30 Self-Advocates: Tracy Thresher, Scott Brodie, Kris Medina, Tiara Mendala, Lori Jones, Marylyn Shank, Patti Grasset, Debbie Demars, Thorin Brigham, Cy Trombley, Nicole Leblanc, Antoine Polgar, Craig Davis, Gary Bergeron, Mary LaFountain, Karen Dopp, Erik Johnson, Edwin Place, Alyssa Christopher, Dan Dunn, Bret Sweeney, Robert Martin II, Adam Mozdzierz, Randy Lizotte, Nicole Villemaire, Kyle Moriarty, Todd Washburn, Amy Guinard, Rachel MacMartin, Ken Jacobs, Max Barrows.


✓ Group Updates:

GATSA – Lamoille

- Lori’s last name changing from Cyr to Jones
- Selling little Caesar’s pizza next month for fundraiser to go to state conference
  - Didn’t meet in January because of the ice storm
  - Meeting next month

Speak Up Addison County

- Game night last Friday and sold hot chocolate as fundraiser
- Spring fling dance planned for March 20th at the American Legion in Middlebury
**Randolph – R.A.P.S group**
- Learning sign language
- Made happy new year poster in sign

**Friends Helping Friends**
- Had potluck last Thursday
- Talking about raising money to go to conferences
  - Talking about people living on their own
  - Planning a healthy living class about eating healthier

**Communication Alliance**
- Group is fundraising to raise money for Autism Summer Institute in Syracuse. Raised $250 in New Year’s bake sale
  - Tracy is presenting at 2 colleges in Boston next week
- Real Abilities Film Festival showing W&J

**Vermont Choices**
- Getting ready for Valentine’s day dance next week at VFW in Lyndonville

**SAVY**
- Met in January
- Had a Christmas party

**Next Step Self-Advocates**
- Planning a dance (a late Valentine’s dance)
- Max is coming up to do a MAPS project on 2/14 with our group
System Of Care Plan Survey
- We broke into 4 groups and answered questions for the State System Of Care Plan. The extensive responses are at the end of the minutes.

Voices and Choices: May 29th and 30th at Killington Grand Hotel.
- Randy explained all the forms for Voices and Choices. Registration forms are now available, and members are encouraged to register early, as there is limited capacity at Killington.
- Presenter applications, life histories project, and local group award forms were also passed out. The theme has been chosen … We Are Self-Advocates! Hear Us Roar! 20 Years of Self-Advocacy in Action.
- We will update the group on the Theresa Wood Award nominations at the February meeting.

Legislative Update
Randy reviewed the State House days. Forms were passed out as he was doing so. Days to come to the State House are: January 30, February 19, March 14 and April 10 & 24. GMSA will post times and dates on Facebook and website.

Nicole gave a legislative up on the following:
- S. 27 Respectful Language Bill: GMSA has been working to get this passed for more than 3 years. The Governor will sign this Bill sometime around the 2nd week of February. Come to the statehouse and get your picture taken with the Governor when he signs the respectful language bill!
- Budget Bill: Almost $10.5 million of new money for Developmental Services.
- There is a new Bill to Strengthen the DD Act. Now the state can make changes to the system of Care Plan (most often is cuts) without involving the legislature. This bill
says that as a final step the legislature must review any changes.

- **H. 208 Paid Sick Days for all workers**: This bill gives all workers in Vermont the ability to earn sick time for personal or family health reasons without loss of pay.

**Life Histories Project**
- Skye explained project for Stirling.
- Lots of people are interested and everyone got a nomination form.

**Jenny Hatch as Keynote Speaker for Voices & Choices?**

Would you like to see Jenny’s lawyer be support staff for Jenny during the keynote? Need to provide a chance for Jenny to speak alone. We like the subject of guardianship but would rather hear her perspective than the lawyer’s.

- Group Conclusion: Want more information and Nicole to report back at next board meeting

**Peer Mentor Proposal**

People really like this idea and want to learn more, Use Nicole and Randy as resources. Could use peers to teach about safety when going to conferences. “What better teacher than those who can relate?” “I think the community will become stronger with peers too.” “This would make a great Voices and Choices workshop idea – Randy and Nicole talking about what they do as Professional Self-Advocates” “People who relate to use can understand and have been through the same thing that we have” “Relationships will get stronger” Lori would like to do a workshop on independent living Some of us probably know different things than other people know. “We are really good at helping others with disabilities.” Group wants to stay updated and be involved as we move forward with this project

**NEAT Project Update**

Max thanked everyone who applied to work on this project. Skye explained what the
project was all about. Max said we hired an Outreach Coordinator.

**Chester Finn: Will visit Vermont on 2/18.**

Lori explained who Chester Finn is.

Here are ideas for GMSA for his day with GMSA that people came up with:

- Have him work with us to communicate better
- Help with the peer mentor proposal and get his ideas on that
- Get his Tips for implementing a statewide peer to peer network
- Do a roundtable discussion to send ideas to President Obama
- Want to hear about his vast journey to advocacy
- Leadership training – about speaking up and giving presentations! Lots of people liked this.
- Q&A (make sure questions are relevant).

**List of People Interested in Doing Disability Awareness Trainings**

Nicole would like to get out there and give presentations in the community about disability awareness. Those who would also like the opportunity to give Disability Awareness presentations are: Rachel MacMartin, Nicole Villemaire, Scott Brodie and Tiara Mendala.

Question: Could GMSA do a training on how to present at Voices and Choices?

Answer: YES!

**Adjourned at 12:30pm.**

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System of Care Plan Survey Responses from Green Mountain Self-Advocates
January 31, 2014

1. **Name:** Green Mountain Self-Advocates
2. **Please check what best describes you:**
A focus forum was conducted during a statewide GMSA meeting. Close to 50 people who receive developmental disabilities services and their support staff participated. They represented 10 local self-advocacy groups:
1. Capital Advocates Together of Montpelier
2. Next Step Self-Advocacy of St. Albans
3. Vermont Choices of St. Johnsbury
4. Getting Acquainted Through Self-Advocacy of Lamoille County
5. Advocates for Action of Bellows Falls
6. Speak Up Addison County
7. Randolph Area Peer Support
8. Friends Helping Friends of Barre
9. Communication Alliance of Washington County
10. Strong Advocacy Voices and You of Morrisville

Some relevant comments were also taken from quality assurance focus forums conducted by GMSA in 2013 at agencies being reviewed.
We also included SOCP comments we submitted last year that were not acted on for further consideration.
Similar comments stated by different people were grouped together.

3. What is the one thing about individual developmental disabilities services (for you or someone you know) that you think is great?

Self-advocacy
- Self-advocacy! We are working on educating our society and community about presumption of competence and inclusion for everyone
- The peer advocacy supports that are available to me
- Our agency hires people with developmental disabilities to work as professional staff to promote self-advocacy and provide peer support
- Speaking up for ourselves; Making sure our needs are met; Making sure we are listened to
- Listening to others’ questions and concerns or even feedback or comments from others
- Agency support of self-advocacy and groups:
  - They are behind us for whatever decision we all make and they give us support and input
  - No one tells us what to do in peer support. The allies help out but actually it is really our group we support ourselves
  - I would not be at this meeting without staff support

Individualized
- One thing great about individual services… is that they are individual! Individual services are the way to go to support people. We do not agree with group setting type of services
  - Do not fund center based day programs
  - Do not open sheltered workshops or fund enclaves
  - Do not allow more than 2 people to live in a shared living arrangement
• I got to interview new staff. I got to know her before she got to know me, before she got hired.
• They matched me with the right person
• In September I got my own apartment. At first it was scary.

Employment
• Having vocational supports in order to pursue my passion to advocate, individual services allow me pursuit of my goals to educate others
• Working at an advocacy job and getting paid fits my individual needs
• Without services, we would not have any jobs
• They helped me figure out how I do things best, to get a job

Emotional Support and Crisis response
• Staff are always there for you
• I get to spend time with my respite person whom I get along with very well
• There is help for people in crisis, this is a safety net for parents when they can no longer take care of their sons/daughters
• I think the agency is doing well, in the fact that they are supporting us in the way they should. Looking forward instead of backward. They are always looking for our futures, not looking in the past.
• I like to have someone (staff) check in with me
• If we are feeling bad, we have something we can’t get off our chest, can’t control anger for example, we go to a person for help.
• Services keep us stable when we are going through periods of anxiety or chaos.
• If it weren’t for services we wouldn’t get any help
• When my staff and team work together and collaborate
• Having a home provider
• Like getting along with my workers

Life-long Learning
• I think they’re great because staff works with you to get your goals done
• The freedom they offer
• I like having someone to help me with my budget and making sure my bills get out on time.
• I like going to taking college classes because I like to learn skills and spend time with my friends and other people.
• I like it that I am more disciplined after having independent living services
• If we don’t get services we won’t learn the skills; We need to be independent and successful; ISA goals

Community Involvement and Inclusion
• We would not have any homes or be in the community with other people or families that we know
• It’s all about community inclusion; without support I would be sitting at home on the couch.
• Having friends
4. If you could change one thing about individual services (for you or someone you know) what would you like to see?

Funding Issues
- Increase the number of hours (staff support) so I have more time to present my ideas of inclusion to schools and other groups
- Many people said they want more time in the community
- More funding to improve alternative communication programs and the communication alliance
- Change (increase) the allocated amount of money I receive annually. I need more time to build social life outside of home.
- Higher wages for staff
- They cut the mileage. Get more mileage for workers. Sometimes they use their own money to pay for gas to take us places.
- We have lost some people. You get to know a person real well that you work with and all of sudden they are gone. After they leave here they find a better job, a little bit more money.
- Don’t cut community hours because this helps us to be integrated
- Without respite, I wouldn’t be here today (at GMSA meeting)
- More people should be getting helped
- Many people said more money should be in a person’s budgets so they get more staff time

Employment Issues
- More hours of services for work
- Last Wednesday I was supposed to go to work but there was nobody to give me a ride.
- I used to have people checking up on me. Now they don’t check up with you they call on your day off to see how many days you did work. I had 3 people, then 2 checked up on me, now it is nothing. I think it is better to have ones in the community to check up on you instead of leaving you to do it on your own.
- Sometimes you might want to change your job but can’t because of lack of transportation.
- Thinking about opening up a business. Need help doing that.
- More help finding jobs. I don’t have one yet. I got help to put in applications at places and haven’t heard back yet. Probably due to economy and government shutdown.

Policy Issues
- Be proactive not crisis-based
- Adopt Employment First policy.
- Support peers living with peers independently but without staff.
- Change HOW people received personal care. I think some are getting lost in the system.
- Services should be MORE individualized
- I am going to be dating a new person. Could use some support.
- Staff and teams need to be better coordinated and better organized

Attitudinal
- Attitudes should be changed; Being respected as a human being – respected for who we are not what we are or not
- More moral support
• Staff need to be more attentive to what the person says they need
• I would rather be called a person then my disability. They need training to treat me as a person instead of as disability.
• Schedules should be more conducive to work with what the person wants
• Staff talking (maintaining confidentiality is something self-advocates consistently say needs improvement)

Communication
• Better communication between staff and clients
• Consistency and communication is poor between my shared living provider and my casemanager.
• Better communication, not letting us know until the last minute.
• One person says one thing, another person says another thing

Staff Turnover
• It’s kind of hard when you get someone new and they leave.
• Frustrating when you get used to somebody and you don’t have them anymore. I had a case manager I had for a while and then I had a new one – that was frustrating.
• I had a new staff person and they had to leave. I didn’t want them to leave. There were money budget issues.
• If you lose a worker, they quit, (the agency has) difficultly finding another worker, I still haven’t got a new one

5. Please tell us what you think is working well with developmental disabilities services in Vermont?

ALL OF THE ANSWERS WE GAVE IN #3 ALSO ANSWER THIS QUESTION.

• Support for self-advocacy has improved people’s lives by making people feel accepted for who they are instead of wishing they were always “Normal”. It Teaches us life skills like how to speak up at our ISA meetings, learn life skills for independent living, sex education, how to achieve our dreams and survive “low expectation syndrome”. Here are a few comments about what people get out of belonging to a self-advocacy group
  o I feel better about myself. I make better decisions.
  o We help each other. We make things better for others in the community
  o We are educating others about disability
  o Knowing about myself, my body, knowing how to protect myself.
  o I am developing my own skills & helping others.
  o I didn't have a life before, was very isolated.
  o I have plans for the future
  o I know myself better. I respect myself more because we give each other respect.
  o I know how to speak up for disability rights and services.
  o It helps me speak my mind and tell it like it is. Before I would go to meetings about my kids with DCF and not say anything.
  o I feel good about having the skills to make responsible choices.
We push for Social Change by going to meetings and the Statehouse (i.e. Walk with Your Class, Safety in School. Respectful Language, Funding For Services)

We are making a difference through our local community activities and volunteer work.

Other Misc. Comments

- Getting employment and job supports
- Support people taking us to medical appointments
- Be able to speak out
- Have options to self and family manage
- Agency support clients and support staff to go to conferences
- System responsive to new needs of people and their families
- Respite works well
- I got the best staff in the world, a new respite person. She and I have so many things alike. She helped with the internet and took me to see a concert I really wanted to see. We are cooking together and she was impressed that my apartment was spotless. She loves me to death and treats me like I am her daughter. She took me to hockey games and we made cookies for all the players. The other staff is new but he is following the goals after I told him he had too.
- Support to go to college!
- Having a case manager works because they are the ones you can count on when your direct support isn’t there for you. And they can help in the event of no or very limited staff.
- I like the services because they’ve helped me grow emotionally and in terms of being responsible.
- I think community services are working well. It gets people out (several people said this)
- I have so much more freedom
- When I almost lost my case manager, they let me know I was within my rights to ask for who I want.

6. Please tell us what you think is not working well with developmental disabilities services in Vermont and how it could be better?

ALL OF THE ANSWERS WE GAVE IN #4 ALSO ANSWER THIS QUESTION.

FUNDING ISSUES

- Staff not paid a livable wage – we need trained staff to STAY
- It is not working how people get their services cut due to funding. We need to stay on the legislature to let them know we need services.

Policy Issues

- Attitude of public officials on budget cuts – why was no other program in state government cut? Cut programs more equally and fairly across the board.
- The legislature needs to have oversight of the DS system of care plan
- I think we are doing well but need more help in the political arena.
- Vermont must keep its commitment to individual services
Quality Assurance
- There needs to be better communication. Staff need to talk with other staff and case managers more.
- Sometimes staff are too cautious about decisions.
- Staff need to call the clients more and keep them informed of what is going on.
- We need more staff and people who are willing to go about their work with respect and dignity. To improve this they need more sensitivity training.
- Staff needs to be held more accountable and work better with clients. One way to have this happen is with better communication.

Lack of accountability because of Wrap Services
Overall, to save money in response to pressure from budget cuts, many providers have reduced the number of people they employ and directly supervise. An increasing number of independent contractors are paid to provide services. This can be problematic because there is a greater degree of training, support and supervision with employees. In a number of situations agencies use what is referred to as "wrap" services. This means an agency sub-contracts with a shared living provider who then is responsible for hiring and supervising support workers. We worry about agencies moving farther away from directly supervising the people who are actually providing services. This trend seems to be the opposite from recent calls from AHS for more accountability. We need more checks and balances in the system.

More strategic approach to serving victims of abuse/crimes
A critique of the system held by many advocates is that the system is designed to do a better job serving offenders than it does supporting victims. We need parity. People with intense needs and those experiencing challenging behaviors should be given the same access to funding and a dedicated systemic approach as is already provided to offenders. DDAS needs a plan of action for providing increased monitoring and technical assistance to ensure that the state’s Behavior Management Policy is implemented.

ISAs need to be written every year and increase accountability
Another overall system concern is that ISAs were historically written every year and now the state is allowing them to be written every 2 years. In an age when agencies have less in-person contact with the people they serve, reducing the number of meetings to discuss, plan and evaluate how services are provided seems like a bad idea.

Do not fund center based day programs.
The agencies running “learning centers” mean well, but the ones we have seen tend to look childish and are run by staff – not people with disabilities. DAIL quality assurance staff need to do unannounced visits of these “learning programs”. The state needs to make sure that agencies clearly explain that attending a day program is just an option and that all people are told they have the option for individualized services.
7. What ideas do you have to better support families?

- GMSA needs to reach out to students with disabilities.
- Families should be involved immediately for conflict resolution
- It would take some problem solving and knowledge to create more resources. Please involve self-advocates.
- We appreciate our families but need others in our lives to go to when solving problems. Help our parents understand that and respect our privacy.
- More financial support
- Better communication
- Be proactive and avoid crises – it ultimately costs less.
- Have families support other families
- Show more trust to families
- I think it is important that families receive information and communication about their son or daughter’s program. Home providers also need to be up to date.
- We need to establish an initiative to increase the use of natural supports. Begin with a group receiving training from folks in NH who teach a process for developing natural supports in people’s lives.

8. What ideas do you have to support aging caregivers as they find it harder to care for their family members with developmental disabilities?

- Introduce the person to self-advocacy
- I think if the caregivers know they are the individuals’ lifetime “support staff” they need to start looking for natural support or services of some kind once they hit middle age to take over for them when they pass.
- Increase respite budget
- Support the person with a disability and their family to do lifelong planning.

9. In addition to the types of home supports described above, what ways can we support people to live in their own homes or with others?

- With respite or natural supports
- Find one person who receives services who is more independent and pair them with another person who receives services is newer to independent living, so there can be peer support.
- People need to be with peers to they can learn from each other to develop goals and independence. But this does not mean with staff. The rules for no more than 2 people in a shared living situation much remain. If an organization wants to have more than 2 people living together with shift or live in staff they must follow the existing rules for group living so we can protect our rights.
- The rules for Section-8 housing only allow one person to use a voucher. As we understand it, two friends living together as roommates cannot both receive Section-8. (Reportedly some agencies keep individuals with vouchers from sharing a household to avoid someone having to give up their voucher.) GMSA is concerned that it may set someone up for failure if they have to live alone. Most people without disabilities avoid living alone for both social and financial reasons. We need to develop a peer support residential option where two people with
complementary skills can share an apartment. The shared living stipend is given to one or both of them depending on support provided. The stipend would make up for the loss of financial support from Section-8. But more importantly, the shared living stipend would promote using a peer support model for independent living.

- Establish supervised apartment programs but contract with people with disabilities who have strong independent living skills to live in one of the apartments and provide support to peers learning how to live on their own. A few providers have talked about doing this but for a variety of reasons it did not work out. Involve peers and their organizations in the development and running of this type of initiative.
- Consider training and hiring talented shared living providers who know that once someone comes to live with them that they have 2 years to teach the person how to live more independently. This could also include a situation where two people who eventually want to be roommates begin by living with a shared living provider who teaches them independent living skills.

10. What other types of services and supports can help someone to live more independently on their own or with others?

- Skill building (ex. Cooking, independent living)
- Transportation
- Case management
- Budgeting and money management
- Public transportation that goes more places; maybe that has less commotion and more polite drivers
- Invest in an initiative to use technology to support independent living. There are many more options than just Safety Connections.
- Support ways for peers to get together and make friends. Support community membership and making of friends.

11. How can we best support young adults leaving high school?

- Better communication about what to expect
- Peer mentors

12. Do you have ideas on how to help people to be more independent at their jobs and not rely as much on paid support?

- Matching the right job to the right person means less support is needed.
- As people learn their jobs better, make sure staff drop back
- Staff should be professional, trained to set up, support, and FADE from the job site.
- More training for staff and more confidence in the person with a disability
- Agencies should be given incentives for hiring and supporting people with intellectual disabilities to work for the agency in professional jobs (not just janitorial or clerical tasks).
- Take a closer look at how technology can increase a person’s ability to stay organized on the job. Keep track of what it is exactly that staff do to support someone then work with assistive
technology project to identify what type of devises and software could be used to increase independence.

13. How can we better support people who have special medical needs?
   • Make sure all team members are in the know
   • Help with financing supplies

14. How can we better support people who are a danger to others and/or themselves?
   • More investment in staff training to use positive supports. Use philosophical approach of taught by Al Vechionne and Pat Frawley. The lack of resources to support staff training is unacceptable.
   • Have that person with supportive staff
   • Providing training is complicated by the fact that many providers of direct service are contracted. In an increasing number of situations, shared living providers are hiring, training and supervising direct support workers. There needs to be a task force looking into the training and supervising of contracted workers.
   • When someone is in crisis or challenging the system we need to be at our very best. Several years ago, DAIL eliminated their training position during the first round of budget cuts. We understand that training is the responsibility of agencies but in light of quality assurance reductions and an increase in contracted workers, we feel the state needs to address this training need.

15. What ideas do you have to increase the use of technology to help people be more independent, safe and supported?
   • Adopt National Core Indicator that people receiving services must have access to the internet if they want it.
   • DAIL needs to make sure that people receiving residential services have access to a telephone. Shared Living Providers must have a land-line telephone placed in an area where the person receiving services has access. Many Shared Living Providers only have cell phones which significantly limits access for the person receiving services.
   • Increase support for use of devises to help communicate
   • Increase training of staff to use technology to increase a person’s independence.
   • More access to speech recognition software

16. Do these Funding Priorities make sense? Which priorities do you think are the most important?
   • Health and Safety
   • Employment

17. If you were to change the Funding Priorities, what changes would you make?
   • More support for employment
   • Support for job security
   • Support priority for social isolation
18. In order to use the funding we have the best way possible, what ideas do you have on how we can save money?

- More funding for peer support options – they provide a unique service and are much more cost effective.
- Watch for fraud
- Families getting involved to decrease the budget
- We need more open-source text-to-speech software solutions available and in use.
- Do not pay parents to provide services to their adult children. This is a major conflict of interest. A parent should never be a person’s service coordinator. People need a neutral independent source for information. Parents typically are a person’s guardian and payee for SSI benefits. DAIL does not allow a shared living provider to be a person’s guardian or payee so why would this be okay for parents. Many people with developmental disabilities are abused or exploited by their families. For women without disabilities, studies show that 1 in 5 have been physically or sexually assaulted in their lifetime. For women with disabilities, the rate is 4 to 10 times greater. Studies report that 97% to 99% of women with developmental disabilities know their perpetrator. 32% of those abusers are family. People need regular contact with advocates and providers for safety reasons.
- One of the least expensive ways of providing support to people with developmental disabilities is the support the self-advocacy movement. As services are decreased, people rely more on their friends for natural support. The dollars that DAIL invests in self-advocacy enables GMSA to maintain local self-advocacy groups that are available across the state. Local and state self-advocacy events provide unique support options for people with developmental disabilities including:
  - Access to a “safe person” who can provide safety advice without being a mandated reporter
  - Training on essential independent living skills, problem solving skills, social skills, job skills, advocacy skills, healthy relationship skills and support to fully participate in your community.
  - Opportunities to learn about self-determination and speaking up for your rights
  - Opportunities to learn from a peer mentor
  - Opportunities to provide community service
- The state should set up a toll-free number so people can call in and give suggestions on how to save money. Support staff have a lot of first-hand information but they do not feel free to speak up. And sometimes when they do speak up agencies do not take them seriously. Many of the support staff that attend our meetings continue to tell us that there are people who get way too much support and others who do not get enough.

19. Do you have any other comments you wish to share?

- One striking inconsistency is that AHS is asking for more accountability yet the state employees responsible for quality assurance have been reduced approximately 75% over the past few years. The decrease in the state’s capacity for quality assurance began around 2006 when the Division of Developmental Services was eliminated and the focus broadened to
become DDAS. In the past, each agency had a primary state contact that just focused on one or two agencies. The Quality Assurance Specialist (QAS) assigned to an agency was very familiar with the staff who worked there, knew many if not all of the people who received services, read all of the incident reports, maintained regular contact, provided on-going technical assistance and lead the annual review of the agency. In the past, many self-advocates had a personal relationship with the QAS assigned to their agency and would use the 800 number at the Division to contact this person with concerns about their agency. Today that does not happen because the 800 number was reassigned to another program and the remaining 3 QAS staff are doing the work of 12 which reduces their availability.

- In the past agency reviews were done once a year. Now they have gone to once every two years. The review process states that DDAS will take a close look at the services provided to approximately 5% to 10% of individuals receiving services. (I've heard in some agency it is less than 5%). A person receiving services could go more than 20 years before their services go through a quality review conducted by the state. GMSA advocates for more QAS staff.

- In the past service coordinators were required to make in-person home visits once a month for individuals receiving residential services. DDAS has allowed this to be reduced to once every 2 months. Consider that many people have “wrap” services which means all of their staff are contracted workers (home providers, respite workers, community support staff). Our concern is that in situations where a person has no direct staff employed by their agency it increases vulnerability since they may only meet with their service coordinator 6 times a year.

- The state needs to increase monitoring of the Policy on Education and Support of Sexuality. Reportedly there are Shared Living Providers who prohibit people receiving services from expressing their sexuality.