

A world of opportunities: Incorporating the patient voice in ECHO

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Holland B∞**view**

Kids Rehabilitation Hospital

Disclosure of Financial Support

- This program is fully funded by **The Ministry of Health and Long Term Care**
- We have no conflicts to disclose

Learning Objectives

- The value of patient and family centred care
- Why is it important to include the patient voice in ECHO Autism?
- Why not the patient him/herself in ECHO Ontario Autism?
- Benefits of a family/patient advisor
- What to look for in a family/patient advisor
- Outside of the hub team -how to involve the patient voice

Introductions:



ECHO Ontario Autism

- Goals
- Paediatric Hospital
- Professionals involved
- Type of cases we deal with
Management, Medication



The patient Voice in ECHO Autism

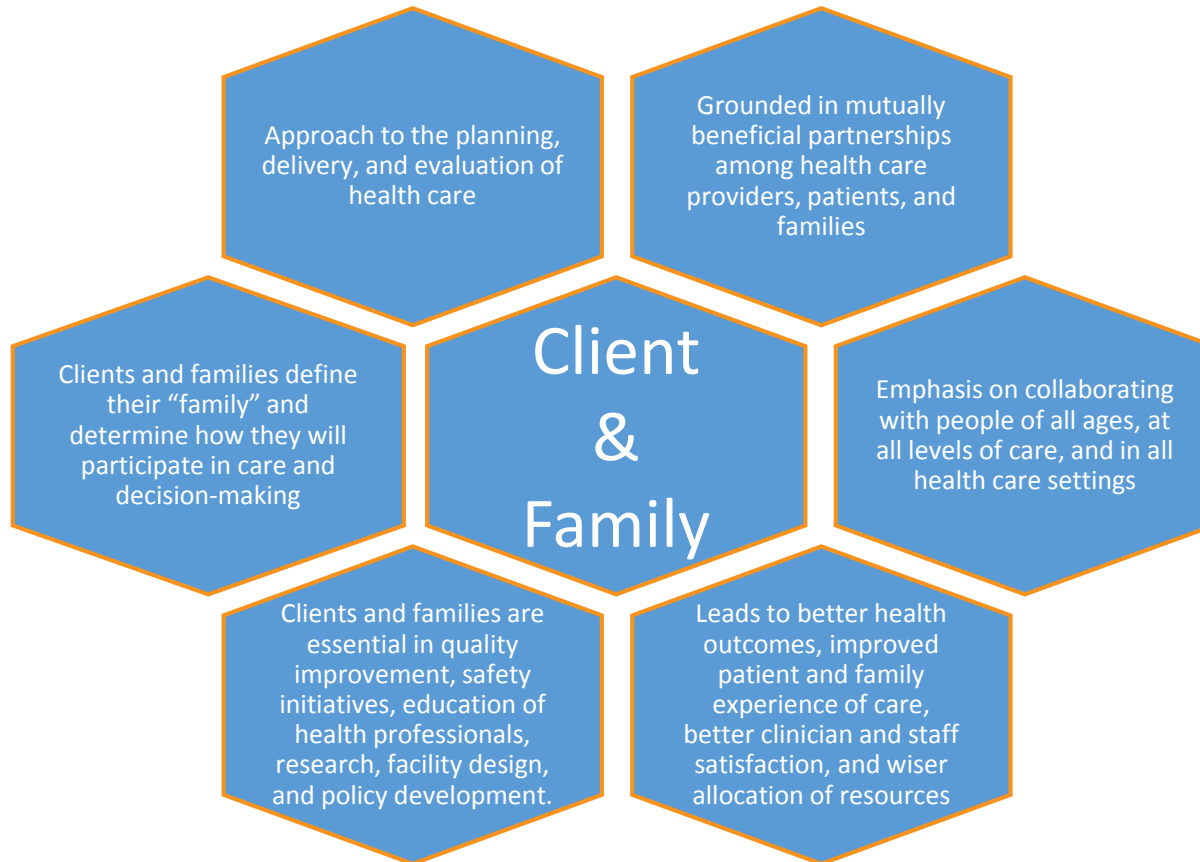
- The focus of our ECHO program is on diagnosis and management of Autism Spectrum Disorder (ASD) comorbidities and symptoms
- Diagnosis of ASD primarily happens in early childhood
- In the case of Autism, we chose to use parents as our patient voice
- It is very helpful if there is an established leadership program or a youth advisory connected to the hospital



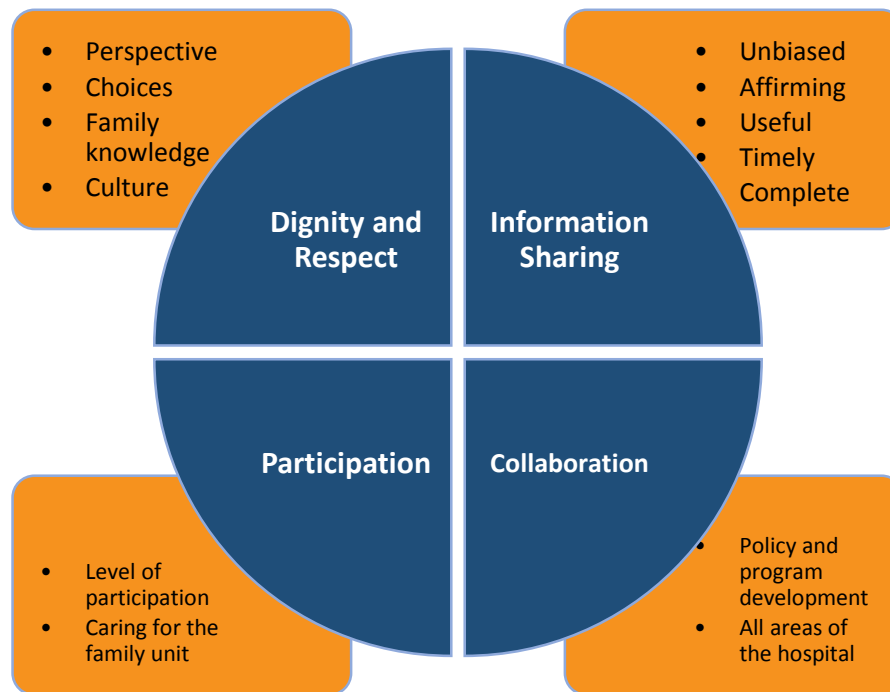
ECHO Autism Family Advisors



Client and Family Centred Care



Core Concept of CFCC



*Adapted from: Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

Benefits of CFCC

Families

- Improves services
- Provides a chance to create positive and meaningful change
- Gives a chance for families to help other families
- Builds knowledge and skills
- Models community involvement and leadership

Healthcare Professionals

- Improves a health care provider's ability to do their job
- Improves relationships between families and health care providers
- Gives new ideas for improving services
- Increases responsiveness to family needs

My Family



Susan's experience with the system

- School
- Medical
- Case Co-ordination
- Funding
- Advocacy



Qualities of a Family Advisor

Objective

Experience in
the system

Concise
approach

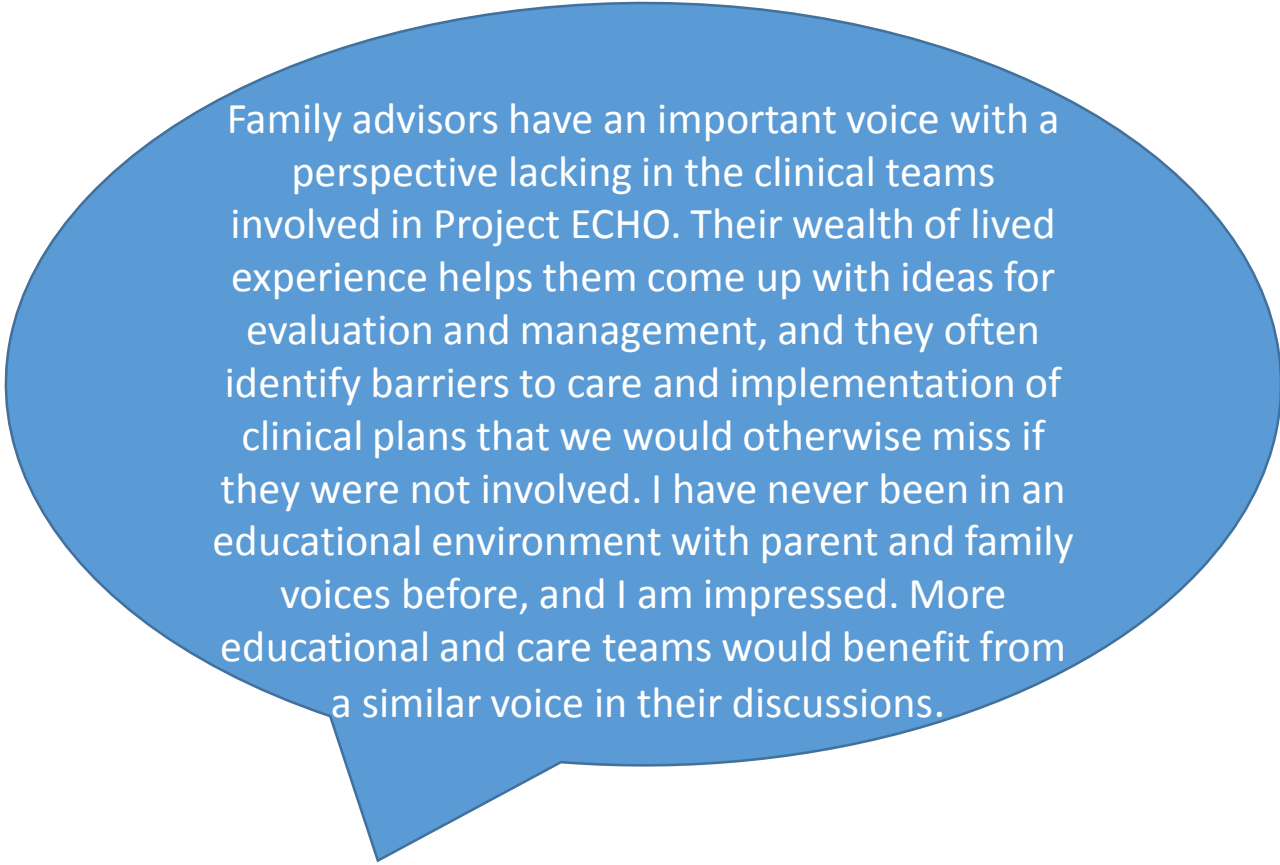
Avoidance of
judgement

Confidentiality/
PHI

Open to
learning and
guidance

Understanding
of professional
best practice

Physician Feedback

A large blue speech bubble with a white border, containing text about family advisors' perspectives.

Family advisors have an important voice with a perspective lacking in the clinical teams involved in Project ECHO. Their wealth of lived experience helps them come up with ideas for evaluation and management, and they often identify barriers to care and implementation of clinical plans that we would otherwise miss if they were not involved. I have never been in an educational environment with parent and family voices before, and I am impressed. More educational and care teams would benefit from a similar voice in their discussions.

Physician Feedback

Families help us know how to get the relevant histories from other families i.e. how can we word questions in a sensitive manner

Having people who have “been there” provides insight the rest of us will never have

We “professionals” learn so much from families !!!! I am getting practical ideas from families that I can pass on to other families

I appreciated the life experience offered by one of the participants who has children with ASD and felt her input was valuable - especially when considering significance of impairment due to symptoms

Helps us to understand how to phrase things effectively so that families understand, while being sensitive to their needs and where they are on their journey

It is a great way to hear about how things directly affect families. Things I may not have thought of

Helps us to find the best way for us to support the families, not only with referrals but in the time we spend with them i.e. empathizing with their struggles and giving them credit for their hard work

Ideas for incorporating the Patient voice

Hub team

Advisory committees

Reviewing didactics

Sharing a family story in the didactics (with permission and not including PHI)

Invite family or patient for a specific didactic to share a story

Summary

- It is extremely important and valuable to consider including the Patient voice in ECHO
- The patient/family voice adds the human element (the only non-clinical perspective)
- Based on our experience, the most important qualities to consider when choosing a patient/family member are **objectivity** and **experience and knowledge re: the system**

Resources

- <https://content.oma.org/wp-content/uploads/patient-centredcare.pdf>
- Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: Institute for Patient- and Family-Centered Care.