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WHEN BEHAVIORS CHALLENGE:
Exploring the Needs of Individuals with
Intellectual Disability/Autism (ID/A)



In both personal and professional environments, labels play a significant role in shaping our perceptions and interactions with others, including those we support. Whether positive or negative, these labels can influence how we view ourselves and others. When it comes to the behavior of individuals with intellectual disability/autism (ID/A), the impact of labeling can be profound, often determining the way the individuals are perceived and the support strategies used with them.

Labeling behavior involves attaching descriptions or broad terminology that may or may not be accurate. Labels can be a form of constructive criticism, but they can be stigmatizing and harmful, as well.

Recognizing the power of labeling behavior is an important step in becoming person-centered and providing supportive responses. By promoting awareness and mindfulness, care teams can change the way labels are used to interpret and define behavior, thus embracing a culture of empathy and understanding of the dynamic complexities of each person.

In this newsletter, we will explore the meaning of labels and how they can negatively affect people with ID/A.

WHAT IS A LABEL?

By Erin Sass, Clinical Educator

Consider the phrase, “label jars, not people”. The sentiment has been around for years and implies that it is not okay to judge people by attaching labels to them. The word label is used here to refer to terms like “victim”, “low-functioning”, “elopers”, “attention-seeking”, “lazy”, “spoiled”, “defiant”, etc.

Labels are often used to identify, describe, and categorize various traits or behaviors. Some researchers say it is “a deeply ingrained aspect of human nature” (Kaufman, 2012). Labeling has a useful purpose, because without the ability to group items according to common characteristics, people could easily become overwhelmed in every little detail and new experience. However, labeling can also be harmful, especially when applied to people’s behavior. For example, labeling a person as “defiant” can affect how others perceive and interact with that person. Each time the person says no, others might automatically view the response as “defiance” rather than considering the possibility that the person is saying “no” because saying “no” is sometimes appropriate. In addition, labels can follow people throughout their lives, affecting how new caregivers perceive them (Kaufman, 2012).

Even if the majority of support team members feel that a label has been used appropriately and is accurate, labeling is not a person-centered approach and rarely has a positive outcome for the individual. In fact, labels can do more harm than good and can even limit people’s abilities.



Consider using the following questions to guide caregivers and support teams to move beyond labeling:

- Is the label an interpretation of behavior, or is it an objective description?
- How does the label affect the person?
- How does the label affect the way the person is treated?
- Is the label negative or positive?
- Is the label supportive or harmful for the person?
- What would the person be like without the label? How would the person be perceived?

Carefully think about people's behavior. All people have different traits, personalities, and characteristics, and have their own reasons for doing things. Consider this: "When we change the way we look at things, the things we look at change" – Wayne Dyer.

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THE IMPACT OF LABELING

By Erin Sass, Clinical Educator

After 25 years of working in the field of intellectual disability and autism (ID/A), I have heard a variety of labels used to describe behavior. Many of these labels are considered “suitcase words” because they can be “packed” with different meanings; they are often packed with broad assumptions about a variety of unwanted or unhealthy behaviors and carry negative connotations. Labels are subjective interpretations of behavior and can negatively influence the way a person is regarded.

One such label is “attention-seeking”. Attention-seeking behavior can have underlying factors, some of which include emotional needs, low self-esteem, history of trauma or neglect, mental illness, communication challenges (Schiller, 2023), physical illness, or the nature of the person’s developmental delay (Fletcher, et al., 2016). The attention-seeking label often comes with strategies such as redirection and planned ignoring to stop the behavior, rather than identifying the underlying causes. When the underlying cause of attention-seeking behavior is low self-esteem, redirection rarely works to stop the behavior. In fact, the person may try harder to get attention, to be seen, to feel accepted.

What we should be asking is, what is the reason or need being expressed by the person’s behavior?

As you read the following examples of behaviors being labeled, consider if the strategies used would be helpful for you?

- Someone who expresses wanting to hurt themselves and engages in non-fatal self-harm often gets labeled as manipulative. Their caregiver’s strategy is to ignore the self-harming behaviors to get them to stop. An effort to understand the behaviors might reveal them as “help-seeking” behaviors, since many people who self-harm have a history of abuse and trauma (Taylor, 2022).
- A person with ID/A who has communication challenges expresses feeling lonely by getting caregivers to constantly react to them is labeled “intrusive”. When such behaviors occur, caregivers are advised to redirect the person to an activity in the other room.
- A person with ID/A who has experienced childhood neglect and needs constant approval from others is labeled attention-seeking. Instead of receiving approval or attention, the person’s behavior is ignored in an attempt to diminish their behaviors.
- A person with ID/A who has a developmental age of 5 years old challenges boundaries and desires much attention. When the person is said to have attention-seeking behavior, the team uses strategies focused on decreasing the behavior, rather than addressing the needs per the person’s developmental age.

In each situation, the reason and need driving the behavior is overlooked because the label discounts any other reasons for the behavior. In some situations, labeling people can be considered judgmental as it implies the behavior has no meaning or has not been explored and is misunderstood. It is important to understand the behavior, the circumstances in which the behavior is occurring, the person’s developmental disability, and the possible underlying reasons for the behavior.

Labeling behavior can have several potential impacts:

- It can affect a person's self-esteem and self-concept leading to negative beliefs about themselves (Chen, 2023).
- Labels imply that the person needs to be fixed, which contrasts with the approaches used in trauma-informed care whereby it is assumed the person has experienced trauma, and the thinking shifts to, "How did this person get to where they are right now?"
- Labels can prevent some people from seeking help because they are fearful of being judged.
- Labels spread misinformation and can affect how people are treated by their peers and other caregivers on the treatment team.
- Labels can lead to inadequate support or ineffective strategies, especially when the label is inaccurate.
- It can lead to frustration for all involved – the person, whose needs are not being met, and the care team, whose strategies are not working.
- Labels can reinforce stereotypes and stigmas, leading to a person not getting adequate support; the strategies do not work and potentially result in the behavior worsening (Chen, 2023).
- Labels diminish understanding and reduce empathy as people are perceived through the lens of labels, rather than as people with complex experiences and needs (Chen, 2023).

When people seek attention, for whatever reasons, it is crucial to approach the situation with empathy and an understanding of the possible underlying factors rather than labeling the behavior. Instead of labeling a behavior as attention-seeking, explore the needs behind the behavior – what the person is really seeking, what they really need.

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EXPLORE BEHAVIOR, DON'T LABEL IT

By Elizabeth Hobbs, Clinical Educator

Caregiving can be difficult. When faced with behaviors that challenge, it is not uncommon for caregivers to label them in an attempt to define what is happening. However, there are risks with labels. Consider the following story of a dedicated team who used the label “attention-seeking”:

The care team was deeply concerned for an individual who shoved eating utensils into the back of their throat every time they ate. The caregivers tried everything they knew to help the person. They changed utensils, changed foods, and provided individualized, one-on-one support during meals. They concluded that the person was doing this solely to “seek attention” from the caregivers. The team followed the HCQU’s suggestion to talk with the individual’s physician about what they were observing. The person’s physician ordered tests and discovered that the person had esophageal ulcers caused by gastroesophageal reflux disease (GERD). With prescribed treatment for the medical condition, the behavior ceased. Unfortunately, it did not stop with all the interventions the team tried when they thought the person was “seeking attention.”

As this story demonstrates, there is a real risk in seeing behaviors of concern as solely attention-seeking or labelling them at all. Labels tend to prevent caregivers from exploring other explanations for the behavior. Behavior can serve more than one purpose. The positive approach of exploring any factors that might affect behavior can help teams accurately identify, rather than label, behaviors.

Additionally, focusing solely on behaviors of concern can prevent caregivers from discovering the needs driving the behaviors. If the person’s needs are not explored, those needs typically continue.

The person might feel the need to escalate the behavior that the team finds challenging in an attempt to get their needs met. This often creates an urgent caregiver need to have the person “stop” the behavior which challenges. Focusing on the person’s behavior and not their needs, decreases the likelihood of effective support.



THE “YES, AND?” TOOL

When supporting an individual with behaviors labeled attention-seeking, manipulative, defiant, etc., the “Yes, and?” tool can assist the care team to consider other possible reasons for the behavior. The “Yes” portion of the tool acknowledges that “yes, the person might be doing this to seek attention, manipulate, or defy. The “And?” portion of the tool then challenges the team to identify and consider other possible reasons for the behavior; it encourages the team to think about and answer the question, “Why else might the person do what they are doing?” The result is a brainstorming activity during which many reasons can be considered simultaneously.

The reason for a person's behavior can be many and varied. There could be a combination of reasons that appear differently depending on the situation, making it difficult to identify all the needs involved – almost like hitting a moving target. One approach is to focus on one occurrence of the behavior at a time and consider the person's needs in that particular instance. Common human needs include:

Connection Needs

- Acceptance / Appreciation
- Affection / Warmth
- Belonging / Community
- Communication
- Companionship
- Compassion
- Consideration
- Consistency
- Cooperation
- Empathy
- Equality / Mutuality
- Heard / Seen / Known
- Intimacy / Closeness
- Love
- Nurturing
- Presence / Awareness
- Respect / Self-Respect
- Safety / Security
- Sexual Expression
- Touch
- Trust
- Understood / Understanding (Person Driven Clinical Solutions, (PDCS), 2013)

Autonomy Needs

- Air / Food / Water
- Challenge / Purpose
- Choice / Freedom
- Competence
- Consistency / Stability
- Efficacy / Effectiveness
- Growth / Learning
- Harmony / Ease
- Hope / Inspiration
- Independence
- Joy / Play / Humor
- Matter / Meaning
- Movement / Exercise
- Order / Predictability
- Participation / Contribution
- Peace / Calm
- Physical well-being
- Rest / Sleep / Shelter
- Space / Privacy
- Spirituality
- Stimulation / Discovery (PDCS, 2013)



Additionally, consider the four aspects of the Positive Approaches Paradigm: environmental, communication, clinical, and caregiver/organizational needs to assist in exploring the reasons for people's behavior.

Environmental Needs: Often when people exhibit behavior that caregivers find challenging, looking at the environment in which they are living may show why they are having behavior that challenges. Environmental needs may include:

- Temperature
- Sound
- Lighting
- Adequate space

Challenges might arise from needs not being met related to living and workspaces or the people who they interact with and occupy these spaces. Addressing needs driven by the environment can help people live in a way that helps them to meet their needs (Barol, 2019).

Communication Needs: Communication is the ability to send and receive messages and behavior is often a form of communication. It can be difficult to get one's needs met when there are limited means to communicate with them. Communication needs include:

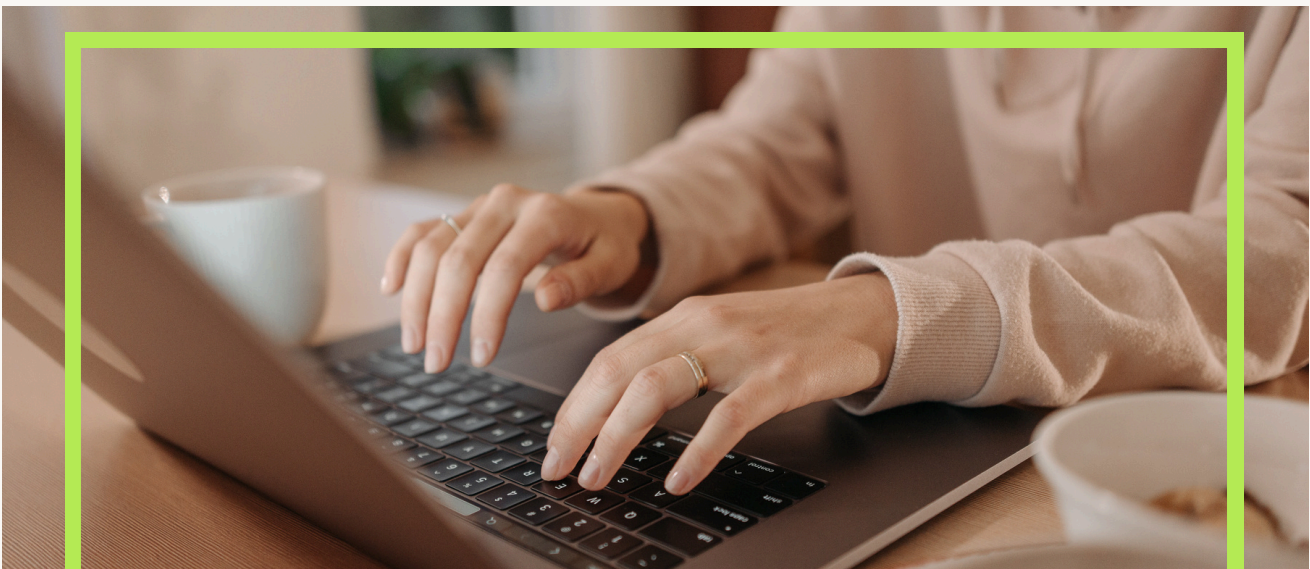
- Verbal
- Non-verbal
- Visual
- Written communication

People will often engage in any means necessary in order to be understood and get their needs met. When a person has a means of communication, frustration decreases, along with the need to engage in behaviors that challenge in order to get needs met (Barol, 2019).

Clinical Needs: Some people engage in behavior that caregivers find challenging as expression of clinical needs that need to be met. Such needs can include:

- Physical and mental health needs
- Abuse, trauma, and loss needs
- Sexuality needs
- Neurological differences

Assessment, followed by treatment and support for these needs can have a positive impact for the person resulting in a decrease in behavior that caregivers find challenging (Barol, 2019).



Caregiver/Organizational Needs: People do their best when they have consistent caregivers who are able to meet their own needs. This means that caregivers need a supportive environment and communication, too. This might be in the form of consistent and competent support for caregivers by the provider agency. Meeting the needs of the caregivers supports them to continue providing quality support to individuals (Barol, 2019).

CONCLUSION

Thinking about needs can lead to a positive result in understanding and supporting the person. Exploring needs, rather than labeling behaviors, enables caregivers to discover the actual causes of the behaviors they find challenging.

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