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## Informational Handout for parents of children with Autism Spectrum Disorder, Cerebral Palsy and Down Syndrome in Tanzania (or other Developing Countries)

Kailee Moran  
*Grand Valley State University*, [morankai@mail.gvsu.edu](mailto:morankai@mail.gvsu.edu)

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## **HONORS SENIOR PROJECT- Fall 2018**

**Kailee Moran Project Advisor- Dawn DeVries**

**Informational Handout for parents of children with Autism Spectrum Disorder, Cerebral**

**Palsy and Down Syndrome in Tanzania (or other Developing Countries)**

**\*Can be translated into Swahili\***

### **Autism Spectrum Disorder**

What may Autism look like? This behavior is usually seen first in children between 18 and 36 months of age- getting care and help for your child as early as possible is important

#### **Socially**

- Limited eye-contact or greetings (shaking hands, schamo)
- Doesn't try to get other's attention
- Minimal facial expression
- May not respond when their name is called
- Very sensitive to certain sounds, textures
- Often not knowing how or when to start a conversation or respond
- Not making friends similar to other children their age

#### **Communication**

- No development of spoken language, or delay
- Saying one word or phrase over and over, talking about something
- Creating new words or using real words in the wrong way
- Using words from songs or books to talk about feelings
- Moving to another topic randomly in conversation
- Do not often use imagination when playing, are not spontaneous in play
- Do not imitate others when playing

#### **Patterns of Behavior**

- Very intense focus on one subject, or unusual interest in object
- Are not happy with changes in schedule or typical routine
- Focus on the the parts of an object

## **Facts about the Disorder**

- A higher number of boys than girls are diagnosed with Autism Spectrum Disorder
- 1-2% of people in Tanzania likely are on the Autism Disorder Spectrum, totaling 60,000-120,000 people in the country and it is becoming more common

## **Advocacy within community and family:**

- Sometimes telling family and friends about your child's diagnosis can be very difficult, especially when you feel emotional. It is hard to predict what they will say. Whether you have a positive or negative reaction, it is important to educate about autism after you have told them what it is. To start, you may talk about specific behaviors.
- For example: "You know those behaviors we were confused about for so long? Well, now we know what they are and why they occur. \_\_\_\_\_ doesn't act the way this way because they are spoiled or shy or because they don't like us – they act this way because they have autism. Autism explains why they do not talk like most children, why they do not seem to understand what we say or interacting with us as the other children sometimes. I know this may be upsetting news. But now that we know what the disorder is, there are a many ways we can help them with therapy and at home. If you need some time to think about this that is okay."
- Do not hide your child, take them outside
- If possible, make friends with other parents who have children with autism so you can have support of families who understand your daily challenges.
- Encourage other children to play with your child and teach them what you have learned
- However, be careful to not let autism complete control your life. Spend quality time with your other children, family, and other supportive people and refrain from talking about autism in every conversation.
- Focus on the things they can do, not the things they cannot do

## **Strengths of those with the diagnosis:**

- Ability to understand concrete ideas and rules
- Strong long term memory skills
- Math skills
- Musical ability

- Artistic ability
- Ability to think in a visual way
- Honesty – sometimes to a fault
- Ability to be very focused – if they enjoy the activity
- Excellent sense of direction

## **Communication tips:**

**Use their name at the beginning so they know you are talking to them**

**Encourage play and social interaction.** Children learn through play, it can be a fun chance for you and your child to communicate. Try many games to find what your child enjoys to help improve social skills. Put position yourself in front of your child and at their eye level if possible so they can easily see and hear you.

**Focus on nonverbal communication.** Gestures and eye contact are important. Imitate appropriate behaviors often so they feel understood. Exaggerate your gestures. For example, by moving your hand to point when you say “look” and nodding your head when you say “yes.” Use gestures they can imitate. Examples include clapping, opening hands, reaching out arms, etc.

**Give time for your child to respond before speaking again** Watch for sounds or movement and respond so they are more likely to communicate again.

**Simplify your language.** If your child does not speak, try speaking in single words. (If playing with a ball, you say “ball” or “roll.”) If your child speaks single words, speak in short phrases, such as “roll ball” or “throw ball.” Use only a couple more words than how your child is speaking.

**Don’t not ask too many questions at one time**

**Follow your child’s interests.** Talk about what they are doing. If they play with a car, you could say the words like “go” “stop” or “fast” and “slow”. You might say the colors on the car or shapes on the car, or count the cars. This helps them learn about the words they should use with these objects.

## **Treatments for Core Symptoms:**

**Visual help.** Visual help can assist in development. This can be pictures and groups of pictures that your child can use to show what they are thinking or want or need. Help to make a schedule for each they can see and predict

**Praise/Reward:** More helpful than punishments, give lots of praise and potentially a reward immediately after a desired behavior, even if very short, they can feel positive about the behavior.

**Focus on what you want them to do, not what you do not want them to do** Ex: “Use a quiet voice please” rather than “Do not yell so loud”

**First/Then:** If they are upset about something they cannot have or do at the exact moment, you can tell them- first you must do this, then we can do this (what they want)

**Finding a calming environment, they can take a break in to calm their senses**

**Breaks:** Provide 5, 2 or 1 minute warnings before you are change activity to help children prepare themselves

**Physical punishment does not teach good or correct behavior**

**Do not beat your child**

**Autism Safety Kit:**

**ID Card to put in shoe or as a necklace, if they get lost without a guardian, someone is able to understand what they need and who to contact**

	<b>I Have Autism</b>	
	Name: _____	
	Date of Birth: _____	
	Call Me: _____	
	Contact Number: _____	
Contact Person: _____		
<p>My medical condition impairs my ability to communicate with others. I may not be able to answer your direct questions or have difficulty understanding your directions. I may become physically agitated if you touch me. <b>Please DO NOT think I am defying your instructions or refusing to cooperate. Please contact the person above immediately!</b></p>		

**Social Stories:** Helps those with autism to better understand how to socially communicate in an appropriate manner.

# Say Sorry

by: theoutlinetool.com



When My friend and I get in a fight, I feel mad.



I need to be done being mad and move on, It's time to say sorry.



I might have hurt my friend's feelings. I don't want to make my friend feel sad. I need to say sorry.



I say sorry to my friend. If he says sorry to me I say, "it's okay." We shake hands.



I am happy my friend and I are done fighting. Now we can have fun!

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Good Behavior	Bad Behavior
 quiet	 run away
 hands to self	 scream
 clean up	 hit others
 listen	 teasing
 work	 poking friends

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 What is a Charley Horse?	 A Charley Horse is not a horse!	 It is a funny name for a cramp in your leg.	 It happens in your calf.
 It hurts a lot!	 Sometimes you get a Charley Horse while you're sleeping.	 Sometimes you get one at your desk.	 It feels like a tight squeeze on the back of your leg.
 What should you do?	 Stand up. Walk around.	 Say: My leg hurts!	 Say: I need help!
 Rub your calf.	 An adult can help.	 Rub your hands down your leg. NOT up. Press down hard.	 Charley Horses hurt. But not for long.
 Stretch every day to keep Charley Horses away!	 Drink enough water.	 Eating bananas or drinking orange juice every day can help.	 Now you know what to do!

What is a Charley Horse?

**Materials for interventions:** cornstarch, water, food dye, paper, glue, salt, flour, drink bottles, marbles, buckets, coloring utensils, rope, cups, sand, beads, balloons, string, egg cartons

**Intervention examples:**

- Ooblex,
- (Finger) painting
- Making jewelry
- Bowling
- Tag
- Mirror, mirror on the wall
- Imaginary play (animals, school, families, cars, bikes, kitchen)
- Hot potato
- Paper airplanes
- Making moldable sand
- Hopscotch
- Making shapes
- Puppets
- Obstacle course
- Mancala
- Marble shoot
- I spy
- Make maracas or drums
- Maze races
- Playdough

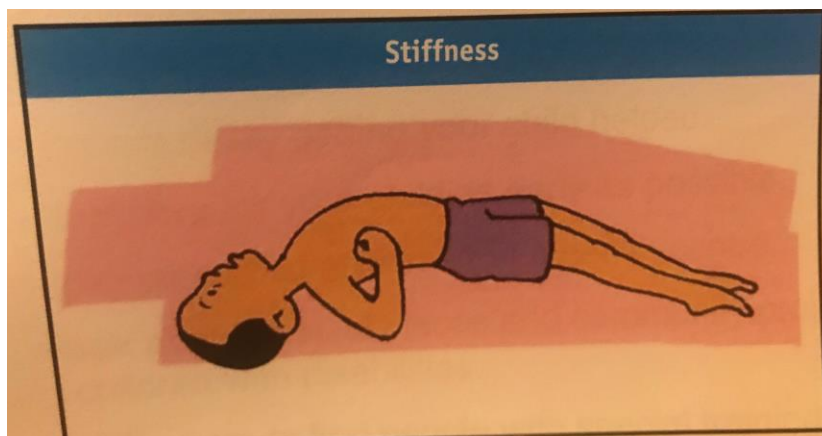
# CEREBRAL PALSY

## What may Cerebral Palsy look like?

Young babies may show some of these signs

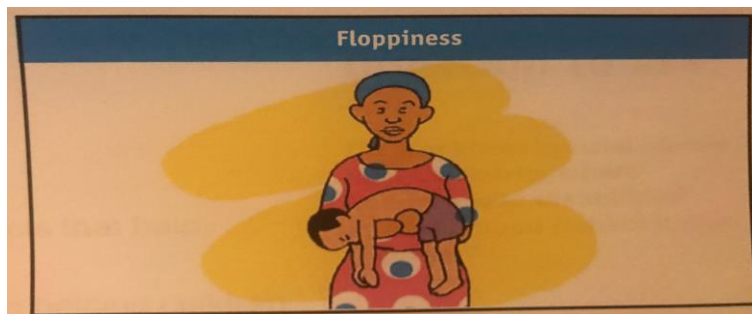
### Stiffness:

- In some positions, like lying on a back, it becomes difficult to bend the baby's body to dress or cuddle them
- Your baby is difficult to handle in some positions, like lying on their back



### Floppiness:

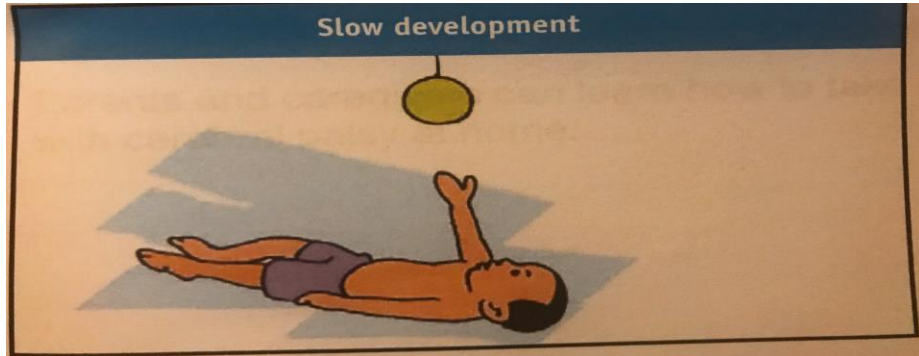
- Your baby's head flops and they cannot lift it. Their arms and legs hang down when they are held in the air. The baby moves less than normal.





### **Slow Development:**

- Learning to lift their head and sitting takes longer than expected and they may not pay attention to certain parts of their body



### **Poor Feeding**

- Sucking and swallowing is poor. Baby's tongue may push the milk and food out. May have difficulty closing mouth



### **Unusual Behavior**

- They may be extremely upset and irritable often and sleep very little, or be very quiet and sleep a lot.
- Getting help and care for your child as early as possible is important
- Treatments happen in the home, not the hospital

### **Communication Tips**

- Look, talk, touch, and sing to your child often



- Tell your child what you are doing
- Give your child choices: Between yes and no, gesturing, communication pictures and eye contact are important.
- Use fewer words and simple gestures- If your child does not speak, try speaking in single words. (If playing with a ball, you say “ball” or “roll.”) If your child speaks single words, speak in short phrases, such as “roll ball” or “throw ball.” Use only a couple more words than how your child is speaking.
- Give time for your child to respond before speaking again. Watch for sounds or movement and respond so they are more likely to communicate again.
- Do not force a child to speak

## **Feeding**

### **Positioning:**

- Hold child in upright position
- Turn their body towards you as far as possible
- Stabilize their head in a neutral position
- Support their jaw

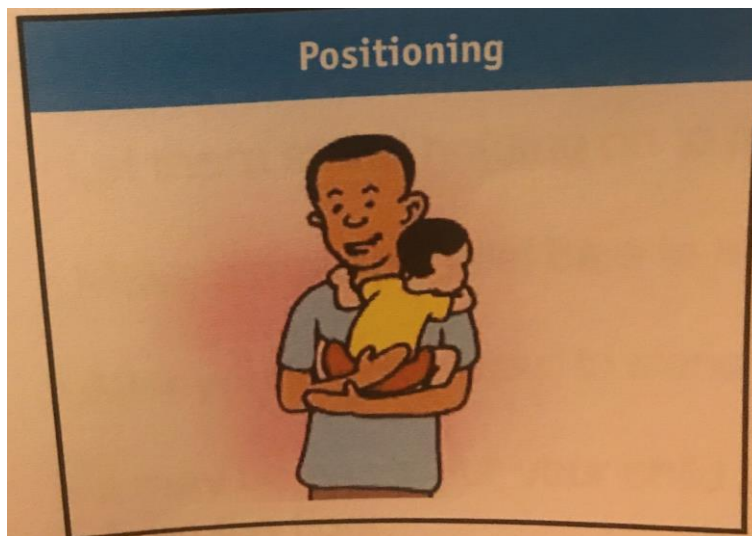


**Introduce foods of different textures:**

- Children with swallowing difficulties may need thicker food
- Give small bites of food with high nutritional value
- Encourage child to feed themselves, give praise when they do

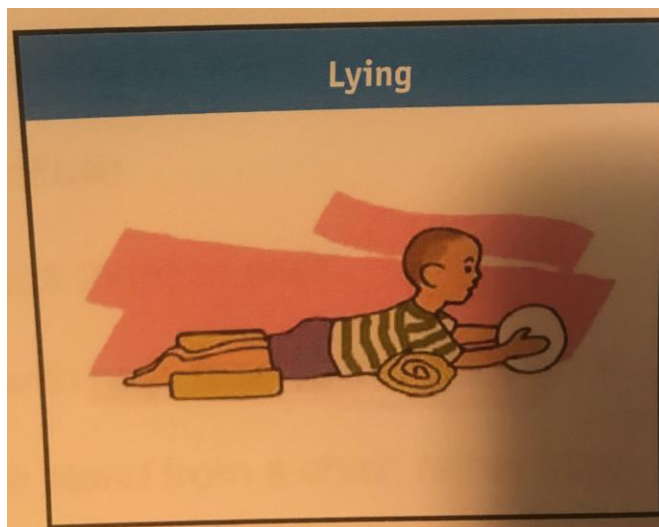
## Positioning

- Carry in upright position
- Bend their hips and knees

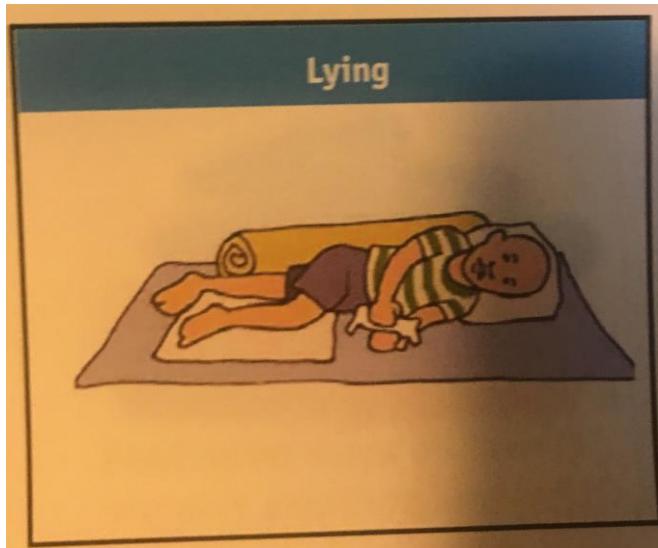


## Helping child lie down

- On stomach: place a roll, wedge, or cushion under your child

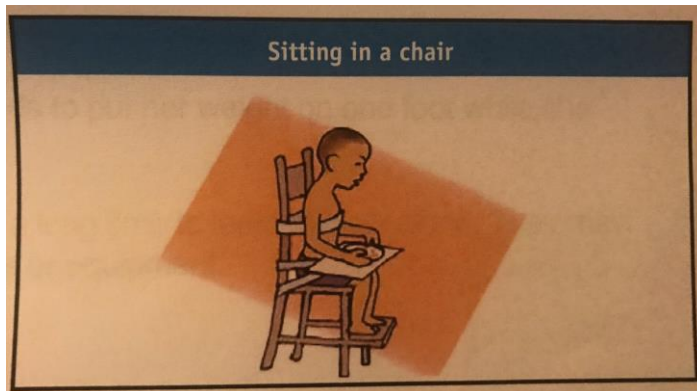


- On Side: Keep both arms forward and bend one hip and knee



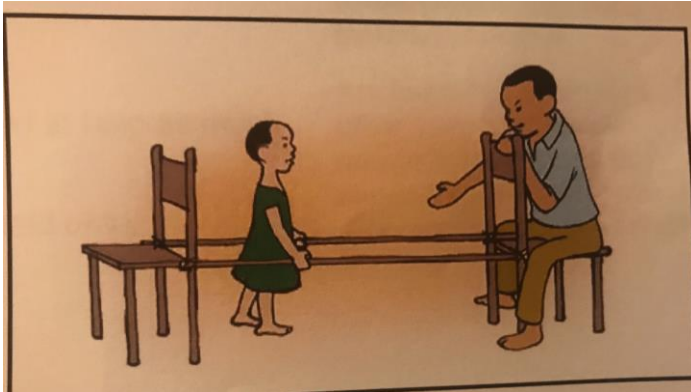
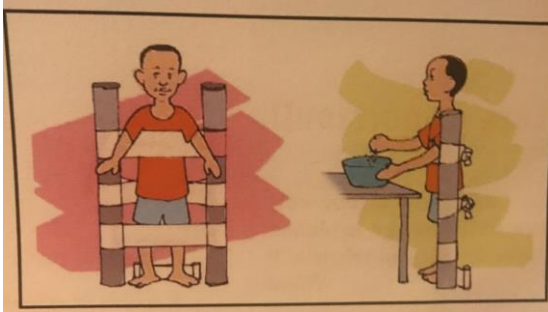
### **Sitting**

- Keep child's feet flat on the floor
- Keep bottom level against back of the chair



### **Standing and Walking**

- Children need to hold onto something to stand and walk
- Let them stand holding onto furniture
- If possible, use parallel bars to teach them to walk. However, it is necessary to have weight on both ends to prevent the child from falling.
- After your child can pull themselves to stand straight, teach them to do it independently
- May be easier to stand from a chair than from the floor
- To take a step, they need to put their weight on one foot while lifting the other
- Many children will take a long time to walk alone, or may always need the help of braces and equipment



\* Have another person on other chair, or object of significant weight

## Using the Toilet

- Encourage your child to help as much as possible undressing and dressing
- If possible, make something, like a bar, for child to hold onto
- Use a box or special chair for them to sit on





## Dressing and Washing

- A child may be able to learn to dress lying on his side



- Sitting in a corner against the wall can help with balance

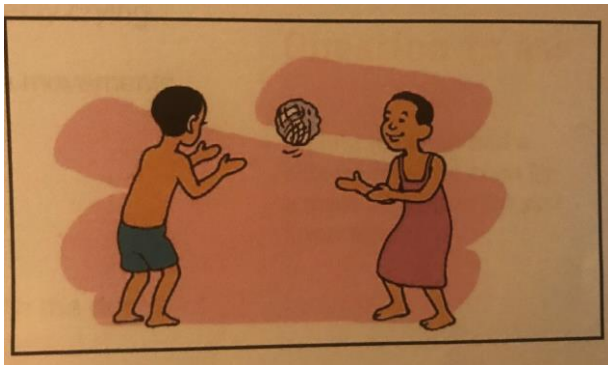


- Allow child to hold onto something if needed



## Play

- Play helps your child develop properly
- Encourage child to move both arms together and separately
- Focus on holding toys and releasing them
- Encourage play in different body positions
- Encourage other children to interact and play with your child



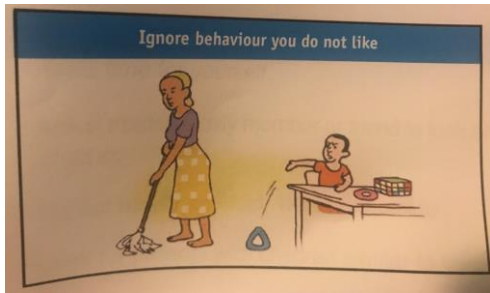
## Behavioral Tips:

- Stick to your rules, be consistent
- Reinforce the behavior you want, for example
  - Giving a reward after a desired behavior. This could be a kiss or a snack.
  - Praise the behavior, not the child





- Ignore behavior you do not like, if it does not put the child in danger.



- If you cannot ignore behavior, try a “time out”. This means taking child to a safe place where you can see them but away from where activity is happening.
- Physical punishment does not teach good or correct behavior
- Do not beat your child



**Materials for interventions:** maraca, drum, string, beads, cups, balls, bottles with caps, paper, legos, playdough, egg carton, paint (equal parts cornstarch, water, and salt, food dye) balloons, toy car

#### **Intervention examples:**

- finger painting (drawing shapes, numbers, and letters)
- tapping and shaking musical instruments
- ripping paper or egg carton into small pieces
- making shapes/letters/numbers from playdough
- taking off and putting on bottle caps
- grasping objects out of bottle
- stringing beads
- throwing/rolling/kicking/hitting the ball and identifying colors
- blowing into balloon, hitting balloon
- driving toy car through a maze on paper

#### **Advocacy in community**

- Let your child participate in community activities the same as any child
- Take your child to social and religious gatherings
- Let your child play with other children

- Let child help in household activities when possible
- Show community that your child is special and loved
- If possible, make friends with other parents who have children with cerebral palsy so you can have support of families who understand your daily challenges.
- Focus on the things they can do, not the things they cannot do

**Advice for caring for the caregiver(s):** Talking to someone, taking a break (walking, deep breathing, dancing) etc. Consider keeping a journal



# Down Syndrome

This disorder can usually be diagnosed at birth, getting care and help for your child as early as possible is important

## Facts:

- Down Syndrome symptoms occurs when a child has a full or part of an extra copy of Chromosome 21, this happens before birth
- Down syndrome occurs in people of all races and economic levels
- Down syndrome is a condition or a syndrome, not a disease.

## What may Down Syndrome look like?

### Physical:

- Decreased or poor muscle tone
- Short neck, with excess skin at the back
- Flattened facial profile and nose
- Small head, ears, and mouth
- Upward slanting eyes, often with a skin fold that comes from the upper eyelid and covers the inner corner of the eye
- White spots on the colored part of the eye
- Wide, short hands with short fingers
- A single, deep, crease across the palm of the hand
- A deep groove between the first and second toes
- Shorter than average height

### Cognitive

- Mild to moderate learning impairment is common
- Speech and language may be delayed

### Behavior:

- Cannot pay attention for long periods of time
- Poor judgment- may not think about what could go wrong
- Impulsive behavior (quick decisions)
- Have need for routine Ex: wanting to the same food, chair, bedtime every day
- Trouble speaking exactly what they need or are feeling
- May have greater difficulty making friends the same age

## Strengths of Individuals with Down Syndrome

- They usually understand non-verbal emotional cues, such as facial expression, tone of voice, eye contact.
- Over time, however, most are competent with self-help and daily living skills
- Reading abilities
- Visual learning






## Individuals with Down Syndrome may be at higher risks for developing conditions such as:

- Hearing loss
- Heart conditions
- Visual impairment
- Blood conditions (anemia, leukemia)
- Early-onset dementia
- Infections because of weaker immune systems

## Behavior Tips

**Give simple and clear directions-** the less amount of steps the better Ex: “Pick up your toys now please” not, “ It is time for you to pick up your toys, we need to leave for church now”

**Make a schedule and follow it:** They will do their best when they can predict what they will be doing that day and in what order. Ex: Going to bathroom, putting clothes on, feeding animals

Hang up coat	Have a snack	Play	Read a book	Eat dinner
				

**Schedule time for fun:** Even if just for 10 minutes, it is important to have positive time with your children every day. It can be reading, playing a game, cooking, taking a walk etc.

**Focus on what you want them to do, not what you do not want them to do** Ex: “Use a quiet voice please” rather than “Do not yell so loud”

**First/Then:** If they are upset about something they cannot have or do at the exact moment, you can tell them- first you must do this, then we can do this (what they want)

**Distract-** If child has unwanted behavior, try to offer them a new toy or object to move focus from behavior to a new and exciting thing






**Ignore-** Children love attention. If behavior is not unsafe, do not respond or give attention.

**Physical punishment does not teach good or correct behavior**

**Do not beat your child**

**Praise/Reward:** More helpful than punishments, give lots of praise and potentially a reward immediately after a desired behavior, even if very short, they can feel positive about the behavior.

**Visual help.** With their skills in visual memory, this chart can be helpful. Make pictures of what you'd like your child to do where they can see it. At first, make goals simple and positive so the child will like it. It's okay to help at first, but encourage child to do it on their own to earn a prize after a few days. Begin to add in more difficult jobs to go with the ones your child can do. You must use chart every day to make it useful.

	Change	Wash hands	Draw picture	Use bathroom	Prize
					
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					

## **Advocating for child:**

- Do not hide your child, take them outside
- If possible, make friends with other parents who have children with Down Syndrome so you can have support of families who understand your daily challenges.
- Encourage other children to play with your child and teach them what you have learned
- Let child help in household activities when possible
- Talk to teachers, friends, community members about facts of Down Syndrome when possible, share about true causes
- Focus on the things they can do, not the things they cannot do

## **Materials for Interventions:**

Playdough, paint (equal parts cornstarch, water, and salt, food dye), paper, crayons, markers, sand, stickers, water, beads, strings, pillows, blankets, bubbles

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