

Technical Assistance Tools Permanency Planning Instrument Section 1. Part 1. Background Information

Describing the child

Purpose of the description: The information in this section should be thorough enough that a person unfamiliar with a child could use it to form a mental picture of the child. However, it should be presented as briefly and concisely as possible to encourage reading the whole description without getting lost in an excess of detail.

The description of the child should *briefly* answer the questions below. The idea is to offer a good, solid *summary* of a child's needs. Note that not all children will have issues warranting explanation in every category.

The descriptions should use "people first" language and avoid jargon that would not be recognized by all readers. This guide includes language to avoid and offers examples of alternative ways of describing children and their needs.

The questions below are followed by some sample descriptions.

Questions to guide description of child:

- 1) Is the child a boy or girl? For older teens and young adults, refer to them as young women or young men.
- 2) How old is the child?
- 3) What is the child's race/ethnicity?
- 4) What does the child look like physically? Large, average, small for age? Does the child have any physical characteristics that might impact the choice of family for that child? For example, does the child's size or position require oversized equipment or a two-person lift? Also, identify something about the child's physical appearance that is appealing nice smile, pretty hair, bright eyes?
- 5) What are the child's diagnoses?
- 6) Does the child have a cognitive impairment? To what degree? What is the child's IQ? State explicitly if undetermined.

7) How does the child move around? For example, does he or she use a wheelchair or orthotic aids? Does he walk with assistance, walk unassisted, have a steady or unsteady gait? If he uses a wheelchair, can he transfer by himself or does he need assistance? Does he require a two-person lift? Does the child have good trunk control or does he need a customized seating system for support? Would a family need accessible transportation?

Avoid words/phrases like "wheelchair bound," "ambulatory or non-ambulatory," or "mobile." Say instead things like:

- a. uses wheelchair for mobility
- b. able to use power wheelchair without assistance
- c. requires someone to push wheelchair
- d. walks without assistance on even surfaces but has unsteady gait and requires supervision and some assistance when using stairs
- e. walks with assistance but is unable to manage stairs
- f. uses orthotic devices when walking
- 8) **How does the child communicate?** For example, does he or she use any words to make needs/wants known, or does the child rely on non-verbal cues like hand gestures or eye blinking? Does he use a communication device? If so, describe.

Avoid the term "non-verbal," say instead something like "does not use words to communicate," "uses some sounds and simple signs," "uses a communication board with pictures of daily activities," or "uses a computerized communication device."

9) **Does the child need assistance with personal care?** To what extent? For example, can the child eat, dress, bathe or do other personal hygiene tasks? With assistance or unassisted? What about toileting?

Avoid the phrase "is (or needs) total care." Consider the following phrases instead, "needs full assistance with all personal care needs, including bathing, dressing, and toileting," or "can eat without assistance using adaptive bowl and utensils" or "needs reminders to go to the bathroom but can use toilet without assistance," or "uses adult diapers" or "can transfer to toilet with assistance"

- 10) **Does the child have any medical issues that require routine or ongoing attention?** For example, does the child have seizures, g-tube, trach or vent, or have a metaboloic disorder, or anything else that would require a family to seek follow-up or ongoing care with specialists for the child, have special skills of their own for routine care of the child, and/or need nursing or other professional support in the home? Is the condition stable or unpredictable? Are there any surgeries pending?
- 11) **Does the child have any behavioral challenges?** What are they and do they have any implications for family composition or caregiver experience/training needs?

If so, describe them in measurable terms. For example, rather than saying someone is aggressive, describe the actual behavior, like "the child will routinely try to scratch or bite other children who physically get too close to him, especially if they touch him" or "the child becomes upset when he hears loud noises and will bite his left hand in response."

Describe how the behavior is effectively managed, like "the child is easily redirected from x behavior by telling him not to do the thing and offering for him to listen to favorite CD as an alternative activity." Or if the behavior is serious and not currently managed well, indicate a need for assessment, training and support planning. Consider saying something like "Hits and bites caregivers on a daily basis. No triggers or effective strategies for managing behavior have been identified. Child needs comprehensive behavioral assessment and positive behavioral support plan. A family will need training and assistance in the home."

If it appears that the child may not do well with other children or children of particular ages or gender, then note that. However, be judicious in your assessment on this issue as some challenging behavior in an institutional setting may be indicative of problems associated with congregate care in general rather than a true inability to be around other children.

Also describe behavior that is appealing to provide a balanced view, such as "has a sense of humor and is usually very playful."

- 12) **Does the child take any medication to manage health or behavioral challenges?** It isn't necessary to name or list the medications, just note that the child takes medication to manage or control a particular condition.
- 13) **How does the child generally respond to other people?** Adults? Other children? How would you describe the child's disposition, personality? What does the child like or respond positively to? People, things, activities? Does the child seem engaged with their environment? To what degree?
- 14) Are there any geographic restrictions on where this child can live? If so, what and why? For example, you might say, "needs a Support Family in the Waco area to be near his grandmother."
- 15) Is there anything else about this child or the child's circumstances that need to be taken into consideration when considering a potential family living arrangement? For example, the child has been in an institutional setting since birth, he or she has had numerous foster placements that didn't work out, the child has specialized health care needs that might be difficult to meet in a rural area, etc. Also, be sure to note if the child is able to express what he or she wants related to family life.

Sample Descriptions

Carter Collins: Carter is a 10 year-old African American boy with an engaging smile. He is small for his age and uses a manual wheelchair (pushed by others) for mobility. His chair has a molded seating system to accommodate his scoliosis and poor trunk control. Carter has been diagnosed with severe mental retardation (IQ 32), seizure disorder, and Cerebral Palsy. He takes medication to control his seizures and spasticity. His physician has recommended he have scoliosis surgery in the next year. Carter needs full assistance with all personal care needs, including eating and bathing, and uses diapers. He does not use words to speak but does make sounds and use hand gestures to let people know what he wants. He is afraid of loud noises and can become agitated (cries out and twists back and forth in chair) in large groups or unfamiliar surroundings. He is easily soothed by calm speech and removing him from the situation. Carter likes to be talked to and held. He also likes soft music and being outside. He seems to get along well with both adults and other children.

Maria Cruz: Maria is a 15 year old Hispanic girl with long dark hair, warm brown eyes and a love of all things pink and "girly." She is slightly overweight but of average height for her age. She has been diagnosed with moderate mental retardation (IQ 54), ADHD (Attention Deficit Hyperactivity Disorder), seizure disorder and intermittent explosive disorder. Her overall health is good, but she does take medication to control her ADHD, seizures and recurring eczema. She walks with a slight limp, but is able to take care of all of her personal care needs with some prompting. She has a moderate speech impairment but is easy to understand after spending a short time with her. She likes to talk a lot and interrupts others frequently, which can sometimes be problematic in school and in getting along with others. Maria will yell, throw things and sometimes hit when she doesn't get her way. However, she is responding well to a positive reinforcement system recently implemented at school and in the group home. She likes to be on the go – movies, shopping, the park, going out to eat. She also likes to help with chores around the house.

Amber Ashton: Amber is an 8 year old Caucasian girl with light brown hair and pretty green eyes who is very small for her age (34 pounds). She has diagnoses of profound mental retardation (IQ undetermined), Cerebral Palsy, Seizure Disorder, and hydrocephalus. She has a shunt, a g-tube, and a tracheostomy and uses a ventilator to breathe. Amber has had numerous surgeries for shunt replacements, has been hospitalized twice in the past year for pneumonia, and is prone to urinary tract infections. She takes numerous medications for seizure control and recurring UTIs (Urinary Tract Infections). She requires frequent repositioning for comfort and to prevent skin breakdown. She is rarely out of bed at the facility, but does have a manual wheelchair, which is modified for portable vent use and which has a molded seating system for trunk and head support. Amber requires full assistance for all personal care needs and uses diapers. Amber does not use words, signs or gestures to communicate but will make a "cooing" or humming noise when she experiences something pleasurable and will cry out if she is in pain or agitated. She seems to like physical touch and having her hair brushed.