

Members

Rep. Dennie Oxley
Rep. Vanessa Summers
Rep. Robert Alderman
Rep. Cleo Duncan
Sen. Kent Adams
Sen. Marvin Riegsecker
Sen. Allie Craycraft
Sen. Connie Sipes
Hugh Beebe
Mike Carmin
Nan Daley
Susan Hansen
Herbert Grulke
John Taylor



INDIANA COMMISSION ON AUTISM

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MEETING MINUTES¹

Meeting Date: September 8, 2004
Meeting Time: 1:00 P.M.
Meeting Place: State House, 200 W. Washington St., Room 130
Meeting City: Indianapolis, Indiana
Meeting Number: 2

Members Present: Rep. Vanessa Summers; Rep. Cleo Duncan; Sen. Kent Adams; Hugh Beebe; Herbert Grulke.

Members Absent: Rep. Dennie Oxley; Rep. Robert Alderman; Sen. Marvin Riegsecker; Sen. Allie Craycraft; Sen. Connie Sipes; Mike Carmin; Nan Daley; Susan Hansen; John Taylor.

Rep. Summers, Chair, called the second meeting of the Indiana Commission on Autism to order at 1:23 p.m.

Indiana Resource Center for Autism

Cathy Pratt, Director of the Indiana Resource Center for Autism (IRCA), provided the

¹ Exhibits and other materials referenced in these minutes can be inspected and copied in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for copies may be mailed to the Legislative Information Center, Legislative Services Agency, 200 West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for copies. These minutes are also available on the Internet at the General Assembly homepage. The URL address of the General Assembly homepage is <http://www.ai.org/legislative/>. No fee is charged for viewing, downloading, or printing minutes from the Internet.

IRCA's most recent annual report,² which includes information on the number of individuals in each county who are receiving the IRCA's newsletter. She noted that the incidence of autism has increased since the 1970's. She also discussed the following from page 24 of the annual report: (1) the IRCA's staff has trained 200 teams from local special education planning districts across Indiana during the past 10 years; (2) last year, approximately 2,944,443 individuals accessed the IRCA's website; (3) the IRCA disseminated 461,860 print and video items last year; and (4) last year, IRCA staff trained 12,167 professionals and family members.

Ms. Pratt also provided the Commission with a pamphlet concerning an IRCA workshop,³ a schedule for parent group meetings,⁴ and a booklet concerning a conference on biomedical research⁵ sponsored by the Autism Society of America and the IRCA. She noted that the IRCA plans to talk about insurance coverage at the parent group meetings this year.

In response to questions from Commission members, Ms. Pratt explained that the rise in the incidence of autism among individuals may be a result of increased knowledge of autism, better reporting, and the expanded definition of the autism spectrum.

The Christian Sarkine Autism Treatment Center

Naomi B. Swiezy, Ph.D., HSPP, Associate Professor of Psychology in Psychiatry and Clinical Director, Christian Sarkine Autism Treatment Center (CSATC), provided a packet of information to Commission members.⁶ This packet includes the following: (1) 3 pamphlets with general information on the CSATC; (2) 3 pamphlets on workshops provided by the CSATC and Riley Hospital for Children; and (3) a handout on the CSATC presentation.

Dr. Swiezy discussed the history of the CSATC, including information concerning additional funding for CSATC that came from a U.S. Department of Housing and Urban Development (HUD) grant sponsored by Congressman Burton, and a Centers for Disease Control and Prevention (CDC) grant in 2004. She indicated that the vision of the CSATC was established and included the following: (1) provision of a continuum of coordinated services to families with Autism Spectrum Disorder (ASD) children and adults statewide; (2) serving as the ultimate source for comprehensive and quality assessment of treatment services to families in Indiana; and (3) providing a high standard of research, clinical, and education/training services. Dr. Swiezy concluded with the current status and plans for the future of CSATC.

In response to questions from Commission members, Dr. Swiezy indicated that CSATC serves 800 children, and CSATC receives a smaller and smaller amount of state funding. In response to questions concerning insurance coverage for services related to autism, Dr. Swiezy indicated that some companies offer such insurance, but the insurance coverage is

² Exhibit 1

³ Exhibit 2

⁴ Exhibit 3

⁵ Exhibit 4

⁶ Exhibit 5

very limited, and in general, insurance is not adequate to cover services at CSATC for autistic individuals. The median age at which Dr. Swiezy begins seeing autistic children at the CSATC is between the ages of 4 and 5, and the current waiting list to receive services is 1 year. The federal funding that CSATC currently receives is only for a limited period of time. The Commission members indicated that they would like to visit the CSATC facility.

Health Care Coordination

Kathy Auberry, RN, CDDN, Director of Health Services, Christole, Inc., provided a handout⁷ on health care coordination. She defined health care coordination and described specialized services that health care coordinators may provide. She indicated that Christole, Inc. received a grant from the Southeast Regional Out Services Committee to assist other agencies in implementing a quality health care coordination/nursing service. Ms. Auberry indicated that individuals need to be educated on the role of the health care coordinator in the field of developmental disabilities, and she provided examples of why such education is important. She also discussed 2 recent events at Christole, Inc. that exemplify how the health care coordinator provides consistent, flexible, and available oversight. Ms. Auberry concluded with suggestions for improvement in the delivery of health care coordination service.

Group Homes for Children

Sue Lindborg, President/CEO, Christole, Inc., provided a handout⁸ concerning group homes for children with developmental disabilities. She explained that Indiana has a total of 169 children's group home beds and there are currently 7 vacancies statewide. She indicated that many parents are likely sending their children out of state. She discussed the rationale for new homes, including the following: (1) there are 23,470 on the waiver waiting list; (2) the diagnosis of autism in children has increased; and (3) 207 adult group home beds are vacant or vacated statewide and are available for assignment within the system. Ms. Lindborg discussed the disadvantages of supported living programs. She also indicated that Christole, Inc., had received a number of referrals for services from 2001-2004, and there had been no significant growth of children's homes in the past 8 to 10 years.

Christole, Inc., submitted a proposal to the Division of Disability, Aging and Rehabilitative Services and the Bureau of Developmental Disabilities Services on August 5, 2004 for the development of group homes in District VIII in or near Jefferson, Clark, Jennings, and Scott counties.

Community Based Care

Nanette Whightsel, Director of Family Education and Community Resources, The Arc of Indiana, provided a booklet⁹ containing information on individuals who had moved from institutional care to community based care. She indicated that results from a survey showed that 90% of individuals who had moved from Muscatatuck Developmental Training Center to community-based care were happier in the community than in Muscatatuck.

⁷ Exhibit 6

⁸ Exhibit 7

⁹ Exhibit 8

Other Business

Members of the Commission discussed drafting bills for the next Commission meeting that would include: (1) a bill that would separate autism waiver slots; and (2) a bill that would redistribute vacated group home beds.

Dorothy Smith, a parent of an individual with autism, discussed the services her son was receiving and requested more accountability for providers and additional staff support.

Deborah Myers, a parent of a child with autism, sent a letter¹⁰ to the members of the Commission concerning the Support Services waiver and waiting list for Medicaid services.

Kim Dodson, Director of Government Relations and Development, The Arc of Indiana, provided a handout¹¹ containing a summary of waiting lists for individuals with developmental disabilities by age group.

Rep. Summers set the next meeting date for October 20, 2004 at 1:00 p.m.

With no further business to discuss, Rep. Summers adjourned the meeting at 2:53 p.m.

¹⁰ Exhibit 9

¹¹ Exhibit 10