individualized worksite accommodations solutions, technical assistance on the ADA and other disability legislation, and self-employment options.  
<http://janweb.icdi.wvu.edu/>
6. Making It Easier to Work: What the Changes at Social Security Mean to You (2008)  
This article explains the incentives or supports that Social Security has developed to assist people with disabilities in entering the workforce, with resources and Web site links.  
[http://www.communityinclusion.org/article.php?article\\_id=56](http://www.communityinclusion.org/article.php?article_id=56)
7. National Collaborative on Work Force and Disability  
Provides information on navigating the road to work, including the workforce development system, with useful links for youth and family to prepare for meaningful jobs.  
<http://www.ncwd-youth.info/>
8. Partners in employment: A self-study course for people with developmental disabilities to find meaningful jobs  
Free web-based course that explains employment trends, the disability gap, supported employment, natural supports, customized employment, the job hunt, hiring process, career planning, resumes, interviews, and accepting a position.  
<http://www.partnersinpolicymaking.com/employment/>
9. Paving the Way to Work: A Guide to Career-Focused Mentoring for Youth with Disabilities  
This 124 page guidebook discusses mentoring approaches and operations, disabilities, accommodations, evaluation, and marketing.  
[http://www.ncwd-youth.info/assets/guides/mentoring/Mentoring\\_Guide-complete.pdf](http://www.ncwd-youth.info/assets/guides/mentoring/Mentoring_Guide-complete.pdf)

10. Road to Self-Sufficiency: A Guide to Entrepreneurship for Youth with Disabilities  
This 80 page guidebook was developed for organizations and policymakers about entrepreneurship, developing successful programs, considerations for youth with disabilities, and resources.

[http://www.ncwd-youth.info/assets/guides/entrepreneurship/entrepreneurship\\_guide.pdf](http://www.ncwd-youth.info/assets/guides/entrepreneurship/entrepreneurship_guide.pdf)

11. Teaching Networking Skills: Paving a Way to Jobs and Careers (Teaching Manual)

A 207 page curriculum for trainers working with individuals with disabilities that have limited work experience to help them become engaged in career and job exploration, primarily through networking.

[http://www.communityinclusion.org/article.php?article\\_id=251&type=topic&id=11](http://www.communityinclusion.org/article.php?article_id=251&type=topic&id=11)

12. Work-based learning for students with disabilities

Two page information sheet on work-based programs including classroom and community-based components, training plan and agreements, accommodations, IEP, progress and resources.

<http://www.pacer.org/parent/php/PHP-c123.pdf>

## **Health and Medical Services**

1. Centers for Medicare & Medicaid Services

Comprehensive Web site with information on CMS, Medicare, Medicaid, SCHIP, Regulations and Guidance, Manuals, and more.

<http://www.cms.hhs.gov/default.asp>

2. Family-to-Family Health Information Centers

List of family-to-family health information centers that offer information, education, training, support, and referral to families and professionals with contact information in different states.

<http://www.familyvoices.org/pub/general/F2F%20Brochure.pdf>

3. Financing Health Care: Insurance, Managed Care, Medicaid and Other Programs

List of 15 linked articles on quality healthcare, private health insurance, DD planning councils, IDEA, Medicaid Waivers, public health payment systems, Rehabilitation Act, SCHIP, Ticket to Work program, Title V of the Social Security Act, and strategies for improving healthcare financing systems.

<http://www.familyvoices.org/pub/index.php?topic=hcf>

4. Health and Medical Issues for Transition-age Adolescents with Disabilities: A Guide for Teenagers and their families

This 84 page guide discusses transition planning, preparing for independence, choosing and working with health providers, paying for healthcare, self-determination, and living a healthy lifestyle.

<http://www.hdc.lsuhsu.edu/Programs/CDP/Products/secdedd.PDF>

5. Healthy and Ready to Work

Information, tools, and links to help youth take charge of their health, and help providers support that growing independence.

<http://www.hrtw.org/>

6. Medical Home Portal

Information and resources to help physicians and parents care for children and youth with special health care needs.

<http://www.medicalhomeportal.org>

7. Planning for Adolescents with Special Health Care Needs and Disabilities: A Guide for Health Care Providers

This 80 page resource guide for healthcare providers provides information, resources and strategies to support adolescents and their families to meet the challenges of transition.

[http://www.communityinclusion.org/article.php?article\\_id=184&type=topic&id=2](http://www.communityinclusion.org/article.php?article_id=184&type=topic&id=2)

8. Youth Involvement in Systems of Care: A Guide to Empowerment  
A 100 page guide for youth, youth coordinators, families and professionals to engage and empower youth to utilize their expertise in leadership development and systems change.  
[http://www.tapartnership.org/youth/docs/Youth\\_Involvement.pdf](http://www.tapartnership.org/youth/docs/Youth_Involvement.pdf)

### **Independent Living Skills**

1. Impact Feature Issue on Meeting Transportation Needs of Youth and Adults with Developmental Disabilities  
A 36 page issue with ideas, strategies and examples for successfully meeting the transportation needs of individuals with disabilities and removing barriers to inclusion.  
<http://ici.umn.edu/products/impact/183/default.html>
2. Independent Living Research Utilization  
A national center for information, training, research, and technical assistance in all areas of independent living with discussion boards, extensive publications, teleconferences, training, Webcasts, resources, and a current listing of Centers for Independent Living.  
<http://www.ilru.org>
3. Money Management  
A one page fact sheet for young adults, families and agencies that discusses roles, determining skills, teaching, and next steps.  
[www.hdc.lsuhscc.edu/Programs/as/Fact%20Sheets/money%20management%20fact%20sheet.htm](http://www.hdc.lsuhscc.edu/Programs/as/Fact%20Sheets/money%20management%20fact%20sheet.htm)
4. Moving towards more health and medical independence: Adolescence  
Fact sheet briefly addressing communication, hygiene, health self-management, difficult challenges, and more.  
<http://www.hdc.lsuhscc.edu/Programs/as/Fact%20Sheets/moving%20towards%20more%20independence%20fact%20sheet.htm>

5. Transition Developmental Checklist

A 2 page checklist of skills to support health and independence.

<http://chfs.ky.gov/NR/rdonlyres/8C5EEDBE-14FC-4488-8C85-1BAC1EDE0516/0/Checklist.pdf>

## **Leadership**

1. Becoming Leaders for Tomorrow

A Youth Information, Training & Resource Center with transition information, tools, and videos for youth, young adults, parents, and providers.

<http://blt.cpd.usu.edu/>

2. Global Youth Action Network

Youth-led, not-for-profit organization that unites the efforts of young people working to improve our world. Connects thousands of organizations to facilitate youth participation, support collaboration, and provide tools and resources.

<http://www.youthlink.org>

3. Guidelines for Organizing a Social Change Group

One page fact sheet with guidelines for forming and managing a group whose purpose is to achieve some kind of social change.

[http://www.familyvoices.org/pub/general/guidelines\\_for\\_organizing.pdf](http://www.familyvoices.org/pub/general/guidelines_for_organizing.pdf)

4. Kids as Self Advocates

National grassroots project created by youth with disabilities to model leadership and spread helpful, positive information about rights, peer support, self-advocacy, training and systems change to youth, policy makers, schools, medical providers, and families.

<http://www.fvkasa.org/>

5. National Consortium on Leadership and Disability for Youth

National youth-lead information, training, and resource center that offers

training and improves professional, leader coalition and CIL capacity to serve youth and emerging leaders with disabilities.

<http://www.nclid-youth.info>

6. National Disabled Student Union  
National, cross-disability student organization dedicated to social justice (full participation, equality, justice, dignity, respect) with a mission to organize and mobilize students with disabilities.  
<http://www.disabledstudents.org/>
7. National Youth Leadership Network  
Organization that promotes leadership development, education, employment, independent living and health and wellness among youth with disabilities across the U.S.  
<http://www.nyln.org/>
8. Youth Development and Youth Leadership  
A 19 page article that assists youth service practitioners, administrators, and policy makers in providing development and leadership activities and programs built on solid principles.  
[http://www.ncwd-youth.info/resources\\_&Publications/background.php](http://www.ncwd-youth.info/resources_&Publications/background.php)
9. Youth Information, Training & Resource Center  
National organization that coordinates the efforts of state grantees to support youth and young adults in expanding self-determination and leadership activities.  
<http://www.addyic.org/>
10. Youth on Board  
National organization that helps young people and adults think differently about each other so that they can work together to change society.  
Provides trainings, designs curricula and programs, develops policy, and publishes resources.

<http://www.youthonboard.org/site/c.ihLUJ7PLKsG/b.2039165/k.BE6D/Home.htm>

## Parents

### 1. Age of Majority

Six page parent brief that discusses preparing your child for the age of majority, decision-making skills, stepping into new roles, guardianship, transfer of rights, and informed choice.

[http://www.pacer.org/publications/parentbriefs/ParentBrief\\_May02.pdf](http://www.pacer.org/publications/parentbriefs/ParentBrief_May02.pdf)

### 2. Dollars and Sense: Teaching Teens with LD Consumer Skills and Money Management

Discusses how learning and attention problems may result in money management challenges with teaching tips.

<http://www.greatschools.net/cgi-bin/showarticle/2992>

### 3. How Can My Child Be Involved in the IEP Process

One page information sheet on why and how to increase your child's involvement in their IEP process.

<http://www.pacer.org/parent/php/PHP-c77.pdf>

### 4. Impact Issue on Parenting Teens and Young Adults with Disabilities

This 28 page issue explores useful strategies, with examples and ideas for families to consider, in navigating the transition years and overcoming barriers to make dreams a reality.

<http://ici.umn.edu/products/impact/192/192.pdf>

### 5. Pacer Center — Champions for Children with Disabilities

The Parent Advocacy Coalition for Educational Rights seeks to expand opportunities and enhance quality of life based on the concept of parents helping parents, with publications, newsletters, and resources on a variety of topics.

<http://www.pacer.org/>

6. Parents with Disabilities Online  
Web site with information and resources, including books, medical information, web links, adaptive products, organizations, toys, and magazines for parents with disabilities.  
<http://www.disabledparents.net>
7. Preparing for Employment: On the Home Front  
Eight page brief that discusses self-determination, volunteering developing work skills, resume basics, supports, and networking.  
[http://www.pacer.org/publications/parentbriefs/ParentBrief\\_Mar06.pdf](http://www.pacer.org/publications/parentbriefs/ParentBrief_Mar06.pdf)
8. Ten Tips That May Ease Your Child's Transition to Adulthood  
Two page information sheet that briefly discusses self-determination, social outlets, community supports, post-secondary accommodations, SSI, volunteering, healthcare, and employment.  
<http://www.pacer.org/parent/php/PHP-c107.pdf>
9. Through the Looking Glass, National parent-to-parent network  
The purpose of this network is to connect parents who share common experiences and face barriers as parents with disabilities.  
<http://www.lookingglass.org/ppn.php> -
10. Transition Coalition  
Online information including documents, workbooks, brochures, and guidebooks on the transition from school to postsecondary settings, training and employment.  
<http://transitioncoalition.org/transition/section.php?pageId=72>
11. Young Adults with Learning Disabilities and Other Special Needs  
Provides information about preparing to let go, fostering independence, training and employment, vocational evaluation, on the job training, transition checklist, and postsecondary programs with resources for parents and professionals.

<http://www.heath.gwu.edu/index.php/Download-document/15-Young-Adults-with-Learning-Disabilities-and-Other-Special-Needs.html>

12. Your Child with Learning Disabilities

Advice on identifying a learning difficulty; managing your child, home, family, school and learning; and assistive technology.

<http://www.greatschools.net/content/specialNeeds.page>

### **Self-advocacy**

1. Advocating Change Together

Grassroots disability rights organization run by and for people with disabilities to encourage and support change. Provides information, skill building, and leadership opportunities.

<http://www.selfadvocacy.com/index.htm>

2. Advocating for yourself in middle school and high school: How to get what you need

Two page article on evaluating what you need, finding a helpful resource at school, talking to teachers, and advocating.

<http://www.fvkasa.org/resources/files/ed-advocating-hsms.html>

3. Be Your Own Best Advocate

Two page information sheet on how and when to advocate for yourself with resources for teens and families.

<http://www.pacer.org/parent/php/PHP-c116.pdf>

4. Being assertive: Reduce stress and communicate better

Article on the Mayo Clinic Web site that provides steps to becoming more assertive, an explanation of assertive vs. passive and aggressive behavior, and the benefits of being assertive with links.

<http://www.mayoclinic.com/health/assertive/SR00042>

5. Self Advocacy Online

Information on self-advocacy, voting, healthy lifestyle, speaking up, relationships, rights, getting organized, and cultural competence with links to self-advocacy organizations nationwide.

<http://www.selfadvocacyonline.org/>

6. Self-empowerment and advocacy for Young People

List of linked fact sheets on self-empowerment, advocacy, policy, materials by and for young people with disabilities, and other topics.

<http://www.nyln.org/Clearinghouse/resourceclearinghouse.html#advocacy>

## **References**

- Agosta, J. (2006). Youth with disabilities just want to grow up. *Impact feature issue on parenting teens and young adults with disabilities*, 19(2), 1 – 28.
- Agosta, J., Barclay, J., Melda, K. & Stenhjem, P. (Eds). (2006). From the Editors. *Impact feature issue on parenting teens and young adults with disabilities*, 19(2), 1 – 28.
- Carol, K. (2006). How to avoid being roadkill on the road to transition. *Impact feature issue on parenting teens and young adults with disabilities*, 19(2)1 – 28.
- Clinton, W.J. (1997, June 9). Remarks on signing the Individuals with Disabilities Act Amendments of 1997. *Weekly Compilation of Presidential Documents*, 33(23), p. 830.
- Edelman, A., Gill, P., Comerford, K., Larson M. & Hare, R. (2004). *Youth development and youth leadership*. Washington, DC: National Collaborative on Workforce and Disability for Youth.
- Disability Nation. (2008). *Obama on employment of people with disabilities*. Retrieved January 10, 2009 from: <http://disabilitynation.net/blog/obama-employment-people-disabilities>
- Dowrick, P.W., Anderson, J., Heyer, K. & Acosta, J. (2005). Postsecondary education across the USA: Experiences of adults with disabilities. *Journal of Vocational Rehabilitation*, 22, 41-47.
- Holt, J., Jones, D., Petty, R.E., Crisp, S., Roth, H. & Galantowicz, S. (2007). *Facilitating consumer partnerships in state policy and program design*. Houston, Texas: ILRU.

- Matarese, M., McGinnis, L. & Mora, M. (2005). *Youth involvement in systems of care: A guide to empowerment*. Washington, DC: Technical Assistance Partnership.
- Mason, C.Y., McGahee-Kovac, M., Johnson, L. (2004). How to help students lead their IEP meetings. *Teaching Exceptional Children*, 36(3), 18-24.
- National Council on Disability. (2000). *Transition and Post-School Outcomes for Youth with Disabilities: Closing the gaps to post-secondary education and employment*. Retrieved December 27, 2008 from: [http://www.ncd.gov/newsroom/publications/2000/transition\\_11-01-00.htm](http://www.ncd.gov/newsroom/publications/2000/transition_11-01-00.htm)
- Noyes-Grosser, D.M. (2007). Children and youth with disabilities and public health: A model syllabus for health professionals. *Infants & young children: An interdisciplinary journal of special care practices*, 20(3), 202-221.
- Obama, B. (2008). *Plan to empower Americans with disabilities*. Retrieved January 10, 2009 from: <http://origin.barackobama.com/issues/disabilities>
- Peterson, K. (2006). Supporting healthy adolescent development for youth with disabilities. *Impact feature issue on parenting teens and young adults with disabilities*, 19(2), 1 – 28.
- Powers, L.E., Garner, T., Valnes, B., Squire, P., Turner, A., Couture, T. & Dertinger, R. (2007). Building a successful adult life: Findings from youth-directed research. *Exceptionality*, 15 (1), 45-56.
- Powers, L. E., Deshler, D. D., Jones, B. & Simon, M. (2006). Strategies for enhancing self-determination, social success, and transition to adulthood. In D. D. Deshler & J. B. Schumaker (Eds.), *Teaching adolescents with disabilities: Accessing the general education curriculum* (pp. 235–274). Thousand Oaks, CA: Corwin.

Timmons, J.C., Whitney-Thomas, J., McIntyre Jr., J.P., Butterworth, J. & Allen, D. (2004). Managing service delivery systems and the role of parents during their children's transitions. *Journal of Rehabilitation*, 70(2), 19-26.

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal Child Health Bureau. (2004). *The national survey of children with special health care needs chart-book 2001*. Rockville, MD: author.

White House. (2008). *The Agenda: Disabilities*. Retrieved February 27, 2009 from: <http://www.whitehouse.gov/agenda/disabilities/>