

Members

Rep. Sheila Klinker, Chairperson
Rep. Robert Alderman
Sen. Marvin Riegsecker
Sen. Rose Ann Antich
Sylvia Marie Brantley
Christopher Durcholz
Suda Hopkins
Sally Lowery
Ervin Picha
Joanne Rains
Thomas Van Meter
Betty Williams



INDIANA COMMISSION ON MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

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MEETING MINUTES¹

Meeting Date: August 29, 2000
Meeting Time: 1:00 P.M.
Meeting Place: State House, 200 W. Washington
St., Senate Chambers
Meeting City: Indianapolis, Indiana
Meeting Number: 2

Members Present: Rep. Sheila Klinker, Chairperson; Rep. Robert Alderman; Sen. Marvin Riegsecker; Sen. Rose Ann Antich; Sylvia Marie Brantley; Christopher Durcholz; Suda Hopkins; Ervin Picha; Joanne Rains; Thomas Van Meter; Betty Williams.

Members Absent: Sally Lowery.

Call to Order

Representative Klinker called the meeting to order at approximately 1:00 p.m.

John Hill, former Deputy Director, Division of Disability, Aging, and Rehabilitative Services (DDARS) of the Family and Social Services Administration (FSSA)

John Hill spoke to the Commission regarding the achievements that have been made in

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DDARS, areas that still need improvement, and his desire to continue to work on behalf of individuals with developmental disabilities as a private citizen. ("Exhibit A" is a written copy of Mr. Hill's testimony.) Representative Klinker thanked Mr. Hill for his dedicated service with DDARS and agreed that although great strides have been made in serving individuals with developmental disabilities, many challenges remain.

Criminal History Checks for Direct Care Staff

Bob Brown, American Federation of State, County, and Municipal Employees (AFSCME) Council 62, told the Commission that his organization represents many state employees, including employees of the two state developmental centers that care for individuals with developmental disabilities. AFSCME is not opposed to the idea of requiring criminal history checks for direct care staff, but would like to be involved in the process of drafting any legislation on this issue to assure that the due process rights that state employees currently have are protected and that any non-state employees covered by the legislation are also afforded due process. Responding to a question from Representative Klinker, Mr. Brown stated that AFSCME is not opposed to the idea of a direct care staff registry as was proposed in SB 370-2000 as long as there are due process protections.

Melissa Durr, Executive Director, Indiana Association of Area Agencies on Aging (IAAAA), informed the Commission that the area agencies on aging are the largest private employers of Medicaid waiver case managers in the state. The IAAAA supports a criminal history check requirement for case managers as an important part of the quality assurance process. ("Exhibit B" is a written copy of Ms. Durr's testimony.) Responding to a question from Representative Klinker, Ms. Durr stated that the IAAAA also supports including case managers in the direct care staff registry.

Mark Scherer, General Counsel, Indiana Health Care Association (IHCA), told the Commission that private intermediate care facilities for the mentally retarded (ICF/MRs) are included in the statutory definition of a health facility (commonly called a nursing home) and as such are subject to many regulations, including a requirement to conduct criminal history checks for all employees who have contact with residents. The IHCA requests that any legislation requiring criminal history checks on direct care staff contain an exception for private ICF/MRs so that these facilities do not have to conduct duplicate checks on the same employees. The IHCA also endorses having cross-referral between the current nurse aide registry and any direct care staff registry that might be created. Responding to a question from Representative Klinker, Mr. Scherer stated that the IHCA has no problem with the current nurse aide registry.

Commission member Betty Williams stated that as a person with disabilities, requiring direct care staff to undergo a criminal history check is very important for the person being served to feel protected.

Introduction of and Comments from Katie Humphreys, Secretary of FSSA and Don Mohnke, Acting Director of DDARS

Katie Humphreys informed the Commission that she has been involved in serving individuals with developmental disabilities for over 29 years, having started her career at the former Northern Indiana Children's Hospital. She also introduced the Commission to Dan Mohnke. Ms. Humphreys and Mr. Mohnke presented a Power Point presentation outlining FSSA's main goal and core values in serving persons with developmental disabilities, progress made, lessons learned from experience, and ideas for going forward. Ms. Humphreys informed the Commission that FSSA is investigating whether money from the transition fund can be used to implement some of the ideas for going forward. She

stated that any planning for the future must include input from all stakeholders and must be done in an acceptable time frame. ("Exhibit C" is a printed copy of Ms. Humphreys' and Mr. Mohnke's presentation.)

Representative Alderman raised a concern that an emphasis on outcome-based incentives could result in profoundly handicapped individuals being left behind. Ms. Humphreys stated that the person-centered planning process, which sets goals based on a specific individual's strengths, goals, and weaknesses, should prevent these individuals from being left behind. Responding to a question from Senator Antich, Ms. Humphreys acknowledged that there are probably not currently enough service providers to provide all the services that will be needed by persons who are transitioned from institutional settings to the community.

Responding to a question from Representative Klinker regarding what kinds of incentives the state can offer to get more people to work in direct care staff positions, Ms. Humphreys stated that she needs to meet with providers to establish definite plans because different incentives would work better for different providers, although an increase in wage rates would probably help all providers attract more staff. Representative Klinker noted that individuals with developmental disabilities are very vulnerable and the state needs to look at wage parity as a way to address the high turnover of direct care staff, especially because of the disruption that staff turnover creates for the individual being served. Commission member Sylvia Brantley suggested that the waiver programs should be looked at to see if it is possible to streamline the process so there are fewer individuals who are receiving a portion of a waiver recipient's funds, especially individuals who never actually have any direct contact with the recipient. Ms. Humphreys stated that FSSA is going to review the waiver programs to determine if there is any streamlining that can be done.

First Steps

Senator Connie Lawson explained to the Commission that First Steps is a relatively new program that has undergone rapid growth since its inception. She stated that this rapid growth underscores the need to be sure that quality assurance measures are in place. She presented the Commission with PD 3193 ("Exhibit D") which she described as a starting point for discussion. This draft would require all organizations and individuals who provide vocational rehabilitation services to adults or early intervention services to infants and toddlers with disabilities to be accredited by an independent national accreditation agency, with an exception for an organization or individual who does not receive more than \$15,000 in reimbursement from the state during a state fiscal year. This draft would also require the MRDD Commission to annually review the First Steps program.

Senator Lawson explained that the First Steps program provides early intervention services to infants and toddlers (up to age three) with developmental disabilities. She stated that there are currently about 14,000 children enrolled in the First Steps program. [Prior to the date of the meeting, Senator Lawson provided two documents to Commission members with information regarding the First Steps program: 1) 1999 Annual Performance Report "Colors for Every Star, Caring for Every Child" ("Exhibit E"); and 2) "Marion County First Steps" ("Exhibit F").]

At the request of Senator Lawson, Marissa Manlove, Director of External Relations, Noble of Indiana, gave the Commission members a letter from The Council on Quality and Leadership in Supports for People with Disabilities ("Exhibit G"). Ms. Manlove explained that this letter expresses the council's willingness to work with Indiana to develop an accreditation review process for independent practitioners. The letter also includes a

general overview of the council's current accreditation process. Ms. Manlove stated that Noble does not endorse one accreditation organization over another but does believe that accreditation is a way to look at assuring quality of services.

Representative Klinker informed the audience that the issue of requiring accreditation of First Steps providers is new to the Commission and that the Commission does not have any bias in favor of or against accreditation. She assured the audience that the Commission was willing to hear the opinions of people on all sides of the issue.

Marge Gurnik, Director of Policy and Budget, FSSA, presented Commission members with a handout regarding some of the financial aspects of First Steps ("Exhibit H."). Ms. Gurnik explained that there was initially some federal funding which was limited to infrastructure and program development only. Ms. Gurnik stated that First Steps is a non-income-based entitlement program which provides early intervention services to all children who meet state-established eligibility requirements. There are 16 services federal law requires to be provided. Although federal law allows cost sharing (e.g., a sliding fee scale), Indiana does not currently utilize cost sharing.

Between 1994 and 2000, the number of Indiana children served by First Steps increased 95%, from almost 6,900 children in 1994 to an estimated 13,400 children in 2000. FSSA projects an increase to more than 16,600 children by the end of 2002. Since fiscal year 1998, expenditures have gone from \$24 million to \$44 million, with spending estimated to be near \$75 million by the end of fiscal year 2003. Ms. Gurnik noted that although First Steps is an entitlement program, it does not have entitlement funding (i.e., the funding for the program is capped and does not increase based on increased program expenditures). FSSA has worked to find other sources of funding for First Steps, including Medicaid and Temporary Assistance to Needy Families (TANF) funds. However, Medicaid and TANF funds can be used to benefit only low income families. Approximately 38% of Indiana families receiving First Steps services are not considered low income. FSSA projects a funding shortfall for the program of \$5.4 million in 2001, \$9.4 million in 2002, and \$13.5 million in 2003. FSSA believes that the program's funding shortfalls can be covered by shifting some services currently provided through the Division of Family and Children to other areas in order to maximize federal reimbursement, thus freeing up funds to use for the First Steps program. FSSA does not anticipate requesting additional state funding for First Steps in the upcoming biennial budget.

Ms. Gurnik explained that one of the most difficult factors in projecting future program expenditures is the uncertain growth rate of the program and that a higher or lower than anticipated growth rate could have great impact on the projected funding needs. In order to address the financial uncertainties of the program, FSSA is working to make sure that effective management and data oversight mechanisms are in place. Some of these mechanisms include: quarterly data analysis, quarterly county management reports, expansion of training for service coordinators, formation of a statewide quality assurance review team, research into options used by other states (including cost sharing) and other Indiana programs (e.g., Children' Health Insurance Program), and the creation of a fiscal work group that includes representatives of providers, families, the Interagency Coordinating Council, and advocates.

James Hmurovich, Director, Division of Family and Children (DFC), FSSA, explained to the Commission that the DFC is the division of FSSA that is responsible for, among other programs, child care, child support, child welfare, and other services for children's development, including First Steps. Mr. Hmurovich stated that two key issues come into play in operating a successful early intervention program: 1) building community capacity to provide quality choices for the consumer; and 2) the mere perception that a program is

not working properly can adversely affect the actual operation of the program. He expressed his belief that accreditation of providers is important to address both of these issues and that most stakeholders could agree that any legislation regarding accreditation should: 1) support an improvement in the quality of services provided; 2) continue to promote the development of good services and outcomes; 3) continue to maintain family choice; 4) make good common sense to the children and families served, the providers, and the taxpayers; and 5) recognize that there are inherent differences in the delivery of services to children and to adults. FSSA believes that accreditation of providers is a way to assure confidence, credibility, accountability, and quality of services in the First Steps program.

Responding to a question from Representative Klinker, Mr. Hmurovich stated that he did not know of any reason why the state would not want to require accreditation. However, he explained that he understood the concerns of some smaller providers regarding the cost of accreditation, but that legislation could be enacted with a threshold of the amount of reimbursement a provider would have to receive in order to be accredited or perhaps exempting family members who provide certain services.

In response to a concern raised by Commission member Joanne Rains, Mr. Hmurovich explained that FSSA is putting an emphasis on trying to prevent the need for early intervention services by providing services through such programs as Healthy Families and Building Bright Beginnings.

Responding to Commission member Tom VanMeter, Mr. Hmurovich stated that one possible "common sense" approach to requiring accreditation of providers might be to provide some sort of state funding for smaller providers that might find the accreditation cost overwhelming. He did caution, however, that this type of an option would be limited by available funding. Senator Lawson noted that although there were some very high numbers quoted for accreditation costs during the Senate Health Committee meeting last session, those costs were based on existing accreditation procedures for organizations. Both The Council on the Accreditation of Rehabilitation Facilities (CARF) and The Council on Quality and Leadership in Supports for People with Disabilities estimate that the cost for accreditation of an individual provider would be between \$1,000 and \$3,000.

Carla MacDonald, Early Intervention Administrator, Pathfinder, Huntington, and parent of a First Steps child, expressed her belief that quality assurance in the First Steps program is critical for the recipients, the taxpayers, and the community. She stated that she endorses the CARF accreditation process and had formerly been involved in that process as a surveyor for 10 years. The accreditation process involves much more than a review of paperwork, including confidential interviews with parents, staff, and funding and referral sources and observation of children receiving services. She stated that CARF surveyors are also providers so they have a complete understanding of the issues that providers face. The CARF process is a consultative approach that seeks to avoid conflict. Accreditation of First Steps providers is of great importance because of the rapid increase in the number of children receiving services and the rapid growth of independent providers. Ms. MacDonald also noted that current Indiana law requires accreditation of organizations and individuals who provide services to adults and the children and families who participate in First Steps deserve no less. The question should not be whether to require accreditation but how to implement such a requirement in such a way as to be accessible, affordable, and reasonable for all providers regardless of size and to not adversely affect the choice of families participating in the program.

Denise Arland, Chairperson, Interagency Coordinating Council (ICC), and parent of a First Steps child, presented the Commission members with a packet of information titled "First

Steps: Indiana's Early Intervention System for Infants, Toddlers & Their Families" which included a written copy of her testimony. (Exhibit I.) Ms. Arland gave an overview of the history, composition, and responsibilities of the ICC. She stressed that Indiana's First Steps program is considered a model program across the country. Ms. Arland stated that the ICC is committed to assisting FSSA in pursuing measures to improve the quality of outcomes for children and their families and that several projects are already under way to achieve this goal, including tying funding to local outcomes and the implementation of a peer to peer review process. She also explained that FSSA has developed an extensive credentialing process to ensure that all First Steps providers have experience and training in core early childhood competency areas. Ms. Arland stated that one of the most exciting current projects of the ICC is the establishment and implementation of statewide system outcomes for children, families, and communities by which to measure the success of First Steps. Ms. Arland stressed that a one-size-fits all approach to quality assurance will not serve the First Steps population well and that quality assurance in early intervention must be a process that is flexible and equitable and that encourages participation by all providers.

Responding to a question by Representative Klinker, Ms. Arland remarked that requiring accreditation of all First Steps providers might adversely affect the ability of those children who need services to obtain them.

Stephan A. Viehweg, Associate Director for Administration, Riley Child Development Center, explained the First Steps Unified Training System (UTS). Mr. Viehweg noted that the program's personnel standards establish minimum requirements for each specific early intervention service. In addition to meeting these minimum education and/or licensure requirements, all providers must complete an orientation to First Steps which covers the legal, procedural, and due process aspects of the program. Service coordinators are required to attend special training in addition to the orientation. Several programmatic and topical training workshops are offered, with parents encouraged to attend as well. Several documents are available to both providers and families regarding procedural safeguards, including a number of brochures, publications, and manuals. Regular monitoring of data available to FSSA as well as complaints filed by families or providers has resulted in corrective action or even disenrollment of some providers. Beginning October 1, all new service coordinators and developmental therapists must obtain 12 months of supervised experience in early intervention. Other disciplines currently have licensure requirements. All credentialed providers must submit an annual update of information regarding their credentials to document continued experience, training, licensure, and liability insurance coverage and must provide an updated criminal history background check. Mr. Viehweg noted that there are already many procedures and safeguards in place to assure the quality of services provided to First Steps families. (A written copy of Mr. Viehweg's testimony is included as part of "Exhibit I.")

Responding to questions from Representative Klinker, Mr. Viehweg questioned whether requiring accreditation would be any different than what is required under the current training and credentialing requirements, other than the providers having the additional expense of the accreditation process. He also stated that the credentialing system was not adopted under the threat of an accreditation requirement but has been in place since 1994.

Sarah O'Brien, parent of a First Steps child, shared with the Commission her family's experiences with selecting and changing service providers. Ms. O'Brien explained that the changes of providers her family made were not because of problems with the quality of services provided, but because they decided that their daughter's needs required a different approach. The fact that they had a choice of providers to select from was very

important for their daughter and their family. Ms. O'Brien stated that she believes that the First Steps program works well and that the requirements placed upon the providers to remain in the program assure that providers have the continuing education and training necessary to serve children with special needs.

Bobbi Leaird, Service Coordinator, Hillcroft Services, Muncie, explained to the Commission what her job as a service coordinator entails. She stated that she provides information to First Steps families regarding choosing service providers and their rights in receiving services. She remarked that she contacts each family and the service providers for that family at least quarterly and often attends therapy sessions to encourage an open and active interaction between herself and each service provider. Her goal as a service coordinator is to enhance and empower family involvement, decisions, and support of the Individual Family Service Plan process.

Marti Nelson, Regional Director, Anthony Wayne Services, South Bend, discussed with the Commission the requirement to provide services in natural environments and noted that a previous handout ("Exhibit I") contained a copy of an ICC position paper on natural environments. Ms. Nelson explained that "natural environment" should not be thought of as a location but as the routines and daily activities that families and children participate in. This approach emphasizes: 1) all children are unique, with individual strengths and talents and that the child's disabilities do not define the child; 2) children grow and learn in the context of relationships with their families and other members of their communities; 3) children with and without special needs learn much from each other; and 4) the lives of families are enhanced when services are provided within their regular routines.

Ms. Nelson explained that one concern that is sometimes raised regarding providing services in natural environments is that some providers might refuse to go to certain locations due to fear for their safety. She explained that there are some common sense rules that providers can follow to help assure their safety. Ms. Nelson remarked that if the concerns and needs of the families are given first priority, therapy can progress much more quickly and achieve positive results.

In response to a question from Representative Klinker, Ms. Nelson stated that the state has historically been very willing to work with providers in finding locations other than the home to provide services if there is a real concern over the provider's safety.

David Mank, Indiana Institute on Disability and Community, Indiana University, Bloomington, remarked that while quality assurance is a common goal, reasonable people can disagree as to how to achieve that goal. He stated that whatever method is used to reach that goal should address the following four principles: 1) quality and accountability of providers; 2) on-going improvement; 3) emphasis on results; and 4) equity in the process. Issues important to consider regarding the quality of services provided are: 1) qualifications and experience; 2) attention to outcomes; 3) attention to on-going skills of providers (i.e., technical assistance and training); and 4) satisfaction and choice of consumers.

In response to a question from Commission member Erv Picha, Mr. Mank, Denise Arland, and Stephan Viehweg informed the Commission that the ICC is currently in the process of developing standards for individual, family, and community outcomes and a process for measuring how the First Steps program as a whole is meeting those outcomes. Representative Klinker suggested that some sort of evaluation tool be developed to measure the satisfaction of families who receive services.

Dale Turner, President, Marion County First Steps Council, Inc. and a First Steps provider,

remarked that requiring First Steps providers to be accredited by an independent national accreditation agency would not serve to increase the competency of providers. She stated that accreditation only ensures that a minimal level of standard policies and procedures are in place, most of which are not focused on the services themselves. She expressed her belief that the standard of the current First Steps credentialing process is much higher and more stringent than that of CARF or the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). She also expressed concern that if accreditation were required, organizations that had the required accreditation but no programs aimed specifically at providing early intervention services might be allowed to provide services in the First Steps program. She also stated that the cost of accreditation would likely be prohibitive to many smaller providers which could result in some providers ceasing to participate in the program, thus reducing choice for families. Ms. Turner suggested that a mentoring program be implemented that would allow providers with less than one year of early intervention experience to be supervised by more experienced providers. Ms. Turner also remarked that implementing a sliding fee scale for First Steps would likely not add significant funds to the program as 65% percent of the families participating in the program are considered low income and, by federal law, would not be subject to this fee scale. ("Exhibit J" is a written copy of Ms. Turner's testimony.)

Melissa Wingate, physical therapist, representing a group of independent providers from Marion and Hancock counties, offered the Commission some suggestions on areas in the First Steps program that could be improved, including: 1) quarterly meetings for all providers; 2) mentoring; 3) parent education regarding expectations for services; 4) written documentation of each visit; 5) enrollment based on submission of quarterly reports; 6) higher level of professional in-services and trainings in Indiana; 7) higher quality credentialing guidelines; and 8) better communication system from state to providers. ("Exhibit K" is a written copy of Ms. Wingate's testimony.)

Responding to a question from Representative Klinker, Ms. Wingate stated that she believed most providers want continuing education but the number of hours or the cost may be difficult for some.

Kirsten Johnson, Indiana Speech, Language & Hearing Association (ISHA), provided the Commission with a copy of several Indiana statutory and administrative rule citations regarding the licensure of speech-language pathologists ("Exhibit L"). Ms. Johnson stated that due to the stringent standards currently imposed on speech-language pathologists, requiring these providers to be accredited would not serve to further enhance the quality of services provided but would only increase the frustration level of families who are already overwhelmed by the "red tape" in the system.

John Dickerson, Executive Director, The Arc of Indiana, expressed the Arc's support for First Steps and noted that the program has achieved much success due to the efforts of many dedicated people. The Arc supports PD 3193 and believes that families should be able to have confidence in whatever service provider they choose. The Arc also supports choice, which is a problem in some counties where there are not enough providers to provide the needed services. Equal access and equal protection in the program will not exist until children in all parts of the state have access to the same services. The Arc has recently launched a new web site (www.thearcclink.org) that helps families find service providers and communicate with other families about providers and the system.

Costa Miller, Executive Director, Indiana Association of Rehabilitation Facilities (INARF), noted that PD 3193 was the result of an effort to try to bring requirements for First Steps providers in line with requirements for providers who serve adults. He noted that in any discussion regarding accreditation, it is important that the information considered be

accurate so that decisions are not made on the basis of erroneous information. He also expressed the opinion that at some future point, the state may find the First Steps program so internalized that it will eventually require outside accreditation.

Senator Lawson thanked the Commission and all those who testified for their consideration. She noted that PD 3193 contained an effective date of July 1, 2003, which would provide time to work out details of an accreditation process. She also remarked that the list of organizations that could provide the accreditation was not an exhaustive list, so the possibility exists for FSSA to allow more options for providers. She stated that the current training program for First Steps is very good and will only make it easier for providers to achieve accreditation.

Committee Discussion & Next Meeting Date

Senator Riegsecker, who had taken over as Chair of the meeting upon Representative Klinker's departure, asked the Commission members, due to the later hour, to hold their questions and comments on First Steps until the next meeting, which will be Tuesday October 3, 2000, at 11:00 a.m. The agenda for the next meeting will include criminal history checks for direct care staff and First Steps. (Please note that indications of meeting times and dates in these minutes are subject to change. Consult the most recent Calendar of Meetings available from the Legislative Information Center for official meeting information.)

With no further business to come before the Commission, Senator Riegsecker adjourned the meeting at approximately 4:20 p.m.