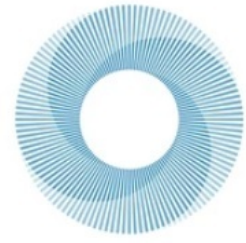




Transitioning to Adulthood:

Resources for Patients with Developmental Disabilities, Parents, and Health Care Providers



<https://alternativestoguardianship.com/transitioning-resources.pdf>

For Patients

Title: Turning 18: What it Means for Your Health

Publisher: Got Transition

Link: <https://www.gottransition.org/resource/?turning-18-english>

Description: This one-page leaflet alerts young people that when they turn 18, medical providers must deal directly with them and that federal law prohibits disclosure of their medical information to others without their consent.

Title: Turning 18: A Guide to Healthcare Decisions

Publisher: Seattle Children's

Link:

<https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe2751.pdf>

Description: This four-page brochure explains to youth what their rights and responsibilities will be in terms of medical care when they turn 18. They are advised that their parents can still play a role, but only with their consent.

Title: Transition Readiness Assessment for Youth with Intellectual and Developmental Disabilities

Publisher: American College of Physicians

Link: https://alternativestoguardianship.com/idd_transition_readiness_form.docx

Description: This form is completed by youth with intellectual or developmental disabilities who are under the age of 18 in order to assess their readiness to transition to an adult health care provider.

Title: How Do I Talk to My Doctor?

Publisher: Florida Center for Inclusive Communities / University of South Florida

Link:

http://flfcic.fmhi.usf.edu/docs/FCIC_EFLH-6-TalkingToMyDoctor_Fact%20sheet.pdf

Description: This two-page fact sheet gives information to patients with developmental disabilities on how to prepare for a doctor visit, what to do and say at the visit, and steps to take afterwards.

Title: My Health Passport for Hospital/Clinic Visits

Publisher: Florida Center for Inclusive Communities / University of South Florida

Link: https://alternativestoguardianship.com/Passport_Form.pdf

Description: Patients with developmental disabilities or their families fill out this four-page form with information about the patient, their communication methods, medical history, medications, allergies, assistance they may need dressing, eating, bathing, sensitivities, and other information relevant to a hospital or clinic visit. It is given to medical providers when the patient checks in and accompanies the patient throughout the hospital/clinic stay.

Title: My Health Report

Publisher: Florida Center for Inclusive Communities / University of South Florida

Link: https://alternativestoguardianship.com/My_Health_Report.pdf

Description: Patients with developmental disabilities or their families fill out this two-page form in preparation for visit to the doctor. It contains information on the patient, the reason for the doctor visit, and has sections on “Since My Last Visit,” “Medications I Am Taking,” “My Medical/Surgical History,” “My Daily Life,” “My Abilities,” “My Sexual Health” and other relevant topics.

Title: Taking Charge of My Health Care Toolkit

Publisher: Oregon Office on Disability and Health

Link:

<https://www.ohsu.edu/oregon-office-on-disability-and-health/taking-charge-my-health-care-toolkit>

Description: This toolkit is designed to provide self-advocates with the knowledge, skills and tools to learn how they can advocate for their health care. It can also be used by medical professionals and family members who want to support self-advocates in their learning. It contains modules on: Being a Self-Advocate, Finding a New Doctor, When I Should Visit My Doctor, Me and My Doctor, Me and My Medications, Signs of Sickness, When My Doctor Recommends Surgery, Mental Health, Staying Healthy, Oral Health. and Me and My Accommodations.

For Parents

Title: Moving On –Transition to Adult Living for Young Adults with Disabilities

Publisher: Warmline Family Resource Center

Link: https://health.ucdavis.edu/mindinstitute/resources/resources_pdf/moving-on-2021.pdf

Description: This guidebook provides information for parents on how they can help their child with a developmental disability plan for the transition to adulthood decision-making in matters pertaining to health care, education, work, finances, and residence. There are sections on “Transitioning to Adult Health Care” and “Questions to Ask a New Health Care Provider.”

Title: Checklist for Transitioning to Adult Healthcare

Publisher: Seattle Children’s

Link:

<https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe2643.pdf>

Description: This three-page brochure was made by parents who have gone through the process of helping their child transitioning to adult health care. It was created to help parents know what to expect and how to plan.

Title: Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual and Developmental Disabilities

Publisher: American College of Physicians

Link:

https://alternativestoguardianship.com/idd_transition_readiness_for_caregivers.docx

Description: This form is completed by parents or other caregivers of youth with intellectual or developmental disabilities who are under the age of 18 in order to assess their youth's readiness to transition to an adult health care provider.

For Providers

Title: Incorporating Health Care Transition Services into Preventive Care for Adolescents and Young Adults: A Toolkit for Clinicians

Publisher: Got Transition / Adolescent and Young Adult National Resource Center

Link:

https://provider.amerigroup.com/docs/gpp/WAWA_EPSDToolkit_Eng.pdf?v=202005261916

Description: This toolkit was created with input from professionals throughout the country. It focuses on health care transition, providing suggested questions and anticipatory guidance specific to adolescents' transition to adult health care.

Title: Letter from Provider to Patient

Publisher: Seattle Children's

Link:

<https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe3709.pdf>

Description: This letter is sent from the hospital to patients who are about to turn 18. It explains their new role as a decision-maker and advises them that they will be transferred to an adult provider prior to them turning 21.

Title: Transition to Adult Care

Publisher: Center for Consumer Engagement in Health Innovation and Association of University Centers on Disabilities

Link: https://www.youtube.com/watch?v=e4_JsdZOTxo

Description: This 21-minute video includes statements from patients with developmental disabilities, parents, and health care professionals about the importance of transition planning as patients move from specialized pediatric care to adult health care services.

Title: SHARE Transition Plan

Publisher: Surrey Place Developmental Disabilities Primary Care Program

Link:

<https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/09/2.6-TAY-Transition-Transition-Plan.pdf>

Description: SHARE Transition Plan is a guide for healthcare providers to discuss transition to adulthood with young people with intellectual and developmental disabilities and their families. It covers five key areas important for planning a transition from child to adult services: Supports for communication and capability; Healthcare transition and transfer; Activities and engagement; Relationships and well-being; Exploring services and supports (SHARE).

Title: Transitioning patients with developmental disabilities to adult care

Publisher: The Journal of Family Practice

Link:

<https://www.ucucedd.org/wp-content/uploads/2022/08/Transitioning-patients-with-dd-to-adult-care-1.pdf>

Description: The pre-visit questionnaire, instructive videos, and Internet resources described in this article can help health care providers play a pivotal role in planning, commencing, and solidifying the transition from childhood to adulthood.

Title: Transitioning from Pediatric to Adult Healthcare for People with Intellectual and/or Developmental Disabilities

Publisher: University of Colorado

Link:

https://medschool.cuanschutz.edu/docs/librariesprovider95/default-document-library/transition-for-jfk-partners-webinar-4-28-21-ppt.pdf?sfvrsn=1bbf7cba_0

Description: This PowerPoint presentation defines transition and transfer, discusses health care disparities for patients with developmental disabilities, reviews research on healthcare for this population, outlines the process of an ideal health care transition, and shares the perspectives of patients and their families who have gone through the transition.

Title: Transitioning to Adulthood: Unique Health Care Challenged for Youth with Intellectual / Developmental Disabilities

Publisher: PolicyLab - Children's Hospital of Philadelphia

Link:

<https://policylab.chop.edu/policy-briefs/transitioning-adulthood-unique-health-care-challenges-youth-intellectualdevelopmental>

Description: This paper identifies specific barriers facing this population and recommends actions that health systems and policymakers can take to help address them.

Title: Health Care for Adults with Developmental Disabilities: Toolkit for Primary Care Providers

Publisher: Developmental Disabilities Health Care E-Toolkit Project

Link: <https://iddtoolkit.vkcsites.org/>

Description: This toolkit for health care providers addresses a wide range of issues involving medical care for patients with developmental disabilities, such as: communicating effectively, informed consent, supported decision-making, ER-IDD stabilization protocols, behavioral crisis risk assessment, psychiatric symptoms checklist, and crisis prevention and management planning. It also has health watch tables for autism, Down Syndrome, Fragile-X Syndrome, and other developmental disabilities.

Title: Health Care and the Americans with Disabilities Act

Publisher: ADA National Network

Link:

<https://adata.org/sites/adata.org/files/files/Health%20Care%20and%20the%20ADA%20FINAL%202-11-2020.pdf>

Description: These guidelines explain how the ADA applies to health care providers. The ADA requires that health care entities provide full and equal access for people with disabilities. This can be done through: Reasonable Modifications of Policies, Practices, and Procedures. Adjusting policies, practices, and procedures, if needed, to provide goods, services, facilities, privileges, advantages, or accommodations. • Effective Communication. Making communication, in all forms, easily understood. Accessible Facilities. Ensuring physical accessibility.

Title: How Do I Determine if My Patient has Decision-Making Capacity?

Publisher: The Hospitalist

Link:

<https://www.the-hospitalist.org/hospitalist/article/124731/how-do-i-determine-if-my-patient-has-decision-making-capacity>

Description: This article provides guidance to health care providers on assessing the capacity of patients with mental or developmental disabilities to make medical decisions and provide informed consent to medical procedures. The four key components to address in a capacity evaluation include: 1) communicating a choice, 2) understanding, 3) appreciation, and 4) rationalization/reasoning.

Title: Integrating Young Adults with Intellectual and Developmental Disabilities into Your Practice: Tips for Adult Health Care Clinicians

Publisher: Got Transition

Link: <https://www.gottransition.org/resource/?tips-integrating-idd-into-practice>

Description: This publication contains a list of ideas and activities for clinicians who are accepting new young adult (YA) patients with intellectual and developmental disabilities into their practice. It offers suggestions that medical practitioners can consider, depending on their resources, to prepare office and staff as well as tips to consider prior to, during, and after the initial visit. These suggestions are consistent with the 2018 Clinical Report from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians.

Title: Primary care of adults with intellectual and developmental disabilities

Publisher: Canadian Family Physician

Link: <https://www.cfp.ca/content/64/4/254>

Description: These guidelines provide advice regarding standards of care for patients with developmental disabilities. References to clinical tools and other practical resources are included. These approaches to care can be applied to other groups of patients that have impairments in cognitive, communicative, or other adaptive functioning.

Title: Providing Excellent Care for Patients with Developmental Disabilities

Publisher: Florida Center for Inclusive Communities

Link: http://flfcic.fmhi.usf.edu/docs/XCEL_Fact%20Sheet.pdf

Description: This two-page fact sheet provides tips for health care providers on improving communication, adapting the environment, and addressing logistical issues involving patients with developmental disabilities.

Title: Partners in Health: Implementing Supported Healthcare Decision-Making for Users of Augmentative and Alternative Communication in California

Publisher: Office of Developmental Primary Care - University of California

Link:

<https://odpc.ucsf.edu/advocacy/supported-health-care-decision-making/partners-in-health-implementing-supported-healthcare>

Description: This consensus guide provides practical advice about implementing supported decision-making in healthcare settings. Most people for whom speech is not a reliable form of communication use one or more forms of augmentative and alternative communication (AAC). This guide provides practical advice on how health care providers can interact effectively with patients who use AAC.

Research

Title: Gaps in helping adolescents with mental, behavioral, and developmental disorders make the transition to adult health care

Publisher: Centers for Disease Control and Prevention

Link:

<https://www.cdc.gov/childrensmentalhealth/features/health-care-transition-gaps.html#print>

Description: This paper explains that most youth with developmental disabilities do not receive the recommended supports from their health care providers to help them transition from pediatric to adult health care. It makes recommendations on how to improve this situation.

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

Publisher: Autistic Self Advocacy Network

Link:

https://autisticadvocacy.org/wp-content/uploads/2013/12/HealthCareTransition_ASAN_P

[olicyBrief_r2.pdf](#)

Description: This paper describes the need for transition planning and the necessary elements for successful transition planning.

Title: Advocacy for Adults with Intellectual and Developmental Disabilities Assisting in the Transition from Pediatric to Adult Medical Services

Publisher: University of Louisville

Link: <https://louisville.edu/medicine/cme/documents/mcchane-idd-2016-5>

Description: This PowerPoint presentation explains the rationale for transitioning from child-oriented to adult-oriented health care for young adults having developmental disabilities; identifies some of the barriers to successful health care transition; reviews components of health care transition from the perspectives of pediatric and adult health care providers; gives some tips for adult health care providers to integrate young adults with developmental disabilities into their practice; discusses proposed future initiatives in the transitioning and care of adults with developmental disabilities; and reviews some resources.

Title: The New Jersey Action Blueprint for Transition to Adult Health Care

Publisher: The Boggs Center on Developmental Disabilities

Link:

<https://boggscenter.rwjms.rutgers.edu/documents/BOGGS/Publications/HealthandWellbeing/TransitionBlueprint.pdf>

Description: This blueprint is the culmination of the ideas and work of the stakeholder group, The New Jersey Developmental Disabilities Transition to Adult Health Care Forum. It is designed to provide practitioners, advocates and policy makers with achievable, meaningful recommendations and strategies that will move health care for transition age youth with developmental disabilities closer to the ideal expressed in the forum's guiding vision and the Patient Centered Medical Home model.



Alternatives to Guardianship Project

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