



UNIVERSITY OF
ILLINOIS CHICAGO

**Division of Specialized
Care for Children**



YOUTH ADVISORY COUNCIL GUIDEBOOK



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Part 1: DSCC YOUTH ADVISORY COUNCIL

Mission

The Youth Advisory Council's mission is to provide youth with a platform where they can freely identify barriers and areas of need for more successful transitions to adulthood.

Purpose

The purpose of the Youth Advisory Council is to help the Division of Specialized Care for Children (DSCC) develop more youth-focused ways to help participants, families, and DSCC staff with transition planning, resources, and services. The goal is to support positive outcomes in employment, health care, independence, and quality of life in adulthood for all Illinois youth with special healthcare needs (YSHCN). DSCC will share these tools to help transition-aged youth outside of DSCC. Youth members will participate in projects on a statewide advocacy level as agreed upon.

Role

1. Bring a different and personal perspective on issues important to youth.
2. Partner with DSCC staff to enhance care coordination by helping develop more youth-focused ways that can help all YSHCN in Illinois.
3. Develop strategies to improve transition needs and communication between 15- to 24-year-old youth/young adults and older adults (such as parents, caregivers, care coordination teams, doctors, specialists, school providers, community organizations, insurance companies, and state agencies).
4. Empower youth to envision their life, health, and career goals as well as practice decision-making skills to promote a successful transition.

Membership

Eligibility

1. Youth with special healthcare needs who are living in Illinois, between the ages of 15 to 24 and who are planning for the transition to adulthood in the areas of education, healthcare, employment and home and community-based support.
2. Members must be able to join virtual meetings and have time available to attend.
3. Membership is a one-year commitment with the option to continue for two years. Once a member completes their term, they can reapply for the council if they remain within the age limits of the membership qualifications.



Member Qualities

- Shares insights and information about their experiences in ways that others can learn from.
- Sees beyond their own personal experiences.
- Demonstrates good listening skills.
- Respects the perspective of others.
- Speaks comfortably in a group or has interest in building on these skills to gain more comfort in group settings.
- Interacts well with many different types of people.
- Works in partnership with others.

Application and Selection Process

The Transition Specialist will send an electronic copy of the Youth Advisory Council flyer and application to all care coordination teams. Care coordination teams can offer insight on possible youth candidates. DSCC will also post the flyer and application on its website and share them on DSCC's social media channels. There is an option to mail the flyer to all transition-age youth participating in DSCC programs as well.

Members must complete a formal application to join. The transition team will review applications and invite members based on the vacancies available. The team will take different demographic perspectives into account. The team will send acceptance letters to those invited to join. Those not selected will receive a denial letter and may be considered for future openings.

Members will sign a Letter of Agreement that clearly defines the term limits, expectations, and processes in place to include the youth voice. Members and their parent/guardian (if applicable) will sign consents to participate in the council.

Confidentiality

DSCC will trust YAC members with information about DSCC, by nature of committee participation. To follow Health Insurance Portability and Accountability Act (HIPAA) requirements and to safeguard protected health information (PHI), YAC members and their legally responsible adult must sign a consent form. To facilitate discussion and describe potential changes, members are welcome to disclose information about themselves during the discussion. We ask that all YAC members respect the privacy of other members and maintain confidentiality of information disclosed during the committee meetings, but there is a risk that other members may disclose information you share outside the committee setting. We will remind members to keep information about other members private and will apply reasonable safeguards to protect your confidentiality and reduce this risk. Minor members must provide parental consent.



Meetings

Youth Advisory Council members, the Youth Chair, the YAC Adult Navigator, the Transition Specialist and other DSCC-appointed staff will initiate and direct action together. The Transition Specialist will co-facilitate the meeting with the YAC Adult Navigator and continue to work collaboratively with the YAC.

There will be four virtual closed meetings per calendar year. Special meetings may happen during the year if necessary. Meetings will follow a general standing agenda in addition to updates/news from agreed-upon subcommittees.

Meeting Ground Rules

- No swearing, name-calling, or yelling at other participants.
- Show respect for other participants. Challenge others respectfully.
- One person talking at a time.
- Step up, step back: if you are sharing more than others, step back and let someone else share. If you are under participating, try to step forward more.
- Have cell phones on vibrate or silent.



Part 2: OPERATIONAL LOGISTICS

Organizational Structure

Group Size

- Fifteen Youth Advisory Council members representing all DSCC regions from different demographic backgrounds (e.g., age, gender, ethnicity, cultural, geographic, socioeconomic, etc.).
- One member will be the YAC Chair.
- YAC members may decide optional subcommittee youth chairs.
- Two DSCC staff members (YAC Adult Navigator, Transition Specialist) will attend and participate.
- Other DSCC team members may participate as needed.

Roles and Responsibilities

Youth Advisory Council Chair

The YAC Chair will act as a youth leader of YAC meetings, along with the YAC Adult Navigator and Transition Specialist. The YAC Chair is a youth member of the council. It is the responsibility of the YAC Chair to:

- Keep meetings active, productive, and inclusive of all members.
- Act as a role model to other members.
- Ensure activities and outcomes are clearly communicated and understood by members.
- Act as a liaison between the YAC and DSCC. As a representative for the community of youth with special healthcare needs, the YAC Chair will gather ideas from members and provide input to guide the direction of work of the YAC.
- Enforce ground rules of the group. The Chair leads by example and communicates concerns in a thoughtful manner to all individuals involved. The Transition Specialist and Adult Navigator will take the lead in decision-making during times of debate.
- Attend and participate in YAC meetings. Meetings will consist of creating agendas, organizing planned activities/projects, and evaluating how the group is doing based on member feedback.
- Provide partnership and support to members.
- Appoint committees when necessary to research issues.



YAC Members

It is the responsibility of Youth Advisory Council members to:

- Serve as an advisory resource to DSCC.
- Participate in Youth Advisory Council meetings.
- Provide input for policy and program development.
- Review recommendations from DSCC staff and/or administration.
- Provide information on needs and concerns of other youth within the CYSHCN system.
- Review and comment on DSCC activities, programs, services, and strategies related to transition to improve participation and access to services.
- Provide feedback on materials DSCC develops for youth and families.
- Participate in optional subcommittees to attain agreed-upon goals.

YAC Adult Navigator

The YAC Adult Navigator works collaboratively with the Transition Specialist to facilitate and structure YAC meetings. A care coordination team member should fill the YAC Navigator position. It is the responsibility of the Adult Navigator to:

- Work with the Youth Chair and Transition Specialist to complete and distribute the meeting agenda.
- Act as a contact for DSCC staff interested in involvement in the YAC.
- Assist with coordinating and facilitating meetings.
- Assist with note-taking during YAC meetings as needed.
- Provide guidance and support to YAC members and chair.

Transition Specialist

The Transition Specialist works collaboratively with the YAC Adult Navigator to facilitate and structure YAC meetings. The Transition Specialist will act as the first point of contact for YAC members and DSCC staff. It is the responsibility of the Transition Specialist to:

- Facilitate recruitment and review of new YAC members.
- Assist with note-taking during YAC meetings and ensure meeting minutes are published within two weeks of the meeting. Meeting minutes may be distributed to all YAC members, DSCC staff, and participants.
- Work with the Youth Chair and Adult Navigator to complete and distribute the meeting agenda. YAC members can submit any additions by one week prior to the meeting.
- Support the YAC and its members in ensuring activities of the YAC are integrated into system improvements.
- Initiate and track annual surveys about YAC members' experiences.
- Work with the university financial team to provide compensation, etc., to attending members of the YAC.



Funding and Budgeting

Youth Advisory Council members will receive compensation for meeting participation and mission-related work. Compensation will be in the form of a gift card. Members will receive a \$30 gift card for each meeting they attend. Members will receive the gift cards following each meeting.

Annual Survey

Youth Advisory Council members will complete an annual survey related to their experiences as a member. Evaluating the YAC is an essential key to understanding the role and effectiveness of this youth-adult partnership within DSCC. It will allow the team to assess whether the council is meeting goals and reflect on common problems and successes, overall group processes, and youth satisfaction.

Policy

DSCC staff will follow the UIC Protection of Minors Policy, <https://hr.uic.edu/employees/protection-of-minors/> in order to provide a safe environment. The YAC Team will explore other national laws/guidelines for involving youth and implement them as applicable. DSCC will share a dispute and resolution process that is understandable and accessible to youth.

While we respect and know that there is a debate in the ability community about using person-first language or identity language to describe a disability, as a Title V Children and Youth with Special Healthcare Needs organization, person-first language will continue to be used in transition policies, procedures, and other materials. This is not to say that we believe disability is something negative; however person-first language closely fits with person-centered planning. The Youth Advisory Council offers youth opportunities to develop talents, skills, and strengths in a culture that appreciates and values youth contributions and resourcefulness.