

Outline for PT Annual Exam:

Population	Why
<p>Down Syndrome in the School Age Pediatric Population</p>	<p>Each year approximately 6,000 babies are born with Down Syndrome (DS), a genetic condition associated with abnormal cell division of the 21st chromosome, and subsequent formation of an extra partial or full 21st chromosome.^{1,2} The prevalence of this condition increases with advancing maternal age.^{1,2} Babies diagnosed with down syndrome have a higher risk of a multitude of health conditions, including, but not limited to heart defects, hearing loss, obstructive sleep apnea, ear infections, eye problems, intestinal blockage, thyroid disease, and anemia.¹ Additionally, neuromusculoskeletal physical findings which may be present and should be monitored include hypotonia, ligamentous laxity, problems with the upper spine, foot deformities, and hip dislocation.^{3,4} Over the past few decades there has been a drastic increase in the life expectancy of people with down syndrome, although longevity is still heavily influenced by health problems.² Most notably, poor aerobic capacity and cardiometabolic risk profile can further increase the burden of care as the patient and caregiver age.⁵ Those with DS are also at an increased risk for secondary pathologies related to inactive lifestyles and poor nutritional choices.⁶ A recently published systematic review in <i>Pediatric Physical Therapy</i> found that children with DS are not meeting PA guidelines and engage in less physical activity than their typically developing peers.⁷</p> <p>An ongoing annual assessment is especially appropriate for this pediatric school aged population to optimize their functionality, advocate for healthy lifestyle changes early on, monitor any malformations or physical findings, and aid in identifying areas of impairment or limitation that may warrant a referral.⁴ An annual exam for this population would provide an opportunity to help promote personal family support, examine the child for age specific DS related medical and developmental conditions, and offer support on modifiable risk factors such as nutrition and activity to maintain a healthy weight.⁴ In children with DS, after 2 years of age the obesity risk is increased, and can be associated with problems such as obstructive sleep apnea, dyslipidemia, hyperinsulinemia, and gait disorder.⁸ Not monitoring lifestyle habits from an early age puts the child with down syndrome at risk for serious medical complications.⁹</p>

Name of Physical Therapist Completing this Form: _____
 Name of Child: _____ Date of Birth: _____ Sex: Male Female
 Is the child currently enrolled in early intervention/pre-school/school: Yes No
 If applicable, current grade level (pre-K, K, 1, 2, 3): _____
 Race: _____
 Language Preference: _____

Annual Exam: Subjective/Objective

Question/Test	What Testing	Positive Finding	Clinical Reasoning (Evidence if indicated)
Questions relating to the child’s medical and surgical history. Information regarding whether or not the child has a PCP, interacts with other healthcare specialists, takes any medications, etc. List of health problems the child has had within the past year. (See Appendix, Figure 1) ¹⁰	Medical, surgical, and family history.	Current Injury Polypharmacy Recent surgery	Babies born with down syndrome are screened at birth but often require follow up on medical problems. Vision and hearing disorders are among the multitude of medical issues prevalent in children with DS and often these conditions progress or change with age. ⁴ In a study by Heifi and Blanco the authors reported that while surgery is sometimes performed to correct physical deficits, often medications are used to manage the “various comorbid health conditions” in this population. ¹¹ While seizure disorders may be treated with anticonvulsants, polypharmacy of this drug class can cause epilepsy or even unexpected death. ¹¹ PTs should also be aware of any cardiac deficits or corrective surgeries the child has had due to the high risk of congenital heart disease in the population with DS. ⁴ Heifi and Blanco also noted the impact of living arrangements and social conditions on medical adherence. ¹¹ Poor medical adherence can promote issues regarding disease progression, healthcare costs, and further complicate treatment. ¹¹
Height, Weight, Waist Circumference, Head	Clinical Growth	On standard charts, at or above the 85th	O’Shea et al. found a higher prevalence of overweight and obese children and youth with DS compared to the general

<p>Circumference (See Appendix for example, Figure 2)¹²</p>	<p>Charts (Sex and Age Dependent)</p>	<p>percentile BMI indicates overweight, and at or above the 95th indicates obesity.¹⁴ Percentiles rank the child based on “what percent of the reference population the child would equal or exceed.”¹² A z-score may relate the child to the average value for the reference population.¹²</p>	<p>population.⁹ The <i>American Academy of Pediatrics</i> (AAP) calls for greater attention to growth and development of those with DS.⁴ Measurements of body mass index, waist circumference, and waist to hip ratio can be used to classify whether a child is underweight, normal, overweight, or obese.⁹ The CDC has developed growth charts specific to age range and sex in children with down syndrome.¹² Growth charts for weight, length, height, weight-for-length, BMI, and head circumference are available.¹² A study by Zemel et al. concluded that these growth charts could be used as screening tools for growth and nutritional status, as well as allow for comparison against same age and sex peers with DS.¹³ According to a follow-up article in <i>AAP News</i>, the researchers of the aforementioned study recommend using the CDC charts for BMI in children 10 years and older with DS, while the DS specific charts should be used for all other measurements and ages.¹⁴</p>
<p>Are there any barriers in the home setting that limit the child’s ability to move independently?¹⁰ Are there any barriers in the school setting that limit the child’s ability to move independently throughout the school?¹⁰ Does the child use any adaptive equipment?¹⁰ Any assistive</p>	<p>Environmental Factors / Barriers</p>	<p>Reported problems related to accessibility and exclusion in the community, home, and/or school environment</p>	<p>According to a study by Heller et al., if caretakers of those with DS “perceived greater benefits of exercises” and fewer barriers to access, adults with DS were likely to exercise more frequently.⁶ This emphasizes the need to reinforce improved community and school access. Pitetti et al highlighted that inactivity in youth with DS may be a “learned behavior” associated with exclusion.¹⁵ Notable barriers to physical activity for youth relate to lack of accessible and appropriately designed programs, negative attitudes, family responsibilities, parental income and education, and insufficient friends.¹⁵ The physical therapist may be able to offer resources for accessible parks and/or recreational centers in the area.</p>

technology? ¹⁰			
<p>How much time per day does the child spend engaged in physical activity?¹⁰</p> <p>How much screen time does the child engage in per day (TV, computer, tablet, videogames)?¹⁰</p> <p>Describe what limits the child's ability to engage in desired level of physical activity.¹⁰</p>	Physical Activity	Children ages 6-17 engaging in less than 60 minutes of physical activity each day. ¹⁶	<p>A 2019 review published in <i>Pediatric Physical Therapy</i> found that children with down syndrome across all ages are not meeting the U.S. recommended guidelines of 60 minutes of physical activity per day.¹⁶ Fox et al makes the recommendation for recreational activities to be dispersed throughout the day.¹⁶ A study by Whitt-Glover et al. found that children with DS had higher BMIs and participated in less total and sustained vigorous activity than their siblings.¹⁷ Cross sectional data from a study by Pitetti et al. suggests that physical activity likely declines with the growth of youth with DS.¹⁵ The authors of this study emphasize the fact that youth with DS often have the potential to participate in many types of "culturally-relevant physical activities" and an altered gait pattern may not be a barrier to physical activity.¹⁵</p>
<p>Does the child get adequate fluid?¹⁰</p> <p>Does the child eat a well-balanced diet?¹⁰</p> <p>Number of glasses of sugary drinks/juice on average per day¹⁰: ___</p> <p>Is the child on a special diet? If so, please list the diet:¹⁰</p>	Nutrition	<p>Excessive consumption of added sugar, sodium, and calories from solid fats (major sources of saturated and trans fatty acids)¹⁸</p> <p>Recommend: variety of fruits and vegetables, whole grains, protein foods, fat free/low fat dairy products, oils¹⁸</p>	<p>Ongoing stomach and bowel problems, such as constipation or loose stools are common in children with down syndrome.⁴ These symptoms could potentially be related to celiac disease, which is prevalent in approximately 5% of individuals with DS.⁴ It may be appropriate to review the symptoms associated with celiac disease and recommend a referral¹⁹ for the child to have lab tests such as a "tissue transglutaminase immunoglobulin A (IgA) level and simultaneous quantitative IgA."⁴ As previously mentioned, patients with DS are at an increased risk of secondary pathologies related to poor nutritional choices.⁶ Nutrition plays a large role in helping the child maintain an appropriate weight.⁴</p>

<p>How many hours of sleep does the child get on average per night?¹⁰</p> <p>Does the child snore?</p> <p>Is the child a restless sleeper?</p> <p>Does the child take age-inappropriate daytime naps?</p> <p>Is the child sleepy during the day?</p>	<p>Sleep</p>	<p>OSA cannot be diagnosed based on signs and symptoms alone, but a PT may note parent or guardian concerns/complaints regarding the child's snoring, gasping, excessive daytime somnolence, behavioral problems, and/or uncommon or abnormal sleeping positions.^{20,21}</p>	<p>The incidence of OSA is higher in the population of individuals with DS, than in the general population.²² OSA has been associated with concentration deficits, lower cognitive function, and developmental delay.²³ If untreated, it can exacerbate problems associated with down syndrome and have serious pulmonary sequelae.²² A population based cross sectional study by Austeng found a high prevalence of OSA in 8 year old school children with DS.²³ Sleep apnea syndrome in children is related to cardiovascular complications, metabolic syndrome, and cognitive and social development.²³ If untreated OSA can aggravate behavioral problems and learning deficits.²² The study by Austeng also found a high prevalence of undiagnosed OSA in 8 year old children with DS, which further indicated the importance of screening for this condition.²³ A guideline from the <i>American Academy of Pediatrics</i> recommends screening for symptoms related to obstructive sleep apnea, which may include snoring, restless sleep, daytime sleepiness, nighttime waking, behavioral problems, and abnormal sleep positions.⁴ Shires et al. found a positive relationship between BMI and OSA in the pediatric DS patient population.²²</p>
<p>Discuss the child's behavioral and social progress.</p> <p>How would you describe your child's typical behavior?</p> <p>Does the child demonstrate any specific behaviors of concern?</p>	<p>Mental Health</p> <p>Cognitive Function</p> <p>Neuro-behavioral Disorders</p>	<p>Problems associated with disruptive behavioral disorders, such as attention deficit hyperactivity disorder, conduct/oppositional disorder, or aggressive</p>	<p>According to the <i>AAP Clinical Report</i> there is about a 1% risk of autism co-occurring with down syndrome.⁴ A study by DiGuseppi et al. found ASD prevalence in the population with DS to be 17-20x higher than the general population.²⁴ In addition, children with down syndrome often have more pronounced neuro-behavioral and psychiatric problems and more than 25% of adults with down syndrome have a diagnosed psychiatric disorder.¹⁹ Symptoms of autism and behavioral problems typically manifest when the child is between 2-3 years old.⁴</p>

		behavior. ¹⁹	Discussion regarding potential neuro-behavioral issues may help prompt a referral for further evaluation and implementation of appropriate interventions.
<p>What activities does the child enjoy and do best?¹⁰</p> <p>What dreams do the child/family have for the future?¹⁰</p> <p>Does the family have an adequate support system?¹⁰</p> <p>What concerns does the parent(s)/ caregiver(s) have?¹⁰</p>	Child and Family Goals and Aspirations/ Quality of Life	Reported low emotional well being from the parents, minimal or absent social relationships, lack of emotional support	Parent supported behavioral intervention can also be an appropriate adjunct to a nutritional education intervention for body weight management. ²⁵ A pilot RCT of people age 13-26 with DS by Curtin et al. found 6 months into the intervention, the group that received the nutrition, activity education, and behavioral intervention had significantly higher reduction in body weight than the group that received nutrition and activity education alone. ²⁵ Family stress has been negatively linked to child outcomes, and therefore supporting the family can have a positive effect on family quality of life. ²⁶
Vital Signs	HR, Respiration (breathing rate), blood pressure, and temperature	<p>Values outside normal ranges²⁷ -</p> <p>Normal ranges for children 1-11 yo:²⁷</p> <p>HR: 70-120 bpm</p> <p>RR: 20-30 bpm (1-5 yo)</p> <p>RR: 12-20 (6-11 yo)</p> <p>BP: 90-110 / 55-75 mmHg</p> <p>Temp: 98.6 F (range 97.4-99.6F)</p>	Routine monitoring of vital signs is especially important in children with down syndrome due to the risk of respiratory tract infection. ⁴ If there are any signs or symptoms of a lower respiratory tract infection this would warrant evaluation by a medical provider. ⁵ Infants born with down syndrome have about a 50% risk of congenital heart defects. ⁵ Respiratory infections can be secondary pathologies to heart problems. ⁴ If a child has a congenital heart disease it is important to routinely monitor for the signs and symptoms of congestive heart failure. ⁴ Tachypnea may indicate heart failure. ⁴
Visual Acuity Chart Test (Ex: Snellen Eye Test,	Vision (visual acuity)	Bell et al recommends the following age	Approximately 60% of those diagnosed with down syndrome have vision problems ⁴ , such as nearsightedness, farsightedness, or astigmatism. ²⁹ The

<p>HOTV, Lea, and/or Allen⁴ - See Appendix, Figure 3)</p> <p>Does the child complain of any blurred vision?</p> <p>Does the child complain of any hearing problems? Have you noticed any hearing problems?</p>	Auditory problems	<p>appropriate criteria for referral: 20/50 or worse in either eye (3-5+yo) 20/40 or worse in either eye (4-5+) Worse than three of five optotypes on 20/30 line or two lines of difference between the eyes (5+ yo)²⁸</p> <p>Signs of hearing loss</p>	<p>American Academy of Ophthalmology “recommends the use of an eye chart by three years of age.”²⁸ If the child is preliterate, picture charts (Lea or Allen) or matching charts (HOTV) may be used.⁴ If there are vision concerns the child should be referred to a pediatric ophthalmologist with expertise working with children with disabilities.⁴ The AAP recommends children with DS obtain an ophthalmologic evaluation every 3 years.⁴ UpToDate recommends screening for hearing loss since nearly 80% of children with DS have a hearing impairment.²⁹ Children with DS are also more prone to ear infections.²⁹</p>
<p>FACES Pain Scale – Revised (See Appendix, Figure 4)</p>	Pain	<p>Scores closer to 10 indicate greater pain.³⁰ The MCID for the FACES Pain Scale “depends on the type of face, starting pain level, but overall, a change of one face” on the FACES pain scale has been reported.³⁰</p>	<p>Communication problems or intellectual deficits in children with disabilities can impede pain detection and subsequently leave pain unmanaged.³¹ An article by Zabalía found that children with DS were able to use the Faces Pain Scale - Revised with the same accuracy as children with typical development.³¹ Zabalía also found that children and adolescents with DS used the FPS-R more appropriately than the VAS.³¹ In a pilot study of adults with DS, the researchers found that the participants were able to recognize pain qualities above chance level in a set of pictograms and were able to comprehend facial pictograms for pain affect.³² Recognizing pain is especially important in those with DS as they are “extra vulnerable to age-related painful conditions.”³²</p>
<p>Does the child have any skin discoloration?</p>	Integumentary	<p>Very dry skin can be sign of</p>	<p>According to an article by Hefti and Blanco, children with down syndrome are at risk of multiple skin conditions.¹¹</p>

<p>Presence of any dry or rough skin? Does the skin appear scaly or thick?</p>	<p>system - skin assessment</p>	<p>hypothyroidism⁴</p>	<p>Certain dermatologic diseases are more frequently seen in children with DS, and may include alopecia areata, vitiligo, seborrheic eczema, folliculitis, and syringoma.¹⁹ These conditions can lead to recurrent skin and soft tissue infections.¹⁹ The <i>AAP Guideline for Children with Down Syndrome</i> states that very dry skin may be a sign of hypothyroidism.⁴ The National Down Syndrome Society website states that approximately 10% of children with down syndrome have congenital or acquired thyroid disease.³³</p>
<p>Sharp Purser Test (SPT)</p>	<p>Atlanto-axial Instability</p>	<p>Sliding motion of the head posterior in relation to the axis indicates atlantoaxial instability³⁴</p>	<p>Atlantoaxial instability affects around 10-20% of individuals with DS, but about 1-2% have symptomatic AAI from spinal cord compression.³⁵ If AAI becomes symptomatic it can manifest in neck discomfort, gait abnormalities, problems with sphincter control, and paralysis, and requires urgent management.³⁵ Since individuals with DS are more often asymptomatic if they have AAI, education should be provided on universal precautions to protect the cervical spine.⁴ If there are any new symptoms of myelopathy a physician should be contacted immediately.⁴ Other upper cervical instability tests in addition to the SPT may be appropriate.</p>
<p>9 Point Beighton Hypermobility Score and lower extremity range of motion (See Appendix – Figure 5)</p>	<p>Assessment of hypermobile joints and/or stiffness/reduced ROM</p>	<p>Hypermobility defined as a Beighton score $\geq 4$³⁶ Abnormal end feel for the joint³⁷</p>	<p>According to St. Louis Children’s Hospital hypermobility syndrome may lead to “arthritis, dislocated joints, sprains and strains.”³⁸ In a study by Foley and Killeen, children with DS often presented with hyperextensibility in the 5th metacarpophalangeal joint and thumb to forearm maneuver.³⁶ Additionally, a high proportion of children had hypermobility in the hips and ankles.³⁶ Hip instability is relatively common in DS (incidence between 1-7%), and hypermobility can evolve to dislocation, subluxation, and</p>

			<p>fixed dislocation.³⁶ If not addressed appropriately it can lead to loss of independent mobility, and limping is often a sign of hip pathology.³⁶ Galli et al noted subjects with DS walked with more hip flexion during the entire gait cycle and knee flexion during the stance phase, as well as plantarflexion during initial contact.³⁹ Reduction in hip ROM can be associated with reduced stride length³⁹ and decreased ROM at the knee may indicate patella instability.³⁶ Foley and Killeen concluded that a high proportion of children with DS presented with hypermobility in joints other than those assessed with the Beighton scoring system.³⁶ To manage symptoms or prevent joint injuries it's important to maintain good posture while standing and sitting, stand with knees slightly bent, avoid extreme ranges of motion, and wear shoes with arch supports.⁴⁰ PT can help to strengthen a child's muscles and stabilize joints to prevent injuries.</p>
<p>Surveillance of foot development⁴²</p> <p>Forefoot and rearfoot exam</p> <p>Examination of medial longitudinal arch</p>	<p>Medial longitudinal arch (functional or structural pes planus)</p>	<p>Entire sole of the foot touches the floor.</p> <p>*should be noted that pes planus may resolve by adolescence⁴¹</p>	<p>A study Pau et al. maintained findings to confirm children with DS present "marked differences in foot structure and functionality."⁴² In children with DS flatfoot is often explained as a functional result of hypotonia and ligamentous laxity, and may be exacerbated by excess mass.⁴² Weight bearing mechanics are altered when there is an expanded midfoot contact surface and this can involve the midfoot and forefoot.⁴² Weijerman and de Winter noted that pes planovalgus from marked pronation may be seen in childhood and influence stability during ambulation.¹⁹ If young individuals with DS demonstrate pes planus and have incorrect footwear, this may increase the risk of callus formation over pressure points, ligamentous injury, and potentially cause bone spur development.³⁶ Additionally, if the calcaneus is stuck in eversion this may</p>

			cause hindfoot valgus and subsequent postural changes. ³⁶ While active support may be required to address this issue ¹⁹ , PT can play a role in strengthening foot musculature and building core and lower extremity strength. ⁴²
Pediatric Balance Scale (PBS) (See Appendix – Figure 6)	Posture and Balance	<p>Cut-off scores for typically developing children are based on age range.⁴³ The median score on the PBS for a group of ~6 yo children with DS was 50 points⁴⁴</p> <p>Observation of greater body sway in the mediolateral and anteroposterior directions⁴⁵</p>	<p>According to Malak et al. the low muscle tone and postural abnormalities common to DS contribute to the delayed development of balance and balance reactions when upright.⁴⁴ This can have further implications for delay in walking ability.⁴⁴ In a study by Zago et al, children with down syndrome that had “reduced velocity and quality of postural reactions” produced and developed inappropriate compensatory movements to remain relatively stable during gait.⁴⁵ Subsequently, interventions aimed at postural control training were found to facilitate motor function and influence gait.⁴⁵ The PBS examines functional balance skills, so the higher a score, the better functional balance in relation to daily life.⁴⁴ A study by Malak et al found a statistically significant correlation between the PBS and GMFM-88 scores.⁴⁴ The One Leg Standing Test (OLST) and/or Romberg’s Test (RT) have also been used to assess static balance.⁴⁶ In a study by Jung et al, children with down syndrome had significant differences in all areas of balance ability compared to typically developing peers, with the greatest differences seen in static balance ability.⁴⁶ It is important to identify balance impairments to guide appropriate and functional interventions.</p>
10 MWT or TUG Observational Gait Analysis	Mobility - gait speed and characteri	Spatiotemporal abnormalities: reduced gait velocity and step length or	Disorders such as acquired hip dislocation, patellofemoral instability, and slipped capital femoral epiphysis can occur in children with DS and often “manifest” once the child starts walking. ³⁶ Motor development delays can have

	<p>stics of gait and transfers</p>	<p>larger step width⁴⁵</p> <p>Kinematic abnormalities: increased hip flexion throughout the gait cycle, ankle stiffness, reduction in peak PF at pre-swing phase, reduction in peak DF in initial phase⁴⁵</p> <p>Researchers have found mean TUG time in children 3-18 yo with DS to be 5.61 sec (SD 1.06)⁵¹ MDC: 1.26 sec⁴⁷</p> <p>10MWT: no cut-off values for children with DS, but generally accepted values: <0.4m/s (household amb), 0.4-0.8 m/s (limited community amb), >0.8 m/s (community amb)⁵⁰</p>	<p>implications on postural control, symmetrical movement patterns, compensatory movement strategies, and movement variability.³⁹ Smith et al., looked at patterns of gait variability across the lifespan in persons with DS and found that closer to optimal walking performance is seen in preadolescents compared with younger and older peers with DS⁴⁸ and Wu similarly reported “best motor ability” is generally seen in the preadolescent phase.⁴⁹ Children with DS frequently present with lower gross motor skills than their typically developing peers⁴⁶ and often have greater instability in the mediolateral direction.⁴⁴ Additionally, they often have an increased energetic cost.⁴⁴ The 10MWT has been shown to have excellent test/retest reliability in children with neuromuscular conditions and requires very little resources.⁵⁰ A study by Russell et al. found the GMFM to be more responsive to change in gross motor function and demonstrates reliability, validity, and responsiveness when assessing children with DS.⁵² This assessment of gross motor function may be appropriate for this population, although one should consider it takes approximately 45-60 minutes to administer and therefore may not be appropriate for an hour long annual exam. A study by Martin et al determined the TUG to be a clinical relevant outcome measure to use with children and adolescents with DS.⁴⁷ These researchers found a MDC of 1.26 seconds.⁴⁷ A study by Nicolini-Panisson and Donadio found that the TUG scores correlated with the GMFM total scores and GMFM Dimension E scores.⁵¹ The TUG allows for observation of both transitions and gait, and may expose postural and gait instability related to ligamentous laxity and/or hypotonia.⁴⁷</p>
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Resources/Referrals:

Test Item	Resource/Referral	Reasoning
Sleep Questions	Physician with expertise in pediatric sleep ⁴	According to the Mayo Clinic, the soft tissue and skeletal changes common to down syndrome, ² such as smaller upper airway, midfacial hypoplasia, and lingual tonsillar hypertrophy, ⁸ can lead to the obstruction of airways and place children with DS at greater risk of obstructive sleep apnea. As previously mentioned, if OSA is left untreated, it can have serious pulmonary consequences, to include hypercarbia, acidosis, and pulmonary hypertension. ²² In addition to sleep fragmentation, sleep deprivation, and daytime somnolence, OSA can intensify behavioral problems and learning impairments. ²² Obesity has also been positively associated with obstructive sleep apnea ⁸ and lower SaO ₂ levels. ²² The NIH recommends the health provider refer the child to a sleep study to detect issues and establish possible solutions. ³ Surgery to remove the tonsils or use of a CPAP may be recommended to improve airflow during times of sleep. ³
Child's Behavioral and Social Progress Behavioral Concerns	Psychosocial services for consultative care or behavioral specialists with experience working with children with special needs ⁴	According to the <i>National Institute of Child Health and Human Development</i> , children with DS often experience behavioral and emotional problems. ³ Young and early school age children may be more vulnerable if they have limitations in language and communication skills and cognition. ⁵³ Common conditions or disorders include disruptive, inattentive, hyperactive and oppositional behaviors, anxiousness or inflexible behaviors, as well as aggression or social withdrawal. ⁵³ As the child enters older school age years they are still vulnerable to mental health and behavioral problems, such as depression, social withdrawal, anxiety, and OCD. ⁵³ Behavioral problems can also be associated with medical conditions, such as thyroid dysfunction, OSA, or bowel issues, and baseline tests should rule these in or out. ⁵³ A behavior specialist may help find appropriate ways for the child to communicate more effectively and examine the child's behavior in the context of their developmental age. ⁵³ The <i>North Carolina Down Syndrome Alliance</i>

		<p>additionally offers information on “medical outreach,” community groups, and the Parent’s First Call Program to help set families up with a trained parent mentor.⁵⁴ Duke Children’s has a comprehensive down syndrome program as well.⁵⁴ In a study by Curtin et al, the researchers emphasize the importance of family based behavioral interventions.²⁵ He found that when instruction on behavioral strategies, such as diet/activity monitoring, modification of “stimulus control”, goal setting, and positive reinforcement was incorporated into home life, it had positive implications on reduced body weight.²⁵ This ties in the importance of interdisciplinary care teams working together to help manage various conditions associated with DS.²⁵</p>
Diet	Nutritionist or Registered Dietician	<p>In a review article by Mazurek and Wyka, the authors highlighted the excessive or deficient nutrient intakes of children with DS.⁵⁵ They also discussed the preference for “consuming foodstuff made of simple carbohydrates” since they are easier to chew and swallow than fresh foods and vegetables.⁵⁵ As a result of these unfavorable dietary habits, children with DS often have low dietary fiber intakes, precipitating issues regarding slower intestinal processing and constipation.⁵⁵ Children with down syndrome are additionally at risk for celiac disease, and therefore may require recommendations on gluten free diets to prevent related symptoms.⁴ Micronutrients are important for intellectual development, thyroid function, and bone metabolism, and early dietary interventions may help to minimize or reduce the risk of conditions associated with DS.⁵⁶ A referral to a registered dietician or nutritionist is also paramount for weight management, as a recent literature review has found youth with DS more likely to be overweight and obese than their peers without DS.⁸</p>
Pes planus and associated functional mobility limitations and/or	Pediatric Podiatrist	<p>Flat foot is a well-known orthopedic problem in children with DS, and is associated with joint laxity.⁵⁷ A study by Pau et al found that children with DS had larger midfoot and reduced forefoot contact areas compared with age and gender matched peers.⁴² The authors of this</p>

pain		<p>study recommended careful podiatric surveillance throughout childhood to minimize balance and gait impairments.⁴² A pediatric podiatrist may monitor physical abnormalities common in the feet of individuals with DS, to include pes planovalgus, metatarsus primus varus, and hallux valgus.⁴² Careful examination and follow up may help in implementing preventative and corrective measures such as physical therapy and/or prescription of orthotic devices.⁵⁷ Orthotic prescription can help to correct and support hypermobile joints in children with down syndrome, particularly foot orthoses (FOs) and supramalleolar orthoses (SMOs).⁵⁷ They have been found effective in improving standing posture, gait, and functional mobility.⁵⁷ While orthoses may help to improve gait parameters, there is some debate as to whether or not they limit a child's ability to develop upright locomotor skills.⁵⁷ A 2018 study published in the <i>Journal of Physical Therapy Science</i> found that most children with DS were prescribed their first insole prescription after they had begun to walk.⁵⁸ Since foot deformities caused by flat feet can lead to secondary disability and inefficient walking, the authors recommend for children with DS to have their feet assessed soon after they begin to walk.⁵⁸</p>
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Figure 3.²⁸

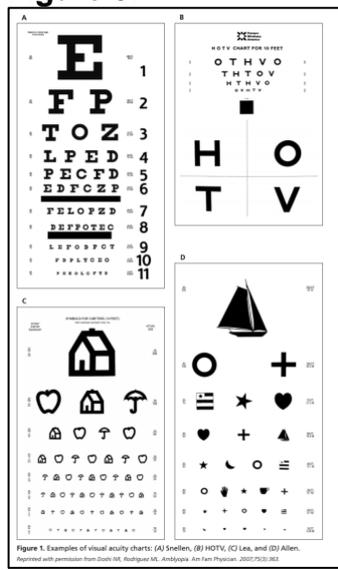


Figure 4. *FACES Pain Scale*

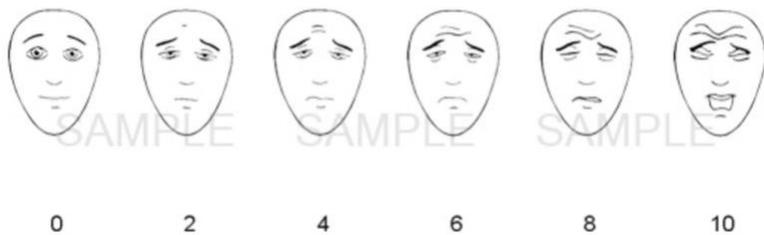


Image from: <https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1519>

Figure 5. Beighton Hypermobility Score

	LEFT	RIGHT
1. Passive dorsiflexion and hyperextension of the fifth MCP joint beyond 90°	1	1
2. Passive apposition of the thumb to the flexor aspect of the forearm	1	1
3. Passive hyperextension of the elbow beyond 10°	1	1
4. Passive hyperextension of the knee beyond 10°	1	1
5. Active forward flexion of the trunk with the knees fully extended so that the palms of the hands rest flat on the floor	1	1
TOTAL	/ 9	

Screenshot from: http://www.physio-pedia.com/Beighton_score

Figure 6.⁴³

PEDIATRIC BALANCE SCALE		
<u>Name:</u> _____	<u>Date:</u> _____	
<u>Location:</u> _____	<u>Examiner:</u> _____	
<u>Item Description</u>	<u>Score</u> <i>0 - 4</i>	<u>Seconds</u> <i>optional</i>
1. Sitting to standing	_____	
2. Standing to sitting	_____	
3. Transfers	_____	
4. Standing unsupported	_____	_____
5. Sitting unsupported	_____	_____
6. Standing with eyes closed	_____	_____
7. Standing with feet together	_____	_____
8. Standing with one foot in front	_____	_____
9. Standing on one foot	_____	_____
10. Turning 360 degrees	_____	_____
11. Turning to look behind	_____	
12. Retrieving object from floor	_____	
13. Placing alternate foot on stool	_____	_____
14. Reaching forward with outstretched arm	_____	
Total Test Score	_____	

Screenshot from: https://www.sralab.org/sites/default/files/2017-06/PediatricBalanceScale_3.pdf