The following information corresponds to the bulleted information on page 1 of the survey:

1. The UCEDD continued its training partnership with People First, the DD Council supported consumer group. Project II (a local People First chapter) members help us to offer meaningful training experiences from the perspective of consumers. These consumers continue to assist in training sessions offered for para-professionals at the UCEDD. The consumers are part of the overall training team. They conduct presentations on an ongoing basis during staff training events.

2. Mr. Mark Smith, the UCEDD Parent/Consumer Coordinator, has been involved in numerous advocacy, capacity building and systems change activities, including presenting at the People First Annual Convention. One of his major activities has been providing staffing support to the MMI Consumer Advisory Board. This has included organizing and facilitating meetings among specific CAB member groups. This past year, the Board played a key role in the MTARS. Members of the Consumer Board met with the reviewers directly, and participated in implementing the recommendations emerging from the review. The CAB continued to take a strong role overall in advising the UCEDD on consumer and family issues. For example, the Consumer Board provided extensive input into the annual report to ADD, including potential areas of emphasis for the UCEDD during the coming year, and into the revised Consumer Satisfaction Survey instrument, which is utilized as a quality improvement tool for activities provided by the UCEDD. Mr. Smith also attended and supported the activities of the Recreation Parent Advisory Committee (RSPAC), assisting in planning and running quarterly advisory meetings and participating in planning and fund raising efforts.

Mr. Smith advocates both systemically and individually. He has provided referral and informational assistance to family members and consumers seeking assistance related to service and support needs and provides feedback and information to families and consumers via the FamilyTalk Listserv administered by the Nebraska Center on Public Policy. He serves on various boards and workgroups related to disability advocacy including the Governing Board of PTI-Nebraska; the Nebraska Consortium for Citizens with Disabilities; the Together for Kids grant to the state DHHS (an early childhood planning activity); the Consumer Task Force to the Real Choice grant, (this included assisting in the development of training curricula for consumers on the principles of and strategies for self-direction); the YouthCare Inc. Human and Legal Rights Committee; the Governmental Affairs Committee to DEC; and others. In addition, he served on two standing committees for AUCD. These included membership on the Legislative Affairs committee and the Consumer Advisory Council. More recently, he is participating in a State Legislature study regarding aspects of state community developmental disability services.

3. Last year, the UCEDD, with funding from the Hattie B. Munroe Foundation, established a pre-school autism treatment program, Project Best Case. Children with autism and related spectrum disorders are one of the most difficult and costly group of children with developmental disabilities to treat. Numerous children have been successfully returned to their home school program and the program has expanded to include school programs from western Iowa and rural Nebraska. Technical assistance has been provided to teachers across the state. As part
of the State’s plan to serve children with autism and autism spectrum disorders, UCEDD staff have been extensively involved with the Nebraska Department of Education in developing a state plan that establishes a Statewide coordinator position, training requirements, and a series of six regional autism educational teams that provide education and support to children with Autism in school systems and their families.

4. As seen during the Nebraska MTARS review, the three ADD funded programs in our state routinely and consistently collaborate. Monthly joint meetings facilitate communication and planning. We have found that the most effective strategies in Nebraska are based upon frequent communication, joint planning and common goal setting. The UCEDD Director serves on the DD council, the DD Council President on the UCEDD’s Consumer Advisory Board and the P&A Director serves on the UCEDD’s CAB and on the DD Council. Collaborative activities have included our joint Waiting List Initiative efforts, Ticket to Work Incentives Act activities, Health Disparities efforts and efforts to address personnel shortages in Nebraska. The three programs worked jointly to protect the Tobacco Settlement funds which were earmarked for use to reduce the waiting list and have jointly worked to affect changes in the process used by the state to assess client needs. There have been no problems encountered among the agencies. We continue to work together on key areas. For example, the three programs agreed to a common goal of reviewing transportation in Nebraska which will be one area of emphasis for the UCEDD in the coming year.

5. In addition to community-based pediatric behavioral health clinics in Columbus, Hastings, Plattsmouth, and Papillion, we added clinics in Nebraska City, Valley, and Council Bluffs, Iowa, over this past year. These clinics are designed to integrate behavioral health services into pediatric primary care offices and expand the capacity of both the UCEDD and the local medical providers to support individuals in medically underserved areas. Over 3,000 clinic visits for children and adolescents with behavioral difficulties and their families were provided this past year.

6. The UCEDD continued to provide interdisciplinary clinics in Winnebago, which are funded by the Indian Health Service. Six times each year a geneticist, psychologist and a developmental pediatrician travel to the Winnebago reservation to provide screening and triage for Native-American children with developmental and behavioral problems.

7. “Project DOCC”, a parent-driven course designed to enhance the education of medical students so that they will be better equipped to provide care to children with chronic illness and their families, was introduced into the Pediatric Resident Developmental/Behavioral Pediatrics Rotation in February, 2004. The curriculum was designed and taught by parents of children who have chronic illness or disability. “Project DOCC” was developed from the perspective of family-centered care and is designed to enhance family involvement in the direction of health care delivery and to influence the education of health care providers. It offers perspectives to students that faculty usually do not have and promotes provider / patient partnerships while giving families more empowerment over their healthcare.

8. The Nebraska Department of Health and Human Services was awarded the “Real Choices for Nebraskans” grant in 2001 from the Centers for Medicare and Medicaid Services. DHHS has contracted with the UCEDD to address the grant’s training and quality assurance goals. The overall purpose of this project is to design and implement effective, enduring improvements in Nebraska’s health and long term care service system to enable children and adults who have a disability or long term illness to live in the most appropriate integrated community setting, to
exercise meaningful choices about their living environment, to select providers of services, and to obtain quality services. The UCEDD is assisting in the overall planning for the project, is responsible for training consumers and service coordinators, and the development and implementation of a quality management process.

Current activities in Real Choice have included development of an awareness video, implementation of training for services coordinators, and development and implementation of a training curriculum for consumers and family members. The Real Choice video is a 17 minute video which illustrates how people with disabilities are directing their own services within the Nebraska system. In the video, the viewers meet five individuals who share their life experiences and self direct supports to live their lives as they choose. Each story is a tribute to the desires and dreams of the persons to have freedom to grow, to be independent, and to live their own lives. The creation of the video was a year long process. Staff have also identified legislative needs to better address issues related to risks in self determination as part of the recommendations from grant efforts.

Nebraska has also received a second Real Choice grant that is working to implement a system of intermediary service organizations for access to personal care assistants that will support persons with disabilities to direct their own services. We are helping to design the model for Nebraska during this first year of planning.

9. The UCEDD continued its efforts to develop a Telehealth Program for children with special health care needs (CSHCN) in Nebraska. The Nebraska Telehealth Network began conducting clinical genetic and behavioral health services from the UCEDD to Scottsbluff, Nebraska. The Governor is expected to officially kick off the service in August or September of this year. Start-up funding has been received from the Nebraska Departments of Education and Health and Human Services. We anticipate expanding to Kearney, Grand Island, and Hastings this next year.

10. The UCEDD continued “Developmental TIPS.” Developmental TIPS is a statewide neonatal intensive follow-up program which has developed a standardized evaluation process for seven hospitals across the state of Nebraska. Funded through both the Nebraska Department of Education and Title V, many agencies, programs and parents have been part of the planning of this program. Data is collected via an Internet database and managed by the UCEDD. The data on outcomes for these children is used for policy planning. We are presently awaiting notification if funding is available to expand this program during the coming year.