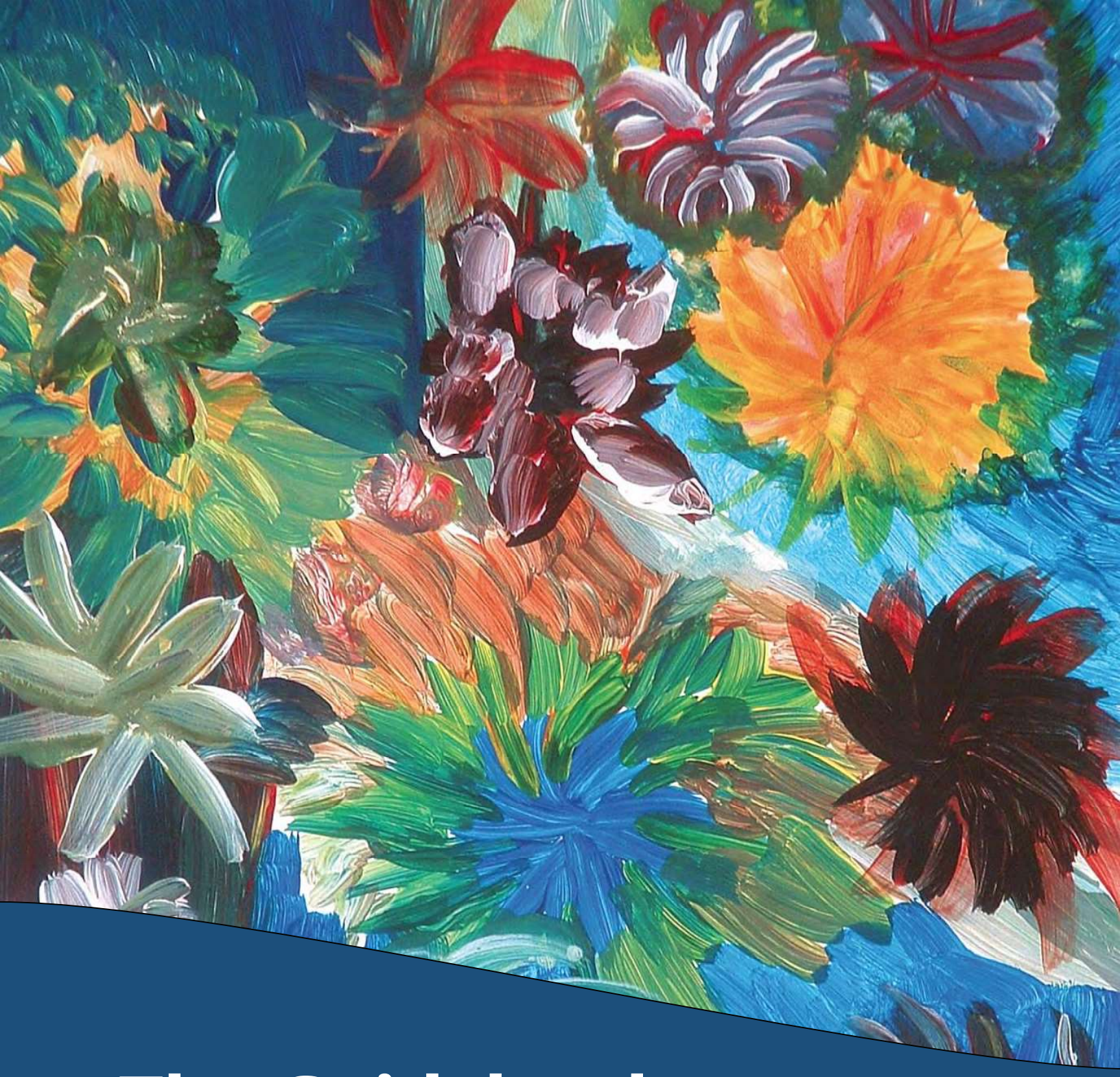

The Guidebook:
Meeting the mental health needs of people with intellectual disabilities

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Cover artwork by Rachel Canavor

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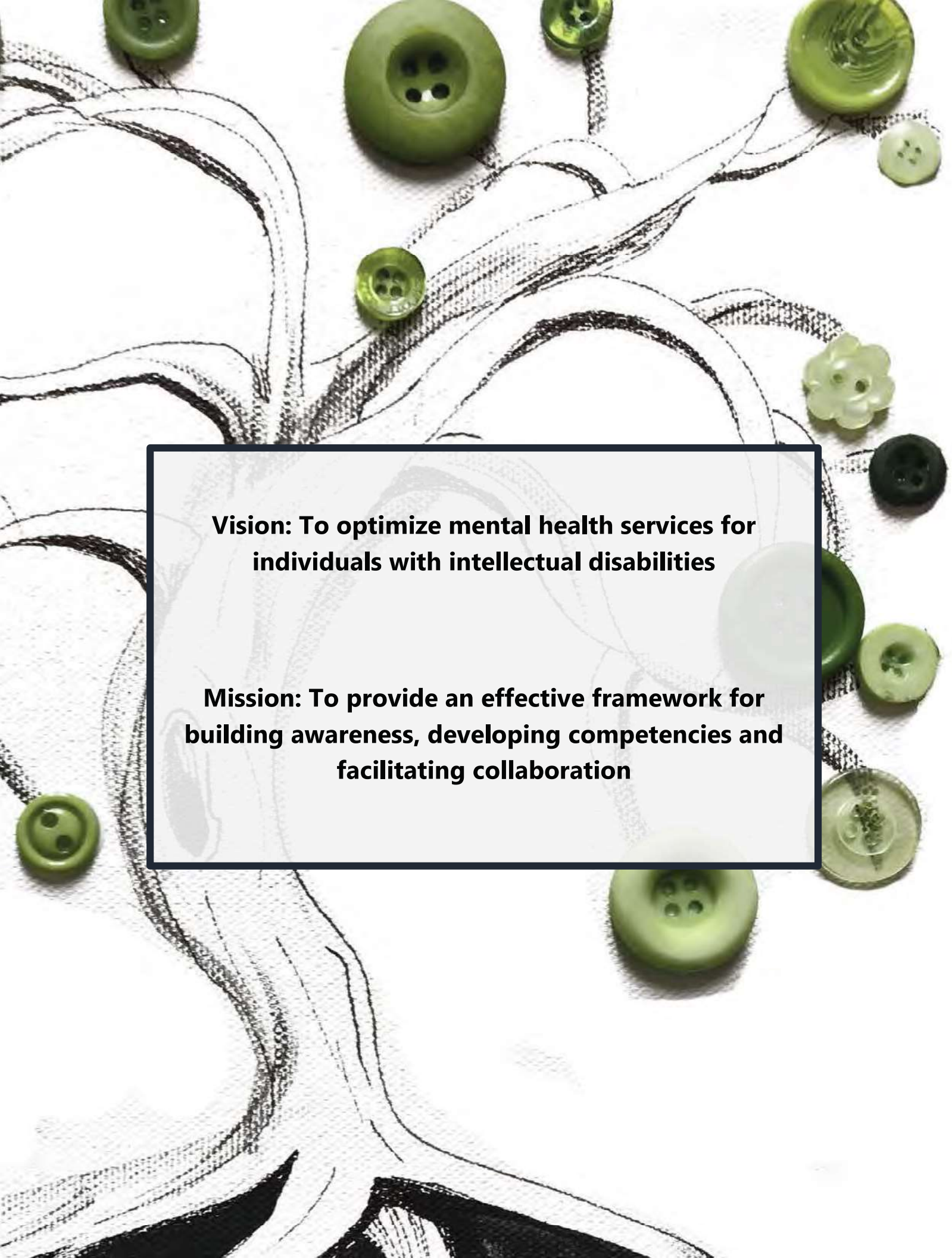


Vision: To optimize mental health services for individuals with intellectual disabilities

Mission: To provide an effective framework for building awareness, developing competencies and facilitating collaboration

Introduction

Purpose and Intended Audience

Phil Diaz, Ph.D. and Katie Kimball, MSW-c

The Guidebook was developed by a team of professionals currently serving individuals with intellectual disabilities in the community. It originated out of the need to open the dialogue among providers and systems to better serve people experiencing co-occurring intellectual disabilities and mental health disorders. It is intended to be a resource for mental health providers who serve, or would like to serve individuals with intellectual disabilities and mental health disorders. It applies to all settings where mental health care is provided, from intake to crisis.

Language

We all understand the importance of language and the significance of the terms we use. The words we use are powerful and evolve over time. This is especially true when discussing what is known as intellectual disabilities. The evolution of the terms mirrors the growth of research, treatments for various disorders, sensitivity to individuals diagnosed with intellectual disabilities, and public policies and law.

The history of society's use of terms dramatically effects perceptions of people who are diagnosed with intellectual disabilities. The first issue surrounding communication about people with or without intellectual disabilities is the position of the person when a disorder or condition is referenced. Medical terminology described the disorder, not the person. This example made its way into the common language. In this manner, individuals were referred to as their diagnosis, not as a person. This is hurtful, in the extreme, to refer to a person as a diagnosis. In doing so, the person loses their humanity. Instead, they are an object, not a person. "Person First Language" is more than reordering words in a sentence. "Person First Language" is a philosophy that recognizes the individual's status as a person who is more than a label, a place, or his or her current state. Each has rights, feelings, aspirations, desires, and dignity that must be honored, respected, and preserved. "Person First Language" describes the person's attributes and does not render the person down to a diagnostic label or funding category. Language matters; it drives other's reactions.

People diagnosed with an intellectual disability were labeled many things in the past. Previous diagnostic language used the term "Mental Retardation." This term drove much unjust treatment of people with intellectual disabilities. This term encouraged health professionals to counsel parents to institutionalize their loved one. This term found its way into the cultural slang and was changed into severe epitaphs. This term gave license to schoolyard taunts and tricks that continued into work places, housing, and community venues. It is this history that prompted the community of individuals with intellectual disabilities to speak out and raise awareness that words matter. Through their advocacy, the term has changed and "Mental Retardation" is no longer accepted. "Person First Language" has driven policy change to produce an era when individuals with intellectual disabilities have the same rights as all people. People with intellectual disabilities are people who are appreciated for their capabilities. Each are described by their name, activities, accomplishments, status, etc. Like every other person, individuals with intellectual disabilities have the right to a fully integrated life in the community they call home.

What is Intellectual Disability?

Phil Diaz, Ph.D.

Intellectual Disability (ID is categorized in the Diagnostic and Statistical Manual of Mental Disorders, 5th Ed. (DSM-5 as a Neurodevelopmental Disorder[1]. Diagnoses in this group occur during the human developmental period. They generally become observable early in the person's life, most prior to the child entering grade school. These disorders have in common effects that show themselves through the child failing to achieve developmental milestones within the customary time-frames for the larger population. The effects are seen in the person's ability to gain skills and use them to function in the areas of life including: taking care of themselves; recruiting, making and maintaining social relationships; learning new skills; and functioning in settings that expect consistent production of effort like learning in school or accomplishing job tasks.

ID is marked by deficits in general reasoning skills, problem solving, planning, thinking abstractly, exercising judgment, learning academic skills, and drawing conclusions from their personal life experiences. Difficulties in these general cognitive abilities are observed to affect the person's ability to function independently and take care of responsibilities. This translates to significant delays in being able to take care of their person and personal care needs; communicating with others using language; developing and maintaining friendships; social judgment; managing their financial affairs; and learning and using practical knowledge. These tendencies are pervasive and seen in multiple contexts including the person's home, the academic or work place, and in the community.

Appendix A: Washington States Definition of Intellectual and Developmental Disability

Prevalence

Katie Kimball, MSW-c

People with ID experience mental illness at an increased rate that is greater than the general population[2]. It is estimated that 30-35% of those with ID have a co-occurring mental health disorder compared with 15-19% in the general population[3,4].

Approximately 1.58% of the general population is estimated to have an intellectual disability[7]. In Washington State, this means that about 111,582 children and adults may have an intellectual disability. Of that 111,582 it is estimated that 39,054 have a co-occurring mental health disorder.

Artist: Eddie Remington

"People with ID are at least 2-3 times more likely to experience a mental health disorder than the general population[2,5,6].

Relationship between Intellectual Disability and Mental Health

The content in this section is used with permission from the Centre for Addiction and Mental Health[5]

People with an ID are more vulnerable to mental health disorders. This is due to the complex interaction between the ID, biological, psychological and social factors[2].

Biological factors

Genetics

Some genetic disorders that cause ID can predispose a person to having specific mental health conditions. For example, someone who has fragile X syndrome is at increased risk for developing social anxiety, and someone with 22q11 deletion is at increased risk for developing schizophrenia[8].

Brain chemistry

Research indicates that chemical processes in the brain are involved in the development of mental health conditions. Recent research points to abnormalities in brain structure as a possible factor in the development of mental health conditions, particularly schizophrenia. People with ID may be predisposed to developing mental health disorders because people with ID have physical brain structures and chemical processes that differ from those in a neurotypically developing person[9].

Medical vulnerabilities

Individuals with ID have a higher incidence of medical conditions compared to the general population[10]. Medical problems are often missed because of communication differences or misattributed as "challenging behavior".

Seizures are more common among people who have ID. There is a complicated relationship between epilepsy and mental health conditions in people with ID that may reflect the underlying brain disorder causing the seizures rather than the epilepsy itself[11,12]. Seizure disorders are important to consider because they may explain a person's challenging behavior.

At least nine genetic conditions have been shown to overlap with mental health disorders and challenging behaviors[8].

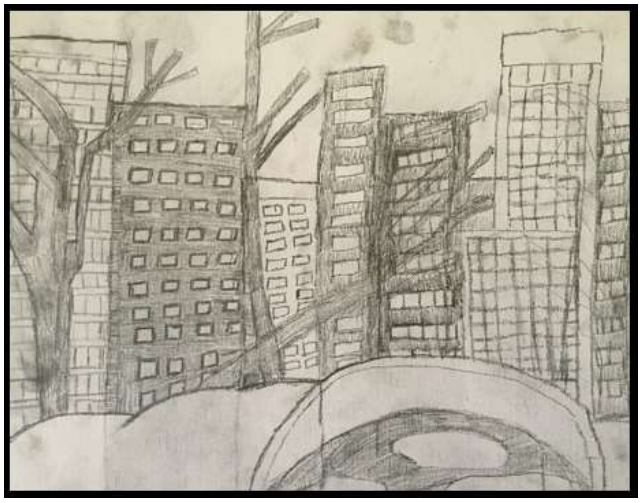
Artist: Esther Anderson

Psychological factors

The temperament a person is born with (e.g., a person's tendency to internalize feelings) may increase the risk of developing mental health conditions. Psychological risk factors interact with life stressors, biological predispositions, and skill development resulting in a person's often impacting a person's ability to cope with stressors and remain resilient. Psychological risk factors include: poor social skills; poor coping and self-soothing skills; poor problem-solving skills; problems with communication; and low self-esteem.

Stress

Although stress does not cause mental health conditions, it can trigger or make them worse. People with ID experience a lot of stress in their lives and may have an even more difficult time coping with stress than do people in the general population.



Artist: Eddie Remington

Social factors

Negative life events have been tied to the development of mental health conditions in individuals with ID[13]. Research suggests that early childhood trauma and losses, such as the death or separation of parents, or adult events, such as the death of a family member or loss of a job or day activity, can be precursors to a mental health disorder. Conflicts with family members, residents or staff may be an important area of concern for individuals with co-occurring diagnosis.

Other environmental risk factors include poverty and lack of social support. People with ID are more likely to experience poverty and poorer housing conditions and live in high-crime areas compared to the general population[14].

Physical, sexual and psychological abuse

Individuals with ID are at increased risk for maltreatment and neglect. Those admitted to psychiatric hospitals, as well as those living in the community, should be screened for a history of maltreatment.

Transition from adolescence to adulthood

In the general population, the transition from adolescence to young adulthood (16–25 years) is a high-risk period for developing mental health conditions. This risk is higher in young adults with ID[15]. Young adulthood is the most likely time for psychiatric hospitalization in individuals experiencing ID[16].

People with ID are affected by the stresses of puberty, as well as by the specific stresses associated with transitioning from the child to adult service system, which often means losing school supports and not getting sufficient services. This transition may also be a period of increased stress on family and parents.

Presentation

Katie Kimball, MSW-c

Mental health disorders can present in different ways in people with ID and how they present can change over time[2,5].

As ID ranges in severity from mild, moderate, severe and profound so too does the individual's ability to communicate what they are experiencing. Symptoms may present differently in individuals with more severe ID and often manifest in the form of what is frequently termed "challenging behaviors".

Artist: TJ Goldsby

Behavior is a form of communication.

Artist: Willie Preston

Barriers to Accessing Services

Katie Kimball, MSW-c

Though the prevalence is high, individuals with ID face daily barriers to accessing necessary mental health services. Impediments to accessing services include:

- Provider capacity and a shortage of professional expertise[17,18].
  - Overshadowing, the presenting issues, often challenging behaviors are attributed to the individual's disability, instead of considering underlying medical and mental health conditions.
  - Atypical presentation
  - Differences in communication styles, can make it difficult to assess, diagnose and treat both medical and mental conditions.
- Design and operation of the existing delivery systems and funding, often resulting in a lack of cross system collaboration[17,18].

Additional barriers to accessing mental health services may include stigma, lack of support in seeking services and a lack of awareness of symptoms one may be experiencing.

Guiding Principles and Values

Rights and Inclusion

Katie Kimball, MSW-c and Phil Diaz, Ph.D.

Individuals with ID are entitled to access all services available to the public. The criteria used that guide acceptance and treatment for the general public are the same policies and criteria for accepting a person with an ID into services; however, they may require accommodations to be made so that they can access and benefit from services. This is how a person with ID becomes fully integrated in their community. Individuals who have been diagnosed with a mental health disorder have experienced similar prejudices and inability to be fully integrated in their community.

Artist: Angela Stevens

While people who have been diagnosed with mental health disorders and individuals with ID face similar problems of access, the community support system developed dramatically different systems to address each constituency. Never-the-less, both systems share similar values:

- People have a right to a quality life or life of recovery in which they are defined by their strengths, abilities and inherent value[19,20].
- People are entitled to respect, dignity and equality[19,20].
- People have a right to live a life that is independent and inclusive with opportunities that optimize personal power and choice[20,21,22].
- Services for people should be person centered or person driven[20,22].
- People are culturally diverse. Services should be provided in a culturally competent manner.
- People have a right to a life that is healthy and safe[20,22].
- People are entitled to a life that is "free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights"[21].
- People have a right to live a life where they have meaningful opportunities to be "productive" and are "recognized for their contributions" where they are "fully included and actively participate in all aspects of society"[19, 20, 21].
- People benefit from being active members of their community where they have "relationships and social networks that provide support, friendship, love and hope" [20].

In the context of providing mental health services, people with ID have the same rights as the general population. This means we need to ensure that people with ID have the same: Access to quality mental health services, without discrimination and that we support people to understand their rights[2].

Disability Competent Care

Katie Kimball, MSW-c

Disability Competent Care (DCC) is person-centered and places an emphasis on treating the whole person utilizing an interdisciplinary team. It is a model designed to "respond to the participant's physical and clinical needs while considering their emotional, social, intellectual, and spiritual needs"[23].

DCC offers a framework in which services and supports are optimally engaged.

DCC engages health care professionals across settings and requires cross systems collaboration around a unified care plan.

> ***"Rather than focusing on a diagnosis, disability competent care focuses on providing care and support for maximum function and addressing the barriers to integrated, accessible care"[23].***

Artist: Rachel Canavor

Artist: Terry Smith

Person Centered Approach

Katie Kimball, MSW-c and Phil Diaz, Ph.D.

Person centered or a person driven approach to mental health services values the person's abilities, interests, desires, and power. Person centered treatment is predicated on the individual being an active participant in their care. It encourages the person to focus on their goals. Person centered treatment engages the individual and promotes independence. It builds upon the person's strengths and empowers them to realize their greatest potential and achieve the life they desire.

The person centered approach provides the person with personal power and choice regarding their care. The person centered approach invites opportunities to collaborate and coordinate with other support systems such as family, care providers and health care providers on a unified and holistic care plan.

Recovery Oriented Care

Katie Kimball, MSW-c and Jessica Shook, LMHC

Congruent with DCC, and well known within the provision of mental health services, are Recovery, Recovery Oriented Care and Recovery Oriented System of Care (ROSC).

Recovery as defined by SAMHSA is "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential" [20].

Recovery Oriented Care (ROC) is "the treatment and rehabilitation that practitioners offer in support of the persons own recovery journey" [24].

Recovery Oriented System of Care (ROSC) – "a coordinated network of community-based services and supports that is person-centered and builds on the strengths and resiliencies of individuals, families, and communities to achieve improved health, wellness, and quality of life" [25].

Individuals with ID can engage in the process of "recovery." Through creative, traditional and non-traditional approaches and coordinated, collaborative efforts, individuals with ID can learn and gain coping skills to manage and improve their mental health and quality of life.

This requires flexibility and support from mental health providers, and respect for a multitude of life experiences. A key tenet of recovery is that the individual is guided and supported, but defines their own goals and success. Instead of a cookie cutter picture of health and recovery, meeting the individual where they're at.

Whole Health

Jessica M. Shook, LMHC

Whole health, a biopsychosocial model, is both a method of assessment and a philosophical view of others– it is fundamentally respectful to see and interact with an individual as a whole person with hopes, dreams, goals, challenges, strengths, and resources of their own – not simply a diagnosis. The biopsychosocial model looks at the whole person – providing a better picture of possible solutions without "missing the forest for the trees". Particularly for individuals with ID, focusing on one symptom or factor can seriously impact the ability to truly assess and understand how to best help and support the person.

There is a tendency to focus on and attribute pathology to one particular symptom or behavior without seeing the context of the individual's whole life and circumstances. There are many behaviors that, if identified alone, appear to be indicative of poor cooperation, poor motivation, unresolvable maladaptive behavior, or overt defiance and aggression. When noted in the context of the whole person's experience, they are often indicators of trauma or mental health concerns. Disorganized sleep, irritability, aggression, self-harm, destructive behavior, restlessness, refusal to cooperate, and refusal to go to appointments can all be the result of an individual struggling with anxiety, depression, or Posttraumatic Stress Disorder (PTSD). For someone who has little to no control over their life, poor cooperation or aggression can be a way to experience control over their circumstances and cope with symptoms. These symptoms, observed in the context of the whole person, are strategies for survival.

Two clinical strategies that support the biopsychosocial model:

Disability Competent Care (DCC

This provides care and supports for maximum function and addresses the barriers to integrated, accessible care, rather than focusing on provider competence regarding each specific disability (which would be nearly impossible, given the range of human experience). Focus on the individual as the best source of information about what is needed.

A-B-C (Antecedent – Behavior – Consequence

This is used in assessment of the whole person in context to map a pattern around specific symptoms and behavior. Once the pattern is identified, antecedents and consequences can be addressed or modified. Components of the biopsychosocial model rely on observation, eliciting self-report, gathering history from credible sources, establishing baseline function, and identifying strengths and resources.

It is imperative that the whole person be considered with relation to health, mental health, ID, social support and life stressors.

Artist: Rachel Canavor

Evidenced Based Decision Making

Katie Kimball, MSW-c

In the assessment and treatment of people with ID it is important to utilize evidenced based decision making. Asking questions, gathering information from all available sources, considering the whole person, context, available research, resources, and the mental health provider's expertise all contribute to making the most informed decision regarding the individual's care.

Things to consider

Psychological

- Reported mood
- Observed mood
- Reported symptoms
- Observed symptoms
- Mental health diagnoses and history of treatment (both inpatient and outpatient)
- Family history of mental health diagnoses
- Baseline functioning and current functioning (self-report and others' report)

Social

- History of trauma
- Daily routine and responsibilities (activities, employment, role in family)
- Living situation
- Family structure/contact
- Supports and resources
- Culture

Medical

- Current and past medications – both medical and psychotropic; any interactions, allergies, or side effects noted; any recent changes or adjustments
- Medical diagnoses and history of surgeries/procedures
- Reported symptoms (headache, nausea etc.)
- Observed symptoms (tremor etc.)
- Pay special attention to symptoms and history of medical conditions with behavioral/mental health presentation (UTI, seizures, dental infection, etc.)

Optimizing Mental Health Services for People with Intellectual Disabilities

Access to Care

Jessica Shook, LMHC and Katie Kimball, MSW-c

People with ID experience barriers to accessing care. These barriers come in a variety of forms and there are modifications available. Access to Care Standards are just that, standards, and are not as flexible as many individuals may need. Therefore, it is important for the intake worker and clinician to work collaboratively, think flexibly and creatively, and engage in evidenced-based decision making. More information is better than less, gather information from all available sources including the individual being assessed via report and observation, and seek consultation and perspective from other professionals. This includes seeking input from a Developmental Disabilities Specialist in the form of a special population consult prior to making that ultimate determination.

It is human nature to want to feel valued and understood and as an intake worker and clinician you have the opportunity to permit access to necessary services. Your role is vital to the well-being of the individual in front of you.

Artist: Greg Shea

Modification of Approach: From Intake to Crisis

Jessica M. Shook, LMHC and Katie Kimball, MSW-c

Modifying your approach to assessment and maintaining flexibility in meeting the person you are serving where they're at will give you the best picture and most accurate evaluation of their needs.

Environment

- Allow individuals to schedule intakes, if they call ahead and request an appointment use that opportunity to request that they or their care provider bring additional information i.e. a log of what has been occurring, etc.
- Allow more time for assessment and consultation.
- Allow for a larger space when appropriate and available.
- Individuals may be challenged by long wait times.
- Individuals may be challenged by over stimulating environments such as waiting rooms.

Be aware of mobility and sensory impairments, including access for assistive devices, seating options, potential difficulty arranging transportation to meetings, sensitivity to light or sound, and a need for more or less space.

Artist: Eddie Remington

Approach

- Avoid yes/no questions, if someone is trying to please you, they might answer yes to everything.
- Avoid abstract questions, keep your requests for information clear and straightforward. You can always ask follow-up questions.
- Simplify language, meet the person where they're at, remembering that someone who is nervous, uncomfortable, or in crisis may have difficulty functioning as well as they normally do.
- Increase structure, clearly explain the purpose of the meeting and your role. Also ask what they need and want to incorporate into your purpose.
- Minimize distractions, give yourself and the individual the best opportunity to focus. A high stimulation environment can increase anxiety and decrease their ability to participate fully in the assessment.
- Be direct and concrete, especially when asking questions about safety and suicide.
- Allow time for responses, individuals may vary in the amount of time needed to process questions and provide the most accurate answer.
- Use visuals, not everyone communicates best verbally.

Arrange for interpretation as needed, you will collect more accurate information if the individual is able to understand and express themselves fully. If the individual is comfortable with it, a support person or family member may be able to assist with interpretation. A certified interpreter is needed for any involuntary assessment.

Particularly for crisis and Involuntary Treatment Act (ITA) assessments, flexibility and awareness of the individual's experience is key. Within reason (and when safe) go to where the individual is. This may involve sitting on the floor, starting a conversation through a door, walking and talking, or keeping an assessment extremely brief. Emphasize their comfort, they are not required to talk to you. This may mean that you leave the lights off, let them remain in bed, or give them full permission to pace or move around as needed. If it results in further participation, it's worth it.

Appendix B: Intake Interview Expanded

Engaging the systems of care and collaboration are integral to the individual's success.

Artist: Rachel Canavor

System of Care and Collaboration

The people we serve present with unique challenges. It is vital to incorporate other parts of their system of support. People with co-occurring disorders require providers and systems to collaborate and wrap around the person. To achieve cross-system collaboration:

- Develop points of contact within systems
- Develop relationships with people in different parts of the system
- Develop a team, incorporating the different systems
- Facilitate team meetings
- Create a unified care plan and define roles

What Am I Seeing Here? Symptoms? Behavior?

David O'Neal, M.S.

Individuals with ID experience the full range of mental health disorders. Symptoms may have an atypical presentation and are often demonstrated behaviorally. Diagnostic criteria relies heavily on self-report and reflection which can be challenging for some individuals with ID.

The following section highlights the more prevalent disorders with discussion and a side by side including some of the possible behavioral presentations. For a more in-depth view and understanding of how disorders may present in people with ID, we encourage you to utilize the DSM-ID and similar resources[4,26].

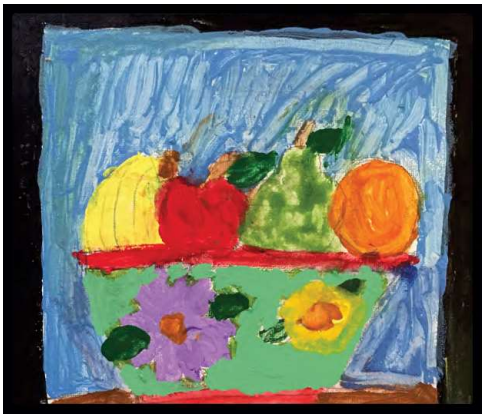
When assessing mental health disorders, you should consider deviations from the individual's baseline.

DSM-5 Criteria for Schizophrenia[1]

- Delusions
- Hallucinations
- Disorganized speech
- Disorganized catatonic behaviors
- Negative symptoms
    - Autism rule out now in DSM-5

Behavioral Presentations[4]

- Behavior indicating fear and suspicion of others, irrational beliefs not previously expressed, false accusations
- Talking, listening, smelling things not perceived by others, scratching, reporting on conversations
- Regression in language skills, lack of sense or coherence
- New unusual mannerisms, assuming positions for periods of time, regression in performance, agitation
- Inappropriate or lack of emotional response, depression



Artist: Eddie Remington

Schizophrenia and Other Psychotic Disorders:

Research suggests that the risk of schizophrenia in individuals with ID is around 3% compared to about 1% of the general population[27]. Schizophrenia is now considered to be neurodevelopmental condition. A clinician must take into account the cognitive level of functioning and whether impairment is related to psychosis or severity level of ID. Another defining characteristic is the "break" – the sudden onset and change in functioning. The individual's full history is needed to compare level of functioning prior to and after the onset.

Psychosis is a defining characteristic of schizophrenia, and is not a common disorder. Psychosis is often misdiagnosed or minimized in individuals experiencing ID. There are many possible causes, many are medical, and caution must be paid since people with ID may have self-talk, imaginary friends, fantasy play and beliefs, which can be misidentified. Psychosis indicates severely distorted perception, abnormal thinking, or loss of reality, and is a symptom of many illnesses. Primary symptoms include hallucinations and delusions, and secondary are other observable symptoms (e.g. catatonia.

Delusions are fixed ideas believed despite evidence. These typically present as persecutory-TV news stories about the affected individual, being controlled, religious fanaticism, somatic complaints and false pregnancy.

Hallucinations are sensations one believes to be real even though others do not experience them. They can involve any of the five senses, although the most common is auditory – e.g. voices talking over them, arguing over them, a running commentary in third person, commands telling them to do something.

There is evidence that the new DSM-5 diagnostic criteria can be used reliably but the behavioral disturbances as a result of psychosis are more significant for people with higher severity of ID[1,4]. As with many of the disorders any significant change should be noted. If there is an increase in self-injury, aggressive behavior or just atypical or non-baseline behavior and medical concerns have been ruled out it may signify the possibility of psychosis.

Bipolar Disorder:

Characterized by extreme mood swings. It is typically defined by the presence of mania where the person has markedly changed grandiose thinking, euphoria, irritability, and lots of energy and confidence. Bipolar disorder is evidenced to have strong genetic links and it is estimated that 1-5% of people with ID experience co-occurring Bipolar Disorder[28, 29].

Mood Disturbance/Elevated or expansive may be demonstrated by the person getting angry when in a calm state, or loudly or inappropriately laughing and singing, behaving boisterously, acting giddy, intruding, smiling excessively, and behaving above baseline mood.

Sleep behavior is generally an issue for people in a manic phase. This can be disruptive as the manic person is up and disturbing others trying to sleep. This is a common reason an initial referral may be made to a mental health provider. The lack of sleep associated with mania is a physiological symptom.

Grandiosity and inflated self-esteem might look like a person with ID stating they fly an airplane, or taking things apart and think something is done well when it is obvious that it isn't. "I'm making a four course dinner" but they are too disorganized to do so.

Pressured speech and flight of ideas might present as an increase in vocalizing, screaming, not listening or wanting immediate answers, a rambling monologue, may increase in perseverative themes, and this can also be a disorganization of speech that they normally communicate clearly.

Distractibility can be observed by reduced productivity, or when asked to do something the person used to do, has an unexplained skill loss and might be unable to finish it.

Goal directed activity might present as pacing and fidgeting and rarely sitting in someone less verbal or skilled.

Excessive pleasure might be exhibited as an increase in masturbation, sexual activity, and spending or giving away money.

Some genetic disorders that correlate with bipolar disorder include: Fragile X, Rubenstein-Taybi, and Prader-Willi[4].

DSM-5 Criteria for Mania[1]

- Mood Disturbance/Elevated or expansive
- Grandiosity
- Decreased need for sleep
- Talkative/Pressured speech
- Flight of Ideas
- Distractibility
- Increase in goal directed behavior
- Excessive involvement in pleasurable activities with potential for poor consequences

Behavioral Presentations[4]

- Mood is inflated or excessive and doesn't change regardless, irritable or angry
- Believes/acts as if they can do more than developmental level
- Sleeps 4 hours or less; sleepless nights, problems at night
- Nonstop rapid talking or singing; not conversing just thoughts coming out
- Rapid changes from topic to topic; often unrelated
- Too alert to stimuli, work goes undone or done sloppy, skips between activities
- Increased speed but no attention, creates new tasks and projects that are unrealistic, increased rituals
- Increase in sexual interest and behaviors with people not previously favored, preoccupied with hobbies or activities, intrusiveness, disinhibition, can't follow known rules
- Self-injurious behavior
- Aggression

Major Depressive Disorder:

Prevalence data has estimated that 1-4% of individuals with ID may suffer from Major Depressive Disorder[30].

Due to the often complex lives that individuals with ID live, depression is relatively common, though frequently underdiagnosed or recognized.

Depressive criteria often present as challenging behaviors and also might be seen as withdrawal, a loss of adaptive skills, psychotic features, etc.

A depressed mood can be observed and it can be felt. When an individual with ID stops engaging in preferred enjoyable activities it is a problem. When there is a change and refusal of things increases despite the continued offer of various reinforcements, or they begin increasingly becoming isolative, it is a sign of the third criteria. They may not tell you they don't feel like it as a typical developing person might and it is often misinterpreted as manipulative or "non-compliant".

Watch for changes in weight (up or down) and sleep patterns – these are signs of many things but are a clear observable disruption and play a role in major depressive disorder.

Psychomotor issues require a knowledge of baseline or when a person is at their best. Is there an irritated restless energy to them causing pacing, disruptive behaviors, or are you observing or being told they are moving much slower than typical?

Fatigue can be observed through body posture, or in difficulty completing tasks.

Feelings of worthlessness might be hard to assess in a person with limited verbal or communication skills but in those that can you will hear statements such as "I'm dumb", "I should die", "I'm an idiot and I should go to jail". This can also be part of the suicidal thought criteria. Individuals may gesture, or verbalize thoughts of harm or preoccupation with other deaths they have experienced (family, friends, celebrities).

DSM-5 Criteria for Major Depression[1]

- Depressed Mood
- Irritability
- Decreased interest
- Appetite change
- Sleep Disturbance
- Psychomotor agitation/Delay
- Fatigue
- Guilt or worthless
- Suicidal thoughts
- Decreased concentration

Behavioral Presentations[4]

- Crying spells, appears sad
- Screaming, aggression
- Social withdrawal
- Weight change
- Wakes early or middle of night
- Pacing, rocking
- Sleeps all day
- Self-deprecation
- Statements or gestures
- Inability to stay on task or have focus

Artist: Danielle Bowers

DSM-5 Criteria for Anxiety Disorder[1]

- Excessive Anxiety and Worry
- Worry cannot be controlled
- Symptoms cause distress or impairment
- At least 3 behavioral symptoms are present

Behavioral Presentation[4]

- Restlessness
- Difficulty concentrating
- Irritability
- Muscle tension
- Sleep disturbance/easily fatigued
- Increase in pacing, activity, aggression
- Increase in perseverative thoughts and statements, talking and vocalizations

Anxiety Disorder:

Anxiety is one of the most prevalent disorders experienced by individuals with ID. Anxiety disorders are characterized by panic, fear, uneasiness, uncontrollable obsessive thoughts, nightmares, problems sleeping, nausea, muscle tension, a sense of apprehension, physiological symptoms, and perception of threat, etc.

The diagnostic formulation for generalized anxiety disorder in the DSM-5 is very applicable to individuals who experience ID with the exception of anything that relies on a subjective description. In persons with ID the insight about thoughts or the ability to articulate these thoughts and feelings can be difficult.

Post traumatic Stress Disorder (PTSD):

PTSD is a common diagnosis and is likely under recognized. Meeting PTSD criteria is not always the same as suffering traumatically. We cannot assume an event isn't traumatic because it doesn't meet the definition of a DSM-5 event (abuse, injury via accident, natural disaster, war). With chronic symptomology, trauma type reactions may develop. Trauma research has developed language of Big T and little t. "Big T" are heavy hitters meeting DSM-5 criteria clearly, and include physical and sexual abuse, neglect, and witnessing domestic violence. "Little t" are emotional, developmental, social, and interpersonal traumas. Among people with ID, 30- 90% have experienced traumatic stressors[31]. Individuals with ID experience significantly higher rates of both types of T. Individuals with ID are twice as likely to experience victimization or abuse compared to someone without ID[31].

DSM-5 Criteria for Posttraumatic Stress Disorder[1]

- Traumatic Event
- Flashback/Intrusive recollections
- Avoidance and Numbing
- Hyperarousal
- Duration

Behavioral Presentations[4]

- Reactivity to cues of events, repetitive play with trauma theme, frightening dreams, dramatic behavioral change, reenactment
- Non-compliance, isolation, elopement
- Sleep difficulties, poor concentration, and vigilance
- Self-injurious behavior
- Compare to pre-trauma information, function with trauma vs developmental level and severity of ID

Some of the manifestations of PTSD that might be seen in someone with ID are: flashbacks- though the re-experiencing is more behavioral and overt; self-injurious-behavior; re-enactments; and aggressive or inappropriate sexual acts. If you experience a flashback and are not able to communicate that experience it will likely be misunderstood. In fact, most people with PTSD experiencing a flashback only get sensations, or feelings, or intrusive thoughts in bits or pieces of memory and have trouble explaining it. The criteria of avoidance might look like noncompliance or isolation. Hyperarousal may present as the person introducing themselves to everyone aggressively when new people arrive and getting up at night to check on things. Depression often follows trauma. If the person you are serving is presenting with symptoms of depression, gather and review historical information to determine if symptoms may be the result of trauma.

Artist: Eddie Remington

Artist: Rachel Canavor

What do I do?

David O'Neal, M.S.

Therapeutic approaches can be adapted to support individuals with ID. This has been evidenced in the Modification of Approach section and the modifications hold true throughout the treatment process. Interventions for mental health disorders in individuals with ID are the same as for any other individual suffering from the collection of symptoms, they just need to be tailored to meet the developmental and intellectual level of the person in front of you. Many practices have already developed additional protocols and versions which can be applied when working with an individual with ID. Level of intelligence is not a sole indicator for appropriateness of therapy. The key is in the adaptation and expectations of the treatment chosen.

Most disorders should be treated with a multi-modal approach utilizing an interdisciplinary treatment team and a combination therapeutic and pharmacological interventions.

Therapeutic principles to optimize mental health services for ID

1. Benefit of therapy does not depend on a person's level of assessed intelligence.

Abstract reasoning and verbal skills are often utilized within traditional therapeutic processes. However, there are many methodologies that focus on things such as thoughts, emotions, self-identity, emotional maturity, and development of relationships which are less reliant upon the traditional process and IQ level. Regardless of the assessed developmental and intellectual age, the therapeutic process should acknowledge the life experience associated with the individual's chronological age. Common struggles might include independence, interpersonal relationships, work or vocational problems, sexuality related issues, family, etc.

2. Transference and Countertransference issues are going to come up.

People with ID are more likely to respond to any adult as figures of authority, or potential care givers, or some other image they have formed during their lifetime. Explaining the role of clinician is important especially as it may relate to other relationships they have such as staff, parent, friend, partner, etc.

3. Individuals with ID have often been rewarded for being dependent and compliant.

This can hinder therapy and the relationship, and consideration of the system of care and environment they are in is a factor. Often a referral to mental health comes when someone with ID is "non-compliant" or "manipulative". These are often very helpful strengths in a person's character but are interpreted as outside of the norm and a problem behavior when in fact a skill we often find ourselves teaching is assertiveness. So the goals of therapy may at times conflict with the goals of other service systems so teamwork and problem definition is vital.

4. Empathetic understanding.

It is important to express empathy. Trying to understand the inner world of the individual, considering what it would be like to be in their shoes, navigating in the world with the disability they have.

5. Confidentiality

This is always an expectation of mental health care. However, when working with an individual with ID it is important not to work in isolation and to work as a member of the overall treatment team including family, other care providers, etc. Communication should be around conceptual issues and homework or information gathering vs details about what is discussed in therapy. And of course can only be done after the person has given consent.

Artist: Eddie Remington

Adapted Approaches to Therapy

We can provide intellectual and cognitive access to therapy starting with the recommendation, "go slow, be concrete, repeat" [32].

In the absence of teaching, learning still occurs. We have to maximize learning opportunities outside of the individual session. This can be done with the inclusion of various methods including the use of visuals, group therapies and homework assignments. A gentler pace and the utilization of multiple styles allows for improved generalization and absorption.

Role play or psychodrama is a useful technique for practicing or observing new or tough situations, coping skills, and role reversal. It can be very helpful for a person with ID when drawing out clarity around feelings.

Skills teaching is often more effective than traditional talk therapy. It focuses on building coping skills rather than insight[33]. Incorporate different learning styles; break down more complex skills into smaller more achievable steps; take your time and practice.

"At our facility we tracked bed making - seriously other than my mother - what the hell does that have to do with improving my life. Teach skills that lead to abilities that are important to quality of life. Bed making is a neat room, friend making is a neat life" [34].

Feedback can be useful and challenging. The key is to be as specific as possible in your recommendations for change[33]. Reframing statements can be helpful "I like how you asked for help when you got stuck on that" can also be framed on how others are impacted "how do they feel when you yell?"

Task analysis and chaining are another beneficial tool. Use pictures, art, social stories, music, audio and lists, etc. This could be used to identify relaxation steps, for example.

Many books, manuals, guides and research articles have been written regarding how to adapt therapeutic approaches to meet the needs of individuals experiencing ID.

Cognitive Behavioral Therapy[35]; Dialectical Behavioral Therapy; Mindfulness-Based Cognitive Therapy; Positive Psychology Practices; Interactive Behavior Therapy; Narrative Therapy; Eye Movement Desensitization and Reprocessing Therapy; Motivational Interviewing; and Group Therapy all have an evidence base that supports the use of these techniques in populations with ID[36,37].

Feedback can be useful and challenging. The key is to be as specific as possible in your recommendations for change[33].

Artist: Maggie Craughan

Make it as concrete as possible, write it down, make it visual, use music, art, social stories, therapeutic games, yoga, repeat, review, practice

Benefits of Mental Health Service

Jessica M. Shook, LMHC

As professionals who work in mental health, we know about the benefits of a therapeutic relationship. The goals and specific methodology can vary from psychodynamic to behavioral, you may be working on past trauma or teaching skills to manage anxiety, but the benefits of a supportive, empathetic counseling relationship are always beneficial. The same holds true for individuals with an intellectual disability.

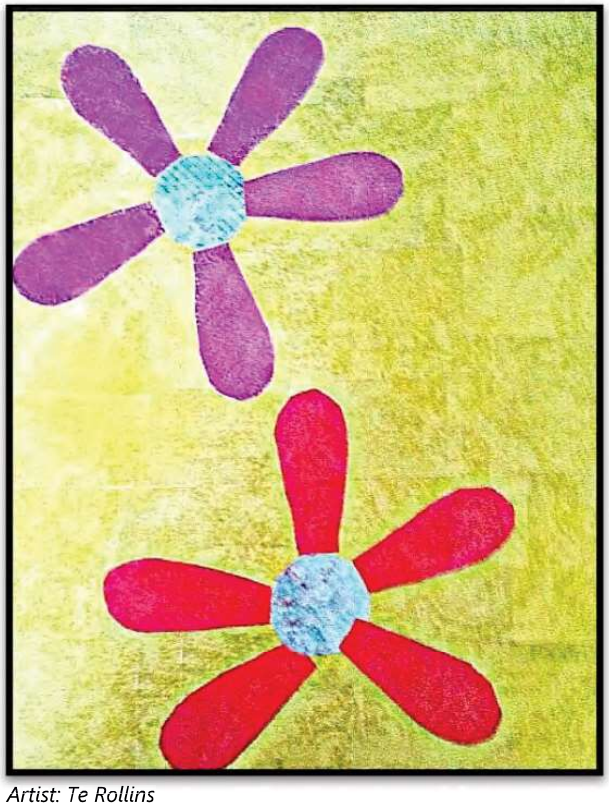
As professionals in our field, we follow a code of ethics. We are tasked with reducing suffering, providing equal access to treatment without discrimination, and assisting our clients to improve and maintain their quality of life. Mental health professionals, more than other professions, recognize the importance of individual personhood and lived experience, because we see it every day in our clients' lives.

Leaving aside all ethical and compassionate arguments, there are significant benefits of mental health services for individuals with ID. Individuals who receive appropriate treatment to manage their symptoms will be healthier, care for themselves better, manage their behaviors more appropriately, and maintain their functioning in the community. This will result in less incarceration, likely less medical care, and fewer episodes of crisis which can result in ambulance trips and admits to the ER. All of these things are costly and can be prevented with mental health care to help individuals maintain at baseline.

From a strictly practical standpoint, providing integrated mental health services for individuals receiving services for ID makes sense. When all the professionals involved can pool their knowledge and resources, effectively utilize specialists, and collaborate on treatment plans, the individual has a significantly better experience.

Medical complications, deterioration, and changes in functioning and mood are noticed and caught before they become a significant problem. A collaborative team approach results in the best care.

Individuals are not a series of compartments, and are not neatly divided into the different factors in their lives. We cannot separate physical health from mental health any more than we can separate challenges related to substance use, housing, education, employment, relationships, or social interaction. A struggle in one area will affect other aspects of an individual's life. Why would we compartmentalize treatment? Integration of mental health and ID services is more efficient, effective, compassionate, and respectful.



Artist: Te Rollins

Appendix A

Washington State's definition of Intellectual Disability[38]

Phil Diaz, Ph.D.

In Washington State the definition of Intellectual Disability is outlined in the Washington Administrative Code (WAC) and Revised Code of Washington (RCW). The Developmental Disabilities Administration Intake and Eligibility Determination WAC is 388-823. These are the "rules" that govern the Administration's decision-making by outlining the requirements and the things that are excluded as Intellectual Disability. For Intellectual Disability the subsections 200 and 210 outline:

- There must be a diagnosis from DSM-IV-TR as Mental Retardation or DSM-5 as Intellectual Disability documenting all three criteria listed in these manuals
- The diagnosis must be from a licensed psychologist or a certified School Psychologist
- The evidence supporting the diagnosis include:
  - A full scale intellectual quotient (FSIQ) more than two standard deviations below the mean
    - Intellectual testing must be administered by a licensed psychologist or Washington certified School Psychologist or National Association of School Psychologist certified School Psychologist (WAC 388-823-0730)
    - Resulting full scale intelligence quotient cannot be attributable to the effects of a mental illness or other psychiatric condition at any age or illness or injury after the age of 18 years
  - Adaptive functioning skills measured more than two standard deviations below the mean
    - Adaptive testing must be administered and scored by professionals with background in individual assessment, human development and behaviors, and measurement, as well as understanding of individuals with disabilities. (WAC 388-823-0750)
    - Tests must be administered following the specific test instruction
    - The adaptive test score cannot result from an unrelated mental illness or other psychiatric condition at any age; or other illness or injury after the age of 18 years

Artist: Kenneth St. Germain

Artist: Eddie Remington

Washington State's definition of a Developmental Disability

The Developmental Disabilities Administration serves people who have Developmental Disabilities in addition to people who have an Intellectual Disability. Who may qualify as an enrolled client of the Developmental Disabilities Administration is governed by the Washington Administrative Code chapter 388-823. Conditions outlined for inclusion for intake and eligibility decisions are: Cerebral Palsy; Epilepsy; Autism; and Another Neurological or Other Condition Similar to Intellectual Disability. There are specific requirements for each condition for which the applicant must provide documentation. Common requirements to all conditions is the onset during the developmental period (i.e., before the 18th birthday), the person's ability to function is significantly impacted by the symptoms of the disorder, and the diagnosis originated from the appropriately qualified professional.

Washington Administrative code defines Developmental Disability through four categories: Cerebral Palsy, Epilepsy, Autism, and Another Neurological or Other Condition Similar to Intellectual Disability. All demonstrate their effects prior to the 18th birthday. Each results from a physical mechanism. Diagnosis is made by licensed or certified professionals. Documentation must include biological assays, standardized testing, and clinical judgment. The expression of the condition affects intellectual and adaptive skills functioning, and that functioning is expected to continue indefinitely without being alterable by training or learning.

Cerebral Palsy

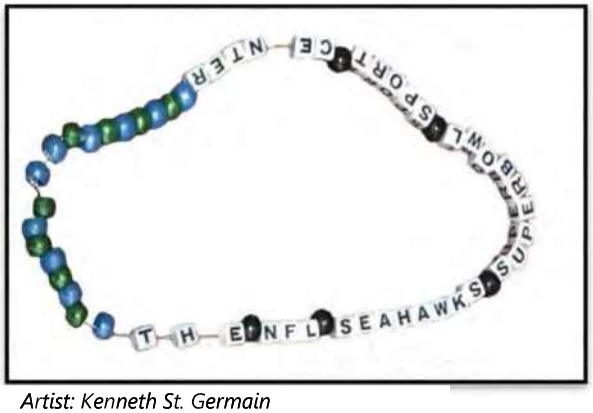
- There must be a diagnosis of Cerebral Palsy or similar brain damage causing quadriplegia, hemiplegia, or diplegia
- Onset must be prior to the age of 3 years
- The diagnosis must be from a licensed physician
- The evidence supporting the claim of substantial limitations requires direct physical assistance in two or more of the following areas
    - Toileting
    - Bathing
    - Eating
    - Dressing
    - Mobility
- Communication
- Direct physical assistance means the applicant needs the presence and assistance of a person to accomplish the task physically on a daily basis. (WAC 388-823-0760)

Epilepsy

- There must be a diagnosis of Epilepsy or a neurological condition that produces seizures
- Onset must be prior to the age of 18 years and must be expected to continue indefinitely
- The diagnosis must be from a board certified neurologist
- Must be supported with documentation of a medical history with neurological testing
- Must provide physician or neurologist confirmation that seizures are currently uncontrolled and ongoing or recurrent and cannot be controlled by medication
- The evidence supporting the claim of substantial limitations requires adaptive skill test scores reflecting daily functioning more than two standard deviations below the mean (WAC 388-823-0740)

Autism

- There must be a diagnosis of:
  - Autism Spectrum Disorder 299.0 per the DSM-5 with severity level of 2 or 3 in both columns of the severity scale
  - Autistic disorder 299.00 per DSM-IV-TR
- Evidence of onset must be prior to the age of 3 years and must be expected to continue indefinitely
- The diagnosis must be from a board certified neurologist, board certified psychiatrist, licensed psychologist, advanced registered nurse practitioner (ARNP) associated with an autism center or developmental center, or board certified developmental and behavioral pediatrician
- Must be supported with documentation of all diagnostic criteria specified in the DSM (IV-TR or 5)
- Must provide physician or neurologist confirmation that seizures are currently uncontrolled and ongoing or recurrent and cannot be controlled by medication
- The evidence supporting the claim of substantial limitations requires adaptive skill test scores reflecting daily functioning more than two standard deviations below the mean (WAC 388-823-0740) and a full scale intelligence quotient of one standard deviation below the mean as described in WAC 388-823-0720.
  - Completed autistic disorder confirmation form



Artist: Kenneth St. Germain

Another Neurological or Other Condition Similar to Intellectual Disability

- There must be a diagnosis of a neurological or chromosomal disorder that is known by reputable authorities to cause intellectual and adaptive skill deficits
- Condition must meet all of the following:
  - Onset must be prior to the age of 18 years and must be expected to continue indefinitely without improvement
  - Is other than intellectual disability, autism, cerebral palsy, or epilepsy
  - Not attributable to nor itself a mental illness, or emotional, social, or behavioral disorder
  - And results in substantial functional limitations
- The diagnosis must be from a board certified neurologist
- The evidence supporting the claim of substantial limitations requires:
  - Impairments in both intellectual and adaptive functioning which are separate from any impairment due to an unrelated mental illness, or emotional, social, or behavioral disorder
  - Full scale intelligence quotient 1.5 standard deviations below the mean (WAC 388-823-0720)
  - Or if under the age of 20 year, l significant academic delays of more than 2 standard deviations below the mean at time of testing in broad reading and broad mathematics
  - Or statement by a licensed physician, psychologist, or school psychologist that your condition is so severe that you do not demonstrate the minimal skills required to complete an intelligence test
  - Adaptive skill test scores reflecting daily functioning more than two standard deviations below the mean (WAC 388-823-0740)

Appendix B: The Intake Interview Expanded

Intake Interview

Phil Diaz, Ph.D.

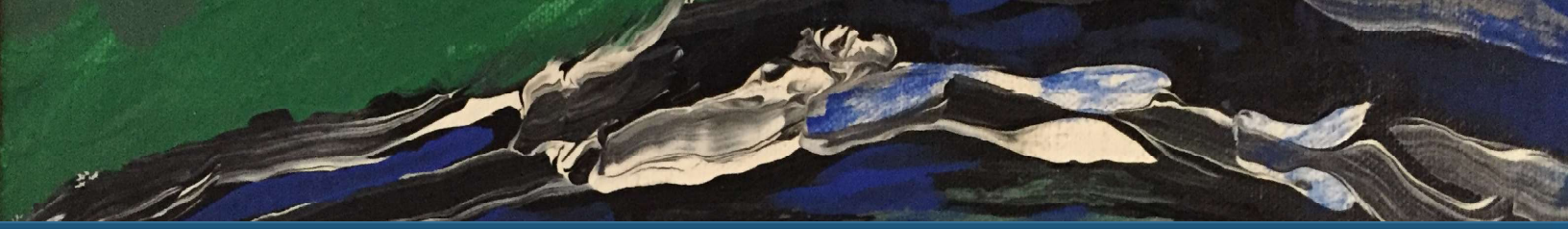
Correctly identifying mental health issues is a difficult task. So much so, the authors of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), fifth edition state, "The diagnostic criteria identify symptoms, behaviors, cognitive functions, personality traits, physical signs, syndrome combinations, and durations that require clinical expertise to differentiate from normal life variation and transient response to stress" (pg. 5). The current version of the DSM is predicated upon broad variability in how symptoms present in the general population. This variation is augmented in specialty populations, including the subpopulation consisting of individuals who are diagnosed with ID and a mental health disorders.

When faced with this task, intake workers and diagnosticians rely on the individual to report symptoms when they seek treatment. The diagnostician takes the self-report and compares that content with the verbiage in the manual. However, it is not just the verbal report of symptoms (behaviors) that is compared with diagnostic criteria. The clinician confirms the report of symptoms (behaviors) with observations of the individual in the interview. When the observation and description of symptoms (behaviors) is congruent, the clinician is more confident in their diagnostic impression. This confidence is upset when the clinician cannot speak directly to the client for whom treatment is sought and has to rely on another person. Clinicians must now split their attention while reconciling what they are hearing with the physical presentation of the client for who treatment is sought. As a result, the potential client is at an instant disadvantage.

When the potential client must rely on an interpreter or someone to speak for them, this separates the potential client and the diagnostician. That separation is not merely in the direct connection of the conversation; the separation is relational. The effect of a conversation brings the two speakers into a relationship and the reality created through conversation causes the formation of perceptions, shared understandings, and processes to move into the future. When a person must rely on a translator or someone speaking for them, that co-created reality and resulting relationship is not personal. This subtle, but not inconsequential, consequence affects the therapeutic relationship and the client's trust. Uncertainty is increased resulting in greater potential inaccuracies that mask themselves in behaviors like denial, non-reporting, refusal to speak, refusal to attend appointments, etc.

Because the primary source of information is not self-report, symptoms are reported and interpreted as "behaviors" and not perceived as symptoms or signs of a mental health disorder. Instead, reported behaviors are thought to be volitional, meaning they are used to gain or avoid something; however, if time is taken to understand the potential client, that experience may belie the misperceptions, personal interpretations, and professional bias for those who fluently use language.

Even if the potential client has fluent skills in language, mental health disorders present in different ways for groups within the general population. People with ID are no different. As in the general population, symptoms change over time.



As stress, social support, and personal abilities wax and wane symptom expression and consequence change. Thus, the symptoms reported at intake will change. There will be inconsistencies in reports both those collected earlier and between reporters describing the same person. This is normal for the general population and those who have an intellectual disability. The difference being for those who self-report, the intake worker may have greater confidence and be more willing to reconcile differences in reporting with the self-report.

The mental health intake worker and clinician must understand when dealing with a person who is dually diagnosed with an ID and a mental health disorder, the clinician will have to establish a relationship with the client. This takes time. This takes meeting the person on their terms. This means establishing trust. This means finding a way to share understanding (with or without the use of language). This requires the therapist to open themselves to other ways of reaching another human, understanding another human, and helping another human.

Artist: Marshall Porter

Intake Interview Questions:

When speaking with an individual who has ID, language and its pace are important. Yet the type of language is crucial to any hope of communicating. Individuals with ID use "concrete," simple language formulations. Context is used as an active member in the conversation. Language is literal, and deliberate. Shared meaning requires the interviewer to construct it.

Because he or she has more difficulty getting others to understand them, the potential client has learned to answer in a way that is pleasing to the interviewer. This means the potential client will seek to please the intake worker. The potential client may not understand the interviewer wants to accurately know their experience of symptoms. Thus the potential client may want to gain a friend and answer in a way they think will please the interviewer.

Because interviewers often have structured or semi-structured interviews generated by the Minimal Data Set or other assessment instruments, questions are often asked and answered once in predominately closed-question formats with a "Yes," or a "No". The person with ID has developed skills to compensate for not understanding or not being able to cope with the pace of the conversation. They may rely on "Yes," or "No" responses (response set answering). As a result, they may say yes to every close-ended question on the symptom questionnaire. Open-ended questions may be met with varying responses. Questions may be answered with very concrete communication. The therapists asks, "What brought you here today?" To which the person may answer, "The bus." The therapist intended the question to generate a list of symptoms or perceived problems. The individual understood the language concretely and gave a concrete answer. If the person with an ID does not understand the open-ended question, a broad range of responses may ensue. They may say nothing. The individual may change the subject for something in which they are interested or feel confident. Or the individual may resort to the, "Don't know," option.

Given the challenges with closed and open ended questions, it would seem there is no way to gain information from a person who has an ID. This is not true. The clinician needs to understand there is a person in front them, not an answer providing machine. The person seated in front of the clinician has feelings, insecurities, and a history that will limit their natural ability to provide accurate information. A person with ID is trained to be compliant when reared and when in adult services. This predisposes them to try to please the authority. But authorities cannot always be trusted. So how does the person with an ID minimize risk but comply? They give as little as possible. It is incumbent upon the clinician to overcome this when establishing a rapport with the person who has ID.

When asking Yes/No questions, ask the information in the positive and negative position. This allows the interviewer to observe whether or not the individual understands the question's content. For example, the interviewer may ask, "You have been arrested?" Once the client answers continue questioning for a minute or so and follow up with, "You have never been arrested?" Contrast the answers and follow up on the content.

For open-ended questions, the interviewer needs to introduce the topic. They need to let the potential client understand what is going to be talked about and that their answers are important. This might look something like, "Most people come here to tell me how they have been feeling and problems they have. Would you mind telling me about your problem? Wait for the person's answer. Okay, let's start…" The "Would you mind…" asks permission of the person to talk about these issues. When each topic or context changes, the clinician needs to make a concrete transition into the next conversational topic. This helps the potential client know where things are going without the anxiety of having to guess.

During all of this, the clinician must be acutely aware of pacing. Individuals with ID accommodate language at differing rates. The more complex the question or concept, the more processing time the individual will require in forming an answer. The clinician must carve out extra time to accommodate this need for processing. Similarly, the clinician may need to accommodate the individuals need for questions to ask about one concept in a concrete, straight forward manner. This may take the form of simplifying the language used; however, it should not take the form of patronizing or speaking to the person as if they were a child when the individual is an adult.

Interpreting the content of the individual's communication must account for context. Because the person with an ID may have a vocabulary of words that convey concrete or specific concepts, care needs to be taken to understand the context driving the individual's use of those words. This can range from the idiosyncratic use of works (Mom = all females) to neologisms (a word only the individual understands). This is not limited to spoken language. This can be observed in sign language, picture exchange communication systems, or in text. It is important to understand what the individual intends with these forms of communication; yet, the non-verbal accompanying these forms of communication can be more informative.

As with any interview, the interviewer must observe and understand the non-verbal communication surrounding the form of communication to comprehend the intended message. It is no different with individuals who have an ID. "MAAAAA", said while the individual is smiling and jumping up and down may mean something totally different when "Maaaaaa." is articulated while under a blanket in the corner of the room. The help of a collateral contact and observing the behavior will help inform the interviewer's understanding and comprehension.

Interpreting Content Gleaned from the Clinical Interview

Everyone wants facts. Frequency, intensity, duration, and severity that symptoms (behaviors) have on the person's function are desired. They assist in making a diagnosis in which the intake specialist is confident. Yet, much interferes with gathering this data.

First is the clinician's professional and personal preconceived notions of what a symptom or sign is. According to Dorland's Medical Dictionary, a sign is, "any objective evidence of a disease, i.e., such evidence as is perceptible to the examining physician, as opposed to the subjective sensations (symptom) of the patient"[39]. The crucial, but subtle issue in the definition is objective evidence that is perceptible. Perceptible evidence is empirical evidence, which is evidence that is observed. Results of test are observed, changes in skin are observed, and changes in metabolism are observed through physical means of measuring them. Changes in psychological process are observed in behavior.

"Are you hearing voices," tests for an internal state. Usually, it is assessed by asking and the potential client answers (observed behavior) giving an indication of their internal state. However the fact that a person may be hearing voices can be confirmed by observing them. Listening to the content of the person's language, hearing the tone, and observing where that tone and content are directed. For a person who does not use language, one looks for "attending to internal stimuli." In this case distractibility, irritability, and isolating while using self-soothing behaviors may be seen. This may indicate the existence of some sort of hallucinogenic content. The point to drive home is: all symptoms of mental health disorders listed in the DSM-5 require a behavior to be present and an inference made about the person's internal state.

So what happens when the person with an ID uses a specific behavior throughout their day? When should this behavior be considered as a potential symptom of a mental health disorder? When the behavior changes from the individual's known baseline rate. Without considering the individual's baseline rate, the clinician runs the risk of allowing the existence of baseline behavior "mask" the existence of a symptom. Most people have an adult beverage. This would be like a clinician stating the person does not have a substance use problem or dependency because they have always consumed adult beverages. Instead the clinician collects reports (data) on rate, duration, intensities, and impacts on the person's functioning, relationships and work. In the same manner the existence of a "behavior" in the life of a person with ID only means it must be evaluated from the person's baseline to understand its impacts and potential as a sign of a mental health disorder.

Artist: Gilbert Rollolago

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Artist: Marshall Porter

Artist: Willie Preston

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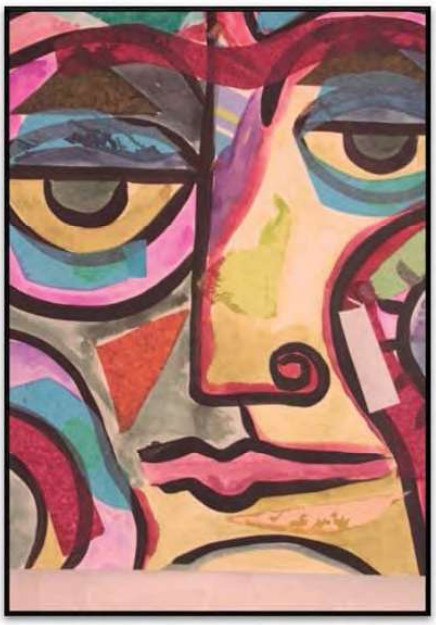
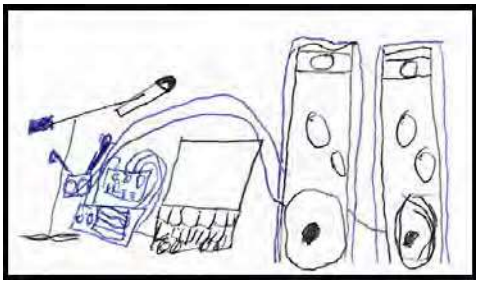


Artist: Rachel Canavor

Artist: Eddie Remington



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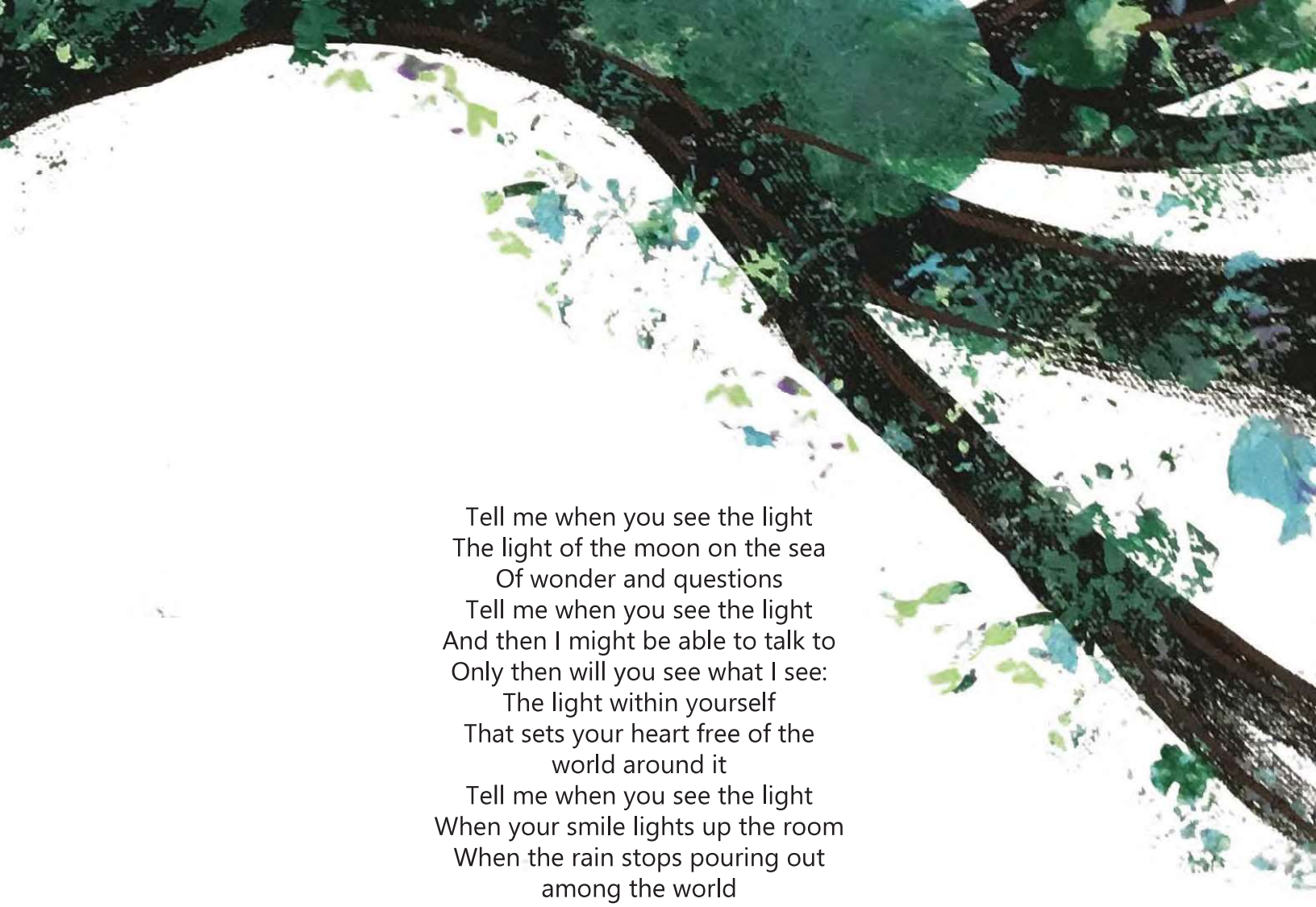
Artist: Angela Stevens

Artist: Eddie Remington

Artist: Rachel Canavor



Tell me when you see the light
The light of the moon on the sea
Of wonder and questions
Tell me when you see the light
And then I might be able to talk to
Only then will you see what I see:
The light within yourself
That sets your heart free of the
world around it
Tell me when you see the light
When your smile lights up the room
When the rain stops pouring out
among the world
When I can see you for who are

Tell me when you see the light

The light within us all, in every
human heart
I have seen the light
And now
You have to see your own

Rachel Lee Canavor

Washington State
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Transforming lives