



# Outcomes: A Family Perspective

Maureen Casey



Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has—Margaret Mead.

# Today's Outcomes



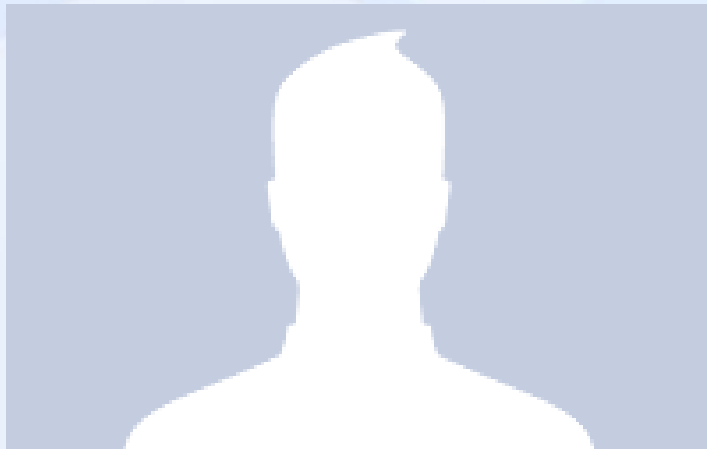
- More than the sum of our data parts
- Interrelate all data sources
- Find and support champions

# My perspective is based on:



- My life
- My understanding of the outcomes
- My experience with the system
- My experience as a stakeholder
- My experience working to improve the system

# Who am I?



- A Wife
- A Mother
- A Parent of a child with a disability
- A former Legislative staffer
- An ICC Member
- Chair of an ICC
- Founding Member & President of EIFA

# My son



- My second happily anticipated child
- Arthrogryposis Multiplex Congenita—Distal variant
- Hydronephrosis/UPJ obstruction
- NICU
- Feeding Difficulties/Failure to thrive

# My data cohorts in 1998 in NY:



- 27.5% my age
- 63.8% married
- 96.6% singletons
- 73.8% PNC in 1<sup>st</sup> trimester
- 32.4% 2<sup>nd</sup> birth
- 12% 17+ yrs of educ



# My son's data cohort



- ICD-9 728.3
- ICD-9 754-89
- AMC = 1 in 3000
- 150 subtypes
- 46% have amyoplasia
- 1.4% Hydronephrosis
- 64% UPJ

# My Children



13, 10 and 5

# Our experience with the system



- 110 days from referral to intake
- Traveling to clinic 1.5 hrs away 2 x week by mass transit
- “Clinic in my living room”
- Natural environments
- Focus on Declan



# EI Family Partners Training Project



- Sponsored by Just Kids Foundation and funded by the NYS Department of Health—Bureau of Early Intervention
- A Part C Family Leadership project



# ICC involvement



- NYS SEICC
  - 2000-2003
  - Vice Chair
  - Data, Parent Involvement & Executive
- Arizona ICC
  - 2004—present
  - Chair
  - Policy, Structure and Flow, Executive





2009 Spring Board Retreat

# Family Outcomes



- To what extent has intervention helped your family know and understand your rights?
- To what extent has intervention helped your family effectively communicate your child's needs?
- To what extent has intervention helped your family to help your child develop and learn?

# Know and understand your rights



- **Link to APR data**

1. Percent of infants and toddlers with IFSPs who receive the early intervention services on their IFSPs in a timely manner.
7. Percent of eligible infants and toddlers with IFSPs for whom an evaluation and assessment and an initial IFSP meeting were conducted within Part C's 45-day timeline.
8. Percent of all children exiting Part C who received timely transition planning...
9. General supervision system (including monitoring, complaints, hearings, etc.).
10. Percent of signed written complaints with reports issued that were resolved
11. Due process hearings
12. Resolutions
13. Mediations

# Know and understand rights



- How else do we learn about the experiences of families & professionals?
  - Monitoring—Interviews
  - Monitoring—site and team visits
  - “Cookie cutter” IFSPs
  - Blogging
  - Does this anecdotal data match our outcomes?
- How is the lead agency using the outcomes data to ensure that families know and professionals know how to inform families?

# Know and understand rights



- Families often aren't aware of what they don't know
- Families tell us that they don't have enough information
- Families tell us they are overwhelmed when they do get information

# Know and understand rights



- Correlation between family and child outcome data
- Available trainings, number and types professionals and families participating in trainings
- What other information is available on rights



# effectively communicate your child's needs



- Link to monitoring—site and team visits
- How are we assisting families to effectively communicate their child's needs?
- Incorporate into professional development
  - Tools—checklists
  - Training & skill development
  - Information

# Effectively communicate



- Are there barriers that professionals encounter when trying to assist families to effectively communicate?
  - Time
  - Billing
  - Scheduling
  - Skills
  - values

# Effectively communicate



- Do families and early interventionists know how to handle conflict?
- Do trainings specifically address these issues?



# Effectively communicate



- Use the COSF process to help families
- Families say they lack access to the same information as professionals—
  - Lingo
  - EBR



# Help your child develop and learn



- Link this data to other data
- Talk to families & professionals
- Review how your system supports families and professionals



# Positive social emotional skills



- First social experience is with your family
- How do interventionists include other family members? Where else is this data?
- Intervention is a small part of our day!



# Acquisition & use of knowledge & skills



- Again, pull this data from a variety of venues, family involvement is critical



# Use of appropriate behaviors to meet their needs



- Input from family members and teachers is critical, help both to think about what is appropriate, what are they doing to assist the child



# Data trends

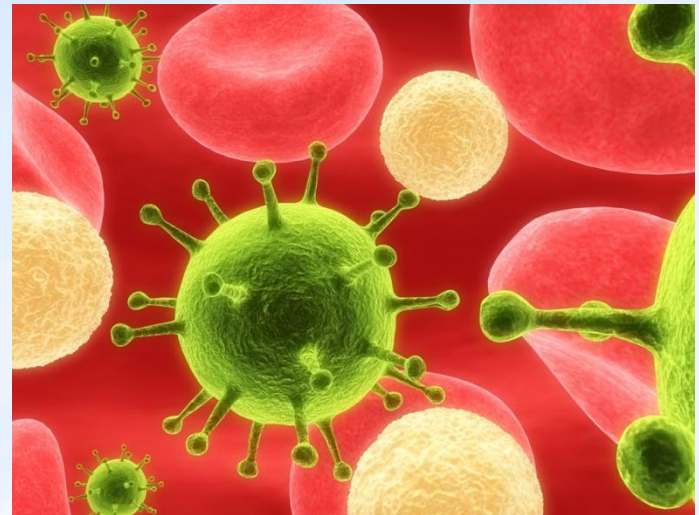


- We need to be aware of other related data trends
  - Insurance coverage reduced/eliminated if not making improvement
  - Effect of children with disabilities on AYP

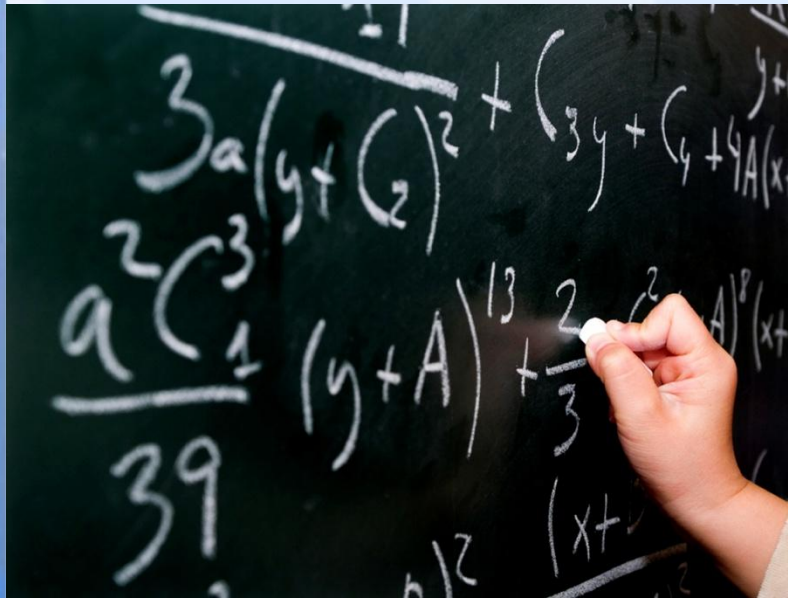
# Other systems



- We need to be aware of changes in other systems.
- How our data can affect other systems
- How their data can affect our system



# Analyzing the data



- Families, EI professionals and other stakeholders need to understand the importance of the outcomes data collection efforts underway, their interrelatedness and how to interpret and share the data.

# Involving stakeholders



- Share the data
- Explain the data
- Analyze the data
- Use the data
- Discuss data for quality improvement activities



If one cannot state a matter clearly enough so that even an intelligent twelve-year-old can understand it, one should remain within the cloistered walls of the university and laboratory until one gets a better grasp of one's subject matter—Margaret Mead

# Teamwork





- At the end of the day, data is not an end, but a means to justify an end. That end is to support infants, toddlers and preschoolers with disabilities and their families! Thank you for all your hardwork!

