

A Family Care Perspective & Experience

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1. Share about your family.

Loved one's strengths, challenges and support needs.

- Dedication, Attitude, Personality, Making Lists, Grocery Shopping, Routine-Oriented
- Impact of Disability, Safety
- Needs 24/7 support
 - Job coaching
 - companion support
 - Transportation
 - daily living assistance

2. Did you select Family Care or IRIS?

What do you remember about making that decision?

- Waiting list – Entered at age 19

What led you to choose the program you are in?

- Time to manage
- Interviewed both Managed Care options

Is this the first Adult Long-Term Care waiver you have utilized?

- First and only

3. Did you change from one program to another?

- No change.
- Same Family Care organization for over 7 years.

4. Who is part of your team and how does it work together?

- Team includes: Eric, husband & I, case manager, and nurse.
- Case manager handles the coordination of support.
- Family determines what we provide in the form of support.
 - Daily support & general care – all but 8:30-4:30 each day/M-F
 - Transportation to and from work-Mondays and community activities
 - When seizure cycle, provide 100% support
 - Family communicates changes in needs to manager.
- Visits and Contact times:
 - In-person visits every 6 months in our home.
 - Monthly visits with my son.
 - Periodic email communications.
 - Case manager attends day program meetings 2X/year
 - Case manager attended all DVR and IEP meetings

5. What kind of supports does your loved one have access to?

What supports have been most useful?

- Supportive employment – job coaching
- Transportation to and from community-based program
- Community-based day program
- Companion support
- Self-directed supports

Were there services that you declined to use when offered?

- No.

6. Have you had to request additional services/funding?

How did that process work?

- Have requested additional services and funding.
- The ISP had identified both current and future services based on a comprehensive Discovery profile.
- A simple email request
- If an agency needs to be determined, interview and research.
- Usually cared for within a few weeks

7. What have been the most positive and most challenging experiences with the program?

Positive Experiences:

- Awesome case manager who I trust and cares
- Options that fit my son's needs
- Transportation has been pretty reliable and trusted
- My son is very happy

Challenging Experience:

- Opening up my home to agency people who I do not know.
- To find people who we know

8. How has life changed since you started using Family Care/IRIS?

- My son feels like a contributor – he works like everyone else and brings home a paycheck
- Family Care has been responsive to our family's changing situation – allowing everyone to work
- My son has a community-based program that he truly enjoys, learns new skills, volunteers, and socializes

9. What do you know now about FC or IRIS that you wish you had known earlier?

- Being able to articulate the needs of your loved one in a comprehensive way made it easier to identify and write a ISP
- Finding a case worker who partners with your loved one and family is essential. One who...
 - Listens
 - Advocates
 - Works hard to fulfill needs and respond
- Relationships Matter!