

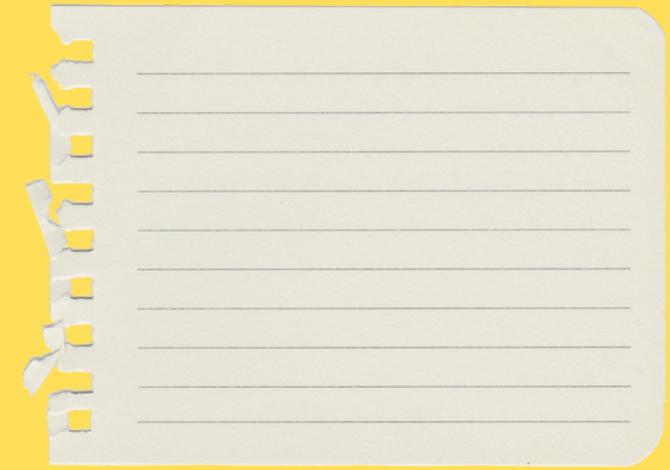
# A Trauma-Informed Lens to Family Engagement in IDD Services

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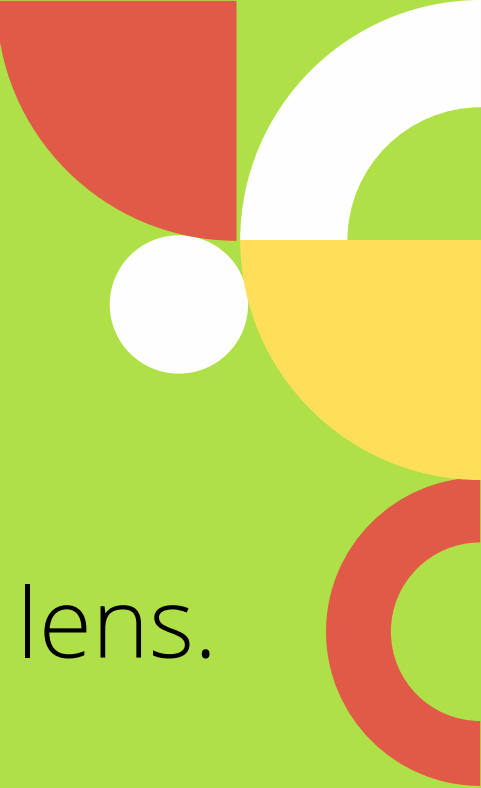


# Notes



- Take care of **YOU** in the next 90-minutes: Move, snack, and stretch as needed.
  - Today is a day for co-creation & your presence makes the (virtual) room better.
  - Participate as fully as you can.
  - I will share the slides, resources & references. Feel free to reach out after if you have any questions or ideas.
  - Please try to stay muted unless you are talking.
- 

# What We Will Accomplish



**After this webinar I hope you will be able to:**

- Trouble the idea of “difficult families”& meet families with a different lens.
  - Describe the importance of family engagement in IDD services.
  - Discuss the need for trauma-informed approaches to family engagement.
  - Identify elements of trauma-informed approaches to family engagement.
  - Identify strategies to promote RICH (respectful, informative, connected, hopeful) relationships and collaborations with families.
  - Identify and challenges and potential paths to navigate challenges to family engagement.
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# Our Schedule

- Introductions
- Brief case study
- The role of families in the lives of people with IDD and IDD services.
- “Buckets” to fill for family engagement.
- The intersect of trauma and the IDD service system.
- The unique power of families and professionals.
- Strategies for building RICH relationships, collaborative and effective partnerships with families.
- Breakout room discussion
- Wrap-up, Questions & Session Evaluation

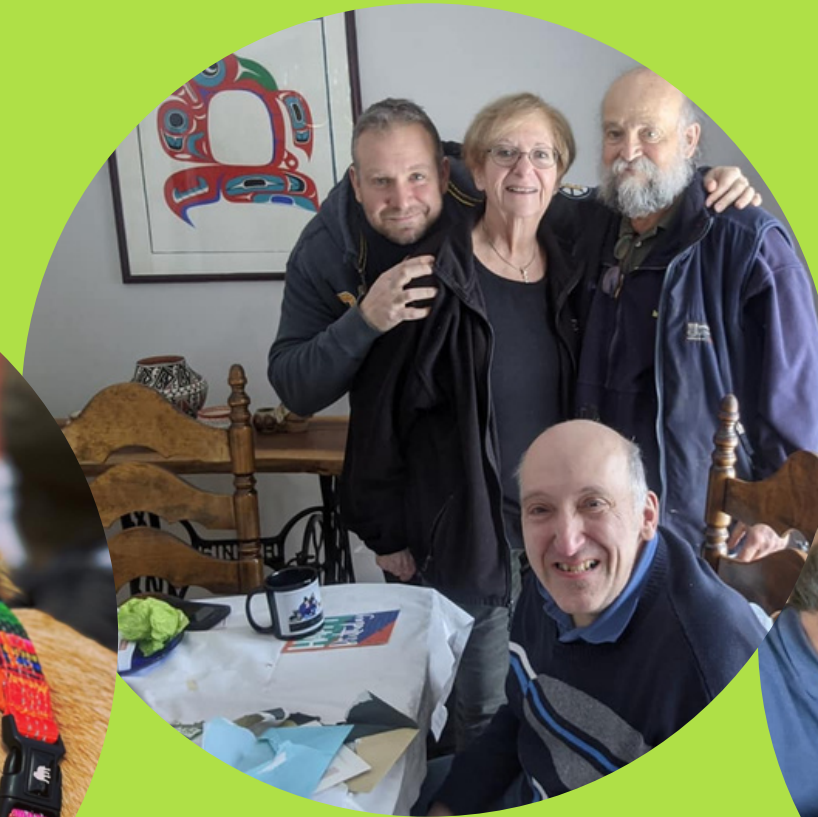
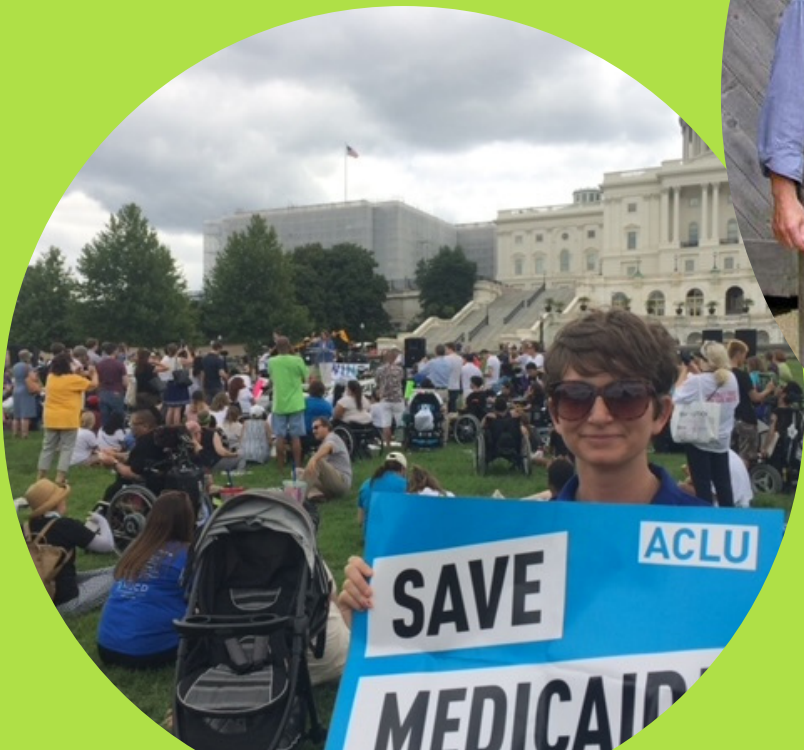


# Introductions To Each Other

- In The Chat, Please Introduce Yourself:
    - Your name
    - Organization name and your role within your organization.
    - Place you are sitting in the world (where you are joining from).
    - How long have you worked in the field?
  - Introductory Poll Questions:
    - How frequently do you interact with families of the people you support?
    - How did that compare to what you expected?
    - Have you ever worked with “difficult” or “challenging” families?
- 

# A Bit About Me:

Proud member of a “difficult family”, former DSP, special education teacher, program specialist, human service faculty, current activist, research, evaluation and training consultant.





# What I Mean When I Say Trauma-Informed

TIC shifts in the approach to human services and the questions we ask about people, families, and communities.

It centers safety, hope, connection, and compassion.

SAMHSA's 4-R's

1

**Realization** of the impact and prevalence of trauma on people, groups and systems of care and the political nature of trauma exposure and resources that support healing.

2

**Recognition** of strengths, sources of resilience and the signs and symptoms of traumatic and chronic stress.

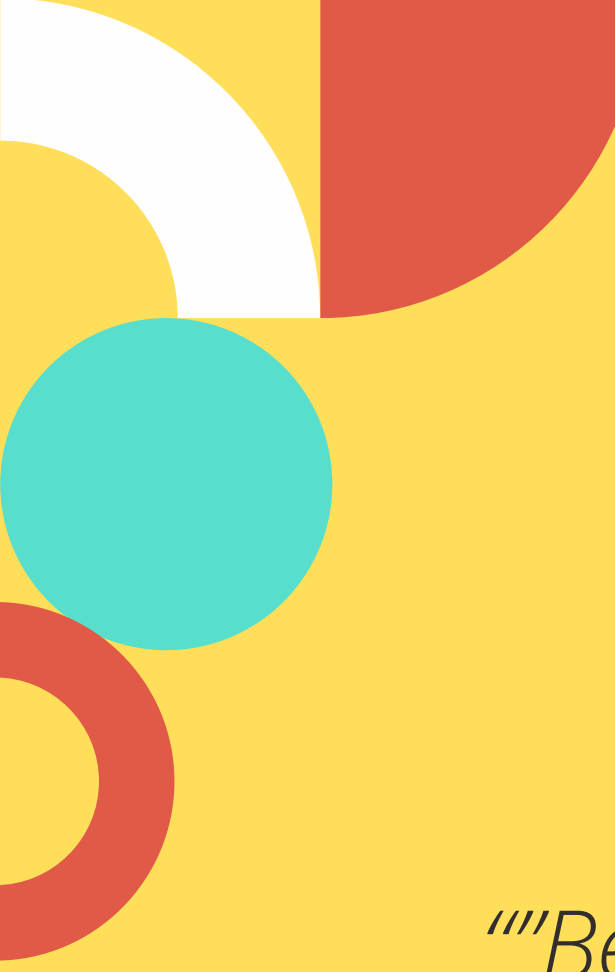
3

Active **resisting** of policies and practices that exasperate existing or cause new harm.

4

**Responses** that promote hope and healing.





# Trauma-Informed Care Can Create Space for the Best Part of Human Services...Being Human Together

*“Being in human services is cool because, in essence, you are paid to be human. Paid to explore the commonalities of the human condition. Paid to discover the incredible diversity of the human spirit. Paid to spend the day doing something that matters; something that makes a difference. Something that you are proud of.”-David Hingsuburger*



# A Brief Intro to Family Engagement



- **Families:** A group with one shares
  - Sense of history
  - Emotional ties
  - Strategies to meet needs of individual members and group as a whole
  - Often, a future

- **Engagement:** Involves a professional/family partnership in which there is
  - Relationship Building & Communication
  - Collaboration & Power-Sharing

**What does it mean  
for a family to be  
“difficult”?**

**Please share in the chat**



# Some Assumptions



- All families are unique, (and often complicated).
- All families are important.



- Families are the experts on their own experiences.
- Engaging families is one of the foundations for ethical and effective services.

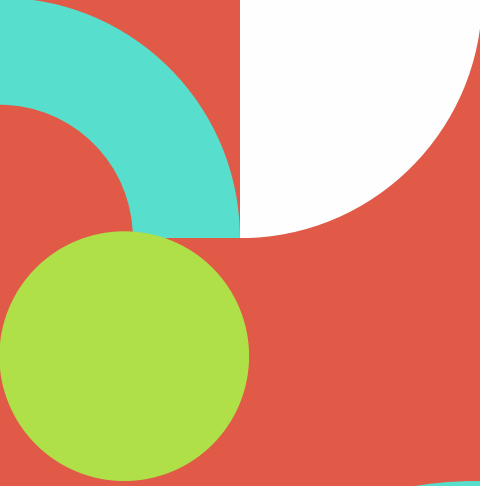


- Paid staff cannot serve as a substitute for family.
- In social services family engagement builds BOTH our **service** and **social** infrastructure.



# **Family Engagement Is Good For The People We Support**

- Fewer relapse of symptoms for adults with mental health conditions (1).
  - Reduced hospital admission & shorter in-patient stays (2).
  - Reduce severity of symptoms of MI and decreased challenging behavior (3, 4).
  - Higher quality of life (4, 5).
  - Eases caregiver stress and burden (4).
  - Higher school attendance and achievement (6).
  - Reduced loneliness (7).
- 



# **Families and Professionals Often Find Forming Positive Relationships Difficult**

**Professionals may perceive families as overly demanding, critical or uninvolved and hard to reach.**

**Families may not trust that staff will meeting their loved ones needs and keeping them safe.**

**Families may feel judged and or fear being replaced or forgotten.**

**Lack of guidance on what can one expect from the other and how to build positive connections.**

**Lack of time and resources.**

**Differences in risk tolerance.**

**Concern about maintaining the privacy and autonomy of the person receiving support.**

# Brief Case Study & Reflection

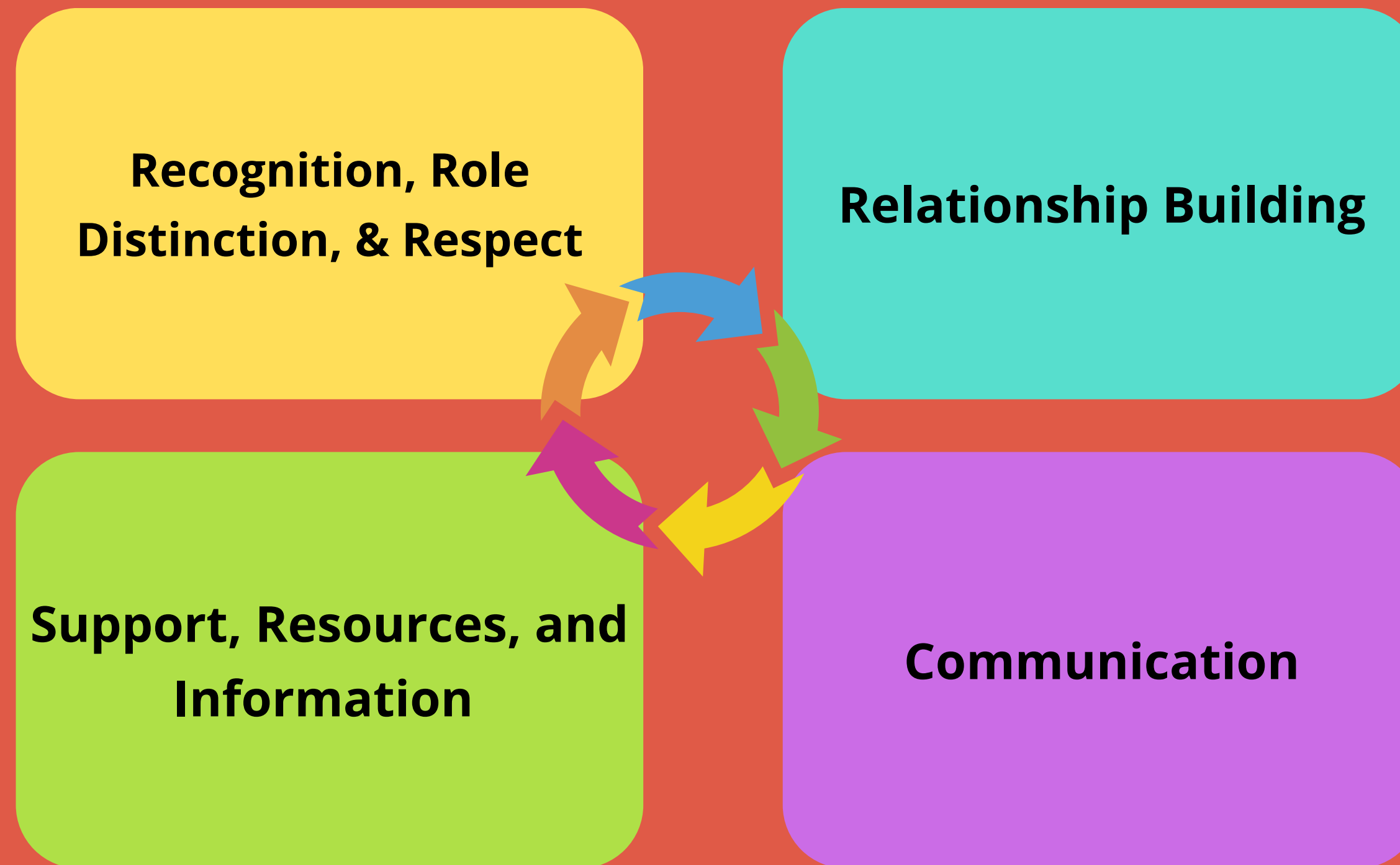
- Sean is an employee with 'Your Life Services'. Sean is one of the people who provides support services to Devon. Devon had a hard day. They were asked to cut mailing labels as their worksite, got sad or upset and threw the scissors. The scissors hit a manger. The manager was not injured but they told Sean that this work-place was not a good match for Devon. Devon uses gestures and vocal approximations to communicate, but not standard, spoken, words and has remained upset even upon arriving back to their group home.
- Sean is getting ready to call and update Devon's parents.



# **Take a Moment to Think About the Following. Then Please Share Your Thoughts in the Chat**

- 1. How do you think Sean is feeling right before making this call?**
- 2. What things from the past and present might influence or shape how Sean feels about making the call and how they approach the conversation?**

# Charting the Life Course Framework: Thinking about Family Engagement as Filling Different Buckets



# Recognition, Role Distinction, and Respect

- Recognition of whoe families are, what role they play, and what they may have experienced.
- Between 60-85% of people with IDD live with a family caregiver (8).
- Only about 22% of people with IDD are known to state agencies and fewer (19%) are supported are supported through long-term support services (9).
- Families with a member with IDD often wear many hats across their loved one's life:
  - Support with ADL's IDL's
  - Advocacy
  - Medical support
  - Service coordinators
  - Record keepers
  - Innovators & Vision crafters



# Recognition, Role Distinction and Respect



- **Most (over 80%) family caregivers of children and adults with IDD are parents. They also may include:**
    - **Siblings**
    - **Grandparents**
    - **Aunts, Uncles, Cousins and Fictive Kin**
  - **24% of caregivers of adults with IDD are over the age of 60 (10).**
  - **Over 50% of caregivers do not have a plan for their loved one when they die or are unable to provide care (11).**
- 

# Family Engagement is Important Even if the Person Does Not Have a Large/Involved Network: Reciprocal Roles Tool

|  <b>Caring About</b> | <b>Who serves this role now?</b> | <b>Who are you doing this for?</b> | <b>Next steps</b> |
|-------------------------------------------------------------------------------------------------------|----------------------------------|------------------------------------|-------------------|
| Shares Love, Trust, and Affection                                                                     |                                  |                                    |                   |
| Spends Time and Creates Memories Together                                                             |                                  |                                    |                   |
| Knows about Personal Interests, Traditions, Cultures                                                  |                                  |                                    |                   |
|                                                                                                       |                                  |                                    |                   |

# Family Engagement is Important Even if the Person Does Not Have a Large/Involved Network: Reciprocal Roles Tool

|  Caring For | Who services this role now? | Who are you doing this for? | Next steps |
|----------------------------------------------------------------------------------------------|-----------------------------|-----------------------------|------------|
| Supports Day-to-Day Needs                                                                    |                             |                             |            |
| Ensures Material and Financial Needs are Met                                                 |                             |                             |            |
| Connects to Meaningful Relationships and Roles                                               |                             |                             |            |
| Advocates and Supports Life Decisions                                                        |                             |                             |            |



# Recognition, Role Distinction, and Respect

## Joys & Unique Stressors:

- High parenting satisfaction, sibling social-emotional skill development.
- For some first time experiencing through their child a minoritized identity.
- Additional out of pocket costs.
- The knowledge of the increased rates of abuse and neglect.
- For some, medical trauma
- For some, grief.
- Accessing needed and high-quality services can be painfully difficult.
- Different cultural meaning of disability.

# Welcome to Holland as Read by the Author



# Recognition, Role Distinction and Respect

Families often “meet” the formal adult service system during times of stress & crisis.

- Many have gone a long time without needed support. Average wait to access IDD HCBW waiver services is 3+ years.
- Painful legacy of the service system can shape families views of services.
- Thankfully not all families have firsthand experience of abuse, neglect, or other indignities within the service system but, many know someone who does.
- Ideally the transition into formal services would be slow, but that is not always possible.

***“When we go to a new agency, sometimes I feel like they want a picnic and don’t realize that we are sitting in the same field I have fought battle after battle.” -***

***Family Member***



# Who Will Love My Child When I'm Gone:

## Esther Morrow, March 31, 2021

*"David, my wonderful David. I miss him so much, and we just took him back today. I had a lump in my throat all the time we were getting ready to go. He was ready to go 'home.' He's been here for a week. We've had a good visit even though we've been snowed in most of the time. I felt like crying even after we got back. His life is so narrow, but I don't know how to change that. I'm thinking of the Christmases we won't be here any longer, and he will probably have to stay there or somewhere. Will he understand, and how much will he cry, and how angry will he be? Who will care as much as I do? No one, because he is MY child. I wanted to keep him at home, but that wouldn't work. We can't keep up with him."*

# Recognition, Role Distinction and Respect

- **Families and Professionals Have Different, Important Lenses:** Both can be resources for each other.
- **Families: Long and Deep**
  - Families have a long, deep lens onto their and their loved one's life
  - They may be able to provide context, history and understanding to current or new challenges.
  - They may know what has worked well and what hasn't in the past.
- **Professionals: Wide and Scoping**
  - Professionals have wider lenses.
  - They have worked with many people and have ideas as to what has worked or not worked well for many others in the past, but do not have the same depth of understanding the person's history.
  - Unless you are, you aren't a family therapist.



# Building Relationships: Trust Takes Time

***“Change moves at the speed of trust.”-Steven Covey***

***“Trust is choosing to make something important to you vulnerable to the actions of someone else.” -Charles Feltman***

***“Trust without journey is compliance.”-David Hinsburger***

# Trust is not “1 Thing”: University of Minnesota Cooperative Extension-Types of Trust in Collaborations



**Contractual Trust:** Follow through on commitments and respect the boundaries of others.

**Communication Trust:** Clear, transparent, frequent communication.

**Competency Trust:** Perform your roles well, and be honest about what you can and can't do.

**Caring:** Show interest in others as full humans.



# Strategies for Relationship Building

**Ideas:** *Talk to the family member about their life (while respecting boundaries) and remember what you can. Interest, kids, work, pets ect.*

## **Support Valued, Reciprocal Family Roles**

- **Help The Person Keep Track of Important Days:**

- *Birthdays, Holidays or Important Cultural Traditions*
- *Support the person in buying small gifts to recognize those days.*
- *This involves internal strategies to determine who on the team will help find out what the important days are, when the important days are and how to recognize them.*

- **Support Connection:**

- *Help the person reach out/help families with technology.*
- *Help navigate transportation barriers.*
- *Help navigate health and safety barriers for visits.*

# Communication

Develop communication strategies *with* the person you support:

- **Who**
- **What: Note:** It's important to share the good and mundane and not only reach out with problems or asks.
- **How**
- **When**

**Note:** When developing these strategies it is important to take stock of internal communication as well.



# Communication

- How we speak shapes how we think and how we act.
- Be cautious not only about how you communicate **to families** but how you communicate **about families**.
- **Confidentiality applies to families too.**
- Seeking support and supervision is not the same as complaining or gossiping.



# Support, Resources and Information

- Supporting families to become **partners in hope** for their loved one and the organization.
  - Involvement in goal/setting or vision crafting
  - Involvement in identifying paths
  - Celebrating past wins to maintain momentum or a sense of agency.
- Opportunities for peer support
- Provide accurate information about the service system and service system navigation (health care, mental health care, transportation).

# Breakout Rooms

***Discuss the following in your breakout room:***

- 1. What strategies have you (or your organization) used in building relationships and communicating with families?***
- 2. What has worked well and what hasn't?***
- 3. What challenges to engaging families have you faced?***
- 4. What strategies will you try in the future?***



# Wrap-Up Themes and Resources

- Engaging families is essential for providing high quality support services to people with IDD of all ages.
- A trauma-informed approach may help providers find more compassionate and effective ways to engage families.
- Family engagement involves respect, role distinction, communication, and the provision of support, resources and information.
- **Useful Resources:**
  - **Charting the LifeCourse Framework:**  
<https://www.lifecoursetools.com/>
  - **Open Future Learning:** <https://www.openfuturelearning.org/>
  - **National Center for Supported Decision Making:**  
<https://supporteddecisionmaking.org/>



# Questions/Thoughts





# **Thank You and Keep In Touch!**

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