

Beyond the Diagnosis Module 7: Clinical Companion Resources

Emotional, Social, and Systemic Challenges Within the Rare Disease Community

This companion document was developed to support mental health providers participating in Module 7 of the Beyond the Diagnosis Rare Disease Training focusing on Emotional, Social and Systemic Challenges within the Rare Disease Community.

Rooted in trauma-informed care, this resource includes clinical tools and language guidance designed to:

- Normalize and validate the emotional experience of those affected by rare disease.
- Support safe, shame-sensitive client engagement
- Equip providers with practical, evidence-informed interventions

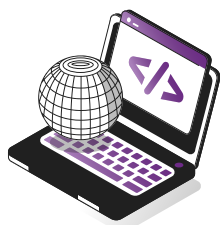
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Contents Include:

- Clinical Transition Mapping Tool
- Transition Reflection Tool
- Responsibility Mapping Tool

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Usage

This document is designed for use alongside the Module 6 slide presentation and facilitator guide. It may be distributed to CE participants, clinical trainees, or supervisors seeking to implement trauma-informed support for rare disease patients.

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Contributor Note

These materials were developed in collaboration with Al Freedman, PhD., Psychologist, Educator, & Jennifer Caughlin, PhD Psychologist, President, Caughlin Research

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Transitions Within Transitions

Mapping the Ripple Effect

Rare disease transitions rarely occur in isolation. A change in health, function, development, caregiving, or systems may create changes across multiple areas of a person's life.

Use this tool to explore the ripple effects of a current or anticipated transition, including what may change, what may be lost, and what the person wants to protect or preserve.

START AT THE CENTER: WHAT IS CHANGING?

What is the primary transition happening right now, or anticipated in the near future?

This might include a developmental milestone, change in function, hospitalization, new treatment, change in caregiver, school or employment transition, move to adult healthcare, loss of services, relationship change, or another significant transition.

Then ask: Is this transition expected, unexpected, or somewhere in between?

- ☐ Expected / planned
- ☐ Somewhat anticipated
- ☐ Unexpected / sudden

Whose transition is this?

- ☐ Patient
- ☐ Caregiver
- ☐ Family
- ☐ Multiple people

DAILY LIFE

What could change in everyday life?

Consider:

- Routines and schedules
- Activities of daily living
- Transportation
- Mobility
- Medication or treatment routines
- Energy and symptom management
- Recreation and social participation

Clinical prompt:

What might an ordinary day look like before and after this transition?

Transitions Within Transitions

Mapping the Ripple Effect

IDENTITY & AUTONOMY: What might this change mean for the person's sense of self?

Consider:

- Independence or dependence
- Control and decision-making
- Self-advocacy
- Body image
- Disability or disease identity
- Confidence and competence
- Future expectations
- "Who I was" versus "who I am becoming"

Clinical prompt:

What does this transition mean to the person, beyond what is practically changing?

This is where I'd specifically listen for language like:

"I used to be able to..."

"I don't want to need..."

"I finally get to..."

"People are going to see me differently."

"I don't feel like myself anymore."

RELATIONSHIPS: How might relationships or roles change?

Consider:

- Parent/child relationships
- Partners or spouses
- Siblings
- Friendships
- Intimacy and sexuality
- Dependence and reciprocity
- Privacy
- Social belonging

Clinical prompt:

Who may become more involved, less involved, or involved differently?

Does the person want that change?

- ☐ Yes
- ☐ No
- ☐ Unsure
- ☐ It's complicated

Transitions Within Transitions

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CAREGIVING: How might caregiving responsibilities change?

Consider:

- Who currently manages care?
- Who may need to assume more responsibility?
- What might the patient begin managing?
- What might a caregiver need to relinquish?
- What responsibilities should remain shared?
- Is the caregiver's own capacity changing?

Clinical prompt:

What needs to be shared, transferred, retained, or supported?
Where might there be tension between autonomy and safety?

WORK • SCHOOL • COMMUNITY

How might participation change?

Consider:

- School or educational setting
- Employment
- Accommodations
- Attendance
- Accessibility
- Community participation
- Religious/community spaces
- Hobbies and recreation
- Peer relationships
- Transportation

Clinical prompt:

What might make continued participation possible?

I like continued participation here rather than only “what accommodations are needed?” because it keeps the focus on the person's life rather than the system.

SYSTEMS & CARE: What systems may also change?

Consider:

- | | |
|---------------------------------|-------------------------|
| • Healthcare providers | • Equipment |
| • Pediatric/adult healthcare | • Transportation |
| • Insurance or benefits | • School-based services |
| • Medicaid or other eligibility | • Community supports |
| • Home nursing | • Care coordination |
| • Specialists | |

Clinical prompt:

What will the person or family have to learn, explain, prove, or navigate again?

That last question is particularly important for this module because AI repeatedly described transitions as requiring families to re-establish themselves within systems, including retelling their story and re-advocating after they had finally developed familiarity and stability.

Transitions Within Transitions

Mapping the Ripple Effect

LOOK BENEATH THE TRANSITION

WHAT MIGHT BE GAINED?

What new opportunities, choices, relationships, abilities, resources, or forms of independence might become possible?

WHAT MIGHT BE LOST?

What roles, abilities, routines, relationships, services, expectations, identities, or sources of security may be changing or ending?

WHAT FEELS MOST UNCERTAIN?

What questions cannot be answered yet?
What is the person or family most afraid they may not be able to control?

WHAT NEEDS TO BE PRESERVED?

What does the person most want to remain the same, even as other things change?

Preservation might mean: a relationship • a routine • privacy • independence • identity • belonging • a trusted provider • participation • choice • dignity • connection

PAUSE BEFORE PROBLEM-SOLVING

Not every difficult response to transition represents resistance to change.

Consider:

What might this response be protecting?

- ☐ Safety
- ☐ Autonomy
- ☐ Identity
- ☐ Familiarity
- ☐ Connection
- ☐ Privacy
- ☐ Belonging
- ☐ Hope
- ☐ A valued role
- ☐ Something else: _____

What would make this transition feel safer, more manageable, or more collaborative?

Transitions Within Transitions

Mapping the Ripple Effect

PLANNING INTO ACTION:

WHAT NEEDS ATTENTION NOW?

PREPARE

What can we anticipate or prepare for?

CONNECT

Who needs to be brought into the circle?

COMMUNICATE

What information, preferences, or needs need to be communicated, and to whom?

SUPPORT

Where does the person or family need more support?

PROTECT

What are we intentionally trying to preserve through this transition?

The goal is not simply to help someone accept change. It is to understand what the change means, what else it changes, and what matters enough to carry forward.

PREPARE → CONNECT → COMMUNICATE → SUPPORT → PROTECT

Transitions Within Transitions

Mapping the Ripple Effect

“Who Holds What?” Responsibility Mapping

Use this tool to explore how care responsibilities are currently distributed and where responsibilities might be shared, practiced, transferred, or further supported.

Care Task	 Patient Leads	 Shared	 Caregiver Leads	 Additional Support Needed
Taking medication	☐	☐	☐	☐
Remembering medication	☐	☐	☐	☐
Ordering refills	☐	☐	☐	☐
Scheduling appointments	☐	☐	☐	☐
Speaking during appointments	☐	☐	☐	☐
Recognizing symptom changes	☐	☐	☐	☐
Contacting providers	☐	☐	☐	☐
Managing equipment	☐	☐	☐	☐
Transportation	☐	☐	☐	☐
Insurance / benefits	☐	☐	☐	☐
Emergency planning	☐	☐	☐	☐

What would the patient like more control over?

What is the caregiver most afraid to relinquish?

What could be practiced before responsibility changes?

REFLECT TOGETHER

AUTONOMY: What would the patient like more control over?

CAREGIVER CONCERNS: What feels hardest or riskiest for the caregiver to relinquish?

READINESS: Which responsibilities could the patient begin practicing with support?

SUPPORT: What would need to be in place for that responsibility to shift safely?

PREFERENCE: Are there responsibilities the patient does not want to manage independently?

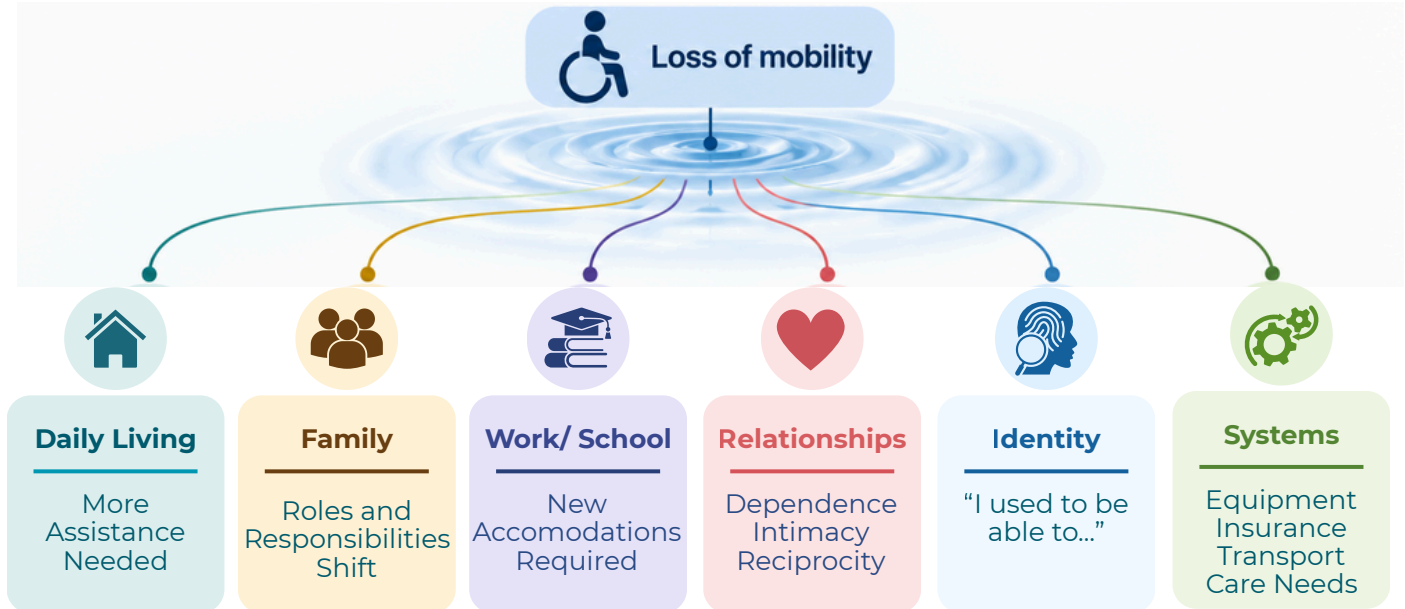
NEXT STEP: What is one responsibility that could be practiced, shared, or approached differently?

INDEPENDENCE IS NOT THE ONLY GOAL.

Responsibility should reflect the person's preferences, developmental readiness, abilities, support needs, and the complexity and consequences of the task.

Interdependence may be the most appropriate outcome.

ONE CHANGE CAN CREATE MANY TRANSITIONS



Developmental Timeline

A change in one can trigger changes across the other.



Rare Disease Timeline

CONTINUALLY INTERSECT



PREPARATION CHANGES THE EXPERIENCE OF TRANSITION

