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INDIANA COMMISSION ON AUTISM

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MEETING MINUTES[1]

Meeting Date:	**October 18, 1999**
Meeting Time:	**10:30 A.M.**
Meeting Place:	**State House, 200 W. Washington St., Room 128**
Meeting City:	**Indianapolis, Indiana**
Meeting Number:	**2**

Members Present: **Sen. Kent Adams, Chairperson; Rep. Vanessa Summers; Rep. Robert Alderman; Rep. Cleo Duncan; Nan Daley; Michael Carmin; Herb Grulke; Donna Ott.**

Members Absent: **Sen. Marvin Riegsecker; Sen. Allie Craycraft; Sen. Connie Sipes; Rep. Dennie Oxley; Hugh Beebe; Becky Zaseck.**

Senator Adams called the meeting to order at 10:35 AM and informed the members that Cathy Pratt, Indiana Resource Center for Autism, would present the Center's annual report to the Commission following consideration of the Preliminary Draft.

Preliminary Draft (PD) of Proposed 2000 Legislation

Sen. Adams explained PD 3377 (See Exhibit 1) regarding nonreversion of funds from the Developmentally Disabled Client Services Account. Sen. Adams informed the members that, since there were insufficient legislative voting members to officially approve the PD as

[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.

a commission draft, Sen. Adams would file the bill in the Senate. He noted that a member from the House of Representatives could also file the bill in the House. Members of the Commission who were present agreed by consent.

Indiana Resource Center for Autism (IRCA) - Annual Report

Cathy Pratt, Indiana Resource Center for Autism, presented IRCA's annual report and a handout (See Exhibits 2 and 3). She discussed capacity building, dissemination of information, research, training and consultation, and community outreach efforts. She showed a video of an advertisement that is shown during National Football League games featuring Hoosiers with autism. In response to a question from Ms. Ott, Dr. Pratt stated that there is follow-up done by IRCA of individuals trained by IRCA to see whether they remain active or not. She stated that teams of trained individuals work with teachers and families.

Ms. Daley stated that she was proud of the accomplishments made within Indiana. She noted that individuals and organizations concerned about autism issues are frequently critical of themselves, but that progress is being made in organization and movement toward solutions to many of the problems facing individuals with autism.

Implementation of the "317" Plan

Lauren Polite, Legislative Liaison, Family and Social Services Administration (FSSA), introduced Marjorie Gurnik, Director of Budget and Policy, FSSA, and John Hill, Division of Disability, Aging, and Rehabilitative Services, FSSA, to speak regarding implementation of the "317" plan.

Ms. Gurnik provided a copy of a news release regarding the "317" plan (See Exhibit 4). She stated that an advisory group comprised of public and private individuals was formed to guide implementation of the plan. She described the process through which determinations of how to spend the $39 million appropriated under the plan were made. Ms. Gurnik informed the Commission of the numbers of individuals on the various Medicaid waiver waiting lists and discussed the number of individuals with autism who have moved from waiting lists to the waivers. She stated that the policy is to place individuals with autism on both the autism waiting list as well as the ICF/MR waiting list and that FSSA will track the numbers and percentages of individuals with autism moving from waiting lists to waivers and report to the Commission.

In response to a question from Sen. Adams, Ms. Gurnik stated that implementation of the plan has resulted in individuals with autism comprising more than 10% of the individuals targeted for waiver services. In response to a question from Mr. Grulke, Mr. Hill stated that budget planning for waiver services includes predictions of individuals vacating the waiver and that slots from which an individual has left are not filled with a new individual until the following year. Korryn Fairman, FSSA, explained that this is due to federal requirements. She stated that waiver funds are available for a certain number of people, not slots, each year, so if a person vacates a slot that slot is not fully funded for another person to fill it until the following year. There was further discussion regarding movement from the autism waiver to the ICF/MR waiver and the impact of the vacancies that are created by this movement. Ms. Gurnik stated that FSSA is cognizant of the need to monitor the best use of the waiver slots.

John Dickerson, Executive Director, ARC of Indiana, stressed the importance of blending funding without losing accountability for provision of specific services. He stated that the goal of the "317" plan was to blend sources of funding to make it easier for individuals to

access services that are available, rather than being required to go to multiple funding sources for the services. He stated that there is now a priority emergency process for the waiver waiting lists. This allows an individual who encounters an emergency such as a caregiver's death to receive waiver services earlier. Mr. Dickerson also discussed expansion of the respite program. He explained that these changes are the first steps in the blending process and elimination of waiting lists which will take several years of streamlining to achieve. Mr. Dickerson provided a handout of the ARC News in Indiana, Fall, 1999 edition (See Exhibit 5).

Group Homes

John Hill, Division of Disability, Aging, and Rehabilitative Services, provided a folder containing several handouts (See Exhibit 6). Mr. Hill discussed quality assurance initiatives for the waiver programs. He explained provider monitoring and consumer feedback efforts including outcomes monitoring, incident reporting, diagnostic evaluation teams, waiver ombudsman, and protection and advocacy services. In response to a question from Rep. Duncan, Mr. Hill responded that there has been decreased overall funding for developmental disability services during the past few years as individuals have moved into community based settings.

In response to a question from Rep. Summers, Ms. Gurnik replied that some of the "317" money was used for administrative structure, as recommended by the advisory group and as permitted by the legislation that provided the funding. In response to a question from Rep. Alderman, Mr. Hill responded that all individuals who move from institutions to community based settings can be found within 48 hours and are being followed to ensure that they receive appropriate services.

Mr. Hill stated that group homes are one of a range of services that should be provided to meet the needs of developmentally disabled individuals. He stressed that increased data is needed to see how many group homes are actually needed and that waiting lists for group homes will decrease with the use of the "317" funding which will move individuals out of group homes and into waiver services. He acknowledged that the availability of group homes for children is a concern because of the conversion of the group homes to adult group homes as the children living there age.

Preschool Intervention Programs

Cathy Pratt, IRCA, pointed out a 1999/2000 work plan at the end of the IRCA Annual Report (See Exhibit 2), and discussed efforts being made by IRCA in the area of preschool intervention. She stressed the need for structure for individuals with autism, whose numbers are increasing, and that different approaches are effective for different individuals. She mentioned a report to be issued late this year by the National Academy of Sciences regarding the best approaches. She stated that an early childhood training program is being developed at IRCA and that a IRCA has applied for a grant and is working with First Steps and the Division of Special Education to explore the early intervention area. Dr. Pratt stressed that in her position she must focus on the entire spectrum of children with autism, not just one group in one place on the spectrum.

Rep. Duncan emphasized the need to prepare teachers to recognize and serve the needs of autistic children, especially very young children.

Bob Marra, Director, Special Education Programs, Indiana Department of Education, provided handouts (See Exhibits 7 and 8) and discussed the needs of disabled individuals aged 3 through 21 years. Mr. Marra stated that the family is at the center in meeting the

needs of these individuals. Mr. Marra referred to a study done by the Indiana Education Policy Center (See Exhibit 9) regarding alternative/residential services. He stressed the importance of moving toward redirection of funds to more localized uses and filling in gaps in services. Mr. Marra said that it is easier at this time to obtain $300,000 to send an individual student out of state for residential services than it is to obtain $3,000 to serve students in local programs. He acknowledged the need to begin to treat problems earlier in the lives of disabled individuals and to treat them locally, rather than treating them later at a higher cost. He said that there are system-based problems that prevent this from happening, and that the problems are not specific to individuals with autism.

Sen. Adams requested that Mr. Marra commit his thoughts and recommendations to paper for dissemination among members of the General Assembly. Mr. Marra stated that he would do so. In response to a question from Rep. Alderman, Mr. Marra stated that complaints of noncompliance with or inappropriateness of an education plan are investigated by his office or an external reviewer, depending on the specific type of complaint. In response to questions from Ms. Ott, Mr. Marra stated that it is up to the teacher and the administration of a school to ensure that the school system has the training that it needs to serve its students. There is no specific endorsement for autism in Indiana. He stated that teachers can request and receive training to help them serve individual students as needed.

In response to a question from Rep. Summers regarding the increasing incidence of autism in Indiana, Mr. Marra stated that there is a new definition of "developmentally delayed" in 511 IAC 7 to assist in prevention of inappropriate labeling, but allowing First Steps services to be accessed by children. He reiterated that the same amount that could be spent for one child's education out of state could be spent for three children's educations in Indiana and that appropriations need to be made to promote in-state services, rather than waiting until later when out-of-state services are necessary to serve the child. Mr. Marra stated that the current special education funding formula for preschool children needs to be revised so that increased money can be spent for children to be served at home for less than would be needed for residential services. Mr. Marra stated that he believes there is money in the system to do this, but it needs to be redirected, and that will require much information sharing and work to accomplish. Sen. Adams restated the need to get this information and Mr. Marra's recommendations out to the General Assembly and others.

Tom Hansen, Director of Legal and External Affairs, Professional Standards Board, provided a handout regarding licensure standards (See Exhibit 10). Mr. Hansen discussed the future system for licensing of teachers in Indiana. He stated that new licensure methods will be followed within the next couple of years including certifications for specialty areas. Mr. Hansen introduced Barb Horvath, volunteer on the advisory group for development of exceptional needs standards, to testify. Ms. Horvath explained that all students aged 3 through 21 years with exceptional needs were considered in the creation of the future standards.

In response to questions from Sen. Adams and Mr. Grulke, Mr. Hansen explained the current five year renewable licensure. This will change to two year initial licensure with five year renewable licensure if the teacher meets certain continuing education and performance requirements.

Sen. Adams stated that it is important to keep the education issue alive and that the 2001 session will be the best time to act legislatively. Sen. Adams stated that 2000 should be a year to lay groundwork by informing people about the issues discussed during the 1999 interim meetings of the Commission so that people will have the information needed to act

during the 2001 session.

Sara Neill, parent, Indianapolis, Indiana, stated that she has two children with autism. She emphasized that autism has no standard picture, but rather multiple manifestations of the same disorder. She expressed her belief that educators are the friends of children and need to be educated about how to assist children with autism in learning. She stated her additional belief that schools want to provide the services needed by children with autism, but that financing those services is a major problem. She noted that certain forms of treatment work for certain children, but various forms of treatment need to be available as all treatment types do not work for all individuals with autism.

Raymond Higgenbaum, an adult with autism, Indianapolis, Indiana, stated that he is involved with work to form support groups for adults with autism. He is involved with the Central Indiana Autism Society and expressed a desire to work with Ms. Daley in the Partners in Policymaking program. Ms. Daley stated that she would discuss this with Mr. Higgenbaum.

Jill McNeil, parent, Highland, Indiana, discussed her belief that the special education standards in 511 IAC 7 are very low and that she dropped a due process hearing that she was pursuing for her son who has autism because it was apparent to her that she would lose. She stated that she would provide information on the Wisconsin Medical Assistance Program (See Exhibit 11).

Andrea Kellar, parent, Valparaiso, Indiana, inquired as to what movement could be anticipated in the future. Sen. Adams responded that information should be disseminated to the members of the General Assembly as mentioned during the meeting, and contacts by interested parties to their individual representatives in the General Assembly regarding the issues discussed during the meetings should be pursued. Sen. Adams stressed that the more interest that can be generated, the better the chances for movement to occur. Ms. Daley stated that the power of any movement that occurs is in the hands of the individual with autism who teaches the individual's family, and the family who advocates for the needs of the individual by teaching others.

Sen. Adams adjourned the meeting at approximately 1:00 PM.

*Following the meeting, Mr. John Leemhuis provided a handout of prepared testimony (See Exhibit 12) regarding early intervention with his son.