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STATE OF MINNESOTA
OFFICE OF ADMINISTRATIVE HEARINGS
FOR THE DEPARTMENT OF HUMAN SERVICES

In the Matter of the Proposed Rules
Governing Positive Support Strategies

OAH DOCKET NO. 8-1800-32056
REVISOR NO. R-04213

The Hearing in the above-entitled matter came on for hearing before Eric L. Lipman, Administrative Law Judge, taken before Marcia L. Evenson, taken on the 23rd day of February, 2015, at Elmer L. Andersen Human Services Building, 540 Cedar Street, St. Paul, Minnesota, commencing at approximately 9:00 a.m.

A P P E A R A N C E S

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2
3 APPEARING AS THE HEARING OFFICER:

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5 ADMINISTRATIVE LAW JUDGE
6 OFFICE OF ADMINISTRATIVE HEARINGS
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10 E-mail: Eric.Lipman@state.mn.us

11 ALSO PRESENT:

12 Karen Sullivan Hook
13 Alexandra Bartolic
14 Charles Young
15 Tim Moore

16 *The Original is in the possession of
17 Administrative Law Judge Eric L. Lipman.
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1 P R O C E E D I N G S

2 THE HEARING OFFICER: Good morning.
3 I'd like to ask folks to take their seats and if need
4 be, take the conversations to the hall for an on-time
5 start. I appreciate everyone joining us this morning.
6 My name is Eric Lipman, I'm an administrative law judge
7 with the Minnesota Office of Administrative Hearings.

8 The Office of Administrative Hearings
9 is an independent agency in state government. We're
10 independent of the Department of Human Services that is
11 proposing to adopt rules today and many of the groups
12 that are participating in the hearing today.

13 The role of our office is to provide
14 hearing services in cases of rulemaking proceedings just
15 like this hopefully in a way that's fair to all
16 participants.

17 We're here for a rulemaking hearing
18 in the matter of the Proposed Rules Governing Positive
19 Support Strategies, person-centered planning, limits on
20 the use of restrictive interventions, and emergency use
21 of manual restraint and repeal of rules governing
22 abusive and deprivation procedures.

23 These rules are in Minnesota Rules
24 Part 9525.2700 to 9525.28010. It's just after 9:00 a.m.
25 in the morning on Monday the 23rd of February, 2015.

1 And we've convened in Conference Rooms 2370 and 2380 of
2 the Elmer Andersen Human Services Building.

3 Among the other directions given by
4 the Legislature to the Department of Human Services, in
5 Minnesota Statutes 14.14 and 14.15, rulemaking hearings
6 are to be conducted so that members of the public are
7 treated impartially and fairly and welcomed.

8 Because we rely in Chapter 14 to
9 develop administrative rules on the wisdom of the group.
10 So, we're grateful that you're contributing to our
11 knowledge, our understanding, our insight, our
12 collective wisdom on the best types of administrative
13 rules that we can have in our state. So, thank you for
14 being a part of this enterprise.

15 I'm here as part of a larger set of
16 regulatory controls to ensure that people are treated
17 fairly and that we develop the best hearing and
18 rulemaking record that we can.

19 There's a handout on the table,
20 two-sided handout, very handy, it has lots of detail
21 about the rulemaking procedures. I'm not going to read
22 it word for word, I'm going to hit some of the
23 highlights in introduction right now.

24 If you don't have the handout, I
25 commend it to you. Lots of rich information about how

1 you can participate most meaningfully and effectively in
2 this process.

3 As I suggested, the hearing is part
4 of a process by which agency rules are adopted under the
5 Minnesota Administrative Procedures Act. The purpose of
6 this hearing is to develop and receive information on
7 the three key issues set out in the Minnesota
8 Administrative Procedures Act.

9 Namely, whether the agency has the
10 legal authority to adopt the proposed rules; whether it
11 fulfilled all of the legal and procedural requirements
12 in order to adopt those rules; and among the choices --
13 the regulatory choices that the Department had and the
14 possible alternatives for promulgating the rules, the
15 ones that finally set on in Revisor Draft 4213 are
16 needed and reasonable.

17 I refer to those items as the big
18 three. I'm going to just repeat them a couple of times,
19 the legal authority to adopt the proposed rules, whether
20 the agency has fulfilled all of the legal and procedural
21 requirements, and whether they demonstrated that among
22 the choices that they had, the rules that they proposed
23 are needed and reasonable.

24 I'm glad to give anyone who has
25 signed the roster the order in which we're going to be

1 receiving witnesses to make any comments that they'd
2 like.

3 What is most helpful, however,
4 mindful that my report is going to be focused on those
5 three things; authority, the compliance or not with
6 procedural requirements, and the reasonableness of the
7 choices that the agency made.

8 That if folks can aim those comments
9 in those areas, those will be the criteria that I will
10 be applying in a later report.

11 Again, I'm mindful that folks
12 participate in rulemaking hearings for lots of different
13 purposes and are speaking to many audiences, not
14 necessarily just me, the legislature, folks at the
15 county commission, the people in the trade association,
16 the agency, history, lots of other audiences.

17 If you're focused on the crafting of
18 this particular rule and the key features of this
19 proceeding, it's those items; the authority, the
20 compliance with procedural requirements, and the need or
21 reasonableness of the particular selection.

22 For today's agenda I'll complete the
23 explanation of the hearing procedure, then I'm going to
24 introduce our agency panel. They're here to make a
25 couple of presentations. They're going to be offering,

1 and they're set out in front of us here at the table
2 here, a series of exhibits that they say support their
3 particular drafting choices in the proposed rules.

4 And then we're going to take a short
5 break to allow folks who haven't had a chance to look at
6 the binder a brief opportunity to do so. Mindful that
7 those same materials are going to be posted to the
8 Internet on the DHS rulemaking page.

9 You can 24/7 in your pajamas at the
10 leisure of your house or wherever you have your chai
11 latte and look on the Internet, you can access these
12 documents, download them, they're all available for your
13 review. And there's a posthearing comment period, which
14 I'm going to talk about, where you can give your
15 reaction.

16 So, we want to have a chance for
17 folks to have a look at the exhibits, the physical
18 exhibits today. Mindful, they're going to be available
19 at the conclusion of this hearing on the web for your
20 own copies and for your later reflection and comment and
21 circulation amongst other stakeholders and a comment
22 period after that.

23 So, I'm hoping that this sort of
24 perusal will be brief so we can get to the main event,
25 which is to hear feedback and public comment from you in

1 this hearing.

2 In order to make sure that we have an
3 accurate record of the number of people attending the
4 hearing, I would be grateful if folks sign the roster,
5 whether they want to speak or not.

6 As an initial matter, I'm going to be
7 calling folks in the order that they signed in to speak
8 on the roster, if they designated checking the box that
9 they would like to be recognized.

10 Again, for clarity of the record,
11 we're going to ask folks to join us at the table down
12 here in order to give remarks. We tried to make it as
13 neighborly as possible to simulate presentations to the
14 library board or the planning commission or city
15 council.

16 You can talk neighbor to neighbor,
17 stakeholder to stakeholder, concerned Minnesotan to
18 concerned Minnesotan. And that's why we set up the room
19 in this particular way.

20 Also, having you nearby makes sure
21 that the agency panel can hear what you say and likewise
22 that our court reporter, Ms. Evenson, can understand
23 clearly what is being said and can ask you any questions
24 if you're either moving too fast or what you have said
25 has been unclear.

1 So, again, while it may be a little
2 bit intimidating, we don't mean to be, we tried to
3 structure the process and the setup so, again, it will
4 seem more neighborly, a conversation across the kitchen
5 table. So, we hope that folks will join us down here.

6 Much like the planning commission or
7 the local library board, you can feel free to hit the
8 highlights of your key claims, mindful that there's
9 somebody in line behind you with an absolutely brilliant
10 argument they need to get to.

11 You have a 20-calendar-day period to
12 write in after this hearing. So, you can go on as
13 lengthy as you would like, submitting whatever
14 refinements or extensions that you would like.

15 But rather than one particular
16 stakeholder run down the clock and miss the argument
17 that is on their side that is brilliant, captivating and
18 that we need very much is in line behind them, I'm going
19 to ask folks, at least for an initial round, to try to
20 limit their remarks to five or seven minutes or so.
21 Mindful that there's some great insight that the wisdom
22 of the group needs in line behind them.

23 I'm always the last person to leave
24 the room. We'll do subsequent rounds. If we've gone
25 through the roster and everyone who has wanted to be

1 recognized to give testimony has been recognized at
2 least once, my record is seven rounds, so we'll go round
3 and round and round, hearing from folks multiple times.

4 And obviously the length that we're
5 willing to give folks extends to the seventh round. If
6 you're here and still want to put items into the record
7 we're delighted for you to do that.

8 Again, for courtesy of the others and
9 for our effort to try and reach as many stakeholders as
10 we possibly can, if folks can just hit the highlights
11 first and we'll have those subsequent rounds and a
12 written round following this hearing.

13 Any speaker can ask questions of the
14 agency panel. And, likewise, it goes both ways, it is a
15 conversation in any direction. Witnesses who testify
16 can be asked questions by the administrative law judge
17 or members of the agency panel, neither side necessarily
18 has to answer.

19 That might be a clue of something
20 else. But you can raise questions, they may or may not
21 be helpful. They may raise questions and you may or may
22 not be helpful, depending upon how things go.

23 Because it's not like a court hearing
24 you don't have to make the points that you want by
25 asking questions of folks. You can state your own views

1 and go directly to the point and making sure that you
2 leave room for, as I said, other stakeholders.

3 With respect to Ms. Evenson's work
4 here, our court reporter, it's very important that you
5 speak clearly and slowly and loud enough for folks to
6 hear. It's important that your statements are clearly
7 spoken. The court transcript can't record a nod of the
8 head.

9 Also, if you'll notice to my left,
10 there is a conference call microphone set up. We're
11 being broadcast somewhere between zero and 300 callers
12 who have dialed in because of either travel or weather
13 constraints. The Department, DHS, has made this hearing
14 available by way of audio only to a toll free line.

15 And for the benefit of those folks
16 who may be listening to this hearing on the call, again,
17 we're grateful that folks come to the table, speak
18 clearly and slowly so that they can be understood and
19 heard.

20 Likewise, it's very helpful that only
21 one person can speak at a time, again, for clarity of
22 the written transcript, so we know what's happened. And
23 also, so the folks that are listening by way of audio
24 teleconference can benefit from what's being said.

25 Because of the international

1 convention on the humane treatment of court reporters,
2 we'll break every 90 minutes for a short break to allow
3 Ms. Evenson to change paper or to put her hands in ice,
4 as the case may be. And we'll structure lunch breaks
5 and afternoon breaks around our obligations in that
6 respect.

7 The first break obviously will be
8 closer to 90 minutes because we're going to have a break
9 to look at the hearing exhibits, but resume shortly
10 thereafter. And we'll go in 90-minute slots until the
11 end of the day.

12 I did want to make, because of the
13 nature of the hearing topic, another important
14 advertisement. Rulemaking comments on this particular
15 rule are comments that are in the public domain.

16 I know that they relate to the care
17 and cares for disabled people, but if it's medical
18 patient sensitive information and patient identifying
19 information, please think carefully about introducing
20 that into the public record, diagnosis information.

21 It may be relevant to the rule, but
22 these comments are in the public domain. Things that
23 are made at the public hearing are in the public domain.
24 There isn't any protective order. They're being
25 broadcast to whomever would like to join us on the audio

1 conference call.

2 They may well be available, this
3 hearing, by MP3 file on the Department's website later.
4 So, we're very much in a public setting. I think we can
5 inform the record about case specifics, not necessarily
6 with using patient identifying information.

7 So, if you have a sensitive
8 diagnosis, even in the written comments, you're not just
9 writing to me, it is in the public domain.

10 I will tell you that DHS will make an
11 effort to contact stakeholders to say did you really
12 want to put the diagnosis about your brother Fred in the
13 public domain in your rulemaking comment before we post
14 that to the web.

15 But the system is not perfect and
16 it's very staff intensive. So, people should just
17 assume because of the nature of the topic what we're
18 saying is in the public domain. Everybody clear about
19 that? Great.

20 Let me talk about the posthearing
21 comment period. We are going to have a posthearing
22 comment period of 20 calendar days. Because the 20th
23 calendar day falls on a Sunday, we go to the next
24 business day, which is Monday, March 16th.

25 You can write in whatever comment you

1 would like or anyone within your Outlook network,
2 anywhere in your staple or mailing list, anyone active
3 in your Cub Scout group, your church group, whatever,
4 they don't need to be here, anywhere on the globe, we
5 truly rely upon the wisdom of the group, can send in and
6 write in comments.

7 However, the rule is they have to be
8 received by 4:30 p.m. on Monday, March 16, 2015. If
9 they're after 4:31, they're late. 4:30 p.m. on Monday,
10 March 16, 2015. We have a special dedicated rulemaking
11 e-mail, which is on the handout, and also my contact
12 information about where to send those comments.

13 Again, by 4:30 p.m. on Monday,
14 March 16, 2015. Those materials will be bundled late
15 Monday evening and early Tuesday morning and posted to
16 the DHS website.

17 We'll have a five-calendar-day
18 rebuttal for new material -- not new material, things
19 which have already been said, not new material, not new
20 material, rebuttal, X stakeholder said Y thing in the
21 first round of comments, that's not true because.

22 But it's not I should have said
23 before, I'm raising a new topic. We're responding only
24 to the things that have been said before by the agency
25 or another stakeholder. And that comment period goes

1 for five business days, will close on Monday, March 23,
2 2015, Monday, March 23, 2015. And again, ends at 4:30
3 p.m. on that particular day.

4 After that second deadline passes,
5 I'll prepare a written report, which will contain my
6 decisions about whether the agency has met the burdens I
7 discussed earlier, demonstrates statutory authority,
8 fulfilled all the relevant legal and procedural
9 requirements, demonstrated the need and reasonableness
10 for each portion of the proposed rules.

11 If you'd like a copy of that report,
12 put your name on one of the envelopes. Do a
13 self-address, YOU don't have to stamp it, we'll send you
14 a notice later. But if you put your address on one of
15 those envelopes and leave it for me either on the table
16 or in the folder, we'll make sure we send you a notice
17 when that report is available.

18 Lastly, I should have mentioned it
19 before, there are two key numbers in this case that are
20 useful in making reference to any of the comments or
21 other materials that you'll send in. They are the OAH
22 Docket Number 8-1800-32056, 8-1800-32056, that's the OAH
23 docket number. That's very handy if you put that on
24 comments.

25 There's an even more powerful, more

1 important number than that, which is the revisor number.
2 The revisor number, as part of an interagency agreement,
3 is used by all agencies in the Minnesota state
4 government, both executive and legislative.

5 Even the governor has abandoned his
6 own tracking number, now uses the revisor number. The
7 revisor number is on the draft of the proposed rules,
8 it's R-4213, R-4213.

9 So, if your e-mail or your written
10 correspondence or your fax or YouTube video, your
11 Instagram hash tag, whatever, however you send in your
12 comments reflects those numbers, we'll make sure we
13 route it to the right place.

14 Anyone have any questions about what
15 we're doing today or the procedures that we're going to
16 be using in today's hearing? I know I talked long.
17 Seeing none, Counselor, if you wouldn't mind introducing
18 yourself, stating and spelling your name for our record.

19 MS. SULLIVAN HOOK: Karen Sullivan
20 Hook, last name is S-u-l-l-i-v-a-n, H-o-o-k. I am the
21 administrative law advisor for the Minnesota Department
22 of Human Services.

23 THE HEARING OFFICER: Did you want to
24 start the presentation?

25 MS. SULLIVAN HOOK: Thank you.

1 First, a couple of housekeeping items. If anyone is
2 looking for the restrooms, if you leave the building,
3 turn to your left, go to that yellow wall at the end of
4 the hallway and follow the signs, there's signs down
5 there. The restrooms are actually right behind us here.

6 Also, there's a few vending machines
7 behind that same yellow wall, leave this room, turn to
8 the left, go to the yellow wall, walk around the wall
9 and there's a couple of vending machines back there if
10 you need something to drink.

11 As Judge Lipman mentioned, the agency
12 has a number of exhibits that we are submitting today.
13 They are available in these binders (indicating).

14 There are actually three copies of
15 the binders available to look at today, the one on the
16 table there (indicating), there's a copy on the table
17 back by the door, and then I have this copy here on the
18 table during the break in case, just to make it easier
19 for people to access.

20 Those exhibits include all of the
21 documentation of the fulfillment of the legal and
22 procedural requirements that the Minnesota
23 Administrative Procedures Act requires the agency to go
24 through.

25 The first exhibit, Number 1, is the

1 request for comments that was published in 2012.

2 Number 2 is the request for comments that was published
3 in 2013. Number 3 is actually two documents regarding
4 the request for comments that was published in August of
5 2015 -- excuse me, August of 2014.

6 Number 4 is the Revisor's certified
7 version of the proposed rule. Number 5 is the statement
8 of need and reasonableness. And I should mention that
9 both of those documents, the proposed rule and Statement
10 Of Need And Reasonableness, are available at the back of
11 the room, if you haven't gotten a copy of those.

12 Exhibit Number 6 is the certificate
13 of mailing of the statement of need and reasonableness
14 to the legislative reference library.

15 Number 7 is two documents relating to
16 the additional notice plan, first the letter that was
17 sent to the Office of Administrative Hearing, requesting
18 approval of that plan and, second, the order from Judge
19 Lipman approving the additional notice plan and the
20 notice of hearing.

21 Exhibit 8 is two documents, the
22 notice of hearing that was signed by the agency on 7/15
23 and the notice of hearing as published in the state
24 register in December of 2014.

25 Exhibit 9 is seven documents that are

1 related to the mailing of that notice of hearing, the
2 certificate of accuracy and the number of certificates
3 that detail how the notice went out as required by
4 statute.

5 Exhibit 10 is two documents, the
6 first is a letter to Judge Lipman regarding the need to
7 published an amended notice of hearing due to an error
8 in that first publication. And the second is a letter
9 from Judge Lipman memorializing the Court's decision
10 regarding a timeline issue due to that error in
11 publication.

12 Exhibit 11 is two documents, first
13 the amended notice of hearing as signed by the agency,
14 and second, the amended notice of hearing as published
15 in the state register.

16 Exhibit 12 is a number of 11
17 documents related, again, to mailing that amended notice
18 of hearing. So, it's the same certificates plus a
19 couple more that relates to giving notice of that
20 amended notice of hearing.

21 Exhibit 13 is four documents that
22 relates to the statutory requirement for the agency to
23 give notice to the legislature and to the legislative
24 coordinating council.

25 Exhibit 14 is a letter -- two

1 documents, a letter from the agency to Minnesota
2 Management and Budget and then the letter back from
3 Minnesota Management and Budget regarding their review
4 of the rule.

5 And, finally, Exhibit 15 is the
6 public comment that has been received since the
7 publication of notice of hearing up through Friday. And
8 Judge Lipman noted that these exhibits will be available
9 on our public website. And we will continue to add the
10 public comment that comes in through today and as the
11 comment period goes forward.

12 So, I would submit and offer those
13 exhibits into the record at this time.

14 THE HEARING OFFICER: They're
15 received.

16 MS. SULLIVAN HOOK: There is one
17 change that the Department intends to make to the rule
18 and there's a single sheet available on the back counter
19 as well detailing that. It's a typographical error on
20 Page 10, Line 6, the proposed rule uses the word
21 "country" when it should be "county." So, we intend to
22 fix that error.

23 The rulemaking process, as Judge
24 Lipman described, is really designed to gather public
25 input. And Minnesota Department of Human Services

1 values that input and the participation of the public.

2 So, I want to thank you for being
3 here today and for the contributions that you've already
4 made and that you will continue to make to making this a
5 better rule.

6 This rulemaking does go back a few
7 years. The first request for comments was published
8 back in January of 2012. Around that same time the
9 agency convened a group called the Rule 40 Advisory
10 Committee.

11 Now, as many of you in this room
12 probably know, Rule 40 is the rule that's already in
13 existence and has been for many years that govern the
14 use of aversive and deprivation procedures. And that is
15 the rule that DHS is tasked here with what they're
16 calling modernizing.

17 Part of that modernization is to stop
18 calling it Rule 40. So, you will be hearing us refer to
19 it as the Positive Supports Rule. The Positive Supports
20 Rule is intended to replace Rule 40.

21 But just so there's some clarity
22 there between those two. And the group that was
23 convened back in 2012 at that time was still called the
24 Rule 40 Advisory Committee.

25 That committee was comprised of a

1 variety of persons with interest in the topic area,
2 including experts in the field, advocates, and persons
3 receiving services. That committee was active for 18
4 months and it produced detailed recommendations for
5 reforming the rule.

6 The proposed rule that we present
7 today closely adheres to the recommendations of that
8 advisory committee. As the agency developed the
9 proposed rule, we continued to consult with experts,
10 both inside and outside the agency.

11 We also published two additional
12 requests for comments, one in August of 2013 and then
13 again in August of 2014. Finally, last fall we held
14 seven informal public input sessions.

15 We made these sessions available
16 across the state by video conference and by Internet
17 streaming and we publicized them broadly to all types of
18 services, programs, facilities, advocates, and
19 individuals who will come under the purview of the rule.

20 The public input that we received
21 from those processes over that period was seriously
22 considered and was incorporated as possible and
23 appropriate into the rule as it stands today. The
24 agency has met all of the relevant legal and procedural
25 requirements to promulgate this rule.

1 And the exhibits submitted here today
2 demonstrate that all publication and notice of
3 requirements, including the additional notice plan
4 approved by Judge Lipman, have been carried out and that
5 the agency has met its burden with respect to the
6 requirements of the Minnesota Administrative Procedures
7 Act.

8 I'm going to turn it over now to Alex
9 Bartolic to talk a little bit more about the policy.

10 THE HEARING OFFICER: Madam Director,
11 if you could introduce and state and spell your name for
12 our record.

13 MS. BARTOLIC: Thank you. My name is
14 Alex Bartolic, B-a-r-t-o-l-i-c. I am the director for
15 the Disability Services Division at the Department of
16 Human Services.

17 Minnesota is joining states across
18 the country that are embracing evidence-based,
19 person-centered, positive support strategies and
20 improving the quality of life for people who use our
21 services.

22 We're committed to implementing these
23 policies and practices and ensuring that Minnesotans who
24 are served through our licensed programs are served with
25 dignity and respect.

1 Our field has learned a great deal
2 about the limits of practices that may gain immediate
3 compliance, but they may also cause physical or mental
4 pain or emotional distress. They may stop a person from
5 doing something, but they're not necessarily teaching
6 that person what to do.

7 Evidence has demonstrated that
8 positive support strategies are able to teach people new
9 skills and sometimes substitute behaviors and strategies
10 to be able to allow that person to generalize behaviors
11 over time.

12 Like other states before us, we're
13 adopting and requiring person-centered planning and
14 positive support practices as a model for service and
15 we're prohibiting the use of restrictive interventions,
16 such as restraints and seclusion, which can be
17 dangerous, punitive, and inappropriate for use in
18 community centers.

19 The federal government recognizes
20 this as well and has issued a Medicaid funded home and
21 community-based services rule that requires states to
22 implement person-centered practices and provide very
23 detailed explanation and conditions if any use of
24 restraints or seclusion is even considered.

25 The Department of Human Services

1 agreed to modernize our practices and develop a positive
2 supports rule as part of the 2011 Jensen settlement.
3 The Jensen lawsuit alleged unlawful restraint of persons
4 with disabilities in a Department run facility.

5 The Department agreed to modernize
6 the rules that previously governed restraint and
7 seclusion as an important step to ensure that our
8 services reflect best practices. This rule is the
9 result of that commitment.

10 The advisory committee established by
11 the Department to provide recommendations for the new
12 positive support rule also informed 2012 and 2013
13 statutory changes in licensing standards.

14 These standards require positive
15 support strategies and established restrictions and
16 prohibitions on the use of aversive and deprivation
17 procedures. The new provider standards and this rule
18 covers services across disabilities and all ages.

19 This is not just for people with
20 developmental disabilities, it also includes services
21 for people with mental illness or brain injury or
22 someone with dementia who is served by a Department
23 licensed program. This rule builds on the statutory
24 framework that was already established with the new
25 licensing standards.

1 Adoption of this rule and
2 requirements do set a standard. However, we recognize
3 that across our system providers have varying levels of
4 capacity and expertise in actually implementing and
5 applying those positive supports.

6 The Department has a positive support
7 community practice that engages providers all across the
8 state. And we're also launching a similar community
9 practice for case managers.

10 We've contracted with the University
11 of Minnesota to conduct training on person-centered
12 training, person-centered thinking and to work with
13 cohorts of providers in order to build skills and
14 expertise in the area of positive supports.

15 The university is also developing
16 tools and a website as a reference that can provide
17 information, training and other resources. Our goal is
18 to have a one-stop shop.

19 We want to know that providers and
20 families and anyone interested can go to this website
21 and get the information they need to understand the
22 requirements, to understand resources available and to
23 be able to apply them.

24 Minnesota's Olmstead plan also
25 includes strategies to increase positive supports and

1 eliminate the use of restrictive procedures. The
2 development of an Olmstead plan was agreed upon as part
3 of the Jensen settlement.

4 The plan describes how Minnesota will
5 meet our obligations under the Americans With
6 Disabilities Act to ensure that people with disabilities
7 receive services in the most integrated setting.

8 Minnesota's plan is unique compared
9 to other states. And at this point covers services for
10 people with all types of disabilities, covers people of
11 all ages and it requires all state agencies to work
12 together in order to ensure its implementation.

13 As part of our Olmstead plan we
14 created a statewide person-centered positive support
15 plan. This plan includes the creation of a training and
16 technical assistance infrastructure for positive
17 supports and data-based decision-making.

18 This statewide plan is a
19 collaboration between the Departments of Education and
20 Human Services. And as we learn more we will be able to
21 expand as applicable across other state agency services.
22 It applies evidence-based strategies to affect systems
23 change.

24 We want individuals to learn how to
25 use it and we want to make a difference in particular

1 services, but mostly we want to create a culture change
2 and a systems change in order to improve the quality of
3 life for Minnesotans with disabilities.

4 I'm going to turn it over now to
5 Charles Young, who is our lead for positive supports
6 rule and to talk more about the rule itself.

7 THE HEARING OFFICER: Mr. Young, if
8 you wouldn't mind stating and spelling your name for our
9 record.

10 MR. YOUNG: My name is Charles Young,
11 last name is spelled Y-o-u-n-g. I'm the positive
12 supports lead for the Department of Human Services
13 Disability Services Division.

14 As in our effort to show the need and
15 reasonableness of this rule, I'm going to provide a
16 brief summary of what the rule will do for license
17 holders, where the content came from and discuss the
18 areas that DHS is aware of that may raise questions and
19 comments here today.

20 THE HEARING OFFICER: Mindful,
21 Mr. Young, that folks tend to read faster than they
22 speak. And out of courtesy for Ms. Evenson and for the
23 later transcript, just be mindful of that. Mr. Young.

24 MR. YOUNG: I am a fast talker.

25 THE HEARING OFFICER: Which is

1 ordinarily a great skill.

2 MR. YOUNG: Take it as you will, I
3 guess. I'd like to start off by explaining how this
4 rule would fit with the existing regulation that governs
5 the treatment of persons with disabilities.

6 Most regulations inform caregivers
7 already what not to do in situations. Notably, the
8 Vulnerable Adult Act protects vulnerable adults, which
9 includes persons with disabilities from abuse, neglect,
10 and exploitation.

11 Use of aversive or deprivation
12 procedures, unreasonable confinement, and the
13 involuntary seclusion in many cases is already
14 considered to be a form of maltreatment under this act.
15 The Maltreatment of Minors Act protects all minors from
16 very similar practices as well.

17 Both the Vulnerable Adult Act and the
18 Maltreatment of Minors Act instructs caregivers what not
19 to do. While many versions of punishment are already
20 considered abuse under these acts, certain procedures
21 have been allowed of they could be considered
22 therapeutic or reasonable.

23 Not all uses of aversive or
24 deprivation procedures are considered maltreatment. In
25 determining whether an accident is maltreatment, the

1 investigating agency, in our case it would be the DHS
2 licensing division, must consider factors such as
3 whether the use of procedures could or reasonably be
4 expected to produce physical pain or injury or emotional
5 distress.

6 Also to be considered is whether the
7 use represents an accident or a therapeutic conduct.
8 Both accident and therapeutic conduct are defined in
9 statute.

10 And additionally, while an accident
11 may be prohibited, it might not be determined to be
12 maltreatment if the investigation determines the
13 incident represented an error in the provision of
14 therapeutic conduct by an individual.

15 Therapeutic conduct is defined in the
16 Vulnerable Adult Act as the provision of program
17 services, health care or other personal care services
18 done in good faith in the interest of the vulnerable
19 adult by an individual facility or employee or person
20 providing services in a facility under the rights,
21 privileges, and responsibilities inferred by state
22 license certification registration.

23 So, if the condition of a license
24 allows for seclusion, for instance, secluding could be
25 utilized by a license holder under certain conditions

1 without that being considered maltreatment.

2 However, the scope of this rule will
3 impact the Department's determinations, as I'll discuss
4 more in a moment. Much has changed in recent decades in
5 our view of what types of punishment may be considered
6 therapeutic.

7 Spanking, using a switch, rapping
8 rulers on knuckles, time-out rooms, all of these
9 practices were once considered to be a therapeutic
10 practice that taught people how to behave. But over the
11 course of the last few decades we've come to learn more
12 about the side effects of punishment techniques.

13 While it's been known for sometime
14 that punishment techniques can be useful for putting an
15 immediate end to a problem behavior, we now know that
16 punishment does not appear to teach skills or have
17 long-term behavior benefits.

18 Punishment can be shaming, has great
19 potential for abuse by caregivers, can escalate
20 behavior, can create new or unwanted behavior and arouse
21 emotions on both the punisher and the punished. It can
22 harm therapeutic relationships and ultimately only
23 teaches a person about power.

24 Punishment teaches that powerful
25 people get to hurt less powerful people. We now know

1 that parents who were abused as children are more likely
2 to become child abusers themselves.

3 The Minnesota Maltreatment of Minors
4 Act was created in 1975. The Vulnerable Adult Act was
5 created in 1980. The rule we are here today to replace,
6 Rule 40, which governs the use of a person in
7 deprivation procedures to persons with developmental
8 disabilities, was promulgated in 1987.

9 While these laws had been amended
10 since their inception, for the most part they again
11 inform caregivers what not to do and were based upon
12 most likely the best knowledge we had at the time of
13 what constituted therapeutic treatment or conduct.

14 We now know that certain techniques,
15 which the draft refers to as positive supports
16 strategies, are more effective in teaching appropriate
17 skills and reducing challenging behavior in the long
18 term. Positive support techniques are more likely to
19 generalize in many settings any reduction in challenging
20 behavior achieved.

21 We now know that it is more important
22 to teach a person what to do rather than what not to do.
23 And in that light we're doing the same with this rule.
24 The Jensen lawsuit brought to life the use of
25 potentially abusive practices in the state run

1 facilities.

2 As one of the conditions of the
3 settlement agreement the Department of Human Services
4 agreed to bring together a group of experts to advise
5 the Department on how to modernize the rule that govern
6 the use of aversive and deprivation procedures,
7 practices I'll refer to as punishment procedures for
8 persons with a disability served by a DHS licensed
9 provider.

10 The draft presented here today is
11 meant to reflect the recommendations of the Rule 40
12 Advisory Committee. This rule is also meant to work in
13 tandem with other existing laws governing the use of
14 abusive practices and restrictive interventions used to
15 maintain safety.

16 It is meant to build on the
17 regulation of the Vulnerable Adult and Maltreatment of
18 Minors Act to inform caregivers what not to do in some
19 cases, but also to tell them what to do when working
20 with persons with challenging behavior.

21 Some of the Rule 40 Advisory
22 Committee recommendations have found their way into the
23 statute already and are not replicated here in the
24 draft. One of their more notable recommendations that
25 found its way into the statute is the scope of the rule.

1 The advisory committee advised that
2 their recommendations be placed in Minnesota Statutes
3 245A so that it would have broad application to all DHS
4 licensed program settings.

5 The Minnesota legislature, for its
6 part, placed the scope in Minnesota Statutes 245.18251.
7 Nevertheless, the broad scope is still meant to apply to
8 all DHS licensed programs and services.

9 Some of the hardest decisions the
10 Rule 40 Advisory Committee had to make centered around
11 the use of procedures like manual restraint, which can
12 be used as both punishment and as a safety technique.
13 They heard that these restraints are sometimes necessary
14 to protect someone from imminent danger.

15 The difficult thing to determine was
16 how often safety interventions could be used before we,
17 the Department, should require more extensive planning
18 to diminish the use of those techniques when we are
19 planning and maintain oversight of those services.

20 Another tough decision that they had
21 to make was determining at what point the excessive use
22 of safety techniques was used in an attempt to punish
23 you.

24 The rule is meant to provide
25 additional clarification on techniques that are

1 prohibited, as well as provide directions to DHS
2 licensed caregivers on what to do when they're working
3 with an individual who exhibits challenging behavior or
4 interfering behavior as defined in this rule.

5 In summary, we believe the rule has
6 the following major effects. The first is on direct
7 service provision, the second on assessment and planning
8 process, the third, staff training requirements, and the
9 fourth has to do with reporting.

10 When it comes to direct service
11 provision, this rule will require the use of positive
12 support strategies, which in term prohibits the use of
13 discipline, restraint, punishment.

14 Specifically the hand restraint,
15 seclusion, time-out, aversive or deprivation procedures,
16 the problematic use of manual restraint.

17 We'll also require the use of
18 person-centered planning and in some cases multiple
19 behavior assessments when a person receiving service
20 exhibits challenging behavior. It will also focus on
21 improving a person's quality of life rather than working
22 to stop problem behaviors.

23 When it comes to reporting, there's a
24 number of reasons why reporting is included in this
25 rule. It will allow the Department to monitor the use

1 of potentially harmful practices, as well as incidents
2 that may occur in lieu of the safety of the individual.

3 This will allow DHS to monitor
4 provider and teams that may need assistance and to
5 ensure that persons who are receiving services are
6 receiving quality care.

7 As Karen noted earlier, we've edited
8 this draft through our stakeholders and community at
9 large. We've determined that a majority of comments and
10 concerns we have heard from our stakeholders has to do
11 with four topics.

12 The first topic is the scope of the
13 rule. As provided in Minnesota Statutes 245.8251, the
14 rule will apply to all facilities and services licensed
15 under Chapter 245D and all licensed facilities and
16 licensed services serving persons with a developmental
17 disability or related condition.

18 For the persons in this section,
19 developmental disability related condition does have a
20 definition within Minnesota rules. Basically this rule
21 will govern all providers licensed by the Department.
22 For 245D providers it will govern their service
23 provision to all their clients regardless of disability.

24 For all other license holders it will
25 govern service provision to persons they serve meeting

1 that definition of having a developmental disability or
2 related condition.

3 This complies with the State's
4 efforts to create a single set of standards as required
5 by the Centers for Medicare and Medicaid Services and
6 the conditions of the Jensen settlement and successive
7 comprehensive plan of action.

8 The scope of this rule is provided in
9 statute. So, we believe the issue of scope fell outside
10 the bounds of the rule writing process itself. The
11 authority was clear that the rule would ensure the
12 applicability of Chapter 245D prohibitions and limits on
13 the emergency use of manual restraints and on the use of
14 restrictive interventions to all facilities and services
15 governed by the rule.

16 The second issue that we encountered,
17 which is related to the first, is the prohibition on the
18 use of time-out when working with children. Further
19 conditions of the rule authority, the prohibitions of
20 245D were to be applied to the broader set of license
21 holders.

22 Time-out is considered a prohibited
23 procedure by Minnesota Statutes 245D.06, Subdivision 5.
24 And this prohibition is reiterated in the rule, Part
25 9544.0060. We do believe that part of the issue of

1 prohibition on time-out is that there are many kinds of
2 intervention that are used under the term "time-out."

3 What we've heard most often is that
4 time-out is considered a best practice when working with
5 children for teaching skills. This could be true
6 depending on what definition of time-out you're using.

7 And we believe that the definition of
8 time-out provided in 245D allows for the version of
9 time-out that is known for teaching skills. I'm going
10 to read the definition of time-out here.

11 "Time-out means the involuntary
12 removal of a person for a period of time to a designated
13 area from which the person is not prevented from
14 leaving. For the purpose of this chapter, time-out does
15 not mean voluntary removal or self-removal for the
16 purpose of calming, prevention of escalation or
17 deescalation of behavior, nor does it mean taking a
18 brief break or rest for an activity for the purpose of
19 providing the person the opportunity to regain
20 self-control."

21 We believe it's that last sentence,
22 the allowances in that last sentence that allows for the
23 version of time-out that we understand to be successful
24 and assisting people learn self-regulation when it's
25 used properly.

1 Nevertheless, even if this weren't
2 the case, the directive and statute was to apply the
3 prohibition of 245D to the license holders governed by
4 the rule. Additionally, the Rule 40 Advisory Committee
5 recommended that time-outs, as we've defined it, should
6 also be averted in technique.

7 And that's not an exhibit here, but
8 that can be found on Page 41 of their recommendations.
9 For those few purposes the definition from 245D was
10 applied to the treatment of all persons governed by this
11 rule.

12 The third major concern that we've
13 heard from the public is the effect that the rule may
14 have on the placement and care for persons who exhibit
15 self-injurious behavior.

16 Self-injurious behavior is a
17 situation in which restraints is almost always certainly
18 meant to protect the person from harming themselves.
19 For certain individuals self-injurious behavior may be a
20 symptom of their disability.

21 Persons with Pica, for example, can
22 exhibit behavior that places them in danger of harming
23 themselves. For these individuals, restricted
24 interventions, like rope prohibiting areas of the home
25 or using arm braces or helmets, are oftentimes

1 recommended in the short term while other strategies are
2 implemented to reduce these behaviors.

3 For these types of situations, the
4 rule does allow for the possible extended use of
5 restrictive intervention. For most individuals certain
6 providers would be able to use the procedure for up to
7 11 months if they have a plan in place. That plan under
8 the rule would be called a positive support transition
9 plan.

10 If after the 11 months had passed the
11 team has been unsuccessful in reducing the
12 self-injurious behavior and removing the restrictive
13 intervention and would appear to place the person in
14 danger of serious injury, the team could seek approval
15 from the External Program Review Committee to continue
16 using the intervention, including the positive support
17 transition plan while concerted effort to reduce and
18 ultimately eliminate the need for the intervention to
19 continue.

20 Interim Review Panel, which is acting
21 in the place of the External Program Review Committee at
22 the moment, is already offering technical assistance to
23 teams and we have heard positive results from this
24 process.

25 So, we believe that the issue of

1 persons who exhibit self-injurious behavior and whose
2 teams are unable to discontinue the use of restrictive
3 procedure in the allotted time has a solution in the
4 form of this External Program Review Committee.

5 The last issue of the draft rule,
6 which has drawn frequent questions, is that there
7 appears to be no room for a clinician to recommend the
8 use of a punishment technique.

9 Should a family or caregiver have
10 tried all positive strategies and have had no success in
11 diminishing the challenging behavior and then seek
12 clinical guidance, even a clinician cannot recommend the
13 use of procedures such as mechanical restraints,
14 seclusion or time-out to achieve immediate safety while
15 positive support strategies are developed.

16 Our response to that is that
17 intrusive and restrictive interventions are not
18 generally considered to be clinical interventions. We
19 would consider the services the Department licenses.
20 The purpose of these services is primarily to provide a
21 therapeutic environment and to teach a person skills.

22 Review of literature did not provide
23 evidence that the use of punishment or restrictive
24 interventions teach skills. Instead, punishment and
25 restrictive interventions appear to come with many

1 negative side effects.

2 Even if this weren't the case,
3 ultimately the Department was directed in statute to
4 apply the prohibitions of 245D to the license holder
5 governed by this rule. And the Department agrees to
6 adopt the recommendations of the Rule 40 Advisory
7 Committee.

8 Both these factors mean that the
9 Department's draft must include a prohibition on the use
10 of mechanical restraints, seclusion, et cetera.

11 So, even though this rule is meant to
12 provide caregivers direction on what to do when working
13 with persons who exhibit interfering behaviors, I
14 focused on the portion of the rule that tell caregivers
15 what not to do. For the most part these areas are where
16 we heard most of the public feedback.

17 But that said, I am going to pass the
18 presentation over to Dr. Tim Moore, a member of the
19 Rule 40 Advisory Committee and clinical director at
20 Minnesota Life Bridge and an expert on positive supports
21 to talk more about the process of developing the Rule 40
22 Advisory Committee recommendations surrounding these
23 positive supports.

24 THE HEARING OFFICER: Before you
25 begin, Dr. Moore, with your introduction and remarks,

1 let me ask, one of the key features that we have to
2 assess is the impact that the proposed rule would have
3 on licensees that have less than 50 employees, one of
4 the statutory criteria.

5 And I'm just wondering whether it is
6 in your experience that a 245D license holder is likely
7 to be an entity, an organization with more than 50
8 full-time employees or less?

9 MR. YOUNG: That is a good question.
10 I think I would have to defer to our DHS licensing
11 division.

12 THE HEARING OFFICER: Director, do
13 you have insight as to whether any 245D licensee is
14 likely to be more than 50 full-time employees or less?

15 MS. BARTOLIC: It's a combination.
16 There's certainly many large agencies that have more
17 than 50 employees and there are some who also are
18 smaller organizations.

19 THE HEARING OFFICER: Okay. Thank
20 you kindly. Dr. Moore, if you wouldn't mind stating and
21 spelling your name.

22 MR. MOORE: Tim Moore spelled
23 M-o-o-r-e. After I establish my credentials I'll make
24 brief comments on the critical nature of positive
25 supports, ensuring effectiveness of supports, and the

1 contraindications of punishment.

2 I'm a licensed psychologist in the
3 state of Minnesota and a board certified behavior
4 analyst. My academic training includes a master's
5 degree in applied behavior analysis from Northeastern
6 University in 2002. I was board certified as a behavior
7 analyst later that year.

8 My doctorate is in educational
9 psychology at the University of Minnesota where I
10 completed the degree in 2010. I'm was a licensed
11 psychologist in 2011.

12 My career began in 1996 at a
13 residential school in Massachusetts. We served children
14 and adolescent adults with developmental disabilities
15 and severe challenging behavior.

16 Our work at the time included the
17 best practices that we knew, which included proactive
18 and reinforcement-based procedures, but also restraint,
19 seclusion, and aversive procedures, such as privilege
20 restriction and response cost.

21 In 2003 I moved to Minnesota for the
22 purposes of home-based work. And I developed a
23 family-centered behavioral intervention program and
24 managed that program for ten years, where aversive
25 procedures were never recommended to families. We were

1 highly effective and that program remains in use in my
2 absence today.

3 In 2010 to 2013 I had a post-doctoral
4 appointment and eventual full-time employment at the
5 University of Minnesota Institute on Community
6 Integration. Among other things there I established a
7 training program and positive behavioral support and sat
8 on the Rule 40 Committee as a clinical expert.

9 In 2013 I took the position of
10 clinical director at Minnesota Specialty Health Systems
11 Cambridge, which is now Minnesota Life Bridge. There I
12 oversee or I oversaw the transition to a community-based
13 clinical program rooted in positive behavior support.

14 I currently maintain oversight over
15 the clinical work in that program, as well as the
16 clinical work in what we call the Successful Life
17 Project, where our team get in touch with and follow all
18 of the 300-plus Jensen settlement class members across
19 Minnesota.

20 My work also includes consultation on
21 cases throughout the state, direct care and treatment
22 division, as well as in the private sector, as we try to
23 stabilize living situations for people whenever
24 possible.

25 I've taught courses in applied

1 behavior analysis and family systems at the University
2 of Minnesota. I continue to contribute as a guest
3 lecturer in the medical school. I present frequently in
4 conferences and workshops locally and national.

5 And I've published several research
6 papers in peer-reviewed journals, recently co-edited a
7 positive behavior support brief published by the
8 University of Minnesota's Institute on Community
9 Integration, and co-authored a chapter on the assessment
10 and treatment of self-injurious behavior in a
11 publication of the American Academy of Pediatrics
12 scheduled for release next month.

13 Last fall I completed a six-year term
14 on the executive board for our regional chapter of the
15 Association for Behavior Analysis, including three years
16 as president, during which time I released a standards
17 of practice document and an official position statement
18 supporting the abolition of restraint and seclusion,
19 both of which have contributed to state policy
20 discussions.

21 My career arc has tracked the
22 evolution of best practices in behavioral supports, from
23 facility-based to community-based, from regular use of
24 aversive and restrictive procedures to their reduction
25 and elimination, adoption and maturation of a

1 person-centered practices framework for behavioral
2 assessment and treatment, and understanding and use of
3 person-centered practices as an umbrella under which
4 several fields of expertise in mental health, physical
5 health, and therapeutic supports converge and must be
6 synthesized in order for their individual and combined
7 effects to be optimized, and for a person's overall
8 well-being and quality of life to meaningfully improve.

9 A few comments on the critical nature
10 of positive supports. The best behavioral supports are
11 ineffective when the life a person is living is
12 inconsistent with the life they want to live.

13 That is to say, there is no treatment
14 plan I can develop that could or should teach a person
15 to tolerate circumstances that he or she finds
16 unpleasant.

17 The housemates they live with, the
18 staff, we support them, the community they live in,
19 their proximity to family and friends, their work, their
20 daily living. They can all be out of balance and they
21 can all lead to a life that doesn't work for them.

22 Finding out what sort of life a
23 person wants to live, behavioral and related supports
24 can be synchronized to achieve it. A person and their
25 team get to pick what behaviors are the target for

1 improvement towards the life they want to achieve.

2 Professionals no longer pick what
3 skill to teach or behaviors to reduce. Working on a
4 person's behalf is different conceptually and
5 practically than sorting out what's wrong with them and
6 trying to fix it. This is the fundamental nature of the
7 shift from traditional practices to person-centered
8 positive supports.

9 Finally, our literature speaks to the
10 powerful impact of choice and self-determination in
11 achieving higher quality of life and reduction in
12 challenging behaviors or is the empirical basis for the
13 work we're doing.

14 A few comments on objective
15 determination effectiveness and optimizing supports.
16 People have the right to effective supports. This has
17 been a central tenet of applied behavior analysis since
18 the 1960s. So, this is certainly not unique to ABA.

19 Board certified behavior analysts
20 practicing in Minnesota and elsewhere are required to
21 see to it that their services are effective and that the
22 data say so. While the proposed rule does not
23 professionalize all services for people with
24 disabilities, it draws on elements of professional
25 practice such as this.

1 By requiring services to be
2 effective, all providers are held to a high standard
3 whether or not a behavioral or mental health
4 professional is at the helm, the bar is being raised for
5 all.

6 For people who use supports,
7 particularly those with complex needs, no one
8 professional has all the answers all the time.
9 Professional consultation within and across disciplines
10 is expected practice among credentialed persons,
11 particularly when treatments and support are less than
12 optimally effective.

13 This practice should be commonplace
14 as positive supports are brought to statewide scale and
15 the needs of people are matched effectively with the
16 services they receive.

17 As Charles alluded to, there are
18 several contraindications for punishment; emotional
19 responding, escalation of the situation, punishment
20 induced behaviors, such as aggression, property
21 destruction, and self-injury. That escalation being a
22 barrier to learning new skills or recalling skills that
23 have been learned.

24 Staff being paired with aversives are
25 more likely to be avoided across the day. It's hard to

1 play the role of a support person and punisher. And
2 people habituate to punishment, it takes more and more
3 intense punishment all the time to suppress behavior.

4 Punishment has a seductive power, is
5 often misdirected faith in its efficacy. It may keep a
6 person's behavior suppressed under certain conditions.
7 And as Charles noted, there is potential for abuse of
8 this kind of power.

9 Punishment is entirely inconsistent
10 with recognized best practices in person-centered
11 positive behavior support, including the emphasis we
12 have on supporting people to learn skills that will
13 allow them to live the life they hope for.

14 Punishment is not an assessment-based
15 practice, it generally is an imposition of values of a
16 person in authority over others in subservient
17 positions. From a human rights perspective, we resolve
18 to not treat people this way anymore.

19 In summary, paradigm shifts do not
20 happen quickly without effort or without resistance.
21 Well before my career began, best practices included
22 bleeding, ice baths, and faradic skin shock.

23 We're in the middle of this current
24 paradigm shift. Our work today is predicated on
25 positive support efforts over the last two decades and

1 much is left to be done.

2 Finally, human services has two
3 parts. Human should cause us to look at the person in
4 front of us, not simply the problems in their life. See
5 their hopes and dreams first and their human rights as
6 updated and current as our own.

7 Services should cause us to consider
8 the best possible match of available resources and
9 technologies to the needs presented to us and not be
10 satisfied with less. Thank you for your time.

11 THE HEARING OFFICER: Thank you so
12 much, Dr. Moore. And so, what we're going to do is
13 we're going to take our standing break. I'm not going
14 to leave the room, I'm just going to go as far as the
15 roster table to get the rosters.

16 For those folks who would like to
17 spend their time with either the copy that is up here at
18 the desk or the copy that's in back, I invite you to do
19 so.

20 As soon as that process is done and
21 folks have satisfied themselves as to the contents of
22 the items and had a chance to visit with them briefly,
23 I'm going to return promptly, do an all-y all-y in come
24 free to start the hearing because our key purpose today
25 is to hear from you.

1 So, with that, we're going to be in a
2 standing recess to allow folks to read those binders.
3 We're in recess.

4 (At this time a brief recess was taken.)

5 THE HEARING OFFICER: We're going to
6 start with Ms. Howe and Ms. Janecky will follow her.
7 Just to give you a little preview about where we're
8 going, we're going to do another 90-minute slot and then
9 break about 11:45. So, we'll try to accomplish as much
10 as we can in the next 90 minutes or so.

11 The panel has put the numbers, the
12 OAH docket number and revisor number up on the board so
13 folks can have that for their later comments.

14 And again, I'm just asking folks to
15 hit the highlights in their comments, the key points
16 that they want to get into the record. Mindful that
17 they can write in. And I am foreseeing multiple rounds
18 to hear from folks again.

19 So, with that admonition, Ms. Howe,
20 if you could state and spell your name for our record
21 and tell us what we need to know.

22 MS. HOWE: I'm Valarie Howe, H-o-w-e.
23 I'm a mother of a 19-year-old disability son who has
24 violent explosive behavior. I know it took a lot of
25 time and hard work and dedication to redevelop and

1 develop the 245D positive support rule. And I applaud
2 and appreciate your efforts.

3 There's a couple areas of the 245D
4 positive support rule that I want to be looked at to
5 develop or tweaked more, especially for the violent
6 behavior individuals, disabled individuals.

7 The first area of concern is the
8 9544.0060, prohibitions and restrictions, Subpart 2,
9 special prohibition Item Q. It's a use of token
10 reinforcements and program levels with consequence
11 components.

12 I firmly believe in the program level
13 with consequence for violent behavior disabled
14 individuals. My son went into a group home three years
15 ago, he started with a token and program level with
16 consequences component.

17 They also worked on his skills that
18 he needs for self-regulations and stuff. And my son
19 went two years without a violent episode, two years,
20 then 11 months without no behavioral -- minimal
21 behavioral stuff.

22 Then in May of 2014, of course, with
23 the new law being implemented in January, they had to
24 switch to this positive support. And the Ombudsman
25 recommended that they need to take away this program

1 level with consequences.

2 So, in May of 2014 they did. And
3 they tried to develop a program, but there wasn't stuff
4 out there, DHS hasn't had too much training for this.
5 So, they were trying to develop.

6 Anyway, my child's violent behavior
7 came back. And he attacks staff and broke \$5,000 worth
8 of windows in their group home. Anyway, the police was
9 called by a neighbor and he was put in the hospital.

10 The hospital discharged him on the
11 street because the group home had less than 50
12 employees, they probably only have 30. They could not
13 have a program for him to protect the staff or himself
14 or the residents in that group home. They needed more
15 specialized trained staff.

16 So, I had to take him home because he
17 was released to the street. Two weeks after he was
18 home, he tried to burn down my house in the middle of
19 the night while my 12-year-old daughter, myself, and my
20 husband were sleeping.

21 He took off with our van, we caught
22 up to him. The police did not arrest him, I had to take
23 him back home. Then I got a hold of my social worker.
24 And he couldn't stay home, so he was put in the
25 hospital.

1 We tried Minnesota Bridge of Life and
2 Mensa, tried to get him in there because of his violent
3 behavior. Nobody wanted to take him. I was told that
4 the Minnesota Life Bridge and Mensa are the safety nets
5 for these violent behavior disabled people.

6 We could not get him in there, there
7 was a waiting list a mile long. Then finally he was
8 being violent in the hospital, he was discharged and
9 luckily we had a crisis bed for him.

10 And I'm worried because these program
11 levels are taken away and my son's violent behavior
12 returned and there's nowhere for these people to go with
13 these violent behaviors. Because everybody has a
14 waiting list a mile long.

15 They're either on the street or at
16 home or being warehoused in hospitals that cannot help
17 them or crisis beds.

18 Your Honor, I want to ask, have you
19 asked DHS how many violent behavior disabled individuals
20 are being warehoused in the hospitals or crisis beds, to
21 find a home and to help them? And how long these
22 violent behavior individuals have to wait to get
23 services in a home.

24 And how many community-based
25 facilities are closing their doors because they cannot

1 handle these violent behavior clients with the
2 implementation of removing these program levels?

3 The second concern I have is lack of
4 resources. Like I said, the group home was notified
5 they had to take away these level programs and they were
6 having troubles finding out how to do this.

7 Plus, my social worker, they were all
8 confused, everybody was confused on how to go about with
9 these violent behavior disabled individuals. So, a lot
10 of them were being discharged or not being admitted to
11 their facilities.

12 So, my concern is it took -- thank
13 God as today, my son is moving into a home that is
14 unlicensed, but is licensed for 245D staffing. Because
15 I could not find a licensed place to take him because of
16 his violence, his property destruction.

17 I even had to interview a home with
18 sexual predators. Is that a place for my son? No. So,
19 it took finally six months to find a home for my son.

20 And I find this appalling that my
21 son's life and my life has been put on hold for six
22 months because of the lack of resources DHS has out
23 there for violent behavior disabled individuals.

24 Without resources for implementing
25 the 245D positive support rule is going to create even

1 more of a mess for these violent disabled individuals.
2 If facilities are closing, that is creating less
3 resources for the violent behavior individuals.

4 Because everybody is confused about
5 this rule and they're all scared that they're going to
6 lose their license because they're not doing stuff
7 right.

8 In conclusion, I would ask, Your
9 Honor and DHS, to review the token and program level for
10 the violent behavior disabled individuals and a need to
11 develop more resources for the violent behavior disabled
12 individuals so they will have a home to live in and
13 receive services and not wait for six months or more
14 being warehoused in hospitals and crisis beds.

15 I appreciate your time and please
16 consider my concerns.

17 THE HEARING OFFICER: Thank you so
18 much, Ms. Howe, we're very grateful for your time and
19 contributions to our record. Ms. Janecky. And
20 following her will be Cristin Heil of Minneapolis. Is
21 Ms. Heil here? Great, you're next.

22 Ms. Janecky, if you wouldn't mind
23 stating and spelling your name for our record.

24 MS. JANECKY: My name is Marietta
25 Janecky, J-a-n-e-c-k-y.

1 THE HEARING OFFICER: Ms. Janecky,
2 what should we know?

3 MS. JANECKY: I am currently a senior
4 behavior analyst and clinical supervisor of a local
5 agency that provides behavior analytical services to
6 children with autism in a center-based setting.

7 I will submit my resume as well so
8 you have the information. I'm a board certified
9 behavior analyst and I have a master's degree in
10 education.

11 THE HEARING OFFICER: Just a little
12 slower for Ms. Evenson. Thank you.

13 MS. JANECKY: Sorry. I've been
14 working with children with autism and other
15 developmental disabilities since 2003. From 2003 to
16 2004 I worked one-to-one providing behavior therapy
17 services to a child with autism in his home.

18 In 2004 I began working in a
19 center-based setting as an instructor of behavior
20 therapy under the supervision of board certified
21 behavior analysts.

22 I provided instruction to children
23 with varying levels of functioning on the autism
24 spectrum, including those with whom positive support
25 strategies resulted in clinically significant gains in

1 communication and social skills and clinically
2 significant reductions in maladaptive or problem
3 behaviors.

4 I also work with children who, after
5 the carefully programmed and meticulously analyzed
6 positive support strategies were found to result in only
7 a minimal amount of reduction of problem behavior, the
8 use of punishment procedures were necessary to reduce
9 the severe aggression and self-injury that was
10 preventing them from participating in public education
11 settings, their community and most unfortunately their
12 home settings.

13 After working one-on-one with these
14 children for three years, in 2007 I began providing
15 outreach consultation services to families with children
16 with autism, as well as schools and centers whose
17 responsibility it was to provide educational services to
18 children with autism.

19 I provided consultation to families
20 in ten states in the U.S., in Canada, in Italy, in
21 England, in the Bahamas, and Bermuda.

22 In the home, school, and center-based
23 settings in this array of locations around the world, I
24 found a similar need for the use of both positive
25 support strategies along with the occasional need for

1 use of punishment.

2 Since 2013 I have been working as a
3 senior behavior analyst and clinical supervisor of a
4 therapy center in Minnetonka. The goal of our center is
5 to provide evidence-based analytic services to children
6 with autism through direct services, as well as training
7 family members and educators.

8 We accomplished this by ensuring that
9 the children's progress occurs through the arrangements
10 of teaching environments, which are mostly positive, and
11 arranged ultimately to allow the learner to continue to
12 develop language and other skills in typical
13 educational, community, and family settings.

14 Many of these services can be
15 delivered using positive support strategies. These
16 services do, however, at times require the use of
17 procedures that will effectively and efficiently
18 decrease target behaviors that are interfering with an
19 individual's quality of life by limiting their
20 integration in community and inclusion into integrated
21 settings.

22 The proposed rules state that the
23 purpose is to improve the quality of life of persons
24 receiving home and community-based services by, and I
25 summarize, promoting community participation,

1 person-centeredness, ensuring collaborative team-based
2 development of positive support strategies, increasing
3 self-determination abilities so the person may engage in
4 community activities to the greatest degree and
5 reasonably attainable, and the list goes on.

6 The list also indicates the need to
7 eliminate all uses of aversive or deprivation
8 procedures. This list needs to include the possibility
9 for the use of procedures that will help clients achieve
10 these goals by receiving treatment that will allow for
11 the supervised, appropriate, controlled, and consented
12 use of punishment when it is deemed necessary and when
13 all positive-based strategies have been unsuccessful.

14 Rule 9544.0030 titled "Positive
15 Support Strategies and Person-Centered Planning"
16 describes the requirement of the use of positive
17 supports strategies when providing services to a person.

18 In Subpart 4, the professional
19 standards for positive support strategies rule states
20 that the license holder must use professional standards
21 for positive support strategies and provides examples of
22 those professional standards, including the Behavior
23 Analyst Certification Board Guidelines for Responsible
24 Conduct for Behavior Analysts.

25 These guidelines do not call for the

1 exclusive use of positive support strategies. Rather,
2 they state that the behavior analyst recommends
3 reinforcement rather than punishment whenever possible.

4 If punishment procedures are
5 necessary, the behavior analyst always includes
6 reinforcement procedures for alternative behavior in the
7 program.

8 In addition to those guidelines, to
9 provide guidance when punishment procedures are
10 necessary, the board has endorsed the Association for
11 Behavior Analysis International's statement on the Right
12 to Effective Behavioral Treatment, which Dr. Moore
13 referenced earlier.

14 This is described in more detail in
15 Van Houten's 1988 article, "The Right to Effective
16 Behavioral Treatment." In this article the authors
17 describe an individual's right to programs that teach
18 functional skills.

19 In this they describe that the
20 improvement of function may take several forms,
21 including the reduction or elimination of certain
22 behaviors that are dangerous or that in some ways serve
23 as barriers to further independence or social
24 acceptability.

25 In addition, the Association for

1 Behavior Analysis International published a position
2 statement, which Dr. Moore also referenced, on
3 restraints and seclusion.

4 In the position statement they state
5 that their members strongly oppose the inappropriate or
6 unnecessary use of a seclusion, restraint or other
7 interest of interventions.

8 Although, many persons with severe
9 problem behaviors can be effectively treated without the
10 use of any restrictive interventions. Restraint may be
11 necessary on some rare occasions with meticulous
12 clinical oversight and controls.

13 In addition, a carefully planned and
14 monitored use of time-out for reinforcement can be
15 acceptable under restricted circumstances.

16 Seclusion is sometimes necessary or
17 needed, but behavior analysts would support only the
18 most highly monitored and ethical practices associated
19 with such use. Such use is detailed in the position
20 statement.

21 The position statement continues on
22 to outline the critical guiding principles and with a
23 strong adherence to professional judgment and best
24 practice.

25 It also describes the condition under

1 which the seclusion and restraint may be necessary and
2 it outlines the proper strategies to implement those
3 procedures appropriately and safely.

4 I strongly urge you to consider both
5 this position statement as well as the statement on the
6 right to effective behavioral treatment, along with
7 those guidelines for responsible conduct in your
8 consideration.

9 I feel that the proposed rules would
10 be more aligned with best practices if these position
11 statements were taken into account.

12 A portion of the proposed rules
13 addresses the emergency use of manual restraint. For
14 individuals with severe aggression who do not have an
15 effective behavior plan it is sometimes necessary to
16 implement emergency restraint in order to protect the
17 individual and others.

18 Research has shown that when problem
19 behavior requiring emergency restraint occurs at a high
20 rate, it is merely an illusion that the student is being
21 treated with a nonaversive intervention.

22 Only minor changes in the procedure
23 are required to make this a punishment procedure,
24 including the addition of a predetermined duration and
25 release criteria. These small changes may make a large

1 difference in the effectiveness of the intervention.

2 Research also shows the planned use
3 of restraint versus an emergency restraint was
4 significantly less dangerous than an emergency restraint
5 and that the number of injuries was minimal with the use
6 of a planned restraint. I also encourage you to take
7 that information into consideration.

8 THE HEARING OFFICER: Ms. Janecky,
9 are we able to mark that item that you're reading from?

10 MS. JANECKY: Yes, absolutely.

11 THE HEARING OFFICER: So, I think you
12 can just feel free to hit the highlights, mindful that
13 we'll have as an exhibit all of the words.

14 MS. JANECKY: Absolutely. I think
15 that you should also consider the Professional Crisis
16 Management Association's review of prone restraints.
17 There is an excellent review that I will also submit
18 called "The Premature Call for a Ban on Prone
19 Restraint," a detailed analysis of the issues and
20 evidence.

21 I do want to comment and say that I
22 think in the description of the need for the proposed
23 rule that has been given here by the members of the
24 panel, the term "punishment" seems to be used
25 interchangeably with the term "abuse." I think that it

1 should be noted that these are not the same and that we
2 should speak about these things technically.

3 It seems as though the Department is
4 attempting to absolve themselves from their
5 responsibility to make determinations regarding whether
6 specific conduct constitutes maltreatment or abuse by
7 banning the use of punishment as a broad category.
8 Rather, we should parse through the basic principle and
9 decide what might be okay and what isn't.

10 A few finishing comments. I feel
11 that in the prohibitions, restrictions section, speaking
12 about banning the use of punishment of any kind seems
13 like a very broad statement. I think that should be
14 considered.

15 One example includes the use of
16 positive practice overcorrection when toilet training
17 individuals. With the use of reinforcement for
18 successful toileting initiations and positive practice
19 correction for accidents, I have treated individuals who
20 underwent years of unsuccessful toilet training and have
21 trained them to independence in a matter of days or
22 weeks.

23 I have treated individuals who are
24 scheduled training or trained to wait until somebody
25 reminded them it was time to use the toilet. Those

1 individuals have also been trained independence in a
2 matter of days or weeks.

3 Many of the caretakers of these
4 individuals were told that these children would be
5 reliant on them for their toileting needs for the rest
6 of their lives.

7 When using terms like
8 "person-centered" and "self-determination" and "quality
9 of life," I don't know how you can get closer to these
10 qualities that are listed in the purpose of the proposed
11 rules and by procedures that can accomplish this in an
12 exceptionally short amount of time after years of
13 dependence upon adults for such a personal daily
14 necessity.

15 In addition, piggybacking off the
16 woman who spoke before me, another standard that should
17 be reconsidered is Item Q, using token reinforcement
18 programs or level programs that include response cost or
19 negative punishment component.

20 We operate on a token economy during
21 our every-day lives. Money has been conditioned as a
22 form of reinforcement, we work to get paid. We exchange
23 our money for the things we need and want. This is a
24 reality that nobody argues with.

25 The other reality is that response

1 cost is at play in our lives every day as well. We get
2 charged for not returning a library book on time. We
3 have to pay speeding tickets or parking tickets when we
4 break the law. We get overdraft charges at a bank. We
5 get charged extra for going over on cell phone minutes.

6 These are examples of response cost
7 at play in our lives every day. How are we going to
8 prepare our clients for independence in life if we are
9 going to remove this naturally occurring consequence
10 from our teaching?

11 I strongly urge you to remove these
12 prohibitions from the proposed rules, they are not best
13 practice and are unnecessarily restrictive. I think
14 that's it.

15 I would like to finish by saying that
16 Hanley published an article in the Journal of Applied
17 Behavior Analysis in 2005. The authors in this article
18 investigated the relative effectiveness of functional
19 communication training with and without the use of
20 punishment.

21 The results of this study found that
22 when the children were given the opportunity to select
23 behavioral intervention, they chose the intervention
24 that involved both a reinforcement contingency for
25 alternative behavior and a punishment contingency for

1 problem behavior.

2 This suggested reasons for this
3 include that perhaps being ignored is more aversive than
4 being punished. Or perhaps when problem behavior occurs
5 less frequently, because it is decreased through
6 punishment, kids have greater opportunities to receive
7 reinforcement.

8 Generally speaking, the results of
9 this study suggest that the children prefer conditions
10 under which they were more effective and more efficient.

11 The authors state that the fact that
12 the children committed to treatment conditions involving
13 punishment contingencies is seemingly at odds with the
14 anti-aversive movement and the recent practice of
15 designing positive behavioral intervention for
16 individuals with problem behavior.

17 If treatment options were restricted
18 to those to be considered nonaversive or positive, the
19 participants in this study would have been prescribed
20 treatments that were both ineffective and nonpreferred.

21 These data clearly emphasize the
22 notion that evidence-based values can and should guide
23 the treatment selection process. After all, shouldn't
24 the treatments be in the best interest of the people we
25 serve? That is it.

1 THE HEARING OFFICER: Thank you,
2 Ms. Janecky. We can mark that item as Exhibit B. Thank
3 you kindly. And it has the peer-reviewed article you
4 mentioned?

5 MS. JANECKY: Yes, it does.

6 THE HEARING OFFICER: Okay. So,
7 Exhibit B is Ms. Janecky's remarks and her vitae and the
8 Van Houten article. Is the Hanley article in here as
9 well?

10 MS. JANECKY: Yes, that's the last
11 one.

12 THE HEARING OFFICER: Okay. So, B is
13 a multi-page item, but it does have some peer-reviewed
14 materials with that. With that, Ms. Heil, if you
15 wouldn't mind joining us up here. Mr. Hood, are you
16 joining us as well? We have two seats.

17 Okay if I start with you, Ms. Heil,
18 and then move to Mr. Hood?

19 MS. HEIL: We're presenting together.

20 THE HEARING OFFICER: So, how does
21 that work?

22 MS. HEIL: I'll ask him some
23 questions. I'll be leading and he's going to tell a
24 story, but I'll ask him questions.

25 THE HEARING OFFICER: Okay. If you

1 could introduce yourself for our record.

2 MS. HEIL: My name is Cristin Heil,
3 C-r-i-s-t-i-n, H-e-i-l. I am the mother of a little boy
4 who's three and he has special needs. And Daniel Hood
5 here is one of my friends. Did you want to introduce
6 yourself?

7 MR. HOOD: Yes, my name is Daniel
8 Hood, it's D-a-n-i-e-l and it's H-o-o-d.

9 THE HEARING OFFICER: Okay. What
10 should we know, Ms. Heil?

11 MS. HEIL: We're here today to share
12 a story about seclusion with you to help express my
13 support of adopting and strengthening the rule against
14 restraint and seclusion. We're here to urge you to
15 adopt the rule.

16 We want you to know that seclusion is
17 equally as destructive, easier to hide because bruises
18 typically aren't a result of seclusion. And it's easier
19 for seclusion to be overlooked.

20 Seclusion may take many forms, from
21 isolated padded windowless rooms in schools to being
22 held prisoner in your own home. What I'd like you to
23 hear today is my friend Daniel's story.

24 So, let's go back to 1995. Daniel,
25 how old were you in 1995?

1 MR. HOOD: I was 20 years old.

2 MS. HEIL: And where were you living
3 when you were 20?

4 MR. HOOD: I was living in Oakdale,
5 Minnesota.

6 MS. HEIL: In what setting?

7 MR. HOOD: It's a group home setting.

8 MS. HEIL: Did you have a job at that
9 time?

10 MR. HOOD: Yes, I did.

11 MS. HEIL: Where were you working?

12 MR. HOOD: I was working at

13 McDonald's.

14 MS. HEIL: Did you like your job?

15 MR. HOOD: Yes, I did.

16 MS. HEIL: Did you work full time or
17 part time?

18 MR. HOOD: It was a full time.

19 MS. HEIL: And what did you
20 especially pride yourself in at your workplace?

21 MR. HOOD: Well, I like my job. I
22 was sweeping and also learning how to cook. Basically
23 it was -- I can't find the words. Basically cooking and
24 basically looking into more work.

25 MS. HEIL: And can you tell me about

1 the day that you had trouble getting to McDonald's on
2 time?

3 MR. HOOD: Yes, I can. I was
4 cooking, I was asked to cook and I was running out of
5 time. And the staff told me I had to finish. And I
6 actually cooked and they refused to take me to work
7 because it was scheduled.

8 So, I basically asked them if I could
9 do it a different day and they told me no, I couldn't.
10 And they told me I couldn't and they would make me late.
11 Until I cooked, they refused to take me to my job.

12 MS. HEIL: Just to clarify, you were
13 at your group home and you needed to go to work. And
14 the staff asked you to cook the meal before you could go
15 to work, correct?

16 MR. HOOD: That's right.

17 MS. HEIL: Okay. And when you told
18 them that you weren't able to cook that day because you
19 had to get to work and you didn't want to be late, what
20 was their response?

21 MR. HOOD: It was simple, they told
22 me, these are the rules, these are set, and you have to
23 comply.

24 MS. HEIL: Did they tell you what you
25 could or couldn't do if you didn't cook the meal?

1 MR. HOOD: Well, there was other
2 stuff. Well, if you were going to do something, if you
3 were going to the store, there was stuff that -- I can't
4 find the words.

5 MS. HEIL: I remember when you were
6 telling me the story, you told me that they said to you
7 that if you didn't cook the meal, you had to stay in
8 your group home and you couldn't go to work.

9 MR. HOOD: That's right.

10 MS. HEIL: That's what I was
11 wondering. So, how did it make you feel when they told
12 you that if you didn't cook this meal you couldn't go to
13 work?

14 MR. HOOD: I felt bad and I was
15 upset.

16 MS. HEIL: And so, what did you
17 decide to do to get to work?

18 MR. HOOD: Well, I wanted to go to
19 work and I wanted to let people know I was angry, so I
20 went up on top of the roof. And I wasn't trying to
21 commit suicide, but I felt trapped. And so, I looked
22 down and I didn't think anything of injuries before I
23 jumped.

24 So, when I jumped, I realized that
25 when I hit the ground, I broke my back, I broke my foot.

1 So, for that time when I was injured, it took me about a
2 year. And, basically, I didn't think about cost.

3 If you did the math, for a whole year
4 it was, like, \$10,000 for the hourly wage that I was
5 making at the time.

6 MS. HEIL: That makes sense because I
7 think you told me at the time you were earning about \$5
8 an hour working full time. So, I think you're right,
9 that you probably lost out on about \$10,000 of income
10 that year?

11 MR. HOOD: That's right.

12 MS. HEIL: What we're trying to
13 illustrate with this story is just the fact that
14 seclusion not only is shutting someone in a room, but
15 seclusion can also be telling someone that they cannot
16 leave their home. It comes in so many different forms.

17 I just wanted people to realize that
18 there's many ways it can affect people. And in Daniel's
19 case, as a result of being told he could not leave his
20 home, he wanted to get to work, he jumped off the roof.

21 He, as you heard, broke his back and
22 he had to go live in a foster care setting after this
23 because the group home could no longer accommodate him.

24 So, we just want to ask you to
25 consider the unemployment and poverty rates among people

1 with disabilities and that there's many stories of
2 seclusion and restraint that contribute to the poverty
3 and unemployment rates among vulnerable adults.

4 According to the Bureau of Labor and
5 Statistics in 2013, 17.6 percent of persons with a
6 disability were employed. And in contrast, the
7 unemployment population ratio for those without a
8 disability was 64 percent. Was that confusing at all?
9 I don't know.

10 So, as you can see, in Daniel's
11 situation, his poverty and inability to provide for
12 himself was in direct correlation with being secluded by
13 the staff of his group home.

14 This example of seclusion is atypical
15 in that it's a different kind of seclusion from being
16 locked in a room, but it just comes in many different
17 forms.

18 As we wrap up, I wanted to ask you to
19 remember that a fundamental human need is to be included
20 in a community. And I want you to consider a time in
21 your life that you felt isolated, secluded, ignored or
22 unwanted. I think these are things that everyone can
23 relate to.

24 And as you are considering the rules
25 we are proposing be adopted, just remember times in your

1 own life that someone maybe secluded you from something.
2 And just remember that even though it may not physically
3 hurt, it can hurt people on many different levels.

4 So, Daniel and I are asking that you
5 support the adoption of the proposed rules. And we
6 believe that the use of restraint and seclusion is just
7 plain wrong. Thank you.

8 THE HEARING OFFICER: Thank you,
9 Ms. Heil. Thank you, Mr. Hood. Appreciate your time
10 and contributions, very grateful. So, following them
11 will be -- should we mark this?

12 MS. HEIL: Yes, please.

13 THE HEARING OFFICER: Thanks so much.
14 So, this is Exhibit C.

15 Ms. Barb Turner of ARRM. And
16 following Ms. Turner will be Steven Schmidt of the
17 Minnesota Disability Law Center. Ms. Turner, if you
18 could state and spell your name for our record.

19 MS. TURNER: My name is Barb,
20 B-a-r-b, Turner, T-u-r-n-e-r.

21 THE HEARING OFFICER: Ms. Turner,
22 what should we know?

23 MS. TURNER: I'm here representing
24 ARRM and its members. ARRM is an association whose
25 members provide services to people with disabilities,

1 including developmental disabilities, mental illness,
2 brain injury, and physical disabilities.

3 THE HEARING OFFICER: Just a little
4 slower because folks read faster than they speak.
5 Ms. Turner.

6 MS. TURNER: ARRM represents
7 approximately 160 providers. ARRM supports the
8 Department's effort to modernize the rules regarding use
9 of aversive procedures and use of positive support
10 strategies, but we do have some concerns regarding the
11 proposed rule and the potential for some unintended
12 consequences.

13 One of those things is the cost of
14 implementation as well as the lack of exceptions which
15 may result in providers being unwilling or unable to
16 serve some of the most challenging individuals in the
17 community.

18 One of our initial concerns is that
19 the scope of this rule considers that everyone that
20 falls under it has the same sorts of issues that respond
21 in the same sorts of ways.

22 We feel there's a need for some
23 consideration in regards to people who may fall within
24 the scope who do not have a developmental disability,
25 but perhaps a brain injury or dementia.

1 These are individuals who it's not a
2 matter of teaching a skill, it's a matter that they
3 can't remember what you're trying to teach them. And
4 the opportunity for them to use those trainings to make
5 changes in behavior simply aren't there.

6 ARRM is concerned about the cost of
7 implementation to providers. The training, additional
8 administrative responsibilities, and additional
9 reporting responsibilities will be required with no
10 proposed funding to cover these costs.

11 With a turnover rate of 50 percent or
12 more in our industry, training becomes a significant
13 cost to providers. Specifically on 9544.0090, that
14 section talks about not only initial training, but then
15 a requirement for four hours of annual training for
16 every staff. And this is an extreme cost to providers.

17 ARRM also feels that it should be
18 acknowledged that this new rule covers a much, much
19 larger group of individuals than the old Rule 40 did.
20 So, all of the changes for that segment of providers is
21 even more significant than the changes for people who
22 are already familiar with the use of Rule 40.

23 There are some concerns over some
24 specific requirements in the new proposed rule. One of
25 those in the number of incidents of emergency use of

1 manual restraint that would result in the requirement
2 for development of a positive support transition plan.

3 Currently as written, a second
4 incident requires that development. And those can be
5 quite time-consuming. At times there are reasons that
6 someone has an intermittent issue with the need for
7 manual restraint, but no ongoing issue. And this does
8 not allow any exception in that area.

9 It's important to note that prior to
10 the implementation of 245D in January 1st of 2014, many
11 individuals who now fall under this rule did not have
12 any rules or regulations or statutes governing the
13 behavior management practices. There's a significant
14 difference in the changes and cost associated with the
15 changes for those providers.

16 Another concern for us is the
17 definition of mechanical restraint. One of the things
18 that makes people able to use transportation is
19 something called a seat belt clip or seat belt buddy.
20 And those are used to ensure that someone does not undo
21 their seat belt.

22 These are considered a mechanical
23 restraint by the rule. And our concern is that this
24 will result in people who simply won't be allowed to go
25 into the community because they can't be safely

1 transported.

2 A solution that sometimes people
3 bring up is the possibility of using a one-to-one staff.
4 And if the funding were available for that type of
5 alternative, I can tell you that with the current
6 workforce, we don't have enough people to provide
7 one-to-one staffing on a regular basis for people in the
8 community. It's just not an option.

9 We feel that the intended consequence
10 of not being able to use these seat belt buddies could
11 be people not going into a day program and also not be
12 able to attend a day program. We feel there should be a
13 process for exception for this device.

14 As currently written it concerns us
15 that it appears that any use of a program to change
16 behavior could require a functional assessment and
17 extensive programming. And many times much less complex
18 plans can resolve a behavior issue.

19 We're also concerned that when a new
20 functional assessment is required, any change in a plan
21 requiring a new functional assessment in many cases is
22 not necessary and, again, another drain on resources.

23 As providers continue to adjust to
24 new statutes, rules and other regulations it becomes a
25 possibility that they may choose to -- they won't be

1 people who will choose to serve these most challenging
2 individuals.

3 Potential for licensing sanctions
4 with limited resources for support may cause providers
5 to make some very difficult decisions.

6 Although the Department has stated
7 that there are resources available to support providers
8 as we go to implement this new rule, the reality is
9 there just aren't enough.

10 And the further you get from the
11 metro area, the more likely it is that there won't be
12 those resources available. So, we need to figure out
13 how to address that as we move forward with this rule.

14 THE HEARING OFFICER: Ms. Turner,
15 when you're talking about the functional assessment,
16 you're talking about the functional behavioral
17 assessment?

18 MS. TURNER: Yes. And the last thing
19 is although we certainly believe in person-centeredness
20 and making people able to gain the skills so that they
21 can live in the most integrated situation as possible,
22 we are concerned that as we're trying to protect the
23 rights of people who have some challenging behaviors, we
24 are at times imposing on the rights of the people that
25 they live with in the community.

1 And we would like that to be a
2 consideration as we look to the possibility of some
3 exceptions within this rule.

4 THE HEARING OFFICER: Thank you so
5 much, Ms. Turner, we're grateful for your time and your
6 contributions to our record. Mr. Schmidt. And
7 following Mr. Schmidt, Jason Hoffrogger, Orion
8 Associates.

9 MR. HOFFROGGER: No, I did not
10 indicate I was speaking.

11 THE HEARING OFFICER: Forgive me, I'm
12 sorry. Jeri Espeseth, you'll be following Mr. Schmidt.
13 Is it Counselor?

14 MR. SCHMIDT: Yes.

15 THE HEARING OFFICER: Counselor, if
16 you wouldn't mind introducing yourself for our record.

17 MR. SCHMIDT: Thank you, Judge
18 Lipman. My name is Steven Schmidt, S-c-h-m-i-d-t. I'm
19 a staff attorney at Minnesota Disability Law Center, a
20 statewide project between Mid-Minnesota Legal Aid.

21 Mid-Minnesota Legal Aid is
22 Minnesota's federally mandated protection advocacy
23 system for people with disabilities. We represent
24 individuals with disabilities throughout the state with
25 legal issues related to their disabilities.

1 THE HEARING OFFICER: Mindful that
2 people read faster than they talk. Use them as notes,
3 Counselor, if you could. Mindful that you can mark that
4 as an exhibit and write it in later, either way,
5 whatever you wish.

6 MR. SCHMIDT: So, Minnesota
7 Disability Law Center does support the Department of
8 Human Services' efforts to modernize the rules to
9 eliminate the use of aversive procedures and require
10 positive support strategies for persons with challenging
11 behavior.

12 Restraint and seclusion are abusive
13 practices and deny placement in treatment, service or
14 support setting. The goals of the PSS rules is to
15 ensure that individuals with disabilities who receive
16 services from programs licensed by DHS will be treated
17 with dignity and respect.

18 However, the Disability Law Center
19 has serious concerns regarding various provisions of the
20 rules. Instead of ensuring improved treatment, services
21 and support, some provisions in the proposed rules are
22 not related to the agency objective and will have
23 unintended negative consequences on service
24 participants.

25 We have already submitted extensive

1 written comments, which identify these problems in
2 detail and propose changes to ensure that the rules
3 provide a clear and comprehensive framework for improved
4 practices across the state.

5 We do believe that certain provisions
6 of the rules are unreasonable and defective and that DHS
7 must correct these provisions prior to the adoption of
8 the final rules. My testimony will highlight the key
9 portions of our written comments.

10 First, we believe that DHS has not
11 fulfilled its obligations with respect to portions of
12 the Statement Of Need And Reasonableness. Specifically,
13 the cost estimates for implementation, enforcement, and
14 compliance with the rules are unrealistic and
15 unreasonable.

16 These estimates fail to account for
17 important parts of the new rule, such as the behavior
18 intervention report forms and the External Program
19 Review Committee.

20 The estimates also do not account for
21 245A providers cost in phasing out the use of
22 restraints, which will include expert consultation and
23 staff training. DHS should be asked to provide a
24 realistic cost estimate prior to the final adoption.

25 Second, the applicability --

1 THE HEARING OFFICER: Counselor, if I
2 could just stop you on that point. Do you have a view
3 about what these things are likely to cost? Is that in
4 your written comments?

5 MR. SCHMIDT: We do not have an exact
6 figure for you. The SONAR says 30,000 for the provider
7 cost.

8 THE HEARING OFFICER: That are above
9 a hundred.

10 MR. SCHMIDT: For the implementation
11 cost I believe it was above a hundred and then the
12 provider cost was 30, I believe. So, we don't have a
13 specific number.

14 I think speaking with more than one
15 provider would be the next step for DHS as far as
16 figuring that number. We do believe it would be much
17 more than those figures.

18 THE HEARING OFFICER: So, what I
19 understood your critique to be is they've left out some
20 pieces in the cost calculation?

21 MR. SCHMIDT: Correct.

22 THE HEARING OFFICER: And that, even
23 as to the pieces that they measured, it's not large
24 enough. So, those are two different pieces. I'm
25 talking about the first part, do you have a sense of

1 what the magnitude should be? And you don't have to
2 have an answer.

3 MR. SCHMIDT: I guess I don't have an
4 exact answer.

5 THE HEARING OFFICER: That's fine.
6 Like I say, it's not jeopardy, you get full credit.
7 Counselor, what should we know?

8 MR. SCHMIDT: The second point is we
9 believe the applicability provision of the rules does
10 not comply with the enabling statute. And this is
11 9544.0010, Subpart 2.

12 And as that is currently written, it
13 applies to facilities and services licensed under
14 Minnesota Statute 245A when those facilities and
15 services are providing services to an individual with a
16 developmental disability or related condition.

17 When these providers are providing
18 services to an individual without a developmental
19 disability, they're not required to comply with the
20 rules.

21 The language of the enabling statute,
22 which is listed as Minnesota Statute Section 245.8251,
23 Subdivision 1, states that the rules governing positive
24 support strategies must apply to all licensed facilities
25 and licensed services serving persons with developmental

1 disability or related condition.

2 This plain language clearly refers to
3 facilities and services and not just specific
4 individuals based on disability type.

5 Under plain reading of this language
6 any facility or service that serves a person with
7 developmental disability must follow provisions of the
8 PSS rules for all the services that it provides.

9 So, apart from not complying with the
10 enabling statute, this provision will cause confusion.
11 And basically two individuals who are in the same
12 treatment program or the same child care center who
13 receive the same service will be treated differently
14 subject to different requirements based on disability
15 types.

16 A person with a developmental
17 disability will be covered by the rules. A person
18 without a developmental disability will not. Uniform
19 staff training, policies and procedures and methods will
20 be difficult, if not impossible, to implement.

21 MDLC urges you to order DHS to
22 correct this provision and adopt the language of the
23 enabling statute prior to the final adoption of the
24 rules. Third, MDLC --

25 THE HEARING OFFICER: Sorry, just so

1 I understand the point that you're making, Counselor.
2 So, a family child care, let's get an extreme example,
3 which may hold a DHS license which provides services to
4 a disabled individual couldn't use tokens with
5 nondisabled young people, in your view, as correctly --
6 if the statute is correctly interpreted?

7 MR. SCHMIDT: They couldn't use it
8 with anyone in their program if they had a child with a
9 developmental disability.

10 THE HEARING OFFICER: Right. So, for
11 the kids without a developmental disability, can't use
12 tokens as to them?

13 MR. SCHMIDT: Correct.

14 THE HEARING OFFICER: That's your
15 view of how the statute should read, but not how they
16 phrased the rule. Is that your argument?

17 MR. SCHMIDT: Correct. Essentially,
18 in Page 16 of the SONAR they added the word "when" and
19 the statute doesn't have that word. And that word makes
20 a big difference how the statute talks.

21 THE HEARING OFFICER: Okay. Thank
22 you kindly.

23 MR. SCHMIDT: MDLC has identified
24 seven specific areas of the rules that are unreasonable
25 and defective and must be corrected prior to final

1 adoption.

2 Our written comments provide details
3 on these provisions, as well as suggested language that
4 MDLC believes will correct these deficiencies. At this
5 point I'm willing to just list them now and then reserve
6 more extensive discussion for Round 2 in the interest of
7 other folks.

8 THE HEARING OFFICER: That would be
9 great. Like I say, I'm glad for you to outline briefly
10 your concerns and then we can develop them in greater
11 detail, if you wouldn't mind yielding to others.

12 MR. SCHMIDT: Absolutely not. I'll
13 just go through each of the seven points, what they are.
14 The first one is the rules fail to include and should
15 include a definition of adaptive aids or equipment,
16 orthotic device or other medical equipment. And the
17 definition should go at 9544.0020.

18 The second point is that there should
19 be established criteria for the number of episodes of
20 emergency use of manual restraint required for the
21 development of a positive support transition plan. And
22 that would go to 9544.0070.

23 Third, we believe that the informed
24 consent provision, which is at 9544.0080, is confusing
25 and problematic and should be replaced with a notice

1 provi si on.

2 We believe DHS must set forth how it
3 will process the behavior intervention report forms at
4 9544.0110.

5 As mentioned by Ms. Turner, we
6 believe there should be an exception for the use of an
7 auxiliary seat belt device in the proposal, to put that
8 at 9544.0130.

9 Also at that provision we believe
10 that there should be criteria for the External Program
11 Review Committee to use when approving or denying a
12 request for the emergency use procedures and for
13 reviewing a license holder's response to emergency use
14 of manual restraint.

15 And finally, at that same provision,
16 9544.0130, individuals who experience significant change
17 in condition should be allowed to request the use of
18 restrictive procedure through a positive support
19 transition plan and External Program Review Committee.

20 THE HEARING OFFICER: Excellent.
21 Thank you so much, Mr. Schmidt. And like I say, we look
22 forward to additional detail on the subsequent round.

23 MR. SCHMIDT: All right. Thank you.

24 THE HEARING OFFICER: Ms. Espeseth.
25 And following her will be Theresa Vickery. Thank you so

1 much. Espeseth. If you wouldn't mind stating and
2 spelling your name, Ms. Espeseth.

3 MS. ESPESETH: Yes, I'm Jeri,
4 J-e-r-i, Espeseth, E-s-p-e-s-e-t-h.

5 THE HEARING OFFICER: Thank you so
6 much. What should we know?

7 MS. ESPESETH: I would like to thank
8 you for the opportunity to come up and speak for just a
9 few minutes about my son, who is a 21-year-old autistic
10 individual.

11 My first priority today was to speak
12 from the heart rather than speaking from my paper. So,
13 I hope I get through this.

14 First of all, I guess, I want to
15 thank DHS for my son's living situation that he's
16 currently in. He lives in a group home, it's run by
17 Meridian Services. And both DHS and Meridian Services
18 has been very receptive to our son's needs and his
19 living situation.

20 It's evidenced by them being at this
21 hearing and supporting my husband and my goals for our
22 son as he transitioned and lived in this group home.

23 He's been there for a little over
24 five years now and he's functioning very well there. A
25 number of changes have happened over the years in order

1 for him to be successful in his living situation.

2 My story is involved -- it involves
3 the use of his safety harness in his transportation.
4 When he was a seven-year-old child I was transporting
5 him in our family vehicle with my five-year-old son,
6 they were both in the back.

7 My younger son was in a car seat,
8 Tanner was just in a seat belt. And we were driving
9 down 694 and Tanner unbuckled his seat belt and reached
10 forward and opened the car door. That was the
11 right-hand passenger door of a two-door car.

12 So, I, of course, immediately slammed
13 on the brakes. And fortunately the car moving as fast
14 as it was made the door shut after he opened it, so he
15 wasn't able to fall out of the vehicle on the freeway.

16 So, I told my husband that day I'd
17 never travel with my son in the car ever again until I
18 knew he was secured. So then, we decided to use the
19 four-point safety harness that was used in his school
20 programing in our own vehicle.

21 So, we took our vehicle in and had it
22 modified so the harness could hook up to the floor.
23 It's just a simple four-point harness, looks like a
24 tic-tac-toe board on the front. It has shoulder straps
25 and hip straps. There's four different places where it

1 connects. And then he puts his seat belt on over that.

2 So, we adapted our vehicle. And I
3 also went out and immediately purchased a pair of safety
4 scissors so that I knew if the vehicle were ever to
5 catch fire or if there was a reason we needed to get him
6 out in a hurry we could cut right through that harness,
7 something I made sure has been in every vehicle that his
8 harness has been in.

9 When he was 15 years old he was in a
10 school program and he had it written into his IEP that
11 his safety harness would be used for all transportation.

12 He was on his way home from school
13 and his safety harness had been locked in his locker and
14 it was accidentally put in there and they did not know how
15 to get the locker open, so they said one day doesn't
16 make a difference, we'll just send him home.

17 I work from home, I could have easily
18 come to school to pick him up. He got on the bus. He
19 was willing to go, which surprised me in the first place
20 because this has become so much a part of his routine he
21 usually won't even go out to the vehicle without the
22 harness, but he did.

23 He went out, was on the bus ride home
24 on Highway 35 in a special ed bus and preceded to get up
25 and open the door to the bus. And if it weren't for the

1 aid that was carefully watching him on the bus, and the
2 driver, both of whose lives changed that day, he was
3 safe.

4 They were in the left-hand lane on
5 35W with two lanes to the side and he very easily could
6 have gone right down those steps. So, again, we make
7 sure in his IEP that it's important that he always have
8 the safety vest on when he's transported.

9 So, my goals are to keep him safe.
10 My goals are to keep his staff, who transport him in the
11 vehicles with the group home, and also to keep everyone
12 on the road safe.

13 Because if he gets out of his vehicle
14 or out of his seat restraint and goes after the driver
15 or distracts the driver or tries to open the doors,
16 everyone that's on that road is at risk. And I just
17 can't see that happening, I just can't allow that.

18 So, the other concerns that I have is
19 having a meeting every 90 days to review the PSTP plan.
20 That's a lot of time out of a lot of people's busy lives
21 to review something that's probably not going to change
22 very much every 90 days.

23 If we look at having 11 months to
24 institute a change or try to change a behavior, it's
25 still a short period of time in a person's life with

1 autism to try to change the way they're thinking.

2 My son recently started having
3 seizures. And in order to change his behavior plan,
4 right now we're changing medications and a lot of other
5 things that are affecting his behavior.

6 And I don't find it reasonable for
7 him to be able to make that change at the same time that
8 he's going through these other changes in his life as
9 well.

10 So, in closing, I just want to say
11 that I disagree a little bit with the disparity in the
12 fact that my husband or I can come to Tanner's group
13 home, put him in our vehicle with a four-point safety
14 harness, he can go to school every day in his
15 transportation vehicle with a four-point harness, but he
16 can't be accessing the community through the group home
17 with that harness.

18 I don't understand the difference.
19 And I also don't understand that someone that functions
20 at a three to five-year-old level should be able to
21 understand safety and keeping himself and others safe.

22 Because you don't ask a three to
23 five-year-old whether or not they want to sit in their
24 car safety seat. So, it seems a little inconsistent.
25 Thank you.

1 THE HEARING OFFICER: Thank you so
2 much, appreciate your time. And as Ms. Vickery makes
3 her way to the table, Natalie Homa, you're next.

4 MS. VICKERY: Good morning.

5 THE HEARING OFFICER: Ms. Vickery,
6 once you get settled, if you could state and spell your
7 name for our record.

8 MS. VICKERY: Theresa, T-h-e-r-e-s-a,
9 Vickery, V-i-c-k-e-r-y.

10 THE HEARING OFFICER: What should we
11 know, Ms. Vickery?

12 MS. VICKERY: I'm going to tell you.
13 First of all, I'd like to thank you for this opportunity
14 to speak on this important issue. I'm going to read it
15 because I tend to ramble and I can get off topic, so
16 this will keep me disciplined.

17 The fact that you're willing to
18 listen to feedback regarding this topic shows a
19 commitment to and understanding of the care involved in
20 dependent clientele.

21 It is my hope that a new
22 understanding of independence will become clear from
23 this hearing, especially those that are in the gray
24 area, which my son was. My name is Theresa Vickery.
25 First and foremost I'm a mom to a dependent young man

1 who has severe autism.

2 I'm also a mother of two daughters,
3 I'm married to a pretty wonderful man and father. In
4 addition to my family connections to this topic, I also
5 have a master's in social work from the University of
6 Iowa.

7 I worked for several years for the
8 Iowa Department of Human Services, as well as Lutheran
9 Social Services and Catholic Charities. I also served
10 as a parent rep on several group home overseeing boards.

11 However, my experience on this topic,
12 most of it comes from being a mom. And I wouldn't
13 change that for anything in the world. Mark, let me
14 introduce you to Mark. He's the greatest kid in the
15 world.

16 He's a 20-year-old man who happens to
17 have autism. He's nonverbal, but if he could speak I'm
18 pretty sure that he would tell you that you are the ones
19 with the problem, not him. He'd say, "Fine, thank you
20 very much."

21 If there's one thing, one gift that
22 my husband and I were able to give him is this, his
23 self-confidence. He's very comfortable with who he is.
24 It goes without saying that my husband and I love Mark
25 and would do just about anything for him. But what we

1 couldn't do is keep him safe in our own home.

2 Due to his obsessive, repetitive and
3 sometimes dangerous behavior, thus at age nine he was
4 placed in a group home with Creative Care Resources. In
5 general, Mark is a pretty happy guy as long as things go
6 as expected.

7 However, life just isn't always that
8 predictable and consistent. And this is where things go
9 horribly wrong in Mark's eyes and in his world.

10 Let me back up and tell you how
11 things were with him when he lived with us as a child.
12 As I've stated, in general he's a pretty happy guy.
13 However, we, my husband, my daughters, and myself have
14 experienced times where Mark has been violent, not only
15 to himself, but to us and to property.

16 We understand that in his mind it's
17 not personal and he doesn't mean to harm us, but he has.
18 When he was young and smaller than me, I was able to use
19 body pillows to fend him off. I'm pretty little, I'm
20 not very big. He would bite and scratch me, I still
21 have the scars of when he did that.

22 If I was able to get him in a full
23 body and squish him down to the ground, that's when he
24 would calm down. And usually I would say about 10 or 15
25 minutes later he might start to cry. And then I knew it

1 was really over.

2 Let me digress a bit here. Mark
3 needs and loves full body squishes. He has since he was
4 a baby. He would always get under blankets or pillows.
5 He needs that sensory input. He will purposely seek out
6 another person to lay on and help him count through his
7 agitation into his calming period.

8 I would defer to Creative Care
9 Resources to speak more on this, but Mark in his own way
10 asks for this. And as a parent I listen to him and
11 respect what he needs.

12 Mark has physically attacked each of
13 our daughters. I can recall a time where our older
14 daughter was probably about ten, she was on the
15 trampoline playing with him, jumping on the trampoline.
16 And he was eight.

17 He came at her in a full body attack,
18 scratching her body. And luckily my husband was home
19 and he was able to pull him off.

20 He was also physically abusive to our
21 younger daughter. She's four years younger than him and
22 he nearly killed her when she was a baby by jumping in
23 on a Pack-and-Play where she was laying before I could
24 get to him.

25 I've never seen a kid move faster

1 than Mark. He could win every Special Olympics if he
2 chose to, he just doesn't want to. And I had to pull
3 him off several times from choking her. She was a
4 selective mute until he went into his group home.

5 I called the police on him one night
6 because he attacked my daughters and myself while my
7 husband was at work. We all had defensive wounds on our
8 body and some of our dishes were broken. He was simply
9 out of control. And when he came out of it, he was calm
10 and docile as if nothing had ever happened.

11 So, when I say I get what it looks
12 like for someone with autism to be opportunel, I get it,
13 I get it. This is never ending for me. I live it 24/7,
14 it is my life, it is Mark's life.

15 I don't get to go to work for eight
16 hours and talk about it, I don't get to go visit him for
17 one hour, this is my life and it will be every time my
18 daughters have children themselves, I'll wonder and I'll
19 watch.

20 After many years of loving and caring
21 for Mark I can now tell when most of his rages or
22 behaviors are coming. Our goal quickly became how to
23 recognize and anticipate when he was likely to have
24 aggressive behavior and avoid him at all costs.

25 Once Mark has reached the point of

1 behavior the risks for others getting hurt as well as
2 himself are too great and, frankly, none of us are
3 comfortable taking.

4 And I have pictures of his
5 self-injury right here that he has done to himself. He
6 gave himself his own black eye by pulling his knee up
7 into his nose and hitting himself.

8 Being Mark's mother I have to be
9 realistic. I knew early on in his life that I might
10 outlive him. His lack of understanding of danger and
11 running into traffic and starting fires and picking
12 locks, et cetera, et cetera, makes him more vulnerable
13 and more likely to harm himself.

14 I had to come to a point that I knew
15 he could kill himself. And while it would be awful, I'd
16 miss him terribly. However, it would pale in comparison
17 if I would have to know that somehow he killed someone
18 else with his behaviors, that I could not live with.

19 How could I live knowing that he
20 harmed someone else? When he nearly killed Jenna, our
21 youngest daughter, I wondered later how would I have
22 lived through that? How would I continue to love and
23 forgive him?

24 Which brings me to today. The
25 concerns about the correct guidelines, my concern is the

1 law or the statute as written is so black and white it
2 ends up a disservice to clients like Mark.

3 I'm totally in favor of keeping folks
4 like Mark safe and evaluating procedures and policies.
5 However, there are some concerns that pertain to Mark
6 and those like him.

7 Mark craves deep pressure. We have
8 seen with our own eyes by proactively giving those deep
9 squishes we can avoid a melt-down or violent behavior.
10 By placing him under a weighted blanket, by placing him
11 in a harness when he rides in a van, Mark is less likely
12 to have aggressive behavior.

13 I've ridden in the car when Mark has
14 not been in a harness and has had behaviors. We've come
15 close to having a car accident. How could we live with
16 ourselves if we killed another family because our
17 precious son had behaviors so severe it caused the
18 driver of our car to swerve into oncoming traffic?

19 Mark gave a school bus driver a
20 broken arm one time when she tried to interfere with a
21 behavior he had. She was able to pull the bus over
22 before she ran into someone. After that he was required
23 to wear a harness at the school.

24 Just think about that for a few
25 moments. Even if he managed to get out of the harness,

1 and trust me, he knows how, he's so brilliant at getting
2 out of these kinds of things, the noise of unbuckling
3 can give you a few precious seconds to get the vehicle
4 pulled to the side of the road.

5 And as much as -- the goal is to get
6 him to participate in the community. And that's the
7 only way he's going to be able to do that is if we can
8 make the car, the van ride safe for everybody.

9 If I'm reading the guidelines
10 correctly it states that the staff must wait until Mark
11 is in imminent danger before permitting a hold or
12 restraint.

13 I'm telling you from my experience of
14 what I know about Mark, if you wait until he's in full
15 rage, you're about five to ten minutes too late. And he
16 will hurt someone or himself. And I have the pictures
17 here that will show you what he can do.

18 To be honest, this way of thinking is
19 illogical to me. Shouldn't there be a measure of
20 proactiveness when working with individuals like Mark?

21 The very reason autistic individuals
22 are placed in occupational therapy to receive sensory
23 integration, which is just another fancy way of saying
24 let's help these kids navigate and manage the world
25 without falling apart at every turn, so they don't have

1 the need to have aggressive behaviors or meltdowns to
2 cope.

3 If you look at Mark's autism from a
4 medical point of view, would you allow a diabetic person
5 to get into a diabetic coma before you intervene? Or
6 would you use all you had at your disposal to avoid a
7 potentially hazardous and fatal outcome?

8 What if Mark were to knock on a staff
9 person, knock on the clashes, what risk would the other
10 clients in the home face? And to be brutally honest,
11 this is real, who would want to work in a job like this,
12 a job where you could be harmed or killed?

13 If you know anything about group
14 homes, the turnover of personnel is high and the
15 abundance of people wanting to work them is low.

16 The people sitting with me today have
17 known and worked with Mark for 13 years. They're in it
18 for the long haul. They know Mark well and I have 100
19 percent faith and trust in them and what they do.

20 I should add that my daughter Rachel
21 is 22 and she works for the same company, not at this
22 house, but in a different one. She would have been here
23 today, but she's a senior at University of Iowa and
24 she's a psych major.

25 She will graduate in May. And she

1 loves Mark and will most likely enter into a field where
2 she will be working with kids like him.

3 So, let me conclude today by saying
4 what my hopes are for this hearing. My hope is that the
5 wisdom in this room today will guide the changes to this
6 law that will only help the clients it's supposed to
7 serve.

8 I understand that Mark's restraint
9 policy is that he must be reviewed every 90 days. As a
10 social worker and a reasonable intelligent adult, I'm a
11 stickler in the fact that time break is not realistic in
12 the real world.

13 I really don't want a staff person
14 that works with Mark to be bogged down with bureaucratic
15 paperwork. The term is too soon for me, as standard
16 social work practice is six months to yearly reviews are
17 usually standard, seem more practical and realistic,
18 especially if you have a parent or guardian agreeing to
19 that.

20 Keep in mind, too, that it takes a
21 while for these kids to learn things, if they ever do.
22 It took me two years to teach Mark how to kiss me. By
23 God I was going to do it and I did. I taught him to
24 kiss me.

25 And it took me seven years to potty

1 train, doing the same thing every day, saying the same
2 thing every day, "Poop goes in the potty, poop goes in
3 the potty."

4 Which brings me to this: My husband
5 and I are legal guardians to Mark. Why would we even go
6 through the process of guardianship only to have our
7 hopes and desires for Mark ignored? There has to be
8 room for some gray areas in these types of situations.

9 I'm here as Mark's voice. And on his
10 behalf I would like to see these guidelines given to the
11 law that would support him and have them implemented in
12 a way that preserves and respects his rights.

13 My wish would be, however unlikely,
14 for those that make the guidelines is to visit these
15 group homes for several days. A mere hour isn't going
16 to give you or anyone a real feel for someone like Mark
17 on how he lives his days and what's effective in helping
18 him.

19 The fact that I'm here with CCR and
20 all these great people is to attest to the fact that we
21 know what is best for Mark. Would it work for everyone?
22 Absolutely not. But neither do the guidelines as they
23 are written today.

24 I respectfully ask that some
25 allowance be made for those clients that are the

1 exceptions and not the rule.

2 I was once told by someone that Mark
3 was the most autistic person they had ever met. And I
4 said, "Of course he is, he's an overachiever."

5 Mark is a smart man and I implore
6 this governing body to listen to what he's saying to us
7 about his needs. In summary, I'm asking for an addendum
8 or allowance to these gray areas. Mark craves deep
9 pressure and oddly finds harnesses rather comforting.

10 None of these have ever been used as
11 a form of punishment, they're all used as proactiveness
12 to avoid those behaviors. Thank you for this
13 opportunity to speak on a subject I'm very passionate
14 about and a young man that I adore to the moon and
15 back.

16 THE HEARING OFFICER: Thank you so
17 much. I appreciate your time and contributions.
18 Ms. Homa. Following Ms. Homa, Jeffrey Eul. Mr. Eul,
19 you're going to follow Ms. Homa. Ms. Homa, if you would
20 mind stating and spelling your name for our record.

21 MS. HOMA: My name is Natalie Homa,
22 my last name is H-o-m-a.

23 THE HEARING OFFICER: Thank you so
24 much. What should we know, Ms. Homa?

25 MS. HOMA: First of all, I want to

1 thank you for allowing me to comment on the rule and the
2 proposed changes. I want to tell you a little bit about
3 myself.

4 I am a board certified behavior
5 analyst and I am also a sibling of a person with autism.
6 So, both of those things bring me a lot of passion
7 towards this issue. And my main goal really is to make
8 sure that people like my sister are allowed the most
9 effective and best practice in their treatment.

10 And so, a little more about my
11 background. I worked as a therapist after seeing how
12 applied behavior analysis therapy could be useful to my
13 sister, I began to work as a therapist with other
14 children with varying degrees of disability.

15 And through my work as a one-to-one
16 therapist I learned that not all kids were like my
17 sister with not much aggression and cute little girl.
18 So, I realized that there was quite a bit of need for
19 other procedures besides just reinforcements.

20 And realizing that with teaching
21 children communication comes problem behavior. A lot of
22 times people get used to what they had always found to
23 be effective, which might be crying or hitting or simply
24 just reaching for things.

25 When you try to teach communication,

1 it's going to help someone further down the line in
2 their life, a lot of times it comes with problem
3 behavior.

4 So, in my career, I got my bachelor's
5 in psychology and I got my master's in applied behavior
6 analysis because I wanted to make sure I understood the
7 science while it was going to change behavior.

8 In addition, I received training in
9 the system of professional crisis management, which is a
10 crisis intervention system that is behaviorally based.
11 And it was developed by a board certified behavior
12 analyst and incorporates many of the principles of
13 behavior that are allowed for effective behavior change.

14 So, being trained in the system, that
15 has helped me a lot in my work. I currently work at a
16 center that serves children with autism. And we use
17 that system there and it's been very effective for
18 making sure that we can effectively manage people that
19 do have problem behavior that requires protecting
20 themselves and other staff.

21 A little bit more about the system of
22 professional crisis management, also known as PCM. This
23 system includes physical and nonphysical strategies.
24 So, nonphysical strategies, which are helpful for the
25 prevention of problem behavior, and also physical

1 strategies that are designed for emergency use.

2 The nice thing about this system is
3 that it allows for a range of different interventions
4 based on the severity of the problem observed.

5 The point of bringing this up is that
6 I feel that some of the proposals in the rule are all
7 encompassing, but maybe don't clearly define some of the
8 terms described.

9 So, for example, in the prohibitions
10 and restrictions section of Subpart 2, it is mentioned
11 that one of the restrictions would be using prone
12 restraint, metal handcuffs or leg hobbles.

13 I'd like to propose a change to that
14 to reconsider the use of the word "prone" because I
15 think there's been a lot of misuse and misunderstanding
16 of this word.

17 One thing I'm going to reference is
18 the paper written by the Professional Crisis Management
19 Association, who has designed and regulated this system
20 of PCM. They have a paper termed "The Premature Call
21 for a Ban on Prone Restraint, a Detailed Analysis of the
22 Issues and Evidence."

23 And this was written in 2009. And I
24 reference that for you when you have time. This paper
25 talks about the fact that prone in its misuse has been

1 either incorrectly defined or hasn't even included any
2 kind of specific procedures to be laid out. And it's
3 also been incorrectly misused, basically.

4 So, I think this would be something
5 to consider when you're looking at the use of the word
6 "prone" because not all prones are created equal.

7 The system of PCM is one example of
8 how prone can be effectively applied as a physical
9 intervention to help people to deescalate and those
10 people that do require a certain level of intervention
11 to calm.

12 I also want to talk about some of the
13 other proposed rules. And this again falls under the
14 prohibitions and restrictions, using punishment of any
15 kind. So, again, as other people have mentioned,
16 reinforcement. Behavior analysis talks about the fact
17 that reinforcement should always be considered first.

18 And that is something that the
19 Applied Behavior Analysis International position
20 statement on restraint/seclusion also talks about. It's
21 definitely important to note this as well. And I will
22 reference that later.

23 But one of the things that the
24 position statement talks about is that the welfare of
25 the individual being serviced is the highest priority.

1 And I think that's in agreement with what this group
2 proposes. And that's something that I'm in favor of and
3 would like that to be included.

4 This statement also talks about that
5 a regulation that prohibits treatment that includes the
6 necessary use of restraint violates individuals' rights
7 to effective treatment.

8 The irresponsible use of certain
9 procedures by unqualified or incompetent people should
10 not result in policies that limit the rights of those
11 duly qualified and responsible for an individual through
12 the process of making informed choices.

13 Again, if a procedure is misused by
14 one person, that shouldn't be a catchall that everybody
15 should not be able to use it.

16 The other thing that Applied Behavior
17 Analysis International has put in their statement is
18 that they support the position that treatment selection
19 should be guided by the principle of least
20 restrictiveness.

21 And I think that's part of what the
22 rule is trying to do is talk about the fact that
23 positive strategies should be used.

24 However, I think that if we exclude
25 any sort of punishment procedures, that's going to be

1 failing the people that we're trying to serve.

2 Again, the paper -- the Association
3 for Behavior Analysis position on restraint and
4 seclusion discusses that the least restrictive treatment
5 is defined as the treatment that affords the most
6 favorable risk-to-benefit ratio with consideration of
7 probability of treatment success, anticipated duration
8 of treatment, distressed caused by procedure, and
9 distress caused by the behavior itself.

10 So, again, I want to make the point
11 that there is a risk of not intervening. So, when you
12 have people that are displaying severe self-injury and
13 aggression and you don't make a choice to do restraint,
14 I think that also causes a disservice to the individuals
15 that we're trying to serve.

16 And then I continue to quote, "One
17 may conclude from this premise that a nonintrusive
18 intervention that permits dangerous behavior to continue
19 while limiting participation in learning activities and
20 community life or results in a more restrictive
21 placement may be considered more restrictive than a more
22 intensive intervention that is effective and enhances
23 quality of life."

24 I think we need to consider that if
25 we're going to use nonintrusive procedures or only

1 reinforcement-based procedures, I believe that we're
2 limiting the individuals that we serve by not allowing
3 them to learn behaviors.

4 Again, some other people have spoken
5 or mentioned, if you're at a three to five-year-old
6 level or younger, which a lot of individuals I serve are
7 at that level, they cannot make decisions about what's
8 going to help them benefit later in life. They don't
9 have the ability to make those decisions. So, we need
10 to help them.

11 And I do agree that reinforcement
12 needs to be considered first. However, I have also seen
13 in my practice and through the review of literature that
14 there is a lot of times where reinforcement only does
15 not work.

16 I know that earlier it was mentioned
17 that the Hanley article on looking at functional
18 communication training with or without the use of
19 punishment has also demonstrated that sometimes the use
20 of punishment is necessary in order to teach individuals
21 to use the correct or alternative behavior.

22 So, just kind of summarizing, I would
23 like to propose changes to 16.15A about prone restraint,
24 considering the use of a modification to the definition
25 of prone. And also, just considering that that be

1 monitored and implemented according to a system of
2 crisis management, such as Professional Crisis
3 Management.

4 I would like to have you consider
5 looking at the Number 17.8J, using punishment of any
6 kind. Again, I think that punishment should be used in
7 conjunction -- if necessary to be used at all to be used
8 in conjunction with reinforcement.

9 And it should also be closely
10 monitored by a board certified behavior analyst in order
11 to ensure that it's being properly implemented. Because
12 I think that's another thing to consider is it seems
13 that the use of the definition of punishment has been
14 correctly used according to the conceptual framework.

15 However, in saying that it's not
16 necessary or at all to be used, I think that's not
17 consistent with what ABAI would say or with what
18 behavior analysts would say.

19 THE HEARING OFFICER: So, Ms. Homa,
20 is your prescription that a different word be used in
21 that rule or that punishment be defined as a particular
22 term of art?

23 MS. HOMA: I think saying using
24 punishment of any kind, I think, is a very broad
25 statement. I think if you were to include something

1 like monitoring the use of punishment, that would make
2 more sense in terms of not using punishment of any kind
3 without close monitoring by a board certified behavior
4 analyst, something to that extent. And I can submit
5 that with my written comments.

6 One of the things that is a very
7 careful consideration in the center that I work in
8 currently, if we do use any time-out, we are constantly
9 looking at data, we are there on a daily basis to watch
10 the implementation and ensure that it's be safely done.

11 Same thing with using any kind of
12 physical crisis management. Again, I think that any of
13 these things when used out of context can be
14 inappropriate and be abused.

15 And I do want to make a point also
16 that I don't believe that abuse is the same thing as
17 restraint or seclusion. I think that those two things
18 are not the same, not one and the same.

19 THE HEARING OFFICER: Any final
20 thoughts, Ms. Homa?

21 MS. HOMA: I also want to just
22 mention that 18.14Y, I would like to suggest that that
23 section be removed. It says that it's prohibited to use
24 any other interventions or procedures that may
25 constitute an aversive or deprivation procedure.

1 When I'm working with clients, my
2 goal is to teach them how to talk, whether it is with
3 sign language or augmented device such as an iPad or a
4 picture exchange communication system.

5 The point is, in order to teach them
6 to ask for things, I have to briefly withhold those
7 things to build motivation for them to want to ask for
8 those things.

9 If I just freely give them all the
10 time, I'm never able to teach them how to communicate
11 and ask for those things when they actually want them
12 and they can't get to them and they need someone to help
13 them.

14 So, in order to teach children to ask
15 for things, I would consider that may be using
16 deprivation. I would be concerned that this kind of
17 statement would be in here. I think that it could be
18 taken way too far. I think that would be one
19 application of how it can be misunderstood.

20 And then, I also just want to talk
21 about some positive examples that I have, which I'll
22 also submit in my written feedback.

23 When children or people of any type
24 of age or disability are displaying problem behavior or
25 stereotypy, which is a very common thing with autism,

1 they're doing those things because of automatic
2 reinforcement.

3 It doesn't matter what anybody else
4 is doing, it's going to happen across environments,
5 across different situations. Because it's kind of like
6 nail biting, somehow that creates satisfaction for me
7 whether or not people are watching or not.

8 In order to reduce that type of
9 behavior, the research literature shows that punishment
10 is really the most effective intervention for that. So,
11 I had a situation where we had a boy that was five years
12 old and very close to being able to be mainstreamed.

13 However, he had a lot of repetitive
14 and restrictive behavior that limited him from being in
15 a general education setting where he would probably be
16 teased by his peers if he exhibited those types of
17 behaviors. He also spoke out in class to receive
18 attention, things like that.

19 And we were able to put in a
20 procedure that functioned as a punisher. Again, I think
21 to look at the definition of punisher is to see
22 something that follows a certain behavior and results in
23 the future decrease in that behavior and frequency which
24 decreases.

25 And with this child we were able to

1 implement a procedure that involved a task. So, a
2 little fine motor task that we also noted strengthened
3 up his hand fine motor release, which he also needed to
4 practice with.

5 So, we were able to implement this
6 contingent upon any motor, which means moving his hands
7 in a stereotypically or vocal nonsense words that were
8 occurring, as well as speaking out of turn. And we were
9 able to go from close to 250 incidents of this behavior
10 per day to actually to zero. And this was only over the
11 course of a few days that we saw this reduction. And I
12 can share that data with you.

13 But again, the point that I'm making
14 is that this behavior is not necessarily something that
15 was so severe, it was just something that would limit
16 him from being in the general education setting, which
17 really he needed because he needed to have typical peers
18 in order to grow and develop.

19 So, we were able to reduce this
20 behavior and he was able to successfully transition into
21 a general education environment and has done really
22 well. So, I just want you to consider the fact that
23 punishment is not always bad.

24 And although there are some side
25 effects that have been mentioned, those are things that

1 need to be considered when you're implementing the
2 procedure and obviously to design that with
3 reinforcement as a part of the treatment plan as well.

4 THE HEARING OFFICER: Thank you so
5 much, Ms. Homa. I appreciate your time and
6 contributions to our record. Mr. Eul, if you wouldn't
7 mind stating and spelling your name for our record.

8 MR. EUL: My name is Jeffrey Eul,
9 last name is spelled E-u-l.

10 THE HEARING OFFICER: Mr. Eul, what
11 should we know?

12 MR. EUL: Thank you. I have run
13 through a gamut of emotions today from being angry to
14 being touched to being -- swinging back and forth. I
15 just want to outline a few points, a little bit of my
16 timeline with my son, Milo, he's four and a half and
17 autistic.

18 I want to outline really what I think
19 is critical, which I'm calling it balance. And I think
20 that there's really important things to both sides and I
21 appreciate some of the touching stories that we've heard
22 this morning.

23 And I just want us to reconsider and
24 make sure that the things that I find are useful for my
25 son are at least available to me, especially in the

1 environment that he receives.

2 I'm a little emotional, so bear with
3 me. My son, we knew something was wrong right away,
4 12 months, 18 months. We got in early intervention
5 through the St. Paul school system. It turned out to
6 be, pardon my being blunt, pretty worthless.

7 Basically it was through some sign
8 language teaching, some of the positive practice that we
9 see here, which I do completely agree with positive
10 practice is the best method for a lot of cases.

11 And I really appreciate the work that
12 you guys did to help bring that forward as well. So, I
13 want to be mindful of that as well.

14 But really it was about a little over
15 a year ago that my son started at the Holland Center
16 here as well. He really changed for the better. And it
17 was all through just a combination.

18 So, it was mostly positive practices
19 and mostly rewarding and mostly through teaching him to
20 do what he wanted to do. He still had to go through
21 what he didn't want to do. So, if Milo had his perfect
22 day -- this goes back to Dr. Moore, your comments of
23 what life does he want to live and what life is he
24 choosing.

25 He can't choose that, right? He's

1 not able to say he wants to go to McDonald's or go
2 swimming or do anything like that. So, we're trying to
3 get him to a point where he can function with us.

4 So, he goes through activities
5 throughout the day, but you're kind of forcing him to do
6 some of those activities in a sense. So, is that
7 punishment? I get a little concerned with how it's only
8 positively impacted.

9 So, a little more of the tangible
10 stuff that we'll go through is positive practice for
11 toilet training. So, through early intervention and
12 through the first couple months at Holland Center I
13 thought Milo would be in diapers until he was 20. I
14 thought that was never a possibility.

15 We have a 90-day ITPs where we review
16 with the parents, he's in a one-on-one setting with
17 teachers and a behavior therapist all day. It came up
18 in one of our ITPs that maybe we should try potty
19 training. And I had no idea how this was going to work.

20 We did some of the positive practice
21 and Milo went from completely diaper dependent to maybe
22 an accident a week at this point in time. So, we go out
23 to the mall, we're able to use public restrooms. It's
24 an incredible change of life for him.

25 And I think that would be really hard

1 because I did some math to try to figure out how often
2 he would have to be on the toilet to actually evacuate,
3 in a positive way I don't know how you make that happen.

4 So, I think just ask you to think
5 about those types of situations where I know there's
6 group homes and stuff and it feels like the balance is
7 towards that direction. The balance is to correct what
8 happened, right?

9 The balance shouldn't be to
10 overcorrect so far that you don't have those other
11 options available to you. So, I really just call for
12 that balance for that gray area.

13 In that one-on-one setting is there
14 ways of using -- I hate using the word "negative," but
15 punishment, right? And it's documented, what is abuse,
16 what is punishment, what is necessary, what is not
17 necessary, right?

18 It just seems so sweeping and so
19 overcorrected that that scares me. Milo is going to
20 continue to do better. I know there's negative side
21 effects to bad punishment, seclusion, like, touching,
22 terrible story earlier.

23 When Milo goes -- he went through
24 this thing a month ago where he just started tantruming.
25 And these tantrums would last 10, 15, 20 minutes and he

1 had them multiple times per day. How is he learning
2 anything when that's happening?

3 So, we implemented a small time-out
4 procedure, which is an open door, which is a teacher
5 right next to him and he just goes and kind of chills
6 out for two minutes. And we saw those tantrums go from
7 10 to 15 a day to one a day.

8 Hopefully that becomes a distinction
9 process where that doesn't have to continue, where he
10 understands that there's this impact, this impact of
11 life. That's what happens, right? You learn not to
12 touch the grill because maybe you touched it on
13 accident.

14 Not to say that it's pain that's
15 teaching because that's not the only way to learn.
16 Let's not make it that it's so sweeping in the opposite
17 direction. Let's keep some balance in this, please,
18 please, that's all I'm asking.

19 I'll submit the rest of my stuff, but
20 that's where I need to be. That's what we need from
21 Milo. I totally understand why you go that far in
22 certain cases. They're not abusing him.

23 We're using our best judgment with
24 whatever we can do because this is survival for me, this
25 is real, this isn't just a piece of paper. So, I think

1 that's all I have.

2 THE HEARING OFFICER: Thank you so
3 much. I appreciate your time and contribution. So,
4 we're going to take a one-hour luncheon recess. We're
5 going to have an advertisement from the agency panel as
6 to local restaurants.

7 But you'll want to be back when we
8 start because we're going to hear from Kim Whelan from
9 Mt. Olivet. Kim, you're going to be first. You won't
10 want to miss it, be sure to be back.

11 (At this time a lunch recess was taken from
12 11:45 a.m. until 12:45 p.m.)

13 THE HEARING OFFICER: We're back on
14 the record after the luncheon recess. We're going to
15 start the next 90-minute session with Ms. Whelan and
16 following her will be the Ombudsman for mental health,
17 Ms. Ophein.

18 So, Ms. Whelan, if you wouldn't mind
19 stating and spelling your name for our record.

20 MS. WHELAN: My name is Kim Whelan,
21 K-i-m, W-h-e-l-a-n.

22 THE HEARING OFFICER: Thank you so
23 much. Ms. Whelan, what should we know?

24 MS. WHELAN: I'm a behavior analyst
25 with Mt. Olivet Rolling Acres. And part of my job is to

1 train all the staff in positive behavior supports and
2 create the programing and write the transition programs
3 for our company and other companies.

4 I also do physical intervention
5 training and we create strategies that are positive
6 support the first three hours. And the second we do
7 basic hands, releases, things like that.

8 So, we train all of North Dakota in
9 restraint. And what we do is a side restraint, which
10 has been approved by North Dakota.

11 So, what I'm going to talk to you
12 about is the need for reasonableness with what I would
13 say would be the staff qualification and training.

14 If I look at the definition of
15 positive behavior support strategies, it means a
16 strength-based strategy based on individualized
17 assessment and emphasizing teaching a person preventive
18 and self-determined skills and alternative strategies
19 and behaviors without the use of restrictive
20 interventions.

21 To me this sounds perfect, what you
22 want everyone to do day in and day out, from the time
23 they get up, organizing the environments, organizing
24 what makes a person get up easiest during the day, do
25 you need to give them time, are there transitional cues,

1 you have reinforcement.

2 I'll make flapjacks with smiley
3 faces, whatever you have to do. These are all positive
4 things from sensory integration, how to address sensory
5 needs, how to address incompatible behaviors, can you
6 hold my books while we go through the store so they're
7 less likely to have behaviors.

8 These are all positive things
9 reinforcing alternative behaviors to the ones you --
10 communication skills, coping skills, waiting, it goes on
11 and on and on. They're all positive strategies.

12 But then when I flip the page to see
13 what one has to do to implement a positive support
14 strategy, and that would be staff training, 9544.0090,
15 staff qualifications and training, for me to do those
16 positive things that I train my staff to do, to
17 implement those, I have to complete an additional four
18 hours of training with an annual recert of another four
19 hours and documentation of that.

20 So, my fear is this: Because I see
21 very clearly -- I train people from all over Minnesota
22 and outside Minnesota on physical intervention. And I
23 hear story after story where they say -- because this is
24 kind of confusing to them. They say we cannot touch, we
25 cannot block, it's hands off completely.

1 So, if someone grabs your hair or
2 tries to choke you, no, it's hands off completely. They
3 misunderstand, so they freeze and they do nothing. They
4 freeze and the individual gets kicked out of their day
5 program because they can't block, they can't turn, they
6 can't release a shirt or grab a choke.

7 They misinterpret because they don't
8 want to get in trouble. So, my fear is these wonderful,
9 wonderful things, transitional skills, choice making,
10 environmental manipulation, best interaction, best
11 environment to put a person in to organize
12 self-regulation, all these wonderful things, people will
13 say, well, I don't have the training for that, sorry.

14 This is what in reality -- I've been
15 in this field 35 years. They freeze because they don't
16 understand. And not all of it -- at MCCP, we're more
17 skilled in this type of thing, behaviors, assessing,
18 positive supports, communication, anything to support a
19 person.

20 But once you get a little bit further
21 out, they don't have the resources, they don't have the
22 training like we do. And even the people in the metro
23 still will say no. As you've defined positive support
24 strategies, which is all good things, we can't implement
25 that.

1 So, it's going to do a disservice to
2 the individuals we serve because we're going to go back
3 to the days where we can't do anything, just let it
4 happen. We're not teaching them the skills they need,
5 organizing so much, their structure, helping them
6 anticipate, predict so that they can transition.

7 All these wonderful things that we've
8 been teaching, I don't know, for 25 years. Positive
9 peer support is not new, I understand that. I was with
10 Travis Thompson at the U, these are not new things, it's
11 just repackaged. But now it's confusing everyone, they
12 think they're new, like this brand new thing. It's not.

13 They don't get it though. The
14 public, the providers, they're going to go hands off, we
15 can't do any programing because if we do, we have to
16 spend all this money for training.

17 So, what I will ask of you to
18 reconsider is the four hours here and the four hours
19 here to develop a program, to implement a program, to
20 oversee. They're going to say forget it, I'm not going
21 to do it, it's too spendy, we don't have that kind of
22 money for training.

23 We flip staff over left and right.
24 So, they won't get the services they need. They won't
25 learn how to deescalate, they won't learn how to

1 communicate other ways. The staff won't learn how to
2 present things in a way that's choice-making for someone
3 that needs choice-making as your directive.

4 So, I'm afraid that the skills that
5 individuals need will be put to the wayside because the
6 staff will be frozen in confusion and say we don't have
7 this training, we can't implement it and we don't have
8 any time to change a program.

9 On Number C it says that I have to
10 make -- any time it's a relevant content to behavior
11 support transition program, I understand that, but this
12 transition plan, what happens if an individual has a
13 sinus infection or an abscess tooth or UTI and they have
14 two manual restraints in the day? Now I have to go
15 through all this?

16 It took me 20 hours at least as a
17 behavior analyst at 50 bucks a crack an hour to write an
18 assessment, to interview the team, to do an observation,
19 to write this transitional program.

20 My concern is they'll under report
21 restraints, which is a no-no, or they'll say hands off,
22 we can't do anything. Where the individual is severely
23 hurting themselves or other people and it's something
24 that will resolve itself, but by the time it resolves
25 itself, we have to put this in place, but it's no longer

1 needed.

2 The transitional program is good to a
3 point, I agree, because it makes you look at it one more
4 time, two more times, three more times, look at the big
5 picture, make sure you have everything covered.

6 What if it's a shorter thing? I ask
7 that the two restraints, maybe in an interval of time be
8 looked at as being there's something medically going on,
9 figure it out. But it doesn't need a transitional
10 program and a functional assessment.

11 You need to know the person needs to
12 go see an M.D. because they have a UTI or they have an
13 abscess tooth or they have something underlining. So,
14 looking at the Number 2, I don't know that that's the
15 magic number.

16 Because you can have a rough day and
17 then it won't happen for six more months, on occasion.
18 But two is going to cost a lot of money and it might not
19 be needed.

20 So, looking at the training
21 requirements for something that is positive behavior
22 supports, is that even a behavior support plan? I don't
23 even understand that definition.

24 That would be my strategies, making
25 sure there's sensory, making sure the environment is

1 right, making sure I know the triggers, making sure I
2 understand not to put him in this type of environment,
3 making sure that I'm reinforcing alternative behaviors
4 to ones that they say -- go like this, oh, what do you
5 need?

6 Those are all those positive things.
7 That's just part of my positive behavior support plan,
8 just a part of it. There's more to it. Maybe when they
9 do do something, I'll redirect them, that would be a
10 reactive strategy. But does that need all this
11 training? I don't know. It's not negative.

12 Maybe the negativity -- it says that
13 this is positive. Your definition says it's all
14 positive, basically, but the training requirements to
15 implement positive seems to not balance what's important
16 to the person. There's an imbalance right there.

17 I just -- reconsider the training
18 requirements so people don't freeze and people get the
19 services they need. There's positive and teaching
20 alternatives, teaching a lot of skills that they need,
21 reinforcing for all the things that you want to go well
22 in their lives so they can live in the home, that they
23 continue to live in the home, they don't end up in the
24 hospital.

25 The bigger picture, just because I've

1 done this for 35 years, is yes, you do have to assess,
2 but proactive strategy and the positive supports, that
3 does need some training, but it seems like a negative
4 thing, but it's not. That's the heart of my program,
5 that's where it's at.

6 The positive -- I mean, there might
7 be a couple reactive, like, walk away, give them time.
8 Does that need all that training? It just has to be
9 well defined so that I read it, you read it, you read
10 it, we all know what to do, it's very simple.

11 Mine are one page, no more, they're
12 very comprehensive. That's my signature, a one-page
13 behavior support plan that anyone can read, anyone can
14 implement and we all understand.

15 So, just balance the training
16 requirements a little bit with something that's so
17 positive, the positive support. It seems excessive.
18 And I don't think people will do it.

19 They'll say, well, they don't need a
20 program. Yes, they do, they need guidelines to work
21 with people. Because we turn over staff so often, they
22 need a guideline that is clear and teaches all the
23 things they need to know. Thank you.

24 THE HEARING OFFICER: Thank you
25 kindly, Ms. Whelan, appreciate your time and

1 contributions. Next is Ms. Ophein, following her will
2 be Tim Schmutzer of PHASE. Thank you so much, you're
3 next. If you wouldn't mind stating and spelling your
4 name for our record.

5 MS. OPHEIN: Yes, Judge Lipman, my
6 name is Roberta, R-o-b-e-r-t-a, Ophein, O-p-h-e-i-n. I
7 am the State of Minnesota Ombudsman for Mental Health
8 and Developmental Disabilities.

9 I'm here today to support the rule as
10 necessary as we begin to change the culture of the
11 services that are provided to people with disabilities.
12 The right to be free from restraint is a civil right,
13 not a treatment issue.

14 Although, it can be a component in a
15 treatment issue, but it's a civil right. The right to
16 not have your bodily parts limited except for due
17 process of law. And in this case, the rule indicates
18 that the one exception is in an emergency. We all know
19 that it makes sense.

20 And I do not mean to equate people
21 with disabilities simply to children, but we all know
22 that a parent will grab a child's arm when they're about
23 to run into the middle of the street. That's
24 appropriate to stop the potential of danger.

25 So, we know that there are situations

1 where nothing can be avoided. But the very importance
2 of the rule comes in knowing that person, knowing what
3 upsets the person, knowing what the triggers are,
4 talking to them in a way that is respectful and
5 anticipating ahead of time.

6 Too often when we look at the
7 behavior intervention reports, what we see is what
8 people did in the 15 minutes before the restraint.

9 And this rule really talks about
10 knowing the individual and saying, what happened in the
11 morning? Did they have a bad morning? Did they get a
12 negative phone call? Were they overstimulated? Were
13 they taken to the Mall of America when they can't stand
14 that much stimulation?

15 So, this is about getting to know the
16 person that you are responsible for providing treatment
17 for. In 2008, we wrote a report on the use of handcuffs
18 and leg hobbles on people with developmental
19 disabilities. And we were told that that was best
20 practice standards.

21 And we asked them for the research
22 they had done on the best practice standards. And every
23 single site they cited was criminal justice. So, they
24 were using criminal justice devices on people whose
25 behavior often was not in their control, was not

1 intentful behavior.

2 Certainly not what I would call
3 acceptable behavior, but maladaptive for what they have
4 lived, what kinds of experiences they've had in their
5 life.

6 Now, I absolutely understand where
7 all the parents are coming from. Their lives are in
8 chaos. Raising a disabled child is a very hard thing.
9 And I say that because I have two nephews with
10 developmental disabilities, a son with mental health
11 issues, and probably many family members who are
12 undeclared in there.

13 So, I know, I've watched my
14 sister-in-law who is younger than I am age to look older
15 than I am simply because of the challenges of raising a
16 disabled child.

17 But I think that people given the
18 right information, the right training and the right
19 supports can live in a relatively restraint-free
20 environment except for those cases of emergencies.

21 The reasons they were using handcuffs
22 and leg hobbles, again, was problematic, it had nothing
23 to do -- it was to teach them. It was so negative or
24 punishing that they thought that that would correct the
25 behavior, which it simply did not do.

1 The people -- someone might like the
2 feel of someone's hair, so they go up and touch it.
3 Now, they need to be taught to ask permission and not to
4 breach boundaries. But is that really a reason for
5 handcuffs and leg chains, leg hobbles, whatever you want
6 to call them?

7 One was for touching a pizza box.
8 One young man was restrained 295 times in a year and
9 they said, oh, that's what his program required us to
10 do. So, whose being programmed? Is he learning
11 anything or is his staff simply responding?

12 In our research we talked to many
13 people in the field. I don't purport to be an expert in
14 any one of these clinical fields, but I am an expert in
15 humanness, in how we treat people, the kindness, the
16 dignity, the respect, even with people who are doing
17 things that we might not like.

18 We talked to psychologists, school
19 psychologists, behavioral analysts and any number of
20 professionals. And universally what they told us was
21 punishment doesn't work. It might have a very
22 short-term effect to moderate behavior.

23 An example for that would be if I get
24 a speeding ticket, the next time I get in the car, I'm
25 looking around, are the police there. But six months

1 later I'm not thinking about that ticket I got, it is
2 not enough of a deterrent.

3 If it were, we wouldn't have
4 recidivistic rates in prisons that we have and some of
5 the other places. Punishment alone does not work. And
6 I don't believe punishment works at all.

7 Natural consequences work. If I
8 break my cell phone, I don't have it to use the rest of
9 the day until I'm in a position to either get another
10 one or if I can't afford it, I go without. That's a
11 natural consequence. But punishment is something that
12 does not work.

13 Minnesota is actually behind many
14 states. Many states have banned seclusion and restraint
15 and most often it is in the social service world or the
16 school world. But even some states, like Ohio, have
17 banned even in prisons and jails. Now, if they can do
18 that, I would challenge Minnesota to say why can't we?

19 I understand that there are concerns.
20 We are talking about a culture. Unfortunately, I worry
21 that it's a culture of punishment, a culture of
22 seclusion and restraint. And changing a culture takes
23 time.

24 I have great empathy for the
25 difficulty that the providers will have and the

1 confusion that's out there. Because we are talking
2 about the broad spectrum of people highly trained in
3 behavioral analysis down to a high school student that
4 comes in after school to help out in a group home.

5 So, there will be a lot of
6 challenges, but I would challenge to say we have to
7 start someplace. It's just like banks don't like
8 regulation, but at the end of the day when the
9 regulation comes, they may fight them, but when they
10 come in, they adjust the business model to adapt.

11 This case is unique in a sense
12 because not only does DHS have to meet the standards of
13 Minnesota rule writing process, which we are here to do
14 today, but they also have to meet the expectations of
15 the federal court in the federal class action lawsuit
16 referred to as the Jensen settlement agreement, which
17 absolutely requires the Department to eliminate these
18 mechanical restraints.

19 And we've been working towards that.
20 But the other thing it must do -- so, the judge will
21 determine whether or not the state as a whole, which is
22 everybody, not just DHS, but the state as a whole is
23 living up to the agreement made with DHS.

24 But they also must meet the
25 requirements of CMS under the home and community-based

1 services rule where they were asked to develop some
2 common standards for seclusion, restraint, some
3 different approaches.

4 And the Department of Justice has
5 been looking extensively at the Olmstead mandate, which
6 is not the least restrictive, but the most integrated.
7 And the most integrated is not being --

8 THE HEARING OFFICER: Let me just ask
9 you, as to the Jensen settlement, it's my understanding
10 that the obligation under the settlement was that DHS
11 propose, not a bound. That the request for comments was
12 its -- what was the obligation that it agreed to, which
13 is we will develop something, we'll gather the advisory
14 group, we'll propose.

15 Whether they get adopted, whether
16 they're approved is another question. It's not
17 something that was the feature of the settlement. Was
18 that your understanding?

19 MS. OPHEIN: Well, there are features
20 of the settlement and then there's the spirit and intent
21 of the settlement. I agree with you, it said DHS should
22 write a new rule, which they have done. And we are
23 going through the rulemaking process.

24 But I have spent since 2008, but in
25 specific, since 2011 as a consultant to the court

1 monitor on this. And there were many affirmations made
2 by the Department about what was going to be done and
3 what is the purpose of this.

4 And I know the federal judge is very,
5 very concerned if we meet the technicalities of the law
6 and totally miss the spirit and intent of the settlement
7 agreement.

8 So, I can't speak to what a federal
9 judge will do, but I know that there's broad expectation
10 that they will live up to both the spirit and intent as
11 well as the letter of the agreement.

12 THE HEARING OFFICER: Indeed.

13 MS. OPHEIN: With the CMS rules for
14 home, community-based waived services, DHS went beyond
15 the settlement agreement by saying we're going to make
16 it across all of 245D rather than just people with
17 developmental disabilities.

18 Our argument at that time was it
19 should apply to all facilities because if it's not okay
20 to restrain a person with development disabilities, why
21 is it okay to restrain anyone else?

22 I would fight like heck if someone
23 tried to keep my arms behind my back against my will or
24 tie my legs up or sit on me. And I believe we should
25 treat people as we would want to be treated.

1 So, I thought it should be all of
2 245A. They went with 245D and then realized the
3 settlement agreement said, "But for all persons with
4 developmental disabilities."

5 So, they kind of have this hybrid
6 that says anyone under 245D and anyone with
7 developmental disability, wherever else they might be
8 that is not a 245D facility. And I agree that that does
9 create some confusion for other providers.

10 Or the dichotomy is you would say
11 with the -- what would happen with a child with
12 developmental disability in a day care versus a
13 nondisabled one?

14 I don't agree that they can't use
15 tokens. The tokens are allowed, they can't be taken
16 away once earned. Just like our paychecks are not taken
17 away once we have earned those dollars.

18 Yes, we pay consequences for choices
19 we make, but many of the people we're talking about here
20 are not making choices, they're responding to their
21 internal voices as well as externally what they have
22 learned to expect.

23 I'm just trying to keep this as short
24 as I can because I could probably expound on this.

25 THE HEARING OFFICER: I'm mindful

1 that you have some scheduling constraints, but there are
2 other folks we need to hear from. So, if there are some
3 final thoughts that you might have. Mindful that you
4 can write in for 20 days.

5 MS. OPHEIN: Yes, and I will do that
6 if I feel like I can't get the significant points down.
7 To succeed -- I agree there's a lot of confusion.

8 So, for this rule to succeed as
9 envisioned, it will take DHS to make training available
10 in enough quality, but also enough quantity so that you
11 won't have everyone out there being afraid to turn
12 around, being afraid to move, being afraid to do
13 anything.

14 I'm speaking today for the many who
15 have been subjected to these practices. As I said
16 before, restraint is necessary, it's very limited
17 circumstances, but not nearly as many in which it has
18 been used in the past.

19 Punishment is an aversive. While
20 some support the concept of such punishment, people live
21 in homes with providers who do not have trained
22 professionals always at their availability. So, you
23 need a consistent rule across the board so everyone
24 knows what to do.

25 Unfortunately, Minnesota has lacked

1 for a number of qualified behavioral analysts throughout
2 the state, but I think that's beginning to change. So,
3 we need to get that out there.

4 I want to tell you about the stories
5 of people who were punished for what I would call silly
6 things. If punishment were used only in those
7 high-theory situations with a trained professional, that
8 might be one thing.

9 But the day-to-day lives of people,
10 whether it's a restraint or aversive, a loss of the use
11 of the phone because they talked two minutes longer than
12 the stated time on the wall. You and I don't have a
13 stated time on the wall. Maybe when we had teenagers we
14 had a guideline, but we don't do that.

15 No visitors because the staff don't
16 like the friends or relatives of the person that they're
17 serving. Withholding mail because it might contain
18 some -- I mean, they withheld a birthday card from
19 someone because sometimes the mother upsets the person.

20 Those are all aversive procedures,
21 not positive procedures. It would be better to give
22 them the card and sit with them and if they get upset,
23 help them process this, not just withhold the mail
24 because you think something might happen.

25 Restraints cause trauma, they cause

1 trauma for everybody involved, the person being
2 restrained, the person executing the restraint, and
3 anyone witnessing the restraints. So, you have a lot of
4 traumatized people by the use of restraints.

5 It's humiliating to people, it
6 destroys their self-esteem, and often for things that
7 the person has trouble controlling on their own.

8 People who have been subjected to
9 some of these restraints, they become one of two things,
10 they become angry or they become passive. Passive to
11 accept whatever happens to them, not in charge of their
12 own destiny.

13 And yes, many of these individuals
14 need help in choosing their own destiny, I'm not
15 proposing that they all function at a level of cognition
16 that allows them to make these decisions.

17 They have to be guided, they have to
18 be taught, they have to be helped in that balance of
19 what's important for them and what's important to them.

20 Positive includes tone of voice,
21 asking rather than ordering. Respect for differences,
22 it works. We have to start somewhere to change the
23 culture of seclusion, restraint, and punishment. We've
24 seen it work when it's done right.

25 If I trust you I will more likely

1 respond to what you want me to do than if I'm afraid of
2 you, in which case I don't trust what you have to say.
3 I know there's a fear of demittance. And in the chaos
4 of change, there will be some who do that.

5 I would challenge providers to think
6 about what is my new business model in a new world
7 order? Because the clients were easy to serve, they
8 have no behavior issues, they have no problems.

9 If we follow Olmstead in the state of
10 Minnesota, they're going to be out in a more
11 self-directed life and more integrated into the
12 community. They will still need support, but their life
13 will be more of a balance for them.

14 That means those who need group homes
15 and some of these other settings will be the people left
16 to fill some of the vacancies than some of the people
17 who have moved on into the community. I don't minimize
18 in any way how difficult this change will be, but we
19 have to start somewhere.

20 THE HEARING OFFICER: Thank you so
21 much, appreciate your time. Mr. Schmutzer. And as he
22 makes his way, Joe Fuemmeler, you'll be following
23 Mr. Schmutzer. Mr. Schmutzer, if you wouldn't mind
24 stating and spelling your name for our record.

25 MR. SCHMUTZER: Certainly. Tim

1 Schmutzer, S-c-h-m-u-t-z-e-r.

2 THE HEARING OFFICER: Mr. Schmutzer,
3 what should we know?

4 MR. SCHMUTZER: Well, I'm a service
5 provider, I work for PHASE, Inc. We are a licensed 245D
6 licensed provider of employment -- supported employment,
7 rehabilitation, structured day, and pre-vocational
8 services in out state Minnesota, rural east central
9 Minnesota. We serve about 270 adults with developmental
10 disabilities.

11 THE HEARING OFFICER: Can you give us
12 an idea of the service territory?

13 MR. SCHMUTZER: Pine County down to
14 Chisago County across to Kanabec and Isanti and almost
15 to Carlton.

16 THE HEARING OFFICER: Thanks so much.

17 MR. SCHMUTZER: You're welcome. I'm
18 speaking on behalf of PHASE, as well as being a member
19 of the Minnesota Organization for Habilitation and
20 Rehabilitation, MOHR today.

21 At MOHR we have and continue to work
22 on actions and advocacy efforts aimed at enhancing the
23 quality and the future viability of services delivered
24 to individuals with disabilities.

25 As part of this effort we, the last

1 couple months, have met with the Minnesota Disability
2 Law Center, ARC Minnesota, and ARRM, and brought two
3 issues that we feel are relevant and important to the
4 table regarding this proposed rule.

5 First, we focused on the
6 establishment of a minimum threshold of the quantity of
7 emergency use of manual restraints required to trigger
8 the component of a positive support transition plan.
9 I'll talk a little bit about the justification behind
10 that.

11 And, secondly, we share in the
12 concern that the proposed rule as written would
13 segregate and isolate individuals with certain
14 characteristics, namely, from our perspective, dementia,
15 memory loss, and brain injury because of the way in
16 which the definition of mechanical restraint is outlined
17 in the proposed rule, along with the failure of the
18 proposed rule to provide for an exception process in
19 these limited circumstances.

20 First, I want to express a really
21 deep appreciation for the movement to repeal a very long
22 overdue adjunct in repealing Rule 40. I think we've
23 heard today how ineffective it can be. And it's good
24 that we are developing systematically a more positive
25 service delivery model.

1 I think it's truly a monumental
2 moment and it carries a lot of potential to
3 systematically improve services and supports if it's
4 implemented thoughtfully and comprehensively and
5 expertly.

6 Conversely, if it's implemented, we
7 risk losing that potential, losing it to mediocrity if
8 it's compelled by hastiness, complexity for a removal of
9 the Department from the very services it seeks to change
10 or the failure to adequately fund the money to make the
11 change.

12 Repealing Rule 40 is necessary but
13 not sufficient action needed to realize the objective of
14 the Department as stated in the Statement Of Need And
15 Reasonableness.

16 Proposed Rule 9544 reflects a needed
17 step towards the objective, but the specific provisions
18 of the proposed rule fail to effectively support the
19 Department's objective as stated to improve the quality
20 of life of persons. And if it's implemented as stated,
21 it will negatively affect service recipients in its
22 current form.

23 In concert with the recommendations
24 from the Minnesota Disability Law Center, we recommend
25 modification to the proposed rule language to

1 specifically exclude from the definition of a mechanical
2 restraint "the use of an auxiliary device to ensure a
3 person does not unfasten a seat belt in a vehicle when
4 they reasonably pose an imminent risk or serious injury
5 to themselves or others."

6 At MOHR we went a step further and
7 wanted to specify the circumstances in which this would
8 be excluded, targeted to memory loss caused by dementia
9 or brain injury.

10 As an individual provider of
11 transportation services in out state Minnesota, it would
12 cover millions of miles of transportation here. I can
13 tell you it's the most dangerous service we can provide.
14 Nowhere else are the consequences of actions, compounded
15 by the actions of others, nature of physics so
16 significant and potentially deadly.

17 Because of this it's crucial to the
18 safety of every passenger that the driver is focused,
19 unobstructed, and free from distraction. Part of our
20 service at PHASE is to provide transportation to and
21 from the individual's home, to their work or service
22 site and back.

23 We use 12-passenger vans and up to
24 28-passenger buses in order to accomplish this. The
25 vast majority of time it's peaceful, comfortable, and

1 safe. When behavior interruptions do occur there's
2 typically a staff member on board to assist.

3 There are situations when behavioral
4 disruptions threaten the safety of everyone in the
5 vehicle, along with other vehicles nearby.

6 And the vast majority of situations,
7 almost all the service providers at MOHR we spoke with
8 explained how they utilize positive programming,
9 temporary additional support and staffing and can
10 successfully mitigate the threatening behavior or
11 dangerous act.

12 Sometimes that's not enough, it just
13 simply is not enough. There are rare and incredibly
14 dangerous circumstances, we've heard of at least one
15 today already, in which positive support strategies or
16 additional staffing failed to achieve safety.

17 They're individuals, for example,
18 with memory loss due to brain injury, dementia or other
19 neurological degenerative diseases that they may not
20 remember that they need to wear their seat belt. They
21 may not remember that they are on a moving vehicle and
22 will attempt to leave the vehicle while it's moving.

23 THE HEARING OFFICER: So,
24 Mr. Schmutzer, just so I can understand, you would
25 modify mechanical restraint to not only include the seat

1 belt, but the auxiliary device as well?

2 MR. SCHMUTZER: Correct.

3 THE HEARING OFFICER: If that were to
4 happen would that concern be addressed or have I missed
5 a piece?

6 MR. SCHMUTZER: It would partially
7 addressed.

8 THE HEARING OFFICER: Okay. Tell me
9 the other part.

10 MR. SCHMUTZER: The second piece
11 would be through allowing for the monitoring and
12 oversight of an auxiliary seat belt device as an
13 exception through the External Program Review Committee.

14 So, we're proposing two changes in
15 the rule, which will be submitted in writing as well.
16 That one excludes under manual restraint the use of the
17 auxiliary belt. And two, provides a mechanism for which
18 it can be regulated and monitored, evaluated, and
19 planned around.

20 THE HEARING OFFICER: I'm just going
21 to yield myself for just a moment here. If folks have
22 drafting suggestions or modifications, I think even
23 though the process contemplates a different result, as a
24 practical matter, if you want the agency panel to
25 consider that, don't wait until the end of the 20-day

1 comment period.

2 Because if you're there and they have
3 five working days for rebuttal before the rulemaking
4 record closes and you have a 15-page set of written
5 interlineations, that won't get the kind of thoughtful
6 consideration, with regret, because time is what it is.

7 If you have interlineations and
8 modifications, this word should be changed to that word,
9 it's not a requirement, you have the full 20 days and
10 you can write multiple times. There's no page limit and
11 no number of time limit.

12 But if you have specific drafting
13 suggestions, as a practical matter, you will be more
14 effective in persuading the agency panel if they have
15 some days to think about that and huddle about that,
16 rather than you using all of your 20-day comment period
17 and getting it in at 4:20.

18 This is just advice. You get full
19 credit by suggesting your regulatory revision at the
20 last minute. But as a practical matter, to persuade the
21 folks to whom the delegation has been made, and I think
22 folks have some good ideas in this room, to have those
23 fully and thoughtfully considered and shared with other
24 folks, if you get that in sooner rather than later.

25 Particularly if you know today what

1 you would suggest, I would urge you to quickly submit
2 those comments so that they can have the most number of
3 those 20 days to consider your various suggestions. I
4 appreciate you giving me some time. Mr. Schmutzer.

5 MR. SCHMUTZER: Thank you. Now,
6 where was I?

7 THE HEARING OFFICER: You are on seat
8 belt, as well as the adaptive device.

9 MR. SCHMUTZER: Thank you. So, there
10 are situations, again, limited situations in which some
11 individuals may not even be aware that they're riding on
12 a vehicle. And those are the situations we're focused
13 on.

14 Alternative interventions have been
15 attempted, positive reinforcement, support plans,
16 reminders, extra staff, attempts to eliminate the
17 underlying cause of behavior has been unsuccessful due
18 to the loss of long or short-term memory.

19 And, as some might suggest, that's
20 why the emergency use of manual restraints can still be
21 allowed. We believe that's ill-advised. It is
22 incredibly dangerous on a vehicle that is either moving
23 or trying to stop or get off the road, it's dangerous on
24 a vehicle with 20 or more passengers to the person, to
25 the driver, to the other passengers.

1 And it's very difficult for the staff
2 member, as an individual said earlier, traumatizing.
3 Restraints are -- and I wholeheartedly agree, they're
4 traumatizing both to the individual and in these
5 circumstances, most certainly to the staff. We've lost
6 more than one very, very qualified staff when these
7 situations have arose.

8 The proposed rule not only fails to
9 provide for that exception of definition, but also does
10 not provide for the exceptions of process that I spoke
11 to briefly.

12 Speaking as an individual service
13 provider who believes equally in person-centered
14 positive supports, free from restraints and ideally free
15 from restraint 100 percent of the time, I'm not willing
16 to risk human lives in these limited circumstances.

17 Service providers have and will demit
18 individuals who they cannot reasonably and safely
19 support. And specifically in the provision of
20 transportation, nowhere else does the ability to engage
21 in an exception process more important.

22 When we talked to some of the MOHR
23 members, and MOHR is comprised of about a hundred
24 service providers representing or serving about 19,000
25 Minnesotans with developmental disabilities, we asked

1 for any examples, is this real, do we need to bring this
2 up as a concern, do we just let it go in the proposed
3 rule.

4 And to our surprise, there were many,
5 many stories. And I just wanted to share a couple of
6 them. One MOHR member, service provider, described a
7 situation in which in 2014 they were, of course, under
8 the new statute and positive support transition plan,
9 transitioned away from an auxiliary seat belt device, a
10 seat belt buddy.

11 And within months or across those
12 months the individual repeatedly unbuckled their seat
13 belt, aggressed towards others, fell down almost every
14 time while the vehicle was in motion.

15 And despite the positive support
16 transition plan, seat assignments, additional staff, the
17 provider did eventually discontinue transportation
18 service to the individual after they unbuckled their
19 seat belt a hundred times over a two-month period.

20 We believe the rigidity proposed will
21 virtually ensure that this individual will become more
22 socially exploited and less integrated into her
23 community. The provision of the proposed rule creates
24 such a consequence, fails to rationally relate to the
25 Department's judgment.

1 Another MOHR member described that
2 years ago they had used a seat belt guard with an
3 individual who was experiencing exacerbations and
4 worsening of her symptoms brought on by Alzheimer's.

5 And the short period of time which
6 they were allowed to use the seat belt guard ensured
7 that there was uninterrupted, continued services. Under
8 the proposed rule, that would not occur, it would be
9 prohibited.

10 And lastly, again, a similar story, a
11 young man who was on a positive support transition plan
12 in 2014 to eliminate the use of an auxiliary seat belt
13 device. And while that resulted in partial success, it
14 wasn't enough because the near misses still occurred,
15 pulling over multiple times in heavy traffic when the
16 individual unbuckled.

17 And, finally, when the individual
18 attempted to elope in heavy traffic, the provider deemed
19 that the most ethical and prudent decision was to
20 discontinue that service under those circumstances.

21 And that individual no longer
22 receives transportation service. And again, is less
23 integrated into the community as a result of such.

24 The proposed rule must allow for an
25 exception process for the use of auxiliary seat belt

1 devices and limited circumstances. I believe it
2 protects the rights and safety and access to the
3 community for individuals.

4 I'll refer to what we haven't read
5 and specifically state where that exceptions process
6 would occur. But we've already heard that individuals
7 have lost access to the community and services because
8 that exception process is not in place.

9 And, finally, we recommend that the
10 proposed rule be amended to identify when a positive
11 support transition plan must be developed because of the
12 repeated implementation of the emergency use of manual
13 restraints.

14 The current DHS instructions for
15 publications require that the positive support
16 transition plan occurs when a person and their team
17 identify the need for the therapeutic fading of a
18 prohibited procedure or if a person requires multiple
19 uses of a manual restraint. So, we take that to mean
20 more than one.

21 I believe in 2014, in about a
22 14-month period, the Department received roughly 12,000
23 behavior intervention reporting forms. I'm assuming
24 many of those were EMRs or all of them were EMRs.

25 With the requirement of more than one

1 a year, we have reason to believe that there's not
2 adequate resources or oversight by the Department or
3 Ombudsman's office or by providers or the system of
4 service provisions, State of Minnesota, i.e., behavior
5 analysts or specialists, to be able to effectively
6 develop positive support transition plans for those who
7 are most in need.

8 Because instead of focusing on the
9 group that most needs them, that group set has been
10 expanded to everybody who endure more than one EMR
11 during any given year.

12 It's not advisable to restraint and
13 EMR should be avoided. And that shift in Minnesota's
14 system will occur and, I believe, reduce the number of
15 EMRs. And overusing or overacquiring positive support
16 transition plans will, in essence, water down the
17 effect -- the positive effect that the Department
18 intends to create.

19 Finally, I just want to reiterate,
20 besides those two changes, appreciation again to the
21 Department and the Court for engaging in this exchange
22 and the transformation of this system in Minnesota.
23 Thank you.

24 THE HEARING OFFICER: Thank you so
25 much, Mr. Schmutzer, appreciate it. Mr. Fuemmeler. As

1 you're making your way, Ms. Bender, you'll be following.
2 Please. Mr. Fuemmeler, if you could state and spell
3 your name for our record.

4 MR. FUEMMELEER: My name is Joe
5 Fuemmeler, that's F-u-e-m-m-e-l-e-r.

6 THE HEARING OFFICER: Mr. Fuemmeler,
7 what should we know?

8 MR. FUEMMELEER: I want to thank you
9 for listening to me in this process. I'm a program
10 director at Chrestomathy Center.

11 THE HEARING OFFICER: Could you spell
12 that for me?

13 MR. FUEMMELEER: Sure.
14 C-h-r-e-s-t-o-m-a-t-h-y.

15 THE HEARING OFFICER: Thank you so
16 much.

17 MR. FUEMMELEER: We're a day training
18 habilitation center for adults with intellectual
19 disabilities. And in particular we serve a lot of
20 people with challenging behavior, dual diagnosis of
21 mental health issues. And as such would be really
22 affected by this rule.

23 We've been in business for 30 years.
24 I've been with the company for 15 of those years. And I
25 participated in the Rule 40 Advisory Committee meetings,

1 as well as other meetings regarding this rule.

2 A lot of people have talked already
3 about concerns of providers. And I'd like to say that
4 Barb Turner's comments from ARRM, Steve Schmidt from the
5 Minnesota Disability Law Center's comments, Kim's from
6 Mt. Olivet Rolling Acres, and the most recent comments
7 from PHASE are all concerns that we share. So, I won't
8 go over them a lot.

9 Part of what I want to talk about is
10 in our commitment to moving forward on positive behavior
11 supports, our commitment to person-centered planning,
12 and the reduction of the use of restraint, that we look
13 at how reasonable this rule is in achieving those goals.

14 Many of us have the capability and
15 the understanding of these concepts to work on these
16 issues of reducing manual restraint. Part of what I
17 want to know is how willing providers will be and how
18 willing the staff will be, given the constraints of the
19 rule right now.

20 One of those things is cost, one of
21 the concerns. And one of the things in the Statement of
22 Reasonableness is the estimated cost that was brought up
23 by Steve earlier and some of the unintended consequences
24 that might come from an estimate that is incorrect.

25 I will start with training costs. If

1 you look at what some of these things might cost a
2 provider, there's the cost of the person who is
3 training, whether it's in-house or out of house.
4 There's the cost of paying employees while they're being
5 trained.

6 There's the cost of paying the
7 employees who are covering for those staff while they're
8 away at training. So, those are definitely costs that
9 will be there.

10 For the initial training for that
11 staff group of 100 for a year, you would want to take a
12 look at the turnover rate and figure into that -- figure
13 into the cost the amount of initial training for that
14 turnover.

15 You want to take a look at ongoing
16 training costs and cost for training due to the revision
17 of a positive support transition plan. Because there's
18 a requirement for training after any changes to those
19 plans. So, those are just some of the factors that
20 would go into the training costs for a provider. A lot
21 of staff hours.

22 There's also the cost for support,
23 the increase of staffing that's needed during behavioral
24 crises in order to avoid emergency use of manual
25 restraint using other techniques, having more staff

1 there to keep others safe.

2 If a manual restraint is used and a
3 positive support transition plan is needed, as Kim
4 mentioned earlier, it takes a lot of staff hours and
5 attention to develop that plan, to implement that plan,
6 to train that plan, and to review that plan throughout
7 the year.

8 There's also an increased need for
9 staffing in transportation, as has been reiterated
10 several times today. If you put a staff on instead of
11 using a seat belt device, that cost would be figured
12 into a daily -- that would be a daily cost for an
13 individual.

14 So, I think the costs may be grossly
15 underestimated for some providers in particular. For
16 providers such as ourselves, who have knowledge and
17 expertise in dealing with and serving people with
18 challenging behavior, they tend to magnify because
19 people come to us for those services.

20 And we have an extraordinary amount
21 of people who have high needs. So, taking this example
22 of one provider and using that as an example for the
23 cost may not reflect that specialized providers, such as
24 ourselves, have more of these individuals to serve.
25 And, therefore, there's an exponential cost increase for

1 us.

2 THE HEARING OFFICER: So, tell me,
3 Mr. Fuemmeler, are there added costs that the day
4 training and habilitation program would undergo because
5 of what you might be able to do if there were a problem
6 during the workday?

7 MR. FUEMMELER: There are costs as
8 far as keeping people in their employment settings.

9 THE HEARING OFFICER: Right. What
10 I'm interested in is your company's experience. I know
11 that you spoke eloquently about your client partners'
12 experience in the group home setting, but are there
13 impacts that you would be able to talk about from if the
14 rule is implemented, how your operations would change?

15 MR. FUEMMELER: Sure. I think for
16 our provider and for our services, we would be looking
17 at the transportation, of course, which we provide for
18 our clients. So, we provide staffing for that, that
19 would definitely be one.

20 And because we are open only during
21 the day, the cost I outlined before as far as training
22 and providing coverage for that.

23 I don't know if there's anything
24 additional other than occasionally needing to go out to
25 a community job site to assist with someone who's having

1 a behavioral crisis, which is sort of an emergency
2 response.

3 THE HEARING OFFICER: Okay.

4 MR. FUEMMELEER: So, with these added
5 costs we want to take also a look at whatever the rule
6 puts forward is useful. If we're going to have the cost
7 in the monetary cost, as well as the time and attention
8 cost of the staff, I think it's important to take a look
9 at the requirement for the positive support transition
10 plan, the frequency of it, whether having two holds in
11 365 days is not a good number.

12 I think other recommendations I've
13 heard was maybe three holds within 90 days or four holds
14 within 120. I think it would address some of the
15 concerns that Kim brought up earlier and make that
16 process more useful for providers instead of just being
17 an added burden.

18 I think the frequency of review for a
19 positive support transition plan could be extended
20 further, as was brought up by other people, that the
21 amount of change that happens within 90 days may not be
22 significant enough to require that.

23 I think it's important to take a look
24 at the online behavior intervention report form and how
25 the information is used.

1 If the form could be revised and
2 shortened to the crucial aspects that would be necessary
3 for DHS to oversee what's going on, it would reduce the
4 amount of time that was put into meeting that
5 requirement. And providers would be more willing if
6 they could see the usefulness and how it plays out.

7 And as Kim mentioned, the training
8 requirements are another thing that we would want to
9 make sure we saw the usefulness of as a provider.

10 In general, there's a lot of very
11 good and positive things in the list of required
12 training, but my concern is that the sheer volume of
13 that may not lead to the actual results that we want to
14 see, it might just lead to people having paperwork
15 compliance with the topics that are listed. So, it
16 would be good to examine that as well.

17 And, finally, in talking about the
18 willingness of providers to step forward and work with
19 these individuals, which I absolutely love working with
20 some of the people that we work with who have these
21 challenging behaviors.

22 I think we have to take a look at the
23 overall stress that it does put on a provider. If in
24 the implementation of this rule if we can revise some of
25 those things, I think that would be lessened.

1 I think the managers and the direct
2 care staff, if they are able to see the usefulness
3 and -- of the reporting procedures and it's clear, it's
4 useful, it makes sense and it provides good results for
5 the individual, then they would be more willing to stay
6 on with the providers instead of freezing, as Kim had
7 mentioned, and also just fleeing from the job because
8 they don't feel safe.

9 I think it's important to consider
10 that in the cost as well. If we don't have a system
11 that works well, the people who step up to be a part of
12 it may not do so.

13 And, lastly, I want to bring
14 attention to one individual that we serve and the
15 definitions with mechanical restraint.

16 We have currently a definition of
17 mechanical restraint may include devices that a person
18 wears of their own choosing that helps them to resist
19 their urge to self-harm.

20 We have a person, a man, in his 40s
21 who has worn arm braces for many years. And they're
22 more of a comfort item. He's able to put them on
23 himself, he's able to rotate them so that they offer
24 full bending of his arm.

25 And we have tried to eliminate them

1 because they appear to be mechanical restraints, we
2 tried to find alternatives, but his self-injurious
3 behavior has increased.

4 And we're concerned about
5 jeopardizing the one good eye that he has. He's
6 detached the retina in one of his eyes from repeated
7 hand-to-head hits over the years.

8 So, we're concerned about him and
9 others like him in the state of Minnesota who may be
10 asked to get rid of these devices because they appear to
11 be mechanical restraints, without taking into
12 consideration the person-centered nature of allowing him
13 to have a device that does not limit his freedom, that
14 seems to provide him some comfort and some self-control
15 over his urges.

16 So, I'd strongly want the people
17 reviewing this rule to consider how that might fit into
18 their definition of a mechanical restraint and whether
19 or not it might be excluded. Thank you.

20 THE HEARING OFFICER: Mr. Fuemmeler,
21 one question before you go. And I don't mean to bring
22 you back on costs, but in thinking about your firm's
23 transportation-related costs, your training-related
24 costs, your reporting-related costs, and your community
25 assistance cost, four categories that you mentioned

1 about compliance, do you imagine that within the first
2 year of the effective date of this rule that your firm
3 would have \$25,000 in such costs?

4 MR. FUEMMELER: If you look at just
5 the amount of cost it takes to support people with
6 transportation and behavior intervention, the \$25,000,
7 the cost of employing one person, one staff person who's
8 a direct care professional for a year, with benefits and
9 wages, you're getting close to that number right there.

10 And if we have to provide one-to-one
11 support for two clients, you've already crossed it. Not
12 to mention the training hours that I already mentioned
13 we'd have to do regularly.

14 So, I could ask our business
15 administrator to put together some numbers and submit
16 those later, but in just looking on the face, the cost
17 of employing one employee for a year would bring us up
18 to there.

19 THE HEARING OFFICER: My second
20 related question is, does your firm have less than 50
21 full-time employees?

22 MR. FUEMMELER: No.

23 THE HEARING OFFICER: Okay. Thank
24 you. And grateful for your time and contributions to
25 our report. Ms. Bender. And as she makes her way, Erin

1 Today, you're next. Ms. Bender, if you wouldn't mind
2 stating and spelling your name for our record.

3 MS. BENDER: Jean Bender, J-e-a-n,
4 B-e-n-d-e-r.

5 THE HEARING OFFICER: Thank you so
6 much, Ms. Bender. What should we know?

7 MS. BENDER: I am representing today
8 the Autism Society of Minnesota or AuSM. I am a board
9 member and their Chair of their advocacy committee. I'm
10 also the parent of an adult with multiple disabilities.

11 So, thank you for the opportunity to
12 speak. A high number of individuals with autism are
13 among those for whom restrictive interventions and
14 aversive and deprivation procedures are used.

15 So, we at AuSM appreciate and support
16 the Department of Human Services' proposed changes, for
17 the most part, and will be providing written testimony
18 that speaks to specific recommendations.

19 I want to speak today as my son's
20 parent. I often communicate best by telling a story, so
21 I want to use my time today to provide a concrete
22 example of how effective positive supports can be.

23 David is now 28 years old, he has
24 multiple disabilities, including autism and significant
25 sensory issues and both craves some type of sensory

1 input and is extremely averse to others.

2 He has a very difficult time
3 tolerating shoes, for example, but he likes to have the
4 soles of his feet massaged or scratched and he finds
5 that relaxing.

6 These sensory issues made it very
7 difficult to perform some routine foot care,
8 specifically clipping his toe nails.

9 And as he grew older and larger, the
10 only way to accomplish clipping his toe nails were
11 either when he was under sedation for a medical
12 procedure or while being held down by both his dad and
13 brother while I quickly tried to do the best that I
14 could.

15 We knew that that was unacceptable
16 and we knew he might continue to grow larger and we also
17 knew that because of his fight response to being held
18 down that it was only going to get tougher. In short,
19 we knew we had to change that dynamic.

20 And we knew the only way that would
21 happen was by doing something extremely different and
22 unrelated. And one day I had an aha moment and decided
23 to try a foot massage, which we knew he liked, followed
24 by a pedicure at a day spa or salon that had a very
25 relaxing environment.

1 So, the first time we took him in we
2 let him have a half-hour foot massage to get him nice
3 and relaxed and tolerable. And I stayed in the room
4 with him the entire time for everybody's comfort.

5 And then we went to the pedicure room
6 where I sat next to him and had my own sample pedicure
7 so he could see this was something fun that we were
8 doing together.

9 That very first time he loved the
10 massage, liked putting his feet in the water. The
11 minute the technician tried to pick up his foot to do a
12 toenail, he said he was all done. So, I said, "Okay,
13 I'm all done, too." And away we went.

14 The next time we went in for our
15 appointment again, he had the massage and that time she
16 was able to clip one or two toe nails before he said he
17 was all done. The third time we went I opened the door
18 to the spa and David said, "Relax."

19 Let the record show that the word was
20 accompanied by a stress relieving sigh. Keep in mind
21 that David has a profound intellectual disability. He
22 only speaks in one to two-word utterances. So,
23 consistent modeling of deep breathing to calm anxiety is
24 what taught him that word, relax.

25 And that third time David had all ten

1 toes clipped and attended to. From that point on, we
2 came to a point where his massage therapist had changed
3 jobs and was not able to provide his massage.

4 And rather than switching to a new
5 person, we said, "Let's just try it without the
6 massage." And it was successful. So then, over time we
7 weaned away from going to the spa and we bought a home
8 foot bath for about \$29.99 and that's how David gets his
9 toe nails clipped.

10 I have no doubt in my mind that we
11 could now clip David's toe nails without any resistance.
12 But I say why? That would be like me going to a
13 pedicure and having someone hand me a toenail clippers
14 and say, "Just do this."

15 We already have the spa, we took what
16 was a traumatizing event for David, my husband, his
17 brother, and myself and turned it into something that's
18 pleasant and relaxing. And David will even request it
19 at times.

20 So, I think while I acknowledge the
21 comments of other people here today, and I know that
22 there are some challenges with implementing, we also
23 believe at the Autism Society that if you don't push
24 change and push for creative solutions, we tend to do
25 the same old things we've always done.

1 So, again, commend the Department for
2 the proposed changes and we look forward to some of the
3 creativity that we can all come up with to resolve some
4 of the issues that arise. Thank you.

5 THE HEARING OFFICER: Thank you so
6 much, Ms. Bender. Appreciate your time and
7 contributions. Ms. Today. And as she's making her way,
8 we've exhausted the list of those folks who would like
9 to speak once.

10 Is there anyone who hasn't yet had an
11 opportunity to speak and would like to speak? Your
12 name, ma'am?

13 MS. GREELIS: Amber Greelis.

14 THE HEARING OFFICER: Oh, yes, you
15 are on the list, forgive me. Ms. Greelis, yes, and?

16 MS. BASSEKLE: Jodi Bassekle. I
17 signed up late.

18 THE HEARING OFFICER: Just give me a
19 second, Ms. Today. Okay. So, Ms. Greelis and
20 Ms. Bassekle. Any others who haven't yet want to speak
21 a first time? So, we're then going to hear from
22 Mr. Schmidt again.

23 Any other folks who in a prior round
24 had some comments that would like to speak again? I'm
25 just doing a quick survey. Ms. Whelan and Ms. Janecky

1 and Ms. Howe. Ms. Today, you've been very patient. If
2 you wouldn't mind stating and spelling your name for our
3 record.

4 MS. TODAY: My name is Erin Today,
5 T-o-d-a-y.

6 THE HEARING OFFICER: Ms. Today, what
7 should we know?

8 MS. TODAY: I'm a registered nurse,
9 but first and foremost I'm a single mother of an almost
10 13-year-old girl name Aziza (phonetic). Aziza suffered
11 from a brain infection at six months of age and has
12 developmental delays as a result of the trauma that her
13 body endured during that illness.

14 A little over a year ago Aziza's
15 agitation and aggressive behaviors had worsened in
16 severity. Considering Aziza was becoming stronger and
17 more difficult to calm, I realized I was being faced
18 with the dreadful thought that I may no longer be able
19 to handle her on my own at home.

20 Sending Aziza to school daily became
21 a constant worry for me. I received e-mails sometimes
22 multiple times a day in great detail, a play-by-play of
23 aggressive outbursts and concerns from Aziza's teachers.

24 Reports from the school would
25 indicate that some of Aziza's outbursts would last for

1 nearly an hour and may even occur several times
2 throughout any given school day.

3 I was at a loss. I felt like I was
4 alone. Aziza would bite and pick at her fingers and rub
5 her toes against the carpet until the skin was cracked
6 and bleeding. She would pull hair, she would bite,
7 kick, and destroy property with little or no warning.

8 Her anxiety was noticeably worse and
9 I felt like I was losing my little girl. I remember
10 feeling hopeless and heart broken all at the same time.

11 I realized that if I didn't quickly
12 find another approach for us to try, I may be forced
13 into a placement that I might not be comfortable with
14 for my own child.

15 Aziza began attending an outpatient
16 treatment center for children with autism this past
17 November. This center utilizes an ABA approach to
18 learning. Part of Aziza's programming includes utilizing
19 a token system. This allows Aziza to earn a preferred
20 activity as a reward for good listening, rule following,
21 and keeping her body safe.

22 If Aziza does not follow through with
23 the clear guidelines that are set before her, she may
24 lose a token, but have the opportunity to earn it back
25 again. According to Subpart 45B, this is a form of

1 punishment.

2 As a parent of a child who is
3 atypical in development, I value the importance of
4 teaching my daughter that our actions do have
5 consequences, both good and bad.

6 By teaching Aziza this concept, I
7 have seen a tremendous change in her willingness and
8 even a desire to be held accountable for her actions.

9 She has her own safe area at home and
10 at the center where she can safely be to calm herself if
11 she's having a difficult time regulating her body.

12 If this rule as written is passed,
13 this too would be considered a punishment. I disagree.
14 Any typical person may take several time-outs on any
15 given day. A typical time-out for you or I may be
16 taking a walk, meditating, practicing yoga or just
17 simply removing oneself from the noise of the world
18 surrounding us.

19 My daughter needs those breaks also.
20 However, she is sometimes unable to let that be known
21 and may have a meltdown when she becomes overwhelmed.
22 Allowing her a quiet and safe place to take a break or
23 have a time-out is far from a form of punishment. It
24 becomes her lifeline in order to help her regroup and
25 get back on task.

1 Aziza is no longer picking her skin
2 until it bleeds. She is learning new ways to cope with
3 the frustrations. And I even hear her coaching herself
4 sometimes, whispering phrases such as, "waiting is hard"
5 and "take a deep breath."

6 Over just three short months I had
7 begun to get my daughter back. I have seen the sparkle
8 in her eyes return, as well as her care-free smile, two
9 things that a parent cherishes.

10 I had once feared that that sparkle
11 was forever stolen from us. But I am grateful to be
12 able to share our story of success with you. Thank you.

13 THE HEARING OFFICER: Thank you so
14 much, Ms. Today. I appreciate your time and
15 contribution. Ms. Greelis.

16 MS. GREELIS: Would you like me to
17 spell my name?

18 THE HEARING OFFICER: Yes. Just give
19 me a moment while I catch up here. And following you,
20 Ms. Greelis, will be Ms. Bassekle. So, if you wouldn't
21 mind stating and spelling your name for our record.

22 MS. GREELIS: Amber, last name,
23 G-r-e-e-l-i-s.

24 THE HEARING OFFICER: Ms. Greelis,
25 what should we know?

1 MS. GREELIS: I'm here today to share
2 our story. I'm going to try really hard not to cry.
3 So, I'm here today to share my story on behalf of my
4 son.

5 And although I don't have a degree in
6 law, psychology or social work, I feel like I have what
7 is equivalent to what is a doctorate in autism relating
8 to my son.

9 My son is a nine-year-old boy with
10 moderate to severe autism. He is cognitively around
11 three and suffers from severe apraxia and uses sign
12 language and gestures to communicate.

13 He's been attending a center-based
14 school for autism for over three years. His school
15 offers behavioral-based programing. We love his school
16 and feel it is exactly what our son needs.

17 His school has given my son a voice
18 that has allowed him to have a greater quality of life
19 than we ever dreamed possible and were told he would
20 ever have. The director and therapist are what we feel
21 to be family and an extension of the vision we have for
22 our little boy.

23 My guy, for the most part, is an easy
24 going and pleasant little man. However, over the summer
25 of 2014 he started having extreme obsessive behaviors,

1 some of them harmless like light switch flipping,
2 watching doors open and close, opening and shutting
3 cupboards.

4 Some of them were more extreme and
5 problematic, especially when the obsessions were high.
6 He would grab other children's drinks, food off the
7 floor, teachers' drinks, all of these which could make
8 him sick. He would bolt, climb to get the desired
9 objects, et cetera, and often putting himself in a very
10 unsafe position if no intervention happened.

11 His obsessions became so bad that his
12 behavioral therapists were recording an average of 65
13 attempts of these unwanted behaviors daily. He was no
14 longer able to sit and learn because he became so stuck
15 on the obsessions.

16 When the behaviors continued to
17 escalate, I met with his team, always a team, and we
18 determined that this was affecting not only his
19 learning, but also his safety. Redirection and other
20 troubleshooting had not worked.

21 It was then that we talked about
22 time-outs for these behaviors. Incidentally, this is
23 what his father and I were already starting to use at
24 home. It was mutually determined that he would take a
25 two-minute timed time-out, sitting away from his peers

1 after he did not listen to the first warning.

2 The time-out started in August of
3 2014. And initially there were many, but he quickly
4 started learning that after a warning, he needed to
5 stop. I can proudly say that now when I pick him up at
6 school, many days he's had no time-outs. On tougher
7 days, maybe about five.

8 He's back to learning and gaining the
9 skills to continue to be the best student possible and
10 have the greatest quality of life. I have data, because
11 that's what we do with ABA, that shows how high it had
12 spiked. And this was even a couple weeks ago. And he
13 really in the last couple of weeks is having zero
14 time-outs.

15 The other concern I have about the
16 policies where there are no time-outs or punishments
17 would be safety. Due to the level of my son's autism he
18 will most likely be in specialized schools surrounded by
19 peers with like diagnosis.

20 And although my son is mild mannered,
21 not all children on the spectrum are. And sadly, when
22 many of them go through puberty, things change. My son
23 is also extremely tiny due to his health issues.

24 Both of these factors are very
25 important to consider in a setting where there is no

1 option for restraining or ramifications due to erratic
2 behaviors. It creates immense complications and is
3 frankly downright scary.

4 I fear for my child's safety and the
5 safety of others. As I had mentioned about children on
6 the spectrum often lack the ability to share not only
7 their desires, but also their frustrations. This can
8 result in a multitude of behaviors, actions, and
9 impulsive behaviors.

10 I beg you as a mother of this sweet
11 little boy that you please not make any rulings for
12 everyone and that you look at there being so many
13 different components and that you do further research
14 and dive deeper into these topics.

15 Making one rule that applies to all
16 people with disabilities is irresponsible and could
17 impede countless young people's progress in future
18 development.

19 My goal for this little boy is not
20 only for him to be the best version of himself possible,
21 but also to save money for everyone. Autism is
22 expensive.

23 And I know if I can invest in him now
24 and give him the hard core intervention that he needs
25 that his future will be much brighter and much more cost

1 effective for the state of Minnesota and many.

2 I thank you for your time and I
3 appreciate be given a platform to share. I'm sorry for
4 my high emotions, but this little man is my
5 everything.

6 THE HEARING OFFICER: Thank you so
7 much, Ms. Greelis, appreciate your time and
8 contribution. Ms. Bassekle. If you can state and spell
9 your name for your our record.

10 MS. BASSEKLE: Jodi Bassekle,
11 B-a-s-s-e-k-l-e.

12 THE HEARING OFFICER: Ms. Bassekle,
13 what should we know?

14 MS. BASSEKLE: Well, I would like to
15 believe as a society of diverse individuals that our
16 level of consciousness has risen to a point of positive
17 practices to guide us as a whole.

18 However, whether it's a typical child
19 or an autistic child or any other label of varying
20 degrees, we as a people have not reached that level of
21 human consciousness. This is why we still have laws
22 that govern us for that very reason.

23 And a law that is as prohibiting and
24 as limiting, that lacks a clear-cut balance of common
25 sense, as this particular law we're considering,

1 concerns me greatly as a parent, especially with a child
2 on the spectrum.

3 I would want the people that I've
4 chosen carefully to work with my son be given all the
5 tools and resources necessary to help him on his
6 journey.

7 Could it not be argued that a token
8 or a time-out that is effective in teaching and training
9 a child with disabilities, that there are consequences
10 to their choices, even in a basic level such as these, a
11 positive practice if, in fact, it helps to correct and
12 change a negative behavior?

13 Personally I think the all or nothing
14 approach that the DHS has presented falls short of a
15 real solution to prevent the components of abuse that
16 have happened as a result of not changing these laws
17 sooner.

18 I appreciate that these laws need to
19 be changed and I appreciate that people have suffered
20 because of the way these laws were written. And there's
21 stories after stories that we can hear about that.

22 However, to do this all or nothing
23 sweep it all away approach, it binds the hands literally
24 of those that are trying to help us care for our
25 children. And consciously and mindfully we need to find

1 a way that is inclusive that will have created some sort
2 of balance.

3 As a mom it's my job to raise my
4 child to be a law-abiding citizen. And the standards
5 that this has created -- I'll give you a for instance.
6 My son has never gone to the time-out room, he doesn't
7 have to, he doesn't have those types of issues.

8 However, his conscious level will not
9 kick in to the point of if I gave him a plate of bacon,
10 he would eat the entire pound of bacon with absolutely
11 no problem, if I let him. If I don't take that bacon
12 away from him at a certain point, do you understand what
13 I'm saying?

14 There has to be some governing law.
15 There has to be somebody in charge telling our kids that
16 no, that's not good for you, if you do that, this is the
17 consequences. We expect that from typical children.
18 Why don't we expect that from children with disabilities
19 if we can help them learn those things by using things
20 like tokens and time-outs if it's governed in a safe
21 practical way?

22 But to take it all out just seems
23 completely unnecessary. As a parent I have to ask
24 myself, who benefits the most from these changes,
25 especially financially? Who does this benefit

1 financially to create all of these changes?

2 It's going to cost us as parents,
3 it's going to cost them as the centers, it's going to
4 cost the state of Minnesota a lot of money to change all
5 of this in the current way it's being asked to be
6 changed.

7 If we can find a way to bring some
8 balance to these changes, I think that that's the way to
9 go. So, I'm going to ask you as a judge, as a panel,
10 before you pass this law, I want you to ask yourself
11 these two things: Before you act, before you speak, is
12 it kind, is it true, and is it necessary.

13 And if you can wholeheartedly say
14 that what you've presented is complete, then so be it.
15 If you think that there is still room for some changes
16 so that it will bring a greater balance so when it is
17 working, we don't take it away, that's all we're asking
18 as parents. Let's just find the balance.

19 Nobody wants to see any child abused.
20 Nobody wants to see any child hurt, at least I don't.
21 But we do have rules and we do have laws that govern us
22 for these reasons. Let's not throw the baby out with
23 the bath water, right?

24 I guess that's what I have to say.
25 Thank you for listening.

1 THE HEARING OFFICER: Thank you so
2 much, Ms. Bassekle, appreciate your time. We're about
3 at our Ms. Evenson break. We're almost at 90 minutes
4 for this slot.

5 So, we're going to recess until
6 precisely 2:25. You will want to be back here because
7 we're going to hear from Mr. Schmidt, Ms. Whelan,
8 Ms. Janecky, and Ms. Howe. You won't want to miss it.
9 We're in recess.

10 (At this time a brief recess was taken.)

11 THE HEARING OFFICER: Just so we can
12 have an on-time start, if folks could take their seats
13 or conversations to the hall, that would be great. So,
14 we're back on the record after a short recess.

15 What our plan here in the next
16 90-minute slot, we'll hear from Mr. Schmidt, Ms. Whelan,
17 Ms. Janecky, Ms. Howe, and Ms. Rachel Lucy. I'll do
18 another all-y all-y in come free to see who might be
19 inspired at that point, but that's what our plan is so
20 far.

21 So, with that, Mr. Schmidt, what else
22 should we know?

23 MR. SCHMIDT: Thank you, Judge
24 Lipman, for the opportunity to offer additional
25 testimony. I just want to re-emphasize that the

1 Minnesota Disability Law Center does support the overall
2 adoption of these rules.

3 But these areas, as I mentioned in my
4 first round, we identified seven areas. And we think
5 these are areas that can and need to be improved prior
6 to the final adoption of the rules.

7 The first area is setting forth a
8 definition of adaptive aids or equipment, orthotic
9 devices or other medical equipment.

10 Minnesota statute states that when
11 these devices are ordered by a licensed health
12 professional to treat a diagnosed medical condition,
13 they do not in and of themselves constitute the use of
14 mechanical restraint. And that's at 245D.06,
15 Subdivision 7D.

16 However, neither that statute, nor
17 the rules as proposed define what this term means. So,
18 our office is concerned that without defining these
19 terms, this could be an exception that eliminates the
20 rule. A provider could order the use of a restraint
21 chair, for an example, and call it medical equipment
22 without a definition.

23 We're also concerned that providers
24 who are using things like braces or orthotic devices
25 will stop using them because they don't know what these

1 terms mean. So, we urge you to adopt a definition. In
2 our written comments we had proposed one, which have
3 already been submitted, include the statutory rule
4 language.

5 A second, the informed consent
6 provision of the rules, which is at 9544.0080, is
7 illogical and unreasonable. This is a provision that
8 requires a provider at the beginning of service to get
9 informed consent from a service recipient that at some
10 point in the future a provider may use manual restraint
11 in an emergency.

12 Under these rules emergency manual
13 restraint will be used essentially against the will of a
14 service recipient to prevent physical harm to self or
15 others. It doesn't make sense to ask someone to consent
16 to something in the future that they're not going to
17 want to occur.

18 We're also very concerned that
19 informed consent is going to be a prerequisite for
20 services and thus eliminating the purpose of consent.

21 Rather than consent we think a
22 thorough notice provision is appropriate, which provides
23 information to participants that the use of manual
24 restraint will occur in an emergency and provide a
25 suggestion provision in our comments.

1 Third, we've heard about these
2 behavior intervention report forms, the supposition that
3 the rules need to set forth how DHS will process these
4 forms. DHS's recent experience with the forms
5 demonstrates why there needs to be specific details
6 about how these forms will be processed.

7 The court monitor in the Jensen
8 versus Department of Human Services settlement
9 agreement, Mr. Ferleger issued a report that found that
10 12,121 behavior forms that DHS received in a 14-month
11 period received little but aggregate computation.

12 As a result, the incidents of
13 restraint were ignored and the providers did not receive
14 needed help. The rules should set forth particular
15 requirements for how DHS will process these forms to
16 ensure that providers get the help they need and that
17 aversive procedures are not ignored. Without specific
18 requirements these will just become paperwork without a
19 purpose.

20 Fourth, DHS must provide more details
21 on how the External Program Review Committees will
22 function. The committees are set forth at 9544.0130.

23 Under the rules, these committees
24 will play an important role in approving or denying
25 requests for emergency use procedures and reviewing

1 license holder's response to the emergency use of manual
2 restraint.

3 I think some of the individual
4 stories that we heard today may fall into some of these
5 exceptions that could be approved by the committee.
6 However, the rules don't set forth criteria on how the
7 EPRC is going to make these decisions. They're not
8 setting forth criteria.

9 This provision does not meet the
10 definition of the rule as defined in Minnesota law
11 because it's not a statement of general applicability
12 and future effect because when the membership of the
13 committee changes, the criteria has a possibility of
14 changing as well. We believe that the rules must set
15 forth clear criteria for the EPRC.

16 Page 7 through 9 of the positive
17 support transition plan instructions have standards for
18 behavior intervention. And I'll submit this form to be
19 part of the record. I think those are good starting
20 points for developing criteria.

21 THE HEARING OFFICER: Is that
22 something you can part with?

23 MR. SCHMIDT: Yes.

24 THE HEARING OFFICER: I'd like to
25 mark it as Exhibit E.

1 MR. SCHMIDT: Okay. As part of the
2 EPRC criteria we also believe that participants must be
3 given a right to address the committees prior to a
4 decision to approve or deny a request for the emergency
5 use of procedures. And this right is essential for due
6 process and person-centeredness, which is the overall
7 purpose of the rule.

8 Fifth, the rules must establish the
9 number of emergency uses of manual restraint that will
10 trigger the requirement of a positive support transition
11 plan. And providers have discussed this already in
12 detail, so I won't repeat them.

13 We have proposed language in our
14 written comments that three episodes of emergency use of
15 manual restraint within 90 days or four episodes within
16 180 days are appropriate timelines.

17 Sixth, the rules must allow
18 individuals already in service the opportunity to
19 develop positive support transition plans and request
20 emergency use procedures. The current framework does
21 not allow someone who is receiving services prior to
22 January 1, 2014 to request the emergency use of
23 procedures through a PSTP.

24 This framework doesn't account for
25 the fact that people change and develop new conditions

1 over time. So, someone may suffer a traumatic brain
2 injury where they didn't have a behavior before and were
3 in service and now they do.

4 For example, the seat belt, they may
5 have been able to use a seat belt independently, but now
6 require an auxiliary device to travel safely because of
7 agitation and anxiety.

8 Under the current setup, if a person
9 has already been in service, there's no way for them to
10 develop an exception process. And we believe the
11 External Program Review Committee portion of the rule
12 should be amended to allow this to occur. And we
13 included proposed language in our written comments.

14 Seventh, the rules must allow for an
15 exception on the use of auxiliary seat belt devices.
16 Again, we've heard a lot from other folks about those
17 devices. I believe the statement in the SONAR is
18 incorrect.

19 And on Page 22 of the SONAR DHS
20 stated that it must include mechanical seat belt devices
21 in definition mechanical restraint because the Rule 40
22 Advisory Committee members deemed these devices as
23 indistinguishable from other mechanical restraints.

24 However, I have the recommendations.
25 And on Page 21 states that the committee was unable to

1 reach an affirmative consensus on this particular issue.
2 And I would like to submit the full recommendations as
3 another exhibit as well.

4 THE HEARING OFFICER: Okay.

5 MR. SCHMIDT: As you've heard from
6 other folks here, our office also knows individuals
7 who've developed conditions like dementia where they're
8 not able to learn how to use a seat belt.

9 And the program was not funded to
10 provide the one-on-one staff. And we're very concerned
11 that folks like this will be either not allowed to be
12 transported in the community or placed in a nursing
13 facility that falls outside the scope of these rules.

14 And denying someone the ability to be
15 transported by passenger vehicle in order to participate
16 in the community is contrary to the mandate set forth in
17 Olmstead and in the purpose of the rules.

18 I just wanted to clarify, for our
19 office, our proposal that you'll see in our written
20 comments is a bit different than, I think, what MOHR is
21 proposing. We're just proposing an exception process
22 through the External Program Review Committee.

23 We're not proposing to exclude seat
24 belt devices from the definition of mechanical
25 restraint. I think if you excluded them from the

1 definition, you wouldn't need an exception process
2 because then they would just be like seat belts, people
3 could just use them.

4 Our office believes that there should
5 be oversight with these devices because they do limit
6 movement. And people have learned how to use seat belts
7 over time.

8 However, this exception process
9 should be clearly set fourth through the External
10 Program Review Committee. We propose two different ways
11 to do it in our written comments. And we urge you to
12 order DHS to adopt one of these alternatives.

13 Finally, our comments identify seven
14 other areas where DHS can improve the rules, but they
15 don't rise to a level of unreasonableness that would
16 prevent adoption. So, I won't go into them in detail,
17 they're in the written comments.

18 We think changing the provisions
19 would improve the overall operation of the rules. I did
20 want to point out one of them, which is that we urge DHS
21 to return to the legislature and have these rules apply
22 across the board to all 245A providers.

23 My first round of comments we talked
24 about the applicability provision. In either the one
25 that we adopted or the one that's in the proposed rules,

1 either way, unfortunately, incentivizes providers to not
2 serve people with developmental disabilities if they
3 don't want to comply with the rules because by either
4 demitting or refusing to accept that person, you can get
5 out of the rules.

6 And we are very concerned,
7 particularly in our social services system, it often
8 falls back on the counties. There's not that many,
9 apart from licensing, that the rights of -- an
10 individual has against the provider. So, we urge DHS to
11 take those steps to apply these rules across the board.

12 That's all I have. I'd be happy to
13 answer any questions.

14 MS. SULLIVAN HOOK: Judge, may I ask?

15 THE HEARING OFFICER: Please.

16 MS. SULLIVAN HOOK: Just a quick
17 clarification question. The recommendation regarding
18 current service recipients should have the opportunity
19 to enter into a phase-out if conditions change, would
20 you envision a situation where that might happen
21 multiple times for a single person?

22 MR. SCHMIDT: I guess the purpose of
23 our provision, it could be possible. Right now, if you
24 were in service prior to January 1st, you're pretty much
25 trapped, you don't have the PSTP process available to

1 you.

2 So, like I said, dementia or
3 traumatic brain injury, someone may have already had
4 that phased out and then had a change in condition. So,
5 that is a possibility. The overall goal is obviously
6 not to use these aversive procedures, but it could
7 happen on more than one time for someone.

8 MS. SULLIVAN HOOK: Thank you.

9 THE HEARING OFFICER: Anything else,
10 Mr. Schmidt?

11 MR. SCHMIDT: Actually, I do have a
12 one-page handout I'd like to make part of the record. I
13 have copies if anyone is interested.

14 THE HEARING OFFICER: So, in the
15 order that you presented them, they will be E, F, and G.
16 Thank you kindly. Ms. Whelan, if you wouldn't mind.
17 And, Ms. Janecky, you'll be following her. Just give me
18 a second, Ms. Whelan.

19 (At this time there was a brief pause.)

20 THE HEARING OFFICER: Ms. Whelan,
21 welcome back. What should we know?

22 MS. WHELAN: I'm looking to seek a --
23 as he was, an exception process for a variance granted
24 for mechanical restraints, auxiliary devices.

25 I've done quite a few assessments and

1 positive behavior transition plans for individuals that
2 are putting themselves in imminent harm of death or
3 blindness.

4 And, unfortunately, all the
5 assessments that we have done, all the specialists that
6 they have seen, here's a story of an individual who has
7 multiple disabilities, physical, probably function
8 around three to six months.

9 He has so many medical issues. He's
10 in a home that has 24-hour nursing. And this is the
11 highest end of medical care. Otherwise, he'd be in a
12 hospital. He pulls out his tracheotomy and his
13 respirator, anything. Everything is kind of irritating,
14 he just pulls it out.

15 It's irritating in itself to have
16 these things on him, but he needs them to sustain his
17 life. So, increasing the staffing, all the assessments
18 we've had done in this past year, aside from the
19 transition program, the different things, the speech,
20 the OT, anything we can come up with to try to figure it
21 out.

22 He just finds things irritating, so
23 he does wear mittens, which is a mechanical device. His
24 behavior has actually gotten worse. And they tried to
25 assign -- when he had a pick line put in, they assigned

1 one-on-one and tried to keep it in place for I don't
2 know what period of time. It has to stay put for it to
3 stay in. And it became life threatening if he pulled it
4 out.

5 So, you end up with a situation where
6 you have a high-end individual who doesn't understand
7 cause and effect, increasing supervision and trying all
8 the sensory things, all the speech, all the OT, anything
9 that we can think of to make everything in his world,
10 interactions, whatnot, it hasn't seemed to make the
11 situation safe.

12 Another individual, as Joe mentioned,
13 I work with another individual who strikes his face with
14 such force and always has through time that he actually
15 creates more problems because he's broken his nose so
16 many times, there's really nothing left of his nose
17 hardly.

18 His teeth, he can't breathe very well
19 because he's got so much damage. He's detached his
20 retina, it's been put back twice, now that eye is blind.
21 His right eye has been detached twice and they said the
22 next time he will be blind.

23 So, he's riding on losing his
24 eyesight, which would change his quality of life quite a
25 bit. So, I can get a variance, which I have, from the

1 External by doing A, B, C, and D and another behavioral
2 assessment with a medical focus with assessments from
3 specialists, with all these things that we're doing, but
4 it isn't resolving the issue.

5 So, I ask you to consider looking at
6 the mechanical restraints and auxiliary devices and
7 maybe looking at when you go through the whole process
8 and we've done everything we can do and an individual is
9 not changing because of their degenerative cognitive,
10 there's something going on that doesn't allow them to
11 not change that impulse.

12 This individual could be laying in
13 bed and he'll still do it 24, pull it out during his
14 sleep. He'll come out completely bloody when he's in
15 his room doing his preferred thing, listening to music,
16 doing the rocking chair.

17 So, we try to fortify and make
18 everything -- he's not a day program. We reduce all of
19 his stress because that would cause him to bloody
20 himself all the time. Transportation, he hates it, so
21 he doesn't like being in a car. Unfortunately, you do
22 have to be in a car sometimes.

23 I created like a Lacrosse helmet that
24 he can take off and put on. He does sensory all the
25 time, he's got a bouncing ball that he has all the time.

1 So, he's doing the things he likes to do, but through
2 time it continues.

3 He will lose his sight. His parents
4 will be very upset. If this other individual, if they
5 can't protect the trach, he will lose his life also.
6 So, you're kind of put into a precarious situation when
7 you've done everything you can. I'm just wondering
8 what's next.

9 Can you have a variance that would
10 talk about that's been verified medically not to be
11 counter -- medically contraindicated? It's verified by
12 medical specialists that there will be a permanent --
13 there will be death or a permanent disability that's
14 irreversible, like paralysis, blindness, dismemberment,
15 things that will change their quality of life.

16 Some people will wear a helmet and
17 that will save their eyesight and their life will be
18 that with a helmet, but they'll still have a quality of
19 life that they like. They'll still be able to do the
20 things they like to do.

21 We can take someone out and if they
22 hurt themselves, they can't destroy themselves. So, I
23 think across Minnesota there's going to be just a few
24 people like this that I'm running across.

25 We've done everything we can in this

1 one-year period, but for the individual that's going to
2 be blind, I'm not going to do any more, there's nothing
3 more I can do. Someone else can come in and try, but it
4 is what it is, unfortunately. I can hold his hand 24/7,
5 but he still has to sleep, I still have to hold his
6 hand.

7 He won't sleep when I'm there because
8 that activates him and he can't sleep, we've already
9 tried that. They've tried one-on-one. We've tried
10 everything. So, what then? Is there an exception for a
11 few people in the state that their quality of life
12 inadvertently will be bad? He'll die.

13 So, if you could look at maybe an
14 exception for if you go through all the work and maybe
15 look at that as being -- the bottom line is, it's nice
16 to have sight, it's nice not to have paralysis and
17 you're alive and enjoying life as you can. Thank you.

18 THE HEARING OFFICER: Thank you so
19 much, Ms. Whelan, appreciate your contributions.
20 Following Ms. Janecky, Ms. Howe will be following her,
21 you're next, you're on deck. Ms. Janecky, welcome back.

22 MS. JANECKY: Thank you. Do you need
23 me to spell my name again?

24 THE HEARING OFFICER: J-a-n-e-c-k-e?

25 MS. JANECKY: -k-y. After listening

1 to all the wonderful testimony that we've heard today, I
2 just have a couple of other points that I think are
3 important to make.

4 I think that the parent, maybe the
5 last parent who spoke, who spoke about her son's issues
6 with feet and toe nail cutting and things like that,
7 it's such a wonderful example of when positive support
8 strategies are successful.

9 And I think that is the diligence
10 with which we need to address behavior from a
11 perspective of reinforcement. I think that doesn't
12 always work for every individual however. And I think
13 that is where we need to make considerations for when it
14 doesn't.

15 I'm recommending two changes in
16 addition to what I spoke about before. The first issue
17 that we need to address is the fact that I feel that
18 kids have been largely left out of this document.

19 I think that we need to -- I would
20 like to recommend a change that we allow these
21 procedures to be used when parents have given informed
22 consent. I think that's an important component of this.

23 I also think that we should be
24 allowed to use these procedures if they are closely
25 monitored by a board certified behavior analyst or a

1 similarly trained professional.

2 I think Ombudsman made some excellent
3 points as well when she spoke. And I think that one of
4 the things that she spoke a lot about was that we have
5 to start someplace.

6 However, I see that we should start
7 someplace being let's train people, let's get proper
8 implementation of programing that does have a focus on
9 positive support strategies, but that we are allowed to
10 use the use of punishment when absolutely necessary,
11 when overseen diligently by a behavior analyst and when
12 clients or clients' guardians have given full informed
13 consent.

14 And I also suggest that you utilize
15 the position statements and the documents that we
16 already spoke about today that Dr. Moore had brought up
17 earlier and that I submitted as evidence, the BACB's
18 guidelines for responsible conduct, the ABAI's position
19 statement, as well as their responsibility for -- the
20 document that is called their position statement, as
21 well as their responsible -- the right to affect
22 behavioral treatment.

23 I think if using those documents as
24 guidelines, I think that we should be able to do that.
25 And I do want to touch on the Ombudsman's statement that

1 punishment does not work. And that, I think, is a
2 misinformed statement.

3 Punishment by definition is
4 effective. It's not called punishment unless you see a
5 reduction in behavior following the use of it. And that
6 is the definition that is listed in the proposed rule.

7 So, I don't think we can talk about
8 this as something that doesn't work. It isn't
9 punishment if it doesn't result in the decrease of a
10 target behavior. I don't think that we define this by
11 form, by what it looks like. However, we have to define
12 it by the results that we see. And that's it.

13 THE HEARING OFFICER: Ms. Janecky,
14 thank you so much, appreciate your time. Ms. Howe? And
15 Rachel Lucey, you'll be following Ms. Howe. Ms. Howe,
16 welcome back.

17 MS. HOWE: Thank you. Again, I
18 wanted to talk about the program levels with
19 consequences. I'm very involved in developing a program
20 for my son when he goes to these group homes. To me,
21 that's person-centered planning already.

22 My plan for my son might not work for
23 the next three down that come in. He's autistic also
24 and everybody knows each individual is so different and
25 you have to have ten different kinds of plans for them.

1 So, I feel like the law is kind of
2 pigeon holing him into a plan, especially with this
3 program level with consequences that I have proof, I
4 have living proof that this program level with
5 consequences worked because it took a year to get him
6 going in this program.

7 Then he went, like I said before, two
8 years without a violent incident. And he's a very
9 violent person. He attacks people, he killed our puppy,
10 he tried to set fire to my house. So, he is very
11 violent. So, this program level with consequences
12 worked.

13 I had a Behavior Analyst 3, I don't
14 know what one, two, or three means, from community
15 support services of DHS. And he e-mailed me because he
16 talked to my previous group home that had my son. He
17 said that my son's previous program level appeared to
18 have provided the structure for his success.

19 And it was success until it was
20 removed and they tried to implement other stuff. I'm
21 pleading with DHS for violent behavior disabled
22 individuals that you need to look at case by case of
23 these providers using these program levels with
24 consequences.

25 You need to see if it's working or

1 not. Yes, it needs to be overseen, which I agree. I
2 raised my son if he's violent, he gets consequence. And
3 I take it very seriously. Because if we're violent, we
4 have consequences, we're arrested or thrown in jail.

5 Because he's such a violent person
6 I'm scared he's going to kill or hurt somebody. And
7 that's on my head, it's not on your head, your head or
8 your head. I can't live with that if my violent son
9 does that to somebody.

10 Then about the resources, I don't
11 think there's enough resources in the state of Minnesota
12 to handle these violent behavior disabled individuals.

13 Because providers are scared of them
14 because people have talked before, hands off, they don't
15 want to deal with these violent -- you guys say
16 challenging, I don't know what challenging means.
17 Violent is violent, it's very serious. A person's life
18 is at stake.

19 So, a lot of these providers are just
20 hands off. I really have a hard time finding a home.
21 Thank God I did, after six months, that would take him
22 in and start working with him.

23 But we talked about training for this
24 positive support, you said the University of Minnesota
25 is working with you and developing a website, which is

1 great.

2 My question is, it's just me, why
3 isn't training being done before this is implemented?
4 Because it's causing a lot of confusion out there with
5 providers, it's causing a lot of trouble for me to find
6 a provider for my violent son.

7 So, I think it would be less
8 confusion, probably a little -- I'm sure there's going
9 to be bumps on the way, but a little more smoother
10 sailing if this training was done first before this was
11 implemented. And thank you for your time.

12 THE HEARING OFFICER: Thank you so
13 much, Ms. Howe, very grateful. Ms. Lucey, if you could
14 state and spell your name for our record.

15 MS. LUCEY: Rachel Lucey,
16 R-a-c-h-e-l, L-u-c-e-y.

17 THE HEARING OFFICER: Thank you so
18 much, Ms. Lucey. What should we know?

19 MS. LUCEY: I've been in the field
20 for 35 years. And I think Rule 40 was developed to
21 protect people. And the way it was developed was that
22 we had positive behavior support plans as we were trying
23 to wean off mechanical restraints or manual restraints.

24 And with this new rule, it feels like
25 the people we support aren't being protected. If you

1 can't have a restraint, what are they to do?

2 I've asked several people, if you
3 injured yourself and you beat on yourself, what would
4 you want staff to do immediately, put a soft helmet on
5 you, restrain you or take you to a psych hospital?

6 The majority of answers were having a
7 soft helmet on. And to this day we couldn't help
8 someone that way because mechanical restraints aren't in
9 the guidelines anymore. And sometimes they were used
10 just to protect people, not as a punishment.

11 And meanwhile, you work on the
12 communication, what's causing this person this distress
13 and you build on positive behavior support plans as
14 you're protecting them. I feel this rule has gone to
15 the extreme and it may hurt people more.

16 Rule 40, I think you could just set
17 up guidelines that you're not taking away rights. You
18 can take away a token without taking away a right. All
19 of our actions have consequences. And I feel like we're
20 putting people with disabilities in a different category
21 again, they're not having any consequences.

22 And not all punishment needs to be
23 severe, it can just be more of a consequence of taking a
24 token away. In the end, the bottom line is the golden
25 rule, do unto others as you would like them to do unto

1 you.

2 If I had a problem with violence and
3 attacking people, how would I want people to teach me
4 otherwise? And I would want them to protect other
5 people and maybe restrain me when needed while still
6 trying to teach me. And I would rather have a token
7 taken away from me and learn right from wrong instead of
8 in the end hurting somebody because I didn't know any
9 better.

10 I just want us to treat people with
11 compassion and respect. And I don't feel that taking
12 tokens away is taking away respect or compassion or
13 using deprivation or mechanical restraints in a violent
14 situation. That's it.

15 THE HEARING OFFICER: Thank you so
16 much. Appreciate your time and contribution. Anyone
17 else who would like to be recognized to speak? Anyone
18 else? Anyone else? Seeing none, I have a couple of
19 last advertisements.

20 First, let me begin with a thank you.
21 I think we've begun taking an initial step to assemble a
22 very robust and thoughtful and detailed record for which
23 you have my grateful thanks.

24 Continuing we'll have a lot of
25 thoughtful and useful things to say. And that was

1 because of what the people here in this room contributed
2 today. So, a very great start, but we're not done.

3 By 4:30 p.m., we're all going to
4 repeat that, 4:30 p.m. on Monday, March 16, 2015 is the
5 close of the initial comment period. You don't have to
6 have been here at the Elmer L. Andersen Building in
7 order to participate.

8 If you are on the globe somewhere and
9 have had something to say and contribute to our process,
10 you are very much invited. So, someone with you or
11 someone who has another view who you think could
12 contribute to the wisdom of the group, I hope you
13 encourage them on behalf of me and the panel to write
14 in, again, by Monday, March 16, 2015 by 4:30 p.m.

15 After which, when the materials --
16 and they'll be going up in batches onto the DHS website,
17 so I encourage folks to tune in to the rulemaking page
18 there to see not only these exhibits, but the materials
19 that will be coming up from fellow stakeholders and the
20 hearing exhibits today. So, folks can be part of the
21 discussion.

22 After the close of the initial
23 comment period on Monday, March 16, we'll have a
24 five-day rebuttal period, where folks can comment on the
25 items of other stakeholders and what has been developed

1 in the record to that day. That period will close at
2 Monday, March 23, 2015, a week later, by 4:30 p.m.

3 If it's on the other side of either
4 of those deadlines, it's late. So, if you're foreseeing
5 putting things in electronically, we're delighted to
6 receive them. We have a special e-mail address. Try to
7 send it by 4:20 because my clock is the only one that
8 counts.

9 And we don't want you to spend time
10 developing thoughtful contributions to our record which
11 are excluded as late, that would be a tragedy for you
12 and for us. So, please, if you can turn to it earlier,
13 that's better, to make sure that you're in and part of
14 this dialogue and also accessible to the agency panel.
15 But like I say, we will be adhering strictly to these
16 deadlines.

17 We're also agnostic as to format.
18 So, the e-mail works, if you want to fax, if you want to
19 deliver to the Office of Administrative Hearings, which
20 is in the Stassen Building across the street here,
21 across 94, however you want to get those materials to
22 us, we're delighted to have those materials as part of
23 the record. But we will be adhering to the deadlines
24 that I mentioned before.

25 With that, a very great start, please

1 tune into the DHS rulemaking page. You have my very
2 grateful thanks. And we're adjourned.

3 (Hearing adjourned at 3:00 p.m.)
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1 REPORTER'S CERTIFICATE

2
3
4 I, MARCIA L. EVENSON, do hereby certify that I
5 recorded in stenotype the hearing on the foregoing
6 matter on the 23rd day of February, 2015 at St. Paul,
7 Minnesota;

8
9 I further certify that thereafter and on that
10 same date I transcribed into typewriting under my
11 direction the foregoing transcript of said recorded
12 hearing, which transcript consists of the typewritten
13 pages 1 through 217;

14
15 I further certify that said hearing transcript
16 is true and correct to the best of my ability.

17
18 WITNESS MY HAND AND SEAL this the 2nd day of
19 March, 2015.

20
21
22 _____
23 MARCIA L. EVENSON
24 Court Reporter
25

