

POSITIVE SUPPORTS RULE

WRITTEN COMMENT

February 27, 2015 – March 15, 2015

1. Email from Julie Kenney (12 pages)
2. Email from Jill Lindman Kinney (2 pages)
3. Letter from Robin Rodenborg (7 pages)
4. Form from Matt Newquist (10 pages)
5. Email and attachment from Joe Fuemmeler (5 pages)
6. Email from Robert Klukas (2 pages)

Sullivan Hook, Karen E (DHS)

From: Julie Kenney <julie.kenneyipsiiinc@gmail.com>
Sent: Friday, February 27, 2015 1:43 PM
To: *OAH_RuleComments.OAH; Julie Kenney
Subject: IPSII Inc. comments to Positive Behavioral Support Rulechanges
Attachments: IPSII Inc. comments Positive Behavioral Supports Rule.docx

Hi,
Attached are my comments to the proposed Positive Behavioral Support Rules.

Julie Kenney

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Julie Kenney
Executive Director IPSII Inc.
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Richfield, MN 55423
612.861.3215
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www.ipsiiinc.com



IPSII Inc.

Independence, Productivity, Self Determination, Integration & Inclusion [IPSII]

www.ipsiiinc.com

Date: February 27, 2015

To: Administrative Law Judge Eric L. Lipman

Office of Administrative Hearings

600 North Robert Street

P.O. Box 64620

St. Paul, MN 55164

651.361.7900

Re: IPSII Inc. Supports proposed Positive Behavioral Supports

Comments to Proposed Changes to commonly known as Rule 40

Minnesota Statutes, Section 14.131 to 14.20

Minnesota Rules, parts 1400.2000 to 1400.2240

From: Julie Kenney, MPA

Executive Director IPSII Inc.

6611 Lynwood Blvd.

Richfield, MN 55423

612.816.9648

Julie.Kenneyipsiiinc@gmail.com

www.ipsiiinc.com

Dear Judge Lipman,

My name is Julie Kenney. I am the Executive Director of IPSII Inc. (Independence, Productivity, Self Determination, and Integration & Inclusion). IPSII Inc. is a 501 (c) (3) non-profit organization our mission is to increase Independence, Productivity, Self Determination, Integration and Inclusion (IPSII) for people with disabilities and their families. IPSII Inc. was founded in 2002 by graduates from the Minnesota Governor's Council on Developmental Disabilities Partners in Policymaking® program.

IPSII Inc. strongly supports the Minnesota Department of Human Services proposed Positive Behavioral Supports Rules. Through our projects IPSII Inc. has been working with individuals with intellectual and developmental disabilities and their families in North Minneapolis. Our focus is initiating adaptive change creating welcoming schools, workplaces and communities. We teach Person Centered Planning, Positive Behavioral Supports and Leadership Training.



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Our Projects:

- **On Eagles Wings** An African American Disability Leadership Program.
 - Project dates 2004-today.
 - Funded by the Minnesota Governor's Council on Developmental Disabilities and IPSII Inc.
 - Trained over 100 parents of kids with intellectual and developmental disabilities through our 30 hour leadership training program.
 - On Eagles Wings participants as part of our 'Day at the Capitol' met with Rep. Thissen, Senator Kelash and others describing their experiences at Minnesota Extended Treatment Options (METO), other Minnesota Institutions, and care facilities.
- **Being Prepared Center** Minnesota's Emergency Preparedness Center 90DN077.
 - Project dates 10.1.10-9.31.12.
 - Project of National Significance funded by the U.S. Department of Health and Human Services.
 - Trained over 140 individuals with intellectual and developmental disabilities, their families and services providers how to be safe in an emergency.
 - Trained over 122 Minnesota First Responders how to safely work with individuals with autism in an emergency situation.
 - Presented at the 2012 **National Homeland Security Conference, Columbus, Ohio 5.21.12 to 5.24.12** [See: *Preparedness Partnerships for Whole Communities* <http://nationaluasi.com/dru/node/41>]. On how to work with individuals with autism in emergency situations
- **Pathways Youth Center** MN Information and Training Center 90DFN0210-90DN0233
 - Project dates 10.1.04-9.31.10
 - Project of National Significance funded by the U.S. Department of Health and Human Services.
 - 30 Hour Leadership Training Program to over 150 individuals with intellectual and developmental disabilities.
 - All day Positive Behavioral Support workshops to over 125 parents of individuals with intellectual and developmental disabilities, their families and teachers. We partnered with Joe Reichle, PhD University of Minnesota expert in the communicative nature of challenging behavior.
 - Pathways Youth testified to Minnesota Legislators, Senior Policymakers and others regarding their treatment at Minnesota Extended Treatment Options (METO)
 - Pathways Youth testified to extreme punishment while in Minnesota State Institutions and other care facilities.



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IPSII Inc. graduates their personal stories that they shared with legislators and policymakers.

Please note their names have been changed

1. **Heidi.** Heidi was at Minnesota Extended Treatment Option (METO) for a couple of years. Heidi is a person with intellectual and developmental disabilities who graduated from On Eagles Wings, Pathways Youth Center and our Being Prepared Trainings. In addition Heidi was a paid staff person. While at METO Heidi was shackled, restrained and harshly punished when she would ask for additional food. Heidi says she was scared. She was afraid to ask for food when she was getting sick. Heidi said she felt like a thing. Not a person. Heidi is diabetic and she has a mental health diagnosis.
2. **Dan.** Dan was at METO for several years. Dan is a person with intellectual and developmental disabilities who graduated from On Eagles Wings, Pathways Youth Center and our Being Prepared Training. Dan recruited a participant for our Pathways Youth Center and mentored this person throughout the 30 hour leadership training program. While at METO Dan was restrained. Dan stated he did not understand why he was restrained; only that he was hurt by the restraint and felt very sad. Dan has high blood pressure.
3. **John.** John was at METO for several years. Jon is a person with intellectual and developmental disabilities who graduated from Pathways Youth Center. While at METO Jon was placed in seclusion and restraints. Jon reports that he hated METO and tried to run away. Sadly, Jon passed away. Jon was mobility obese and had multiple health issues. I believe the stress and anxiety from his years at METO contributed to Jon's death in his early 20's.
4. **Frank.** Frank was at METO for several years. Frank is a person with intellectual and developmental disabilities who graduated from On Eagles Wings and Pathways Youth Center. While at METO Frank was restrained and secluded.
5. **Cathy.** Cathy was at METO for one year. Cathy is a person with intellectual and developmental disabilities who graduated from Pathways Youth Center. Cathy wanted to get married. She ran away from her group home because her guardian said she could not get married. Cathy was restrained because she wanted to see her fiancée.
6. **Gracie.** Gracie was at another state institution for many years. Gracie is a person with intellectual and developmental disabilities who graduated from On Eagles Wings, Pathways Youth Center, and Being Prepared Center. Gracie is nonverbal and has no communication system. Gracie bit a staff person and the institution removed all her teeth. Gracie was a paid staff person for On Eagles Wings and Pathways Youth Center.
7. **Penny.** Penny was at another state institution for many years. Penny is a person with intellectual and developmental disabilities who graduated from On Eagles Wings, Pathways Youth Center, and Being Prepared Center. Penny was a paid staff person for On Eagles Wings. Penny was restrained, secluded and drugged.

Summary:



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Through the proposed Positive Behavioral Supports rule changes I believe these stories would be much different. Person Centered Plans would be developed so that each person with an intellectual and developmental disability will have choices in their life. Choices that you and I take for granted.

Joseph Kenney, our son

For the past 35 years our family has lived in Richfield, Minnesota in a small Cape Cod house that backs onto Woodlake Nature Center. Our son Joseph is a young man with complex intellectual and developmental disabilities. In 1987 the Minnesota Department of Human Services rated Joseph as the most costly and difficult to service child in the State of Minnesota. Because of his high needs he had one of the first individuals in Minnesota to receive Waivered Services.

Joseph was restrained, excluded and punished. Joseph's autism teacher believed Joseph chose not to speak and she put him in timeout whenever he didn't answer a question. The result was devastating. Joseph stopped eating. He screamed none stop. Every once in a while he would go stand in the corner in his autism classroom. Like 'Dan' Joseph had no idea why he was being punished. As you know, public schools and public school teachers are exempt from Rule 40. Just like many of the staff from METO, other State Institutions and Group Homes believe they are exempt in emergency situations.

The proposed rules will define what is Minnesota's Community Standard for treatment of individuals with intellectual and developmental disabilities. The proposed rules through Person Center Planning will give all citizens a choice in how they live their lives. Through the proposed rules, we can begin to create welcoming environments for people with intellectual and developmental disabilities.

Respectfully Submitted By

Julie Kenney, MPA

Julie.kenneyipsiiinc@gmail.com

www.ipsiiinc.com

For a detailed work history and CV please check out my LinkedIn:

https://www.linkedin.com/profile/preview?locale=en_US&trk=prof-0-sb-preview-primary-button



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Julie Kenney Background:

Education: 2002 Master's in Public Administration (MPA)

Harvard Kennedy School of Government <http://www.hks.harvard.edu/>

Courses Harvard Kennedy School of Government: Microeconomic (David Elwood); The Art of Communication (David Gergan); Executive Leadership (David Gergan); Leadership on the Line (Ron Heifetz); Negotiation (Alread); Global Warming Case Study Exercise (Brian Mandel); Interest Group Activism and Representation (David King); Mobilizing Groups (Williams)

Courses (3rd Year) Harvard Law School:

Disability Law (Sam Bagenstos) ; Education Law (Martha Minow)

1997 Minnesota Partners in Policymaking <http://mn.gov/mnddc/pipm/>

This intensive eight month leadership training program on disability was developed by the Minnesota Governor's Council on Developmental Disabilities.

In May 1987, the Minnesota Governor's Council on Developmental Disabilities created a ground-breaking, innovative training program called Partners in Policymaking® to teach parents and self-advocates the power of advocacy, and change the way people with disabilities are supported, viewed, taught, live and work. On the 25th Anniversary of the Partners program, celebrated on May 10, 2012, in addition to celebrating the occasion, it was important to recognize that important issues had been confronted and dramatic changes had been made. At that time, there were 21,000 Partners graduates in the United States and 2,000 Partners graduates internationally.

Fellowship: 2001 Bush Leadership Fellow <https://www.bushfoundation.org/fellowships/bush-fellowship-program>

July 2001 – July 2002 (1 year 1 month) Harvard University Cambridge, Ma.

As a Bush Leadership Fellow I earned a Master's in Public Administration (MPA) at Harvard Kennedy School of Government in Leadership and Disability Law.

The Fellowship funded our family moving from Minnesota to Cambridge MA. This was the first time we had lived outside of Minnesota and it was a wonderful experience.

Our son Joseph, a young man with multiple disabilities had just graduated from high school, loved living on campus and exploring the historical towns with his dad. My husband Mike left his position and became Joseph's caregiver. And I went to the ocean every chance I had, a new experience for a landlocked Minnesotan.



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Activity: **LEND** (Leadership Education in Neurodevelopmental and Related Disabilities)

September 2010 – Present (4 years 6 months) 103 Pattee Hall, 150 Pillsbury Drive SE, Mpls., MN 55455

I am a charter Advisory Committee Member of the University of Minnesota LEND Program Advisory Committee.

The University of Minnesota LEND (Leadership Education in Neurodevelopmental and Related Disabilities) Program is an interdisciplinary leadership training program spanning 12 disciplines across the University of Minnesota and is funded by the Maternal Child Health Bureau (MCHB) of the US Department of Health and Human Services.

With the formation of the University of Minnesota’s LEND program the university community now has the opportunity to have increased training, engagement, and support for children with Autism Spectrum Disorders (ASD) and other neurodevelopmental disabilities. This will translate into real change and growth for Minnesota children and families. Twelve academic disciplines within the University have collaborated to create a unique and powerful learning experience for students and community trainees.

Association for Positive Behavior Support www.apbs.org : Family Member

2015-2016

The Association for Positive Behavior Support (APBS) is an international organization dedicated to improving the support of individuals in order to reduce behavioral challenges, increasing independence, and ensure the development of constructive behaviors to meet life goals in the areas of social relationships, employment, academic achievement, functional life-skills, self-determination, health, and safety. We believe that the competent and skilled use of PBS (i.e., focusing on strategies that are compassionate, constructive, and educationally oriented) can help individuals make meaningful progress toward these goals.

The Association for Positive Behavior Support is a multidisciplinary organization made up of professionals (teachers, researchers, university professors, and administrators), family members, and consumers who are committed to the application of PBS within the context of the school, family, and



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community including across systems (e.g., entire schools, organizations), for small groups, and for individuals with complex needs for support.

Grants: **Program Director: On Eagles Wings** is funded by the Minnesota Governor's Council on Developmental Disabilities and IPSII Inc.

August 2003 – Present (11 years 7 months) North Minneapolis

On Eagles Wings is an African American outreach program designed for African American parents of children with developmental disabilities and African American adults with disabilities in North Minneapolis a high crime urban setting.

On Eagles Wings is funded in part by the Minnesota Governor's Council on Developmental Disabilities with funding from P.L. 205-402 U.S. Department of Health and Human Services.

Participants learn through our 30 hour training program the following topics: Disability History; Inclusive Education; County Based Services for Medicaid eligible people with disabilities; Supportive Housing and Employment; Independent Living vs. Medical Model; System Change; Introductory Leadership; Legislative Process and more.

The nearly 100 graduates from the On Eagles Wing's program have increased their Independence, Productivity, Self Determination, and Integration & Inclusion (IPSII).

Principal Investigator: Being Prepared MN Emergency Preparedness Center #90DN0277 A Project of National Significance: Emergency Preparedness Special Initiatives, and funded by U.S Department of Health & Human Services and IPSII Inc.

October 2010 – September 2012 (2 years) North Minneapolis

Of the 12 entities funded to Plan Emergency Preparedness Centers, IPSII Inc. was one of five entities awarded funding to implement their proposed Emergency Preparedness Centers.



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Five Emergency Preparedness Centers:

1. Cerebral Palsy of Middlesex County, NJ
2. IPSII Inc., MN
3. University of Delaware
4. University of Hawaii, Honolulu, HI
5. University of North Carolina, Chapel Hill

Mn Being Prepared Center Purpose:

To create a multiagency partnership to assist unserved underserved people with a developmental disability who are at risk of institutionalization, their families, and group home providers. The Center Advisory directs this project and is comprised of people with developmental disabilities and their families.

Highlight of Center outcomes:

1. Trained 140 people with developmental disabilities, their families, and group home providers how to develop their own emergency preparedness plan.
2. Trained over 400 First Responders how to work with people with autism during an emergency situation.
3. Disseminated over 600 thumb drives that have Center developed workbooks: My Personal Safety Plan; Extreme Cold & Winter Storms; A Influenza & H1N1; Tips for First Responders on How To Work with People with Autism.
4. Highlights of Julie Kenney's presentations on the Center:
 - *PacRim International Conference on Disabilities, Honolulu, HI. April 2011 and March 2012
 - **FEMA September 2010 and September 2011
 - ***National Homeland Security Conference chosen to represent disability access May 2012

Principal Investigator: Pathways Planning Grant #90DN024 A Project of National Significance funded by the U.S. Dept. of Health & Human Services and IPSII Inc.

October 2009 – September 2010 (1 year) North Minneapolis

IPSII Inc. was one of 12 entities funded to develop a Plan for an Emergency Preparedness Center.

1. Cerebral Palsy Edison, NJ



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2. Goodwill Easter Seals, OH
3. IPSII Inc., MN
4. Quality Trust, Washington, DC
5. University of California, LA
6. University of Delaware
7. University of Hawaii, Honolulu
8. University of New Mexico, Albuquerque
9. University of North Carolina, Chapel Hill
10. University of Vermont, Burlington
11. Utah State University, Logan
12. Wayne State University, Detroit

Purpose:

To develop with our partners, an Implementation Plan for our Center that will provide in depth training and support to at least 60 individuals with developmental disabilities and their families annually on, 'how to' plan & implement emergency preparedness plans for themselves and their families, for a variety of emergency events.

Planning Year:

Our major activity was our in-depth training with 40 individuals with developmental disabilities who are Medicaid eligible 'how to' develop your own Emergency Preparedness Plan.

Trainings included PowerPoint's accessible to non-readers, supplemental materials, homework, role playing activities, how to make your own 'Go Kit' and culturally competent supports including transportation to and from trainings, stipends and homework assistance.

Statement of Need: In the Request For Proposal for this project, stated only 21% of emergency managers are planning to develop guidelines for people with disabilities. In Minnesota, counties provided training to providers, but no direct training to people with developmental disabilities.



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Principal Investigator: Pathways MN Youth Center #90DN0233 a Project of National Significance

funded by the U.S. Department of Human Services and IPSII Inc.

October 2004 – September 2010 (6 years) North Minneapolis

IPSII Inc. was one of 21 entities that developed Youth Information Training and Referral Centers (YITRC) nationwide funded by the U.S. Department of Health and Human Services.

Purpose:

The goal was to support individuals with developmental disabilities to exercise greater choice, self-determination and to engage in leadership activities in their communities. see the Grantee Information page. <http://www.addyic.org/granteeProjects.php>

Pathways Youth Center:

The primary areas of focus were employment, education, housing, and quality assurance. The Center offered activities to youth and emerging leaders with developmental disabilities (DD) who are Medicaid eligible in North Minneapolis.

The Center provided youth friendly products via the IPSII Inc. web site. The Center Advisory Committee directed the funding of activities and reviewed all outcomes. The Center 30 hour leadership program for emerging leaders throughout the six years this project was funded. The Pathways Center disseminated information on 'How to Access the General Education Curriculum and Graduate with a Standard Diploma'; and the workbooks 'How to Seek and Maintain Employment' and 'The Roadmap to Supportive Employment' were disseminated nationwide.

Center 'Positive Behavioral Interventions' workshops trained over 100 family members of youth and emerging leaders with developmental disabilities and their service providers including classroom special education teachers.

With warm regards,

Julie Kenney, MPA Please contact me if you have any questions at julie.kenneyipsiiinc@gmail.com



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Sullivan Hook, Karen E (DHS)

From: Nichols, Mary Jo (ADM)
Sent: Monday, March 02, 2015 8:58 AM
To: *OAH_RuleComments.OAH
Subject: Positive Support Rule Comments
Attachments: pos sppt rule kinney comments.pdf

The Honorable Eric L. Lipman
Administrative Law Judge
Office of Administrative Hearings
Rulemaking Proceedings

RE: OAH Docket No
Revisor Number

Additional comments regarding the proposed Positive Support Rule are attached. We hope these can still be accepted.

Thank you.

Mary Jo Nichols
MN Governor's Council on Developmental Disabilities

The Honorable Judge <Name>
Judge of <Name of Court>
Mailing Address

February 28, 2015

Dear Judge <Name>

I was unable to attend the public hearing regarding the possible adoption of rules governing Positive Support Strategies, use of restrictive interventions and emergency use of manual restraint and repeal of rules governing aversive and deprivation procedures on Monday February 23, 2015 to personally deliver my opinion.

I am a mother of a child with Down Syndrome, who is now 5 years old. He is about to start his educational journey and frankly, I am terrified. I am having anxiety thinking about what he will face, by himself, at school. Aidan has communication difficulties due to having Apraxia of Speech as well as a sensory-motor disorder. I feel these two issues make school unpredictable. Aidan displays behaviors when frustrated, because of his communication difficulties, and is easily overwhelmed. He can become overwhelmed from the littlest thing but the behavior can be or become huge. In that, I am worried how he will be treated and worried he will be "handled." Handled, meaning forced restrained and secluded if undesirable behaviors arise and judged as dangerous to himself and to others.

I completely encourage the passing of the Positive Support rule. My son and those who have behaviors need to be treated first gently and with respect, remembering they are human and in my case, a child. I understand things can go out of control and dangerous situations can arise, without warning. I want my son to learn and live in a safe environment. I do believe with Positive Support Strategies, these situations can be diffused and resolved safely and effectively without restraint and seclusion.

I believe knowing the child and the extent of their challenges is *the* important part of the puzzle. If we can know the trigger and avoid the trigger, there would be less instances of potentially dangerous behavior and therefore less need for adverse action. This, I believe, can be achieved through training and better procedures documented for staff and support staff in regards to each student.

Thank you for your time and consideration.

Jill Lindman Kinney
8987 Underwood Lane N.
Maple Grove, MN 55369

Dear Law Judge;

8-1800-32056

March 12, 2015

I am writing in regards to the Rule Making Hearing held Feb 23rd. I have concerns about the Rule and implementation, populations included in the Rule, the strategies and outcomes, lack of person centeredness, and the structure of particular places as it pertains to use of emergency procedures, PRN's, understaffing, and reporting. Thank you for hearing my comments.

I work specifically with higher level and Severely Emotionally Disturbed teen girls. My home is a treatment foster home for a foster care agency called Kindred Family Focus and I also am a foster parent for a program called MITH (Multi Intensive Therapeutic Treatment). I get some very challenging youth who have already accessed many other resources to get on track and need a higher level of Care and structure. Working with severe mental illnesses in a playing field that is losing provides and medication management options make this more challenging. These are youth who are assaultive, are still trying to develop more socially acceptable social skills, may not have had parental role models to build the basic thought process of cause and effect. Though many may be older teens, they are still learning skills of a much younger child. Even typical parenting (which most of these kids have not had) in a working family home, would not meet the strategies within this rule. I am happy to give examples:

On one evening, a very challenging child started to assault me in a vehicle. She then spent 20 minutes spitting in my face, trying to damage the inside of my car, I called 911 and because we were near traffic there was extra danger and I needed to keep her there. The police were slow in responding and she continued to spit in my face. Once law enforcement arrived, she challenged them too. She told them she wanted to be arrested and started listing off hospitals of her choice because she wanted to go swimming. Sending her to the hospital for 4 weeks, so she could swim was not in her best interest. The officers told me to bring her home and if I had further problems to call them again. I asked them to please escort her to my house as I had other youth riding in the car and it didn't feel safe. She got home and continued. I called the police again. The police came in the home and tried to reason with her, she spit on them, she swore, called them names and demanded to go swimming at the hospital. The police came out in the kitchen and told me to parent this child. They told me to take away her fun things, TV, video games...I told them I couldn't. They told me to punish her. I told them I couldn't. They told me to close her door and ground her to her room. I told them I couldn't. They told me that the neighbor can parent their child, why can't I? I said I live under different rules and it is not allowed to take things away, close a door or remove an activity she enjoys. The police were shocked. Because of multiple calls for this youth, it was known that once she went to bed, tomorrow she would have a good day and the actions of the night before would not carry over. Giving in to the demand of going to the hospital of her choice so she could swim, would have

set a precedence for her and taught her that this is how she gets what she wants in the moment.

It would have involved a lengthy and costly hospital stay and undone the daily routine of school and home. She would have had to re enter school and home and this would have set her back. There was a reason she was not successful in multiple places and most of it had to do with unlearning this behavior and replacing it with more socially acceptable ones. There became other issues. Was a youth this aggressive appropriate for a family home. The police didn't think so. I did. Then came other issues like liability to the agency as this youth was very assaultive to me (kicking me in the head, hurt my arm so I couldn't use it...) We have a goal of moving youth to homes in hopes they will "become" socially appropriate and productive citizens. This is hard to do when typical parenting tools are not at our disposal.

At a training for this new rule, I asked specific questions about how this new rule does not provide person centeredness in care, the specific needs of youth, natural consequences and felt tip toed around. In a socially appropriate setting, a youth disrupting during an activity is brought out from the activity for 2 reasons. The other youth being appropriate have a right to continue with what they are doing in a safe way and it is a teachable moment to instruct and teach the disrupting youth about skills like: thinking of others, safety, cooperation...Within this rule, I cannot pull a youth from an enjoyable activity if they are disrupting. I am to pull the kids back who are doing well, using their skills, earning the activity they waited for.

The youth I work with come with extensive histories of using force, assaultive behaviors, coercion, threatening family members, some are already in the justice system because of these behaviors. They come here with a faulty belief that this is how they get their needs met. The goal is to "teach" them better ways to meet their needs so they can experience more age appropriate things like mainstream schools, sports, clubs, entertainment facilities like YMCA's, movie theaters, public pools, bowling. They first have to be "taught" how to be safe with themselves and others.

In a home, we need tools to accomplish this. We need to be able to "teach" the lesson in a natural setting. Relationship skill building doesn't always feel cozy and fun. Sometimes this particular youth is the aggressor and other people experience unwanted feelings of anger, frustration, jealousy, life is unfair, or they don't feel safe because of this youths behaviors and acting out. Sometimes, to learn the lesson, this same youth needs to experience the same emotional feelings and "learn" how to address these feelings properly. They view feelings as an action word. Teaching youth with emotional distturbances is hard. It is harder is they are not allowed to feel guilty for what they did, said or who they hurt. They do not understand the purpose of an apology or typical communication skills. Because their anger has become their tool and their safety survival skill, they instinctively revert to what is familiar to them until they

learn a better way. Many lack the empathy skills to feel what other people are feeling and this makes relationship building tougher. This population has experienced multiple hospitalizations and many, not all, prefer the setting of a hospital and become combative with the exposure of a less restrictive environment like a home. The hospital feels safe to them. They will fight to be put back in the hospital vs learning better skills in a home.

One of the typical tools parents use is encouragement and working towards something. In the adult world they are called goals and adults for the most part, understand this concept. When working with youth, they are usually trying to attain "something" and not a goal or concept. They are hands on. They need to see and hold and play with, or participate in what they have earned. Removing the language and concept of rewards, also removes valuable lessons a youth needs to learn. They learn about working towards something, the skills needed to attain it, the disappointment of falling short of that thing, the natural emotions related to disappointment, the skills of trying again, the joy of success. I struggle with the idea that not achieving a reward, is considered punishment and that the language attached to this has been viewed as "to cause" shame, guilt, creates a harmful therapeutic environment. That is not the goal. The goal is to teach new skills, reduce challenging behavior, and teach youth better options which leads to better choices. This starts with short term goals, maybe hour to hour, then day to day, week to week and so on. Schools use a rewards system, other parents use rewards of some form, employers use rewards, car insurance companies use rewards for good driving, courts and probation use rewards. This is how society operates. I challenge the concept that our consumers would do better if they did not feel the natural process they will be held to adhere to when they turn 18 and are sent out into society.

Youth and facilitating foster parents working with these youth have one more component most other providers do not have; NorthStar Childrens Act. As foster parents we are taxed with providing results to move these youth back home or into adoptive settings in 12 to 16 months. These youth have years of trauma, multiple failed placements or failed adoptions and as a provider, I struggle with undoing 10 years of trauma in 12 to 16 months. NorthStar and the new Rule, as it pertains to youth, do not present as person centered and acknowledge the unique needs of each youth in care.

Given the youth population and the different challenges and goals attempting to be achieved, I would like to see youth exemptions considered. The Vulnerable Youth Act and Maltreatment of Minors, addresses forms of abusive behaviors or neglectful caregiving. Including all youth receiving waivers, into the Rule, side by side with the Maltreatment of Minors Act contradict each other. If, as a caregiver, I am not using, even the basic parenting procedures to bring up a youth, that would be considered neglect. (the exact situation the police challenged me with by telling me to parent) That is what the Rule is steering me to do.

Some youth require what we call a PRN medication. In the Rule, it is viewed as a chemical restraint. In the home, it is a tool. It is reserved for emergencies only. A youth can request a PRN if they feel they need it to prevent them from getting violent or acting out while dealing with a very difficult situation. Typically, there is some problem solving and processing first, and if it appears the youth really needs the PRN, the request has not only been honored, but encouraged by their workers and teams. With the new procedures in place, a youth would not be able to take charge and self-request a PRN to prevent a larger episode that might include law enforcement. A caregiver, trained and familiar with the warning signs, could not be proactive and offer the PRN. Given the protocol on the new emergency forms, the adult could not administer the PRN ahead of the episode. The new protocol for the PRN is that it is given after the event starts. By this time, the adrenaline has increased and the PRN has less of a chance of having the desired effect. The goal is to bring the youth to a calmer, more workable state and to prevent an event. When the PRN is used properly, it prevents an event and provides a chance to keep the situation teachable, eventually no longer needing a PRN when the skills are mastered.

I would request that the PRN be moved to a more therapeutic place within the emergency procedure checklist. I request an exemption for youth, if their prescribing physician can document what symptoms need to be present to use a PRN. I request the exemption to be person centered and not a one size fit all plan.

Understaffing is another area of concern. There is no clear definition for what understaffing is? Is a van driver transporting disruptive youth considered under staffed? Is a case manager of agency employee transporting a youth, considered understaffed? Is a foster parent within their licensing limits considered understaffed if a youth becomes explosive? Would a skills worker, meeting their goal to bring their consumer in community be considered understaffed? When a foster parent goes to bed at night, and there is known runaway history in a consumers file, is that considered understaffed? The budget does not allow for there to always be two people with a consumer and many of our programs are not designed that way. The use of emergency procedures specifically addresses understaffing without defining it.

The timeline for phasing out and phasing in new requirements, appear to be a one size fits all. One size fits all is not person centered and does not apply to the youth population, severely emotionally disturbed, mentally ill, population we are trying to bring up. Their emergency procedures may need changing based on a change in family dynamics, school issues, transportation issues, relationship skills building, and emotionally charged behaviors. There is always a honeymoon phase when a youth comes into care. When the tough work begins, there typically is an increase in behaviors, some physical, some more self-defeating. A person centered plan would follow the needs of the youth and would require an exemption to be

removed from the expectations and requirement of the Rule. I have had youth in my care for 16 months and seen that same youth require an increase of care 3 separate times over their stay. Youth have rapid changes, emotional setbacks, dating, school changes, team frustrations and require support, encouragement and motivation in an age appropriate way. This too, would require an exemption.

Trainings and reporting, I understand are necessary. I also feel it is starting to become too big. The majority of my contact with employers, is becoming about paperwork. The majority of time I do not have youth in my care is filing our, organizing, filing, sending out paperwork. I was hired because I like to work with kids and some days I surprise myself. The majority of people in my field were hired because of their hands on care for youth, tough youth. As more protocols change and more paperwork, reporting, computerized documentation...some of our best people in the field are struggling or considering leaving. We need these people. They are like anchors in the field. Some of the language is beyond what a home provider can understand or answer. This leaves agencies with further responsibility to get compliance paperwork done and taking valuable time away from supporting those who do the actual hands on cares in the day to day. Trainings take us away from the youth we care for, often without backup or respite providers. State Trainings are not scheduled in a way that respects our time constraints or the youth we care for. There are not enough computer generated trainings to assist 24 hour employees and State run trainings do not consider the time constraints on employees who do not have backup. These State trainings are not offered at times where most employees in our field would be most available: MSSA Conference, MACMH conferences, places where we can focus without hurrying or worrying about our youth. I ask that it be considered that the training be offered at these type of locations, so 24 hour employees can be more involved. I suggest a Sunday evening MACMH training or Monday night MACMH training. The same be offered at MSSA, the October St. Louis County Conference...There are good ways to help providers. Just as we struggle with 24 hr time constraints, so do our employers. They would benefit from better scheduling of mandatory training.

Because we work exclusively with youth, a huge factor to their success is their ties to strong family support. Many youth have legal guardians who we wish to support and validate. They are also a strong voice in preparing a person centered plan for their child. As a provider, my most valuable resource is the parent or legal guardian. This Rule does not ask what or how the legal guardian wants their child cared for. I do not see their input acknowledged in this Rule. I have seen limited parent involvement as it pertains to the rule and some offered through the Positive Support Plan and as a parent; I would want more input and more meaningful channels. If their families homes work best, by using rewards and natural consequences and our goal is to

return them home, are we really supporting the family's goal by creating such an artificial environment that cannot be duplicated in their family home. It has to be real and functional. This is another reason I request that youth be excluded from this Rule. Youth have adequate workers and caregivers, and existing legislation to protect them from harm and inadequate care.

There doesn't seem to be a clear definition between what is adaptive and what is considered mechanical. Some things are necessary for a youth's safety. Some things are considered medical and others are preventative, such as door or window alarms. Some would argue that alarms cause fear while others believe it is a safety device to keep youth in a safe and supervised area, especially at night.

The informed consent procedure where a consumer signs for the use of emergency procedures before there has ever been an emergency, contradicts the Rule and contradicts the concept of person centered care. I can only see one area where this type of informed consent would be person centered and that would pertain to youth who have been in long term care where they are actually soothed by this procedure. There are those youth who try to access a physical hold as it comforts them.

I watch the Senate and the constant increase to "Mandatory Sentencing" without acknowledging contributing factors at all. One size fits all justice? I watch this population of youth struggle with cause and effect reasoning. I acknowledge how many youth are already tied to the criminal justice system and receiving mental health services in a cell or long term facility. We want these youth to grow up productive and want to keep them clear of courts and jails and really dangerous or bad choices, but we can't give them a token or a reward because that is considered a punishment? How are we to raise kids that feel good about making the right choices. How can we blindly allow them to walk into a system they don't understand, because the concept of earning, working hard, having strong emotions appropriately, and socially acceptable behavior is foreign to them. They need to learn this as youth, in the homes, from caregivers they can trust with the same opportunity and benefits it offers them.

Thank you

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Positive Supports Rule
Informal Comment on Draft Rule (preceding formal rule proposal and hearing)

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'l Services, Inc.	

General Comments:

- 1) Mains'l Services, Inc. supports the public comment submitted by the Minnesota Disability Law Center (MDLC). They have submitted a thorough comment that provides excellent recommendations and will allow for a rule that is more feasible for providers to implement, while continuing to strive for the main goals that the department wants to accomplish with the rule. Throughout the remaining sections of our comment we will be highlighting specific areas of the MDLC comment that we would like to support.
- 2) Mains'l Services supports and emphasizes the MDLC comment regarding the need for DHS to work to apply the PSS Rules to all licensed providers. As the MDLC points out, not requiring all 245A providers to comply with the PSS Rules will create negative unintended consequences for individuals with disabilities. Specifically, 245A licensed providers may discontinue providing services to individuals with disabilities if they see the PSS Rule requirements as too difficult to comply with.
- 3) Direct Support Staff can include parents in some licensed services. How do parents reconcile their parenting strategies that are legal as a parent (i.e., Time Out), but are prohibited as a staff?
- 4) There are several sections where it is unclear whether that section or subpart is referring to all license holders or only to programs with a Positive Support Transition Plan (PSTP). Currently, sections of the rule addressing the use of positive supports by all providers are not clearly distinguished from sections addressing the implementation and monitoring of PSTPs, prohibited procedures, and restricted procedures. This makes it difficult to determine what applies to all license holders and what only applies to programs with a PSTP which could lead to incorrect implementation of or compliance with the rule.
- 5) As an agency, Mains'l Services, Inc. believes that the proposed rule will result in great improvements to the quality of life of individuals receiving supports; however, in light of all of the changes occurring to Home and Community Based Services (i.e., 245D, CMS changes, Rate Setting changes) it will take significant resources to implement the additional changes that this rule is requiring above and beyond all the other changes. Specifically, the upfront cost of training new employees will increase significantly under this rule. While many of the training topics are already covered for most employees, it has not been standard practice to complete training on all of these topics prior to providing supports to people. As an agency we have learned over time that employees do not retain the information from training when a large amount of training is completed prior to having any opportunity to practice what they have been trained on. Adding the training requirements from the proposed rule to the 245D training requirements that must occur before an employee is able to work alone may create a situation where employees are not able to retain all of the information that they have been trained on. In addition, as an agency these new training requirements will take a great deal of personnel resources in order to create and implement all of the new trainings, the changes to policy and procedure, and the changes to practice.

Comment on Proposed Positive Supports Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'I Services, Inc.	

PART 9544.0020 DEFINITIONS

Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 2		245D, Subd.2, c defines "aversive stimulus" as the presentation of any stimulus following behavior in an attempt to suppress behavior. Given this definition, any procedures used to reduce the occurrence of target behaviors would be prohibited. That means that prompting appropriate behavior when target behaviors are occurring (a procedure meant to reduce the occurrence of the target behavior) would not be allowed by the letter of this definition. We do not think this was the intent of those drafting the rule; however, we are concerned about how this might impact service provision. It appears that section 9544.0050, Subpart 1, item A allows prompting appropriate behavior even though this procedure would meet the definition of "aversive stimulus." It would be beneficial to provide clarification in the definition of "aversive stimulus" that permitted procedures are not considered to be an "aversive stimulus."
Subp. 13		Based on the current definition of Emergency, it is unclear what meets the definition of imminent risk of physical harm to self or others. For individuals for whom Emergency Use of Manual Restraint (EUMR) is approved, it would be beneficial to allow the EST to more clearly define what constitutes and Emergency for that individual. This would allow for better staff training and implementation of EUMR when it is needed. For example, for some individuals elopement places them at imminent risk of physical harm, but for others it does not.
Subp. 20		The current definition of Functional Behavior Assessment (FBA) only requires 1 item from A-D. At bare minimum it should require at least 2 of the items. It would be best to require assessing all the items. The current definition of FBA leaves a great deal of room for what qualifies as an FBA and subsequently allows for low quality FBAs to be in compliance with the rule.
Subp. 35		How are service providers supposed to determine whether an individual is experiencing mental pain or emotional distress? Both of these are private events or internal experiences that are not observable or measurable in a clear or consistent manor.
Subp.46		The definition of Qualified Professional requires 2 years work experience in writing or implementing positive support plans. Will organizations who do not have individuals on staff with the experience requirements be required to contract with external qualified professionals? If so, will there be funding to support that?
Subp. 46		The current rule does not recognize Board Certified Behavior Analysts (BCBAs) or Board Certified Assistant Behavior Analysts (BCaBAs) as qualified professionals. BCBAs and BCaBAs are uniquely qualified to conduct functional behavior assessments and write positive behavior support plans based on the results of the functional behavior assessment. By excluding BCBAs and BCaBAs from the list of qualified professionals, the rule is excluding a critical subset of professionals who are able to significantly impact the positive supports provided to those who receive services. In addition, the rule is unnecessarily limiting the pool of professionals who

Subp. 50		<p>are able to conduct functional behavior assessments and who are able to write positive behavior support plans.</p> <p>The definition of seclusion in 245D, Subd.29 (2) does not allow separating a person from a situation that places them or others at imminent risk of physical harm. When an individual is engaging in behaviors that place themselves or others at imminent risk of physical harm, it would seem prudent to remove them from the situation and prevent their return until they are able to return safely. For example, if an individual is physically assaulting one of their housemates it would be prudent to separate the two individuals and prevent the individual engaging in assault from returning to interacting with the individual being assaulted until they (the individual engaging in assault) are able to interact safely with the individual who was being assaulted.</p>
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Comment on Proposed Positive Supports Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'I Services, Inc.	

PART 9544.0030 POSITIVE SUPPORT STRATEGIES AND PERSON-CENTERED PLANNING

Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 2	Item B	(1) How is evidence-based defined? What will determine whether positive support strategies meet the criteria of evidence-based? Is 9544.0030, Subp. 4 the reference for this? (6) Who will determine whether a procedure is deemed as effective? What are the timeframes for making a determination on whether a procedure is effective?
Subp. 2	Item E	Minnesota Statutes 245D.07, Subd. 1a, paragraph b, clause 3 (iii) says license holders are to provide the least restrictive supports necessary in the most integrative setting possible. As providers, how do we reconcile this mandate with situations where families or funding sources do not support or allow the most integrative setting? For example, an individual could live in their own apartment with appropriate staffing, but the waiver is not able to pay for appropriate staffing to support this integrated setting.
Subp. 2	Item G	(3) Will all people receiving supports require a goal/outcome around supporting the individual in the most integrated setting? What if someone is already living in the most integrated setting?
Subp. 3		Does this subpart mean that a new person centered plan must be conducted every six months or that the current person centered plan must be evaluated every six months to determine whether it meets the criteria of person-centered?
Subp. 4	Item F	(1) - (3) These criteria seem quite vague and open to individual interpretation. Who will determine whether a standard, approved by the commissioner, meets these criteria and is therefore in compliance with licensing standards?

Comment on Proposed Positive Support Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'l Services, Inc.	

PART 9544.0040 FUNCTIONAL BEHAVIOR ASSESSMENT		
Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 1		Mains'l Services supports the comment by Minnesota Disability Law Center (MDLC) regarding the need for the commissioner to assist license holders in locating external qualified professionals.
Subp. 2		Mains'l Services supports the MDLC comment proposing a change to this subpart. Specifically, is of critical importance to making the rule more cost effective that the requirements are changed so that a new functional behavior assessment (FBA) is needed only when significant changes to the current plan are required.
Subp. 3		Mains'l Services supports the MDLC comment on requiring qualified professionals (QP) to evaluate all of the four listed elements. In addition, we support requiring QPs to consider each of the four elements when conducting the initial FBA and then note if a given element was determined to not be related to the function of the behavior.

PART 9544.0050 PERMITTED PROCEDURES		
Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 1	Item A & B	These items are extremely important to have as permitted procedures! Please ensure that they remain included.
Subp. 2		Where must license holders document a procedure approved under subpart 1?

Comment on Proposed Positive Support Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'l Services, Inc.	

PART 9544.0070 EMERGENCY USE OF MANUAL RESTRAINT		
Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 3		Mains'l Services supports the recommended change proposed by the Minnesota Disability Law Center (MDLC). Specifically, changing the requirement for a Positive Support Transition Plan (PSTP) to three episodes of emergency use of manual restraint (EUMR) within 90 days or four episodes of EUMR within 180 days allows for a more reasonable implementation of the rule. This proposed change will allow PSTPs to be developed for those who truly need them and will allow providers to focus their resources where necessary.

PART 9544.0080 INFORMED CONSENT		
Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 1		Mains'l Services supports the Minnesota Disability Law Center's comments on changing the section on informed consent to be a section giving notice. They make several excellent points regarding why the requirement should be to give notice rather than to obtain consent.

Comment on Proposed Positive Supports Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'I Services, Inc.	

PART 9544.0090 STAFF QUALIFICATIONS AND TRAINING

Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 1		The requirement of core training makes sense; however, it is unclear what will qualify as core training. For example, are the 245D training requirements for a designated coordinator sufficient to meet the core training requirements for someone who is responsible for developing, implementing, monitoring, supervising, or evaluating positive support strategies?
Subp. 1		There is no definition given to the requirement of a qualified trainer. How are agencies to determine whether a trainer meets the definition of a qualified individual?
Subp. 2		Do the 245D training requirements for Direct Support Professionals (DSPs) fall under "Previous equivalent training approved by the commissioner?"
Subp. 2		Does "Prior to assuming these responsibilities" mean that these trainings must be completed before a staff person works alone with someone receiving supports? While many of the training topics are already covered for most employees, it has not been standard practice to require staff to complete training on all of these topics prior to providing supports to people (i.e., assuming their role). As an agency we have learned over time that employees do not retain the information from training when a large amount of training is completed prior to having any opportunity to practice what they have been trained on. Adding these training requirements to the 245D training requirements that must occur before an employee is able to work alone may create a situation where employees are not able to retain all of the information that they have been trained on. In addition, as an agency it will take a great deal of personnel resources in order to meet these new training requirements.
Subp. 2	Item A-E	For each item, four hours of additional training are required and required topics of training are listed. Is there a necessity to require an arbitrary number of hours of trainings when topics are specified and competency testing is required?
Subp. 2	Item A&B	Based on 9544.0020 Subp. 12 and 9544.0030 Subp.1 it is unclear what the distinction between Item A and Item B is. It is our understanding that any staff that would meet the criteria for Item A would automatically meet the criteria for Item B and vice-versa. Specifically, under 245D are there service types where a direct support staff (Item A) would not be someone who implements positive support strategies (item B)?

Comment on Proposed Positive Supports Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'l Services, Inc.	

PART 9544.0090 STAFF QUALIFICATIONS AND TRAINING CONT.

Subp. 2	Item A	(3) & (4) These two items pertain specifically to positive support transition plans. Are staff who do not implement positive support transition plans required to be trained on these items?
Subp. 2	Item B	(1) What are the specific principles of positive support strategies that providers are expected to train on?
Subp. 2	Item C-E	Is the expectation that providers create these trainings and maintain experts on staff or will the state provide external resources to license holders who do not have the capacity or resources available?
Subp. 2	Item E	What is the intent of requiring license holders, executives, managers, and owners in nonclinical roles to complete four hours of training each year on items 1-6? Who would be responsible for providing this training? Would conducting the training count as training hours? Often executives and managers are the experts in these areas, so if conducting the training doesn't count where would they get the training? How does an agency determine which roles are expected to meet this training requirement (e.g., Does the Accounts Payable Manager or the Chief Financial Officer need to meet these annual training requirements)?
Subp. 4	Item C	In reading Item A, it sounds like it is referring to all positive support strategies; however, this section makes it sound like Item A is only referring to a Positive Support Transition Plan. Does item A apply to all positive support strategies or only to Positive Support Transition Plans? If Item A refers to all positive support strategies, does the wording of C mean that staff are not required to demonstrate competency if changes are made to a positive support strategy that is not part of a Positive Support Transition Plan?

Comment on Proposed Positive Supports Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'l Services, Inc.	

PART 9544.0100 DOCUMENTATION AND RECORD REQUIREMENTS

Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 3		<p>Tracking progress or lack of progress specifically on quality of life indicators is a new requirement of this rule for 245D providers. Are providers required to distinguish outcomes that are quality of life indicators from other outcomes in their person-centered plan?</p> <p>How as providers do we reconcile the requirements to document goals around quality of life indicators with a person's request that a provider does not get involved with their quality of life goals? For example, an individual receiving ILS services 4hrs a month to assist with paying bills does not want the provider to work on quality of life goals. In some cases, these individuals may even be offended by asking them to work on quality of life goals as to them it suggests their quality of life needs improvement.</p> <p>When providing 245D basic services, a provider may not be assigned the responsibility of working on goals with the individual (e.g., respite). In this situation, under the current language of the PSS rule it is unclear if the documentation requirements regarding outcomes and quality of life indicators are applicable.</p>

PART 9544.0110 REPORTING USE OF RESTRICTIVE INTERVENTIONS AND INCIDENTS

Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
	Item E	<p>Mains'l Services supports the recommendation from the Minnesota Disability Law Center to add language to this section requiring the commissioner to review and respond to each behavior intervention reporting form (BIRF) within 30 days as well as report on how many BIRFs are submitted and the number of people that are the subject of BIRFs.</p> <p>It seems that for Item E, the Behavior Intervention Reporting Form (BIRF) is being used solely as a reporting function. Given that, are the reviews that typically follow a BIRF still required?</p>

Comment on Proposed Positive Supports Rule

Name of Person Submitting:	Matt Newquist	Date: 3/13/15
Organization	Mains'l Services, Inc.	

PART 9544.0120 QUALITY ASSURANCE AND PROGRAM IMPROVEMENT

Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
		This section provides a very vague mandate. It is unclear if this applies to all organizations or only organizations where positive support transition plans are being used. It is unclear how organizations are supposed to conduct the assessments or what specifically must be assessed. In addition, an every six-month evaluation and reporting for all licensed services would require a full time employee or more than one full-time employee for larger license holders. With the increased expectations on providers and the gradually decreasing rates, it seems that providers are heading toward a point where service provision may no longer be financially viable.

PART 9544.0130 EXTERNAL PROGRAM REVIEW COMMITTEE

Subpart	Item	Comment
Example: Subp. 2	Example: Item B	The description of your comment.
Subp. 3		Mains'l Services supports the Minnesota Disability Law Centers comments regarding the need for DHS to allow an exception for the use of auxiliary seat belt devices. They make many excellent points regarding why DHS needs to allow the addition of the exception.
Subp. 3	Item A	Mains'l Services supports the Minnesota Disability Law Centers comments regarding the need for "the emergency use of procedures exception" to be available to individuals who have not needed a positive support transition plan (PSTP) in the past, but need a PSTP now due to a significant change in condition.
Subp. 4		Mains'l Services supports and emphasizes the importance of the following points that the Minnesota Disability Law Center makes when commenting on this section. "However, the PSS Rules lack sufficient detail on how the EPRC will function." "Similarly, the PSS Rules do not establish any criteria for how the EPRC will review a license holder's response to the emergency use fo manual restraint." "A clear regulatory framework is needed so that providers and service participants understand when emergency procedures can be used." "... the PSS Rules must allow individuals with developmental disabilities the ability to participate in the EPRC process." "DHS should advocate for additional funds in the budget to cover the cost of additional EPRCs."

Sullivan Hook, Karen E (DHS)

From: Joe Fuemmeler <joe@chrestomathyinc.org>
Sent: Friday, March 13, 2015 4:25 PM
To: *OAH_RuleComments.OAH
Subject: Positive Behavior Supports Rule comments
Attachments: Rule comments 3-13-15.docx

Please see the attached comments on the Positive Behavior Supports Rule.

Thanks,

Joe Fuemmeler
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March 13, 2015

The Honorable Judge Eric Lipman:

Chrestomathy respects the efforts of those contributing to the creation of the Positive Supports Rule and its intent to improve the lives of people with disabilities. As a provider, we been working for many years with Positive Behavior Supports, Person Centered Planning, and other evidence-based practices to minimize the use of restrictive interventions and improve the quality of life for the people we serve.

There were several areas of the Rule that the **Minnesota Disability Law Center (MDLC)** highlighted as needing revision in the comments they submitted, and we would like to offer out comments supporting theirs and clarifying the impact of the new Rule as a provider. Making changes in the Rules does not come without costs, and it is important that the resources of time, money, and effort go as much as possible to support the improvement of the lives of the people we serve. It is extremely important that the State of Minnesota understand these costs clearly so that they can provide resources to support providers in creating necessary changes, and avoid changes that provide more burden than benefit to those trying to create a better life for people with disabilities.

The Statement of Need and Reasonableness is deficient because DHS failed to make reasonable efforts to ascertain information on both the probable cost to the agency and to licensed providers, as required by Minnesota Statutes, section 14. 131(2), (5).

MDLC was asked if they knew the cost to a provider could exceed the estimate of "just over \$30,000 in the first year" for a provider with over 100 residents. MDLC did not have numbers, but that only one provider was consulted by DHS, and that more should be consulted.

For providers who have knowledge and experience in serving individuals with challenging behavior, these costs tend to be larger, and the regulatory requirements for reporting and documenting more difficult to manage, as there are more people who are affected by them receiving services from us. The intense needs of these clients leads to a larger staff, and more people to train. There is an exponential difference in the burden on providers who take up the challenge of trying to integrate those individuals who have the most difficulties.

Some areas of cost would include:

Training -The cost of additional training required for new staff (staff hours times number of staff hired each year)

- The in-house trainers' hours for developing and providing trainings to all staff on new mandated subjects. (or an outside trainer's cost)
- The cost for staffing to cover the rooms while staff are being trained. (Number of hours per staff x number of staff)

Support

- The cost of enhanced staffing ratios used when dealing with crises to safely reduce usage of EuMR's and/or PSTP's--in one case, arm braces (over 4 hours a day of 1:1) for that client.
- This would include adding a staff to support van routes without holds (for several of our clients), time spent handling client behavior without holds by providing 1:1 counselling or opportunities to separate from the group, and including time spent waiting clients out who refuse to move (several of our clients) and get 1:1 support.
- The cost of supporting clients adequately at community jobs (Several of our clients have had behavioral incidents requiring 1:1 coaching)
- All of these costs either requiring hiring more staff to cover or replacing staff who are leaving due to "burnout" from extra work.

PSTP

- The hours required to set up a meeting, meet with the team, and to develop and review the PSTP every 90 days, as opposed to annual meetings
- The hours required to collect and process data for the PSTP
- The cost of providing more training on a new PSTP and following any changes made to them (Number of hours per staff times number of staff)

Reporting

- The hours spent collecting information for BIRF forms talking with teams and entering the forms themselves (# of BIRFs times average time for submission)

Also to be considered are the unintended consequences of the Rule that result in the shifting of participants from providers who are increasingly unwilling to work with interfering behaviors to providers who are. This concentrates the known costs and risk in programs such as Chrestomathy. We have already seen an increase in referrals of clients with needs for intensive supports. If providers such as ourselves are expected to accommodate the influx of people with greater needs, they will increase their exposure to costs related to the above support, PSTP, and reporting concerns as well as risk of injury, including higher insurance rates.

9544. 0110, fails to establish how the commissioner will process behavior intervention report forms.

The online Behavior Intervention Report Form is currently 7 pages long. The process for gathering this information and reporting is time-consuming and often involves several people, so we collect the information using paper forms before entering it. I would recommend a revision of the form by DHS and the Ombudsman's office after analyzing which parts of the form are of essential use to these agencies in tracking the use of these procedures and which could be kept just as a part of the individual's records by the provider. This would reduce wasteful and redundant documentation and facilitate compliance with reporting within the timeframes established in 245D.

It will be to the benefit of the people we serve if we are able to make documentation requirements in general more useful and less cumbersome. Additional funding for the hours spent on paperwork and reporting has not been provided, and the result of extensive paperwork requirements is to directly take away time spent involved with the client and time supervising/processing with staff after an incident. If providers are asked to shift their focus away from service provision to devote significant resources towards paperwork compliance that does not produce better outcomes, we are doing people a disservice.

The challenges of providing care that is responsive to the clients' needs, which may change suddenly, is difficult when hampered by a large list of things that must happen during a change in program plan. There is the consultation of the team, the FBA by qualified professional, possibly a PSTP, the training and competency testing of staff. All of this must happen while the person is still receiving supports, and alongside others with similar needs in the provider's care. This is not a responsive system, but rather one that is overburdened by requirements.

9544.0070, fails to establish criteria for the number of episodes of emergency use of manual restraint which require the development of a positive support transition plan.

The requirements around the development a PSTP make it challenging to use it in the way it seems to be intended. The requirement of starting one after 2 uses in a 365 day period can result in a lot of effort to set up a plan for an individual that may have been going through two unrelated events, months apart that would not need the systematic methods and data collection model of the PSTP. The additional effort directed to setting up a meeting with the others who support the individual to set up this additional plan would be better used in supporting the person through an acute crisis and getting back on track to their goals. It would be helpful to adjust this guideline so that PSTP's were set up for individuals who had more frequent holds in a shorter time period.

9544.0080, incorrectly requires informed consent in circumstances where such consent is not possible.

See the MDLC's recommendations.

9544.0020 DEFINITIONS

Subp. 25

The current definition of Mechanical Restraint includes devices that a person wears of their own choosing that help them resist the urge to self-harm. This does not give the individual the freedom to choose their own supports in managing their behavior in a way that they have identified as helpful for them. We have a man who has worn arm braces as a comfort item; he is able to put the braces on and even rotate them to allow normal flexing at the elbow. As we have tried to find alternatives, his SIB has increased, jeopardizing the vision in the one good eye he has; the other eye was damaged from repeated hits and has a detached retina. A balanced approach in the lives of people such as this man is advised so that their quality of life is not sacrificed in a rush to end anything that might look like a restraint.

I would also suggest that the use of passenger door safety locks that prevent a person from opening the passenger door from the inside, can be a non-intrusive way of ensuring safety with people with volatile emotions and impulse control issues are able to have access to the community. 2:1 staffing in transportation is not easily budgeted, and public transportation is not always available.

PART 9544.0090 STAFF QUALIFICATIONS

As a general comment in this section, the sheer volume of training areas and the requirements of competency testing is too large and broad to be of real use. Each provider may serve different populations with different needs, and having a long list of general training areas does not seem any more likely to produce the desired positive changes in services as letting service providers identify what is of key importance in their particular setting. It is important that the rules allow providers to be able to manage their own specific training needs without being steered to procure a "one size fits all" training from specific institutions by overly prescriptive rules.

Subp. 1, Item B

There are also many requirements around the implementation and review of a PSTP, including training that could lead to discouraging providers from serving clients with intensive needs. A decreasing number of willing providers may lead to the concentration of clients with PSTPs within the remaining providers, creating an abnormally large burden. Developing, training on, reviewing, and revising a PSTP for one person is a large

but manageable task; handling several simultaneously is extremely challenging. Reviewing at least every 90 days is also challenging for many guardians, case managers and other service providers; we have had difficulty with non-participation and delaying of scheduled meetings from guardians.

Also, the current rule appears to indicate that any staff who may perform some role in the implementation of a PSTP be trained and pass a competency assessment in that specific plan or revision before participating in it. A large training burden is likely to delay implementation and making changes to the plan. In a program with a sizable staff (we have over 30), any of whom might be called upon to help if there is an emergency, it would take a serious amount of time and effort to train, test and document them all, and very unsafe and limiting to prevent them from assisting in an emergency if they were not trained on the specific version of that specific person's plan. It would make more sense to specify that at least one trained and competent staff has to be present to ensure the correct implementation of the plan and that others may assist as directed.

Thank you for your attention to the concerns of persons with disabilities and the people who support them.

Sincerely,

Joe Fuemmeler
Program Director
Chrestomathy Center

Sullivan Hook, Karen E (DHS)

From: Lipman, Eric (OAH)
Sent: Monday, March 16, 2015 6:24 AM
To: *OAH_RuleComments.OAH
Subject: Minnesota Rules, Parts 9544.0005 to 9544.0140 DHS Restrictive Procedures

From: Kluka001 [kluka001@gmail.com]
Sent: Monday, March 16, 2015 12:21 AM
To: Lipman, Eric (OAH)
Cc: robert_klukas@yahoo.com
Subject: Minnesota Rules, Parts 9544.0005 to 9544.0140 DHS Restrictive Procedures

Dear Judge Lipman:

I read the hearing transcript and must agree in general that DHS's proposed rules are not reasonable in all respects as noted by the parents of autistic children and several professional care givers who pointed out that the rule does not allow providers to give reasonable and necessary care to each person because the rule does not recognize that each individual has specific needs. The proposed rule includes prohibitions against accepted care practices which are currently needed to help some persons in treatment.

As a person who worked on the rule for several years, it is sad to see that the rule has not fixed any of the short comings that were present when I left DHS in September 2014. DHS leadership continues to believe that one size fits all people in treatment. DHS leadership still persists in claiming massive public input into the proposed rule. However, DHS leadership intended to present the rule you have before you since it began rule writing activity in 2011. The so-called advisory group was run through the wringer of a consensus achievement process, not a public participation process that DHS has used for other rules it proposed. Lengthy meetings went on for months and parents of Jensen complainants and rural providers could not continue to spend entire days listening to the department's presenters explaining the care system from DHS's point of view. These legitimate committee members were filibustered by DHS management. The only people left to comment at the end were a few people who agreed with the direction DHS always intended to go.

In addition to a questionable public input process the rule documents have several problems. In no particular order those problems are as follows:

* In violation of MR 1400.2070, the Statement of Need and Reasonableness contains a rule making authority description which is too vague to be acceptable as a "citation". Failure to comply with MR 1400.2070 means that the Statement of Need and Reasonableness [SONAR] does not comply with MS 14.131, which requires that the SONAR meet the requirements of MR Chapter 1400. The vagueness or absence of a clear cite to rule making authority means that the public's ability to participate in the rule making process is impaired and the public has no ability to say whether the rule is within the legislative grant of rule making authority. No specific rule making authority cite was made in the usual place in the SONAR

* It does not appear that DHS made a reasonable effort to determine the cost of the rule to affected parties within and outside of government. DHS has been training providers about the implications of MS 245D for more than a year. Thus, DHS knows from its own experience about the costs of training providers about the proposed rules which will implement MS 245D. It could have readily asked the providers who attended training to say what the training they have received thus far cost each provider to receive and then extrapolated the costs of training to providers based upon the recent experience training providers about MS 245D. DHS's denial that it exceeded cost thresholds for the first year of rule

implementation should have been proven with reasonable effort. The SONAR is too vague about costs to allow a reasonable person to comment on DHS's cost claims during the hearing process.

* Part 9544.0020, subparts 16 and 46 deal with the definitions of "qualified professional". This definition contains vague requirements which are troubling for several reasons. The rule allows the department to establish requirements for professionally licensed people, although DHS has not specified the requirements that licensed professionals must have to be qualified. The commissioner has no authority to assess professionally licensed persons for some ill-defined special skills. Licensed professionals have to meet their licensing rules which were established by law and rule. The proposed rule prohibits licensed professionals from exercising their rights to lawfully practice their profession by the commissioner's use of an unspecified test that does not yet exist. In addition there is no specified due process by which a licensed professional can appeal a determination by the commissioner that the licensed person may not practice. The proposed rule is a licensing rule, but it is not a professional licensing rule that can be used to disqualify otherwise qualified persons. If the legislature wanted the commissioner of Human Services to do professional licensing standards, it would have done so. There is no professional licensing assessment authority in MS 245.8251. In addition there is no recognition that county employees have some rights and protections regarding job qualifications and hiring, which are established within the Merit System and its related laws and rules. Merit system rule making is governed by MS 256.012.

* It should be noted that the SONAR made no attempt to address the costs to the state or to qualified professionals of being assessed by the commissioner. Presumably the qualified professionals would have to be trained or schooled prior to taking the assessment. Although SONAR establishes classes of persons to be assessed by the commissioner in part 9544.0020, subpart 46, the SONAR does not do cost accounting for training these classes of professionals for the analysis required by MS 14.131, although these classes of professionals seem to be parties affected by the rule.

There are other problems with rule that I will not go into.

I hope that at a minimum, you consider the testimony of the good citizens who attended the hearing and requested that the proposed rule be changed to allow persons with disabilities to get the treatment that they need. You would not be out of bounds if you found the SONAR to be defective because of its pitiable lack of reasonable effort to determine the likely costs of the proposed rule.

Thank you for your consideration of my opinion and concerns.

Robert Klukas
Retired DHS Rulewriter