



# Shared Care: Building Support Networks

# Introductions

## Sean

- Self Advocate living with Fragile X Syndrome
- Volunteer
- Guest Speaker
- Participant at Park Lawn
- Com Ed Ambassador
- Special Olympian

## Christine

- Social Worker, Clinical Professor & best job: Mom



# Who are you?

Self Advocates

Caretakers

Siblings

Educators

Professionals working in disability settings

Friends

Others?



# What are we going to talk about today?

- \* Talk about Sean's life and how shared care and his support network help him live like to the fullest & achieve his goals
  - Showcase real-life examples that encourage a shift towards shared care

- \* Why support networks are important and help people
  - Understanding the value of support networks and their role in promoting independence for people with IDD
  - Demonstrating mental health benefits of shared caregiving.
- \* Think about ways you can build your own support network
  - Offering tools for building and maintaining support networks.

# What is a shared network of care/circle of support?

A collaborative approach that shares caregiving across a trusted network.

How it has helped Sean and our family: Helps lower stress, prevent burnout, and supports caregiver mental health—while increasing opportunity and autonomy for Sean

How it's worked for us: Both informal & structured; it depends on needs and requires communication, planning, and trust for long-term wellness & gain.



# Sean's life

## Who's in the network

Friends, family members, professionals, and educators each play a unique role—offering encouragement, education, and opportunities for fun and social connection.

## How shared support works

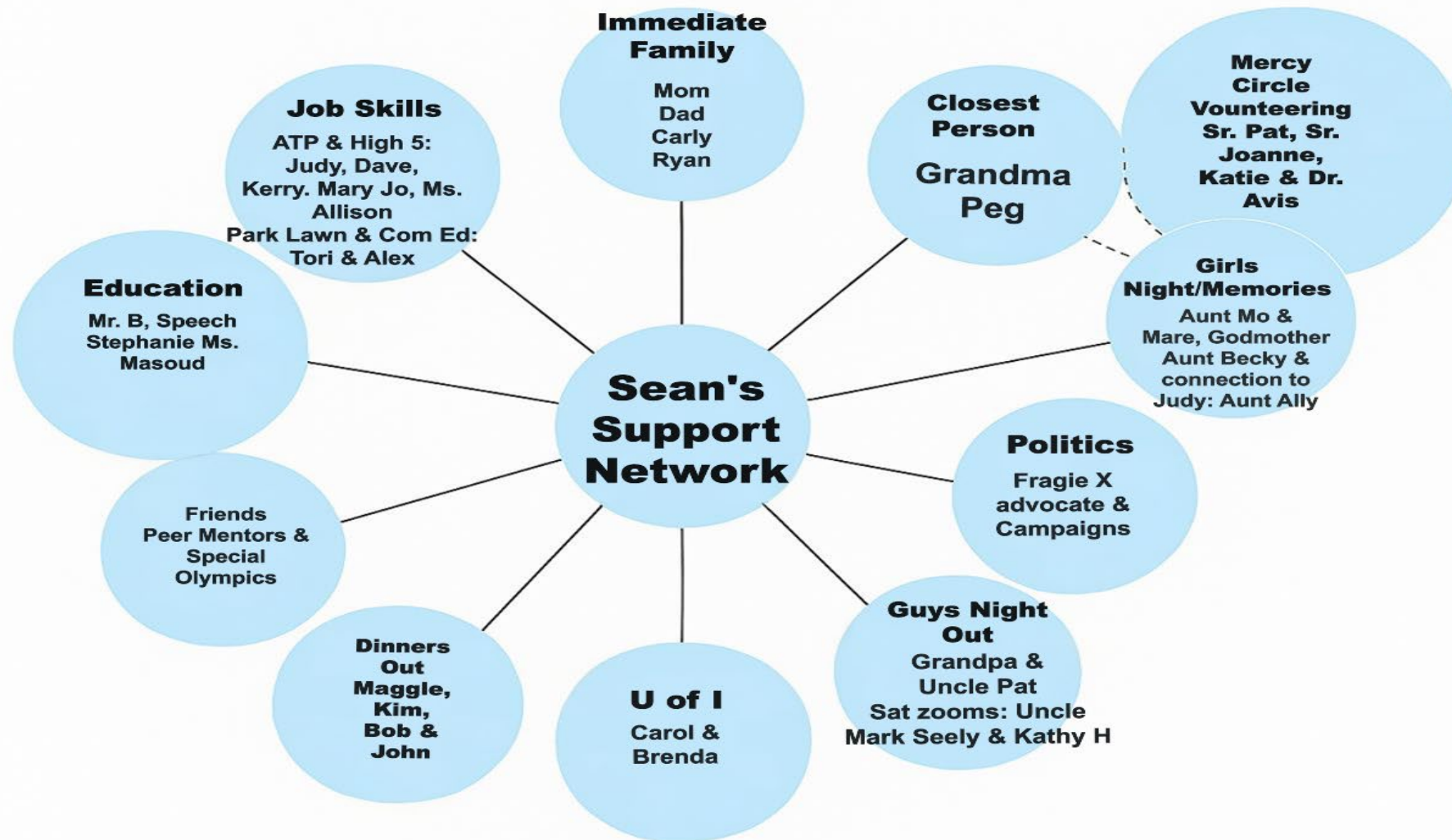
Mutual respect, clear communication, and common understanding help make it all work.

## Why it matters over time

Support is dynamic: it evolves as needs change. Sean's examples show how networks can be built and nurtured—benefiting the person receiving support AND the caretakers AND the people providing the support.

**REMEMBER: It's not about the numbers; it's about the connections!**

# Circles of Support



# For caretakers: Self care is essential!

While rewarding, caretaking isn't always easy: role overload, emotional fatigue, and the pressure to manage everything alone

- \* Stress and burnout can impact mental and physical health

Caregiving doesn't have to mean self-sacrifice or isolation

- \* Shared-care systems support balance, resilience, and hope.

Barriers: guilt, lack of time, and fear of letting others step in can make self-care feel “optional.”

What can self care look like? Rest, emotional support, professional help, and personal fulfillment. Consider things that bring you joy. Delegating is an act of strength.



# How to build a network of care?

Notice existing supports, clarify your needs, and make a clear ask with expectations and boundaries.

Begin with small steps, let relationships evolve naturally, and remember most people want to help when invited.

Keep communication ongoing, show appreciation, and stay flexible as roles and circumstances change over time.



# My Care Network

1. Who helps me now?

2. What are things I enjoy doing?

3. Who can help me do things I enjoy?

## 4. Building My Support Network

Ways you can build your support team:

- Call, text or email someone you know
- Help someone else
- Say hello to a new friend
- Join a group or game
- Ask someone to play or join you in doing something
- Practice asking for help
- Say “thank you” when someone helps you

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No one person, no one relationship, will fulfill your every need. Not every friend can offer you safety or support on every day. Not everyone can, or will, show up precisely when or how you need them to. And this is why it's good to always continue making room at your table, to keep yourself open to gathering more friends. You will never not need them, and you will never stop learning from them.

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Michelle Obama