I/DD AND MENTAL HEALTH

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The Arc of Bergen & Passaic

The Arc of Bergen & Passaic Counties: Achieve With Us

The Arc of Bergen and Passaic Counties is a private not for profit 501 (c) 3 organization for individuals with disabilities and their families. The Arc was the first organization for individuals with disabilities in NJ and has been serving the Bergen and Passaic Communities for over 75 years.

We provide services for individuals with disabilities throughout their lifespan – from birth to senior years

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Hi – I'm Deirdre

I am a LCSW – Licensed Clinical Social Worker and specialize in working with dual diagnosed individuals

Currently a Vice President of The Arc of Bergen & Passaic with varied clinical experience

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What is mental illness?
Trauma risks
Promoting Mental Wellness in your home
When should I get help?
What does getting help look like?
Parent Self Care

OUTLINE FOR TODAY – We are talking about hard topics!
Please take care of yourself

WHAT IS MENTAL ILLNESS?

MENTAL ILLNESS

- Mental illnesses can affect our
  - Thinking
  - Feelings & Sensations (Mood)
  - Actions & Behaviors

- Mental illnesses interrupt our lives

Recovery is possible!

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WHAT IS A DEVELOPMENTAL DISABILITY?

Developmental Disability means a disability that is manifested before the person reaches twenty-two (22) years of age, is likely to continue indefinitely,

results in substantial functional limitations,

is attributable to intellectual disability or related conditions which include: cerebral palsy, epilepsy, autism or other neurological conditions, and reflects the individual's need for assistance that is lifelong or extended duration that is individually planned and coordinated.

I/DD = Intellectual and/or Developmental Disability

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RATES OF MENTAL ILLNESS

Dual Diagnosis here refers to the co-occurrence of I/DD and a mental illness

There have been discrepancies in the rates of dual diagnosis, research has suggested that the rate of mental illness 6 times higher than the neurotypical population

Some studies in the US (which has the highest rates of mental illness in the world!) are at a 25% lifetime prevalence, whereas having a developmental disability puts that up to 30-40%

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Getting and Accurate Diagnosis is Hard

Mental illness can often present differently, especially for anxiety and depression, in people with I/DD

- Ex: Irritability

Sometimes what can look like a symptom of mental illness is actually a common characteristic for someone with I/DD

- Ex: Self-talk

Let's look at sneezing … one symptom lots of potential causes

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SIGNS & SYMPTOMS

- early recognition and intervention for symptoms is key, people with I/DD are often under diagnosed

- Things to look for:
  - Sleep – more or less than normal?
  - Weight gain/loss – appetite is more or less than normal?
  - Are they no longer interested in things they used to enjoy?
  - Baseline exaggeration – has challenging behaviors that used to occur at a low rate suddenly spiked in frequency/intensity/duration?
  - Sudden loss of skills, especially around hygiene?

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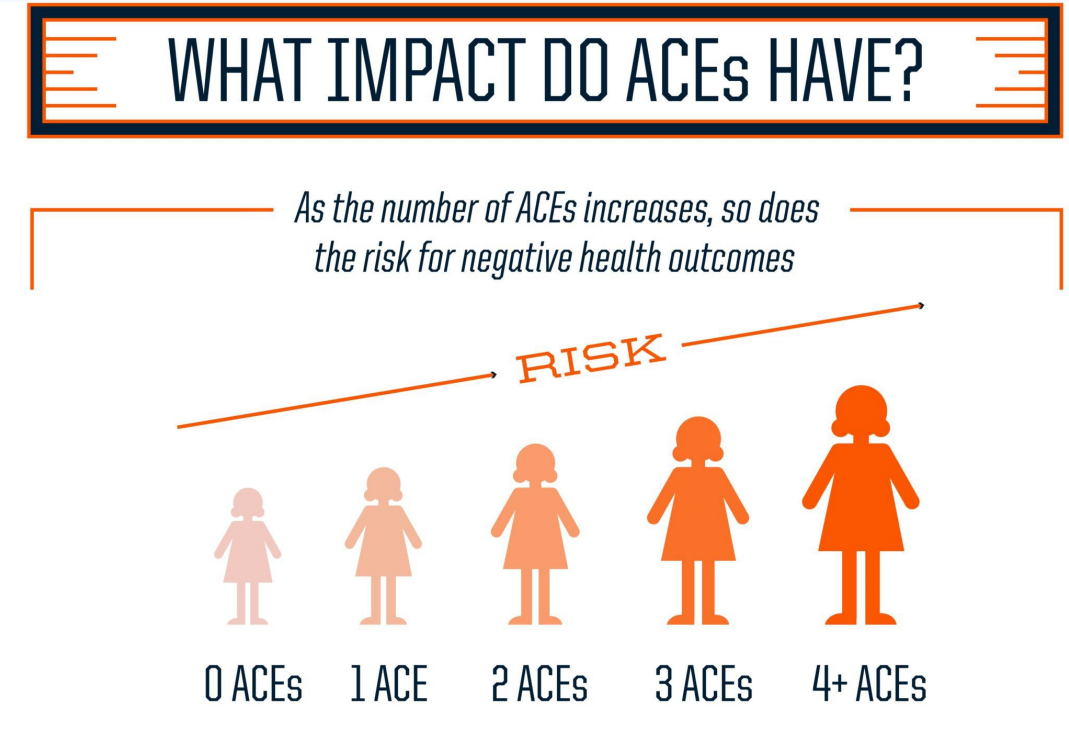
TRAUMA RISKS



PREVALENCE OF TRAUMA: VIOLENCE & ABUSE

Limited research on intersection of violence and disability but the link is undeniable

In 2015 disabled people were 2.5x more likely to experience violent victimization

Violent crimes (assault, robbery) are 3x more likely to impact disabled people

Over 70% of people with disabilities report being victims of abuse

- 62% of people with I/DD

Source: https://thearc.org/wp-content/uploads/2019/07/Webinar%2013%20slides.pdf

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PREVALENCE OF TRAUMA: SEXUAL ABUSE & ASSAULT

NPR did an investigation (2018) which ran data from the Justice Department from unpublished federal crime data. They found:

- People with I/DD are sexually assaulted at a rate 7 times higher than those without disabilities

Various studies have shown:

- 90% of people with I/DD will experience sexual abuse in their life
  - 49% will experience this abuse at least 10x (Hein & Schwartz, 1995 *The Sexual Abuse Interview for Those with Developmental Disabilities*)
- Most female victims (72%) tend to have a mild intellectual disability with no other hearing, visual, mobility problems and most male victims had severe intellectual disability (Furey 1994)

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WHY?

People with I/DD are at heightened risk at all moments of their daily life

- 2018 NPR data showed they are more likely to be assaulted by someone they know and during daytime hours
- They need high levels of assistance for long periods of time, for invasive daily living functions
- Their families/caregivers are under high levels of stress

Predators target people with I/DD because they know they are easily manipulated and have difficulty testifying later

- These crimes go mostly unrecognized, unprosecuted, an unpunished. The abuser is free to abuse again

Source: https://www.npr.org/series/575502633/abused-and-betrayed

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PREVALENCE OF TRAUMA: OTHER FACTORS

Uncertainty of safety & basic needs being met (neglect)

Psychological distress secondary to medical procedures

Source: https://thearc.org/wp-content/uploads/2019/07/Webinar%2013%20slides.pdf

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Risk factors
are not
predictive factors
because of
protective factors

Dr. Carl Bell, University of Illinois

… but don't forget about Neuroplasticity

The brain IS changeable … one of the biggest ways to change it is changing the pattern of activation

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NORMALIZE THE CONVERSATION – KEY TO PREVENTION

This is a difficult, and scary, topic to talk about. But we talk about lots of scary and difficult things with people.

Normalizing the conversation (meaning: having regular conversations about abuse, risk of abuse, and prevalence of abuse) makes it easier for individuals, families, and staff to talk about these topics.

Normalizing the conversation gives individuals the language to know HOW to talk about abuse.

Talk about consent every day, normalize asking for consent

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RISK

- Bullying and/or isolation
- Move out of family home
- Abuse & sexual assault
- Physical illness & disability

PROTECTIVE FACTORS

- friendships & social networks
- Self esteem & safety skills
- Sex education, body awareness, self advocacy skills
- Good health foundation & nutrition, connected to good doctors

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PROMOTING MENTAL WELLNESS IN YOUR HOME

TEACHING EMOTIONS

Most of us have limited language to name our emotions

People with developmental disabilities have even less words than neurotypical people. Autistic people may struggle with naming their emotions even more.

Brene Brown did a study of 7,000 participants who on average were able to name 3 emotions in the moment – happiness, sadness, and anger

Psychologist David Rock states, "when you experience significant internal tension and anxiety, you can reduce stress by up to 50% by simply noticing and naming your state."

- If we can see the emotion, we don't have to be the emotion

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NAME IT TO TAME IT

There is a lot of power in teaching various emotion states so that the individual can self identify what they are feeling. This goes a long way in teaching the groundwork for emotional regulation.

Do an assessment of what emotions your loved one knows and what kind of knowledge base they are coming from

Use visual aids, short video clips, social narratives, etc to talk about the emotions in others, what those emotions are, and if the individual has ever felt this way. This will help build emotional recognition in themselves along with in others (important social skill!) along with empathy

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DEALING WITH ANGER

There is often a gap between the demands placed on an individual and their coping skills

Alter the demands and teach better ways to cope

Use distraction, novel items

When hard: try a little or watch first, take a break and try again

Decrease length of time, use a timer

Relaxation or sensory boxes

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TEACHING COPING SKILLS

People with I/DD might be more likely to favor more avoidant coping strategies than active ones when dealing with stressful situations.

In order to teach people to recognize and use problem solving skills and ways to actively deal with stressors, it is important that the link between emotions and thoughts is established.

Teaching coping skills and then linking to problem solving was found to be effective in a 2008 (Hartley & Maclean) study

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POSITIVE USE OF SELF

Research with the neurotypical population in Positive Psychology has shown that "happiness interventions" work and can reduce depressive symptoms compared to that of a control group.

Tomasulo (2014), hypothesizes that utilizing a more strengths based approach for people with I/DD is also effective based on his years of individual and group therapy for people with I/DD. The therapist should notice and explain character strengths seen in their clients.

Research across a variety of fields (couples therapy, corporate team effectiveness) has shown that there is a "magic" ratio of positive to negative statements made to someone. This is important for working with this population to develop an alliance and a good working relationship.

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DEVELOPING RELATIONSHIPS

For everyone friendships enhance physical and mental well being and promote quality of life.

For people with I/DD friendships help them to increase community participation and increase sense of belonging

Physical integration into the community alone does not mean the individual will develop friendships!

Help develop reciprocal relationships with family & friends

Look into social skills groups & training

Group therapy/Support groups can be a great option

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OTHER FACTORS

Work now on developing good sleep hygiene, nutrition, and exercise habits

Having a sense of purpose and being a part of your local community is huge

Explore personal interests and develop hobbies

Remember that maturity and progress can come later for individuals with I/DD

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WHEN SHOULD I GET HELP?

WHEN IT'S TIME TO GET HELP

When something traumatic has happened

When you are seeing signs & symptoms and all other medical explanations have been ruled out

When the transitions have happened & some time has been given to adapt to the change

When the environment has been modified and you've taken steps to ensure quality of life

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WHAT DOES GETTING HELP LOOK LIKE?

GETTING HELP IS OFTEN HARD & FRUSTRATING

Many mental health professionals don't receive training in working with this population

Lack of resources and money

Diagnostic Overshadowing

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DIFFERENT TYPES OF HELP

PSYCHIATRIST, MENTAL HEALTH NURSE PRACTITIONER

PSYCHOLOGIST, LICENSED CLINICAL SOCIAL WORKER, LICENSED PROFESSIONAL COUNSELOR, MARRIAGE & FAMILY THERAPIST

Number one difference is that these folks can prescribe medications

Ideally a psychiatrist should specialize or be familiar with I/DD as dosing can be different and different medications can work better

Your PCP/Developmental Pediatrician can be a good resource or may be willing to prescribe in the short term

Often these providers do not spend long talking to your or your loved one

This person specializes in helping you through therapy – ask if they use different modalities as talk therapy alone is often difficult for people with I/DD

Your therapist should be following a treatment plan that the individual has input in

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WHAT MAKES A GOOD PROVIDER/THERAPIST?

- Form relationships with range of clients, encourage them to talk
- Warm
- Accepting
- Empathetic
  - What are you feeling?
  - What are you processing?

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ADAPTATIONS THAT MIGHT BE HELPFUL

In the beginning stage of therapy, it may be useful to have sessions held more frequently than one would with a neurotypical person.

It takes more time to establish a therapeutic relationship as compared to a neurotypical person.

There may be a challenge to maintain the person's attention and focus on therapeutic issues that last the usual 45-60 minutes.

Increase length of treatment to allow for needed repetition.

Increase length of treatment to allow for newly acquired skill sets to be generalized.

Increase length of treatment to build upon therapeutic relationship and needed time to work on goals and objectives.

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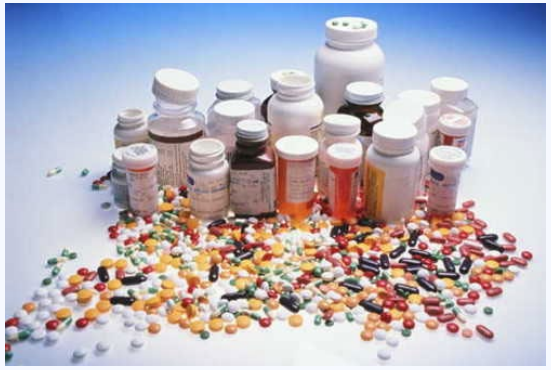
MEDICATIONS

Medications can play a major role in "behavioral problems" – too many meds, not the right meds, side effects of medications

High rates of antipsychotic prescribing – sometimes needed sometimes not



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SELF CARE IS NOT AN EXPENSE – IT’S AN INVESTMENT

PARENT SELF CARE

The emotional and physical demands of constant caregiving leads to chronic stress and exhaustion

Self care is ESSENTIAL for your own emotional stability and providing quality care

Components of self care: good nutrition, sleep, exercise, and enjoyment of life

Please seek help if you are feeling anxious, depressed, detached from loved ones, losing focus from your own needs, lack of interest in things you used to enjoy

Make time for friends and develop relationships with other parents with kids who's needs are similar to your own where possible

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Call 201-343-0322 and ask to speak to the Family Support Department

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