

What is essential is invisible to the eye

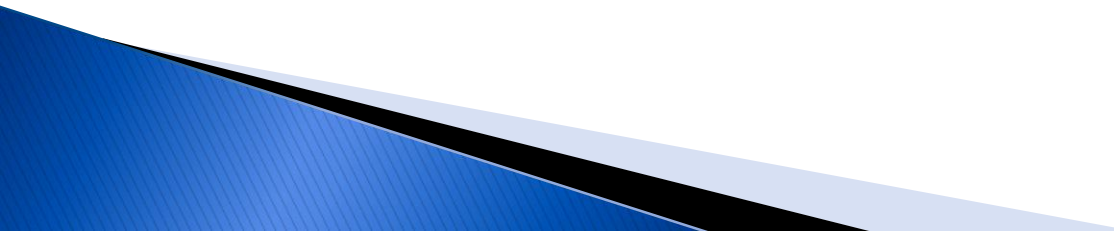
Families partnering with their pediatricians

Mel Lewis & Sue Robins
Grand Rounds
March 18, 2010

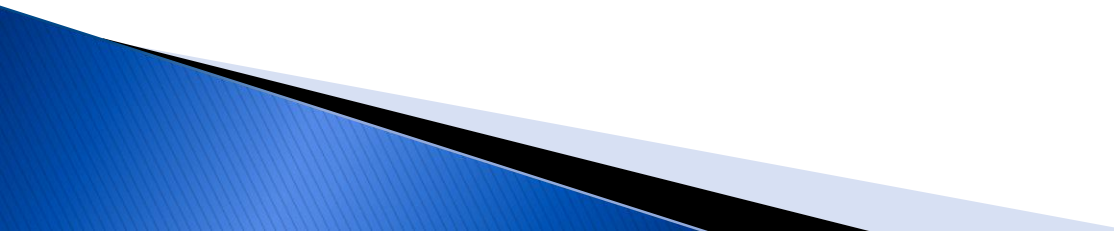
Objectives

- ▶ Introductions
- ▶ Partnerships defined
- ▶ Reality for physicians
- ▶ What you need from families
- ▶ Reality for families
- ▶ What families need from you
- ▶ Dialogue
- ▶ Contact Us

We have no relationship that could be perceived as placing us in a real or apparent conflict of interest in the context of this presentation



Introduction – Mel Lewis

- ▶ Medical Director, Edmonton Down Syndrome Medical Clinic at the Stollery
 - ▶ Director, Undergraduate Medical Education
 - ▶ General Pediatrician
 - ▶ Hockey Mom
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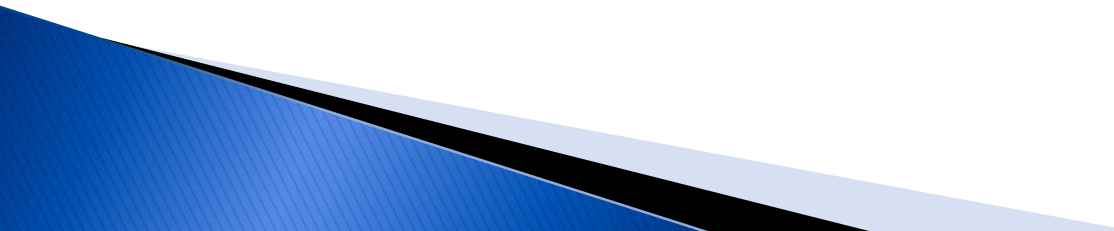
Edmonton

Down Syndrome Medical Clinic

- ▶ Lifespan model – prenatal to geriatrics
- ▶ Referrals, consultation and active practice
- ▶ Medical guidelines and current research repository
- ▶ Presentations – families, health, education
- ▶ Family centred care – case coordination, resources and information about community supports and services for families

Mel Lewis, Medical Director
Gayle Parks, Nurse Coordinator

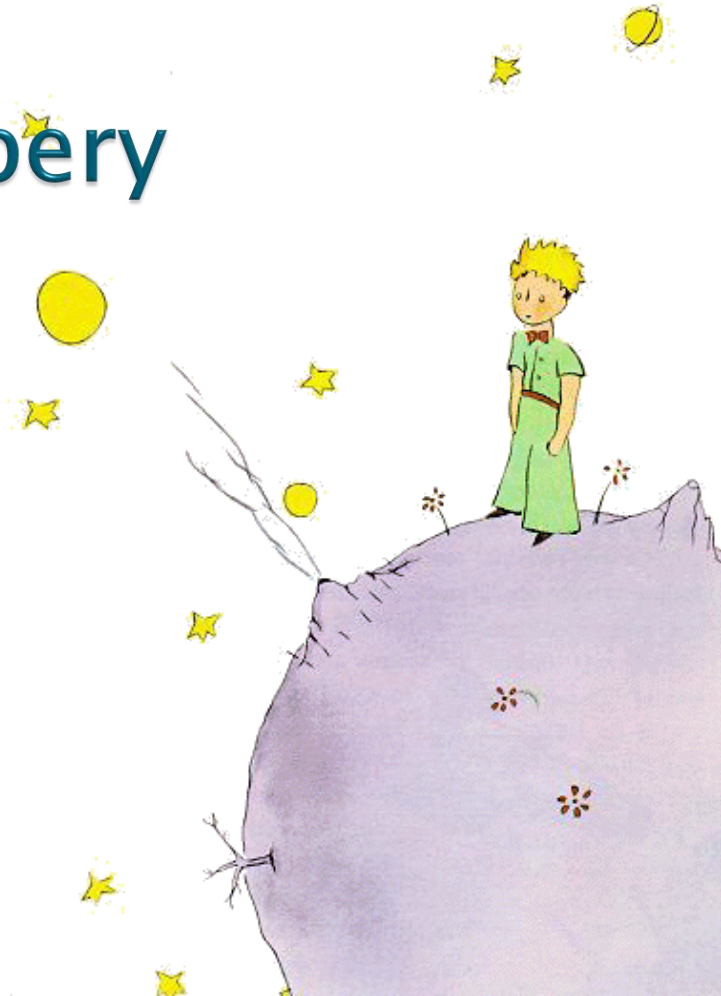
Introduction – Sue Robins

- ▶ Mom of three
 - ▶ Coordinator, Visiting Parents Program
 - ▶ Chair, Canadian Family Advisory Network
 - ▶ Freelance writer and photographer
 - ▶ Writing and communications for Stollery Family Centred Care Network
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It is only with the heart that one can
see rightly, what is essential is
invisible to the eye.

~Antoine de Saint-Exupéry



Disclosing diagnosis: a story



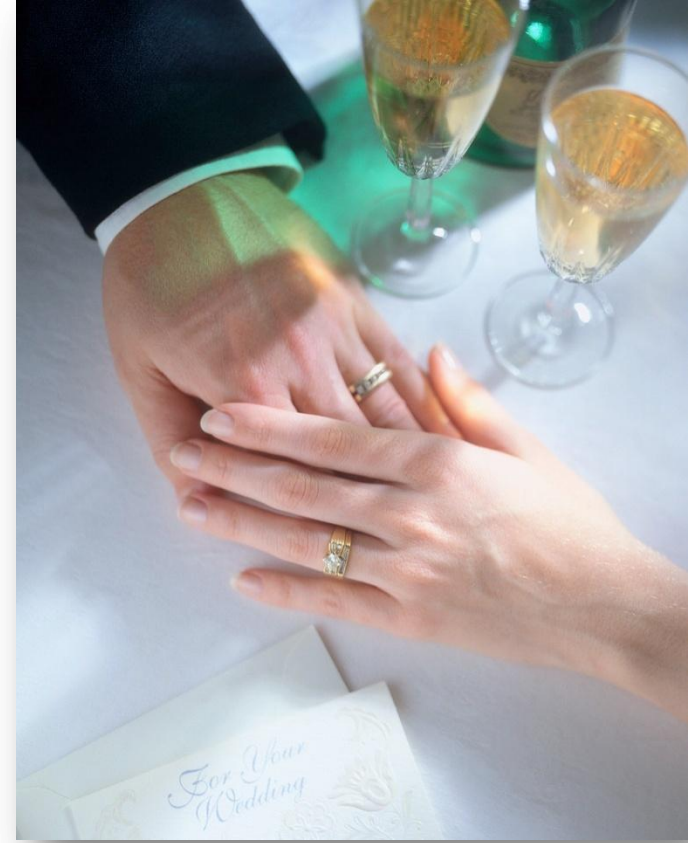
Partnership defined

Partnerships come from reciprocal trust...both from trust in the health care professionals AND trust in the patient's competence.

~Thorne & Robinson



Partnership defined



Reality: What it is like for you

Patients want their doctors to be confident, empathetic, humane, personal, forthright, respectful and thorough.

~New York Times



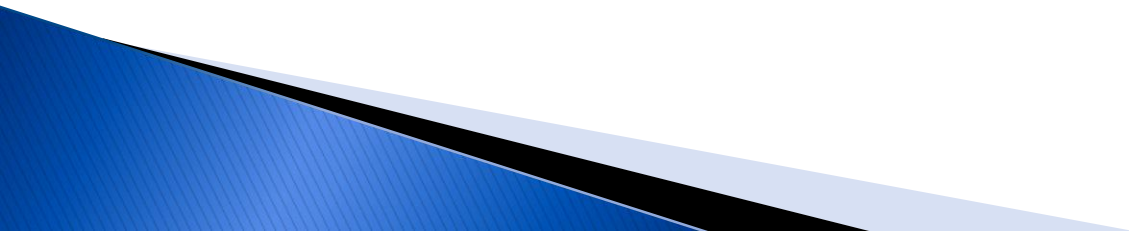
Reality: What it is like for you

These are the pressures in my day:

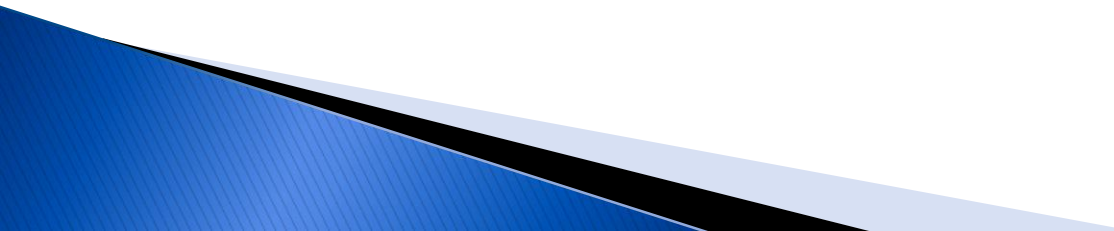


What doctors need from families

Here's what I need from families:

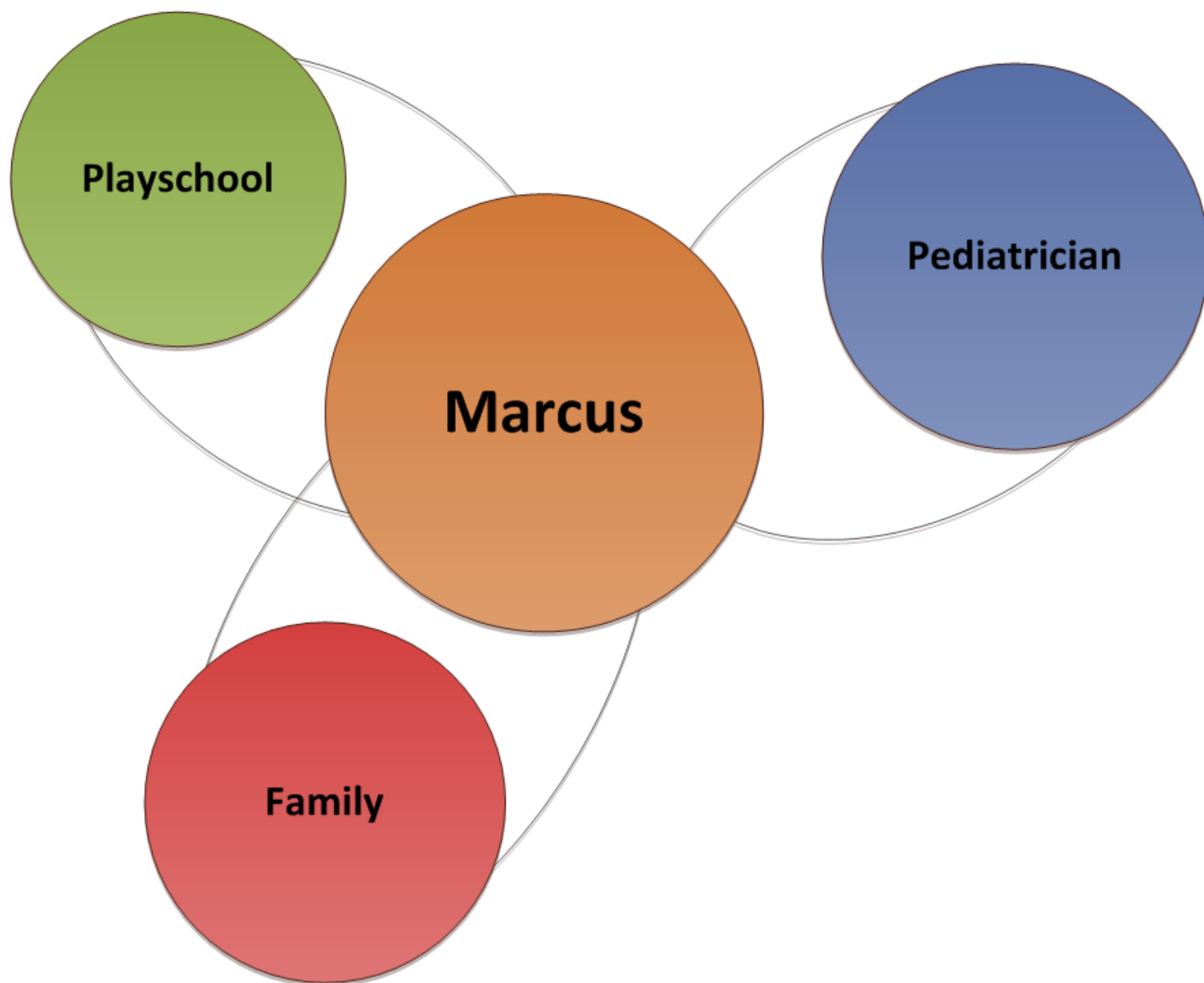


Reality: Barriers for parents being effective partners

- ▶ Loss of control
 - ▶ Fear
 - ▶ Information overload
 - ▶ Lack of confidence
 - ▶ Lack of responsibility
 - ▶ Feeling hopeless
- 



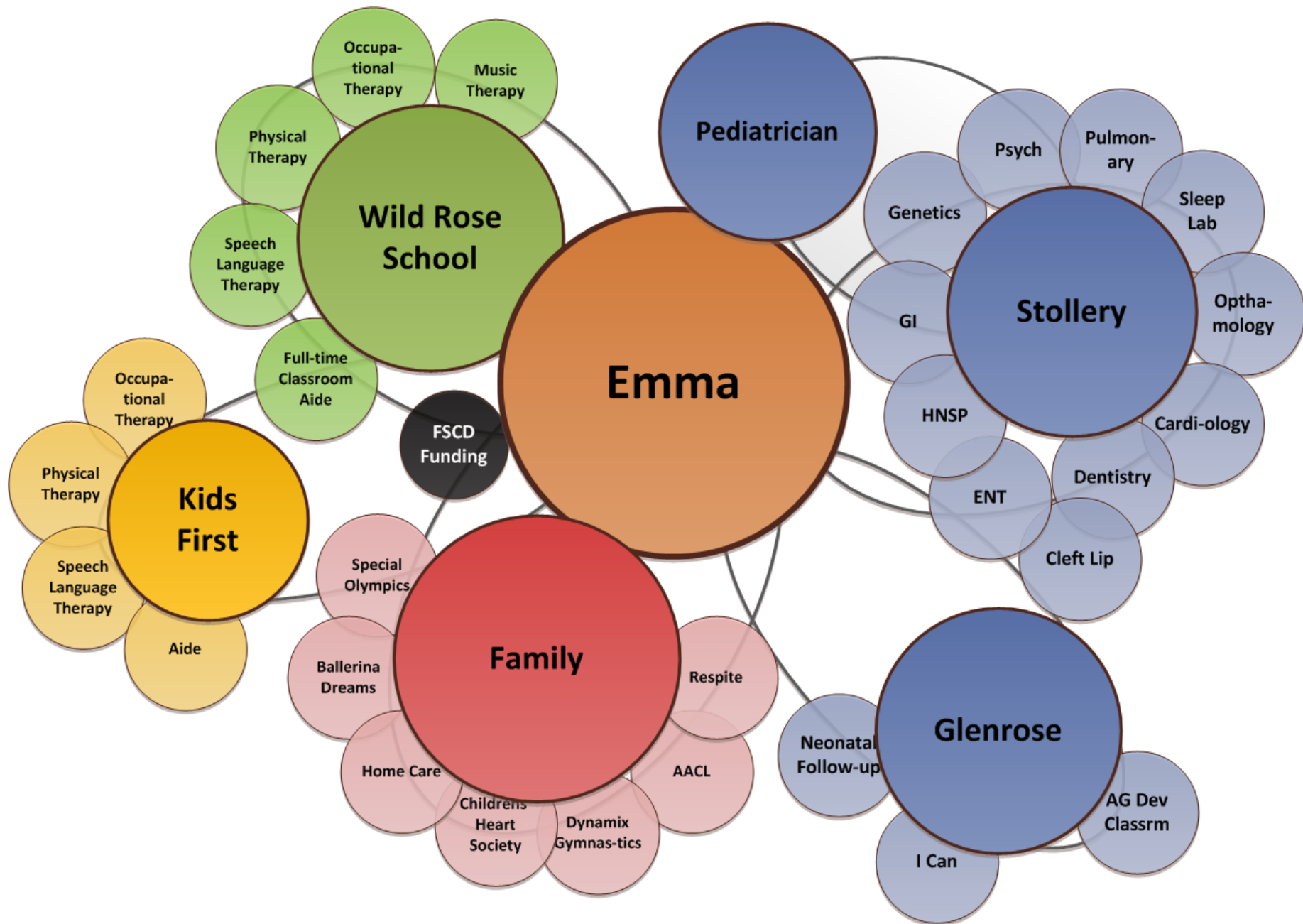
Marcus and Emma



Emma is seven years old
and in Grade 1.

She's very tall and very
blonde. She loves
animals, dancing,
reading, and babies.





Reality – What it is like for families



- ▶ The bigger the corporation,
the more callous its heart.
~Dennis Prager

Reality – What it is like for families

In the beginning...



Reality – What it is like for families

When it is dark enough,
you can see the stars.
~Charles Austin Beard



Reality – What it is like for families

- ▶ You are not guaranteed a blue ribbon baby.



Reality – What it is like for families

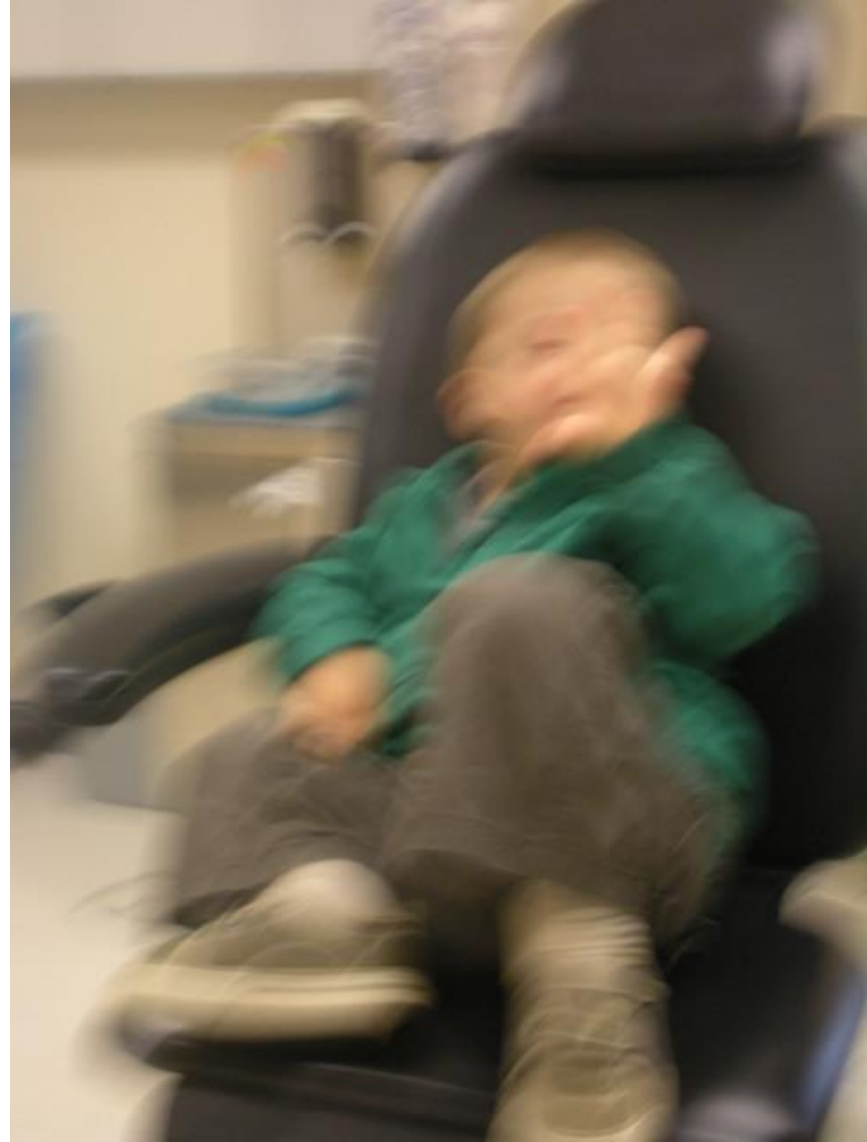
- ▶ Life with Aaron is normal for our family



Reality – What it is like for families



Reality – What it is like for families

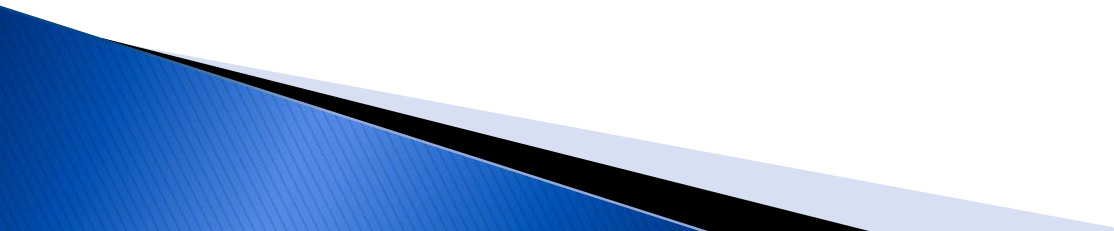


Reality – What it is like for families



Me at the end of my rope.

What families need...

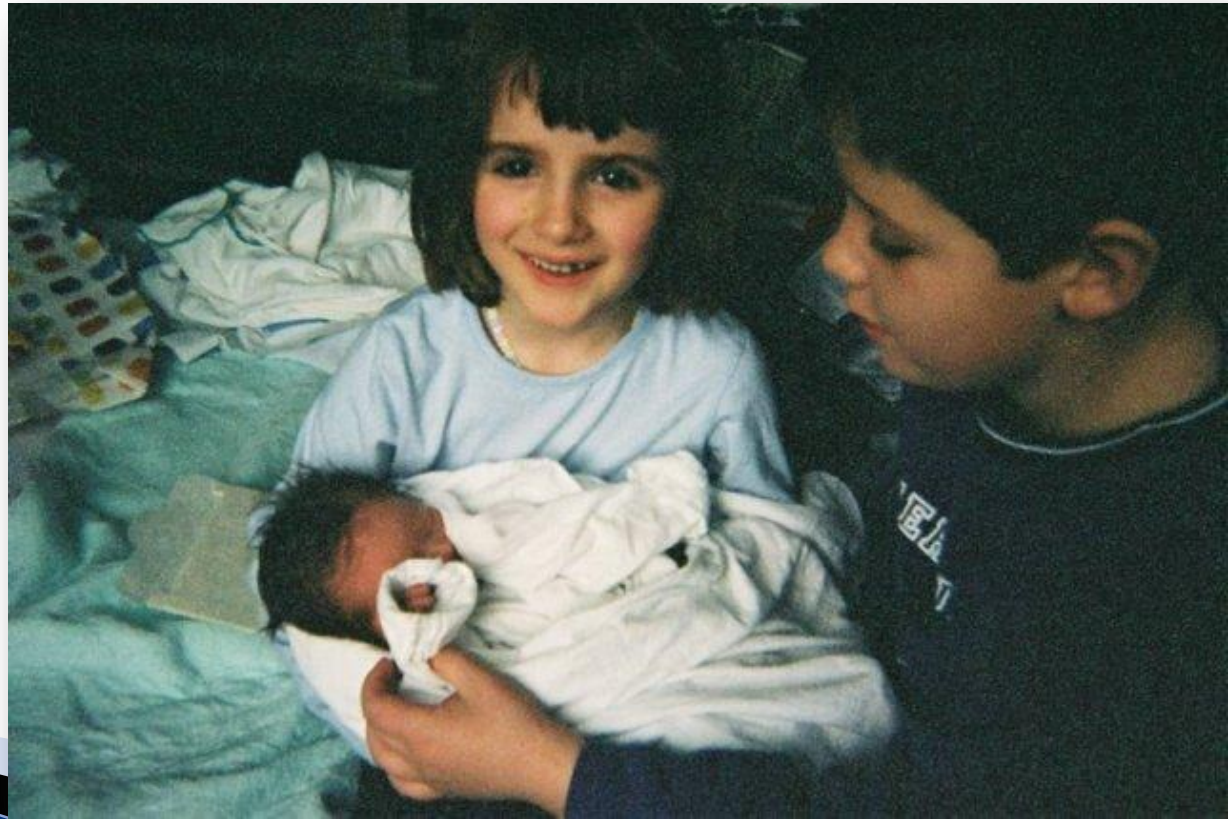
1. Compassionate disclosure of diagnosis
 2. Celebration of the birth of our baby
 3. Connection with other families
 4. Positive clinic experience
 5. Human Touch
 6. Build confidence in our abilities
 7. Hope
- 

Disclosing Diagnosis

- ▶ The trajectory of our entire lives is changed with the delivery of your words



**The birth of every baby
deserves to be celebrated.**



Connections with other families



Positive Clinic Experience

There are no traffic jams
along the extra mile.

~Roger Staubach



Human Touch – Time

- ▶ An unhurried sense of time is in itself a wealth.
— Bonnie Friedman



K.I.D.S.

K = KNOCK

I = INtroduce yOURSELF

**D = DeScribe WHY you are
there**

S = Sit dOWN



Human Touch – Language

- ▶ He's not your buddy.
- ▶ And I'm not your Mom.



Human Touch Alleviating fear



- ▶ Knowing what's going to happen next helps alleviate fear and anxiety

Build confidence in our abilities

- ▶ Ordinary parents doing extraordinary parenting



Build confidence in our abilities

- ▶ Compliment us if we've done a good job



Build confidence in our abilities

- ▶ What is routine for you is not routine for us



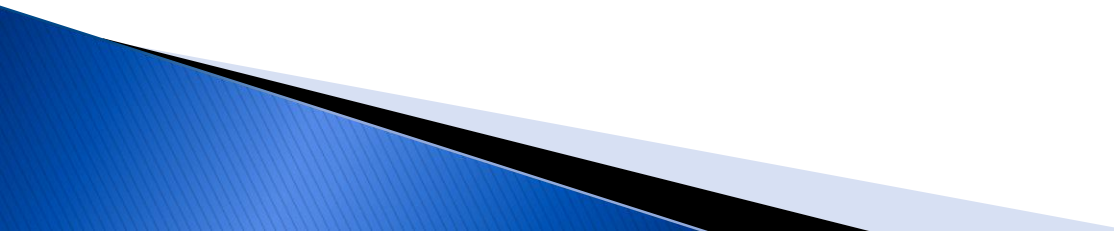
Hope (and believe)

If there were not hope, the
heart would break.

~ Ancrene Wisse



Building partnerships

- ▶ Respect for the teaching families can provide you and your students
 - ▶ Be up to date on medical guidelines
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Building partnerships

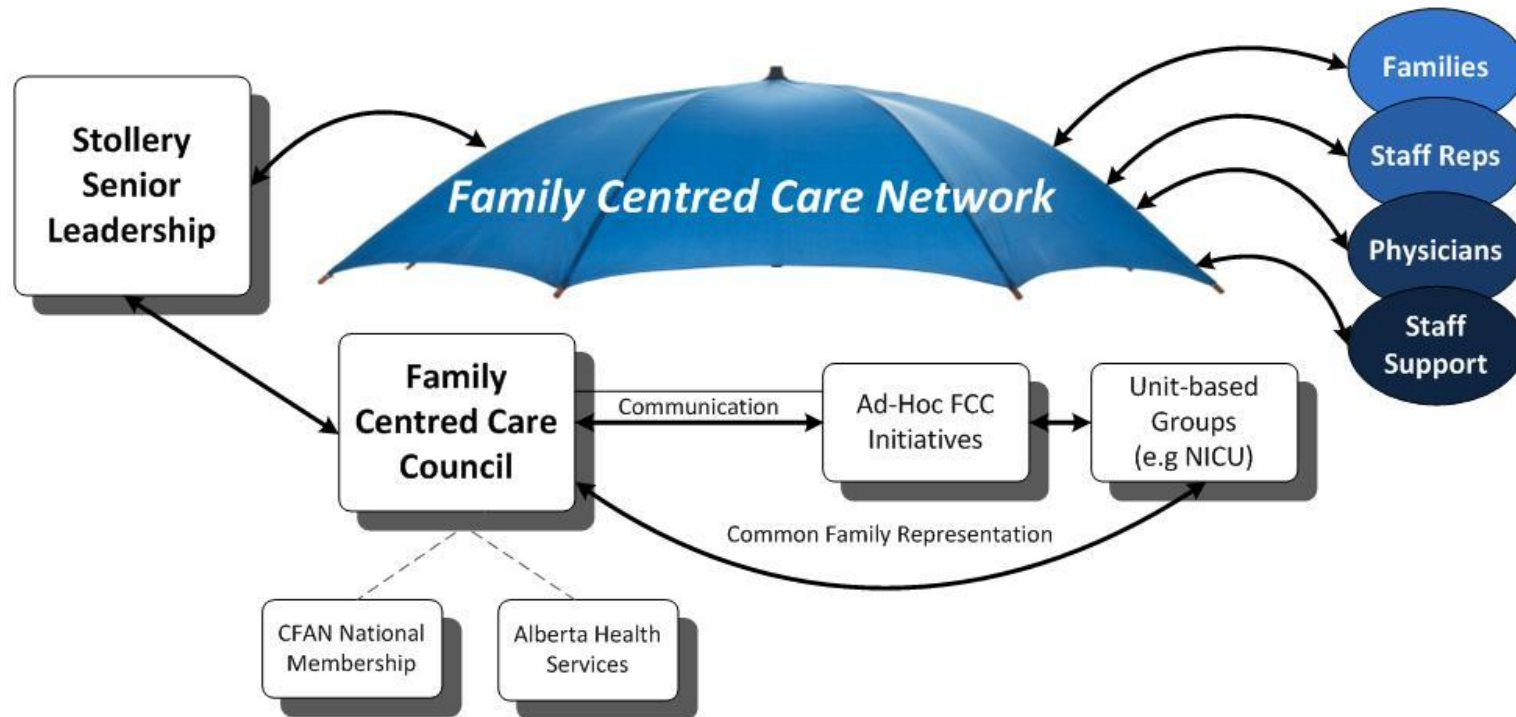
- ▶ Why are we asking specific questions?
- ▶ Help families make informed decisions about surgery and treatments

Building partnerships

- ▶ Coordinate one message from all the health professionals
- ▶ It is ok to say 'I don't know'

Partnerships at the Stollery

Stollery Family Centred Care Model



Dialogue



Contact Us

- ▶ Mel Lewis

- mel.lewis@albertahealthservices.ca

- 780.407.3209 (Gayle Parks)

- 780.407.6370 (clinic)

- ▶ Sue Robins

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