Public Comments Received

9/12/18 – 10/16/2018
Kristina,

My name is Meredith Howell and I have the most awesome seven-year-old little girl named Lola. She has a smile that can light up the room, she has the most gorgeous thick brown hair, and she also happens to have an ultra-rare genetic condition called Bosch Boonstra Schaaf optic atrophy syndrome. She was one of about 20 in the entire world with it when she was diagnosed. That number has grown slightly since 2015 when she received the diagnosis.

As a result of BBSOAS, she has autism, global developmental delays, cortical visual impairment, epilepsy, nystagmus, hypotonia, and a lot more. In spite of all of these diagnoses, she continues to prove the doctors wrong by making great strides through her hard work and determination. I’m in awe of her strength.

I’m writing to you today to express my extreme disappointment in the way that the Medicaid Waiver funds are distributed to provider agencies who offer assistance to our families such as respite and PAC. Lola has been on the Medicaid Waiver for a few years now. The entire first year of her being on the Waiver, we were on waitlist after waitlist for respite services, music therapy, etc. It seemed sort of pointless. But then after doing some research, I found that I could actually find my own respite care providers and so I did. My mother and two of Lola’s ABA therapists now provide respite for us which has been incredibly helpful as Lola’s father and I are on 24/7 with Lola. The extra help has been amazing and much needed. So I don’t want to sound like we are ungrateful because that we are not. We realize that Waiver funds don’t have to be distributed at all so we take nothing for granted.

We chose LEL Home Services as our agency and have been very pleased until recently. I was told by one of our respite care providers that Lola’s respite hours seemed unusually low. I contacted our wonderful case manager from IPMG and she confirmed that number appeared to be correct. This didn’t make much sense to me as I was calculating the math in my head. The most one of our respite care providers makes per hour is something like $13. Lola is allotted $17,300 per year. I know the case management company takes a cut of $125 per month for 5 months and then it was upped to $131.25 per month for 7 months. So that’s $1543.75 total for the year. That would still leave a very large chunk of money for services for my daughter. So I was shocked when I found out that LEL gets paid $26.15 per hour for EACH HOUR OF RESPIRE while the DSP only makes less than HALF of that money. Same thing with PAC. LEL gets paid $24.40 and the DSP makes less than half of that. I totally understand that LEL has overhead in order to make their services work, but to take more than half of my disabled daughter’s money each hour she is given services is unethical and insane.

I work for a nonprofit. I totally get the overhead costs that come with providing good services, but this news was so beyond shocking to me. I called the Chief Compliant Officer at LEL and expressed my disappointment. She gave me this long-winded answer about paying to be accredited, needing to
have technology like MyLyle for employees, and the rest of the overhead costs. But again to take more than half of my daughter’s money for every hour of service provided to her is simply unacceptable. I asked Cathy if they disclosed their financial statements to the state legislature and she was silent. She said it was not required but I would be very curious to see how much they are making off of our disabled kids. LEL is a privately held company but I guarantee they are not sitting on a flat budget.

So I’m mad. I’m disappointed. I’m beyond appalled. I want my voice heard and I was told that you were the person to contact. What can be done about this? That money either needs to go to the DSP or my daughter needs to receive more services because right now—as it stands—they are being taken from her. And isn’t this tax-payer dollars?

Anyway, I am more than happy to discuss this more if you’d like. I don’t plan on letting this go and I’m well connected at the state legislature so I intend to continue to be a thorn in the side of these agencies not only for my family but for all of the families in Indiana who have children on the Waiver. Why can’t we cut out the middleman? I know this is possible with the Aged and Disabled Waiver. Why can’t this be done for the Family Supports Waiver?

I’m attaching a picture of Lola so you can see that she is a real person and this is a family whose lives are truly affected by this absurdness.

Gratefully,
Meredith
Hi Dan,

I’m so sorry…i hope this info isn’t too late and helps in some way. I have attached some files with info on the census in Indiana (Birth – 21). What might be most important is the information on the transition age kids. More than ½ of the students we have identified are transition age and will be moving into adult services soon. They will likely need support from waivers and there will be considerable effort put into coordinating adult services to make sure that they have the supports to be successful as they transition to adult life. It is also important to note that our students are mostly living with families at home and that the majority of them are in the regular education classroom less than 40% of the time. This is an indication of the fact that a majority of the students identified as deaf-blind have multiple disabilities, many of them significant. As children get older and move into adult services, families find it difficult to navigate the resources that they do have…and many times the services and resources change and parents don’t know it until they need that resource.

I don’t know how many adults who are deaf-blind are in Indiana. I know that Helen Keller National Center did have about 150 on their census for Indiana…I also know that that number is too low, just as my number (219) is too low based on the incidence rate for deaf-blindness and Indiana’s population. I know that Helen Keller National Center has an “Indiana Deaf-Blind Interagency Coalition,” which is a group of agencies (including me) who provide services to individuals who are deaf-blind and some deaf-blind consumers who are looking at issues for adults who are deaf-blind. The two needs that are currently being discussed is emergency preparedness for individuals who are deaf-blind – what that looks like and what extra accommodations need to be made and the lack of trained Support Service Providers in Indiana.

The following information is a little old (2016) but probably still pretty on point. It came from the American Association of Deaf-Blind and HKNC.

**rends and Unresolved Issues**

**Impacting Individuals who are Deaf-Blind**

*Document developed for the National Council on Disability*  
*by American Association of the Deaf-Blind*  
*and Helen Keller National Center.*

Individuals who are deaf-blind, regarded as “most significantly disabled” by state vocational rehabilitation agencies continue to face significant social, economic, educational and psychological barriers. The lack of available services and resources is often an obstacle to achieving self-sufficiency for individuals who are deaf-blind. Throughout the United States this low incidence diverse community remains unserved and under served, the impact on the individual and the service delivery system...
continues to be a challenge. We appreciate this opportunity to point out the many areas that continue to be barriers for people who have both a hearing AND a vision loss (deaf-blind).

Individuals who are deaf-blind make up a diverse group. The degrees and kinds of hearing and vision losses vary: hard of hearing and low vision, deaf and tunnel vision, hard of hearing and blind in addition to totally deaf-blind. The age of onset also varies from being born with both losses, born with one loss and experiencing the other loss at some point in their lives, or experiencing both losses due to aging, illness, or injury. Because of this variable in degrees, age of onset, and etiology, communication methods become diverse: American Sign Language (close up or tactile), assistive listening devices, Braille equipment. Moreover, deaf-blind people have diverse socioeconomic backgrounds, family support, and education.

Despite this diversity in the deaf-blind community, they all have the same needs: to lead productive and independent lives with equal access to the community where they live and work, the same as non-disabled people.

It is our firm belief that without specialized services for this population, barriers will continue to exist. Many individuals who are deaf-blind do not have the resources to self-advocate, nor have access to agencies. For many people who are deaf-blind throughout this country the opportunity to obtain or access educational, vocational, economic, social and political opportunities is denied or severely limited. Service providers often are at a loss on ‘how to’ appropriately serve this population and resources within the community are slim to none. Some service models have the unintended consequence of perpetuating the “learned helplessness” and dependency among the deaf-blind community members which reinforces the barriers that prevent this community from living a full, productive, satisfying and empowered life. The current trend to group all people with disabilities together, while helping the majority, tends to further hinder accessibility to this minority population.

Although deaf-blindness is considered a low incidence population during a presentation in Atlanta, 2005, William Sansing, MS State University provided the following statistics:

**NATIONAL TOTAL AND DUAL SENSORY LOSS: 2005/2010 AND BEYOND**

- Total Sensory Loss 2005: 9.79 Million
- Total Sensory Loss 2010: 10.63 Million
- Dual Sensory Loss 2005: 1.134 Million
- Dual Sensory Loss 2010: 1.214 Million

Beyond 2010 the largest single age group will be people age 44-55, with an additional 26.4 million people “moving” into the 55 and above category. Assuming constant mortality and incidence rates, this will result in approximately 1.7 million people with hearing loss, 1.01 million vision loss, and 290,000 with dual sensory loss. (William Sansing — 2005-MSU)

It is predicted that by the year 2010, 1.214 million Americans will have both a vision and a hearing loss. How do we prepare our nation and local communities to be ready to meet the needs?

Below are listed the current barriers in our communities. This list was developed from feedback from consumers and professionals across the United States. It is believed to be comprehensive and the
barriers identified exist to some degree in all communities. There are pockets of more accessible communities in the U.S. and we commend those communities, namely, Boston, DC, Seattle, Minneapolis-St. Paul. The difference is strong and effective advocacy efforts resulting local county and state funding that supports programs, along with a strong national program that provides leadership, and resources.

The Need for Support Service Providers

American Association of the Deaf-Blind, a national consumer organization of, for, and by people with dual hearing and vision loss, conducted a survey of deaf-blind consumers about the top needs in the deaf-blind community. Support service providers (SSPs) were identified as the #1 need.

At this time no coherent and consistent system exists for local, state, or national funding for SSP services. Only 28% of the states have any level of SSP services. If the future expansion of SSP services is to succeed, greater and more consistent funding resources must be identified and secured.

Excerpts from the SSP White Paper (available on www.aadb.org):

“A support service provider (SSP) can be any person, volunteer or professional, trained to act as a link between persons who are deaf-blind and their environment. They typically work with a single individual, and act as a guide and communication facilitator. They may be hearing, deaf, blind, or deaf-blind.”

The SSP serves as the eyes and ears of the person who is deaf-blind. There are two key components of an SSP’s function:

1. 1) The SSP provides access to the community by making transportation available (by car, bus, or other conveyance), and serves as a human guide while walking.
2. 2) The SSP relays visual and environmental information that may not be heard or seen by the person who is deaf-blind. This is done in the person’s preferred language and communication mode.

An important aspect of the relationship between the person who is deaf-blind and an SSP is that the former makes all decisions. The SSP can provide information to the individual to assist in considering options, but at no point should the SSP make choices and decisions. The professional SSP strives to be helpful but objective, supportive yet empowering, and sparing in expressing their personal preferences while providing services.”

Without SSP support, deaf-blind individuals are often stuck at home and isolated, leading to frustration and depression at not being able to communicate, access information, get out in the community, maintain employment and vote. It is no wonder that deaf-blind consumers listed SSPs as their number one need.

Deaf-blind people are not the only disability group that benefits from having SSPs. Senior citizens with good mind and motor function, but who are unable to drive would benefit from the support of SSPs to access their community. Hearing blind people appreciate people to guide them in unfamiliar places and describe what is happening around them, tasks that SSPs do for deaf-blind people.
Health Services

The medical community does not typically have the sensitivity and awareness that ensures appropriate access to services by the deaf-blind community. When specialists with this knowledge and skills do exist they are few in number and are often not an option due to limitations in insurance coverage by the deaf-blind consumer.

Communication renders the deaf-blind person a passive recipient of medical service with limited or erroneous information regarding diagnosis and prognosis. Numerous accounts of personal experiences by deaf-blind people are shared whereby doctors erroneously declared “you are going to go blind someday” and this coupled with lack of supports and resources leads to personal tragedy and missed opportunities.

Qualified and trained interpreters with the skills and knowledge to work with the deaf-blind community are lacking. In addition, deaf-blind individuals must often rely on family members and friends for support and transportation to medical appointments. The provision of SSP services would enable a deaf-blind person to obtain needed services independently.

The barriers of communication lead to social isolation among the deaf-blind community and this factor can contribute the need for mental health services. There is a severe shortage of mental health practitioners who are trained in addressing the needs of the deaf-blind community.

Other Barriers to Health Services:

- Lack of trained medical and mental health professionals with knowledge and skills to serve/work with individuals who are deaf-blind; also, those few medical or mental health professionals with this knowledge and skills are often out of deaf-blind people's insurance network.
- Lack of trained Interpreters in Medical settings
- Lack of training for respite care and respite care providers for deaf-blind individuals
- Lack of support service providers — Support, guide to doctor’s, therapist’s office
- Deaf-blindness leads to Isolation-need for mental health support — lack of access to communication, lack of services to address mental health needs
- University programs — in Health fields - no attention to disability issues specific to deaf-blindness
- Increase of Veterans — dual hearing/vision loss needing medical and mental health care
- 15 states — reporting outbreaks of Congenital Rubella Syndrome
- Limitations of services in health system (limited doctors visits, knowledgeable doctors may not be in insurance network, hearing aids not covered by insurance, cost of hearing aids too high for many people to afford, audiology visits not covered by insurance except for testing)
- Increase in number and availability of qualified and trained professionals who can provide accurate cognitive, neuropsychological, personality and achievement tests to deaf-blind people.
- Specialists may have knowledge in blindness only, or deafness only; very few have thorough knowledge of both disabilities, or the unique needs of deaf-blind individuals.

**Technology**

The information and advancing of technology in society creates a gap of “the have-nots” and “the have-nots.” Technology is a necessary link toward information and communication access, independence, access to community resources and maintaining a competitive edge in today’s employment market. There is a need for affordable adaptations to technology with consideration to the needs of individuals who are deaf-blind as well as qualified trainers and services.

Other technology barriers:

- Lack of technology among individuals who are deaf-blind to ensure equal access to information, communication and various community environments in which they travel.
- Lack of funding available for assistive technology for children who are deaf-blind.
- High cost of adaptive technology (example: Braille displays for computers cost about $10,000).
- Companies are often not willing to develop new products that will benefit deaf-blind people due to the small population.
- Difficulty in servicing and repairing available technology
- Inadequate training available for deaf-blind individuals to gain much needed skills in adaptive technology
- Local, state agencies not accessible due to high cost of adaptive technology or interpreter services.
- Lack of training of adaptive technology professionals and tech support personnel at adaptive technology companies to work with deaf-blind consumers.
- Often technology is designed exclusively for people who are blind (auditory output only), or for those who are deaf (visual output only); few are designed with the needs of those who have both vision and hearing loss.
- Expensive access technology becomes outdated in five years or less.
- Most technological devices do not stand-alone; they need another device to accomplish their tasks; in addition, they are often not portable and not easy to use.
Employment

Attitudinal barriers/Low Expectations for Youth with Deaf-blindness (Petroff, 1999) found that one third of the parents of transition age deaf-blind youth did not think that their young adult was capable of employment. This is compounded by society’s attitudinal barriers which result in deaf blind people being frequently unemployed, underemployed and underpaid.

In addition there is a lack of qualified personnel to meet the educational and vocational training needs of individuals who are deaf-blind. In a recent survey performed by HKNC the greatest obstacle to employment identified by respondents was the lack of supported employment programs.

Other employment barriers:

- Accessibility on the job
- No Technology — left behind — no information access and communication,
- Affecting independence and productivity
- Lack of Employment training opportunities
- Lack of qualified personnel on Vocational Rehabilitation programs
- Lack of Supported Employment Programs or customized employment programs
- Vocational Rehabilitation services are strained and often do not have the resources or funds to assist deaf-blind people to find jobs.
- Lack of employment opportunities for deaf-blind people who have pursued higher education and possess bachelors or master’s degrees.
- Lack of health care becomes disincentive to employment

Housing/Independent Living

- Lack of support from support service providers
- Lack of affordable housing near public transportation
- Inadequate housing options for deaf-blind senior citizens (including nursing homes and assisted living facilities).
- Lack of qualified personnel such as Rehabilitation teachers, Orientation and Mobility Specialists and Low Vision Specialists, advocates, interpreters to enable individuals to receive training to gain and maintain independence
- Lack of access to community services such as on-line banking
- Lack of and need for accessible currency.
• Deaf-blind people need to be able to travel on their own without being forced to fly with someone else or pay for the price of someone to travel with them.

• More restaurants and places of business need to provide large print and braille menus and other written documents.

• Limited funding is available for available support service provider programs, and these programs are also limited in scope.

**Insurance**

• Few deaf-blind people are employed full time with health benefits
• Employment is barrier to getting insurance
• Medicare/Medicaid inadequate Coverage out of state is not available; hearing aids not covered by insurance at all, audiology visits not covered except for testing, technology needed for independence not covered by insurance.
• Insurance limitations (limited doctors visits, knowledgeable doctors may not be in insurance network)

**Transportation**

• Difficulties for deaf-blind people in rural areas
• Difficulties for deaf-blind people in larger cities with suburbs because of lack of public transit between cities and outlying suburbs.
• Lack of training by qualified Orientation and Mobility instructors in order to access public transportation.
• Need more Orientation and Mobility instructors skilled in ASL
• Paratransit operators need to have TTY equipment and know how to use it.
• Taxi services can be very expensive for deaf-blind people, even with taxi discounts.
• Paratransit services are often limited.

**Education**

• Self-determination skills not a priority in educating deaf-blind children
• Need for “accountability” in transition services for deaf-blind from HS to Employment/College
• Deaf-blind teens and young adults lack socialization, leadership skills education

**Recreation**
• The severe lack of Support Service Providers (SSPs) results in a lack of access and therefore social isolation.

• Consumer organizations — difficult to bring together regularly for support and education, thus advocacy efforts are challenging. The internet is not accessible to all limiting virtual peer support and networking.

• Due to high cost of SSP support, AADB faces unique challenges for hosting regular national conferences. This national consumer organization is unable to foster a strong community and provide much needed and desired leadership to other state and local consumer organizations.

**Family Issues**

• Inadequate support for families with deaf-blind children

• Not enough trained personnel to work with deaf-blind children or their families.

• Inadequate support for families of individuals who become deaf-blind as adults.

**Emergency Preparation**

• Lack of communication and access to information — on emergency shelters and evacuation plans

• Lack of training of first responders on how to interact with people who are deaf-blind (including use of such things as communication cards, etc.)

• 9-1-1 systems, especially in small towns and rural areas, having TTY equipment and knowing how to use it when seconds count.

• Lack of SSP services when someone needs to go to a shelter (communication, signing documents, etc.)

We believe the answer lies in more trained professionals in the community, a strong national leadership, resource development, and training for the population.

**Recommendations**

• The establishment of a consistent, nationally funded service delivery system providing SSP services to individuals who are deaf-blind so they may live and work in their community of choice.

• More training for individuals who are deaf-blind in independent living, technology, leadership, legislative advocacy, etc, preferably in partnership with American Association of the Deaf-Blind.
• More trained professionals in the community:
- Support Service Providers
- Technology teachers
- Interpreters
- Communication instructors (tactile sign language, Braille)
- Employment — job developers, job coaches, job placement personnel
- Mental Health
- O & M instructors
- Deaf-Blind Specialists
- Community Services, i.e., Housing, Transportation, Banking, Recreation & Leisure programs, University Training Programs

- Agencies at the state level working together, preferably in partnership with Helen Keller National Center (HKNC).

- State agencies for the deaf and the blind working together to serve this vastly underserved community. HKNC does not have the financial resources/capacity to ensure service needs are met and barriers are transformed into opportunities.

- Adaptive technology professionals and tech support personnel at adaptive technology companies need basic training on how to work with the deaf-blind community, especially given that we are a diverse community with diverse methods of communication.

- Removal of income requirements for training and services due to extreme costs.

**In Closing**

We thank the National Council on Disability for their consideration on including these trends and issues from the deaf-blind community in their document to the President. If we can be of further assistance, please feel free to contact us:

- Susan Lascek, Director of Field Services, HKNC sl4hknc@aol.com;
- Jamie Pope, Executive Director, AADB Jamie-Pope@aadb.org; and
- Sue Ruzenski, Director - Direct Services, HKNC HKNCTRNG@aol.com.

I also added the project brochure. I hope this helps.

Lisa
Lisa Poff, Project Coordinator
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www.indbservices.org
www.facebook.com/INDBServices
Indiana Geography and Statistics

Population: 6,699,629
Amish: 45,144 (est.)
African American: 608,226
Hispanic: 426,000
Land Area: 35,826 Square Miles
Counties: 92
Total School Enrollment: 1,139,822
Special Education Population: 166,914
Percentage of Special Education Students in Indiana: 14.64%
Special Ed. Planning Districts: 253

Figure A-1
The anticipated range for reporting in Indiana is from 256 to 312 children and youth with deaf-blindness (one standard deviation above and below the estimate of 284). This is based upon the expected incidence rate of deaf-blindness in comparison with the special education population in Indiana.

**Figure A-2**

### Ages of Individuals who are Deafblind in Indiana 2017

- 6 to 13: 37%
- 14 to 18: 33%
- 19 to 21: 20%
- 0 to 2: 3%
- 3 to 5: 7%

**Transition Ages**

- 14-21: 53%

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**Figure A-3**
Figure A-4

Degree of Vision Loss

- Documented Functional Loss: 27%
- Low Vision: 37%
- Further Testing Needed: 1%
- Diagnosed Progressive Loss: 2%
- Totally Blind: 5%
- Light Perception Only: 9%
- Legally Blind: 19%

Figure A-5

Degree of Hearing Loss

- Documented Functional Loss: 21%
- Mild: 14%
- Further Testing Needed: 1%
- Diagnosed Progressive Loss: 0%
- Profound: 17%
- Severe: 9%
- Moderate-Severe: 17%
- Moderate: 21%
Living Arrangements

- Pediatric Nursing Home: 0
- Apartment (with non-family person): 0
- Group Home (6+ Residents): 1
- Group Home (<6 Residents): 0
- Private Residential Facility: 6
- State Residential Facility: 1
- Home: Foster Parents: 5
- Home: Extended Family: 18
- Home: Parents: 188

Figure A-7
**Diversity: Race/Ethnicity**

- American Indian/Alaskan Native: 0.91%
- Asian: 2.74%
- Black or African American: 1.94%
- Hispanic/Latino: 9.08%
- White: 74.43%
- Native Hawaiian or Other Pacific Islander: 0.00%
- Two or more races: 3.20%

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**RACE/ETHNICITY**

**Figure A-8**
Educational Placement

Ages 6-21
Parentally Placed in Private School: 19
Correctional Facilities: 0
Homebound/Hospital: 4
Residential Facility: 16
Separate School: 13
Regular Class <40%: 84
Regular Class 40-79%: 17
Regular Class 80% or More: 40

Ages 3-5
Home: 5
Service Provider Location: 0
Attending Residential Facility: 0
Attending Separate School: 2
Attending Separate Class: 6
Regular EC Prg. <10 hrs/wk w/Services Elsewhere: 0
Regular EC Program <10 hrs/wk w/Services: 0
Regular EC Prg. 10+ hrs/wk w/Services Elsewhere: 0
Regular EC Program 10+ hrs/wk w/Services: 4

Ages Birth-2
Other: 0
Community Based: 1
Home: 5

Figure A-9
Indiana Deaf-Blind Services Project

What is the Project?
The Indiana Deaf-Blind Services Project is a federally-funded grant administered by the Blumberg Center for Interdisciplinary Studies in Special Education.

The project’s goals are to:

- ensure that children and young adults with combined vision and hearing loss have the educational support necessary to successfully complete school and be better prepared for adult life;
- empower families so that they are better able to participate in educational and life planning, as well as become better advocates and leaders in their school, community and state;
- provide educators with increased skills in using evidence-based practices so that students can participate more fully in inclusive settings; and,
- foster leadership and collaboration among state/local education, early intervention, and community agencies.

What does the Project Do?
The project provides technical assistance, training and support for children and young adults who have a combined vision and hearing loss, their families and educators who work with these individuals.

Project activities include:

- child-focused consultations;
- in-service training;
- technical assistance and information dissemination on topics relevant to each individual’s needs;
- assistance in the development of IEPs, person-centered plans, and transition-focused educational planning;
- family leadership training;
- intervener training;
- a statewide newsletter;
- a network for information and support; and,
- a Statewide Registry of students, ages birth through 21, who are deaf-blind.

Who is eligible for services?
Students with hearing and visual impairments occurring together in any combination are considered to be deaf-blind. The combined sensory loss causes such severe communication and other developmental and educational needs that they require special education and related services beyond those provided solely for children with vision or hearing impairments or severe disabilities.

Any family member, care provider and/or educator of individuals ages birth to 22 years, with combined vision and hearing loss, may request services from the project. There are no fees for these services.

Visit the Project’s website - http://www.INDBServices.org
Follow us on Facebook - https://www.facebook.com/INDBServices
Follow us on Twitter - @INDBServices
Follow us on Pinterest - http://www.pinterest.com/inbsp/
Contact Information

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Improving the quality of educational services and outcomes for Indiana infants, toddlers, children and young adults with combined vision and hearing losses.
Good morning, Kristina,

I am emailing to submit the attached written testimony regarding transit and transportation options for the 1102 Task Force in its assessment of services and support for people with intellectual and developmental disabilities. I will be attending today's meeting, and based on timing, hope to share a few comments verbally. Please let me know of any questions or needed follow-up. Thank you very much!

Take care,

Kim

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September 19, 2018

Intellectual and Developmental Disabilities Task Force
c/o Division of Disability and Rehabilitative Services
Indiana Family and Social Services Administration
402 W. Washington Street
Indianapolis, IN 46204

Subject: Written Testimony re: Transit and Transportation Options

Dear Task Force Members,

On behalf of Health by Design coalition partners throughout the state of Indiana, please accept this written testimony regarding transit and transportation options for the 1102 Task Force in its assessment of services and support for people with intellectual and developmental disabilities.

Health by Design partners work at the intersection of the built environment and public health and are invested in four core program areas: walking, biking, transit and land use. Our mission is to collaborate across sectors and disciplines to ensure Indiana communities have neighborhoods, public spaces and transportation infrastructure that promote active living for all. Our vision is vibrant, thriving communities that help all people live active, healthier lives. Ensuring access, mobility and safety for people with disabilities is a core aspect of our initiative.

We support the vision established by the Task Force. These comments focus on ensuring transportation opportunities as part of the necessary community-based supports and services for Hoosiers with intellectual and developmental disabilities, in alignment with Task Force values.

For individuals with disabilities, accessible, reliable transportation is one of the most critical support/service components in becoming an active, productive member of a community and the workforce. Unfortunately, it is often the least valued. As a result, many with disabilities are still unable to equitably participate in and benefit from their communities like their non-disabled counterparts. For example, the unemployment rate of those with disabilities is twice as much as the unemployment rate of the general population and lack of transportation is often identified as one of the most significant barriers to employment, contributing to this substantial employment gap. Sadly, 25% of the two million individuals with disabilities who never leave their home, never do so because of difficulty with accessing transportation. This percentage will only continue to increase as baby boomers age, leaving more individuals with disabilities isolated in their homes and cut off from their communities.

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Equity in transportation is critical to the independence and self-sufficiency of people with disabilities. It strengthens their ability to not only survive but thrive in their communities and contribute to their neighborhoods, towns and cities economically, socially and politically.

As such, Health by Design provides the following recommendations to the Task Force in an effort to expand accessible and reliable transportation options in Indiana for individuals with intellectual and developmental disabilities:

PROVIDE TRANSPORTATION-RELATED OPPORTUNITIES THAT FOSTER INDEPENDENCE AND CONTROL AND EMPOWER PEOPLE WITH DISABILITIES

According to the National Gateway to Self-Determination, multiple research studies find that an individual’s self-determination status predicts higher quality of life and is positively correlated with more positive post-secondary outcomes, including employment, independent living and community inclusion. In addition, individuals with disabilities with greater self-determination are healthier, more independent, more well-adjusted and are better able to recognize and resist abuse.\(^3\) Being in control of accessing and utilizing accessible transportation plays a significant role in the achievement of these post-secondary outcomes for individuals with disabilities, as does understanding and advocating for one’s own accessible transportation rights. As such, Health by Design recommends the following:

- Work with consumer-led disability advocacy organizations to provide training opportunities for riders with disabilities that utilize public and private transportation options. The majority of these trainings should be conducted by people with disabilities.
- Educate transit providers on disability etiquette, disability culture and the rights of riders with disabilities. The majority of these trainings should be conducted by people with disabilities.
- Ensure riders with disabilities have opportunities to serve in meaningful roles alongside individuals without disabilities on transportation-related Boards, Councils, Committees and Coalitions in all areas of the state.
- Support the development and use of assistive technology as a means for individuals with disabilities to easily access and be in control of utilizing accessible transportation.

COORDINATE & COLLABORATE ACROSS AGENCIES AND WITH ORGANIZATIONS (PUBLIC & PRIVATE) AND STAKEHOLDERS AS A KEY STRATEGY TO INCREASING AND IMPROVING ACCESSIBLE TRANSPORTATION INFRASTRUCTURE THROUGHOUT THE STATE

Bolstering coordination and collaboration across systems is essential for the growth of a successful, interconnected, accessible transportation network that supports the needs of individuals with disabilities. Coordination of transportation funding, planning, and policies and practices between state agencies, human service organizations and public and private transit providers can have a profound impact on the availability of accessible and reliable transportation options for individuals with disabilities. As such, Health by Design recommends the following:

- Create state legislation that mandates cooperation, collaboration and coordination by establishing an Interagency Accessible Transit Advisory Commission, to ensure the development of a coordinated human service delivery system to address accessible transit needs and barriers. This commission must

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\(^3\) Khemka, Hickson, & Reynolds, 2005; O’Conner & Vallerand, 1994; Wehmeyer & Schwartz, 1998.
consist of individuals with disabilities and consumer-directed (disability) advocacy organizations working to expand accessible transit in local communities across the state.

- Individuals with disabilities must have the opportunity and be included at all levels and in all processes of collaboration to ensure an equitable transportation framework is developed that truly meets the needs of the disability community. Individuals with disabilities bring unique and valuable experience to the table having navigated transportation systems not suited for their disability-related needs. They are some of the best experts in identifying significant gaps and barriers to utilizing transit.
- State agencies and human service and transit provider organizations need more flexibility to enable service delivery across geographical boundaries, as barriers are often created by restrictive and conflicting policies and practices from different funding sources. Individuals with disabilities must play a meaningful role in the development of these coordinated policies and practices.

ELIMINATE ACCESS BARRIERS AND IMPLEMENT INNOVATIVE TRANSPORTATION POLICIES AND PROGRAMS ACROSS PUBLIC AND PRIVATE SYSTEMS TO INCREASE EMPLOYMENT, SELF-DIRECTION AND COMMUNITY INTEGRATION OF PEOPLE WITH DISABILITIES

Everyone faces challenges or barriers at one time or another. However, people with disabilities experience barriers more frequently, which has a greater impact on their ability to equitably access services.\(^4\) This is often the case for people with disabilities when trying to access and utilize accessible and reliable transportation. The access barriers they experience with transit are more than just physical obstacles, there are also policy and programmatic related impediments. The policy and programmatic barriers tend to be related to a lack of awareness or enforcement of existing laws and regulations that require programs and activities be accessible to people with disabilities and that limit the effective delivery of accessible transportation programs for people with different types of impairments.\(^5\) As such, Health by Design recommends the following:

- Establish and enforce policies that support the availability of accessible, reliable and timely transportation options for individuals with disabilities from private transit providers (taxis, rideshare vehicles – Uber/Lyft, buses, etc.) receiving public funding.
- Transform policies to shift funding support to Medicaid non-emergency medical transportation for individuals with intellectual and developmental disabilities receiving supports/services in integrated (non-congregated) community settings, particularly for employment and community engagement activities, as opposed to funding support for Medicaid non-emergency medical transportation for individuals with intellectual and developmental disabilities utilizing day centers and sheltered workshops.
- Establish a pilot program for Medicaid non-emergency medical transportation that supports reimbursement for the use of accessible vehicles, like Uber and Lyft, as cost-effective alternatives to paratransit service.
- Establish an employment pilot program for individuals with intellectual and developmental disabilities with reliable, accessible vehicles to become accessible transportation providers for public and private transportation entities, such as Uber/Lyft, to provide accessible transportation to their peers with disabilities.

\(^5\) http://www.hhs.gov/ocr/civilrights/resources/factsheets/504.pdf
Accessible and reliable transit is paramount to opportunity. It is access to jobs, education, health care, family and a high quality of life. It is more than just ensuring accessible buses. It is about choices and control, broad transit networks, rural and urban equity, access to assistive technology and more. Equity in transportation is an important civil rights issue. It is critical to the independence of people with disabilities, however accessible transportation options remain unacceptably limited for Hoosiers with disabilities. The expansion of accessible transportation opportunities in Indiana has the potential to increase the employment opportunities, community integration, and positive health outcomes for people with disabilities. Therefore, more efforts must be made to address the systemic barriers to accessible and reliable transportation.

Health by Design partners are thankful for the opportunity to provide these comments to the Task Force and welcome further discussion of recommendations that will lead to strategies that address the barriers to accessible transportation for Hoosiers with disabilities. Please let me know if I can provide any additional information or answer any questions. I can be reached at 317-622-4821 or by email at kirwin@hbdin.org.

Sincerely,

Kim Irwin, MPH
Executive Director
Kristina:

Thank you for the opportunity this morning. Please see my attached written testimony. This is the same as I spoke this morning.

With Gratitude.

Megan Gumbel, MBA
CEO
9400 W 650 S
Pendleton, IN 46064
Cell: 574-304-2754
www.givingfamilyhope.org
Good Morning Task Force Committee and thank you for the privilege to speak to your group.

My name is Megan Gumbel. I am the chief executive officer of the Giving Hope Foundation.

I am here to ask the committee to consider solutions beyond the current system. Solutions that will help families and caregivers.

The task of evaluating the current system is difficult. It must be addressed from both a provider and family standpoint. I want to encourage you to find a way for the solutions to intersect.

The Giving Hope Foundation has spoken with multiple families and I would like to share 4 main themes/concerns.
The first is a lack of understanding. Families struggle to understand the current system. More importantly there is a level of intimidation or feeling of being overwhelmed with when and how to apply for available benefits.

Families seek a simple way to do this. Once they receive benefits, they are not always confident that they have all services or benefits they are eligible for. If they are denied services, they struggle to understand why and how to appeal.

The second is a need for respite. Many families want to care for their loved one. However, in order to survive one or both of the caregivers often must work and this can lead to fatigue and burnout. What we have heard is that the caregivers need a break. However, locating a reliable respite provider is a challenge.
Third, we have heard concern with access to quality and compassionate medical care. Please do not forget to take into account ways to address a disjointed medical system with access and quality concerns in both urban and rural areas.

Fourth and finally, we consistently hear concerns about transportation. I encourage you to seek to understand why transportation is a barrier. Together we should strive to create best practices that allow the individual, their family and caregivers to focus on the quality of care; not how to get to the service or the care. I understand transportation is often funded by each county. However, for a family or individual in services; their home county may not have the adequate service they seek.

Your task is large but please seek to understand the root of the issue. Please speak with families and caregivers. It is our responsibility to address these concerns. Thank you for taking on this tremendous task.
Hello, my name is Alexis Swinney. I have been a Direct Support Professional in The Lifelong Learning Program at Stone Belt in Bloomington for 3 1/2 years.

I started my journey as a DSP when I was 18 years old. I was hired on at $8.60 per hour, I'm currently at $10.50 per hour. My job can be very mentally, physically, and emotionally draining but I LOVE my job.

Here is my job in a nutshell:

I arrive at work and I am happily greeted by clients who know me by name. I have developed some wonderful relationships with clients and their families over the past few years. I have also become like family to clients who don’t have families of their own. In fact, my so-called “twin brother” is about 40 years older than I am!

I’ve also made great memories over the years such as assisting clients at Holiday World, The Indianapolis Zoo, IU basketball games, the movie theatre, on a train ride at French Lick and much, much more!

But, my job isn’t fun and easy all the time.

I assist at all different kinds of appointments, carefully pass medication, document the many aspects of human health, responded to emergencies, behaviors, and seizures without a moment’s notice. I’ve ridden in ambulances, and have stayed by my client’s side for
hours in the hospital not knowing what the outcome may be. I have memorized health and safety plans for each client that I have served. (That’s A LOT of reading and training)

I have assisted in bathing, changing and restroom-usage. I’ve done tube feedings, and assisted clients who can’t feed themselves with every meal, snack, and drink. I’ve wiped noses and hands, cleaned up drool, vomit, blood and other bodily fluids.

I have been trained multiple times in first aid, CPR, the Heimlich maneuver, universal precautions, CPI (non-violent crisis intervention), administering medication, abuse and neglect prevention and more. Overall, I had to do 40 hours of classes of training before doing on the job training.

I have worked with individuals with autism, mental health issues, cerebral palsy, Down syndrome, dementia and Alzheimer’s, the deaf and non-verbal, wheel-chair bound, individuals with up to severe behavioral issues, chronic pain and other disabilities not listed. I have served the old, young, and in between.

I have had the opportunity to teach clients life skills in cooking, community volunteer work, personal hygiene, household and financial management, pedestrian and community safety and more. As a DSP, I have always
tried to find teachable moments to increase independence in my client’s life.

I have conversed in a positive manner and celebrated every achievement big or small even when I’ve had major troubles in my personal life. I’ve cared tremendously, I’ve helped reach goals. I’ve helped clients integrate into the community and live as regular, fullfilled, and happy of a life as possible.

With all of those many jobs within one jobs, why do I still want to be a DSP, you may ask. Over the years, I’ve developed close relationships with the most PRECIOUS people my heart has known. They have become one of the most major parts of my life, some, like family. They have inspired me to keep going when things get tough. Through this job I’ve discovered my life’s calling and passion.

People with disabilities are people too
People with disabilities are people, just like you
September 19, 2018

Dear taskforce members,

Self-Advocates of Indiana is a statewide organization run by and for self-advocates. Our goal is to empower people with disabilities to educate and advocate for equal rights, respect, and inclusion in the community. We have 44 local self-advocate groups across the state and we are run by a board of directors made up of self-advocates.

At a meeting in 1990, SAI’s founder, Darcus Nims, brought the self-advocates together and asked any helpers to leave. She asked them what they wanted for their lives. They decided to keep meeting so that they could work towards their goals together and advocate for the services and supports that would help them reach their goals.

We have made a lot of improvements since 1990 to provide more independence and inclusion for people with disabilities. However, there are still a lot of barriers standing in our way.

Transportation is a huge problem for people with disabilities. Transportation can be inconsistent, inflexible, and inaccessible. If we live in a rural community, there may be no options. If we cannot access our community, we are limited in employment, living options, and involvement in our community. If we want to work towards more inclusive communities and workplaces, we have to make it easier for us to access them.

Staffing also limits our independence. Staff shortages put our health and safety at risk and limit our access to the community. It limits our choice in how we spend our days. Many of our staff leave for higher paying jobs so they can support themselves and their families. For these reasons, SAI fully supports the increase in wages for DSPs.

SAI supports increased housing options so that we have more choice in where we want to live and the support we receive. Many of us do not qualify for the CIH waiver, so our choices are often limited to our family homes, group homes, or affordable housing programs. Many of us want to move out of our family home for more independence. Group homes don’t always provide the opportunities for us to access our community the way we want to. Housing assistance programs are hard to access and may require us to move out of our community and support system. We all require different levels of support and so our living options should not be one-size-fits all.

SAI believes that people with disabilities want to work, have a career, and contribute to their communities. Many of us want to be able to support ourselves and not rely on government assistance programs, but we are limited by the issues listed above, lack of opportunities, attitudes of employers, fear of making too much and losing the services we need, and lack of access to employment supports. We must work together to increase options for competitive and integrated community employment. We must build a system that will support us to have meaningful careers in areas that interest us, where we can make a living wage.
At our last board meeting, we asked our board members what they felt were the most important issues to them. Although we discussed the issues listed above, we also discussed the culture of our services and support.

Here are some of the things they said:
- We need more choices
- We need more information about our choices so we can make the best choice for us
- Help us learn how to make decisions instead of making them for us
- I need more flexibility so that I can use my services when and where I want to
- Inform us about how our services work so we can use our budget the way we want to
- Recognize that we are independent adults
- Our opinion matters
- Treat us like people not just numbers or clients
- Nothing About Us Without Us—talk with us not about us

We believe a change is necessary to create a system that allows us to have support, choice, and independence.

Let us direct our supports and understand that we each have unique goals and needs, so services should also be unique and flexible. Educate us about all our options, don’t just tell us what our options are. Make sure the information you give us is accessible and understandable, so we can make the best choice.

Above all, make sure you aren’t making any decisions about us without us. Make sure you are listening to us first. Continue to invite us to the table to discuss these issues and make sure you are valuing us as fellow advocates, community members, and human beings.

Sincerely,
Self-Advocates of Indiana Board of Directors
I am happy but not enough staff in the community, getting around, to place not enough jobs out there will hire people with disabilities.
Nick - better options for transportation want to have job but you can't because of benefits. More options for Section 8 housing.

Eric - don't shut down workshops.

Courtney - don't cut benefits. Just because we choose to work and give us more accessible options for housing.
Independent living and staff and transportation speak up using your voices and making choices with help from staff to help you make the choices you want to make.
My name is Randy Wize from Columbus, Indiana, and I would like to tell you what I like about my wife. I have trouble walking and balance and my wife lets me have a carer come into my house and help me clean. That's very important to me to have that help so I can keep my house clean and what I don't like about my wife is that the carers don't get paid enough.

Thanks, Randy.
I need help us last week. What time can I come on time.
We want more reliable transportation to go out in the community and to be more flexible benefits and the structure to still get what we need to live productive lives. We are human beings not just statistics and our voices need to be heard and our opinions matter and better people being better educated on our choices we have "nothing about us without us."
Willie Rosendahl

1. Bus service in my community
2. Uber (safe) service for persons with disabilities
3. Job services
4. Providers having available staff
5. Ability to work within my provider as DSP
   (I was told they could only have 1 person in each center)
6. Providers need to put focus on DSP
   and individuals first. Why do staff quit
   all the time
Nick Parker

1. I want my driver lis.

2. New Staff - to take me places

* Where you can work and not lose your benefits
1. raising money for stuff
2. for stuffing to set a
3. food & gas
4. we going around the town and out to eat
   Movie, Shopping
5. Job's
6. Sheltered Workshop
   Group Homes
   Transported

Dec 6
Notes

1. Hire more staff
2. More staff
3. How to work with the clients
4. Help clients find community jobs
5. Pay increases
6. More work
7. Services and deployment
8. Lack of staff
9. Schedule time and transportation and benefits
10. Education
11. Trust funds
12. Lack of choices
Money
Strengthen independent education
Housing
Before the housing employment
Transportation
Choices
Empower
be advocating for new hope
**** This is an EXTERNAL email. Exercise caution. DO NOT open attachments or click links from unknown senders or unexpected email. ****

I have worked for agencies serving individuals with IDD for 15 years as a Program Director in residential and day services and have read about the 1102 Task Force’s activity with interest. I am particularly encouraged by the measures targeting the DSP workforce shortage and making CIH Waiver slots available on a non-emergency basis. DSP’s absolutely deserve to make more and to have a structure for professional development.

As you consider changes to the service system to allow people to direct their services and use funding to further their goals, I encourage you to consider the service definitions for Waiver services such as Facility Group Hab and Community Group Hab. Having Facility-based and Community-based services divided as we do now actually creates barriers to community participation. When people have to plan out months or a year ahead of time how many hours they will be in the facility and in the community, they cannot take advantage of chances to spend extra time in the community. If they decide they don’t want to go out when planned, they will be provided with facility hours exceeding what’s in their budget. Having a service definition that does not specify community vs facility would allow flexibility that would benefit both service participants and providers.

Thank you again for taking a look at Indiana’s system, listening, and considering new things. It’s good to see how many issues are being addressed.

Barbara Pickut, The Studios at LOGAN (Adult Day Srvcs) Director
LOGAN Community Resources, Inc.
LOGAN Center
2505 East Jefferson Blvd.
South Bend, Indiana 46615
Office: (574) 289-4831, ext. 51506
Fax: (574) 234-2075

LOGAN Industries
3621 Boland Drive
South Bend IN 46628
Office: (574) 289-0385
Fax: (574) 233-6149

Hannah & Friends
51250 Hollyhock Road
South Bend IN 46637

LOGAN supports people with intellectual and developmental disabilities so that they, and their families, may achieve their desired quality of life.

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**Hi Kristina**

I was the last speaker today at the Task Force meeting – Trish Ierino. I became emotional and was unable to finish my last talking points. I’m attaching my presentation if anyone would like to read it. I’m glad I attended today and feel hopeful that some changes will take place. I have to believe it will get better, it must. Families members must believe it will get better for their loved ones.

Thank you so much.

Trish Ierino

Sent from Mail for Windows 10
Task force Speech

Trish Ierino, 3900 East Stonegate Dr., Bloomington IN 47401

My Sister Cheryl is 52 years old, I’m her guardian and only remaining family member who can support her. I am able to work because of the supports we receive from Stone Belt.

Our Dad passed away in 2005 and in 2006, my job took me to Bloomington Indiana. Mom and Cheryl came with us. At age 40, Cheryl had never been on Medicaid or received any supports or services. She had only been with family, never in any program or in the community. My parents didn’t understand the impact this would make in Cheryl’s life in later years.

For our move to Bton, We were fortunate to be able to build an addition on to our home for Mom and Cheryl. I had to go through a city zoning process to care for my own family. And had to do the zoning process again to bring in a roommate which was required in order for us to receive more support for Cheryl.

Mom knew in 2006 that we needed to change in order to help Cheryl prepare for the future. I reached out to the state to complete paperwork for waiver services. When I asked how long would we have to wait, his exact words were - 7-10 years or if your Mom turns 80 or dies. I appreciated his honesty but was definitely a reality check for me.

We took small steps, by enrolling Cheryl in a Stone Belt program for 2 days a week and paying out of pocket. Mom did turn 80 and passed away in 2016.

With the supports from Stone Belt and Fogerty Music Therapy, Cheryl has blossomed into her own person and gained so many experiences.

There are many high points – SB helping her to discover she is an artist and has sold art work and even has a piece displayed in someone’s home in Amsterdam. She has done volunteer work at the library and animal shelter. She’s been featured in a United Way campaign. She had a
wonderful job at IU Police Dept for 5 years. She was also featured in an Arc Documentary called Pathways to Employment and our local paper did an article on Cheryl.

As in life, there are lows too.

- In 2015 a new and inexperienced staff member left her alone in a store and Cheryl left the store in search of staff. She crossed back and forth in the street looking for staff and to go home. It’s a miracle she wasn’t hit by a car. Police located her. She developed an extreme distrust of any new staff (diagnosed with PTSD).
- SB has developed a special training process for new hires to interact with Cheryl before working in her apartment.
- We had to choose between support for her community job or staffing at home. Had to select staffing.
- In 2017 her depression and anxiety increased to all time high. Had to increase medications to deal with constant changes/turnover of staff.

Cheryl is fortunate to have the full waiver but we still have to make tough choices.

- Paying for certain services out of pocket is not always possible. Sometimes we have to choose between music therapy out of pocket or volunteering in the community.
- Will we ever have the budget to help her find a community job again.
- Finding a good roommate match which is all about the budgets. You have to find another client to match Cheryl’s algo. And those individuals have high behaviors which increases Cheryl’s depression and anxiety.

As you determine what changes are needed – please consider

1. 80 year old parent rule – is outdated. It is cruel not to give funding earlier to help our loved ones prepare to be without their parents. I know several parents that are in the 50’s with health issues and keep being denied for the waiver.
2. Reimbursement rates must improve. The turnover and recruitment for support agencies is not acceptable. I was serving on the SB Board when the state did an increase in 2015. The reimbursement rate was brought to the 2010 level. I believe I heard there will be or was an increase this year but still is inadequate.

3. DSP wages must increase which is tied to the reimbursement rates. People may love their work but they can't afford to work at these agencies. Majority have 2\textsuperscript{nd} and 3\textsuperscript{rd} jobs just to barely make ends meet. Many receive food stamps. We have 2 staff at our apartment that are working 70-80 hours a week. How long before they burn out and it impacts their health.

4. It's a vicious cycle. Agencies can't hire and keep DSPs. Supervisors end up having to work DSP shifts on a regular basis, unable to adequately coach, train and oversee operations. And many clients suffer with no stability.

5. Revisit algo designations. Are there better models in other states? PA? Is our system too complicated and create barriers.

6. Stone Belt has an incredible creative leadership team. They want to increase services, add programs, say yes to more individuals. But there are hinder due to Medicaid reimbursement rates.

Families must know services and support are here for our loved ones. We need to know Agencies will survive and be able to provide care for our loved ones.

Thank you

Trish Ierino
Kristina,

I am so grateful the state of Indiana is taking the time and effort to gather input from the public to better serve our neighbors with disabilities. My husband and I have 2 adult sons that are severely disabled. Both boys currently still reside at home with us. They both require 24/7 care.

I have worked for the past 13 years the best I could to bring additional options to our state. I was a founding parent of The Village of Merici, and my husband has served the Board of Damar for the past 14 yrs.

What we see if a dire need for better pay for direct support professionals. There is a terrible shortage and we can personally speak to the challenge in attracting trustworthy, qualified staff. They leave or resort to poor behavior themselves because they can’t support their own families, nor do they feel respected in their work. It usually falls on us families to provide them with an environment where they feel respected and supported when working out in the community.

Which brings me to the topic of community. I am very aware of the HCBS final rule by the CMS. I find it tragic that the option of intentional housing is so often vilified as if we actually want to separate our loved ones from the greater community. The facts are, however, that intentional living options (campus styled, working farms, clustered housing) often provides a wonderful community for residents and support professionals that prefer that setting. It prevents isolation and allows opportunities for individuals within the community to actually get to know their neighbors and allow for the benefits of true community living. More eyes and ears on the ground to respond to the needs of the residents. I have visited dozens of such communities across the US.

Our sons cannot speak. They both are on the severe end of the Autism spectrum, one also has CP, heart defect and seizure disorder.

I pray our state will recognize that it’s residents are all unique and thrive in varying environments. The team assembled to support the families and the families are in a much better pairing to geo the individual find the living environment that best allows them to thrive and grow. Supported living is necessary for many to reach their optimal independence.

Thank you! May God Bless your efforts Mary Pat Torbeck

Sent from my iPhone
Hello,

Someone said that you were taking comments from parents for the task force regarding the waiver. I have a couple from personal experience and from parents I work with.

- Many families desperately need supports for kids who wander. They need funds for fences, tracking devices, alarms for doors and windows, and locks for their doors. They also need funds to cover swim lessons, to teach the kids to float in case they find themselves in water, since the leading cause of death in young children with autism is drowning after wandering from a safe place. Many of the families I work with can’t afford these tools and need assistance, and they have a difficult time applying for grants. It would be wonderful if their waiver funds could cover these things, since they aren’t covered under the FSW but are desperately needed to keep these kiddos safe.

- Respite. Families can’t find anyone to help with respite. Our center has locations in three counties and I hear the same issues with respite from all three. Families really want a break but can’t find anyone to help them.

- Training of Case Management companies: the information provided to me by my waiver case manager has sometimes been inaccurate. I wonder what type of training is required of them by BDDS or FSSA.

- Parent training: It would be nice if transportation and lodging was also covered so that we could attend conferences several hours from home.

- Other therapies: Many families would like to use hippotherapy or art therapy, but these aren’t covered services.

- My son is higher functioning but still needs services. None of the things he needs are options or are currently unavailable. He needs: help with transportation from school to therapy (no providers are available in our area), counseling for family issues, exercise (help pay for sports or activities that get him moving and more involved with peers and his community), behavior therapy in the home (the behavior therapist we had wasn’t very well trained and I have heard the same from other families), swim lessons, parent training (I have asked for a list of options that I could go to and no one seems to know). No services are available to us on the weekends, and our weeks are so busy with school, study groups and ABA that it’s hard to find time during the week for him to access waiver services. Weekend services would be ideal.

- Lack of communication between BDDS/FSSA and Medicaid: Many parents are required to provide documentation of financial status even though it’s waived as part of the waiver process. It would be nice if this were more understood by the Medicaid workers to save everyone time and headache.
Just a few things I have seen, and maybe some of them are just my understanding and don't reflect the system as a whole, but I wanted to share them in case they're helpful. Thank you for your time and work to help improve the waiver system.

Sheila Edwards, CHC
Parent Liaison
Certified Health Coach
317.888.1557 ext. 225

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Dear Kristina,

I was pleased to attend the “Building Bridges with BDDS” session held last week at Easter Seals/Crossroads where there was mention made of the 1102 Task Force. Earlier that day, Rep. Ed Clere encouraged me to reach out to BDDS regarding the work of the Task Force.

We’d like to offer public comment regarding the upcoming BDDS waiver redesign, and I hope to attend the final meeting of the Task Force in October in Columbia City.

The three comments we would ask BDDS’ consideration of are:

1. IAAA is in full support of the ongoing discussions regarding a comprehensive children’s services waiver that would encompass services available through BDDS as well as the Division of Aging waivers. We hope to alleviate the agonizing decision parents face regarding what waiver to choose when their children are in need of both sets of services. Having to choose the A&D waiver over a Family Support or other BDDS waiver is a terrible decision to have to make, especially when parents will always default to the waiver that essentially keeps their child alive over a waiver that helps them reach their full developmental potential.

2. In a similar vein, we hope the same considerations can be extended to aging persons with I/DD. With so many persons with I/DD living much longer and fuller lives, we anticipate we will continue to see demand for services available through the Division of Aging waivers by persons currently served through BDDS. It would be a shame for a person currently enjoying supports through the CIH waiver, for example, to have to relinquish those services in order to receive A&D services which may be more fundamental to health and safety as they age.

3. Finally, we would hope that services available through MFP or other BDDS waivers will fully support transition services related to de-institutionalization of persons with I/DD, and services related to prevention of institutionalization. For example, assuring handicapped accessibility and other modifications of a residence, rent and utilities application fees and deposits, emergency housing repairs, etc., are all things we would want to assure consumers on BDDS waivers have access to.

Please feel free to reach out to me with further questions and comments. Thanks very much for your consideration!

Kristen
Hello Kristina,

Unfortunately, I was unable to attend the task force meeting regarding updates to the waiver. I would like to provide a written testimony for the support of art therapy’s inclusion on the BDDS waiver.

Art therapy is a master’s level mental health profession in which clients, facilitated by the art therapist, use art media, the creative process, and the resulting artwork to explore their feelings, reconcile emotional conflicts, foster self-awareness, manage behavior and addictions, develop social skills, improve reality orientation, reduce anxiety, and increase self-esteem. A goal in art therapy is to improve or restore a client’s functioning and his or her sense of personal well-being. Art therapy practice requires knowledge of the creative process, as well as of human development, psychological, and counseling theories and techniques.

In the nearly 80-year establishment of the art therapy profession, the effective practice of art therapy treatment for those with developmental disabilities and related conditions has been studied. Studies show that art therapists are uniquely qualified to utilize their training in human development, psychological theories and the creative process to help clients express themselves utilizing non-verbal communication. Because the art making process is versatile, art therapists can utilize this training to apply their knowledge in specialized ways to develop goals for each individual based on their needs.

At this time, Indiana offers three graduate training programs for art therapists. Each year graduates are entering the workforce and will work with individuals with a wide range of neurological, psychological, and cognitive diagnoses. Art therapy has the unique ability to unlock emotional expression by facilitating non-verbal communication. This is especially useful in cases of impairment of verbal expression that is characteristic of various neurological, psychological and cognitive diagnoses, including but not limited to, intellectual and developmental disabilities and individuals on the autistic spectrum. Art therapy’s singular benefits and success is increasingly recognized by the medical community as a valuable asset, whether provided in one on one session or by inclusion on interdisciplinary teams that treat people for a wide spectrum of mental and physical disorders.

I strongly believe that the inclusion of art therapy on the waiver will be an asset to clients, their families, and larger communities. It is undeniable that creativity, self-expression, and agency are the cornerstone in living well. Art therapy provides an avenue and for many the language to express themselves, understand their world, and engage fully with those around them.

Please let me know if I can provide any additional information regarding my testimonial and if any additional opportunities arise to speak on behalf of the benefits and inclusion of art therapy on the waiver.

Sincerely,

Eileen Misluk, ATR-BC, LPC, LMHC, CEDCAT
Director, Art Therapy
Assistant Professor & Field Studies Coordinator

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From: Daniel Cohn <dnl_cohn@yahoo.com>
Sent: Monday, October 01, 2018 5:31 PM
To: Blankenship, Kristina
Subject: Vocational Rehabilitation; Other Services

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From: Daniel Cohn
798 Baltimore Rd., Apt. 88
Valparaiso, IN 46385

To: Task Force on the Assessment of Services and Supports for People with Developmental and Intellectual Disabilities
Division of Disability and Rehabilitative Services
Attn: Kristina Blankenship
402 W. Washington St.
IGCS/W453/MS26
Indianapolis, IN 46204

Oct. 1, 2018

Dear Ms. Blankenship:

If I may, I would like to have the following comments submitted to and distributed among the members of the state Task Force on the Assessment of Services and Supports for People with Developmental and Intellectual Disabilities.

Vocational Rehabilitation provides vocational services to people with various types of disabilities. A former supervisor at the local office years ago once stated to me that Vocational Rehabilitation historically has done better in serving people with physical disabilities than with those with a mental illness.

I have read several articles pertaining to both Vocational Rehabilitation as well as supported employment. One of these articles said that throughout the country, there were problems with the Vocational Rehabilitation program. Inadequate funding and waiting lists in many states were cited. Also, the author of the article stated that Vocational Rehabilitation counselors often deny services to applicants who could have successfully benefited from them and should have been found to be eligible. An example was given of a young man who was disabled and wanted to go to a trade school of some kind to study heating and air conditioning technology and maintenance. He visited the school where the admissions counselor told him that they have had students with his same type of disability who completed the same program he was interested in pursuing. The young man then went to VR in his state and said that he was interested in receiving training in the heating and air conditioning field. The VR counselor told him that he was too disabled to be successful in the program, and denied him assistance with the tuition. Another article I once read talked about a man who was some kind of disability expert. He advised disabled people to forget about trying to get any help with employment or education from Vocational Rehabilitation, because it is too difficult and demeaning.

Government officials in this state do not adequate understand that any kind of social service program relies on trust. When an agency makes judgements about people and can deny them service, that setup adversely affects the client’s trust in the agency. In Vocational Rehabilitation, the administrative law judges are described as being impartial. Since the VR counselors are not described in the same way, and the very presence of administrative law judges who are there to review and possibly contradict the decision made by the VR counselor, I have to assume that these counselors, so-called, are judgmental and subjective, not impartial. Using an email address provided in the handbook that VR gives to applicants, I wrote an email to VR. I received a letter in response to my email. I felt that the administrator who replied to my letter did not address the points which I raised in my letter, and instead ignored what I said in favor of quoting from a Vocational Manual. The manual as quoted states that VR can provide supported employment for only a maximum of 24 months. The paragraph then continued by saying that because of the severity of their disability, many individuals are in need of supported employment on a long-term basis, beyond the 24 month limit. The manual says that individuals should find some other provider or funding source for supported employment other than VR. There is no alternative source. The community mental health center in the county in which I live told me that they once had a supported employment program, but that the service was cancelled, due to occurrences “downstate,” meaning budget cuts. A few developmental disability agencies offer job coaching, but that
is only one part of supported employment. I was told that a person would have to have a source of funding to receive job placement assistance from one of these agencies. Job coaching through one of those organizations is only for people who are eligible for the Bureau of Developmental Disability Services. There are certain individuals who have a disability which is classified as being a developmental disability who do not meet the current eligibility criteria to be eligible for services through the Bureau of Developmental Disability Services.

If a person has experienced some issues and difficulties with a job, the person may not trust a VR counselor with this information. VR has made it clear through its policy that they want people seeking supported employment to look elsewhere. They don't want to pay for this service. In my letter to VR, I said that I did not believe that VR counselors had either the educational background or practical experience to understand different types of disabilities as well as the various types of jobs that different applicants may have. To understand a job, you can't be a government bureaucrat who sits behind a desk all day in a government office. That just doesn't cut the mustard. The applicant knows about his or her own personal experiences. I am afraid, based on past experience, that VR counselors would claim that the person has mental problem and should get mental health treatment. None of these VR counselors or supervisors are licensed to practice medicine. I for one do not consider rehabilitation to be an actual, legitimate profession. Trying to explain difficulties pertaining to a specific job to someone at VR is probably a lost cause. These VR counselors and supervisors are judgmental. They have no real basis to assess what a disabled person's overall situation is, and factors that may affect one's employment and job performance, and outside considerations affected by the nature of a person's job, such as the wages that it pays and the degree of social status, or lack thereof, associated with it, or complex educational and sociological characteristics in a given community, which could affect the quality of life of an employed individual.

The administrator who responded to my letter did not say anything about confusion on the part of VR employees or a lack of ability to provide supported employment. Instead, something was said about VR providing some funding for training of employment specialists who provide the service and who work for the private, non-profit agencies. This may be helpful in increasing the skill level of providers, but it does not address the trust issue that I have and was alluded to in these articles I read regarding the overall system.

Yesterday, on the local evening news, it was reported on all of the T.V. stations that gunshots had been fired at Wal-Mart on U.S. 30 in Hobart. One report said that customers were frightened. The police were called, but no arrests were reported. From what I saw on T.V., I could not tell how many people were shooting, or if anyone had been actually hit. I had the impression that one or more individuals were attacking some other person or persons. The people involved with the gunfire may have gone inside the store for a while, but I was not clear about this. Some people a reporter said went to the back of the store to the warehouse area to get away from the shooting. The newspaper said that a witness had heard about 12 shots fired, and that some people got into a vehicle and drove away. Hobart is considered to be a safe area, although several years ago, there was an incident of shots being fired at the Southlake Mall, across the highway from Wal-Mart. The people who work at these retail stores may be somewhat traumatized when such criminal activity takes place. The United States has a higher rate of gun violence and crime than is found in other advanced industrialized countries. There are other kinds of problems which employees sometimes encounter. These problems can involve a person's cognitive functioning. They might also involve other individuals. The VR counselor was not there when something took place. VR counselors do not know about the sequence of events at a job which can unfold. What is of concern to a worker very likely is of little concern to a subjective, judgmental state employee with an interest in rules and regulations to follow, not the reactions and personal experience of a disabled applicant, who is low man on the totem pole.

One thing that tells me that VR counselors are superficial in their assessment -- and don't care all that much about applicants -- is that I do not recall anyone asking about past difficulties in being able to find employment and in being able to function in previous jobs. Even if a person has been employed for some time, especially if the applicant is older, there were prior years in which there may have been problems in being able to find a job and in being able to retain jobs over time. This would be an indication that the worker may have some problems or difficulties with a current job which could occur unexpectedly, at any time. The nature of psychological disabilities is that they are abstract, not physical. I think it is difficult for a VR counselor to understand the context and the nature of symptoms that might impact a person's decision-making or functioning at work when they involve psychological interpretation and functioning. It is not feasible for someone to explain these types of experiences to a government bureaucrat who has decision-making authority and who in most cases does not have all that much knowledge of mental functioning, of situations encountered on a specific job, and the interaction of the person's understanding, perception, etc. and the type of social environment which exists. An employment specialist might be in a better position to understand the problematic aspects of a person's employment, but people are forced to go through Vocational Rehabilitation to approve funding for supported employment.

I was told that if someone is not in danger of being fired from a job, the person is doing o.k. as far as Vocational Rehabilitation is concerned. Depending on one's past experience, the nature of the person's job, and the nature of the person's disability, this may be a falsehood. If someone does not feel secure with a job, then the person is not doing as well as possible, even if the person is at no risk of being fired. Very few people, irrespective of whether they have a disability or not, are at risk of being fired for not doing their job properly. If a person is mentally or physically unable to do a job, no amount of supported employment will save the person's job. In some cases, an employer may be able to shift someone to a different job that gets around the limitations caused by a disability. It takes a level of expertise and empathy which is lacking in both the state and federal governments to realistically understand what concerns and experiences a disabled person might have.
A previous VR supervisor told me that the employment specialists who provide job placement assistance did not have much knowledge concerning how to help someone to go about asking for a reasonable accommodation under the Americans with Disabilities Act. This may be exactly the type of assistance that a disabled worker may need, but if VR counselors and employment specialists do not understand what this means and what it entails, then the applicant for supported employment will not be understood, and service will be denied. Not all clients would necessarily need or desire continuous follow-up visits or appointments with an employment specialist. Other people would feel better supported and more secure in their jobs if they could periodically meet with the employment specialist, even if advocacy with an employer is initially provided to an applicant. Disabled people who are isolated and alone would feel more secure in their ability to continue living on their own over time, or to figure out our very expensive, confusing Medicare/private health insurance system, or get in-home care upon reaching an advanced age when it no longer to be completely independent, would feel much less threatened if someone was available to provide information, advice, and encouragement. In looking into the Family and Social Services Administration, and taking into account some past problems with certain state as well as private, non-profit institutions, it seems clear to me that there is an administrative desire, which is found in many bureaucracies, to maintain the status quo, instead of change procedures, policies, and regulations, and make any needed personnel changes to better serve disabled citizens.

When you simply ignore the employment history and prior experiences of someone with a disability, you will have a decision based on a lack of understanding about a client's life experiences, which might indirectly pertain to future situations faced while working. There are aspects of employment which are specific to the job, and do not mean that the person would have the same types of experiences and problems outside of the context of work. At the same time, when a person with a disability is low-income and is rightly worried about future economic survival, with possible cuts to federal benefit programs, excess competition possibly resulting in corporate downsizing, and an inadequate system of health care coverage for retired people living on a limited income and budget, a worker may sometimes have difficulty doing one's job because of all of the instability, apathy, and negative judgments that often plague our society. Supported employment might not solve all problems or take an unexciting, boring job and transform it into something more interesting, but it would still be better than nothing, and nothing is what many disabled people are left with under the current policies and regime.

If a disabled, retired person has medical or other expenses and runs out of limited savings, simply blaming the victim and letting someone wither away and die from a lack of services or lack of housing or food or medicine is something that should be brought up as a serious failure of public policy, not something to be ignored or even celebrated. There is a health coverage system which is like a piece of Swiss cheese because of all the holes it has. The contradictions made by different people who work for the same government social services agency, or even within the same paragraph of a manual, show that certain policies are too confusing for people to have trust in personnel and in the system. The impersonal tone of the Division of Disability and Rehabilitative Services as well as employees of community mental health centers which fall under the Division of Mental Health and Addictions show that too many individuals have as their central priority the protection of their own jobs, not providing service to others. In Vocational Rehabilitation, there should not be any need for a Client Assistance Program which only repeats the rules and regulations and has an advocate who does not care about disabled people but only in reinforcing the existing bureaucracy, and a lack of expertise in being able to make sure that anyone with any type of developmental disability, mental illness, and/or physical disability will be taken seriously and will be put at the center of the services that have been established. Jobs that do not directly assist clients should be reduced, and more emphasis should be placed on those who directly assist clients with social or health care services.

Sincerely,

Daniel Cohn
Hello Ms Blankenship,

I received your contact information from someone I am acquainted with through my interactions with Vocational Rehabilitation services. I was unable to attend the Listening session on September 19, and I saw an option was to submit email comments. I am the mother of an 18 year old daughter with higher functioning Autism who is currently in her senior year of High School at a private school for students on the Autism spectrum. Being in the midst of "transition" with her, I can't describe the overwhelming sense of uncertainty, angst, and fear for her future I live with on a daily basis, although there are many other parents in my same shoes. Being on the higher functioning end of the spectrum, my daughter is relatively bright (but not an astronomical IQ as some of these kids can have), and she is able to learn the usual high school subjects (algebra, chemistry, history, etc) with A's and B's, although she struggles with executive functioning (e.g. organization, time management, self-motivation), communication, and social skills, which are all part of the Autism diagnosis, but make the possibility of attending College daunting.

Thus, the challenge becomes what kind of training can she do after High School, in the state of Indiana, where she can be taught in the way she best learns, and she can use and grow her intellectual abilities in an area she has interest in, while recognizing her other deficits, and also help her to reduce those deficits, and grow her Independence.

I appreciate the programs that have been put into place in the state of Indiana, such as pre-Employment Transition Services, to help assess what a job/career option might look like, and I have my daughter in pre-ETS. Some Colleges in our state have also put into place additional supports to help those with various disabilities who are able/interested to take college level courses, but need additional support such as the STEP program at Vincennes, BUILD at Univ of Indianapolis, and the disability support services program at Ivy Tech. There aren't many though that are focused on the unique deficits in the executive functioning, communication, and social skills that are so prevalent in individuals on the Spectrum. The College Internship Program(CIP) in Bloomington is one that does, although with a cost of @ $90,000 per year it is unaffordable to a lot of families, and Ancilla College just started the APAC (Autism Program at Ancilla College) in 2017. I am also familiar with Erskine Green Training Institute, although they are limited in their current training/job options and the ones available aren't necessarily a good fit for individuals on the Autism spectrum.

It is daunting to realize the current estimates of an Autism spectrum diagnosis in the United States are 1 out of 37 boys and 1 in 151 girls. From a health economic perspective it has been forecast that annual direct medical, direct non-medical, and lost productivity for parents and persons with ASD costs combined will be $461 billion (range $276–$1011 billion; 0.98–3.6 % of GDP) by 2025 [Leigh JP and Du J. Brief Report: Forecasting the Economic Burden of Autism in 2015 and 2025 in the United States. J Autism Dev Disord (2015)45:4135–4139]. If our current and future adults on the Autism spectrum are not able to access, or have available to them training programs that can build on their unique strengths and develop their unique deficits, they are not going to be able to be functioning, contributing, productive, and satisfied members of society.

I don't have a specific one size fits all recommendation. My wish would be for the state of Indiana to support development of more post High School training options geared towards the unique talents, abilities, as well as deficits of
those on the Autism spectrum. Whether these be more specific supports developed at local Colleges/Universities or alternative training programs, or both. A couple of example alternative training options I have come across in my research include organizations such as Non-Pareil Institute which is an Information Technology training program for adults on the Autism Spectrum that was started in Texas and is now expanding to Connecticut, and Florida. Another unrelated initiative in Florida is called the Autism Shifts Training Center, a consecutive, progressive training program, specific to adults on the Autism Spectrum.

Thank-you for considering my comments

Julie Birt
Hi Kristina,

I am not able to attend the task force meeting in Columbia City on the 17th. I would like the task force to hear a public comment regarding the waiver program. My daughter was born with Down syndrome. Since her birth, she has endured many challenges related to her health and development. Just to mention a few, she had open heart surgery at 8 months old to repair a defect, dysphagia, Infantile spasms, which has developed in to uncontrolled epilepsy.

We are a family of 5. My husband and I work full time jobs. We have many doctor and therapy appointments to attend to. Our situation is stressful and tiresome, but our family continues to thrive. We have had an extremely difficult time obtaining the medical waiver through Indiana Medicaid. We still have not been approved. The disability portion was approved December 2017. We've applied/been denied for medicaid multiple times, yet, we are still not approved. There are many families that have struggled with the same complications.

There needs to be an advocate, representative, or department to assist these families. It is apparent that the employees for Indiana Medicaid are not aware of what the waiver is, let alone how to properly process/apply for these applications.

Families dealing with the stress of having a family member with disabilities should not be put through the torment of getting their loved one a services they are qualified to receive that would benefit the the disabled.

I appreciate that Indiana has created this task force to address the issues effecting families for Intellectual and Developmental disabilities.

Thank you for your time.

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From: Daniel Cohn <dnl_cohn@yahoo.com>
Sent: Saturday, October 13, 2018 5:06 PM
To: Blankenship, Kristina
Subject: Official's Comments on State

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From: Daniel Cohn
798 Baltimore Rd., Apt. 88
Valparaiso, IN  46385

To: Task Force on Services and Supports for People with Developmental and Intellectual Disabilities
Division of Disability and Rehabilitative Services
Attn: Kristina Blankenship
402 W. Washington St.
IGCS/W453/MS26
Indianapolis, IN  46204

Oct. 13, 2018

Dear Ms. Blankenship:

I am writing to the members of the state Task Force on Services and Supports for People with Developmental and Intellectual Disabilities because of a recent news story concerning an elected official in state government. Superintendent of Public Instruction Dr. Jennifer McCormick announced that she is not going to be seeking a second term in office. Dr. McCormick explained the decision not to run for a second term is caused by the governmental structure of Indiana. Dr. McCormick went on to say that accomplishing anything constructive in Indiana is very complicated. She said that parents would be disappointed to learn that the state superintendent has had to spend time dealing with noise, as that is what the job of state superintendent of public instruction has become, instead of working on efforts to improve education throughout Indiana.

When it comes to education and human development, I have experienced in the area in which I live much aggression, hatred, and childish, ridiculous irrational beliefs coming from individuals I have to serve at work. The parenting and child rearing that was experienced growing up by a certain significant number of people I encounter in local communities was poor, and that is combined with a mediocre education. If we had a more competent, professional, effective educational system, I believe I would experience less animosity, pettiness, ignorance, impatience, and intolerance from local residents. Some politicians and some private citizens claim that they want people to work and have employment. Yet, as a working individual, I am often treated with one degree or another of disrespect, demonstrating the hypocrisy of many Americans, including many elected officials. I have found that in expanding the knowledge of students about the world, be it in the sciences, the arts, or the humanities, our educational system has frequently failed individuals and society.

If we had better-educated citizens, there would be the likelihood that we would have better-qualified, better-informed people in public office and in government, who would do more than what has been done to improve both education and services for the disabled. When a disabled person faces the possibility of running out of the basic financial means to continue with housing, health care, and to live some kind of decent life, living in the community in the least restrictive environment in accordance with the Americans with Disabilities Act, and when a disabled person who may not easily be able to make some important decisions on one's own, or to be aware of some needed source of help, and is deprived of advice and support due to restrictive government policies, then it is clear that the criticism of state government that the highest education official in the state made have relevance to the lives of any number of citizens.

As I have already stated, too many people in government lack either the empathy or health-care related professional expertise to respect both individuals and human life.
I like many people wear glasses. I cannot see without them. Medicare, if that is the type of health insurance that someone has, does not pay for routine eye exams and glasses or contacts. These are expensive, but are a necessity. Someone might have the beginnings of an eye disease that could result in eventual blindness, such as glaucoma or macular degeneration. There might not be any noticeable symptoms. The only way to find out if one's eyes are in good health is to have a regular eye exam. Many employed people who may not be eligible for Medicaid do not receive vision insurance from their jobs. The types of lenses I have are more expensive than more basic lenses. Even though I have vision insurance currently, glasses are still rather expensive. I have found a way to buy new glasses that would be less expensive than going to an eye doctor's office or optical company. There is a non-profit health care organization in my area which some time ago started an optical department. I went there and spoke directly with the optometrist. He found out how much my lenses would cost at their dispensary, and the price was less than at for-profit offices. The price for their frames is much less than at any other place I have gone to, with the exception of some which my insurance covers completely at 100%. But the cost of lenses for my glasses at these other places, after taking into account my vision insurance, would still be more expensive than the cost I was quoted at the non-profit health facility. On top of it, the optometrist at the health center gave me a claim form for my insurance company. A percentage of the amount I would pay for new glasses would be reimbursed to me when I send in the receipt with the claim form. This would reduce the cost of the glasses to a much smaller amount than I would pay even with using the insurance at any other optical facility. I had read that this non-profit health organization had opened an optical department. It is important that I save as much money as possible in purchasing anything, especially expensive items such as eyeglasses. But many people who may have limited resources and could be living on a fixed income would not know that this optical department exists, or where it is located, or that their prices are much less than at other eye clinics. If a developmentally disabled person, person with some other type of disability, or elderly individual had a case manager who was well-informed about health care options, the person might be able to find out such significant information as I found out through my own efforts. Northwest Indiana has extremely limited public transportation. Gary, Valparaiso, and Michigan City have local bus lines, but other places are limited to paratransit vans, which only go to places in the same county and require one or two days advance notice. A case manager might be able to drive a consumer to a doctor's appointment, outpatient medical procedure, or to an optical office, to purchase glasses or contacts, as needed. A humane society, which in many respects we are not, would plan for these needs and make sure that people with limitations are properly and adequately taken care of.

I have found that living and/or working in the community is no guarantee that someone will develop acquaintances or friends. Presence alone does not mean anything in and of itself. Sometimes, a person would benefit by having a social contact who is a working professional with a background in a field such as social work or psychology. Technology has and is replacing certain face-to-face social contacts, from social media to Internet shopping instead of visiting a retail store. I personally disagree with and don't especially like what is going on. People have been oversold by convenience. Businesses are pursuing the same greedy agenda that they have always followed. We are lacking in social services for the poor, disabled, and elderly. As I mentioned, this is largely a reflection of the academic inadequacy and failure in our society to educated people about what a competent government would include in the services it helps to provide.

I find it interesting that, over the years, I have experienced a certain amount of frustration dealing with government, including both some private and state agencies associated with the Family and Social Services Administration, and that the superintendent of public instruction, who holds a doctorate degree, has had a similar experience serving as an agency administrator and public official.

Sincerely,

Daniel Cohn