

**REPORT
OF THE
COMMISSION ON AUTISM**



**Indiana Legislative Services Agency
200 W. Washington St., Suite 302
Indianapolis, Indiana 46204-2789**

November, 2000

Indiana Commission on Autism

Membership Roster

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Vanessa Summers, Chair
Indianapolis

Robert Alderman
Ft. Wayne

Cleo Duncan
Greensburg

Dennie Oxley
Milltown

Senators

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Warsaw

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Goshen

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Michael Carmin
Upland

Nan Daley
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Herbert Grulke
Crown Point

Donna Ott
South Whitley

Becky Zaseck
South Bend

Legislative Services Agency Staff

David Hoppman, Fiscal Analyst
Ann Naughton, Staff Attorney

A copy of this report is available on the Internet. Reports, minutes, and notices are organized by committee. This report and other documents for this Commission can be accessed from the General Assembly Homepage at <http://www.state.in.us/legislative/>.

INFORMATION REPORT

INDIANA COMMISSION ON AUTISM

I. STATUTORY DIRECTIVE

The Indiana General Assembly established the Indiana Commission on Autism (the Commission) via Public Law 2-1992 to do the following.

(1) Study the service delivery system for individuals with Autism and the families of individuals with Autism, including the following:

- (A) An analysis of the number of Indiana citizens believed to have Autism.
- (B) Funding amounts and sources.
- (C) Types of expenditures and services provided.
- (D) The number of clients served.
- (E) Relationships among agencies and organizations.
- (F) Residential options for individuals with Autism.

(2) Study the need and effectiveness of programs for individuals with Autism.

(3) Oversee and update the development of a comprehensive plan for services for individuals of all ages with Autism.

The comprehensive plan must include an interagency cooperation agreement among the following:

- (A) The Department of Education.
- (B) The Division of Mental Health.
- (C) The Division of Family and Children.
- (D) The Division of Disability, Aging, and Rehabilitative Services.
- (E) Any other appropriate agencies.

II. INTRODUCTION

The Commission met five times during the 2000 interim session on July 26, August 28, September 26, October 18, and October 31.

The Commission is not required to file a final report. However, Representative Vanessa Summers, Chair of the Commission, requested a report outlining the scope of topics addressed during the five meetings of the 2000 interim.

Complete meeting minutes for the Commission can be accessed from the General Assembly Homepage at <http://www.state.in.us/legislative/>.

III. SCOPE OF TOPICS

Meeting #1

Roundtable Discussion

The Chair conducted a roundtable discussion to develop a plan-of-study for the upcoming interim work of the Commission. The following items were identified as potential study topics:

- 1) Non-reversion of funds regarding monies in the Developmentally Disabled Client Services Account;
- 2) Insurance coverage for individuals with autism;
- 3) Professional development;
- 4) Group homes;
- 5) Early intervention and education;
- 6) 317 Task Force Integration Plan status; and
- 7) Waiting list reduction through waiver expansion.

Meeting #2

Possible Causes of Autism

Congressman Dan Burton (R-IN) gave a brief overview of his involvement with Autism:

Autistic Grandchild

- Personal experience with Autism.

Hearings

- Started holding hearings in Washington, D.C., approximately 1½ years ago regarding Autism and its possible causes.
- International experts have produced a growing body of evidence suggesting that contents of vaccines are possibly responsible for the increased rates in Autism.
- In some parts of the United States, a significant increase in Autism has occurred.
- More attention should be paid to Autism at the State and Local levels.

Insurance

- Health Insurance carriers should provide coverage for children with Autism.
- Medicaid Waivers for Autism will hopefully be addressed by the Indiana General Assembly.

Vaccines

- Personally convinced that some of the contents of vaccines are one of the major causes of the current increase in Autism.
- 1982 law passed by Congress and FDA outlawing the use of mercury for topical dressing on human bodies.
- However, mercury is still used as a preservative in many vaccines that are given to children.
- Other vaccine preservatives include aluminum and formaldehyde

ICFMR Medicaid Waiver

The Family and Social Services Administration (FSSA) presented information regarding the Intermediate Care Facility for the Mentally Retarded (ICFMR) and Autism waiver waiting list management and integration.

317 Task Force ICFMR Medicaid Waiver Slots as of August 24, 2000

- Diverted: 332 slots allocated with 213 individuals starting services. Of the 213 individuals who started services, 17 started services with a diagnosis of Autism.
- De-institutionalized: 172 slots allocated with 92 individuals starting services. Of the 92 individuals who started services, none started services with a diagnosis of Autism.
- Priority Basis: 120 slots allocated with 55 individuals starting services. Of the 55 individuals who started services, 5 individuals started services with a diagnosis of Autism.
- Total: 624 allocated slots with 360 individuals starting services. Of the 360 individuals who started services, 22 started services with a diagnosis of Autism.
- Total average authorized monthly cost: \$96,417.19 (17 diverted individuals @ \$49,445.97 and 5 priority individuals @ 46,971.22).

Data Base for ICFMR Waiver Data

- Crashed on or about December 17, 1999.
- Data unretrievable but not lost.
- Bureau of Aging and In Home Services hired a computer specialist to retrieve data and install a new and more reliable data base.
- New employee hired to manage the day-to-day activities associated with waiver waiting list management and integration.

Total ICFMR Wait List as of August 24, 2000

- 5,535 on wait list for services.
- 2,158 individuals receiving services.

Total Autism Wait List as of August 24, 2000

- 1,197 on wait list for services.
- 196 receiving services with four additional individuals targeted to achieve the maximum

of 200 individuals.

Management of Wait Lists

- FSSA is currently exploring outside entities to assist with the development of strategies to manage existing wait lists.

HCFA Review

FSSA presented information regarding the 1999 Health Care Financing Administration's (HCFA) Medicaid Waiver Review of Indiana's ICFMR services.

Medicaid Waivers

- There are currently five Medicaid waivers in Indiana.
- ICFMR is one of the current five.
- The ICFMR waiver gives the State the authority to offer in home and community services to individuals who are eligible to receive Medicaid, and who are eligible to receive institutionalized care but prefer to receive care elsewhere.

HCFA

- HCFA grants initial waivers for three years and renewals for five years.
- HCFA conducted a review of Indiana's ICFMR waiver in November, 1999 prior to waiver renewal.
- FSSA had the opportunity to make changes before actually receiving HCFA's final review.

Indiana Resource Center for Autism

The Indiana Resource Center for Autism provided the Commission with an update on the activities of the Resource Center, and presented survey data from Spring and Summer of 2000 related to Autism issues.

Annual Report (July 1, 1999 to June 30, 2000)

- During the past six years, the Resource Center has trained 76 teams from local special education planning districts across Indiana.
- During 1999-2000, 22 of those teams were trained.
- Currently, 24 teams are being trained.
- During 1999-2000, the Resource Center worked on seven research projects as well as continued to disseminate approximately 21,000 copies of its newsletters.

Family Needs Assessment Survey 2000

- Goal: to gain a better understanding of services and resources for individuals with autism spectrum disorders, to compare the progress that the State has made by using 1998 needs assessment survey data, and to gather various data for the Indiana

Commission on Autism.

Topics Addressed in Survey 2000

- Medicaid Waiver.
- Funding for Private Services.
- Insurance Coverage.

Meeting #3

Shift from Institutional to Community Services

FSSA gave a brief overview of the recent shift from institutional to community services.

Shift to Community Services

- FSSA has been aggressively moving individuals with developmental disabilities into community-based settings over the last several years.
- Since 1997, over 1,500 people with developmental disabilities have moved into community-based settings or are targeted to soon begin receiving services in the community.
- Over the last four years, the shift in funding from large institutional settings to smaller group homes and community-based services is clearly visible from Medicaid expenditure data.

Expenditures

- In 1995, the State spent almost \$94M on State-operated facilities as opposed to \$66M in 1999 (a decrease of almost 30%) reflecting closures of New Castle and Northern Indiana State Developmental Centers in 1998.
- During the same time, expenditures for large private intermediate care facilities for the mentally retarded decreased from almost \$46M to \$36M, and smaller group home settings experienced increases from \$166M to \$191M.

Cost Savings

- Initially, policy makers and others believed that the above transition would result in a cost savings to the State.
- Based on an analysis by FSSA, it appears that the cost for supporting these individuals in the community is almost the same as the costs to support them in State-owned facilities.

House of Delegates, Indiana State Medical Association

The Indiana State Medical Association addressed the Commission regarding its resolution endorsing efforts to require by statute health insurance coverage for children with Autism.

Health Insurance Coverage

The Insurance Institute of Indiana addressed the Commission regarding insurance coverage of children with Autism.

- The Insurance Institute of Indiana is a full-service trade association representing approximately 150 companies.
- The Insurance Institute of Indiana is against mandating the insurance coverage of children with Autism.
- Mandates drive up the cost of insurance for all customers.
- The State should financially assist the insurance industry to implement any mandate requiring the coverage of children with Autism.
- Autism should not be legislatively excluded from insurance coverage, but a requirement of coverage for Autism should not be imposed either.

Anthem addressed the Commission regarding insurance coverage of children with Autism.

- Three directors and several onsite consultants determine what conditions will be covered at Anthem.
- Anthem can only provide payment for covered services.
- Medical policies are based on scientific evidence.
- Medication has to be on the market for at least six months in order to be considered for coverage.
- Anthem looks at the risk of a drug treatment to patients when deciding on prospective coverage.

The Indiana Department of Insurance gave a brief overview of the Department's function.

- There are approximately 1,800 insurance companies in Indiana of which approximately 500 are associated with health insurance.
- The Indiana Department of Insurance reviews the financial solvency of insurance companies, and ensures that all policy forms comply with State law.
- The Indiana Department of Insurance also investigates consumer complaints.
- Although health insurance is a private contract driven by the consumer, contracts have to be enforced as written by a separate entity such as the Indiana Department of Insurance.
- Contract clauses cannot be taken out of a policy simply due to high costs.

Autism as a Neurobiological Disorder

Eli Lilly and Company addressed the Commission regarding Autism as a neurobiological disorder by testifying to the following:

Scientific Literature

- Vast amounts of scientific literature clearly define Autism as a neurobiological disorder characterized by disturbances in 1) social relatedness; 2) communication; and 3) routines and interests.
- It is widely accepted in the scientific community that Autism is neurobiological in origin.

Autism as a Disease

- Just as Juvenile Diabetes is a disease of the pancreas and can be treated with molecules like insulin; Autism is a disease of the brain which has an early onset (defined as before the age of 3 years) and can respond to various types of pharmacological molecules.
- Both Diabetes and Autism are life-long diseases, but the symptoms of each can be effectively reduced with treatment.
- In fact, the National Institute of Health funds research on pharmacologic intervention in Autism, and there are several US patents issued to pharmaceutical companies which provide evidence that Autism is viewed as a treatable neurobiological disorder.

Early Intervention

- Early intervention is the key to the treatment of Autism.
- While it is known that most childhood disabilities can be improved with the earliest possible intervention, this is especially true for the autistic child.

Social Interaction

- Autism is the only disability that causes a deficit in social interaction. As a result these children are unable to benefit from the stimuli of their environment.
- It is well documented that autistic children who receive one-on-one intervention early in life can learn to attend to their environment, and begin to learn from other people in typical setting.

Brain Plasticity

- Neurons are activated in the brain as information is processed.
- Near the age of 10 years the brain shifts from rapidly acquiring new synapses to undergoing a process of "remodeling" where un-activated neurons are actually lost.
- If autistic children do not receive one-on-one intervention to achieve stimulation of neurons, those neurons will actually be lost during the remodeling process.
- There is a narrow window of opportunity to make lasting changes in an autistic child's brain.

Cost Benefit

- Indiana has nearly 1,200 autistic children between three and nine years of age.
- A recent cost benefit study from Ohio states that a savings of \$1.6M to \$2M can be realized over the life-time of each autistic child who receives three years of average early intensive behavioral intervention.

Meeting #4

Hoosier Healthwise for Children

FSSA addressed the Commission regarding Hoosier Healthwise for Children (Hoosier Healthwise)

- Hoosier Healthwise:
 - is a health insurance program offered by the State for children;
 - is available for pregnant women and low-income families;
 - is partially funded through the Children’s Health Insurance Program (CHIP) created by Congress;
 - provides two healthcare packages (Package A and Package C);
 - offers the same healthcare provisions as covered under Medicaid through package A;
 - requires certain co-payments through package C.
- Hoosier Healthwise coverage is based on the concept of “prior authorization”.
- Hoosier Healthwise and Medicaid are not authorized to cover early intervention of individuals with Autism.

Autism Coverage at Indiana University

The Chair asked Legislative Services Agency to distribute a letter from Indiana University regarding Autism coverage at Indiana University. The letter addresses the elimination of Autism as an excluded diagnosis from two self-funded health care plans at Indiana University.

Meeting #5

Coverage of Applied Behavior Analysis (ABA) under Medicaid and Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)

FSSA addressed the Commission and stated that there are two possible avenues through which ABA services could be defrayed. They are as follows: 1) The Autism Waiver Program; and 2) Medicaid funding via EPSDT. FSSA testified to the following:

Autism Waiver Program

- Funding of ABA services could be accomplished more realistically via the Autism Waiver Program than via Medicaid dollars through EPSDT.
- Services provided through ABA could possibly be redefined as “habilitative” rather than “educational” with approval by the Health Care Financing Administration (HCFA) in order to allow funding via the Autism Waiver Program.
- It is possible that HCFA would not object to such a scenario.

EPSDT

- Funding of ABA services via Medicaid through EPSDT is a complicated process.
- Certain states (like Wisconsin) have adopted eligibility categories in their respective Medicaid plans for children who meet Social Security Insurance (SSI) disability standards.
- Children with a disability severe enough to qualify under SSI, can be covered under Medicaid for ABA services through Wisconsin’s eligibility category if their EPSDT evaluation indicates a need for ABA services.
- Wisconsin is currently re-thinking its position on this method of funding for various

reasons.

Legislation Recommended For Introduction

The Commission discussed the following bill drafts and made recommendations for introduction (final votes were taken for each bill draft).

1) PD 3453 - Autism Waiver Funding

PD 3453 (Exhibit #1) appropriates to the office of Medicaid Policy and Planning from the State General Fund an amount sufficient for use in funding an increase in the number of eligible individuals served under the Medicaid autism waiver.

The above bill draft was voted to be placed in the minutes as a recommendation for introduction by the Commission.

Final Vote: 10-0

2) PD 3452 - Developmentally Disabled Client Services Funding

PD 3452 (Exhibit #2) provides that money remaining in the Developmentally Disabled Client Services Account or any other State account or fund used to serve individuals with developmental disabilities does not revert to the State General Fund at the end of a State fiscal year.

The above bill draft was voted to be placed in the minutes as a recommendation for introduction by the Commission.

Final Vote: 10-0

3) PD 3518 - Insurance Coverage for Autism

PD 3518 (Exhibit #3) defines pervasive developmental disorders, including Asperger's Syndrome and Autism, as neurological conditions for purposes of coverage under group health insurance and group health maintenance organization contracts. It requires group health insurers and group health maintenance organization contracts that provide basic health care services to offer to provide coverage for treatment of a pervasive developmental disorder of an individual covered under the plan.

The above bill draft was voted to be placed in the minutes as a recommendation for introduction by the Commission.

Final Vote: 10-0

4) PD 3517 - State Health Plan Coverage for Autism

PD 3517 (Exhibit #4) defines pervasive developmental disorders, including Asperger's Syndrome and Autism, as neurological conditions for purposes of coverage under group

insurance for State employees. It requires that group insurance for State employees must provide coverage for treatment of a pervasive developmental disorder of an individual covered under the plan.

The above bill draft was voted to be placed in the minutes as a recommendation for introduction by the Commission.

Final Vote: 10-0

5) PD 3614 - Autism Waiver Amendments

PD 3614 (Exhibit #5) requires the Office of Medicaid Policy and Planning to amend the autism waiver to provide coverage for applied behavior analysis treatment. It appropriates from the State General Fund an amount sufficient to increase the number of individuals served under the Medicaid autism waiver.

The above bill draft was voted to be placed in the minutes as a recommendation for introduction by the Commission.

Final Vote: 10-0