



WIC Developmental Monitoring Program (Learn the Signs. Act Early.)



U.S. Department of Health
and Human Services

Centers for Disease
Control and Prevention





Talking with Caregivers about their Child's Special Needs

Definitions

What does it mean to YOU when
you hear the term
“SPECIAL NEEDS”?

Early Start Definition

Used to qualify babies for mandated services.

- **Children who have, or are at-risk for a developmental disability as defined by the Individuals With Disabilities Education Act (IDEA) Part C (Early Start 0-3 years old) or have a specific diagnosis as defined by IDEA part B (3 years and above)**

MCH Definition:

Those children who have or at risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

“Special Needs” may mean the baby has a Disability

- “IT” has a name.
- Or the ADA definition.
- Some people mean a physical condition.

“Special Needs” may mean the baby has a Developmental Delay

- The baby isn't meeting milestones.
- Isn't consistent with his or her peers.
- Is mentally retarded or has an “intellectual disability”

Often in the special needs world “developmental delay” = cognitive delay = mental retardation

Caregiver's Definition:

- My baby is different than other babies.
- My baby needs specific things to be healthy or happy.
- My baby is “harder” than other babies.
- My baby is more fragile than other babies.
- My baby is sick.
- My baby might die.
- I need help and/or support to parent this baby.

**MOST CAREGIVERS HATE EUPHAMISMS
BUT LIKE THE TERM “SPECIAL NEEDS”
OR “DEVELOPMENTAL DELAY.”**

Caregivers/Parents of ill babies prefer “a
baby with...”

Why do Definitions matter at all?

- Helps us refer to the right and most likely service system:
- Helps us with urgency issues
- Helps us formulate a way to talk to caregivers about what we are seeing.

How Common are Special Needs birth to three years old?

4-6% of children birth-3 have special needs
or are at risk for special needs.

(IDEA definition)

Developmental Delays – “Global or General”

Not meeting milestones or keeping up with peers.

- Most developmental delays are the result in some underlying condition, but not all.
- There are many kinds of situational delays. **These are still delays.**
- Eligibility for services happens when there are several areas of delay, several risk factors and a delay, or a delay in one area that is at least two standard deviations below normal.

***YOU DO NOT NEED TO KNOW WITHOUT A DOUBT THAT A CHILD
WILL QUALIFY TO REFER!***

Refer based on caregiver concerns!

OK – So now we know what
we are talking about...

How do we talk to caregivers
about any concerns we might
have?

FIRST – SELF REFLECTION

Know your Communication Style

Know how your own experience colors your
observation or advice

Check yourself around judgement
re: parenting choices

CONVERSATION PILLOWS

Most of us use “conversation pillows” when we talk with other people.

Pillows are the words you use to cushion your main message – the gentle lead in, “I like your sweater” or our standard disengagement phrases, “I’m glad we talked.”



Typically the more personal and difficult the message, the more pillows we use.

Sometimes we use so many pillows, our message gets smothered.



Sometimes we use too few pillows and our message lands heavily – too hard to be taken in.



We might get caught up in a verbal pillow fight – no one saying what really needs to be said.



Ask yourself:

How many pillows do I usually use in conversations?

Is this too many or not enough?



The Communication Process

Good communicators use the

KISS principle

"Keep It Simple and
Straightforward"

When making referrals...

DON'T LIE TO CAREGIVERS...

OR BE OVERLY OPTIMISTIC...

OR ASSUME THAT EVERYONE HAS THE
SAME EXPERIENCE...

OR...

Referral Delays

- Know the latest research on milestones!
- Yes, all children develop at their own pace. BUT, MOST fall in a range of “normal.”

WELL, LET'S LOOK
AT THE BRIGHT SIDE...
HOW MUCH WORSE CAN
IT POSSIBLY GET?



BE SPECIFIC ABOUT WHAT YOU WANT PARENTS/CAREGIVERS TO DO NEXT

Know the basics of the system

REFERRAL SPIDER WEB

There are several basic questions to ask that will point you, (or parent/caregiver) to the right place to start.

What is the main concern?

Behavioral?

Developmental?

(And whose concern is it, yours or theirs?)

If it is Behavioral:

Know the early childhood resources in your area. Young children can definitely have anxiety, eating or sleeping issues, trauma reactions, etc.

Professional support for caregivers and direct services for children are important, both to address the issue AND as a child abuse prevention strategy.

If it is Developmental:

EARLY START – Part C – Early Intervention –
These services have lots of names.

BEST – *have caregivers call.*

If you send in a referral:

- 1) Tell caregivers you are making referral and why
- 2) Tell them TO ANSWER THEIR PHONE!!
- 3) Typically, if “you” want to be in the feedback loop, you must send in a consent to exchange information signed by the parent. Otherwise we can’t talk to you.

Development (con't)

Medical Provider

It is always prudent to ask the caregivers if they've discussed what you are seeing with the child's care provider. You can do some "anticipatory guidance" about how to talk to a medical provider.

Sometimes caregivers are worried about being "that" parent/caregiver...

Parental Resistance

What do you do when the caregiver/parent:

- 1) Doesn't agree with you
- 2) Tells you the MD isn't worried
- 3) Doesn't take any action after several conversations
- 4) Makes an initial call but doesn't follow through
- 5) Tells you their partner sees nothing wrong

System Failure

Most frustrating thing for those of us working with young children is to identify a need, have the caregivers in agreement and then have no place that can serve the family or it may not be “bad enough” – yet.

Be sure to set the family up with some kind of expectation that this may happen.

FINAL THOUGHTS

Understand and Reflect on your own experiences and biases

Unconscious motivations?

Have a way to let go

Questions?

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