Scott Leitz
Minnesota Department of Human Services
PO Box 64998
St. Paul, Minnesota 55164

RE: 2020 Reform for Waivers

Wednesday, October 10, 2012

Mr. Scott Leitz,

I am involved both personally and professionally in the lives of people with disabilities. My letter to you is personal. My son [redacted] is [redacted]. He has spastic quadriplegic cerebral palsy, profound mental retardation, and a mixed seizure disorder.

[redacted] is totally dependent on another person or two other people in all of his activities of daily living and all of his instrumental activities of daily living. [redacted] weighs 189 pounds and he is 5'7" tall. He uses a wheelchair for mobility. He sleeps in an electric "sleep safe" bed. He has and requires the use of a ceiling lift, and adapted bathing equipment. He requires the use of adapted transportation to leave his home, and he has a wheelchair adaptation to our van. [redacted] is diapered, fed, groomed, toileted, repositioned, and transferred. He is dependent on another person to provide all of these cares. [redacted] though 18 years old, can never be left home alone. He requires 24 hour 1:1 supervision at all times.

I believe in advocacy for all people who have disabilities, including autism and mental health diagnoses.
However, my concern is that people like my son get lost in the advocacy and lobby for Autism spectrum disorders and mental health diagnoses.

[redacted] cannot walk, talk, toilet himself, or feed himself. Without 1:1 assistance 24-hours per day; he would die. I hope that statement alone emphasizes a difference in level of care and care needs. Please do not lose sight in these debates and discussions of the increased need and cost of care to keep a person with profound physical and cognitive disabilities alive, healthy, and living in the community, with their families if they choose, and out of institutional settings such as nursing facilities.

I realize that it is difficult for all families and supporters and providers for differing disabilities to provide care. Reform 2020 is meant to reduce costs and alleviate tax burdens while still providing care. People like my son with quadriplegia with or without the cognitive disabilities are already left with inconsistent, unreliable, unprofessional personal care staff in many cases. It is extremely difficult to find good personal support staff due to the low rate of pay per hour and the lack of any benefits. Personal Care provision is a job that some people will just outright refuse to do because they have an aversion to performing the toileting part of personal cares. If anything, my son's care providers should receive a pay increase, not continual pay cuts. Rates of pay to agencies are $15.60 per hour, while the direct care provider is paid $8.00-$12.00 maximum without any health care benefits.

I am a stakeholder in the community of people with severe to profound physical and cognitive disabilities, and I ask for you and your colleagues to remember people like my son in your decision-making. It is my hope that MN Choices and any Consumer Directed Budget Methodology changes will reflect the difficultly of care and high needs of my son and people with disabilities similar to his.

Sincerely,

[redacted]

[redacted]

From: [redacted]
Sent: Thursday, October 04, 2012 2:16 PM
To: *DHS_Reform2020Comments
Subject: ASD
Attachments: +I_am_a_Public_Health_Nurse_and_mother_of_a[1].docx

Attached is the story of my son that has ASD. There was not enough waivers to go around and he could not get one. We were repeatedly told there was not enough money to provide him with services. This is his story and what happened to one young person that "feel through the cracks".

April 28th 2012

[redacted]

To whom this may concern:

I am a Public Health Nurse and the mother of a son with Asperger's. I read the article in the West Central Tribune on April 19, 2012 and appreciate the efforts made by the Counties and Commissioner [redacted] to fill the gaps in services to disabled people because they do not "fit the mold". Our son is one of those individuals that fell through the cracks after graduating from high school. He is not severely disabled physically but people with Asperger's have disabilities that leave them just as "vulnerable."

The courts assigned my husband and me to be his legal guardians after he turned 18 years old. The guardianship papers read that he is an "incapacitated person" that "lacks sufficient understanding or capacity to make or communicate responsible decisions" and "demonstrated behavioral deficits evidencing inability to meet his needs for medical care, nutrition, clothing, shelter, or safety." Our son also meets the strict guidelines to receive Social Security Benefits related to his mental health needs. So why doesn't he meet the criteria to receive any type of service after graduating high school that could teach independent living skills and to enable him to go off social security? This could be accomplished in a day program just for Asperger kids that have special needs apart from other disabled individuals. This would also allow them to live at home while preparing them for their future.

These kids do not need to be in a group home like the majority of the those offered today for long term care of the seriously disabled, who will most likely spend the rest of their lives in that type of care setting. The Commissioner and counties are right on when they voice concern to the state about filling a gap in services for people with disabilities.

Young people with Asperger's are not prepared to live independently after high school, but with some guidance and a little extra help they can learn the skills needed to be productive hard working individuals in our community. High school does not teach these kids the social skills they need or prepare them for the job market. People with Asperger's tend to be immature in relation to their peers and need time to "catch up" mentally. With the growing rate of kids diagnosed with Aspergers today, (1 out of 88) it is time to make the needed changes in our health care services and meet the needs of this growing population.

Recently I had a discussion with a Medical Doctor from [redacted] regarding the issues these kids face. He stated he was asked by a group of community leaders, "why the facility near the [redacted] was not filled to capacity, when it was first built?" And they wanted to know, "where are all the people with mental health needs ending up?" Sadly, he reported many are "filling our prisons". [redacted], who oversees the [redacted] county public health and family services department, states that counties are "ramping up" efforts to bring "mental health professionals into the jail to provide treatment," however, "jail is not a therapeutic setting", and makes a good point in saying "that's not what our jails are intended to do" but also added the fact that there are "no other place for them to go."

Governor Dayton signed a law protecting vulnerable adults the same day I read the article about counties "ramping up" efforts to bring mental health professionals into the jail. The new bill signed makes intentional abuse and neglect of vulnerable adults a felony. The abuse or neglect includes depriving a vulnerable adult of food, shelter, supervision, clothing or health care. Great bodily harm would carry up to 10 years in prison, up to $10,000 fine or both, while substantial bodily harm would bring five years in prison and/or up to $5,000 in fines. How many vulnerable adults do you think are filling our prisons today?

I know for sure one is; and that is my son. Prior to his incarceration he had no criminal history. He was active in Special Olympics all through high school and served as team captain in basketball and track. He was proud of his gold medals from state tournaments and we were very proud of him. He attended a school in [redacted], MN for kids with autism. He did not mind the hour bus ride to school and back each day because he had found a place that he belonged. His grades went from failing to A's and B's and when I asked him what made the difference, he stated, "They know how to teach me mom." His self esteem soared and his goals became lofty. He had found a purpose for his life and he wanted to be a security guard.

[redacted]

This is a picture of our son. He is number [redacted]. His name is [redacted].

After [redacted] graduated from high school we were sickened to discover there were no services to help him in his continued growth and development. Other kids his age were working or went to college. He did not have the skills to work nor was he prepared to go to College. My husband and I were faced with some difficult decisions. Does one of us quit our job? And stay home and ensure our son's safety? We looked into PCA services. He was able to do most of his own personal cares with reminders and some supervision so he did not fit the criteria for that program.

With reservations and considerable worry we gave into allowing our son to live in a small apartment. One that had security doors that locked and was close enough to our home that we could check on him frequently. His greatest trial during that time was the lack of structure in his day to day living. It was overwhelming to all of us, but there was no perfect answer to our situation. [redacted] was a good kid and if we could keep him away from trouble he should be fine. We helped [redacted] with his grocery shopping and laundry. [redacted] did not have a driver's license. He needed more then what we could provide, but we did the best we could for him. We just prayed no one would take advantage of him. Asperger kids have a difficult time differentiating good from bad when it comes to people. They are so trusting. They think "everyone" is their friend.

On the 23rd of April 2011, our son introduced us to his "new friend." We needed to be [redacted] eyes and ears when it came to signs of trouble in his life. So we immediately told his friend (whom we thought was higher functioning than [redacted]) that we were [redacted] guardians. We told him what that meant and that we were responsible for helping our son make good decisions. His friend [redacted] said he understood. We thought he seemed genuine in his friendship to [redacted]. We learned later this new friend had a long criminal history and that he told our son upon meeting us, not to tell us his "real" last name. Within in a two week time period our nightmare began to unfold. The first thing we noticed was [redacted] wrote on Facebook that he got a new apartment (with no mention of our son); he began wearing our son's shoes and clothes and when I asked [redacted] about this he said "they share everything." I asked what [redacted] shared with him and he had no reply. [redacted] began asking for more money than usual. [redacted] shaved our son's hair off and pierced his ears and told [redacted] they were "brothers now", we asked [redacted] to leave [redacted] apartment, but every time we returned he was there. He somehow convinced our son that he was "going to take care of him." The TV and X Box went missing and it was not long after that our keys to our son's apartment disappeared. We realized this total stranger had taken over not only our son's life but his apartment as well. We could no longer "drop in" unexpectedly without our keys. It happened so fast. This kid had some kind of hold on our son and we did not know why. We later learned he had been threatening [redacted] with a gun. [redacted] father came to our house and said his son stole his gun. All we knew was that we needed help and decided to call the police. It wasn't soon enough because that day we heard on the radio that our son had been arrested. It was May 3rd 2011.

I was in shock. Our son's picture was on the news that night. I will never forget the broad cast as they described our son as a man. He's not a man! He is a child in a man's body. He looked so young, even though he was nineteen years old. At that moment we knew our lives, our son's life, and the lives of many other people had been critically altered.

Although [redacted] was found guilty to nearly all of the crimes, our son was sentenced to 36 months in prison as an accomplice. His mental health issues were irrelevant to the court system. It did not matter that this was his first time in serious trouble, he was found guilty by association. And that is not the only thing, to makes matters worse it was the same judge that sentenced him to prison that had signed the guardianship papers stating our son was a vulnerable adult.

All I could think of was how wrong this all seemed. The judge asked before he sentenced our son to prison if anyone had any other ideas as to where he could be sent besides prison and no one could think of any other place. There is nowhere for vulnerable adults to go if they get into trouble? They do not belong in prison. They are vulnerable, gullible, naïve, and incapable of taking care of themselves. They do not have criminal minds. I pleaded with the prosecuting attorney, [redacted] and stated that "[redacted] does not belong in prison". It did not matter; there was "no other place for him to go."

I faxed the guardianship papers to the prison before our son arrived to serve his time. It was all I could do to help [redacted]. I hoped someone would read them and care about our son's safety. The case manager for [redacted] at the prison called me after he arrived and said, "In the history of the prison they have only had possibly two other cases of a vulnerable adult being sentenced to prison." I'm guessing there have been many prisoners that were vulnerable but did not have the documentation to prove it. She went on to say, "He doesn't belong here", and stated "what he needs is independent living skills, not a prison. They placed him by the guards' desk in a cell by himself so that they could keep an eye on him. The case manager told me upon our next conversation she would transfer him to a minimum security if at all possible and told me that [redacted] was doing alright. She said the older prisoners were watching after him and making sure no one "messed with him." I thanked her from the bottom of my heart. She cared.

We visit [redacted] weekly and try to keep his spirits up. They started him on an antidepressant this last week. He tells us stories about what it's like in prison. He described it as hell. He said that every morning when he wakes up he waits for the guard to come to his cell and tell him to pack his stuff because he was going home and that there had been a mistake. He reassures us that he is doing fine when he sees the worry on our faces. We listen to his stories about the other prisoners he has met, a boy who is serving a life sentence for killing his whole family, another person that hit his mother in the head with a hatchet and killed her, the rapist, the chimo's (child molesters) that no one likes. He has told us that there are bi-sexual people there too, but not to worry, he is getting use to them starting at him when he is in the shower. And he told us that every time we visit him he is strip searched before he can go back to his cell, but he does not want us to stop coming to see him. He has been given a nick name too, they call him Smiley.

I can't help wondering what our son will be like when he gets out of prison. Will he be the same sweet person? Will he be hardened and uncaring and someone we do not know any more? Will he be emotionally distraught? Or suffer from some post traumatic stress? I know one thing for sure; he will never be the same person that left.

Through this experience I will continue to be an advocate for my son. Although physically I cannot be there to protect him, and God knows I would have taken his place in a heartbeat, I can be there in prayer and in words through letters. And there is one more thing I can do for my son, and that is to be a voice for him and others like him that are "falling through the cracks." I can tell his story for him and hope that someone will listen and his time will not be served in vain. I hope that maybe, just maybe, God did have his hand in this horrific event and something good will come out of it for those still suffering in our prisons with mental illnesses and disabilities … and better yet maybe, just maybe someone will listen and help to make changes in our health care system to provide services to the vulnerable adults in our communities that are "falling through the cracks" so they do not end up in jail. Too many times after high school these kids end up on the streets unsupervised and that makes them easy targets for those looking to manipulate and take advantage of other people more vulnerable. To me "those people" who take advantage of vulnerable adults are the "real criminals."

The MN Consortium for Citizens with Disabilities
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To: MN State Medicaid Director

From: The MN Consortium for Citizens with Disabilities (MN-CCD)

Re: Public Comments on the Reform 2020 Section 1115 Waiver Proposal (Second Round)

Date: October, 2012

On behalf of the Minnesota Consortium for Citizens with Disabilities (MN-CCD), a state-wide, cross disability public policy coalition, we thank you for the opportunity to submit a second round of public comments on the Reform 2020 Section 1115 Waiver Proposal.

We appreciate the changes that DHS made to their Section 1115 Waiver Proposal in response to the public comments that we and many other organizations and individuals submitted. We were particularly pleased to see some of the specific changes around the nature of school districts' involvement in the Demonstration for Intensive Service Coordination for Children. Additional changes that we feel strengthen the Section 1115 Waiver Proposal include the changes in eligibility groups for the employment supports initiative as well as the removal of age limits in conjunction with the Autism services section of the proposal (although we understand that the latter section does not require federal authority and will be discussed extensively in the newly formed Autism Spectrum work group).

While there are certainly pieces of the proposal that we continue to have concerns about, we identified those specific concerns at length in the initial public comments we submitted this past summer (available as an attachment to the proposal) and therefore we will not review them again here. Additionally, despite these areas of concern, we have overall been encouraged by the MN Department of Human Services' willingness to discuss issues of concern with stakeholders throughout the entire Section 1115 Waiver Proposal creation process. There has been strong stakeholder involvement since the very first stages of work on this proposal began.

In summary, we continue to remain in agreement with the Section 1115 Waiver Proposal's vision for achieving better health outcomes, simplifying programmatic administration and access, ensuring the long term sustainability of the Medicaid program, increasing the flexibility and responsiveness of the LTSS system, and supporting Minnesotans to have a meaningful life at all stages according to their own desires. These proposal goals align well with the three founding principles that guide MN-CCD in our disability policy advocacy work: access to needed services, empowerment and choice, and quality of care. We look forward to CMS's feedback on the proposal, and to continuing our work with DHS on the critical and significant implementation and operational decisions that will have to be made as we move forward.

Thank you again for the opportunity to comment.

Steve Larson and Chris Bell, 2012 MN-CCD Co-chairs

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October 24, 2012

Scott Leitz
Interim Medicaid Director
Minnesota Department of Human Services
P.O. 64998
St. Paul, MN 55164-0983

RE: Comments on September 24 Version of
"Reform 2020: Pathways to Independence,
Section 1115 Waiver Proposal"

Dear Mr. Leitz:

Thank you for the opportunity to comment on the changes the Department of Human Services (DHS) made to its June 18, 2012 version of the above-named 1115 waiver request. Our office is Minnesota's designated Protection and Advocacy (P&A) System which represents children and adults across Minnesota with significant, often lifelong, disabilities, including mental illnesses, physical disabilities, brain injuries and intellectual and developmental disabilities. These comments relate to the changes made in Minnesota's Reform 2020 1115 waiver request provided to the public September 24, 2012. We also submitted comments on the June 18 version of Reform 2020 and urge DHS to make additional changes as recommended.

I. SUPPORT

A. Availability of Fiscal Analysis

We appreciate the additional information on Minnesota's fiscal assumptions and analysis for the changes and 1115 waivers requested. However, we still do not have enough information to understand some points we believe are important to persons with disabilities and will continue to request clarification.

B. CFSS

1. As stated in our comments on the June 18 Draft Reform 2020 version, we are in strong support of reforming and modernizing Minnesota's PCA services program using the 1915k Community First Choice federal

authority, under the title Community First Services and Supports (CFSS), for a number of reasons which we will not repeat here.

II. OPPOSE

A. Community First Services and Supports (CFSS) Fiscal Issues

While we strongly support Minnesota's effort to both move to the 1915k state plan option and obtain an 1115 waiver using 1915i in order to continue current eligibility for PCA services, we strongly oppose the use of any of the additional 6 percent federal match for anything other than changes to the new CFSS program to restore eligibility for those who need cuing and supervision (42 C.F.R. § 441.500) to accomplish activities of daily living (ADL) and instrumental activities of daily living (IADL), to cover the projected caseload increase, to increase the payment rate due to added responsibilities such as teaching and skill development and to raise the minimum amount of service from 30 minutes to 75 minutes. Because of the harsh and discriminatory 2009 cuts primarily affecting persons with mental illnesses, brain injuries and intellectual and developmental disabilities, any additional federal financial participation is needed to restore this program and eliminate the unfair treatment of persons who need cuing and supervision to accomplish essential activities in their homes and communities.

It appears that funding generated under CFSS, 1915k is projected to be used for a demonstration on Intensive Care Coordination for Children and for Essential Community Supports needs due to the Nursing Facility Level of Care (NF/LOC) changes adopted in 2009 (also the subject of an 1115 waiver request in February 2012). We oppose the use of CFSS-generated funds for purposes other than necessary changes to the PCA/CFSS program.

B. Demonstration of Innovative Approaches to Intensive Care Coordination for Children with Complex Services

We oppose the use of any the 1915k additional funds for the Demonstration of Innovative Approaches to Intensive Care Coordination for Children with Complex Needs.

We continue to oppose this demonstration program despite changes made in the September version of Reform 2020 for the following reasons:

1. No data has been provided on the amount of Medicaid funding schools are currently providing through the Medical Assistance (MA) program by district. We think this essential to analyze this information in order to predict whether there would be any interest in such coordination from school districts.

2. Our state spent many years working on interagency collaboration (IIIP), including DHS, health care and education for children. After an enormous amount of effort, untold hours in meetings and travel, many legislative adjustments, this effort has been terminated. It is important to learn from this experience and not repeat the same failed practices under a new name.

3. As stated in our earlier comments, we often find that school resources are not robust enough to meet the complex needs of children in school, much less in other environments. Many districts are in need of significant training on positive behavior supports because they are still resorting to the use of prone restraint in school for children as young as five years old.

We urge the Intensive Care Coordination Demonstration request be withdrawn. Instead, we think that improvements in intensive care service coordination for children should proceed with the other reform efforts, including case management, health care coordination, state innovation model initiative, health home and health care home efforts. Minnesota is awash in proposals to coordinate and manage health care and other services for persons with complex needs. We think that another coordination project to develop and manage in addition to the multiple efforts already occurring is excessive duplication. As stated above, we firmly oppose the use of any additional CFSS related federal financial participation for anything other than restoring eligibility in order to end the serious discrimination against persons with mental illnesses and other behavioral issues in the newly-designed PCA program called CFSS.

C. <u>Essential Community Supports (ECS) Program for "Transition Group"</u>

Is this item listed in order to cover the cost of providing ECS to those who lose HCBS waiver eligibility due to the Nursing Facility Level of Care (NF/LOC) change? We oppose use of 1915k additional federal matching funds for this purpose. We think all 1915k increased funds are needed to make changes in our PCA program to eliminate discriminatory provisions which are contrary to 1915k requirements. The costs for alternative services were included in the NF/LOC 1115 waiver and should not be paid for with funds needed to correct discriminatory practices in the current PCA program.

We appreciate numerous other changes as described in the September Reform 2020 proposal, including eligibility for and emphasis on competitive employment for the Employment Supports demonstration and the change in eligibility (elimination of the functional assessment), change in the 18-year-old age requirement and the addition of Community Living Assistance services for the Housing Stabilization Services demonstration.

In sum, thank you for the opportunity to comment. We appreciate all of the public meetings and information provided by DHS as the 1115 proposal has been developed.

Sincerely,

/s/

Anne L. Henry
Attorney

ALH:nb