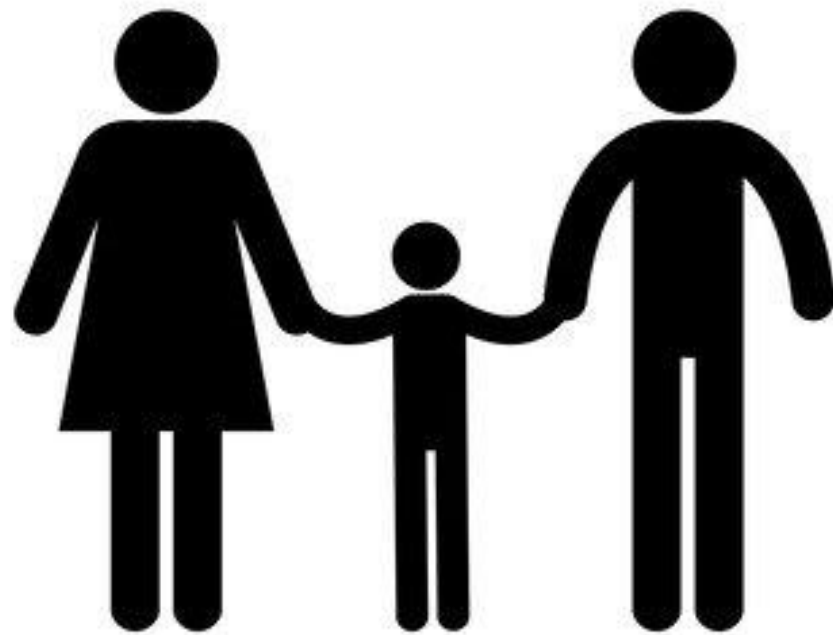


Family Advocacy



The Family



Diversity of Families

Family advocacy applies to many types of families

- Families with child/children on the spectrum
- Self-advocacy with supportive family involvement
- Tradition, blended, same sex etc.
- Families with dependent adult child/children on the spectrum
- Siblings
- Families with parents on the spectrum (children may or may not be on the spectrum)
- Extended Families
- Loving marriages or domestic partnerships (traditional, same sex etc.)
- Ethnic, racial and cultural diversity
- Rural, urban or remote

And many more...

Navigating the system



- ▶ The process or activity of accurately ascertaining one's position and planning and following a route. (Oxford dictionary)

In this context:

- ▶ The process of finding appropriate services for an Autistic person either by the autistic person themselves, a caregiver or service provider

Identification home, preschool, school, ped'n

Uncertainty, fear, unclear route to diagnosis, referral, waitlist,

Diagnosis – Y / N

Grief, loss, isolation, family strain & fatigue; unsure of pathway, ? Intervention, wait

Options narrow
Funding Y / N

Paperwork, interviews, forms, more assessments, geographical considerations, not clear where to go from there; wait, multiple funders

Shifting & episodic service needs

Multiple approaches, multiple providers, difficult/few choices, geography, little guidance, out-of-pocket expenses; repeat story +++

Intervention

Inconsistent access; multiple service providers incl'g medical,

Options narrow
Find Program

Hope but uncertainty; what are the goals for the child & family?

Intervention narrows at school entry, still multiple service providers

Episodic intervention for episodic need

Few choices, little guidance, who do you go to?

Identification of social support need

Access depends on who you speak to, their knowledge, their connections, advocacy, availability, geography, multiple pathways, inconsistent guidance

Transition to adult

Service options narrow further, need to consider funding, housing, employment, guardianship, social opportunities

Navigation: The Challenges

Multiple services and sectors (e.g., government, health, mental health, specialized services):

- Multiple programs with varying eligibility criteria and funding structures
- Application processes for programs/resources involve multiple steps and require specific information
- Providers and sectors often focus on specific areas and operate independently

The Challenges

Lack knowledge about services...

- ▶ In region
- ▶ Service costs for families or individuals
- ▶ Beyond service provider scope
- ▶ Appraisal/quality of services



The Challenges

Family specific:

- Recognition of rights to services
- Limited focus on social barriers
 - Poverty, employment, citizenship status, racial/identity etc.
- Caregiver burnout
- Advocate Capacity



Advocate Capacity

Capacity

- ▶ Family health
- ▶ Family dynamics (siblings, grandparents ...)
- ▶ Education
- ▶ Experience
- ▶ Knowledge (systems, lingo...)
- ▶ Language

Approach

- ▶ Passive / assertive
- ▶ Cultural influence

Bias and Stereotypes

- ▶ Gender
- ▶ Race / Culture
- ▶ Age

The Outcome

Individual advocacy vs. Systems advocacy

Inspired / fueled by a barrier or gap

Factors that may interfere:

- ▶ Validation of hardship (foundation of trust)
- ▶ Social presentation of an Advocate
- ▶ Focus on achieving a desired outcome

Opportunity to identify gaps, needs,...

Every Stakeholder Plays a Role

Lead advocate can be the individual or guardian

Everyone is a Key

- ▶ Researchers: inform practice / inform decisions
- ▶ Clinicians: document need, baselines, impact, & next steps
- ▶ Government: funding, oversight, public awareness...
- ▶ Individual / Family: expertise of lived experience, accountability gauge

Good Samaritan

- ▶ Recognizing a person/family in need
- ▶ Rising to the occasion

Community groups

Our Responsibility



Panelist Experience in Advocacy

- ▶ 4 testimonials
- ▶ Sharing an individual experience in advocacy
 - ▶ self, loved one, others and/or the community
- ▶ Our own journey is unique
- ▶ Opportunities lie in the similarities & differences



A Call to Action - Forming Provincial Working Groups

- ▶ The aim of each panel today is to inspire dialogue about the possibilities in each theme.
- ▶ The ultimate goal is to establish provincial working groups.
- ▶ The report summarizing insight from the conversation today will guide the Alliance planning committee in establishing the working groups to engage those stakeholders volunteering to join the conversation.

