

RESOURCE SECTION
TRANSITION TO ADULT HEALTH CARE

I. BEST PRACTICE GUIDELINES

1. Standards for Systems of Care for Children and Youth with Special Health Care Needs 2.0
<https://www.lpfch.org/publication/standards-systems-care-children-and-youth-special-health-care-needs-version-20> and background white paper,
https://www.lpfch.org/sites/default/files/field/publications/developing_structure_and_process_standards_white_paper.pdf
2. Got Transition has developed a new practice tip sheet to assist practices who are looking for resources to obtain National Committee on Quality Assurance (NCQA) Patient-Centered Medical Home (PCMH) certification around transition. This tip sheet includes an easy-to use table displaying specific NCQA criteria and guidance with links related to Six Core Elements of Transition tools. See
<http://www.gottransition.org/resourceGet.cfm?id=444>
3. Action Brief, Steinway C, Gable J, Jan S, "Transitioning to Adult Care: Supporting Youth with Special Health Care Needs." This PolicyLab Evidence to Action brief summarizes research findings around patient, family and provider perceptions of the transition process, as well as policy recommendations that various stakeholders can use to address these barriers for youth with special health care needs.
http://policylab.chop.edu/sites/default/files/pdf/publications/Transitions_Of_Care.pdf
4. The Best Journey to Adult Life for Youth with Disabilities: An Evidence-based Model and Best Practice Guidelines for the Transition to Adulthood for Youth with Disabilities. Debra Stewart, Matt Freeman, Mary Law, Helen Healy, Jan Burke-Gaffney, Mary Forhan, Nancy Young, & Susan Guenther, 2009. Published and distributed by CanChild Centre for Childhood Disability Research
5. These are generic guidelines which can be used and adapted by different communities and services. For more information see: <https://www.canchild.ca/en/resources/108-transition-to-adulthood-services-and-supports-for-youth-with-disabilities-in-ontario-best-practice-guidelines>
6. Standards for Systems of Care for Children with Special Health Care Needs with this including Transition: <http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20White%20Paper%20FINAL.pdf>
7. Recommendations for Adult Health Care Providers, Families, Transitioning Youth:
<http://www.gottransition.org/>
8. Transition to Adulthood Issues for Children Who Have Had Transplantations [Annunziato RA, Shemesh E.](#) "Tackling the spectrum of transition: what can be done in pediatric settings?" [Pediatr Transplant.](#) 2010 Nov;14(7):820-2. doi: 10.1111/j.1399-3046.2010.01404.x.
9. Transition to Adulthood Issues for Individuals with Congenital Heart Problems [Alison Knauth Meadows, Valerie Bosco, Elizabeth Tong, Susan Fernandes](#) and [Arwa Saidi](#). "Transition and transfer from pediatric to adult care of young adults with complex congenital heart disease," [Current Cardiology Reports.](#) 2009, [Volume 11, Number 4](#), 291-297, DOI: 10.1007/s11886-009-0042-8
10. A brief video about the transition program at Nationwide Children's Hospital (Columbus, Ohio) for youth with congenital heart disease can be found at http://www.youtube.com/watch?v=T-j9Bd_dAfE

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11. Transition to Adulthood Issues for Individuals with Diabetes
[Gee L](#), [Smith TL](#), [Solomon M](#), [Quinn MT](#), [Lipton RB](#).. "The clinical, psychosocial, and socioeconomic concerns of urban youth living with diabetes," [Public Health Nurs](#). 2007 Jul-Aug; 24(4):318-28.
12. Transition to Adulthood Issues for Individuals with Arthritis
 Scal Peter, Horvath Keith, Garwick Ann. "Preparing for Adulthood: Health Care Transition Counseling for Youth With Arthritis," *Arthritis & Rheumatism (Arthritis Care & Research)*. January 15, 2009, Vol. 61, No. 1, pp 52-57.
13. Transition to Adulthood Issues for Individuals with Developmental and Behavioral Disorders
 Palfrey JS, Foley SM, Sharma N, "Developmental and Behavioral Disorders Grown Up," *Journal of Developmental & Behavioral Pediatrics*. December 2008, Vol. 29, No. 6, pp 524-33.
14. Transition to Adulthood Issues for Individuals with Inflammatory Bowel Disease
 Hait EJ, Barendse RM, Arnold JH, Valim C, Sands BE, Korzenik JR, Fishman LN. "Transition of Adolescents With Inflammatory Bowel Disease From Pediatric to Adult Care: A Survey of Adult Gastroenterologists," *Journal of Pediatric Gastroenterology and Nutrition*. 2008, 48:61-65.
15. Transition to Adulthood Issues for Individuals with Cystic Fibrosis
 McLaughlin SE, Diener-West M, Indurkha A, et al. "Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices," *Pediatrics*. 2008, 121::el 160-6.
16. Transition to Adulthood Issues for Individuals with Cerebral Palsy
 Wiegerink DJ, Roebroek ME, Donkervoort M, et al. "Social, intimate and sexual relationships of adolescents with cerebral palsy compared with able-bodied age-mates," *J Rehabil Med*. 2008;40(2): 112-8.
17. List of adolescent HIV transition resources on the USAID/AIDStar-One database for Adolescents Living with HIV, moderated by Edward D. Pettitt II of Baylor International Pediatric AIDS Initiative:
<http://www.k4health.org/toolkits/alhiv/general-resources-transition-care>
18. 2012-2013 handbook helps youth with disabilities transition to adult life
<http://vanderbi.lt/grt0o#.UVWLa2fClog.email>
19. Helpful articles for professionals caring for young adults with special health care needs with these being suggested by Dr. Janet E. McDonagh, Clinical Senior Lecturer in Pediatric and Adolescent Rheumatology at Birmingham Children's Hospital, Birmingham, United Kingdom:
 - a. Lostein DS, Inkelas M, Hays RD, Halfon N, Brook. "Access to care for youth with special health care needs in the transition to adulthood," *J Adol Health*. 2008;43:23-29.
 - b. Park MJ, Irwin CT. "Youth with special health care needs: facilitating a healthy transition to young adulthood," *J Adol Health*. 2008;43:6-7.
 - c. Committee on Adolescence. "Achieving Quality Health Services for Adolescents," *Pediatrics*. 2008;121:1263-1270. 2013 reaffirmation of 2008 AAP statement can be found at <http://pediatrics.aappublications.org/content/121/6/1263.abstract>
20. Article regarding where children with chronic illness go for health care as adults:
 Steinbeck KS, 1 Brodie,, L, , Towns SJ. "Transition in chronic illness: Who is going where?" *J of Paediatrics and Child Health*. Article first published online: 19 AUG 2008 DOI: 10.1111/j.1440-1754.2008.01321.x

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21. Identified Needs of Physicians and Patients for Improved Transition to Adult Health Care
Peter NG, Forke CM, Ginsburg KR, Schwarz DF. "Transition From Pediatric to Adult Care: Internists' Perspectives," *Pediatrics*. 2009, Vol. 123, pp 417-423.
22. Oct. 2008 Article from National Alliance to Advance Adolescent Health Care:
"Pediatric Perspectives and Practices on Transitioning Adolescents with Special Needs to Adult Health Care," can be located by going to <http://thenationalalliance.org/publications/index.cfm?topicID=3>
23. Useful resources from the Transition Treatment Team at the Hospital for Sick Children in Toronto, Canada:
<http://www.sickkids.on.ca/myhealthpassport/> once on that website, health passport can be obtained
<http://www.sickkids.ca/good2go/> once on that website, click "Transition Intervention Menu" to find readiness checklists, easy interventions, clinical pathways, graduation, graduation letter, facilitation of first adult appointment, special transition clinics, and materials for families
24. A good practice guide on effective transition from children's to adult services for young people with complex health need published by the Department of Health and the Department for Schools, Children and Families: in the United Kingdom: Transition: moving on well can be down loaded for free at
https://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf once on that website, click "view item"
25. Helpful health-related training materials that can be used with schools, health providers, families, and directly with youth having disabilities to help those youth learn to more effectively manage their health care concerns (developed by The Wisconsin Community on Transition Health Practice Group):
Health and the IEP, Transition to Adult Health Care: A Training Guide in Three Parts-2nd Edition, The Workbook for Youth, My Health Pocket Guide, The Transition to Adult Health Care Checklist: Preparing for Life as an Adult can all be downloaded for free at <http://www.waisman.wisc.edu/cedd/products.php>
26. Helpful articles regarding transition planning through public schools:
 - a. Barger, Jodie, et al. "Transition planning for youth with special health care needs (YSHCN) in Illinois schools." *The Journal of School Nursing* 31.4 (2015): 253-260. <http://bit.ly/2tUo620>
 - b. Repetto, Jeanne B., et al. "Investigation of health care components in transition IEPs." *Career Development and Transition for Exceptional Individuals* 39.1 (2016): 4-11. <http://bit.ly/2elv1tv>
27. Example of a children's hospital's transitional care policy:
<http://www.schn.health.nsw.gov.au/policies/pdf/2014-9015.pdf>
28. Many national, state, local support groups for specific conditions causing chronic illness and disabilities have guides for transition to adulthood planning on their websites. Most guides can be found by going to the homepage of the group then clicking "Transition to Adulthood" or a similar topic on that homepage or by putting in "Transition to Adulthood" on the search device offered on the group's homepage. Below are examples of such guides from the Autism Speaks, National Fragile X Foundation, Spina Bifida Association, and Chron's and Colitis Foundation of America, Children's Mental Health/National Alliance for the Mentally Ill (NAMI) websites. (Many support groups have information regarding health insurance for adults with the specific condition supported by the group.) These guides often have information useful to anyone transitioning to adulthood with a chronic illness, not just those with the specific condition.

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- a. Autism
<http://bit.ly/1Da1Q89>
<http://www.autism-society.org/in-the-news/heading-back-to-school-or-off-to-college-tips-resources-for-transitioning-youth/>
 - b. Chron's Disease/Colitis
<http://www.ccfa.org/campus-connection/>
 - c. Mental Illness
<http://www.cmhnetwork.org/news/nami-mental-health-awareness-college>
 - d. Duchenne/Becker Muscular Dystrophy including great information on hiring personal care attendants with this being useful for anyone needing a PCA, not just those with a muscular dystrophy
<http://community.parentprojectmd.org/m/blogpost?id=1187424%3ABlogPost%3A218599>
<http://transitions.mda.org/>
 - e. Fragile X
<http://fragilex.org/>
click "Lifeplanning" at top of website page
 - f. Spina Bifida
<http://spinabifidaassociation.org/>
29. **Health Care Transition Training for Health Care Professionals**, a series of 10 online modules that last approximately 15 minutes each, is now available from FloridaHATS. The course is appropriate for any practitioner or support staff involved in the care of adolescents and young adults, and offers free CME/CE for Florida physicians, nurses and allied professionals. It assists with developmental, legal, financial and social considerations in planning for transition from a pediatric to adult care model. The modules integrate new evidence-based materials and interactive tools, including 'Six Core Elements of Health Care Transition 2.0' from Got Transition/Center for Health Care Transition Improvement, a Transition Toolkit, and our Florida-specific planning algorithm with links to local services and resources. The modules can be accessed at www.FloridaHATS.org (available to all) then clicking "Education for Health Care Professionals" on left column or www.aheceducation.com (CME/CE for Florida practitioners). Also see: <https://education.ufl.edu/education-healthcare-transition/>
30. **Illinois Chapter, American Academy of Pediatrics Reopens Web-Based Training and Quality Improvement Project on Transitioning Youth to Adult Health Care**
The Transitioning Youth to Adult Health Care for Pediatric Providers course and quality improvement activity is open again! The course includes a wealth of resources that can be used to improve the care of transitioning patients – including national clinical guidelines, videos, skills building tools for youth, and quality improvement tools. The course teaches learners how to use medical home strategies to improve care of transitioning youth, especially those with special health care needs. The first phase of the curriculum includes 11 educational modules; topics include discussing benefits and services with patients, developing a written transition policy, identifying adult primary care providers, and more. The second part of the course includes data collection for pediatricians who wish to pursue Maintenance of Certification (MOC) Part IV credit, approved by the American Board of Pediatrics for 20 points. The activity is open to primary care and specialty care pediatricians across the country. From 2012-2014, 35 pediatricians completed the educational course and data collection track. The participants saw significant improvements in their transition care. Based on user feedback, the data collection requirements and timeline were

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Illinois Chapter, American Academy of Pediatrics Reopens Web-Based Training and Quality Improvement Project on Transitioning Youth to Adult Health Care (continued)

shortened. Participants are now only required to implement and report on three Key Clinical Activities (KCAs) for patients ≥ 14 years of age. These include: Provide/Explain Transition Policy, Assess Health Care Skills, and Develop or Review Transition Goals. The data collection cycles were also shortened from eight weeks to six weeks so the MOC track can now be completed in 18 weeks instead of 24 weeks. For more information about the course, please contact Kathy Sanabria, MBA, Associate Executive Director, ksanabria@illinoisap.com

31. The PATHS Certificate Program is your path to a successful career as a Direct Support Professional working with people with disabilities. The PATHS Certificate Program is a program offered at the [Center on Disability and Development at Texas A&M University](#) that will prepare graduates to be Direct Support Professionals. This two semester certificate program prepares graduates for employment in a career serving people with disabilities.
<http://paths.tamu.edu/>

II. PRACTICAL TOOLS/TIPS

1. **Making the Move to Managing Your Own Personal Assistance Services (PAS): A Toolkit for Youth Transitioning to Adulthood**

<http://www.ncwd-youth.info/PAS-Toolkit>

Accessing and maintaining long-term supports such as PAS has often been a significant barrier to employment youth and adults with disabilities. This new toolkit assists youth in strengthening some of the most fundamental skills essential for successfully managing their own PAS: effective communication, time-management, working with others, and establishing professional relationships. Such skills are key to not only enhancing independence, but also thriving in the workplace and growing professionally.

2. **Transition Tools**

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

3. **Transition Tools**

<http://www.waisman.wisc.edu/cedd/products.php>

4. HRTW/Healthy and Ready to Work National Resource Center

<http://youth.gov/federal-links/healthy-ready-work-national-resource-center>

5. My Health Passport Tool

<http://www.sickkids.on.ca/myhealthpassport/>

6. **FROM NCSET E-NEWS**

Youth Transition Toolkit Available Online from Talent Knows No Limits (2011) (Toolkit)

The “Youth Transition Toolkit: A Guide for Young People with Disabilities Transitioning to Adulthood” is available online from [Talent Knows No Limits \(TKNL\)](#), a public information campaign of the California Health Incentives Improvement Project (CHIIP). Developed in partnership with young people, the toolkit is a guide on preparing for transition to adulthood and making choices about their own health care, education, employment, finances, independent living, and social and recreational activities. While some of the services and resources provided are California state-specific, much of the guidance applies to youth in any state.

<http://tknlyouth.sdsu.edu/>

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7. The Office of Disability and Employment Policy (ODEP) has created an **Integrated Employment Toolkit** that offers resources for individuals and families, policymakers, employment agencies, employers and researchers about integrated employment for people with disabilities. Reports, papers, policies, fact sheets, case studies, and discussion guides are included in the Toolkit.
<http://www.dol.gov/odep/ietoolkit/>
8. The Research and Training Center on Community Living (RTC) at the University of Minnesota and the Arc have created a self-advocacy website called **Self-Advocacy Online** for people with intellectual and developmental disabilities. The site contains personal stories, a listing of self-advocacy groups by state, self-advocacy in different areas of life, and links to other online resources.
<http://www.selfadvocacyonline.org/>
9. The Maryland Developmental Disabilities Administration has partnered with a team of self-advocates to create My Health – My Decision, a **training module about informed consent for healthcare** for people with disabilities. The module contains fact sheets, workbooks, and trainer cards to help individuals become in charge of their healthcare decisions.
<http://myhealthconsent.org/myhealthmydecision.html>
10. Transition Toolkit developed by the CSHCN Services Program in partnership with members of the Texas Title V Transition Workgroup. The toolkit includes Texas organizations and state/national websites helping transitioning adults with regards to the following need areas: academic, health care/medicaid waivers/SSI/finding adult providers/medical home, mental health, employment/vocational, health/safety including sexuality/abuse prevention, housing, transportation, legal/financial, social/recreational, disability-specific resources, advocacy/policy, caregiver support, making portable medical summaries/transition assessments, other/unclassified, general resources. It also includes helpful websites in English/Spanish for Transitioning Youth and Caregivers/Providers as well as websites for inclusion/community integration and finding helpful articles on transition subjects. The toolkit provides transition planning worksheets.
<https://www.dshs.state.tx.us/cshcn/Transition-Resources.aspx>
11. Health Care for Adults with Intellectual and Developmental Disabilities: **Toolkits for Primary Care Providers and Families**: <http://vkc.mc.vanderbilt.edu/etoolkit/> and <http://vkc.mc.vanderbilt.edu/etoolkit/resources/>
12. **Autism Speaks Transition Toolkit** - A toolkit to assist families of youth with autism as they prepare for the move to adulthood. Topics include self-advocacy, transition plans, community living, employment, education, housing, legal issues, health, and technology. The site also offers state-specific transition timelines. <http://bit.ly/1Da1Q89>
13. 8 Common Principles to Assist with Transitions of Care, <http://bit.ly/2vrk4QJ>. An interactive tool developed by the Child Neurology Foundation to help youth, families, and providers with medical transition. Focuses on neurologic conditions but has wider applicability.
14. Barbara Wirth, MD, MS, and Alex Kuznetsov, RD, National Center for Medical Home Implementation, “A Shared Plan of Care: A Tool to Support CSHCN and their families,” <http://bit.ly/2inKxKV>
15. National Center for Medical Home Implementation- Tools and Resources to Assist with Transition from Pediatric to Adult Health Care, updated in March, 2017. <http://bit.ly/2uJmxZ2>
16. **Texas Parent to Parent, Medical Home Toolkit**, <http://bit.ly/2u9NeWF>

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17. Tool developed by American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, American Osteopathic Association, Got Transition/Center for Health Care Transition, Health Care Transitions Research Network, Medicine-Pediatrics Program Directors Association, Society for Adolescent Health and Medicine, Society of General Internal Medicine assessing ability of individual with intellectual disability in determining transition to adulthood needs:
https://www.acponline.org/system/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/gim_dd/idd_transitions_tools.pdf

III. PREPARING FOR ADULTHOOD

1. Holland Bloorview Kids' Rehabilitation Hospital's Timetable and Checklist to help families identify what areas their child needs to work on to prepare for adult transition
<http://hollandbloorview.ca/clientfamilyresources/familyresourcecentre/growingup>
 once at home page, click Holland Bloorview resources and list of transition aids will pop up
2. Village Learning & Achievement Center's Transition Program, offered in partnership with Humble, TX Independent School District to help high school students prepare for transition into life after high school
<http://www.villagelac.org/programs/transition/>
3. Preparing High School Students for Successful Transition to Postsecondary Education and Employment by M. Bangser issued by The National High School Center <http://www.mdrc.org/publication/preparing-high-school-students-successful-transitions-postsecondary-education-and>
4. College and Career Readiness and Success Center:
<http://www.ccrscenter.org/>
5. Autism Speaks "Preparing for Adult Transition" Slides
http://www.autismspeaks.org/docs/sciencedocs/atn/Transition_from_Pediatric_to_Adult_Services.pdf
6. Summary of Society for Adolescent Health and Medicine list serve on Transitioning as of June 2011 submitted by Kerri Meyer, MD (2011-2013 President of Midwest Region SAHM Chapter)

Key Points made to the listserve:

- Need to broaden our focus from the individual to also consider the role of the new service provider in contributing to the successful transition from adolescent to adult services.
- Possibility of partnering with Family Practice on transitioning.
- Encourage partnership with state department of education and school nurses.
- Potential for conferences on the topic
- Increasing work in the area with many places creating toolkits, websites, electives, and trainings for residents and providers.

Article:

Berg.Kelly Kristina. "Bridge over troubled water - a different view" (2010) Acta Paediatrica 99:1782-84s

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Resources:

National Health Care Transition Center: www.gottransition.org

Florida state organization for transition: www.floridahats.org

Consider attending Florida Pediatric Society's educational session, It's Time For Me to Do What?: Effective Health Care Transitions for Youth With Special Health Care Needs held during the 35th Annual Florida Suncoast Pediatric Conference/4th Annual Pediatrics of Tomorrow at the Ritz Carlton in Sarasota, Florida.

Iowa resources from Sharon Yearous, PhD, ARNP, CPNP, NCSN:

<http://www.transitionassessment.northcentralrrc.org/>

The Kennedy Krieger Institute and the Maryland State Department of Health and Mental Hygiene maintain an Adolescent Transition Resources website for adolescents with special health care needs that may provide some useful tools specifically for health care providers. Website is

<http://resourcefinder.kennedykrieger.org/> and then click "adolescent transition" on side panel. They also have an Adolescent Transition Lecture series that can often be accessed through the website's calendar. To find out more information, you can contact the Resource Finder: 1-800-390-3372 or <http://resourcefinder.kennedykrieger.org/>

North Carolina's materials from the CHAT (Carolina Health and Transition) project:

<http://www.mahec.net/quality/chat.aspx?a=10>

If you revise any of the materials, we ask that you include a statement to the effect "adapted from (whatever document) Carolina Health and Transition (CHAT) project materials".

FYI, we also expect to have a 3-module web-based training on transition of youth with special needs that will care nursing and CME credit. Please let me know if you wish me to re-contact you when the web courses are available online. Submitted by Irene Jurczyk, Director Interdisciplinary Education, Mountain Area Health Education Ctr. in Asheville, NC. 828-257-4400 phone.

Individuals cited with special interest or expertise (I know there are many more!)

Dr. Kitty O'Hare, a med-peds doc with a special interest in transitioning teens with SHCN. She runs a monthly multidisciplinary transition conference between Children's Hospital Boston and Brigham and Women's Hospital in Boston.

Dr. David Wood, Co-Director of Jacksonville Health and Transition Services program (JaxHATS), has been running a transition clinic called JaxHATS for >5 years. He has been working with John Reiss, Maria Ferris and others on the development of assessment tools, intervention approaches, etc. to support transition. They have a group called the International Health Care Transition Research Consortium (or something like that...the name is too long) that is very dynamic group of about 40 practitioners around the country and internationally that share ideas around HCT education, practice models and research. They have a monthly conference call at 5 pm on the first Monday of the month. You are welcome to join in. The call in number is: (877) 397-7143 Participant code is 267.

Mychelle Farmer, M.D. is working with a number of people on transition care toolkits and guides for adolescents living with HIV. There is also a Center for Transition Care. She works for an international relief organization, developing tools to us overseas. Catholic Relief Services, HIV AIDS Technical Advisor, Baltimore, Maryland.

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7. University of Houston-Parent Education Project-Families CAN Transition Workgroup

University of Houston-Parent Education Project-Families CAN offers Transition Workshops on the 3rd Thursday of every odd-numbered month at 6:30 p.m. The workshops focus on children transitioning into adulthood (14 years and up). Speakers are brought in from community agencies to educate and give parent tools on accessing adult services for their young adults.

The workshops are held at the Shriners Hospital located at 6977 Main St., 6th Floor Cafeteria area. Parking is FREE in their covered parking garage. For more information or to be added to the Transition Workshop email list, call 713-743-5435. The website is <http://www.coe.uh.edu/pep/families-can/>

8. Go to the following website's homepage and put "Adult Transition" to pull up helpful information regarding medical homes for transitioning to adulthood <http://www.medicalhomeinfo.org/>

9. Transitions for Adolescents & Young Adults with ASD: 4 part webinar series/part 3=Social Relationships on 10/31/13 and part 4=Higher Education & Jobs on 11/12/13
<http://www.johnson-center.org/webinars> (These are archived and can be requested.)

10. Social Motion-Houston training of individuals with social integration difficulties due to their learning differences to help them prepare for as independent life as possible
<http://www.socialmotionskills.org/about>

11. Resources for training individuals with intellectual disabilities about sexuality:

- a. <http://vkc.mc.vanderbilt.edu/healthybodies/>
- b. Sexuality: Your Sons and Daughters with Intellectual Disabilities by Karin Melberg Schwier, David Hingsburger, and Dave Hingsburger (2000)
- c. Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality (Topics in Down Syndrome) by Terri Couwenhoven (2007)
- d. Sex(Abled): Disability Uncensored (2009). 15 minute documentary about physical disability and sexuality. This film was created in conjunction with the San Francisco State University's Health Equity Institute. You can watch this online for free at : <http://www.healthequityinstitute.org/doc/title/sexabled.html>
- e. The Last Taboo (2013). Documentary specifically about physical disability and sexuality. DVD copies are \$8.00 to order; <https://topdocumentaryfilms.com/last-taboo/>

12. Pacer's National Family Advocacy and Support Training Project's parent training in English and Spanish on how to prepare children for adulthood including new curriculum on "Getting and Keeping the First Job" which includes information for how parents can determine their child's abilities and whether/not they can do a job can be found at <http://www.fastfamilysupport.org/fasttraining/index.asp>

13. Menstrual Management for Adolescents With Disabilities. Elisabeth H. Quint, Rebecca F. O'Brien, THE COMMITTEE ON ADOLESCENCE, The North American Society for Pediatric and Adolescent Gynecology. Pediatrics Jun 2016, e20160295; DOI: 10.1542/peds.2016-0295
<http://pediatrics.aappublications.org/content/early/2016/06/16/peds.2016-0295>

14. Jacobson, Rae, "Managing Medication in College" Child Mind Institute <http://bit.ly/2t4xWTg>

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15. Autism Self Advocate Network/ASAN guide on health care transition for self advocates to follow:
<http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf>
16. National Alliance On Mental Illness tools for helping transitioning adults know how to take charge of their mental health: Infographic <https://www.nami.org/NAMI/media/NAMI-Media/Infographics/NAMI-Taking-Charge-of-Your-Mental-Health.pdf>
17. Instructions to Transitioning Adolescents/Young Adults Regarding Being Self-Advocates developed by Florida Health Care Transition Services Task Force for Youth and Young Adults with Disabilities/ Las Instruccionen en La Transicion =given at website below:
<http://www.floridahats.org/for-youth-families/>
18. A website with activities and tools to help TEENS build the skills needed for independence:
<https://www.smoothmovesyht.org/>

IV. POST-SECONDARY: JOB TRAINING/COLLEGE/WORK

1. Sept. 2010 press release from U.S. Dept. of Education announcing \$10.9 million in awards to help students living with intellectual disabilities transition to post-secondary education:
<http://www.ed.gov/news/press-releases/us-secretary-education-duncan-announces-109-million-awards-under-new-programs> (pull up Sept. 2010 press releases by putting Sept. 2010 in all releases search box on right column)

In TX, Houston Community College received one of these grant awards for the Vocational Advancement and Social Skills Training (V.A.S.T.) Program about which information is given at website below

<http://vast.hccs.edu/>

2. AspFi's College Resource Guide
a directory of colleges and universities and their services for college students on the autism spectrum and a DVD on success in college can be found at the website below
www.aspfi.org
3. Reference Points, administered by the Pacer Center as part of TATRA Project funded by the Rehabilitation Services Administration, to which one can subscribe for updated postsecondary news at
<http://www.pacer.org/tatra/list/index.asp> also lists the following websites regarding postsecondary scholarships/student aid

REFERENCE POINTS Financial Aid Resources

JOSHUA O'NEILL & ZESHAN TABANI ENRICHMENT FUND

This fund offers financial assistance to young adults with Down syndrome who want to enroll in postsecondary programs or take classes that will help them with employment, independent living and life skills. To date, over thirty students have received grants from the National Down Syndrome Society (NDSS) to help cover the costs of pursuing their postsecondary education and enrichment goals. More information is available at <http://www.ndss.org/>

APPLICATION DEADLINE: is usually in July of each year

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AUTISM SOCIETY AWARD SCHOLARSHIP

The Autism Society of America (ASA) offers various awards and scholarships. Among them is the CVS/All Kids Can Scholars Program, providing a scholarship in the amount of \$1,000 to a qualified individual with autism to be applied toward the completion of an accredited, postsecondary educational or vocational program of study (e.g., college, trade school, etc.). For more information on eligibility, and to apply, visit:

<http://www.zinch.com/Scholarships/CVSAll-Kids-Can-Scholars-Program>

APPLICATION DEADLINE is usually in March of each year.

SCHOLARSHIP OPPORTUNITY FOR GRADUATE STUDENTS

The American Psychological Foundation (APF) is now accepting applications for the 2015 Violet and Cyril Frank Scholarship, which supports a graduate level project to reduce the stigma associated with mental illness. For more information go to <http://www.apa.org/apf/funding/franks.aspx>

DEADLINE FOR APPLICATION: May 15, 2018.

SCHOLARSHIPS AND INTERNSHIPS FOR LATINO STUDENTS WITH DISABILITIES

The World Institute on Disability (WID) has a five-year grant to establish the National Technical Assistance Center for Latinos with Disabilities living in the United States, through Proyecto Vision. Proyecto Vision's website has a list of scholarship opportunities for college students who are Latino and who are living with disability, <http://www.proyectovision.net/english/opportunities/scholarships.html>

COLLEGE FUNDING FOR STUDENTS WITH DISABILITIES

From DOIT, this guide to funding a college education includes a list of disability-related scholarships and awards. <http://www.washington.edu/doit/Brochures/Academics/financial-aid.html>

FEDERAL STUDENT AID - GRANT PROGRAM

From Disability.gov, this fact sheet provides an overview of the major federal student aid grant programs. The federal government provides grant funds for students attending colleges, including career colleges and universities. Grants, unlike loans, do not have to be repaid. To access the fact sheet in English see <https://www.heath.gwu.edu/disabilitygov-financial-aid-update-federal-student-aid-grant-programs-fact-sheet>

DISABOOM SCHOLARSHIP DIRECTORY

Disaboom maintains a scholarship directory for students with disabilities. The directory includes over 125 scholarships. The list can be found by going to

<http://livespecial.com/BusinessDetailView/tabid/81/ItemId/415/Disaboom.aspx>

ONLINE COMPILATIONS OF SCHOLARSHIPS SPECIFICALLY FOR STUDENTS WITH DISABILITIES

From Michigan State University

<http://staff.lib.msu.edu/harris23/grants/3disable.htm>

Fall 2017 National Scholarship for College Students with Disabilities:

<https://www.disabledperson.com/scholarships/22/registrations/new>

FUNDING EDUCATION BEYOND HIGH SCHOOL - FEDERAL STUDENT AID AT A GLANCE

A quick reference guide and Federal Student Aid Summary Chart that describes various federal student aid programs, who may be eligible, and how to apply.

<https://studentaid.ed.gov/home>

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4. FROM REFERENCE POINTS, the TATRA Project Newsletter

ON THE JOB: STORIES FROM YOUTH WITH DISABILITIES This resource from the Waisman Center at the U of WI, Madison features youth with developmental disabilities who began working in competitive-wage, community-based jobs early (between the ages of 16-18) and who used natural supports, as well as some paid supports at first, to be successful. It includes the community, employer, school, and family factors that led to the youths' success on the job. For more information go to <http://www.waisman.wisc.edu/naturalsupports/pdfs/YS.pdf>

5. THE INFLUENCE OF FAMILIES ON THE EMPLOYMENT PROCESS From ICI at the U of MA-Boston, this "Tools for Inclusion" resource seeks to share people's thoughts and feelings about how their families help them make decisions throughout their lives. Family is important for many reasons: family members can motivate people to work, and can help them understand why work is important. Families can also have a big influence on self-determination and empowerment, helping people develop a real understanding of themselves and their place in the workplace. Their involvement is important throughout a person's life. This resource also includes tips so that families can be more involved in helping people find and keep jobs. Findings and ideas for families are offered for each of the four phases of the employment process, including: The Early Years, Planning for Work, the Job Search, and Making Decisions to Accept a Job. The resource can be found at http://www.communityinclusion.org/article.php?article_id=326

6. **JobTIPS** is a free program designed to help individuals with disabilities explore career interests, seek and obtain employment, and successfully maintain it. JobTIPS addresses the social and behavioral differences that might make identifying, obtaining, and keeping a job more difficult for someone. Though JobTIPS is designed for direct use by individuals with autism and other disabilities, this program (including all of the printable, assessments, and videos) is also suitable for delivery by teachers, family members, clinicians, mentors, and job coaches. JobTIPS can be found at <http://www.do2learn.com/JobTIPS//index.html> [Especially check out the Social Skills Assessment tools.]

7. PACER's National Parent Center on Transition and Employment: <http://www.pacer.org/transition/> and video library: <http://www.pacer.org/transition/video/topic.asp?se=Health>

8. National Center on Secondary Education and Transition website offers a wealth of information related to secondary education and transition for youth with disabilities <http://www.ncset.org/>

9. The Down Syndrome Assn. of Houston offers an Education for Life Program. Information can be found at <http://dsah.org/programs/education-for-life/>

10. Texas Centers for Independent Living Directory listing by Texas Department of Assistive and Rehabilitative Services of these centers located across Texas can be found at http://www.dars.state.tx.us/drs/directory_cil.shtml

11. The Houston Center for Independent Living, affiliated with these Texas Centers, offers work incentives planning and assistance programs, information on social security administration rules, computer skills classes, emergency preparedness classes, etc. (This organization has now taken over what the now dissolved "Disability 101" organization had been doing.) Information on these programs can be found at <http://www.coalitionforbarrierfreeliving.com/>

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12. Disability Law handbook-information regarding downloading for free is at <http://adata.org/publication/disability-law-handbook>
13. National, Texas, Houston information (including self-advocacy training) from Jobs for Progress can be found at
<http://www.ser-national.org/>
<http://tcdd.texas.gov/tcdd-awards-grants-for-advocacy-training-and-2-higher-ed-projects/>
<http://www.serhouston.org/>
14. Below is excellent advice for college bound students with intellectual disabilities written on the blog site of attorney Matthew Stoloff which also includes left-column links to information on disability discrimination, etc.
<http://stoloff-law.com/blog/college-bound-students-with-intellectual-disabilities/>
15. Information regarding the Social Security Administration Ticket to Work Program:
<http://www.yourtickettowork.com/>
<http://www.ssa.gov/work/>
16. Information from the City of Houston Mayer's Office for People with Disabilities and the Houston Commission on People with Disabilities with the implication that most cities have similar offices and websites for which those in other cities should search for similar services:
<http://www.houstontx.gov/disabilities/>
<http://www.houstontx.gov/disabilities/commission.html>
17. General information from the U.S. Department of Labor Office of Disability Employment along with a tool kit on registered apprenticeship for providers who work with young people, including those with disabilities:
<http://www.dol.gov/odep/index.htm>
<http://www.dol.gov/odep/categories/youth/apprenticeship.htm>
18. A bilingual website that offers information on internships, scholarships, grants, awards, graduate fellowships: <http://www.proyectovision.net/english/opportunities/internships.html>
19. H.E.A.R.T., a program established for the purpose of preparing the participants for gainful employment through an innovative client-managed entrepreneurial venture: <http://www.heartprogram.org>
20. **Baer Reintegration Scholarship.** Scholars are awarded financial assistance in the form of tuition, books, laboratory supplies, and other mandatory fees to help individuals with bipolar, schizophrenia, schizophreniform disorder, or schizoaffective disorder attain a certificate or degree from an accredited institution. For more information and to apply, <http://www.reintegration.com/>
21. The [American Association on Health and Disability](http://www.aahd.us/) (AAHD) is accepting **applications for the 2017-2018 AAHD Frederick J. Krause Scholarship on Health and Disability.** Scholarships under \$1,000 are available to support students with disabilities pursuing higher education in a field related to disability and health. The deadline to apply is November 15, 2015. For more information see <http://www.aahd.us/initiatives/scholarship-program/>

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22. Texas Education Agency's Transition In Texas Website <http://www.transitionintexas.org>
23. University of Montana's Rural Institute for Inclusive Communities Transition & Employment Projects <http://ruralinstitute.umt.edu/transition/default.asp>
24. Information about Project Search, a now worldwide program for making sure individuals with disabilities are trained for employment. which started at Cincinnati Children's Hospital <http://www.projectsearch.us/GetINVOLVED/StartaProjectSEARCH.aspx> and <http://www.cincinnatichildrens.org/service/p/project-search/default/>
25. Jobs for disabled individuals: <https://www.disabledperson.com/>
26. **A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities**, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Revised 2017, <http://bit.ly/2uj8IYA>
27. Think College <http://thinkcollege.net/> The site is made possible through grants The National Institute on Disability and Rehabilitation Research, the Administration on Developmental Disabilities, the Office of Special Education Programs and the Office of Postsecondary Education. The site provides information about college possibilities for students with intellectual disabilities. The site offers resources for students, family members, and professionals.
Piense en la Universidad <http://thinkcollege.net/>
El sitio es posible gracias a subvenciones del Departamento de Educación de los EE.UU., la Oficina de Programas de Educación Especial y el Instituto Nacional de Investigación de Discapacidades y Rehabilitación y el Centro Nacional de Estudio del Apoyo Educativo Postsecundario. El sitio ofrece información sobre posibilidades universitarias para estudiantes con discapacidades intelectuales. El sitio ofrece recursos para estudiantes, miembros de familia y profesionales
28. Going to College- The site contains information about college life with a disability. It's designed for high school students and provides video clips, activities and additional resources to offer a head start in planning for college. Through interviews, youth hear firsthand success stories. <http://www.going-to-college.org/>
29. Zarrow School of Education <http://www.ou.edu/education/centers-and-partnerships/zarrow.html> The Zarrow Center facilitates student-directed educational, employment and adult living outcomes for individuals with disabilities, fosters innovative self-determination oriented instruction and transition education practices, and prepares educational leaders.

V. WEBSITES: YOUTH/FAMILIES/PROFESSIONALS

1. **2-1-1** – the Texas Information and Referral Network - a single point of coordination for statewide health and human services information and referral in Texas. <https://www.211texas.org>
2. **The 411 on Disability Disclosure: A Workbook for Youth with Disabilities** – A resource designed to help young people make informed decisions about whether or not to disclose their disability and understand how that decision may impact their education, employment, and social lives. The Workbook helps young people think about and practice disclosing their disability. <http://bit.ly/1p9ViKN>

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3. **Adolescent Health Transition Project** - Sponsored by the Children with Special Health Care Needs Program of the Washington State Department of Health, this site is a resource for information, materials, and links to others with an interest in health care transition issues. <http://depts.washington.edu/healthtr/>
4. **Annie E. Casey Foundation** - The site offers pages on foster care, youth transition, youth development and others. <http://bit.ly/2uiFABs>. **The Casey Life Skills** assessment, available in English and Spanish, helps young people prepare for adulthood. Account registration is offered free of charge. <http://bit.ly/2eHRhn7>
5. **Autism Speaks Transition Toolkit** - A toolkit to assist families of youth with autism as they prepare for the move to adulthood. Topics include self-advocacy, transition plans, community living, employment, education, housing, legal issues, health, and technology. The site also offers state-specific transition timelines. <http://bit.ly/1Da1Q89>
6. **Care Notebooks** - A tool to help parents and caregivers organize vital health information. Templates are available at:
 - Medical Home Portal, <http://bit.ly/1m96bAG>
 - Texas Parent to Parent, <http://bit.ly/2ujTA6p>
7. **The Children with Special Health Care Needs Systems Development Group, within Title V Maternal and Child Health at the Department of State Health Services**, works to strengthen community-based services to improve transition outcomes for children and youth with special health care needs in Texas. The website includes transition resources, downloadable brochures on health care transition, medical home information, community integration and more. <http://bit.ly/2uHuH4E>
8. **Child Welfare Information Gateway** - A service of the Children's Bureau, Administration for Children and Families, U.S. Department of Health and Human Services, this site provides a list of resources for transition-age youth in out-of-home placement. <http://bit.ly/2uJPLHc>
9. **Girlshealth.gov** - A website with information for girls age 10 and older and includes pages devoted to illness and disability and transitioning from adolescence to adulthood for young women with disabilities. <http://bit.ly/2txuh0X>
10. **Going to College** - The site contains information about college life with a disability. It's designed for high school students and provides video clips, activities and additional resources to offer a head start in planning for college. Through interviews, youth hear firsthand success stories. <http://www.going-to-college.org/>
11. **Got Transition** - a center for Health Care Transition Improvement which is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. <http://www.gottransition.org/>
12. **I'm Determined** - This resource focuses on building self-determination and self-advocacy skills in youth, as well as strategies for supporting youth in running their own Individualized Education Programs (IEPs). There are lesson plans, checklists, curricula, and more. <http://bit.ly/2uJFbzS>
13. **Kids As Self Advocates (KASA)** - a national, grassroots project created by youth with disabilities for youth who are leaders in their communities sharing helpful, positive information to increase knowledge on various issues. Members are teens and young adults with disabilities speaking out to help health care professionals, policymakers and others understand life with a disability. <http://www.fvkasa.org/index.php>

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14. **Muscular Dystrophy Association Transitions Center** – A website with resources for teens and young adults with neuromuscular diseases. Includes blogs of self-advocates, resources on independence, education, employment, technology and more. <http://transitions.mda.org/>
15. **Navigate Life Texas**, a website created by parent of children, youth and young adults with disabilities and special health care needs for parents. The site offers comprehensive information for youth, families, professionals, advocates and others including dedicated pages with resources on transition in both Spanish and English. <https://www.navigatelifetexas.org/en>
16. **Parent Advocacy Coalition for Educational Rights (PACER) Center’s National Center on Transition and Employment** - A website for parents of children and youth with disabilities. Includes information about self-determination and person-centered planning, education transition, employment, and more, <http://www.pacer.org/transition/>. Also includes the video series, “Preparing for Adulthood: Taking Charge of My Own Health Care, <http://bit.ly/2uhM9K2>
17. **Texas Education Agency**, Transition in Texas, <http://www.transitionintexas.org/>
18. **Texas Parent to Parent** - The state’s Family Voices affiliate, Texas Parent to Parent empowers families to be strong advocates through parent-to-parent support, resource referral, and education. Pathways to Adulthood Transition workshops are offered across the state and address health care transition, funding and services, legal issues, and creative approaches to housing, employment and personal networks of support. <https://www.txp2p.org/>
19. **University of Montana’s Rural Institute Transition & Employment** - Provides webinars for youth and families related to education, vocational rehabilitation, housing, health care and more transition-related topics. <http://ruralinstitute.umt.edu/transition/>
20. **Youthood.org** - Sponsored by the National Center on Secondary Education and Transition (NCSET), housed at the Institute on Community Integration (ICI), University of Minnesota, this youth friendly site is a tool to help young adults with disabilities plan for the future. It provides information on transition topics such as education, jobs, rights and public policy. Additional online features are available with free registration. <http://www.youthhood.org/index.asp>
21. **Youth on the Move** - A project of the Institute for Community Inclusion at the University of Massachusetts Boston designed to share strategies, and resources to transition teachers, counselors, family members and community providers to guide youth in transition. The site offers age-based timelines, personal stories, and news and resources relevant to transition. <http://www.youth-move.org/>
22. **Apps for organizing and managing health information**
 - CareSync, <http://bit.ly/2tfvRo>
 - My Health, My Choice, My Responsibility, <http://bit.ly/2uamTrL>
 - Pill Boxie, <http://bit.ly/2ujpTIV>
 - Seizure Log- Trak It, <http://bit.ly/2t4GpWV>
23. **Young Person’s Guide to Health Care Transition** (National Collaborative on Workforce and Disability), <http://bit.ly/2uSIJP2>

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24. YouTube Videos

- Mr. Rogers and Jeff Erlanger, <https://www.youtube.com/watch?v=5BZlyxS37Kk> Mr. Rogers talks with a young boy with special health care needs.
- Becoming an Adult: Taking Responsibility for Your Health Care, Nemours, <https://www.youtube.com/watch?v=cjXurYrFMZM>

25. **Journey to Adulthood: A Transition Travel Guide** developed by Shriners Hospital for Children, Lexington, KY
<http://chfs.ky.gov/NR/rdonlyres/DC84A5A3-2EEF-490C-BE6D-1E7171595DBD/0/TransitionBookDecember122011Final100pages.pdf>

26. Texas Project First Transition Resources: <http://texasprojectfirst.org/node/242>

27. Planning for a Healthy Transition: A Family Transition Plan by the Washington State Department of Health
<http://here.doh.wa.gov/materials/healthy-transition-plan>

28. HealthVault by Microsoft for keeping family member's medical records: <https://www.healthvault.com/>

29. Medical Home Portal Care Notebook Resources <https://www.medicalhomeportal.org/living-with-child/after-a-diagnosis-or-problem-is-identified/caring-for-children-with-special-health-care-needs/managing-and-coordinating-care/care-notebook>

30. Texas information regarding confidential personal health information, the Health Insurance and Portability Act, and Supportive Decision Making: <http://www.dads.state.tx.us/providers/hipaa/> and <http://www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/>

31. State by state information about the TAX-ADVANTAGE ABLE SAVINGS ACCOUNTS allowing families to put back money for the futures of their children with disabilities: <http://www.ablenrc.org/>

32. Look under information for youth with regard to transition to adulthood health care at Sick Children's Hospital in Toronto, Canada: <http://www.sickkids.ca/good2go/For-Youth-and-Families/Transition-Tools/Getting-Ready-for-Adult-Care/Index.html>

VI. INSURANCE/HEALTH CARE UPDATES

1. U.S. Dept. of Health and Human Services' online tool providing consumers with information on public and private health coverage options, combining information about programs ranging from Medicare to the Pre-Existing Conditions Insurance Plan with future inclusion of pricing and plan performance information planned:
<http://www.healthcare.gov> and <http://www.pciplan.com>

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2. The Texas Consumer Health Assistance Program (CHAP), a part of the Texas Department of Insurance and also created by the Affordable Health Care Act provides information about health plans, consumer rights, assistance with appeals and complaint resolution. CHAP provides information on commercial insurance but also has information available about public insurance. CHAP will help persons without a computer enroll in the Pre-Existing Insurance Plan (PCIP) by inputting the information and mailing the application to them to sign and submit. (PCIP provides insurance coverage for persons who have been uninsured for at least 6 months and who have a pre-existing condition. There are premiums, deductible and co-pays/co-insurance associated with PCIP but this is an option for people who have previously been turned down for insurance or who have a pre-existing condition.) The phone number is toll-free: 1-855:TEX-CHAP (1.855.839.2427). The website is www.texashealthoptions.com and has fact sheets given in English and Spanish.
3. Information from Texas Council for Developmental Disabilities about some adults with disabilities in Texas being able to stay on parents' insurance PAST the age of 26 years old: <http://www.tcdd.texas.gov/extending-insurance-adults/>
4. Information from Talk About Curing Autism website about some adults with disabilities being able to stay on parents' insurance PAST the age of 26 years old with website allowing viewer to click individual states to read about what each state allows: <http://www.tacanow.org/family-resources/dependent-disabled-adults-continuation-of-private-health-care-coverage/>
5. Florida Health and Transition Services' guidance and tips for identifying, securing and maintaining health care coverage that meets the needs of young adults, including those with chronic health conditions or disabilities with planned updates as more information about provisions in the Patient Protection and Affordable Care Act becomes available: <http://www.floridahats.org/> when at website, go to Toolbox, then Health Insurance & Financing
6. HRSA Updates about the Affordable Care Act
As you know, the [Affordable Care Act](#) , the health care law passed in 2010, creates unprecedented opportunities for millions of Americans to access health insurance coverage. A healthier country is one in which more Americans are able to access the care they need to prevent the onset of disease and manage disease when it is present. The Affordable Care Act creates new state-based marketplaces to offer millions of Americans new access to affordable health insurance coverage. In addition, the law helps make prevention affordable and accessible for all Americans by requiring health plans to cover certain recommended preventive services without cost sharing. Outreach efforts are needed to ensure that families and communities understand these new developments and to provide eligible individuals the assistance they need to secure and retain coverage as smoothly as possible during the transition and beyond.

We encourage you to assist your beneficiaries in obtaining information about these changes and enrolling in available sources of insurance through the Health Insurance Marketplace, such as subsidized private insurance, Medicaid, and CHIP. Please share information with your beneficiaries about these options and assist them, to the extent it is an appropriate activity under your grant, in enrolling in available insurance plans so that they will have available to them all possible resources for supporting their health needs. Thanks for helping us spread the word about the Marketplace – we can't do it without you!

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- **Social Media:** Stay connected through social media and post links to the healthreform.gov website, Facebook, and twitter accounts on your organization's website:
 - Post the healthcare.gov [widget](#)
 - Joining the discussion on [Facebook](#)
 - Following Healthcare.gov on [Twitter](#)
 - Reading the Healthcare.gov [Blog](#)
- **Sign up to get updates:** Encourage your staff and beneficiaries to [sign up](#) for Marketplace email and text message updates geared towards consumers.
- **Spread the word:** Help share information with your community and beneficiaries:
 - You can find additional education materials including presentations, factsheets, brochures, and more <http://www.healthcare.gov/news/brochures/index.html>
- **Learn More:** Learn more about the Marketplaces, HHS' outreach efforts, and populations eligible for coverage:
 - Check out new information for consumers at HealthCare.gov

VII. RECREATION

1. Power Soccer
<http://www.powersoccerusa.net/>
<http://www.youtube.com/watch?v=Apx1gnDep48>
2. The River Performing and Visual Arts Center
<http://www.tuts.com/river>
3. Dionysus Theatre
<http://www.yelp.com/biz/dionysus-theatre-houston>
4. Morgan's Wonderland
<http://www.morganswonderland.com/>
5. Club 21 and other Adult Social Activities at The Down Syndrome Association of Houston
<http://dsah.org/programs/>
6. Discover Fitness Foundation
 Go to <http://www.discoverfitnessfoundation.org/> & click "Programs" to learn about programs to help individuals, including those with special needs, get in shape by age 18 years old
7. Waves of Impact
 Go to <http://www.wavesofimpact.com/> to learn about what this non-profit does to help individuals with special needs ride waves at the beach
8. Special Olympics
 Go to <http://www.specialolympics.org/> to learn about athletic events and free health screens for adult athletes with special needs

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9. Peaceable Kingdom - <http://business.beltonchamber.com/list/member/peaceable-kingdom-retreat-for-children-killeen-2664>
10. Candlelight Ranch - <http://candlelightranch.org/>
11. Gigi's Playhouse, a national family run organization for caregivers for children with Down Syndrome; Houston chapter: houston@gigisplayhouse.org
12. Special Needs Events @ Rodeo Houston: <http://www.rodeohouston.com/Visit-the-Show/Special-Days-Events/Special-Needs-Events>

VIII. INSPIRATIONAL MATERIAL

1. The film, "Including Samuel" can be found at the website below: <http://www.includingsamuel.com/home.aspx>
2. CREATIVE CARING: the Vita-Living story by Renee Wallace
3. Herskowitz, Valerie. Always Leave Them Laughing. Publisher: Smashwords. 2012
Fiction story about family facing transition of child with autism to adulthood
4. The Story of Nick Vujicic, born without arms or legs
<https://www.youtube.com/watch?v=gNnVdlvodTQ>

IX. EDUCATIONAL MATERIAL

1. End of life issues: <http://cordcuttersnews.com/netflix-just-released-new-trailer-extremis-short-documentary-looking-end-life/>
2. Circumventing health care problems without insurance in Texas: <http://www.newyorker.com/news/news-desk/poor-and-uninsured-in-texas>

X. MISCELLANEOUS

1. Resource Guide for Parents of Children with Disabilities Houston and Surrounding Areas by Elaine Hime
<http://www.projectdocchouston.org/resguide.pdf>
2. Texas Microboard Collaboration Information can be found at
<http://www.twogetherconsulting.com/services/texas-microboard-collaboration-project-of-the-arc-of-texas/>
3. TASH (The Assn. for the Severely Handicapped which has a conference this year on Self-Determination) information regarding employment, community living, inclusive education, etc. can be found under pull down advocacy & issues at top of TASH homepage <http://tash.org/>
4. Information about Family Advocacy and Supports Training (FAST) Project including curriculum in Employment, Sexuality and Youth Development, Advocating for Your Family, Strategies for Systems Change and results of the national survey of parents of young people with disabilities 12-22 years old can be found at <http://www.fastfamilysupport.org/>

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5. University of Houston-Parent Education Project-Families CAN offers Transition Workshops on the 3rd Thursday of every odd-numbered month at 6:30 p.m. The workshops focus on children transitioning into adulthood (14 years and up). Speakers are brought in from community agencies to educate and give parent tools on accessing adult services for their young adults. The workshops are held at the Shriners Hospital located at 6977 Main St., 6th Floor Cafeteria area. Parking is FREE in their covered parking garage. For more information or to be added to the Transition Workshop email list, call 713-743-5435. The website is <http://www.coe.uh.edu/pep/families-can/>
6. Special Life Network
Go to <http://speciallife.org/> to learn about this non-profit formed to help individuals with special needs integrate into their faith communities from childhood through geriatric years with special emphasis on training leaders of faith-based groups regarding such integration. (While this organization is in Houston and Christian-led, consultation requests from all faith communities and from all geographical areas are welcomed.)
7. An example of a special needs environment in a church setting can be found at Chapelwood United Methodist Church, Houston <http://naomimitchum.com/special-needs/church-environment/special-needs-environment-at-chapelwood/>
8. Light and Salt Association's Special Needs Caring Center
<https://www.navigatelifetexas.org/en/services-groups-events/services/light-and-salt-association-asian-special-needs-caring-center>
9. Resources and Success Stories about Adult Transition published and maintained by James E. Williams Jr.
<http://www.transitionmatters.org/>
10. Information given by Bazelon Center for Mental Health Law <http://www.bazelon.org/>
11. Disability Rights Education & Defense Fund trainings and information (see homepage and pull downs at top of homepage) <http://www.dredf.org/>
12. The Texas Medicaid & Healthcare Partnership (TMHP), a coalition of contractors headed by ACS, a Xerox company, carries out the Medicaid claims payment and Primary Care Case Management administrator duties for the state of Texas, under contract with the Texas Health and Human Services Commission. TMHP consists of:
 - [Affiliated Computer Services](#) (ACS), a Xerox company, is responsible for meeting the contract terms with the state.
 - [Accenture](#) provides technology infrastructure, application maintenance, program management, and data center operations.
 - [Computer Associates](#) (CA) provides performance engineering and programming expertise.
 - [Hewlett Packard](#) (HP) provides hardware and technical expertise.
 - [MMC Group](#) provides technical and operations staff.
 - [Health Management Systems \(HMS\), Inc.](#) provides third party recovery activities.
 - [SBC Communications](#) provides data and voice connectivity and network management.<http://www.tmhp.com/Pages/default.aspx>

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13. MAINTAIN (Medicines Assistance for Those who Are in Need) is designed to help recently unemployed Americans and their families who have lost their insurance and who are taking Pfizer medicines to continue treatment at no cost for up to one year.
<http://www.pfizerhelpfulanswers.com/pages/misc/Default.aspx>
(Many pharmaceutical companies have assistance programs and thus, providers and consumers should go to the website of the company making the drug they need to determine where to inquire about assistance for their specific drug.)
14. Easter Seals funds programs for adults with disabilities
http://www.easterseals.com/site/PageServer?pagename=ntl_wfd_main
http://www.easterseals.com/site/PageServer?pagename=ntl_adult_and_senior_services
15. Transportation for Medicaid and Children with Special Health Care Needs clients who live in Austin, Brazoria, Chambers, Fort Bend, Galveston, Hardin, Harris, Jasper, Jefferson, Liberty, Matagorda, Montgomery, Newton, Orange, Polk, San Jacinto, Tyler, Walker, Waller and Wharton counties: call toll-free 855-687-4786 to set up a ride through Medical Transportation Management/MTM.
16. Houston public transportation including metrolift information can be found at <http://www.ridemetro.org/>
17. For the latest disability statistics for researchers and planners, see <http://disabilitystatistics.org/>
18. Website to help families of individuals with special needs prepare for hurricane season
<http://togetheragainsttheweather.com/>
19. Care Connection Respite Care Program issues vouchers that can be used to pay for someone to come into the home; adult daycare services; or certified individuals outside of the home to provide recipient care while the caregiver is away; covers Texas counties of Austin, Brazoria, Chambers, Colorado, Fort Bend, Galveston, Harris, Liberty, Matagorda, Montgomery, Walker, Waller, and Wharton.
http://www.careconnection.org/site/456/care_connection_lifespan_respite_care_program.aspx
20. Free Program

**Saturday Wellness Program**

Texas Children's Hospital invites qualified families to participate in a **FREE** wellness program supported by the Texas Department of State Health Services. The purpose of the program is to **promote wellness** of Children with Special Health Care Needs (CSHCN) and their **families** through facilitated play and integrated learning. Activities and programs include a variety of games, exercise activities, arts and crafts, group discussions and nutrition classes. Exercise specialists, physical/occupational therapists, child life specialists, dietitians and social workers from Texas Children's Hospital lead these activities.

<https://www.texaschildrens.org/departments/saturday-wellness-program>

Qualification for the program: A family with at least one child with special health care needs (diagnosis of BMI>95th%ile, elevated cholesterol and/or metabolic syndrome included) between 6 and 16 years of age (CSHCN), as identified by his/her physician. Siblings of the CSHCN, ages 6-16 are welcome as well.

RESOURCE SECTION

TRANSITION TO ADULT HEALTH CARE

Program Rules:

At least one parent/guardian must be in attendance with the child with special needs at all times.

Brothers and sisters between the ages of 6 and 16 years are strongly encouraged to come as well.

All those attending are expected to participate in games and activities, and should be dressed in comfortable clothing (tennis shoes, pants or shorts).

Families are required to be in attendance on the first day of the desired session.

Families should plan to attend all four weeks of the desired session.

Have questions? E-mail Paula at pkmrowcz@texaschildrens.org

21. Helping individuals with disabilities develop original costumes: <http://cosability.tumblr.com/>