Pediatric Resident Training Program (Toolkit)

A Project of PACER Center’s Family to Family Health Information Center
Pediatric Resident Training Program (Toolkit)

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1) PACER’s Pediatric Resident Training Program for Transition Youth and Their Families

PACER is a Minnesota and national nonprofit parent center with 35 years of success providing innovative resources, training, and support to families of children with special health care needs and all disabilities, including 20 years of operating Maternal and Child Health Bureau (MCHB) family projects. PACER’s Family-to-Family (F2F) Health Information Center reaches thousands of parents and professionals annually through one-to-one assistance, trainings, website and publications.

Since children with special health care needs are best served by Family-Centered Care delivered through a Medical Home model, PACER Center identified a need to increase pediatricians’ understanding of the health care system from the family’s perspective in order to provide the highest quality treatment.

PACER’s Parents as Teachers (PAT) resident teaching program has been operating successfully at the University of Minnesota’s Department of Pediatrics since 1991 and has more than 20 years of data that demonstrates important outcomes for more than 600 residents and over 50 families who have participated. As a result of the program, pediatric residents have been able to successfully incorporate what they have learned into their medical practices, potentially impacting thousands of individuals in the community. At the same time, parents have learned how to become better advocates for their children, and partner more effectively with their physicians.

Program evaluations indicate that 97% of residents who have participated say the program was useful and worthwhile. Upon completion of the program, residents gave themselves 4.18 on a scale of 5 as being prepared to incorporate families’ points of view into clinical or hospital visits.

PACER’s Parents as Teachers program enables residents to participate during the Developmental Behavioral Pediatric (DBP) rotation. This rotation focuses on establishing the family/parent perspective with regard to family-centered care, medical home, community-based resources, and coordinated care for children and youth with special health care needs by matching each family with a resident who visits them in their home or community. Information about these areas is provided to residents during training sessions prior to the family visit.

In 2012, PACER expanded the Parents as Teachers program so that the pediatric residents had a second opportunity to meet with families during their adolescent rotation. Known as the Pediatric Resident Training Program (PRTP), this opportunity includes an expansion of the key concepts of medical home, family-centered care and children and youth with special health care needs. In addition, the curriculum
focuses on both cultural competency and transition of pediatric medical care to adult services. Residents are matched with families, including those with diverse backgrounds, who have experienced health care, education, and community living transitions with their teenager or young adult with special health care needs or disabilities. The Pediatric Resident Training Program’s family visit helps residents develop a more comprehensive understanding of the complex issues families face as their children develop, and make the transition to a more independent life. Residents receive information and resources they will need to create medical homes for families as these physicians establish their practices in rural and urban areas nationwide. Residents also receive training about diverse cultures and the unique issues associated with health care delivery in these communities.

Youth and young adults with special health care needs also participate in the resident visit, providing an opportunity for the physicians to learn about health care access and transition skill development in ways that may not occur in a traditional health care setting. When residents visit, many families include them in whatever normal activities are occurring that day – from family events to multi-generational home environments, community cultural activities, or youth-directed recreational activities.

2) Parents, young adults and youth with special health care needs or disabilities

PACER’s Pediatric Resident Training Program provides leadership training to parents of children and youth with special health care needs and disabilities. The parents are their child’s best advocate, and PACER seeks parents and families who are willing to participate in the program and share their health care experience with residents.

The Pediatric Resident Training Program identifies families with youth and young adults ages 14 to 25 who are beginning the transition process at school, and need to begin addressing the many issues they’ll face in the years ahead. Some participating families have previously been in the Parents as Teachers program and their children are now at the age when they are starting the transition process. There is also a focus on recruiting more racially and culturally diverse families and at least three to four families are trained each year to participate in the program. Through each family’s cultural lens, the Pediatric Resident Training Program participants share their experiences of navigating the health care system, adapting their family life and integrating their child or young adult in the community based on their needs.

3) Medical residents

Medical residents are physicians. They have graduated medical school, and earned a medical doctor degree (MD) designation. Prior to that, they will have completed an undergraduate education, and some may have acquired additional graduate degrees before entering medical school. Residency is the training required to become board certified in a specific medical area such as family practice, pediatrics, or internal medicine. Residency programs range from three to eight years, depending on the specific program and specialty involved, and residents are paid, practicing doctors who work with patients while under supervision.

Residency schedules are organized into ‘rotations’ where residents spend several weeks with a specific focus and then move on to another focus or setting. Residencies are unique to each program and specialty, with first-year residents (usually called interns) practicing under the supervision of more senior residents and attending physicians. The Pediatric Resident Training Program is designed to be a part of a pediatrics, or joint internal medicine and pediatrics (often called MedPeds), residency program. It was specifically developed in collaboration with the Department of Pediatrics at the University of Minnesota for residents on their adolescent rotation.
In order to improve the system serving children and youth with special health care needs, PACER's Pediatric Resident Training Program relies on partners and collaborators in all aspects of program design and delivery. A collaborating parent center is needed to coordinate the various aspects of the program. Center staff identify and train families of teens and young adults with special health care needs to host resident visits in their homes. The University of Minnesota has incorporated the Pediatric Resident Training Program into its residency education program, and it provides administrative support to arrange resident visits, and stipends to families who participate.

1) Coordinating partner

In Minnesota, PACER Center serves as the coordinating center for the Pediatric Resident Training Program. The coordinating partner has the initial responsibilities to:

- Identify staff to implement the program.
- Identify parents of teens and young adults with special health care needs and disabilities to participate in the program.
- Identify a source of health care providers in training, such as physician assistants, nurse practitioners, or other health care professionals if there is no pediatric resident program nearby, or if the new project is looking for alternatives.
- Collaborate with a program director, clinic director, or organization that will be responsible for the availability and scheduling of the health care providers each month.
- Develop orientation curriculum (see p.9).
- Develop an agenda and activities for a debriefing session.
- Develop pre- and post-visit surveys, or use PACER's.
- Collect, enter, and evaluate data.

PACER Health Information Center staff and multicultural advocates also help identify, recruit, and introduce families to the Pediatric Resident Training Program staff. PACER provides language and American Sign Language (ASL) interpreters for resident visits based on family and youth requests.

There are several options available for community agencies that can act as coordinating centers:

- Family-to-Family Health Information Centers
- Parent Training and Information Centers
- Family Voices, or State Affiliate Organizations
- Parent-to-Parent Organizations
- Other parent disability organizations
2) Families

The Pediatric Resident Training Program relies on parents as well as youth and young adults with special health care needs who are willing to participate and share their health care experience with residents. There are a number of different sources to help identify these families. These include:

- **Family-to-Family Health Information Centers** which are in every state and help families of children with special health care needs or disabilities navigate various systems.
- **Parent Training and Information Centers** provide information, training, and assistance to families of children with disabilities ages birth to 26, and to professionals who work with them.
- **Disability-specific organizations** in each state: Organizations with connections to families whose children have specific diagnoses, such as autism, Down syndrome, cerebral palsy, and cystic fibrosis, may be able help identify potential participants on a local level.
- **National Association of Councils on Developmental Disabilities** has information on how to locate each state’s Council on Developmental Disabilities, which may have members who are parent representatives or self-advocates who would be interested in joining the Pediatric Resident Training Program.
- **Cultural leaders in diverse communities** can help find multicultural families who have children with special health care needs. Contact PACER Center for the name of a Parent Center in your area to find local cultural leaders.

3) Medical residents

While the Pediatric Resident Training Program is designed to be a part of a pediatrics or joint internal medicine pediatrics residency program, other residencies, such as family practice or psychiatry could potentially be a good fit. Clinics where residents do their rotations may also be good partners. Physician assistants, nurse practitioners, or others who see patients independently may offer an avenue to raise awareness and achieve program goals. Some universities also have Public Health Training programs.

Here are some resources for identifying potential resident program partners:

- The Association of American Medical Colleges website lists residency programs and specialties through its Electronic Residency Application Service (ERAS), which is the national application site for physicians seeking residency and fellowship programs.
- Community clinics or federally qualified health clinics where residents do rotations.
- Physician assistant, public health professional programs and nursing programs: The Physician Assistant Education Association has a list of U.S. physician assistant programs, the Council on Education for Public Health lists accredited public health programs, and the Accreditation Commission for Education in Nursing lists accredited nursing programs.
1) Community agency

Once partners have been determined, the community agency, parent center, or coordinating center needs to take multiple actions. These include:

a) Identify agency staff to implement the program. Characteristics of potential program leaders include:
   - Family or individual experience navigating health care systems in the community. This gives credibility when working with families.
   - Experience and ongoing working relationships with families of children with special health care needs and disabilities.
   - Current working relationships with multicultural families or leaders in diverse communities.
   - Ability to work closely with residency staff to review current curriculum and prevent duplication of information.

Staff should become familiar with PACER’s Orientation curriculum (see Appendix 8a-9b) and the For Medical Professionals section (part of the Family to Family Health Information Center resources) at PACER.org. Other opportunities for staff development include participating in webinars, attending national conferences, or serving on national, state or local health care-related boards.

b) Once coordinating center staff are identified and trained, the following steps need to be taken to implement the program:
   - Train parents who have been identified and agreed to participate.
   - Conduct an orientation session for residents to review important issues for transitional youth who are moving toward adulthood. This includes family insights and resources and community issues such as housing, transportation, and guardianship as well as educational issues such as post-secondary education, employment, or day services. There should be an emphasis on transition from pediatric to adult health care systems (see page 9).
   - Administer a self-assessment survey at the beginning of the orientation to determine the residents’ baseline level in working with teens with special health care needs, and people of other cultures. The survey also assesses the residents’ knowledge of the identified core concepts of medical home, family-centered care, and available community resources. (see Appendix 1, section A)
   - Determine the best match between participating families and residents. Begin by contacting families to determine availability for a particular rotation. Then assign each resident to a particular family based on individual interests and availability.
• E-mail contact information to families and residents so they can arrange a visit. Ask parents and residents to agree on a location for their first meeting, either in the community or at the family’s home. Be sure to include the teen or transition age youth in the meeting. (see Appendix 2)

• Send surveys and invoice forms to families and let them know you will be collecting the completed forms after the resident visit. (see Appendix 3 & 4)

• Hold a debriefing session at the end of the rotation. At PACER, the debriefing includes:
  o Residents describe their experience and share what they’ve learned.
  o Residents tour PACER Center.
  o Residents learn about and tour PACER’s Simon Technology Center (PACER.org/stc), and other PACER programs.
  o PACER’s multicultural staff from the Hmong, Somali, Latino, and African American communities participate in a panel discussion about issues that people from diverse cultures face in navigating the health care system.
  o Residents complete the post-visit survey, which repeats questions from the pre-visit survey, and specifically addresses details of the visit, what they learned, and their recommendations for the program. (see Appendix 1, sections B through G)

• Send follow-up surveys to parents and residents six months after the rotation to assess what they gained from their experience in the program, and to ask if they have had the opportunity to utilize the skills they acquired by participating. (see Appendix 4)

2) Parent/family participation

Once parents have been identified and agree to participate in the program, they receive training at PACER Center where they are treated as professionals, and their commitment and expertise is recognized with a monetary stipend. Training can be done as a group or individually. It lasts about an hour and includes a PowerPoint presentation, review of Pediatric Resident Training Program forms, and time for parents to ask questions about the program. The training concludes with a tour of PACER Center to introduce or remind participants about workshops and resources available to the families and residents.

PACER offers both initial and ongoing parent training resources:

• **Initial training includes:** (see Appendix 5, presentation)
  o Parents as Teachers program history and goals
  o Expansion of Parents as Teachers to Pediatric Resident Training Program
  o Information on the residency program
  o Tips on sharing experiences and telling their story
  o Ground rules on discussing experiences
  o Information on planning the visit
  o Sample discussion topics

• **Ongoing training includes:**
  o Annual educational event: PACER utilizes its annual Family and Resident Appreciation Dinner as an opportunity to build and maintain parent-professional relationships. Participants include residents, parents, teens, young adults, university resident coordinators, PACER staff coordinators, as well as PACER multicultural staff, and staff of the Simon Technology Center. Pediatric Resident Training Program parents and young adults give presentations on topics such as a parent’s perspective on building a health care team, coordination between health care teams and educational teams, and collaboration between parents and professionals. New families gain peer support at the event by meeting families
who have been in the program for some time. Residents and university staff deliver presentations on best practices of transition from pediatric to adult health care and on parent-professional relationships. (http://www.pacer.org/health/For-Medical-Professionals/pediatric-resident-training.asp)

- **Periodic updates and opportunities:** Pediatric Resident Training Program staff keep families informed about current national, regional, state, and local health-related topics, including new leadership opportunities such as committee openings at the state or local level. Families have an opportunity to network, participate in workshops, and gain valuable experience. They also receive periodic updates on new research-based parent and youth resources to assist in their navigation of the health care systems they are involved with.

3) **Resident training**

- **Resident orientation:** Resident orientation reviews key curriculum components and concepts including family-centered care, medical home, and children and youth with special health care needs. It describes the family visit and outlines transition issues that young adults and teens face.

- **Family visit:** A day or two after the orientation, the program coordinator e-mails residents with the contact information for the family they will be visiting (see Appendix 6). It is up to the resident to follow up with the family and arrange a meeting. Sample questions and topics for discussion are included in the e-mail and are reviewed during orientation. Contact information for the program coordinator is also included in case unforeseen challenges arise when arranging the visit.

- **Resident debriefing:** The two-hour debriefing session is a key component of the program that provides residents an opportunity to process what they have learned during the family visit. It helps make the connection between concepts discussed at the orientation with what they experienced during the family visit, and time is provided to complete the evaluation and discuss additional resources. Residents meet with PACER’s multicultural staff to learn about the perspective of parents from diverse communities and ask related questions. Residents also tour PACER’s Simon Technology Center to learn about assistive technology (AT) options available to families of children with special health care needs and disabilities, and learn about PACER’s National Bullying Prevention Center, and COUNT ME IN® and KIDS AGAINST BULLYING puppet programs. Residents are asked to provide their personal e-mail addresses so that they can receive surveys six months after their family visit. (see Appendix 7)
Included below is an overview of the information covered during the orientation session. Copies of the lecture handouts and lecturer’s notes can be found in the Appendix. There is a shorter, more concise version of these notes (Appendix 8a and 8b) and a longer, more detailed version (Appendix 9a and 9b).

1) History of Pediatric Resident Training Program (PRTP)

- Pediatric Resident Training Program is based on the Parents as Teachers (PAT) program, a collaboration of nearly 25 years between PACER Center and the University of Minnesota Pediatric Resident Training Program. Parents as Teachers occurs during the Developmental Behavioral Pediatrics (DBP) Rotation in the first year of residency.
- The program was expanded in 2012 to provide additional opportunities for residents to meet with families, and to increase the focus on transition from pediatric to adult healthcare and cultural competency.
- During the Adolescent Rotation, Pediatric Resident Training Program allows families and youth to share their knowledge, experience, and expertise with residents.

2) Goals of Pediatric Resident Training Program

- Review concepts of medical home, family-centered care, and community resources to support children and youth with special health care needs and/or disabilities
- Increase understanding, skills, and cultural competence among residents for working with diverse families and youth
- Increase knowledge of community resources to support transition from pediatric to adult systems of care.

3) Review and expand definitions*

a) Children and Youth with Special Health Care Needs: Children and youth who have a higher risk of chronic physical, development, behavioral, or emotional condition, and require a type or amount of health care services greater than most children.

b) Family- and Patient-Centered Care: Standard of practice that assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to the relationship.

* Please see page 17 for more detailed information and source of the definitions.
c) **Medical Home**: The definition of a medical home is not a building, house, hospital, or home healthcare service, it is an approach to comprehensive primary care where the pediatric care team works in partnership with the child and the child’s family to assure that all of the medical and non-medical needs of the patient are met.

d) **Identification of available community resources**: For a complete listing of resources in Minnesota, visit PACER.org/health for the “Resource List of Disability Organizations.” Many organizations have lists of resources for their states or communities. To locate a Parent Training and Information Center (PTI) or Community Parent Resource Center (CPRC) in your area, visit the Center for Parent Information and Resources (http://www.parentcenterhub.org/find-your-center/).

4) **Transition areas**

The adolescent rotation focuses on the transition and adult skills that parents and youth with special health care needs/disabilities will have to prepare for as the young adult transitions into a more independent life. There are three primary areas, each of which is outlined below:

a) Transfer from pediatric health care to adult providers
b) Transfer from high school to post-secondary education/vocational school or employment
c) Dependence on family to independence in the community.

a) **Transfer from pediatric health care to adult providers**

Transition planning goals:

- Identify short- and long-term goals toward independence and employment. These may change as the individual matures, and learns more about the potential long-term impact of their disability. The goals may also shape the care coordination when the health care transition process begins.
- Be respectful of diverse cultures that may have a different view of transition and how it impacts their youth with special health care needs and disabilities.

**Self-advocacy**: Typical teens, as well as youth with special health care needs, display a wide range of abilities related to self-advocacy. Each clinic visit offers an opportunity to build advocacy skills, empowering the youth to be more involved in transition and increasing the opportunity to gain more comprehensive skills. The following list offers suggestions of where to start the process of addressing each teen's skills, and building on their knowledge and ability to self-advocate.

- Does the individual know his or her diagnosis?
- Can the young adult describe his or her disability?
- Is the young adult able to express her needs and advocate for needed accommodations?
- Is the individual able to understand her physician's instructions?
- Can he be responsible for his own medications?
- Can he follow directions?
- Does she know the names of her medications?
- Does he know the side effects of his medications?
- Is she able to understand the importance of medication compliance?
- Would it be beneficial for the youth to have a medical binder, portable medical summary, or one-page summary outlining his or her disability and medical challenges and how these may impact behavior?
- Is there a role for assistive technology to help with tasks such as scheduling, reminders, and contact information?

**Emotional needs**: Transition is a time for youth that may include increasing awareness of their disability. Youth, including those with disabilities, begin seeing
themselves as adults. They want to participate in conversations with their physician, and should be part of the decision-making process.

- While some youth meet various goals, youth with special health care needs and his or her family may experience concerns and anxiety as they recognize that some goals may not be possible at this time. This might include a desire to obtain a driver’s license, or the goal of being able to live independently.
- Consider referral to a counselor, therapist or diagnosis-specific support group if appropriate.
- It is helpful to know what resources are available in the community to support both parents and youth as they start the process of transition. This may include respite care for the parents or personal care attendants (PCA) services for the youth.
- Each culture takes a different view of transition, and some young adults with disabilities or special health care needs from diverse communities may continue indefinitely in their current living situation.

**Addressing basic health care needs:** There are issues most youth in transition face, including young adults with special health care needs or disabilities. These issues include:

- Nutrition
- Hygiene
- Exercise
- Substance abuse
- Safety and risky behaviors
- Reproductive education
- Sexuality

However, some young adults may need extra support in these areas to make good decisions and master these skills.

**Organizational skills needed for success:** It’s important to identify skills that the parent and youth can include in the Individualized Education Program (IEP). Transition goals on the IEP can also be connected to medical transition needs. Potential IEP objectives and goals might include:

- Setting up appointments, including scheduling and arriving on time
- Learning about medications from the school nurse
- Carrying an insurance card and understanding co-pays and deductibles
- Carrying or using a one-page summary of medical history and a medical binder
- Learning how to fill prescriptions, when to order refills, and how to pay for medications

It’s important to begin developing these skills early to minimize the number of surprises a student will face. Some items may also need to be revisited along the way.

**Ensuring compliance:** Compliance with a medication regimen is often the cornerstone to successful transition for many youth with special health care needs or disabilities. It is important to answer these questions:

- Does he have reasonable organizational skills?
- Who will be responsible for administering or overseeing medications?
- Will she need help managing her medication, or will she be able to be independent by using helpful tools such as a daily pill organizer?
- Can she be trusted to take her medication?
- Does the young adult understand the importance of staying on their medication?
- Will technology be helpful as a way to remind him to take his medications?
- What supports have been put in place? Are there additional supports needed?

**Health care financing:** Does the individual need to continue on the family’s insurance plan? Under the provisions of the Affordable Care Act, individuals can stay on the family plan until age 26, and some insurance plans allow adult children with disabilities or special health care needs to remain on their parents’
plan for life.

- Is the individual eligible for adult Medical Assistance based on disability or income?
- Is he or she eligible for Supplemental Security Income (SSI)? Many young adults are eligible depending on their resources and/or disability.
- Does he or she qualify for home and community based waivers that provide flexibility in selecting housing options in the community?
- Are there other state-specific resources or grants that might be available?

**Transfer as an integrated plan:** There are multiple steps that take place in the transition process, and these need to be well-integrated.

- Interview new adult providers with a support person, such as a parent, guardian or caregiver.
- Maintain the link with the current pediatrician to answer questions, provide information, and assist with interim communication with new providers.
- Have the young adult receive health care from both adult providers and his or her pediatrician during the transition process. This kind of collaborative care can make the transition go more smoothly for everyone involved.
- The pace of transition varies greatly. For some young adults it may be a more gradual process that could last a year or two, especially if multiple medical specialists are involved in the delivery of care.

**Changes that occur during transfer from pediatric to adult health care systems:** There are many changes that take place during this period. For example, some pediatric specialties may not have an equivalent in adult health care, such as a developmental behavioral pediatrician or the unique family care provided in a children's hospital.

- Will the individual attend appointments alone? If not, who will accompany her?
- How will information about the individual be communicated to medical personnel?
- How will information from health care providers be implemented by the individual?
- How will compliance be ensured?
- How will the family or guardian stay informed about their youth's health care needs?
- What role will technology play in this process?

**Checklists for transition readiness:** It’s important to begin the process early to reduce the number of surprises along the way. At times, certain steps may need to be repeated or updated. Some of the basic checklist items include:

- Making appointments
- Health insurance
- Medical history, one-page summary, medical binder
- Prescriptions
  
  *(See Appendix 10 & 11)*

**Develop a health transition plan:**

- Determine the individual's short- and long-term goals for independent living and employment while respecting each family's unique cultural perspective.
- Assess the youth's health care understanding early in the planning process. This will empower the youth to be more involved, and increase the opportunity for him or her to obtain a set of skills in the future.
- Set up a health transition plan with the family and their youth or young adult to acquire the skills they will need in the future.
- The health transition plan should identify skills that the parent and youth can include into his or her Individualized Education Program (IEP). The transition goals in the IEP can be connected to medical transition needs. For example, if a student needs to learn how to keep appointments, the IEP could include a goal of arriving to class on time as a way to reinforce that skill.
- Every visit is an opportunity to assess skill
level on goals and determine if new resources are needed.  
(See Appendix 12)

b) Transfer from high school to post-secondary education, vocational school or employment

This section looks at the individual’s abilities, goals, and future plans after the young adult graduates from high school, and how she or he will achieve those goals.

I. What is his level of functioning, and what kind of activities is he able to participate in?

i. Post-secondary education: Is the individual interested in pursuing post-secondary education? In what setting might that occur, and with what supports and services?
   • How are the individual’s organizational skills?
   • Are there disability services available on campus?
   • Is the student able to order medications or carry an insurance card?
   • Will she be able to make and keep appointments?
   • Is there a role for technology to assist with developing organizational skills and assisting with compliance?
   • Who will be the support staff and emergency contacts if there is a medical problem or some other unexpected event?

ii. Will the young adult pursue further education, such as community college, a job training program, or training for a technical certificate?

iii. Is the individual able to work? If so, it needs to be established what type of jobs are a good fit, how many hours the young adult is able to work, and what types of supports might be needed in a work environment.
   • Is the individual eligible for vocational rehabilitation services?
   • Is he eligible for county supported employment through Medicaid?
   • Will she need a job coach to be successful?

iv. Is the young adult interested in a day program?

II. Transition planning as part of the Individualized Education Program (IEP) process:

   • What prior planning does the IEP team need to do in order to prepare the student for life after high school, including post-secondary education, work, independent living, and assuming responsibility for their own health care? (see Appendix 13 for a list of potential IEP goals and objectives)

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c) Dependence on family to independence in the community

This section identifies the youth or young adult’s areas of dependence and explores the transition services needed for youth and their families.

Accessing services: Until age 18, family members and other adults have been responsible for locating information and services for their young child with special health care needs and disabilities. As youth and young adults begin to plan further transition, these expectations of families may change.

   • Who will be responsible for arranging the individual’s care?
   • What responsibilities will the young adult have? What will have to be done by others?
   • Who will identify community resources for the youth or young adult such as Parent Training Centers, Independent Living Centers, and Family-to-Family Health Information Centers?

Housing: Where will the young adult live?

   • What are the youth’s goals and attitudes toward future housing?
   • Is the family proactively developing a plan for future housing needs?
   • Will the family choose to have their adult child live at home for a period of time?
   • Are group homes and more individualized
settings such as adapted apartments available in the community?

- How does housing need to be customized to fit the individual's needs for the least restrictive environment, including physical accommodations such as lower counters, and other modifications?
- See PACER's resources at PACER.org/housing

**Transition to new in-home care staff:** There are a number of services available to support youth with special health care needs and disabilities.

- Will the young adult need a personal care attendant (PCA), service support professional (SSP), or nursing staff to provide support for independent living?
- Could other support staff deliver such services as cooking, personal care, and budgeting or money management to assist with the transition from dependence on family members to more independent living?

**Transportation:** It's important to look realistically at how a young adult making the transition to more independent living will travel to appointments, a place of employment, or community activities.

- Does the young adult have a driver's license? If not, has an assessment been done to determine if he or she has the ability to operate a car safely, with or without adaptations?
- Is the individual able to use public transportation?
- Is he or she eligible for adapted mobility services?
- Does he use medical transportation through Medical Assistance?

**Decision making:** Until age 18, an individual's parents or guardian make all of the important decisions. After age 18, the individual will need to sign an official Consent for Release of Information form if a court-appointed guardian is not in place.

- Will the individual be able to make medical, financial, or legal decisions independently, or does the family need to obtain legal guardianship prior to his or her 18th birthday?
- Similar decisions will need to be made regarding conservatorship, power of attorney, and advance health care directives.

**Self-care and chronic condition management:** What self-care skills does the young adult need, and what is he or she able to do?

- Can the individual perform basic activities of daily living such as dressing, grooming, and feeding?
- Can she manage her place of residence and do her own cooking, cleaning, and laundry?
- Is he capable of managing his own finances?
- Can he or she comply with a medication regimen?
- Is the young adult able to make and keep appointments?

**Communications:** How effectively is the individual able to communicate his or her needs and have those needs met? At the age of transition, family dynamics tend to change and some young adults may have difficulty expressing their desire for more independence.

- Is there a support network in place for the individual and his or her parents?
- Is there assistive technology available that will enable the young adult to communicate more effectively, or function more independently?
There are many different factors that will impact the development of a Pediatric Resident Program, and no two situations are alike. The following is a suggested timeline for establishing and growing a Pediatric Resident Training Program.

**Year 1:**
- First, identify a medical partner and agree on program goals and objectives, and evaluation tools.
- Identify a community partner that can refer and train parents of youth with special health care needs. Establish an agreement to work together.
- Contact PACER Center for guidance, questions, or advice if there is interest in establishing this program (e-mail pacer@pacer.org or call 952-838-9000)
- Establish curriculum items and resources (paper and web-based).
- Train staff.
- Train parents.
- Seek opportunities to recruit diverse families.
- Conduct a pilot program with residents and families.
- Utilize PACER’s evaluation process and tools.

**Year 2:**
- Train additional families.
- Host annual education event for families.
- Establish resources to link from website.
- Evaluate curriculum.
- Assess program outcomes.
- Establish and maintain listserv for participants who have been trained.
- Distribute follow-up surveys to evaluate effectiveness.
- Continue collaboration with defined partners.
- Program implementation, continued monthly orientation, family visits, and debriefing.
- Send information about your project to PACER Center: 8161 Normandale Blvd. Bloomington, MN 55437 or e-mail pacer@pacer.org.

**Year 3:**
- Consider forming a medical advisory board, or inviting medical professionals to join the organization’s advisory board, to provide input and feedback on the program.
- Collaborate with other Pediatric Resident Training Programs to gather new resources.
- Continue program implementation.
- Look for expansion opportunities.
TIPS FOR SUCCESSFUL IMPLEMENTATION

- **Consider terminology:** Language varies from culture to culture. Staff should seek input from diverse families on vocabulary used in the curriculum and resources that are provided to parents and residents. The use of certain language may impact a family’s perception of the program and could affect their decision on whether or not to participate.

- **Focus on the family, not the place:** Program terminology was changed from “home visit” to “family visit” because some families may not be comfortable with residents visiting their home. This subtle change helped residents and families consider other, more comfortable meeting locations in the community.

- **Look at opportunities to add diverse families:** It is important that diverse families participate in the program. Cultural liaisons helped identify families to attend events and be introduced to the program. PACER multicultural staff facilitated initial family visits, provided training for the families, and helped build the relationship with Pediatric Resident Training Program staff. Multilingual resources and information are also helpful.

- **Empower families through information:** One way PACER was able to encourage parent and family involvement was by consistently finding ways to enhance each family’s knowledge and leadership opportunities.

- **Provide a stipend or reimbursement:** Most families are willing to participate in the resident visits regardless of the financial incentive, but the stipend is a nice way to thank participants for the important role they are playing as teachers and the value of the time they are spending with residents.
DEFINITIONS

Children and Youth with Special Health Care Needs: The Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) defines as: “Those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.”

Family- and Patient-Centered Care: The National Center for Family Professional Partnerships says “Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services.”

The Institute for Family-Centered Care says “Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care. Patient-and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them. Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.”

Medical Home: According to the National Center for Medical Home Implementation, “A family-centered medical home is not a building, house, hospital, or home healthcare service, but rather an approach to providing comprehensive primary care. In a family-centered medical home, the pediatric care team works in partnership with a child and a child's family to assure that all of the medical and non-medical needs of the patient are met. Through this partnership the pediatric care team can help the family/patient access, coordinate, and understand specialty care, educational services, out-of-home care, family support, and other public and private community services that are important for the overall health of the child and family.”
Pediatric Resident Training Program (PRTP): Self-assessment and Evaluation of Training

Date of Orientation: ______________________ E-mail address: ____________________
Title (PL-1, PL-2, etc.): _____________________

The following evaluation is meant to assess the program’s ability to increase your knowledge and understanding of family-centered care, medical home, and community resources available for families and youth; and to improve your ability to work with diverse families and with transition-age youth. Please rate the following according to its ability to meet these goals:

Pre-orientation survey:

A. PRE-ORIENTATION: How would you rate your…?

<table>
<thead>
<tr>
<th>How would you rate your…?</th>
<th>Poor</th>
<th>Fair</th>
<th>Neutral, Unsure</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of community resources for families of teens/young adults with special health care needs and disabilities</td>
<td></td>
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<tr>
<td>Understanding of family-centered care</td>
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<tr>
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<tr>
<td>Understanding of concepts of cultural competence</td>
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<tr>
<td>Ability to work with diverse families in culturally competent care</td>
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<tr>
<td>Understanding of issues related to teens/young adults with special health care needs’ transition to adult care</td>
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<td>Ability to work with transition-age youth</td>
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</tbody>
</table>

B. ORIENTATION: Did the orientation session…?

<table>
<thead>
<tr>
<th>Did the orientation session…?</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral, Unsure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide useful information about the principle of medical home and key concepts of family-centered care</td>
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<tr>
<td>Demonstrate the importance of professionals’ involvement, promotion, and facilitation of family-centered care</td>
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<tr>
<td>Prepare you for a family visit</td>
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</table>

Suggestions to improve orientation:

__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
### C. FAMILY VISIT: Did the family visit…?

<table>
<thead>
<tr>
<th>Provide a more in-depth understanding for daily life for teens/young adults with special health care needs and their families</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral, Unsure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reinforce the need to have teens/young adults (and their families) involved in health care decision-making</td>
<td></td>
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<tr>
<td>Provide an overall worthwhile experience</td>
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Suggestions to improve the family visit:

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

### D. PROCESSING: Did the processing session…?

<table>
<thead>
<tr>
<th>Provide an opportunity to discuss and reflect on experiences from the family visit</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral, Unsure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help connect the family visit experience and the concepts discussed during the orientation session</td>
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</table>

Suggestions to improve the family visit:

__________________________________________________________________________________________

__________________________________________________________________________________________

### E. OVERALL PROGRAM EFFECTIVENESS

a. Did the program increase:
   i. Your understanding of family-centered care concepts and the medical home principle? ___Yes ___No
   ii. Your skills of working with families? ___Yes ___No
   iii. Your knowledge of community resources for families? ___Yes ___No
   iv. Your skills of working with transition-age youth? ___Yes ___No

b. Did the program change your ideas about children and youth with special health care needs or disabilities and their families? ___Yes ___No

c. Do you now feel prepared to better incorporated families in decision-making and work with them as a team to determine treatment and care? ___Yes ___No
F. POST-ORIENTATION: How would you rate your…?

<table>
<thead>
<tr>
<th>Knowledge of community resources for families of children and youth with special health care needs and disabilities</th>
<th>Poor</th>
<th>Fair</th>
<th>Neutral, Unsure</th>
<th>Good</th>
<th>Excellent</th>
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<tr>
<td>Understanding of medical home</td>
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</tbody>
</table>

G. OVERALL PROGRAM SATISFACTION

a. Was there sufficient time for:
   i. Orientation session? ___Yes ___No
   ii. Family visit? ___Yes ___No
   iii. Processing session ___Yes ___No

b. Was the video helpful and informational? ___Yes ___No ___Not applicable

Suggestions to improve the PRTP program: ____________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

What additional information or training would you like to have relating to working with families? ____________
__________________________________________________________________________________________
__________________________________________________________________________________________

THANK YOU FOR COMPLETING THIS EVALUATION!

Please return to: PRTP Coordinator – PACER Center
8161 Normandale Blvd., Minneapolis, MN 55437
e-mail: pacer@pacer.org
Parent Match Letter

Dear Parent,

Thank you for agreeing to meet with a resident this month; Dr. ___________, who is a resident, should be contacting you soon to schedule the visit. I will pass along your e-mail address and phone number. Attached is the survey and stipend form for you to complete after the visit. Feel free to e-mail or mail them back to me at your earliest convenience.

The resident should be asking about your perspectives on family-centered care, medical home, and what’s working or not working with a focus on transitioning from pediatric to adult systems of care. They may also cover other areas of transition, such as housing, plans for after high school, personal care, guardianship, self-care, and communications.

The following are sample questions the resident might ask (or areas that you might consider discussing with him or her):

- Has your pediatrician or primary care provider talked to you about the transition to adult providers?
- Do you see a specific transition process in place at your clinic?
- Do you have the information and resources you need for transition to the adult system of care and community supports?
- What concerns do you have about the transition to adult health care and community independence?
- Who makes the decisions about your young adult’s health care and services, and how will this change as your son/daughter transitions to a more independent life?
- Do you feel that there are enough adult providers for both primary and specialty care to meet the needs in the community?
- What could doctors and clinic staff do that would be helpful in the transition?
- What other transition needs do you have, and how will these be met? Transportation? Housing? Financial? Guardianship?

Let me know if you have any trouble with scheduling or if you don’t hear from the resident in the next week. Thank you for taking time to meet with the resident!

Sincerely,

Pediatric Resident Training Program Coordinator
PACER Center
8161 Normandale Blvd.
Minneapolis, MN 55437
952.838.9000
952.838.0199 (fax)
e-mail: pacer@pacer.org
Parents as Teachers Program

On ___________________, a pediatric resident visited my home as part of the Parents as Teachers Program for University of Minnesota residents-in-training. The home visit was part of the resident’s rotation in:

- [ ] Adolescent Medicine
- [ ] Developmental-Behavioral Pediatrics

I understand that a stipend of $50 will be paid to me.

Signature ___________________________ Date ___________________________

For office use only

Invoice received: ___________________________ PDF created/sent: ___________________________

OK to pay this invoice.

Signature ___________________________ Date ___________________________

Please return to: Pediatric Resident Training Program Coordinator
PACER Center, 8161 Normandale Blvd., Minneapolis, MN 55437
Tel: 952-838-9000  e-mail: pacer@pacer.org
Parent Survey

Please return the completed survey to:

Pediatric Resident Training Program Coordinator
PACER Center, 8161 Normandale Blvd., Minneapolis MN 55437
Tel: (952) 838-9000    Fax: (952) 838-0199    e-mail: pacer@pacer.org

Your name: ___________________________________________    Visit date ____________________________

Name of the resident who visited you: ____________________________________________________________

Please mark an “X” in the box that best describes the visit you had with the resident. If the comment does not apply to your circumstances, put an “X” in the column headed “NA.”

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>The resident was polite, respectful, and professional.</td>
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<tr>
<td>The resident interacted with my transition-age youth.</td>
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<tr>
<td>This experience improved my understanding of a family/professional partnership.</td>
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<tr>
<td>This was a worthwhile experience.</td>
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</tbody>
</table>

What did the resident do on the visit?
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________

Please summarize what you think the resident learned from the visit.
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________
_________________________________________________________________________________________

THANK YOU for your valuable contributions!
We appreciate your generosity in opening your home and giving your time for this important experience. If you have any questions or additional comments, please contact PRTP coordinator at (952) 838-9000.
Parents As Teachers Training Curriculum

Parents as Teachers
Pediatric Resident Training Program

PACER’s Family-to-Family Health Information Center

Agenda

• Pediatric Resident Training Program History and Goals
• Information about the Residents
• Ground Rules
• Home visit
• What’s next?
• Questions
Parents As Teachers History

• PACER Center: Parent Training and Information Center for 35 years
• Collaboration with University of Minnesota’s Pediatric Resident Training Program for more than 20 years
• Expanded in 2011: Increased focus on Transition from Pediatric to Adult Health Care and Cultural Diversity

PAT Goals

Pediatric Residents will gain insight on:
• How child accesses community resources and family activities
• Adaptations to family environment for child
• Managing health care in home setting
• How providers can be more supportive of family needs
The Residents

- Completed medical school
- Chosen specialty (Pediatrics or Med-Peds)
- 1st to 3rd year of Residency: Adolescent Medicine Rotation

PAT Ground Rules

- Give examples of family/child’s experience with medical providers
- Keep it non-specific
- Focus on your child with Special Health Care Needs
- Consider your family’s schedule
- Child, teen/young adult should be present at home visit
Home Visit Ideas

Look for activities that a Resident does not always see:
- Visit to the school, transition program, or work environment
- Community event
- Involve family or caregivers

Home Visit Ideas

Provide an opportunity for the Resident to engage with your child:
- Favorite activity
- Role model “Person First” Language
- Give insight into communication with your child
“What do we talk about?”

- Child’s strengths
- Challenges
- Family impact
- Diagnosis
- Medical experiences
- Community Systems

What’s next?

- Availability of family
- Evaluation and stipend forms
- Interpreter needs
- Questions or concerns:
  Contact PACER at (952)838-9000
Dear _________________,

It was a pleasure visiting with you Monday at the orientation session.

You have been assigned to visit___________________ and her son/daughter ________________. You can reach _______________ by phone at ________________. Her e-mail address is _______________. Please try to contact her as early in the rotation as possible to set up the visit.

Please talk with _______________ about her perspectives on family-centered care and medical home. During this visit, try to find out what she is considering for the future of health care, community integration, and supports for her son/daughter and see if transition from pediatric to adult systems of care has been considered, or what information they will need to help with a transition.

We’ve created sample questions you can use. Please take some time to develop others, as well.

- Has your pediatrician or primary care provider talked to you about the transition to adult providers?
- Do you see a specific transition process in place at your clinic?
- Do you have the information and resources you need for transition to the adult system of care and community supports?
- What concerns do you have about the transition to adult health care and community independence?
- Who makes the decisions about your young adult's health care and services, and how will this change as your son/daughter transitions to a more independent life?
- Do you feel that there are enough adult providers for both primary and specialty care to meet the needs in the community?
- What could doctors and clinic staff do that would be helpful in the transition?
- What other transition needs do you have, and how will these be met? Transportation? Housing? Financial? Guardianship?

Let me know if you have any questions or have trouble with scheduling. I will see you again on _______________ at PACER Center to discuss the family visit experience. For directions to PACER visit PACER.org/directions.asp

Thank you for your efforts!

Pediatric Resident Training Program Coordinator
PACER Center
8161 Normandale Blvd.
Minneapolis, MN 55437
952.838.9000
952.838.0199 (fax)
e-mail: pacer@pacer.org
6-Month Follow-up Survey for Parents

1. Prior to hosting your first visit with a resident, you participated in training with PACER staff regarding the Pediatric Resident Training Program (PRTP). How helpful was your training experience?
   - Helpful and relevant to prepare you for the resident visit
   - Somewhat helpful and relevant to the resident visit
   - Not helpful to the resident visit
   - Other (please specify)

2. What information could be added to the parent training that would help the Pediatric Resident Training Program prepare future families for their first resident visit?

3. Has the training and opportunity to work with residents through the Pediatric Resident Training Program impacted your ability to advocate for your child with his/her health care providers?
   - Yes
   - Yes, somewhat
   - No
   - Not sure
   - Other (please specify)

4. Has your involvement in the Pediatric Resident Training Program increased your understanding of the importance of families partnering with professionals to improve health outcomes for children and youth with special health care needs?
   - Increased significantly
   - Increased somewhat
   - Stayed about the same
   - Not sure/need more information

5. Since becoming involved with the Pediatric Resident Training Program, how has the ability to partner with your child's health care team changed?
   - Improved significantly
   - Improved somewhat
   - Stayed about the same
   - Not sure/need more information

6. If appropriate, has your son/daughter with special health care needs become more involved in his/her health care visits since becoming involved with Pediatric Resident Training Program?
   - Yes, significantly more involved
   - Yes, somewhat more involved
   - No, involvement has stayed the same
   - Not sure
   - Not applicable

7. Is there any other information that would be helpful for us to know?

Thank you for taking the survey. We appreciate your time and involvement in the Pediatric Resident Training Program.
Agenda: Pediatric Resident Training Program (PRTP) Orientation

Introductions of Participants
- Residents and staff
- PACER: www.pacer.org
- Family-to-Family Health Information Center

History of Pediatric Resident Training Program

Goals of Pediatric Resident Training Program (PRTP) and Today’s Agenda:
1. Review concepts of family-centered care, medical home, and community resources to support children and youth with special health care needs and/or disabilities
2. Increase understanding, skills, and cultural competence for working with diverse families and youth
3. Increase knowledge of community resources to support transition from pediatric to adult systems of care

Review Concepts: (See page 17 for definitions)
- Children and Youth with Special Health Care Needs (CYSHCN)
- Family-Centered Care
- Medical Home
- Community resources

Three Transition Planning Areas:
1. Pediatric to adult health care system
   - Individual goals: short-term and long-term
   - Self-advocacy
   - Emotional needs
   - Remember, all youth have these health needs to consider:
     - Nutrition
     - Hygiene
     - Exercise
     - Substance abuse
     - Safety and risk-taking behaviors
     - Reproductive education
     - Sexuality
   - Health care financing
   - Transfer as an integrated process/plan
   - Changes that occur during transfer from pediatric to adult health care system
   - Checklist for transition readiness
2. School to post-secondary education and work
   - Areas of interest after graduating high school:
     - Post-secondary education (e.g., university, community college, vocational training, transition program)
o Vocational rehabilitation
o County supported employment through Medical Assistance
o Day program
• Transition planning in the IEP process

3. Dependence on family to independence and community living
   Coordinating youth, family, and provider responsibilities:
   • Accessing services
   • Housing
   • Transition to in-home care staff
   • Transportation
   • Decision making (e.g., guardianship, consent, etc.)
   • Self-care and chronic condition management
   • Communication

Setting Up the Appointment:
• Call soon!
• Make sure you schedule enough time to talk with the family and youth, preferably together and separately
• Ask questions about their transition process: Have they discussed needed skills with IEP team? Do they have a medical home?
• Visit can take place at home or in the community
• Thank-you note

Family Visit:
• Sample questions?
• How does the family maximize the young adult’s independence?
• How is the transition process normalized for the family and young adult?

Questions? Please contact: Pediatric Resident Training Program Coordinator at PACER Center
   Tel: (952) 838-9000   e-mail: pacer@pacer.org

See you again at ____ (insert time) on ______ (insert date) for the processing session at PACER!
Agenda: Pediatric Resident Training Program (PRTP) Orientation

Introductions of Participants

- Residents and staff
- PACER (PACER.org): Minnesota and national parent center for parents of children and youth with all disabilities and special health care needs. PACER is also the National Bullying Prevention Center (PACER.org/bullying).
- Family-to-Family Health Information Center: Check out more information at PACER.org/health, a source for families of children and young adults with special health care needs and disabilities to obtain support, advocacy, and information about the health care system.

*Pre-assessment:* Include e-mails and name of family previously visited.

History of the Pediatric Resident Training Program

- Based on the Parents as Teachers (PAT) program at University of Minnesota in Developmental Behavioral Pediatrics (DBP) Rotation, which was started in 1990
- Families and youth share their knowledge, experience, and expertise with you.

Today's Orientation

- Next step: Connect you to the family to set up one or two visits during the next month
- After the visit: Residents meet with the Pediatric Resident Training Program Coordinator at PACER (and parents and/or youth if possible) to discuss what you have learned and how to incorporate it into your future work.

Goals of the Pediatric Resident Training Program and Today's Agenda:

1. Review concepts of family-centered care, medical home, and community resources to support children and youth with special health care needs and/or disabilities.
2. Increase understanding, skills, and cultural competence for working with diverse families and youth.
3. Increase knowledge of community resources to support transition from pediatric to adult systems of care.

Tell Me About:

**Children and Youth with Special Health Care Needs (CYSHCN):** Defined by the Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as: “Those who have, or are at increased risk for, a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

**Family-Centered Care:**

- Recognizes family as a constant influence
- Facilitates family/professional collaboration
- Honors racial and cultural diversity
- Recognizes family strengths and differences
- Understands methods of coping needed
- Supports family-to-family support networks
- Looks at entire child when supporting family
- Supports the emotional and financial needs of the family

**Medical Home:**
• Care coordination: In Minnesota it needs to be a certified medical home in order to bill for care coordination. Do you see care coordination in any of the medical settings you have worked in? Is it effective? Are there needs?
• Longer appointments may be needed to provide for family’s concerns or youth with special health care needs to address problems, bridge communication, etc.

A list of community resources to support children and youth with special health care needs and/or disabilities can be found PACER.org.

Three Transition Areas:

I. Pediatric to Adult Health Care System

1. Transition planning goals:
   • Take time to identify the short- and long-term goals toward independence and employment.
   • These may change as teen matures and learns more about his or her disability.
   • They may also shape the care coordination when the health care transition process begins.
   • Be respectful of cultural differences regarding transition.

2. Self-advocacy:
   There is an opportunity to help the individual build advocacy skills during each physician visit.
   • Does the individual know his or her diagnosis?
   • Can she eventually be responsible for her medications?
   • Is he able to advocate for and express his needs?
   • Will she be able to follow directions?
   • Does he need support?

3. Emotional needs:
   • Transition may be a time of realization and increasing awareness of a youth’s disability
   • There may be anxiety or grief as the family and youth realize that previous goals may not be met at this time.
   • In some cultures, family may choose to keep the individual with disabilities at home as part of the family and community

4. Remember, all youth have these health needs to consider:
   • Nutrition
   • Hygiene
   • Exercise
   • Substance abuse
   • Safety and risk-taking behaviors
   • Reproductive education
   • Sexuality
   • Some young adults will need extra supports in place to make good decisions.

5. Health care financing:
• Does the individual need to be removed from the family insurance? They are able to stay on parents’ insurance longer under the provisions of the Affordable Care Act.
• Are they eligible for adult Medical Assistance, based on disability and/or income?
• Will the young adult qualify for SSI at age 18 based on their resources and disability?
• Waivered services for housing?
• Other state-specific resources?

6. Transfer as an integrated plan
• Interview new adult providers with a support person.
• Maintain a link with pediatrician to answer questions or provide information; interim communication.
• Some adult care and some pediatric care to “tie up loose ends.”
• For some, transition may be more gradual, especially if multiple specialists are involved.

7. Changes that occur during transfer from pediatric to adult health care systems:
• What adult provider will deliver care for specialists that are unique to the pediatric care system (e.g., developmental behavioral pediatricians)?
• Will the individual attend appointments alone? If not, who will accompany him or her?
• How will information be communicated to medical personnel?
• How will information be implemented by the individual?
• How will compliance be ensured?
• How will the guardian or family be informed? How will they be impacted by letting go of this role?
• What is the role of technology?

8. Checklists for transition readiness (Got Transition: Parent and Teen; Spanish):
• Setting up appointments (give example where using IEP can be helpful)
• Insurance
• Medical history, one-page summary, medical binder
• Prescriptions
• May need to come back to items
• Start early to decrease “cliff” or surprise
• Consider additions to IEP team discussions or look for community ed/other opportunities

II. School to Post-Secondary Education and Work:
This section looks at the individual’s abilities, goals, and future plans once they have graduated from high school, and explores how he or she will achieve those goals.

1. What is the youth’s level of functioning, and what activities does he or she want to participate in?
   a. Post-secondary education: Is the individual interested in pursuing further education? In what setting? With what supports?
      • How are the individual’s organizational skills?
      • Are there disability services available on campus?
      • Will the student be able to order their meds? Use an insurance card? Make insurance co-pays? Make and keep follow-up appointments?
• Is there a role for technology to assist with any of the above skills and compliance?
• Who will be the support staff and emergency contacts if there is a problem, medical or otherwise?

b. Will the young adult pursue further education, such as community college, a job training program, or training for a technical certificate?

c. Will the youth be able to work, and at what type of job, for how many hours, and with what kind of support?
   • Is she eligible for vocational rehabilitation and county supported employment through Medical Assistance?
   • Will he need a job coach?
   • How many hours will she be able to work? What degree of support will be needed?

d. Will he be interested in a day program?

2. Transition planning in the IEP process: What prior planning does the IEP team need to do to prepare student for the next setting, such as organizational skills, making appointments, and necessary reminders?

III. Dependence on Family to Independence and Community Living:

Coordinating youth, family, and provider responsibilities

A. Accessing services: Until age 18, family members and other adults have located information and services for their young child with special needs.
   • As an adult, who will be responsible for arranging the individual's care?
   • What responsibilities will the young adult have, and what will be done by someone else?
   • Who will identify community resources such as Parent Training Centers, Independent Living Centers, and Family-to-Family Health Information Centers?

B. Housing: Where will the young adult live?
   • What are the youth's goals and attitudes toward future housing?
   • Is the family proactively developing a plan for future housing needs?
   • Some families will choose to keep their adult child at home with them for a period of time, or until they are no longer able to care for them.
   • Are there group homes or more individualized settings, such as adapted apartments, available in the community?
   • Housing needs to be customized to fit the individual's needs for the least restrictive environment, including physical accommodations such as lower counters and other modifications.

C. Transition to new home care staff:
   • Will the young adult need personal care attendants, interveners, service support professionals (SSP), or nursing staff to provide support for independent living?
   • Can support staff assist with cooking, personal care, budgeting, or money management to facilitate transition from dependence on family members to more independence?

D. Transportation:
   • Can the individual drive?
   • Do they need an assessment to determine if their ability allows them to operate a car safely, with or
without adaptations?

- Can they use public transportation?
- Are they eligible for adapted mobility services?
- How will they get to appointments? Place of employment? Community activities?

E. Decision making:

- Up to age 18, the individual’s parents or guardian makes all decisions of consequence.
- After age 18, the individual will need to sign a consent form to release information, if a court-appointed guardian is not in place
- Will the individual be able to make medical, financial or legal decisions independently, or does the family need to obtain legal guardianship prior to his or her 18th birthday?
- Similar decisions need to be made regarding conservatorship, power of attorney, and advance directives.

F. Self-care and chronic condition management: What skills does the individual need to have, and what is he or she able to do?

- Can he or she perform basic daily activities such as dressing, grooming, and feeding?
- Does she know how to cook, clean, and do laundry?
- Is she capable of managing her finances?
- Can he comply with his medication regimen?
- Can she make and keep appointments?

G. Communications: How effectively is the individual with disabilities able to communicate his or her needs and have them met?

- Is the teen able to express his or her desire for more independence and feelings about the changes in family dynamics that are taking place?
- Is there a support network for the individual and/or parents?
- Is referral to a counselor or therapist appropriate?
- Is there assistive technology that will enable the young adult to communicate more effectively, or function more independently?

Setting up the appointment:

- Call soon.
- Make sure you schedule enough time to talk with the family and youth, preferably together and separately.
- Ask questions about their transition process: Did they discuss needed skills with IEP team? Do they have a medical home?
- You can visit them at home or in the community.
- Thank-you note.

Family visit:

- Sample questions in the binder.
- How does the family maximize the young adult’s independence?
- How was the transition process normalized for the family and young adult?
Questions? Please contact the PRTP Coordinator at PACER Center
Tel: (952) 838-9000 e-mail:pacer@pacer.org

See you again at ____ (insert time) on ______ (insert date) at PACER!
Agenda: Pediatric Resident Training Program (PRTP) Orientation

Introductions of Participants
- Residents and staff
- PACER: www.pacer.org
- Family-to-Family Health Information Center

History of the Parents as Teachers Pediatric Resident Training Program

Goals of the Pediatric Resident Training Program and Today’s Agenda:
1. Review concepts of family-centered care, medical home, and community resources to support children and youth with special health care needs and/or disabilities.
2. Increase understanding, skills, and cultural competence for working with diverse families and youth.
3. Increase knowledge of community resources to support transition from pediatric to adult systems of care.

Definitions: (See page 17 for definitions)
- Children and Youth with Special Health Care Needs (CYSHCN)
- Family-Centered Care
- Medical Home

Transition can be divided into three major areas:

I. Transition from pediatric to adult health care systems
II. Transition from school to post-secondary education and work
III. Transition from home to independence in the community

I. Transition from pediatric to adult health care systems:

1. Transition goals: It is essential to identify the short- and long-term goals toward healthy living, independence, and employment
2. Self-advocacy: Typical teens, as well as children and youth with special health care needs, display a wide range of abilities related to self-advocacy. There is an opportunity to build advocacy skills at each clinic visit, empowering the youth to be more involved and increasing the opportunity to acquire more comprehensive skills.
3. Addressing emotional needs: Transition is a time of realization and increasing awareness of a youth’s disability. Those with special health care needs, like their typically developing counterparts, may start to see themselves as adults and want to participate in conversations with their physician, and feel that they are part of the decision-making process.
4. Addressing basic health care needs: All teens, including those with special health care needs, have basic health needs to consider, including nutrition, hygiene, exercise, substance abuse, safety, risk-taking behaviors, reproductive education, and sexuality. Some young adults will need extra supports in place to make good decisions and master these skills.
5. Organizational skills needed for success: Identify skills that the parent and youth can embed into the Individualized Education Program (IEP). IEP transition goals can be connected to medical transition needs.
6. Ensuring compliance: The cornerstone to successful transition for many youth with special health care needs/disabilities will be based on compliance with their medication regimen.
7. **Health care financing:** There are a number of resources available to youth with special health care needs to cover their health care related expenses, but they must apply for these resources by contacting their city, county, or state disability services office.

8. **Transferring care:** The transfer should occur as an integrated plan and be as seamless as possible. There are some changes that occur during transfer from pediatric to adult health care systems.

9. **Develop a transition health plan:** Set up an action plan with the family and youth for acquiring needed skills. Here are some assessment tools to help determine what skills the individual needs and can realistically accomplish through the IEP or at each doctor visit.

   *(Resident handout, See Appendix 10, 11, 12)*

### II. Transition from school to post-secondary education and work

1. What is the youth's interest and level of function, and in what kind of activities does he or she want to participate?
   - Post-secondary education: Is the individual interested in pursuing further education or vocational training? In what setting? With what supports?
   - Will the young adult pursue further education, such as community college, a job training program, or training for a technical certificate?
   - Will the individual be able to work? At what kind of job, for how many hours, and with what support?
   - Will he or she be interested in a day program?

2. Transition planning in the IEP process: How can the IEP team prepare the student for the next setting? Talk to the family about working with the school and incorporating various goals within the IEP. Each subsection identified in this document allows for opportunities to develop IEP goals. For example:
   - Organizational skills:
     - Does the individual know how to sort or file?
     - Is she able to plan ahead?
       Can he sequence several steps to complete a process, such as planning a meal, obtaining prescription refills, or scheduling and arriving on time for an appointment?
   - Identifying emotions:
     - Can the youth recognize her feelings, such as happiness, sadness, anger, and frustration?
     - Does he have a plan for how to cope with different feelings in various settings?
   - Using assistive technology:
     - Can the youth keep a calendar?
     - Does she know how to schedule an appointment?
     - Does he understand safety issues when using the Internet?
     - Is there assistive technology available to meet his specific needs?
   - Transportation:
     - Is driver’s education appropriate?
     - If public transportation is needed, does the youth need to learn how to read a map, navigate different neighborhoods, and understand transit schedules?
• Job applications:
  o Does the individual know the basic information to complete a job application?
  o Does she need practice with job interviews?
  o Is she able to articulate her strengths and weaknesses appropriately?
• Work skills
  o Does the youth understand how to dress appropriately for work?
  o Does he know appropriate subjects to discuss at work?
  o Does she understand what language is appropriate or inappropriate at work?
  o Is he clear about work ethic and what it means to do a good job?
  o Does she understand the role of a supervisor or manager and how that will impact her as an employee?
• Money management and budgeting:
  o Can the youth count money?
  o Can he make appropriate change?
  o Does she know how to write a check?
  o Can he make a budget?
• Cooking and cleaning:
  o Does the youth understand what constitutes good nutrition?
  o Can he read a recipe or find one online?
  o Can she make a grocery list?
  o Does he know how to shop for ingredients?
  o Can she follow basic cooking instructions?

III. Transition from home to independence within the community

1. Accessing services: Until age 18, family members and others have located information and services for the individual with special needs.
2. Housing: Where will the young adult live?
3. Transition to new in-home care staff: There are a number of services available to support individuals with special health care needs and disabilities.
4. Transportation: In order to get to appointments, work, community activities, or family events, youth and adults with special health care needs and disabilities will need to have a plan for transportation.
5. Decision making: Until age 18, the individual's parents or guardian makes all decisions of consequence for teenagers. Once an individual turns 18, they are legally considered an adult, and if they are unable to make reasonable decisions, measures must be taken to protect them.
6. Health care financing: There are a number of resources available to youth with special health care needs to cover their health care related expenses, but they must apply for these resources by contacting their county disability service office.
7. Self-care and chronic condition management: What skills are needed and what is the individual capable of doing?
8. Communications: How effectively is the individual with disabilities able to communicate his or her needs
and have them met?

**Setting up the Appointment:**
- Call soon!
- Make sure you schedule enough time to talk with the family and youth, preferably together and separately.
- Ask questions about their transition process: Did they discuss needed skills with IEP team? Do they see a physician in a medical home? What plans do they have to transition to adult medical care?
- You can visit the family in their home or in the community.
- Thank-you note.

**Family Visit:**
- Sample questions
- How does the family maximize the young adult’s independence?
- How is the transition process normalized for the family and young adult?

Questions? Please contact: Pediatric Resident Training Program Coordinator at PACER Center
Tel: (952) 838-9000; e-mail: pacer@pacer.org

See you again at _____ (insert time) on ______ (insert date) for the processing session at PACER!
Agenda: Pediatric Resident Training Program (PRTP) Orientation

Introductions of Participants
- Residents and staff
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History of the Pediatric Resident Training Program

Goals of the Pediatric Resident Training Program and Today’s Agenda:
1. Review concepts of family-centered care, medical home, and community resources to support children and youth with special health care needs and/or disabilities.
2. Increase understanding, skills, and cultural competence for working with diverse families and youth.
3. Increase knowledge of community resources to support transition from pediatric to adult systems of care.

Review Concepts:
- Children and Youth with Special Health Care Needs (CYSHCN)
- Family-Centered Care
- Medical Home
- Community resources

Definitions:

Children and Youth with Special Health Care Needs: The Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) defines as, “those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

Family- and Patient-Centered Care: The National Center for Family Professional Partnerships indicates, “Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services.”

The Institute for Family-Centered Care defines family-centered care as: “Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care. Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them. Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and day-to-day staff interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.”

Medical Home: According to the National Center for Medical Home Implementation, “A family-centered medical home is not a building, house, hospital, or home health care service, but rather an approach to providing comprehensive primary care. In a family-centered medical home the pediatric care team works in partnership with a child and a child’s family to assure that all of the medical and non-medical needs of the patient are met. Through this partnership the pediatric care team can help the family/patient access, coordinate, and understand specialty care, educational services, out-of-home care, family support, and other public and private community
services that are important for the overall health of the child and family.”

What is Transition?

Transition is a process that occurs as teens develop and become young adults and learn to function more independently. It is a time of realizing potential, developing a sense of self, and functioning more autonomously. Transition can be difficult. Youth with special health care needs (YSHCN), including those with disabilities, can find this time challenging. Many transition areas will require learning of new skills that will take time, practice, and adaptations to be accomplished.

Transition planning for these youth requires planning, and will evolve and may change over time. Some articles recommend that the process begin as early as age 12, but clearly by 14. Skills such as organization, self-advocacy, learning about one's disability, and addressing the many areas of life where assistance might be needed takes time to develop. Transition can be divided into three major areas:

I. Transition from pediatric health care to adult providers
II. High school to post-secondary education or employment
III. Transition from home to more independence in the community

I. Transfer from pediatric health care to adult providers

A young person’s health is critical to his or her overall well-being. Good health is crucial for individuals to be successful at home, work, school, and in the community. For individuals with disabilities, transition planning may involve understanding how to manage their underlying chronic health, have the ability to recognize and address issues related to an acute illness, and develop a healthy lifestyle. To ensure a successful transition, youth with special health care needs have to secure accommodations or needed supports that will enable them to be successful.

1. Transition planning goals: It is important to identify the short- and long-term goals that lead to healthy living, independence, and employment. These may change as the teen matures and learns more about the potential long-term impact of his or her disability. An individual’s goals may shape care coordination when the health care transition process begins. When setting goals, it is also important to consider the cultural and racial needs of individuals with diverse backgrounds.

Areas of specific goals physicians can discuss with parents and youth:

- Will she be able to take care of herself or have her health care needs met?
- Where does the youth plan to live?
- Will she pursue additional education, or want to work after high school?
- What are his interests? How will these be incorporated into his life?
- Can he learn to advocate for himself?
- What kinds of supports will be needed?

2. Self-advocacy: Youth with special health care needs display a wide range of abilities related to self-advocacy. Each clinic visit offers an opportunity to build advocacy skills, empowering the youth to be more involved in transition and increasing the opportunity to gain more skills. The following list offers suggestions of where to start the process of addressing each teen’s skills, and building on their knowledge and ability to self-advocate.

More information for professionals and parents:

- Does the individual know his or her diagnosis?
• Can the young adult describe his or her disability?
• Is the young adult able to express her needs and advocate for herself?
• Is the individual able to understand her physician's instructions?
• Can he be responsible for his own medications?
• Can he follow directions on a medication label?
• Does she know the names of her medications?
• Does he know the side effects of his medications?
• Is she able to understand the importance of medication compliance?
• Would it be beneficial for the youth to have a medical binder, portable medical summary, or one-page summary outlining his or her disability and special health care needs and how these may impact behavior?
• Is there a role for assistive technology to help with tasks such as scheduling, reminders, and contact information?

3. Addressing emotional needs: Transition is a time for some young adults that may include increasing awareness of their disability. Youth, including those with disability, begin seeing themselves as adults. They want to participate in conversations with their physician, and should be part of the decision-making process.

   Information for physicians:
   • While some meet various goals, youth with special health care needs and his or her family may be experiencing concerns or anxiety as they recognize that some of their goals may not be possible at this particular time. This may include the desire to obtain a driver's license, or the goal of being able to live independently.
   • Consider referral to a counselor, therapist or diagnosis-specific support group if appropriate.
   • It is helpful to know what resources are available in the community to support both parents and youth as they start the process of transition. This may include respite care for the parents or personal care attendants (PCA) services for the youth.
   • In some cultures, there is no transition into the larger community as the individual with disabilities or special health care needs is expected to remain with his or her family.

4. Addressing basic health care needs: All youth, including those with special health care needs, have basic health needs to consider including nutrition, hygiene, exercise, substance abuse, safety, risk-taking behaviors, reproductive education, and sexuality. Some young adults will need extra supports in place to make good decisions and master these skills.

5. Organizational skills needed for success: Identify skills that the parent and youth can embed into the Individualized Education Program (IEP). Transition goals on the IEP can be connected to medical transition needs. Revisit those transition areas where additional practice is necessary to ensure competency. Start the transition process early to allow plenty of time for the youth to develop effective skills.

   Potential IEP objectives/goals:
   • Does the youth know how to keep a calendar? Can he follow it?
   • Does he know how to make an appointment and the importance of being on time?
   • Can the school nurse be a resource to teach the youth about their specific medications, including the drug names, indications, dosage, and possible side-effects?
• Can the youth explain basic insurance principles such as deductibles and co-pays? Does he know how much money he will need to pay at the time of the medical appointment?
• Does she understand why she needs to carry an insurance card, and when it will be needed?
• Does the youth know how to have a prescription filled, when and how to order refills, and how to pay for the medications?

6. Ensuring compliance: Compliance with medication is often the cornerstone to successful transition for many youth with special health care needs or disabilities. It is important to answer these questions:

   Considerations for professionals and families:
   • Does he have reasonable organizational skills?
   • Who will be responsible for administering medications?
   • Will she need help managing her medication, or will she be able to be independent by using helpful tools such as a daily pill organizer?
   • Can she be trusted to take her medication?
   • Does the young adult understand the importance of staying on his or her medication?
   • Is there technology available that can remind him to take his medications?
   • What supports have been put in place? Are additional supports needed?

7. Health care financing: There are a number of resources available to youth with special health care needs to cover their health care-related expenses. Families or guardians need to contact their city, county, or state disability service office to apply.

   Information for physicians to share with families:
   • Does the individual need to continue on the family’s insurance plan?
     o The Affordable Care Act enables individuals to remain on their parent’s health insurance plan until age 26.
     o Some plans allow adult children with disabilities and/or special health care needs to stay on their parents’ plan for life.
   • Is the individual eligible for adult Medical Assistance, based on disability or income?
   • After age 18, will the young adult qualify for Social Security based on her resources and/or disability?
   • Does he qualify for waivered services for housing?
   • Are there other state-specific resources available?

8. Transferring care: The transfer should occur as an integrated plan, and be as seamless as possible. There are some changes that occur during transfer from pediatric to adult health care systems:

   A. The process of transferring from pediatric to adult health care:

      Suggestions for pediatric physicians to discuss with families:
      • Interview new adult providers with a support person, such as a parent, guardian, or caregiver.
      • Maintain a link with the pediatrician to answer questions or provide information; plan on some interim communication.
      • Plan for the possibility of overlapping adult and pediatric care, especially if multiple specialists are involved.
      • Understand that for some youth, the transition may be a more gradual process.
B. Changes that occur during transfer from pediatric to adult health care systems:

**Considerations for professionals and families:**

- What adult provider will cover specialty care for specialists that are unique to the pediatric care system (e.g., developmental behavioral pediatricians)? Will the youth attend appointments alone? If not, who will accompany him?
- How will information be communicated to medical personnel?
- How will information be implemented by the youth?
- How will compliance be ensured?
- How will the guardian or family be informed? How will the family be impacted by no longer having the primary role in this process?
- Is there a role for technology in this process?
- Would it be useful for the family to develop a one-page summary or medical binder?

**9. Developing a transition health plan:** Set up an action plan with the family and the youth for acquiring needed skills. Here are some assessment tools to determine what skills the individual needs and can realistically accomplish through the IEP or at each doctor visit.

(_Distribute checklists, Appendix 10, 11, 12_)

**10. Additional resources:** For additional resources, please visit PACER.org/health.

II. Transition from high school to post-secondary education or employment

After leaving high school, young adults, including those with special health care needs and disabilities, take a variety of paths toward further education or work experiences depending on their interests and abilities. Some may have the abilities needed to pursue higher education but will need physical accommodations.

1. **What is the youth's interest and level of functioning, and what kind of activities are they able to participate in?**
   a) Post-secondary education: Is the individual interested in pursuing post-secondary education? In what setting, and with what supports?

   **Considerations for college-bound students:**
   - Does the individual have good organizational skills?
   - Are there disability services available on campus?
   - Will the student be able to order his medications? Will he carry an insurance card? Can he make insurance copays? Will he make and keep appointments?
   - Is there technology available to help the youth develop organizational skills to ensure medical compliance?
   - Who is the support staff and emergency contacts if case of a medical or other problem?

b) Will the young adult pursue further education, such as community college, a job training program, or training for a technical certificate?

c) Will the individual be able to work? What kind of job might he be able to do, for how many hours, and with what supports?

**Work supports/options:**
- Is she eligible for vocational rehabilitation services or supported employment through Medicaid?
Will he need a job coach?
How many hours will she be able to work, and what degree of support will be needed?

d) Is a day program a good resource?

2. Transition planning in the Individualized Education Program process: How can the IEP team prepare the student for further education or work? The family should work with the school, and incorporate various goals within the IEP. Each subsection in this document allows for opportunities to develop IEP goals.

Examples of IEP considerations:

Organizational skills:
- Does the individual know how to sort or file documents?
- Is she able to plan ahead? For example, when completing a process such as planning a meal, refilling a prescription, or scheduling an appointment, can she organize the steps in a logical order?

Identifying emotions:
- Can the youth recognize her feelings such as happiness, sadness, anger, or frustration?
- Does he have a plan to cope with different feelings in various settings?

Using assistive technology:
- Can the youth accurately keep a calendar?
- Does she know how to schedule an appointment?
- Does he understand the safety issues associated with using the Internet?
- Are there specific devices available to meet his or her individual needs?

Transportation:
- Is driver’s education appropriate?
- If the youth needs to learn how to use public transportation, does he or she also need to learn how to read a map, navigate unfamiliar neighborhoods, and understand transit schedules?
- Is the youth able to be safe when using public transportation?

Job applications:
- Does the individual know the basic information to complete a job application?
- Does she need practice with job interviews?
- Is she able to articulate her strengths and weaknesses appropriately?

Work skills:
- Does the youth understand how to dress appropriately for work?
- Does he know appropriate subjects to discuss at work?
- Does she understand what language is appropriate or inappropriate at work?
- Is he clear about work ethic and what it means to do a good job?
- Does she understand the role of a supervisor or manager and how that will impact her as an employee?

Money management/budgeting:
- Can the youth accurately count money?
- Can she make appropriate change?
- Does she know how to write a check or use a debit card?
- Can he develop a realistic household budget?

Cooking and cleaning:
- Does the youth know what constitutes good nutrition?
- Can he read a recipe or find one online?
- Can she make a grocery list?
- Can he know how to shop for ingredients?
- Can she follow basic cooking instructions?
- Does the youth know how to safely operate home equipment such as a vacuum cleaner or stove?
- Does she know how to safely use common household cleaners?

III. Transition plan from home to more independence within the community

The issue of adolescence for all teens and young adults is the transition to interdependence, learning to take care of themselves, and functioning as a contributing member of their community. At this age, some youth with special health care needs and disabilities may not have mastered all of the basic skills of daily hygiene, or may be physically unable to perform tasks without assistance. Additional supports in housing, transportation, decision making, and financial management may be needed in order for the individual to be successful.

1. Accessing services: Until age 18, family members and others have located information and services for their young child with special needs. How will that change? As youth and young adults begin to plan further transition, these expectations of families may change.

   Questions for physicians to pose to families:
   - Who will be responsible for arranging the youth's care?
   - What responsibilities will he or she have? What will need to be done by someone else?
   - Who will identify community resources such as: Family-to-Family Health Information Centers, Parent Training and Information Centers, and Independent Living Centers?

2. Housing: Where will the young adult live? Housing is one of the most challenging aspects of the transition process for youth and their families.

   Topics for physicians to discuss with families:
   - What are the youth's goals and attitudes towards future housing?
   - Is the family proactively developing a plan for future housing needs?
   - Does the family have a case manager, or do they need to call state or county disability services to arrange for a case worker to assist them?
   - Will the family choose to keep their adult child at home for a period of time, or until they are no longer able to care for them?
   - Are group homes and more individualized settings (e.g., adapted apartments) available in the community?
   - How does housing need to be customized to fit the individual's needs for the least-restrictive environment, including physical accommodations and other modifications?

3. Transition to new in-home care staff: There are a number of services available to support individuals with special health care needs and disabilities.
Types of staff available to families:
- Personal care attendants (PCA), service support professionals (SSP), and nursing staff provide a variety of support for independent living and can serve different functions.
- Support staff for supports such as cooking, personal care, and budgeting or money management can assist with the transition from dependence on family members to more independence.

4. Transportation: In order to travel to appointments, work, community activities, or family events, youth and adults with special health care needs and disabilities will need to have a plan for transportation.

   Considerations for physicians and families:
   - What form of transportation will the youth be able to access?
     - Will he or she be able to drive? (Individuals may need an assessment to determine if their mental and physical capacity allows them to operate a car safely.)
     - Does he have a vehicle? Will he need adaptations to a vehicle?
     - Can he learn to use public transportation?
     - Is she eligible for adapted mobility services?

5. Decision making: Up to age 18, the individual's parents or guardian make virtually all of the important decisions. Once individuals turn 18, they are legally considered adults, and legal measures need to be taken to protect them if they are unable to make reasonable decisions on their own.

   Information for physicians to share with families:
   - Adults need to sign a consent to release information if a court-appointed guardian is not in place.
   - Will the individual be able to make sound medical, financial, or legal decisions independently or does the family need to obtain legal guardianship before the youth turns 18?
   - Similar decisions need to be made regarding conservatorship, power of attorney, and advance directives.

6. Self-care and chronic condition management: What skills does the individual need to have, and what is he or she able to do?

   Considerations for families:
   - Can he or she perform basic daily activities such as dressing, grooming, and feeding?
   - Does she know how to cook, clean, and do laundry?
   - Is she capable of managing her finances?
   - Can he comply with his medication regimen?
   - Can she make and keep appointments?

7. Communications: How effectively can the individual with disabilities or special health care needs communicate his or her needs and have them met?

   Considerations for physicians and families:
   - Is the teen able to appropriately express his desire for more independence, and his feelings about the changes in family dynamics that are occurring?
   - Is there a support network for the individual and/or parents?
   - Is there assistive technology that will enable the young adult to communicate more effectively, or function more independently?

Transition for youth with special health care needs can be a very positive experience as well as a challenging
process that requires the collaboration of medical providers, schools, and families. It is important for families to start the process when the youth is 12 to 14 years old, and identify short- and long-term goals. Progress toward these goals can be broken down into small steps and included in both the IEP and physician visits. The goals will likely be modified over time as the individual matures and becomes a young adult. The discussion points and checklists provided here are intended as a helpful starting point for physicians and families to assist teens and young adults as they transition into independent living.

**Setting Up the Appointment:**
- Call soon!
- Make sure you schedule enough time to talk with the family and youth, preferably together and separately.
- Ask questions about their transition process: Did they discuss needed skills with IEP team? Do they have a medical home?
- You can visit the family in their home or in the community.
- Thank-you note.

**Family Visit:**
- Sample questions:
  - How does the family maximize the young adult’s independence?
  - How is the transition process normalized for the family and young adult?

Questions? Please contact the Pediatric Resident Training Program Coordinator at PACER Center: Tel: 952-838-9000 e-mail: pacer@pacer.org

See you again at _____ (insert time) on ______ (insert date) for the processing session at PACER!
# Health Care Skills

<table>
<thead>
<tr>
<th>KEEPING MYSELF WELL</th>
<th>I do this on my own</th>
<th>I am part way there</th>
<th>I need to learn how to do this</th>
</tr>
</thead>
<tbody>
<tr>
<td>I manage my personal care (bathing, hair, getting dressed, etc.) on my own.</td>
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<tr>
<td>I brush and floss my teeth every day.</td>
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<tr>
<td>I get at least 8 hours of sleep every night, and I know that lack of sleep affects my appetite, weight, mood, and energy.</td>
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<tr>
<td>I eat healthy food.</td>
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<tr>
<td>I eat regular meals and healthy snacks.</td>
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<tr>
<td>I shop for groceries myself.</td>
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<tr>
<td>I prepare meals for myself.</td>
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<tr>
<td>I try to maintain a healthy weight.</td>
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<tr>
<td>I am an active person and exercise regularly for good health.</td>
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<tr>
<td>I join in community activities with family and friends.</td>
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<tr>
<td>I avoid risky behavior: illegal drugs, tobacco, alcohol, inhaled substances, and unsafe sex.</td>
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<tr>
<td>I have a plan to be safe if there is a natural disaster such as a tornado, earthquake, or flood.</td>
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<tr>
<td>I have a plan to find help and support if I need it.</td>
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</table>

<table>
<thead>
<tr>
<th>MY MEDICAL CARE</th>
<th>I do this on my own</th>
<th>I am part way there</th>
<th>I need to learn how to do this</th>
</tr>
</thead>
<tbody>
<tr>
<td>I keep the number of people to call in an emergency in my wallet or cell phone.</td>
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<tr>
<td>I have a doctor who takes care of me.</td>
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<tr>
<td>I know who my doctor will be when I am an adult.</td>
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<tr>
<td>I can get a ride or know how to take the bus to my medical appointments.</td>
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<tr>
<td>I get regular health check-ups and dental care.</td>
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<tr>
<td>I call or e-mail my doctor or dentist to schedule my medical appointments or talk to my doctor.</td>
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<tr>
<td>I use a calendar to keep track of my medical appointments.</td>
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<tr>
<td>I carry my important medical information (e.g. health insurance card) in my wallet or other handy place.</td>
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<tr>
<td>I keep a list of my allergies and reactions to medication.</td>
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<tr>
<td>I get regular flu shots and immunizations.</td>
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<tr>
<td>I keep a record of my immunizations.</td>
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<tr>
<td>MY MEDICAL CARE Continued</td>
<td>I do this on my own</td>
<td>I am part way there</td>
<td>I need to learn how to do this</td>
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<tr>
<td>--------------------------------------------------------------------------------------------</td>
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<tr>
<td>I have a medical alert bracelet (or another type of alert) so that people know about my life-threatening allergies or conditions.</td>
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<tr>
<td>I keep a list of questions for my doctors and other health care providers and ask these questions at my appointments.</td>
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<tr>
<td>I have a thermometer and know how to take my own body temperature.</td>
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<tr>
<td>I can tell what symptoms need urgent care and where to go if I need care.</td>
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<tr>
<td>I know how to get family planning information and birth control when I need it.</td>
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<tr>
<td>(For girls only) I keep a record of my periods.</td>
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<tr>
<td>(For girls only) I take care of my personal hygiene during my periods.</td>
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<tr>
<td>(For boys only) I know how to do a testicular self-exam.</td>
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<tr>
<td>I work with my family to be sure I have health insurance, or I know how to do that myself.</td>
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<tr>
<td>ABOUT MY HEALTH CONDITION OR DISABILITY</td>
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<tr>
<td>I can find information about my condition/disability either online or at the library.</td>
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<tr>
<td>I can describe my condition/disability to my friends or family.</td>
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<tr>
<td>I can describe my condition/disability to doctors I haven't met before.</td>
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<tr>
<td>I keep my Emergency Health Record up to date</td>
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<tr>
<td>I can describe how my condition/disability affects puberty and my sexual functioning.</td>
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<tr>
<td>I can explain what accommodations I need to work or be active in the community.</td>
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<tr>
<td>I know my medications, what they are for, when I am supposed to take them, and how much I am supposed to take. I keep this information with me or on ICE (In Case of Emergency at <a href="http://www.icesticker.com">www.icesticker.com</a>).</td>
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<tr>
<td>I can explain the side effects of my medications.</td>
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<tr>
<td>I take my medication without any help.</td>
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<tr>
<td>I know how to have a prescription filled and how to pay for my medications.</td>
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<tr>
<td>I take responsibility for doing my own treatments when the doctor asks me to (e.g. urinary catheter, asthma treatments, etc.)</td>
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<tr>
<td>I can ask for genetic counseling which is available for my condition/disability if I need it.</td>
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<tr>
<td>I can connect with advocacy and support organizations for my condition/disability.</td>
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</tbody>
</table>
### ABOUT MY HEALTH CONDITION OR DISABILITY Continued

<table>
<thead>
<tr>
<th>I do this on my own</th>
<th>I am part way there</th>
<th>I need to learn how to do this</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a health advocate and can work with him or her if I need to.</td>
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</tr>
<tr>
<td>I can decide if I need a Personal Care Assistant (PCA).</td>
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<tr>
<td>I can hire, manage, and fire my own PCA if needed.</td>
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<tr>
<td>I know how to arrange for repairs to my medical equipment (e.g. wheelchair).</td>
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</tbody>
</table>

### PREVENTING COMPLICATIONS OF MY CONDITION/DISABILITY

| I can describe common complications of my condition/disability and how to help prevent them. |                     |                               |
| I have a plan for how to manage stress and I know how to find help if I need it. |                     |                               |
| I can describe the risks and signs of anxiety and depression and know how to find help managing these conditions if I feel anxious or depressed. |                     |                               |
| I can describe how using alcohol or drugs that were not prescribed by my doctor can affect my condition/disability. |                     |                               |
| I can describe the additional problems that being underweight or overweight can cause for my condition or disability. |                     |                               |
| I know how to find information on sports and activities for people with disabilities – e.g. National Center on Physical Activity in Disability (NCPAD), National Sports Center for the Disabled (NSCD), Special Olympics. |                     |                               |
| I can demonstrate how I would tell emergency workers (e.g. paramedics, police, fire fighters) about my condition/disability (e.g. I need insulin) in an emergency. |                     |                               |

Revised 2014. Adapted from the Adolescent Health Transition Project, University of Washington Center on Human Development and Disability.
Ready to Manage Your Own Health Care?

Name: __________________________________________   Date: ______________

School/Program: __________________________________   Grade: _____________

Teens and young adults can manage their own health conditions or disabilities in a variety of ways. Read the following statements and decide how you feel about each one. Please choose only one answer for each statement.

<table>
<thead>
<tr>
<th>Example: In my free time I would rather watch TV than play baseball.</th>
<th>Agree</th>
<th>Sort of Agree</th>
<th>Sort of Disagree</th>
<th>Disagree</th>
<th>Doesn’t apply</th>
</tr>
</thead>
</table>

General Medical Information

1. I know about my medical insurance and carry a health insurance card.
2. I take good care of myself.
3. I know where my private medical records are kept.
4. I know how to have my health questions answered.
5. I know who to contact in case of an emergency.
6. I think that smoking, drinking alcohol, and using drugs can affect my health.
7. I have trouble falling asleep at night.
8. I only see the doctor when someone tells me I have to.
9. I know how to arrange a ride or take the bus to medical appointments.
10. I schedule my own medical appointments.
11. I have a doctor who takes care of adults, not just children.
12. I know about my physical changes in becoming an adult (e.g. puberty, sexuality, pregnancy, sexually transmitted diseases).
13. It’s easy to talk with doctors about my health.
14. I have nice doctors who help me.
15. I like to have someone with me when I visit the doctor.
16. I have someone to talk to when I feel sad.
17. I know how to get help with my health care if I need it.
18. I feel afraid of the people I work or live with.
19. I live in a safe place.
### Disability or Health Condition

*Insert your condition/disability in the blank spaces below.*

<table>
<thead>
<tr>
<th></th>
<th>Agree</th>
<th>Sort of Agree</th>
<th>Sort of Disagree</th>
<th>Disagree</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>20. I know a lot about my __________________________</td>
<td></td>
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<tr>
<td>21. I feel my ________________________ controls my life.</td>
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<tr>
<td>22. I worry about my health.</td>
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<tr>
<td>23. I think my _________________ will get in the way of what I want to do in the future.</td>
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<tr>
<td>24. I know how I can get my own Personal Care Assistant (PCA) or nurse.</td>
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<tr>
<td>25. I am embarrassed about my __________________________</td>
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</table>

### Medications & Treatments

<table>
<thead>
<tr>
<th></th>
<th>Agree</th>
<th>Sort of Agree</th>
<th>Sort of Disagree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. I get help taking medications and receiving treatments.</td>
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<tr>
<td>27. I think that the treatments or medications I take make a difference in my health.</td>
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<tr>
<td>28. I can get the things I need to help with my condition.</td>
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<tr>
<td>29. I know how to get a prescription and have it refilled or get over-the-counter medications.</td>
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<tr>
<td>30. I know what medications I take and when I need to take them.</td>
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</tbody>
</table>
TRANSITION PLANNING QUESTIONS

Health Care Financing
1. What are your insurance options as an adult with special health care needs or disabilities?
2. Will you need to apply for Medicaid Disability?
3. Would Medicaid Waiver services benefit your family?

Medical Home
4. Do you have a primary physician to provide you with adult care?
5. What types of adult specialists will you need to see?
6. Will your current doctor want you to transfer to a new doctor at some time?
7. What other community resources can help you with specific health care needs?

Health Habits
8. Do you eat a healthy diet and live a healthy lifestyle?
9. As an adult, do you have questions about participating in adult activities?

Self-Management
10. Do you manage your own health care or does someone help you?
11. How well do you understand your own condition?

Mental Health
12. How well do you enjoy life?
13. Would you like to see a counsellor?

Decision Making
14. Who makes decisions about handling your finances and health care?
15. Do you need more information on living wills, guardianship options, or advance care plans?

Family/Caregiver Support
16. What groups are available to provide your family with support or advice?
17. What resources or groups would your family recommend to other families?

Education/Employment
18. What are your plans for continuing your education?
19. Do you have an IEP (Individualized Education Program) or 504 Plan at school?
20. What kind of career interests you?
21. Do you plan to work and keep your benefits?

Socialization
22. What clubs and activities are you involved in at your school or in the community?
23. Do your friends help you in a positive way?

Independent Living
24. Where do you want to live in the future?
25. What steps are you taking to toward that goal?
26. How do you plan to become more independent in your care at home, work, and school?

Transportation
27. What types of transportation do you use?
28. What transportation problems might you run into as an adult?
29. Are Medicaid transportation services available to you?

Care Coordination
30. Does your family have a Care Manager or Care Coordinator helping you now?
### PERSONAL LIFE GOALS

<table>
<thead>
<tr>
<th><strong>Health Care Financing</strong>: Have an adult insurance plan in place and know how to manage it.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical Home/Primary &amp; Subspecialty Care</strong>: Understand how to use primary care and have an established relationship with a Primary Care Provider. Know how to involve specialists in your care to meet your health needs</td>
</tr>
<tr>
<td><strong>Health Habits</strong>: Maintain a plan for healthy diet, exercise, sleep, hygiene, and avoiding risky behavior.</td>
</tr>
<tr>
<td><strong>Self-Management</strong>: Manage your own treatment plan. Get supports and use as needed.</td>
</tr>
<tr>
<td><strong>Mental Health</strong>: Maintain mental health wellness, manage stress, and use resources as needed.</td>
</tr>
<tr>
<td><strong>Decision Making</strong>: Develop self-advocacy skills and use decision-making supports as needed.</td>
</tr>
<tr>
<td><strong>Family/Caregiver Support</strong>: Work within support system for long-term positive relationships that meet needs.</td>
</tr>
<tr>
<td><strong>Education/Employment</strong>: Have a plan for post-high school education, employment, and/or meaningful day activities.</td>
</tr>
<tr>
<td><strong>Socialization</strong>: Engage in enjoyable community activities.</td>
</tr>
<tr>
<td><strong>Independent Living</strong>: Live as independently as desired.</td>
</tr>
<tr>
<td><strong>Transportation</strong>: Have sources of transportation for various needs.</td>
</tr>
<tr>
<td><strong>Care Coordination</strong>: Have knowledge of needs, use appropriate resources, and know how to have new needs met.</td>
</tr>
</tbody>
</table>

*Source: Center for Health Care Transition Improvement – Washington, DC – GotTransition.org Revised 2014. © PACER Center, Inc. – 8161 Normandale Blvd., Minneapolis, MN 55437 – PACER.org – (952) 838-9000*
IEP Goals/Objectives

These are potential goals and objectives to consider for transition-age youth when developing an Individualized Education Program (IEP)

1. Organizational skills:
   - Does the individual know how to sort or file?
   - Is she able to plan ahead?
   - Can he sequence several steps to complete a process, such as planning a meal, obtaining prescription refills, or scheduling and arriving on time for an appointment?

2. Identifying emotions:
   - Can the youth recognize her feelings, such as happiness, sadness, anger, and frustration?
   - Does he have a plan for how to cope with different feelings in various settings?

3. Using assistive technology:
   - Can the youth keep a calendar?
   - Does she know how to schedule an appointment?
   - Does he understand safety issues when using the Internet?
   - Is there assistive technology available to meet his specific needs?

4. Transportation:
   - Is driver's education appropriate?
   - If public transportation is needed, does the youth need to learn how to read a map, navigate different neighborhoods, and understand transit schedules?

5. Job applications:
   - Does the individual know the basic information to complete a job application?
   - Does she need practice with job interviews?
   - Is she able to articulate her strengths and weaknesses appropriately?

6. Work skills
   - Does the youth understand how to dress appropriately for work?
   - Does he know appropriate subjects to discuss at work?
   - Does she understand what language is appropriate or inappropriate at work?
   - Is he clear about work ethic and what it means to do a good job?
   - Does she understand the role of a supervisor or manager and how that will impact her as an employee?

7. Money management and budgeting:
   - Can the youth count money?
   - Can he make appropriate change?
   - Does she know how to write a check?
   - Can he make a budget?

8. Cooking and cleaning:
   - Does the youth understand what constitutes good nutrition?
   - Can he read a recipe or find one online?
   - Can she make a grocery list?
   - Does he know how to shop for ingredients?
   - Can she follow basic cooking instructions?