THE ARC OF BERGEN & PASSAIC PROVIDES SERVICES TO PEOPLE WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES FROM BIRTH TILL END OF LIFE

SERVICES WE PROVIDE AT THE ARC OF BERGEN & PASSAIC

SERVICES FOR YOUTH

- Early Intervention
- Family directed respite services through children linked to Perform Care/CMO
- Help at Home Companion– county funded self hired respite. We have a small grant to provide families with additional respite funds based on need

CAMP RAINBOW

- An educational, fun experience for age 5+ that runs for 6 weeks in the summer 9am-3pm.
- Campers can come for all, some, or part of season
- Applications live on our website! www.arcbp.com

SPECIAL QUEST

- a community based after-school recreation program (respite) for teens through 21 years

SERVICES FOR ADULTS (21+)

- Day Habilitation
- Residential Services – group homes, supervised apartments, community based supports in own/family home
- Vocational Services – job training, job coaching, sheltered workshop

THE ARC PLANNING & GUARDIANSHIP CORPORATION

- To provide individuals with disabilities and their families, assistance to envision and plan for their future needs and to assist them in completing all of the related steps required to put their plans into action.
- ·To provide caring, competent and responsive guardianship services for individuals with disabilities who are adjudicated in need of a guardian.
- ·To provide advocacy and guidance for individuals with disabilities, their families and their guardians.
- ·To provide trust administration for special needs and other trusts so as to ensure that the needs of the individual with a disability are met and that the funds are used as intended.
- ·To provide benefits management for individuals with disabilities to ensure they acquire, and maintain eligibility for the benefits to which they are entitled and that their benefits are used for their well being.

THERAPY & CLINICAL WORK FOR PEOPLE WITH INTELLECTUAL &DEVELOPMENTAL DISABILITIES

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 can be 4-5 times higher than the neurotypical population

ASSESSING MENTAL ILLNESS

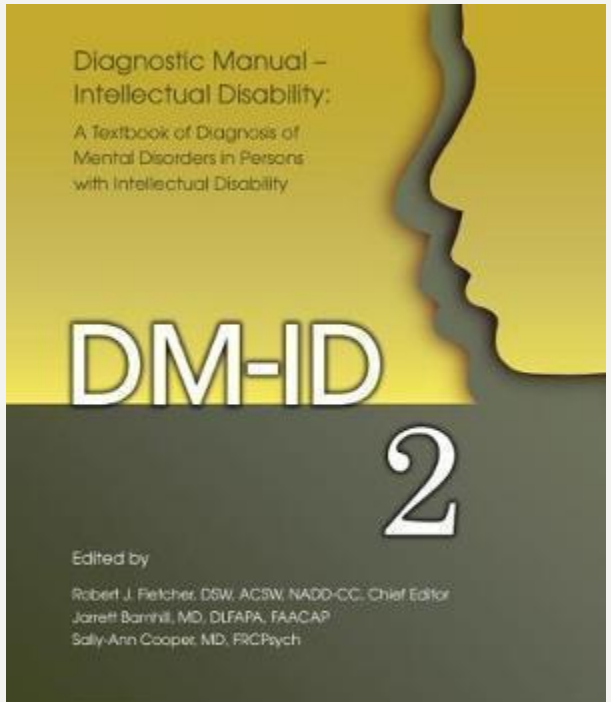
Mental illness can often present differently, especially for anxiety and depression, in people with I/DD

- 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

Finding a psychiatrist who knows the unique needs of a person with I/DD is extremely important



BASIC TIPS: RESPECT AND ENGAGE BY

- Speak clearly and slowly
- Allow space within the conversation
- Give time to respond
- Speak in a calm, normal tone
- Consider the environment
- Use simple, short statements or questions
- Practice turn taking
- Avoid using abstract ideas and jargon
- Be specific
- Be aware of your body language

BASIC TIPS

- Check the person's understanding from time to time. If you are not sure they have understood, ask them to explain to you in their own words what you have just asked or said.
- Do not assume the person's ability to express themselves is an indication of how much they understand.
- Be patient; give the person time to respond.
- Don't assume the person with an intellectual disability is able to generalize skills learned in one context or situation automatically to another.
- Don't pretend to understand. Use checking questions or paraphrasing to assist your understanding. Ask them to repeat what they have said in another way if they can.

ADAPTATIONS WE CAN MAKE

1. Language
2. Frequency of sessions
3. Shorter sessions
4. Duration of therapy
5. Utilize a more structured and directive approach
6. Communication with collaterals
7. Modify complexity of interventions
8. Therapist needs to be supportive
9. Therapist needs to be flexible
10. Use of visual supports

LANGUAGE

- Need to understand person's level of language skills
- Need to know the expressive and receptive language skills of the person
- Need to adjust the language used by the therapist that correlates with the language skills of the client
- Adapted to person's cognitive level

FREQUENCY OF SESSIONS

- 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.
- For some people, it may be recommended to have therapy two times per week for a relatively brief period of time, and then weekly.

SHORTER SESSIONS

- There may be a challenge to maintain the person's attention and focus on therapeutic issues that last the usual 45-60 minutes.
- Allow for a degree of flexibility with regard to the length of any given therapy session.
  - For some people, a 30-minute session is the time period for which their cognitive reserve will allow them the maximum benefit.
  - In the beginning the sessions may need to be even shorter than that – maybe you only meet for 10-15 minutes

DURATION OF THERAPY

- 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.
- Effective termination process may take longer.
- We often come back to people and periodically work on the same skills, re-run the same groups, discuss the same themes. Patterns of behavior are hard to break and refreshers are very helpful for this population.

BE MORE STRUCTURED & DIRECTIVE

- Structure is often needed in therapy to help bring and maintain focus on the therapeutic material being addressed.
- A more directive approach can be useful to facilitate meaningful interaction between the therapist and the person.
- Silence can be perceived as rejection.
- Even very verbal people might not be able to handle the pressure & organize a 45 minute conversation
- Be prepared with therapeutic activities that relate to their goals for each session. You may not always have to use but it is helpful to have them in case you need them. Teaching and reviewing coping skills is always helpful

COMMUNICATING WITH THE TEAM

- With appropriate permission, therapist should communicate with others (care providers, parents, psychiatrist, teachers, etc.).
- Therapist should not work in isolation, but be part of the holistic treatment/habilitation/care planning team.
- If individual is living with natural family, employing a family systems approach can be incorporated as an adjunct to individual therapy.
- Other caregivers can provide important collateral information

MODIFY INTERVENTIONS

- Repetition is important in order for the person to internalize the material discussed in therapy.
- Discuss one therapeutic issue at a time with attention to beginning, middle and end stages of the material discussed.
- Break down interventions into smaller pieces to ensure understanding before moving on to the next topic of discussion.
- Use reflection to ensure understanding the materials discussed.
- Review often
- Therapeutic homework where staff/family members can assist them is often very beneficial

BE SUPPORTIVE

- Provide a lot of support.
- Give recognition to even small improvements.
- Provide a sense of hope
- Provide a sense of normalization

BE FLEXIBLE

- For neurotypical people, when progress is not made, the therapist might assume resistance. With people who have IDD, the therapist needs to adjust and consider an alternative approach.
- An elective approach or at least the knowledge and skills of using more than one model is suggested.
- A supportive approach can be beneficial.

USE VISUAL SUPPORTS

Employing visual supports, such as graphics and pictures, can help a person increase their understanding of the therapeutic process:

- Flip charts
- Games
- Social narratives
- Reminder cards
- Coping Skills Toolkit/Calm Down Kit
- Handouts
- Multisensory approach

BEHAVIORAL NEEDS

- Unmet Needs: Could be sensory, coping skills, fears, avoidance, loss, learning deficits, processing speed, working memory, feelings of rejection, lack of exposure/experience, attention, missing skillset
- Look at functional relationship with behavior and the environment: focus on proactive rather than reactive - Respect Neurodiversity!
  - Communication
  - Sensory needs
  - Escape
  - Attention
  - Tangible
- Remember- we can easily adapt to changes in our environment or routine, engage with others if we need help, figure out if we are boring our audience, etc. Often for our clients, various situations can provoke high levels of anxiety which can then lead to reactions that get termed "bad behavior"

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

NAME IT TO TAME IT

- There is a lot of power in teaching various emotion states so that the client 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 client 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 client has ever felt this way. This will help build emotional recognition in themselves along with in others (important social skill!) along with empathy

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

COGNITIVE BEHAVIORAL THERAPY (CBT)

- This treatment is beneficial to those with mild intellectual disabilities; and it is key to provide psychoeducation to clients using the modality
  - Pairing visuals and concrete examples is important
- CBT teaches people to monitor thoughts and change thought patterns that lead to problems. There is a strong evidence base showing utility for persons with IDD if proper adaptation is made (Gaus, 2007).

ADAPTING CBT

Increase	Use	Involve	Enlist
Increase the number of sessions to help the person understand abstract concepts.	Use repetition to help the person with internalization of the material under discussion.	Involve care providers to assist the person in identifying maladaptive cognitive appraisals.	Enlist care providers to assist with carryover.

DIALECTICAL BEHAVIORAL THERAPY (DBT)

- DBT's approach balances therapeutic validation and acceptance of the person along with cognitive and behavioral change strategies.
- The emphasis of the DBT model is on teaching the individual 1) to modulate extreme emotions and reduce negative behaviors that result from those emotions and 2) to trust their own emotions, thoughts, and behaviors.

ADAPTING DBT

- Principles of treatment remain the same, but the presentation and language are modified
- Concepts are pared down or simplified
- Handouts are rewritten to increase attention and aid in understanding
- Much individual feedback is provided
- Repetition is used to assist with learning, retention and generalization

TALK THERAPY

- Research on providing psychotherapy & training for professionals is rare which means few attempt to provide it and instead focus on psychoeducational work
- Often people think of people with I/DD as poor candidates for talk therapy as difficulty with abstract concepts and lacking insight into one's actions are traits of intellectual disability
- Research points to the benefits of talk therapy for people with I/DD with a few modifications - psychodrama techniques of using the empty chair, role playing, and role reversal.

SUPPORTIVE PSYCHOTHERAPY

We often incorporate a variety of therapeutic theories or models
We are interactive between therapist and client – we provide supportive psychotherapy
The supportive relationship can help the client to make a positive change
Therapist assumes a strong empathetic stance and nurturing positive transference, which strengthens the relationship.

SUPPORTIVE PSYCHOTHERAPY ADAPTIONS

- We primarily focus on "here and now" issues.
- Therapist facilitates improved affect regulation, improved healthy emotional response to stress and improved interpersonal relationships.
- Reduce complexity by shrinking down time into smaller units
- Augment with games, drawings, role play, etc.
- Therapy may involve family and/or others who have significant impact on the client.

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

SOCIAL NARRATIVES

- Social Narratives help to make abstract concepts more concrete using the type of language the client would use.
- This is also a great way to break down options for more complicated topics.
- For those who have less reading skills, more pictures should be incorporated.
- Often this can spark conversation and learning in a way that doesn't feel like they are being spoken down to or lectured at.

SOCIAL NARRATIVES

- Remember: We often take for granted our innate ability to navigate the social world.
- A social narrative is just a simple description of an everyday social situation, written from an individual's perspective
- They can help prepare for upcoming events, changes in routine, de-mystifying social interactions, etc
- They can relate coping skills to real life experiences
- The idea is that the client rehearses the social narrative ahead of time, with someone, so that when the situation is actually occurring the individual can use the story to guide their behavior
- We try to be as positive in these as possible, providing encouragement, empathy, normalization, and praising accomplishment
- Like any story you have a title, introduction, body, and conclusion

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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The Arc™
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The Arc of Bergen & Passaic provides services to people with intellectual and/or developmental disabilities
from birth till end of life