



**Testimony by Thomas Cook, Executive Director
February 8, 2017 Joint Finance Committee Hearing
Division of Developmental Disabilities Services (DDDS)**

Good afternoon, Representative Smith, Senator McDowell, and other members of the Joint Finance Committee. My name is Thomas Cook. I am the Executive Director of the Ability Network of Delaware, the statewide association of service providers formerly known as DelARF. Our 40 members provide services to individuals with intellectual and developmental disabilities (I/DD) and to people who have mental health and/or substance use disorders. More than half of our membership is comprised of organizations that provide community-based services to adults with I/DD.

Since 2005, the rates for services for adults with I/DD have not been rebased, causing a shortfall of \$39 M when comparing the February 2016 data from DDDS with the funding levels recommended in the market study that was conducted by DDDS in calendar year 2013. Rates for wages, salaries, and benefits for Direct Support Professionals (DSPs) and their supervisory staff have fallen 25% below the funding level recommended in the market study.

When the DDDS Rate System (aka the “DSP Rate” or erroneously as the “ICAP Rate”) was implemented in 2005, the consultants recommended rebasing at least every three years, or when significant changes occur in the costs of providing services. So, if their recommendation had been followed, rate adjustments would have been made in 2008, 2011, 2014, and again this year. The fact that these adjustments have not been made is why the rate system is underfunded by such a large amount. It would take \$17.86 million in state funds to reach the market rate set in the 2013 study, combined with \$21.14 million in federal matching funds (FY 2017 FMAP),

for a total of \$39 million.

With the possibility of federal Medicaid funding being delivered by block grants in the future, instead of via the current system of federal funds to match state spending, A.N.D. believes that Delaware should attempt to close as much of the gap in the DDDS Rate System as possible this year, so that if this change it made, the state will have a higher funding base on which the block grant funding levels would be set.

The Ability Network of Delaware would suggest that one of the revenue enhancers that should be considered for the FY 2018 budget should be dedicated to paying for the increases that are needed for the DDDS Rate System. Perhaps, for example, the Joint Finance Committee should consider an increase in the excise tax on alcohol sales in view of the numerous societal issues caused by the misuse of alcohol, which include the birth of babies with Fetal Alcohol Syndrome who require life-long care. Recent research, which was posted recently on the Facebook page of the Delaware Fetal Alcohol Spectrum Disorder Task Force and which I have attached to my written testimony, indicates that there may be 46,500 people or more living in Delaware who are affected by this Syndrome. Not all of these individuals have Fetal Alcohol Syndrome, with its physical and mental effects, but many have other disabilities and can be found in our state's early intervention programs, special education classrooms, foster care homes, and correction centers.

The consequences for failing to increase the rate for DDDS services will be to jeopardize the health and safety of individuals served. Unfortunately, the funding shortfall has already caused providers to be hesitant to accept new referrals, which causes problems for the families and individuals in need of care. Most recently, abuse and neglect of people receiving services in the state of Illinois were highlighted in a series of front-page articles in the *Chicago Tribune*,

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which points out the serious consequences of an underfunded system of care. You will find the headlines of this series and the first few paragraphs from each article attached to this testimony. We don't want to read a similar expose in *The News Journal* in future years because of a failure to pass the appropriation needed to fund the rate system in the state's FY 2018 budget.

More than a decade ago, Delaware privatized its system of care for people with I/DD, taking people out of Stockley Center and bringing people back from out-of-state placements. The responsibility for the proper funding of this system rests squarely with the General Assembly. The Ability Network of Delaware looks forward to working with the Joint Finance Committee and DDDS to ensure we are using these funds as efficiently and effectively as possible in providing services to Delawareans with I/DD.

Recent Research on FASD

Dr. Ira Chasnoff is a Chicago pediatrician who tested kids and teens who had been adopted or were in foster care and had serious behavioral problems (see the study published in 2015 below).

His examinations were more comprehensive than most assessments for Fetal Alcohol Spectrum Disorders (FASD), involving a thorough assessment of intelligence, executive functioning, speech and language, sensory processing, and social skills, among other factors. They involved a team of professionals and took a full day or more to complete.

Nearly 30 percent of these youngsters examined by Dr. Chasnoff and his colleagues had fetal alcohol spectrum disorders. Eighty percent had not received a diagnosis of this kind previously.

In another study, Dr. Carl Bell, a Chicago psychiatrist, examined 611 of his psychiatric patients on Chicago's South Side and found that almost 40 percent had Fetal Alcohol Spectrum Disorder.

These studies suggest that there is a hidden Fetal Alcohol Spectrum Disorder epidemic that affects up to 5 percent of Americans — and in poor communities, possibly far more.

Read more here: <http://www.pbs.org/newshour/rundown/this-chicago-doctor-stumbled-on-a-hidden-epidemic-of-fetal-brain-damage/>

Given the challenges of poverty in disadvantaged populations in Wilmington and other communities in Delaware, the upper end of the incidence of Fetal Alcohol Spectrum Disorder cited above may be an underestimate. Evidence for this can be found in a 2002 study using the Behavioral Risk Factor Surveillance System, in which Delaware had one of the highest rates nationwide of at-risk drinking by females age 18-44, at a rate of 20%.

Bottom line: We may have significantly underestimated the incidence and life-long consequences and costs to the state of Delaware of Fetal Alcohol Spectrum Disorder. Hence, the recommendation A.N.D. is making to the Joint Finance Committee to consider an increase in the excise tax on alcohol sales to support the rebasing of the DDDS DSP Rate.

Misdiagnosis and Missed Diagnoses in Foster and Adopted Children With Prenatal Alcohol Exposure

Ira J. Chasnoff, Anne M. Wells, Lauren King

[Pediatrics](#)

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Abstract

OBJECTIVE: The purpose of this article is to assess the rate of misdiagnosis and missed diagnoses of fetal alcohol spectrum disorders (FASD) among a population of foster and adopted youth referred to a children's mental health center.

METHODS: Data were collected from a sample of 547 children who underwent a comprehensive multidisciplinary diagnostic evaluation. Utilizing current diagnostic criteria, children were diagnosed, as appropriate, with fetal alcohol syndrome, partial fetal alcohol syndrome, alcohol-related neurodevelopmental disorder, or alcohol-related birth defects. Changes in rates of alcohol exposure-related diagnoses and co-occurring mental health disorders pre- and post-assessment were analyzed by using McNemar's test for dependent proportions.

RESULTS: Among 156 children and adolescents who met criteria for a diagnosis within the fetal alcohol spectrum, 125 had never been diagnosed as affected by prenatal alcohol exposure, a missed diagnosis rate of 80.1%. Of the 31 who had been recognized before referral as affected by prenatal alcohol exposure, 10 children's FASD diagnoses were changed within the spectrum, representing a misdiagnosis rate of 6.4%. The remaining 21 (13.5%) children's diagnoses stayed the same. There also were significant changes in the rate of mental health diagnosis, and learning disorders, communication disorders, and intellectual disability, objective signs of neurocognitive damage, were not recognized in a significant number of children with FASD.

CONCLUSIONS: Within this clinical sample, 86.5% of youth with FASD had never been previously diagnosed or had been misdiagnosed. These high rates of missed diagnoses and misdiagnosis have significant implications for intervention and therapeutic services.

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From the *Chicago Tribune* series **SUFFERING IN SECRET,
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Part One - Illinois hides abuse and neglect of adults with disabilities

The house had no address; the dead man had no name.

Illinois officials blacked out those details from their investigative report. Nobody else was supposed to learn the man's identity or the location of the state-funded facility where his body was found.

The investigation was closed as it began, with no public disclosure, and the report was filed away, one of thousands that portray a hidden world of misery and harm.

No one would know that Thomas Powers died at 3300 Essington Road in unincorporated Joliet, in a group home managed for adults with developmental and intellectual disabilities . . .

Part Two - Flawed investigations ignore victims of neglect

On her last night at a Lockport group home, Tina Marie Douglas tossed her few possessions in the trash and warned caregivers that she planned to run away in the morning.

It was not an idle threat. In the last three months, the 48-year-old state ward diagnosed with psychiatric and intellectual disabilities had slipped out of the home eight times and repeatedly run into the street. Her caregivers were considering moving her to a different home, one on a block with less traffic.

But that never happened. Shortly before dawn in October 2013, she broke away again, sprinted down a four-lane state road and was fatally struck by a car . . .

Part Three - In the rush to close institutions, Illinois ignored serious problems in group homes

Adults with mild disabilities were the most coveted.

In April 2012, as Illinois moved to close several state institutions and relocate adults with disabilities into the community, representatives from group home businesses gathered inside the Jacksonville Developmental Center for a hastily organized auction.

A state official read aloud medical histories of residents with intellectual and developmental disabilities, prompting group home officials to raise their hands for desired picks.

Group home operators knew that then-Gov. Pat Quinn wanted to empty Jacksonville quickly — before any serious union or community opposition could be mounted — but some were taken

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aback by what they saw as a dehumanizing approach. "We were appalled by the auction," said Art Dykstra, executive director of Trinity Services, the state's largest group home provider.

The problems with Quinn's rapid-deployment plan, however, went beyond mere awkwardness. Officials from the Illinois Department of Human Services promised residents that group homes offered a new beginning — one that would bring them more independence, safe and compassionate care, even a private bedroom.

But those promises obscured evidence found in the state's own investigative files that revealed many group homes were underfunded, understaffed and dangerously unprepared for new arrivals with complex needs, a Chicago Tribune investigation found . . .