

# Draft 10-Year HRTW/Transition Plan

## Healthy & Ready to Work

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Submitted by the Health People 2010  
Healthy and Ready to Work (HRTW)/  
Transition Work Group

To Maternal and Child Health Bureau  
Division of Services for Children with  
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## Brief History and Overview

While rapid advances in medical science have enabled over 90% of children born with special needs to reach adulthood, youth with special health care needs are much less likely than their non-disabled peers to finish high school, pursue post-secondary education, get jobs, or live independently. Few coordinated services have been available to assist them in their developmental transitions from school to work, home to independent living and pediatric-based care to adult-based health care.

During the 1990's, federal legislation affecting children and youth with special health care needs (CSHCN) has undergone sweeping reform. Some of these reforms mandate new supports for children (and adults) with disabilities.

However, these new services are not well-integrated, due in part to a lack of coordination among organizations charged to work on behalf of this population. (Woods, Haberman & Packard, 1993).

As is documented in a 1996 General Accounting Office report, only 26 of the 130 federal disability programs focus on employment as an issue, and only 1% of the resources of these programs were used to address this issue.

The result of this lack of focused, coordinated, well-funded services is that many youth and young adults with special health care needs are forced to remain dependent on family members, pediatric service providers, and public programs such as Supplemental Security Income (SSI), Welfare, and Medicaid, rather than having access to opportunities that will enable them to become Healthy and Ready to Work.

### HP2010 Performance Core # 6

#### HRTW / Transition \*\*

Ensure that all youth with special health care needs receive the services they need to make necessary transitions to all aspects of adult life, including adult health care, work, and independence.

\*\* The HP2010 HRTW/Transition Workgroup believes that ALL children deserve a future, to grow up and to be as independent in their lives and in their communities as possible. For many of our CSHCN, this will mean employment, for others improved recreational and social opportunities in their communities, and for ALL an improved or sustained health status as they age into and access adult health care delivery.

In this era of "outcome based" programs, one may ask, What is the outcome of all these federal programs, health care services, education, and rehabilitation? Are futures of children and youth who have a disabilities or chronic health conditions, maximized by the current system of federal supports? What will it take to convert ideas into practice?

## The Role of Title V and Health Providers

An amendment to Title V of the Social Security Act authorizes the State Maternal and Child Health programs for CSHCN to provide rehabilitation services to children under age 16 who are receiving SSI, when Medicaid does not pay for those services.

Through the "Healthy and Ready to Work" (HRTW) initiative of the Division of Services for Children with Special Health Needs, MCHB is taking a leadership role in developing and assessing strategies and mechanisms for promoting needed changes in attitudes, opportunities, and systems of care.

In regard to medical practices, health care services must not only be delivered in a family-centered manner, but must also be expanded to include guidance and support that facilitates youth empowerment and preparation individuals to take charge of their own health care and to lead productive lives as they so choose.

## 5 Concurrent Action Steps HRTW/Transition services and supports for youth with special health care needs a reality by, if not before, 2010.

### 1. Systems Development

Every state Title V CSHCN Program provides, coordinates, and/or pays for Healthy and Ready to Work (HRTW)/ Transition Services. In addition, Title V facilitates the development of HRTW/Transition systems for children, youth, and young adults with special health care needs.

### 2. Youth Participation in Decision-Making

Youth with special health care needs participate both with their health care providers as decision-makers and with policy-makers as partners.

### 3. Health Insurance

Youth with special health care needs have affordable and accessible health insurance that provides those services, which supports well being, optimizes their quality of life, and facilitates their participation in education, the workforce and the community.

### 4. Health Care/Medical Home

Youth with special health care needs have a medical home that addresses their comprehensive needs (in age and developmentally appropriate\* settings). Pediatric and adult health care providers, programs, and systems will be organized, financed, and receive training to provide a medical home.

The transition from pediatric to adult health care providers is planned, coordinated, and facilitated.

### 5. Education, Employment, & Independent Living

Federal, state, and community-based services and programs (including education, support for employment, housing, transportation, and recreation) are organized, financed, and delivered in ways that promote and sustain the wellness of children, youth, and young adults with special health care needs and promote the integration of these individuals into the competitive workforce and community activities.

**Issue:** The federal/state Title V Program has a unique responsibility for facilitating the development of community-based systems of services for children and youth with special health care needs.

### Specific Barriers

Limited financial resources for dedicated positions to staff key-issue positions are available through Title V to fund the provision of care and to facilitate the development of community-based systems of services for children and youth with special health care needs.

State Title V CSHCN Programs have not uniformly or adequately incorporated families (let alone youth) as decision-making partners. This is equally true of the adult health care system.

State Title V CSHCN Programs do not have an adequate number of funded family leadership positions in their agencies (either as paid staff with benefits or consultants).

### Strategies to Achieve

1. Create a funding stream and accountability mechanisms, through the MCH Block Grant Program, to assure that all State Title V CSHCN Programs
  - Provide, coordinate, and/or pay for HRTW/Transition services and
  - Facilitate the integration of GRTW/Transition services supports into the continuum of care
2. Through Special Projects of Regional and National Significance (SPRANS), fund projects that develop and test innovative approaches to the organization, financing and delivery of HRTW/Transition services and supports, in response to the changing needs of youth with special health care needs and the evolving health and social environments.

### Action Step 1: Systems Development

**Every state Title V CSHCN Program provides, coordinates and/or pays for Healthy and Ready to Work (HRTW)/ Transition Services.**

**Title V facilitates the development of HRTW/Transition systems for children, youth, and young adults with special health care needs and their families.**

3. Formalize the Federal Healthy and Ready to Work (HRTW) Interagency Work Group, through a Presidential Directive or legislative change, that has clear responsibilities and authority for the appropriate Federal Agencies to work together to address the issue of youth with special health care needs transitioning to adulthood (Federal precedence, Federal Interagency Coordinating Council for Infants and Toddlers.)
4. Develop collaborative partnerships, through a National Title V/HRTW Workgroup. The membership of this workgroup would be representatives from: state Title V CSHCN Programs; American Academy of Pediatrics; American Academy of Family Physicians; family-leadership and other agencies; professional organizations and stakeholders. These collaborative partnerships will assure that the HRTW/ Transition Agenda is incorporated into the goals, objectives and activities of these organizations and their constituencies.

5. Develop models that State Title V CSHCN Programs can use to provide and pay for HRTW/Transition services and b) facilitate the integration of HRTW/Transition services and supports into the continuum of care.

6. Facilitate the integration of successful HRTW/Transition models into state Title V CSHCN Programs and related state and community systems.

7. Provide technical assistance and consultation to State Title V CSHCN Programs, key stakeholders' agencies, and other organizations to support state and community-based efforts to develop and maintain HRTW/Transition services and systems.

### Strategies to Measure

- Conduct an annual review of MCH Block Grant Application narratives and conduct annual surveys of state Programs to determine the extent to which Title V CSHCN Programs provides, coordinates and/or pay for services; and facilitate development of HRTW/Transition systems.
- Survey youth with special health care needs and their families to determine the extent to which HRTW/Transition services were provided by Title V and community-based organizations', the degree to which these services were organized in ways that were easy to use, and the assess effectiveness of service provided.
- Survey staff of community-based health, educational, employment, and other organizations on their understanding of HRTW/Transition services and their perception of the degree to which these services were organized in ways that were easy to use by youth and their families.

**Do IEP's, ITPs, and 504 plans include a health component; do medical charts include IEP's, ITPs, or 504 plan goals?**

**Does the Title V Program develop a transition plan for Program participants at age 14 (younger when possible) that includes an educational and vocational component?**

### When are indicators developed?

- Conduct an annual review of SPRANS "Calls for Proposals" and review abstracts of funded projects to document the number of and total funding of projects that address the issue of HRTW/Transition.
- Conduct an annual review of the annual reports and/or strategic plans of selected Federal agencies and other stakeholder organizations and document the extent to which HRTW/Transition is addressed.
- Conduct a review of the GPRA progress reports of selected federal agencies to document progress on goals related to health status, education, employment, and living arrangement of youth with special health care needs.

**Issue:** Youth are not expected, given the opportunity or education, or supported to participate as decision-makers with their health care providers or policy-makers.

Growing up, as a youth with special health care needs is different in significant and fundamental ways, and at the same time is similar to growing up without special health care needs. These differences and similarities can manifest themselves across all of life's domains

## Specific Barriers

Professionals have traditionally lacked training in identifying and addressing the long-term issues of individuals with special health care needs.

Historically, youth with special health care needs have not been expected to participate in their health care, community, and/or adult activities.

Policy-makers have not recognized the contributions that youth can make to the development of policies, programs, and services that youth need.

There are no tools to monitor or evaluate the knowledge, skills, and/or behaviors of professionals in promoting participation of youth in the health care decision-making. Strategies to address these issues are critical to assessment and assurance.

## Strategies to Achieve

Through collaborative efforts with family-leadership, professional and other organizations and agency stakeholders, training will be developed, provided and supported that promotes self-determination in youth processes.

## Action Step 2: Youth Participation in Decision-Making

**Youth with special health care needs (YSHCN) participate with their health care providers as decision-makers and with policy makers as partners.**

This will be accomplished through interprofessional education, joint federal and state funding initiatives, and peer mentorship programs.

**1.** YSHCN carry out their developmentally age appropriate and culturally relevant role as decision makers in their own health care (physical & mental), educational training, transportation options for independence, social, and recreational activities, employment experience and advancements, interpersonal relationships, sexuality, living arrangements, inclusion in the community and other areas that improve the quality of life.

Moving from informed assent to informed consent.

**2.** Families and other components of youth's support networks enable and promote the development of YSHCN as decision-makers about their own health care (physical & mental), educational training, transportation options for independence, social, and recreational activities, employment experience and advancements, interpersonal relationships, sexuality, living arrangements, inclusion in the community, and other areas that improves the quality of life.

3. Youth with Special Health Care Needs actively participate in health, education, employment, and disability policy development, as respected partners.

4. Professionals support and promote the development of youth with special health care needs as respected partners in decision-making and policy development, and account for their performance.

### Strategies to Measure

- Conduct focus groups with youth with special health care needs to determine the extent to which they received training and support and had opportunities to act as decision-makers and participate in policy development. (Target populations include youth in Title V and youth with 504 Plans.)
- Conduct focus groups with families of youth to determine the extent to which they received training and support in assisting their children as decision-makers in their own health care and as participants in policy development.
- Conduct an annual review of MCH Block Grant Application narratives and conduct annual surveys of state Programs to determine the extent to which Title V CSHCN Programs provide training, support, and opportunities for youth to act as decision-makers. (Does the Title V CSHCN Program have a Youth Advisory Board?)
- Conduct focus groups with primary and specialty health care professionals regarding their attitudes and beliefs about the role of youth as partners in medical decision-making.

**Issue** Most health care plans do not provide the services that youth need to transition successfully to adult health care and adult life activities.

In order to assure that youth with special health care needs receive the HRTW/Transition services and supports they need: affordable, accessible, and appropriate health insurance coverage must be available through a combination of public, private, and employment-based plans.

### Specific Barriers

Many youth with special health care needs are uninsured or are underinsured because of caps on life-time benefits, co-payment requirements, and limits on the amount, duration, and scope of the covered benefits.

The benefits package of public, private, and employment-based plans do not include a broad range of services and supports that are needed by youth with special health care needs to be healthy and to be productive citizens, as they so choose. There are no standards of care for youth with special health care needs; existing plans cover “rehabilitation” services but do not cover habilitation services and services, needed to maintain function.

Existing health insurance plans (public, private and employment-based) are not designed to address the reality of varying YSHCN eligibility status.

### Action Step 3:

#### Accessible & Affordable

#### Health Insurance

**Youth with special health care needs have accessible and affordable health insurance coverage that coordinates services which support well being, optimizes quality of life, and facilitates participation in education, the workforce, and the community.**

Youth may reside in several different communities during the year (i.e. attending college, or employment training out of home state); or they may transition from family-coverage to single head-of-household status.

Public, private, and employment-based insurance plans do not include provisions to facilitate the transition of individuals between and among plans (as individuals age out of eligibility, i.e., SCHIP)

Benefit packages lack a mechanism to assure coordination of benefits across plans (i.e., there are significant disincentives to providing quality, interdisciplinary, coordinated care; there are no CPT codes for “comprehensive care”.)

## Strategies to Achieve

### Accessible & Affordable Health

#### Insurance

1. Assure the expansion of public and private health insurance benefits packages so that they are more uniform and meet the needs of youth with special health care needs and promote their well being, wherever they live. Such benefits packages should include, but are not limited to:

- personal health services, and supports;
- assistive technology and other customized durable medical equipment;
- personal assistance services (PAS)\*;
- youth/family education;
- comprehensive psychosocial services and referrals; and
- other services and supports that promote health and well being, and prevent the development of conditions secondary to the disability/ primary health care condition.

2. Develop guidance and recommendations regarding appropriate levels of reimbursement and billing codes for HRTW/Transition services, supports, and equipment for youth with special health needs, as provided by pediatric and adult providers, programs, and facilities.

3. Promote participation of every state in the Medicaid Buy -In Program legislated through the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) through collaborative efforts with other agencies, professional organizations, and family-leadership stakeholders.

4. Coordinate public, private, and employment-based health plans to promote flexibility and assure access and affordability (e.g.) use state Medicaid funds to pay employer premiums or use employer funding to use high-risk pool premiums).

## Strategies to Measure

- Review the benefit packages of the Federal Employees Health Benefits Program and selected public-employee, and private-sector plans, to document the degree to which HRTW/Transition services are included.
- Review the reimbursement rate for selected HRTW/Transition services, supports and equipment paid by state Medicaid, state Title V, FEHBP and other selected public-employee and private sector plans.
- Review and document state participation in Medicaid buy-ins, as authorized by the Ticket to Work and Work Incentives Improvement Act of 1999.
- Conduct an annual review of MCH Block Grant Application narratives and collect self-reports of state Programs to determine the extent to which youth with special health care needs have “adequate/affordable” health insurance.

**Issue:** Health care professionals and providers of therapeutic services have critical roles and responsibilities in helping to assure that YSHCN are healthy and prepared to make transitions to adulthood, including the transition to adult health care providers.

### Specific Barriers

Professionals lack (inter-professional) training, support, and opportunities to promote the development of youth with special health care needs as partners in health care decision-making and policy development.

Health care providers have not received training in supporting youth and families to address short- and long-term goals, including education, health care (physical and mental), employment, and community living options, or to identify and prescribe necessary assistive technology.

Adult health care providers are not prepared to treat patients with complex medical conditions beginning in childhood.

Providers lack the knowledge of available community-based resources and how to make referrals for necessary HRTW/Transition services and to assure that “prescribed” (quality assurance /follow-up) occur.

Pediatricians and families may resist transition to adult health care providers because they are afraid to change a health care routine that has proven successful.

#### Action Step 4:

#### Health Care/Medical Home for Youth

Youth with special health care needs have a medical home that addresses their comprehensive needs (in age and developmentally appropriate\* settings).

Pediatric and adult health care providers, programs, and systems are organized, financed, and receive training to provide a medical home.

The transition from pediatric to adult health care providers is planned, coordinated, and facilitated.

Medical professionals, families, and youth lack sufficient support in identifying a new medical home (due to residential relocation, school placement, or periodic recreational travel).

Many facilities and programs are not barrier-free: environmental or physical setting; communication methods (services/support in other languages, accessing sign language, respecting and changing practices to assure cultural relevance, patronizing attitudinal low expectations mentality and bias).

## Strategies to Achieve a Health Care/Medical Home for Youth

1. Provide training, support, and opportunities for pediatric and adult health care professionals to provide developmentally and age appropriate and respectful care to children, youth, and young adults with special health care needs, through training programs, professional organizations, and through collaborative efforts with youth and family-leadership stakeholders.
2. Assure that there is universal access to a “medical home” for all youth with special health care needs where services are barrier-free (in terms of environmental/ physical setting, communication methods, cultural relevance, language, attitude, etc.) in all settings in order to achieve 100% access and zero disparities in health care.
3. Through the Title V program plan for the eventual transition to adult health care providers; coordinate and facilitate that transition over a period of time that meets the needs of the YSHCN.
4. Develop medical “smart cards” for youth with special health care needs that include comprehensive medical information (e.g. medical history, protocol for relevant social and mental health treatment) and includes a directory of relevant community-based health care resources.

## Strategies to Measure

- Follow-up with “graduates” of state Title V CSHCN Programs and selected specialty care programs (i.e. Cystic Fibrosis) to determine the proportion of youth receiving primary and specialty care from adult providers.
- Review ADA-related complaints made about health care facilities and programs.
- Collect self-reports from state Title V CSHCN Programs to determine the degree to which adult providers (Internists and Family Physicians) provide primary and specialty care to Title V beneficiaries
- Determine the number of adult providers that complete the AAP Medical Home Transition Curricula.
- Assess medical home knowledge and skills of adult providers.
- Assure the HP 2010 medical home workgroup addresses adequacy of transition planning; incorporated parameters, and into the Medical Home curriculum

**Issue:** The transition of youth with special health care needs from pediatric to adult care, and from school to work and independence is complex. There is a growing consensus that youth with special health care needs should transition from pediatric to adult medical care; and should be given the opportunity and supports needed to work, be productive, and fully participate in society.

## Specific Barriers

Youth with special health care needs, like other youth, are NOT typically provided with:

- sufficient knowledge, skills, and/or supports needed to promote healthy behaviors and to prevent or reduce the incidence of risky behaviors and secondary disabling conditions.
- training, knowledge, skills, and/or supports they need to develop self-efficacy\* beliefs and to function as self advocates.
- training, knowledge, skills, or the services and supports (including assistive technology, and mentorship\*) they need to attain and sustain desired levels of “independent living” and “consumer direction.”
- The same opportunities for full life experiences\* as other children.
- The current legislative acts related to youth with special health care needs do not coordinate comprehensive HRTW/Transition services.
- Effective mechanisms to uniformly measure and monitor the implementation and effectiveness of family-centered care have not been fully developed or implemented, in many State Title V programs.

## Action Step 5: Education, Employment and Independent Living

**Federal, state and community-based services and programs are organized, financed and delivered in ways that promote and sustain the well-being of youth with special health care needs and their integration into community activities and the workforce.**

Most state Family-centered care models currently do not include a component related to the transition of YSHCN to adulthood.

The complimentary roles and responsibilities of state Title V/CSHCN programs and educational agencies have not been defined in ways that assure students with special health care needs are not only healthy and ready to learn, but are also healthy and ready to work.

Individualized, federally mandated plans and/or program (Individualized Education/ Transition/ Work) typically do not include a health component that assures access to comprehensive health services and promotes well-being

## Strategies to Achieve

1. Through the formal Federal Healthy and Ready to Work (HRTW) Interagency Work Group, promote coordination of agency activities, and facilitate cooperative funding that increases state and community infrastructure capacity for HRTW/Transition services and supports for youth with special health care needs who are transitioning to adulthood.
2. Develop regional and state-level interagency workgroups that promote coordination of public and private organizational activities and facilitate cooperative funding of HRTW/Transition services and supports (i.e. health services that promote well being, education, independent living, and employment).
3. Promote and provide inter-professional educational opportunities for professionals to assure that community-based services and supports for YSHCN are comprehensive, coordinated, and not duplicative.
4. Provide training, & support/opportunities for YSHCN to acquire employability skills through family activities, education, volunteer experiences, and entry-level work experiences.

## Strategies to Measure

- Conduct an annual review of state annual reports of selected federal funding initiatives, including Education, Vocational Rehabilitation, and Housing narratives and conduct surveys of selected state Programs to determine the extent to which Program activities include a health component and coordinate /promote well-being of YSHCN.
- Conduct a review of the discretionary funding initiatives of selected federal agencies, to determine the extent to which there is federal interagency coordination and the extent to which these initiatives require inter-agency collaboration at the state and community-level.
- Conduct a review of the annual reports and/or strategic plans of selected federal agencies and other stakeholder organizations and document HRTW/Transition services.

Specific outcomes (data) that could be used to measure performance  
on one or more of the proposed actions.

THE PROPORTION OF YSHCN WHO:

### Education

- Have 504 plans nationwide, by state
- Have IEP and/or 504 plan (in comparison to the expected prevalence – based on CSHCN state specific data being developed by MCHB)
- Participated in school graduation mandated “volunteer experiences;”
- Received or entered vocational training;
- Graduate from high school (Regular, Special Ed, & GED);
- Drop-out of high school and/or;
- Entered post secondary educational training.

### Health

- Received “interdisciplinary” care; and
- Had an individual plan (education, transition, or employment) that includes a health component.

### Employment

- Level of employability readiness or vocational orientation of C&YHCN (in comparison to children without a special health care needs;
- Experience employment prior to high school graduation; and
- Are employed and earning less than the SSA criteria for substantial gainful employment currently (\$700 per month).

### Life Experiences

- Engage in “productive activities;”
- Participate in federal or state funded recreational programs;
- Participated in school activities;
- Participated in sport teams

### SSI

- Left the SSI rolls at or before age 24;
- Who Received SSI benefits but also have an appropriate Plan to Achieve Self Support “PASS; “
- “Graduate” from a state Title V Program and participate in the Ticket to Work “Medicaid Buy-In” component;
- Left the SSI rolls due to employment;
- Left the SSI rolls due to improvement of their medical condition.

# System of Care Values and Principles for Youth in Transition and Their Families

## Core Values

- The system of care is youth-focused and family-centered, with the needs of the youth and the family dictating the type and mix of services necessary before, during, and after transition to adulthood.
- The system is community-based, with the locus of management and decision-making responsibility resting at the local-level with the youth, family, and community.
- The system of care is culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

## Guiding Principles

- YSHCN receive self-determination skills, training, educational, health, and employment services in the most appropriate and least restrictive environment.
- YSHCN have access to a comprehensive array of services that address their physical, emotional, social, and educational needs that support their long-term life goals.
- YSHCN receive individualized services in accordance with the unique needs and potentials of each youth, guided by an individual plan with built in funded supports, assistive technology, accountability and evaluation measures, as mandated by federal law and individualized needs.
- The families and surrogate families of YSHCN are full participants in the different aspects of planning, delivering, and evaluating/assessing services.
- YSHCN receive services that are integrated, with linkages between child and adult service agencies and programs and mechanisms should existing for planning, developing, and coordinating these services.
- YSHCN are provided with transition care coordination to ensure that multiple services are delivered in an organized and responsive manner and that they can move between the systems of care in accordance with their individual needs.
- Early identification of transition needs should be promoted by the system of care to ensure the likelihood of positive outcomes to lead as independent a life as they so choose.

Adapted from

Stroul, B. & Friedman, R. (1986). A System of Care for Children and Youth with severe Emotional Disturbance (rev. ed., p. 17) Washington, D.C. Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health.

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| <b>ADLs</b>  | Activities of daily living: Basic activities necessary for self-care and independent living. These activities include dressing, bathing, toileting, grooming, mobility, and eating. Limitations in ADLs are often assessed to determine the need for PAS and subsequently, eligibility for government PAS benefits.   |
| <b>Biopsychosocial model</b>                           | An approach to addressing the overall needs (physical, psychological, social and spiritual) of the person with a chronic condition or physical disability. The biopsychosocial model visualizes the individual in continuous interaction with internal (physical and psychological) and external (social) influences. It is believed that to effectively care for persons with special needs, such a holistic approach is essential. (ref: Schwartz, G.E. (1982)). Testing the biopsychosocial model: The ultimate challenge facing behavioral medicine. <u>J. Consulting and Clinical Psychology</u> , 50: 1040-1053.  |
| <b>Children with Special Health Care Needs (CSHCN)</b> | (CSHCN) MCHB def-Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require services of a type or amount beyond that required by children generally.   |
| <b>Chronic condition</b>                               | See CSHCN def   |
| <b>Community-based</b>                                 | 1) Ideas and approaches to service delivery that originate in the community and are implemented in community settings and 2) groups and organizations (e.g., collaborative, consortia's, etc.) that carry out their activities at the community-level. (Refs. Fawcett, S., Andrews, A., Francisco, V., Schultz, J. A., Richter, K. P., Lewis, R. K., Harris, K. J., Williams, E. L., Berkley, J. Y., Lopez, C. M., & Fisher, J. L. (1996). Empowering community health initiatives through evaluation. In D. Fetterman, S. Kaftarian, & A. Wandersman (Eds.). <u>Empowerment evaluation: Knowledge and tools for self-assessment and accountability</u> , (pp. 161-188). Thousand Oaks, CA: Sage Publication; Israel, B. A., Checkoway, B., Schulz, A., & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. <u>Health Education-Quarterly</u> , 21, 149-170.) |
| <b>Community-oriented</b>                              | Refers to ideas and approaches to service delivery that originate outside of a community, but are meant to be implemented in community settings. (refs – same as in previous term)  |
| <b>Consumer direction:</b>                             | 1) Entails some degree of decision-making on the part of the consumers (i.e., people with a special health care needs) about the specific services they need and want. 2) Consumer direction means that the consumer defines services to be delivered and makes employment decisions about caregivers/personal assistants. 3) The ability for consumers to manage their lives in all capacities.  |
| <b>Consumer direction barrier</b>                      | Disability research and public policy efforts aimed at increasing independent living and consumer direction have focused primarily on adults with special health care needs and have not addressed the unique issues related to the transition of youth with special health care needs.   |

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| <b>Cultural Competence</b>                 | A set of values, behaviors, attitudes, and practices within a system, organization, program or among individuals and which enables them to work effectively cross-culturally. Further, it refers to the ability to honor and respect the beliefs, language, interpersonal styles and behaviors of individuals and families receiving services, as well as staff who are providing such services. Striving to achieve cultural competence is dynamic, on-going, developmental process that requires long term commitment of time. System, organizations, and programs can strive towards cultural competence by: 1) valuing diversity, 2) having the capacity for cultural self-assessment; 3) being conscious of the dynamics inherent when cultures interact; 4) having the ability to institutionalize cultural knowledge, and 5) being capable of making adaptations to service delivery reflecting an understanding of cultural diversity. (MCHB National Center for Cultural Competency) |
| <b>Culturally relevant</b>                 | (see cultural competence)   |
| <b>CYSHCN</b>                              | Children and youth with special health care needs.  |
| <b>Developmentally and Age Appropriate</b> | Providing services and information in a setting consistent with the person's chronological age (e.g. a pediatrician setting up a teen area with work and college literature away from the toy room would be appropriate) and in a format that the person can comprehend (e.g. asking simple one-part questions would be appropriate with a 20 year old female who has developmental delays.)  |
| <b>Disability</b>                          | A person with a disability is any person who (i) has a physical or mental impairment which substantially limits one or more major life activities; (ii) has a record of such an impairment; or (iii) is regarded as having such an impairment.  |
| <b>Disability Identity</b>                 | Subscribing to a social/minority view of the self as a person with a disability. A belief or feeling that the primary lens with which one is viewed and views oneself is that of a person with a disability.  |
| <b>Disability Policy</b>                   | Whereas public policy in general refers to, "a local, state, national, or international government action that affects what happens in society" (Policy Studies Associates, 1998), disability policy specifically explores governmental actions that affect the main life domains that affect people with disabilities. These domains include but are not limited to employment, education, access to public accommodations, telecommunications, income maintenance, housing, assistive technology, personal assistance, and healthcare.  |
| <b>Disabling Condition</b>                 | (see CSHCN def)   |
| <b>Empowerment</b>                         | Personal and social actions and attitudes that serve to reinforce the individual's sense of valued identity (positive valuation) and life role. The goal of empowerment for those in the role of helper is to engage in a set of activities aimed at reducing the individual's sense of powerlessness so that individuals can <u>build the capacity</u> to take actions to improve their life situations. (Refs. Guiterrez, L.M., GlenMaye, L., and DeLois, K.A., (1992). Improving the Human Condition through Empowerment Practice. <u>Information Exchange Presentation: NASW/IFSW World Assembly</u> . Washington, D.C.; Eng, E., & Parker, E. (1994). Measuring Community Competence in the Mississippi Delta: The Interface between Program Evaluation and Empowerment in <u>Health Education Quarterly</u> . 21(2), family pp. 199-220).   |
| <b>Family</b>                              | 1) Family is defined by each culture as the primary system of support and preferred intervention, 2) Family refers to parents, foster parents, extended family, or others significant in a youth's life who serve in a supportive capacity that is essential to his/her well being. Youth may drive their own definition of family and its membership, choosing to be a family of one if they have no one they consider essential supports in their lives.  |
| <b>Full Life Experiences</b>               | The opportunity to be part of one's community, enjoy recreational and social activities, participate in age-appropriate activities to the greatest degree possible with supports and in the individuals natural environment, without harm, limitation, or prejudice due to an individual's abilities and/or limitations.  |

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| <b>Health related Quality of Life</b>                             | The concept of QOL is synonymous with the WHO definition of health as “a state of complete physical, mental, and social well being, and not merely the absence of disease or infirmity”, with the primary emphasis being on efforts aimed at promoting and maintaining (to the best of one’s ability) this standard of health. As such it is consistent with the holistic approach to health promotion and disease/illness prevention. Health related QOL refers to the specific impact of an illness or injury, medical treatment, or health care policy on an individual’s quality of life (QOL). (ref. – World Health Organization. (1948). Constitution for the World Health Organization. Geneva: author; Levi R, Drotar D (1998). Critical Issues and Needs in Health Related Quality of Life Assessment of Children and Adolescents with Chronic Health Conditions. In Drotar, D (ED) <u>Measuring Health-Related Quality of Life in Children and Adolescents. Implications for Research and Practice.</u> (3-245). New Jersey: Lawrence Erlbaum Associates, Publishers.) |
| <b>Healthy and Ready to Work Transition Services and Supports</b> | 1) Array of coordinated services delivered to individuals who have a disability or chronic health illness that promotes or maintains the quality of their lives, and will allow access to full life experiences over the life of that person, 2) Expectation that individuals deserve to have a future that is not limited by others expectations or past experiences; 3) When appropriate support and services are provided the person’s health status is maintained, sustained or improved so as not to interfere with the enjoyment of one’s daily activities of daily living and long-term living goals; and 4) Providing the individual with supports, information and access to appropriate education, assistive technology, and pre-employment experiences that enable the person to go to work and become as independent as he/she chooses.  |
| <b>IADLs</b>  | Instrumental Activities of Daily Living: Basic activities that pertain to the ability to live at home independently. These activities include: preparing meals, shopping for personal items, managing money, using the phone, doing laundry, doing light and heavy housework, taking medications, getting around outside, and going places outside of walking distance. Limitations in IADLs are often assessed to determine the need for PAS and, subsequently, eligibility for government PAS benefits.  |
| <b>Independence</b>   | The ability to self-direct one’s life. This is not reliant upon accomplishing life activities alone, but by having the choice, freedom, and opportunities to make decisions about the direction of one’s life.   |
| <b>Independent Living</b>   | Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities, and self-respect. Independent Living does not mean that people with disabilities do everything by themselves and do not need anybody, or that we want to live in isolation. Independent Living means that people with disabilities demand the same choices and control in their every-day lives that non-disabled individuals are granted.   |
| <b>Inter-professional</b>   | An approach to the provision of health and human services that involves the use of professionals and non-professionals. The basic position of this approach is the respect and use of the expertise each person brings to the service that requires a shared philosophy to service provision and has the potential for any of the partners to take a leadership role, depending on the problem and need. Also known as an “Interdisciplinary” approach. (ref. Klerman, L.V. (1985). Interprofessional issues in delivering services to Chronically ill children and their families. In Hobbs, N., & Perrin, J.M (eds). <u>Issues in the Care of Children with Chronic Conditions: A Sourcebook, on Problem, Services and Policies.</u> (420-440). San Francisco, CA: Jossey-Bass Publishers; another reference is forthcoming).  |

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| <b>Lay professional (para-professional)</b> | Individuals who provide specialized services or have specific duties and responsibilities that are usually adjunctive to those with more formalized training (e.g., individuals who provide translating services in clinics, but who have not been formally trained or have the requisite credentials to be translators) [reference forthcoming].   |
| <b>Multi-disciplinary</b>                   | An approach to the provision of health and human services that involves the use of professionals and non-professionals. The basic position of this approach is the respect and use of the expertise each person brings to the service, however a shared philosophy is not required. There is clear hierarchy of leadership that usually does not vary. . (ref. Klerman, L.V. (1985). Interprofessional issues in delivering services to Chronically ill children and their families. In Hobbs, N., & Perrin, J.M (eds). <u>Issues in the Care of Children with Chronic Conditions: A Sourcebook, on Problem, Services and Policies.</u> (420-440). San Francisco, CA: Jossey-Bass Publishers; another reference is forthcoming).  |
| <b>PAS</b>                                  | Personal Assistance Services (PAS) is defined as “involving a person assisting someone with a disability to perform tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interaction with the community and society as a whole.”  |
| <b>Self-Determination</b>                   | The self-determination movement was founded on four basic American principles: 1) FREEDOM: the exercise of the same rights as all citizens. People with disabilities, with assistance when necessary, will establish where they want to live, with whom they want to live, and how their time will be occupied, 2) AUTHORITY: the control over whatever sums of money are needed for one's own support, including the re-prioritizing of these dollars when necessary. 3) SUPPORT: the organization of these resources as determined by the person with a disability. This means that individuals do not receive "supervision" and "staffing," 4) RESPONSIBILITY: the wise use of public dollars. Dollars are now being used as an investment in a person's life and not handled as resources to purchase services or slots. Responsibility includes the ordinary obligations of American citizens and allows individuals to contribute to their communities in meaningful ways. See: <a href="http://www.self-determination.org">www.self-determination.org</a>                    |
| <b>Self-efficacy</b>                        | Self-efficacy, a component of social learning theory, which refers to personal judgments concerning one's capacity to perform specific actions, which result in specific outcomes. In particular, self-efficacy focuses on individual's convictions that they can exercise control over their motivations, behaviors, and social environments. Typically, self-efficacy is conceptualized in a situation-specific manner, rather than as an overarching personality trait, indicating that efficacy beliefs may vary widely across environments and situations. (refs. Bandura, A. (1977a). <u>Social learning theory.</u> Englewood Cliffs, NJ: Prentice-Hall; Bandura, A. (1977b). Self-efficacy: Toward a unifying theory of behavioral change. <u>Psychological Review</u> , 84, 191-215; Bandura, A. (1982). Self-efficacy mechanism in human agency. <u>American Psychologist</u> , 37, 122-147; Smith, R.E. (1989). Effects of coping skills training on generalized self-efficacy and locus of control. <u>Journal of Personality and Social Psychology</u> , 56, 228-233). |
| <b>Well-being</b>                           | A personal sense of feeling and being content with a variety of areas of one's life including but not limited to: physical, emotional, and mental health, interpersonal relationships, social activities, and occupational opportunities and activities.  |
| <b>Wellness</b>                             | (See well-being)  |
| <b>Workforce</b>                            | All potential workers (those individuals who mentally and/or physically perform activities that lead to the production/accomplishment of something); often grouped by geographic region, by industry, or by age group.  |
| <b>Youth with special health care needs</b> | See MCHB def (age range 11-25)  |

