

Nebraska Council on Developmental Disabilities  
April 17, 2020 9:00am  
**VIRTUAL Meeting**

Copies of the agenda were emailed to Council members prior to the meeting. The meeting was chaired by Jennifer Meints and called to order at 9:00am. Quorum was present.

**Present:** Jessica Barrett, Reagan Boyer, Brenda DeLancey, Jason Gieschen, Tony Green, Matt Kaslon, Seamus Kelly, Jennifer Meints, Cheryl Montgomery, Ryan Moore, Sara Morgan, Stephen Morton, Sharon Orduña, Erin Phillips, Amy Rhone, Paige Rose, Debbie Salomon, Rachel Siffring, Wayne Stuberg, Dee Valenti, Haley Waggoner, and Jane Ziebarth-Bovill.

**Absent:** Dale Johannes, Mikayla Johnson, and Heather Leschinsky.

**Guests:** Eric Evans, Dr. Barb Jackson, Susan Gieschen, Kristin Mayleben-Flott, Marla Moore, Jennie Schneider, and Nate Watson (on behalf of Heather Leschinsky).

**Staff:** Kristen Larsen, Joni Dulaney, and Nikki Krause.

### **Welcome**

Jennifer Meints and Kristen Larsen welcomed new Council members Tony Green, who replaced Courtney Miller, as the Agency Representative for the Division of Developmental Disabilities and Amy Rhone, who replaced Steve Milliken, as the Agency Representative for the Department of Education – Special Education. Kristen also welcomed future Council member Nate Watson. Nate will be the Agency Representative for the Division of Medicaid and Long-Term Care, replacing Heather Leschinsky. The Council is waiting for Nate’s official appointment letter from the Governor’s Office.

### **Nebraska Open Meetings Act**

Jennifer explained that Council meetings fall under the Nebraska Open Meetings Act. Due to COVID-19, Governor Ricketts issued an Executive Order to give public boards the flexibility to hold virtual meetings. A link to the Zoom meeting was provided to Council members ahead of the meeting.

Members of the public were directed to email the DD Council by April 15, 2020 to receive a link to the meeting and log-in information on the Council’s website and the Governor’s Public Meeting Calendar. Council staff were not contacted by any members of the public.

### **Approval of Minutes**

Brenda DeLancey asked if there were any corrections to the February 7, 2020 DD Council meeting minutes. As there were no corrections, Jennifer called for a motion to approve the minutes. Jason Gieschen made the motion and Debbie Salomon seconded.

A roll call vote was taken: **Yes – 16, No – 0, Abstain – 5.**\* Motion carried.

### **Financial Report**

Kristen presented the FFY 20 Financial Report, a handout at the meeting. For FFY 20 (October 1, 2019 – September 30, 2019), the Council budgeted \$299,233 and the *Year to Date Expenditures* for the first two quarters of FFY 20 (October 1, 2019 to March 31, 2019) was \$126,376 – 42.2% of the FFY 20 budget.

The report reflects the balance of funds from FFY 18, FFY 19, and FFY 20 as of March 31. *Current Funds Available* was \$888,120.18; *Total Expenditures* totaled \$166,878.00; and the *Balance of Current Funds Available* was \$721,242.18.

Written permission has been secured from the Office of Grants Management (OGM) to continue spending down FFY 18 funds. The Council continues to do a good job of spending down funds so we don't have to return funding to the feds.

Kristen mentioned that due to the COVID-19 pandemic, Joni Dulaney will be following up with DHHS' Legal Division about possibly extending the end date of the Council's current subawards so subrecipients can complete their projects.

Of the \$10,000 budgeted for Collaboration Funds, there is approximately \$7,000 available. The Council is working to get non-medical cloth facemasks that will be sent to Direct Support Professionals who continue to provide the services and supports needed by individuals with developmental disabilities in their care during the COVID-19 pandemic.

### **Upcoming Conferences**

Council staff are asking the Council to approve funding to send up to three Council members to the 2020 Administration on Intellectual and Developmental Disabilities (AIDD) Technical Assistance Institute and the National Association of Councils on Developmental Disabilities (NACDD) Conference that is currently scheduled for July 7-10 in Washington, D.C. Attendee preference will be given to Executive Committee members and funding would not exceed \$3,000 per attendee. Kristen mentioned that the conference is not being cancelled, but AIDD/NACDD is in negotiations with the hotel to see if the conference could be moved to a later date. Jennifer called for a motion to approve the funding request as proposed by Council staff. Matt Kaslon made the motion and Ryan Moore seconded.

A roll call vote was taken: **Yes – 20, No – 0, Abstain – 1.**\* Motion carried.

Seamus Kelly announced that the Social Role Valorization Workshop scheduled for June 9-11 at Nebraska Wesleyan University is currently on hold. Due to COVID-19, Disability Rights Nebraska is exploring the possibility of either a shortened workshop elsewhere or a teleconference. Eric Evans explained that Wesleyan University will not be opened during the summer. [If the Social Role Valorization Workshop is held, either as a shortened workshop or teleconference, this could count as one of the FFY 20 two in-state conferences/trainings for Council members.]

Ryan Moore requested funds not to exceed \$2,333 to attend the 2020 Little People of America National Convention, July 3-10 in Austin, TX. By attending this conference, he will be able to visit with several medical professionals who specialize in treating people with dwarfism. By meeting with these professionals, as well as attending other breakout sessions, he will develop learning strategies for people with disabilities who encounter various physical, emotional, and societal issues. Ryan mentioned that the conference organizers are considering postponing or cancelling the conference, but as of now, the conference is still on. Jennifer called for a motion to approve Ryan's funding request and if the conference date is moved, the approved funds would carry over to the new conference date. Seamus made the motion and Sharon Orduña seconded.

A roll call vote was taken: **Yes – 19, No – 0, Abstain – 1.**\* Motion carried. [Tony Green was absent from voting.]

**Election of Council Officers & Applying for Reappointment to the Council with the Governor**  
Officer elections for FFY 21 will be conducted at the August 14 Council meeting. This includes the offices of Chair, Vice-Chair, and Secretary. If you are interested in any of these offices or would like more information, please contact Kristen.

Eligible Council members whose term expires on October 1, 2020, and are interested in continuing to serve on the Council, are encouraged to apply with the Governor. Applications can be submitted either online at the *Boards & Commissions – Application for Executive Appointment* webpage at <https://governor.nebraska.gov/board-comm-req> or by mailing a *completed Executive Appointment Application* to Kathleen Dolezal at the Office of the Governor. Council members eligible to apply for reappointment are:

- Seamus Kelly
- Erin Phillips
- Dee Valenti

The following Council members have terms that expire October 1, 2020 and are ineligible for reappointment due to term limits:

- Dale Johannes
- Debbie Saloman
- Haley Waggoner

Wayne Stuberger announced that Mark Shriver, PhD has been selected as the new UCEDD Director effective July 1 and that he will transition to Associate Director until his retirement in December. Wayne explained that he will be submitting paperwork to step down as the Council's Agency Representative for the Munroe-Meyer Institute (MMI)/University Center of Excellence for Developmental Disabilities (UCEDD) and that MMI/UCEDD will be recommending Mark as the new Agency Representative. Wayne will continue to attend Council meetings as a member of the public for the rest of the year.

### **Report of the Planning Committee: State Needs Assessment Survey**

The Council contracted with Dr. Barbara Jackson from the Munroe-Meyer Institute to develop the State Needs Assessment Surveys and complete the Comprehensive Review and Analysis Report for the Council. Dr. Jackson met (virtually) with the Planning Committee on March 30 to review the results of the Comprehensive Review Analysis (CRA). The focus areas of the CRA includes a portrait of *State Services* and a summary of *State Issues & Challenges*.

#### *State Services*

- Transportation
- Health/Healthcare, including disparities
- Education/Early Intervention
- Employment
- Housing
- Childcare
- Recreation
- Informal and Formal Services and Supports
- Quality Assurance

### State Issues & Challenges

- Adequacy of home and community-based waiver services
- Adequacy of current resources and projected availability of future resources to fund services
- Waiting lists
- Adequacy of healthcare and other services and supports
- Criteria for eligibility for services
- Barriers to full participation of underserved groups
- Availability of assistive technology

Dr. Jackson then asked the Planning Committee members to prioritize the issues in each focus area to narrow down the focus areas which will be included in the State Needs Assessment Surveys. The results of the State Needs Assessment Surveys will help guide the Council in establishing its goals and objectives for the next 5-Year State Plan.

Dr. Jackson met (virtually) with the Planning Committee yesterday (April 16) to review the results of the CRA prioritization and review the drafts of the State Needs Assessment Surveys (one for family members/guardians, professionals, and others concerned with services for people with developmental disabilities and one for self-advocates). Of *State Services*, transportation was prioritized the highest followed by health/healthcare and education/early intervention. Of *State Issues & Challenges*, adequacy of home and community-based waiver services was prioritized the highest followed by adequacy of current resources and projected availability of future resources to fund services, and waiting lists.

**NOTE:** A PowerPoint indicating the top concerns within each *State Services* area and each *State Issues & Challenges* is attached to the end of the minutes for review. The PowerPoint also includes: a family/provider survey sample, a self-advocate survey sample, survey distribution suggestions, and a slide providing information about focus groups.

Dr. Jackson shared the drafts of the State Needs Assessment Surveys (one for family members/guardians, professionals, and others concerned with services for people with developmental disabilities and one for self-advocates) with the Council. The State Needs Assessment Survey that will go to for family members/guardians, professionals, and others concerned with services for people with developmental disabilities includes an introduction about the Council and briefly describes why the Council is important and highlights some projects previously funded.

Both surveys request demographics which will help the Council to identify any gaps. Both surveys will be available electronically and in paper/pencil form and will be available in English and Spanish.

Dr. Jackson reached out to People First of Nebraska and they shared a survey format that they used at their annual conference. Dr. Jackson took that format and applied the Council's focus areas. It was recommended that the self-advocate survey needs to be at a 6<sup>th</sup> grade reading level.

Dr. Jackson asked the Council whom the survey should be distributed to. Dr. Jackson added that an electronic link to the surveys can be sent out to those that are not comfortable releasing email addresses. Some of the suggestions were:

Educational Service Units  
Advocacy Groups  
The Arc of Nebraska

Early Development Network  
Therapy Centers (Madonna)  
Local Arcs

Schools/School Nurses  
Childcare Centers  
O'Hana Kids  
Ollie Webb Center  
Nebraska Head Start Association  
Disability Rights Nebraska  
Council for Exceptional Children  
Nebraska Association of Service Providers

Churches  
DHHS List Serve  
PTI Nebraska (other parent groups)  
Cultural Centers  
Munroe-Meyer Institute  
Minority Outreach Resource Education  
Past/Current DD Council Subrecipients

If there are any other suggestions, please email those to Kristen.

Dr. Jackson will also be conducting three focus groups and 20-25 interviews across the state to supplement the results of the State Needs Assessment Surveys. These can:

- be intentional to include refugee populations;
- focus on family members and self-advocates; and
- include both rural and urban settings.

(The number of focus groups can be increased while decreasing the number of interviews or vice versa.)

The intent is to finalize the two State Needs Assessment Surveys and distribute them around May 15. Once the results of the surveys is summarized, this will be presented to the Council which will help guide the Council in establishing its goals and objectives for the next 5-Year State Plan.

### **Report of the Planning Committee: Subaward Recommendations for FFY 21**

Ryan Moore, Planning Committee Chair, reported that the Committee met on April 16 to review and make recommendations for formal subaward projects for FFY 21 (October 1, 2020 – September 31, 2021). The Planning Committee recommended releasing three Requests for Applications (RFAs) for formal subawards in the areas of Emergency Preparedness, Technology, and Direct Support Professionals.

The Committee recommended an RFA to address Emergency Preparedness in the amount of \$30,000. Some areas to address could include:

- the current COVID-19 pandemic;
- flooding and tornadoes in Nebraska;
- training first responders on working with individuals with developmental disabilities; and
- bringing individuals with developmental disabilities and families together with policymakers to discuss the specific and unique needs they face in times of emergency/health crisis.

Jennifer called for a motion to approve releasing a RFA in the amount of \$30,000 for Emergency Preparedness leaving Council staff the flexibility to determine the exact scope of the RFA. Dee Valenti made the motion and Jane Ziebarth-Bovill seconded.

A roll call vote was taken: **Yes – 19, No – 0, Abstain – 0.**\* Motion carried. [Matt Kaslon and Erin Phillips left the meeting.]

The Committee recommended an RFA to elevate the role of the Direct Support Professional (DSP) in the amount of \$30,000. Some areas to address could include:

- sharing success stories during COVID-19;
- spotlighting the important work DSPs do; and
- alternate/temporary funding to address the high turnover rate of DSPs in Nebraska.

Jennifer called for a motion to approve releasing a RFA in the amount of \$30,000 for Direct Support Professionals leaving Council staff the flexibility to determine the exact scope of the RFA. Debbie made the motion and Tony Green seconded.

A roll call vote was taken: **Yes – 19, No – 0, Abstain – 0.**\* Motion carried.

The Committee recommended an RFA to address Technology in the amount of \$45,000. Some areas to address could include:

- enriching the lives of students with DD;
- addressing social isolation;
- addressing targeted disparity;
- addressing initial training and ongoing support;
- addressing responsible use; and
- purchasing equipment for individuals.

Jennifer called for a motion to approve releasing a RFA in the amount of \$45,000 for technology leaving Council staff the flexibility to determine the exact scope of the RFA. Sara Morgan made the motion and Sharon seconded.

A roll call vote was taken: **Yes – 17, No – 0, Abstain – 2.**\* Motion carried.

The Committee also recommended to continue funding People First of Nebraska (PFN) in the amount of \$42,000 contingent that PFN would continue its collaboration with the Nebraska Youth Leadership Council and push for Nebraska to be an employment first state.

A roll call vote was taken: **Yes – 16, No – 0, Abstain – 3.**\* Motion carried.

It was explained that the \$45,000 earmarked as continuation funding for Fritz & O'Hare Associates for updating the *Along the Way* guides would best be served as a contract as opposed to a subaward.

The Committee recommended funding for four Opportunity subawards in the amount of \$15,000 each and designating \$10,000 for Collaboration Funds.

A roll call vote was taken: **Yes – 18, No – 0, Abstain – 1.**\* Motion carried.

### **Updates from State Agency Representatives Relating to COVID-19**

**NOTE:** Written reports from Agency Representatives are attached to the end of the minutes for review. [Sara Morgan, Maternal and Child Health, Division of Public Health; Paige Rose, Nebraska Vocational Rehabilitation; Amy Rhone, Department of Education – Office of Special Education; Tony Green, Division of Developmental Disabilities]

#### Maternal and Child Health (MCH), Division of Public Health

Sara Morgan reported that the Title V MCH Needs Assessment will determine the 10 priorities affecting Nebraska's NCH population, including those with special needs. Currently small groups are meeting to develop issue briefs that will describe issues they feel should be priorities for the Nebraska MCH focus. Sara said she would let the Council know what the priorities are at the Council meeting in August.

#### Nebraska Vocational Rehabilitation (VR)

Paige Rose reported that due to COVID-19, all VR staff are required to work from home unless an essential duty cannot be completed from home. As of March 25, there are 2,824 individuals on the wait list. 1,665 are in Priority Group 1. 794 are in Priority Group 2. 365 are in Priority Group 3. On April 6, 100 people were removed from the waitlist of which 21 were confirmed DD recipients. VR will continue to remove people off the waitlist.

### Department of Education – Office of Special Education

Amy Rhone reported that the Office of Special Education has been working on and putting out guidance to special education directors and providers regarding Special Education services and supports within the COVID-19 pandemic. They are working to develop continuous guidance to support schools, teachers, administrators, and families in the development of continuity of learning and remote learning environments, and continue to create partnerships and develop supports for a summer remote learning environment. Amy explained that the Department of Education's authority is regulatory and it does not have the authority to *run* the school districts.

### Developmental Disabilities Division (DDD)

Tony Green reported that Waiver Amendment Appendix K: Emergency Preparedness and Response was submitted to the Centers for Medicare and Medicaid Services (CMS) on March 31. Tony was hopeful that CMS would approve it today. For anyone affected by the potential outbreak of COVID-19, recommended closures, and quarantines due to potential exposure, or for those following the CDC guidelines for those with disabilities, the Nebraska Department of Health and Human Services Division of Developmental Disabilities (DHHS-DD) will temporarily:

- allow certain services to be delivered in alternative sites;
- allow caps on certain services to be exceeded;
- allow electronic methods of service delivery;
- change enrollment requirements for providers;
- modify person-centered service plan development process;
- increase certain payment rates; and
- allow retainer payments when certain services are not available to the participant.

A *draft* copy can be found on their website at: <http://dhhs.ne.gov/Pages/Developmental-Disabilities.aspx>

### Medicaid and Long-Term Care and Aging

Nate Watson reported, on behalf of Heather Leschinsky and DHHS MLTC, that on March 30 Nebraska Medicaid submitted an 1135 Waiver application to the federal government as part of its response to the ongoing COVID-19 pandemic. This waiver will give Nebraska Medicaid certain flexibilities to make sure Medicaid beneficiaries are able to continue to receive needed health care services through the emergency.

- It will provide flexibility to waive **prior authorizations** for services for Nebraska Medicaid's fee-for-service beneficiaries, when clinically appropriate.
- It will provide flexibility to waive certain **provider enrollment** criteria, such as revalidations and site visits, through the public health emergency.
- It will provide flexibility to waive the annual renewal of **Pre-Admission Screening and Annual Resident Review** (PASRR, levels 1 and 2) for nursing facility residents for 30 days and provide other flexibilities around these requirements.
- It will extend the time beneficiaries have available to request **state fair hearings** and allow Nebraska Medicaid flexibility in scheduling hearings and issuing state fair hearing decisions.
- It will allow facilities flexibility to **evacuate their patients** and **provide care in alternative settings** if needed.
- It will provide flexibility regarding the requirements around **public notices and tribal consultation** for disaster relief state plan amendments and waivers.

This waiver will be in effect until the public health emergency related to COVID-19 is declared to be over.

Nate also provided an update on the implementation for Medicaid Expansion. Due to COVID-19, CMS has delayed the 1115 Medicaid Expansion waiver approval process. DHHS will accept Medicaid applications from the adult expansion group on August 1, 2020, and benefits will still begin on October 1, 2020.

Pregnant women, adults aged 19 and 20, and medically frail individuals will still receive the prime benefits package (which consists of the basic benefits package plus dental, vision, and over-the-counter medications coverage) without having to engage in the wellness, personal responsibility, or community engagement activities. All other participating individuals will receive the basic benefits package that includes physical, behavioral health, and prescription drugs coverage. Once CMS approves the 1115 Medicaid Expansion waiver, individuals receiving the basic benefits package will have the opportunity to qualify for prime benefits.

### **Updates from DD Network Representatives Relating to COVID-19 and the 2020 Tri-Board Meeting**

**NOTE:** Written reports from DD Network Representatives are attached to the end of the minutes for review. [Seamus Kelly, Disability Rights Nebraska; Wayne Stuber, Munroe-Meyer Institute]

#### Disability Rights Nebraska

Seamus reported that at the close of business on March 20, Disability Rights Nebraska closed its physical offices and staff began teleworking on March 23. On March 27 Disability Rights Nebraska sent a letter to Governor Ricketts regarding concerns about care rationing and the need to establish statewide guidance that protects the rights of people with disabilities. Due to no response from the Governor, on April 8 Disability Rights Nebraska, along with 15 other disability advocacy organizations and social justice partners, sent a second letter to the Governor asking him to take a leadership role in insuring that people with disabilities are not subjected to care rationing during the COVID-19 pandemic.

#### Munroe-Meyer Institute (MMI)/University Center of Excellence for Developmental Disabilities (UCEDD)

Wayne Stuber reported that MMI remains open as a health care facility, but non-essential staff are working remotely. The volume of clinical work has decreased by 25-30% with over 75% of services now being provided via telemedicine. The MMI new building construction remains on schedule and Mark Shriver, PhD has been selected as the new UCEDD Director effective July 1. Data collection for the NCI surveys has been suspended for the remainder of the year due to the COVID-19 pandemic. The suspension of the data collection has resulted in staff layoffs for the project.

#### VIRTUAL Nebraska DD Network Tri-Board Meeting

The **VIRTUAL** Nebraska DD Network Tri-Board meeting will be on June 5. Since it will be a **VIRTUAL** meeting, the timeframe will be shortened. This year's theme is *How Nebraska State Agencies and FEMA Are Responding to the Needs of People with Disabilities during the COVID-19 Crisis*.

### **Council Chair and Staff Updates**

Jennifer mentioned that The Arc of Lincoln is hosting BINGO everyday Monday through Friday at 10:00am via Zoom. This is open to anyone that loves BINGO. The Arc of Lincoln has individuals join all the way from Scottsbluff and the group is growing every week. The Arc of Lincoln is also hosting a social hour every afternoon at 1:30pm via Zoom for activities such as games, projects, social gatherings, and more. You can check The Arc of Lincoln's Facebook page where Michelle Johnson posts the activities for the week are posted as well as the Zoom links. If you have any questions, please contact Michelle at 402-421-8866.

Kristen encouraged Council members to watch the DHHS COVID-19 Facebook Live events. Kristen has found that these events are touching on some of the COVID-19 topics that are being mentioned on the national calls she participates in.

Joni mentioned that the legislature remains in recess, but the budget still needs to be passed.

### **Member Updates**

Jason mentioned that he gave a presentation to approximately 40 ESU #16 teachers regarding Special Olympics.

Jessica mentioned that People First of Nebraska has extended her contract for three additional months. She has been working on making other videos.

### **Public Comment**

Jennifer opened the meeting for public comment. No public comments were made.

### **Adjourn**

The meeting adjourned at 12:23pm.

**The next Council meeting is scheduled for August 14, 2020. The Grant Review Committee meeting is scheduled for August 13, 2020. A determination on whether or not the meetings will be held in person or virtually will be announced closer to the meeting date.**

### Nebraska Council on Developmental Disabilities

#### Mission

The Council engages in **Advocacy**, **Capacity Building**, and **Systemic Change** activities that assure that individuals with developmental disabilities and their families participate in the design and have access to needed community services, individualized support, and other forms of assistance that promote *self-determination, independence, productivity, and integration* and *inclusion* in all facets of community life.

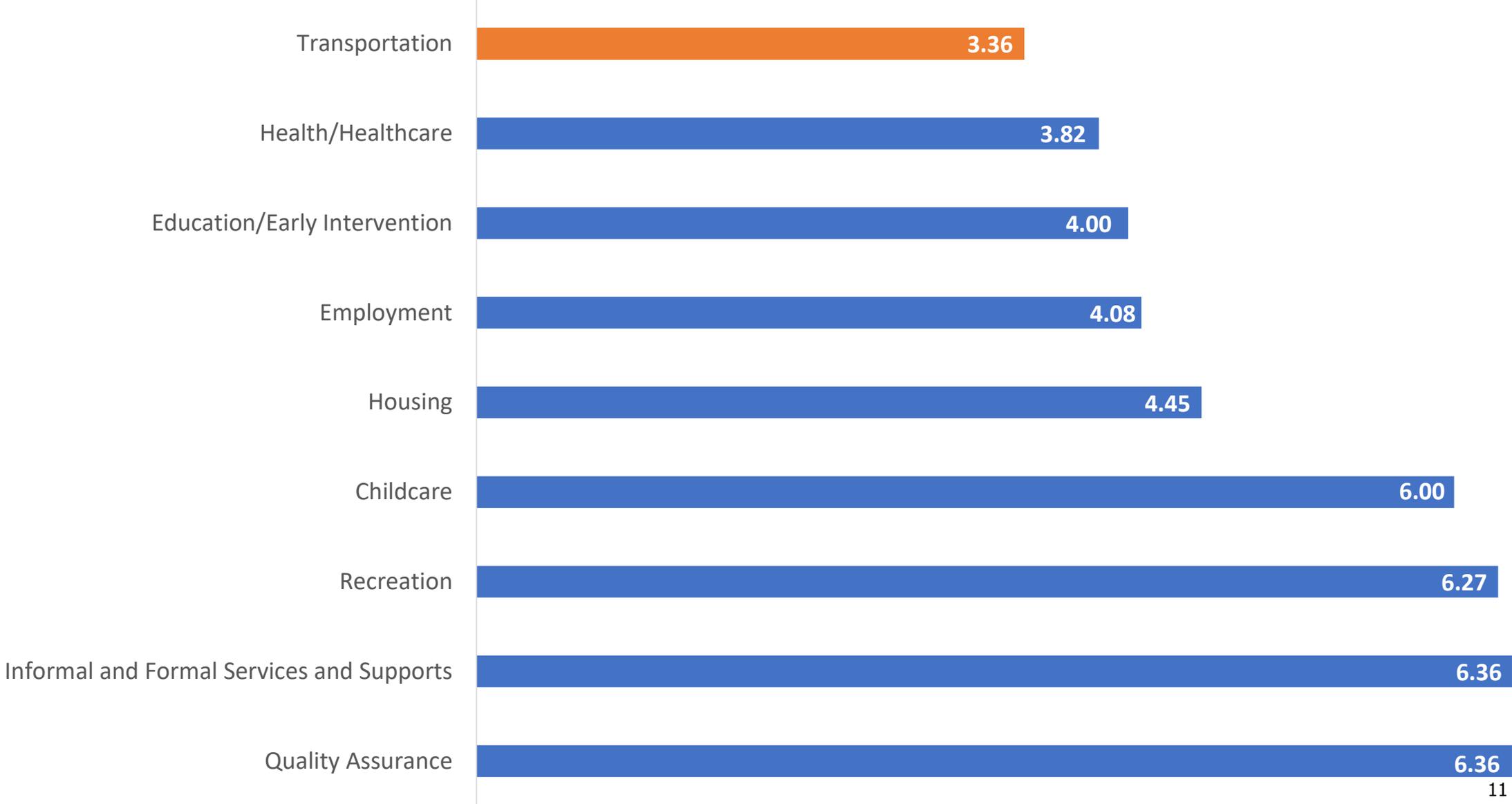


# DD Council Survey Results

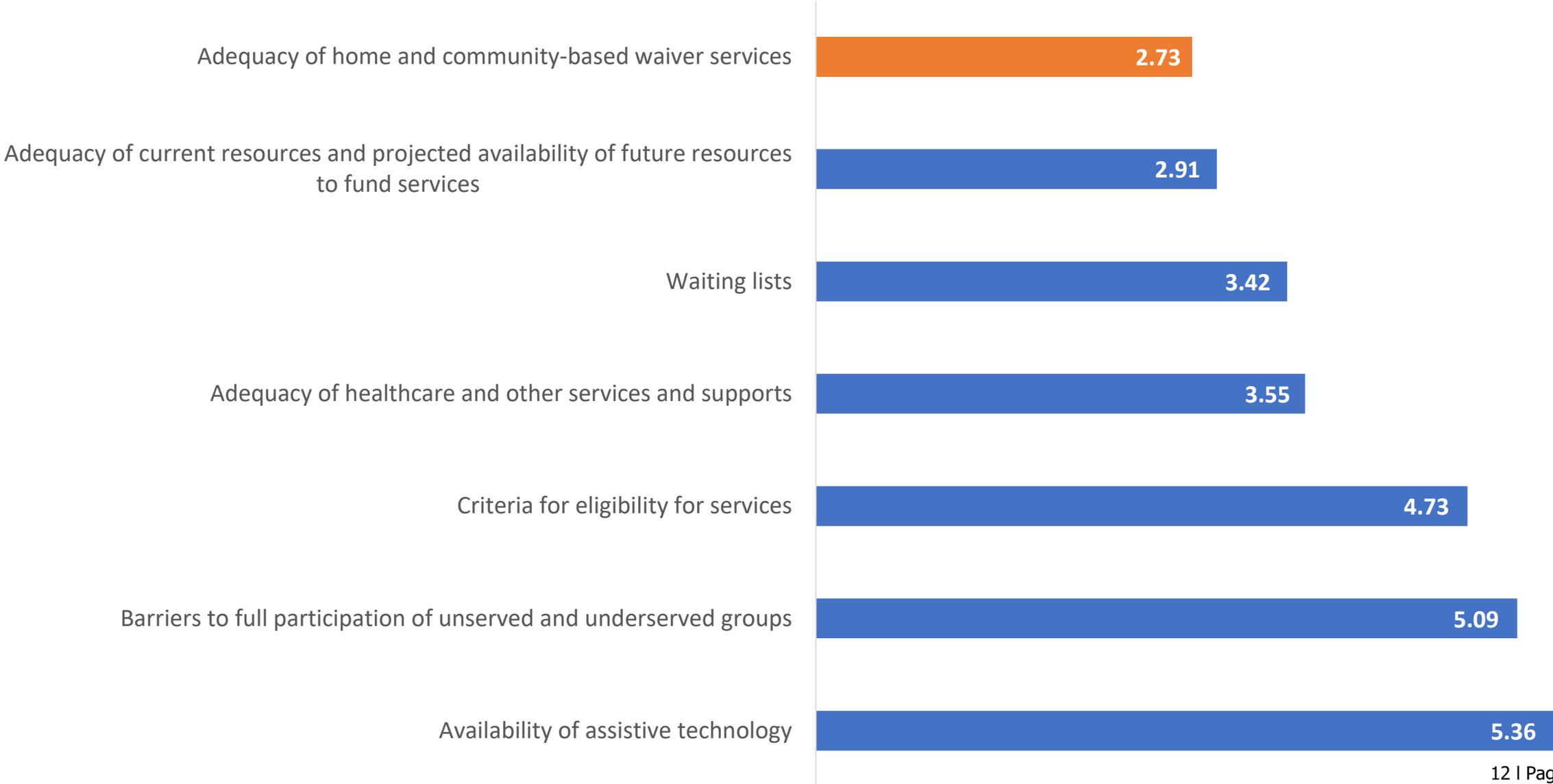
*Items are ranked according to importance level,  
with '1' being most important*

*n = 13*

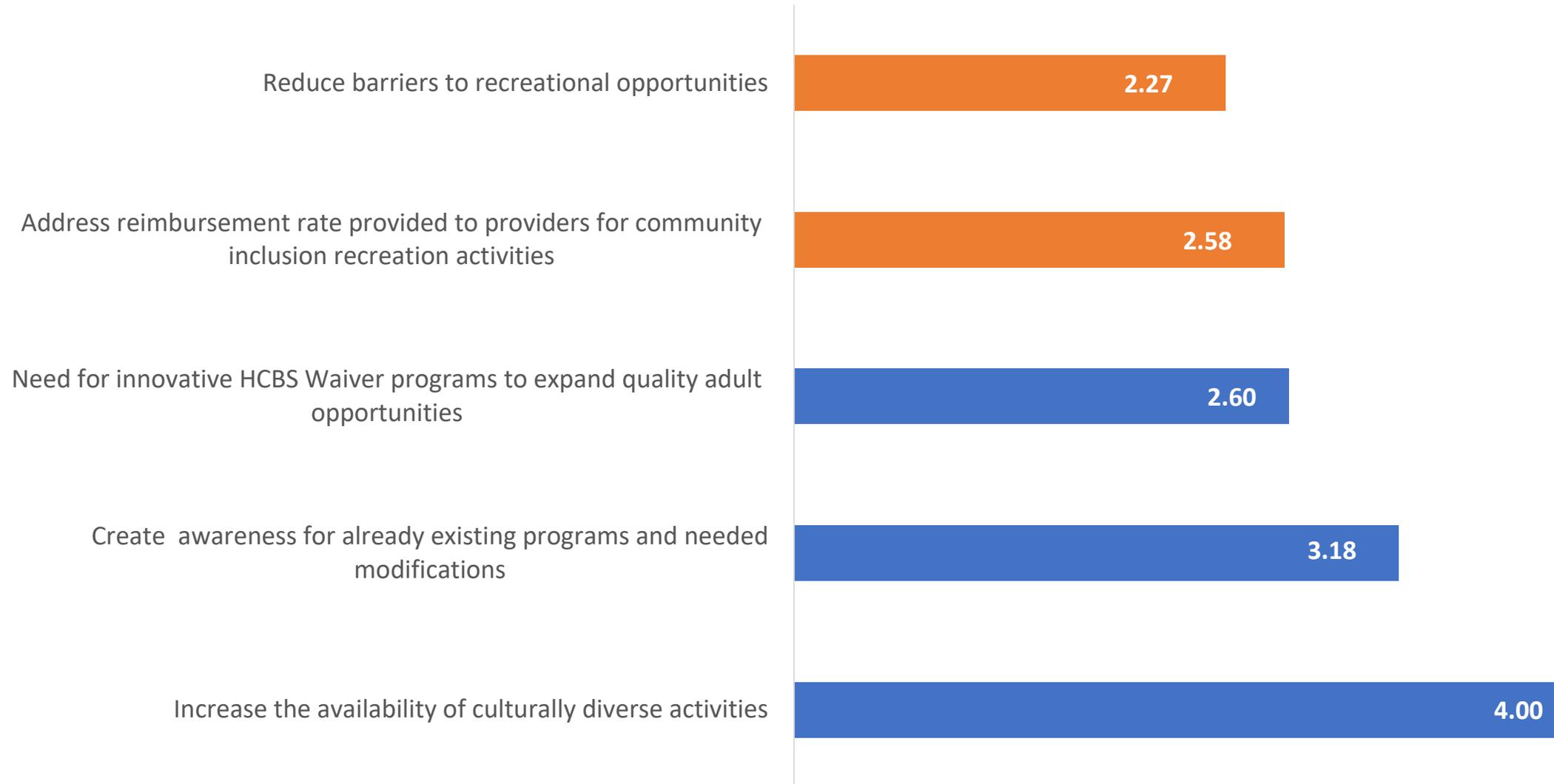
# Portrait of State Services (ranked 1-9)



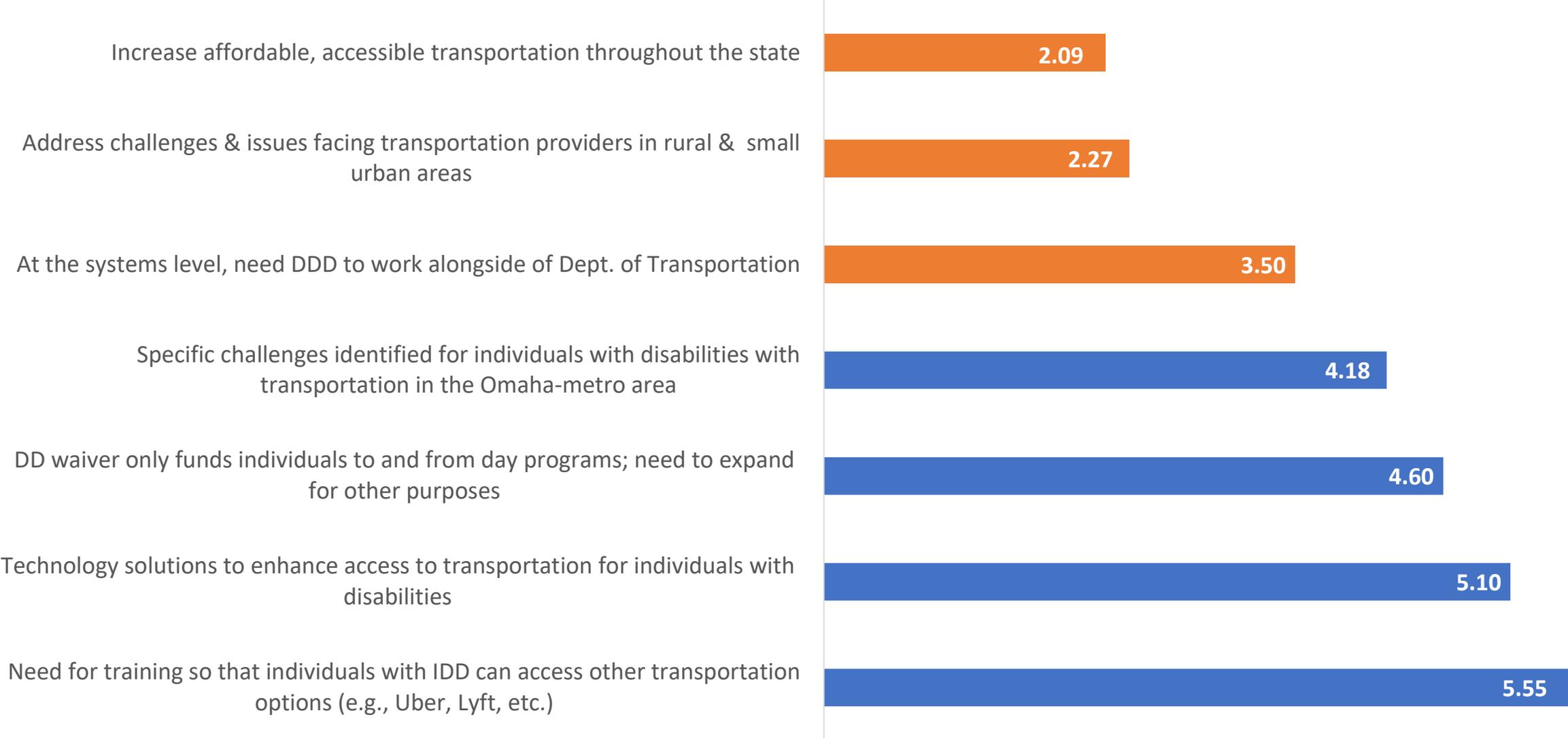
# State Issues & Challenges (ranked 1-7)



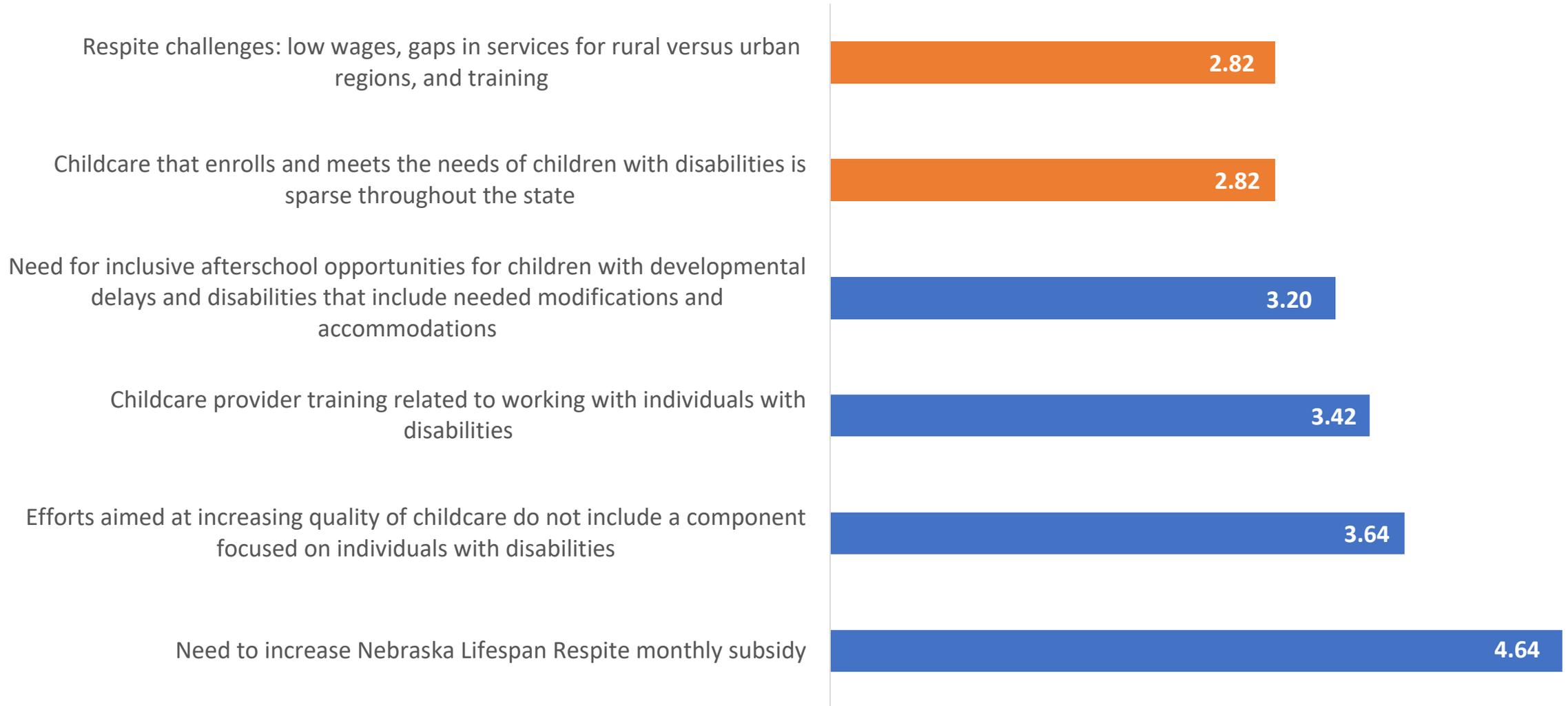
## Recreation (ranked 1-5)



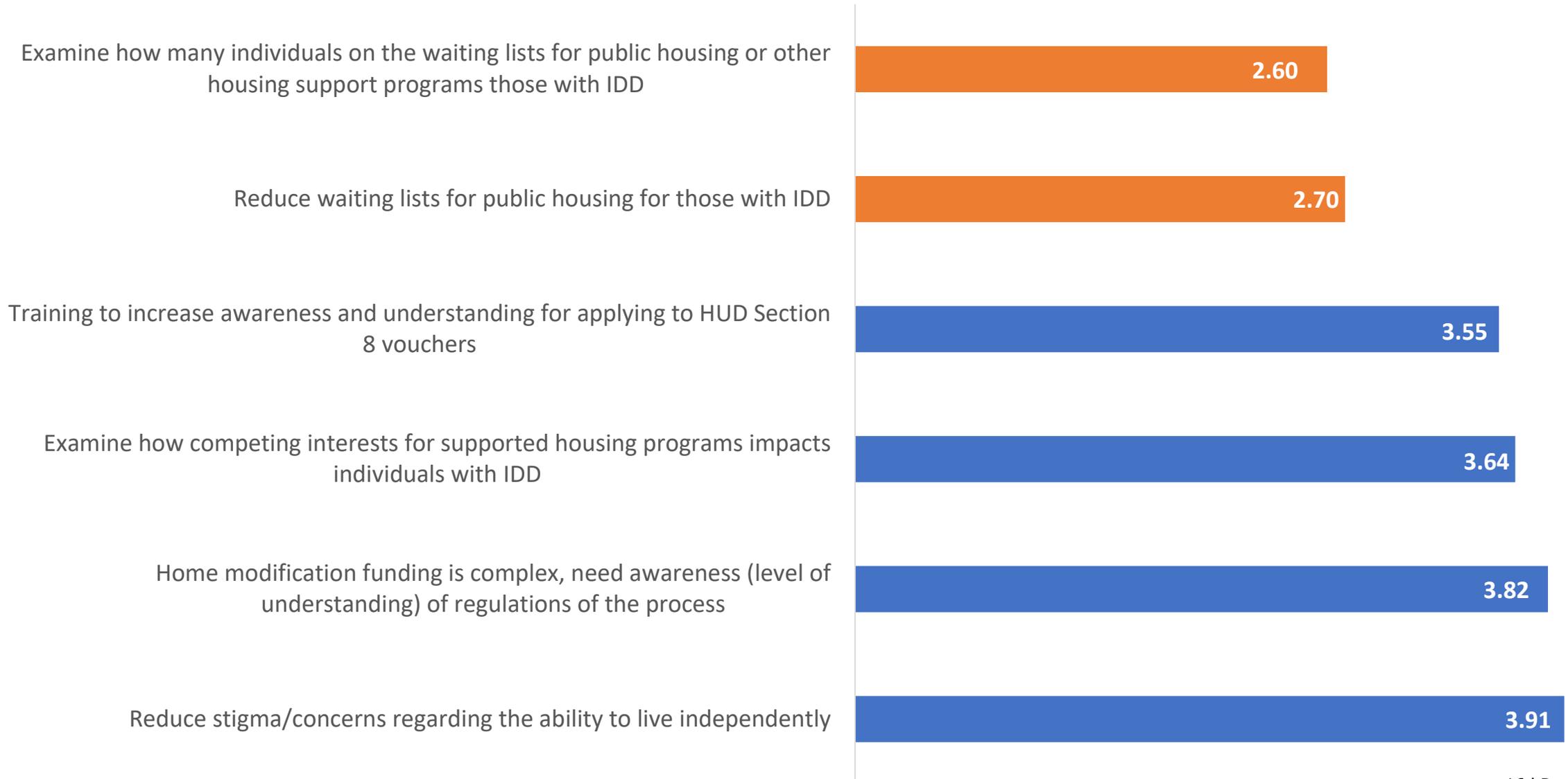
# Transportation (ranked 1-7)



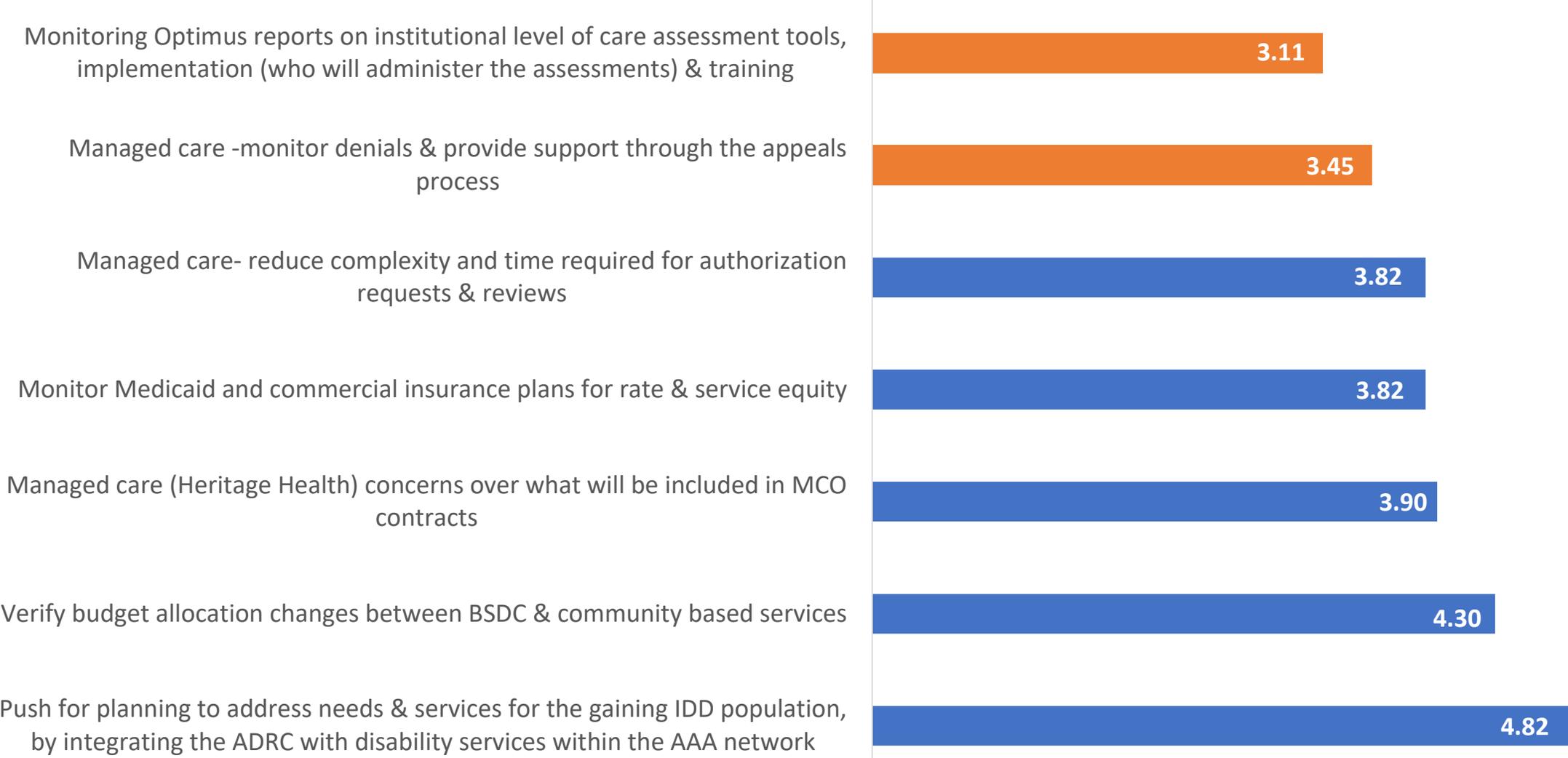
## Childcare (ranked 1-6)



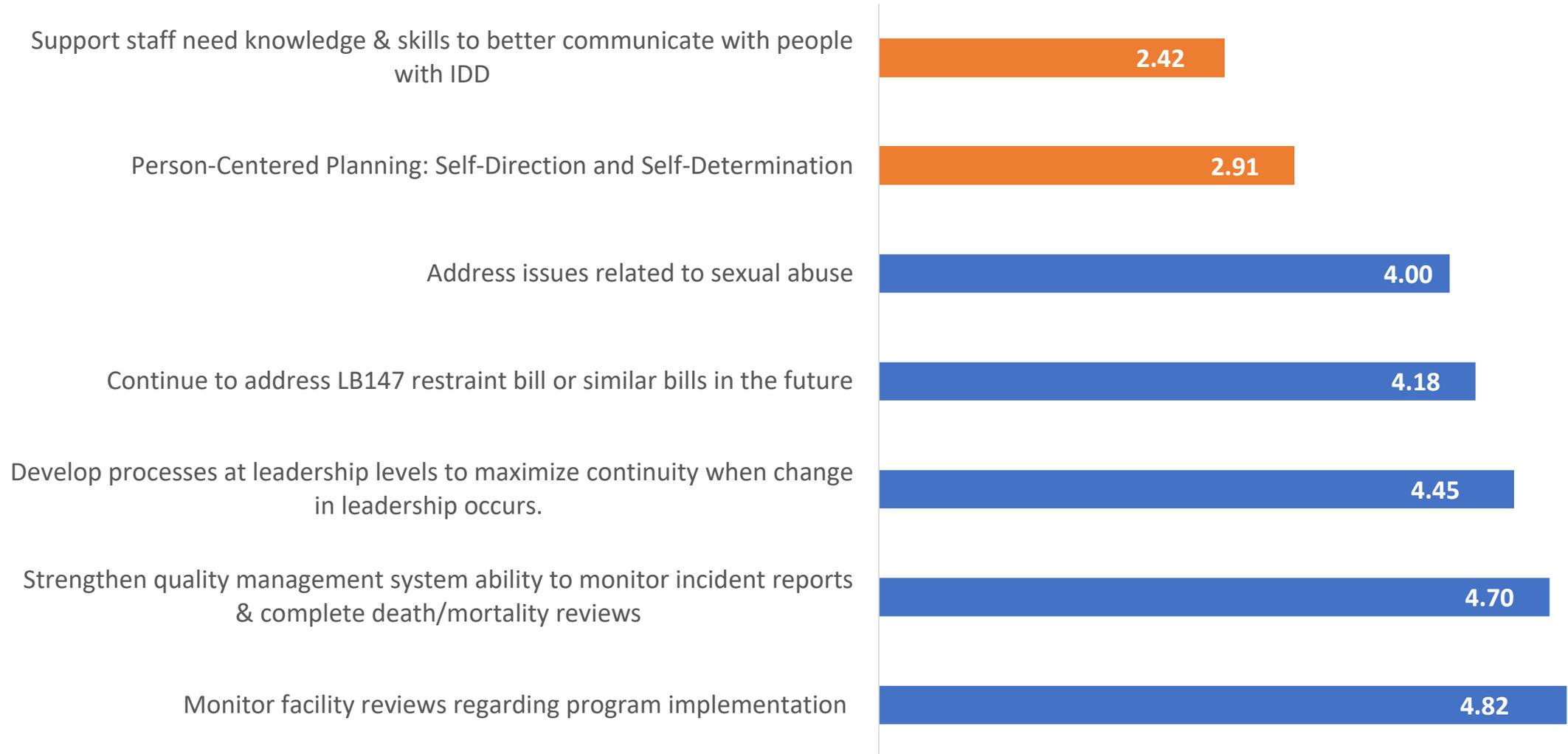
## Housing (ranked 1-6)



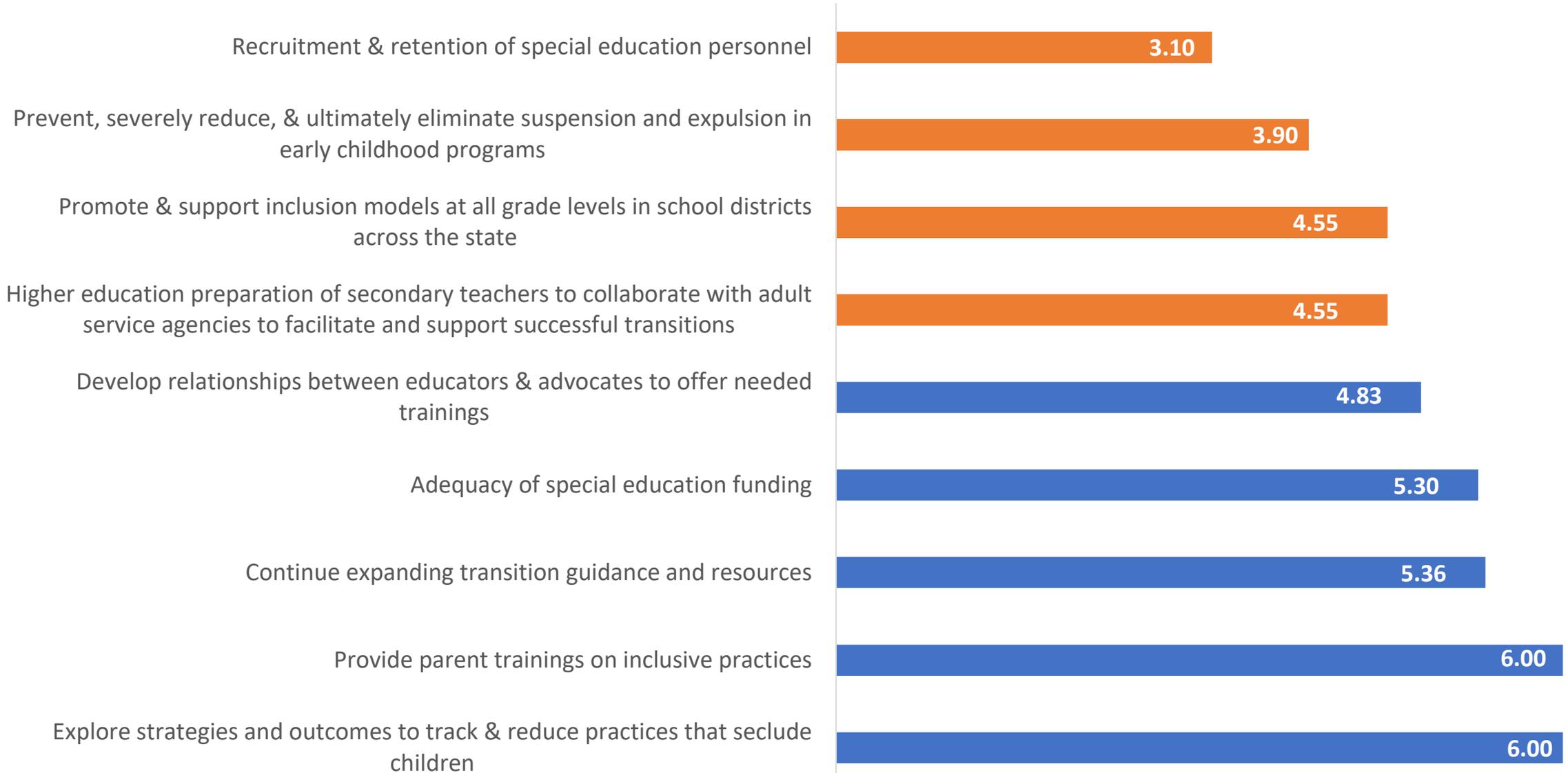
### Health/Healthcare (ranked 1-7)



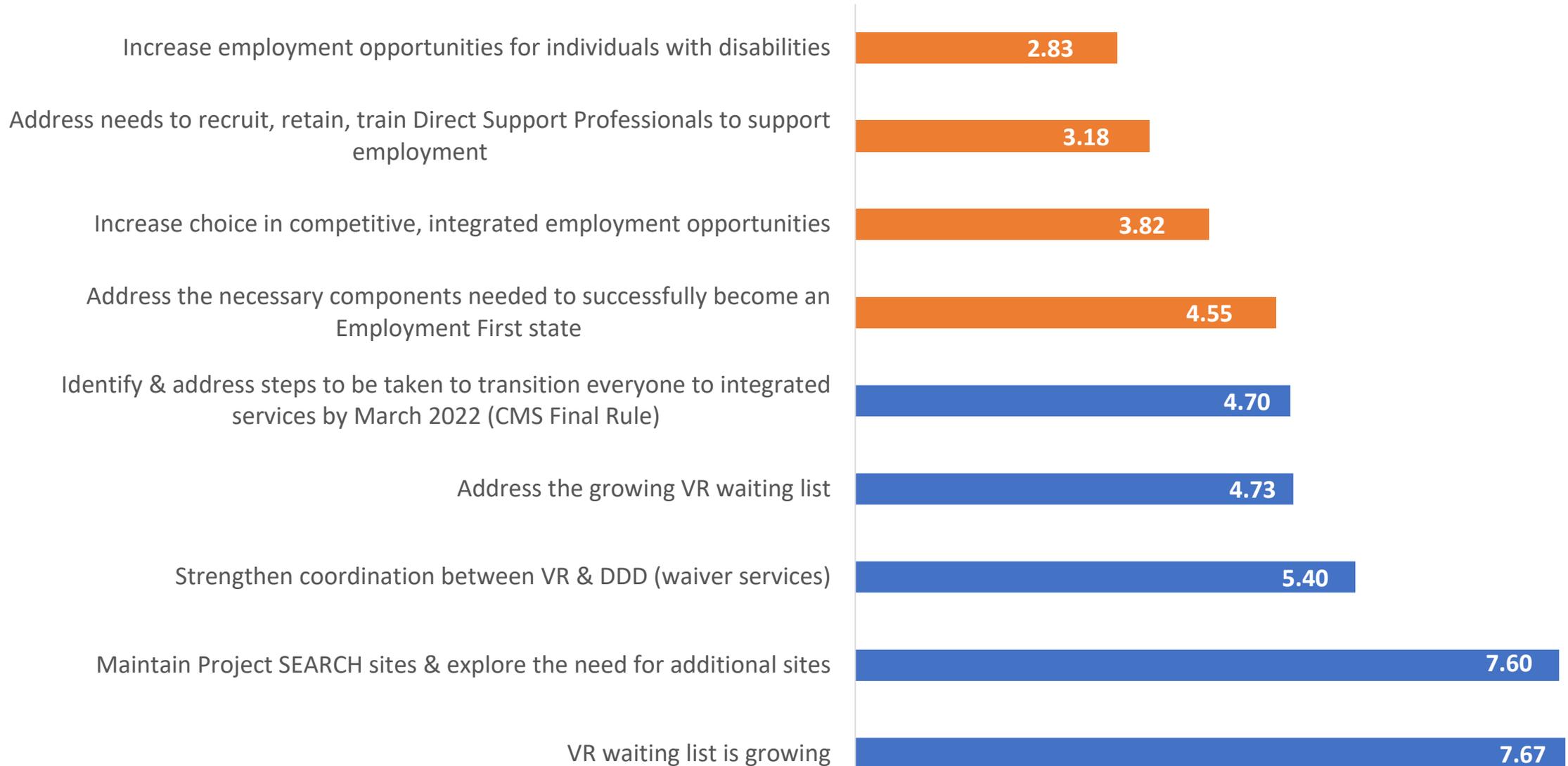
## Quality Assurance (ranked 1-7)



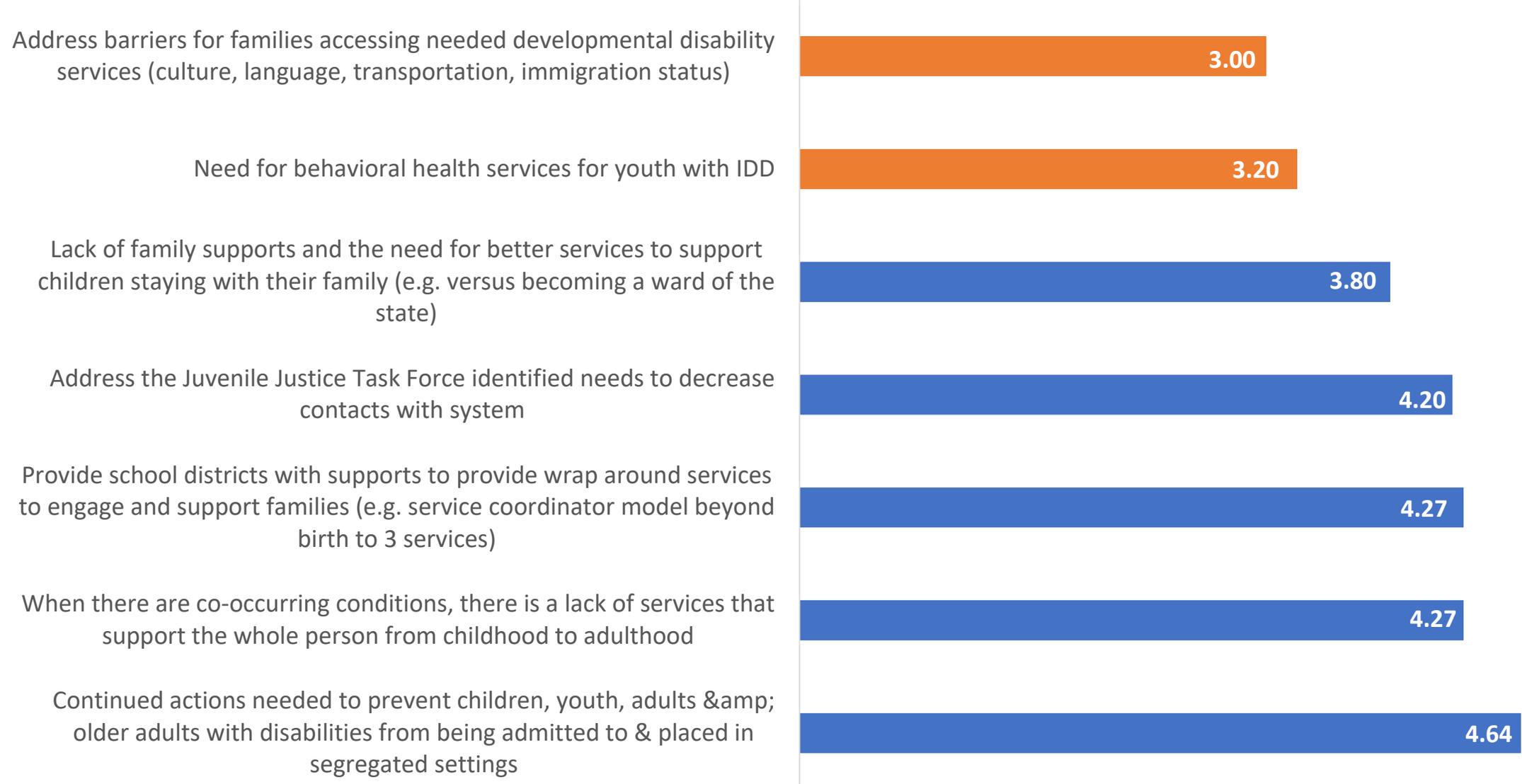
## Education & Early Intervention (ranked 1-9)



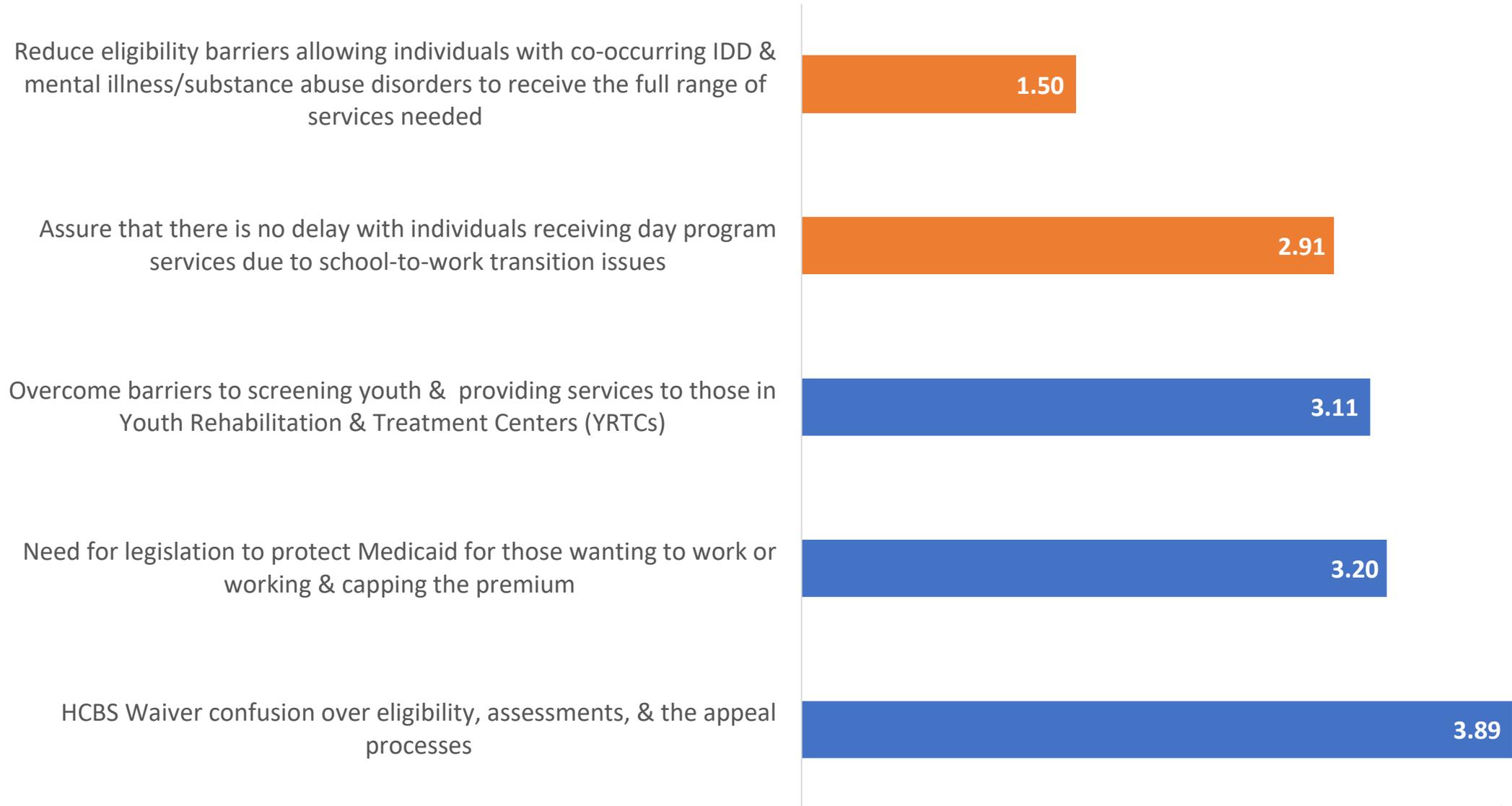
## Employment (ranked 1-9)



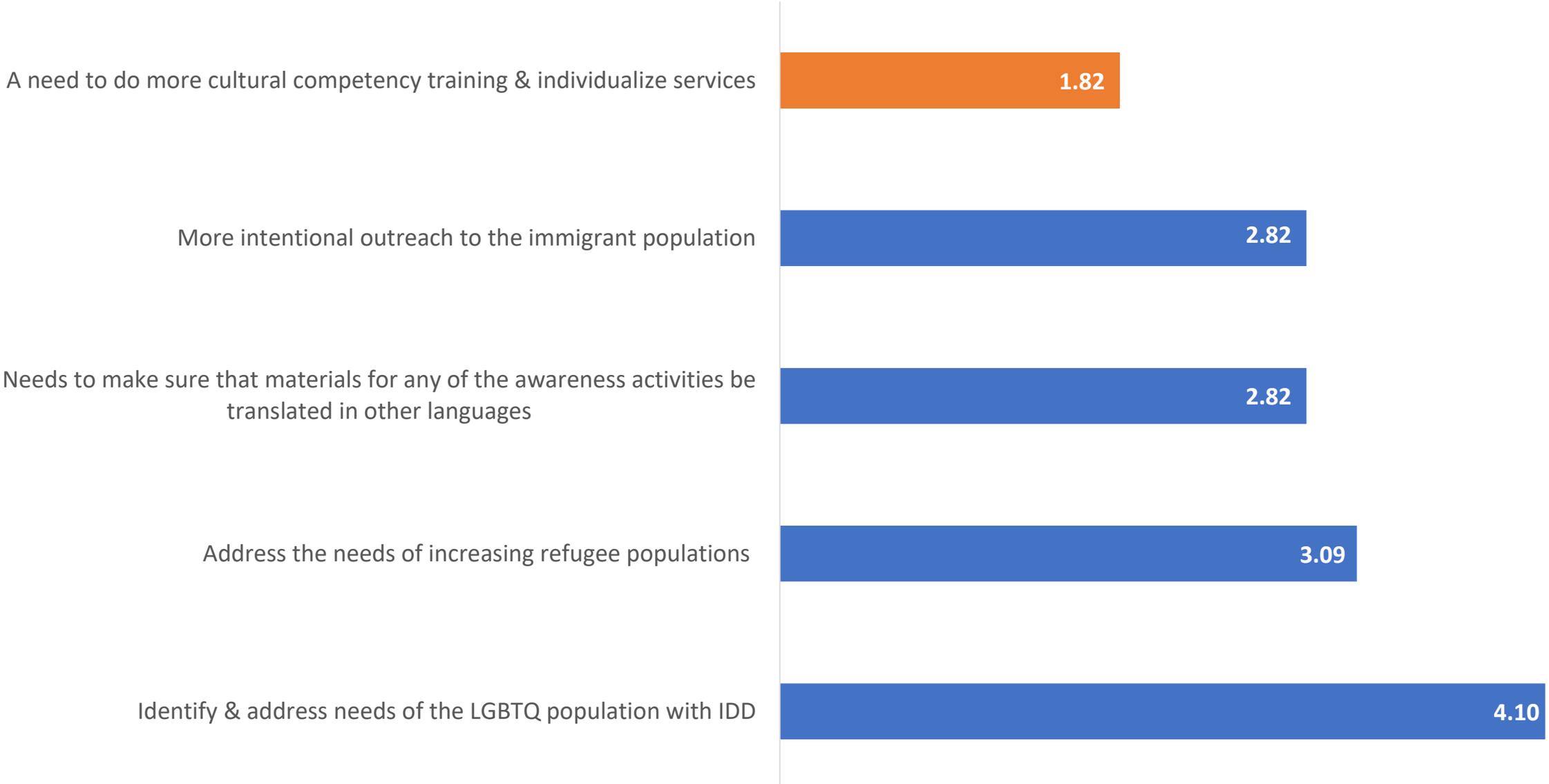
## Informal & Formal Supports (ranked 1-7)



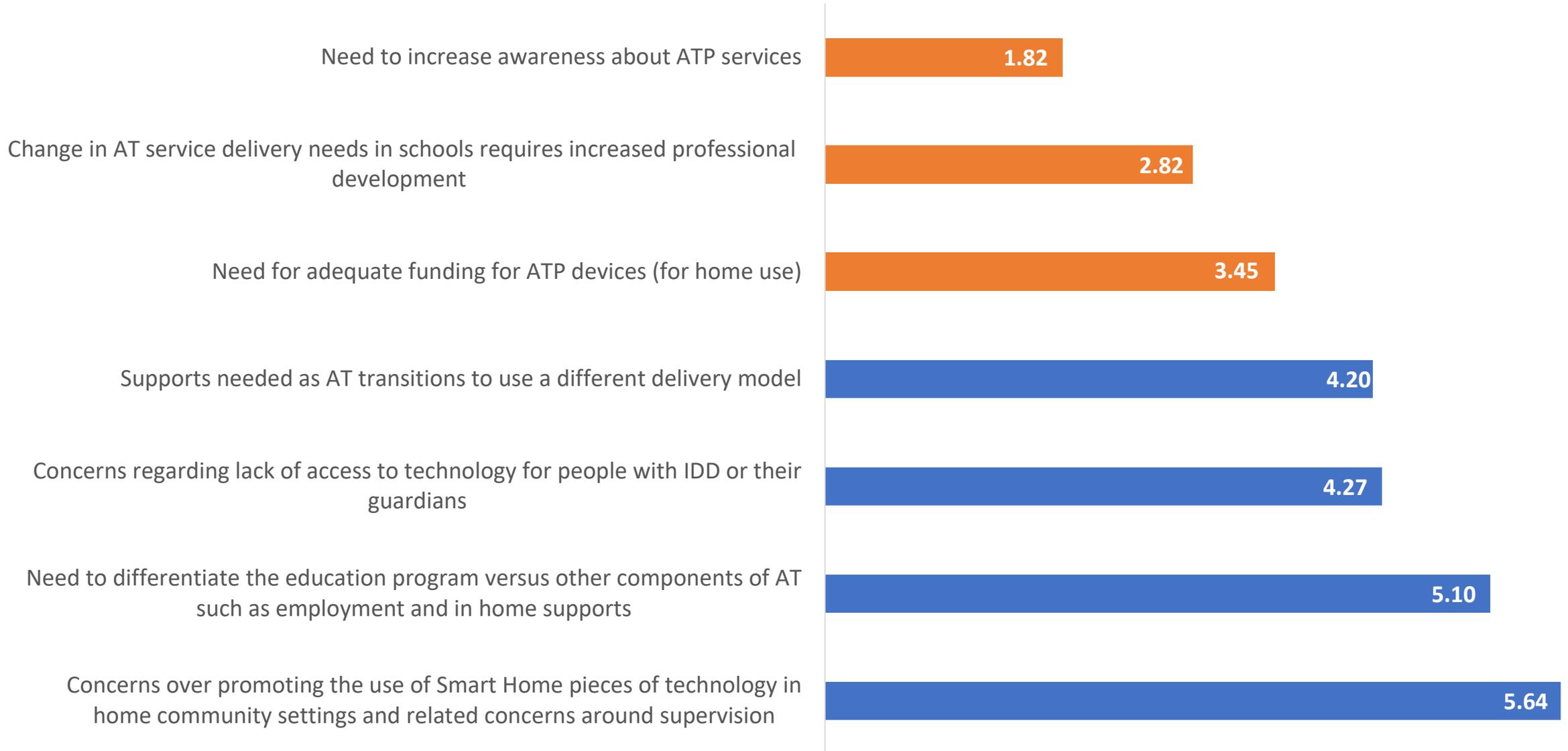
## Criteria for Eligibility of Services (ranked 1-5)



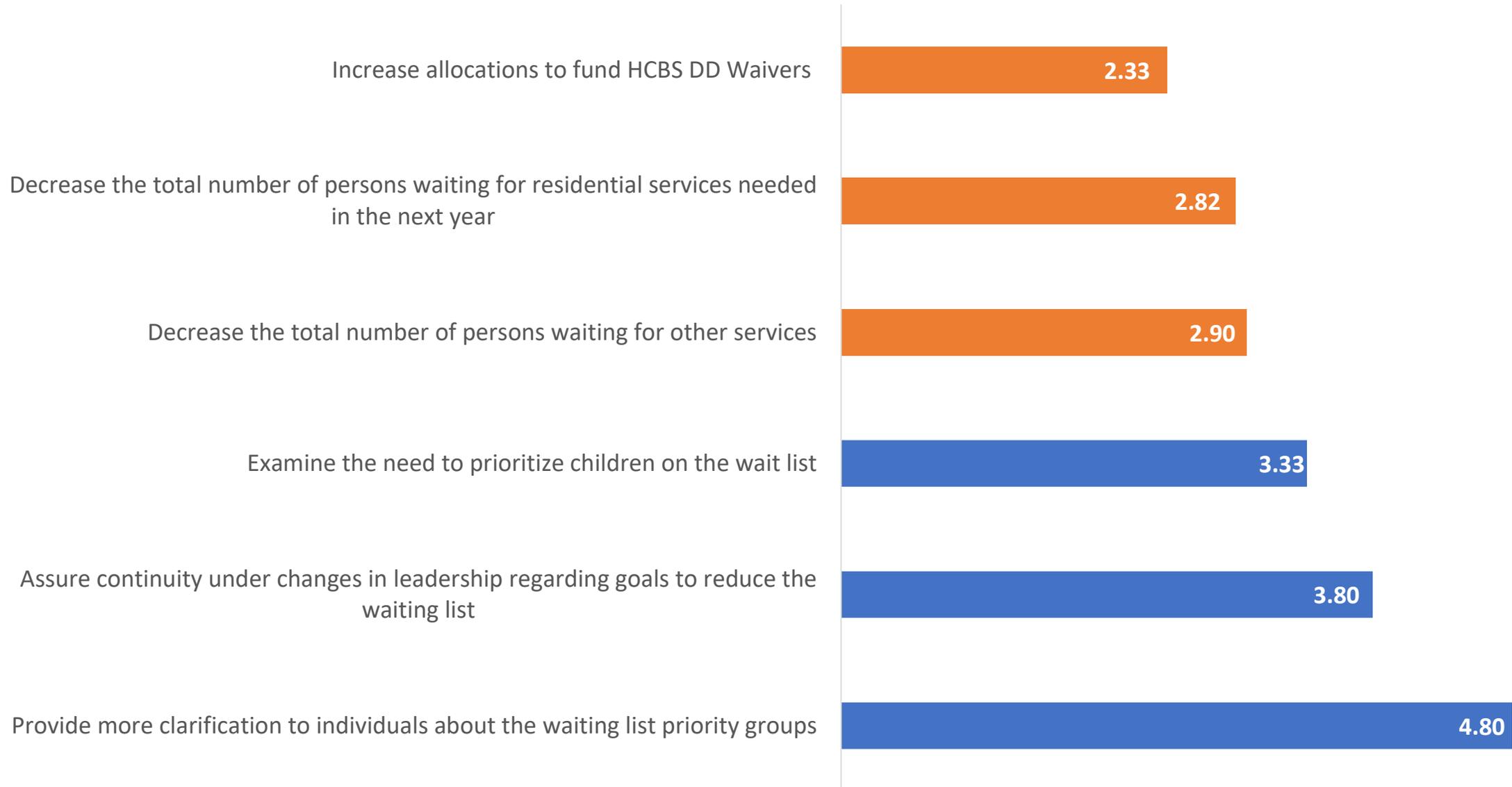
# Barriers of underserved/unserved (ranked 1-5)



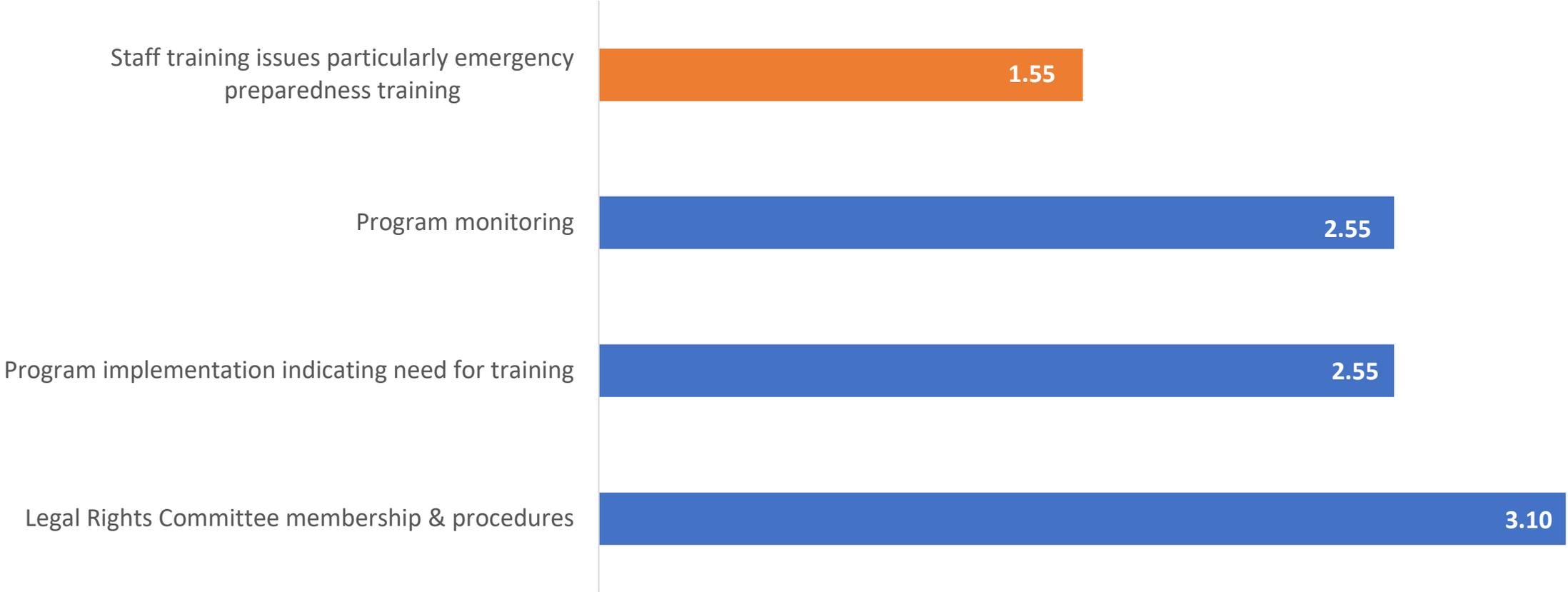
## Adequacy of Assistive Technology (ranked 1-7)



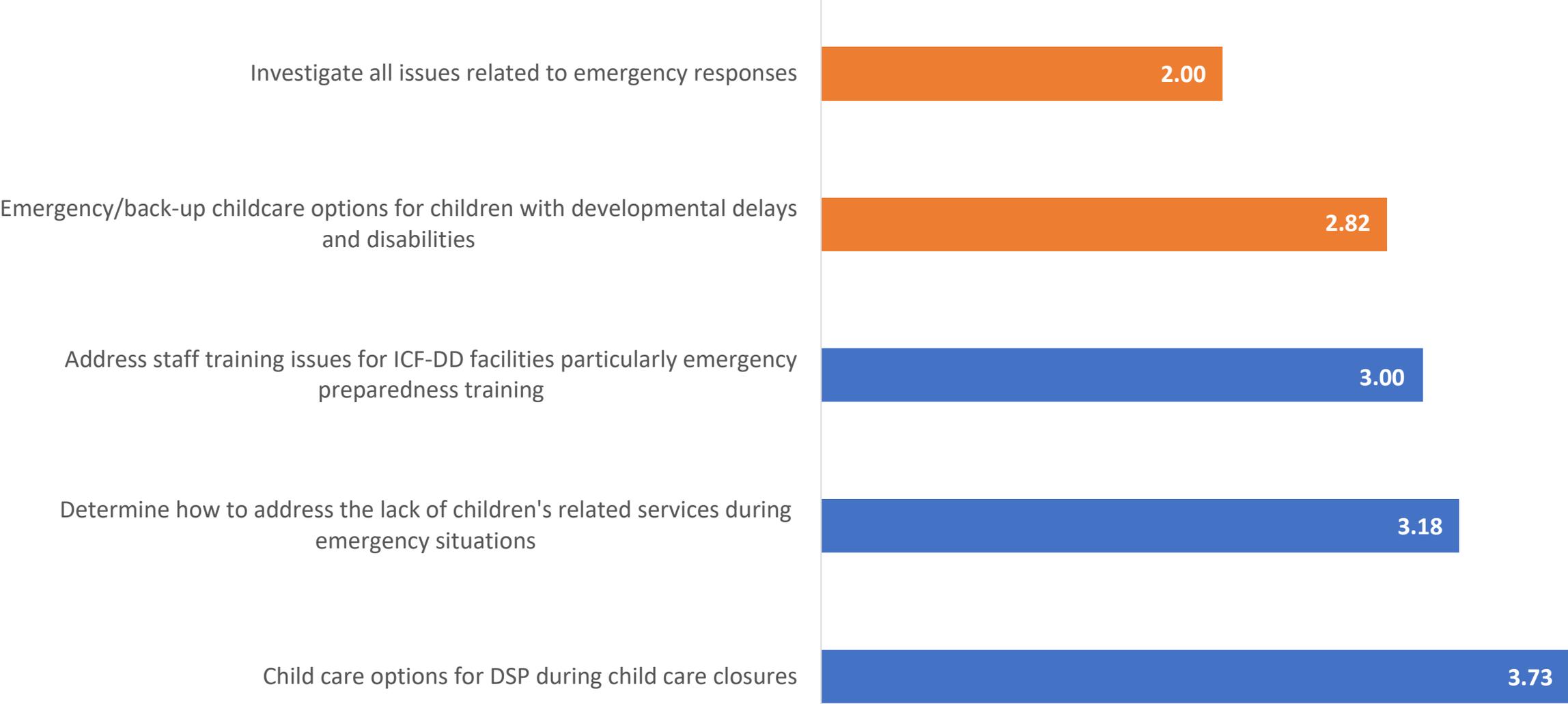
## Waiting Lists (ranked 1-6)



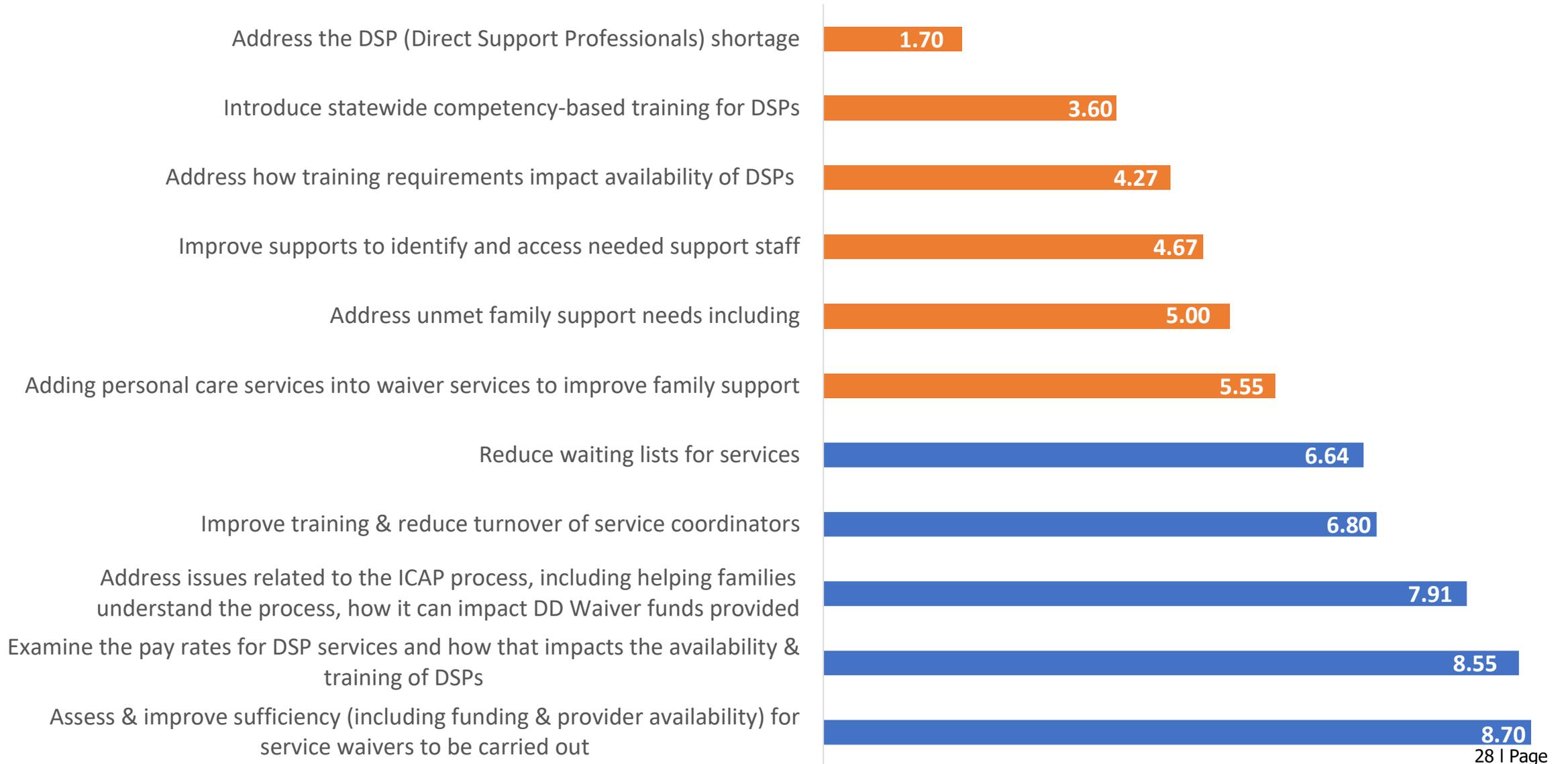
### Adequacy of Health Care in Facilities (ranked 1-4)



# Emergency Preparedness (ranked 1-5)



## Adequacy of Waiver Services (ranked 1-11)



# Family/Provider Survey Sample

Introductory Letter

Demographics

Survey Ratings

Considerations: Short and Long Form or Branch the questions  
Assure it is 508 compliant  
Reading level is at appropriate level (eliminate jargon)

How do you rate the importance of each area?					
Example Category					
	Not Important	Slightly Important	Important	Very Important	Not applicable/ I do not know
Example Area #1	1	2	3	4	NA
Example Area #2	1	2	3	4	NA
How do you rate the importance of each area?					
Recreation					
<i>There is a need to:</i>	Not Important	Slightly Important	Important	Very Important	Not applicable/ I do not know
Create more recreational opportunities in the community.	1	2	3	4	NA
Address the provider reimbursement rates in order to increase community inclusion recreation activities.	1	2	3	4	NA
Comments:					

# Self-Advocate Survey Sample

Please circle a Thumbs Up (for Yes) or a Thumbs down (for No) for each of these questions:	
 	In my community, I have many recreation activities that I can participate <u>in</u> .
 	I have transportation to get where I need to go.
 	I live where I would like to live in my community.
 	I need training on how to work with my insurance.
 	My support staff needs more training to better communicate and understand me.
 	I am concerned about being bullied or abused or I feel safe.
 	I wish I had more employment opportunities.
 	I know about what equipment devices services are available to me.
 	I cannot get the services I need because of the Waiver waiting lists.
 	There are not enough staff to support those that need help.
 	My community is prepared to address a widespread emergency, e.g. flooding, COVID-19.
Please tell us about a time you needed a service or support and it was not available.	

# Survey Distribution Suggestions

- Provide Electronic or Paper Copies
- Distribution Suggestions
  - Advocacy Groups
  - Therapy Centers (e.g., Madonna)
  - ARC of Nebraska
  - Schools/school nurses
  - Churches
  - Child care centers
  - DHHS List Serv
  - O'Hana Kids
  - PTI and other Parent groups (Phil Gray is a contact)
  - Ollie Webb
  - Cultural Centers

## Focus Groups

- 3 focus groups and 20-25 interviews
- Be intentional to include refugee population
- People First Board Meeting
- Focus on Family Members and Self-Advocates
- Consider topic related focus groups
- Rural and Urban settings

Nebraska Council on Developmental Disabilities

State Agency Representative  
Report to Council Members

Representative: Sara Morgan

Agency: Department of Health and Human Services

Update on activities/trends/improvements/issues impacting individuals with I/DD since the last Agency update:

Continuing to work on:

- CYSHCN Transition Program for youth aged 16-21 years old, as well as the Parent Resource Coordinator Program with UNMC MMI
- Pediatric Mental Health Care Access program work to increase screening of children with and without special health care needs in community settings
- Contract with the US Census Bureau to oversample Nebraska and obtain more data on indicators specific to CYSHCN
- Title V MCH Needs Assessment to determine the 10 priorities affecting Nebraska's MCH population, including those with special needs. Currently small groups are meeting to develop issue briefs that will describe issues they feel should be priorities for the NE MCH focus.

Current Agency activities/trends/improvements/issues impacting individuals with I/DD:

- Increase mental health screening of children in primary care clinics through the Pediatric Mental Health Care Access program partnership with UNMC MMI;
- Provide education and technical assistance for school staff as they seek to increase screenings for students in a school setting;
- Maintain partnership with UNMC MMI to develop the Transition and Parent Resource Coordinator programs as ways to further serve families of CYSHCN;
- Develop a library of validated and appropriate screening tools for use by a variety of individuals (parents, community health workers, home visitors, etc) through the Pediatric Mental Health Care Access program

Future/upcoming Agency activities:

- Holding an April 2020 meeting to make decisions on the 10 priorities for Nebraska's MCH population, including those with special needs, which is one of the final steps of the Title V MCH Needs Assessment.

Nebraska Council on Developmental Disabilities

State Agency Representative  
Report to Council Members

Representative: Paige Rose

Agency: Nebraska VR

**Update on activities/trends/improvements/issues impacting individuals with I/DD since the last Agency update:**

WIOA Combined State Plan was submitted.

March 25, 2020 Wait List numbers-  
Priority 1- 1665  
Priority 2- 794  
Priority 3- 365

On 4/6/20, 100 people were removed from the waitlist of which 21 were confirmed DD recipients.

**Current Agency activities/trends/improvements/issues impacting individuals with I/DD:**

Due to COVID-19, all VR staff are required to work from home unless an essential duty cannot be completed from home.

Constant Contacts have gone out to Service Providers on 3/31 (General COVID-19 info) and 4/8 (Temporary Measures or Obtaining Signatures)

VR Leadership and Program Directors are reviewing practices in other states that provide for virtual service provision.

**Future/upcoming Agency activities:**

NE VR was 1 of 10 VR agencies nationwide awarded an intensive TA opportunity from the Center for Innovative Training in Vocational Rehabilitation at the George Washington University on developing innovative methods to train VR personnel to support work of state VR agencies in delivering high-quality services and improve employment outcomes for individuals with disabilities.

National Opportunity: The Institute for Community Inclusion (ICI) is looking to host a few virtual "huddles" for front line staff. Nebraska VR is one of several agencies contacted to explore interest.

- General reactions how staff are doing working and delivering services in a remote environment; and
- How client needs have changed and how VR can be responsive.



Nebraska Council on Developmental Disabilities

State Agency Representative  
Report to Council Members

April 17, 2020

Representative: Tony Green, Interim Director

Agency: Department of Health and Human Services – Division of Developmental Disabilities

**Update on activities/trends/improvements/issues impacting individuals with I/DD since the last Agency update:**

**Institutional Level of Care Assessment Redesign**

- Phase I (Nursing Facility) Update: DHHS and Optumas are working through the alignment of proposed revised criteria and the interRAI Home Care standardized assessment tool. This is expected to be completed this month. Next steps is to develop a plan and assess implementation from a policy and fiscal standpoint.
- Phase II (Intermediate Care Facility) Update: Work on Phase II has begun on is on schedule. Optumas is researching what criteria and tools other states use for institutional admissions and HCBS waiver program participation. The ICF listening sessions will be combined for adults and children since Nebraska currently utilizes one tool for both. The first listening session was held February 18, 2020. This next WebEx listening session has been scheduled for Wednesday, April 22, 2020 from 5:00-7:00 PM CST.

**Rate Rebase and Objective Assessment Process Redesign:**

- The Objective Assessment Process redesign project remains on schedule. Standardized risk screen tools are currently being considered to replace Nebraska's homegrown screening tools. A pilot is underway that is assessing DD Providers abilities to submit required financial data that allows the tracking of revenue and expenditures down to the exact service level.

**Waiver Amendment Appendix K: Emergency Preparedness and Response**

- Submitted to CMS on 3/31/20
- DRAFT copies can be found on website at: <http://dhhs.ne.gov/Pages/Developmental-Disabilities.aspx>

**Quality Management Update:**

- The RFP for contracting with a quality improvement organization-like (QIO) entity to continue our commitment and implement model practices for components of a robust quality oversight framework is expected to be released in May 2020.

**Olmstead Plan Update:**

- The Olmstead Plan was submitted to the Legislature on December 16, 2019.
- The Legislative Resolution hearing was held by the Health and Human Services (HHS) Committee December 18, 2019. The draft plan submitted to the Legislature was the first step and the framework towards achieving the Nebraska Olmstead vision.
- While DHHS is waiting for feedback from the HHS committee, DHHS will begin to initiate the strategies and measures that we committed to in the plan.

**Future/upcoming Agency activities:**

- COVID-19 Weekly Stakeholder Calls – Mondays at 4:00 PM – 5:00 PM CST (last call May 25, 2020). 888-820-1398 Attendee 3065334#
- DD Advisory Committee Meeting WebEx Meeting - April 23, 2020, 10:00 AM WebEx Meeting number 923 887 979 – Details on DD Event Calendar <http://dhhs.ne.gov/Pages/Developmental-Disabilities.aspx>

## Nebraska Council on Developmental Disabilities

State Agency Representative  
Report to Council Members

Representative: Seamus Kelly/Eric Evans

Agency: Disability Rights Nebraska

### **Update on activities/trends/improvements/issues impacting individuals with I/DD since the last Agency update:**

We closed our physical offices at close of business on March 20<sup>th</sup> and began teleworking March 23<sup>rd</sup>. We spent the first two weeks of March leaning as much as we could about the impact of COVID-19 on people with disabilities, following what our counterparts in other States were doing and making all the necessary preparations that would enable staff to telework from home. With the able assistance of our fabulous Administrative Services Team we were able to get everyone equipped for working from home and, despite an occasional technical glitch here and there, things have been going quite well. All Teams are meeting regularly by videoconference and the chat function through Microsoft Teams. Also, the Leadership Team is meeting on a weekly basis so we can stay informed and be responsive to any issues that might arise. On a lighter note, we had a VIRTUAL FAC at 4:00 last Friday afternoon that people really enjoyed.

We anticipate that the Disability Rights Nebraska office will remain closed until at least May 6, 2020. All staff are fully connected and working from home. We are still receiving requests for service. There is no change in how people can contact us. If they call into the office (402.474-3183 or 1-800-422-6691) our receptionist will answer and route the caller to an advocate. People can also contact us by email –

[info@disabilityrightsnebraska.org](mailto:info@disabilityrightsnebraska.org)

We also have an intake form on our Website. Go to “Need Our Assistance” tab. Click “Request Assistance” to fill out intake form

[https://www.disabilityrightsnebraska.org/need\\_our\\_assistance/request\\_for\\_assistance.html](https://www.disabilityrightsnebraska.org/need_our_assistance/request_for_assistance.html)

A Case advocate will respond by phone or email, depending on what works best for the caller.

**Current Agency activities/trends/improvements/issues impacting individuals with I/DD:**

During the course of the past month, our federal partners have provided helpful guidance and we have received assurances that our funding can be used to cover the costs of disruption to our work that has been caused by the COVID-19 pandemic. For example, the Social Security Administration issued a directive stopping all monitoring activities of Representative Payees. Right before we closed the office and began teleworking we hired a new staff person, Nikki Evans, as our Representative Payee Program staff. Since it takes time for new employees to be credentialed under this program, Nikki wouldn't be qualified to do the monitoring, so she is busy learning about our organization and participating in a variety of webinars hosted by our national association.

Similarly, with the guidance issued by the U.S. Department of Health and Human Services, we are no longer able to do on-site monitoring of the Beatrice State Developmental Center, the Lincoln Regional Center or Assisted Living Facilities. However, we are still monitoring all incident reports from the Centers to insure there aren't problems that we should be addressing. We have also developed a virtual monitoring approach where we contact the Assisted Living Facilities that are on our watch list and talk to the people living and working there about their situations in light of COVID-19. We are also developing a reporting page that will be on our website where people who living in facilities or their family members and friends can provide information about problems they are having.

On March 13th Disability Rights Nebraska sent letter to Nebraska Department of Health and Human Services (DHHS) addressing the state's planning and response to public health crisis. Their reply was to send us the plan they have in place, whether or not that plan addresses the issues our letter raised, we don't know yet. Our focus turned to care rationing. Care rationing, where hospitals decide who gets treatment for COVID-19 and who does not, is a big concern because it brings us face to face with Dr. Wolfensberger's concerns about death-making of people with disabilities. The state of Alabama recently said they would not provide ventilators to people with intellectual and cognitive disabilities who came to the hospital for COVID treatment. The Alabama Protection & Advocacy system filed a complaint with the Office of Civil Rights. This policy has been reversed. We are seeing this happen in other states where the attitudes, biases and prejudices that are conveniently hidden when life is "business as usual" rear their ugly heads when things get complicated. Our national organization has been really good about keeping us all connected and providing us the language and tools to fight these policies.

So, to make sure that does not happen in Nebraska on March 27<sup>th</sup> Disability Rights Nebraska sent letter to Governor Ricketts regarding concerns about care rationing and the need to establish statewide guidance that protects the rights of people with disabilities. Since we have not received a response from the Governor, on April 8<sup>th</sup>,

Disability Rights Nebraska, along with 15 other disability advocacy organizations and social justice partners, sent a second letter to the Governor asking him to take a leadership role in insuring that people with disabilities are not subjected to care rationing during the COVID-19 pandemic. Check out our COVID-19 page on our website for more information and copies of the letters noted above:

<https://www.disabilityrightsnebraska.org/covid-19-updates.html>

We have also weighed in on a number of issues at the national level. On March 19<sup>th</sup> we signed on to a letter to the U.S. Department of Health and Human Services asking the Department to quickly provide this information to the P&As is necessary to facilitate timely investigations and advocacy that may be necessary to bring a quick end to any harm that may have occurred to people with disabilities related to COVID-19 testing. On March 27<sup>th</sup> we signed on to a letter to President Trump asking that he immediately use the manufacturing authority in the Defense Production Act (DPA) to increase the domestic production of medical supplies and equipment that hospitals, health systems, physicians, nurses and all front-line providers so desperately need, so as to save hundreds of thousands of American lives. On April 7<sup>th</sup> we signed on to a letter joining members of the Consortium for Citizens with Disabilities (CCD) Education Task Force and allies advocating that NO ADDITIONAL waivers are necessary under either the IDEA or the Rehab Act.

**Future/upcoming Agency activities:**

The Social Role Valorization Workshop scheduled for this summer may be replaced with a half-day or one-day virtual event instead of a 3-day workshop in case the Wesleyan campus will not be open to us.

Nebraska Council on Developmental Disabilities

State Agency Representative  
Report to Council Members

Representative: Wayne Stuberg

Agency: UCEDD - April 2020

Update on activities/trends/improvements/issues impacting individuals with I/DD since the last Agency update:

- President Ted Carter shut down the NU system on April 8 for two weeks with continuation of courses remotely. MMI remains open as a health care facility, but non-essential staff are working remotely. The volume of clinical work has decreased by 25-30% with over 75% of services now being provided via telemedicine.
- MMI new building construction remains on schedule, current completion Jan – March 2021.
- Search for new UCEDD Director has been completed with Mark Shriver, PhD selected. Mark will become the UCEDD Director July 1, 2020 with Dr Stuberg transitioning to the Associate Director until his retirement in December.

Current Agency activities/trends/improvements/issues impacting individuals with I/DD:

- Education series on transition is continuing via telecommunication with DHHS DD Interim Director, Tony Green, presenting on 4/14/2020. The series is being repeated in 2020-21 with companion session for self-advocates at the same time as presentation to foster self-determination around topics. The series is being delivered via Zoom.
- DD Council collaboration for Self Advocacy series entering year 3 with delivery format and dates/locations to be determined due to COVID.
- Data collection for the NCI-AD & NCI-DD surveys has been suspended for the remainder of the year due to the pandemic. NE surveyors had collected an adequate sample for NE to have NCI-AD data for the year, but not NCI-DD. Suspension of the data collection has resulted in staff lay offs for the project.

Future/upcoming Agency activities:

- Transition and Postsecondary Program for Students with Intellectual Disabilities (TPSID) grant funding for the 2020-21 cycle has been approved through the US Department of Education with MMI and UNO to submit a joint project grant for the Think College postsecondary transition program.