

In The Matter Of:
Comprehensive Supports Wavier Program

Public Comment Hearing
November 18, 2020

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GEORGIA DEPARTMENT OF COMMUNITY HEALTH
PUBLIC COMMENT HEARING

IN RE:

Comprehensive Supports

Waiver Program (COMP) Waiver

Renewal, and the New Options

Waiver Program (NOW) Waiver

Amendment

The Department of Community Health Public Hearing

held via Webex

November 18, 2020, 10:30 a.m. EST

10:30 a.m. to 12:02 p.m.

Reported by:

Maureen S. Kreimer, CCR B-1379, Notary Public

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1 APPEARANCES:

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1 (Time noted 10:31 a.m.)

2 MR. KRULL: Good morning. I'm Matthew
3 Krull. I'm the Health Policy counsel with the
4 Department of Community Health in the Office of General
5 Counsel. Today is November 18th, 2020. It is now 10:31
6 a.m.

7 This is the Webex Public Hearing on
8 Comprehensive Supports Waiver Program, Waiver Renewal,
9 and the New Options Waiver Program Waiver Amendment.

10 This public notice was issued by
11 Commissioner Frank Berry on November 12th, 2020. The
12 notice is incorporated into these proceedings. Pursuant
13 to 42 CFR 447.205 the Georgia Department of Community
14 Health is required to give public notice of any
15 significant proposed change in its methods and standard
16 for setting payment rates for services.

17 At the November 12th, 2020 DCH Webex board
18 meeting, the Department received approval to release for
19 public comment this notice. This public comment period
20 will expire on December 14th, 2020.

21 Please note if anyone wishes to make or
22 submit a comment in writing you can fax it to
23 404-651-6880. You may also email comments to Danisha
24 Williams. And Ms. Williams' email address is
25 D-A-N-W-I-L-L-I-A-M-S, danwilliams@dch.ga.gov, or mail

1 your comments to the Board of Community Health, P. O.
2 Box 1966, Atlanta, Georgia 30301-1966.

3 At the conclusion of our comment period all
4 oral comments presented today will be transcribed and
5 provided to the Board of Community Health along with a
6 copy of any written comments received. The board will
7 be asked to vote on this item for final adoption at its
8 January 14, 2021 meeting.

9 Each participant on the Webex that would
10 like to provide oral comment will have the opportunity.
11 Please limit your comments to 10 minutes, and keep your
12 comments limited to the issues that directly relate to
13 the proposed public notice.

14 At the end of your 10 minutes if you have
15 not completed your presentation, I may ask for a brief
16 closing statement, and you'll be able to submit your
17 remaining comments in writing.

18 And this is a Webex -- this being a Webex
19 hearing, it's a little different than just signing in,
20 so we're working with the technology that we have; so
21 for anyone who wants to make an oral comment during this
22 public hearing, there is a participant panel on the
23 right-hand side. If you open that panel on the
24 right-hand side, lower right-hand corner, there is a
25 little hand. If you hover over it, it says "raise

1 hand." If you want to make a public comment, please hit
2 that raise hand comment and we will call on you.

3 Looks like Dan Southern has already done
4 that. Look, we've got a whole bunch of people wanting
5 to make comments. This is great.

6 So what we're going to do, with that being
7 said, we'll call on the first individual. I'll ask you
8 to please state your name, the entity you represent, and
9 begin presenting your oral comments, and we'll go down
10 the line from there.

11 So as we go, if you want to unmute yourself
12 when I call your name, that would be helpful.

13 The first person I see on my list is Dan
14 Southern. So, Mr. Southern, if you'll unmute yourself
15 and start your comments.

16 DAN SOUTHERN: Yes. Thank you. So as he
17 said, my name is Dan Southern, and I represent my son
18 Matthew Southern.

19 These proposed changes to CLS and the
20 skilled nursing are effectively forcing individuals like
21 my son out of his home and into somebody else's home.

22 On the surface, that doesn't really sound
23 like a big deal, but this change makes a huge difference
24 in my ability to make decisions that impact my son's
25 environment and quality of life.

1 My son Matthew has tried living in a CRA
2 residence. In fact, initially I thought that that was
3 the place that he was going to stay for the rest of his
4 life.

5 However, I have seen over time that that
6 program began to slip. They started making changes.
7 They made some changes in their leadership team, which
8 led to other changes, shifting their focus from the
9 clients' best interest to cash profits.

10 They began filling vacancies in the home
11 with whomever they could; no consideration was given to
12 whether or not they would be a good fit with the
13 existing residents. Other clients and family members
14 had no input whatsoever. They were forced to live with
15 it or to leave.

16 Over the last year there I discovered there
17 that I had very little control within the CRA home. The
18 CRA provider could refuse to follow doctor's orders if
19 they did not feel comfortable with them. The CRA
20 provider could take our loved ones to the ER against,
21 you know, our wishes as their parents or guardians, even
22 during this COVID-19 pandemic.

23 This particular provider ran off good staff
24 that advocated for clients in favor of uncaring,
25 unconcerned staff that did the minimums quietly. They

1 treated the DSP staff poorly, which resulted in high
2 turnovers. This led to a consistently understaffed
3 home, which meant less care for our loved ones, but
4 netted them more money.

5 As parents and guardians we have no input or
6 say in who works in the CRA home, or how the staff are
7 treated. In fact, I couldn't even change the paint
8 color in my son's room.

9 I tell you all of this because these are but
10 a few of the reasons I chose to move to CLS for my son
11 in his own home, a place where he or we could make
12 decisions about his environment, and how best to support
13 him in ways that make a real difference to him.

14 I realize not all CRA homes are like the one
15 that Matt was in. But that one started out good, and I
16 had no control when it started to slip. My only two
17 choices were to live with it or to leave.

18 Individuals and their families have little
19 to no control in CRA homes or host homes. The providers
20 have the final say in so many aspects of our loved ones'
21 lives. It's a dictatorship where the CRA provider or
22 host home holds all the powers; again, you live with it,
23 or you leave.

24 If you choose to leave, it can take months
25 of searching to identify another suitable home for your

1 loved one. This is incredibly detrimental to them and
2 disruptive for them. Their world is turned upside down.

3 Please, since residents and services are
4 tied together, recognize CLS as a 24-hour service
5 thereby giving people the choice to live in their own
6 homes, i.e., not a provider-owned or operated setting,
7 and work with the constituency on funding the service in
8 a transparent logical way. Thank you.

9 MR. KRULL: Thank you, Mr. Southern, for
10 your comments. They'll be presented to the board at the
11 board meeting.

12 The next person I'm going to call on is
13 Deborah Poulos. If you'll unmute your microphone,
14 Ms. Poulos, and make your comments.

15 DEBORAH POULOS: Yes, sir. Thank you so
16 much. And good morning, everyone. Let me just start
17 out and preface this with I'm very grateful for my son's
18 waiver, and what it has done. It's made a huge, huge
19 difference in his life of independence.

20 I'm a retired special education teacher and
21 career technology instruction coordinator. I also am
22 the proud parent of Jim, who is 33 years old, and has
23 autism and an intellectual disability due to a seizure
24 disorder, tuberous sclerosis, that he was born with.

25 Being in the field, I have conducted

1 hundreds of Individualized Education Plans. The key is
2 individualized. It's imperative that we consider
3 individuals' needs, abilities and desires for their
4 life, not just create basically two pigeon holes for
5 them to fit into.

6 Please reconsider the changes you are
7 proposing for the CLS program, as many families will be
8 affected. My son will have to move, not his choice, to
9 what you say is best, a group home or host home.

10 As a parent, the hardest part of having the
11 responsibility of a child with special needs is what
12 happens after I'm no longer here. I want a situation
13 that is stable and has a consistent number of staff and
14 is safe. My loved one should be the focus of his
15 services, not finances or money.

16 This was not the case when in a CRA. My
17 input was not welcomed; although the guardian, I was not
18 able to make decisions about trips to the emergency room
19 due to his seizures, his medication purchases, or
20 outside activities, which didn't exist due to others in
21 the house not being able to participate since they were
22 in wheelchairs, and also not enough staff to stay home,
23 one stay home and one go outside the home.

24 In closing, I ask if you don't already have
25 one to form a parent guardian of individuals with

1 special needs advisory board to consult and discuss the
2 appropriate environment for our individuals, and try to
3 understand from another perspective for future changes
4 and/or adjustments.

5 I have been advocating all my son's life and
6 I will not give up now. However, it's extremely
7 frustrating for him to have so few choices as to where
8 he can call home. Thank you.

9 MR. KRULL: Ms. Poulos, I ask you to unclick
10 your raise hand button so we don't call on you again.
11 Just trying to keep order since we're virtual here,
12 trying to be flexible with the system we have here.

13 The next person I'm going to call on is John
14 Zoller and I'll ask Ms. Jackson to please unmute Mr.
15 Zoller. He's on the list.

16 Okay. Mr. Zoller, you can go ahead and make
17 your comment now.

18 JOHN ZOLLER: Again, my name's John Zoller.
19 I'm the father of Katie Zoller, and Katie is a
20 34-year-old developmentally disabled young lady who
21 lives in her own home and lives independently. And this
22 is made available because of the funding that she
23 currently receives, the CLS and the (inaudible)
24 services.

25 I have a real problem with the proposed

1 changes that DBHDD has made in this proposal.
2 Essentially what they are recommending is that we're
3 reducing the levels of support for individuals that have
4 been deemed some of the most vulnerable in our state,
5 and moving that funding over to another list of
6 individuals, essentially so we can reduce the number of
7 people that are on the waiting list.

8 That's what I heard in the last meeting
9 where this proposal was discussed; essentially it's a
10 robbing Peter to pay Paul. We -- as an ex-manager of
11 government programs, I know that I'm looking at things
12 in the macrolevel, and I want things to look good, and I
13 want to reduce those waiting lists, et cetera,
14 et cetera. But this is not the way to go about doing
15 it.

16 There is a real cost associated with this
17 when you're not looking at the big picture and you're
18 looking at individuals. You've already heard from a
19 couple of parents, and I'm in the same boat as them.

20 My daughter started off in a group home. We
21 thought it was great. My daughter began assaulting
22 other individuals. My daughter rips the hair out of her
23 head. My daughter punches herself in the face as hard
24 as any man has ever hit me, and does this repeatedly
25 until you intervene.

1 I've spent much of my life intervening with
2 my daughter's inappropriate behaviors, and it's not
3 something that is readily addressed by either medication
4 and/or behavioral supports because we tried both avenues
5 and are continuing with those avenues.

6 It is untenable for her to live with other
7 individuals. I can't tell you why, and if you could
8 tell me why, I'd be most appreciative.

9 We tried it. It's failed. We tried it with
10 a roommate. It failed. We've tried it with multiple,
11 you know, multiple group homes. Each of those homes
12 failed. They failed because it was something that she
13 couldn't live with.

14 Now, she can't talk but she can communicate.
15 The way that she communicates, again, is assaulting
16 others and assaulting herself: Again, again and again.

17 We are asking, or I am asking, you to
18 consider either establishing CLS as a means for people
19 to get 24-hour service living in their own homes; not in
20 a group home, not in a host's home.

21 Those avenues don't work for my daughter.
22 They might work for other individuals, and I actually
23 hoped they would work for my daughter because it looked
24 like a really nice arrangement until she imploded. If
25 we move her again, she will implode again, and we're

1 left picking up the pieces, as you've heard from other
2 individuals, and you'll likely hear from other people
3 who are providing you with comment this morning.

4 Thank you very much for your time.

5 MR. KRULL: Thank you, Mr. Zoller, for your
6 comments. They will be presented to the board in
7 December. If you'll please unclick your raise hand
8 button for me.

9 The next I'm going to call on, Megan Bryant.
10 Ms. Jackson will unmute you. Oh, there you go.

11 Go ahead, Ms. Bryant, you can go ahead and
12 make your comment now. Thank you for being here today.

13 MEGAN BRYANT: Okay. Thank you. My name is
14 Megan Bryant. I am here on behalf of my outstanding
15 brother Martin Ruff. He's a 36-year old man. He has
16 cerebral palsy, and he is wheelchair bound.

17 Growing up I always worried about him and I
18 wondered what would happen to him when we became adults.
19 But over ten years ago, he was able to move into his own
20 home. This has been a dream come true for him and for
21 the rest of our family, something we never thought he
22 could do.

23 But Martin loves his home. He loves getting
24 to have a choice about what to do, where to go and
25 choosing who he gets to spend his time with. He gets to

1 do these things just like any other 36-year-old man.

2 The proposed changes to the waiver program
3 will result in my brother and his roommate losing their
4 home and being forced to live in a group home or host
5 home.

6 I believe that CLS should be recognized as a
7 24-hour service so people like Martin can continue to
8 have the choice to live in his own home. Thank you.

9 MR. KRULL: Thank you, Ms. Bryant, for your
10 comment. We'll present it to the board in December.

11 Next we'll call on Pamela Walley. And we'll
12 get you unmuted, Ms. Walley, and you go ahead and make
13 your comment now. Thank you for being here. Oh, you're
14 still muted. Now you're unmuted. Go ahead and begin.
15 Oh, you keep getting muted.

16 MS. KIANA JACKSON: Ms. Walley, I'll unmute
17 so you don't have to touch anything.

18 PAMELA WALLEY: Okay. Thank you. I
19 appreciate this opportunity, and thank you for your
20 patience with the technological challenges.

21 I'm Pam Walley and I am calling on behalf of
22 my daughter who's a 25-year-old young woman living in
23 the Athens area, and also for others, I know, like her,
24 who are very concerned about these proposed changes to
25 the COMP waiver.

1 Callie has been blessed to live in a time in
2 history when people with disabilities are recognized as
3 real people, and that they have real purpose and that
4 they can live real lives as long as they have supports
5 and they can be in their own communities where they
6 belong, and not shut away and forced to live in
7 facilities and institutional settings as was the case in
8 the past. And we're very grateful for the fact that we
9 do live in times when this is an option.

10 Callie lives with a roommate in an
11 apartment. She has a very full and very rich life.
12 She's an active part of her community. She spends her
13 day the way that she -- the way that she chooses, and
14 she contributes to the world that she lives in. Even --
15 you know, even in the midst of a pandemic like the rest
16 of us, you know, there have been challenges that she's
17 faced, but through the use of assistive technology and
18 avenues like what we're enjoying right now, she's
19 continuing to live the life that she was intended to
20 live because she has the COMP supports in place to
21 enable her to do that.

22 The plan, the way that this -- these
23 proposed changes are written will mean that all that
24 will change for Callie, and not in a good way. The plan
25 as written is going to mean that Callie will lose her

1 home, and she will lose her community, and she will even
2 lose her life.

3 The CLS caps and the restrictions on
4 eligibility mean that Callie won't be able to stay in
5 her apartment. She won't be able to stay in the
6 community that she's chosen. She'll be forced into a
7 group home or a host home or maybe even a nursing home
8 because Callie also has very extensive medical needs.

9 And so the COMP supports, the skilled
10 nursing supports, that she receives right now, would
11 also be reduced if the cap of 16 hours is pushed
12 forward. 16 hours of skilled nursing care will
13 literally endanger Callie's life. There aren't eight
14 hours in every 24 hours or even eight minutes of any
15 hour when Callie can live safely without skilled nursing
16 support. It's well documented. And I wish it weren't
17 so, but it is.

18 And so the COMP nursing supports that she's
19 receiving right now are literally what is keeping her
20 alive. Callie even -- and I have her permission to
21 share this information -- she contracted COVID in
22 August.

23 And I can tell you that as a mother my
24 biggest fear when this pandemic started was not for my
25 safety, or -- what I worried most was what is going to

1 happen if Callie gets COVID. She has respiratory
2 compromise. She has uncontrolled seizures. She has
3 severe cerebral palsy. She can't swallow her own spit.

4 But because of the skilled nursing supports
5 that Callie had during the month of August when she
6 contracted COVID, she made it through the illness. Her
7 nurses provided the suction, the respiratory treatments,
8 the seizure management, the necessary medications,
9 everything that she needed to help her fight her fight.
10 And I'll just say it the way we say it: She kicked
11 COVID's butt.

12 Now, it was really, really important not
13 only for Callie's benefit, but you need to know that
14 during this time I had COVID, too. So under the
15 proposed plan I would be the person responsible for
16 eight hours every day of Callie's nursing care. That
17 would not have been possible when I was sick in bed with
18 COVID myself.

19 I'm entering my 60s. I'm getting older, I am
20 tired, and I cannot be her nurse for the rest of her
21 life, and so it is vital to her very existence that the
22 16-hour cap on nursing not be approved.

23 Now, Callie is only one person whose life
24 would be so critically impacted by these changes. I
25 heard during a meeting Ron Wakefield say that the

1 changes would only affect a small number of people, that
2 the vast majority of individuals who receive COMP
3 services would not be affected by CLS redefinition,
4 eligibility changes, caps on services, or the 16-hour
5 cap on nursing.

6 And that may be true. But for those of us
7 whose family members are in that group, this means the
8 difference between living a life and not.

9 So I implore you, please do not let these
10 changes go through as they are written. Thank you.

11 MR. KRULL: Thank you, Ms. Walley, for your
12 comments. They'll be presented to the board in
13 December.

14 And there are a number of people that have
15 called in that are not using the Webex platform, and we
16 understand that, we're cognizant of that. I can't see
17 your names, but as we go through -- and we understand
18 that you can't do the raise hand feature on your
19 phone -- so when I go through the list of the names
20 through Webex, once we go through this list and we've
21 completed those comments, we will call on the people on
22 the phone and inquire whether they want to make a
23 comment, okay?

24 So be patient with us. We have a large
25 number of people in this hearing, and we're going down

1 the line as I see them on my list and we'll move on from
2 there.

3 Ms. Walley, I'll ask you to go ahead and
4 unclick your raised hand button since you made your
5 comment. And we'll go to the next commenter. The next
6 commenter is Shelly Dollar.

7 And, Ms. Jackson, if you could unmute
8 Ms. Dollar.

9 Ms. Dollar, go ahead you can make your
10 comment now.

11 SHELLY DOLLAR: All right. Thank you. My
12 name is Shelly Dollar, and I'm the mother of Gabriella.
13 She's a 31-year-old lady with cerebral palsy. She also
14 has diagnoses of autism and multiple physical
15 disabilities. She's wheelchair bound, unable to do
16 anything independently at all. She needs one-on-one
17 care for all her ADLs, can't be left alone for any time
18 during the day or night.

19 She's been denied entry into multiple
20 residential communities because of the intensity of her
21 ADL needs, as well as all her required medical care.
22 We've even been told that she would be accepted to one
23 of these residential communities if we allowed them to
24 deny her the medical care required for her
25 doctor-ordered procedures.

1 She's also been refused entry into multiple
2 day programs because of her physical needs and her
3 emotional needs.

4 Fortunately, because of the CLS waiver,
5 which we are so grateful for, she lives independently in
6 her own home with 24-hour care. She's happy, relaxed,
7 her behaviors are minimal, and she's able to live the
8 life that she was meant to lead.

9 But the proposed changes to this waiver
10 result in Gabby being moved out of her own home and
11 being forced to live in a group home or host home -- and
12 honestly, she is not well enough to be living with a
13 group of people because of her behaviors. We've tried
14 roommates. When she had a roommate, she stayed awake 24
15 hours a day and we needed to give her additional
16 psychotropic medication to control her behaviors.

17 That's, in my opinion, completely unethical
18 that I should have to medicate her so she can be in a
19 home with other people.

20 Gabby requires one-on-one care, and we've
21 been so grateful that we've been able to give her what
22 she needs because of the waiver.

23 I also reiterate what's been asked by
24 everybody here, that the current definition being
25 proposed that cap her care at 12 hours a day be

1 unequivocally denied, and that CLS is written to include
2 no cap and 24 hours of care when needed. And we agree
3 that assessment need to be done with her and everyone
4 else. She's already been assessed. She needs 24 hour
5 care. She needs extensive help.

6 And I appreciate you giving me a chance to
7 talk, and I appreciate my comments being forwarded.

8 MR. KRULL: Thank you, Ms. Dollar, for your
9 comments and we'll take them to the board. And if
10 you'll -- there you go. Thank you very much.

11 The next person -- and I'll remind everyone
12 that are calling in on Webex that have raised their
13 hand, so if you're on Webex, and you haven't made a
14 comment and you do want to make a comment, please click
15 the hand -- the raise hand button on the participant
16 panel on the lower right-hand side of the Webex
17 platform.

18 Once we get through all the people that have
19 raised their hand through Webex, we'll move on to the
20 people that have called in as we are moving through
21 this.

22 The next person I'm going to call on is
23 Tracy Moretz. Tracy Moretz?

24 TRACY MORETZ: Hi, my name is Tracy Moretz,
25 and I'm speaking on behalf of my daughter Jordan Mavity.

1 I don't have the skilled nursing, but I do work
2 full-time. She's 21 years old. She actually lives in
3 our home. I'm able to continue caring for her at home.
4 She's medically fragile, wheelchair bound, and needs all
5 assistance for everything from, you know, dressing her,
6 changing her diaper, she's G-tube fed, et cetera.

7 I'm able to take care of her because I have
8 someone here that can do it while I'm working. But like
9 the other parents have said, my biggest concern is when
10 I'm no longer here. I have other children that will be
11 able to take on this responsibility, but it's an
12 additional burden on them, and none of them are in a
13 position where they can't work.

14 By cutting the hours to six hours for CLS
15 care it is absolutely impossible to work to actually
16 maintain health insurance, pay for all the extras that
17 aren't funded through the waivers that it costs to take
18 care of a child like this. So please consider that.
19 Thank you.

20 MR. KRULL: Thank you, Ms. Moretz, for your
21 comments. We will present them to the board in
22 December. And, again, I'll ask you to please click your
23 raise hand button to take your hand down.

24 We're going to go to the next person is
25 Alyssa Lee. Alyssa Lee. Okay. Ms. Lee, you can go

1 ahead and make your comments.

2 ALYSSA LEE: Thank you. Thank you for
3 allowing me the opportunity to provide public comment
4 today. My name is Dr. Alyssa Lee, and I am the Public
5 Policy and Research Director for the Georgia Council on
6 Developmental Disabilities.

7 The mission of GCDD is to bring about social
8 and policy changes that promote opportunities for
9 persons with developmental disabilities and their
10 families to live, learn, work, play and worship in
11 Georgia communities, and we envision a state in which
12 all persons are included in all facets of community
13 life, have choices while exercising control over their
14 lives, and are encouraged to achieve their full
15 potential.

16 We view the NOW and COMP programs as
17 essential components to ensuring Georgians with
18 developmental disabilities are fully included in
19 community life, and we believe that innovative waiver
20 proposals can have an immensely positive impact on the
21 disability community when done with the needs of people
22 with disabilities and their families in mind.

23 Today we would like to present brief oral
24 comments on the proposed changes, and plan to provide
25 additional details in writing.

1 We are encouraged to see inclusion of
2 assistive technology in the current proposal, and
3 believe when done well these options can have a positive
4 impact on the disability community.

5 We do ask that the choices of people with
6 developmental disabilities and their families are always
7 included in the decisions of use of technology, and this
8 requires robust, effective persons in their planning
9 assessment that includes ensuring the person receiving
10 services is a meaningful part of the decision to use
11 these supports, understands how to use them, and
12 understands how to request changes if their needs or
13 preferences change.

14 Access and improvement of services for the
15 community should always be prioritized over the cost and
16 easier path of service delivery for the state.

17 Although we do believe there are positive
18 additions in the current proposals to innovate services,
19 GCDD does want to express our concern regarding certain
20 proposed changes that we believe have the ability to
21 cause regression in our path to truly inclusive
22 community services for people with disabilities and
23 their families, and will significantly limit the choice
24 and control that we believe are rights of people with
25 developmental disabilities and their families.

1 Individualized community-based services are
2 the precise function of Medicaid waivers. The goal has
3 always been to move disability services away from
4 integrated -- away from segregated settings and into the
5 community, and we believe some of the proposed changes
6 could ultimately risk Georgia being out of compliance
7 with the HCBS settings rule.

8 We would like to articulate our concerns
9 over a potential definition change of community living
10 support services. Although not specifically highlighted
11 by DCH or GBHDD as a potential change, it appears that
12 the following language has been added to the service
13 definition of CLS: "Community living support services
14 is available for individuals who spend periods of time
15 throughout the day with unpaid unsupervised supports and
16 services."

17 We are concerned that this added language
18 may impact eligibility criteria for this particular
19 service and negatively impact the services currently
20 being received. In order for people with more
21 significant disabilities to receive the service, they
22 may be put in positions of having to leave their
23 preferred choice of residence for a congregate setting
24 such as a group home.

25 We are particularly concerned regarding the

1 caps placed on additional staffing and skilled nursing
2 as (inaudible), given the impact on the disability
3 community. These caps have the potential to move us
4 further from our goal of providing for people with
5 developmental disabilities' control and choice over
6 where they live.

7 This current proposal undercuts our efforts
8 of creating truly inclusive communities for Georgians
9 with disabilities by effectively removing the option for
10 people with more significant disabilities to live on
11 their own.

12 Regarding savings, which was discussed
13 during the proposal to DCH's board meeting last
14 Thursday, November 12th, we may be saving approximately
15 \$3.8 million dollars in state funds for the fiscal year
16 '22 -- 2022, but we are losing approximately \$7.8
17 million dollars in federal drawdown, which is quite
18 concerning, given Georgia's already poor ranking
19 regarding our ability to maximize federal dollars for
20 our spending on developmental disability services.

21 Finally, we would like to note that we were
22 especially concerned during the presentation to DCH's
23 board when it was stated by the presenter that family
24 members may be asked to step in and provide services as
25 a way to circumvent the proposed cuts and caps.

1 We believe, especially as November is
2 National Family Caregivers month, that it is important
3 to note the immense lift we already ask family members
4 to engage in regarding informal supports of their loved
5 ones. To suggest that the solution to capping services
6 is to rely on family caregivers could be described as a
7 quick Band-Aid fix, without thinking strategically over
8 the long-term regarding how to conceptualize and
9 implement home- and community-based services that does
10 not heavily rely on unpaid supports that may only be
11 available for a short time.

12 We would like to thank you for the
13 opportunity to share our concerns, and we look forward
14 to the Agency's response and to working together to
15 create innovative waiver services that aim to improve
16 the lives of Georgians with disabilities. Thank you.

17 MR. KRULL: Thank you, Ms. Lee, for your
18 comments. We appreciate them, and we'll present them to
19 the board next month.

20 Next on our list looks like Ashley, and I
21 believe your last name probably begins with the letter
22 J, since that's what you put in with your name. So
23 Ashley J. And could you please state your last name for
24 the record. You can go ahead and make your comment.

25 ASHLEY JARVIS: Sure. Hello, my name is

1 Ashley Jarvis (phonetic). I have a child on the Georgia
2 COMP waiver and we self-direct our waiver services.

3 The proposed changes of the PD option being
4 no longer available for behavioral support services will
5 negatively impact my child. We live in a rural area in
6 south Georgia with obsolete behavioral services. We
7 currently have one board certified behavior analyst that
8 travels 1.5 hours to our home to provide these services.

9 My behavioral analyst is not a provider, and
10 he is our only choice. Our child is unable, due to
11 challenging behaviors, to travel to clinics that are
12 more than an hour away. He has severe self-injury and
13 aggression.

14 I have spoken to medical physicians and case
15 managers on our child's team and in our area, and we are
16 all in agreeance that there are no behavioral providers
17 in our rural area.

18 If this proposed change passes, our fear is
19 that my child will significantly regress, and he will
20 receive a lapse in services as it would take at least
21 months to establish a provider in our area.

22 Consistency is crucial for our child. The
23 PD option also allows us to utilize more hours than
24 using a traditional provider. Please keep the
25 Participant Direct model for behavioral support

1 consultation services under the COMP waiver. Thank you
2 for your time.

3 MR. KRULL: Thank you. Next, Bob Rosen.
4 Unmute Bob Rosen.

5 BOB ROSEN: Can you hear me?

6 MR. KRULL: Mr. Rosen, we can hear you now.
7 You can go ahead and start making your comment.

8 BOB ROSEN: Okay. Thank you. First, I,
9 like so many other parents, I want to say thank you. It
10 took a long time and a lot of work to get COMP waiver
11 for both of my daughters ages 22 and 27, and I'm most
12 appreciative of that. It's been life changing in an
13 extremely positive way.

14 We have a small condo that the girls are
15 doing all their Covid daily work out of, a lot of
16 virtual work, and it's possible because we have support
17 during the day for them.

18 If we were to have the limits as proposed on
19 CLS staffing, it's quite likely that the girls would not
20 be able to eventually move into this house and live
21 semi-independently, but instead be remaining with their
22 aging parents, which is far from an ideal.

23 But the main thing I wanted to say other
24 than how much I appreciate the service is I know that
25 this sentimentality doesn't come into your

1 dollars-and-cents calculations: But as a parent with
2 two disabled children I don't know if you have any
3 concept of how difficult it is to maneuver through
4 DBHDD, VR, Social Security -- it's a full-time job just
5 trying to manage the administrative side of having these
6 children, let alone their medical and mental needs and
7 other wellbeing. And so every time we're confronted
8 with revisions that -- which are usually going
9 downwards, it just puts an incredible amount of strain
10 on families who are already under intense strain.

11 And while I know money has to be considered
12 in all of this, it would be nice for you-all to also
13 consider that the challenges and the difficulties that
14 are imposed on parents by virtue of simply having kids
15 with disabilities, it would be wonderful if the state
16 programs could actually support and nurture and provide
17 the necessities for the parents instead of creating
18 additional barriers.

19 Otherwise, I just would reflect what most
20 everyone else has said. There is a strong need here,
21 and reducing services in a state where we're really not
22 in an abundance to begin with, just is contrary; it
23 seems to be contraindicated.

24 And, finally, returning people more towards
25 an institutional setting, which is what many group homes

1 are -- school is an institution, and a group home is an
2 institution -- this seems counter to Olmstead back in
3 '99, and I'm really surprised the state is considering
4 any actions that even remotely speak to that.

5 So, again, thank you so much for your time,
6 and I appreciate it. I hope that we get to a better
7 outcome than what's proposed.

8 MR. KRULL: Thank you, Mr. Rosen, for your
9 comments. They'll be presented to the board, and we
10 appreciate you participating in the call today. If
11 you'll click your raise hand button, and that will take
12 you off the log.

13 The next person we're going to call on is
14 Brian Lackey. Ms. Jackson will unmute you. And now
15 you're unmuted, you can go ahead and make your comment,
16 Mr. Lackey.

17 BRIAN LACKEY: Thank you very much. I
18 appreciate the chance to comment on this. I'm providing
19 comments on behalf of my brother Will Lackey, who
20 receives the CLS services.

21 The proposed changes to the program may well
22 result in my brother being moved out of his own home, or
23 being forced to live in a group or a host home.

24 Will is severely mentally handicapped, and
25 has severe cerebral palsy. My parents Bill and Carol

1 Lackey were strategic in their approach to set up a
2 long-term care situation for my brother in a home they
3 bought for him prior to their passing, and Will has
4 lived in this situation for over 25 years.

5 I understand the fiscal pressures that the
6 state faces in trying to meet the balance expenditures
7 and revenues, however, it is extremely unjustified to
8 take someone such as Will and move them out of a safe
9 environment they've been in for over 25 years, and make
10 them move to a less safe environment in a group home.

11 Now, please remember that we're not talking
12 about the next road to be resurfaced, or the next bridge
13 to be replaced, or the next new library. These are
14 human beings. And just because people like Will cannot
15 communicate their mental stresses does not mean that
16 they should be disregarded. And his mental health will
17 be greatly degraded through such a move.

18 Please keep in mind that families have made
19 major financial decisions and sacrifices to establish
20 the quality of life for their loved ones.

21 As a compromise perhaps we can suggest or I
22 can suggest that people such as Will who have been in
23 this program for decades continue to receive the
24 traditional CLS support, and any new participants fall
25 under these new rules.

1 Again, thank you for the time to comment.

2 MR. KRULL: Thank you, Mr. Lackey.

3 A couple of housekeeping matters. I know
4 there is a chat feature and there is a Q&A feature on
5 the Webex platform, and if you have a quick question
6 about the technical aspects of Webex, that's great. If
7 you have a quick question about, you know, how long the
8 hearing is going, that's great. If you have a quick
9 question for me or one of the panelists, we're not going
10 to respond to these things. I can only respond very
11 briefly on certain things that if you can't, you know,
12 press the raise hand button, or something.

13 So I want to reiterate that if you have a
14 comment and you're providing it through the Q&A or the
15 chat feature of Webex, that's not the proper avenue in
16 which to submit the comment. You need to do it per the
17 public notice, which we have added to the chat feature,
18 and I'm going to pop it back up there.

19 And I know I said it earlier today, it may
20 have been a little quick for some of you-all to write
21 down, but I'm going to add it to the chat feature so all
22 the participants can see it. And I'm going to add it
23 right now.

24 And if you look in the chat feature, I have
25 just added all of the information on how to submit

1 public comments through the fax, through the mail, or
2 through email. The email address for Ms. Williams is on
3 there, the fax number for her is on there and also her
4 mailing address to mail your public comments.

5 So, if you're putting comments in the chat
6 feature, that is not considered a proper medium for this
7 public hearing for your public -- for any written
8 comments, and I just want to reiterate that, you know,
9 and this is not us being, you know, kind of being
10 difficult. There is a Code of Federal Regulations that
11 we have to abide by. We have to do it in the proper
12 manner in which to make sure that everyone has the
13 ability to make their public comment. We want to make
14 sure we're transparent in the process, and make sure
15 that we are giving to everyone their ability to make
16 their public comment.

17 So if you put it in the wrong medium, it
18 really can't be considered by the board because this is
19 the way the public notice is set up. And, you know, in
20 the age of Covid we're trying to do this so we don't
21 have to get to the boardroom at 2 Peachtree and get in
22 the same room. I mean, I don't want to be in a room
23 with a bunch of people, and I am sure that y'all
24 probably don't want to do that, too; so just a couple of
25 housekeeping reminders while I'm talking to y'all about

1 this, I want to make sure y'all understand and give
2 everyone the ability to do their comments the proper
3 way.

4 So with that being said, we're going to go
5 on to the next person that has a hand raised. Actually,
6 it's going to be Phil and Sue Gaffney. I think you made
7 a comment that you couldn't raise your hand on the Webex
8 platform, so I want to give you an opportunity.

9 So, Ms. Jackson, if you'll unmute Phil and
10 Sue Gaffney. There you go. Mr. and Mrs. Gaffney, you
11 are unmuted. You can go ahead and make your comment if
12 you're ready to do it right now.

13 SUE GAFFNEY: Thank you so much. Good
14 morning. We are Phil and Sue Gaffney. We are the proud
15 parents of Matthew Gaffney, who is a 42-year-old
16 gentleman, and his handsome face hides significant
17 challenges with severe autism, non-verbal, bipolar and
18 chronic GI issues.

19 Matt's bumpy road to quality care began
20 25 years ago. Matt was toxic on medications and no
21 Augusta hospital would take Matt. We had no choice but
22 to seek the help of Gracewood Hospital in Augusta, which
23 is an institution.

24 The medical help he received there to become
25 stable on meds was most appreciated. However, the

1 amount of physical abuse and injuries sustained at
2 Gracewood were concerning and heartbreaking.

3 After 18 months at Gracewood Matt was moved
4 into group homes. We were hopeful this would be
5 positive for him. Unfortunately, housemates were not
6 matched by similar ages, interests, things that would
7 typically bring people together. Once again, Matt's
8 medications had to be raised, risking health, and later
9 we learned his life, to tolerate the ups and downs of
10 housemates and the tension in the home.

11 After four-and-a-half years, the provider
12 gave up on our Matt, literally packed him up, drove him
13 to Georgia East Central Hospital in Augusta, another
14 institution, and dropped him off, not a word of warning
15 to us as parents and legal guardian.

16 We learned from Matt's job coach he didn't
17 show up for work, and she drove to the group home to see
18 why. We were devastated to learn our son had been
19 returned to an institution.

20 This is when we decided to purchase a home
21 for Matt located in Athens, where providers might come
22 and go, but thinking Matt would always have his home for
23 security and stability.

24 For the past 19 years Matt has been living a
25 person-centered life, just as families and professionals

1 taught us all a few years ago in many trainings held
2 throughout the state. Yes, Matt is still autistic and
3 has his ups and downs, but he has a wonderful support
4 staff that do their best keeping him active and involved
5 in the community to keep him as stable as possible.

6 We fear if Matthew is forced to move to a
7 group home or a host home, he will once again take a
8 nosedive with his autism, bipolar, and chronic GI
9 issues. When the provider decides it's more than they
10 want to deal with, where will our Matt be taken the next
11 time? A homeless shelter? The corner of Broad Street
12 and Lumpkin? The thought of this scares us to death.

13 We hope and pray that each of the board
14 members consider what they would want for their own son
15 or daughter with severe developmental challenge. Please
16 allow people with disabilities the right to live in
17 their own home or apartment. And please do not reduce
18 the hours of support. The trauma that this would cause
19 our son and many throughout the state would be
20 significant. Thank you.

21 MR. KRULL: The next commenter -- I'm sorry.
22 Thank you, Mrs. Gaffney, for your comments.

23 The next commenter is Robert Vosburgh.

24 ROBERT VOSBURGH: Hi, can you hear me?

25 MR. KRULL: Yes, sir.

1 ROBERT VOSBURGH: Okay. I'll be as brief as
2 I can. I'm having problems with my computer. It's
3 already blown me off twice, and I had to get back on.

4 But I'm calling in regards to Andy Gunther.
5 He's my stepson. He's been my stepson now for 21 years.
6 He lives in an apartment by himself. He needs -- he is
7 totally wheelchair bound or bedbound. He can do
8 absolutely nothing for himself. You can see that by
9 looking at his -- what is it, his ISS or SIP?

10 (UNIDENTIFIED FEMALE SPEAKER): (Inaudible.)

11 ROBERT VOSBURGH: But anyhow, if he were to
12 have his waiver capped, and he only had like 12 hours of
13 coverage, I'm wondering what would happen if he's laying
14 in bed and he can't do anything for himself and there is
15 a fire? Does he just lay there and burn up? If he has
16 to go to the bathroom, does he just mess the bed and
17 have to lay in it until somebody comes in?

18 But he lives in a one-bedroom apartment by
19 himself right now. He's extremely happy. And we're
20 afraid that if this waiver is capped not only will that
21 put him in danger, but it would just -- the only thing
22 he has right now is his happiness, because -- like I
23 said, he's totally dependent upon his staffing. He
24 cannot get out of bed or into the wheelchair by himself.
25 They have to use a Hoyer device to get him lifted out.

1 A couple of times he's actually -- his legs
2 gave out and he went down on the floor. And he weighs
3 close to 200 pounds, so fortunately in Gwinnett County
4 there is a service, if you call 911 there is a service
5 where the fire department will come out at no charge and
6 lift you up and put you back in the bed.

7 But that's basically our main concern is
8 he's on heavy medications for -- psychotic medications,
9 because in the past he experienced intermittent
10 explosive disorder where he wanted to injure himself,
11 and go as far as jump out of the car.

12 So he needs the staffing, and if he has the
13 waiver capped, or he's only allowed 12 to 17 hours, I'm
14 afraid what would happen to him.

15 But I appreciate you-all letting us all make
16 our comments. Many of my concerns are similar to the
17 ones that have already been expressed, and, again,
18 thanks for giving us consideration.

19 MR. KRULL: Thank you, Mr. Vosburgh, for
20 your comments.

21 Next I'll call on Camille Yahm. Ms. Yahm,
22 you can go ahead and comment.

23 CAMILLE YAHM: My name is Camille Yahm, and
24 I appreciate this community to speak my voice.

25 Because of the proposed changes to the COMP

1 waiver, I'm compelled to share with you our personal
2 story, and it's my fervent wish that you will adhere to
3 all of our personal stories. They may all be different,
4 but with similar needs and challenges.

5 On July 29, 1975 our daughter Wendi Funk was
6 born with anoxia. In utero the umbilical cord had
7 wrapped itself around her neck cutting off the supply of
8 oxygen to the brain. It was an emergency cesarean
9 birth, and her life for several days was in the balance,
10 but her precious life was spared, but with developmental
11 delays.

12 I'm a speech pathologist, and utilize my
13 skills to assist her with speech and language
14 proficiency. Regular visits to Easter Seals aided her
15 in walking and climbing stairs, but it was a matter of
16 time before she began having seizures and respiratory
17 infections that were, and still are, controlled with
18 appropriate medications, through Medicaid.

19 She attended special education classes in
20 Decatur city schools, and reached the mental age of a 4-
21 or 5-year-old. We enrolled her in DeKalb Training
22 Center, where she spent her days continuing to develop
23 and mature.

24 At the age of 25 space opened at a group
25 home where she attempted to adjust to live with other

1 young women with various disabilities. Group homes at
2 that time were primary residences. There were few
3 alternatives for our children. But 16 years ago we
4 discovered an agency that believed in a person-centered
5 approach to caring for adults with multiple
6 disabilities. Our daughter is able to live in her own
7 apartment she calls home, and learned to take care of
8 it.

9 She has had a cadre of trained, dedicated
10 caregivers that are with her for 24-hour care in
11 eight-hour shifts. Although she cares for her personal
12 needs, her caregivers aid her in important household
13 activities. They provide various activities that she
14 enjoys during the week and on weekends. She has thrived
15 under their care, and our family appreciates them as
16 extended family.

17 We do trust that the DCH board will
18 unequivocally deny the proposal before them for the
19 following reasons that will affect our daughter and our
20 family.

21 One, she cannot be left alone for any length
22 of time without support services.

23 Two, she's incapable of managing money,
24 preparing meals, or taking her medications.

25 Three, she's not technologically adept and

1 would not be able to use the phone for help if needed.

2 Four, she obviously cannot drive a car, but
3 will need transportation for outings of every kind and
4 getting to the doctor or to the hospital when needed.

5 Five, her father and I are in our 80s and
6 physically unable to provide 24-hour care for her
7 special needs. Her safe, stable living arrangements
8 will be impossible to maintain, and her quality of life
9 would be simply curtailed and affected most seriously.

10 I have been an advocate for those with
11 mental and physical disabilities all of my adult life.
12 Today I'm here again as a speech pathologist, as a
13 mother, to continue to lift my voice to those who are
14 voiceless. Thank you.

15 MR. KRULL: Thank you, Mrs. Yahm, for your
16 comments.

17 Looks like we have a few more people. I'm
18 going to call Amy. Your last name is not posted on
19 here, so could you when you make your comment, please
20 give us your last name for the record when we transcribe
21 all the comments to the board.

22 AMY ODOM: Ms. Jackson, it's all the way at
23 the top, the very first name at the top right now.

24 MS. JACKSON: What's the first name?

25 MR. KRULL: It's Amy, A-M-Y.

1 MS. JACKSON: Amy. And also (inaudible) --

2 MR. KRULL: Yeah, I've got another name
3 already, so --

4 AMY ODOM: Hey, good morning.

5 MR. KRULL: Yeah. Hey, you can go ahead and
6 start. Thank you.

7 AMY ODOM: Great. Thank you for the
8 opportunity to speak with you today. My name is Amy,
9 A-M-Y. The last name is Odom, O-D-O-M. I am
10 professionally a consultant with Parker Poe Consulting
11 here in Atlanta. I have a sibling, Laura Owen. She is
12 a 44-year-old developmentally disabled woman who is
13 living in Athens, Georgia right now.

14 My parents, too, are in their 80s. My father
15 has Alzheimer's. And they have been advocates for her
16 for the 44 years that she has been here with us. And
17 she is actually on the phone with us today and is
18 wanting to be an advocate for herself and talk with you
19 a little bit about how she perceives that these changes
20 would affect her.

21 But from my perspective, we have seen so
22 much change over the course of her lifetime in the
23 services that are available to individuals who would
24 otherwise be situated in a group home. And I echo the
25 comments that everyone else has made. I'm not going to

1 take up any more time going through all of the same
2 things that have been said already today. But I do
3 implore you to reconsider these drastic changes that
4 would result in many, many families having to move their
5 loved ones out of an independent living situation with
6 support to a group home.

7 That's not what we need to be doing with as
8 innovative as I believe that the state of Georgia has
9 been with respect to the 1332 waivers and the 1115
10 waivers, and I feel like we're taking a step backwards,
11 and respectfully request that the board reconsider these
12 cuts.

13 At this time I would like to -- Laura, I
14 don't know if you can hear her, she's probably muted.
15 She, too, has a caregiver that is with her right now
16 during the day that is helping her with the technology.
17 I do believe she's on Webex.

18 Laura? Is there a way to unmute her? She'd
19 like to speak to the group.

20 MR. KRULL: Yeah. Go ahead. Is it Laura
21 Owen?

22 AMY ODOM: Yes.

23 MR. KRULL: She's unmuted, she can go ahead
24 and speak.

25 LAURA OWEN: Okay. I just want to say that

1 cutting the waiver is going to be very devastating
2 because then that would make me have to live in a group
3 home. I was really unhappy in that situation. I really
4 enjoy being in the independent living program, and have
5 individual staff that take me places and help me do
6 things to be more of the adult I'm supposed to be at my
7 age.

8 I can't rely on my parents to do much
9 anymore. As my sister pointed out, my dad has got
10 Alzheimer's, my mom is in her 80s, can't really get
11 around as much as she used to, and I just simply need
12 this waiver. I can't -- I don't know what I'd do
13 without it.

14 So please do not make it where I have to go
15 back to a group home institutional setting. I would be
16 very miserable, and I'm happy now being in my own home
17 with my staff. So please don't take that away.

18 AMY ODOM: I might also add that Laura does
19 have a roommate in his 80s. He is non-verbal and has a
20 seizure disorder. Laura, too, has some medical issues
21 with respect to diabetes and some other conditions that
22 do require skilled nursing.

23 So, again, just to reiterate the concern
24 that we all have on this call and at this meeting today,
25 I realize it may not be a huge universe of people to

1 those that are making these decisions, but to that
2 universe of people it is their whole world, and it is
3 their way of life. And for the families that support
4 them and have supported them and will continue to
5 support them in the future, going this way is really,
6 really truly taking a Draconian step back.

7 So with that, I appreciate your time and
8 look forward to the board meeting in December.

9 MR. KRULL: Thank you, Ms. Odom and Ms. Owen
10 for your comments. They'll be presented to the board in
11 December.

12 It looks like another person on Webex we
13 have is Francis Jose. Ms. Jose, go ahead, you can make
14 your -- I'm sorry. Hold on. Francis Jose, you can go
15 ahead and make your comment, please.

16 FRANCIS JOSE: Good morning, and thank you
17 for hosting this event to allow us parents and siblings
18 to voice our concerns. I am the father of Sabrina, Bri
19 for short.

20 Bri is a 29-year-old with severe autism and
21 other health and mental disorders. I was a C-level
22 executive, but had to retire five years ago due to
23 severe health reasons.

24 Bri lives in her own home right now, a home
25 we built for her several years ago. We've tried Bri

1 having a roommate, but that did not work as the staff
2 were unable to give Bri the care she needs as her
3 behaviors and health needs require one-on-one care.
4 Additionally, roommates were not compatible and caused
5 Bri severe physical and mental stress.

6 As you've heard from pretty much all the
7 other parents, Bri, you know, our daughter Bri cannot be
8 left alone at any time due to her behaviors and her
9 other health needs. Fortunately, the current caregiving
10 agency we've used to staff Bri has given her the care,
11 and I'd even go further to say love for our daughter.
12 And while she has had her ups and downs, she continues
13 to thrive.

14 As with everyone on this call, we are
15 requesting that you reconsider the proposal as it would
16 severely impact our daughter as well as all the other
17 children in Georgia. Thank you.

18 MR. KRULL: Thank you, Mr. Jose, for your
19 comment. All right. It looks like we're done with the
20 folks on Webex, and --

21 MS. JACKSON: We have one.

22 MR. KRULL: I'm sorry?

23 MS. JACKSON: Kathryn Hill. I believe she
24 has a question.

25 MR. KRULL: Okay. Go ahead and unmute

1 Kathryn Hill.

2 Ms. Hill, you can go ahead and make a
3 comment. Ms. Hill? Kathryn Hill? Okay. Ms.
4 Jackson --

5 MS. JACKSON: (Inaudible.)

6 MR. KRULL: -- you can go ahead and just
7 mute her. It looks like it was handled. All right.
8 I'm sorry.

9 Now we have Deanna Gasbarro. Ms. Gasbarro.
10 Deana Gasbarro? Okay. You can go ahead and go ahead
11 and mute her. She maybe will just submit her comments
12 in writing.

13 Okay. Now we're going to try and do this
14 with the folks on the phone. Okay. So if you're
15 calling in and you want to make a comment, what we're
16 going to do is unmute everyone, and only those -- Ms.
17 Jackson, if I'm doing this wrong, you just let me know,
18 okay, but I think we're going to have to unmute them, or
19 do you want to unmute them one at a time? We don't know
20 who they are, though. It just shows they are a call-in.
21 We only have a telephone number for them, though, right?

22 MS. JACKSON: Correct. Correct.

23 MR. KRULL: So in order to kind of keep this
24 orderly, if you're calling in, everyone else, in order
25 to do this we're going to have to unmute everyone,

1 please kind of keep the background noise to a minimum,
2 and then we can kind of identify who wants to make a
3 comment.

4 Okay. Ms. Jackson, when you're ready, go
5 ahead and we're going to let the call-in users kind of
6 identify themselves, who wants to make it. And I'll try
7 and keep track of it over on my side.

8 MS. JACKSON: I'll unmute the callers and
9 then we'll go from there.

10 MR. KRULL: Okay. That would be great.

11 UNIDENTIFIED SPEAKER: Hello?

12 MR. KRULL: I can hear you. Who are you?

13 DEANA GASBORRO: Can you hear me?

14 MR. KRULL: I can hear you. Who are you?

15 DEANA GASBARRO: This is Deana Gasbarro.

16 MR. KRULL: Oh. Deana Gasbarro?

17 DEANA GASBARRO: Yes, I had a person
18 volunteer to interpret for me, but I wanted to be part
19 of this call.

20 I'm going to make it really brief. So I
21 have a sister. My sister's name is Christa, Christina,
22 Gasbarro. She's 45 years old. She does have a
23 developmental disability, and she's severely autistic,
24 non-verbal.

25 I agree with all the comments that have been

1 made by the different family members, and I disagree
2 with taking those hours away from our family members who
3 need that on an individual basis. I imagine -- I'd want
4 you to imagine if you're in their shoes, you know,
5 you're taking their life away from them. Imagine what
6 that's going to cause, the negative effects.

7 I plan to email more sentiments, but I just
8 wanted to say that I'm completely in support of all the
9 different people who made the comments today. The
10 services that my sister is receiving, they finally have
11 gone from a rough planning to a more smooth transition,
12 and now you're going to take it away from us again.

13 So thank you very much.

14 MR. KRULL: Thank you, Mr. Gasbarro.

15 Okay. You want to unmute the callers again
16 and see if anyone else is available.

17 MS. JACKSON: I'll just go by the list.

18 MR. KRULL: If you're on the call, go ahead
19 and we're trying to unmute you one at a time.

20 NAOMI WILLIAMS: Hey. This is Naomi
21 Williams. Can you hear me?

22 MR. KRULL: Yes, Ms. Williams. You're up.

23 THE WITNESS: Okay. Great.

24 Since I'm calling in I'm unable to see what
25 you have put in the chat, but could you just say what

1 the email is for us to be able to make public comments?

2 MR. KRULL: Absolutely. All right. Are you
3 ready? I'll give it to you.

4 NAOMI WILLIAMS: Yes.

5 MR. KRULL: It's D as in dog, A as in Adam,
6 N as in Nancy, Williams. So it's W-I-L-L-I-A-M as in
7 Mike, S at dch.ga.gov. And the person is Danisha
8 Williams. That's her email address, and you can submit
9 comments to her.

10 NAOMI WILLIAMS: Thank you.

11 MR. KRULL: Do you have any other questions
12 about --

13 NAOMI WILLIAMS: Not a question. Just going
14 to make a quick comment. I'm the parent of a child who
15 is 11 years old, Noah Williams. He's 11. So even
16 though he's not an adult, the decisions that are made
17 now will impact those coming behind him. You'll hear
18 some in my background. We're at therapy now.

19 So I do appreciate you-all taking the time
20 to listen to our comments, and would really implore you
21 to see and hear these stories not just as stories, but
22 to imagine if this is your family member and imagine
23 what the -- we take care of our children because we love
24 them, we take care of our siblings because we love them,
25 we give up a lot because we love them. So to have not

1 only our lives stifled, but to also have our loved ones
2 life stifled, it's heart wrenching. And to not just see
3 our loved ones as dollars and cents, but as people who
4 actually contribute to the bigger means of society. So
5 thank you.

6 MR. KRULL: Thank you, Ms. -- thank you,
7 Naomi, for making the comment.

8 We're going to go down to the next call-in
9 user. Let's move on down, Ms. Jackson. I think we're
10 going to have to unmute them all and just ask them.

11 If you're a call-in user, just state that
12 you want to make a comment and we'll call on you.

13 MIKE HOWARD: Hi, my name is Mike Howard.

14 MR. KRULL: Okay. Mr. Howard, go ahead and
15 let's get your comment in.

16 MIKE HOWARD: My wife Debbie and I are
17 representing our -- I'm sorry. We're representing our
18 son Tyler Howard, who is a 28-year-old young man. Like
19 most of the people you've heard from today, you know,
20 our child, sibling, loved one, face a tragic situation
21 in their life, and we as their parents or relatives or
22 caregivers face something that we never thought we would
23 encounter, or could have imagined.

24 We, like many have said, we are grateful for
25 the support that we received through the waiver program,

1 and an important aspect of that is that it gives people
2 choice. Everybody's situation is different, and we have
3 currently choices that allow us to find the best
4 approach for our loved one.

5 You know, that doesn't always happen right
6 away as you've heard, you know, people have tried
7 different things until they found something that works
8 for their child, and gives their loved one the best
9 chance at living, at living life to its fullest.

10 You know, we're in a situation where our son
11 is -- he's at home with us. We would never consider
12 having him in a group home. I know that's, you know,
13 that's not the best approach for everybody, but and
14 right now our son is allocated 24-hour care because of
15 his needs. However, due to our location, the provider
16 hadn't been able to provide 24-hour care for him.

17 So a lot of times my wife and I end up doing
18 that, which is fine, except in providing that care it
19 gives us little time to try to, you know, advance things
20 for him, and to make his life better. We're just trying
21 to keep him stable, and keep him going from day-to-day.

22 Putting us in a situation where we don't
23 even have the option for 24-hour care is going to mean
24 our son will never be able to advance. He has a lot of
25 opportunity to move ahead. He has, in fact, moved ahead

1 many times only to encounter setbacks. But if, you
2 know, if the 24-hour care capability isn't there, then,
3 you know, the outlook for him and being able to achieve
4 his greatest potential is very dim.

5 So I, you know, somebody said earlier that
6 Mr. Wakefield had said in a prior call that the vast
7 majority of people in the program will not be impacted.
8 Well, that's great. But I think you've heard from
9 people who will be impacted, and will be impacted in a
10 very, very negative way; not only the caregivers, but
11 more importantly the individuals whose life they are
12 seeking to improve.

13 And it's, you know, it's good that you are
14 opening up this forum so people can share their stories.
15 And I hope somebody, you know, listens to what is said
16 there and realizes that, you know, many people under
17 this program have been able to advance and, you know,
18 realize things that they thought were never possible in
19 the life of their loved one, and to take all of that
20 away would be an incredible tragedy.

21 You know, on my tombstone I want it to say
22 that I dedicated my life to my child, and helped my son
23 achieve the most that he could given his disabilities,
24 and I know many other people probably feel the same way.
25 It's a passion and a focus that, you know, is with us

1 every minute of every day. And it's -- for this kind of
2 thing to even be considered and for the, you know,
3 obvious benefit that this brings to many, and for, you
4 know, for somebody to suggest this is going to be pulled
5 away, it's disturbing.

6 And I hope that the impassioned pleas that
7 have been made today and the letters that you will
8 receive give you further details, and will help the
9 people making the decision quickly decide that this is a
10 bad idea, and they should not do this.

11 And they -- the fact that this was even
12 considered to me shows a lack of understanding of what's
13 really involved, and a lack of real commitment -- I
14 mean, there may be words out there, but real commitment
15 to help improving the life, the lives, of those who are
16 most vulnerable in our state.

17 Thank you for allowing me to talk, and I
18 hope that you will listen to what everybody has said
19 today and get this to the people who make the decisions.
20 I thank you very much.

21 MR. KRULL: Thank you, Mr. Howard, for your
22 comments, and your time and participating in this
23 hearing.

24 As I stated earlier on numerous times, these
25 comments that are made today will be transcribed and

1 passed along to the board at their December board
2 meeting.

3 And so is there anyone else? I think we've
4 got to go through the rest of the callers that are
5 calling. Ms. Jackson will you --

6 KATHRYN HILL: I finally got on. Kathryn
7 Hill.

8 MR. KRULL: Oh, hey, Ms. Hill. How are you?

9 KATHRYN HILL: Good.

10 MR. KRULL: It's good that you got through
11 the phone. So go ahead and we'll get you to go ahead
12 and make your public comment for the public hearing
13 today. You can go ahead and begin.

14 KATHRYN HILL: Okay. Thank you. And thank
15 you for having this.

16 I live in Eatonton, Georgia, and my son
17 Bobby is 19 years old with several disabilities that
18 require that he receive skilled nursing through the
19 Medicaid program called GAPP.

20 He has 12 hours a day nursing, and his
21 parents, which are me and my husband, 54 and 55, are the
22 other 12 hours of skilled nursing care.

23 My husband and I both work, and we haven't
24 gotten much sleep in the last six years when the skilled
25 nursing care began to be needed.

1 Let's see.

2 The life support services, I think that's
3 how it said -- I'm new to it because we're still under
4 GAPP right now -- give services to the families that
5 need it, and the individuals. And the cap for six hours
6 for most people unless they are in a group setting would
7 not be enough. My child, of course, needs 24 hours of
8 skilled care. So right now 24 hours of care is possible
9 for the people that need it.

10 My son, when he graduates out of GAPP at 21
11 will go into this waiver program, and because of all his
12 critical care medical disabilities he would qualify and
13 receive 24 hours of skilled nursing care at this time.

14 As an aside, these nurses are paid less than
15 the GAPP program nurses. And we live in rural Georgia,
16 so it is already very hard to find quality nursing; so
17 that's not even addressed that we can't even have
18 quality nursing because the nurses aren't being paid as
19 much as the pediatric program. There is so many other
20 jobs the nurses could have making so much more money,
21 they have to really want to do this sort of thing.

22 Many people need this program. So that's
23 why I'm wanting to comment and, obviously, there is
24 other people, but in the scheme of things that's not
25 very many. The changes would require him to in the

1 future move into a group home, possibly even a nursing
2 home due to his medical needs, or he'd have to continue
3 to live with his parents, who are currently working and
4 do the other eight-hour shift as we continue to work and
5 aid.

6 These programs are designed to do different
7 things in the population, and it's things like
8 independence, jobs, daily care, shopping, housekeeping,
9 entertainment, medical necessity and so much more.

10 The Olmstead Act has addressed this in the
11 past. And year after year families have to advocate and
12 fight for their family members to keep and have services
13 that allow them dignity, and for other family to --
14 other family members to feel more hopeful about the
15 future without them in it as their care person.

16 When I was reviewing the state budget back
17 before it was approved, many of the special needs
18 population programs seem to be getting eliminated as if
19 they are not needed. I really question that. On the
20 other side, it takes mountains of paperwork to be part
21 of any of these programs from birth to death.

22 I know that the fraud is real and people
23 take advantage of the system, but we are the families
24 with the least energy, the least time, and the most to
25 lose when we're kicked out for not dotting an I

1 properly. And that does happen. I don't know if you're
2 aware of that, but that does happen.

3 I hope I was able to convey accurately what
4 my concerns are, and thank you for your time.

5 MR. KRULL: Thank you, Ms. Hill, for your
6 comments and being part of this hearing today.

7 Ms. Jackson will unmute some other people on
8 the call and see if they are wanting to make comments.

9 Anyone out there in telephone land wanting
10 to make a comment?

11 ANN OWEN: I'm Ms. Owen. I want to thank
12 you for allowing --

13 MR. KRULL: Ms. Owen.

14 ANN OWEN: I want to thank you for
15 allowing --

16 MR. KRULL: Yes. Go ahead.

17 ANN OWEN: A-N-N.

18 All right. I just want to thank you for
19 hearing everyone's comment. I also want to -- excuse
20 me -- thank you for allowing both my daughters Amy Odom
21 and Laura Owens to speak. I hope their words will be
22 heard, and I have heard you say many times that all of
23 this will be transcribed and sent to the board for the
24 December meeting. I'm just grateful to you. I was not
25 able to get on Webex, but I have been listening the

1 entire time, and I thank you all.

2 MR. KRULL: Thank you, ma'am, for your time.

3 Let's see, is anyone else calling in? Let's
4 unmute the rest of these phone callers.

5 Okay. Anyone on the phone that hasn't made
6 a comment that would like to make a comment, please
7 speak up.

8 MIKE MCBROOM: It's Mike McBroom, and I'd
9 like to make a comment and maybe ask a question.

10 MR. KRULL: Sir, can you go ahead and start?
11 What is your name again?

12 MIKE MCBROOM: Mike McBroom.

13 MR. KRULL: McBroom. Okay. We can't --

14 MIKE MCBROOM: M-C-B-R-O-O-M. (Inaudible.)

15 MR. KRULL: And that's great, Mr. McBroom.
16 We don't take questions through this forum. You can
17 obviously email them to Ms. Danisha Williams at
18 D-A-N-W-I-L-L-I-A-M-S a-t dch.ga.gov.

19 MIKE MCBROOM: Okay.

20 MR. KRULL: And I'll post that again. She
21 will get your question routed to the appropriate person
22 so hopefully they answer the question for you okay.

23 MIKE MCBROOM: Okay. That would be great.
24 I do want to make a comment.

25 MR. KRULL: Sure.

1 MIKE MCBROOM: We have CLS in-home care.
2 Our son has autism, seizure disorder, behavior
3 disorders, all sorts of things. And I'm not sure how
4 these cutbacks are going to hit us at this point, but I
5 know that it's a regression and it will later.

6 But we also have two-on-one support when
7 he's out in the community, and I'm concerned if you
8 start limiting the number of hours that that may affect
9 the two-on-one.

10 Obviously, he has to have an ARS, and I have
11 heard that that may be going away, and if it is, that's
12 a problem too. And I'm going to put through written
13 comments. But, you know, it's a concern to us that it
14 sounds like after 20 years, 30 years -- well, 20 years
15 since HB100 that we've been trying to improve services,
16 it sounds like DCH is trying to start rolling them back,
17 and that is the wrong direction. And I will email my
18 comments and the questions to Ms. Williams.

19 MR. KRULL: Thank you, Mr. McBroom. We
20 appreciate your comments, and we'll look forward to
21 receiving those in an email and presenting those to the
22 board in December.

23 Ms. Jackson will -- if you want to unmute
24 the rest of the phone callers, and I'll inquire whether
25 anyone has another comment.

1 Okay. If you're on the phone and you're
2 calling in, and you want to make a comment go ahead and
3 state your name. And I'll try and capture their --
4 okay. Once again, if you're calling in and you haven't
5 made a comment yet, please state your name and we'll
6 capture your comment. We give everyone the opportunity
7 to make their comment before we mute those phones again.

8 Okay. Go ahead, Ms. Jackson, you can mute
9 those phones. I think that's captured all of them.

10 And we're going to go ahead and look one
11 more time to see if anybody has a hand raised on the
12 Webex platform.

13 (60-second pause 12:00-12:01 p.m.)

14 MR. KRULL: We've asked several times.
15 We've also went through the list of attendees to check
16 if they are or anyone are wanting to make comments.
17 We've looked at the chat, and no one has indicated they
18 want to make any comments.

19 So I want to thank you each of you for
20 providing your oral comments today. And let me
21 reiterate the period for the public comment will expire
22 on December 14th, 2020. As I indicated earlier, earlier
23 comments will be entered into the official record as
24 well as the transcription of the oral comments that
25 we've heard this morning.

1 The board will be asked to vote on this
2 public notice for final adoption at the January 14, 2021
3 meeting, which will be held at the Department of
4 Community Health at 10:30 a.m., and I'll just indicate
5 make sure everyone checks the meeting notices to see if
6 they are in person or virtual based on public health
7 emergency and Covid-19 pandemic.

8 So at this time it looks like it's going to
9 be in person, but it may be a Webex meeting. But you
10 just want to make sure, just check the public notice on
11 the DCH website. There is a lot of information out
12 there, including this public notice, with the
13 information on how to get the comments.

14 So thank you once again for your attendance,
15 and we really appreciate everyone participating today.
16 There being no further person who wishes to make a
17 comment, this public hearing is adjourned at 12:02 p.m.
18 Have a good day, everyone.

19 (Concluded at 12:02 p.m.)
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21
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25

C E R T I F I C A T E

STATE OF GEORGIA:

COUNTY OF DEKALB:

I, Maureen S. Kreimer, Notary Public and Certified Court Reporter in and for the state of Georgia at Large, do hereby certify that the foregoing proceedings were taken down and reduced to written form by me, that the foregoing pages 1 through 64 represent a true and correct and complete transcript of the proceedings as they transpired, to the best of my knowledge, skills and ability; that I am not a relative or employee of any attorney, counsel, or person associated in any way with this matter or attendant at this proceeding; nor am I anyway financially interested in this matter or action or outcome of same.

This, the 23rd day of November, 2020.



MAUREEN S. KREIMER, CCR-B-1379
Notary Public in and for the
State of Georgia. My Commission
Expires August 14, 2024.

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