

Indiana Complex Care Coordination Collaborative
Family Satisfaction Follow-Up
Themes and Example Questions

We want to learn about your unique experience participating in care coordination part of the Indiana Complex Care Coordination Collaborative. Based on the Family Satisfaction Survey, we would like to learn more about how care coordination meets the needs of your family, its impact on quality of life and care workload, and how we can improve the program.

Theme 1: Needs – met/unmet

Example Questions:

- Can you describe a time when your care coordinator helped you get health care or services (e.g., coordinating specialty care visits, prescriptions, therapy, transportation, etc.)?
- Can you describe a time when your care coordinator helped you with non-health care issue or challenging situation?
- Are there needs or challenging situations that your care coordinator **cannot** help you meet?

Theme 2: Care coordinator services

Example Questions:

- Can you describe a service the care coordinator provides that you value/appreciate (e.g., dealing with difficult referrals or follow-up appointments, finding services, communicating our family needs, etc.)?
- What important services are **not currently provided** by care coordinators?

Theme 3: Accuracy, use, and utility of the shared plan of care?

Example Questions:

- Does the shared plan of care reflect your goals and needs?
- How do you use the shared plan of care?
- How can we improve the shared plan of care process and use?

Theme 4: Quality of life – child and parent

Example Questions:

- Can you describe how **your child** has a good quality of life (e.g., has fun, can do activities with friends/family, participates in school or community activities, etc.)?
- Can you describe how **you** have a good quality of life (e.g., have fun, have support from family/friends, participate in school, work, or community activities)?
- How can IC4 help improve the quality of life for you or your child? For example, do you need support working with your child's school to advocate for changes in the IEP? Do you need support connecting with other community resources?

Theme 5: Care workload

Example Questions:

- Can you describe how caring for your child has impacted your personal or financial well-being (e.g., affected your ability to work, created financial burden, increased social/emotional stress)?
- How has your participation in care coordination reduced some of these negative impacts?
- How can care coordination reduce the stress or care workload that you face caring for a child with complex medical needs?

Theme 6: Medical home

Example Questions:

- How does the primary care team (including the care coordinator) improve your child's care?
- Can you describe when your primary care team helped you deal with a challenging situation or unmet need?
- Can you describe when your primary care team **could not** help you with a challenging situation or unmet need?