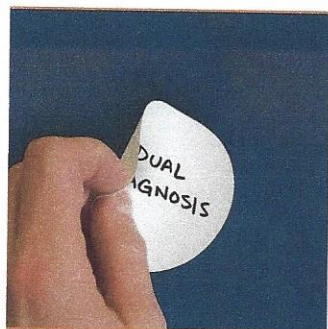# PEELING BACK THE LABEL OF DUAL DIAGNOSIS

Posted 4/25/18 **via Capstone e-Newsletter**

By Mary Kay Rizzolo | CQL President & CEO
mkrizzolo@thecouncil.org
(mailto:mkrizzolo@thecouncil.org)

The term dual diagnosis is often used to refer to people with intellectual and developmental disabilities (IDD) who also ha psychiatric disabilities. Although estimates of prevalence of dual diagnosis vary, research suggests people with IDD are likely to have a psychiatric disability than the general population (Friedman, Lulinski, & Rizzolo, 2015).

So what does having a dual diagnosis mean for people's lives? How does it impact outcomes? And, what can support providers do to ensure that they are supporting people with dual diagnosis in the most effective way possible? As usual **Capstone e-Newsletter (/resource-library/capstone-e-newsletter)**, the perfect place to start with all of this is data. Let begin by taking a look at the disparities people with dual diagnosis experience in comparison to those with only intellectu disabilities.

QUALITY OF LIFE DISPARITIES OF PEOPLE WITH DUAL DIAGNOSIS

By Carli Friedman | CQL Director of Research
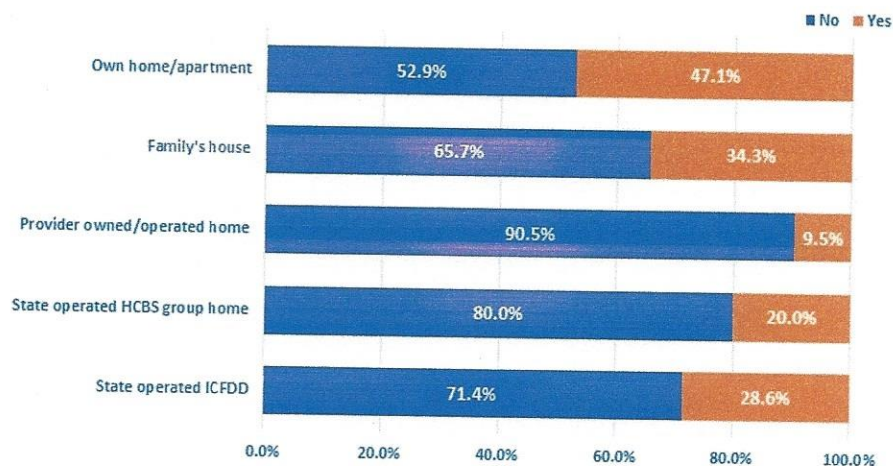cfriedman@thecouncil.org (mailto:cfriedman@thecouncil.org)

Out of the 850 people with IDD in our 2017 sample (through CQL's **PORTAL Data System (/PORTAL)**) 47.7% (n = 404) dual diagnosis. People with dual diagnosis faced a number of disparities in quality of life outcomes. Compared to people IDD only, people with dual diagnosis were less likely to live in integrated environments, participate in the life of the comm have natural supports, have intimate relationships, perform different social roles, choose where and with whom to live, cl where to work, and choose their services (see figure).

Outcome Disparities

Legend: ■ IDD only ■ Dual diagnosis

Outcome	IDD only	Dual diagnosis
Live in integrated environments	49%	40%
Participate in the life of the community	46%	45%
Natural supports	51%	50%
Intimate relationships	41%	40%
Perform different social roles	37%	35%
Choose where and with whom to live	30%	20%
Choose where to work	33%	31%
Choose services	34%	29%
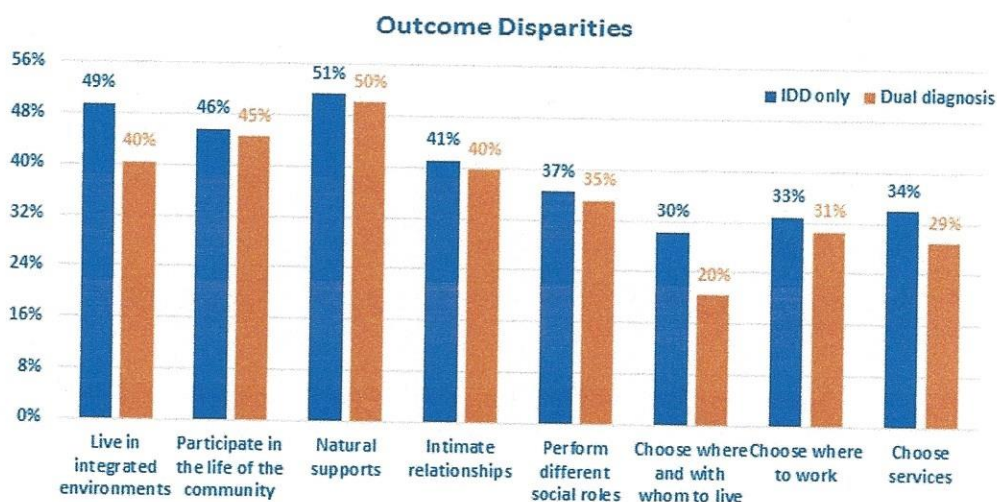
The largest quality of life disparity people with dual diagnosis faced was choosing where and with whom to live; this diffe was significant even when impairment severity was controlled. Only one-fifth of people with dual diagnosis chose where with whom to live. In terms of residence types, people with dual diagnosis living in their own homes most often chose to there (see figure below). However, only 9.5% of people with dual diagnosis who lived in provider-owned or operated hom
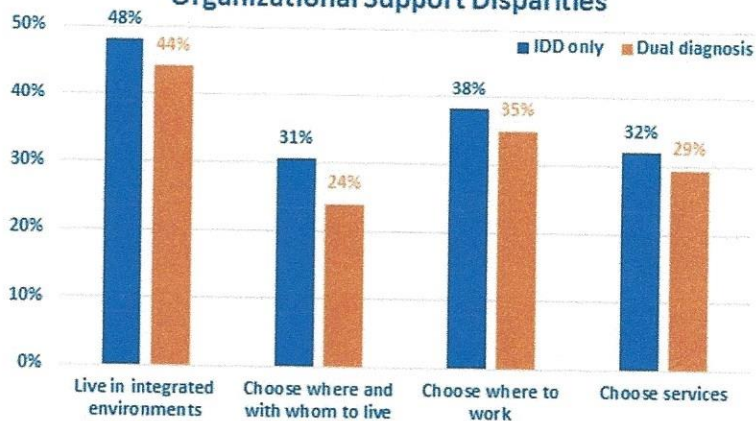
had the "choose where and with whom to live" outcome present. In fact, people with dual diagnosis who lived in provider owned or operated settings were approximately 5.1 times less likely to choose where and with whom to live compared to people who lived in their own home.

People with Dual Diagnosis: Choose where and with whom to live

■ No ■ Yes

| Setting	No	Yes
Own home/apartment	52.9%	47.1%
Family's house	65.7%	34.3%
Provider owned/operated home	90.5%	9.5%
State operated HCBS group home	80.0%	20.0%
State operated ICFDD	71.4%	28.6%

0.0%   20.0%   40.0%   60.0%   80.0%   100.0%

In terms of organizational supports, people with dual diagnosis also faced disparities receiving supports for: living in integ environments, choosing where and with whom to live, choosing where to work, and choosing their services (see figure). choosing where and with whom to live had the largest disparity, with only 23.9% of people with dual diagnosis receiving organizational supports for this area.

Organizational Support Disparities

■ IDD only   ■ Dual diagnosis

	Live in integrated environments	Choose where and with whom to live	Choose where to work	Choose services
IDD only	48%	31%	38%	32%
Dual diagnosis	44%	24%	35%	29%

Moreover, provider-owned or operated settings were 3.5 times less likely to provide supports for people with dual diagno choose where or with whom to live compared to organizations that supporting people living in their own homes. This is particularly problematic as people with dual diagnosis who are supported to choose where and with whom to live have be overall quality of life (14/21 versus 9/21 outcomes) (see figure).

Quality of life of people with dual diagnosis depending on organizational supports for choose where and with whom to live

	Value
Supports present	14.0
Supports not present	9.4

0.0   2.0   4.0   6.0   8.0   10.0   12.0   14.0
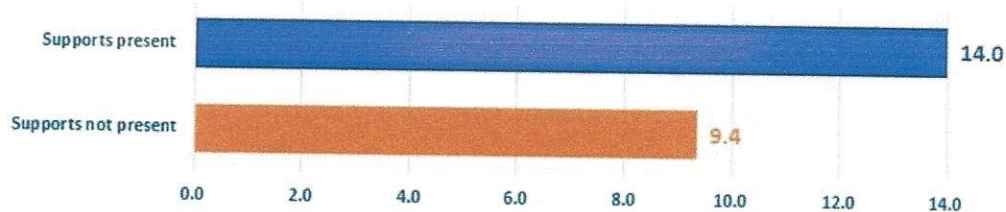
EDUCATION & INDIVIDUALIZED SUPPORTS

By Katherine Dunbar | CQL Director of Accreditation
kdunbar@thecouncil.org (mailto:kdunbar@thecouncil.org)

One of the most important aspects of supporting people with dual diagnosis is education. Organizations must acknowledge that people can have dual diagnosis, not just dismissing symptoms or attributing them to "behaviors." This means learning about the symptoms of a diagnosis and what they look like for that person, including what factors exacerbate symptoms, as well as how to remove or minimize those triggers. This may be particularly pertinent for instances of post-traumatic stress. This can go unrecognized and underdiagnosed, leaving people to relive trauma.

Knowledge is power; learning more about what dual diagnosis looks like for that person is the first step to supporting the person through what they are experiencing and helping them determine the best ways to acclimate to their symptoms and reduce their triggers.

Supporting people with dual diagnosis also relates to control and choice. Sometimes a person's symptoms may be exacerbated by the lack of control they feel they have. If people with dual diagnosis get frustrated because they feel they not allowed to make a decision, consider what you can do to ensure people are able to make the decisions they want. Ensuring the person has the fewest rights restrictions possible and the most opportunities can be one way to support pe

> "Ultimately, it's about ensuring organizational supports are individualized…"

In terms of the large disparities in supporting people to choose where and whom to live that Carli mentioned above, it is really about talking to people listening, and then following through. If someone is fighting with their room talk about it and compromise. Helping with conflict resolution – giving peop tools to resolve conflict – might help them to be more satisfied. It's also imp to recognize adding more staff is not always the answer; often people need staff time. All people have an innate need for personal space and determin best to support that person to have the physical and psychological space tl need.

Ultimately, it's about ensuring organizational supports are individualized rat than 'one-size-fits-all' approach. While this may be hard because of funding limitations, creative and low-cost solutions can be implemented to improve quality of life of people with dual diagnosis. For example, it is helpful for organizations to track data to determine where the largest support dispariti in their organization, so they can be more intentional about providing speci targeted and individualized supports to counteract those disparities. To lea more about specific steps support providers can take, we turn things over t Jason Buckles who emphasizes the need for being more empathetic in our approaches through the 'TIC' model.

FOCUS ON THE STRESS, NOT THE LABELS

By Jason Buckles, PhD, LPCC | Executive Director, A Better Way of Living (http://abetterwaynm.org/)
JasonB@ABetterWayNM.org (mailto:JasonB@ABetterWayNM.org)

You've seen the paperwork. The seemingly endless lists of diagnoses that may be in the charts of the people we suppor Major depression, anxiety, intermittent explosive disorder, schizophrenia, attachment disorder… and on and on.

Taking these at face value can be overwhelming. It can seem as if there are so many things going on that it's difficult to find a place to begin to help. Yes, it is important to have some understanding of what all of these terms and labels may mean but always remember, behind all of these diagnoses are people. People with the same ordinary needs, hopes, and desires as you have. People who are doing the best they can with the tools they have to navigate the intensities of this world.