**John Doe**

**Care Information**

**And**

**Communication/Education Care Giver/Camp Manual Updated January, 2022**

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**John Doe MEDICAL HISTORY**

**EMERGENCY CONTACTS**

**XXX**

OTHER CONTACTS

XXX

**MEDICAL CARE/DOCTORS AND PHONE #’S**

PRIMARY DOCTOR – XXX

(Neurologist/Epileptologist) XXX (call if problem with seizures)

**St Louis Children’s Hospital – 314-454-6000**

Poison Control: 314-772-5200

John Doe’s HEALTH INSURANCE:

**Medicare A & B, D: Primary**

**MO HealthNet (Medicaid): Secondary**

**Medical History**

**Main diagnosis**: **XXX Father/Guardian: XXX**

**John Doe is approximately XX pounds, X’ X” tall**

**Routine Medicines LIST WITH DIRECTIONS**

**Emergency Seizure Recovery Medicines**

**LIST AND REFERENCE SEIZURE PLAN**

**Medicines as needed**

**LIST**

**DO NOT INTUBATE – NO CARDIAC PADDLES/COMPRESSIONS (any cardiac med can be administered and meds to support comfort.)**

**BASELINE – XX Heartrate, XX Respirations, BP - XX, XX F Temp.**

**John Doe IS SENSITIVE TO XXXXXX.**

**John Doe is fully vaccinated and Boosted for COVID-19.**

**ABBREVIATED MEDICAL HISTORY AND PLANS PROVIDED (3 PGS)**

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**How to keep John Doe Safe?**

John Doe must be monitored and placed in safe positions. John Doe has limited neuromuscular control compared to us and has issues with balance and maintaining his body posture while sitting or upright. Generally speaking, recognizing his needs is the first step in maintaining a safe environment. Using adaptive equipment and providing him support will avoid his falling and hurting himself.

The main concern you will face with safety revolves around mobility and positioning. John Doe’s mobility has declined in recent years as his hip and leg muscles are tightening and pulling his legs out of alignment. **It is important to do hamstring and abductor stretches to keep his muscles as loose as possible.** John Doe likes to explore and walk with assistance. This is the only way he can make autonomous choices as he will lead you to where he wants to do something. You are his walker providing balance and support. John Doe’s KFO’s (Knee and Ankle Orthotic braces) help him stand better and provides support when his knees are locked. John Doe loves to walk in his KFO’s. John Doe also has a Jenx stander and Kid Walk to allow him to be vertical and weight bear through his legs. He likes to dance in his stander as it has wheels to allow him to swing and move. It is important that John Doe walks and is on his feet throughout the day at various times. He wears the KFO’s 1-3 hours and does the stander for up to 1 hour. More than this can cause stress to his knees.

John Doe uses an EZ Rider chair to get around inside and on paved paths. Put the foot rests down so his feet do not hit the front wheels. His jogging stroller is used to walk him on uneven surfaces or soft paths and trails. You do not need to buckle the shoulder straps. John Doe eats his meals at home and residential camps in a Rifkin chair with table top.

John Doe loves to swim and uses special water wings. John Doe could flip over and drown if he just uses just a life jacket! The lifejacket is fine for boat rides or in combination with the water wings for lake swimming (he swims with mouth open and swallows small amounts of water when he does this). In a swim pool John Doe maneuvers by himself and flips over from front to back with his water wings.

John Doe is quite proficient using his sign for eat and drink to let you know he wants/needs food. John Doe will indicate if he is hungry or thirsty by pointing his finger to his mouth repeatedly. He will also lead you to his chair that he eats in. Ask “John Doe, are you thirsty or hungry?” He will sign if he is. If you offer him a drink or food he does not want, he will gently push away. John Doe will throw the straw cup on the floor when it is empty or he is done drinking. John Doe will also let you know when he doesn’t want a specific food or drink by shaking his head no, pulling his hand back (instead of taking the spoon) or pushing it away. Do not force him to take food or drink as it increases the risk of aspiration.

For Drinking

John Doe drinks liquids thickened liquids with simply thick/thicken at honey consistency or prepared as thick smoothies. See Eating and Drinking section for details. He uses his straw cup to drink. Staff should not pull the cup away from John Doe while he is drinking. He has demonstrated that he can control the amount of liquid he consumes. Make sure John Doe has plenty of fluids to remain hydrated during summer. Yogurt is another good substitute to help keep John Doe hydrated if he doesn’t want to drink. John Doe may not drink if he knows he will cough and he will guide you.

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For Eating

John Doe use to eat a variety of food textures – hard crunchy, coarsely chopped, small pieces, pureed or mashed entrees and pureed or soft fruit pieces. But recently he started aspirating on foods at honey consistency and below. This was revealed during a swallow study done in January and April, 2021 at SLCH. John Doe is chewing better since coming home from the hospital and it is unknown what he will be able to safely eat as time progresses. If the entrée is too thin (soup), crushed crackers or thickener can be added to thicken the consistence. If too thick, water or juice can be added. SEE FOOD CHART and eating section later in the manual.

**INTRODUCTION TO John Doe**

**Who is John Doe?**

John Doe is 24 years old. He lives in XXX with his XXX. John Doe aged out and graduated from XXX High School (date). There are now limited recreational programs available as he has aged out of most. And his higher risk to aspiration eliminates other opportunities. Adult day programs often do not meet John Doe’s wants and needs or cannot support him. XXX Camp, one of the

few residential camps that will feed campers with high aspiration risks, refused to accept him. Hopefully he will improve in his ability to eat different texture and thickened foods as he recovers from recent hospitalizations and illnesses.

John Doe has matured and grown over the years in ways unique to him and some paralleling any young man. John Doe has a good sense of humor and is generally fun to be with as long as you actively interact with him. He is good natured and wants and likes to engage in activities with the help of others. **Personal interaction with others is very important to John Doe. He is very social** and likes to be with people and once he gets to know someone, he will develop a bond and personal way to relate and communicate with them. **John Doe likes to be with others and be part of the group even if he cannot participate fully. Please be creative in ways to get John Doe to meet and participate with others and in group activities.** (This is more difficult during the pandemic but he likes to be around others.) John Doe likes exploring, although with decline in mobility he requires more assistance to do this. **John Doe’s world revolves around personal and social interaction.** He likes to interact with objects/items that provide physical activity when presented by a person. John Doe does not play with toys for very long independently or watch TV or videos unless a person is interacting with him.

**John Doe is very concrete and has a very limited grasp of abstract ideas and concepts. Things need to MAKE SENSE and HAVE MEANING to and for John Doe.**

Does this MAKE SENSE?

• Refers to Whether the learner can understand the item on the basis of experience. • Does it “Fit” into what the learner knows about how the world works?

• When you say “I don’t understand,” it means the student is having a problem with making sense of the learning.

Does this HAVE MEANING?

• Refers to Whether the item is relevant to the person. Why should I remember it?

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• Meaning is very personal and is greatly influenced by that person’s experiences. Questions like “Why do I have to know this?” or “When will I ever use this?” shows that the person has not accepted that this learning is pertinent or relevant to their life or needs.

David Sousa and Carol Ann Tomlinson, in their book, *Differentiation and the Brain: How Neuroscience Supports the Learner-Friendly Classroom*, declare that nothing goes into long-term memory unless it makes sense and has meaning. Of the two, they say, meaning-making has much more impact on long-term memory than sense-making.

John Doe is a pretty patient guy and has learned how to wait. Peers and schoolmates acknowledged John Doe, but it was hard for them to interact and play with him. John Doe works very hard and is curious about his immediate surroundings; he always wants to know what’s going on. John Doe wants to be with others his age or younger which is harder now that he has aged out of school.

John Doe likes to play with a few objects such as cloth books, balls, blocks, squigs and other objects he can grasp and throw. His favorite game is to play fetch with you – he throws, you fetch. He likes to push trays back and forth with you on a flat surface. John Doe enjoys physical contact and massages. John Doe likes physical and vestibular stimulation such as roughhousing and bouncing on the trampoline in the basement lying down or sitting with you. John Doe likes to go for walks outside in his stroller or to playgrounds where there is a high back swing. He loves to visit new places or go to friend’s houses. He prefers to be out and about! All of this is done with verbal and physical cues and reinforcements. John Doe needs to know you are there for him and engaging in a way that he enjoys connecting with you.

**Another major difference about John Doe is he does not do screens –** TV, Movies, Computers, iPad, cell phones, X Boxes, etc. Sometimes he will want to sit with you (on your lap is best) in front of the TV if you are talking and moving him to the TV sound track or the visuals he sees. John Doe has lost interest in using MyTalk on the iPad (sometimes he will make choices if presented correctly by a person and is interactive and has immediate results from his choice). It is better to provide real objects for choices and follow up immediately with his choice!

John Doe absolutely loves swimming and being in the water. He likes exploring and walking around with support from an adult. John Doe enjoys funny words and noises (Velcro, false hiccups, pig sounds, kissy sounds, etc.). He likes to pull hats and cloth off people’s heads, and general slapstick humorous behavior. He likes having a conversation with you with his expressive language. He can really get engaged with music and dancing/swinging around in his stander or other playful activities. John Doe really likes food with hummus his favorite. He likes teen foods such as mechanically ground pizza, veggie chips, soft ice cream/yogurt, smoothies prepared in a way he can eat it safely.

Because of his lack of independent play with objects, John Doe does not like to be left alone for more than 5-10 minutes. He often becomes upset or will fall asleep out of boredom when his parent or caregivers have to leave him, but he gets over this quickly if engaged by new caregiver. John Doe usually requires contact with a person, either direct or indirect 80-90% of his waking hours. Loud, startling noises, and hot or uncomfortable places may upset him at times.

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John Doe likes theatrics and exaggerated movement, interactions and talking. He likes that you can get in his face and be funny. Be expressive with him and read his response. He sometimes likes to be read to (in a very animated theatrical voice) by some people in which he listens.

John Doe has limited signs and is using them more consistently and purposefully. See later section on communication to help you implement it. John Doe has a well-developed expressive language to communicate with Dad, care providers and those close to him. It takes a long time to understand the subtleties associated with his vocalizations, behavior, signs and the specific context in which he is communicating. He uses different communication modes depending on whom he is interacting with.

It is important to have conversations with John Doe and once he knows you, he will respond back in his own expressive language which speaks volumes once you know him well enough and can interpret its meaning. Even if you do not understand his responses, use of intonation by both you and John Doe can help the conversation flow. **It is important for John Doe to know that you are interested in how he is doing, his current mood, and activities you two will be doing. It is also extremely important for you to be expressive and excited when you talk and play with John Doe. You should communicate expectations, choices, and what he will be doing later that day as you interact with him**.

**John Doe’s Disability**

John Doe n was born XXX with a very rare genetic disorder – XXX. Unique has a great fact sheet summarizing XXX which I will share with you.

John Doe spent the first five weeks of his life in the NICU and many subsequent hospitalizations in the PICU for infections (pneumonia) and seizures. He is very resilient and has defied the medical community’s prognosis. XXX is a severe and profound condition, and as a result John Doe has multiple disabilities in all areas of physical and mental development. Most of his disabilities have a neurological basis and often may be manifested in a lack of neuromuscular control. John Doe dan will never be independent and his life span is unknown. John Doe is one of the older males with XXX. It is unknown what medical conditions will develop later in his life, for instance his swallow has declined and he is now aspirating on thicker substances this past November through January. **John Doe is significantly delayed in all developmental areas and is nonverbal/nonmobile and will not function cognitively above a PreKg – 1st grade level in most circumstances.**

As a result of its rarity, the medical professionals do not have much information to predict outcomes or prognoses for John Doe. They often refer to John Doe and Dad to guide them on how to treat him and what to expect for his future. Besides his regular pediatrician, John Doe sees a neurologist, movement disorder specialist, dentist, and physiatrist on a regular basis. John Doe use to receive physical, occupational, and speech therapies on a limited basis at school in the past. Other specialists are seen as the need arises for potential or existing treatment.

**What is Important to John Doe**

• To enrich John Doe’s day to day life and keep him engaged in a variety of activities • John Doe and dad are able to maintain an emotionally healthy and happy family relationship.

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• **That John Doe maintains a high quality of life in all areas. This should not be compromised and is a major consideration in medical interventions.**

• To continue to allow John Doe to eat and drink in a safe manner even though the risk of aspiration is a concern.

• To include John Doe in the community to the fullest extent possible

• To provide a variety of fun and familiar activities as well as new and challenging experiences that engage John Doe cognitively, emotionally, and physically

• That John Doe walks in his KFO’s and uses the stander/kid walk daily to maintain his limited mobility, good health and muscle tone and participate in activities such as dancing and walking to places of his choice

• That John Doe has normalcy and routine so his day-to-day life is not disrupted • That John Doe continues to meet new “friends”; both peers and adults • That John Doe continues to remain healthy in body, mind and spirit

• That John Doe’s care providers develop a strong relationship with him, help him progress developmentally and provides stimulating and enriching experiences

• That John Doe has the means and resources to reach his full potential and be supported and cared for the rest of his life

**John Doe Communication Profile**

**Non-verbals/Verbals**

Anticipation and Recognition: It is important to know that John Doe recognizes many concrete objects, places, routes, verbal messages and replies with anticipation and preparation. These memories are persistent and many people miss this. Only a few people understand this to the full extent that it happens.

• Going to familiar places such as camp, school, pool, playground, to car or stroller, he recognizes many people’s houses that we visit regularly. He also understands if you tell him we are going to a favorite place or going to do a fun activity that he has done many times.

• Oftentimes if you ask John Doe what he wants to do, he will look at a place he wants to go to or an object he wants. If he is standing, he will walk you to what he wants. • Bag with braces, swim bag to go to pool, he knows the house layout and what is in each room, food containers or opening refrig for snack or drink, door opening and closing to announce the entrance of someone. He recognizes individual voices.

• John Doe does understand simple statements and questions. He probably understands more than you realize or that he can demonstrate.

Happiness: This is shown through his whole body (position, poster, vocalizations, expressions, and a general lightness to his personality)

• Smiling.

• Looking at you and gesturing for you to interact with him.

• Reaching out to touch you.

• Excited body language and responses to you.

• More sign or Clapping.

• Happy vocalizations – squeals, giggle, cooing.

• Reacts to funny noises with delight and laugh or snicker.

• Holding your hand.

• Playing with you in a sustained manner.

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• Pulls you towards him if he wants affection, to cuddle and or relax (cause and effect).

Upset: This is shown through his body language. Often it starts with subtle cues which many people ignore or miss and then escalates into pinching or grabbing or other frustrated actions. • Reaching out and touching you to get your attention.

• Vocalizing in a different way as he tries to indicate what he wants or needs. • Pinching or grabbing (hair or glasses) – escalated communication.

• Pushes items away with vocalization–telling you he wants something new. • Throwing to get rid of an object you are trying to engage him with – telling you he wants something new.

• Vigorously shaking head–telling you he wants something new .

• Crying and biting (extreme at his limits).

• Tantrum that needs to have a time out to end or cuddling.

Calming Techniques – John Doe does not like to be upset and giving him attention and being directed to engage appropriately will help calm him. He most often gets upset because he is being ignored (you are talking interacting with another person and not including him), not being understood and he cannot communicate his wants and needs to you, or his wants and needs are being ignored and you are not paying attention to change what you are doing. • Say out loud calm and slowly “John Doe, sorry and I am here for you, I want you to . . . “ • Ask John Doe what he wants while being directly in front of him at eye level. Look for his response.

• Remove the source of agitation or stimulus he does not want any more or at all. • Touch or Hold him or use funny noises or techniques to get him in a happy calm mood again. • Sometimes he needs a timeout laying quietly by himself or with you massaging his shoulders. • Giving a drink, snack or pacifier can also calm him.

• Try not to let it escalate to a temper tantrum as it takes a long time for him to reach equilibrium again.

Interactive Play

• John Doe loves physical contact with people holding your hand and swinging, dancing, movement. You can do this while he is sitting, in his braces or in stander/walker. • John Doe will lead you as he walks to what he wants to do or where he wants to go. He likes to do trust falls in his braces.

• He likes playing "here I am!" with sheets or laundry after they're tossed on top of him. He looks at you to see if you are going to interact.

• His favorite is to play catch or fetch with a soft object or small ball.

• Fooz bottle or tray on a table top, pulling squigs off counter top.

• When we're outside, we talk about the surrounding environs as well as listening to the sounds we hear and imitate some, naming the creature or object that makes that sound. • John Doe imitates and pays attention through directing his eye gaze and gets excited when something or someone familiar appears.

• He likes to "visit" with dogs as we are out on walks. He may not pet them, but he is aware of them and sometimes claps his hands in enjoyment of their presence.

Signs- This are limited and some like yes are very subtle. John Doe may do certain signs with some people and not with others.

• John Doe looks at what he wants to do or who he wants to engage with. **Follow his eyes**.

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• Drink and eat (the same bringing his hand up to his mouth repeatedly). • Greeting or Saying Goodbye – handshake or Hi Five or Fist Pump.

• Yes – Head swooping down to his left one time means "yes" or gets excited/signs more. • No – different type of head shakes means different types of no or all done. • No – pulling hand back from object you offer him (especially food or drink). • No – pushes and object away gently.

• All Done – No more – pushing an object away gently.

• More – will generalize so it can mean more, I’m happy, I want something else (when food/snack is present), head shake 'no' (meaning is not consistent) When hungry or need wanting to be met when (when in walking position) leads care giver to a preferred location.

• Get up - If he is sitting or lying, he lifts his hands up to you to pull him up or legs up to his arms indicating he is ready to get up.

Prompted wanting attention – touching person, making verbalizations, biting, pinching, looks at the person

Ignoring activity – put head down, look away, pushes away

Tired/fatigued or being ignored – falling asleep, putting down head

Acknowledging a person’s presence – touching, taking your hand or looking at the person, giggling, clapping, signs 'more'

ENGAGEMENT

• John Doe will physically show attention and participate in an excited manner. • John Doe will make eye contact with you and often vocalize expressively. • John Doe does respond well to the count of 1,2,3 and anticipates the action thereafter. • Activating iPad by touching screen for use of MyTalk application and cause & affect apps Fist

pump with person - is initiated by communication partner Touching people, wall. • He will start to sit up if reclined when he wants to get up and do activity. He will also throw the pacifier to indicate finished resting in bed and wants to get up.

• John Doe recognizes scenery/landmarks when going somewhere he's been before and gets excited: claps his hands, wiggles, makes happy sounds which suggests a certain degree of visual recognition.

**Making John Doe Happy/Calming Techniques**

John Doe can get upset if his immediate physical and emotional needs are not met. If John Doe does not receive the personal attention to be engaged, he may also get upset. He vacillates between 2 – 8-year-old regarding his ability to regulate his moods. John Doe sometimes will put his fingers in his mouth when he is bored for an extended period of time or put his finger up his nose. This has greatly decreased in recent years. John Doe has few sensory issues and is able to tolerate many environmental sounds or intrusions that a typical child does, but not all. Sudden loud, harsh sounds and noise will make John Doe upset. He is less tolerant of normal interactions when he is tired, needs his diaper changed, or is hungry/thirsty.

**Hierarchy of Frustration Behavior John Doe May Exhibit**

1. Look at you and try to sign or vocalize

2. Try to get your attention through signs (often more sign meaning I want a change), touch or push an object, subtle change in body language/posture

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3. Vocalize and reach out to grab you (pinch) to get your attention, big change in body language/posture

4. Push something away repeatedly or throw object, facial expression and body language shows distraught mood

5. Very loud vocalization/cry, grabbing and shaking, pushes everything away. 6. Meltdown

In order to get John Doe “back on track” you can use various calming techniques. These are ranked ordered in what could be most successful, but it varies from person to person, time of day and situation to situation.

• Remove John Doe from the source of discomfort or upsetting sensory input. • Distract John Doe from the source of discomfort or upsetting sensory input with personal interaction, touch, calm talking or funny noises.

• Check to make sure his diaper is not too full or soiled.

• Provide food or drink. When other interventions fail, try giving John Doe a snack or drink and that could settle him down.

• Hold and comfort John Doe through gentle rocking.

• Give John Doe choices!!!

• Sing songs or make funny noises and gestures.

• Short rest or cat nap.

• Massage, shoulders, back, stomach, arms or legs.

• Stroke John Doe’s face from TMJ (temporal mandibular joint - (at sideburns) to mouth. • Provide John Doe a chance to move by assisted walking where he directs you to where he wants to go.

• Dance with John Doe in his chair/stander or standing on floor to music. • Change of scene – take John Doe for a walk or to a new environment.

• Time alone to chill.

Making John Doe laugh also helps calm him and ignore the source of agitation. Funny noises like Velcro being undone, slurping or kissing sounds, and using a finger to push out a full cheek of air with a sound are irresistibly funny. You will discover other funny noises that turn John Doe into the giggle box and uncontrollable whole-body laughs.

Saying funny words with the right intonation can get him laughing and change his mood. He likes rhyming words!

Sneaky Pete or the Sneak!

Silly Sam

Smiley Wiley

Talking like Crocodile Dundee

**Handsome Hank!**

John Doe Sweets Edison

Hungry Hound/Starvin’ Marvin

Mista Bigs

Mista Busy Bee Body Boy

**John Doe Home or After Camp Routine:**

Schnay Ray

Giggle Box

Buddy Boo

Red Fred or Freddy Starvin Marvin

Mr Man Mango Meglomaniac Man

Buddha Boy or Bear

Chick Magnet

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1. Stretches – John Doe should do stretches 2-3x/day to keep his legs, upper body and arms limber. See photos and descriptions in the PT and OT section at the end of the manual for different stretches. Father will also show you the stretches.

2. Standing and Walking – John Doe must use the KFO braces to walk at least once or twice each day. Walking is the only way he can make an autonomous choice. Father will train you on walking with braces. John Doe enjoys the stander for dancing and activities in the basement (30-60 minutes). John Doe likes to shuffle around the house and driveway/alley in the kid walker. He can dance, do activities at the counter, and explore. Father will also show you how to position and use the stander/kid walker. John Doe enjoys spinning and dancing in the stander. You can also use the Hula Hoop so John Doe can pull himself with the stander.

3. Chest Vest Shake N Bake Therapy (2x/day when he wakes up and in the late afternoon) • Wrap John Doe’s upper torso in shake therapy band (green/grey side on his back and the white part on his belly over his shirt).

• Follow directions on top of the shake therapy machine to start: John Doe will be shaking for 20 minutes total on two separate settings.

o 12Hz 6 for 10minutes and 14Hz 6 for second 10 minutes.

• Do leg stretches while John Doe is doing the shake therapy.

4. Checking/Changing John Doe’s diaper: John Doe wears Tranquility All Through the Night and often only requires 2 diapers per day – 1 when he finishes morning shake and being changed into clothes before breakfast and another in later afternoon which will often go through the night. Father will show how to put on with tabs for best fit and checking him if needed.

• John Doe gets constipated from the seizure meds so dad gives him a fleet saline enema every three days to cause a BM. He is given it laying down and after it starts working, transfer him onto the toiler where he is able to sit and go. Because of this he rarely has BM’s in his diaper during the day.

• Typically, John Doe will not need to be changed before 4 or 5 pm unless there is a bowel movement (BM). These diapers can hold more liquid than most. Check for blue streaks *at the bottom* and for fullness/overflow in the front corners where the sticky straps attach to the sides. If both of these are full, change him.

• If BM, take a mental note of the amount, consistency, etc. Let Father know later. • Snack: John Doe doesn’t need a mid-morning and rarely an afternoon snack. He may need to drink something from his straw cup or be spoon fed between meals. John Doe should not have a snack within 30 minutes of afternoon shake minutes before or 10 minutes after shake therapy. If John Doe is coughing a lot, wait a little more time. • Veggie Sticks/chips or pretzels sticks and hummus (his favorite) or pureed fruit or drink for snack.

• During snack, you can hold two options up for John Doe do choose from (drink/food). Ask him, “John Doe, would you like \_\_\_\_\_(drink)\_\_\_\_ or \_\_\_\_(food)\_\_\_\_” indicating which item is which to him through movement. John Doe will reach and grab the one he wants first.

5. Play/Exercise:

• Be creative, make silly noises, and encourage activity. If John Doe is vocal with you, he is enjoying the activities and/or interactions with you.

• Have John Doe differentiate and identify between two common items in his daily routine like clothing, toys, and eating utensils

• It is important to use the KFO braces and/or the stander during play. John Doe likes to do trust falls at the couch in the living room. John Doe can kick a ball while walking in

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his braces or knock over blocks or talk cylinder. Father will show you how. You can play at the house (upstairs or in basement) or take John Doe out into the community. • The KFO braces are very helpful on playgrounds, parks and museums! It is up to you if you put them on before you leave the house or when you get to your destination. You can put the braces on while he is in the EZ rider.

• John Doe has different activity areas in the basement you can engage him in. He likes laying on the trampoline or sitting with you and being bounced, being in the stander at the ping pong table and throwing balls or batting pink trays, sensory table with moon sand, chairs etc.

• **Accessible playgrounds**: Oak Knoll, Clayton’s Shaw Park (high back swings were changed out and are too small), Tilles Park (feet drag a little on swing), Wehner Park in Shrewsbury (High back swing in forested playground on west side is the best swing we have found), Forest Park playground (by History Museum).

• If go out make sure you use a booster seat in either front or rear seat. EZ Rider can be collapsed to fit into trunk or on back car seat. TAKE PARKING TAG and GARAGE DOOR OPENER (by back door) but MAKE SURE YOU RETURN THEM.

• Free indoor Institutions: Science Center, History Museum children's exhibit, Zoo, Art Museum, the Arch Museum, CAM/Pulitzer (walk him through exhibits), Powder Valley Nature Center, Pet Smart or PetCo, Menards, IKEA sitting on chairs and walking, The Galleria or other malls (John Doe enjoys flying fabric/clothing), and anything else you can think of - be creative!

**Activities** - **John Doe often chooses an activity by walking you over to the object or activity he wants. He will also look at it or vocalize when he gets to his desired choice.**

Basement – John Doe loves playing in the basement and that is where the stander resides. He will play with his care providers for up to 3 hours in the basement and be a happy boy. There are different activity areas set up and he also can walk in his KFO’s in the basement. He can also be put in the black Zippy chair and hold the hula hoop to be pulled around. The hammock requires extra care so he doesn’t flip over but the hammock chair swing can work.

Upstairs and driveway – John Doe likes to use the kid walk in the house and outside in the driveway. He likes to roll down the gentle slope. He can do the kid walk for up to 1 hour and you can push him up to the kitchen counter to play.

Kitchen counter and bed – John Doe can also play with toys upstairs at the counter and on the bed. He loves to walk in his KFO’s and goes to the couch where he will push off the back for trust falls that you catch him as he falls backwards.

Rolling on mat or soft surface, not grass

John Doe**’s** favorite position besides sitting is lying on his back so he can play. John Doe does not roll off his back. He loves throwing items and playing catch or fetch with you. He likes his clothe books, small pillows, and other items that he can play with.

Playing with Toys

**John Doe is unusual when compared to most other kids in that he does not independently play with toys very much**. He may play with his cloth book or small pillow for 5 minutes at a time. Other toys require you to play with him and assist him in using them. He also likes to throw objects as a form of play. You will have various length of engagement with

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the toys ranging from 1 – 15 minutes. John Doe likes squigs and foos bottle/pink tray on the counter top or ping pong table in basement. If you sing a song while playing with the toys you can often increase the time John Doe will actively explore and play with an object. Be creative and try different toys. John Doe often likes rhythm instruments for a short time. Hand over hand shaking a rattle while music is playing is sometimes a fun activity.

Reading Books

John Doe sometimes likes to have books read to him. It depends on his mood and the person. His favorites are Dr Seuss or Shel Silverstein books or others with rhyming cadence. You should read with lots of expression and you can hold him close to you. Point to pictures in the book. If John Doe continually tries to shut the book it is a good indication, he is ready to do something else.

Interactive Play

**John Doe thrives on interactions with others**. It is essential that you show excitement and enthusiasm with him. He will use expressive language to show if he likes something or is excited. He does not play with very many toys and rarely focuses on the 2-dimensional media of TV, movies or iPad/computers. There are many different ways to interact with John Doe in a fun and meaningful manner. John Doe has different preferences for interactive play depending on who he is with and his mood at the time. Experiment and try new things as well as offering tried and true play options. Tell John Doe what you are going to do, ask him a question and offer him choices just as you would any youngster. **There are videos and documents on Father’s computer to give you ideas of how to engage John Doe in creative ways.**

John Doe loves theatrics and exaggerated communication, both voice and body language. He likes physical contact and hugs/holding hands. Making him laugh and giggle while playing indicates you are successfully engaging him. Have conversations in which he responds with expressive language as you play. Develop your own form of communication and creating a bond with John Doe.

Providing choices and working on communication is an important aspect of interactive play. See the communication section for more information and techniques. Give John Doe choices. Unfortunately, the iPad My Talk program is not appealing to John Doe and he stopped making good choices a few years ago. Use real objects or ask him what he wants and see where he looks or if in braces or kid walk, where he leads you.

IPAD

You can try various apps on John Doe IPAD to interact with him or calm him down, but he will not pay attention to the screen. He likes music in the background and you can use music apps.

Rough Housing

This is one of John Doe’s favorite things to do as he loves vestibular stimulation and movement. Do not be afraid to swing and play with him in a physical way. He is not frail. If he falls down, he may cry but he is like any other boy and loves active play. Rough housing may calm him down if he is not to upset as well as making him happy and content. He likes to be held and enjoys physical contact with movement. John Doe loves swinging in high back swings, a favorite playground activity. He can do this for 10 minutes or more.

Music/Dancing

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John Doe grew up listening to mom and dad singing to him as well as music from the stereo. Music can have a calming effect on him, especially singing familiar songs or a way to get him excited. John Doe likes to dance, especially if you take both hands and swing him back and forth and side to side. Putting him on your knee and bouncing him to the music is another way you can dance, but the best way is having him standing on the floor, using the KFO’s or in the stander. He likes a variety of music as long as it has a danceable beat and is melodic.

Stander

The Stander is a good choice for John Doe to play with a variety of items, move and spin on the floor (in the basement) and move him to the ping pong table or counter top where he can grab, throw, slide objects or roll balls, etc. Be creative and dad will show you different things to do.

Stretching

John Doe tends to be very tight in his arms and legs, especially in the morning. There are simple stretches that are good for him and will increase both his flexibility and mobility. There are diagrams from the PT that will show you some simple stretches for the arms and legs. Be careful and do not push him too much at the beginning as this can be an unpleasant activity for John Doe. Bicycle leg movement holding his ankles is a great way to loosen him up. **Please do at least 10 minutes of stretches 2-3x’s each day.**

**Swimming and Boating**

**John Doe’s favorite activity is swimming. Dad takes John Doe swimming most of the time, but we bought a porch kid pool that he can float in and you can play with him from the side without getting in.** John Doe is very proficient in the water and you do not have to hold on to him. His favored position is on his back, but he rolls around as he enjoys the pool. He loves it when you bounce him in the water.

The swim bag has swimming gear – suit, towel, water wings. There is also sun screen in the pocket. Use the swim shirt if it is sunny and there is a chance, he will get sun burn. He uses swim discs 4 on each arm and is independent in the water. Be careful of the wet tile floors at each pool as they can be slick and John Doe can quickly lose his footing on the slippery wet floor. John Doe will walk you to the areas he wants to go to when swimming.

John Doe would do best on a pontoon boat in his EZ Rider chair of sitting with someone on a chair with back. Canoeing is harder. You need to have a canoe chair or a person sit in the middle with him (behind John Doe and have him lean again you). The problem with canoeing is that John Doe wants to be in the water, not in a boat so close to the water.

John Doe loves field trips. **Make sure you bring the gray diaper bag with snacks and thickened water in the outer side pockets and extra bandanas to wipe him with. Also bring the spray bottle if it is hot to cool him down**

John Doe is very congenial around other kids and enjoys being out and about. He likes meeting and saying hi to both kids and adults. He is very flexible in what you do as long as his basic needs and wants are met.

**Activity Levels**

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As long as John Doe is engaged with you, other people and activities, he will participate for hours at a time. You may need to change activities to keep him engaged. John Doe may take a power nap in the afternoon if he has had a full day of activities. Do not let him sleep more than 10-15 minutes in the afternoon. He usually goes to bed between 7:30 – 9 pm. If he is really tired, he will fall asleep while you are engaging him. He will fall asleep out of boredom, not being tired if he is not engaged. John Doe does enjoy being with his peers and being part of the group. This will keep him mentally stimulated even if he is not physically involved.

**Fun Activities for John Doe at Home (NUMEROUS Videos explaining how to do these and other activities are on Fathers’s computer and Ipad)**

**Fooz Bottle or ball –** Place squigs on opposite size of the table to prevent bottle or ball from rolling off. Give John Doe the ball with two pegs stuck inside or rectangular block to use as a bat. Roll ball or bottle to John Doe and help him hit it back. You can also do this where John Doe grabs and throws bottle or ball back to you.

**Matching\Building Blocks –** Use two sets of foam colored pegs and blocks or other items so you have 2 colored pairs. Have John Doe match each corresponding-colored pegs with blocks. Once he has finish guide him using hand-over-hand to put them together. He should use both left and right hand.

**Basketball –** Use a Pink tub, place Jenga blocks or dominoes inside, place Jingle bell wreath on top have John Doe use (preferably Nerf ball with holes for him to practice gripping), any ball will work. He can practice tossing ball with both hands into the pale. This is activity is best used while he is in stander or chair.

**Build Demolish with Rain stick or ball –** Stand Jenga blocks up, place squigs on opposite size of the table to prevent rain stick from rolling off. Take rain stick and hand over hand aid John Doe in rolling the rain stick and knocking down the Jenga blocks. He can also use the ball with two pegs stuck in its side.

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**Cards with Squigs –** Place two cards of the same kind and one different (ex: one 5 of spade and two 4 of hearts) on the table. Squish squigs on the odd card off and ask John Doe to match. Using the Squig he will be able to pick up the card and place it on the correct card, while you use hand over hand to guide him. Repeat multiple times.

**Bigger vs. Smaller –** You can foam blocks or cylindrical pegs/ tubes/ balls of various sizes should be pre-selected. Place two oblivious size differences on the table. Ask John Doe to pick up the requested size. If he does not pick the right size place the correct object closer so that he may achieve success. Give constant praise no matter the outcome, but always say “nice trying”. This exercise should be used with both hands, With the left-over pegs and blocks help John Doe build any random contraption.

**Bowling –** John Doe can do this activity in the stander or chair. Place big foam blocks and cylinders on the floor like bowling pins. If he is in the chair, he likes to be pushed rapidly and then swiveled around, then immediately ask hm to drop ball. Repeat. He will never tire but you will. Use the “Perfect” button have him press it once if he makes any pin fall and praise him and blow fart horn. If not say nice trying, then start over.

**Puzzle –** After saying the name of object on puzzle piece, have John Doe touch each puzzle piece. Keep the field small. Next, ask John Doe to pick up one puzzle piece. Once he has Identified the puzzle piece help him grab the piece with both hands using hand over-hand. Alternate by giving him a choice between two puzzle pieces to see if he can identify the correct one. Repeat until puzzle is completed. Give him constant praise after he identifies it.

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**Transfer with Squigs/blocks/pegs –** Select a

few of any of these listed items and prompt

John Doe to grab it first with his dominant hand

then, have John Doe transfer it to his other

hand. The same should be done in reverse and

John Doe will need help with guided practice

hand over hand.

**Matching using dominoes –** Place two piles

of dominoes on the table, each should have

up to three dominoes a pile (ex: One red pile

one blue). Pull one domino from a pile and

ask John Doe by color to match it to a pile.

Provide wait time. Use hand over hand to

allow him to match. Give him praise and allow

him to have free play after several trials as to

decrease demands and possible agitation.

**Eating and Drinking**

**In January and April, 2021 two swallow studies at SLCH found John Doe silently aspirated on honey thickness drink. This is a big change from earlier in which he was able to drink regular or nectar/smoothie thick liquids without trouble. John Doe coughing during meals or drinking indicates that he is probably aspirating.** As John Doe’s health improved, he did better at eating pureed/mashed foods and drinking thickened liquids. It appears that his swallow and aspiration is improving. **John Doe will aspirate less if he swallows regularly and doesn’t “pool food” above his esophagus.** He is good at stopping eating or drinking (straw cup or spoon) if it is uncomfortable and possibly aspirating it. Do not force him to continue as it will increase the chance of him aspirating. He will put an item away or move his hand back if he doesn’t want something. A goal of 3 cups of liquid is preferred, but he consumes less during colder months. Monitoring wet diapers (2 full/day) helps determine if he is drinking enough.

John Doe generally eats 3 meals a day and evening fruit for meds, rarely snacks between meals but may need to take thickened drinks between meals. John Doe does not eat meals independently, but can eat some finger foods by himself and other foods with assistance. John Doe drinks from a straw cup with assistance. **If John Doe pushes the spoon or your hand away or throws food he is saying no or I want something else. Sometimes you should give him another choice, but like everyone he needs to eat a healthy diet so it is ok to spoon feed him in this situation.**

John Doe has feeding issues that require special preparation and assistance in eating. **John Doe does have micro-aspiration with both food and drinks. Feed him slowly and with small quantities. He has been aspirating for years!!!!** John Doe chews crunchy foods such as veggie straws, cheese puffs, rice crackers and pretzels. He eats mashed and puréed foods easily. Harder foods to chew like chopped up meat should be put on his molars it helps him

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masticate the food. John Doe always clears and gets food up with a cough. If he gets really fussy, you can try a favorite food with the dinner item such as yogurt or pureed fruit.

**John Doe’s type of chew is predominantly a Munching Motion** - *This early chewing pattern combines phasic biting and some nonstereotypic vertical movements of the jaw with tongue movement to the hard palate. No lateral jaw movement is observed with these five patterns. A person with these patterns would not be able to grind up fibrous foods. Soft, lumpy foods and ground meats are usually the diet tolerated with these patterns.*

*We use a* Circular rotary movement - *This is the most mature chewing pattern, with jaw movement laterally, downward, across the midline to the other side and upward to close. It may occur either clockwise or counter -clockwise. It may accompany transfer of food from one side of the mouth across the midline to the other side of the mouth. This type of chewing is important to physically breakdown fibrous meats, raw veggies, hard bread, etc.*

John Doe sometimes eats crackers, veggie straws/chips or pretzels with food on it, however he may pool it in his high arched pallet and may not fully chew crunchy items which will interfere with his ability to swallow the food. You must monitor John Doe and make sure he doesn’t keep shoveling in food without fully chewing and swallowing it. Example, hummus on pretzels, tuna or other blended meat salad on crackers or entrée on veggie chips, etc. You should finely crush the corn chips and add them into guac with water in order to prevent John Doe from having trouble chewing and swallowing this. He will eat more of a meal if this is offered after he appears to be finished with other food.

A small spoon is used with a small bowl. He turns the spoon upside down in his mouth and it is believed this helps him to move the food with his tongue. He will also use a fork with assistance. John Doe will scoop on his own, but needs assistance to do this. You can also hand John Doe items like chips or small pieces of fruit or put dry food on his table top for him to pick up and eat. It is important to make sure John Doe swallows his food after taking it and chewing it. This is especially true with chips and dips.

If John Doe starts to become short of breath or starts coughing allow him to clear his airway. If he looks in distress and cannot clear his airway, then it is appropriate to perform the Heimlich maneuver as directed by CPR standards. **John Doe is very good at clearing his airway and has never had to have intervention to clear food out.** Thank you for your cooperation with this plan. Although John Doe may aspirate some with feeding and drinking, this is a source of enjoyment and is an integral component for John Doe having a high quality of life.

**JOHN DOE MUST STAY HYDRATED. DEHYDRATION CAN RESULT IN JOHN DOE BECOMING SICK AND REQUIRING HOSPITALIZATION.**

**John Doe is allergic to CASHEWS.** He is NOT ALLERGIC to PEANUTS, ALMONDS, WALNUTS, and PECANS.

John Doe will eat foods cold or warm. John Doe does eat a varied diet and he gets a good portion of vegetables and fruits each day. John Doe also drinks thickened, water, juice, milk and soy/almond milk. At home I give John Doe multivitamins. Yogurt, pureed fruit, and Fruit Smoothies are a good means to provide him with a healthy and balanced snack.

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The following is a typical day’s menu at home:

Breakfast: Oatmeal made with fruit juice/or muffin and mixed with lactulose and Greek yogurt, pureed fruit, and drink

Lunch: tuna salad on crackers or bread (can include shredded cheese) or veggie chips/sticks with guac or hummus and pretzel sticks; pureed fruit; milk or juice.

Supper: spaghetti and meat sauce with cheese (mashed), carrots and green beans “cooked to death” and mashed with butter, and drink

Bedtime Snack: yogurt or applesauce with meds

Food Preparation and Textures – John Doe requires more foods mashed or pureed as he does not chew as well as he used to. The bullet is good for pureeing fruit or making smoothies. The bullet containers can store food in refrigerator.

John Doe needs assistance with eating. He uses a small spoon as well as a fork. With some food, it is important to make sure it gets placed on his molars so he can chew the food. It is important that he swallows between mouthfuls as he can easily store food in his high palate which will interfere with swallowing. John Doe does drool a lot, especially with dip type foods. See the chart on the following page as a guide to what types of food John Doe can and cannot process and eat.

John Doe eats in his adaptive high chair. Walk him to the chair and lift him to put him in. Slide the tray top on, you may need to pull him back in the seat (spring loaded metal underneath rotates down to lock). Put the cloth bib on the Bud. Wipe his hands with wash cloth if needed. To feed John Doe, sit in chair in front of tray facing him and hold onto bowl or plate at all times (see sneak attack below). John Doe is LEFT-HANDED and holds his spoon as such.

John Doe does not have a perfected pincer grasp with thumb and finger. We are working on it and it is getting better. He can easily pick up items from the tray if they are not slippery. **John Doe uses a spoon with a rounded handle or bent handle to eat with most of the time.** A fork can be used but you must put food onto the fork. John Doe does a great job bringing food

up to his mouth and eating it. He needs assistance by propping his elbow up to bring his spoon down to the food and scooping it onto the spoon. Hand over hand can be used, but prefer the elbow prompt. **John Doe prefers to bring the spoon up to his mouth to eat and may refuse to take food if done hand over hand. Sometimes you must make him to take a taste or drink and then he will eat. John Doe doesn’t like to be spoon feed and wants to feed himself.**

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**John Doe Jordan Food and Eating Guide**

**Foods & Liquids Need to be Thickened (Honey-Pudding), Mashed, Pureed or Mechanically Soft**

| **Vegetables can eat** | **Vegetables not to eat** | **Meat can eat** | **Meat not to eat** |
| --- | --- | --- | --- |
| Cooked mashed/  pureed veggies | Raw veggies like  carrots, celery | Ground meat /cold cuts (mechanically soft) | Pieces/chunks of meat |
| V Finely shredded lettuce/cabbage slaw | Whole leaf lettuce | Fish and seafood  mashed w tartar sauce | Tough meat that is hard to chew like beef |
| Veggies in soup/stew pureed & thickened | Large pieces of soft veggies | meat cut/finely chopped and mixed in food/sauce | Dry mechanically soft meats |
| Sauce/Pureed &  thickened Tomatoes | El Dente veggies (they do not fully puree) | Mashed tuna, chicken, ham, egg salad |  |
|  |  |  |  |
| **Fruits can eat** | **Fruits not to eat** | **Starches can eat** | **Starches not to eat** |
| All pureed fruits  Apple sauce | Whole Fruit especially with pits | Mashed, baked or fried potatoes/sweet potatoes | Corn, cooked wheat berries and barley |
| Banana or berries  mashed | Chunks of fruit, Pieces of melon | Soft rice, coos coos, polenta, risotto, pasta | Too thin oatmeal,  cream of wheat, grits |
| Grapefruit and  mandarin oranges | Canned fruit cocktails unless pureed | Bread (small pieces) croissants, | Tortilla chips or taco shell |
| Thin slices of peeled peaches, pears,  watermelon | Very seedy fruits,  Unripe fruit | Veggie Sticks, p chips cheese puffs, pretzel sticks, rice crackers | hard chips, corn chips, pita chips |
|  |  |  |  |
| **Snacks can eat** | **Snacks not to eat** | **Beverages can drink Must be Thickened** | **Beverage Restrictions** |

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| Ice cream/sherbet w/o chocolate/caramel | Chocolate bars (he lets drool out of mouth) | regular/chocolate milk Soy/almond milk | John Doe must drink thickened beverages |
| --- | --- | --- | --- |
| Small pieces of baked goods w yogurt | Marshmallows or  gooey items | Fruit juices  Fruit smoothies | High fructose drinks (give healthy option) |
| Yogurt and Pudding | nuts, popcorn | Thick Milk Shakes | Hot beverages |
| Cottage Cheese  Pieces of cheese | Chewy candy, rice  Krispy treats | Thickened Water  Iced Tea (sweetened) |  |
| Chips and Hummus, Guacamole, French onion/veggie dip | Hot (pepper spicy) dips |  |  |

Eating Aids - John Doe uses different bowls, plates, and cups*.*

*Chair tray* – John Doe will eat finger foods such as cheerios, plain pretzels, dried and cut up fresh fruit, pieces of meat, or other non-moist/messy/slippery food.

*Silverware* – John Doe has his own wide handled bent and straight spoons that allow him to grip the handle better and are smaller. A wide handled fork is best, but it requires more assistance.

*Plastic scoop bowl/plates (cold foods) and ceramic or glass cups and bowls (hot foods)* – His main meal is eaten with a spoon or sometimes a fork. Use the higher side of scoop bowl positioned on his right to help him spoon food and bring it to his mouth. I also use the bowl to catch falling food from his mouth so he can eat it again. If not, he makes a royal mess with his hands which becomes slippery and then he cannot hold onto food as well as before and does not eat his whole dinner.

*Small bowls* – This works well for oatmeal, yogurt, pureed fruit, ice cream or other small quantity foods. ALWAYS HOLD ONTO THE BOWL to avoid sneak attacks (see below). *Straw cups* – This is the best way to give John Doe a drink and he is pretty independent. But beware of sneak attacks (see below).

*Open cups* – John Doe has been trained to rinse his mouth using an open cup. His lower lip must be on the outside of the cup. **Use plastic or metal cups as he will throw glass ones and has bitten through thin glass cups and cut himself as a result.**

**BEWARE OF SNEAK ATTACKS** by John Doe as he is lightning fast at grabbing and throwing things onto the floor when you least expect it. DO NOT LEAVE ANYTHING WITHIN ARMS REACH especially if you go to get something. It will end up on the floor.

**Clothes**

Shoes – Use sneakers for regular activity, KFO’s with special blue Velcro shoes (Dad will show you how to put them on and off), sandals for pool and water activities. John Doe always wears socks with shoes; no socks with sandals. Make sure you put the Velcro back in place so it doesn’t fray on both braces and shoes.

John Doe wears his KFO’s (knee foot braces) with KP shoes during part of the day if he is walking or standing. Remove KFO’s after activity or after 2-3 hours. John Doe cannot fit into his Rifkin chair to eat meals with his KFO’s.

SHOE SNEAK ATTACK – if you haven’t already discovered this, you will soon. Sneaky Pete loves to kick off his left shoe if he has an edge to remove it on.

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Clothes –The main concern is keeping the clothes clean and dry. John Doe’s drooling and spilling while eating and while out on walks or outings require extra attention. **Use bandanas around his neck during the day to keep shirt dry and wash cloths to wipe his face.** The Trans SCOP patch behind his ear (change every 2-3 days) and Botox shots help immensely to reduce drooling and saliva production. The patch is put on with tape over it to keep it on. **Make sure John Doe doesn’t pull the patch off behind his ear. Swimming may cause the patch to fall off.** John Doe can develop a rash and fungus on his face and neck if he is constantly wet. If bad, use Hydrocortisone or A & D ointment after breakfast and at night. **Use of polyester or fleece shirts will keep John Doe drier than cotton shirts**.

Make sure the table top is up snug to John Doe’s waist to ensure that food does not spill on John Doe’s shorts/pants. Don’t leave food on table top within John Doe’s reach as he will smear it into his hair and clothes. If clothes or bibs become badly soiled rinse them and let them dry! He can reuse bandanas after they have been rinsed and dried.

John Doe tends to get hot in summer and cold in winter. He will overheat in the summer in high humidity and temperatures at or above 90°F if in the sun. John Doe doesn’t wear hats, use hood on coat if windy unless it is very cold. John Doe’s arms/legs will get mottled and extremities will turn dark red or bluish more than typical kids if he gets cold. Do not panic, but check to see if you need to take off or put on clothes.

**Transport & Assisted Walking**

John Doe has a variety of means to get around. Some are with the aid of an adaptive piece of equipment (EZ Rider or Cruser chairs), booster or car seat, and people power (walking and carrying him).

Assisted Walking (This varies depending on how his mobility is at that time) John Doe likes to walk with assistance and can climb up and down stairs. John Doe can walk forward the easiest, turning is next easiest, climbing upstairs is 3rd easy, climbing down stairs is more difficult and walking backwards is very difficult. It takes a little bit to figure out the “dance” as you walk with him. Don’t let him bend forward at the waist. He needs to stand up straight and you may need to pull him back towards your body. The main point to remember is that his center of gravity has to be over the weight bearing foot and his body has to be vertical not tilted forward, backward or sideways. You should keep your body right behind and touching him and provide support with your knees on his waist and your stomach for his back. Your feet are on the outside of his. You follow his step immediately and you are basically stepping with him. You may need to lift John Doe slightly at times if he is dragging his feet to help him walk. It is easiest for him to walk on smooth surfaces and harder on uneven surfaces, carpet and grass.

When you walk John Doe, you are basically his walker. You will support John Doe under his arm pits. Keep your arms and back straight! You will need to support some of his weight so stand straight. Your legs are used as a back and hip rest. John Doe tends to lean forward and put his hand to his mouth. If possible, his posture should mimic that of any person who is walking. Try to keep his head up so he is watching where he is going, not the floor in front of his feet. You can say “Head up John Doe” to get his posture correct. John Doe will collapse if he does not want to walk. Do not let John Doe collapse while walking on inappropriate

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surfaces or times. Or if he persists, put him down in a half kneel on one knee and one foot. He will then stand up with your urging to continue walking and pulling him backwards.

**KFO’s – KFO’s lock at the knee so you do not need to support his weight. You use the blue shoes that open up in the back. You will be trained in how to use these. Walking John Doe in the KFO’s makes it so you do not need to support his weight and should only be left on for 1-2 hours. John Doe does not to have braces on to walk, but it is easier for extended periods and requires less support. The braces are also helpful for him to stand at a table to do activities with you behind him.**

If you walk John Doe up and down stairs you must focus on where his center of gravity is and that he does not push back. Stay close to his body in case you have to provide support for him to keep his balance. You can support him under the arm pits while he walks up the stairs if you wish. Going down the stairs is harder for John Doe as he will not keep a vertical posture when

stepping down. He also does not bend his knees easily so it takes him longer and more concentration to walk down stairs. When John Doe is in his KFO’s and they are locked in place, he cannot climb stairs. Unlock them and then lock back up after he climbs the stairs.

Strollers for walking John Doe – John Doe uses two strollers – the Easy Rider most of the time and jogging stroller on trails. The Easy Rider stroller is used on hard smooth surfaces. The jogging stroller is huge and mainly used by dad and at camp. It does collapse but only fits in a large trunk. You do not need to strap John Doe into the jogging stroller, but make sure the red pillow is behind his back!

Car Seat and transport - John Doe still uses a booster or car seat (longer trips) in a vehicle. He can sit in the front seat with you and loves to hold your hand while driving.

**Bathing and Toiletry**

John Doe needs direct assistance with both toileting and washing/bathing. John Doe wears tranquility diapers which have high capacity. He has good bladder control and usually uses only 2 diapers a day. Since he gets regular fleet saline enema every 3 days, he rarely has BM in his diapers.

Washing hands and face John Doe gets a routine washing and teeth brushing twice a day (after breakfast and before bed). You may need to wash his hands after he eats or if he gets them dirty. He sits on the shower seat in the bathroom. This is also used when he is showered. Use a wash cloth with soap.

Brushing Teeth – John Doe will need assistance with brushing but will enjoy brushing some himself after you do the initial brushing. Use his smaller tooth brush with a little toothpaste to brush and then rinsed to finish up and to remove excess toothpaste so he won’t swallow it. Give the toothbrush to his left hand and he will put it in his mouth and chew and brush himself. Finish by holding and giving him a cup of water to rinse his mouth out. John Doe will take water in his mouth and let it out to rinse. Do this a couple times to completely rinse his mouth from toothpaste. It is highly recommended that you do the tooth brushing with a washcloth to wipe and catch toothpaste and water that he spills down his chest.

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Combing Hair – John Doe is known as Handsome Hank by the girls so it is important to comb his hair after a night in bed or after swimming. Either a wet comb or brush is used. His hair parts on the right side. There is product on the counter if you wish.

Showering – John Doe likes to bathe – either a shower or bath. **John Doe likes warm water, but do not get it too hot.** John Doe loves to splash in the tub. If you give him a shower, use a shower seat and he will sit by himself without being strapped in. If you take him to the pool, use the handicap stall with the shower seat. Family locker room at the Heights has an accessible changing room with adult changing table and accessible shower. Ask for a chair to use at the Maplewood Outdoor Pool. I would both bath and dry him in the shower stall. Using a wash cloth with soap is the easiest way to clean him. Dry him in the shower seat and then, if necessary, finish drying on the changing table with a towel underneath him.

**Toileting and Diapers**

When John Doe is urinating, he pauses in his activity and develops a Zen look on his face. He gets a saline enema (entire bottle) every three days to poop on the toilet and keep him from getting constipated. John Doe will have a BM on the toilet after receiving a fleet saline enema. After he starts going or water comes out, sit him on the toilet and he will have a BM in 2-5 minutes. I lay him on top of the bathroom counter with current diaper under his bottom. Insert and squirt entire saline solution in John Doe’s anus. Let him lay on counter for 4-5 minutes or until he starts having a BM. Transfer him to the toilet seat sitting sideways. He will have a BM on the toilet. We give him Lactulose every day in food at breakfast to soften his stool.

Changing diapers – John Doe wears Tranquility diapers. Baby Powder is used in his groin area and desitin on his behind. On the Tranquility the yellow line means that it is dry, and it turns blue with a slight amount of urine. You do not need to change him unless he has filled the diaper. Please only change the tranquility diapers when they get full and he can often go to 4-6 pm before needing to be changed as he loads and dumps.

**Make sure you pull the diapers out on the side of each buttocks so it doesn’t leak. If he has any redness in the groin, use ointment on it.** Use A & D or Desitin – Zinc Oxide diaper ointment when you change him. I also use baby powder to keep him dry. If a red rash develops, use nystatin ointment or powder. **He only needs to be changed if the diaper is full.** He may go up to 7 – 8 hours between changes as he has good bladder control. **John Doe will not urinate in the pool** and often does after he comes out and in the shower room.

**Putting John Doe to Bed for the Night**

At home we use an O2 Concentrator with either a nasal cannula or face mask if he is sick. 2 liters/minute for the cannula and 6 liters/minute with the face mask. He is proficient at pulling it off unless he is asleep. I check on him before I go to bed and when I get up at night or morning to see if he has moved it.

Night: John Doe normally goes to bed between 7:30 – 9:30 pm. Tell him that it is time for bed and we are going to the bathroom to get ready for bed. Wash his face and hands, brush his teeth, and change into diaper if needed and into his PJ’s (upper drawer of dresser or on hooks above toilet) and socks in cooler months. Hand him his pacifier. Check on him after he has

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fallen asleep to make sure he is warm enough and has not wiggled out from under sheets/blanket. John Doe rarely needs to be changed or have a diaper check during the night. It is important that he stays warm in colder months and I turn down the thermostat to 68F at night. In the Summer make sure he isn’t hot and you can use the ceiling fan on low if needed. He usually sleeps under a sheet in the summer unless the house is hot.

Nap: John Doe rarely takes a cat or power naps unless he is tired or unengaged. He falls asleep in his chair if you do not engage him in activities or take him out. Unless he is sick, do not let him nap longer than 10-20 minutes. John Doe naps in his clothes, except for shoes. He will probably pull his socks off. He rarely will move around to reposition himself.

John Doe sleeps on his back or sometimes on his side, but propped up on pillows behind his head and upper back. He lays on a waterproof white pad when he sleeps. He will not change position on his own at night, but this is not a problem as he does not develop bed soars as he

moves enough with his legs at night. John Doe has sleep apnea and physical obstruction, when sleeping which causes his oxygen saturation to drop into the 70’s. Repositioning him can correct the situation and using the O2 concentrator also helps hm from desatting to low. You can tell by listening to his breathing/snoring. Put a pillow under his head or position him on his side if this happens. Use the full body pillow on his right side to keep him from rolling to his right. I also use a pillow between his legs to keep them apart and somewhat straight. HE USES A PACIFIER which helps him from grinding his teeth and calms him down. Close the window shades and door to bathroom. You do not have to close the bedroom door if you want to be able to hear him.

If John Doe is wet or has had a BM, he will often cry to get your attention. Always check him if he is crying and it is not obvious why. Make sure the sheet does not go over his head as he can get twisted in it and not be able to take it off. Prop John Doe up using a couple pillows. **John Doe does not use bed rails at home and the bed is pushed up against the wall to keep him from rolling off. He will not roll off bed.**

**John Doe will lay quietly in bed in the morning so do not expect him to let you know when he wakes up.** The morning routine is Chest Vest—shake n bake therapy first, then to bathroom for washing face and hands, Flonase in nostrils and diaper change. Dress for breakfast and day, then to kitchen for breakfast. Don’t forget to brush his teeth after breakfast.

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**Communication**

John Doe enjoys being able to communicate and does so through a variety of means. He communicates wants, needs and desires. John Doe is nonverbal, but has a rich expressive language. John Doe uses full body language to communicate as well as limited signs. His facial expressions are most important to key into. He will look at what he wants to do or go to. John Doe shows excitement, happiness, frustration, being bored in ways we do through facial expressions. It takes 2 - 4 months to learn all the nuances of his expressive and body language and communication style. The best way to understand John Doe is to look at his body and facial expressions, combined with his expressive language and gestures in the context of the situation. John Doe cries or acts out of frustration, a basic need not being met, or he is uncomfortable or in pain. It is not usually because he is trying to manipulate the situation. You must figure out what he is trying to communicate.

Since John Doe doesn’t pay attention to screens, he does not use MyTalk on his iPad to effectively make choices. It is best to present one or two objects and let him choose. He is pretty good at letting you know if he wants something or not with gestures. You can also offer him choices verbally if it is something he does often. It is important to allow John Doe to follow through with the choice he made.

**MEANINGFUL COMMUNICATION**

Non-verbal/Verbal:

Happiness – giggle, clapping, squeals, happy vocalizations, smiling and looking at you Upset – crying, pinching, throwing, vigorously shaking head, pushes items away, tries to bites Signs – ‘greeting’ (handshake/high five/fist pump), 'drink and 'eat', modified sign for 'finish', 'more', (when food/snack is present), head shake or pushing an object away 'no' When hungry or need wanting to be met when (when in walking position) leads care giver to a preferred location

Prompted wanting attention – touching person, making verbalizations, biting, pinching, looks at the person

Ignoring activity – put head down, look away, pushes away

Bored or not engaged or tired/fatigued – tries to get your attention with eyes or reaching out to touch you, falling asleep, putting down head, rubs eyes

Acknowledging a person’s presence – looking at the person, giggling, clapping, reaches hand out to touch person or greet them

Tries to get your attention to engage in activity (touching, making verbalizations, grabbing you), If this does not work, he may disengage and fall asleep/put head down

**Current means of communication**:

**John Doe uses limited signs**

**More –** is generalized and means a variety of things including I want something else. When John Doe signs more we acknowledge that he is excited and wants something. **Bye –** High five/fist pump when he leaves someone

**Hi –** Extend your hand to shake he will then shake your hand when he meets someone **Yes –** up and down shake of head only once and can be subtle

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**No –** does this a lot and sometimes it does not mean no. It depends on how he does the headshake and the context. Sometimes he is being the prankster**. A gentle push away of the object when presented or pulling hand back is also no.**

**All Done –** is expressed in 3 different ways: a sign, a gentle push away of the object with his hand or No headshake.

**Up –** Hands extended in front of him when sitting or lying down to indicate he wants to get up on his feet and will often then walk you to a favorite place or something he wants to do **I want to take you someplace –** his walking and guiding you is this sign or he looks to where he wishes to go if he is in his chair. Ask John Doe where he wants to go or what he wants and he will show you a good portion of the time. He is proud of himself when he walks to where he wants to go.

**Eat and Drink –** he sometimes signs this if you ask him “are you hungry/do you want to eat?” or he will lead you to his chair

**Requesting Objects and Activities –** John Doe uses a gesture involving clapping both hands together while looking at the object or person of interest. Sometimes he just looks at the object, person, or place he wants to go to. The following situations describe in more detail the multiple ways in which John Doe might use this signal. John Doe will also sign for food or drink to

request these items.

***Situation 1:*** John Doe uses the clapping signal when an item is offered to him or when an item is shown to him and he is asked, “Do you want this?” After John Doe signals by clapping, the communication partner may give the item to him.

***Situation 2:*** John Doe uses the clapping signal when a preferred activity is interrupted. In this situation, John Doe is using this signal to indicate that “more” is wanted. When this occurs, the communication partner may continue the activity if appropriate.

***Situation 3:*** John Doe uses the clapping signal in a final context in which he is engaged in an activity and sees a person or item of interest and wants to move to that person or item OR when John Doe has been engaged in an activity for a longer period of time and wants to move to another location. In these situations, the clapping signal is usually accompanied by John Doe looking toward the person, item, or location to where he wants to move while moving his torso in that direction and/or by kicking his feet.

**Reaching –** John Doe uses reaching to indicate his desire for a particular object or person. Reaching may or may not be accompanied by the clapping gesture discussed previously. When this occurs, the communication partner may respond by giving the desired object to John Doe or, in the case of a person, moving closer to him to engage with him.

**Signals of Rejection or Frustration –** A primary way John Doe rejects items that are given to him is by throwing/dropping the object to the floor or off of the surface in front of him OR pushing it away. When this occurs, the communication partner can remove the object from him and introduce another. If the communication partner is questioning whether the signal was indeed a rejection signal or simply accidental, he or she may return the object to John Doe. If he continues playing with the object then let him do so. If he throws the object to the ground a second time, the communication partner may remove the object and introduce a new one.

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**Vocalizing –** Some vocalizations in combination with body language is also used to signal John Doe’s rejection of a particular object or activity or to signal his general frustration within an activity. Expressive language may be accompanied by John Doe dropping the object to the floor or pushing it away. When this occurs, the communication partner should remove the object from John Doe or change activities. **See Hierarchy of Frustration Behavior on Page 15.**

**Grabbing Partner’s Body: Face or Glasses or arm –** John Doe will attempt to grab at the communication partner’s body to indicate this discontent OR to get your attention. He sometimes reaches out to touch a person’s arm to say Hi. John Doe grab you is not to say hi, it is because he wants a change or to get your attention to tell you that something needs to change. The behavior should be redirected with another activity being offered if appropriate. It is important to consider the overall context and John Doe’s general affect during times that he attempts to grab at face or glasses. This is because John Doe will occasionally grab a person’s glasses, jewelry, or some other article of clothing out of curiosity. In these situations, John Doe’s affect will be neutral or happy instead of discontented.

**Signals of Happiness –** John Doe smiles and laughs to indicate happiness or to show that a particular situation is funny to him. When this occurs, the communication partner should continue with the activity at hand and respond verbally by saying, “Do you like this?” or “Do you think that’s funny?”

**Making Choices –** John Doe makes choices using both familiar objects and pictures. He makes his choices by touching the object or picture from the field that is offered to him. (Generally, only two choices should be offered at a time.) When John Doe makes a choice, the communication partner should respond by offering the object corresponding to the choice that was made.

**Walking -** John Doe communicates by his body tone and positioning where he wants to go and where he does not want to go when he is being assisted in walking. When John Doe is walking in a direction or to a location that he wants to go, he walks with a fairly steady gait. To indicate his desire to move in a particular direction, John Doe will generally lean his body backward slightly and lead with one foot in the direction he wants to go. To indicate his desire not to move in a particular direction, John Doe will lean his body backward to a greater degree. His steps then become irregular in a kind of “galloping” motion as if to brace himself against the direction in which he is moving.

**MyTalk Communication Choice Program on iPad has limited success and usually John Doe does not want to make choices with technology**

**MyTalk on the iPad and Picture Schedule Apps** – John Doe was trained to use the iPad for purposeful communication and choices at school. This is adult mediated as you have to choose the choice board for him to choose from. The iPad resulted in John Doe focusing more on screens at school but overall it hasn’t been successful.

**Procedure for choice selection on his electronic device:**

1. Take John Doe's hand

2. With the Hand-over-hand method, teacher will state the name of and visually present one object and have John Doe touch the stated picture. This will be repeated for the other picture

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on the selected screen. For each new screen presented to John Doe, steps 1-2 will be repeated.

3. Give verbal prompt to make selection ("Pick one") without physical assistance. Provide partial physical or independent elicited prompt if he does not respond to independent verbal prompt alone.

4. Present John Doe the object/initiate (model use of object if needed) the activity he selected. 5. Mark whether the prompt was Partial Physical (PP), Minimal Assist (MA), Independent (I), or No Response (NR)

\* Data collection should be done in no more than 5 times or opportunity per set of pictures.

**The iPad also is great for recording videos and photos of activities John Doe participated in. If allowed, Please take at least one or two videos a day to send home.**

The iPad has a number of apps that may engage John Doe in activities or for calming relaxing time. Garage band is a fun one for him as well as other apps. You can use the iPad for music if there is WIFI, but you would need to enter the password or sign in as a guest.

The next page provides protocol and iPad setup for using MyTalk with John Doe. You are encouraged to take pictures and import them into MyTalk using edit mode to create your own choices for John Doe to make. We have the MyTalk screens backed up to a desktop.

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**John Doe’s iPad script (for using “new choices”) option**

Place the iPad off to the left midline,

above the left thigh

(See photo on iPad)

Show and verbalize each choice: “John Doe,

your choices are chips (point to chips), juice

(point to juice), or new choice (point to new

choices). What is your choice?”

No responseJohn Doe makes a choice

Wait 5 seconds Say “John Doe you chose \_\_\_.” And immediately offer John Doe the

choice

Show and verbalize each choice: “John Doe, your choices are chips (point to chips), new choices (point to new choice), or juice (point to juice). What is your choice?”

If John Doe communicates “no” by shaking his head, refusing throwing object, or showing disinterest….

John Doe is receptive to the choice.

Say “You chose \_\_ but you are saying no.” Show him the choices again and physically assist him in making the other choice. *(i.e. if he chose juice but wanted chips then help him choose chip and give him a chip.)*

If John Doe communicates “no” by shaking his head, refusing, throwing object, or showing disinterest….

Say “oh, you don’t want\_\_ or\_\_. Then you want new choices.” Physically assist him in touching “new choices.”

Offer a new set of choices and continue at beginning of the flow chart

John Doe is receptive to the choice.

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**PT Therapy Visual Guide**

**VIDEOS ARE AVAILABLE ON FATHER’S COMPUTER AND IPAD**

PT Home Exercise Plan (HEP):

- Ambulation with KFO’s locked

- Standing at counter with KFO’s locked, equal weight through legs, encouraging use of right arm

- Knee extension lying on back, pushing away with feet x10

- Bridges lying on back, lifting hips up x10 and holding 3-5 seconds

- Tall kneeling at surface to reach for objects

- Straddle peanut ball to bounce and rock side to side

- Stretches for 30 sec x 4 repetitions

o Hamstrings – on back with knee straight and elevate heel

o Adductors – on back with knees bent and slowly separated

o Hip flexors – on side bring knee behind body

o Quadriceps – on side bring heel to hips keeping knee behind body

- Sit & Reach at edge of bed and reaching with right side

- Sit-to-Stand at edge of bed x3-5 repetitions

**John Doe Exercise**

Ambulation with KFO

Make sure and double check that sides of the brace are locked.

Stand at counter while in KFO to manipulate objects:

Therapist should be behind John Doe with hand support at hip or trunk depending on need from patient. Try to keep his weight evenly distributed on both sides and emphasize stacking objects for him to knock over on his right side

Knee extension

John Doe is lying on his back with his knees bent.

Cup his heels with one hand and place other

hand on top of the thighs. Place his feet on

your stomach. Lean into to flex his knees and then ask him to push you away. Try for 1-2 sets of 10 reps

Bridges

John Doe is lying on his back with knees bent with his feet flat on the floor. Sit in front of him to block his feet with your knees. Then lift his

bottom up to extend the hips and try to hold it

for 3-5 seconds. 10 reps

Tall knee position:

Place John Doe in a kneeling position on a

pillow next to his mattress or stable

surface approx. 2 feet high. He will need

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support from the waist and the trunk.

Have him reach for objects overhead

and waist level.

Peanut ball

Place John Doe on the peanut ball so he is straddling the middle with his feet flat on the floor. Give him support at his waist/ trunk with your hands. \*Can bounce up and down gently on the ball and rock side to side to challenge his balance.

Hamstring stretch

John Doe is lying on his back with

knees straight. Place your hand on the

mid-thigh and cup the heel. Lift the leg

to gently stretch the hamstring. \*Ease

into the stretch\* Hold 30 seconds 3-4

times each leg. John Doe had a previous fracture on the right leg and will not be able to straighten the knee. Do not

force the knee straight.

Hip flexor stretch

John Doe will lie on his left side with knees straight. From behind support him at the right hip and underneath the knee. Gently bring the right leg behind the body to stretch the hip flexor. Repeat on left side. Hold 30 seconds 3-4 times

Quadriceps stretch

John Doe will lie on his left side with bottom

knee straight and top leg flexed. Support

his trunk from behind. Bring right knee that

is flexed gently behind the body to stretch the quadriceps. Repeat with left leg. Hold 30 sec. 3- 4 times.

Adductor stretch

John Doe will lie on his back with

both knees bent. Gently bring

both knees out towards the

floor to stretch the adductors.

30 seconds 3-4 reps

Sit and Reach

Have John Doe sit at side of mattress

with knees flexed. Therapist should

be in front of him supporting trunk/

waist. Have John Doe reach overhead

to grab objects. Emphasize right

side use.

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Sit to stand transitions at bed side (work hip extensors)

Have John Doe sit at side of mattress with knees flexed. Therapist is blocking shins with ball and feet flat on floor. Give John Doe support at the trunk/waist to help him into a standing position. Hold standing position until he sits down. Usually try for 3-5 reps.

**Occupational Therapy Activities for John Doe at Home**

Kneel at therapy ball: Position Aiden’s knees shoulder width apart for stability and kneel behind him for support. Encourage him to push the ball using one or both hands to another person.

Lying on back over pillow: Stretch Aiden’s back and shoulders by placing a pillow under his shoulders and encouraging him to lie his head on the bed. Stretch his arms over his head by placing your hands gently on his upper arms. Try to move them so that they are even with his ears but don’t force them. You can also gently push on his shoulders to stretch them backwards.

Lying on his side: Position Aiden on either side and position his elbow under his shoulder. Encourage him to reach for toys with his other hand. This strengthens his shoulder muscles. Sit behind him or position pillows behind him for support. A small pillow can also be place under his arm if needed initially.

Hand and Arm Stretches

Theraputty: Encourage Aiden to pull theraputty with both hands or with one hand while you pull the other end. He may need hand-over-hand assistance initially, so he doesn’t drop it. Also hide beads or small objects in it for him to pull out using only his thumb and index finger. Can also use Play-Doh to hide objects.

Releasing items into a container: Encourage Aiden to maintain his grasp while targeting a container or your hand before releasing them. He frequently drops items too soon and doesn’t release into a container. Support him at the elbow if needed but he should maintain his grasp.

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**Speech Therapy Visual Guide**

John Doe’s sign for making a choice

Place iPad slightly to John Doe’s left above mid-thigh when sitting. John Doe will choose from the pictures what he wants.

Give John Doe the item he chose.

Repeat this process through eating and when making choices for an activity.

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