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January 25, 2018

Senator Lee Heider, Chairman
Senate Health and Welfare Committee
Statehouse
Boise, ID 83720

RE: Docket No. 16-0417-1702 Rules Governing Residential Habilitation Agencies

Dear Chairman Heider and Members of the Committee:

The Council on Developmental Disabilities is authorized by federal and state law to monitor systems and policies and to advocate for improved and enhanced services that enable Idahoans with developmental disabilities to live meaningful lives, included in their schools and communities. The Council is comprised of 23 volunteers appointed by the Governor.

The Council supports these pending rules. The Council applauds the work of the Department and specifically Eric Brown and his team on their thoroughness, attention to detail, outreach to all stakeholders, and the two year time commitment investment demonstrated in these pending rules. Since this service was implemented in 1995, over a thousand individuals have chosen this residential living option.

Beginning in the fall of 2016, the Council embarked on intensive, year-long collaborative effort with the Department of Health and Welfare, the Idaho Attorney General's office and the American Civil Liberties Union (ACLU). Thousands of hours were invested in hearing and learning from 93 adults with intellectual and developmental disabilities and 128 families statewide. This collaborative stakeholder process was called Community NOW! The extensive work completed by the collaborative Community NOW! group generated 17 recommendations provided in a report that may be found <https://icdd.idaho.gov/> titled: *Service and Support Recommendations from Community NOW! A stakeholder collaborative to improve supports for Adults with Developmental Disabilities.*

The rules presented before you align with the recommendations presented in the Community NOW! and I would like highlight three specific sections of the pending rules and walk you through how they directly correspond to the recommendations with the Community NOW! report.

On page 233 in Section 202, labeled “Qualifications and Responsibilities of a Residential Habilitation Professional,” the Council is particularly pleased with the addition of the entire section of **01. Education and Experience**, especially in regard to:

- c. Experience writing and implementing behavior and skill training program plans; or
 - The agency must provide documentation the employee received such training from an experienced residential habilitation professional; and
- ii. Demonstrate the ability to write and implement behavior and skill training program plans.

The emphasis on the ability **to write** appropriate **individualized** positive behavioral supports plans, including trauma informed care approaches, and to **consistently implement** these individualized plans over numerous staff changes cannot be emphasized enough within this service provision. The Council is unwavering in our insistence on improvement in this area given that of the 1300 individuals who access this residential option there is a high prevalence of adults with I/DD who have a co-occurring mental health diagnosis. In fact, in December of 2015 the Council made a public information request of the Department that garnered the following data: Of the 3600 total number of adults currently accessing developmental disabilities (DD) services, **2,719** adults were identified as having a co-occurring mental health diagnosis as identified in the assessor’s database. The Council also has data to reflect that over **900** adults who have a co-occurring mental health diagnosis receive support through this specific service provision.

On page 235, in Section 300.02, labeled “Acceptance Standards,” in this section are details that require agencies have the personnel available before accepting new individuals into their agency. This makes common sense, and the Council agrees with this requirement, however, best practice indicates that the rules should reflect that the agency involve the resident or family member in the interviewing of potential staff. On page 17 of the Community NOW! report you will find this desire illustrated by one of the many quotes we learned from individuals with intellectual and developmental disabilities who drove the development of the 17 recommendations.

“When staff first start, they read all the books, see what all the books say, but don’t talk to me at all. I wish my roommate and I got to interview them first, see what they are all about, so we can decide if they are a good fit first. Then when we are finally getting attached to someone the agency pulls them away but don’t tell us why.”

At a conference I recently attended I heard a story that helped bring to light what individuals with intellectual and developmental disabilities experience on a daily basis:

Take a moment to think about someone in your life right now that you don’t care to spend time with. Imagine you go to the grocery store to pick up a few things and when you return, that person that you really don’t care for is waiting outside your door. You open your door and that person enters your house. They sit down on the couch, turn on your TV, play on their phone, watch your TV and tell you how you should be cleaning your house, cooking your food and doing your laundry. After 8 hours with this person, they finally leave

your home. They return the next day for another 8 hours; and the next day; and the next. This is the reality for individuals with intellectual and developmental disabilities.

The Council encourages the Department to continue to work with service providers to make this possibility become a reality so that adults with I/DD have improved control over these big life decisions. The Council has observed the recommended practice of individuals involved in the interviewing potential staff in similar services located in neighboring states, so there is precedent to learn from.

The Council enthusiastically supports section 300.04., which requires agencies to assist people in accessing their community and will serve as gateways to better quality life for individuals accessing these services.

On page 237, **Section 300.09 of the rules it is indicated that each agency must develop and implement written policies that include a clear definition of personal, civil, and human rights. Upon initiation of services, the agency must provide each participant and guardian, if applicable, with written and verbal information outlining participant rights. This information must be in easily understood terms.** Knowing one's rights is a priority voiced over and over again by adults with intellectual and developmental disabilities that is reflected in Recommendation #4 of the Community NOW! report:

*#4. Take a proactive role in creating and fostering **a culture where rights are known, understood, exercised, and respected.** This culture should include an emphasis on understanding and using **supported decision-making processes** to help adults make informed choices.*

Also included in Section 300.09 subsection "t" is a provision for service providers to allow individuals to choose their own roommate. This directly aligns to Recommendation #5 of the Community NOW! Report:

#5. Emphasize and enforce HCBS (Home and Community Based Services) rules related to adults determining where they live, who they live with, and who provides their support.

The Council hears countless stories from adults who have been thrown together as roommates and have been given no choice over who they live with often resulting in some very poor life experiences. A story reflected in the report features an individual who was fearful of his roommate because he was assaulted on more than one occasion. The Council has high hopes that the improvement reflected in these rules will improve the practice of pairing roommates who may have an improved opportunity to create a safe and welcoming home.

Thank you to the Department of Health and Welfare for their commitment to improving the lives of adults with intellectual and developmental disabilities as clearly indicated in this set of pending rules.

Thank you for your time and consideration of the Council's comments.

Sincerely,

Toni Brinegar, Program Specialist