Starting with the End in Mind: The O.U.R. Children Project

January 15, 2015
Harold Johnson & Janet DesGeorges
NCHAM Webinar
Harold Johnson: 1971-2006
A blast from the past...

Do you remember when...

Summary Points:
1. One in four will experience...
2. Most do not want to be bothered with...
3. Many excuse not to deal w/...
4. Some excuses result in broken bones, some in death.

These same points apply to the topical focus of my presentation today, the maltreatment of children with disabilities

Web Link
How our understanding of infants has changed

- How should we treat infants?

Web Link
Role Secure Attachment Plays in Infant Development

- What do infants learn from us?

Web Link

hjohnson4deafed@gmail.com & janet@handsandvoices.org
How does parent behavior impact an infant?

Web Link

hjohnson4deafed@gmail.com & janet@handsandvoices.org
What does a unstressed vs. a stressed infant look like?

[Video: Still Face Experiment: Dr. Edward Tronick]

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hjohnson4deafed@gmail.com & janet@handsandvoices.org
What are the long term consequences when infants, toddlers, young children do not experience secure, loving and supporting families?

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hjohnson4deafed@gmail.com & janet@handsandvoices.org
What is your ACE score?
How can parents enhance the secure attachment, safety and success of their children?

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What would be the developmental progression parents would experience as they bond with, respond to and support their child's development?

1. The parent enjoys their child.

2. The parent is sensitive observer of the child, reads their behavioral cues accurately, and is responsive to them.

3. The parent engages in a quality of interaction with their child that is mutually satisfying and that provides opportunity for the development of attachment.

4. The parent demonstrates an awareness of materials, activities, and experiences suitable for their child's current stage of development.

5. The parent initiates new play activities and experiences based on principles that she has internalized from their own experiences, or on the same principles as activities suggested to or modeled for her.

6. The parent independently generates a wide range of developmentally appropriate activities and experiences, interesting to the child, in familiar and new situations, and at new levels of the child's development.

What would this developmental progression look like if it was going well?
What would it look like if parents were not providing a secure, nurturing and supportive environment for their children?

See Appendix “A” for the definitions and behavioral indicators of maltreatment

Appendix “B” for the General Risk Factors
How often do children with disabilities experience maltreatment?
UNICEF: *The State of the World’s Children 2013: Children with Disabilities*

- “Children with disabilities are among the most vulnerable members of society.”

- “Children with disabilities are three to four times more likely to be victims of violence.”

- “Many of the deprivations endured by children with disabilities stem from and are perpetuated by their invisibility.”
Prior to the 1980s, most studies of child abuse did not include children with disabilities (Westcott & Jones, 1999).

In the course of the past 30-plus years, investigations of maltreatment have evolved to consider people with disabilities in relation to incidence, prevalence, risk factors, contexts, impact, prevention, and support provisions (Hughes et al., 2012; Jones et al., 2012; Stalker & McArthur, 2010).

As a result of this research, we now know that children with disabilities are three times more likely to experience maltreatment than their nondisabled peers (Sullivan & Knutson, 2000).
This rate indicates that at least 25% of children with disabilities will experience one or more forms of maltreatment between birth and 18 years of age (Jones et al., 2012).


“Children with disabilities are often regarded as inferior, and this exposes them to increased vulnerability.”
Why are children with disabilities at particular risk for maltreatment? Children with disabilities often…

- do not understand what constitutes maltreatment;
- do not know they have the right to say “NO!”
- are socially isolated and lonely;
- lack the language, knowledge and communication skills to tell others that they have been maltreated.
- do not understand their own emerging sexuality.
- do not know how to recognize or protect themselves in “risky situations.”
- are not recognized to be at higher risk for maltreatment

= ...an ideal target for maltreatment
A possible reality of being a parent…

What can we do to enhance the safety and success of all children, but particularly those with disabilities?

Web Link
Six Factors that Promote Well Being

- Nurturing & Attachment
- Knowledge of Parenting & Child Development
- Parental Resilience
- Social Connections
- Concrete Support for Parents
- Social and Emotional Competence of Children

Addressing these six factors within the early intervention programming of families of children with disabilities helps to insure the safety and success of the children.
What do these six factors look like...
How the parent observes and attends to the child specific play or stimulation behaviors

How the parent responds to the child’s behavior, emotional needs

How the parent demonstrates affection, models caring behavior, and recognizes child’s accomplishments

How the parent provides a safe and stable home and family environment
Knowledge of Parenting & Child Development

- The parent’s view of his/her child’s strengths and their role as a parent.

- How the parent observes, interprets and responds to the child’s behavior.

- How the parent encourages positive behavior through praise and modeling.

- Whether the parent can identify alternative solutions for addressing behaviors.

- Community, cultural, and ethnic expectations and practices about parenting.

- How the parent understands the child’s development.

- Any parental concern that the child’s behavior appears to be outside the normal range.
Parental Resilience

- What the parent identifies as his or her coping strengths and resilience.

- What the parent identifies as everyday stressors, problem solving skills and the impact of stress on parenting.

- How the parent communicates with his, or her, spouse or partner.

- What are the parents short term supports, e.g., respite care, help with a new baby, help during an illness.

- What is the parent’s ability to set and work toward personal goals.
Social Connections

- The parent’s current social support system, including family, friends, and membership in any formal groups.
- The parent’s social skills and capacity to make and keep friends.
- The parent’s desire for new friends and social connections.
- Needs that might be met with better social connections, for instance: respite care; a sympathetic listener; a role model; etc.
Concrete Support for Parents

- The parent’s view of their most immediate need.
- Steps the parent has taken to deal with the problem.
- Ways the family handles other problems.
- Current connections that might offer help for new problems.
- Other services and supports that would help the family.
- The parent’s desire and capacity to receive new services, including completing applications, keeping appointments, and committing to the solution process.
Social and Emotional Competence of Children

- How the parent provides a safe and stable home and family environment that supports healthy social and emotional development.

- Whether the parent identifies any delays in social and emotional development and where the parent might seek help for any concerns.

- How the parent responds to emotional needs.
How can we possibly add these six safety factors into our existing work?

- We could just give up and expect parents (Moms) to deal with the “realities” of parenting…

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hjohnson4deafed@gmail.com & janet@handsandvoices.org
Or we could have an informal observation and conversation with the parent about...

1) observing, understanding & responding to their child;
2) what to expect from the child as s/he matures;
3) how to deal with the stresses of being a parent;
4) the family social network; &
5) any immediate family needs.

Six Protective Factors that Promote Well Being
During our conversations we should also discuss with the parent...

1) what are safe and unsafe situations for their child;
2) the critical need for parents to speak out concerning a safety concern;
3) their child’s need to learn when, how and why they can say “NO!” & set social boundaries, e.g., who they want to hug or kiss

Kidpower: Personal Safety for Birth to Three Years
Parents also need to know their child’s need for...

1) knowledge re. places on their body that are private vs. public;
2) language to tell how they are feeling and if anyone has: a) scared: b) hurt; or c) told them to keep a secrete from other adults;
3) a “safety plan,” with practice, on what to, in specific places, if they become separated from the adult they are with; and
4) age appropriate friends.

Web Link

Kidpower: Personal Safety for Preschool
Janet DesGeorges will now share with how the preceding information is being integrated into Hands & Voices
Building Child Safety and Success into the 1–3–6 EHDI Model

Janet DesGeorges
Hands & Voices
Janet’s Story
“*I don’t have time for this*, “*This isn’t my area of focus/expertise*, “*This is too hard/sad*”

- The statistic that changed me
- The video that changed me
- Do? Tell? Kids Against Child Abuse
- www.kidsagainstchildabuse.org
- The Life moments that changed me

"*I said ‘Somebody should do something about that.’ Then I realized I am somebody.*"
— *Lily Tomlin*

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Goals:

- Every leader in our organization will have basic knowledge and awareness of how to keep our children safe!
- Every leader in our organization will know exactly what to do in any situation where the safety of a child is in question!
- Every chapter in our organization will have a representative who is committed to ensuring grassroots efforts in his/her chapter’s efforts!
The Obvious Places

- **Family Interactions with Professionals**
  - Beyond the ‘legal mandate for reporting’

- **Parent–to–Parent Support**
  - The H&V O.U.R. Project and resources
  - H&V Guide By Your Side Training
  - H&V Chapter participation

- **Reading Materials/resources**
  - Connecting the dots between National expertise in Child Abuse and Neglect and national expertise of EHDI systems/journey of deafness.

hjohnson4deafed@gmail.com & janet@handsandvoices.org
The Not-so-Obvious Places

- Agenda Item at State EHDI Advisory Meetings
- The National EHDI Conference (built into any presentation)
- Trainings about EHDI to Nurses, Physicians, Audiologists.
- RFP requirements in EHDI grants
- Teaming with efforts already established.
  - The H&V O.U.R. Project
- You! (yes, you)
Ideas in Screening / Identification / Early Intervention

- **Screening**
  - Public awareness from the start
    - Health Dept. efforts/other state government/local efforts

- **Identification**
  - Audiologist awareness
    - American Academy of Audiology Efforts

- **Early Intervention**
  - Safety and parent support Imbedded into the IFSP
    - In the home accessibility
What to do If You Suspect Abuse

If you are unsure whom to call, contact the 24-hour Child National Child Abuse Hotline at 1–800–4–A–CHILD for that information.

Web Link
Most individuals do not want to think, talk, or act concerning the topic of child maltreatment.

While no child should experience maltreatment, the sad reality is that children with disabilities, especially those with significant communication, behavior and physical challenges, experience maltreatment at a rate that is 3–4 times greater than that experienced by their nondisabled peers.

We need YOUR help...

haroldjohnson4deafed@gmail.com & janet@handsandvoices.org
Some educators believe that child protection focused objectives cannot be included in IFSP, IEP or 504 plans because it is a risk, vs. an existing factor that impacts a child’s development.

This belief is wrong: see Safety Attachment Template for an analysis of Federal law.

Just as we now know to “buckle-up” to reduce the possibility of injury, we must also build safety into family/children educational plans of our students.
- We can build both safety and success into our students educational programming by:
  - assisting parents to effectively observe, understand and respond to their children; and
  - incorporating safety focused statements (IFSP), objectives (IEP) information (504 Plans) into their educational plans.

- The following are some possible examples to help guide this effort:
IFSP outcome statements should be drawn from: **Six Factors that Promote Well Being**

- **Nurturing & Attachment**
  - e.g., The parents will be able to observe, understand and respond to the child’s behavior, emotional needs and communication requests.

- **Knowledge of Parenting & Child Development**
  - e.g., The parents will be able to encourage the child’s positive behavior through praise and modeling.

- **Parental Resilience**
  - e.g., The will be able to identify everyday stressors, problem solving skills and the impact of stress on parenting.
IFSP obj. cont.

◦ **Social Connections**
  • e.g., The parent has the social skills and capacity to make and keep friends.

◦ **Concrete Support for Parents**
  • e.g., The parent demonstrates the desire and capacity to receive new services, including completing applications, keeping appointments, and committing to the solution process.

◦ **Social and Emotional Competence of Children**
  • e.g., The parent provides a safe and stable home and family environment that supports healthy social and emotional development.
Age specific IEP and 504 plan objectives can be drawn from the documents provided in “Appendix C”

Such objectives include:

- The student with ___% accuracy, in ____ context, will be able to...
  - **Self Advocacy**: Right to say “NO”
    - ...demonstrated (via acting, drawing, and/or describing) three situations in which they have now the right to refuse, i.e., say “NO,” and three situations in which they do not now have the right to say “NO.”
  - **Language**:
    - Vocabulary: parts of body, emotions, experiences (who – what – when – where), maltreatment, secret, etc.
    - Communication: how to persist in getting an adult’s attention concerning a matter of safety, who to tell if they are scared, hurt, concerned, etc.
  - **Health**: private vs. public parts of body & behavior, puberty & sexuality, appropriate online & dating behavior, etc.
Know that child safety and success occurs when parents...

1. ...enjoy their children.
2. ...are able to effectively observe, understand and respond to their children’s behavior.
3. ...interact with their children in a manner that is mutually satisfying and appropriate.
4. ...demonstrates an awareness of materials, activities, and experiences suitable for her child's current stage of development.
5. ...uses modeled behavior to initiate new play activities and experiences based on the child’s current stage of development.
6. ...independently generates a wide range of developmentally appropriate activities and experiences, interesting to the child, in familiar and new situations, and at new levels of the child's.

Our work should be designed to help this occur

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Our “ASK” of each of you...

1. Share this presentation with a colleague.
2. Incorporate at least one safety element into your students educational planning documents.
3. Send us an email to share the safety element that you used.

That’s it. As easy as “1 – 2– 3”
Never forget, students safety & success depends on YOU!

Thank You
Appendix

- A = Definitions & Indicators of Maltreatment
- B = General Risk Factors
- C = List of Suggested IFSP, IEP, and 504 Plan Safety Objectives
- D = Related Web Resources
Appendix A

Indicators of Maltreatment
*Neglect: [7 per 1,000][63%]*

Neglect is frequently defined as the failure of a parent or other person with responsibility for the child to provide needed food, clothing, shelter, medical care, or supervision such that the child's health, safety, and well-being are threatened with harm.

*Statistics for nondisabled children*
*Neglect:*

- **Child indicators**
  - Is frequently absent from school
  - Begs or steals food or money
  - Lacks needed medical or dental care, immunizations, or glasses
  - Is consistently dirty and has severe body odor
  - Lacks sufficient clothing for the weather
  - Abuses alcohol or other drugs
  - States that there is no one at home to provide care

*Recognizing Child Abuse & Neglect: Signs & Symptoms*
Neglect (cont.)

- Parent indicators
  - Appears to be indifferent to the child
  - Seems apathetic or depressed
  - Behaves irrationally or in a bizarre manner
  - Is abusing alcohol or other drugs

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Physical Abuse: [2 per 1,000][17%]

- Physical abuse is generally defined as "any non-accidental physical injury to the child" and can include striking, kicking, burning, or biting the child, or any action that results in a physical impairment of the child.
Physical Abuse:

- Child Indicators
  - Has unexplained burns, bites, bruises, broken bones, or black eyes
  - Has fading bruises or other marks noticeable after an absence from school
  - Seems frightened of the parents and protests or cries when it is time to go home
  - Shrinks at the approach of adults
  - Reports injury by a parent or another adult caregiver
Physical Abuse: (cont)

- Parent Indicators
  - Offers conflicting, unconvincing, or no explanation for the child's injury
  - Describes the child as "evil," or in some other very negative way
  - Uses harsh physical discipline with the child
  - Has a history of abuse as a child
*Sexual Abuse/Exploitation: [1 per 1,000][9%]
  ◦ "The employment, use, persuasion, inducement, enticement, or coercion of any child to engage in, or assist any other person to engage in, any sexually explicit conduct or simulation of such conduct for the purpose of producing a visual depiction of such conduct

![Image of a child lying on a bed with text overlay: "She's so ashamed, she's Daddy's secret love."]

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Sexual Abuse:

- Child Indicators:
  - Has difficulty walking or sitting
  - Suddenly refuses to change for gym or to participate in physical activities
  - Reports nightmares or bedwetting
  - Experiences a sudden change in appetite
  - Demonstrates bizarre, sophisticated, or unusual sexual knowledge or behavior
  - Becomes pregnant or contracts a venereal disease, particularly if under age 14
  - Runs away
  - Reports sexual abuse by a parent or another adult caregiver

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Sexual Abuse: (cont.)

- Parent Indicators:
  - Is unduly protective of the child or severely limits the child's contact with other children, especially of the opposite sex
  - Is secretive and isolated
  - Is jealous or controlling with family members

hjohnson4deafed@gmail.com &
janet@handsandvoices.org
Emotional Abuse: [1 per 1,000][7%]

- "injury to the psychological capacity or emotional stability of the child as evidenced by an observable or substantial change in behavior, emotional response, or cognition," or as evidenced by "anxiety, depression, withdrawal, or aggressive behavior."

hjohnson4deared@gmail.com & janet@handsandvoices.org
Emotional Abuse:

Child Indicators:

- Shows extremes in behavior, such as overly compliant or demanding behavior, extreme passivity, or aggression
- Is either inappropriately adult (parenting other children, for example) or inappropriately infantile (frequently rocking or head-banging, for example)
- Is delayed in physical or emotional development
- Has attempted suicide
- Reports a lack of attachment to the parent
Emotional Abuse (cont.)

- Parent Indicators:
  - Constantly blames, belittles, or berates the child
  - Is unconcerned about the child and refuses to consider offers of help for the child's problems
  - Overtly rejects the child
Appendix B: General Risk Factors
What are the factors that place a child at risk for neglect?

DePanfilis, (2006)

- Environmental Factors
  - Poverty
  - Community access to health care, social services, and affordable child care
  - Acceptance of violence and neglect in the community

- Social Support Factors
  - Social isolation
  - Lack of positive emotional support
  - Distrust of available social support systems
Family Factors

- Marital problems
- Domestic violence
- Single parenthood
- Unemployment
- Financial stress
- Difficulty in interacting and communicating in a positive manner, e.g., more chaotic, few positive statements, less empathy and openness.
- Substance abuse
- Poor problem solving skills
- Lack of knowledge re. child development
- Engaging in criminal behavior
What are the factors that place a child at risk for abuse?

Goldman, Salus, Wolcott, & Kennedy (2003)

- Caregiver Factors
  - Personality Characteristics: Individuals with:
    - low-self esteem
    - external locus of control
    - poor impulse control
    - depression
    - anxiety
    - antisocial behavior
    - severe mental disorders
Caregiver Factors (cont.)

- **History of Maltreatment**: Individuals who:
  - had poor parental role models
  - did not have their needs met as a child
  - experienced maltreatment as a child

- **Substance Abuse**: Individuals who:
  - use alcohol and drugs that impair their mental functioning, judgment, inhibitions, protective capacity
  - spend money on alcohol and drugs vs. household expenses
  - are involved in criminal activities that jeopardize children’s health or safety.
  - use of alcohol and drugs during pregnancy
Caregiver Factors (cont.)

- **Attitudes & Knowledge**: Individuals who:
  - have inaccurate knowledge re. child development
  - have unrealistic and unmet expectations for child behavior
  - use of inappropriate punishment
  - lack of knowledge re. appropriate child behavior management strategies

- **Age**: Individuals who:
  - are so young as to lack social, economic, and maturity needed to understand and effectively take care of their children
Family Factors: Families in which:
- there is consistent martial conflict
- there is domestic violence
- a single parent must meet all of the family needs
- unemployment has caused financial stress
- social isolation is the norm
- there are frequent changes in the member adults and children
Child Factors that increase their vulnerability

- **Age**
  - The younger the child (i.e., birth to three yrs.)...
    - ...the more dependent they are upon caregivers and the greater their social isolation, thus the increased risk for maltreatment, e.g., neglect and physical abuse
  - The older the child...
    - ...the more likely they are to experience sexual and emotional abuse.
Child Factors (cont.)

- Disability: Children who:
  - have chronic illness, physical, cognitive, emotional and/or behavioral disabilities that overwhelm their parents
  - do not understand what constitutes maltreatment
  - have limited communication skills to tell others that they have been abused
  - are physically dependent upon others to meet their essential needs
  - are considered to be unresponsive, or over responsive, to affection
  - are separated from their caregivers for extensive periods of time
  - interact with a significant number of adults in a variety of contexts

hjohnson4deafed@gmail.com &
janet@handsandvoices.org
Child Factors (cont.)

- Disability: Children who:
  - do not understand their own sexuality
  - do not know how to recognize or protect themselves in a “risky situation”
  - are socially isolated
  - are not recognized to be at higher risk for maltreatment
  - display physical marks and/or patterns of behavior that are difficult to attribute to abuse vs. their disability
  - would be difficult and time consuming to investigate due a lack of professional training, inconsistent definitions, and limited/different patterns of communication
  - would prove to be a unconvincing witness in a court of law
  - would be difficult to place in a foster home
  - are not a “valued” member of a community
Appendix C

List of Suggested IFSP, IEP, and 504 Plan Safety Objectives
Web Based Documents: O.U.R. Children Project

- **Hands & Voices:**
  - A Parent Driven Plan to Keep Our children Safe at Home and at School
  - IFSE, IEP, 504 Plan Safety attachment

- **KidPower:**
  - Personal Safety Issues and Development
    - Early Intervention: Birth to Three Years
    - Preschool: Three to Five Years
    - Elementary: Five to Eleven Years
    - Middle School: Eleven to Fourteen Years
    - High School & Transition: Fourteen to Twenty–Two Years

hjohnson4deafed@gmail.com &
janet@handsandvoices.org
Web Based Resources:

- **Hands & Voices O.U.R. Children Project**
  - Sample:
    - Child Abuse and Neglect: Helping Parents Talk to Children
    - Child Abuse and Neglect: Resources for Parents
    - OUR Children’s Safety and Success Project: One Parent’s Story – Hiding in the Dark...

- **Kidpower, Teenpower, Full Power International**
  - Sample:
    - Choosing Safe People to Care for Your Children
    - Kidpower Answers for Parents of Small Children
    - Teaching “People Safety” to Toddlers and Preschoolers

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Possible safety statements:

- Parent training on child development/understanding of their own child’s personal development including understanding their child’s assessments indicating need for language to understand safe environments/relationships and communicate when something is unsafe/unhealthy.
- Child’s need for training/education around labeling body parts, emotional language, social interactions and self-advocacy.
- Parent training around resources available, specific to child empowerment/safety and/or parent support resources.

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Possible safety statements (cont.)
- regularly checking in with a child to assure them that no topic is off limits, even before they can have "conversations;"
- understanding the importance of a strong emotional connection between parents and child,
- parents demonstrate skills in asking for background checks and safety policies for childcare and other personnel, and changing circumstances with adult caregivers with whom they feel or their child feels uncomfortable,
- taking the time to really know a child’s caregivers, including making impromptu visits while a child is in someone else’s care,
- Parents can describe physical and emotional signs of maltreatment in a very young child.
- understand how a child’s hearing loss may contribute to maltreatment without targeted support for the family regarding nurturing, modeling the ability to set boundaries with others from a young age, (whether known or a stranger to the child), early self-advocacy skills, and proactive communication skills.
- a child will give clear nonverbal, signed or spoken “no” "don't" and "stop" to uncomfortable interaction through role play and real life activities followed by appropriate parent response to that “no.” including an explanation when interaction is necessary for health or safety of child. (e.g., medical visits, hygiene.) Parents positively reinforce skills with child.
- Teaching feeling and thinking words to a young child and family, whether signed, spoken or both.
- Teaching appropriate words for body parts and the concept of "private" to young children.
- Parents can describe the concept of “grooming” and how a potential perpetrator might manipulate a child's feelings to keep secrets
Possible safety statements (cont.)

- **Knowledge and skills for parents.** Parent training on the importance of their role in protecting their kids and the need to take care of themselves in order to fulfill this role and of the impact of adverse childhood experiences on their child's future. Parental training on how to recognize unsafe behavior/situations and how to intervene appropriately to protect their kids. Parental training on child development/understanding of their own child’s personal development including understanding their child’s assessments indicating need for language to understand safe environments/relationships and communicate when something is unsafe/unhealthy.

- **Knowledge and skills for children.** Training and education for children around what safety means, what is and is not safe, labeling body parts, emotional language, social interactions, and self-advocacy to take charge of their emotional and physical safety and well-being.

- **Resources for parents.** Parent training around resources available specific to child empowerment and protection; development of children's personal safety knowledge, skills, and habits; and/or parent support resources for stress management, self-care, anger management, etc.

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Possible safety statements (cont.)

◦ Caregivers will be provided resources to enhance their understanding of typical development.

◦ Child assessments will be conducted quarterly to assist caregiver understanding of typical development.

◦ Community resources supporting positive caregiver/child relationships will be provided. Caregivers will be encouraged to connect with community agencies that support positive caregiver/child interactions.

◦ Caregivers will understand signs of maltreatment in young children.

◦ Caregivers will understand and be informed that "home visitors" are mandated reporters.

◦ Caregivers will encourage and expand a young child's language by using the following feeling words in embedded interventions: sad, happy, hurt, afraid, and scared. Caregivers could help generate a list of words to support feelings.

◦ Body parts could be included; however, when I checked the ASQ assessments, receptively body parts are not included until 27 months of age. I think naming body parts needs to be included early but as a way to enhance language...so caregivers could include this by playing with dolls, animals, etc. Playing with dolls could be very helpful later as a means for a child to express abuse.

◦ Once again, language to support children's ability to "tell" of abuse is critical...these words just need to be embedded into daily routines when possible.

◦ When looking for childcare, caregivers will be provided information regarding "Quality" child care and ways to ensure the backgrounds of the individuals who will care for their child or children do not have any record of substantiated child abuse and or neglect.

hjohnson4deafed@gmail.com & janet@handsandvoices.org
Appendix “D”
Related Web Resources
CEC/DCDD Division for Communicative Disabilities and Deafness: Special Project/Maltreatment Prevention

- Website: [http://community.cec.sped.org/DCDD/home/](http://community.cec.sped.org/DCDD/home/)
- Twitter: [https://twitter.com/dcdddcdd](https://twitter.com/dcdddcdd)
- Facebook: [https://www.facebook.com/pages/DCDD/47023877954](https://www.facebook.com/pages/DCDD/47023877954)
- DCDD/Committee on Infants, Toddlers & Preschoolers: [http://community.cec.sped.org/DCDD/committees/committeeoninfantstoddlersandpreschoolers](http://community.cec.sped.org/DCDD/committees/committeeoninfantstoddlersandpreschoolers)