



HEALTH RISK SCREENING TOOL

Person Centeredness & Understanding IDD Diagnosis

► PRESENTED BY:

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Objectives

- ▶ Overview of Person Centered Thinking
 - ▶ Important To & Important For
 - ▶ Integration
 - ▶ Choice
 - ▶ Language
- ▶ IDD Diagnosis Overview
 - ▶ Developmental Disability
 - ▶ Intellectual Disability
 - ▶ Cerebral Palsy
 - ▶ Prader Willi Syndrome
 - ▶ Autism Spectrum Disorders
 - ▶ Tourette's Syndrome
 - ▶ Spina Bifida
 - ▶ Fetal Alcohol Syndrome
 - ▶ Fragile X Syndrome
 - ▶ Muscular Dystrophy



Working Agreements for the Day

- Cell phones on vibrate
- Misery is optional
- Respectful listening
- All questions are valid
- Only share what you are comfortable sharing
- The trainer is always right 😊



Person Centered Thinking Overview



DISCLAIMER

- The information that follows is a *summary overview*.
- This training is not designed to replace the two day Person Centered Thinking training course.
- More in depth PCT training is available locally in Georgia, and we recommend pursuing this.



Person Centered Thinking

- Underlies and guides respectful listening which leads to actions, resulting in people who:
 - ▶ Have positive control over the life they desire and find satisfying;
 - ▶ Are recognized and valued for their contributions (current and potential) to their communities; and
 - ▶ Are supported in a web of relationships, both natural and paid, within their communities



Introducing the Core Concept:

**IMPORTANT TO
AND
IMPORTANT FOR
AND
THE BALANCE BETWEEN
THEM**



Important TO

What is important to a person includes those things in life which help us to be satisfied, content, comforted, fulfilled, and happy. It includes:

- People to be with /relationships
- Status and control
- Things to do and places to go
- Rituals or routines
- Rhythm or pace of life
- Things to have



Important TO cont.

- Includes what matters the most to the person – their own definition of quality of life.
- What is important to a person includes only what people “say”:
 - with their words
 - with their behavior

*When words and behavior are in conflict,
pay attention to the behavior and ask “why?”*



Important *FOR* (Part One):

- Issues of *health*:
 - Prevention of illness
 - Treatment of illness / medical conditions
 - Promotion of wellness (e.g.: diet, exercise)
- Issues of *safety*:
 - Environment
 - Well being ---- physical and emotional
 - Free from fear



Important FOR (Part Two):

- What others see as necessary to help the person:
 - Be valued
 - Be a contributing member of their community

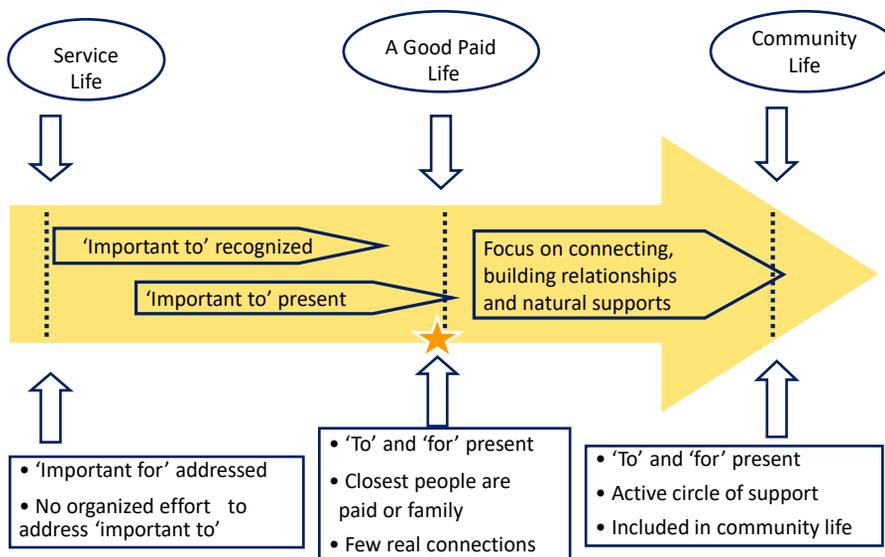


Integration

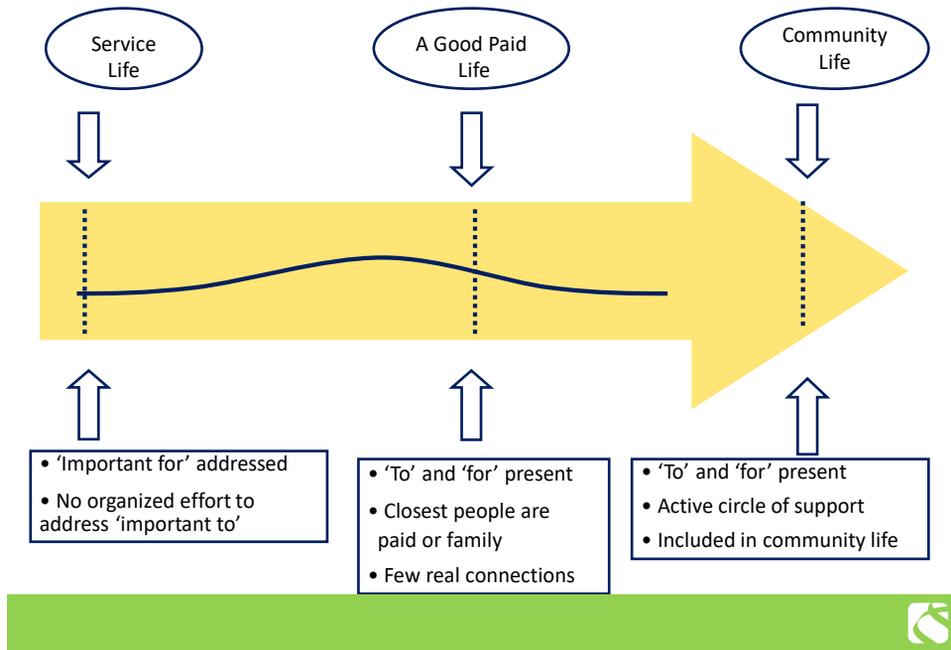
- How do we know if we are a part of our community?
 - If we don't show up, someone asks about us.
 - We are valued for our ability to contribute.
- Supporting someone is more than knowing their diagnosis
 - People we support are more than their clinical qualifiers
 - Each of us have hopes and dreams
 - Each of us need support to accomplish certain tasks
 - These supports do not define us



Moving from Service Life to Community Life



Moving from Service Life to Community Life

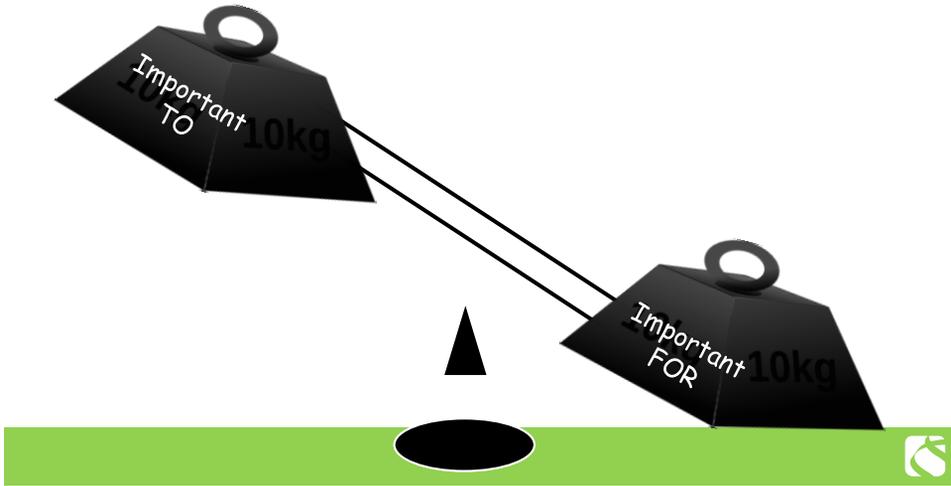


Finding the Balance

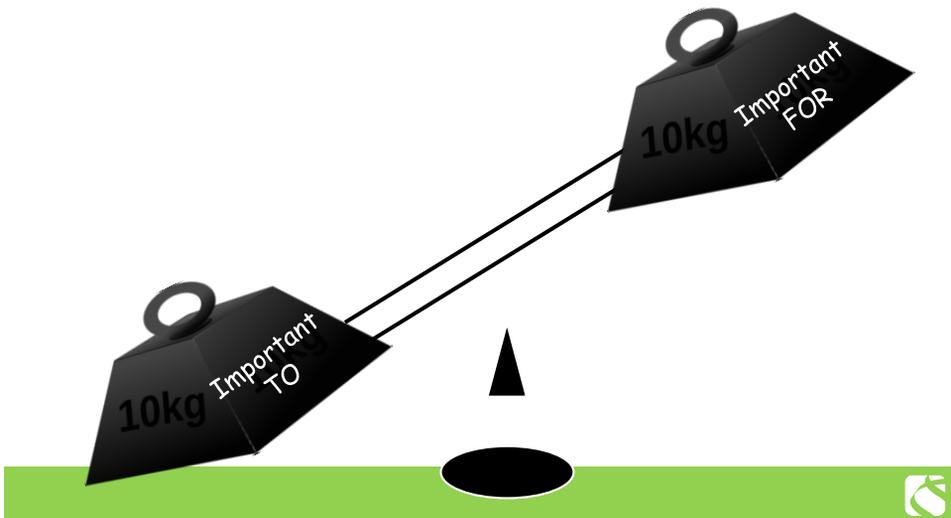
- We all make tradeoffs between the many different things that are *important to us*.
 - Some people may love living in a particular place.
 - And are willing to make the tradeoff when living there means a longer commute to the work they love.
- We also make tradeoffs between what is *important to us* and what is *important for us*. These tradeoffs can be temporary OR long term solutions.
 - Fun time with my friends is important to me. Having a clean house is part of being valued by my friends. House cleaning occasionally comes before having fun with friends.
 - Expressing personal opinions and speaking my mind is important to me, but not cussing in front of my neighbors is important for me



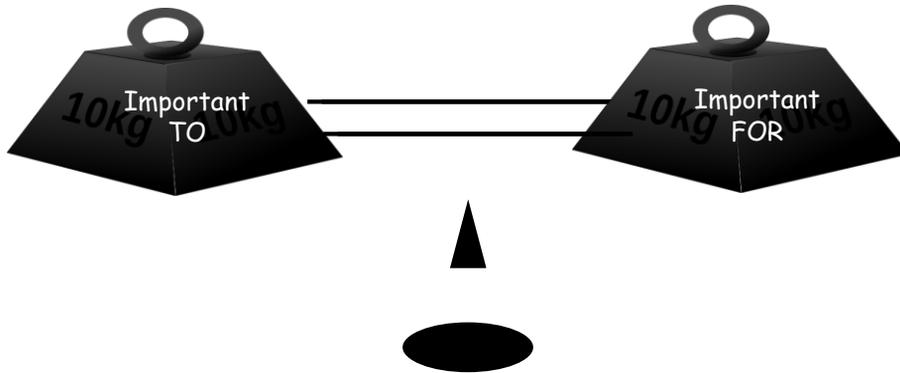
Health and Safety Dictate Lifestyle



All Choice No Responsibility



Balance



How can we work toward balance?

- ▶ Hopes and dreams need not be sacrificed on the altar of liability
- ▶ Seek first to understand, ask about the ask...
- ▶ Having a better understanding of motives and interest will inform meaningful support choices
- ▶ Reaching toward balance takes ongoing conversation

Use of Language

- In this work, each of us are ambassadors
- Our words matter
 - The darker chapters in our history began with words
- How we refer to those we serve
 - Possessives
 - By diagnosis only
 - Promoting Positive Control and Integration
- Nonverbal does not equal to cannot communicate



Promoting choice

- We want to provide informed choice making
 - Educate
 - Have conversations
 - Ask about the ask
- Growth in autonomy
 - Independence is lonely
 - I want to make choices for myself and choose who to have around
- We all need support
 - It is my choice to have my car serviced at a shop, rather than doing so myself
- Document the effort made
 - Our work will always be called into question
 - Jot down what was tried, what was discussed
- The power of choice resides with those we serve!



Expectations, what we see is not always the full picture..

<https://youtu.be/wT9PdS9hPFs>



Questions?



IDD Diagnosis Overview



What is a Developmental Disability?

- ▶ A severe and long term disability that can affect cognitive ability, physical functions, or both
- ▶ Appear in the persons life prior to the age of 22, and follow the person throughout their lives
- ▶ Some Developmental Disabilities are genetic, as in Downs Syndrome
- ▶ Others may be physical in nature, such as Fetal Alcohol Syndrome
- ▶ Physical Developmental Disabilities may include Cerebral Palsy



What is an Intellectual Disability?

- ▶ A group of disorders that present with a limited mental capacity and or difficulty with adaptive behaviors
- ▶ Manifest in the persons life prior to the age of 18
- ▶ This class of disability focuses more on the cognitive component



How can an Intellectual Disability be identified?

- ▶ Intellectual Functioning – Determined through IQ testing
- ▶ Adaptive Behavior
- ▶ Onset prior to age 18
- ▶ Other testing sources:
 - ▶ Conceptual Skills – self direction, concepts of money and time, use of language, and literacy
 - ▶ Social Skills – interpersonal skills, social responsibility, naivete, social problem solving, etc.
 - ▶ Practical Skills – actives of daily living, occupational skills, health care, transportation, schedules/routineness, use of money



Intellectual Disabilities, ideas for support...

- ▶ Allow more time and greater flexibility for training and education
- ▶ Keep instructions simple and bite-size pieces
- ▶ Be aware that a person with an Intellectual Disability may be less aware of social cues and norms
- ▶ Give verbal and written instructions or try giving illustrative examples



Cerebral Palsy (CP) Introduction & Causes



- ▶ A group of conditions that affect someone's ability to move and maintain balance and posture
- ▶ Palsy refers to muscle weakness or difficulty moving
- ▶ CP may be caused by abnormal brain development or damage that impacts the person's ability to control their muscles
- ▶ Note, that this disability falls under the Developmental Disability umbrella (i.e. Intellectual Disability may or may not be co-occurring)



Cerebral Palsy (CP) Presentation

- ▶ Types
 - ▶ Stiff muscles, also called spasticity
 - ▶ Uncontrollable movements, also called dyskinesia
 - ▶ Poor balance and coordination, also called ataxia
- ▶ Case Study
 - ▶ <https://youtu.be/cOfUGUNxEqU>



Prader-Willi Syndrome Introduction

- ▶ Mostly associated with people who have an insatiable appetite
- ▶ May result in morbid obesity
- ▶ Physical appearance may include
 - ▶ Almond shaped eyes
 - ▶ Thin upper lip
 - ▶ Enlarged hands and feet
 - ▶ Narrow bridge of the nose
 - ▶ Narrow forehead

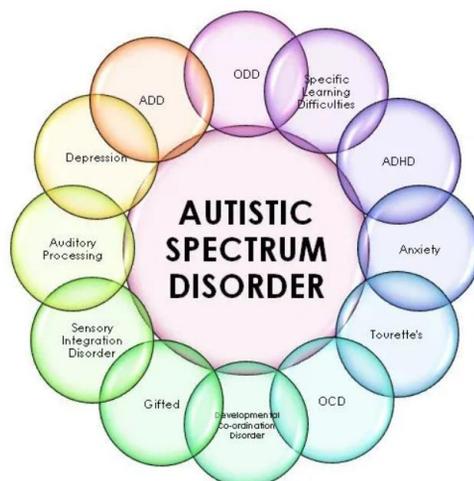


Prader-Willi Syndrome Support

- ▶ If identified in infancy – focus on nutrition
- ▶ For young children – Human Growth Hormone treatment will help with development of muscle tone and promote growth
- ▶ For adults
 - ▶ Weight Management – working with nutritionists and incorporating regular exercise
 - ▶ Behavioral Management – limiting access to food and implementing Behavioral Support Plans. Always go through your Human Rights Council.
- ▶ Case Study:
 - ▶ <https://youtu.be/-6nzi5Rc4wY>



Autism Spectrum Disorders Overview



Autism – Overview



- ▶ A developmental disorder that affects communication and behavior
- ▶ Difficulty with communication and interaction with others
- ▶ Symptoms that hurt the person's ability to function in school, work, and other areas of life
- ▶ Autism has the term 'Spectrum' attached to it, because there is a wide variability in the severity and presentation of symptoms



Autism – Presentation

- ▶ Restricted and Repetitive Behaviors
 - ▶ Repetitive motions with objects (e.g. shaking sticks, flipping levers, spinning wheels)
 - ▶ Ritualistic Behaviors (e.g. repeatedly touching objects in a set order, lining up objects by size)
 - ▶ Need for an unwavering routine and or resistance to change
 - ▶ Narrowed or hyper focus on specific topics
 - ▶ Staring at lights or spinning objects



Autism – Presentation cont.

- ▶ Social Communication
 - ▶ Remember, everyone communicates!
 - ▶ Gestures
 - ▶ Eye contact
 - ▶ Facial expressions
 - ▶ Tone of voice



Autism – Presentation cont.

- ▶ Sensory Concerns
 - ▶ Bright lights
 - ▶ Sudden loud sounds
 - ▶ Large groups
 - ▶ Touch
 - ▶ Proximity to one another



Autism – Types of Support

- ▶ Medication may be used to address the following
 - ▶ Irritability
 - ▶ Hyperactivity
 - ▶ Repetitive behavior
 - ▶ Attention problems
 - ▶ Depression and or anxiety
- ▶ Behavioral, psychological, and educational therapy
 - ▶ Highly structured and intensive programs designed to involve family and other supporters
 - ▶ Life skills to support partial or full independence
 - ▶ Learning social and communication skills
 - ▶ Reduction in challenging behaviors by identifying potential triggers and emphasizing the persons strengths



Autism, ideas for supporting

- ▶ Establishing routines and predictable environments
- ▶ Inform people what is about to happen before it occurs
- ▶ Pay attention to how people respond to light, sound, touch, crowds, and noise
- ▶ Communicate with other members of the team what is learned



Tourette's Syndrome - Overview

- ▶ Neurodevelopmental Disorder
- ▶ Usually first diagnosed between ages 5 and 10
- ▶ Presents as a series of tics
 - ▶ Provisional
 - ▶ Transient
 - ▶ Persistent (or chronic)
- ▶ Types of Tics
 - ▶ Motor Tics – involving movements of the body, such as eye blinking
 - ▶ Vocal Tics – involving sound made with voice such as grunting or repeating words



Tourette's Syndrome - Overview cont.

- ▶ Other conditions that occur with those who have Tourette's:
 - ▶ Attention deficit/hyperactivity disorder
 - ▶ Obsessive compulsive disorder
 - ▶ Also, likely to have depression, anxiety, and or other learning disabilities



Tourette's Syndrome - Supports

- ▶ Focus on management of tic presentation
 - ▶ Medication
 - ▶ Behavioral treatments (usually Comprehensive Behavioral Intervention)
 - ▶ Education of support teams and the person



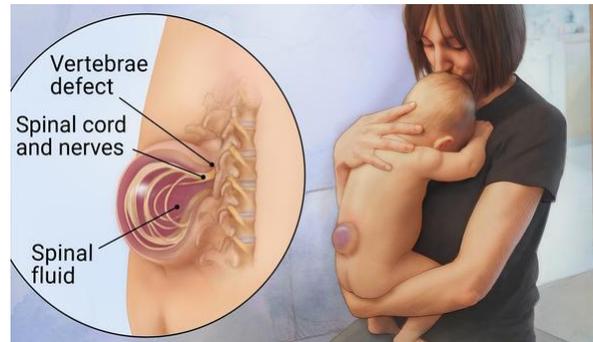
Tourette's Syndrome – Visual Example

- ▶ https://youtu.be/CFaiN_nZsYk



Spina Bifida - Presentation

- ▶ Birth defect that happens when the spine and spinal cord don't form fully



Spina Bifida – Identification and Support

- ▶ Sometimes identified prior to birth, and others at the time of birth
- ▶ Supports may include:
 - ▶ Mobility and physical activity supports
 - ▶ Educational supports
 - ▶ An Individualized Education Plan (IEP)
 - ▶ 504 Plan
- ▶ Checking skin integrity
 - ▶ Checking for redness including under braces
 - ▶ Trying to avoid hot bath water
 - ▶ Making sure that someone does not sit or lie in one position for too long
- ▶ Case example
 - ▶ <https://youtu.be/7u5dAnj573o?t=9>



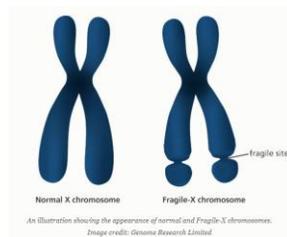
Fetal Alcohol Spectrum Disorders (FASDs) – Overview

- ▶ A condition that exists when alcohol exposure occurs during pregnancy
- ▶ May present with physical defects
 - ▶ Deformities of joints, limbs and fingers
 - ▶ Slow physical growth after birth
 - ▶ Vision or hearing difficulties
 - ▶ Heart defects and problems with kidneys
- ▶ May also experience intellectual or cognitive disabilities
- ▶ Others have difficulty function and coping with daily life

- ▶ Case Study
 - ▶ <https://youtu.be/QuBBLEf2u7I>



Fragile X Syndrome Overview



- ▶ Genetic condition that cause a range of developmental problems
- ▶ Most males with fragile X syndrome have mild to moderate intellectual disability
- ▶ May also have anxiety, hyperactive behavior

- ▶ Case Study
 - ▶ <https://youtu.be/pgUZsOGOfk>



Muscular Dystrophy - Overview



- ▶ A group of muscle diseases caused by a mutation in a person's genes
- ▶ Muscle weakness decreases mobility
- ▶ Many types of Muscular Dystrophy exist
- ▶ Can run in families



Muscular Dystrophy - Types

- ▶ Myotonic (DM)
 - ▶ Affects heart, lungs, stomach, intestines, brain eyes, and hormone producing organs
 - ▶ Can affect men and women equally
 - ▶ Shows up between ages 10 – 30
- ▶ Limb – Girdle (LGMD)
 - ▶ Affects upper arms and upper legs
 - ▶ Can affect men and women equally
 - ▶ Appears in childhood or adulthood
- ▶ Facioscapulohumeral (FSHD)
 - ▶ Affects face, shoulders and upper arms
 - ▶ Can affect men and women equally
 - ▶ Appears in young adulthood
- ▶ Congenital (CMD)
 - ▶ Affects brain, heart, and spine
 - ▶ Can affect men and women equally
 - ▶ Appears at birth or shortly thereafter



Muscular Dystrophy cont.

- ▶ Case Study
- ▶ <https://youtu.be/DG0mN6rnsNk>



In summary

- ▶ Disabilities may present in a variety of ways
- ▶ Our task is to help identify support need with the person, not for them
- ▶ This is a work in progress, and we all learn by doing
- ▶ Reach out for further education



Special needs?

<https://youtu.be/rsinHCZOfg8>



Questions?

