

The Decision Tree

Child Outcome Seeds for Success



Why Culture Matters: Grandparents Raising Grandchildren

(courtesy of SCANVA)

When parents are unable to raise their own children, it is the grandparent who often steps in to assume the responsibility. Today in the United States, more than 2 million grandparents are living with and serving as the primary caregiver for their grandchildren. This trend poses incredible challenges both to the grandparent and the children involved, affecting everything from financial stress to child developmental to general family cohesion.

Why do grandparents become parents all over again? Grandparents often assume the role of parent in an effort to keep their family together and keep their grandchildren out of the foster care system. It might happen when a parent is incarcerated, or struggling with substance abuse, domestic violence, mental illness or other long-term health problem. A parent could be stationed overseas in the military. In some unfortunate cases, a parent may also be deceased. Whatever the reason, when a grandparent steps in to care for a child, they take on an incredibly demanding role at a time in their lives when they might have otherwise been relaxing and relishing time alone.

The challenges for the grandparent: Although a grandparent most often chooses to raise a grandchild for the right reasons, they are usually not prepared for the high demands of raising a child today. Unlike a foster parent, grandparent caregivers are usually offered no training to raise children, let alone a child who might be traumatized by losing a parent in some capacity.

Mental stress: Grandparents almost always take on the responsibility of caring for their grandkids because of a family emergency or tragedy. This means that they have to deal with their own emotional reaction to the circumstances along with those of their grandchildren. Once they overcome the initial shock of the situation, there is still the general stress of parenting. Their grandchildren may also have special medical, educational and psychological needs that require special attention.

Physical stress: As seniors age and require more medical attention, those raising their grandchildren often have less time and money to spend on their own health. In addition, the high physical demands of raising children (especially those under age 5) can take a serious toll on a caregiver's health.

Financial stress: Perhaps the most immediate (and often most stressful) challenge for many grandparents is the financial burden of raising children, especially unexpectedly. Grandparents who are raising their grandchildren are 60% more likely to live in poverty than those who are not. And even if a grandparent is able to sufficiently support themselves, the cost of children can be overwhelming. Many are retired or living on fixed incomes, but they are suddenly forced to feed more mouths, fit more people into their home and pay for the endless other necessities associated with raising a child.

Day-to-day challenges: If the child's original mother and father are absent, grandparents who do not have legal custody of their grandchildren might have trouble enrolling them in school, providing them with proper medical care and accessing their records. But obtaining custody and/or guardianship can be expensive, emotionally draining and confusing.

Grandparents can overcome these challenges! Parenting can be tough. The second time around it might even seem impossible! But there are steps grandparent caregivers can take to make the transition smoother and the new family unit stronger. Children in this situation—regardless of why their parents are no longer there—may be dealing with serious issues of abandonment, parental confusion and emotional detachment.

**The most important piece of advice for grandparents raising their children is the same thing we tell all parents:
Parenting is TOUGH. And asking for help shouldn't be.**

**Please see the Tip of the Month at the end of the Inter-rater Reliability Section for
Specific Resources for Virginia's Grandparents Raising Grandchildren**

To Find the Fact Sheet that is the source document for this Update, please go to https://www.scanva.org/wp-content/uploads/2016/05/Grandparents_English.pdf

Test Your Inter-rater Reliability



**Our state's focus on child outcome ratings has led many to wonder,
"Are we all rating children similarly?"**

As part of our efforts to improve results for children, we are focusing each month on increasing our statewide inter-rater reliability. We are using examples of narratives from around the state that ideally will include observations of functional behaviors, parent/caregiver input, results from assessment tools and informed clinical opinion. Below is an example of a narrative from a recent Assessment for Service Planning. Using the limited information provided in the narrative and the process outlined in the Child Indicator Booklet talk thru the scenario with your colleagues to determine a rating. The ratings given by the assessment team are included.

Disclaimer: This activity is for learning purposes only and is not intended to be an endorsement of any particular narrative. It is intended to help you reflect on the questions that follow.

Questions to Consider:

1. Was there enough information provided to determine a rating? What additional information did you need?
2. Was there input into the narrative from all members of the assessment team including the family?
3. Was the child's functioning across settings in each outcome clear?
4. Were functional skills listed under the correct outcome?
5. How close were your ratings compared to the ratings given by the assessment team? One or two off, in the same color family or way off? Did you agree with the ratings given by the team? Why or Why not?

Precious's Age: 27 months

Adjusted Age: NA

Referral Information, Medical History, Health Status: Precious has been receiving a variety of developmental services since May of 2014. She was originally referred due to a birth history significant for extreme prematurity with a gestational age of 24 weeks, 4 days, 99 days in the NICU and multiple diagnoses including bronchial pulmonary dysplasia, bilateral IVH grade 1, ROP stage1, respiratory distress syndrome, patent ductus arteriosus and GERD, among others. Since that time, her ophthalmological, endocrine, gastroenterological and pulmonary concerns have resolved. Precious has a health history significant for numerous ear infections. She had tubes placed in both ears and has had only one ear infection since that time. An audiological evaluation revealed normal hearing bilaterally. Precious also has a history significant for clinical reactions to penicillin drugs including a rash. Allergy testing was asymptomatic however she was diagnosed with a penicillin allergy based on consistent clinical symptoms. She was also diagnosed with an allergy to mold. Precious has an intolerance for milk products unless they are lactose-free. She also has intolerance for apple products and bananas although no allergy was confirmed during recent testing.

Medical records from Precious's pediatrician indicate that her cardiologist expects her small ASD to close on its own. At Precious's 2-year well-child visit her pediatrician indicated developmental delays in at least motor and language skills and atypical development related to sensory-seeking behaviors based on results of the MCHAT and the ADOS. Precious is up-to-date on her immunizations.

Daily Activities and Routines: Precious lives at home with her custodial maternal grandparents. She has a large extended family that she sees often. Her grandfather's sister helps care for Precious on a regular basis. Precious has had no contact with her mother since shortly after her birth. Precious's family likes to take her on errands, out to eat, visiting friends and neighbors and church but find it a challenge due to Precious's constant mobility, her impatience, her tendency to do what she wants rather than do what her grandparents ask her to do, her tendency to demand constant attention and her easily angered temperament. Precious's Grandmother also expresses concern about her limited attention span; particularly to verbal instructions which makes it difficult to modify her behavior. Another difficult area is Precious's messy eating habits. Grandmother reports that Precious takes an afternoon nap and sleeps well through the night unless she's not feeling well. She goes to bed at around 9:00 pm and wakes at around 6:00 am. She plays by herself in her crib for 15-30 minutes after waking which gives Grandmother a nice break as she does not demand

immediate attention any more. Precious eats her meals with her family but she likes to play with her food and crumbles crackers, spits her food out and drops or throws it which makes mealtimes disruptive. Precious spends the day with both of her grandparents, playing independently, playing with her grandparents and accompanying them on chores around the farm, visiting and running errands. Most evenings the three of them play a game of rolling a ball back and forth in the living room. Precious enjoys the company of her extended family including her uncle, his wife, her great-aunt, and their two grandchildren ages 7 and 10.

Family Concerns: The family's main concerns are that they are not able to take Precious on outings with them due to her temperament which tends to be restless, impatient, demanding and easily upset and angered as well as safety issues related to Precious's tendency to put everything in her mouth. Other concerns include the difficulty of raising a child without adequate financial resources as well as the difficulty inherent in being older caregivers for a young, active child.

Family Priorities: Precious's family always wants what's best for her and carefully attends to her health, safety and development. They're pleased with progress developmentally and medically but know that she has a way to go and are always on the look-out for resources. They'd like to take advantage of public school resources next school year. Right now they'd like to see her learn to attend better to what they're saying to her, use more words to communicate and learn to entertain herself better, particularly when out visiting, shopping or dining, without demanding constant attention or becoming angry. They would also like to see her sit in her booster seat for an entire meal and feed herself with a spoon or fork. The single most important thing for Grandmother is that Precious stop putting everything in her mouth as she's concerned for her safety.

Developmental Levels: Cognitive- 21 months Gross Motor- 16 months
Fine Motor- 18 months Receptive Language- 14 months Expressive Language- 16 months
Social/Emotional- 15 months Adaptive/Self Help- 13 months

Social/Emotional Skills including Positive Social Relationships: Precious's Grandmother describes her as a happy, affectionate little girl who loves to hug and kiss the familiar adults in her family spontaneously and when asked to. Grandmother reports that she will also show affection to her 7 and 10 year old cousins and that, for the first time yesterday, approached a child her own age to hug her. Grandmother reports that Precious is beginning to engage in simple role-playing and pretend behaviors. She pretends to feed her family food and pretends to be asleep. Precious generally ignores the presence of children her own age when in a social situation and goes about her own business according to Grandmother but loves to spend time with older children and watches what they do and tries to follow along. She also likes to play a simple game of throwing a ball back-and-forth with her grandparents in the evening when on the floor in the living room. She is beginning to have a sense of personal possession and although she doesn't resist having a toy removed from her she does cry with anger when this happens. Precious is not, yet, taking the initiative to engage other children in play, or participating in simple games with other children. Although Precious is generally a happy, curious little girl, she expresses anger dramatically when things don't go her way and will yell, scream, frown and throw things. Grandmother reports that she is very skillful at manipulating the adults who care for her and knows which ones will give her what she wants and which ones will not.

Precious is extremely distractible and loses her attention to social games and social interactions or activities with toys after only a few seconds most of the time. She has a very difficult time self-regulating and often dissolves into fits of temper. She is constantly seeking sensory input by putting (non edible) things in her mouth, by running, throwing things, ripping, tearing and destroying things. She has a very difficult time sitting still and will fight being confined in her high chair or her car seat even when entertaining distractions are presented. All of this significantly affects her ability to attend to the language of others and to learn language for social communication purposes; attend to and engage in the social games and activities of other children; manage her behavior in social situations and in the daily activities of living including at mealtimes, when shopping or waiting in the doctor's office.

Child's Development in Relation to Other Children the Same Age: Precious uses many important skills that are necessary for the development of more advanced skills; she is not yet showing skills used by other children her age in this area. Her attention to social events and social communication is easily fractured and compromises her skill development. She seems to have a significant delay in processing social language information and due to her brief attention is off to something else before she processes the information at hand.

Acquiring and Using Knowledge and Skills, including early language/communication: Over the past year, Precious has begun to engage in constructive activities with toys some of the time. Grandmother reports that recently she has discovered that Precious can focus for longer periods of time if she plays with her with toys in the tent that's in her bedroom as there are fewer distractions there. She has also been seen to attend for more than a few seconds following 5 or 10 minutes of deep pressure massage. Grandmother reports concerns that Precious will eat non-edible items and mouth objects. Today Precious was observed mouthing and chewing on a bumpy ball the examiner brought. She held it between her teeth and shook her head with the ball in her mouth. She was also seen to lick other toys. Precious was seen to hold her arms back and out to the side with elbows extended, and wrists bent. She did this several times holding the position for a few moments before relaxing. She sought out the ball and rolled on it and hugged it to her tummy in what appears to be sensory seeking behavior. Grandmother has brought out her old teething rings in an attempt to redirect Precious to mouth them instead of other items.

Precious has always loved looking at pictures in a book and although she hasn't been able to attend to a story or the naming of or pointing to pictures, she enjoys scanning the pages. When asked "Where is the_", she generally stares for several seconds without reacting followed by continuing to look at pictures on her own. During this assessment, Precious attended, for the first time, to the examiner asking her to point to familiar objects in a book and she was able to complete 3 requests successfully (kitty, shoes and banana) before losing attention. Grandmother reports that when she can get her attention focused, Precious will point to several body parts on herself when asked to including eyes, nose, teeth and mouth. She is working on ear.

Precious was observed to place 5 rings on a stacking post with encouragement after repeatedly pressing the button to activate the music. She used two hands to place rings but was seen one time to place a ring with one hand following a deep massage. She stacked one small block on top of another and released it but then proceeded to line them up in a row and could not be encouraged to return to stacking. Grandmother reports that lining up objects is a new fascination for her. Precious placed a circle and a square in a form board after the examiner tapped the appropriate receptacle for the square. She tended to use trial and error for the square but visual matching for placing the circle. Precious consistently relies heavily on visual information rather than on verbal information. The examiner needed to pat the floor when saying "Sit down, please" before Precious would sit (momentarily) and tap the form board to keep her focused and attempt placement. Precious was also observed to solve the problem of removing a Gerber Puff from a bottle by rotating her wrist to dump it and then shaking the inverted bottle when it wouldn't fall out. She located an item hidden in one of the examiner's hands in one trial of three.

Precious inconsistently follows verbal directions but is more reliable with directions related to daily routines where a lot of repetition, familiarity with the event and context clues help her focus on the verbal information associated with these activities. Examples include getting ready to go outside, to eat, to brush her teeth, to go to bed and to take her bath. She attends better to non-routine directions, as mentioned previously, when gestures can be used to help her attend and understand or when in a quiet environment with fewer distractions. Precious always immediately reacts to someone mentioning her grandfather by going to the door to look for him if he's not in the house. Grandmother reports that she reacts mainly to the naming of other familiar people or favorite objects or events if they are routine or something she always loves (like food or a drink). Otherwise, she tunes out the speaker. When she is attentive to a direction, she can follow one part of it but not the other. For example, if Grandmother says "Throw the ball to Paw-Paw", Precious will throw the ball randomly.

Precious vocalizes mainly in short, one-syllable open-vowel utterances. She does not babble or jargon. She uses approximately up to 10 words to label, greet, request and call to her grandparents. Voicing of words is soft, limited to one-syllable, incomplete and indistinct. She consistently uses the words no, milk (spoken as mmmmm), mama, paw-paw, daddy {spoken as dadeeee}, ea(t), bubu (for bubbles) with a lip tap as demonstrated by her Grandmother, ball, kitty, see and hi. She's recently begun saying bye accompanied by a wave although this is not, yet, consistent.

Child's Development in Relation to Other Children the Same Age: Precious uses many important skills that are necessary for the development of more advanced skills used by other children her age in this area. Her attention to tasks is so brief and her need for sensory stimulation so great that it interferes in her skill development; particularly in the areas of toy play, problem solving and language.

Use of Appropriate Behaviors to Meet Needs: Precious uses her eyes to track and focus on objects and people in her near and distant fields of vision without difficulty. She notices objects entering her peripheral fields and uses her vision

to direct her hand in reaching for an object. Precious notices loud and soft sounds in her environment as well as voices but often seems to tune them out or demonstrates a much delayed response. Her recent audiological evaluation revealed normal hearing bilaterally. Precious has learned to walk over this past year but tends to run rather than walk. She can throw a ball forward using both hands on the ball for a distance of up to three feet but directionality is compromised. She climbs up steps using her hands and knees or hands and feet and does not go down steps and needs to be carried. Grandmother reports that on one occasion she walked up a few steps with her hand held but this is not typical as she's not secure doing this. Precious does not shift her weight to kick a ball nor does she kick a ball by walking into it.

Precious reportedly sleeps through the night, now, and takes an afternoon nap. She talks to herself in her crib for 15-20 minutes after she wakes up and no longer needs immediate attention as she did when she was younger. Precious sits in a booster seat for meals and has a hard time sitting still. She shifts herself around in the chair constantly, plays with her food (including crushing crackers, spitting and throwing food) and wants to get down. Grandmother reports that mealtimes are a challenge because of this. Precious finger feeds all table foods but does not use a spoon. If Grandmother hands her a spoon with food on it she'll fling it. Precious drinks from a sippy-cup, primarily, but cannot drink from a cup without a lid.

Precious's self-help skills related to dressing include the ability to remove pants, shirt, diaper, socks and shoes. She can unzip a jacket and remove it, as well. She helps with dressing by holding out arms and legs but is not yet trying to dress herself. She prefers to be naked, according to Grandmother.

As was mentioned, previously, Precious uses some gestures some of the time including pointing but usually yells or screams for what she wants although she does use several words to make requests including milk, eat and bubble. Grandmother reports that she cannot leave Precious unattended due to her tendency to put everything in her mouth, break things and get into unsafe situations. She does not generally follow directions and when told to stop doing something, may stop momentarily but then returns to it. Precious is beginning to show an interest in toileting and Grandmother reports that she's recently been willing to sit on the toilet when Grandmother suggests it.

Child's Development in Relation to Other Children the Same Age: Precious uses many important skills that are necessary for the development of more advanced skills; she is not yet showing skills used by other children her age in this area.



Determining the outcome ratings requires teams to synthesize an enormous amount of information about a child's functioning from multiple sources and across different settings to identify an overall sense of the child's functioning at a given point in time in three outcome areas.

- ✓ Grandparents raising grandchildren is an increasing family situation here in Virginia. The Virginia Department for the Aging has put together a [66 page resource guide](#) specifically aimed at helping grandparents raising grandchildren access available resources in Virginia.
- ✓ Additional Virginia resources can be found at www.vda.virginia.gov/kinshipcare/asp.
- ✓ A resource published by the Virginia Cooperative Extension, thru Virginia Tech and Virginia Commonwealth University discusses some of the [legal rights and challenges for grandparents raising grandchildren](#).
- ✓ The following journal article reviews current research related to the increasing family situation of grandparents raising grandchildren especially those doing so with limited resources and living in poverty: www.ncbi.nlm.nih.gov/pmc/articles/PMC2888319/.
- ✓ Be sure to check out this month's Early Intervention Strategies for Success Blog written by Dana Childress which addresses concerns vs priorities: [Priority or Concern What's the Difference and Why it Matters](#). Grandparents raising grandchildren often have very different concerns and priorities based on their life experiences, limited resources and their own aging health concerns. Precious's team was able to really focus in on the family's concerns, priorities and challenges related to their daily routines and activities, which resulted in meaningful, functional IFSP outcomes.