

Idaho Council on Developmental Disabilities

FALL QUARTERLY BOARD MEETING

AGENDA AT A GLANCE

Thursday, February 8, 2018

- 8:30 Welcome, Introductions, Review Ground Rules and Agenda Review - Debra Parsons, Council Chair 8:45 What is a DD Network? - Jim Baugh, Suzie Hanks, and Robin Greenfield 9:30 **Prepare for Healthcare Policy Luncheon** - All 10:45 **Executive Director Evaluation** - Debra Parsons, Council Chair 11:00 Break - Staff prepare East conference room 11:15 **Executive Director Evaluation - Council Office** 12:00 **Healthcare Policy Luncheon** 1:30 Break - Clean Up from Luncheon **Debrief from Luncheon** - All 2:00 2:30 Teambuilding: 5 to Try - All 3:15 Agency Reports (10 Minute Presentations) DD Bureau Division of Medicaid – Michael Case, DD Program Manager Policy, Bureau of Developmental Disabilities Vocational Rehabilitation - Nanna Hanchett, Deputy Administrator, Idaho Division of Vocational Rehabilitation Department of Education - Charlie Silva, Director of Special Education, Idaho State Department of Education Commission on Aging - Kevin Bittner, Administrative Services Manager, Commission on Aging Center on Disabilities and Human Development, UI - Robin Greenfield, Associate Director DisAbility Rights Idaho - Jim Baugh, Executive Director Maternal and Child Health - Jacque Watson, Manager, Maternal and Child Health
- 4:30 Adjourn

Friday, February 9, 2018

9:00	Welcome - Debra Parsons, Council Chair	
9:35	Consent Agenda	
	 a. Draft minutes October 26-27, 2017 Council Meeting b. Chair Report c. Executive Director Report 	
9:45	Financial Report - Jean Weber, Council staff	
10:00	Proposed Legisaltion: Insurance Coverage for Treatments Specific to Children on the Autism Spectrum - Paul and Richelle Tierney	
10:45	Quarterly Progress Report - All Council Staff	
11:45	What it Takes to be Council Chair – Debra Parsons, Council Chair	
12:00	Review and approve 2019 and 2020 Annual Work Plans (Lunch Served) Tracy Warren, Council Staff	
1:10	Member Recruitment - Toni Brinegar, Council staff	
1:20	Update on Secure Treatment Facility Rules - Christine Pisani and Jim Baugh	
2:15	October Council Meeting Date Discussion – Christine Pisani	
2:30	Council Meeting Evaluation - Council Members	
2:45	Adjourn – Next Council Meeting April 26-27 2018	

*Items in green require a vote.

This agenda is subject to change in accordance with the provisions of the Idaho Open Meeting Law. Items may be discussed in a different order tahan appears on this agenda. Individual items may be moved from one place on the agenda to another by the Council. Time frames designated on this agenda are approximate only. The Council will continue its business in the event that an agenda item is resolved in less that the allotted time.

The mission of the Idaho Council on Developmental Disabilities is to promote the capacity of people with developmental disabilities and their families to determine, access, and direct the services or supports they need to live the lives they choose, and to build the communities' ability to support their choices.

Developmental Disability Network Presentation



Background Information:

The Council on Developmental Disabilities, the Center on Disability and Human Development, University of Idaho and Disability Rights Idaho form Idaho's DD Network. The Developmental Disability Network and the relationship between the three organizations is described and mandated federally under The Developmental Disability Assistance and Bill of Rights Act of 2000.

https://www.acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000

Under the DD Act, the organizations are required to share/collaborate on one goal in the Council's 5 Year Plan submitted to the Administration for Community Living. In Idaho, partly because each organization has multiple funding streams outside the DD Act, the Network Partners often collaborate on projects outside their DD Act shared goal.

Presenters will present a brief overview of the work of each Partner and share the collaborative goal and how each partner is working on it.

Recommended Action:

- 1. Review the attached graphic.
- 2. Ask questions after the presentations by Jim Baugh, Richelle Tierney, and Suzie Hanks.

Healthcare Policy Luncheon

Background Information:

The Developmental Disability Network which includes The Council, Disability Rights Idaho, and the Center on Disabilities and Human Development are sponsoring this luncheon. The first half of the event will feature Brian Whitlock, CEO of the Idaho Hospital Association who will provide information and answer questions about the proposed Idaho Health Care Plan, or Dual Waivers, as it is sometimes referred to as. As legislators are seated with people who live in their legislative districts, board members from the Council, DisAbility Rights Idaho, and the Center on Disabilities and Human Development will be helping legislators understand the value of the optional Home and Community Based Services paid for through Medicaid.

Recommended Action:

Attend one of the two webinars being hosted by the Council on February 1st and February 5th to ask questions and be informed of details to provide during your conversations with policymakers. Review the two power point presentations provided to you:

- Medicaid Waivers-An Introduction sent to you by the Council staff on January 15, 2018. This presentation is also in your packet.
- Threats to Medicaid Disability Services also included in your Council packet. This presentation will be presented on February 1st and February 5^{th.}
- Ask questions during the webinars and during the prep time provided on the agenda from 9:30-10:45 am on Thursday, February 8th.

Executive Director Evaluation

Background Information:

An evaluation of the Executive Director must be completed by members each year. The evaluation will be completed through Survey Monkey on computers and lap tops staff will make available in the Council office during the break from 11:00-12:00 Thursday, February 8th. Hope Marcella, Human Resources Department of Health and Welfare will work closely with the Council Chair to make sure the process collects all of the required information for Human Resources.

Recommended Action:

Please complete the evaluation and add helpful constructive comments on the evaluation. Council members will need to be available to provide support to one another to complete the evaluation on Survey Monkey, as staff will not be available to assist with this support. The Council Chair will compile the results of the evaluations and provide a report to the Council members in a closed session at the April Council meeting.

Agency Reports

Background Information:

Agency representatives will be provided up to 10 minutes to present information with Council members that would be of interest, announce opportunities where Council members could be involved, and present any rules or legislation their agency is working on.

Recommended Action:

Listen to presentation and ask questions if you have them.

Consent Agenda

Background Information:

The Consent Agenda contains items that require a vote by the Members. If there are items on the Consent Agenda a Member wishes to discuss before that vote a Member may make a motion to move the item to the Business Agenda.

- Draft minutes October 26-27, 2017 Council Meeting
- Chair Report
- Executive Director Report

Recommended Action:

Review and approve the Consent Agenda.

DRAFT Minutes – Fall Council Meeting

FALL QUARTERLY BOARD MEETING October 26-27, 2017

Thursday, October 26, 2017

Members:

Emily Petersen	Julie Fodor
Claudia Suastegui	Kristie Oakes
Charlie Silva	Jim Baugh
Jessica Rachels	Korynne Donehey
Carly Saxe	Jacob Head
Coalleen Sisk	lan Bott
Art Evans	Holly Giglio
Joe Raiden	Debra Parsons
David Dekker	
Guests:	
Griselda Camacho	Alan Aamodt
Matt Gallen	Steve Seale
Patrick Rachels	Marsha Bracke
Gary Sandusky	Liz Woodruff
Raul Enriquez	
Staff:	
lean Weber	Tracy Warren

Jean Weber Laurie Lowe Toni Brinegar Tracy Warren Christine Pisani

Call to Order 9:05

Consent Agenda: David Dekker moved to accept the minutes of the July 27, 2017 meeting, the September 28, 2017 meeting, the chair report and the executive director report, Ian Bott 2nd, motion carried.

Update on P3I: Christine Pisani presented an update from the ACL that the P3I proposal is not being pursued at this time. That does not mean that our program will be safe past this year, but this particular proposal is not being pursued this year.

Financial Report: Jean Weber presented the financial report for the period ending September 30, 2017. Art Evans moved to accept, Joe raiden 2nd, motion carried

Conflict of Interest: Tracy Warren explained the Conflict of Interest form that each council member must fill out each year, and requested that council members return the signed forms by the end of the meeting.

Year End Project Report: Christine Pisani and Council Staff introduced the contractors who are working on projects for the council, who each made a presentation about their work.

Cultural Broker Contractor Presentation: Griselda Camacho made a presentation on the work being done on cultural outreach.

DD Network Statewide Advocacy Coalition Contractor: Gary Sandusky made a presentation on the work being done in developing a statewide advocacy coalition.

The council recessed at 11:45 to take the annual council photo and attend a press conference on a Medicaid Storybook Release, and reconvened at 12:15.

Recognition: The council recognized outoing Council Members Raul Enriquez, Kelby Selders, and Alan Aamodt, and two retiring state employees, Ann Beebe, Governor's Office and Steve Seale, Designated State Agency Budget Analyst.

Community NOW! Facilitation Contractor: Marsha Bracke made a presentation on work done on the Community NOW project in response to the KW Lawsuit.

Core Gifts Contractor: Bruce Anderson, Director, Core Gift Institute made a presentation on work planned for FFY 2018.

On the Medicaid Front: Liz Woodruff, Close the Gap & Jim Baugh, Executive Director Disability Rights Idaho presented information about Medicaid.

Recess at 4:30 pm until Friday, 8:30 am.

Friday, October 27, 2017

Call to order 8:30 am: Debra Parsons, Council Chair

Access to Support and Care for Individuals with Alzheimer's Disease and Related Dementias and Their Caregivers: Sarah Toevs, Director, Center for the Study of Aging, Boise State University presented a report on changes being developed in state statute to address the needs of adults facing a behavioral health crisis linked to Alzheimer's Disease and dementia.

National Core Indicator Results from Statewide Adult Study: Presented by Valerie Steffen, Research Analyst, Division Of Family and Community Services, Department of Health & Welfare.

Severe Mental Illness Death Penalty Exemption bill: Kathy Griesmyer, Policy Director, ACLU, presented information on proposed legislation to take the most

severe penalty off the table for those with severe mental illness. An informational hearing has been scheduled during the 2018 session.

DD Council Priorities for Policy Slate

Council members were asked to determine how the council wishes to be involved in the following two issues.

- 1. Access to Support and Care for Individuals with Alzheimer's Disease and Related Dementias and Their Caregivers.
 - a. Change in statute for involuntary commitment
 - b. Change in rules making it easier for set up of geriatric psychiatric treatment centers

Jacob moves we take no position, Joe Raiden 2nd.

Discussion followed.

Jacob amended the motion to monitor. Joe Raiden 2nd.

Carried. Art Evans abstained.

2. Severe Mental Illness Death Penalty Exemption bill

Dave Dekker moved that we continue to lend support on this developing legislation through the informational hearings. Korynne Donehey 2nd.

Art & Ian abstained.

2 nay votes.

Carried.

Adjourn

Ian Bott moved to adjourn, Art Evans 2nd. Carried.

Council and staff travel to St. Alphonsus Hospital to meet with Legislators and participate in a panel presentation waivers

Next Council Meeting February 8-9, 2018

Council Executive Director Report

Summary of Council Director Activity October 1 through December 31

• October 2-6, 2017

VEYO contract issues Council meeting prep Advocacy Coalition Planning meeting Meeting with Gary Sandusky Medicaid story collection Monthly Consortium for Idahoans with Disabilities Meeting Community Partnerships Award Luncheon Work related to Research Analyst position Planning meeting for St. Al's Luncheon

• October 9-13, 2017

Meeting with Close the Gap staff
Monthly staff meeting
Self-Direction Quality Assurance Quarterly meeting
Monthly staff meeting
Meeting with IPUL NEMY Contract
Meeting with Director Barron NEMT Contract
Work related to Research Analyst position
Council meeting prep
Advocacy Coalition planning meeting with Gary Sandusky
Planning meeting for Rexburg Healthcare policy luncheon

• October 16-20, 2017

Executive Director Meeting New Mexico Prep with healthcare panelist on DD Waiver services Work related to Research Analyst position

• October 23-27, 2017

Pre-Council Phone call VEYO contract issues Prep with healthcare panelist on DD Waiver services St. Al's Healthcare Policy Luncheon planning meeting with Close the Gap Quarterly Budget Review Quarterly Council meeting Work related to Research Analyst position

• October 30 – November 3, 2017

Post Council staff meeting
NEMT Contract Meeting with Medicaid
Monthly Consortium for Idahoans with Disabilities Meeting
Community Crisis Intervention Training
Work related to Research Analyst position
Call with Art Evans and Consultant on ID DD Housing Solutions
Interview Reed Mulkey for HCBS film
Edit video footage

• November 6-10, 2017

Scope of Work contract Marsha Bracke Community NOW! Planning meeting with Gary Sandusky and Close the Gap Rexburg Event Edit video footage Film Jim and Gabe Baugh Work related to Research Analyst position

• November 13-17, 2017

Attend Rexburg Healthcare Policy Luncheon Meet with Richelle Tierney Advocacy Coalition DAD planning meeting Work related to Research Analyst position Meeting with parent Edit video footage Meeting with CDHD Interns DD Network Meeting with Tommy Alquist Present at Partners in Policymaking

November 20-24, 2017 Meeting with Director Barron NEMT Contract Meeting with Close the Gap Work related to Research Analyst position DAD planning meeting Vacation

November 27 – December 1, 2017 Filming Jim and Gabe Baugh We Choose All of Us Conference Meeting with parent Work related to Research Analyst position NEMT Contract Discussion with the Department of Health & Welfare

• December 4-8, 2017

PCP Core Team Meeting Meeting with Liz Woodruff Meeting with Art Evans Meeting with Gary Sandusky Advocacy Coalition Public comment on proposed Idaho Healthcare Plan Advocacy Coalition webinar Partners budget review Work related to Research Analyst position

• December 11-15, 2017

Program Performance Report staff meeting Work related to Research Analyst position Meeting with Dean Cameron DOI Private Insurance Coverage for ABA Interviews for Research Analyst Position Council staff meeting

December 18-22, 2017
 DHR Training All Staff Lincoln Auditorium
 NEMT Advisory Committee meeting
 Planning meeting DD Network policy luncheon
 Interviews for Research Analyst Position
 Meeting with Gary Sandusky Advocacy Coalition
 Meeting with ACLU and Gary Sandusky
 ACLU's Mental Illness Exemption Proposed legislation phone call

• December 25-29, 2017 Vacation

Council Chair Report

Summary of Council Chair Activity October through December 2017

Can you believe it is a new year? We are very fortunate to have so many Idahoans who care about the important things in life. Close the Gap....Reclaim Idaho... Medicaid Matters....folks working to have autism services covered by insurance providers...and the list goes on. I have been privileged to work with many of these groups in my remote little corner of the state in the last 3 months and there is a growing sense of pride and empowerment spreading across the counties. We are a "Can and Will Do" state and our Council is at the forefront of all these efforts to lend support, mobilize families and people with disabilities, and provide information and input. Onward and upward!

Financial Report First Quarter – Federal Fiscal Year 2019

(October 1, 2017-December 31, 2017)

Background Information:

A financial statement reflecting our fund balance and the amount spent to date in this Fiscal Year will be presented at the Council meeting. The Council operates on a federal Fiscal Year (Oct. 1- Sept. 30). The Council is responsible for overseeing and approving the budget.

Recommended Action:

Review and approve the financial report that will be distributed at the meeting.

Autism Insurance Reform

Background Information:

Family advocates are leading an effort to introduce legislation this session which proposes to change insurance laws that would require private health insurance policies to cover the treatment of autism spectrum diagnosis. Therapies such as Applied Behavioral Analysis, which is currently only paid for through Medicaid funding, would be paid for through private insurance policies should this pass.

Recommended Action:

Listen. Ask questions. Participate in a Council vote on level of support.



LEGISLATION **C**INFORMATION

This legislative session Autism Insurance Reform legislation will be presented. This legislation would change state insurance laws to require private health insurance policies to cover the diagnosis and treatment of autism spectrum disorders. Therapies, such as ABA, would be paid for by your private insurance.

Did you know...

- Nationally, 1 in 68 American children are being identified on the autism spectrum.
- Autism is a brain disorder characterized, in varying degrees, by difficulties in social interaction, communication, and repetitive behaviors.
- The most obvious signs of autism emerge between 2 and 3 years of age.
- Although there is no known cure, autism can be treated, so that the symptoms are not as disabling.
- A non-verbal child can develop the ability to communicate; a non-social child can acquire interpersonal skills; a child with uncontrolled aggressive or self-injurious behaviors can be freed from this tragic and dangerous condition.
- The most commonly-prescribed treatment is Applied Behavior Analysis (ABA). This one-on-one intervention has been used to treat children with autism for more than 40 years, and its effectiveness is proven.
- When ABA is administered intensively, nearly half of the children who receive it can achieve such substantial gains that they enter elementary school indistinguishable from their peers.

First Quarter Progress Report

Background Information:

The Council has a number of objectives and activities in the current annual plan. Some are part of large projects and some are ongoing smaller efforts. This is an opportunity to share the highlights of progress on our plan goals during quarter one of this year – October 1st through December 31st.

Recommended Action:

Listen to the updates and ask questions or provide comments if you have them. Council members who are involved with any of this work are encouraged to offer their insights.

First Quarter Progress Report

1.1 HCBS DD Services Quality Assurance



Objective Goal Individuals with intellectual/developmental disabilities and family members have the information and support needed to meaningfully participate in Home and Community-Based developmental disability services stakeholder meetings and to develop quality indicators.

Progress:

Support people with I/DD and family members to participate in Community NOW!

Council staff continued to meet with the Community NOW Core Team to plan meetings and strategies to move forward work on implementing activities and systems change

related to the Community NOW recommendations. New working groups were formed to begin developing a plan for implementing person-centered planning services (recommendation #1). Individuals with developmental disabilities and family members were recruited for these working groups (see Obj. 1-3).

Self-advocates and Council staff reviewed content and format of the new Department of Health and Welfare's My Choice Matters



website and provided suggested language. This new website was created for adults in the DD program and will soon have audio availability in order to have text read to the reader. <u>http://www.mychoicematters.idaho.gov/</u>

<u>Program changes in education for Certified Family Homes – Linguistic</u> <u>Competence</u>

Council staff continued work started in FY2017 in talking with state officials regarding lack of access to required Certified Family Home (CFH) provider education and training for CFH providers who speak Spanish. The CFH program manager reports that IDHW staff are working to make the program accessible to Spanish speakers and that he is meeting with Career Technical Education to discuss an alternative to the Assistance with Medications course for CFH providers including offering the course in Spanish.

Educating Policymakers about Medicaid Services

Much of the work of the Advocacy Coalition over this year was spent educating our Congressional representatives as well as state legislators about Medicaid services and how they impact the lives of Idahoans with disabilities (see 3.2 for more information).

1.1 - Outcomes/Work Products:

- Ongoing commitment of people with I/DD and family members to participate in the systems change process
- Individuals and family members new to systems change and policy development work develop advocacy skills

1.2 Best Practice in Services and Supports

Objective Goal Increase the use of best practice in providing direct services that are based on quality person-centered practices through organizational change and training for direct support staff.

Progress:

Training Strategies for Direct Support Staff

Staff participated in discussions with IDHW staff about working on strategies to improve direct support staff training in Residential Habilitation agencies related to Community NOW recommendations.

1.2 - Outcomes/Work Products:

Preliminary ideas shared

1.3 Person-Centered Planning Services

Objective Goal People with intellectual/developmental disabilities have access to Medicaid person-centered planning (PCP) services provided by trained, qualified planning facilitators.

Progress:

Person-Centered Planning Model for Idaho

After the PCP Kick-off event was completed in September, two working groups were established: PCP Advisory Committee made up of only people with I/DD and family members and the PCP Implementation Workgroup (IWG) which also included IDHW administrators, service providers, and DD Act partners. Both groups met over the quarter and the IWG reviewed PCP models/practices utilized in other states and related system policy as background for developing a model for Idaho. Research and development of data/materials for consideration of workgroups was done by ICDD staff and facilitator.



After the group meetings this quarter, a PCP Requirements document was created and approved that will be used to guide the development of system infrastructure and related policy to establish person-centered planning services in Idaho. (This document will be available at the Council meeting along with a PCP status report from the contractor.)

Previously determined objectives and meeting/working schedule was extended and the scope of work narrowed. Contracted facilitator coordinated PCP IWG meetings; ICDD staff coordinated the PCP Advisory Cmte. Video conferencing technology used to support online meetings worked for most people. ICDD staff spent time preparing and gathering feedback from some stakeholders on an individual basis.

1.3 - Outcomes/Work Products:

- PCP Requirements (quality indicators) finalized and distributed
- PCP Status Report
- Outline of system elements developed

1.4 Services for People with Dual Diagnosis

Objective Goal

People who experience dual diagnosis of mental illness and developmental/intellectual disability have access to mental health services from skilled service providers.

Progress:

Education in best practice serving people with dual diagnosis.

The Council approached the Division of Family and Community Services (FACS) in the fall with a request to collaborate on hosting additional training in the coming year provided by Julie Brown, PhD with a focus on the eastern and northern part of our state. FACS and Council staff met three times in the past quarter and agreed to work collaboratively to conduct two three-day workshops planned for the spring in Coeur d'Alene and the fall in Pocatello. Both workshops will be conducted by Julie Brown, PhD.

An unexpected outcome is that Optum, Inc., the managed care contractor for behavioral health services through Medicaid, has agreed to provide financial support for both workshops and will provide marketing of the workshops to all mental health service providers. The Council is contributing \$25,000 that FACS will use to contract with Julie Brown. The Council will also receipt in registration costs that will be used to purchase the textbook used for the training.

1.4 - Outcomes/Work Products:

- Plan developed for training of clinicians
- Funds leveraged from Optum, Inc.

2.1 Secondary Transition

Objective Goal

Increase the number of children and youth who experience a giftfocused, strength-based, person-centered transition planning process.

Progress:



<u>Strength-based Planning - Training in Core</u> <u>Gift Assessment</u>

The Council worked in collaboration with the Idaho Dept. of Labor to plan a follow-up training for Core Gift Master Facilitators in early October. Bruce Anderson of the Core Gift Institute provided a day-long workshop sharing additional strategies and tools with the Idaho Core Gift Master Facilitators trained earlier in 2017. Teachers reported outcomes of using the process in their

classrooms and with their staff. One teacher conducted the Core Gift interview with all of her students and staff members. After learning about their gifts, the students then joined a gift circle where they shared how they saw each other giving their gifts each day in the classroom. The teacher reported that this activity was very emotional and had great impact on the students. Another teacher made Core Gifts a journal assignment for her students. They did one question each day from the Core Gift interview and by the end of the quarter, each student will know their Core Gift. She feels it is a way to "give her students a rudder during these difficult times." A Dept. of Labor counselor helped a client put her Core Gift into her resume – she was able to get a job after a long and difficult time looking for one.

A challenge identified through this early work in Gifts is that students with significant disabilities and communication barriers have difficulty accessing the interview process. The Council will be working with teachers, speech language pathologists, and the

contractor over the coming year to work on solutions and strategies.

Bruce Anderson also provided two presentations at the Idaho CEC conference where additional educators and administrators from around Idaho learned about the promise of using the Core Gift process with students.





Educating and Empowering Spanish-speaking Families

The *"Fortalenciendome Para Ser Exitoso"* transition conference was planned and carried-out by a group of women (La Señoras) lead by Cultural Broker, Griselda Camacho. The purpose of the shared leadership is to build confidence within the group so that these women may go out into their community and educate and empower others to take a role in their child's life as well as become leaders in their community.

The conference was delivered in Spanish by experts in the disability field who also spoke Spanish. Presentations were given by Idaho State Dept. of Education in conjunction with Idaho Vocational Rehabilitation (Alison Lowenthal and Kendrick Lester); Idaho Parents Unlimited (Rosario Beagarie) provided education on how to properly file information into a binder and the importance of keeping this information (binders provided by IPUL; 3-hole punches provided by ICDD); VR counselor, Yannette, was able

to tell the group a little about the services she provides as a transition counselor; FACS case managers, Virgi Blaine and Lucy Olmos also provided information. All materials were in Spanish and there were no interpreters present. This is best practice because it allows people to learn in their own language and there are no details lost in translation.



The keynote speaker was Yabel Giraldez who shared how she overcame the barriers of what she thought was a tragedy. Her youngest son was born with a disability (Cerebral Palsy) in a country (Panama) where there is no support for children/adults with disabilities. She learned that being optimistic, brave and faithful would help her to fight her challenges, fears, deceptions, and worries. She knew that she needed to work hard in order to achieve her goal of helping her son to be independent. The task was not



easy, but she pushed her son to go beyond his limitations, showed him the importance of RESPECT and ACCEPTANCE and to DREAM for a better future. He is now an adult who works to promote the rights of people with DD with a national non-profit organization. Eighty-one (81) people attended (71 adults/transition-age youth and 10 children) and transition-age youth were present at the conference, which is unusual for the Spanish-speaking community. TVDSA's child care providers

were wonderful and provided a lot of great activities for the children. The testimony people gave after lunch was very powerful and the group enjoyed this very much. The Señoras report that they enjoyed the previous speaker (Sandra Caldera) more than Yabel simply because the speaker at the 2015 conference had a disability herself and it was impactful to hear her perspective as a parent and mother. Overwhelmingly, the group felt that it was worthwhile and they would like to have more presentations in Spanish in the future.

There were two main goals for this conference:

- 1. To engage a small group of Spanish-speaking mothers/family members to plan and carry-out all facets of planning and hosting this conference in order to promote leadership with in the community.
- 2. Show parents and transition-age youth how to set high expectations for post-school employment.

Because there is such a large learning disparity between the Spanishspeaking community and the English-speaking community, there continues to be a need for trainings in their own language to close this gap. Additionally, there is a need for their culture to be respected and celebrated during these conferences. For example, there was traditional dancers who came and performed during lunch; there needs to be food for breakfast as well as lunch; and childcare available as well as tolerance for children coming in and out of the training.



Educating Families about Planning for Transition

The Council supported the "Transition: Do You Have Your G.P.S? (Goal, Plan, Support)", a transition conference for parents in Moscow last October. The keynote presenters were Gina Gallagher and Patricia Terrasi who provided information about working with the school through IEP meetings, supports available for transition, helping your child set goals, and other strategies to 20 parents. Presentations were also provided on preparing for the differences in the law when going to college and how to plan for reasonable accommodations; IDHW staff provided information about the transition to adult services.

2.1 - Outcomes/Work Products:

- Families and youth increased their knowledge of the transition process
- Certified Core Gift Facilitators gained additional knowledge about strategies to use with students and young adults
- Idaho educators learned about the possible outcomes of using the Core Gift assessment process

2.2 Customized Employment

Objective Goal Increase the number of youth and young adults with I/DD who achieve integrated community employment.

Progress:

Support Idaho Employment First Consortium Activities

The Idaho Employment First Consortium met in October to review progress towards outcomes outlined in the IEFC strategic plan. Because the Council will not be supporting the Consortium on an ongoing basis, the group discussed how its possible future work and structure could be maintained. Consortium members narrowed the focus of work by prioritizing key issues remaining for the strategic plan. The group also discussed steps to form a new APSE chapter in Idaho. Members volunteered to work towards next steps in chapter formation. A new strategic plan was drafted.

Consortium member, Gordon Graff from the Idaho Dept. of Labor, reported that the new Able to Work website format was complete and available through the Department's website at <u>www.abletowork.idaho.gov</u>.



The Dept. of Labor Disability Employment Initiative grant agreed to provide funding for creating Spanish versions of all six *Social Security Income and Work* animated videos. The videos should be complete by late spring. To view the current Idaho videos go to: https://www.youtube.com/user/IdahoDeptofLabor

Customized Employment Pilot

Council staff met with the Idaho Division of Vocational Rehabilitation (IDVR) and other Workforce Innovation and Opportunity Act (WIOA) partners to plan strategies for the success of the pilot. Staff also participated in the final training for the Customized Employment Pilot teams and provided materials for teams to provide to families and students explaining the customized employment process.

The "Expecting a Bright Future" booklet was updated and provided to teams for distribution in regional areas. The National Technical Assistance Center on Transition (NTACT) with the Transition Coalition asked to include the booklet as a resource for families in modules that are being developed.

2.2 - Outcomes/Work Products:

- IEFC members participated in systems change discussions
- Identified steps for future planning
- Able to Work website launched on Idaho Dept. of Labor site
- Customized Employment pilot teams completed training
- Materials for parents/students updated or created and distributed

3.1 Partners in Policymaking

Objective Goal Build the capacity of individuals and parents to advocate, lead, and mentor others by increasing their leadership and advocacy skills.



Progress:

Partners in Policymaking 2017-2018 Session

Our 2017-2018 class of Partners in Policymaking participants continued to attend



sessions in October and November. The class has 13 parents of children with developmental disabilities and 14 adults with I/DD. During the quality education session this year we asked the Boise Student Transition Education Program (STEP) to present what a student-led individual education program (IEP) looks like in practice. Two STEP students presented their IEP's to the group. Both parents and self-advocates were very engaged and enjoyed this presentation.

We have always struggled to keep self-advocates engaged during the system-specific parts of the education discussion, therefore we chose to offer the adults with I/DD a separate education opportunity that has application to their lives right now - dating and relationships. The

addition of this topic went very well.



Positive Behavior Intervention and Supports training was done by Jason Lowry this year during the November Session. He provided a full day of training and the response from the group was overwhelmingly positive. The picture (left) is from "what it actually takes for someone to understand how to make a peanut butter and jelly sandwich."

Part of the session on institutionalization was the video "Willowbrook." The group also viewed a clip from a video being

produced by Council staff through a contract with an independent video-journalist, Sam Mayfield. The clip shared the perspective of Reed Mulkey, long-time staff person who worked at the Idaho State School and Hospital. The topic of housing was included this year with Zoe Ann Olson, Director, Idaho Fair Housing Council and a Spanish interpreter. This topic will require more time in future years. The employment session included a short evening presentation on Idaho services to support employment followed by a full day with Ellen Condon talking about customized employment.

PIP participants from the Latino community arranged for a piñata to be shared on Friday evening as a way for their culture to be respected and celebrated.

3.1 - Outcomes/Work Products:

- Individuals with I/DD and family members received training in leadership development
- Partners curriculum updates and presentation materials
- Feedback from participants





Winter Meeting: February 8-9, 2018

3.2 Idaho Advocacy Coalition

Objective Goal

Establish a statewide coalition of people with disabilities and families who advocate at the state and local level on policy issues.

Progress:

Coalition Building and Awareness Events

ICDD and the Advocacy Coalition collaborated with Close the Gap Idaho, Brian Whitlock, CEO of the Idaho Hospital Association, and Luke Cavener, City Council member of Meridian, on two news conferences and two policymaker luncheons. The Council coordinated a speaker's panel for both events. A news conference took place on October 26, 2017 with Council members and Close the Gap Idaho. The conference featured the unveiling of "Why Healthcare Matters: Stories from Idahoans," a collaborative publication of the Council and Close the Gap Idaho. Through the Council contractor 30 stories were collected from individuals and families that were

included in the storybook. The press conference also announced the proposed dual waivers, the Idaho Health Care Plan, to provide health care coverage to 35,000 Idahoans without access to healthcare. Debra Parsons, Council Chair, spoke about threats to funding for Home and Community Based Services and the proposed tax bill.

The Health Care Policy luncheon hosted at



St. Alphonsus later that day featured a Council member and two Partners graduates on the speaker's panel. One Council member shared her experience of being in the coverage gap, another spoke about having access to the Katie Beckett waiver, and the other panel member spoke about the full life he has as a result of having access to the self-direction option under the DD Waiver. 14 Council members attended along with 2 Nampa City Council members, 4 physicians involved with health care coverage work, 4 legislators, staff from Senator Crapo's office, Senator Risch's office, and Representative Mike Simpson's office, the Governor and Lieutenant Governor's office.



On November 7, 2017 a press conference was held in Idaho Falls with 4 Advocacy Coalition members, Debra Parsons and Brian Whitlock to announce the policymaker luncheon taking place the next day at BYU-Idaho, unveil the "Stories from Idaho," booklet and share information about concerns with Home and Community Based Services and the tax bill. The policymaker luncheon included Mayor Jerry Merrill, 5 state legislators, and



staff from Senator Crapo's office, Senator Risch's office, and Representative Mike Simpson's office. Three Coalition members participated on the speaker's panel. Coalition members and two Council members provided testimony at regional public hearings on the Idaho Health Care Plan. Part of the plan is to move medically complex and high cost conditions from the Health care exchange with private health care coverage to Medicaid which is projected to reduce premiums in the private insurance industry by 20%.

Council continues to identify Idaho Partners in Policymaking graduates and others to include as core members in the Advocacy Coalition. Through rallies and events hosted this past summer by the Advocacy Coalition, a number of individuals with disabilities and families members voluntarily shared their stories of how their lives intersect with home and community based service waivers. This resulted in 30 stories collected, some of which appear in the publication, "Why Healthcare Matters: Stories from Idahoans." Outreach to Latino families and the Shoshone Bannock tribal members on the Fort Hall reservation have continued in order to create a statewide Advocacy Coalition in a culturally and linguistically competent manner.

Through the two healthcare policy luncheons and news conferences the Council gained five additional allies in our advocacy work with the disability community. Brian Whitlock, CEO of the Idaho Hospital Association, Luke Cavener, City Council member of Meridian, Idaho, Professor Whiting, School of Social Work at BYU-Idaho, and Mayor Jerry Merrill of Rexburg. The Council has also developed a working relationship with Bryan Clark, news reporter with the Post Register newspaper in Idaho Falls.

3.2 - Outcomes/Work Products:

- Contract with Community Organizer, contractor report
- News articles and media coverage = public awareness
- Why Healthcare Matters booklet
- Testimony by individuals and families
- Outreach new allies gained

fellowstone trail Group at BYU-Idaho reviews health care landscape espite federal IN BRYEN CLAPK recircl the fo jacka) nasye

If Sen. Crapo believes that Idaho's lifeline for people with disabilities is Medicaid, he must work to preserve the financial integrity of the Medicaid program, writes Christine Pisani.

Crapo must follow through



with disabilities, He also expressed his strong support for Home and Community Based Services. Positive statements are indeed

merings paired with a statewide listening our provided the additional voices of 94 adults with LDD and 128 families that resulted in a key set of 16 recommenda-tions. These recommendations set out o improve or replace the current adult developmental disability service system to allow for a more flexible and person-cen-tered system. We expect these recommend-ations to inform the development of an improved HCSS system for some of the most vulnerable orizons in our state. The developmental disability com-munity was conducted or how well outreach on the developmental disability com-entered or flexible service systems if the limatical base of the Medicaid protram is undermined. That is exactly

Council Chair Responsibilities Presentation

Background Information:

A presentation will be provided by Debra Parsons, Council Chair, to help members understand the full responsibility that a Council Chair has to the Council. There are many more responsibilities of the Council Chair of the Council than running the quarterly Council meetings. Debra has agreed to give the nitty gritty details. Thank you Debra!

Recommended Action:

Please ask questions and consider your current and future time commitments and your ability to follow through on these responsibilities which are not always fun if you are interested in running for this position.

Proposed 2019 and 2020 Annual Work Plans

Background Information:

The Administration on Intellectual and Developmental Disabilities (AIDD) is having Councils follow a new schedule and process for submitting annual work plans along with annual Program Performance Reports. This year the Council must submit the FY2019 work plan and the FY2020 work plan at the same time we send in our 2017 PPR.

Also this year, the deadline for sending in our PPR report has been extended beyond the normal date of January 1st. No date has been set for the deadline to send in our PPR and work plans but it may be any time in the coming weeks. Staff are working in earnest to write about our progress last year and put outcome data into the report template so we will be ready once the announcement is made.

Council staff drafts each one-year work plan based on the goals and objectives in the Council's five-year strategic plan. The annual plan guides the Council's activities for each federal fiscal year and includes project activities intended to help the Council meet its goals. A draft plan for October 1, 2018 through September 30, 2019 (FY2019) and a draft plan for Oct 1, 2019 through Sept. 30, 2020 (FY2020) will be presented and discussed at this Council meeting.

Recommended Action:

Review the draft annual plans for FY2019 "Sapling Packet" and FY2020 "Oak Packet." We will discuss then members will vote to approve as presented or with changes if proposed during the meeting.



Sapling Packet

DRAFT 2019 Annual Work Plan

October 1, 2018 to September 30, 2019 Year Three of the Five-Year Plan

Goal 1: Adults with intellectual/developmental disabilities experience improved quality in Home and Community Based Services

Objective 1.1

Recruit and support individuals with intellectual/developmental disabilities and family members, to participate in collaborative stakeholder meetings to review and-define Home and Community-Based (HCBS) developmental disability services and develop state quality indicators by October 2020 that will affect ongoing quality assurance activities for HCBS.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Conduct follow-up study of individuals using HCBS services
- Provide information to policymakers at the state and federal level to educate them about the importance of Medicaid Home and Community-Based Services to individuals with intellectual/developmental disabilities and their quality of life.
- Review quality assurance activities and make recommendations for system improvement aligned to quality indicators
- Promote HCBS quality indicators in policy advocacy with state agencies and policymakers

Expected Short and Mid-Term Outcomes

- People with intellectual/developmental disabilities (I/DD), family members and other stakeholders across the state have a voice in policy development and systems change
- State agency administrators have increased knowledge of systems issues
- New HCBS developmental disability service array and definitions reflect input from stakeholders including individuals with I/DD and family members
- Quality indicators measure access by Spanish-speaking families to culturally and linguistically appropriate services for their children and adult family members with intellectual/developmental disabilities
- Idaho service system quality indicators are accepted by state agency administrators and policymakers

- Idaho HCBS quality assurance system infrastructure and processes are aligned to quality indicators and federal requirements
- Quality assurance data is gathered directly from individuals receiving HCBS services through residential habilitation
- Data gathered through quality assurance activities informs improvements to the system and provision of HCBS services

Objective 1.2

Working with the Idaho Department of Health and Welfare, service providers, individuals with disabilities and families, develop and implement a plan for organizational change and support staff development in person centered practices by September 2021.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Work with IDHW to promote/support organizational change opportunity for supported living provider agencies.
- Identify collaborators in supported living provider agency(ies) and gather information from staff about current practices
- Develop support staff training implementation plan based on person centered practices and identified quality indicators from Community NOW activities.

Expected Short and Mid-Term Outcomes

- > Stakeholders have increased knowledge about person-centered practices
- Training model is developed to improve quality assurance and increase personcentered practices in services
- Service providers use person-centered practices throughout their organizations and in providing services

- > Direct support staff report increased satisfaction with their work
- > Direct support staff report understanding and using person-centered practices
- Increased percentage of individuals who report they direct their plan and services

Quality assurance data shows an increase in individuals who report they have more choice, control over decisions about daily activities, access to community, and improved quality in their services

Objective 1.3

Work with individuals with disabilities, their families, and other partners on systems change and policy development so that by July 2021, people with intellectual/developmental disabilities have access to Medicaid person-centered planning (PCP) services provided by trained, qualified PCP specialists by July 2021.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Support PCP Advisory Committee and work with PCP Implementation Workgroup to develop related system policy to establish person-centered planning services and PCP facilitator training in system infrastructure
- Work with people with I/DD and family members to inform policymakers and other stakeholders about best practice in a person-centered planning and services

Expected Short and Mid-Term Outcomes

- New person-centered planning services are established and supported through state policies and procedures
- A PCP specialist training model is established and includes individualized, culturally appropriate strategies and skill development
- PCP specialists are competent in best practice for person-centered planning and are supporting individuals around Idaho
- Families and other members of the circle of support value, and gain skills to facilitate, informed supported decision-making by individuals
- Youth and adults are supported to identify their gifts and strengths and how to use them in planning, directing their services, and reaching their goals

- Increased percentage of individuals report they are supported to lead their plan development and their plans include goals they have chosen
- Quality assurance data shows better outcomes for individuals related to quality indicators

Objective 1.4

Work with the Idaho Department of Health and Welfare to build capacity in mental health services available to individuals who experience the dual diagnosis of mental illness and intellectual/developmental disability by July 2021.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Collaborate with the Idaho Department of Health and Welfare (IDHW) to plan staff training opportunities in best practice in services for people with dual diagnosis
- Work with partners to host related web-based or in-person sessions/lessons
- Review current quality assurance practices and outcomes and develop recommendations for getting data from individuals
- Inform policymakers and other stakeholders about benefit of best practice in services for people with dual diagnosis

Expected Short and Mid-Term Outcomes

- State agency administrators have increased knowledge about best practice in service to people with dual diagnosis
- Training in trauma informed care and best practice in supporting people with dual diagnosis is established for direct support staff
- People with dual diagnosis are able to access an array of quality Medicaidreimbursable mental health services that are appropriate for individuals with intellectual/developmental disabilities

- Service providers have the capacity to meet the individualized mental health needs of people with dual diagnosis.
- People who use alternative communication methods have their mental health needs met.
- > People who experience dual diagnosis report improved mental health
Goal 2: Youth and young adults with intellectual/developmental disabilities transition from school into an adult life that includes competitive integrated employment, community engagement, and full citizenship.

Objective 2.1

Each year of the plan, provide/support education and training for families, teachers, and other team members, to increase the number of youth/young adults with intellectual/developmental disabilities who experience a gift-focused and strength-based assessment and planning process.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Work with partners to develop/support Supported Decision-making training and activities; inform stakeholders
- Continue provide information to Idaho Core Gift Master Facilitators in their practice of the Core Gift process and tools
- Provide Core Gift training in additional areas and promote to school districts
- Promote/support education to families, youth and young adults about advocacy/selfadvocacy in transition planning and employment
- Support Cultural Broker activities in educating Latino families, youth and young adults about advocacy/self-advocacy in transition planning and employment

Expected Short and Mid-Term Outcomes

- Educators, families, and other team members are engaged in identifying their children's/ youth/young adults gifts, strengths, and abilities
- Families, educators and other team members understand student youth/young adults gifts, strengths, and abilities and how they can be supported in school and the community
- Team members gain skills to conduct planning that is student-led and builds upon the student's strengths
- Families have knowledge and are actively involved in supporting their children in the transition-planning process
- Spanish-speaking families are informed, supported and engaged in the transition planning process and activities

Youth and adults who experience significant disabilities and communication barriers are supported to access a process to identify gifts and strengths

Expected Long-Term Outcomes

- Families have high expectations for their children to achieve post-school goals including employment, citizenship, and inclusive community engagement
- Increase in the percentage of positive post-school outcomes for youth/young adults with disabilities
- Quality assurance activities measure outcomes related to identification of gifts and strengths in alignment with individual goals.

Objective 2.2

By September 2021, increase the percentage of youth/young adults with intellectual/developmental disabilities that achieve competitive integrated employment in the community by working with Workforce Innovation and Opportunity Act partners and Medicaid to implement best practice in customized employment.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Work with the Idaho Division of Vocational Rehabilitation to develop a plan to expand Customized Employment training and services statewide
- Work with WIOA partners to educate students and family members about setting employment goals and the employment possibilities through a customized employment approach
- Review access to, and effectiveness of, Idaho Pre-Employment Transition Services by reviewing outcome data and/or surveying families and students

Expected Short and Mid-Term Outcomes

- Students with significant disabilities have equal access to pre-employment transition services/activities and engage in paid work experience
- Young adults have access to individualized services that support their employment goals

Expected Long-Term Outcomes

Increase in the number of youth and young adults with significant disabilities that gain integrated, competitive employment in the community **Goal 3**: Leaders with intellectual/developmental disabilities are engaged with other people with disabilities and families in a statewide coalition that has a strong, collective voice on policy issues and systems change.

Objective 3.1

Build the capacity of individuals and parents to advocate, lead, and mentor others by providing leadership development and advocacy training to adults with intellectual/ developmental disabilities and parents of children with intellectual/developmental disabilities.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Recruit for, plan, and engage partners to support the 2019/20 Partners in Policymaking program
- Conduct 1-year outcomes survey with 2016 Partners in Policymaking graduates
- Conduct outcomes survey with all previous Partners in Policymaking graduates
- Work with partners to implement peer mentoring model that includes selfadvocacy training for people with disabilities planning their services done by trainers who have I/DD

Expected Outcomes

- Increase in the number of individuals with disabilities and family members that have leadership and policy advocacy skills
- Increase in the number of individuals with disabilities and family members from culturally diverse backgrounds that have leadership and policy advocacy skills
- Leaders with intellectual/developmental disabilities mentor youth with disabilities and new leaders to gain leadership and advocacy skills

Objective 3.2

By September 2019, establish a statewide, culturally diverse coalition of people with disabilities and families who have been trained and are supported each following year of the plan to advocate at the local and state level on policy issues.

Activities

Year 3 (Oct 1, 2018 – Sept 30, 2019)

- Work with contractor to support activities of the statewide policy coalition
- Support a Coalition member in a fellowship focused on local community organizing
- Provide support to a local Eastern Idaho non-profit organization that serves the Latino population
- Work with the Utah UCEDD to provide policy advocacy preparation education to Latino families in Eastern Idaho
- Provide information to coalition members about policy issues and opportunities to participate in systems change efforts.
- Meet with DD Network Partners quarterly to review progress and explore additional strategies to strengthen self-advocate leadership in Idaho
- Ongoing outreach to Latino community in Western Idaho about policy involvement and Cultural Broker mentoring of interested individuals

Expected Short and Mid-Term Outcomes

- Increase in the number of individuals with disabilities and family members that have leadership and policy advocacy skills
- Individuals with intellectual/developmental disabilities are partnering with parents/families and exercising their advocacy skills at the state and local level
- Leaders with intellectual/developmental disabilities mentor youth with disabilities and new leaders to gain leadership and advocacy skills
- Coalition members with significant disabilities get the communication support needed to fully engage in policy coalition and activities

- The Idaho DD Network collaborates on the establishment and ongoing support of the statewide policy coalition including:
 - Core member leadership training
 - Expanding contacts in communities of color
 - Cultural competency training
 - Policy advisor to the coalition
 - Internship opportunities with stipends are available for people with intellectual/developmental disabilities to develop advanced leadership skills through mentoring and local/regional coalition activities

- The coalition is recognized as a capable and knowledgeable voice in policy development and systems change efforts
- > The coalition has effectively influenced positive systems changes and specific policies at the national, state and local level.



Oak Packet

DRAFT 2020 Annual Work Plan

October 1, 2019 to September 30, 2020

Year Four of the Five-Year Plan

Goal 1: Adults with intellectual/developmental disabilities experience improved quality in Home and Community Based Services

Objective 1.1

Recruit and support individuals with intellectual/developmental disabilities and family members, to participate in collaborative stakeholder meetings to review and-define Home and Community-Based (HCBS) developmental disability services and develop state quality indicators by October 2020 that will affect ongoing quality assurance activities for HCBS.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Provide information to policymakers at the state and federal level about the importance of Medicaid Home and Community-Based Services
- Review quality assurance activities and make recommendations for system improvement aligned to quality indicators
- Promote HCBS quality indicators in policy advocacy with state agencies and policymakers

Expected Short and Mid-Term Outcomes

- People with intellectual/developmental disabilities (I/DD), family members and other stakeholders across the state have a voice in policy development and systems change
- State agency administrators have increased knowledge of systems issues
- New HCBS developmental disability service array and definitions reflect input from stakeholders including individuals with I/DD and family members
- Quality indicators measure access by Spanish-speaking families to culturally and linguistically appropriate services for their children and adult family members with intellectual/developmental disabilities
- Idaho service system quality indicators are accepted by state agency administrators and policymakers

- Idaho HCBS quality assurance system infrastructure and processes are aligned to quality indicators and federal requirements
- Quality assurance data is gathered directly from individuals receiving HCBS services through residential habilitation
- Data gathered through quality assurance activities informs improvements to the system and provision of HCBS services

Objective 1.2

Working with the Idaho Department of Health and Welfare, service providers, individuals with disabilities and families, develop and implement a plan for organizational change and support staff development in person centered practices by September 2021.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Implement support staff training implementation plan based on person centered practices and identified quality indicators with at least one provider agency
- Evaluate training effectiveness
- Survey agency clients (people with I/DD) based on quality indicators

Expected Short and Mid-Term Outcomes

- > Stakeholders have increased knowledge about person-centered practices
- Training model is developed to improve quality assurance and increase personcentered practices in services
- Service providers use person-centered practices throughout their organizations and in providing services

- > Direct support staff report increased satisfaction with their work
- > Direct support staff report understanding and using person-centered practices
- Increased percentage of individuals who report they direct their plan and services
- Quality assurance data shows an increase in individuals who report they have more choice, control over decisions about daily activities, access to community, and improved quality in their services

Objective 1.3

Work with individuals with disabilities, their families, and other partners on systems change and policy development so that by July 2021, people with intellectual/developmental disabilities have access to Medicaid person-centered planning (PCP) services provided by trained, qualified PCP specialists by July 2021.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Advocate in support of Medicaid rules governing new PCP services
- Inform policymakers and other stakeholders about best practice in a personcentered planning and services
- Help recruit/identify people to be trained as PCP facilitators
- Observe/review PCP Facilitator training
- Survey facilitators and individuals using PCP services based on quality indicators

Expected Short and Mid-Term Outcomes

- New person-centered planning services are established and supported through state policies and procedures
- A PCP specialist training model is established and includes individualized, culturally appropriate strategies and skill development
- PCP specialists are competent in best practice for person-centered planning and are supporting individuals around Idaho
- Families and other members of the circle of support value, and gain skills to facilitate, informed supported decision-making by individuals
- Youth and adults are supported to identify their gifts and strengths and how to use them in planning, directing their services, and reaching their goals

- Increased percentage of individuals report they are supported to lead their plan development and their plans include goals they have chosen
- Quality assurance data shows better outcomes for individuals related to quality indicators

Objective 1.4

Work with the Idaho Department of Health and Welfare to build capacity in mental health services available to individuals who experience the dual diagnosis of mental illness and intellectual/developmental disability by July 2021.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Work with IDHW to develop a plan for implementation of services to support people with dual diagnosis
- Collaborate with IDHW to plan additional support staff training opportunities
- Review quality assurance data and survey individuals about experiences with services

Expected Short and Mid-Term Outcomes

- State agency administrators have increased knowledge about best practice in service to people with dual diagnosis
- Training in trauma informed care and best practice in supporting people with dual diagnosis is established for direct support staff
- People with dual diagnosis are able to access an array of quality Medicaidreimbursable mental health services that are appropriate for individuals with intellectual/developmental disabilities

- Service providers have the capacity to meet the individualized mental health needs of people with dual diagnosis.
- People who use alternative communication methods have their mental health needs met.
- > People who experience dual diagnosis report improved mental health

Goal 2: Youth and young adults with intellectual/ developmental disabilities transition from school into an adult life that includes competitive integrated employment, community engagement, and full citizenship.

Objective 2.1

Each year of the plan, provide/support education and training for families, teachers, and other team members, to increase the number of youth/young adults with intellectual/developmental disabilities who experience a gift-focused and strength-based assessment and planning process.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Work with partners to support Supported Decision-making training and activities
- Evaluate training and survey trainees to develop report on outcomes of training
- Expand peer mentoring model that includes self-advocacy training done by trainers who have I/DD to educational/transition planning process
- Support and survey Idaho Core Gift Master Facilitators and participants on outcomes of process
- Provide Core Gift training in additional areas and promote to school districts
- Provide education to families, youth and young adults about advocacy/self-advocacy in transition planning and employment
- Support Cultural Broker activities in educating Latino/a families, youth and young adults about advocacy/self-advocacy in transition planning and employment

Expected Short and Mid-Term Outcomes

- Educators, families, and other team members are engaged in identifying their children's youth/young adults gifts, strengths, and abilities
- Families, educators and other team members understand student youth/young adults gifts, strengths, and abilities and how they can be supported in school and the community
- Team members gain skills to conduct planning that is student-led and builds upon the student's strengths
- Families have knowledge and are actively involved in supporting their children in the transition-planning process

- Spanish-speaking families are informed, supported and engaged in the transition planning process and activities
- Youth and adults who experience significant disabilities and communication barriers are supported to access a process to identify gifts and strengths

Expected Long-Term Outcomes

- Families have high expectations for their children to achieve post-school goals including employment, citizenship, and inclusive community engagement
- Increase in the percentage of positive post-school outcomes for youth/young adults with disabilities
- Quality assurance activities measure outcomes related to identification of gifts and strengths in alignment with individual goals.

Objective 2.2

By September 2021, increase the percentage of youth/young adults with intellectual/developmental disabilities that achieve competitive integrated employment in the community by working with Workforce Innovation and Opportunity Act partners and Medicaid to implement best practice in customized employment.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Work with WIOA partners to educate students and family members about setting employment goals and the benefits of a customized employment model
- Review effectiveness of Idaho Pre-Employment Transition Services by reviewing outcome data and/or surveying families and students about outcomes

Expected Short and Mid-Term Outcomes

- Students with significant disabilities have equal access to pre-employment transition services/activities and engage in paid work experience
- Young adults have access to individualized services that support their employment goals

Expected Long-Term Outcomes

Increase in the number of youth and young adults with significant disabilities that gain integrated, competitive employment in the community Goal 3: Leaders with intellectual/developmental disabilities are engaged with other people with disabilities and families in a statewide coalition that has a strong, collective voice on policy issues and systems change.

Objective 3.1

Build the capacity of individuals and parents to advocate, lead, and mentor others by providing leadership development and advocacy training to adults with intellectual/developmental disabilities and parents of children with intellectual/developmental disabilities.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Coordinate the 2019/20 Partners in Policymaking program
- Research peer-to peer-mentoring models; engage experts
- Develop plan to implement peer-to-peer mentoring; recruit mentors
- Expand peer mentoring model that includes self-advocacy training for people with disabilities planning their services done by trainers who have I/DD

Expected Outcomes

- Increase in the number of individuals with disabilities and family members that have leadership and policy advocacy skills
- Increase in the number of individuals with disabilities and family members from culturally diverse backgrounds that have leadership and policy advocacy skills
- Leaders with intellectual/developmental disabilities mentor youth with disabilities and new leaders to gain leadership and advocacy skills

Objective 3.2

By September 2019, establish a statewide, culturally diverse coalition of people with disabilities and families who have been trained and are supported each following year of the plan to advocate at the local and state level on policy issues.

Activities

Year 4 (Oct 1, 2019 – Sept 30, 2020)

- Work with contractor to support activities of the statewide policy coalition.
- Support a Coalition member in a fellowship focused on local community organizing
- Provide information to coalition members about policy issues and opportunities to participate in systems change efforts.
- Meet with DD Network Partners quarterly to review progress and explore additional strategies to strengthen self-advocate leadership in Idaho
- Ongoing outreach to Latino community in Western Idaho about policy involvement and Cultural Broker mentoring of interested individuals

Expected Short and Mid-Term Outcomes

- Increase in the number of individuals with disabilities and family members that have leadership and policy advocacy skills
- Individuals with intellectual/developmental disabilities are partnering with parents/families and exercising their advocacy skills at the state and local level
- Leaders with intellectual/developmental disabilities mentor youth with disabilities and new leaders to gain leadership and advocacy skills
- Coalition members with significant disabilities get the communication support needed to fully engage in policy coalition and activities
- The Idaho DD Network collaborates on the establishment and ongoing support of the statewide policy coalition including:
 - Core member leadership training
 - Expanding contacts in communities of color
 - Cultural competency training
 - Policy advisor to the coalition

• Internship opportunities with stipends are available for people with intellectual/developmental disabilities to develop advanced leadership skills through mentoring and local/regional coalition activities

- The coalition is recognized as a capable and knowledgeable voice in policy development and systems change efforts
- The coalition has effectively influenced positive systems changes and specific policies at the national, state and local level.

Member Recruitment

Background Information:

Each year some Council positions become vacant because terms expire, people resign, or choose not to re-apply. Council members help with member recruitment by sharing announcements and helping to identifying possible candidates to apply. Applications are due by March 1st. An ad hoc Membership Committee will be formed from Council members who are **not** re-applying for membership. The Committee will review applications, conduct interviews with applicants, and make recommendations to the Governor for appointment. This year the following terms expire and will need to reapply if desired or required:

- Julie Fodor
- Nanna Hanchet
- Art Evans
- Debra Parsons Has served 9 years; End of term
- David Dekker Has served 9 years; End of term
- Carly Saxe
- Natali Pellens
- James Steed

Recommended Action:

- 1. Discuss open Council positions and member recruitment process and ask questions.
- 2. Volunteer to be on the ad hoc Membership Committee if you are not reapplying for a position this year and you are able to fulfill the responsibilities (see below).

Notes:

COUNCIL MEMBER TERMS FY2017-18

Seat	Held By	Date Appointed	Term Expires	Reg.
Aging Agency	Kevin Bittner	9/27/17	7/1/19	4
Education Agency	Charlie Silva	6/17/2015	7/1/20	4
University Center for Excellence in Dev. Disability/U of I	Julie Fodor	7/9/02	7/1/18	2
Protection & Advocacy	Jim Baugh	4/18/96	7/1/20	4
Rehabilitation Agency	Nanna Hanchet	11/13/2015	7/1/18	4
Maternal & Child Health – Title V	Jacqueline Watson	7/1/11	7/1/19	4
Medicaid – Title XIX	Art Evans	8/17/16	7/1/18	4
Non-Government/Private Org.	Colleen Sisk	7/1/11	7/1/20	1
Local Agency/Non-Profit	Claudia Suastegui	7/1/17	7/1/20	3
Person w/Dev. Disability	lan Bott	7/1/14	7/1/20	4
Person w/ Dev. Disability	David Dekker End of service	7/1/09	7/1/18	5
Person w/Dev. Disability	Jacob Head	6/17/2015	7/1/20	6
Person w/Dev. Disability	Joe Raiden	7/1/10	7/1/19	2
Person w/ Dev. Disability	Carly Saxe	7/1/16	7/1/18	4
Person w/Dev. Disability	Korynne Donehey	7/1/16	7/1/19	7
Parent of Child	Debra Parsons, Chair End of service	7/1/09	7/1/18	7
Parent of Child	Kristie Oakes	11/30/16	7/1/20	4
Parent of Child	Holly Giglio	7/1/16	7/1/19	7
Parent of Child	Rebekah Forster V. Chair	7/1/13	7/1/19	1
Parent of Child	Jessica Rachels	7/1/16	7/1/19	1
Parent of Child	Emily Peterson	7/1/16	7/1/19	5
Parent of Child	Natali Pellens	11/16/17	7/1/18	4
Person living in an Institution	James Steed	6/17/2015	7/1/18	6

*Members in green need to re-apply to continue for another term by March 1st.

ICDD Membership Recruitment Process

Recruitment

RECRUITMENT PACKETS FOR MEMBERSHIP: The Council member applications are always available on our website or by request throughout the year. However, at the beginning of each year, the Council begins a recruitment process to encourage members of the public to apply for open positions.

All Council members are encouraged to take recruitment packets and talk to people in their communities about applying to be a member. We pay attention to the current position openings and area of the state from which the Council lacks representation. The packet includes a brochure about Council membership and how to apply, a flyer about time commitment in being a member, both the ICDD application and the Governor's application, and a general Council brochure.

CURRENT MEMBER RE-APPLICATION: Before the February Council meeting an updated list of member terms is shared that identifies current members whose terms are coming due that year on July 1. The list also includes any vacancies from member resignations. Members wanting to reapply are encouraged to let Council staff know about their intentions to reapply at the Winter Council Meeting. This process helps the Council know of any additional upcoming vacancies if a current member chooses not to re-apply. Current members reapplying for a Council position will be considered alongside new applications.

AD HOC MEMBERSHIP COMMITTEE: At the Winter Council meeting, staff makes a request for Council member volunteers to serve on a temporary Membership Committee. Volunteers *should not* include members who are re-applying for appointment to the Council. This ad hoc Committee is responsible for reviewing membership applications, conducting interviews with new applicants, and meeting to determine recommendations to the Governor for member appointments.

Council staff collects completed/submitted applications. The deadline for applications is March 1. If the Council has a vacancy mid-year, recruitment activities can happen during the year and a different deadline set for applications.

Applicant Interviews

Mid to late March, Council staff sends an announcement to the ad hoc Membership Committee members that we are to begin reviewing member applications and conducting interviews. Staff shares all submitted applications with this group. Staff works with the ad hoc Membership Committee and applicants to schedule interviews. All interviews should be completed by the Spring Council meeting.

Interviews with applicants usually last about 20-30 minutes. All applicants are asked the same questions—it is important to have consistency throughout the interviews. Current Council members reapplying for a position are asked different questions than applicants who have not served on the Council. All questions are sent to every applicant and committee member prior to the interviews so that all involved feel prepared for the interview. During all interviews, Council staff takes notes to record a summary of the applicant's answers to the interview questions. The applications as well as the notes taken by the Council staff person detailing the interviewee's answers are all sent to the ad hoc Membership committee members. ALL INFORMATION IS TO BE KEPT CONFIDENTIAL.

Membership Committee Application Review Meeting

The ad hoc Membership Committee members meet to review applications and interview notes. This meeting can happen before or during the Spring Council meeting. During this meeting, committee members discuss each applicant and people who were involved in the interviews share their perspective. The committee uses a rating sheet to identify a list of top choices of applicants for the open positions.

Applicants Recommended to Governor

Council staff creates a packet to be submitted to the Governor's office. All applications are submitted, along with the list prioritized by the Membership Committee members, as well as an introduction letter describing our open positions and a summary of the process followed by the Membership Committee to make recommendations. The Governor considers all the applications and makes a decision on who will be appointed for each open Council position. Normally, the Governor's office notifies the Council office of his/her choice a few weeks before the Summer Council meeting. The Governor's office notifies selected candidates via mail.

New Member Training

The Summer Council meeting is the first meeting for new members. Because the Council has approved a teleconference meeting for the Summer meeting, Council staff will meet individually with new members for orientation prior to their first or second meetings.

COUNCIL MEMBER APPOINTMENT APPLICATION

Mail Application to address at left or fax to 208-334-3417

You must also fill out a Governor's application online at: <u>http://gov.idaho.gov/pdf/ApplicationForAppointment1.pdf</u>

NAME			STREET ADDRESS				
CITY				СС	OUNTY	STATE	ZIP CODE
HOME	PHONE	WORK PHONE	FAX		E-MAIL ADDRESS		
Are y	ou: 🗌 MALE 🗌 F	EMALE	Do you SPEAK] WRITE a language c	other than Eng	glish?
□ C#	AUCASIAN	HISPANIC	What Language(s)	?			
	RICAN AMERICAN	ASIAN					
	ATIVE AMERICAN						
	-						
1.	I am applying for:	First Tim	e Appointment		Reappointment		
2.	I am applying as:						
	Person With a Devel	opmental Disability	Parent Of A Ch	nild	With a Development	al Disability	
	Immediate Relative, Parent, or Guardian of a Person w/ Dev. Disability who is or was in an Institution or			<u>or</u>			
	Person w/ Dev. Disal	bility who currently is or	was in an Institutio	n			
	Local Non-governmental Agency Representative			resentative			
	Protection and Advocacy Org. Representative University Center for Excellence Representative			ative			
	State Agency Repres	entative, agency name:					
	Other (please list)						
3.	Tell us what qualifies yo	ou for the box you checl	k in # 2.				

4.	What are your specific disability-related interests or concerns?
5.	What have you done to address/resolve your specific disability related interests/concerns?
6.	As a Council member, what do you expect to contribute that will improve the lives of Idahoans with disabilities?
0.	As a council member, what do you expect to contribute that will improve the lives of idanoans with disabilities:

7.	Α.	My commitment level for	or working on r	ny disability related	d issues/concerns is:	
		EXTREMELY HIGH	П нібн	AVERAGE	LOW	
	в.	My commitment level fo	or working on a	other issues affectir	ng people with developmental disabilities	is:
		EXTREMELY HIGH	П нібн	AVERAGE		
	с.	My comfort level for spe	eaking in and b	efore groups and m	naking presentations is:	
		EXTREMELY HIGH		AVERAGE		
	D.	My comfort level for pre	esenting inform	nation to state and	local elected officials is:	
		EXTREMELY HIGH	П нідн	AVERAGE	LOW	
8.		you have commitments of se? NO YES If			I from attending quarterly Council meetin	gs in
			- ,			
9		ase list three (3) non-fam			phone numbers. At least two of these re	ferences
	3110	uld he professional (emp	lover child's ta		elected official clergy etc.)	
		ould be professional (emp	loyer, child's te	eacher, civic leader	, elected official, clergy, etc.).	
	Α.	uld be professional (emp	loyer, child's te	eacher, civic leader,	, elected official, clergy, etc.).	
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	В.	uld be professional (emp	loyer, child's te		, elected official, clergy, etc.).	
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11.	Provide any other information that will help us to know you better. (Use additional paper if needed.)

Secure Treatment Facility

Background Information:

The proposed secure treatment facility rules were published in the January 3, 2018 Administrative Bulletin. A negotiated rules making hearing was held January 24, 2018. The Council, Disability Rights Idaho, State Independent Living Council, and the ACLU each provided comments. Copies of the comments from each advocacy organization will be provided to Council members.

Timeline

After the negotiated rulemaking comment deadline, January 31, 2018, Division management will review all comments and questions and amend the draft rule chapter as necessary based on the comments and questions. The product of this review will be a document listing all comments and questions that were raised in the negotiated rulemaking meeting and, for each comment, whether or not the division incorporated the suggestion, and if they didn't, why they didn't. A meeting is scheduled for February 14, 2018 with the ACLU, the SILC, DRI, and the DD Council to review the results of the negotiated rulemaking meeting and changes the Division plans to make to the draft rule chapter based on the comments received. The document will also be made available to the public.

On February 22, 2018 the Division will present the revised rule chapter to the Board of Health and Welfare for approval. Since the rule chapter is being promulgated as a temporary/proposed rule docket, if the Board approves the rule docket, the new rule chapter will be effective February 22nd. This means the state license for the secure treatment facility will be established on that date, but the secure treatment facility must apply for the license and be approved by the Division of Licensing and Certification before it will be considered licensed for operation. This date is uncertain for actual implementation of the secure treatment facility since these rules address the licensing standards for the facility, not the operation and administration of the facility itself. Policies and procedures will need to be drafted by the Division of Family and Community Services that is responsible for the secure treatment facility and SWITC.

The Administrative Procedures Act requires that a temporary rule approved by the Board be published in the first available monthly Administrative Bulletin. Depending on how quickly the docket can be prepared for publication after approved by the Board, the docket will publish in either the April or May Administrative Bulletin. At the time the docket publishes, there will be another opportunity for public comment. In addition to the mandatory three-week comment period, the division will hold at least one additional public meeting. At that time, we will likely publish an additional notice in the Administrative Bulletin extending the public comment period through June 2018 to allow time for both additional written public comment and to allow time for us to hold at least one more public meeting. During the public meeting(s), the division will again hear and document comments about the proposed rule chapter. At that time, the division will again create a record of the comments received and how the division addressed each comment, and this record will also be made accessible to the public.

The rule docket will then be presented as a pending rule to the Board of Health and Welfare at either their August or November 2018 meeting. If approved by the Board of Health and Welfare, the docket will be presented to the 2019 Legislature for final approval.

Recommended Action:

Listen. Ask questions.

Notes:



DEVELOPMENTAL DISABILITIES

700 W. State St. JRW Building First Floor West Boise, TD 83702-5868 Phone: 208-334-2178 1-800-544-2433 Fax: 208-334-3417

C. L. "Butch" Otter Governor

Debra Parsons Chair

Christine Pisani Executive Director January 31, 2018

Tamara Prisock Idaho Department of Health & Welfare Administrative Rules Unit 450 W. State Street – 10th Floor Boise, Idaho 83720-0036

Sent via email to: dhwrules@dhw.idaho.gov

RE: Comment Regarding Negotiated Rulemaking on Docket No. 16-0315-1801 (16.03.15) Rules Governing Secure Treatment Facility for People with Intellectual or Developmental Disabilities

Dear Ms. Prisock:

The Idaho Council on Developmental Disabilities is pleased to provide written comment to the draft proposed rules found in IDAPA 16.03.15 - Rules Governing Secure Treatment Facility for People with Intellectual or Developmental Disabilities, as announced in the Idaho Administrative Bulletin, Vol. 18-1, published on January 3, 2018.

The Idaho Council on Developmental Disabilities has the following comments:

The Council concurs with all comments submitted by DisAbility Rights Idaho and the ACLU on January 24, 2018. The Council also wants to be on record stating that the secure treatment facility is being used to resolve the states inability to provide community based preventative mental health services for people with a dual diagnosis.

The Council would like to address what appears to be a conflict of interest between the Division of Licensing and Certification and the Division of Family and Community Services. Both divisions report to the same agency director, which does not appear to allow for an independent evaluation. In light of the prolific news coverage over the past year regarding Southwest Idaho Treatment Center an independent evaluation of the secure treatment facility would provide needed assurance that complaints, identified issues, and allegations of abuse, neglect, and mistreatment will be handled with impartiality and transparency. The Council recommends the facility meet already established JCAHO behavioral health standards for treatment rather than creating a new license and navigating the unchartered water a whole new facility type.

https://www.jointcommission.org/accreditation/behavioral health care.aspx

The Council would like to express concern with the January 29, 2018 release of the Office of Performance Evaluation Report titled Residential Care. Given what was learned through the report, the Council strongly encourages an emphasis on thorough training of the surveyors selected to conduct the assessments of the secure treatment facility. Training should include an understanding of adults with a dual diagnosis and best practice in serving this specified population. A recommendation the Council would make is for future surveyors involvement in educational opportunities provided through the

National Association for Persons with developmental disabilities and mental health needs. http://thenadd.org/about-nadd/

A specific recommendation made by the Council during negotiations for House Bill 222 was that the statute include a definition of trauma informed care. The Council desired seeing language provided within the statute that would clarify how an individual's trauma history would be collected. This assessment would take into consideration previous restraint use, seclusion or isolation used in a punitive way, all contributing to useful information for the purpose of treatment planning and in specific de-escalation strategies to avoid re-traumatizing the individual.

During the negotiations, the Council was informed that recommendations regarding trauma informed care approached would be better served within the rules vs. the statute. With this assurance the Council withdrew its' objections to the lack of this specific language in the statute. The Council requests that a specific section be added to the rules that details the definition, trauma history, and treatment planning be addressed with specificity. The Council recommends the following for development of this section of rule:

- <u>http://thenadd.org/trauma-informed-toolkit/</u>
- http://thenadd.org/news/trauma-informed-therapeutic-supports-training/
- http://trauma.jbsinternational.com/traumatool/Module4.html
- 4) http://trauma.jbsinternational.com/traumatool/Module5.html#IssueBrief
- 5) Screening and Assessment http://trauma.jbsinternational.com/traumatool/Module1.html

16.03.15.020 Licensure - General Requirements

The Council recommends providing clarification on the general requirements for licensure, which do not read that the license is specific to one secure treatment facility.

16.03.15.073 - Summary Suspension of Licensure

The Council recommends providing a clearly detailed plan to address the safety and emergency plan to be implemented should licensure suspension occur.

16.03.15.103 – Abuse, Neglect, and Mistreatment Prevention, Detection, Investigation and Resolution Process

The Council recommends the inclusion of rules that address a detailed training plan required for all newly hired direct care staff. Rules should also address the priorities of a detailed plan for continuous education to build on the varied skills sets required of the direct care workforce.

The Council recommends that information in plain language and/or an infographic be provided to each individual served within the secure treatment facility as to who and how a resident reports abuse, neglect, or mistreatment.

16.03.15.204.02 Requirements of Personnel; Training Requirements

The Council recommends specific language be added to the rules that addresses thorough and repeated training for all staff regarding the facility's definitions of abuse, neglect, and mistreatment paired with thorough and repeated training on the facility's policy regarding abuse, neglect, or mistreatment policy, including the requirement to report and how to do so.

The Council is opposed to the use of restraint and seclusion as a programmatic tool. The Council advises the review of NADD's training and information materials on "Intellectual/Developmental Disabilities and Trauma" and "Safety without Seclusion and Restraint," located at: http://thenadd.org/resources/other-resources-of-interest/

16.03.15.320(02) - Written Informed Consent Required; Written Informed Consent for Experimental Research

The Council strongly opposes any experimental research on clients to be performed at this facility.

16.03.15.401 - Best Practice and Evidenced Based Practice

The Council recommends a detailed set of rules that addresses the education of the Human Rights Committee. Rules should address the facility's priority to provide continued education to members of the Human Rights Committee with the purpose of using best practice standards in their review of treatment plans for individuals. A set of rules should be included to emphasize the facility's priority to best practice and evidence based practice by hosting webinars, speakers, attendance at NADD conferences provided to all staff, not limited to administrative staff.

16.03.15.511 Physical Restraint and Seclusion Use

The Council is opposed to the use of restraint and seclusion as a programmatic tool. The Council advises the review of NADD's training and information materials on "Intellectual/Developmental Disabilities and Trauma" and "Safety without Seclusion and Restraint," located at: http://thenadd.org/resources/other-resources-of-interest/

305.07 Right to Be Paid for Work Performed

The Council is opposed to the practice of paying individuals wages commensurate with their abilities. This is demeaning and is not best practice. Best practice would dictate that they earn the prevailing wage for someone doing the same work. The Council believes that the State of Idaho should model practice.

Respectfully,

Christine Pisani Executive Director



January 24, 2018 Ms. Tamara Prisock DHW – Administrative Rules Unit 450 W. State Street – 10th Floor P.O. Box 83720 Boise, Idaho 83720-0036

Sent via email to: <u>dhwrules@dhw.idaho.gov</u>

RE: Comment Regarding Negotiated Rulemaking on Docket No. 16-0315-1801 (16.03.15) Rules Governing Secure Treatment Facility for People with Intellectual or Developmental Disabilities

Dear Ms. Prisock:

The purpose of this letter is to provide written comment to the creation of the proposed rules found in IDAPA 16.03.15 - Rules Governing Secure Treatment Facility for People with Intellectual or Developmental Disabilities, as announced in the Idaho Administrative Bulletin, Vol. 18-1, published on January 3, 2018.

General Comments:

During negotiations with Department representatives over the house bill which eventually became Idaho Code Title 56 Chapter 14, disability advocacy groups asked for the statute to incorporate trauma informed care principles into the bill. In exchange for withdrawing our objections to the bill, the department representatives agreed that trauma informed care principle would be required by the licensing rules. These rules do not reflect that agreement. Although Subsection 403.01(e) requires an assessment of trauma history for residents expected to be subjected to restraint, there is no mention of trauma informed care, and few references to any of its principles. Given the recent history of SWITC concerning staff abuse of clients, the high injury rates and the general justification for the creation of the DD Secure Facility, the need for a trauma informed approach for the target population is of the highest importance. The federal Substance Abuse and Mental Health Services Administration (SAMHSA) has abundant research on the topic and offers information, training and technical assistance on the development of trauma informed policies and procedures. We highly recommend that IDHW take advantage of the resources they have to offer and implement a genuinely trauma informed approach to this facility. We believe that this work and training should be completed before the STF/DD is licensed and opened.

Specific Comments:

Proposed Rule: 16.03.15.001.02- Scope

Comment: The language of this section appears to reference some of the admission criteria of Idaho Code 66-1404. This section should incorporate <u>all</u> of the provisions of Idaho Code 66-1404. It also must be made clear that these rules only allow for the creation of <u>one</u> facility, per the authority granted under Idaho 66-1402.

This section must reference all four (4) mandatory admission criteria as listed in Idaho Code 66-1404.

Idaho Code 66-1402(1) authorized the creation of a single secure facility, however, throughout the proposed rules it appears that more than one secure facility is possible. For example, proposed rule .030.02 refers to "each license" and .830 refers to "Each secured facility" and .831.01.b refers to "each facility" .831.04 refers to "each facility"

Proposed Rule: 16.03.150.010 - Definitions

<u>Comment</u>: The definition of "Physical Abuse" does not appear to incorporate the use of excessive force when placing an individual in restraints, nor does it include the use of inappropriate or non-approved restraints, or the use physical or chemical restrains which are not in compliance with Federal and state laws and regulations.

> By limiting the definition of "physical abuse" to intentional acts, scenarios where a resident was injured when an employee either used excessive force or improper technique while using an approved restraint technique or used an unapproved restraint technique would go uninvestigated. This could subject residents to unnecessary abuse and injury.

> The definition of "Sexual Abuse" does not appear to prohibit sexual activity between clients and staff in circumstances where the client may have given "affirmative permission." It also appears to only prohibit sexual assault against clients when the client is unable to defend themselves. This could be interpreted to mean that if a client can defend themselves, then sexual abuse could not have occurred. Additionally, although sexual assault is specifically mentioned in the definition of sexual abuse, rape is not.

There is no scenario where licensing should approve or allow sexual contact between staff and a resident or two residents at the secure facility. The definition of sexual abuse should require a zero

tolerance for sexual activity between staff and residents or between residents.

The definition of "Available Staff" needs to clarify that "on the premises" specifically means on the Secure Treatment Facility premises, so as not to imply that "available staff" includes those at nearby facilities which are supposed to be separate and distinct from the Secure Treatment Facility.

The definition of "Chemical Restraint" needs to mirror the definition found in 42 C.F.R. 482.13(e)(1)(i)(B), which defines such a restraint as a "drug or medication when it is used as a restriction to manage the patient's behavior or restrict the patient's freedom of movement and is not a standard treatment or dosage for the patient's condition."

For Skilled Nursing & Intermediate Care licensing has defined chemical restraint as, IDAPA 16.03.02.08. "Chemical Restraints. The use of drugs which prevent the patient/resident from doing what he might do voluntarily on his own. (12-31-91)"

For RALFS licensing has defined chemical restraint as, IDAPA 16.03.22. 17. "Chemical Restraint. A medication used to control behavior or to restrict freedom of movement and is not a standard treatment for the resident's condition. (3-30-06)"

For Detox/Mental Health Diversion Units, licensing has defined chemical restraint as, IDAPA 16.07.50.08. "Chemical Restraint. The use of drugs that prevents a client from doing what he might do voluntarily on his own. (3-29-10)"

The definition of "Client" needs to align with the term "person" as defined in Idaho Code §66-1403(8), which is defined as "an individual subject to judicial proceedings authorized by the provisions of..." Idaho Tile 66, Chapter 14 who has been admitted and dispositioned into the secure treatment facility pursuant to Idaho Code §66-1404.

The definition of "Client Advocate" should include a prohibition on decision-making by the Advocate for or on behalf of the client. There is no legal basis for anyone other than a legal guardian or an individual with a previously executed power of attorney or advance directive to make decisions for or on behalf of another person. An advocate who is not a guardian has no legal authority to substitute their consent for a client, or to withdraw consent previously granted. If a person lacks capacity to consent, and has no legally appointed guardian to provide a valid consent, then any treatment provided is involuntary and non-consensual. Involuntary treatment is permitted by federal and Idaho law, only when constitutional and statutory due process requirements are met.

The definition of "Individual Treatment Plan (ITP)" does not reference that it must include programs which include strategies that are effective in ameliorating the behaviors which resulted in the admission to the secure treatment facility and the teaching of self-management strategies to promote discharge to a less restrictive living environment. It also does not include the prevention or deceleration of regression or loss of current optimal functional status.

The definition of "Interdisciplinary Team (IDT)" does not include the individual client themselves and their Guardian, as is required under the definition of this term in the ICF/ID IDAPAs, specifically, 13.03.11.101.16.

Isolation is an undefined term used in Idaho Code 66-412(2) which reads: "A developmentally disabled person shall not be put in isolation."

Idaho Code 66-1406 Rights of Persons in the Secure Treatment facility guarantees that a person in the secure facility "shall" have all the civil rights provided for in chapter 4, title 66, Idaho Code except that the secure facility can limit a person's right to communicate, visit with people and have access to their property. The prohibition from isolation has not been limited.

Idaho Code 73-113. CONSTRUCTION OF WORDS AND PHRASES. (1) The language of a statute should be given its plain, usual and ordinary meaning. Where a statute is clear and unambiguous, the expressed intent of the legislature shall be given effect without engaging in statutory construction. The literal words of a statute are the best guide to determining legislative intent. (2) If a statute is capable of more than one (1) conflicting construction, the reasonableness of the proposed interpretations shall be considered, and the statute must be construed as a whole. Interpretations which would render the statute a nullity, or which would lead to absurd results, are disfavored.

(3) Words and phrases are construed according to the context and the approved usage of the language, but technical words and phrases, and such others as have acquired a peculiar and appropriate meaning in law, or are defined in the succeeding section, are to be construed according to such peculiar and appropriate meaning or definition. History: [(73-113) C.C.P. 1881, sec. 12; R.S., sec. 15; reen. R.C., sec. 15; reen. C.L. 500:15; C.S., sec. 9455; I.C.A., sec. 70-113; am. 2013, ch. 335, sec. 1, p. 873.]

Webster's dictionary defines isolation as: : the state of being in a place or situation that is separate from others : the condition of being isolated : the act of separating something from other things : the act of isolating something.

Licensing has proposed to define Isolation as: "The involuntary confinement of a client alone in a room or area from which the client is physically prevented from leaving that is separate from others, without staff contact or monitoring."

Licensing has proposed to define Seclusion as: "The involuntary confinement of a client alone in a room or area from which the client is physically prevented from leaving that includes continuous in-person staff monitoring."

Pursuant to the proposed rules, the only difference between isolation and seclusion is whether a staff person monitors the person while the person is isolated.

Licensing proposes to allow the use of seclusion, however this is contrary to the implementing statute, I.C. 66-1406 which guarantees the person his rights in 66-406. The plain language of I.C. 66-406 prohibits a facility from placing an individual with a developmental disability in isolation, i.e., separating a person from their surroundings. The prohibition cannot be averted by merely having staff peer through a window to make sure the person is alive. See also our comments below on trauma informed care and the SAMHSA position on reduction and elimination of seclusion in treatment facilities.

Proposed Rule: 16.03.15.011 – Definitions

<u>Comment</u>: The definition of "Legal Guardian" is too broad and appears to encompass individuals beyond the guardianship provisions found under Idaho Code 15-5-301, et seq., or Idaho Code 66-404. The term Guardian is a legal term of art and is specifically defined in the previously mentioned statutory sections. Any "court-appointed surrogate" designated to advocate on behalf of a client that was not appointed as a guardian pursuant to Idaho Code 15-5-301, et. seq., or Idaho Code 66-404 is not a "Guardian."

The definition of "Neglect" does not include a staff's failure to properly implement a client's Individual Treatment Plan (ITP) or

programs.

There is no definition of the term "Restrictive Intervention" although the term is used throughout these rules.

The definition of "Physical Restraint" only applies to holds, devices, materials, or equipment that the client "cannot remove easily." The phrase "cannot remove easily" is currently being removed from the definition of this term in the proposed amendments to the Residential Habilitation administrative rules and should be removed from this definition as well.

The definition of "Punishment" does not include withholding "medical care or treatment" as a means to discipline or penalize a client for the purpose of controlling behavior.

The definition of abuse includes a prohibition of "corporal" punishment. This term is undefined. Further, the use of the proposed defined act of "punishment" is not included in the definition of abuse.

The definition of "Reportable Incident" notably omits the requirement that a facility report allegations of staff abuse, neglect, or mistreatment of clients to Licensing and Certification, including no requirement to report incidents of sexual assault.

The definition of "Seclusion" does not align with the prohibition of isolation of an individual with a developmental disability pursuant to Idaho Code 66-412 – a statute that is applicable to this secure treatment facility.

The definition of "Sufficient Staff" needs to make explicitly clear that such staff be present on the secure treatment facility grounds, on-duty, and awake on a 24-hour basis, as is required per CMS regulations for ICF/IDs. The definition of "Time Out" in these rules does not require constant visual supervision by staff, does not prohibit a client's residential unit from being used as a "designated area", nor does it state that such "designated areas" be free from hazardous conditions including but not limited to the presence of sharp corners, objects, uncovered light fixtures, unprotected electrical outlets, etc. Furthermore, there does not appear to be any restrictions or safeguards in place for the use of timeout as found in 42 C.F.R. 483.450(c), such as constant staff supervision or documentation or record-keeping requirements of time-out activities.

The Association for Applied Behavior Analysis International (IABAI) statement on time out states: "Time-out may be used as part of an integrated behavior intervention plan designed to decrease the future probability of a pre-specified target behavior or to reduce the episodic severity of that behavior.

The behavior intervention plan that incorporates the use of time-out must (a) be derived from a behavioral assessment, (b) incorporate reinforcement strategies for appropriate behavior, (c) be of brief duration, (d) be evaluated by objective outcome data, and (e) be consistent with the scientific literature and current best practices."

Proposed Rule: 16.03.15.020 – Licensure – General Requirements

<u>Comment</u>: The general requirements for licensure do not explicitly state that only <u>one</u> facility is allowed to be licensed as the secure treatment facility pursuant to Idaho Code Title 66, Chapter 14.

- **Proposed Rule**: 16.03.15.051(c) Licensure Surveys Complaint Investigation Surveys
- **Comment**: Considering the recent multitude of deficiencies at the state-run ICF/ID, DRI believes that time allowed for Licensing and Certification to conduct complaint investigation surveys at this secure treatment facility are entirely too liberal. Allowing for such long periods of time before Licensing and Certification arrives to conduct an investigation survey can only serve to potentially subject clients to further abuse, neglect, and mistreatment. Considering that "immediate jeopardy" includes serious injury, harm, impairment, or death of a client, an immediate response by licensing officials is warranted. If the Department's reason for such generous response times is a lack of Department personnel or resources, then the Department should consider whether the potential risk to clients outweighs any costs that may be associated
with the addition of any personnel or resources needed to accomplish this important purpose.

Complaints of immediately jeopardy should render an investigation survey within twenty-four (24) hours or one (1) business day after the allegation is reported. Complaints not alleging immediate jeopardy should render an investigation survey in no more than five (5) business days after the allegation is reported.

Proposed Rule: 16.03.15.073 – Summary Suspension of License

<u>Comment</u>: This provision does not contain any information on what happens to clients immediately upon a summary suspension including but not

clients immediately upon a summary suspension including but not limited to what safeguards are immediately put in place to ensure that whatever "emergency" that constituted the suspension is immediately redressed, clients are immediately transported to other appropriate placements, etc.

- **Proposed Rule**: 16.03.15.100 Standard of Licensure: Facility Administration
- **<u>Comment</u>**: There needs to be specific, detailed, and rigorous qualification education and experience requirements as to whom can be chosen as the administrator for this facility. Please also see our comments to 16.03.15.110.01.
- **Proposed Rule**: 16.03.15.102 Grievance Process
- **<u>Comment</u>**: The rule allows for either the client or their guardian or advocate to be informed as to whom to contact for grievances. This creates the possibility for situations where a client may have a grievance but no knowledge as to whom the grievance should be communicated if this information is only shared with their guardian or advocate.
- **Proposed Rule**: 16.03.15.103 Abuse, Neglect, and Mistreatment Prevention, Detection, Investigation and Resolution Process
- **Comment**: There does not appear to be a specific requirement that the facility immediately train staff on such policies and procedures immediately upon hiring and then continuously re-train staff on such policies and procedures on at least an annual basis to ensure that all staff are aware of their responsibilities under these policies. Considering the highly published issues related to the recent, wide-spread staff abuse and neglect at the state run ICF/ID, it seems prudent that such requirements be explicitly made a part of any licensing rules pertaining the secure treatment facility.

There also does not appear to be a requirement that facility immediately inform each client and their guardian or advocate, where applicable, as to these policies and procedures immediately upon admission to the facility, so that clients and their guardians and advocates can be informed as to what constitutes abuse, neglect, and mistreatment and to whom reports of any suspected abuse, neglect or mistreatment should be made. As the rule is currently worded, either the client <u>or</u> their guardian or advocate are to be informed as to whom to contact for reports of suspected abuse, neglect, or mistreatment. Again, this creates the possibility for situations where a client may want to report abuse, neglect, or mistreatment but they have no knowledge as to whom to communicate it to, if this information is only shared with their guardian or advocate.

- **Proposed Rule**: 16.03.15.110.01 Administrator; Administrator Requirements
- **Comment**: There needs to be specific, detailed, and rigorous qualification education and experience requirements as to whom can be chosen as the administrator for this facility. It is interesting to note that an Administrator at this facility can have less education and work experience/qualifications than a Clinical Case Manager working at this facility. There is also no requirement listed that the administrator not have any substantiated incidents of abuse, neglect, exploitation, or mistreatment in their employment or criminal history. There is also no requirement that the administrator have any experience providing care or services to people with intellectual or developmental disabilities who <u>also have a diagnosis</u> <u>of serious mental illness</u>, even though those are the only individuals who can be placed in this facility.

Further, a facility administrator should have some previous management experience, especially in dealing with those who have violent backgrounds.

- **Proposed Rule**: 16.03.15.110.02 Administrator; Administrator Duties
- **<u>Comment</u>**: As to subsection (b.), the allowance of one (1) business day to notify Licensing and Certification of any "anticipated or actual termination of any service vital to the continued safe operation of the secure facility or health, safety, and welfare of its clients and personnel" is entirely too generous of a time period, considering that termination of such a service may result in immediate jeopardy.

As to subsection (c.), the allowance of two (2) business days to notify Licensing and Certification of all "reportable incidents" is also

too generous, again, considering that such an incident may be the death of a client. Additionally, it is interesting to note that the reporting requirements for the administrator of the secure treatment facility are less strict than the reporting requirements of a community setting provider, such as a Certified Home Provider. For instance, in the recent changes to administrative rules for Certified Family Homes, such providers will be required to report a death or disappearance within twenty-four (24) hours. Additionally, they must also immediately report abuse, neglect, or exploitation to adult protection. For emergency room visits or hospitalizations, they are allotted three (3) business days to report to Licensing and Certification. There is also no reference in this rule as to the Administrator's mandatory reporting requirements under Idaho Code §39-5303, which are applicable to this facility and its staff.

- Proposed Rule: 16.03.15.201 Sufficient Personnel
- **Comment**: Again, as commented in the definition of "Sufficient Staff," this provision needs to make explicitly clear that such staff be present on the secure treatment facility grounds, on-duty, and awake on a twenty-four (24) hour basis, as is required per CMS regulations for ICF/IDs. There should also be a requirement that all staff be trained prior to the facility operating under its license, to ensure that all of the staff who are on-duty are adequately trained prior to working with clients.

According to the wording in this rule, the secure facility would be in compliance if there were two (2) staff present to care for and run the individual treatment plans for four (4) violent, dangerous, clients with a developmental disability and a serious chronic mental illness.

- Proposed Rule: 16.03.15.203 Personnel Records
- **<u>Comment</u>**: There does not appear to be a requirement that any allegations of abuse, neglect, or mistreatment committed by an employee, as well as the results of any investigations into such allegations (i.e. substantiated or not substantiated) be kept in the personnel record along with any disciplinary actions taken against the employee and the reasons why such actions were taken.
- **Proposed Rule**: 16.03.15.204.02 Requirements of Personnel; Training Requirements
- <u>Comment</u>: There does not appear to be any requirement that all staff be trained specifically as to the facility's abuse, neglect, or mistreatment policy and their reporting requirements under said

policy.

As subsection (c.), (training for direct care staff), there does not appear to be any requirement that such staff complete their training prior to working directly with clients, which could lead to the potential misuse of restraints or other restrictive interventions as well as abuse, neglect, or mistreatment of clients.

Why are the training requirments in .204.02.c just limited to direct client care staff? DRI would require that all staff, including administrative staff be trained on the elements listed in c.i – xii.

DRI objects to the use of prone restraint.

As to subsection (c., ix.), it appears as though the language of this subsection allows for the use of prone, supine or other restraints. In reviewing the remainder of these rules, there does not appear to be any restrictions or limitations as to the use of prone, supine, or other restraints. Such restraints are inherently dangerous, inhuman, unnecessary, and should be banned from use in this facility. For further information regarding the inherently dangerous nature of prone restraint, please see the report entitled "The Lethal Hazard of Prone Restraint: Positional Asphyxiation" accessible here: <u>http://www.disabilityrightsca.org/pubs/701801.pdf</u>. Please also refer to our comments to 16.03.15.501 and 16.03.15.511.

- **Proposed Rule**: 16.03.15.300 Standard of Licensure: Client Protections
- **<u>Comment</u>**: Such protections need to be explained to a client and their guardian, if applicable.
- **Proposed Rule**: 16.03.15.301 Advocacy and Advocate Selection
- **<u>Comment</u>**: There appears to be missing from this section the conditions for appointed advocates found in the IDAPAs for ICF/IDs, specifically, 16.03.11.202 as well as the advocates rights found in 16.03.11.203. The decision making ability of the advocate (i.e. the ability for the advocate to provide consent) is also not clearly outlined in this section.

Anyone other than a court appointed guardian or a holder of a previously executed power of attorney had NO legal authority to make any decisions for a client or provide consent to any treatment, medications or restrictive measures.

Proposed Rule: 16.03.15.302.06 – Informed of Rights, Restrictions, and Rules of the Facility; Prompt Notification of Significant Events

<u>Comment</u>: The term "promptly" is not defined and could be subject to broad interpretation. Additionally, allowing for a parent or guardian to be notified of any significant changes in a client's condition, including and especially death, in any timeframe less than immediately is inappropriate.

"Significant Event" should include and injury the client experiences.

Proposed Rule: 16.03.15.303.04 (b) – Documentation of Notifications; Contact Information

<u>Comment</u>: If the "advocacy agency" referred to in this subsection is DisAbility Rights Idaho, then the term should be replaced with "the state protection and advocacy system" to be consistent with all other rules.

- **Proposed Rule**: 16.03.15.305(02) Client Rights Which May Not Be Restricted; Right to be Free from Abuse, Neglect, and Mistreatment
- <u>Comment</u>: It appears as though this section is missing language as the last sentence ends with "The facility must." Additionally, the terms neglect or mistreatment, are notably absent from the provisions of this rule.
- **Proposed Rule**: 16.03.15.305(04), Client Rights Which May Not Be Restricted; Right to Be Free From Unnecessary Physical Restraint and Seclusion
- <u>Comment</u>: It is unclear how this provision aligns with the prohibition of isolation found in Idaho Code 66-412. Additionally, why is isolation not prohibited in these rights?
- **Proposed Rule:** 16.03.15.305(03) Client Rights Which May Not Be Restricted; Right to Be Free From Unnecessary Drugs
- **<u>Comment</u>**: This provision appears to conflict with a later of provision of these rules, 16.03.15.520, which allows for chemical restraints.

Proposed Rule: 16.03.15.310 (01) – Client Rights Which May Be Restricted; Limitation on Communications, Visitation and Participation in Social and Community Events.

- <u>Comment</u>: This rule references Subsections "306.05 and 306.06 of these rules" which do not exist.
- **Proposed Rule:** 16.03.15.310 (02) Limitations on Personal Possessions

<u>Comment</u> :	It is not clear how temporary restrictions of supportive or adaptive equipment, communication devices, or basics clothing which may be used as weapons such as eye glasses, canes, walkers, etc. align with the provision for an individual to function with as much independence as possible as required in their ITP. It also is unclear how the restriction of such equipment or services would not result in an individual being subjected to isolation or in violation of any other rights found in Idaho Code §66-412 in that they could potentially be without a means to communicate or a means to ambulate without the assistance of staff. The term "temporary" is not defined nor limited in its application and could be left for broad interpretation. Therefore, such items could be restricted for weeks, which again, does not appear to align with the protections found in Idaho Code §66-412.

Are "permanent restrictions" limited to just this facility or will these restrictions travel with the client to a lesser restrictive placement or community placement while under commitment? If that is the case, licensing will have exceeded its statutory authority to make rules for the secure facility.

.03 limits a client's ability to purchase a weapon. Every client eligible for this facility has either been civilly committed or is there under an 18-212 order, both of which trigger 18 U.S.C. 922 et.seq federal prohibition on the possession of firearms.

Subsection .05 limits a client's access to records. This rule needs to include the qualifications of staff that can make this determination. DRI would object if direct care staff, and not professional psychiatric staff made this determination.

- **Proposed Rule:** 16.03.15.310 (06) Client Rights Which May Be Restricted; Right to Refuse or Revoke
- **<u>Comment</u>**: Patient needs to be informed of refusal right regardless of guardian/advocate

Some type of hearing within facility with independent decision makers

- **Proposed Rule**: 16.03.15.320.01 Written Informed Consent Required Written Informed Consent Required for Proposed Restrictive Treatment
- **<u>Comment</u>**: Again, restrictive treatment is not defined anywhere in these rules. Additionally, it is not clear from the provision who must provide the written consent.

- **Proposed Rule**: 16.03.15.320(02) Written Informed Consent Required; Written Informed Consent for Experimental Research
- **<u>Comment</u>**: DRI is adamantly opposed to the use of any experimental research on clients being performed at this facility. It should also be noted that there does not appear to be any restrictions in place as to such research, as are found in 45 C.F.R. §46, et seq.

Every person eligible for admission to the secure facility has been civilly committed under Chapter 66 or is there for compentency issues under Chapter 18-212. Both of these statutes require a court to make a determination of on whether the individual lacks the capacity to make informed decisions about treatment. Judges always determine the individual lacks this capacity, therefore there are no circumstances where the individual could provide written informed consent to participate in experimental treatment.

Moreoever, guardians of individuals with developmental disabilities are statutorily prohibited from consenting to experimental treatment without having a separate court proceeding and the issuance of a court order authorizing such consent. See I.C. 66-405(10).

- **Proposed Rule:** 16.03.15.401 Best Practice and Evidence Based Practice
- **<u>Comment</u>**: It is not clear what "best practice" or "evidence based practice" means. It also is not clear from these provisions that trauma informed care principles will be incorporated in assessments for every client, regardless if physical restraint and seclusion are to be used. See also our comments for 16.03.15.411.12.

When compared to section .322.01, criteria the human rights committee must review to approve restrictive practices, it appears that "best practice" and "evidence based practice" is only required for treatment but not for restrictive practices. For example, the secure facility may use a non-best practice or a non-evidence based restrictive treatment on a client.

Moreover, the human rights committee is to ensure that the client, legal guardian or client advocate has provided written informed consent to use a restrictive treatment (.322.01.g). However, for all clients in this facility, the ONLY person who could provide such consent would be a court appointed guardian who has been granted the power to consent to treatment.

Proposed Rule: 16.03.15.402 (02) – Admission Records; Documentation of Court Findings.

<u>Comment</u>: It needs to be made explicitly clear in these rules that a person can only be admitted to this facility if <u>all</u> of the admission criteria found within Idaho Code §66-1404 are met.

- **Proposed Rule**: 16.03.15.411.12 Components of the Comprehensive Functional Assessment; Assessment to Support the Need of Any Restrictions and a Physical Restraint Risk
- Comment: It is not clear from this rule that trauma informed care principles will be incorporated into every assessment for every client, regardless of whether restraints are to be used. As all clients in this facility are subject to emergency use of such restraints, all clients should be assessed using trauma informed care principles and risk factors for restraint. . Trauma informed care should not be restricted to restraint. A thorough knowledge of the client's trauma history is essential to avoiding trigger events that interfere with treatment, or may precipitate situations which require restraints. Trauma informed care is a pervasive system which informs every aspect of treatment (see, https://store.samhsa.gov/shin/content/SMA14-4884/SMA14-4884.pdf and resources at https://www.nasmhpd.org/content/national-center-trauma-informedcare-nctic-0). The restriction of trauma consideration to anticipated restraints and seclusions in these rules does not reflect an understanding of the concept.

Proposed Rule: 16.03.15.441 (02) – Reasonable Preparation Time

<u>Comment</u>: The term "reasonable time" is not defined and is open to interpretation as to what "reasonable time" to prepare for a transfer or discharge may be. Additionally, it is not clear how this provision complies with the requirements of Idaho Code §66-1405.

Proposed Rule: 16.03.15.501 – Prohibitions

Comment: It appears as though the language of this subsection allows for the use of prone, supine or other restraints. In reviewing the remainder of these rules, there does not appear to be any restrictions or limitations as to the use of prone, supine, or other restraints. Such restraints are inherently dangerous, inhuman, unnecessary, and should be banned from use in this facility. For further information regarding the inherently dangerous nature of prone restraint, please see the report entitled "The Lethal Hazard of Prone

Restraint: Positional Asphyxiation" accessible here: http://www.disabilityrightsca.org/pubs/701801.pdf. Please also refer to our comments to 16.03.15.501 and 16.03.15.511. I assume that Subsection 501.02 should read "Aversive conditioning" and not "Adverse". If not, then Aversive conditioning should be included.

Proposed Rule: 16.03.15.502 (01) – Policies, Procedures, and Practices to Manage Clients' Maladaptive Behavior; Conduct Towards Clients

- <u>Comment</u>: Considering the recent, well-publicized issues at the state-run ICF/ID, there should be the addition of policies and procedures that must identify what constitutes abuse, neglect, and mistreatment of a client as well as the reporting requirements that staff must follow if abuse, neglect, or mistreatment is suspected. There should also be some quality assurance policies, practices, and procedures incorporated into these rules as well.
- **Proposed Rule:** 16.03.15.511 Physical Restraint and Seclusion Use
- Comment: The federal Substance Abuse and Mental Health Services Administration (SAMHSA): Has the following policy:

SAMHSA is committed to eliminating the use of seclusion and restraint in the treatment of people with mental and/or substance use disorders. Seclusion and restraint were once perceived as therapeutic practices in the treatment of people with mental and/or substance use disorders. Today, these methods are viewed as traumatizing practices and are only to be used as a last resort when less-restrictive measures have failed and safety is at severe risk.

Seclusion is defined as the involuntary, solitary confinement of an individual. Restraint refers to any method, physical or mechanical device, or material or equipment that immobilizes or reduces an individual's ability to freely move his or her arms, legs, body, or head. A drug or medication also might be used to restrict behavior or freedom of movement.

Studies have shown that the use of seclusion and restraint can result in psychological harm, physical injuries, and death to both the people subjected to and the staff applying these techniques. Injury rates to staff in mental health settings that use seclusion and restraint have been found to be higher than injuries sustained by workers in high-risk industries. Restraints can be harmful and often re-traumatizing for people, especially those who have trauma histories.

Beyond the physical risks of injury and death, it has been found that people who experience seclusion and restraint remain in care longer and are more likely to be readmitted for care.

SAMHSA is committed to reducing and ultimately eliminating the use of seclusion and restraint practices in organizations and systems serving people

with mental and/or substance use disorders. SAMHSA's goal is to create coercion- and violence-free treatment environments governed by a philosophy of recovery, resiliency, and wellness. Successful efforts have eliminated these practices in psychiatric hospitals, forensic psychiatric settings, therapeutic schools, residential treatment centers, and jails and criminal justice settings." <u>https://www.samhsa.gov/trauma-violence/seclusion</u>.

This web page has a list of articles detailing alternatives and studies. Further guidance is contained in SAMHSA's Issue Brief.

"What the Research Shows: For many years, numerous misconceptions have supported the use of seclusion and restraints in mental health inpatient and outpatient facilities, addictions treatment centers and schools, etc. Although seclusion and restraint were long thought to create a safer and more secure environment for consumers and staff, research contradicts this. Studies have shown that psychological harm, physical injuries, and death can result from the use of seclusion and restraint to both the individual subjected to and staff applying these techniques (NASMHPD, 2009; Sailas & Fenton, 2000; Weiss et al., 1998). In fact, injury rates to staff in mental health settings where seclusion and restraint are used have been found to be higher than injuries sustained by workers in high-risk industries such as lumber, construction, and mining (Weiss et al., 1998; Love & Hunter, 1996). In addition, the use of seclusion and restraint has often been perceived as therapeutic to consumers. This misconception has been challenged and refuted (Mohr & Anderson, 2001; NASMHPD, 2009). Increasing research has identified the role of trauma in mental and addiction disorders. Research into trauma1 and trauma-informed care2 identify common themes about the impact of trauma and how traumatic life experiences can impede an individual's ability to manage his or her own behaviors or engage in appropriate behaviors in the community (Fallot & Harris, 2002; Hodas, 2004; van der Kolk, 2007). Subsequently, trauma-informed care has emerged as an approach to care that prevents the re-traumatizing of these individuals. Studies suggest that restraints and seclusion can be harmful and is often retraumatizing for an individual who has suffered previous trauma (NASMHPD, 2009). Further, there is a common misconception that seclusion and restraint are used only when absolutely necessary as crisis response techniques. In fact, seclusion and restraint are most commonly used to address loud, disruptive, noncompliant behavior and generally originate from a power struggle between consumer and staff. The decision to apply seclusion or restraint techniques is often arbitrary, idiosyncratic, and generally avoidable (Haimowitz, Urff, & Huckshorn, 2006; NASMHPD, 2003; SAMHSA, 2003). Moreover, some studies indicate that seclusion and restraint use leads to an increase in the behaviors that staff members are attempting to control or eliminate (Jones & Timbers, 2002; Magee & Ellis, 2001; Natta, Holmbeck, Kupst, Pines & Schulman, 1990). Conversely, it is important to note that programs that have reduced or eliminated seclusion and restraint have realized a number of positive outcomes including reduced youth and staff injuries, reduced staff turnover, higher staff satisfaction, reduced lengths of

stay, sustained success in the community after discharge, and significant cost savings (LeBel & Goldstein, 2005; LeBel, in press)."

Subsection 16.03.15.511.05.02(f) – Given the discussion above, an evidence based, recovery oriented, trauma informed program would not allow the use of restraint or seclusion as a "therapeutic" part of a treatment plan. Individual Treatment Plans should contain information on medical issues, trauma history, and alternative strategies which would limit the use of restraints or seclusion and would dictate specific techniques or risks to be avoided. Subsection (f) should be rewritten to clarify that it is not intended to create an exception to the general language of Subsection 511.02, but to specify that conditions surrounding use of restraint and seclusion as allowed in Subsection 511.02 must be addressed in the treatment plan. This section should also specify time tables for physician reviews, debriefings and data collection in line with SAMHSA's recommendations for reducing restraint and seclusion, and implementing trauma informed care principles.

- **Proposed Rule**: 16.03.15.520 Drugs Used to Manage Mental Health Symptoms or Maladaptive Behavior
- **Comment**: In SAMHSA's "Roadmap to Seclusion and Restraint Free Mental Health Services, Module 3" Pennsylvania's highly successful approach to reducing staff injuries and improving patient outcomes is outlined. Pennsylvania's rule on chemical restraint is "Chemical restraints are prohibited." The position of the American nurses Association is: "Chemical restraint is the use of a sedating psychotropic drug to manage or control behavior. Psychoactive medication used in this manner is an inappropriate use of medication."

These rules should be similar. Use of prescription drugs to treat anxiety, panic attacks, or extreme agitation, when administered in appropriate doses, are not chemical restraint. However, drugs administered for the purpose of sedating or restricting the movement of patients, or at dosages which exceed those appropriate for treatment of symptoms should be prohibited.

Submitted by:

James Baugh Executive Director



Tamara Prisock DHW – Administrative Rules Unit 450 W. State Street – 10th Floor P.O. Box 83720 Boise, Idaho 83720-0036

January 24, 2018

Re: ACLU Comments Regarding Negotiated Rulemaking on Docket No. 16-0315-1801 (16.03.15) Rules Governing Secure Treatment Facility for People with Intellectual or Developmental Disabilities

Dear Ms. Prisock:

The American Civil Liberties Union of Idaho asks the Division of Licensing and Certification with the Idaho Department of Health and Welfare (DHW) to consider the following comments for the proposed rule docket 16-0315-1801 regarding Rules Governing Secure Treatment Facility for People with Intellectual or Developmental Disabilities, as announced in the Idaho Administrative Bulletin, Vol. 18-1, published on January 3, 2018.

After reviewing the proposed rules, we believe they require further edits and revisions to ensure that the due process and constitutional rights of individuals placed within the secure facility are guaranteed. Please see below for specific recommendations and/or questions for clarification.

- <u>001.02. Scope</u>: It must be clearly stated that these rules only allow for the creation of <u>one</u> facility per the authority granted under Idaho Code 66-1402. The language of this section also appears to reference some of the admission criteria contained within Idaho Code 66-1404, but not all. To ensure that only individuals who meet <u>all</u> the admission criteria under Idaho Code 66-1404, we recommend making explicit reference to the following statutory requirements:
 - a. That an individual have a developmental disability as determined by the DHW;
 - b. That the individual be an adult;
 - c. That the individual meet one of the following items:

- i. The individual is being criminally adjudicated and is undergoing evaluation for competency to stand trial in accordance with Idaho Code chapter 2, title 18;
- ii. The individual is being criminally adjudicated and is committed to the DHW for treatment to restore their competency in accordance with Idaho Code chapter 2, title 18;
- iii. The individual is civilly committed to the custody of the DHW in accordance with Idaho Code chapter 4, title 66;
- d. That the individual presents a substantial threat to the safety of others and that a judicial finding has ordered that the individual may be confined to the secure treatment facility.
- <u>010. Definitions:</u> We offer the following recommendations to more appropriately and clearly define "Sexual Abuse" and "Client."
 - a. The definition of "Sexual Abuse" should prohibit sexual activity between clients and staff in circumstances where the client may have given "affirmative permission." Further clarification should also be provided regarding the definition of sexual abuse when the client is unable to defend themselves as it could currently be interpreted to mean that if a client can defend themselves, then sexual abuse could not have occurred. Finally, we also recommend that rape be specifically included in this definition.
 - b. The definition of "Client" needs to align with the term "person" as defined in Idaho Code §66-1403(8). We recommend making specific reference to this definition to ensure that all clients of the secure treatment facility have been subject to a judicial proceeding, which has authorized their admission to the secure treatment facility.
- <u>011. Definitions</u>: We recommend defining "Punishment" to include withholding "medical care or treatment" which can be used as a means to discipline or penalize a client for the purpose of controlling behavior.
- <u>020. Licensure General Requirements</u>: As we stated in 001.02. Scope, we once again request that the general requirements for licensure explicitly state that only <u>one</u> facility is allowed to be licensed per the authority granted under Idaho Code 66-1402.
- 5. <u>051.(c). Licensure Surveys Complaint Investigation Surveys</u>: Considering the recent news of abuse and neglect at the Southwest Idaho Treatment Center, we believe the response times indicated in this section are entirely too broad and will continue to perpetuate ongoing harm faced by patients who are in need of immediate care. Instead, we recommend that complaints of immediate jeopardy should result in an investigation survey within twenty-four (24) hours or one (1)

business day after the allegation is reported. Complaints not alleging immediate jeopardy should result in an investigation survey in no more than five (5) business days after the allegation is reported.

- 6. <u>110.01. Administrator; Administrator Requirements:</u> These administrator requirements appear to be very minimal and fail to include any requirement they have experience working with individuals with severe mental illness, as should be required given that the facility will house individuals with a dual diagnosis of intellectual disability <u>and</u> severe mental illness. The requirements also fail to include any provision that the administrator have no previous incidents of abuse, mistreatment or neglect on their employment record.
- 7. <u>305.06. Right to Practice Religion:</u> In considering required accommodations for protecting a patient's First Amendment right to practice their religion of choice, there is no specific mention that food accommodations would be provided for those with dietary restrictions consistent with their religious beliefs. To ensure full protection of one's ability to practice their religious beliefs without restrictions, we recommend that these rules also include provisions to provide religiously necessary food accommodations consistent with constitutional protections of the First Amendment.
- <u>310 (01). Client Rights Which May Be Restricted; Limitation on Communications,</u> <u>Visitation and Participation in Social and Community Events</u>: It is unclear for what reasons the facility may limit a client's rights to communicate with individuals inside or outside the facility. The reasons for such restrictions should be clearly set out in these facility rules and communicated directly to patients and their guardian, if applicable. Also, the references made to "Subsections 306.05 and 306.06 of these rules" do not exist.
- <u>16.03.15.310 (02). Limitations on Personal Possessions:</u> "Temporary restriction" is not defined and could be interpreted broadly, resulting in property being kept from a client for days or weeks on end without explanation.
- 10. <u>320.02. Written Informed Consent Required; Written Informed Consent for</u> <u>Experimental Research:</u> We question the DHW's inclusion of potential experimental research for individuals within the secure treatment facility as it appears to be entirely outside the scope of the intent of this facility and the expected treatment patients charged under the Department's care expect to receive. The ACLU of Idaho is adamantly opposed to the inclusion of this provision in the secure treatment facility rules.

- 11. <u>402. Admission Records:</u> We once again recommend that <u>all</u> the statutory admission criteria under Idaho Code 66-1404 for admission into the secure treatment facility be explicitly referenced in this provision.
- 12. <u>441. Transfer or Discharge from the Facility:</u> This provision fails to conform to the statutory discharge requirements under Idaho Code §66-1405(4), which requires that "the director or the director's designee shall review the patient's progress every ninety (90) days to determine whether the patient continues to meet the program criteria." Without any inclusion of a review policy, there is no assurance that a person admitted to such a facility will not be allowed to languish there for years without appropriate oversight. The ACLU of Idaho firmly advocated for the review criteria to be included in Idaho Code 66-1405 as an assurance that there would be an external check on the director's power to continue to detain people indefinitely. These rules should include clear reference to the statutory review provisions under Idaho Code 66-1405 as well as additional policy to determine how the review process will be conducted, by whom, and with what involvement from the patients themselves.

We appreciate the ongoing opportunities to provide comments on the proposed rules of the secure treatment facility and encourage the Idaho Department of Health and Welfare to adopt the recommendations we provided today to ensure patient safety and appropriate oversight of the facility. Upon release of a formal draft of these rules, we will provide further, formal comment before the February 2018 deadline.

Thank you,

Kathy Griesmyer Policy Director ACLU of Idaho <u>kgriesmyer@acluidaho.org</u> 208-344-9750 x 1204

October Meeting Date Discussion

Background Information:

Our 2018 meeting dates are as follows:

- April 26-27
- July 26 (3hr video teleconference meeting)
- October 25-26

The October 2018 Council meeting dates are the same dates as the Human Partnership Conference. Because we know many people attend and present at this conference, we want to open it up to discussion about changing the October Council meeting date.

Some date change options could be:

- ✓ The week *before*: Thursday and Friday, Oct. 18-19
- ✓ The week of: Tuesday and Wednesday, Oct. 23-24*
- ✓ The week *after*: Thursday and Friday, Nov. 1-2

*NOTE: If the 'week of' option is chosen, out-of-town Council members who chose to stay in Boise for the conference would be responsible for paying for their own hotel room for the evening of Wednesday, Oct. 24th and Thursday, Oct. 25th.

Recommended Action:

Listen to presentation, ask questions and make a decision about changing the October Council meeting date or leaving it the same.

Notes: