Needs and Goals

The following table shows the relationship between needs, as identified through State plans and research documents and input from the CAC, and the goals and objectives identified in the UCEDD five- year plan, which are detailed in Section 2.

TABLE 1: Relationship between Documented Needs and UCEDD Goals

Documented Needs	Source(s)	UCEDD Goals & Objectives
HEALTH: Ensure and expand access to appropriate and quality health promotion, wellness, medical, oral and health services for children and adults with developmental disabilities.		
Individuals with disabilities experience persistent health disparities, including high rates of poor oral health; increased obesity; higher rates of diabetes and cardiovascular problems; and high rates of co-morbidities, particularly combinations of physical and behavioral or cognitive problems. Access to quality health care remains problematic; people with disabilities are twice as likely to go without needed care; when care is available, there is often a lack of continuity, and that care is likely to be provided by personnel without specific expertise in disability. There is a need for lifelong availability of comprehensive health records in formats accessible to individuals with developmental disabilities and their caregivers. The shift in the focus of health services toward health promotion and prevention must include individuals with disabilities as active partners; health activities need to be integrated into community environments; health education resources developed specifically for individuals with developmental disabilities and their caregivers are rare; and a program of applied research that addresses the progression of health issues over an individual's lifetime, health care strategies that improve access, the quality of services, health outcomes, and cost-benefit analyses of different health models is needed.	Focus group of CAC members, community leaders and WIHD staff (12/15/06). DDPC State Plan, (NYS DDPC, 2006a) NYS DDPC, 2006b. NYS Disability and Health Plan (NYS DOH, 2007) Behavioral Risk Factor Surveillance System (Centers on Disease Control and Prevention, 2006) Horowitz, Kerker, Owens, & Zigler, 2001. Rizzolo, et al., 2005. Scheepers, et al., 2005. Shogren, Wehmeyer, Reese, & O'Hara, 2006. Special Olympics, Inc., 2001. U.S. Department of Health and Human Services, 2002.	- Interdisciplinary fellowship; other internship training - Pediatric, family practice and internal medicine residency training - Collaboration with University of Puerto Rico, University of the Virgin Islands, and the "pipeline" project - Distance learning - Oral health education - Web portal - Health education, including training materials that can be used by individuals with developmental disabilities as trainers or co-trainers - Health promotion and prevention of secondary conditions - Technology applications - Conferences - New knowledge, conference presentations, and dissemination products in all of the above

Documented Needs	Source(s)	UCEDD Goals & Objectives
QUALITY OF LIFE - SELF DETERMINATION: Promote leadership, self-advocacy, and self-determination for individuals with developmental disabilities and their families in support of leading lives as valued community members.		
The self-advocacy movement has made major strides in the past decade, reaching a national level of recognition as a key partner with disability organizations with the Alliance for Full Participation Summit in September 2005. The Summit identified four priority areas – leadership, community participation, self-determination, and enhancing the quality of services and supports. In the area of leadership, the need for systematic efforts at cultivating the "next generation" of leaders, which requires a focus on advocacy and career development in the field of developmental disabilities for self advocates, family members, advocates, staff of disability organizations, and other professionals. Information and training initiatives will need to address values and practices that promote effective and life-affirming self-determination and individualized supports toward the attainment of real lives. This includes person-centered and family-centered practices; individualized, integrated and inclusive supports; self- and family-directed decision making; community building; and flexible and responsive organizational and service systems options. Emergency preparedness has received a great deal of attention in recent years. Despite the growing awareness of the need for families and individuals to have plans, few in fact have them. Peer support offers an efficient and effective model for assisting in the development of emergency plans. The planning process also offers the opportunity to educate emergency personnel in the community about disability.	Focus group of CAC members, community leaders and WIHD staff (11/28/06) New York State Alliance for Full Participation Team, 2005 Levitz & Levitz, 2005 NYS DDPC, 2006b NYS DDPC, 2007 NYS Disability and Health Plan, 2007 Clive, 2004 Hemp & Braddock, 2003	• Volunteer community service model and information to professionals and the general public • Emergency preparedness training model for families and individuals with disabilities living independently, with curriculum and trainers' guides • Community training and technical assistance on self-advocacy, self-determination, individualized supports, and leadership • Accessible information for use by self- advocates in training professionals about self-determination • New knowledge, conference presentations, and dissemination products in all of the above
COMMUNITY SUPPORTS: Enhance community services, including formal and informal community supports that affect the quality of life of individuals with developmental disabilities and their families.		
The 1997 reauthorization of the *Individuals with Disabilities Education Act* (*IDEA*) required that assistive technology (AT) consideration be conducted for all students with disabilities, which remained unchanged in the 2004 reauthorization of IDEA. This federal mandate added 3.8 million students, ages 6-21, to the AT case load.	Focus group of CAC members, community leaders and WIHD staff (11/28/06) Edyburn, 2004 Wright & Wright, 2007	• Assistive Technology School Consortium, publications for professionals and policymakers • Assistive technology -- training and technical

Documented Needs	Source(s)	UCEDD Goals & Objectives
Access to quality AT service delivery systems continues to be problematic, and the profession has been caught unprepared in terms of personnel preparation. Few schools have staff adequately trained in the application of AT to identified learners within school settings, nor the means to provide students with the needed technologies in a timely manner. Currently, there is a need for pre-service training in the area of AT and assisting school district administrators, teachers, therapists, and support personnel in the development of assessment and implementation strategies. Program development should consider the increasing convergence of educational and assistive technology to meet the needs of all students within an educational setting. Behavior problems remain the leading reason for referral to more restrictive settings for school age children and more recently for expulsion from preschools and child care settings; school personnel are still unfamiliar with how to implement requirements of IDEA related to functional behavioral assessments (FBAs) and behavior intervention plans (BIPs); parents and advocates require training in how to enforce IDEA rights related to behaviors "impeding" learning; preschool and child care settings require streamlined methods for FBAs and BIPs; parents require support for developing positive behavioral interventions for home and community. The prevalence of autism is at historical highs. Early detection and interventions are critical to mitigating long-term effects. There is a need for understanding signs and symptoms of autism in young children, and for training and support in evidence-based practices for parents. Youth with special health care needs, chronic health conditions, and disabilities require specialized supports to transition to all aspects of adulthood, including adult health care, employment and independence. Individuals and families want access to information about services options in order to make informed decisions.	Beukelman & Mirenda, 2005 Cook & Hussey, 2002 Cavanaugh, 2006 Crimmins & Farrell, 2006 Crimmins, Farrell, Smith, & Bailey, in press U.S. Department of Education, 2006 NYS DDPC, 2006b CDC, 2006 Interagency Autism Coordinating Committee, 2006 Charman & Baird, 2002 Harris & Handleman, 2004 Mandell, Listerud, Levy, Pinto-Martin, 2002 Keenan & Wakschlag, 2000 McConnell, 2002 Healthy and Ready to Work Center, n.d. American Academy of Pediatrics, et al., 2002	assistance, loans, and demonstrations • Positive Strategies – training and technical assistance for schools, preschools, parents, publications • Autism Spectrum Disorders – training and technical assistance, training video for professionals (including Spanish version) • Transition --demonstration and supportive products • Information and referral through Parent-to-Parent, Early Childhood Direction Center, and Regional Technology Center • New knowledge conference presentations, and dissemination products in all of the above

Documented Needs	Source(s)	UCEDD Goals & Objectives
QUALITY OF LIFE - CHILD WELFARE: Enhance services, supports, and other assistance to ensure the protection, safety, and well-being of children with disabilities in the child welfare and adult protective services systems, and to assure that children with disabilities live in permanent family situations, free from abuse and neglect.		
An estimated 872,000 children determined to be victims of child abuse and neglect in 2004 – a rate of 12 per 1,000 children. Child maltreatment is often only one aspect of children's lives in households that experience poverty, substance abuse, mental health problems, physical disability, stress, or other forms of violence. Mental health and behavioral problems affect 50 to 80% of children in foster care; 60% of preschool age children have developmental delays. Children experience long-term problems in health, cognitive effects, and developmental delays, resulting not only from specific injuries, but from the absence of positive parental nurturance. Successful interventions depend on coordination, continuity, and expertise, which are often lacking in the child welfare system. Care is frequently fragmented across medical, mental health, educational, and social service systems. There is a high turnover in case managers, and children frequently move from location to location and provider to provider. Planning for youth exiting foster is often absent or inadequate. Parents with intellectual disabilities are at greater risk for losing parental rights even though they comply with court directives. Enhancing healthy development in the lives of maltreated children requires attention to increasing positive family and peer interactions – as well as reducing exposure to violence and neglect. Nationally, approximately 15% of child victims were placed in foster care. The ability of the child abuse system to recognize the special health care needs of these children is often limited. Providing multidisciplinary assessments of child victims reduces trauma to those children and increases child safety.	U.S. Department of Health and Human Services, Administration on Children, Youth and Families (2006) Inkelas & Halfon, 2002 Leslie, Hurlburt, Landsverk, Rolls, Wood, & Kelleher, 2003 Chalk, Gibbons, & Scarupa, 2002 Badeau, Perez, Lightbourne, Gray, & Suleiman Gonzalez, 2004 Rubin, Allessandrini, Feudtner, Mandell, Localio, & Hadley, 2004 Focus group of CAC members, community leaders and WIHD staff (12/15/06) Rao, Heller, & Breitner, 2006 Geenen & Powers, 2006 NYS DDPC, 2006b Burns, Wagner, Kolko, & Landsverk, 2004	• System for coordination of health, mental health, and educational services; accessible electronic info system disseminated nationally to child welfare agencies • Supports for parents with intellectual disabilities • Training for child welfare workers; online training modules disseminated • Training for birth, foster, and adoptive parents • Interdisciplinary and interagency approach to serving children and adults with developmental disabilities who are victims of sexual abuse • Person-centered planning for children exiting foster care • Conference and health and educational concerns of children in foster care • New knowledge conference presentations, and dissemination products in all of the above