

Nebraska Waiver Study



Fall 2019

Waiver Study Group Report

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Executive Summary

Nebraska is facing three intertwined crises that have a stranglehold on our Medicaid Waiver System. The following require immediate attention:

1. **Provide support to children with disabilities being found ineligible for Nebraska's Aged & Disabled (A & D) Medicaid Waiver**

Changes implemented to the state's A & D Waiver is causing children/families to be found ineligible based upon increased scrutiny over the Level of Care Assessments.

2. **Provide a pathway for individuals with disabilities to gain access to job coaching and employment supports by identifying a way to eliminate the new Waiting list for services from Vocational Rehabilitation**

State interpretation of federal regulations means that individuals with disabilities are not able to access job coaching or employment supports - something that is not occurring in other states.

3. **Eliminate the 6-8 year Waiting List for Developmental Disabilities**

The lack of a cohesive for the delivery of long-term services and supports, failure to properly leverage alternative funding sources (federal and state funding, private insurance, and families' dollars) has created a fragmented patchwork state system that has had few true updates since its creation.

We can far better serve Nebraskans by stepping back and approaching these issues with a systematic and broader vision. This paper has been assembled by a group of parents, professionals, academics, and self-advocates in order to better analyze and create a framework for some systematic improvements that we believe will make the world a bit easier for individuals with intellectual and developmental disabilities and their families.

Our primary policy opportunities include:

- 1 Creating a Family Support Waiver
- 2 Increase Developmental Disability Funding
- 3 Fund an Autism and/or IDD/Mental Health Waiver
- 4 Revise and streamline our plethora of advisory committees
- 5 Properly implement the Rate Rebase
- 6 Amend our Appeals System
- 7 Increase Adverse Notice Timeline and Notice Standards
- 8 Provide an opportunity to recoup attorney costs on appeals cases
- 9 Be the final state in the nation to have an Employment First Proclamation
- 10 Modify our First Dollar In requirement for Vocational Rehabilitation
- 11 Implement the Family Opportunity Act
- 12 Revise regulatory standards to protect the sanctity of marriage

Aged & Disabled Waiver Issue

Celeste is a beautiful, happy and fun-loving three-year-old. She loves books, knocking down block towers and going to the swimming pool. When you see her, she will most likely have one of her award-winning smiles for you. Her disability doesn't define her, but it is a huge factor in her life. Her diagnoses include: a brain cyst,



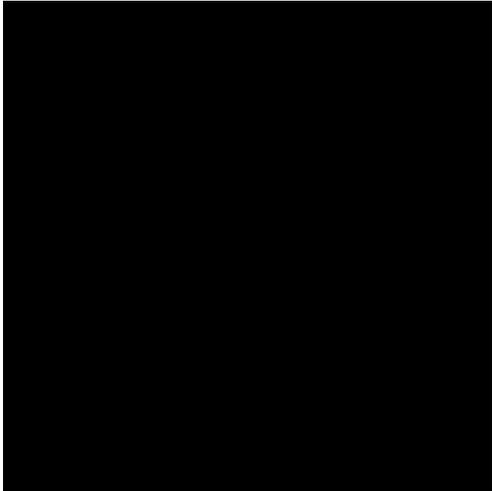
agenesis of the corpus callosum, hypotonia, aberrant subclavian artery, malrotation, hearing loss, exotropia, oral aversion, and previously failure to thrive but now tube fed. Nearly 100% of her calories are put through the tube. She is also suspected (not yet confirmed) to have a tethered spinal cord. Her family is also currently awaiting approval for further genetic testing because even with the feeding tube she's very petite. All these diagnoses together make it difficult for Celeste to live the life of a typical three year old. She doesn't stand on her own, walk or talk and is nowhere near being ready for potty training. She can't consume enough calories on her own to sustain herself. She can't have normal bowel movements without medications to help her. She is at a higher risk of bowel obstructions or life-threatening volvulus in her intestines.

Celeste's family has private insurance, but without the waiver, her family would be paying nearly \$1,400 a month just for the necessary medical supplies and specialized formulas. This doesn't even include the necessary therapies Celeste requires in order to reach her maximum potential or the childcare necessary for her parents to maintain their teaching careers. Without the waiver, her parents would have to work additional jobs to cover the nearly \$2,000 worth of bills; but, that would add additional stress fitting in nearly 40 hours a week on top of teaching and getting Celeste to her therapies--exposure to stress that Celeste doesn't need or deserve. Another option would be for them to quit their careers and move to lower-paying jobs in order to meet the income requirements to qualify for Medicaid, move out of state or take on an astronomical amount of debt. The idea of losing the waiver has led to a great deal of stress and even the consideration of keeping Celeste out of therapy for fear of her making "too much progress."

The waiver for Celeste has meant more than medical bills being paid- its more time with her parents at home helping to extend what she does in therapy. It has meant time for her parents to use respite care and invest in their marriage, son, careers, and community.

Developmental Disabilities Waiver

Erin Phillips is a powerful self-advocate, works for Super Saver, has a second job with People First of Nebraska, and is engaged in her community. This was not the case ten years ago when she was placed on The Waiting List for people with developmental disabilities to get access to residential services. While in school, she had made great strides towards independence and self-sufficiency. Without that support, she slid back. Obviously, this led to a great amount of frustration for Erin. Eventually, she got the call that she had made it to the top of the list. This has helped her be the fun, happy individual we see today.



Sixty years ago, people with developmental disabilities were forced into segregated institutions, unable to live with their friends, families, and communities. Now, 2,332 people qualify for services under the developmental disabilities services waiver but are not receiving funding. Instead, they have been forced onto a waiting list that will require them to wait years to access vital services. This means that they are being supported by their families- many of whom are aging.

Many individuals with IDD who are nearing retirement age themselves are still being cared for by their aging parents. Children with IDD and behavioral health issues who may pose a risk to themselves or others cannot access support. Young adults with IDD who don't have the necessary support frequently encounter police. Rather than providing more preventative and less intensive HCBS, we are supporting these individuals through foster care placements, prison/juvenile detention and nursing facilities. Unfortunately, these are much more costly to tax-payers and is also at a significant cost to both the individual and family.

Over a decade ago, the LR 156 report said, "Nebraska is at a crossroads with its obligation to Nebraska citizens with developmental disabilities. Several Nebraska Senators have recognized the urgent need to develop a strategic plan to address the current and future needs of citizens with DD and their families."

It seems that we have still failed to take the sort of serious action needed to help people with disabilities. It's time to ensure that we fully fund the waiting list.

Vocational Rehabilitation Waiting List



Many individuals with disabilities want to obtain competitive jobs and a career path. Unfortunately, there are systems issues that are preventing them to access the support they need to do so.

Nebraska has one of the lowest unemployment rates across the United States. This means that employers are having difficulty finding individuals to fill their needs. "This is now the most pressing economic issue in the state," stated Bryan Slone, president of the Nebraska Chamber of

Commerce and Industry. "It doesn't get a lot of attention, but we are on the cusp of this becoming the 1,000-pound gorilla." (Omaha World-Herald article) In contrast, many Nebraskans with disabilities have difficulty finding employment, keeping acceptable benefit levels, and ensuring employment stability. It seems that one of the best opportunities to address this workforce crisis is by ensuring people with disabilities can work. However, the system has to be built so that they can do so.

While the Developmental Disability Waiting List is a decades-old issue we have seen a more recent Waiting List pop up. The Vocational Rehabilitation Waiting List is now even larger than the DD Waiting List. Although this only affects employment issues, it seems that this is antithetical to the current Nebraska workforce crisis.

While there is some hope in legislation (such as LB 323 sponsored by Senators Linehan and Crawford), it seems that we still need further steps in order to ensure employment opportunities for individuals with Developmental Disabilities. One unique opportunity is that Nebraska is the last state in the nation to set an Employment First Proclamation. Implementing an Employment First Proclamation would make competitive, integrated employment the first option for individuals with disabilities who are receiving public benefits.

Introduction

At one time, people with disabilities were placed into institutions and Medicaid provided for all of their needs in these settings. Now, both time and research indicate that people with disabilities are better served when they can have their needed services and supports provided in their homes and local communities. Research also indicates that doing so increases their life quality, decreases cost, limits abusive situations, supports consumer-professional partnerships, and ensures community integration. Access to home and community-based services helps to ensure that people with disabilities' human and civil rights are protected. Medicaid programs are now able to provide the same needed services and supports in-home and community-based settings (HCBS) but it is up to each state to implement this programming.

Medicaid is a system designed as a partnership between the state and the federal government. The state agrees to implement a set of mandatory benefits but can also provide optional benefits. One optional service is implementing a 'waiver' to waive Medicaid's mandatory coverage of institutional services and instead provide these in HCBS. A Medicaid Waiver offers medical coverage for individuals with disabilities, provides long-term services and supports that allow individuals with disabilities to work, keeps them within their communities, offers Respite and specialized childcare to working family caregivers, and offers pathways to save states money.

Currently, there are three pressing issues with Nebraska's Medicaid Waivers that are adversely impacting individuals with disabilities and their families. Without action, children with disabilities will not be able to gain access to medical therapies and needed supports to grow and gain skills; young adults with disabilities will not be able to work and will lose skills; and families will be forced to reduce their working hours, quit their jobs and/or get divorced because there is no other pathway for their child to gain access to Medicaid.

This, in turn, will also negatively impact Nebraska's taxpayers because rather than paying for preventive and acute services they will be required to pay for more costly long-term services. When youth with disabilities aren't working, they don't have access to community integration, acquire more skills and cannot pay into the system; when families reduce their working hours or quit their jobs, the state loses out on the insurance coverage from their jobs, their taxes paid into the system and their entire family becomes eligible for Medicaid; when children with disabilities don't have access to therapies that help them acquire skills and maintain healthy growth and development which in turn decreases future costs associated with reliance on services.

Nebraska was an early adopter and international leader in providing home and community-based services to support individuals with disabilities. Over 60 years ago, visionaries like Wolf Wolfensberger (A Prominent Psychologist in Disability Issues that set the tone for Community Based Services delivery today) believed that individuals with disabilities could and should receive support in their home and community and created a system to make this happen. Leadership from across states and even other countries came to Nebraska to 'see how it was done.'

Now, Nebraska ranks 23rd across all states in regards to how individuals with IDD and their families are supported in their communities. (Source:<http://caseforinclusion.org/data/state-scorecards> 2019.) This ranking provides a measure of quality for those who are receiving HCBS; however, it doesn't even consider the number of individuals with disabilities who are waiting for services. Currently, 2,332 individuals who qualify for services under the developmental disabilities services waiver are not able to access services. Instead, they have been forced onto a waiting list that will likely require them to wait between 6-8 years to access vital services. This is not the kind of system that those visionary Nebraska Pioneers envisioned nor does it match with our Nebraska values.

But there's always hope. We believe if we do our due diligence, investigate alternatives, and perhaps be a bit creative, we can once again be recognized as a leader for supporting individuals with disabilities and their families. It is time to approach Nebraska's programs with a renewed lens and a sense of urgency. In this report, we have compiled a variety of experts' opinions on disability issues. We hope that this will serve as a resource for those seeking to understand and address these issues. However, most importantly, we hope that this will serve as a guidance document in developing a comprehensive approach to implementing a continuum of services for individuals with disabilities and their families.

Nebraska System Issues

In the past few years, many national consultants have been hired to conduct comprehensive needs assessments to identify gaps and barriers to the delivery of long-term services and supports and ways to decrease Medicaid expenditures in Nebraska. Many of these studies consistently identify similar systems issues. These include:

- Lack of cohesive vision of care regarding age, level of care, etc.
- Barriers between accessing services for those having both intellectual disabilities and mental health
- Gap in coverage for Applied Behavioral Analysis (ABA)
- Barriers to accessing specialized childcare for children with disabilities
- Lack of insurance or limitations (i.e., does not pay for diapers and formula)
- Lack of funding for or access to transportation
- Insufficient payment and insufficient providers for Respite care
- Insufficient providers/ specialized providers for intensive needs
- Little-to-no transition supports for families having youth with disabilities leaving school
- Lack of Autism supports and services

Nebraska needs a comprehensive vision and a continuum of services and supports that support individuals with disabilities and their families. It also needs to develop a work plan which systematically addresses the gaps and barriers. Cutting programs to reduce Medicaid and state expenditures may decrease state expenditures in the short term. However, history and time have demonstrated that this is likely not the most fiscally responsible response nor leads to improved health outcomes. Increasing Medicaid expenditures are concerns across all states and our aging population adds additional urgency and concern. To address these issues, some states are starting to implement programs that deter institutional placements and support family caregivers in efforts to decrease Medicaid expenditures. They have adopted programming that keeps individuals in the workforce and also keeps individuals with disabilities in their homes -two approaches that have historically been shown as cost-effective strategies.

Unfortunately, Nebraska has not systematically addressed how current programming is accessed nor has assessed if current programming across all DHHS programs and other state agencies could be structured in a manner that reduces duplicity, improves health and long-term outcomes and reduces expenditures. For example, are children who have both intellectual and behavioral health disabilities best served at the Lincoln Regional Center, Beatrice State developmental center or could our state implement a waiver program that would provide intensive day services and the provision of home and community-based services?

Because of the siloed-system within our Department of Health and Human Services and the subsequent budget allocated within each, departments are not inherently motivated to work together which in turn leaves many families struggling to identify pathways for support. This lack of a sensible continuum of services in terms of age and scopes of diagnosis has limited sensible supports for both individuals with disabilities and their families. This likely can be tied back to the fact that many of our current programs have not been updated since their inception.

Nebraska needs to take a broader approach and adopt a comprehensive vision to ensure that there are programs available for individuals with disabilities and their families at the right time, in the right way, and in the right amount. Our hope that we can really begin to approach services in a much more person-centered fashion which aligns more with the Nebraskan value on life.

Aged and Disabled (A & D) Waiver Issue

Situation:

In January 2019, the Nebraska Department of Health and Human Services began assessing the eligibility of children for A & D waiver eligibility using more restrictive regulations. These more restrictive regulations are causing many children with disabilities to lose coverage under the state's A & D Waiver. These changes came about due to the Nebraska Supreme Court case in *Merie B. on behalf of Brayden O. v. State*, 290 Neb. 919 (2015), which found that the children's institutional level of care tool the department was using was improper in part because the requirements had not been properly promulgated. Therefore, the Supreme Court instructed the Department of Health and Human Services to use the eligibility requirements that had already been properly promulgated and which existed and detailed eligibility requirements for an institutional level of care which applied to both adults and children in 471 Neb. Admin. Code 12. The Nebraska Supreme Court ruling also found that the Department had been assessing children also found the children's institutional level of care tool the department had been using was arbitrary and overly restrictive. The court found that the standards used by the department for a children's level of care resulted in the unreasonable exclusion of profoundly disabled children.

The Department followed the Supreme Court's ruling between 2015 and 2018, when new regulations governing children's level of care determinations went into effect. (Source: LR105: <https://nebraskalegislature.gov/FloorDocs/106/PDF/Intro/LR105.pdf>)

The loss of the A&D Waiver has exposed many of Nebraska's gaps in systems delivery. For example, when children with autism had access to the A & W Waiver, they were receiving Medicaid coverage and thereby able to access Applied Behavioral Analysis and other early intervention services. Children with high medical needs who may not necessarily meet 'a nursing home level of care' were able to access Medicaid coverage to help pay for prescription

benefits, co-pays and durable medical equipment- things that many private insurance companies don't pay or don't cover adequately. Finally, there truly are limited programs available to support children with disabilities and their families in Nebraska. The A & D Waiver was the one program that allowed working families in Nebraska access to Medicaid and other supportive services such as specialized childcare.

Background:

Nebraska's Aged and Disabled Waiver provides a pathway for children with disabilities to access both medical coverage and long-term supports through Medicaid. This allows these children to access medical therapies, visit medical specialists, receive specialized formulas and, childcare, durable medical equipment, private duty nursing, respite, and home modifications. This program helps families stay employed, keeps families together, and allows these children access to medical therapies which help them to continue to gain skills and develop. Most families also have private health insurance and the Medicaid Waiver is there to provide supports not otherwise available. Eligibility is currently based on a nursing home level of care. This home and community-based waiver allows needed services and supports to be provided in an individual's home as opposed to a nursing home. For children with disabilities, eligibility is based on the child's income and resources. The A & D Waiver currently has no waiting list and is the only pathway for working families having children with disabilities to gain access to Medicaid.

Assessment:

Loss of the A and D Waiver means that children will not be able to receive the services they need. Families will lose Medicaid coverage for their child with complex needs which in turn means that they will have to quit their jobs or reduce their hours to lower their income to access Medicaid. They may take on medical debt to get their kids the supports they need. The state loses out on increased tax revenues and likely the benefits of the families' private health insurance as the primary insurer. The increased stress impacts marriages, siblings, and employment status. Ultimately, this will also increase state expenditures as loss of early intervention services for children means the loss of the child's skills and dependency on state programs across the child's lifespan. Unless significant changes are made to the state's interpretations of these standards and some new waiver assessment tools are made available, many children will go without needed therapies and their families will be unable to continue paying for life-saving care.

Recommendations:

There are many strategies that can be implemented to reverse the detrimental impacts of the loss of A & D Waiver Coverage. These include:

- A.) Utilize language that would open up a broader range of coverage. For example, utilizing language such as, "Children *at risk of institutional placement*" (nursing home/hospital) would require the state to consider the child's outcome without access to the waiver.
- B.) Require the state to use an assessment tool that considers children's growth and development and their achievement of key developmental milestones.
- C.) Ensure the A & D Waiver (or any Waiver) does not punish children/families for improvements. For example, cutting eligibility when a child exceeds oral feeding by 51% over tube feeding.
- D.) Implement the "Family Opportunity Act"- States like Iowa, Oklahoma, and Ohio offer the "Family Opportunity Act". This program only considers the income and assets of the child with

disabilities/special healthcare needs because their family income disqualifies them for Medicaid eligibility. This, in turn, keeps their parents in the workforce and allows the child access to the services and supports that they need. The state benefits from the children gaining access to early intervention and decreased dependency on state services, the family's work contributions and private insurance as the primary insurance coverage-which means that Medicaid will pay for the services after the family's insurance coverage.

D.) Implement a "Family Support Waiver." This is a program that is gaining attraction across states like Tennessee, Pennsylvania, and Maryland because it takes individuals off of state waiting lists, helps support family caregivers by providing coverage for specialized childcare, Respite, independent living skills training, etc. These waivers offer a limited budget and set a number of slots. Typically managed with contracts through Medicaid Managed Care Organizations they allow families to access long-term services and supports like specialized childcare, respite, and home modifications.

E.) Identify programming to support children with autism, intellectual disabilities and those with more challenging behaviors.

Vocational Rehabilitation (VR) Waiting List

Situation:

As it stands today, over 3000 people across the state are on a waitlist for VR services. These services include, but are not limited to: job development, job placement, job coaching, benefits planning, and assistive technology.

Background:

In 2017, Vocational Rehabilitation went into an "order of selection". Meaning that adults seeking support would be assessed based on need and placed into one of three priority groups. This is very common across the country. What is not common however is to completely close all three groups, which is the case here in Nebraska. Most states are able to serve an individual with the highest level of need within 2 to 3 weeks of that person applying for services. As it stands today, there are individuals with the highest level of need in Nebraska that have waited over a year to receive the funding to participate in employment-related activities.

Assessment:

There are individuals graduating from transition programs all across the state that are ready for competitive employment, given that they have access to the appropriate supports. Right now, they are not able to acquire those supports. The result of this is one of three outcomes:

A) They are being placed into day-programs that use the "Habilitative Community Inclusion" service (These programs are very effective at teaching daily-living and social skills, but lack necessary employment skill-building. This is due to a limit in the service definition defined by our state and approved by the Center for Medicare and Medicaid Services. *"Habilitative activities are designed to foster greater independence, community networking, and personal choice. Making connections with community members is a strong component of this service provision. Participants may not perform work activities, either paid or unpaid, while receiving this service."*)

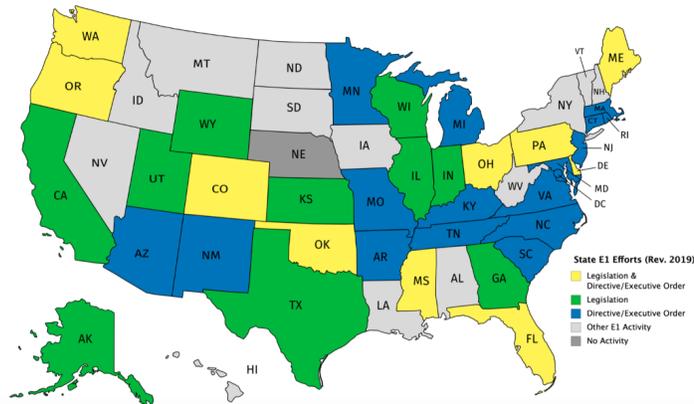
B) Their parent or caregiver is having to supply the necessary supports.

C) They are sitting at home.

Recommendations:

A) Make “Employment First” a priority with a state Proclamation. Employment First is an initiative that works to bring competitive employment opportunities, fair wages and career advancement for people with disabilities. Nebraska is the **only** state without an Employment First Proclamation.

Employment First States



Source: ASPE, 2019

B) Allow individuals with Disabilities to access both DD Funding and VR funding. Pre Vocational Services is a significantly lower cost method to address VR Funding- Pre-vocational services have hit a roadblock in NE. The State Dept. of Disabilities has put a restriction on who is able to access this funding. They have made an interpretation that in order to utilize the Prevocational service through the HCBS waivers an individual must first be deemed ineligible for services through VR. This is not the best practice. The four questions to determine eligibility address the following: Does the person have an impairment? Does the person's impairment impede his/ her ability to work? Does the person require VR services? Will the person benefit from VR services? From these four questions, one could infer that most if not all people with disabilities should be eligible for VR services and therefore, ineligible for prevocational services. If the state were to allow individuals access to these types of programs it would be more cost-effective for the provider as well as the state. For the state, it would ultimately lead to employment which greatly reduces the amount of waiver supports needed for most individuals. For the provider, less 1 on 1 job coaching support would be needed for most individuals leading to serving a greater number of people.

C) Modify the milestones. The VR milestones should clearly and definitively state what services are and are not provided through the milestones. This is to expel any confusion in regards to the “payer of last resort” ruling.

The state needs to interpret the regulations in the same way that Missouri does- In many bordering states it is a requirement that you have an “individual plan of employment” (IPE) through the state VR agency in order to access prevocational programming.

Developmental Disabilities Waiting List

Situation:

Currently, there are over 2300 individuals who are eligible for the state's Developmental Disability Comprehensive Waiver but because there is insufficient funding, they are waiting for these services.

According to Nebraska's Department of Health and Human Services, as of 7/22/2019, there were 2,326 individuals on the waiting list for Medicaid Home and Community-Based (HCBS) Waivers for the Developmentally Disabled (DD Waivers). Of these:

- 586 are receiving services on the DD Adult Day Waiver and are waiting for residential services on the DD Comprehensive Waiver.

- 262 are receiving services on the Aged & Disabled Waiver and are waiting for services on the DD Adult Day Waiver and/or the DD Comprehensive Waiver.

There are 1087 individuals under the age of 21 waiting for services

Because of this waiting list and the lack of support for youth with IDD in Nebraska programs, there are significant gaps. For example, "Douglas County Juvenile Judge Elizabeth Crnkovich said juvenile judges struggle to find appropriate placements for youths who are seriously mentally ill and dangerous. There is literally no safe private placement in the State of Nebraska to keep said child and the community safe until a suitable treatment facility may be located outside the state," she wrote, describing one of the youths she placed in the Regional Center as having a profound intellectual disability and being mentally ill, highly sexually assaultive and physically assaultive and aggressive." (Source: Omaha World Herald, 2018)

https://www.omaha.com/news/courts/omaha-area-teens-ordered-to-adult-psychiatric-hospital-housed-in/article_a876c2ad-eb6f-56f7-91d4-c2ceb77db264.html

Background:

Over a decade ago, LR 156 report said, "Nebraska is at a crossroads with its obligation to Nebraska citizens with developmental disabilities. Several Nebraska Senators have recognized the urgent need to develop a strategic plan to address the current and future needs of citizens with DD and their families." It seems that we have still failed to take the sort of serious action needed to help people with disabilities. The Waiting List. With 2,332 people who still qualify for services under the developmental disabilities services waiver but are not receiving funding. They instead have been forced onto a waiting list that could require them to wait for years to access vital services.

If an 80-year-old parent of a 50-year-old adult with a disability decides they can't do it anymore, that 50-year-old goes into a nursing home. This is a tragedy for that individual who could have been a vibrant part of the community. And it is a tragedy for the State because care in a nursing home will cost significantly more.

If elderly grandparents are caring for their grandchild with IDD (an increasingly common occurrence), they cannot access supports- typically not even under priority funding.

If an individual with IDD and behavioral health disabilities is self-injurious or poses risk to his/her self or family members, they typically cannot access priority funding.

Assessment:

There is insufficient programs to support individuals with disabilities and their families.

As part of the state's movement toward Heritage Health implementation, the then Medicaid Director issued a concept paper which provided an overview of Nebraska's programs that support individuals with disabilities and their families. These programs included:

- Aged & Disabled Medicaid Waiver
- Developmental Disabilities Medicaid Waiver
- Traumatic Brain Injury Medicaid Waiver
- Nebraska Lifespan Respite Subsidy
- Disabled Person & Family Support Program
- Disabled Children's Program
- Medically Handicapped Children's Program
- Katie Beckett Program

(see program comparison chart in Appendix A)

In previous needs assessments, many families are unaware of these programs and indicate they are inaccessible. (Arc Family Support Project, 2012)

The state has argued that the cost to fully fund the DD Waiting list is significant. Courtney Miller, Director of the Division of Developmental Disabilities in DHHS said, "The agency estimates that serving everyone now on the list would cost about \$149 million, of which \$71 million would be state funds. The estimate does not account for future needs. That would be on top of the \$341 million budgeted this year to serve more than 4,700 people with varying combinations of day programs, residential services, and respite. That total includes \$156 million in state funds." (OWH Article) We believe this is an exaggeration as it is significantly higher than previous estimates or any academic studies we can find on the provision of community based services. We also believe that we are serving these individuals - just not in the least costly or least restrictive setting. For example, we are serving them in jails, foster care and institutional settings - such as the regional center.

Could we look at alternative waivers and the development of other programs to support individuals with disabilities and their families?

As a fiscally conservative state, it is our duty to work to curb the growth of governmentally cumbersome institutions and instead encourage the independent entrepreneurship of community-based services. It is also the state's responsibility to ensure that individuals with disabilities' human and legal rights are protected and that they have access to the least restrictive settings in which they live and work.

This is also a values issue. Nebraska is a values-based state and ensuring liberty for all is absolutely key. If we can not ensure people are allowed to be a part of their community, earn a living, or make their own decisions then we are missing our underlying values as Americans.

Recommendations:

A) Increase the funding for the DD Comprehensive Waiver to serve those who are waiting for services

B) Allocate funding to train direct care workers and build a career path for them to increase skills, remain in the field, and provide quality services

- C) Provide funding for other Medicaid Waivers such as a “Family Support Waiver”; an Autism and/or IDD Mental Health Waiver with Residential funding
- D) Conduct a Legislative Review to investigate the number of children with disabilities placed in foster care, those with IDD in our correctional setting and those being court ordered into DD services
- E) Create an Aging and Disability Resource Center that is directed by Medicaid (who supports adult, aging and children with disability programming) that allows individuals to easily gain knowledge and access to Nebraska’s long-term care programs.

Alternative State Options

We have discussed the Nebraska based system and now are changing focus to what other systems look like. While there are some variations, the state/federal Medicaid system does provide some basic structural blocks that do allow some comparison across programs. By looking at other states' systems and implementations we can find beneficial tools that can be offered for Nebraska citizens.

Medicaid Waiver Comparison to Other States

The following chart provides a snapshot comparing Medicaid Waivers implemented in Nebraska to other states. This chart shows the population served, the level of care, the number of slots allocated and the number of children who qualify through a disability determination.

State	Waivers	Level of Care	Slots	Medicaid Enrollment of Children Qualifying Through Disability*
Nebraska	Developmental Disabilities	ICF	4200	4,292
	Aged and Disabled	NF	6500	
Iowa	Children's Mental Health	Hosp (Psychiatric)	1570	12,980
	Health and Disability	ICF/NF	3619	
	Intellectual Disabilities	ICF	14,203	
Colorado	Children with Life-limiting illness	Hosp	301	16,583
	Children's Home and Community-Based Services	NF/Hosp	2249	
	Children's Habilitation Residential Services	ICF	200	
	Children's Extensive Support	ICF	434	
Minnesota	TEFRA	ICF, NF, Hosp	Unlimited	20,608
	Community Alternative Care	Hospital	991	

	Community Alternative Care for Disabled Individuals	NF	31,720	
	Developmental Disabilities	ICF	22,378	
Kansas	Technology-Assisted	Hospital	726	
	I/DD	ICF	9100	
	Autism	Hosp (Psychiatric)	82	
	Serious Emotional Disturbance	Hosp (Psychiatric)	4600	
	Physical Disability	NF	7092	
Missouri	Children with I/DD	ICF	366	6,462
	Partnership for Hope	ICF	3220	
	DD comprehensive	ICF	9182	
	DD Community Support	ICF	5604	

*Source: Kaiser Family Foundation & Urban Institute estimates based on data from FY 2011 MSIS.

Pathways to Medicaid Eligibility

Nebraska currently utilizes 1915c Home and Community Based Services Waivers. However, there are other options available. If we find a way to better match up with the fully offered

spectrum of supports that the federal system offers we believe that we can more properly take advantage of federal funds, properly support more families, and decrease future costs.

Individuals and families can access Medicaid several ways. These include:

- **Income eligibility:**
Individuals who have lower income can access Medicaid and gain coverage to Medicaid's medical services.
- **Supplemental Security Income (SSI):**
Individuals who qualify for SSI are also eligible for Medicaid.
- **Family Opportunity Act (FOA)**
The FOA is a pathway that allows working families to gain access to Medicaid for their child with disabilities. (More details in "Nebraska Answers" section)
- **Katie Beckett**
The Katie Beckett program also offers another pathway for families having children with disabilities to gain access to Medicaid for their child with disabilities.
- **Home and Community Based Services (HCBS) Waivers**
A waiver offers states a pathway to 'waive' certain Medicaid requirements. States can provide HCBS Waivers to support individuals with disabilities and provide their long-term services and support needs in their homes and communities.
- **Foster Care**
Children in foster care are covered by the state's Medicaid program.

The following chart shows pathways to Medicaid eligibility:

Comparison chart

	Income	SSI	FOA Buy-in	TEFRA/ KB	HCBS waivers	Foster care
Income limit	162% - 133%	Around 100%	300%	No	No	No
Functional level of disability	No	Yes	Yes	No	No	No
Institutional level of care	No	No	No	Yes	Yes	No



Boston University School of Social Work
Center for Innovation in Social Work & Health

Lack of Cohesive Vision in Care Regarding Age, Medical Improvement, and Level of Care

Frequently, it seems that we lack a smooth sensible system. Instead, with our efforts to keep to a few waivers, we have created some clear holes in the system. When we add in the weight of the Waiting List, it seems that the system only cracks further. Despite previous small efforts to help increase coordination and efficiency in government, we still seem to have a long way to go.

While we have a wide array of stakeholder organizations and committees, it seems that these committees frequently have significant overlap in mission and discussion. This wastes the time of DHHS Staff, stakeholders, and community volunteers. This environment of not having the left hand know what the right hand is doing has slowed our progress. Looking at the significant restructuring of these committees could help to significantly improve government efficiency.

Stakeholders, families, and state staff have invested a considerable amount of time in these organizations. Some of the stories we have heard of these committee meetings include:

- That the time is wasted
- Stakeholders, families, and providers give input that is ignored in implementation
- The number of meetings and time of meetings (during weekdays and in Lincoln) makes it hard for busy and geographically diverse families to stay engaged
- The right stakeholders are not in attendance (i.e., Medicaid Director doesn't attend)

Appeals Issues

One key issue that prevents us from truly understanding the accessibility of these programs is the complex and state weighted status of departmental hearings and adverse notices. This frequently plays a role in removing people from waivers or preventing them from access. This limits our understanding of how this system should work. With that in mind there are a few pieces that merit consideration.

A) The system lacks the appearance of being arms' length, transparent, or independent.

B) The State has the resources to process appeals while the plaintiff must come up with significant resources to pursue an appeal of the State's decision.

Issues faced by families:

1. Due to failure to calculate mailing time families will frequently only have a few days to understand, address, schedule meetings with attorneys, hire an attorney, and file an appeal.

2. Incorrect individuals will receive notices

3. Notices are unclear, vague, or lack proper directions to properly appeal

4. When families do appeal they face an employee of the department as the hearing officer. This requires an employee of DHHS to make a judgment against DHHS.

5. We lack data regarding the number of appealed adverse decisions, overturn ratio, percentage where an attorney was employed, and the number of cases taken to court should be published as a matter of public record.

6. The cost of hiring counsel is significant, especially for individuals of limited resources, and finding adequate free legal representation is extremely limited

7. If the plaintiff does file without an attorney representative and fails to meet all the legal requirements, fails to properly present evidence, call appropriate witnesses, and conduct proper discovery it can significantly affect future case status. Since only the information in the

transcript is allowed in district court. So filing without knowledge of the statute or procedures would affect the outcome of the District court case.

8. The threat that the department may recoup funds for services offered causes significant concern for families as these are highly costly services

9. Costs of attorneys, transcripts, and all evidence is saddled upon the family with no opportunity to recoup The NAC mandates this practice but seems in conflict with NEB 84-913.

Proposed Nebraska Answers

From review of Nebraska's vital issues and of other states systems we are offering some potential policies that could help to improve our system. By taking this more comprehensive view we are hoping that we will address these systematic issues with a better perspective. This will require actions from the Department, the Legislature, the Governor, and continuing engagement from community stakeholders. What follows is a vision of potential policy steps that can help us to better align with our fiscal conservative values, ensure the sanctity of all life, and ensure "Equality before the Law" as our State motto guides us.

Support to Family Caregivers

Family caregivers are the backbone of our long-term services and support systems (LTSS). In the U.S., the majority of LTSS is provided by unpaid caregivers-family or friends.[1]

Recognizing that our population is aging and state Medicaid budgets continue to grow, states are looking to identify strategies to reduce Medicaid expenditures but also make sure care is provided.

One approach many states are taking is to enhance support for family caregivers.

When family caregivers have the proper supports, they can continue in their caregiving role. Of the estimated 6.2 million people in the United States with intellectual or developmental disabilities (IDD), most live with their families.[2] Recent studies from the University of Minnesota estimates that less than 1/3 of individuals with IDD are actually being served by state agencies.

Some states are identifying strategies to help decrease caregiver stress and burnout and improve the health of both the caregiver and care recipient.



Support Waivers- A New Innovation

A relatively new model that is being used by states to support individuals with Autism and intellectual and developmental disabilities is a “Support Waiver.” These waivers are limited in their services but offer budget predictability for states as there is a set budget and a set number of slots. These states that have started to use “Support Waivers” are doing so to complement other waivers, help to provide limited services to help avoid crisis placements or more costly interventions, and embed them in the DD delivery system continuum. [3] These waivers acknowledge that families provide many informal supports and help to support caregivers.[4]

Support Waivers Examples

<u>State</u>	<u>Waiver Name</u>	<u>Budget</u>	<u>Waiver Name</u>	<u>Budget</u>	<u>Waiver Name</u>	<u>Budget</u>
<u>Tennessee</u>	<u>Essential Family Supports</u>	<u>\$15,000</u>	<u>Employment & Independent Living Support Waiver</u>	<u>\$30,000</u> <u>to \$36,000</u>	<u>Comprehensive Supports</u>	<u>\$45,000</u>
<u>Pennsylvania</u>	<u>Individual/Family Support Waiver</u>	<u>\$33,000</u> <u>to \$48,000</u>	<u>Community Support</u>	<u>\$70,000</u>		
<u>Maryland</u>	<u>Family Support Waiver</u>	<u>\$12,000</u>	<u>Community Support Waiver</u>	<u>\$25,000</u>		

For example, **Tennessee** created a Support Waiver called the ‘the Employment and Community First CHOICES (ECFC), which is managed by the MCOs. This is a voluntary program for those who are already receiving services through the state’s 1915c ID waiver but mandatory for any new enrollees seeking HCBS.[5] When this MLTSS program became approved by CMS, **Tennessee** became the first state in the country to develop and implement an integrated, home and community-based services program, aligning incentives toward promoting and supporting integrated, competitive employment and independent living as the first and preferred option for individuals with intellectual and developmental disabilities.[6] The ECFC program is administered by MCOs. The **Essential Family Supports** provides \$15,000 annually for families caring for a child under age 21 who has an IDD and lives at home. Funds can be self-directed to pay for respite, transportation, specialized childcare, etc. The **Essential Supports for Employment and Independent Living Support Waiver** provides an annual budget of \$30,000-\$36,000 for services for adults age 21 and older who have an IDD but do not qualify for a nursing home level of care. This waiver will pay for job coaching, independent skills training, pre-employment services, respite, transportation, etc. (A person age 18-21 with IDD may be enrolled in this group, if the person cannot live with his or her family anymore.)

Maryland introduced two support waivers have been created to help provide limited supports to individuals and families waiting for services under the IDD Waiting list in January 2018.. Each waiver offers 400 slots and capped budgets. The **Family Support Waiver**[\[7\]](#) provides individual and family support services for children under the age of 22 with IDD. Families are able to direct their \$12,000 annual budget to best support their child's needs. The **Community Support Waiver**[\[8\]](#) provides supports for individuals with IDD of any age on the state's waiting list. Individuals and families receive an annual budget of \$25,000 that they can use for community-based services (with the exception of residential services).

Pennsylvania offers two support waivers as well. The **Person/Family Directed Support Waiver**[\[9\]](#) provides services and supports for individuals with IDD and autism. It provides an annual budget of \$33,000 per individual/year but can be supplemented by \$15,000 for advanced supported employment or supported employment services. Their **Community Support Waiver**[\[10\]](#) provides services and supports for individuals with IDD, autism or for children birth to age 9 who will have autism or IDD. The waiver will serve 1000 individuals and provide an annual budget of \$70,000 per fiscal year.

Implementing Support Waivers Helps Address Nebraska's System-Issues:

- Supports family caregivers
- Reduces the DD Waiting list
- Provide supports to children not being found eligible for the Aged & Disabled Waiver
- Provides medicaid coverage
- Provides LTSS such as specialized childcare, respite, home modification, independent skills training for both children and adults
- Reduce administrative burden as support would fall under the existing Medicaid Managed Care Organizations

[1] <https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer>

[2] <http://aaidd.org/news-policy/policy/position-statements/community-living-and-participation#.WqH5369X6M8>

[3] <https://www.youtube.com/watch?v=ukDikyDxl7c&feature=youtu.be> (Sowers)

[4] <https://www.youtube.com/watch?v=ukDikyDxl7c&feature=youtu.be>

[5] <https://www.medicaid.gov/medicaid/managed-care/downloads/ltss/mltssp-inventory-update-2017.pdf>

[6] <https://www.tn.gov/content/dam/tn/tenncare/documents/introductionToEcfChoices.pdf>

[7] https://dda.health.maryland.gov/Pages/DDA_FAMILY_SUPPORTS_Waiver.aspx

[8] <https://dda.health.maryland.gov/Documents/ARC%20MD%20Convention%20-%20DDA%20Family%20Supports%20and%20Community%20Supports%20Waivers%20-6-2-17.pdf>

[9] <http://www.dhs.pa.gov/learnaboutdhs/waiverinformation/personfamilydirectedsupportwaiver/index.htm>

[10] <http://www.dhs.pa.gov/learnaboutdhs/waiverinformation/communitylivingwaiver/>

·Summary of Supports in the 3 categories:

<https://www.tn.gov/content/dam/tn/tenncare/documents/MemberBenefitTable.pdf>

·MOU that explains how Tennessee Medicaid and Vocational Rehabilitation programs have they will coordinate these employment supports (Source:

<https://www.tn.gov/content/dam/tn/tenncare/documents/VocationalRehabilitationMOU.pdf>)

Implement the Family Opportunity Act

Many conservative states have implemented this program as it allows children to have access to the benefits of Early Periodic Screening Diagnosis and Treatment (EPSDT) within Medicaid

and it keeps families in the workforce. Further, it builds off of families' private insurance as the primary payer and Medicaid becomes the payer of last resort.

Introduced by Iowa Senator, Chuck Grassley, who recognized that many working families that had children with disabilities were 'falling through the cracks' and were turning down pay raises, overtime or better-paying jobs to keep Medicaid health care coverage for their children with disabilities. So, in 2004, he joined with Senator Ted Kennedy and introduced the Family Opportunity Act, which allows more families with disabled children to remain eligible for Medicaid by enabling states to create options for parents to buy into Medicaid while staying in the workforce.

Source: <https://www.grassley.senate.gov/news/news-releases/family-opportunity-act>

Increased Funding for Developmental Disability Waiver

The average cost of an Institutional Placement in Nebraska is \$221,920 this is similar to the national average \$539 per day (\$196,710 per year)

https://ncd.gov/rawmedia_repository/Institutions%20inDetail.pdf In comparison, the average cost of community placement is significantly lower averaging at approximately \$63,811.56 according to the latest numbers from the state.

The deferred cost not only will help Nebraska save significant sums. Community-based placements are more ethical, developmentally supportive, and engage people in the community.

Table 8: Cost Statistics for Entrants to DD Waivers in SFY2018 by priority in Nebraska Revised Statute 83-1216

83-1216 Priority	Description	Number of Individuals	Actual Cost in SFY2018	Estimated Annual Cost	Estimated Average Annual Cost Per Individual
First	Emergency/DDCA (Priority)	32	\$1,253,132	\$4,309,025	\$134,657
Second	Transition of Institutional Persons	4	\$184,450	\$439,430	\$109,857
Third	Transition from Foster Care System	24	\$584,375	\$2,337,794	\$97,408
Fourth	Transition for High School (Graduates)	138	\$1,197,667	\$2,704,172	\$19,595
Fifth	Dependent of member of Armed Forces	-	-	-	-
Sixth	Date of Application (Waitlist)	381	\$5,692,757	\$12,866,570	\$33,771

In addition the deferred cost of emergency placements or more restrictive placements will cut down on that average \$63,811.56. As we can see in the chart below the average cost of these emergency settings costs \$134,657 whereas when families and the state plan well and provide services in a timely fashion the cost on average is only \$19,595.

In addition with the tools in this paper, we expect these costs to be significantly defrayed. In particular, an example of a Family Support Waiver can help to provide these supports at a rate of approximately \$12,000 to \$15,000 would offer a far lower cost. By increasing funding in the short term we will see returns unlike any other investment can make us.

Fund an Autism and/or IDD/Mental Health Waiver

Many children with autism are not able to access medical therapies because their family's private insurance will not cover this service. However, Medicaid will cover this service. Currently, Nebraska has an autism waiver that has been approved by the CMS; however, because there is no funding to support it, it isn't supporting any children/families. The Waiver can provide a pathway for children to gain access to Medicaid by considering only the child's income and resources. Doing so allows the child/young adult to gain access to Medicaid and his family caregivers to remain in the workforce.

The current CMS-approved Waiver could be updated to reflect current community needs and provide an additional pathway to support individuals with autism, IDD, and mental health concerns. Utilizing a Medicaid Waiver would allow the state to obtain federal matching dollars and could offer a venue for individuals with more challenging behaviors to access both residential supports and intensive services they need. Further, it would help the state meet its obligation to serve individuals with disabilities in the least restrictive environment as required by the U.S. Supreme Court's ruling under Olmstead. It is highly likely that Nebraska is already supporting these individuals -just not in the least restrictive or least costly setting.

Revise Advisory Committees/ Stakeholder Groups Into One Entity

One of the clearest issues that have arisen from this study is that there is a lack of comprehensive vision. Departments, committees, and staff are siloed into one area. By not looking at the broader picture they have missed opportunities to close cracks in the system. These boards are also stretching citizens who want to stay engaged thin. By combining these groups we will be able to maximize our efficiency, communication, and help better address these issues.

The duplication of time and effort between committees with many (but not all) of the same members is inefficient. Instead, we suggest combining the committees into a larger committee that would have subcommittees. The Nebraska Commission for the Blind and Visually Impaired, Commission for the Deaf and Hard of Hearing, Developmental Disabilities Advisory Committee, Nebraska Planning Council on Developmental Disabilities, State Advisory Committee on Mental Health Services, Advisory Committee on Aging, Olmstead Advisory Committee, and others could instead function as a more cohesive unit.

Revision of Appeals System

Federally, it is required that any individual who is denied Medicaid coverage has the right to appeal this decision. Many individuals with disabilities and families in Nebraska indicate that when they receive a notice of denial that by the time they receive the notice their time to respond is essentially up. To provide adequate equal access we should open the question of what a system would look like that provided a more level playing field.

One example of a system that is more open and friendly to the plaintiff is the administrative appeal system of the Social Security Administration. Here the plaintiff does not have any direct out of pocket expenses. In a fee agreement case, the attorney representative is only permitted to charge a fee if they win the case and the amount of the fee is limited to the lesser of 25% of the back pay or \$6000, whichever is less. Only the plaintiff is represented and the agency does

not send a representative nor make additional submissions other than the written case record. In addition to the complexities of the Hearing process, there are additional problems within the administration of the programs.

Supreme Court decision of Kelly V. Goldberg in (397US-254) on 3-23-1970 the beneficiary is entitled to a predetermination hearing before the decision is implemented and requires a due process notice be received prior to the implementation of the decision. Normally that decision is accepted to be 10 days in advance of the decision and normally must account for reasonable mailing time. SSA and CMS allow for standard 5 days mailing time.

The State does not have explicit instructions in either the NAC or instructions to caseworkers about providing for mailing time and/or advance notice. There is a calendar on the Department's website which does provide a schedule for mailing advance notices but it is not well understood or generally followed when notices are issued. Normally the notices about a change do not contain enough information about how the decision was reached and what information was used. It is not uncommon for notices to be received after the effective date when mailed the last 10 days of the month. This does not allow enough time for individuals to have time to respond.

Recommendations:

- A) Make the Hearings Officer independent of the Department by establishing a division of Hearings and Appeals with independent funding and administration.
- B) Make the State responsible for a percent of the plaintiff's fee if the plaintiff wins at the Hearing and for all court costs if the plaintiff wins the court case. At least both parties would have a risk in the process.
- C) Start a legislative study of the current system to assess the current system, address gaps and barriers and implement changes.

Appendices

Appendix A

Nebraska's Current Long-Term Care Programs

Nebraska's Aged & Disabled Waiver	Developmental Disabilities Waiver	Medically Handicapped Children's Program	Katie Beckett Program
Offers eligible persons a choice between entering a Nursing Facility (NF) or receiving supportive services in their homes.	Provides supports to individuals who meet Intermediate Care Facility Care	Provides specialized medical services including service coordination/case management, specialty medical team evaluations, access to specialty physicians, and payment of authorized medical services.	Program provides Medicaid eligibility to children who otherwise would be hospitalized because of their high level of health care needs.
-Coverage for therapies, co-pays, formulas, diapers, medication -Specialized childcare -Respite -Home modifications -Assistive Technology	Provides habilitative supports including: -In-home & Residential Supports -Respite -Home modifications -Assistive Technology	-Diagnostic and Consultative Services. - May cover adaptive equipment, up to \$3600 when no other resources are available. -The program does NOT provide or cover general medical care.	-Nursing services including ventilator, a tracheostomy and other complex nursing services to be provided at home -Medicaid coverage (therapies, co-pays, formulas, diapers, medication)
Income of child used as basis for eligibility	Must be eligible for Medicaid and meet program eligibility guidelines	Eligibility for MHCP is based on two components: medical eligibility and financial eligibility.	Only the child's income is considered for the Medicaid eligibility process for children served by the Katie Beckett program.
Nebraska's Lifespan Respite Subsidy	Disabled Person & Family Support Program	Disabled Children's Program	
Offers family caregivers a break from their caregiving.	The Disabled Persons and Family Support (DPFS) Program provides state-funded assistance to persons of all ages who meet certain tests, including income and disability tests. The program helps people with disabilities remain employed, stay independent and live at home.	Assists families with children living at home who receive monthly Supplemental Security Income (SSI) and are age 15 or younger. DCP will only provide services that are not covered through Medicaid services or other programs.	
-Provides \$125/month	Eligible individuals may receive funding for specific services, up to \$300 a month or \$3,600 annually.	Eligible services may include: respite care funding to give caregivers a temporary break, attendant care, out-of-town mileage reimbursement for longer distance travel to medical care and home/vehicle modifications for accessibility, case worker support.	
Up to 312% Federal Poverty Retirement & Home Ownership considered as assets	2-004 Financial Eligibility: The Department shall not provide support under this program to individuals or families whose total gross monthly income exceeds Nebraska's 1989 median family income, adjusted for size as follows: Family Size Gross Monthly Income 1 \$1,364 5 3,043 2 1,784 6 3,463 3 2,203 7 3,541 4 2,623 8 3,620	6-003 Eligibility: Children served by SSI-DCP must reside in Nebraska, be age 15 or younger, be eligible for SSI benefits, and have an identified disability-related need.	

Appendix B

History of Intellectual and Developmental Disability State Services

The Waiting List is not just a recent problem. It originated nearly 60 years ago as we worked to move people into community settings. Here are some of the many steps that have occurred since then.

1850 – 1950

Institutional care began in Beatrice
Nebraska Institution for Feeble-Minded Youth, Beatrice State Home
Forced sterilization: no consent required

1950 – 1960

Greater Omaha Association for Retarded Children (GOARC) founded
Nebraska Association for Retarded Children (NebARC) founded

1960 – 1970

Governor Morrison created Interagency Committee on Mental Retardation (same happening at the national level)
Legislature established the Office of Mental Retardation within Department of Health
Lee Terry of KETV Channel 7 Documentary series on Beatrice State Home (Out of the Darkness)
Legislature passed 14 laws to provide for creation, funding & coordination of community-based programs throughout the State

1970 – 1980

Eastern Nebraska Community Office of Retardation (ENCOR), first regional community services agency, formed by four county governments
Pilot Parents Program in Omaha by GOARC
Horacek v. Exon lawsuit
People First movement began
Individual Program Plan (IPP) process began
PL 94-142—Education for All Handicapped Children Act (later became IDEA)

1980 – 1990

Home & community-based waiver services for children with mental retardation & their families approved for Nebraska

1990 – 2000

ARC began quality review teams
Governor Nelson's Blueprint for Action addressed the waiting list

2000 – 2010

Waiting list grows
Conditions at Beatrice State Developmental Center are brought to light
Changes to services delivery

2010 – present

Introduction of Managed Care
Establishment of Enable Savings Accounts
Historic Budget Cuts, Cuts to Transition Services, and various cuts to Medicaid lead to new struggles that have forced many to reconsider institutions
Centers for Medicaid and Medicare Services require state Home and Community Based Settings to comply with their 'settings rule', states are required to submit 'transition plan'
Nebraska began participation in the National Core Indicators (NCI) survey to assess quality

2019

Olmstead legislation
Campaign to 'End the Waiting List'

2020

End the Waiting List

Appendix C

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<http://dhhs.ne.gov/Legislative%20Documents/LB%20835%20Committee%20Copies%202018.pdf#search=medicaid%20appeal%20process>

Appendix D

Family Stories on Impact of A & D Medicaid Waiver Loss

Below is a compilation of stories. These stories are the experiences that guide our suggestions and are the base of reasoning that drives these suggestions. As a values-based state, we care about the sanctity of life. These are the stories of Nebraskans who need these changes.

Stella

My daughter, Stella, was born September 4, 2014. She was very sick. Within a few days, she was transferred to Omaha Children's Hospital and Medical Center. Stella was not able to keep her oxygen saturation up, failed her newborn hearing screen and had limited movement, soon to



be diagnosed as severe hypotonia. The cause of these symptoms was unknown. Tests were conducted immediately. On the sixth day of Stella's life, Congenital Cytomegalovirus (CMV) was found. This diagnosis did not explain all of her symptoms, but it gave doctors something to try and work with. We started a very expensive antiviral medication immediately. At the time, I was a business systems analyst at a large insurance company and my husband was an electrician. Stella's older sister attended daycare. We didn't go on lavish trips, but we were able to do fun extra things occasionally. After Stella was born, our future became unknown. We left the NICU with over 40 appointments scheduled. I didn't know how I was going to go back to work, but we also didn't know how we were going to pay the accumulating medical bills if I didn't. My husband has good medical insurance, but there were items not covered and we instantly owed the full deductible.

With a new deductible year approaching and the uncertainty of my return to work, I got on the phone and started looking for resources and options.

If I returned to work, I would be working to send my older child to daycare and paying for Stella to attend a medically fragile daycare. We risked Stella being exposed to germs and viruses that could take her fragile life. Because of our income, we didn't financially qualify for Medicaid and Stella did not qualify for SSI. I found the Aged and Disabled Waiver. Our service coordinator helped us with the appropriate forms and Stella qualified. Not only were we able to get financial help with future medical costs, we were provided respite and I was able to mentally and emotionally catch up with everything going on. At that point, I decided to end my employment and stay home to care for Stella. We also made the decision to keep our older daughter in a preschool part time. Having a medically fragile child affects the whole family. We all had to make sacrifices and adjust to changes.

I knew Stella was facing many challenges ahead. I wanted to give her the best outcome possible, whatever that may be. After being discharged from the NICU, Stella attended occupational and physical therapy twice a week. She also saw Orthopedics, Infectious Disease, Genetics, ENT, Audiology, Ophthalmology and Neurology. Stella's foot was casted for clubfoot treatment. Due to the hearing loss, she wore a hearing aid. She had vision loss and wore glasses. Because she was unable to move typically, her head flattened and she attended the helmet clinic. At six months old, she began to aspirate and received a feeding tube. Stella has seen different therapies since birth, but not a week has gone by where she hasn't seen one type of therapist. She is currently in physical, feeding and speech therapy.

Due to the Congenital CMV, Stella's hearing loss has worsened. She now wears two hearing aids. She still wears glasses and at almost three years old, she began to walk independently. Stella recognizes colors, letters, can sing all the nursery rhymes and can count to 20. She attends an early education center where she is in preschool. She has done extremely well academically considering her challenges. She is able to hear her teacher because she has hearing aids. Stella continues to have medical needs. Her foot has been casted and manipulated several times. She has now had three major foot reconstruction surgeries. Stella will need constant medical supervision for a considerable amount of time.

Without the support of Medicaid and the resources offered, I don't know where we would be right now. More than likely, we would be filing for bankruptcy and possibly living with family members. Because the financial burden was lifted, I was able to focus on other things to help Stella improve like take her to the eye doctor even though we don't have vision insurance, take her to extra therapy appointments even though our medical insurance only covers 60 visits a year and seek out the best medical treatment available in our area. Everybody sees Stella today, knows she has come so far because of her motivated and supportive family, early intervention and the financial help from the Aged & Disabled Waiver.

Sincerely,
Katie

Phoebe

This is Phoebe. We call her Phoebe the Fighter because since the day she was born that's what she has been a fighter. Phoebe was born with Congenital Diaphragmatic Hernia. Which means a hole formed in her diaphragm while she was developing in the womb. Because of this defect, all of her organs in her abdomen moved up into her chest, causing her left lung to not develop properly. When she was born she had to be put on a breathing tube to help her breathe and was sedated during this time. Phoebe had severe hypertension at birth and had surgery at ten days old to fix the diaphragm. The surgery was successful and after a few weeks she was able to get rid of her breathing tube and just be on oxygen. When she was well enough, we tried for weeks without success to get Phoebe to eat by mouth. Because Phoebe did not get to learn to eat right after birth like most babies feeding was very difficult. She ended up needing a g-tube placed in her stomach. She was able to go home and work on feeding through home and therapy. She received all of her nutrition through her g-tube until she was about three years old. Through Phoebe's hard work at occupational and speech therapies she was able to accept more textures and was starting to enjoy eating by mouth.



At two years old Phoebe was also diagnosed with severe scoliosis. With the severity of her curve being over 45 degrees, Phoebe was immediately fitted with a back brace that she wears 18 hours a day. We were also told because of the severity of the curves that surgery will be necessary and that the back brace is for there specifically so her curves do not get any worse. We recently discovered that Phoebe had a tethered spinal cord and she had surgery to fix. The tethered spine has affected her scoliosis, toe walking, and potty training. Since her surgery in March, we have been able to have some success in potty training.

At three years old, Phoebe was also diagnosed on the Autism spectrum. She has been going to speech, occupational, and physical therapy since she was two. Phoebe has sensory sensitivities and is behind her peers in speech, which therapy has helped her overcome her obstacles.

Even though Phoebe eats by mouth, she still needs caloric supplements. She eats as much as she can tolerate, but still struggles to gain weight. Phoebe sees a gastroenterologist who believes her extra caloric supplements of Boost is necessary for her to grow properly. She also gets all medication via g-tube as she cannot take medicine by mouth.

Phoebe has also had unexpected illnesses come up since birth. At three years old Phoebe unexpectedly came down with acute pancreatitis and was hospitalized for days to recover from that. When she was four she had pneumonia twice and had to be hospitalized because she had RSV along with pneumonia. Because of her unexpected illnesses we have sought out and have received genetic counseling. We have not been able to find any answers yet and more genetic counseling is likely in Phoebe's future.

If we did not have the Aged and Disabled Medicaid Waiver, Phoebe would be lost of many services and medical necessities that have helped her grow and succeed. Phoebe has made so much progress in speech and fine motor development along with her scoliosis causing some physical disabilities. Being able to attend therapy at a young age has tremendously helped her be where she is today. Without the Medicaid waiver, we would pay approximately \$7,000 to receive therapy services. Despite my spouse working two jobs and I'm about to start a new job, we would not be able to continue therapy services. Phoebe also sees multiple specialists to manage her scoliosis and her g-tube. We live two hours away from these specialists and travel several times a year for check ups and x-rays. Because Phoebe is growing, every couple of years Phoebe gets a new back brace. This costs thousands of dollars. We have family insurance, but the deductible is very high and takes months to reach that deductible. Even with the high deductible, insurance does not completely cover the cost of her back brace. It also does not completely cover the high cost of Boost formula that Phoebe receives monthly.

We also have medical supplies that come with having a g-tube that would not be covered either. I fear if Phoebe lost her waiver that our family would be in tremendous debt and lose a lot of the services that have helped her be successful. I am afraid the cost of medical appointments, g-tube maintenance, scoliosis maintenance, and genetic counseling would severely negatively impact my family financially.

Harrison

Harrison was born with Chromosome 13q deletion syndrome. While he has made great progress in his development, he is still behind in everything. He is almost 3 and still cannot speak, jump, ride a bike use a spoon successfully for a long period of time. He fatigues easily. His fine motor skills are lacking. He cannot pull his pants up or down. Take off or put on shoes. These are all things a typical 3 year old should be able to do. Harrison has been in Physical and Occupational therapy since he was born. He has been doing speech therapy for over a year. Without these therapies he would not be doing half the things he can do today. In addition to having Chromosome 13q deletion syndrome Harrison was diagnosed with Retinoblastoma at 6 weeks old. He has gone through 6 rounds of chemotherapy and several laser therapy treatments at the Children's Hospital University of Iowa in Iowa City. Although he has had no new tumor activity he still requires to have regular exams under anesthesia and MRI. This will affect him his entire life. He is at risk for more cancers and will need routine screening done. He has lost his central vision in his left eye.

Harrison most likely will not qualify next year for the A & D Waiver due to the fact that he will be 3 years old and will not meet the required ADL criteria. Unfortunately at this time, Nebraska doesn't have other programs that would assist with his medical needs. He has private insurance, but without the A & D Waiver, his family will pay over \$10,000.00 a year for his doctor appointments and they won't be able to afford the specialized childcare provider they use when he isn't in school but his parents are still working. Without the A & D Waiver, they have 3 choices: They can pay for everything out-of-pocket and go dramatically into debt, one of them can quit their jobs to lower their income so they will be eligible for Medicaid or

they can move to Iowa, where there is a Medicaid 'buy-in' that allows them to pay into the Medicaid program a certain amount based on their income to receive access to Medicaid.

Celeste

Celeste is a beautiful, happy and fun loving three year old. She loves books, knocking down block towers and going to the swimming pool. When you see her, she will most likely have one of her award winning smiles for you. I tell you all these things first because her disability doesn't define her, but it is a huge factor in her life. Her diagnoses include; a brain cyst, agenesis of the corpus callosum, hypotonia, aberrant subclavian artery, malrotation, hearing loss, exotropia, oral aversion, and previously failure to thrive, but now tube fed. Nearly 100% of her calories are put through the tube. She is also suspected, yet not confirmed, to have a tethered spinal cord. We are also currently awaiting approval for further genetic testing because even with the feeding tube she's very petite. All these diagnoses together make it difficult for Celeste to live the life of a typical three year old. She doesn't stand on her own, walk, talk and is nowhere near being ready for potty training. She can't consume enough calories on her own to sustain herself. She can't have normal bowel movements without medications to help her. She is at a higher risk of bowel obstructions or life threatening volvulus in her



intestines.

Celeste's family has private insurance, but without the waiver her family would be paying nearly \$1,400.00 a month just for the necessary medical supplies and specialized formulas. This doesn't even include the necessary therapies Celeste needs in order to reach her maximum potential or the child care necessary for her parents to maintain their teaching careers. Without the waiver her parent's would have the option of working additional jobs to cover the nearly \$2,000 worth of bills - but that would add additional stress fitting in nearly 40 hours a week on top of teaching and getting Celeste to her therapies. Exposure to stress that Celeste doesn't need or deserve. Another option would be for them to quit their careers and move to much lower paying jobs in order to meet the income requirements, move out of state or take on an astronomical amount of debt. The idea of losing the waiver has led to a great deal of stress and even the consideration of keeping Celeste out therapy for fear of her making "too much progress".

The waiver for Celeste has meant more than medical bills being paid- its more time with her parents at home helping to extend what she does in therapy. It has meant time for her parents use respite care and invest in their; marriage, son, careers, and community.

Sophie

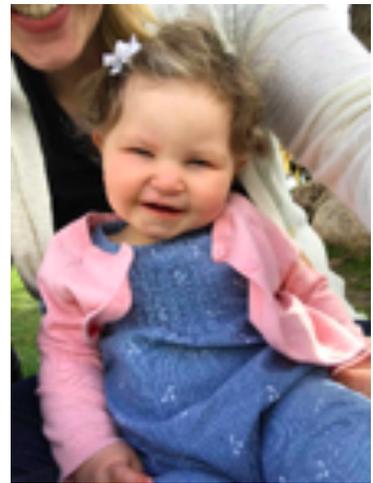
This is Sophie Ishmael. At the gestational age of 20 weeks we found out Sophie's brain was not developing correctly. She has holoprosencephaly, a diagnosis with a 3% survival rate. Against

all odds, Sophie is here and doing amazing! Thanks to access to amazing specialists and therapies since birth, she has made great strides in her development.

Still, at 18 months old, Sophie's progress is slow. Her hypotonia and cerebral palsy mean she is not mobile in any capacity and needs 1:1 care to help her with her daily needs. She requires daily therapy. Physical therapy twice per week. Occupational therapy once per week. Speech therapy once per week. And feeding therapy once per week. Our goal with therapy is to help her become more independent, requiring less help in the long-term.

Because Sophie is completely immobile and unable to feed herself, she requires 1:1 care that a typical daycare cannot provide. We are lucky to have the use of respite services through Medicaid to help fill the gaps in her care with qualified professionals so Mom can continue to work part-time.

We have good private insurance, but it does have limits on the amount of therapy they provide, which is not adequate for cases like Sophie's who need ongoing support at this critical age. Without the Medicaid waiver, we would be looking at an out-of-pocket cost of \$1000/week for her therapies after her limits run out. If we lose the Medicaid waiver in Nebraska, we have already decided we will need to move to another state that better supports our special needs kids and can provide Sophie with the services she needs to really thrive.



Paul

We have had services for our son nearly continuously from the time he was diagnosed with ASD at eighteen months old. Since then, he has been diagnosed with an Intellectual Disability by Gretna Public School District's psychologist. At 20 months old, Paul attended Stones Worth Stepping for a year for Speech therapy and baby sign language then he went to Munroe-Meyer Institute behavior clinic and Applied Behavior Analysis therapy for close to three years. During that time, we participated in Creighton University's Jays for Peds program which provides respite care to families for no charge for one year.

Once our time with that expired, we applied for and Paul was approved for Lifespan Across the Ages respite program. We continued to hire Creighton University students as they are very responsible, reliable and trustworthy with our son. The Lifespan Across the Ages program is based on family income. We were a single income household until our son Paul went into Kindergarten full time, at which point, I (his Mother), decided to work part-time for the school district so that I could have all the same time off as my son because he needs one to one supervision. This little extra income from my part-time position would make us ineligible for the Lifespan Respite Program and that is when we decided to apply for the Aged & Disabled Waiver as well as get Paul on the Developmental Disability Waiver waitlist.

On the Aged and Disable Waiver he could get respite care, childcare (if I returned to work) and Medicaid. Currently, I am still part-time which allows me to be with him before and after school and on all the school breaks, including summer. This is a sacrifice our family has been able to manage so far however it is not an ideal one. This prevents me from getting back to my career as an Account Manager, therefore sacrificing additional family income for the safety and well-

being of our son. He is unable to attend Kids Connection through school as his needs are too demanding.

Paul is eight years old. Paul is non-verbal. He elopes and cannot anticipate or effectively navigate dangerous situations. He has difficulty understanding and completing simple 1 or 2 step directions. This requires constant supervision and assistance. The amount of help that he requires is often exhausting especially when it comes to his entertainment from bathroom antics. At home this requires that we hide or lock up our soaps, toothpastes, deodorants or anything else we think he might decide to ingest. He tends to miss the toilet while urinating nearly every time which requires repeated clean up and he still needs assistance with wiping after toileting, washing and drying his hands, bathing and brushing his teeth. This is the reason why we can't just hire a typical babysitter from up the street. This is the reason why our family needs respite care providers. During the year that he was eligible for the Aged and Disabled Waiver we retained the Creighton University students and requested they meet with DHHS in order to fill out and pay for a necessary background check, be trained on billing requirements and get put into the DHHS system as respite care providers for our family. They complied with all of this and sadly we didn't even have the opportunity to hire all of them by the time Paul was eliminated from the program. It took them eight to twelve weeks to go through all the necessary steps in order to even be approved by DHHS. That was two to three months out of the year on the Waiver that was lost to the process. We enrolled Paul at CRCC for Speech Therapy and respite care, coordinating with the school to provide transportation once a week.

Since losing the waiver he has stopped attending CRCC and they have removed him as a client from their system. We also met with Radical Minds to get on their waitlist for ABA therapy. Ironically as soon as Paul was eliminated from the waiver after his re-evaluation in January, an ABA therapy opening became available for him. We were unable to take that position due to the loss of the Aged and Disabled Waiver. The cost of even the co-pays for therapy are financially strapping. During the time on the program we also met with Children's Hospital Genetics Department and had tests run to decipher more scientifically what Paul's medical condition could be attributed to and upon receiving those results the Geneticist would like him to have more tests run through Neurology. Depending on those costs, we likely will not be able to follow through on these recommendations. If Paul had the Aged and Disabled Waiver benefits there would be no question that this would be completed.

Based on the new Aged and Disabled Waiver regulations it seems to be very subjective in nature. We are unsure where it is written that if a person is unable to hear, then that impairment is somehow more severe than being unable to talk. We also don't understand that mobility is only considered in the physical sense rather than the cognitive sense because although Paul could physically walk to the mailbox, he couldn't follow the instruction to "go to the mailbox". He certainly would not know how to watch for cars while crossing the street or how to get back home. Even someone without physical mobility who has proper mental faculties could get to the mailbox and back home with the use of a wheelchair. These are the things we do not understand when we have a child who suffers from a disability with his brain. Just because it isn't visible does not mean there is not a problem with it. This would not be the same situation with someone who has a heart/lung/kidney/liver problem, why is it determined that the brain is less vital of an organ? There are children and families suffering because of these conditions with the brain and cognitive abilities where they are not being recognized as "severe enough" to be eligible for services immediately. The six year waitlist for families for the Developmental Disability Waiver is absurd especially when Nebraska is one of the highest tax paying states in the nation. Other states offer many more programs and avenues toward benefits for these situations. Please help us re-illustrate this type of thinking and put in place necessary, inclusive

parameters within the Aged and Disabled Waiver and other waivers that will address these types of medical conditions.

Sincerely,
Mr. and Mrs. Stone

Connor

My name is Jennifer Henning. My son Connor Henning is an almost 3 year old little boy with Cerebral Palsy. He has been on the A&D waiver for the past 2 years. Connor suffered a brain injury at 6 weeks old when he was left hypoxic while inpatient at a local hospital for a prolonged period of time due to "alarm fatigue."

Connor is a non-verbal child that is approximately 13 months' developmentally. He requires 24/7 care. He is bottle or tube fed (working on some oral feeding in feeding therapy) and requires PRN oxygen when he is ill. He does not know his name, he does not look when you call his name, he does not follow directions, he cannot speak, he doesn't understand safety or show any signs he understands something is dangerous.

My husband Brian carries private insurance through the railroad for our family. Although it is excellent health insurance, the coinsurance for the high medical needs Connor has is prohibitive for our family. The policy exclusions cause hardship as they exclude some of the most expensive aspects of Connor's care. These include private duty home health nursing, elemental formula, some feeding tube supplies and a neurological medication that Connor requires. Both Brian and I work full time to provide for our families and do not qualify for Medicaid or other income based programs.

The A&D waiver has been a God send to our lives. Connor's brain injury was unexpected and an extreme stressor for our family in so many ways. It allows Connor to attend the most amazing brain injury program at Madonna Rehabilitation Hospital. Connor receives speech therapy, occupational therapy, physical therapy, aquatics therapy, sensory therapy and feeding therapy.

The waiver pays for private duty nursing so we can be gainfully employed and take time for self-care. Without the respite care my husband and I would not be able to go to doctors appointments, therapist appointments, spend one on one time with our daughter, maintain friendships, attend stakeholder meetings for disability advocacy or take time to ourselves. The service coordination provided by the waiver has been instrumental to Connor's well being. Shaylynn Butler is always a phone call away who is an advocate and resource for our family when concerns or problems arise because of Connor's disabilities.

The changes DHHS has made to the children's level of care is very concerning. Connor was initially denied for waiver this year at recertification. After contacting our district representative Senator Justin Wayne, Connor's waiver decision was overturned to an approval. Senator Wayne met with the Department and worked closely with the HHS committee in the senate prior to the sudden reversal.

If Connor does not have the A&D waiver my family will become dependent on the system to survive. One parent will be forced to stay home to provide Connor's care because we will lose private duty nursing. Connor will also not be able to attend Madonna Rehabilitation's Intensive

Integrated Brain Injury Program daily therapies. Without the A&D waiver Connor will be dependent on the system for life. He will not receive the therapies he requires to maximize his potential.

Nebraska's lack of services for disabled children is troubling. Surrounding states have several waiver programs that assist many disabilities not just disabilities that require a nursing level of care. Changing the children's level of care requirements into a nursing level of care duplicates the other waiver Nebraska has. It makes no sense to have an A&D waiver and a Katie Beckett waiver that excludes most children with Cerebral Palsy, genetic conditions, Autism, Intellectual disabilities etc. These new children's level of care ADL guidelines seem discriminatory to the children this waiver was meant to help. It also takes away Medicaid access to children unfairly who depend on this for medical care related to their disabilities that private insurances may not cover.

I urge you to put yourselves in place of the parents whose children who have lost waiver, who are at risk of losing waiver or who are anxiously awaiting recertifications. Taking away access to the vital services the waiver provides is not in the states best interest financially or morally. These children will regress and become an even bigger burden as they age for the state.

Thank you for your consideration and advocacy for the most vulnerable children in our state,
Jennifer Henning

Libby

This beautiful girl is my daughter, Libby. She is the strongest, most determined little girl I have ever known. She has not only brought so much joy and love to our family, but also many around her. Every day I am thankful that I get to be her Mom, and every day I'm a little scared that I won't get to do that for as long as I would like due to medical conditions.

Libby was born 8 weeks prematurely with a diagnosis of Down syndrome, Tetralogy of Fallot, AV canal, and duodenal atresia. The duodenal atresia required her to have surgery at only 2 day old and to have a G-button placed at that time. She has made great progress in her feeding development, which has allowed her to progress beyond tube feedings, but she is still unable to chew solid foods or drink from a cup. Because of Libby's feeding issues, doctors are closely monitoring her growth. She has gained relatively no weight in the last 1-½ years and

they are now considering the need for growth hormones as well. Libby is still fully assisted with all meals and continues to go to feeding therapy weekly.

In addition to her feeding issues, Libby also had her first heart surgery when she was 6 months old. The combination of her two heart defects is quite uncommon, and even in the busiest of children's hospitals, they only average 1-2 of her diagnosis per year. There is no way to repair her heart, so she will need open heart surgeries the rest of her life, to try to keep her heart working. If they are unsuccessful at this, eventually she will need a heart transplant.

If all that wasn't enough, she has also been diagnosed with hearing impaired in one ear and deaf in the other. While having an MRI in the process to get a cochlear implant for the deaf side we found there is no nerve on that side (which means no implant). They also discovered that Libby has had several hemorrhagic strokes and has some degeneration in her brain.



In addition to all of the other conditions that Libby has to deal with, she also has hypothyroid, sleep apnea, several skin conditions, worsening eyes (which we have been told will need glasses eventually), and the need for orthotics.

Libby has shown amazing progress due to being in Speech Therapy, Physical Therapy, Occupational Therapy, and Feeding Therapy on a weekly basis. Because of Libby's therapy schedule, it requires us to either hire a nanny (so they can take her to therapy sessions while we are both at work), or she has to be in the daycare at the hospital where I work, so they can take her to therapy. At this time, we are unable to get into the daycare (we are on the waitlist), so we are paying for a nanny, which is a significantly higher cost.

Our family has private insurance, but without the A & D Waiver, we will pay thousands of dollars per month just for her therapies. We won't be able to afford the specialized childcare provider we use that allows both parents to continue to work. Without the A & D Waiver, we have 3 choices: we can pay for everything out-of-pocket and go dramatically into debt, one of us can quit our jobs to lower our income so they will be eligible for Medicaid or we can move to Iowa, where there is a Medicaid 'buy-in' that allows us to pay into the Medicaid program a certain amount based on our income to receive access to Medicaid.

Please consider our family, Libby, and all the other families in similar situations when evaluating the NE A & D Waiver program. Your decision really will "make or break" so many families. Thank you for taking the time to read my submission,
Nikki Hobelman

Claire

Raising children is an incredible challenge for any parent. Add on top of that challenge raising a child with a disability who is medically complex and the challenges increase immensely.

Suddenly, parents are working with a team of medical professionals who include specialist medical doctors, therapists, school personnel, respite care providers...the list grows year after year. As parents, we do our best to keep track of it all and provide the best care for our children, but in cases that include medically complex children, that child requires and deserves the extra support they need to acquire the skills to help them reach their fullest potential.

Our journey with Claire's disability began with our 20 week anatomy scan where it was discovered that she was missing a piece of her brain called the Corpus Callosum. Because of this condition she has very low muscle tone, delayed receptive and expressive language, behavioral issues and more.

When she was a baby, we applied for Medicaid but were denied because my husband and I were both employed as teachers. Although Claire needed multiple therapies a week, we couldn't afford it. She had several surgeries, specialists appointments and brain MRIs in her first three years of life. On top of every day bills like our mortgage, groceries, and day care, we could only afford to send her once a month for therapy and even that was a huge stretch in our budget.

The financial strain that raising a child with disabilities puts on a family is hard to articulate unless you've lived it and "get it". The desire to provide your child with the care she needs in order to do BASIC skills like swallowing and lifting her head, but not having the resources to do it, is heart wrenching.

It wasn't until Claire turned three and FINALLY was eligible to qualify for the Aged and Disabled Waiver that our family was able to take a deep breath of relief from the financial strain we had felt over the past four years (these medical bills started when Claire was 20 weeks in utero). Keep in mind, we are a dual income family (although I had to switch careers to better suit Claire's numbers monthly appointments), and it is still hard to pay all of her medical expenses. With the A&D Waiver, Claire has been able to have PT,OT, and ST weekly. The skills she has gained through consistent, intense therapy has been hard physically and emotionally, but she has been able to gain a much stronger skill set because we have remained consistent in our efforts. Thirty minutes of PT two times a month at school doesn't even scratch the surface of what Claire needs - we have to seek those resources in medical therapy offices to really see her make progress.

Claire is four years old and unable to be potty trained. Cognitively she is not ready, and her low muscle tone hinders her from being able to have bladder control at this point. The A&D waiver helps cover the cost of her diapers each month. This may seem small, but to our family - it is huge. It's one less thing we need to worry about for her.

Claire's delays and behavioral issues can make it challenging to take our other two, typically developing children, out to do things like eat at a restaurant, go to the Children's museum, or to a movie. The A&D waiver provides respite care so that Claire has someone who is capable to watch and care for her so we can take our other children out to do "normal" things without having to worry about cutting the trip short or leaving due to Claire getting over stimulated or having a behavior.

When Claire was an infant, her geneticist had the Microarray test done. The findings didn't show anything, but Claire's delays continued to become more evident as she got older. She was diagnosed with Dandy Walker Syndrome and this past year her geneticist ordered the entire

exome sequence test to be done. This test was much more intense and ended up giving us some much needed answers. It was discovered that Claire has a gene mutation on the TEAD1 gene, which her doctors believe caused her ACC. There is only ONE other person in the world who has been found with this same gene variant; this child also has ACC.

The A&D waiver allowed us to get a speech device for Claire which allowed her another form of communicating with us. Her receptive language is strong, so she knows what she wants and understands what you are saying. However, her expressive language is very low. It's like being trapped in your own body. No wonder she gets so frustrated and acts out in those moments of anger. This device has given her another way to express her needs to us and has given her a sense of control in being able to relate to those around her. With this device, her confidence in communicating has blossomed. It's amazing what children can accomplish when the proper supports are in place.

Without the waiver, our family will once again be in turmoil physically, emotionally, and financially. Claire will not be able to receive her therapies due to limitations on our family health insurance as well as limitations in our finances. Without consistent therapies, we are worried she will regress. Research shows that due to the brain's neuroplasticity, early intervention is critical in helping children achieve their fullest potential. The A&D waiver is the ONLY option available to Claire RIGHT NOW. Nebraska only has two waivers for children with disabilities, and the other waiver has a seven to eight year wait list. Claire can not, and should not have to wait eight years to *maybe* qualify for the services she needs. That is a huge time gap where critical life skills need to be gained. If she can not do that at a young age, she is set up for failure as an adult.

Our goal for Claire is to get the supports and services in place NOW, while she's s young, in hopes that she will not need as many intense supports as an adult. From a budget stand point, it is much cheaper for the state and tax payers to help these children when they are young because care services are much more expensive as an adult. We would love it if Claire could gain the necessary skills so that she can have a job, live independently, and contribute as a positive member of our society as an adult. But, if we strip away services from her now as a child, she will not have the skill set to achieve those dreams as an adult.

As a "pro-life" state, we need to be supporting life from birth until death and every moment in between. That's what these children with disabilities and families who are raising them need and deserve. Claire did not ask to be born with a disability. She didn't ask for life to be so hard. Why has our state, knowingly and willingly, made it even harder for her, for our family, and for hundreds (if not thousands) of other families across the state?

My husband and I both want to stay working. We want to live in Nebraska. And, we want to stay married. But with these drastic and unjust changes to the A&D waiver, we have had to have some really difficult discussions. Does one of us quit our job, taking us from low-middle class to poverty so Claire can receive services - and the rest of us land on Medicaid as well as a primary insurance, instead of having it as a second insurance just for Claire? Or, do we move to a neighboring state, pay taxes there, and have access to the waiver supports Claire needs? Or...do we get a divorce so that our income can then be counted as a single income family..and put our family through trauma in that way? Those are the conversations families are having in Nebraska right now with these eligibility changes to the A&D Waiver. These are real people being hurt and devastated by the decisions made by DHHS.

The good news is, it's not too late to make changes and do the right thing. Laws can be changed, eligibility criteria can be changed, and these wrongs can be made right. But, we must act now before more families are put in crisis mode, like our family is in right now. We want to link arms and work together with families, DHHS, and the legislature to make the changes necessary so that our children with disabilities have the proper access to support they desperately need.

Samuel

Sam Schreiner was born June 24, 2008. His diagnosis of Down Syndrome was a surprise to us as well as his complete bone on bone duplicate thumb. After his first night in this world Sam was rushed to Children's Hospital from Bryan East in Lincoln. It was there he was diagnosed with Hirschsprung's disease and had 1/3 of his colon removed at just 6 days old. At 6 months he was diagnosed with hypothyroidism and takes a daily pill to control this.

Jumping forward 3 years, Sam was once again fighting for his life. We took him to Bryan East where he was immediately taken back and a blood test showed his blood sugar was over 1200 (normal range is 85-150). Sam was life flighted to Children's where he was diagnosed with Type 1 Diabetes. After being released a week later we worked on finding a new normal for our family. This meant finger pokes 6-10 times a day, insulin shots 5-7 times a day, counting carbs and treating lows and highs. This also meant we struggled to find a babysitter who was willing to do all of the above mentioned. At this time Sam was also diagnosed with Atlantoaxial Instability, basically instability in his neck that calls for extra attention should he fall or have surgery and prevents him from doing any tumbling.

Fast forward just one year to when Sam was diagnosed with Celiac disease. On top of everything, Sam now had a strict gluten free diet. Any gluten indigested by Sam leads to violent vomiting within 5 minutes and a rash on his bottom that often developed into open sores. Approximately 4 years ago Sam was diagnosed to Mega Colon that lead to a complete non-functioning colon just a year later. Now Sam has a g-button attached to his colon that is used to do nightly flushes of 200 units of Saline mixed with 200 units of Glycerin. This is basically an enema each night for Sam and he spends 1 hour of his evening sitting on the toilet to evacuate stool that he otherwise could not get rid of. Without this evacuation he would be extremely ill with vomiting, weight loss, and ultimately death.

In a so called "normal" child/adult any of these conditions would be challenging but manageable. In a child like Sam, these conditions alone are extremely difficult to manage and all together require constant supervision and attention. Sam is incapable of caring for himself. His Down Syndrome makes it so he does not comprehend the numerous steps it takes just to eat, evacuate his colon, or even go for a walk safely. We have been told by over 10 daycare centers and 20 in-home daycares that they cannot or will not care for our child because they cannot manager one piece or all of his conditions. Sam does not recognize his highs and lows with Type 1 and shows no signs. Technology like Continuous Glucose Monitors help but does not eliminate finger pokes. Insulin Pumps remove the need for actual shots unless of course the pump fails then a caretaker must know how to administer insulin through a shot. None of the technology takes away the need for skilled care when watching Sam.

In order for both of us to maintain employment, which is needed just to cover his medical expenses, we have to find a provider who is willing and able to provide the constant care Sam needs. Just for us to go out for dinner or to take our other two boys to a movie we must seek out a nurse to watch Sam and this kind of care is 4 times as much as the neighborhood babysitter.

We have asked non-nurse providers but they all say it is too much to handle. Respite Care providers who don't provide medical services have all turned us down because of his need for insulin and his nightly flushes. They say this is considered medical services and they cannot help with the level of skill his needs require. For someone like Sam who requires constant supervision, insulin, nightly flushes and more life would be unmanageable without the help of the waiver.

Olivia

Nearly 10 years ago our 16-month old daughter, Olivia, suffered a catastrophic event when her heart stopped due to a rare strain of Para Influenza. As the virus attacked her body, she went into respiratory arrest. Before she could be transported via life flight to Children's in Omaha her heart would stop for 30 minutes followed by an additional 30 minutes. She was in multiple organ failure and intubated. Once in Omaha, tests revealed the cause, and we were given the diagnosis. She has hypoxic ischemic encephalopathy or a brain injury as well as minimized heart function. She lost her vision and has what is called a Cortical Visual Impairment (CVI). She also stroked during compressions and has watershed infarct (global insult to her brain). The only organ that managed to function properly during her 31-day hospitalization were her kidneys. She was given several days in sedation to see if her small body could battle and survive. Today she continues to be a fighter, but it does require a team of specialists and therapists to help her make slow yet steady gains towards her independence.

After a 68-day inpatient stay at Madonna Rehab Hospital, Olivia continued to receive daily therapies for months. The frequency of the Speech, Occupational and Physical therapy may



alter, but she is constantly in and out of therapies to continue to make progress towards gaining her own independence. However, this progress is minimized due to her severe cognitive development. At 11, she is gaining letter recognition, but is not consistently able to identify letters. She enjoys math, but she cannot add simple numbers. It is mostly working in patterns. She tries to write her name, but it is not legible. She is more comfortable with a scribble. She tries to talk with her friends but is in the process of choosing a talking device to help her communicate with others more independently. Her vision has improved to Phase III of CVI, but she is still considered to have a visual impairment that impacts her perceptions.

What did this event mean in the lives of our family? Olivia required support that I could not give her as a working mother. In making the decision to be her primary caregiver, then our family lost a significant income. It proved to be very difficult to raise a family of five on one income and pay maximum out of pocket on

Olivia's medical and therapy expenses, we had to seek debt forgiveness. It had become increasingly difficult to support all her medical bills on one income. Then, we learned about the Aged and Disabled Waiver roughly four years post event.

The waiver has allowed Olivia to see as often as needed her specialists that include a Cardiologist, Pediatric Orthopedist, Neurological Ophthalmologist and a Developmental Behavior Specialist. She continues to engage private therapies for growth and development in the areas of Speech, Occupational therapy and Physical therapy. Olivia's severe developmental delays and her inability to adjust for growth require all of these supports on a regular basis. Without waiver services, then we would be forced to choose amongst these specialties. Her growth and cognitive development would digress without all supports in place. She has an amazing Pediatrician that assists us in navigating her needs and aligning on her care. The Medicaid from the waiver has allowed us to see these specialists as needed. As Olivia is entering puberty, these are becoming more critical.

We have been able to support our family by utilizing the childcare from the waiver. I have returned to work, and with the help of childcare can sustain a partial income that allows our family to live a seemingly normal life. Olivia will continue to need providers so that I am able to work outside the home, but without waiver that may change our financial landscape again. We fear that we will not be able to continue to support our family in the way we have become accustomed by the income I have been able to contribute with the help of the childcare and amazing providers.

Olivia has made an incredible amount of progress in so many aspects of her life, however she is severely developmentally delayed. Our hope is that one day Olivia will be as independent as she can be with her disabilities, but she will need services now and into adulthood. We fear that we will be unable to provide her the services and care that she needs to take her into adulthood without the assistance of the Medicaid and childcare from the waiver. We will explore any options that are available to our child. She is on the list for the DD Waiver, but that is years away. Olivia has critical years of adolescence that will require additional assistance as we navigate increased development and growth as her body changes through her teen years. Outside of the Aged and Disabled waiver, currently there are no other waivers to explore. We will go to any lengths to advocate for our daughter, so we ask for your help in finding alternatives to this waiver that will allow us the ability to help our daughter be as successful as she can possible be. Thank you for reading this letter. Please know we are more than willing to do whatever it takes to support our daughter into a bright future, but the waiver has made it bearable and sustainable for our family to also be successful.

Most sincerely,
Michelle and Jason Grieser

Anonymous

My daughter has Autism, Pica, and Lead Poisoning. Some symptoms of her autism are: at risk for elopement, non verbal, poor fine motor skills (meaning dressing and using utensils are very difficult without weekly Occupational Therapy), she is not yet toilet trained, and impulsively. Her Pica means that she must be monitored at all times to be sure she doesn't ingest something dangerous like rocks, gravel, etc. We do yet not know what cognitive or intellectual difficulties she has due to her lead poisoning. She is six years old. She began receiving therapies in school

at age 3. They were great in helping get diagnoses, as well as, helping manage her anxiety and meltdowns. The school therapies are not enough for kids like her, though. With private OT, she has begun using a utensil and dressing herself. Hopefully, with ABA therapy she will become toilet trained. All this against her and she is quite simply the happiest child and certainly the hardest worker in any room. But the State of Nebraska does not see value in her having access to therapies that would change the trajectory of her life.

We applied for the A&D Waiver in March of 2019. We were turned down in May of 2019. The caseworker said she did not meet the requirements for ADLs and behavior. Meaning she does not need enough assistance. Quite simply she is not disabled enough for the A&D Waiver. She requires a 1:1 at school. Day cares and after school care will not admit her because she requires 1:1. She was immediately accepted for the DD Waiver. The wait list is over 2000 people.

Therapies work best and sometimes only work when the patient is a child. We know the earlier the better when treating kiddos with autism. When a kiddo grows up not able to feed or dress themselves or independently use the restroom, they are vulnerable. Even more than disabled adults already are ---disabled adults are sexually abused at a rate 7x higher than those without disabilities. When a kid like my Violet grows up without access to scientifically proven ABA therapy, her autonomy and independence are affected. And we, the State of Nebraska, will absorb these costs. The DHHS says the adult requirements are less because they no longer gain skills. But the kids can. They are putting the financial burden on families. They are putting the responsibilities on schools.

There are parents that are paying \$3-4,000 a month in therapy costs. They carry insurance. There are parents considering divorce because then their children would qualify for Medicaid based on income. And, in turn, their children would receive the services they desperately need. There are families where one parent cannot work. There are parents who are simply relying on the schools and the kids cannot reach their full potential because therapies only go so far in the school system. We are a state that proudly declares our self Pro-Life. Yet, we leave behind our most vulnerable children. We need an Autism Waiver. We need to #EndTheList for the DD Waiver.

Julia

Our daughter, Julia Rose Funk, was born with multiple issues, none known at the time of birth, that have affected her life dramatically and each issue compounds one another. We have worked very hard to stay on top of her health issues, to be ever observant and vigilant of changes, and keep in contact with doctors as needed.

In December of 2018, I was coming home from a urology appointment with Julia. I had just discussed with her doctor the drastic change in her lab work that was greater than expected in a six-month time and the worry of the health of her kidneys and function of her bladder. So we changed some medication and added a straight catheter to be kept in overnight taped to her leg and drain in between two diapers. My brain was trying to process this information and got a phone call from my husband. He said we heard back from DHHS-I was starting to breathe a sigh of relief as her case had been up for review and renewal and I was sure she would have continued coverage-then Chris said she did not qualify and would lose her Medicaid as a secondary insurance. Nothing of her condition had improved or gotten better, and it just so happened that it was the same day and time that I was processing an increase in care, when I felt like we were shut out at the most unlikely time.

Starting from the moment of birth, Julia has given us many reasons to learn lots in realm of her medical world. From the time she was born, we noticed that her bone structures were different in her tailbone area and feet and had x-rays and saw a geneticist. Doctors waited on MRIs until she was bigger and stronger, as she was born weighing significantly less than expected. It was found that Julia had a tethered spinal cord and a mass in her pelvic region. The neurosurgeon had us see a general surgeon to take care of the mass before the tethered spinal cord. The general surgeon discovered anal stenosis and we started dilation to help this. This helped us understand one reason as to why she seemed to struggle to have bowel movements consistently.

As the weeks passed, Julia started eating less and less. At four months of age she was admitted to the hospital for failure to thrive. During these 10 days in the hospital, we had found issues with her bladder and kidneys. She had, and continues still, to have a neurogenic bladder, dilated ureters, and dilated kidneys. She had lots of tests and labs done to try to figure things out. While in the hospital, they wanted to do genetic testing. Julia had a clinical diagnosis of Currarino syndrome. The MRIs that were scheduled when she was born showed mass in her pelvic area and armpit. They were followed for quite some time, but never grew. There was a chance that something in her spine or tailbone area that would have to be drained on fluid at some point in her life.

Over the next few months, Julia endured many UTIs. It seemed like once one was cleared up, another one was starting up. Maybe they just never fully cleared. At the age of 8 months, it was decided with our pediatrician and other doctors that Julia would need a g-button so she could be tube fed. Each time she presented with symptoms of a UTI, she would stop eating. She was having a hard time maintaining and gaining weight. Before the placement of the g-button, her surgeon ordered an upper GI imagining to make sure of the location of the stomach for the placement of the button. These images led to more waiting and the discovery of a full malrotation of the bowels. So at the same time of the g-button placement, she also had her appendix out and the Ladd procedure to hopefully prevent intestinal issues as she grew.

At a year of age, Julia had her tethered spinal cord release with surgery. We were hoping this would help her with movement, because she was definitely having developmental delays in her ability to move. All along, she has very oddly shaped feet and we were unsure if she would be able to stand safely on her feet. Around this time, Julia started seeing an orthopedic doctor to see her feet and her leg length discrepancy. She started wearing braces to help her feet and ankles have more support to bear weight. We started taking her to physical therapy at the hospital since she did not qualify through the schools at this time. Julia learned to roll, sit, crawl, and walk through the help of her physical therapist. Julia continued physical therapy through the schools until she was 5, when she no longer met the criteria to have PT through the schools because she did not have any need for academic goals. She has restarted physical therapy in the summer of 2018 and continues today. One of her physical therapists said she will be a life-long physical therapy patient with her low muscle tone, loose ligaments, and neuro past and tethered spinal cord.

Back to when she was an infant, Julia's kidneys were not always able to drain and her bladder did not always empty. She had several procedures to help her mega ureters to be able to drain better, but did not have success. She continued to have reflux back to the kidneys. Her ureters sat very low on her bladder, so her urologist implanted her ureters higher in the bladder. She had to be rehospitalized after surgery because her "thin and floppy" neurogenic bladder never healed and sealed like they would expect a bladder to do after surgery. Then it was discovered

that her one ureter continued to 'kink' in some way and did not drain properly. She had another surgery to move that ureter and connect it to her other ureter, because her urologist said he would never cut into her bladder again, as it would not heal. She was also rehospitalized after this surgery due to infections.

Also during this crazy time, Julia was fed as much by mouth as possible and supplement fed in the g-button what she would not consume of her Pediasure or Boost Kids 1.5 with polydose added. We had Julia in feeding therapy at the hospital to try to get her gag reflex to move back from the tip of her tongue.

She was diagnosed with diabetes insipidus. When we were trying to get Julia to eat, we were always told we were letting her drink too much and she was never feeling hungry. She would sit at the sink and cry or put her face to the wood floor and try to slurp up liquid that leaked from her diaper. Working with endocrinology, they diagnosed her with diabetes insipidus, where her kidneys are not regulating her fluids as they should. Her kidneys do not concentrate her urine and she produces an extra-large amount of urine. Therefore she is always at a higher risk for dehydration, even when she appears to drink a normal amount of water on a normal day. She needs over 2L of water on a regular day, and more when it's hot or she is physically active. Julia had her g-button removed when she was 5. We also did not send her to preschool till she was 5 because she needed more maturity and strength and childhood. She was not fully potty trained either-not during the day and not at all at night.

When she was 6 she had surgery to close the stoma from the g-button.

For Julia's whole life, we have had to closely monitor how much water intake she has, food intake, how much urine comes out, what kind of bowel movements she has with consistency, size, and frequency.

Julia has never had a night without a diaper. It is not that she just can't potty train for night- but her body produces a huge amount of urine-her kidneys and bladder do not function properly. Even before the use of a catheter all night, she wet her bed and soaked through diapers. Now with a constant flow of urine coming out, she soaks at least two diapers a night and still wakes with urine-soaked bed.

Right now, when Julia wakes up, her night catheter needs to be removed. She needs a full clean up. We are working with her to be aware to fully drain her bladder when she removed the catheter and to be observant of the quality of urine.

We note the time the night catheter is removed so she can start the daily schedule of straight catheterizing every three hours.

Her daily medications consist of a bladder relaxant that is once a day, another bladder relaxant that is three times a day, 17+grams of Miralax, an iron pill, a blood pressure pill, and bicitra twice a day to keep her renal system acid level in check.

At the time she was dismissed from her disabled waiver with Medicaid, we went from catheterizing Julia from four times a day to once every three hours and added a catheter that is placed at bedtime every night and kept in all day. Julia wears two diapers to bed and I go in during the night at least once-sometimes more-to change her diaper to help lessen how wet she gets. Every morning we have Julia get in the bathtub to wash up and we put her bed pads and blankets in the wash, and more times than not, in go the bedsheets and pillows too in subsequent loads.

Julia is working on catheterizing herself. When out in a public place, one of us help her because there is not the same set up as a home bathroom and we are concerned about her staying clean and infection free. In the recent past when she wanted to start catheterizing herself more independently, we did notice more issues with the clarity of her

urine and did have an infection. We continue to work with her on the clean process needed, not just in washing hands, but also in not needing to take the catheter in and out to get it placed. She cannot quite keep up the consistent quality of care herself yet. Timing is also something we work on with her every day. At nine, we cannot expect her to take on that much responsibility herself.

Get up: Remove diapers and catheter; check urine; wash up; get pajamas and bed clothes ready for the wash; take pills and medicine Three hours later: Catheterize

Almost lunch: Take Miralax

Three hours later: Catheterize

Afternoon: Take pill

Three hours later: Catheterize

Three hours later: Catheterize

Bedtime: Set night catheter and place two diapers; take pills and medicine; get water bottles ready for bed

Diaper is changed during the night

During the day we are monitoring how much water goes in, how much urine comes out, when she has a bowel movement with amount and consistency, how much she is eating and paying extra close that protein and dairy are being increased to try and help increase her weight. Julia is being monitored in many ways for many things every day. It takes a lot of effort and care, way above what is required for our 10-year-old son. This is time consuming and wearing, as we are always on a heightened level for Julia.

Julia does not have an average 9-year-old life. She is expected now to take care of things and regulate her health in many ways that a typical 9-year-old can't. She does not go to sleep overs or Girl Scout campouts. When her friend asked her to go to a day camp, we had to decline. As of right now, Julia is very dependent of the adults in her life to help her stay healthy. We watch the clock-making sure we will be at a clean facility to catheterize her on time or shorten the time in between if her have to, as we are not to have more than 300mL of urine in her bladder at a time. When her bladder gets full and bladder pressure rises, the kidneys are not able to work again until the bladder empties. Julia does not have normal sensations for urinating or having a bowel movement. She usually feels it as it is starting to come out with no urges ahead of time. We measure output frequently. We watch for an enlarged belly to help us monitor not only a full bladder, but also stooling issues as well. When we leave the house, we make sure we go with jugs of ice water, cooling towels, medicine, catheters, and extra clothes. We are helping Julia recognize signs of dehydration and heat exhaustion, though she really doesn't recognize she's having symptoms-especially when it's getting bad.

We will always do whatever our daughter needs to keep her as healthy as we can for as long as we can. Chronic kidney disease is one of many issues that affect her daily routines, health, and needs. Julia is not away from someone who we feel can care or understands the urgency of her needs for her for more than three hours at any given time. The last few years, she gets 103 to 104 degree fevers at least four times a year that last 3 or 4 days. We always get in contact with the doctors and always take her in, as they expect us too. She gets too sick too fast and dehydrates at a very quick rate, not good for anybody, especially for a small nine-year old girl with chronic kidney disease.

When we lost her Medicaid coverage, the thoughts crept in my head if a trip into the doctor was needed or could I wait and see- her temperature was approaching 104 quickly, and of course I brought her in. Medicaid as a secondary insurance gave me the peace of mind that we can provide the care she needs WHEN she needs it, and not have to have that financial worry. In

March we had lab work only that was over \$2,000 before insurance. Labs only. This summer she had those same labs and will have them again in September. We had ultrasounds and tests with radiology. Her GI doctor wants to see her and talk about different tests he would like to order to check out the function of her bowels and rectum, as she has been having some stooling accidents. It makes me feel uneasy with the thought of all these appointments and tests. Her physical therapy bills have added up really fast too. However, our kids are our world and we will do what is needed to keep them in the best conditions to help them be able to be their best in life.

We have worked extremely hard to make sure Julia stays healthy. We are very vigilant and swoop in when we see the signs of potential infection or dehydration and do all we can to balance out her body's system. There have been many times where Julia could have easily ended back up in the emergency room or admitted to the hospital for fluids, but we work around the clock to make sure that doesn't happen. We could have let things slide so it would look just by the numbers that she would qualify for a disabled waiver for her multiple conditions, but we don't. However, we don't think we should have to wait for her to be on dialysis or needing a transplant before she should qualify for help. Prevention and proactive measures are what we are interested in, not just helping her when she is on her last leg. We are doing our best. We work very hard at our jobs-with our employment and as parents. We appreciated the security having the disabled waiver for Julia to qualify for Medicaid as a secondary insurance. It gave us financial peace of mind to be able to provide her with the medicine and supplies, appointments, tests, labs, and doctors needed to keep her as healthy as we can for as long as we can. Thank you for listening to Julia's story and taking it to heart.

With appreciation and gratitude, Alexis and Chris Funk