

# BEYOND THE DIAGNOSIS

## EMOTIONAL, SOCIAL, AND SYSTEMIC CHALLENGES WITHIN THE RARE DISEASE COMMUNITY

1.5 HOUR CE Credit Approved (See Page 2)

FREE Virtual ON-DEMAND Training Hosted by  
Give an Hour, and Supported by Alexion



Originally Recorded on  
March 4th, 2026  
12:30 PM

### MODULE 3: BARRIERS AND BREAKTHROUGHS: SUPPORTING MENTAL HEALTH IN THE SYSTEMIC RARE JOURNEY



Hosted on ZOOM- For system requirements please visit: [ZOOM WEBSITE](#)

#### Learning Objectives:



**Describe** how systemic barriers across medical, insurance, and government programs (SSI, SSDI, waivers, school systems) contribute to chronic stress and emotional dysregulation in individuals and families living with rare conditions.



**Identify** common gaps in medical expertise, communication patterns, and care coordination that lead to frustration and grief for rare patients, and outline strategies clinicians can use to validate and support these experiences.



**Apply trauma-informed** and collaborative care principles to strengthen partnerships with overwhelmed medical professionals, educators, and service providers who may know less about a rare condition than the patient or caregiver.

#### Description:

In this module, providers will learn how to support rare disease clients as they navigate complex medical, mental health, insurance, and government systems. Clinicians will explore how limited medical expertise, fragmented services, and overburdened providers contribute to frustration, uncertainty, and emotional fatigue for individuals and families. Using a trauma-informed and collaborative approach, the session offers practical strategies to validate client experiences, and strengthen resilience and hope throughout the systemic rare journey.

#### INSTRUCTORS:

**Dr. Al Freedman**

Psychologist, Educator, & Rare Disease Advocate

**Kaitlin Maud, LPC Associate**

Art Therapist



*Al Freedman, PhD, is a psychologist, educator, and rare disease advocate with more than two decades of experience working with individuals and families affected by rare diseases and disabilities.*

*Dr. Al is inspired by his personal journey as the father of Jack, who lived with spinal muscular atrophy (SMA) for 26 years, as well as his professional training and experience as an educator to provide counseling and consultation. He works with families, advocacy organizations, pharmaceutical companies, healthcare organizations, and schools to create meaningful support systems and impactful change within the rare disease and disability communities.*



*Speaker bio: Kaitlin Maud, LPC Associate, ATR-P (she/they) is an art therapist, mental health counselor, and facilitator based in Austin, Texas. Her work focuses on supporting individuals navigating complex diagnoses and life transitions. Kaitlin brings experience as both a clinician and researcher, and has facilitated trainings, workshops, and groups for patients, providers, and organizational teams. Her approach emphasizes nuance, accessibility, and relational care- helping people build capacity for attunement with those whose needs are often misunderstood or overlooked. In addition to her professional background, Kaitlin brings lived experience as a rare disease patient, informing her commitment to patient-centered, trauma-informed, and ethically grounded care.*

#### Contact Info for Questions or Grievances

<https://giveanhour.org> | Give an Hour, PO Box 1532,  
Clarksburg, MD 20871 | 240-745-5641  
[providerrelations@giveanhour.org](mailto:providerrelations@giveanhour.org)

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### TRAINING AGENDA

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#### **AGENDA – Module 3: Barriers and Breakthroughs: Supporting Mental Health in the Systemic Rare Journey**

**Date:** March 4th | 12:30 PM ET

**Duration:** 90 minutes (1.5 CE credits)

**Format:** Live synchronous distance learning (Non-interactive)

**Instructors:** Al Freedman, PhD and Kaitlin Maud, LPC

#### **12:30 – 12:40 | Welcome & Introduction (10 min)**

- Welcome from Give an Hour and Alexion
- Introduce facilitators (Al Freedman, PhD and Kaitlin Maud, LPC)
- Training overview and CE objectives
- Participant safety and emotional-care reminders

#### **12:40 – 12:55 | Systemic Burden as a Core Clinical Stressor (15 min)**

- Identify how ongoing exposure to medical, insurance, disability, educational, and employment systems can contribute to chronic stress and emotional dysregulation in rare disease populations.

#### **12:55 – 1:05 | Recognizing and Validating Rational Distress Without Pathologizing (10 min)**

- Recognize emotional and behavioral responses that reflect rational distress in the context of chronic systemic strain and uncertainty.
- Validate lived experience without pathologizing adaptive coping or survival responses.

#### **1:05 – 1:15 | Clinical Logic vs. System Logic (10 min)**

- Describe how misalignment between clinical care and system requirements can contribute to frustration, grief, and erosion of trust.
- Define the role of mental health treatment when systemic barriers persist and external change is limited.
- Use validation strategies that acknowledge system mismatch without attempting to rationalize or defend system behavior.

#### **1:15 – 1:25 | Repetition Burden and Capacity Depletion (10 min)**

- Identify the cognitive and emotional toll of repeated retelling, documentation, archiving, researching, education, and advocacy within systems on patients and caregivers.
- Implement practical strategies to reduce advocacy fatigue and preserve client capacity.

#### **1:25 – 1:35 | VI. Work, Income, and Economic Stability as Clinical Domains (10 min)**

- Examine how employment instability, income insecurity, and access to accommodations affect mental health in rare disease contexts.
- Support clients in making autonomous decisions around disclosure, accommodations, and planning for fluctuating capacity

#### **1:35 – 1:45 | Educational Systems as Parallel Sites of Harm or Safety (10 min)**

- Describe how educational processes, including IEPs and 504 plans, can function as sources of stress and/or support for children and families.
- Apply trauma-informed approaches to support families navigating education systems.

#### **1:45 – 1:55 | Timing and Transitions Across Systems (10 min)**

- Identify system transition points (diagnosis, insurance changes, school transitions, employment changes) as periods of heightened psychological vulnerability.
- Anticipate and address emotional, relational, and identity-related impacts associated with system transitions.

#### **1:55 – 2:00 | Closing (5 min)**

- Define the role of mental health treatment when systemic barriers persist and external change is limited.
- Practice role-appropriate interventions grounded in steadiness, ethical hope, and respect for client autonomy.

**Agenda subject to minor adjustments based  
on presenter flow and audience needs.**

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# COURSE COMPLETION AND CE INFORMATION

## FOR GIVE AN HOUR MENTAL HEALTH PROFESSIONAL LIVE TRAINING & WORKSHOPS

### Course completion requirements:

- For any general questions or concerns, including those related to accessibility, please contact: [providerrelations@giveanhour.org](mailto:providerrelations@giveanhour.org).
- At the end of the training session, a link to the post-assessment will be shared in the Zoom chat. The link will also be sent via email the following day.
- Two unique codes will be shared at random times during the session. Please take note of these codes – they are required to complete the post-assessment.
- Licensed Mental Health Professionals must attend the entire course, pass the post-assessment with a score of 80% or higher, and complete a course evaluation to be eligible for CE credit. Once all items are completed, the certificate will be automatically available for download in the ProProfs system.
- Cancellation and refund policies do not apply to Give an Hour trainings, as all of our trainings are offered free of charge. If you are unable to attend, simply do not participate—no penalties will be incurred, and no further action is required.
- You must join the training through Zoom using a web browser or the app. Phone (audio-only) participants are not eligible for credit, as attendance cannot be tracked.

### Approved CE Statements:

- Give an Hour provider # 2097, is approved as an ACE provider to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Regulatory boards are the final authority on courses accepted for continuing education credit. ACE provider approval period: 04/30/2025– 04/30/2026. Social workers completing this course receive 1.5 cultural competence continuing education credit.
- Give an Hour has been approved by NBCC as an Approved Continuing Education Provider, ACEP No. 7552. Programs that do not qualify for NBCC credit are clearly identified. Give an Hour is solely responsible for all aspects of the programs
- Give an Hour is approved by the American Psychological Association to sponsor continuing education for psychologists. Give an Hour maintains responsibility for this program and its content.

For questions, grievances, or special accommodations, please contact us at [providerrelations@giveanhour.org](mailto:providerrelations@giveanhour.org) or 240-745-5641. You can also visit [giveanhour.org](http://giveanhour.org) or write to us at PO Box 1532, Clarksburg, MD 20871.

