



Division of Specialized Care for Children

**Family Advisory Council
Closed Meeting
February 6, 2025, 9:00 AM**

Attendees –

Jaclyn Vasquez	Erica Stearns	Chelsie Hacker	Brittani Provost
Ally Chenoweth	Aida Estrella	Jessica Brafford	Kendra Irby
Aurea Garvin	Mattanah Israel	Krystle Myers	Katie Page
Jaleesha Allen	Claire Cook	Haley Phelps	Jose Jimenez
Jasmine Deida	Lisa Washington	Molly Hofmann	Robin Morgan
Stephanie Leach	Terri-Lynn Jones-Wood	Ebonie Zielinski	
Robert Laib	Dena Chapman	Violet Wiker	
Amanda Simhauser	Thomas Jerkovitz	Adell Scott	
Gail Koshgarian	Christina Kieswetter	Ruann Barack	

Welcome, Erica Stearns & Jaclyn Vasquez –

The meeting was officially opened by ***Erica Stearns***, DSCC Home Care Family Outreach Associate and co-chair of the [Family Advisory Council](#), and ***Jaclyn Vasquez*** co-chair of the Family Advisory Council, who welcomed all participants and emphasized the importance of the FAC meetings as a platform for open dialogue between families and DSCC leadership. The FAC is designed to provide updates on key initiatives and create a collaborative space where families can engage directly with DSCC and HFS representatives.

Leadership Updates, Executive Director Thomas Jerkovitz –

Thomas Jerkovitz, DSCC Executive Director, provided an overview of recent developments affecting DSCC and its families. Thomas also acknowledged the challenges faced by families due to ongoing uncertainties and emphasized DSCC’s dedication to maintaining open communication. He encouraged members to reach out with any concerns and reassured them that DSCC staff had been briefed on how to support families through these challenges.

Following Thomas’s remarks, ***Molly Hofmann***, DSCC Director of Care Coordination, Systems Development, and Education echoed his sentiments, reaffirming that DSCC values feedback from families and welcomes suggestions on how to improve communication and support.

Informed Consent with Authorizations, Brittani Provost –

Brittani Provost, DSCC Benefits Management & Data Analytics Manager, serving as **DSCC's HIPAA liaison**, provided an update on the **informed consent process for authorizations**. She acknowledged concerns from previous meetings, where some families **felt they were not given clear choices** about what information they were consenting to share.

To address this, DSCC has developed **new staff training** to ensure that all **care coordinators follow a consistent, transparent process** when discussing authorizations with families. The training will reinforce:

- The importance of **clearly explaining** what families are consenting to.
- Making sure families **understand their right to limit or adjust** their authorizations.
- Ensuring DSCC staff **communicate options clearly and without pressure**.

Brittani emphasized that the goal is to **empower families** by making them feel confident in their decisions. She encouraged FAC members to **share any additional concerns** so DSCC could continue refining its approach.

With no immediate questions from members, Brittani transitioned to the next agenda item but welcomed **ongoing feedback** as the training was implemented.

Family Survey Update, Brittani Provost –

Brittani Provost provided an update on the annual family survey. She noted that the survey would be distributed via mail and email in the coming week, and she encouraged all families to participate.

She shared a video summarizing feedback from the previous year's survey, highlighting that:

- 95% of respondents found DSCC staff to be professional.
- 92% found them helpful.
- 89% were satisfied with care coordination services.

Key areas for improvement identified in the survey included:

- Access to resources
- Future planning
- Availability of nursing services
- Improved communication

In response, DSCC has launched **NurseNet**, an online tool to help families find nursing care. Additionally, DSCC is expanding its **Family Education Webinar Series**, with a focus on Medicaid waivers for 2025.

Annual Report Update, Amanda Simhauser –

Amanda Simhauser, DSCC Communications Manager, provided a preview of **2024 DSCC Annual Report**, covering **program updates, partnerships, and family survey results**. A special section highlights the **Family Advisory Council (FAC)**, featuring **Ekiko Aiken and her daughter, Davina**, whose story is also shared on DSCC's website.

[Davina's Family Story - UIC Division of Specialized Care for Children](#)

Amanda reminded members about the **ongoing family survey**, noting a **reminder email would be sent that morning**, and the **survey video is available online**.

She also previewed the **2025 Health Insurance Education Series**, starting March 11, focusing on **Medicaid and HCBS waivers**, with sessions in **English and Spanish**.

Youth Advisory Council Update, Claire Cook –

Claire Cook, Title V Transition Specialist, provided updates on the [Youth Advisory Council \(YAC\)](#) which has held three meetings since its formation. A new member joined during the last session on January 29, 2025.

The YAC is currently developing a **College Readiness and Accommodations Project**, which will include:

1. A short, engaging **video** to be shared on social media.
2. A **one- to two-page resource document** summarizing key information.

The youth members prioritized two topics:

- **Exploring Post-High School Options** – Covering college, vocational programs, job shadowing, and certification programs
- **Understanding Accommodations** – Educating students about available supports, self-advocacy, and disability rights

Claire emphasized that the youth were excited to take an active role in shaping resources for their peers. The project is expected to be completed between August and October 2025.

LRA/CNA Updates, Stephanie Leach & Adell Scott –

Stephanie Leach, Associate Director of Systems of Care, and **Adell Scott**, Manager of Home Care Quality Improvement presented updates on the **Level of Reimbursement Assessment (LRA) and Certified Nursing Assistant (CNA) processes** focusing on new policies allowing parents to serve as CNAs for their children. The **State Plan Amendment**, posted by **HFS on December 31, 2024**, received **positive public feedback**, though concerns were raised about the

financial burden and time constraints parents face in obtaining CNA certification. While HFS will review comments before submitting them to **CMS for approval**, no timeline has been set for final implementation.

To support families, DSCC developed **two guidance documents**: one for **families considering CNA training**, detailing **eligibility, certification steps, and expectations**, and another for **nursing agencies**, clarifying **supervision, compliance, and employment conditions** for parent CNAs.

Key updates include **shifting RN supervision to every 60 days** (instead of every 14) and requiring **CNA-appropriate shift documentation**. FAC members highlighted concerns about balancing **caregiving with training requirements**, prompting discussions on **scholarships, online training options, and flexible scheduling** to ease the burden on families.

CNA School Tip Sheet, Katie Page –

Katie Page, DSCC Pediatric Palliative Care Program Manager, introduced a new **CNA School Tip Sheet**, designed to support families navigating the CNA process. The document consolidates essential information in a user-friendly format.

The **CNA School Tip Sheet** includes:

1. **Finding CNA Training Programs:**
 - A **searchable database link** for **Illinois Department of Public Health (IDPH)-approved CNA programs**, allowing families to find **training opportunities near them**.
 - Information on how to **filter results by location** to identify programs that best fit their needs.
2. **Alternative Pathways to Certification:**
 - Guidance for individuals with **previous healthcare experience**, such as **military medics or out-of-state CNAs**, who may qualify for certification through alternate pathways.
 - Instructions on how to **apply for competency testing** to bypass full training if applicable.
3. **Cost Considerations:**
 - Out-of-pocket costs, including **textbooks, uniforms, travel expenses, and certification exam fees**.
 - Considerations for **potential lost income** while attending training.
4. **Financial Assistance Options:**
 - Suggestions to **contact workforce development offices, CNA training programs, and local scholarship opportunities** to explore potential funding sources.
 - Information on **tuition reimbursement programs** available through some nursing agencies for those who commit to employment after certification.

Katie emphasized that **families should begin researching their options as soon as possible**, as program availability and funding opportunities vary by location. She noted that the **final version**

of the tip sheet would be reviewed by DSCC leadership before public distribution to ensure accuracy and clarity.

Several **FAC members** agreed that the **CNA School Tip Sheet should be released as soon as possible** to help families prepare, even though **paid parent caregiving was not yet officially implemented**. One member suggested including a **disclaimer** to clarify that **while funding options are being explored, caregiver compensation policies were still pending approval**.

Caregiver Toolbox, Erica Stearns –

Erica Stearns introduced the **Caregiver Toolbox**, an initiative designed to provide practical guidance for caregivers. Unlike traditional resource lists, the toolbox aims to:

- **Navigating Resources & Insurance** – How to assess services, avoid dead-end referrals, and track interactions with care coordinators.
- **Hiring & Working with Nurses** – Interview questions, agency expectations, and boundary-setting tips.
- **Emergency & Future Planning** – Templates for **daily care plans, emergency medical sheets, and legal planning** for continuity of care.
- **Advocacy & Rights** – Understanding **Medicaid, special education (IEP), and disability benefits**.
- **Caregiver Mental Health & Self-Care** – Strategies to prevent burnout, access support groups, and balance responsibilities.

Erica invited **FAC members to collaborate**, ensuring the toolbox reflects **lived caregiving experiences**. Suggestions included linking it to the **Caregiver Mental Health Toolkit**, adding **financial assistance resources**, and creating a **glossary of key terms**. The project will be developed in phases, with ongoing feedback shaping its final format.

Discussion, FAC members –

FAC members engaged in an open discussion, **shared concerns, and proposed solutions** related to **policy changes, care coordination, and advocacy efforts**. The discussion was highly engaging, with members expressing a strong desire to **actively participate in legislative advocacy**, particularly regarding **home care services and caregiver support**.

Key Discussion Points:

1. **Impact of New Policies on Families**
 - Members discussed how recent policy changes were affecting access to care, particularly for families relying on **in-home nursing and Medicaid services**.
 - Concerns were raised about **potential disruptions in services**, causing increased stress for caregivers.

2. Improving Care Coordination

- Several families shared **challenges in communicating with case managers and navigating the system efficiently**.
- Suggestions included **more frequent check-ins from DSCC coordinators**, enhanced training for care coordinators, and clearer guidelines on available resources.

3. Navigating Nursing Concerns

- A family member shared challenges in **addressing nursing concerns** related to their child's care. **Families exchanged advice** on effective communication strategies and **suggested ways DSCC can support and educate families** in navigating these issues.
- **HCQI provided clarification** on DSCC's process for handling nursing transgressions to ensure families understand the procedures in place.

4. Advocacy for Better Access to Services

- Members emphasized the need for **stronger advocacy efforts at the legislative level to improve funding and policies** affecting home care programs.
- Many members **expressed a commitment to attending upcoming Advocacy Days** and working together to amplify the voices of families in need.

Next Steps & Follow-Ups:

- A **summary of advocacy opportunities** would be shared via email, giving members a chance to participate in **upcoming legislative efforts**.

Closing, Erica Stearns and Thomas Jerkovitz –

Erica and Thomas provided closing remarks, thanking all participants for their engagement. Tom emphasized the importance of these conversations in shaping DSCC's future direction.

The Next **Open FAC** meeting is scheduled for **May 8, 2025**.