What are the needs of West Virginians with Co-existing Intellectual Developmental Disabilities and Mental Illness?

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Background

- The purpose of this study is to assess the needs and potential service gaps of people who have a co-existing developmental disability and mental illness by surveying providers who work with these populations.
- Do people with IDD receive adequate mental health services and how can those services be improved?

Objectives

- Recognize barriers to services for people with co-existing IDD and mental illness.
- Identify levels of need across 26 service domains for people with co-existing conditions.
- Discuss ways to improve the quality and availability of existing services.

Methods or Description of the Program

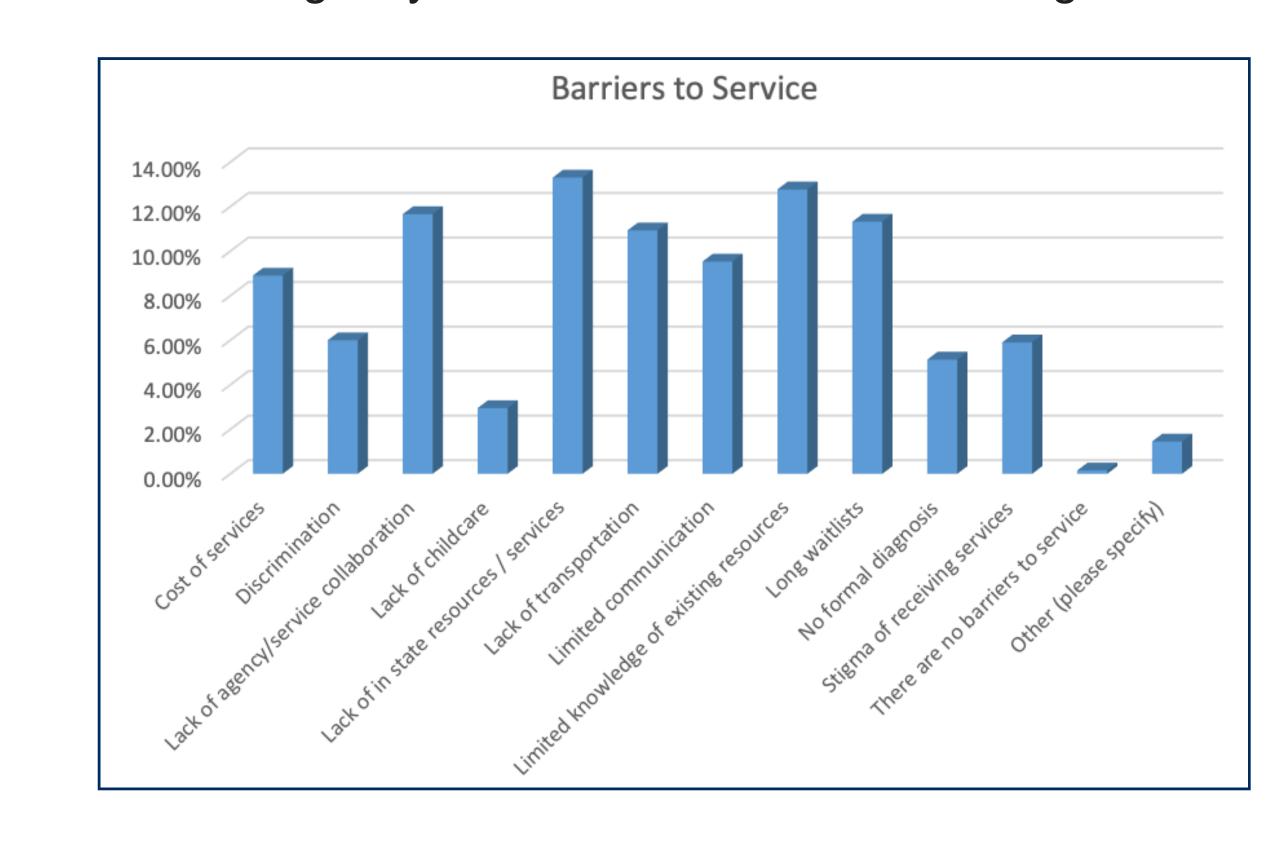
- 395 WV Professionals in the IDD / MH field were recruited to participate in the study by answering an anonymous Qualtrics survey.
- The survey link was distributed through an announcement posted on the CED website, Facebook and email listservs.
- We assessed service barriers including transportation, access to childcare and knowledge of resources among other factors.
- The respondents were asked about service barriers, using both a closed and open-ended format.
- Participants rated the level of need and separately, quality of 26 different service areas for people with co-existing conditions. Participants were also asked about overall opinions of access to mental health services for people with IDD.
- The only identifiable demographics collected from respondents were what counties they served and if they served children or adults.

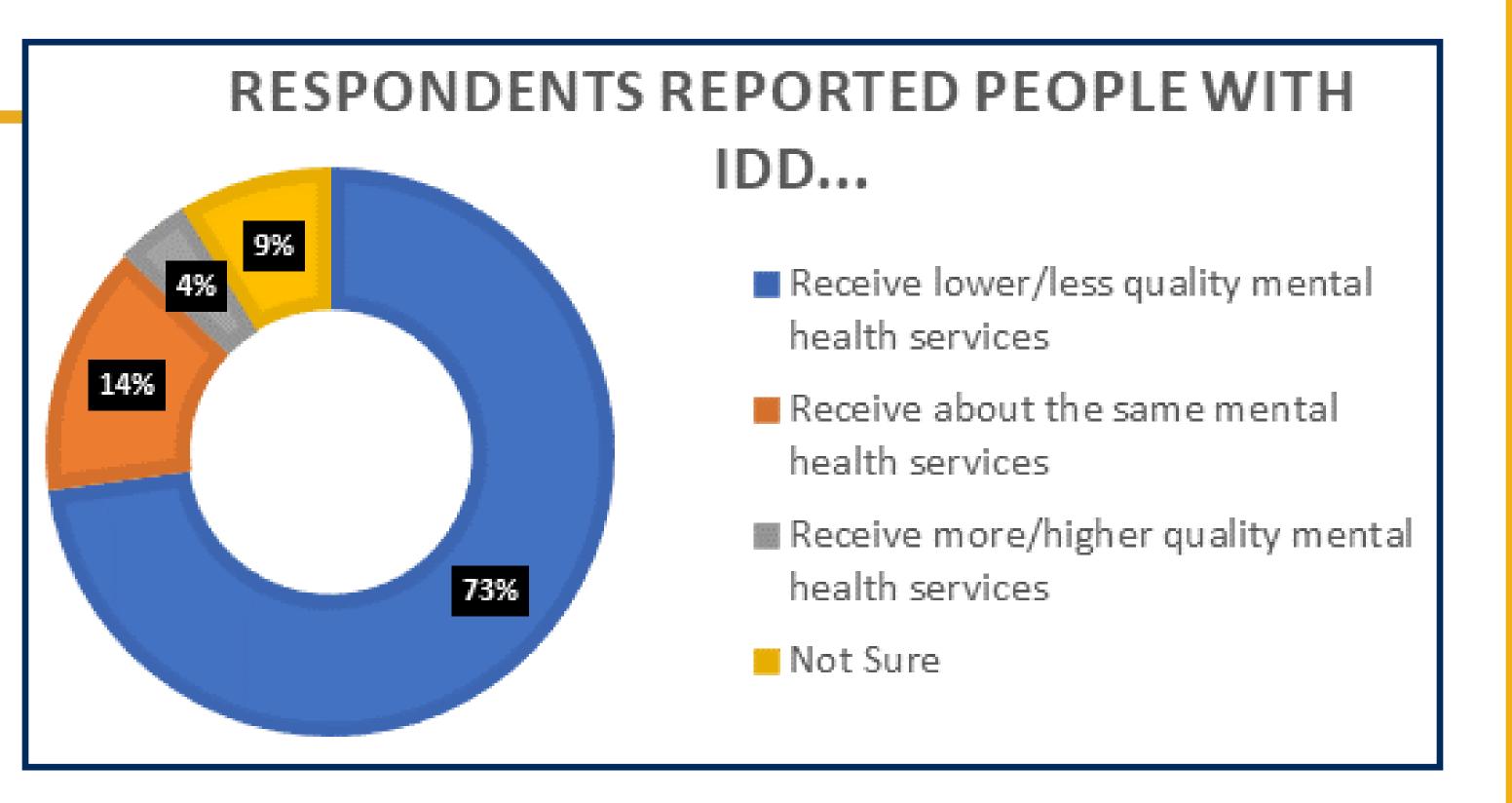
26 Service Donmains

- Collaboration between service models / agencies
- Community integration services
- Comprehensive community mental health resources
- Crisis response services / Crisis respite
- Daily living supports for people with brain injury
- Daily living supports for people with intellectual disabilities
- Daily living supports for people with physical disabilities
- Dietary and nutrition services
- Healthcare professionals knowledgeable of developmental disabilities / working with people who are not the "standard patient"
- Holistic healthcare options
- Long term housing assistance
- Intensive outpatient services
- Legal counsel
- Life skills resources / education
- Mental health treatment groups
- Substance abuse relapse prevention and compassionate treatment
- Music / Art / Recreational opportunities
- Peer support groups
- Positive behavior support services
- Rehabilitation and employment opportunities
- Specialized residential facilities
- Therapist / Mental health providers for people who have limited communication
- Transitional living services
- Transportation
- Trauma Informed care throughout systems
- Wraparound / Safe at home

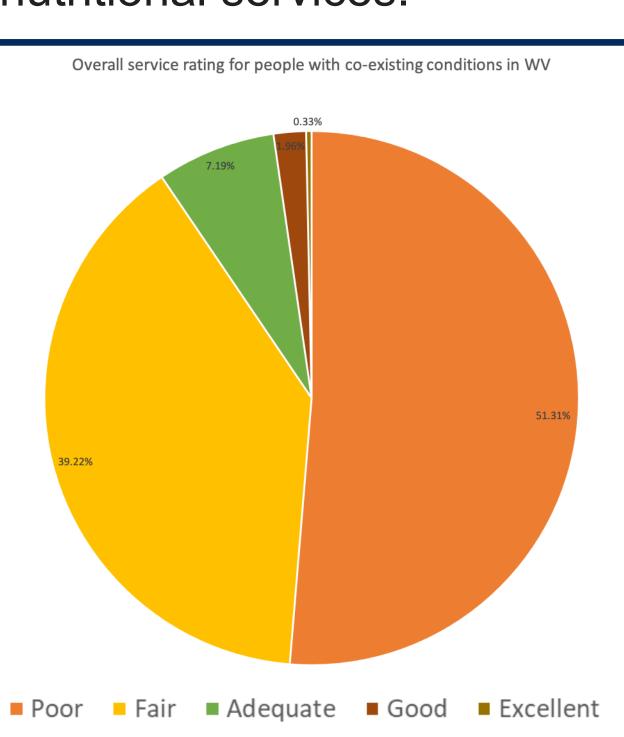
Findings/Results

- Of the respondents 41.2% served adults in WV, 14.29% served children and 44.52% served both adults and children.
- The vast majority of respondents (73%) felt people with IDD received lower/less quality mental health services. Data indicates almost all (98%), respondents felt services were either adequate, fair or poor for people with coexisting conditions in WV.
- As evidenced by the chart below, the top two identified barriers to services were lack of in state resources and limited knowledge of existing resources. These are further compounded by other barriers identified such as lack of agency service collaboration and long waitlists.





- The quality and availability of the 26 service domains were assessed. The services rated as highest included: daily living supports for people with intellectual disabilities; positive behavior support services; and, dietary and nutritional services.
- The level of need reported was high for all services. The highest level of need was in regards to health care professionals understanding developmental disabilities and the ability to provide services to people with limited verbal communication skills, in addition to the need for crisis response services.



Conclusions

- People with IDD have not received the same amount of mental health services however people with IDD often face many traumas and vulnerabilities that create more potential for mental illness¹.
- People with IDD have often faced discrimination in the mental health services² due to barriers including communication difficulties. We were able to identify these barriers by both a closed answer check as well as an open ended "other" option. The barriers identified suggest that access to services can be improved through systematic adjustments such as increased collaborative resource guides.
- The open-ended questions generated some ideas to best serve people with co-existing conditions. Some of these general ideas include:
 - Neuro-psychiatrists working with systems;
 - Educational, employment, and leadership opportunities for individuals with co-existing conditions;
 - Higher pay for social workers and direct care staff, leading to better retention;
 - Increased access to behavior support services for children;
 - Housing assistance for individuals with traumatic brain injury, and;
- Communication of service availability to rural communities
- The information from this research can be used to target service needs to improve systems, overcome identified barriers and advocate for improved mental health services for people with IDD.

References

- ¹ Wigham, S., Emerson, E. Trauma and Life Events in Adults with Intellectual Disability. Curr Dev Disord Rep 2, 93–99 (2015). https://doi.org/10.1007/s40474-015-0041-y
- 2 Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., & Hassiotis, A. (2013). Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. *PloS one*, 8(8), e70855. https://doi.org/10.1371/journal.pone.0070855