

Transition to Adulthood - A Pediatrician's Perspective

Family Voices of California

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Disclosures

No one involved in the planning or presentation of this activity has any relevant financial relationships with a commercial interest to disclose.

Objectives

- Review key aspects of transition to adult care
- Identify ways in which pediatricians can support a patient with intellectual/developmental disabilities (I/DD) in the process of transition
- Discuss different options for supported decision-making for individuals with I/DD
- Review resources that can assist the patient, caregivers and providers in achieving successful transition



What This Talk is NOT:



This talk is not a silver bullet to solve the serious issue of lack of smooth transition to adult providers in our area

This talk will not provide a list of providers eager to care for patients with I/DD transitioning to adult care

Ableism

Ableism is the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior.

At its heart, ableism is rooted in the assumption that disabled people require 'fixing' and defines people by their disability.

Like racism and sexism, **ableism classifies entire groups of people as 'less than,'** and includes harmful stereotypes, misconceptions, and generalizations of people with disabilities.

Medical education is rooted in ableism.

Transition to Adult Care in the United States

Estimated 750,000 Youth with Specialized Healthcare Needs enter adulthood each year in the US

- More than $\frac{1}{3}$ have a developmental, emotional, or behavioral condition such as autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), and speech and language disorder

Broad range of transition issues:

- Medical care, including primary and sub-specialist care, and coordination of care
- Post-secondary education
- Employment
- Legal decision making
- Social inclusion
- Behavioral management
- Acquisition of functional self-care skills
- Self-advocacy
- Caregivers' own coping: anxiety, denial, guilt, awareness of own mortality

Barriers to Transition to Adult Medical Care

- Limited staff training
- Lack of an identified staff person responsible for transition support in pediatric practice
- Financial barriers
- Lack of time
- Anxiety about planning for future health care
- Lack of developmentally appropriate tools for assessing child and family readiness for transition
- Limited availability of adult providers with whom to arrange a smooth transition of care
 - Primary and sub-specialty care
- Lack of time, adequate payment, and training
- Workforce shortages
- Confusing system of case management - Regional Center, CCS, the big cliff once CCS ends

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SUPPLEMENT ARTICLES | DECEMBER 01 2010

The Transition to Adult Health Care for Youth With Special Health Care Needs: Do Racial and Ethnic Disparities Exist? 🛒

[Debra S. Lotstein, MD, MPH](#) ✉; [Alice A. Kuo, MD, PhD](#); [Bonnie Strickland, PhD](#); [Fan Tait, MD](#)

- Overall few Youth with Specialized Healthcare Needs (YSHCN) are receiving adequate transition preparation
 - This situation is worse for racial and ethnic minorities.
- Young adults, including YSHCN, have poorer access to care than children
 - This age-related decline in access is worse for Hispanic and black young adults than for others.
- Low-income YSHCN are at higher risk than other YSHCN of experiencing gaps in access to care as they age into adulthood.

Transition is complex

Transition is a journey, not a one-time event. It is best to start early, to begin thinking about the transition in the context of other areas of transition to adulthood (living arrangements, legal decision making, secondary education, employment, etc)

Some aspects of transition involve **finding new providers** who care for adults and ideally have experience caring for people with developmental disabilities

Some aspects of transition involve **preparing a young adult to be more independent** with issues surrounding their health

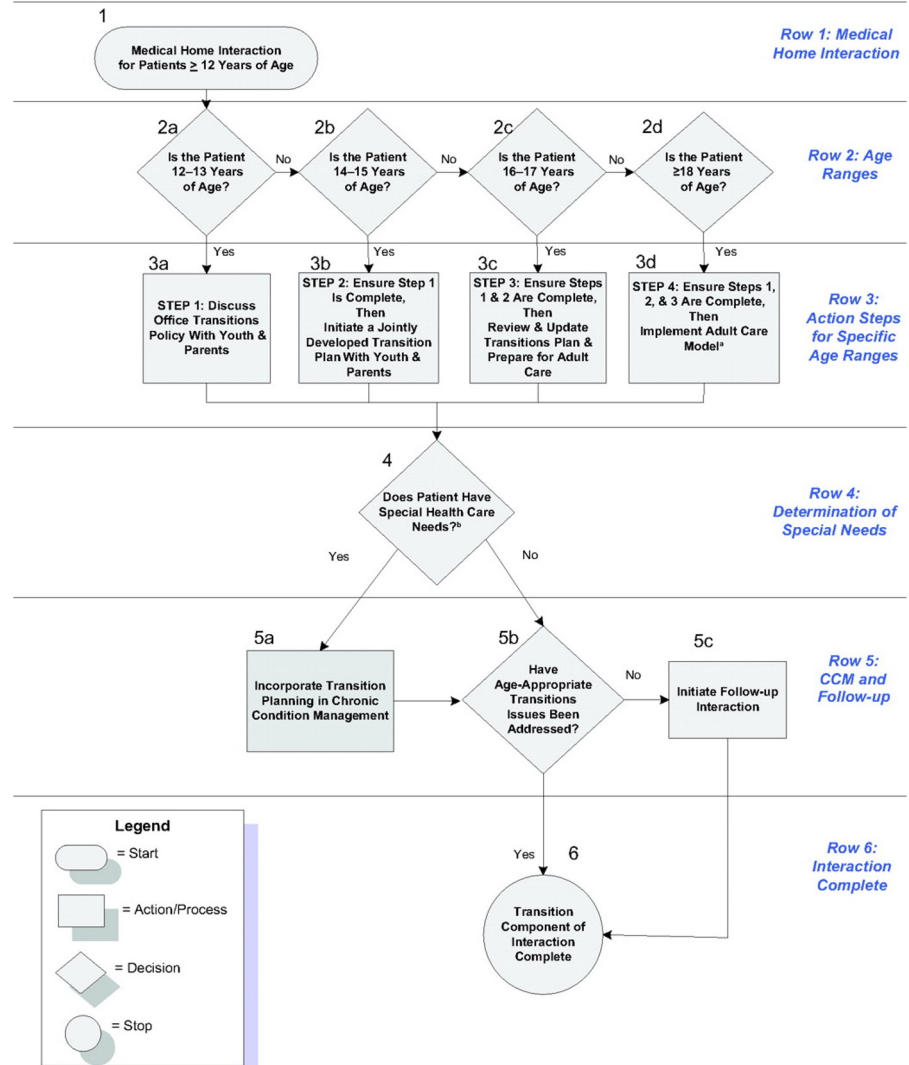
This requires multiple conversations. **Start early.** Schedule visits just to focus on this



AAP Transition Algorithm

Recommendation for a clearly spelled out practice policy for transition

Review caregivers' and youth's readiness for transition throughout the process



ORIGINAL ARTICLE | [Published: 16 February 2021](#)

Factors Associated with Transition Planning in Autism and Other Developmental Disabilities

[Charina Reyes](#) , [Adam Perzynski](#), [Shanna Kralovic](#), [H. Gerry Taylor](#), [Steven Wexberg](#), [Shijun Zhu](#), [Thomas W. Frazier](#) & [Nancy Roizen](#)

[Journal of Developmental and Physical Disabilities](#) **34**, 43–56 (2022) | [Cite this article](#)

589 Accesses | **1** Citations | [Metrics](#)

- Parents may be less likely to plan for the youth's transition to adulthood if their child needed more assistance with functional self-care skills (OR 0.78, 95% CI 0.63–0.96, $p=.021$).
- Greater child need for assistance with self-care was associated with lower parental expectations that their children would live independently by age 22 (OR 0.40, 95%CI 0.24–0.66, $p<.001$) and 35 (OR 0.47, 95%CI 0.35–0.63, $p<.001$).
- The presence of behavioral problems (aggression, sexual behaviors and safety issues) was also associated with lower odds of parental expectations that their child would live independently in adulthood.

Respect for the Patient's and the Family's Goals



What are the individual's goals and aspirations?

- Higher education, employment, relationships, living situation, independence, etc

What are the family's goals for the young person?

- Independence, financial security, safety, relationships, living situation, etc

How can we align our counseling and community resources with the individual and the family's goals?

Taking Care of My Health

Interacting with Healthcare Providers

What type of assistance does the young adult need when they see the doctor?

Has the young adult practiced talking to the doctor 1:1?

Is the parent answering all the doctor's questions at appointments? Could the young adult answer questions about their health? Am I asking questions directly to the young adult?

How does the young adult communicate (with any available communication support) about pain or discomfort? Is this the most effective communication method that they could access?

Does the young adult know how to call the doctor/dentist to make an appointment?

Does the young adult know what to do if they feel sick but the doctor's office is closed?

Health Conditions and Medications

Does the child/young adult know what medicines they take? And why?

Is the child becoming more independent with taking their medications?

Does the child know if they have allergies to foods or medications?

Does the child know when it may be time to get a refill for a medication?



Transition Worksheets



Diagnosis	My doctor	Medicine	Equipment/ treatments	How will I know when to call the doctor?

Make a list of new problems. (Example: a new area of pain, a new rash)

Think about the problems you listed on Worksheet #6. Make a list of things you don't understand about those problems. (Example: Where is the thyroid? What does it do? Why do I need to be on a special diet?)

List questions about tests that need to be done. (Example: Why do I need a blood test? What is a sleep study? Will the test hurt?)

Alameda County CCS Worksheets



ALAMEDA COUNTY PUBLIC HEALTH DEPARTMENT
California Children's Services (CCS)
Right Care. Right Time. Right Place.

LISTA PARA EL CUIDADO DE SALUD Adolescents/ Adultos jóvenes

Utilice esta lista como una guía para desarrollar la independencia en manejando su propia salud. Mire a continuación- ¿Qué habilidades ya tiene y que necesita aprender? Puede completar esto solo(a) o con la ayuda de su médico o miembros de la familia.

Por favor nota: solo para su información. No es necesario devolver el documento completo

Temas	Hago esto solo	Hago esto con ayuda	Necesito ayuda para hacerlo mejor	No necesito saber	Accion(s) necesaria?
Entendo mi necesidades de salud / discapacidad; y puedo explicarlo					
Puedo Explicar cómo mis costumbres y creencias podrían afectar las decisiones de salud y para los tratamientos					
Llevar mi propia tarjeta de seguro de salud diariamente					
Conocer los signos cuando no estoy bien; conocer signos de una emergencia médica					
Conocer mis medicamentos y para qué son					
Ordenar mis propias renovaciones de medicamentos					

	child does this alone	child does this with help	Child Needs to learn	child does not need to know	
Understands their health care need or disability and can explain it to others					
Explains to others how their family customs & beliefs might affect health care decisions and medical treatments					
Carries their own health insurance card everyday					
Knows signs (like pulse, breathing rate, dizziness); they are having a medical emergency					
Knows their medications & what they are for					
Orders their own medication refills					
Schedules own medical/ dental appointments					
Tracks own appointment and prescription refill dates, they keep records					
Is prepared to see their doctor by themselves					



Taking Care of My Health - Nutrition and Exercise Habits

How does the young person do with choosing healthier drink (water) and food options?

How does the young person do with portion control?

Does the individual have healthy exercise habits?



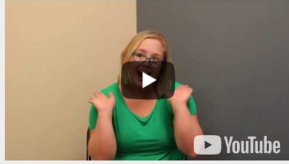


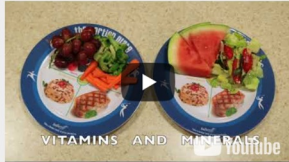



Does the young person need visual reminders of portion control/visual schedules for exercise?

Can the person cook themselves a meal? If so, can they cook themselves a healthy meal?

Video Modeling - Chicago Adult Down Syndrome Clinic



Patient Education and Health Promotion Videos

<p>Appropriate Touch</p>  <p>YouTube</p>	<p>How to Wash Your Hands</p>  <p>YouTube</p>	<p>Erin's Tips for Living a Healthy Lifestyle</p>  <p>YouTube</p>
<p>How to Use a CPAP Machine</p>  <p>YouTube</p>	<p>Tips for Dealing with Stress</p>  <p>YouTube</p>	<p>Fruits and Veggies</p>  <p>VITAMINS AND MINERALS YouTube</p>
<p>Grains</p>  <p>YouTube</p>	<p>Protein</p>  <p>YouTube</p>	<p>Dairy</p>  <p>DAIRY YouTube</p>
<p>Serving Sizes</p>	<p>Tips for Healthy Eating at Buffets</p>	<p>Keeping Hydrated</p>

Reproductive Health

How much support does the young man/woman need with hygiene?

Does the young woman know how to track their periods?

Does the young woman know how to check her breasts for lumps? Does the young man know how to check his testicles for lumps?

Does they young person know that they can talk to a safe adult about any issues related to their genitals?

Sexual Health is Health

Has the young adult received any type of sexual education through school or other means?

Does the young adult understand the concept of private vs. public?

Does the young adult understand the concept of consent? Are they ever allowed to say no in other aspects of life?

Has the young adult been talking about crushes? Relationships? Sex?



Gearing Up for Transition - Making a To-Do List

What specialists does the child see? Make a plan for transitioning specialists

What medications does the child take? Who prescribes them? Does the family have enough supply to bridge through the transition?

What therapies does the child receive and need? Will they be able to continue after the transition?

How do they get to appointments right now (ie transportation)?

Is the young adult prepared for a health emergency? Do they have their “medical ID” information (medical conditions, medications, allergies, emergency contact, insurance information) stored somewhere easily accessible, such as their phone?

If the caregiver were to become sick or incapacitated, is there a place where this information could be accessed by a family member?

More Worksheets



WORKSHEET #7 HEALTHCARE PLAN

When looking for an adult healthcare provider, you may ask for recommendations from your pediatrician, pediatric specialists, insurance provider, friends and local Down syndrome society. When making decisions about transferring care, you may want to consider a doctor's training or special interests, support services (such as access to social workers and psychologists), involvement in a physician network (or hospital system), use of a shared electronic medical record, and office policies (such as their after-hours arrangement). **The main goal in choosing a new doctor is finding someone who is willing to partner with you and your family.**

Specialty	Current pediatric provider	Transitioning to adult provider
General Health (primary care)	Name: _____ Address: _____ Phone/Fax: _____ Why I visit: _____ Records sent? <input type="radio"/> Yes <input type="radio"/> No	Name: _____ Address: _____ Phone/Fax: _____ Why I visit: _____ Records received? <input type="radio"/> Yes <input type="radio"/> No
	Name: _____ Address: _____ Phone/Fax: _____ Why I visit: _____ Records sent? <input type="radio"/> Yes <input type="radio"/> No	Name: _____ Address: _____ Phone/Fax: _____ Why I visit: _____ Records received? <input type="radio"/> Yes <input type="radio"/> No

	I do this by myself.	I do this with some help.	I need to learn how to do this.
Emergencies and safety			
I identify an emergency situation (fire, power outage, water leak).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do when there is an emergency in the house.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know at least two people to contact in case of an emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to contact the people I need in an emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand physical and sexual abuse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand "stranger danger."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I recognize bullying.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I ask for things that I need (like food or help).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical Care			
I know parts of my body.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my diagnoses (problems that the doctor helps me with).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the names of my doctors.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the names of my medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when and how to take my medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to work my medical equipment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when I am getting sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can describe my symptoms (the bad things that I feel).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can ask questions about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can answer questions about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can talk about my worries and concerns.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can make decisions about my healthcare.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can fill out a medical form.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organizational skills			

Choosing an Adult Provider

It's not a marriage! It is helpful to start somewhere and then assess whether it's the right fit

Can ask caregivers: "What do I like about your child's pediatric care that you will look for in an adult provider?"

For the pediatric provider: Recommendation for the last note to be a complete note to send to the adult provider with a thorough review of my child's health conditions

- Nobody has time to read a full medical record, and you will be most familiar with the overall health history, name of pediatric specialists, etc
- Some systems use a complex care note akin to the asthma action plan, that outlines plan for each system and allows easy sharing across specialties

Transition Documentation

Clinical information

- Pediatric specialists and therapists involved in care, including name, institution, last appointment date
- Current functional and neurologic status
- Current cognitive status, including formal test results and date of administration, when possible
- Condition-specific emergency treatment plans and contacts
- The patient's health education history and assessment of his or her understanding regarding health conditions, treatments, and prognosis (include procreation potential and genetic information)
- DME that the patient receives, vendor supplying the DME

Decision-making arrangements

The patient's communication preferences and anticipated needs for accommodations in both communication and clinical care (ie, use of ASL interpreter, augmentative communication device)

Making Decisions

Medical Decision Making

Does the young adult have the capacity to make their own healthcare decisions? What about with support from a trusted adult?

Does the parent have the legal standing to continue to assist their child with decisions once they become an adult?

Are there differences of opinions between patient and parents? Between the two parents (ex custody battles, disagreements about young adult's decision-making capacity)?

Legal Decision Making - Core Principles



Self-Determination: the right to participate in our own decision making

Dignity of Risk: the concept of self-determination, and the right to take reasonable risks, are essential for dignity, self determination and self-esteem, and should not be obstructed by excessively cautious caregivers concerned about their duty of care

Bias check:

How do I, as a provider, feel about this? How might it impact my own counseling?

Legal Decision Making

Supportive Decision Making: A tool that allows people with disabilities to retain their decision making capacity with the support of selected family, friends, and professionals. the individual with I/DD will continue to make their own decisions, supported by a team.

CA Assembly Bill 1663 – went into effect 1/1/2023. Formalized supported decision-making in hope to reduce the number of people who might otherwise have their rights removed by a conservatorship.

Capacity of a person with I/DD to make decision with a support person > capacity of the person without SDM support.

Supported Decision Making Agreement

A private agreement that includes:

- Which areas a decision-maker wants support in (financial matters, education, health care, living arrangements)
- Who is chosen to provide that support, and what are the obligations of those supporters
- What kinds of support (gathering information, helping to weigh alternatives or possible consequences, communicating decisions to others; cannot make decisions or sign documents on behalf of decision-maker)
- How the agreement must be written and executed (in plain language or accessible formats, in the presence of two witnesses or a notary public. Does not have to be a signed/written agreement)
- When the agreement needs to be reviewed (every two years) and terminates (can be revoked at any time by the decision-maker)



Legal Decision Making

Durable Power of Attorney (PoA): Legal document, witnessed by a couple of unrelated individuals, that outlines who can make medical decisions, were the person to lose capacity to make decisions, as determined by the treating physician (or a court, if contentious). Can also be for financial issues (PoA for Financial Mgmt). Can include signing tax returns, signing up for disability benefits, etc.

The person with I/DD needs to have the capacity to understand and sign a PoA, but this can be done with support/modifications/explanations of its contents

A person can have both a shared decision making agreement and a PoA

Legal Decision Making

Limited and General Conservatorship:

Conservatorship is a legal status in which a court determines that an individual lacks the capacity to make their own decisions

Decision-making rights are taken away from the person and given to a judge, who then appoints a person to manage their financial and/or personal affairs. A conservator may also serve as a guardian who is responsible for establishing and monitoring the physical care of the individual and managing their living arrangements.

Under a general conservatorship, a conservatee typically has little to no decision-making powers

A limited conservatorship allows the conservatee to keep control over some of their personal affairs, with the exception of what the court orders the conservator to oversee (e.g: housing, health care, education, financial decisions, relationships)

Conservatorships are a big step. They are difficult to reverse. It should be the last option considered for a person with I/DD

It costs money (court fees, legal fees)

Supporting Transition

The Pediatrician's Role

- Begin the conversation early
 - Consider scheduling interim visits for focused discussions on transition
- Assess the young adult and caregivers' self-management skills
- Educate families on available supports and resources
- Connect families with community organizations that can offer support
- Support transition to adult specialists
- Ensure that up-to-date, complete information about the young adult is transferred to the adult provider



Who Can Help

The IEP/ITP is a powerful document! You can add many goals related to transition to adulthood, including health, sexual health and safety, into the IEP.

The Regional Center IPP (individualized person plan) can include goals and supports related to transition

If the individual is covered by CCS, a transition specialist can help you with the transition

GotTransition.org is a fantastic resource

www.charliesclinic.org has a section called “Teens/Young Adults”

The American Academy of Pediatrics has clinical reports for pediatricians and handouts for caregivers on HealthyChildren.org



Parents & Caregivers

HEALTH CARE TRANSITION QUIZ

Is your child ready to transition to adult health care?



Transitioning your child from a pediatrician to an adult doctor is a big step. Like going to college, getting a job, or going to live on their own, your child's transition to adult care takes independence, self-advocacy, and preparation.

Watching your child grow up always means helping them take on more responsibilities in their life, including their health and health care... Is your child ready to transition?

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Welcome to Charlie's Clinic, the Down Syndrome
Clinic at UCSF Benioff Children's Hospitals

[Are you a parent interested in bringing your child to Charlie's Clinic or a](#)

Community Organizations

- Family Resource Navigators of Alameda County
- Care Parent Network of Contra Costa County
- Disability Rights Education Defense Fund



- Alameda County Developmental Disabilities Council
 - Annual Transition Fair
- Congreso Familiar

You Got This!

Questions?



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Transition to Adult Medical Care: A Parent's Perspective



Connections California: Transition to Adulthood is sponsored in part by the San Andreas Regional Center and the California Department of Developmental Services.

Welcome!

We're glad you're here!

At PHP, we understand the unique joys and challenges of raising loved ones with a disability.



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Connections California: Transition to Adulthood

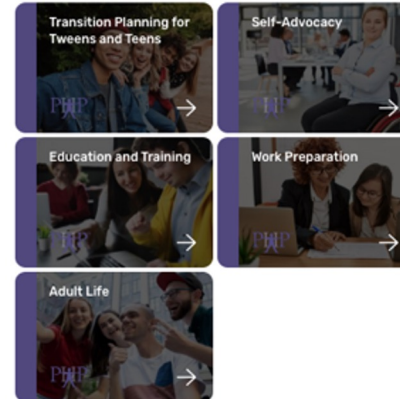


It's never too early or too late to explore the many options available for the transition to adulthood for people with disabilities!

The transition to adulthood for people with disabilities can be overwhelming and complex! For both the individual and their families and allies! Connections California: Transition to Adulthood is here to help!



Categories to Explore



Connections California: Transition to Adulthood

Alyssa DiFilippo
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Takeaways for Today

- Provide an overview of a parent's perspective of pediatric to adult medical care
- Offer practical tips on how parents can approach this part of transition to adulthood - for themselves & their young adults
- Review of health insurance/public benefits and legal issues
- Share resources for parents and young adults
- Touch on how to “let go to let grow”



Parents may approach transition to adulthood with a guarded attitude, which often stems from fear. It's overwhelming, scary, exciting, and sometimes frustrating - all at the same time!

Please Meet Grace





Our Medical Care Transition

**Where we
were 2 years
ago**

**Where we
are now**

**Where
we're going**



2 Years Ago: How We Began

- Asked for referrals from all the specialists - specialists easier to find than GPs
- Asked for referrals from other parents
- Some hand-offs and first appointments happened during covid
- Coordinate the transfer of some very thick paper files and large digital files
- Took the [Got Transition](#) quizzes - for [youth](#) and [parents](#)
- Combed through the UCSF [Office of Developmental Primary Care](#) (ODPC) website for resources

Got Transition Quizzes

Do you see a doctor that sees adult patients, or a doctor who sees only children?



- I go to a doctor who sees adults.
- I still go to a doctor who sees children.
- I haven't been to the doctor's office in years.

Does your child have health insurance? If not, do you know how to help them get health insurance?



- Of course! They're covered through my insurance plan.
- Yep! They're insured through their job.

Do you know the phone number of your doctor's office?



- Yes, I have my doctor's office number in my phone!
- I don't, but I've been meaning to learn it and put it in my phone.
- Huh, I hadn't thought of knowing that.
- It's not in my phone, but I can find it easily online.

Does your child know how their health care privacy changes at age 18?



- They know what happens with their medical records or medical decisions when they turn age 18.
- I don't think they're sure... they know that things change when they turn 18, but I don't think they know exactly what it is.
- No idea. Something changes at the doctor when they turn 18?



Healthcare Transition Resources

[PACER's National Parent Center on Transition and Employment](#) offers [Preparing for Adulthood: Taking Charge of My Own Health Care](#), a video series developed by PACER's Youth Advisory Board
[Got Transition: A Family Toolkit: Pediatric-to-Adult Health Care Transition](#)
[The Office of Developmental Primary Care:](#)

Highlights:


- [Guide on Sexuality and Sexual Health](#)
- [Tips for Organizing Visits](#) - like [Follow-Up From My Visit](#)
- Practical [Tracking Forms](#) (for medications, [sleep log](#), daily living skills, seizures, [menstruation](#), etc.) - for patients and practitioners as well
- [Advice from Self-Advocates](#)
- [Supported Health Care Decision-Making Guide](#)



From UCSF
ODPC:

Getting
Ready for
My Visit

Follow Up
from My
Visit



Getting Ready for My Visit


Name: _____ **Date of Birth:** _____ **Phone Number:** _____

*If you need more space, use the back of this form.

VISIT	
My visit is with:	
Visit date and time:	
Address:	Phone:
How am I going to get there? What supports do I need?	
WHAT TO BRING	
<ul style="list-style-type: none"> 1 Medications: Bring all pills I am taking, including vitamins. 2 Insurance cards 3 My health notebook with logs or tracking forms 4 Copies of notes, reports, tests, or labs ordered by other doctors 5 A calendar for scheduling my next appointment <input type="checkbox"/> Other:	
REASON FOR VISIT	
What do I want to talk about today?	
What happened since my last visit?	
<input type="checkbox"/> I've been fine	<input type="checkbox"/> I was sick
<input type="checkbox"/> I started a new treatment	<input type="checkbox"/> I stopped an old treatment
<input type="checkbox"/> I have seen another doctor or nurse	<input type="checkbox"/> I have had tests done
<input type="checkbox"/> I have been to the emergency room or hospital	<input type="checkbox"/> I have had changes in caregivers or
<input type="checkbox"/> Other:	
What do I need explained?	
I have questions about: <input type="checkbox"/> Eating healthy <input type="checkbox"/> Exercising <input type="checkbox"/> My feelings <input type="checkbox"/> My medications	
<input type="checkbox"/> My teeth <input type="checkbox"/> Pain <input type="checkbox"/> Sexual health <input type="checkbox"/> Other:	
My questions are:	
Do I need any refills or paperwork? <input type="checkbox"/> Yes <input type="checkbox"/> No	
Who needs to be told about the results of this visit?	Tel:



Office of Developmental Primary Care · UCSF Department of Family and Community Medicine
500 Parnassus Avenue, MUE318, Box 0900 · San Francisco, CA 94143
tel: (415) 476-4641 · email: odpc@fcm.ucsf.edu · <http://odpc.ucsf.edu>



Follow Up From My Visit

Name: _____ **Date of Birth:** _____ **Primary Care Office Phone:** _____

APPOINTMENT		
My appointment was on (date/time):		
My appointment was with (name of doctor or nurse):		
PLAN		
New diagnosis:		
Labs or X-rays:		
Changes in my medications:		
Appointments with a specialist/other doctor:		
Referrals to other services:		
Other:		
Reason to call my Primary Care Provider:		
Who needs to be told about the results of this visit?		
Name:	Tel:	Email:
Name:	Tel:	Email:



Legal Aspects of Adult Health Care



[Connections CA: Adult Life: Legal Aspects](#)

[Legal Options for Decision Making as Youth Transition to Adulthood](#)





Medical, Dental, Vision Insurance

Private and Public

- Keep your 26+ year-old on your health insurance with a Disabled Dependent Certification - need to check with your employer and/or health insurance provider:
 - [Lawserver California Insurance Code 10277](#)
 - [Newfront: Post-Age 26 Coverage for Disabled Children](#)
- Public Benefits: [Medicare](#), [Medi-Cal](#), [MediMedi](#)
 - [5 Medi-Cal Eligibility Categories for People with Disabilities](#)
 - [Disabled Adult Child & Social Security Benefits](#)
 - [Connections CA: Adult Life: Health and Wellness](#)
 - [Connections CA: Adult Life: Public Benefits](#)
- [Medi-Cal Dental](#) and [Medi-Cal Vision Benefits](#)

Where Are We Now?

- Going to several of her medical appointments with her self-determination program staff - NOT with me - including annual, ear cleaning, podiatrist, optometrist
- Making some of her own appointments - and working on putting them in her phone calendar and actually *keeping* the appointment
- Created laminated card with medications, dosages, frequencies
- Filling her own prescriptions and keeping on top of when to re-order
- Working on explaining her disability in 3 sentences or less - then laminating a card - important to be able to explain PWS to a medical provider
- Latest - Grace's decision not to have jaw surgery to address sleep apnea
- Working on [One Page Profile](#) for medical appointments



One Page Healthcare Profile

[The Key to Successful Health Care Appointments through One-page Descriptions](#)

LeAnn Bieber parent and Person-Centered Thinking trainer/planner

[Fillable PDF of Healthcare Person-Centered Profile](#) from [National Center on Advancing Person-Centered Practices and Systems](#)

My Health Care Person-Centered Profile

Melissa Bieber



What people appreciate about me

I know what I like / want
My smile
My laugh
My dance moves / appreciation for music

What is important to me

Having people I know around me
Being included even when I may not say anything
Having something in my hands – a bottle, picture, paper

Things I like to do

Watch movies
Listen to music
Look at pictures
Color / Art projects (sometimes)

How to best support me

- Inform me of choices; visual is best for a quicker response.
- Know I need time to answer questions. (3x what you might take) I may or may not respond
- I like to laugh! Sometimes I need extra support to understand why I am laughing. Please see my communication chart to know how to support me.
- I Do NOT like shouting or sudden noises. Sometimes I struggle with children crying, being loud or extra active.
- Sometimes what I pick up may not be mine or be something others may not think I should have. Support my choices; If it is something that belongs to someone else or a safety concern, encourage me to find something else—give me something else.

This Health Care Person-Centered Profile was completed by
 me someone else (specify name and role):



What Have we Learned? Think Big!



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Parents Helping Parents - Connections California: E-Learning Library Examples

- [Navigating Pediatric to Adult Health Care with Dr. Clarissa Kripke of UCSF Office of Developmental Primary Care](#)
- [Navigating Entitlements -SSI, MediCal/Medicare & Disabled Adult Child Benefits](#)
- [Who Helps You Coordinate Your Health Care?](#)
- [Sexuality and Special Needs: “Let’s Talk about Sex”](#)
- [What is Health Care Transition \(HCT\)?](#)
- [Introduction to One Page Profiles](#)
- PHP’s [Family Care Notebook](#)
- Trudy Grable’s [Person-Centered Plans](#)
- [The Learning Community for Person Centered Practices](#)

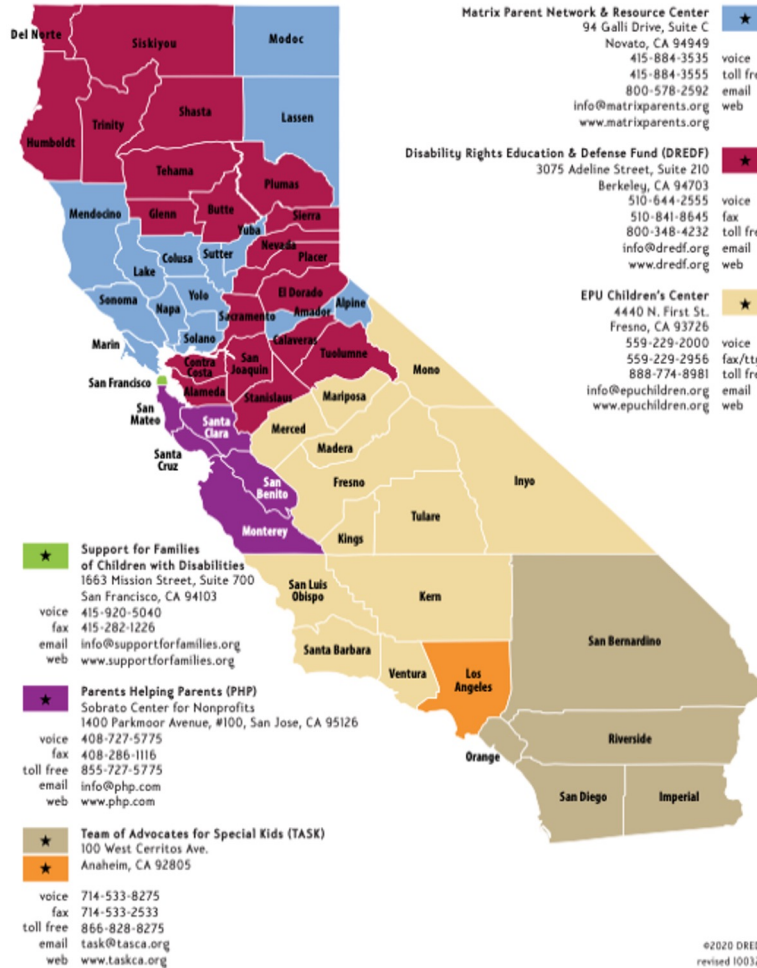
More videos: [Connections California: Adult Life: Health and Wellness](#) & [Connections California: Self-Advocacy](#)

More resources: [Pediatric to Adult Healthcare](#)

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CA Parent Training and Information (PTI) Centers ADMINISTRATIVE OFFICES AND COUNTIES SERVED - 2020



Center for
Parent
Information &
Resources:
[Find Your
Parent Center](#)

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Family Empowerment Centers: Find Your FEC

Map not updated -
now 31 FECs

FEC Contact Information and Counties Served

<p>Rowell Family Empowerment of Northern California Shasta, Butte, Tehama, Trinity, Siskiyou, Glenn www.rfenc.org 530-226-5129</p>		<p>Plumas Rural Service Lassen, Modoc, Plumas, Sierra www.plumasruralservices.org 530-708-2557</p>
<p>Family SOUP Yuba, Sutter, Colusa www.familysoup.org 530-751-1925</p>		<p>Matrix Parent Network and Resource Center Napa, Solano, Sonoma www.matrixparents.org Main: 415-475-2121 Helpline: 800-578-2592</p>
<p>Support for Families of Children with Disabilities San Francisco www.supportforfamilies.org 415-282-7494</p>		<p>Parents Helping Parents Santa Clara www.php.com 408-727-5775 x149</p>
<p>Special Parents Information Network San Benito, Santa Cruz www.spinsc.org 831-722-2800</p>		<p>Exceptional Parents Unlimited Fresno, Kings epuchildren.org 559-229-2000</p>
<p>H.E.A.R.T.S. Connection Family Resource Center Kern www.heartsin.org 661-328-9055</p>	<p>The Parents' Place Family Resource Center Los Angeles (San Gabriel Valley, Pomona) www.parentsplacefrc.com Westside Family Resource and Empowerment Center West Los Angeles www.wfrec.org</p>	<p>Exceptional Family Resource Center San Diego, Imperial www.efrconline.org 619-594-7416</p>
<p>Family Focus Resource & Empowerment Center North Los Angeles (San Fernando, Santa Clarita, Antelope Valley) www.csun.edu/family-focus-</p>	<p>TASK (Team of Advocates for Special Kids) Orange www.taskca.org 714-533-8275</p>	



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