

STATE OF ILLINOIS

DEPARTMENT OF
HUMAN SERVICES



FETAL ALCOHOL SPECTRUM DISORDERS (FASD) REPORT

Findings and Recommendations

As required by Senate Joint Resolution 0007

Dear Honorable Governor Pat Quinn and Honorable Members of the General Assembly:

Consistent with Senate Joint Resolution 0007, I am pleased to submit to you the Fetal Alcohol Spectrum Disorders (FASD) Report of the findings and recommendations to identify and improve services for families, adults and children with FASD.

This report highlights:

- State agencies' assessments of state and federal assistance programs for FASD
- Public hearings held to gather information on issues pertaining to the diagnosis, early intervention, treatment and prevention of FASD
- Services needed to serve families, adults and children with FASD

Illinois needs to work toward making significant improvements in order to better serve families, adults and children with FASD. We look forward to continuing to partner with you and the collaborative agencies within the state in the future.

Sincerely,



Michelle R.B., Saddler
Secretary

I. EXECUTIVE SUMMARY

Each year, thousands of children in Illinois go undiagnosed or misdiagnosed for Fetal Alcohol Spectrum Disorders (FASD). These children and their families face an uphill battle as they seek proper diagnosis and support services necessary for them to succeed in life. Nationally, FASD affects 10 babies per 1000 live US births, approximately 40,000 babies each year. FASD is a 100 % preventable developmental disorder, prevented by no use of alcohol during pregnancy.

In the spring of 2009, the General Assembly urged the Illinois Department of Human Services to conduct an assessment of existing state and federal assistance programs and conduct public hearings on FASD services in Illinois.

This report is a compilation of the state agencies' assessment and testimony from nearly 100 parents, service providers and state agency personnel, each of who spent countless hours preparing their thoughts and recommendations to improve the lives of children and families dealing with FASD.

Overwhelmingly, respondents identified a lack of understanding of FASD within the judicial system, medical and education professions. This overall lack of understanding creates a domino effect where few diagnosticians have emerged, needed support services are almost non-existent and there is no mechanism in place to access what few specialized services are available. Parents also expressed frustration in the lack of respite services available. Although this is not an issue unique to this population, given the severity and nature of the disability, parents of children with FASD universally face challenges associated with accessing short- and long-term respite care. Additionally, parents expressed that significant expense keeps most services out of their financial reach.

A recurring theme throughout the testimony was the need to create a seamless service delivery system that includes all levels of functioning. Many parents expressed frustration with school districts that were unwilling to provide appropriate services to children with FASD who fell within the normal IQ range. Due to this, children who were higher functioning often went without services until the problems were so severe that a new primary diagnosis had to be created.

Most importantly, those who testified concur that Illinois needs to invest in the resources and support services for children with FASD. This investment will not only reduce the pain and suffering of

countless children and families but will save the state millions of dollars in cost reductions in the criminal justice, health, child welfare, and education systems.

II. FASD OVERVIEW

Background

Senate Joint Resolution (SJR) 0007 was introduced in the Illinois General Assembly during the spring 2009 session and was sponsored by Senators Maggie Crotty, Mattie Hunter, Donne E. Trotter and Don Harmon. The Senate Resolution passed unanimously on February 26, 2009. The House version was introduced by Representative Al Riley and was co-sponsored by Representatives Deborah L. Graham, Esther Golar, Andre M. Thapedi, Paul D. Froehlich, Dennis M. Reboletti, Bob Biggins, Sara Feigenholtz, Karen A. Yarbrough, Patricia R. Bellock and Sandy Cole. The Resolution passed the House 116-1 on May 30, 2009.

SJR 0007 urged the Department of Human Services, in collaboration with the Departments of Children and Family Services, Healthcare and Family Services, Corrections, Financial Institutions and Professional Regulation, the Illinois State Board of Education, and the Illinois Council on Developmental Disabilities to complete an assessment of existing State and federal assistance programs involving FASD and conduct public hearings across the state. A series of four public hearings were developed to gather testimony from parents, educators, healthcare providers, clinicians, mental health providers, FASD service providers and others regarding the services they feel need to be in place in this state in order to serve this unique population of children and adults.

Introduction to FASD

Fetal Alcohol Spectrum Disorders (FASD) is an increasingly troubling public health issue. The term “FASD” indicates that there are a variety of effects of prenatal alcohol exposure. FASD is not a diagnosis but refers to a spectrum of physical, mental, learning and/ or behavioral disabilities resulting from alcohol consumption during pregnancy. Recent U.S. surveys have revealed that approximately 12 percent of pregnant women still drink alcohol during pregnancy (SAMHSA, 2007), which translates into one in eight fetuses being exposed to alcohol during gestation. Although the various conditions within FASD are permanent, specific symptoms may be treatable or manageable. Children with a diagnosis of FASD face an increased risk of suffering from mental illness, drug and alcohol addiction, dropping out of school and incarceration.

The brain structure can be permanently altered since individual parts of the brain can be impacted; a large number of behavioral and learning disabilities can be linked to the damage caused by the exposure. Beyond the human costs of the disorders, the societal costs can be astounding.

The sole cause of FASD is women drinking during pregnancy. The direct effects of alcohol on the developing fetus cause permanent central nervous system damage, especially to the brain. Due to the damage, children with FASD may have functional impairments in the areas of adaptive behavior, attention disorders, cognition, executive functioning, language memory, motor skills, sensory integration, and social communication.

Secondary disabilities are problems that result from the primary disability but are not directly caused by it. Prenatal alcohol exposure can cause attention deficits that interfere with schoolwork. The attention deficits are a primary disability, while the academic problem is a secondary disability.

Other secondary conditions associated with FASD include mental health issues, behavioral problems, trouble with the law, incarceration, alcohol and drug dependence, inability to sustain employment or independent living. These conditions could be lessened or prevented through better understanding and appropriate interventions for children and adults with FASD.

Despite the serious nature of the secondary conditions that can occur with FASD, several positive factors have been identified and may mitigate these conditions. These protective factors include early identification and diagnosis, involvement in special education and social activities, caretaking in a loving, nurturing and stable environment, and the absence of violence.

III. PROGRESS IN ADDRESSING REQUIREMENTS BY SJR 0007

A. Assessment of existing State and Federal assistance programs

As per Senate Joint Resolution 0007, the Illinois Department of Human Services in collaboration with Departments of Children and Family Services, Healthcare and Family Services, Corrections, Financial Institutions and Professional Regulations, Illinois State Board of Education and the Illinois Council of Developmental Disabilities, were urged to complete an assessment of existing state and federal assistance programs for FASD.

Summary of Federal Assistance Programs

Only two respondents identified receipt of federal funding specific to FASD. The Children's Research Triangle receives federal funds for FASD services. The Department of Human Service's WIC Program has short term funding for a prevention project (see State Agency Assessment).

Summary of State Agency Programs

Overall, state agencies reported that they do not specifically fund services for people with a diagnosis of FASD. However, they do provide funding for services for secondary diagnosis such as mental illness, developmental disability or developmental delay and substance use disorders.

State agencies echoed provider and parent concerns that there are no mechanisms for public or private insurance reimbursements for services when they are available. State agencies also identified a statewide lack of service providers with expertise in working with this unique population of children and young adults. There are very few agencies that provide specialized training for professionals in order to increase the pool of available services.

State agencies stated that they need additional resources, staff, funding and information in order to serve children and adults with FASD, and the need for specialized screening tools and referral resources.

State Agency Assessments

The **Department of Human Services (DHS)** has several programs that impact the FASD population. The department's services are targeted at children with a secondary diagnosis of FASD, with the exception of the State's Early Intervention System.

- The Early Intervention System had made FASD a primary disabling factor that triggers automatic enrollment in the program.
- The Homeless Youth program provides screening and referral for young people who are suspected of having FASD.
- The WIC program is currently in the second year of a federal subcontract to provide FASD Screening and Brief Intervention (SBI) through WIC clinics. The SBI is currently being piloted at the Winnebago County Health Department. The goal is to implement the SBI statewide in the future.

- The Division of Mental Health provides child and adolescent behavioral and mental health services in both community and residential settings through contracts with community-based providers. Many of the providers that serve children and adolescents with FASD, and related behavioral and mental health services, are funded through the Division of Mental Health. The Division of Mental Health, in collaboration with the Illinois Department of Healthcare and Family Services, also sponsors a psychiatric phone consultation service, DocAssist, for primary care providers throughout the state. This service can serve as a valuable help to primary care providers dealing with this spectrum illness as well as multiple other mental health issues.
- The Bureau of Community-based Prevention provides general alcohol education and public awareness through contracts with community-based providers.
- The Division of Alcoholism and Substance Abuse (DASA) section has a variety of services available. Research in the field of Alcohol and Substance Use Disorders indicates that the prevention of Fetal Alcohol Spectrum Disorders (FASD), begins during routine gynecologic care prior to conception and continues throughout the postpartum period. DASA has a federal responsibility to address this issue within its federal block grant set aside for women.

Providers funded by DASA for treatment services to Pregnant and Parenting Women are contracted as a Priority Population when they present for alcohol and Substance Use Disorders (SUD) treatment within the treatment system in Illinois. Pregnant women must be placed at the top of any waiting list for admission. When there are insufficient services and/or insufficient capacity referral to another program must be made and documented within 48 hours of the request. Where warranted, medical care, prenatal and primary pediatric care referrals must be made either directly or with other public or non-funded entities.

The **Department of Corrections (DOC)** provides FASD awareness programs for incarcerated women. The programs include quarterly seminars on the following information:

- The Impact of Alcohol on the Developing Brain
- Statistics of Children Affected by FASD
- “A Child for Life” Video Screening
- Characteristics of A Child or Adult with FASD

- Living With and Caring For A Child or Adult with FASD

DOC Female Facilities Wells Center Program offers educational videos, handouts and pamphlets regarding FASD to those offenders who are enrolled in the Wells Center programming at all female facilities. DOC also cited a lack of a standardized screening and assessment tool at the receiving and classification level.

The **Department of Children and Family Services (DCFS)** provides screening and referral services for children suspected of having FASD. The department provides funding to the Children's Research Triangle for FASD diagnostic evaluations for agency clients. The department also funds several programs for pregnant and parenting teens to provide the necessary supports for state wards who are pregnant and parenting in order to increase positive birth outcomes and break the cycle of abuse.

DCFS in partnership with Children's Research Triangle, Southern Illinois Healthcare Foundation and Chestnut Health Systems promote the permanency and stability of children and families affected by methamphetamine and other substances of abuse through a grant from the U.S. Department of Health and Human Services.

The **Illinois State Board of Education** reports that students with disabilities, found eligible for special education services through a case study evaluation and eligibility meeting, are provided with educational services through their local education agency. These services may include educational remediation and supports, vocational counseling, mental health services, transportation and transitional services.

A review of the Federal Register finds that the U.S. definitions of a child with a disability as outlined in section 602(3) of the Individuals with Disabilities Act (IDEA) are sufficient to include children with FAS who need specialized education and related services. The Federal Register goes on to say that, a new category of FAS is not necessary to ensure that children with the disability receive special education services designed to meet their unique needs.

The **Illinois Council on Developmental Disabilities** does not provide direct services. The Council is instrumental in advocating for system changes that benefit individuals with development disabilities.

The **Illinois Department of Healthcare and Family Services** provides access to comprehensive medical coverage for Medicaid-eligible individuals, including behavioral health services, that are performed by enrolled providers. Under the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program (required by Section 1905(r) of the Social Security Act) any Medicaid allowable service that is necessary to treat or ameliorate a defect, physical or mental illness, or a condition identified by a screen, is covered for children by HFS enrolled providers. The Department of Healthcare and Family Services also sponsors the Perinatal Depression Consultation Line, a phone service to primary care and obstetrical providers throughout the State. This resource can help to identify and refer for treatment women at risk of and abusing alcohol during pregnancy.

HFS is committed to work with other state agencies, advocates and consumers to make certain that program participants with FASD are provided with medical necessary services. HFS is committed to seek all federal financial participation that is, or becomes, available.

B. Results of Statewide Public Hearings

Public Hearings

The Illinois Department of Human Services, in partnership with the Departments of Children and Family Services, Healthcare and Family Services, Corrections, Financial Institutions and Professional Regulation, the Illinois State Board of Education, and the Illinois Council on Developmental Disabilities formed a Steering Committee to convene regional hearings to gather testimony from parents, teachers, service providers and interested individuals. Testimony was heard from parents, educators, healthcare providers, clinicians, mental health providers, FASD service providers and others regarding the services needed to serve this unique population of children and adults with FASD.

The hearings were intended to address several questions. The overarching question was, “What would be an ideal integrated system of care that benefits children, adults and families of FASD look like in your community?”

Families and providers were also asked to address the following questions:

1. What FASD support and services do you currently receive/or provide but are unable to find, and what support and services do you think are needed based on what families of FASD are asking?

2. What barriers have you faced/or encountered in getting/or offering services for FASD?
3. What strategies or ideas would you recommend to better coordinate existing service for children and adults with FASD?

The format for the public testimony was developed by the Steering Committee to facilitate public input for the report. Committee members attended at least one of the public hearings. Representatives for Prevention First and NOFAS Illinois/Trinity Services, Inc. assisted in coordinating the onsite hearings and providing outreach to interested constituents. Extensive online outreach was conducted to reach a broader audience and promote attendance to the public hearings.

The public hearings took place at the following locations throughout the state:

- November 17, 2009 Bloomington
- November 19, 2009 Carterville
- December 1, 2009 Chicago
- December 2, 2009 DeKalb

Each participant who provided testimony was requested to provide written testimony at the time of the hearing. In instances where written testimony was not available, staff assisted the presenter in putting the key information points in writing.

Summary of Public Testimony

The response for public comment was overwhelmingly from parents of children and adults with FASD. A number of community-based providers also attended and provided testimony at the hearings. At least one newspaper reporter also provided testimony based on her contacts with families living with FASD.

The comments identified the following in the state's present service system for FASD:

- A lack of a data collection mechanism on reporting the incidence and prevalence of FASD
- Limited integration of FASD prevention messages into existing state systems
- Almost non-existent comprehensive diagnostic tool to identify FASD
- No supported living homes for adults with FASD

- Lack of understanding in the judicial system when dealing with individuals diagnosed with FASD
- Lack of a system of FASD prevention, intervention and treatment services in Illinois

Testimonies focused on early identification as critical to children reaching their full potential. Many children are not identified with FASD until they display significant learning, social and behavioral difficulties at home and in school.

The dissemination of FASD research is limited and is not fully integrated into professional training and development. The general lack of understanding among professionals who come in contact with children and adults with FASD in the educational, mental health and early intervention system creates a barrier to appropriate service delivery and access to services.

As children with FASD reach adolescence and adulthood, the services received during the early years may no longer be effective. Upon entering a stage of development that under normal circumstances allows young people the opportunity to thrive, adolescents with FASD tend to flounder. Due to the disability, these young adults lack the skills to maintain employment or a household, and develop positive relationships.

Often times, adolescents with FASD who exhibit skill deficiencies in understanding consequences to behaviors, short-term memory difficulty and executive functioning come in contact with the justice system. Given the judicial systems lack of understanding of the specific impairments that are associated with an FASD diagnosis, these adolescents often circulate in and out of the justice system.

Key Issues Identified

Eligibility

- Children with FASD are not able to access services unless they have a diagnosis that is included in the Diagnostic and Statistical Manual of Mental Disorders (DSM- IVTR) or the International Classification of Diseases (ICD).
- The services available for individuals with FASD are limited and are rarely reimbursable through private or public insurance options.
- Children with FASD who fall within the normal IQ range are less likely to receive services than those with developmental disabilities.

Screening and Diagnosis

- More qualified diagnosticians are needed throughout the state
- A standardized screening and diagnostic tool for FASD is needed. This is a national issue, and research is currently in progress to develop such tools, both for adults and children/youth.
- When children are referred for specific diagnostic services, Medicaid will only cover the medical portion and not the intense psychosocial diagnostic screening. (HFS clarified if the child is Medicaid-eligible and the provider is enrolled with HFS, a diagnostic screening and needed treatment would be covered. The Handbook for Providers of Healthy Kids Services provides an overview of preventative care under EPSDT and references other treatment services and respective provider handbooks.)

Professional Development

- Educators lack training on FASD signs and specific interventions necessary for school success.
- Schools are often not able to provide interventions that are appropriate and effective due to a lack of understanding of the effects of FASD.
- The criminal justice system lacks a basic understanding of FASD and is unable to provide appropriate support services for incarcerated individuals with FASD.

Resources and Referrals

- A centralized resource and referral service for diagnosis, family support programs, clinicians and services is critical.
- The stigma associated with FASD often times prevents families from accessing services.
- Children with FASD lack sufficient opportunities to develop social skills.
- Parents need respite from living with a child who exhibits intense behavior problems associated with FASD.
- Individuals with FASD need supervised living situations through adulthood.

IV. RECOMMENDATIONS

The agency assessments and public hearings identified a need for coordination and expansion of services/processes for identifying those with a FASD and for providing individuals and families with

assistance and support in attaining optimum health and productivity. Given the enormous economic and personal costs associated with FASDs prevention activities must be a priority.

With these concepts in mind the Illinois Department of Human Services makes the following recommendations:

1. Develop a strategy to coordinate existing services across state agencies to address FASD prevention, diagnosis, early intervention and treatment across the FASD continuum.
2. Explore the development of a statewide training system on FASD prevention, intervention and the effects on the brain for members of the judicial, law enforcement and corrections system; physicians, nurses and primary healthcare providers; and educators.
3. Encourage appropriate agencies to identify methods for improving and expanding evaluation and diagnostic services for those suspected of having a FASD.
 - a. Advocate for the inclusion of FASD in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) revision and the International Classification of Diseases (ICD) in order to facilitate service delivery and payment mechanisms. The planned publication release date for the updated DSM-V is 2013.
 - b. Identify federal and not-for-profit funding opportunities to supplement limited state resources. One such Federal resource is the SAMHSA FASD Center for Excellence created to assist States with resources related to prevention, screening, diagnosis, and treatment of FASD.
4. Encourage appropriate agencies to seek out ways to improve and expand FASD services including mental health, substance abuse, respite care, supportive living environments, educational supports, vocational training, and family support systems.
 - a. Explore the feasibility of amending the Illinois Home and Community Based waiver through the Medicaid program to cover services for FASD population.
 - b. Identify federal and not-for-profit funding opportunities to supplement limited state resources.
5. Identify funding and methods of increasing public awareness of the consequence of consuming any alcohol during pregnancy such as planning and implementing a statewide prevention based

FASD Public Service Campaign with Public Service Announcements highlighting the cost/benefit to society in treating FASD across multiple systems.

V. NEXT STEPS

The Illinois Department of Human Services will convene a meeting of key stakeholders including advocacy groups and decision makers from State Agencies to discuss the recommendations. This group should be charged with developing an action plan to address the recommendations.