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Transitions: Helping kids make the leap to adult care

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The new federal physical activity guidelines include the first-ever recommendations for children aged 3 to 5 years, as well as updated guidelines for older kids. Here, we cover what you need to know about the new advice and offer tips from experts to help kids with lower extremity conditions get and stay active.
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15 **Transitions: Helping kids make the leap to adult care**
In healthcare, transition refers to planning for and making the move from child to adult services. When the process isn't managed well, young adults can fall into gaps in care and declining function, health, and quality of life. Transition takes provider time and energy, but reimbursement is available.
By Emily Delzell

From the editor: Seeing Yourself

Children with lower extremity conditions and injuries rarely flip open a book or watch a movie or TV show in which they read about or see other children like them, who might wear a brace, use an assistive device, or need treatment from practitioners like orthotists, podiatrists, and physical therapists.

Children use toys and media characters to spark their imaginations and cast themselves as the star of their own stories. Through play, they connect with other kids and dream about their future. Yet kids with lower extremity conditions rarely find themselves or their challenges reflected in dolls, books, or other types of entertainment.

Earlier this year writer Jill Dorson covered the scarcity of media characters and toys with which kids who have a lower extremity condition can identify (See "Media, toys, and games for kids with disabilities," February 2018, page 15).

That article also highlighted a rarity: a storybook called *Beau and His New AFO* written by three Canadian orthotic technicians. They wrote it, they said, "to normalize what it means to have an AFO or device."

Now, another lower extremity practitioner has stepped up to contribute to the small collection of books in which her patients can see themselves and learn about the treatment she provides.

Benji Bounces Back: A Story About What It's Like to Need Physical Therapy, introduces children to the concept of physical therapy, covering a young boy's course of care from accident to recovery, and providing a lot of education along the way. It's now available on Amazon.com.

Author Smita Charate, PT, wrote the book after she noticed that "children who come for physical therapy are often frightened because they don't know anything about it." She noted, "Concerned parents asked me about the availability of books that might introduce a child to the experience, so I searched and searched only to discover there was nothing."

So, she wrote one. If you've ever felt inspired to write a book or develop a toy or game that demystifies what you do for your young patients—or gives them an opportunity to see someone like themselves in media—2019 could be a great year to create it.

Emily Delzell, *Editor*

Kids with Down syndrome have an increased risk of arthritis

Delayed diagnosis leads to joint damage

By Katie Bell

Arthritis in Down syndrome, or Down syndrome arthropathy, remains under-recognized, according to research from Kansas City, Missouri, that found that while treatment with several classes of medications leads to a significant reduction in active and limited joints, treatment approach, optimal therapy, and escalation are unclear.

"There is a nineteen-month average delay in diagnosis of Down syndrome arthropathy from symptom onset," said lead author Jordan T. Jones, DO, MS, assistant professor of pediatrics in the Division of Rheumatology at Children's Mercy Hospital in Kansas City. "Due to the delay, many patients present with bony changes seen on imaging studies and irreversible joint damage, which contributes to worse prognoses with functional limitations in a population that is already at risk for delayed motor skills and functional limitations."

Awareness of the link between Down syndrome and arthritis among both practitioners and parents is generally low, and is a major reason for under-recognition, he suggested. "Additionally, the matter is made more complex by the underlying risk of delayed motor skills and functional limitations due to hypotonia and ligamentous laxity that are commonly seen in children with Down syndrome," Jones said.

He and his colleagues completed a retrospective chart review at two tertiary care hospitals, identifying through a decade of electronic medical records (1995-2015) patients younger than 18 years with both Down syndrome and juvenile idiopathic arthritis (JIA). The 43 patients (58% female) included in the study had a mean age of 7.4 years at onset of musculoskeletal symptoms, with a mean 19 months to JIA diagnosis.

At JIA diagnosis, 63% of participants presented with polyarticular rheumatoid factor negative disease; 70% reported morning stiffness, with an average of 15 active joints; and 14 presented with limited joints. The mean physician global assessment of disease activity was 4.5 (out of 10).

Most patients (93%) were prescribed nonsteroidal anti-inflammatory drugs (NSAIDs) at diagnosis, with 28% simultaneously starting a disease-modifying antirheumatic drug (DMARD) and 5% a biologic. Over the course of disease, 74% of participants used a DMARD (94% of these took methotrexate) and 47% a biologic (83% received etanercept). Meanwhile, 25% and 39% of patients had at least one change in DMARD or biologic therapy, respectively.

At the last visit (mean follow-up of 6 years), there were significantly fewer active and limited joints, and mean physician assessment of global disease activity was 1.3. Among those prescribed DMARD therapy, 60% discontinued it due to side effects, while 39% of those prescribed a biologic had an inadequate response. Jones noted that kids with Down syndrome had more issues with adverse effects and were more likely than children with JIA alone to have an inadequate response to therapy. The findings were presented in October at the American College of Rheumatology annual meeting in Chicago.

> Down syndrome arthropathy is rarely recognized at symptom onset and remains underdiagnosed.

A study presented last year at the British Society for Rheumatology's annual conference also found that Down syndrome arthropathy is rarely recognized at onset and remains underdiagnosed. Additionally, first author and pediatric rheumatology fellow Charlene Foley, MBBS, BSc, MRCPCH, and her colleagues at Our Lady's Children's Hospital in Dublin, Ireland, observed that Down syndrome arthritis is more prevalent than JIA and has distinct clinical and radiographic features.

Foley and her colleagues in their clinic screened 503 children with Down syndrome for arthritis, diagnosing 22 new cases. Combining those cases with cases in clinic predating the start of the study brought the total to 33 children. "This suggests the prevalence of Down syndrome arthropathy in Ireland is eighteen to twenty-one in a thousand," said Foley. The estimated prevalence of JIA is 1/1000.

Foley and colleagues, who included in the study a convenience sample of 33 children with JIA, found a significant delay in Down syndrome arthropathy diagnosis compared with JIA diagnosis, 1.7 years versus 0.7 years, respectively. Small joint involvement of the hands was significantly higher with Down syndrome arthropathy than in JIA. Those with Down syndrome arthropathy also had more erosive changes than those with JIA, 29.2% and 9.5%, respectively. As with the current study, the Irish researchers noted methotrexate nausea as a barrier to treatment in Down syndrome arthropathy.

"In terms of arthritis, small joint and wrist involvement were most common in children with Down syndrome arthropathy. However, this was followed by involvement of the knees and ankles. This could therefore have consequences in terms of achieving ambulation in a cohort that often has delayed ambulation compared to children without Down syndrome arthropathy," Foley said.

"We advocate that all children with Down syndrome have an annual musculoskeletal examination as part of their health surveillance program," she added.

Education aimed at providers and families about Down syndrome arthritis may also lead to early identification and referral for therapy, said Jones.

"Currently, there is no great way to screen patients for Down syndrome arthritis. The best option is a combination of history about morning stiffness, joint swelling or limitation, a good musculoskeletal exam to identify any abnormality, and basic blood tests looking for inflammation," he said. "It would be helpful to get physical therapy involved earlier to identify and treat the mechanical issues these patients are at risk of developing."

Katie Bell is a freelance writer based in New York City.

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Yoga improves gait, quality of life in obese adolescents

Practice may help kids get active

By Katie Bell

Iyengar yoga can improve both malalignment of the lower extremities during ambulation as well as emotional functioning in children with obesity, according to a pilot study from Milwaukee, Wisconsin, supporting a role for yoga in pediatric obesity.

"This is the first study to examine the benefits of yoga for gait in youths with obesity," reported Keri Hainsworth, PhD, associate professor in the Department of Anesthesiology at the Medical College of Wisconsin.

According to Hainsworth and colleagues, obesity negatively impacts the kinematics and kinetics of the lower extremities in children and adolescents. They noted that following participation in a yoga program, participants demonstrated small but significant improvements in gait, reflecting reduced lower extremity malalignment and increased strength of the hip flexors and adductors during ambulation, especially at the knee and hip joints.

The primary outcome of the study was the benefits of yoga for gait; secondary outcomes included health-related quality of life (HRQoL), physical activity, and pain. The researchers also assessed the feasibility and acceptability of the yoga intervention.

The study included nine participants (five girls) with a median age of 14 years. All of the adolescents had a body mass index in the 99th percentile or above and had no yoga experience. The participants took part in an eight-week Iyengar yoga intervention of biweekly, one-hour classes.

All participants underwent gait analysis within two weeks of the start of the yoga intervention and within a week of its end. Researchers assessed children's self-reported and parent-proxy HRQoL reports and physical activity at baseline and after the intervention. The children self-reported pain at the start of each yoga class.

The children had significant improvements in multiple gait parameters, including hip, knee, and ankle motion and moments, after the eight-week yoga intervention.

Specifically, there was increased hip adduction and decreased hip abduction in both the stance and swing phases of gait. Additionally, gait analysis revealed increased knee valgus at heel contact but reduced knee varus during stance phase and initial swing phase. Meanwhile, the ankle joint showed increased plantar flexion but reduced dorsiflexion during swing phase.

> "The QoL improvements across all functions could increase the willingness of teens to be more active and try new activities."
>
> —Sara Shultz, PhD, ATC

Further, the hip internal rotation moment at heel contact in the stance phase was increased from a median of 0.02 to 0.03 Nm/kg and the maximum adduction moment in stance phase was reduced from a median of 0.12 to 0.09 Nm/kg. While cadence and velocity reduced from pre- to post-yoga, stride length did not change from pre- to postintervention.

"Overall, the pattern of results shows reduced malalignment during walking, particularly at the hip and knee joints," the authors wrote.

Participants self-reported both improved overall HRQoL and psychosocial functioning, while parent-proxy reports of emotional functioning also improved after the yoga intervention.

The authors could not measure of changes in pain intensity because of the sample size and number of participants who reported pain. The amount of time spent in physical activity did not change from pre- to postintervention. Additionally, the study found the yoga intervention to be both feasible and acceptable, as measured by class participation and a Holistic Health Questionnaire, respectively.

The findings were published in July by the journal *Children*.

"Overall, the results of this study suggest that positive changes in gait are achievable with a relatively brief, noninvasive intervention," the authors wrote. "After an eight-week Iyengar yoga intervention, children and adolescents with obesity were able to walk more efficiently, with reduced abnormal alignment of the lower limbs, have less impaired mobility, and better balance," they added.

The authors suggested that "better understanding of activities that improve the daily functioning of obese youth may allow for the development of effective interventions."

Commenting on the study, Sarah Shultz, PhD, ATC, associate professor and chair of the Department of Kinesiology at Seattle University in Washington, said she believed the most important aspect of the yoga intervention were the improvements in HRQoL.

"The changes in gait are really minimal—and are probably not that clinically significant—but the perceived improvements by the students in quality of life across all functions is incredible and could lead to increased willingness by the teens to be more physically active and try new activities," she said.

In many children, said Shultz, the willingness to be active is more important than the capability. "In a lot of cases of youth struggling with obesity, once you get over that initial barrier [to activity], then a more sustained practice of exercise can be achieved," she said.

This study adds to a limited body of knowledge that looks beyond the traditional forms of exercise, such as running, biking, swimming, said Shultz.

"The purpose of exercise interventions should be to help youth with obesity find alternatives that increase their engagement with activity, and thus lead to more sustainable changes in lifestyle," she said. "Yoga practice is an excellent example of how to use more nontraditional approaches to engage students with exercise."

Katie Bell is a freelance writer based in New York City.

Source:

Hainsworth KR, Liu XC, Simpson PM, et al. A pilot study of Iyengar yoga for pediatric obesity: Effects on gait and emotional functioning. Children (Basel) 2018;5(7):92.

High-intensity intervals more enjoyable than moderate activity

Challenging activity boosts good feelings

By Hank Black


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Despite greater rates of perceived exertion teens do not find high-intensity interval exercise (HIIE) unpleasant, and in fact report greater postexercise enjoyment than after completing moderate-intensity interval exercise (MIIE), according to research from the UK.

Interval exercise reflects the normal stop-and-go pattern of playground activity, said lead author Adam A. Malik, a doctoral student at Exeter University in Cornwall, UK. He and colleagues recently explored adolescents' perceptual responses to HIIE or MIIE during and after exercise.

Their small study (n = 13, mean age = 14 years; SD = +/- 0.5) looked at affective, enjoyment, and perceived responses. The participants were healthy boys; two had a low level of fitness and one was overweight.

Of three experimental sessions in the laboratory, the first measured physical variables and cardiorespiratory fitness levels and acquainted the participants with the measurement scales. That was followed by two counterbalanced HIIE or MIIE running sessions on a motorized treadmill, separated by a minimum of three days.

Following incremental testing to determine maximum aerobic speed, the running protocol for HIIE involved eight one-minute work intervals at 90% maximum aerobic speed. The MIIE protocol called for between nine and 12 one-minute intervals at 90% ventilatory threshold (VT). The number of MIIE work intervals equaled the distance performed during HIIE for each participant.

Affective responses were measured using the feeling scale (FS) and the felt arousal scale (FAS) at points before, during, and up to 20 minutes after exercise. Enjoyment was rated during the sessions using an exercise enjoyment scale (EES), and immediately and 20 minutes after the protocol using the modified PACES measure. Finally, the rate of perceived exertion (RPE) was measured using the multi-item Pictorial Children's OMNI questionnaire.

The study found a greater decline in affective valence with HIIE than MIIE but the measure was still positive at the end of the high-intensity work interval (85% positive, 15% negative), whereas all participants in MIIE evoked positive affective responses. During exercise no significant differences on the enjoyment scale were noted between HIIE and MIIE, but HIIE enjoyment was greater immediately after and 20 minutes postexercise. In fact, the researchers found, enjoyment declined 20 minutes after exercise for MIIE, but not for HIIE.

Medicine & Science in Sports & Exercise published the results in May.

> High-intensity exercise evoked feelings of excitement and enthusiasm in study participants

The group used a circumplex model to separate dynamic changes arising during HIIE and MIIE. Affective responses were found to remain in the unactivated—pleasant quadrant, which evoked a sense of relaxation during MIIE. During HIIE, however, affective responses moved to the pleasant—activated quadrant, in which excitement and enthusiasm are evoked. Feelings of excitement and enjoyment, the authors stated, appear to be spurred by the participants' perception that they could complete the HIIT treadmill session when challenged.

Malik said previous studies in this population had confirmed the effectiveness of HIIE in producing health benefits.

"The appeal to adolescents of the high-intensity interval regimen may rest on its positive affect and greater postenjoyment responses compared to one of moderate intensity," he said. "Data from our study could translate to school-based and other nonlaboratory protocols where inexpensive and practical tools are doubly important."

He added, "Perceived exertion during HIIE is important to examine due to its role in modulating affective responses and therefore how youths may view physical activity as they age into adulthood."

This study, he said, also demonstrated the importance of simple psychometric tools such as the FS, EES, and RPE scales to prescribe and monitor the high-intensity protocol.

In previous investigations, adolescents had reported greater enjoyment following intervals of high-intensity exercise compared with continuous exercise of moderate intensity. The current study pointed out, however, that earlier HIIE studies in this population were measured only postexercise, possibly missing important changes during exercise, Malik said. "It is important to employ measurements both during and after exercise to help determine how well adolescents might engage in interval exercise of different intensities," he said.

As a practical application of the study, Mailk pointed out, the study gathered heart rate responses that may be useful in prescribing intensity levels for protocols used outside the laboratory. Combining this with low-cost and easy-to-use psychometric tools such as FS, RPE, and EES, he said, may provide a strategy to monitor HIIE by teachers and coaches as well as exercise professionals.

HIIT is increasingly promoted for time-challenged adults, and even high-intensity continuous exercise appears to produce beneficial health effects at lower and lower times. Biddle and Batterham, in a seminal 2015 point-counterpoint paper, agreed HIIT results in a broad spectrum of positive cardiometabolic effects but disagreed whether it would be adopted or maintained by many people and therefore have a population-level effect.

Malik and his colleagues maintain their study indicates the practice has genuine potential to contribute to addressing health priorities among adolescents, many of whom may be unable or unwilling to give up a sedentary, digitally leashed lifestyle to engage in more physical activity.

Hank Black is a freelance medical writer in Birmingham, Alabama.

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The updated guidelines recommend that children meet daily physical activity goals through a wide variety of play and sport. (Images used courtesy of the US Department of Health and Human Services.)

HHS updates federal physical activity guidelines

The new federal physical activity guidelines include the first-ever recommendations for children aged 3 to 5 years, as well as updated guidelines for older kids. Here, we cover what you need to know about the new advice and offer tips from experts to help kids with lower extremity conditions get and stay active.

By Keith Loria

The US Department of Health and Human Services on November 12 unveiled a second edition of its physical activity guidelines[1] (the first edition was published in 2008[2]). Its message for pediatric lower extremity practitioners is that their care should facilitate as much physical activity (PA) as possible for young patients, including educating parents about why PA is so important and how they can help their kids reach activity goals.

Katrina L. Piercy, PhD, RD, ACSM-CEP, Department of Health and Human Services physical activity and nutrition advisor, said the guideline update is based on new evidence highlighting the importance of physical activity for health for individuals of all ages. It includes the first-ever federal recommendations for children aged 3 to 5 years as well as updated guidelines for youth aged 6 through 17 years. The 2008 guidelines included recommendations for kids aged 6 years and older, but Piercy said there's now evidence to make recommendations for preschool-aged children.

"We realized there had been a huge growth in scientific evidence and felt like we needed to update our recommendations to the public and talk about the fact that most Americans aren't meeting these guidelines," she said. "This also gave us an opportunity develop a communications campaign to help get these messages out and reinforce why physical activity is important."

The "Move Your Way" campaign based on the new recommendations is designed to help health professionals, national organizations, communities, and other physical activity stakeholders clearly communicate the amount and types of physical activity that Americans need to stay healthy—as well individualized strategies to help kids and adults meet those goals. Practitioners can access interactive tools, fact sheets, posters and other educational materials, including those designed for parents, at health.gov/paguidelines/moveyourway.

Piercy noted the key takeaway is that kids of all ages should be getting physical activity through a variety of activities.

> "The guidelines reflect the need to ingrain salubrious activity choices in our children to prevent downstream health consequences such as obesity." Sara Rubinstein, CO, LO, TRS

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My kids are younger than 6. What about them?

Younger kids love to be active naturally!

- Aim to keep them moving 3 hours a day — and more is better
- Limit time when they're just sitting around (like screen time)

What counts?

Whatever gets them moving!

Encourage active play with friends

Give them rewards for active chores

Sign them up for free or low-cost classes

Or get active together!

Make your morning walks a race

Dance while dinner's in the oven

Show them your favorite ways to move

Most of all, help them find activities they really like to do!

It all adds up. And so do the benefits.

Help them get active now, and they'll build healthy habits for life.
So take the first step. Get your kids moving. And when you can, move with them!

Find out how your kids can get 60 minutes of activity every day.
health.gov/MoveYourWay/Get-Kids-Active

The "Move Your Way" website offers fact sheets and other education resources practitioners can share with parents.

Three hours a day for preschoolers

"The new guidelines for children aged three through five emphasize that preschool-aged children should be active throughout the day to enhance growth and development," she said. "Adults supervising children this age should encourage a variety of types of active play."

Although the specific amount of activity needed to improve bone health and avoid excess fat in young children is not well defined, a reasonable target is three hours per day of activity of any intensity (light, moderate, or vigorous), according to the guidelines. This, the guidelines note, is the average amount of activity observed among children of this age and is consistent with guidelines from Canada, the UK, and Australia.

Physical activity for this age group should include unstructured "free" play, as well as activities such as throwing games and bicycle or tricycle riding. To strengthen bones, young children should do activities that involve hopping, skipping, jumping, and tumbling.

"The three hours the guidelines recommend for preschool children can vary in intensity and [the guidelines] are vague in the types of activity recommended," said Carlos Uquillas, MD, a pediatric sports medicine specialist and pediatric orthopedic surgeon at Cedars-Sinai Kerlan-Jobe Institute in Los Angeles. "However, it is important to know what amount of activity is being performed at school and how much should be done at home. It is particularly important to ensure kids of this age are having enough physical activity, as they are undergoing such rapid growth both physically and emotionally."

Moderate-to-vigorous PA for older kids

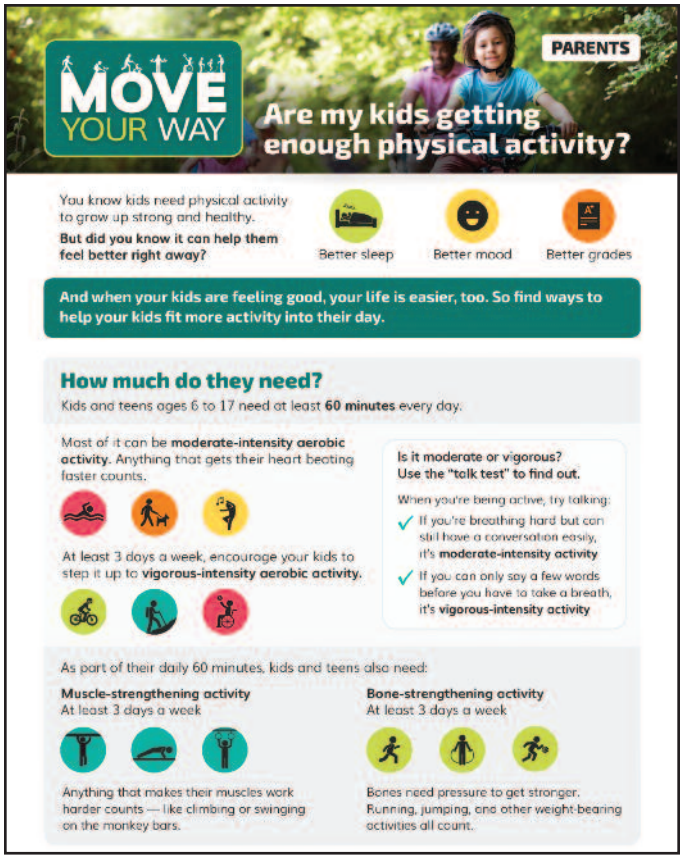
Children aged 6 years and older should get 60 minutes or more daily of a variety of mostly moderate- or vigorous-intensity PA (versus light activity) that's enjoyable and appropriate for their age, the guidelines report. Piercy noted that, at least three days a week, the daily PA goal should be composed of mostly vigorous exercise because of the greater improvement in cardiorespiratory fitness intense workouts offer compared with light and moderate activity.

Evidence indicates that both acute bouts and regular moderate-to-vigorous physical activity improve the cognitive functions of memory, executive function, processing speed, attention, and academic performance of school-aged children, Piercy said.

The guidelines also advise that these children should include three days a week of both muscle-strengthening and bone-strengthening exercises as part of their daily PA goal. Bone-strengthening activities remain especially important for children and young adolescents because the greatest gains in bone mass occur during the years just before and during puberty and the majority of peak bone mass is obtained by the end of adolescence.

Per the new guidelines, any episode of moderate- or vigorous-intensity PA, however brief, counts toward the 60-minute daily recommendation, Piercy said. The 2008 guidelines for adults noted only 10-minute or longer exercise bouts counted toward daily requirements. Now all PA, however intermittent or short, counts toward daily totals for both kids and adults.

"Growing evidence demonstrates the immediate health benefits attainable from a single bout of activity, including reduced anxiety and blood pressure, improved quality of sleep and improved



The "Move Your Way" campaign has many educational resources for parents, including this fact sheet on activity for children aged 6 to 17 years.

Continued on page 12

Continued from page 11

insulin sensitivity; therefore, those time limitations have been removed," Piercy said. "We now emphasize that any amount of physical activity counts, and any type of movement can have positive benefits."

Jennifer Laine, MD, a pediatric orthopedic surgeon at Gillette Children's Specialty Healthcare-St. Paul in Minnesota, said the report shows that regular physical activity can improve health in multiple ways, including reducing gains in body weight and improving bone health, even in the younger age group.

"It is well-recognized that childhood obesity is a significant public health problem. Sedentary activities and lifestyle play a significant role in this," she said. "The updated guideline shows that increased physical activity affects certain aspects of health—weight gain and bone health, for example—that can track into adult life. It supports building physical activity into multiple environments when possible."

School programs can be effective, but it is helpful if activity can be worked into other realms, such as biking for transportation instead of motorized travel, she said.

PA for kids with disabilities

When possible, children and adolescents with disabilities should meet the key PA recommendations for their age group, the guidelines advise. The recommendations encourage as much physical activity as children's individual abilities allow and note that when young people can't participate in the appropriate types or amounts of PA needed to meet key guidelines, they should be as active as possible and avoid being inactive.

"Children and adolescents with disabilities are more likely to be inactive than those without disabilities. Youth with disabilities should work with a healthcare professional or physical activity specialist to understand the types and amounts of physical activity appropriate for them," Piercy said.

At Gillette Children's Specialty Healthcare, Laine works closely with the Department of Therapeutic Recreation to help kids and families find activities that suit them. (See "Therapeutic play plus O&P care is a win-win for kids," November 2016, page 11.)

"There are nearly always ways to build physical activity into a child's life, no matter what the condition," she said. "What is important and essential is getting kids active early in life and involving them in activities that get them moving beyond what they do typically for their activities of daily living. This has different meanings for different children. It is important for children to try a variety of activities when they are young, and then they can pick what they like as they grow older."

In addition to the overall health benefits of being physical active, giving children the opportunity and encouragement to participate in these activities has social benefits, as well, Laine said. "They can interact with other children, learn how to take turns, learn how to be a part of a team, learn sportsmanship, and even learn general social rules such as how to stand in line," she said.

Physical and occupational therapy often plays a key role in maintaining activity levels for kids with disabilities, said Uquillas. "Kids with limited lower extremity function may be able to get significant physical activity and its benefits from upper extremity exercise. The benefits of activity go beyond the physical gains, but also include psychological, social, and developmental gains," he said.

Below, Uquillas and others discuss ways to promote physical activity in kids with several specific lower extremity issues.

Injury

"In terms of people treating injuries, the guidelines didn't look at specific interventions, but the biggest takeaway is to work with someone who knows how to tailor an activity and set the child on a positive path in doing that activity," Piercy said.

Uquillas said that kids with lower extremity injuries face challenges in complying with the guidelines when they have weightbearing restrictions, have to elevate, or are limited due to assistive devices such as crutches. In many cases, he said, injuries are temporary, which can result in just a temporary decrease in activity. "In this case, after consultation with a doctor, kids should try to remain active without compromising their healing," he said.

"In this age group, temporary injuries are typically fractures, and often are treated with immobilization and activity restrictions," he said. "If it's necessary to avoid weightbearing, it becomes more challenging to stay active. Water therapy or swimming can be a good activity in this scenario. Waterproof casts and braces can be used."

In older children and adolescents, fractures continue to be a common injury; however, at this age sprains, strains, and overuse injuries also occur. Physical therapists and athletic trainers can help children rehabilitate from these injuries and safely return to active play and sports, he said.

Lev Kalika, DC, RMSK, clinical director of the New York Dynamic Neuromuscular Rehabilitation & Physical Therapy Clinic in New York City, noted that training the upper body while the lower body heals from injury helps maintain overall fitness.

Cerebral palsy

Adaptations can help kids with conditions like cerebral palsy (CP) participate in a wide variety of activities, said Jennifer Laine.

Even if kids with CP don't use a wheelchair in daily life (instead using a walker, for example), she said, they might use a wheelchair might as a piece of sports equipment so they are able to play adaptive basketball.

"For some children who use a wheelchair for distances, they may walk with a walker as their physical activity for a certain amount of time each day," she said.

Sara B. Rubinstein, CO, LO, TRS, an orthotist at the Ann & Robert H. Lurie Children's Hospital of Chicago, said patients with CP often participate in power chair soccer or bocce competitions.

"Orthotics and a proper wheelchair seating system can provide a secure base for patients to drive their chairs through the games while weaving between players and performing spin kicks," she said. "AFOs with leg straps can protect the lower limbs from potential injury while supporting the athlete while they play."

Joint hypermobility

Patients with joint hypermobility and arthralgia can often benefit from custom foot orthoses and supportive footwear, said Rubinstein. "Presentations we see in these populations include hindfoot valgus, genu valgum, and knee hyperextension. The combination of custom foot orthoses and supportive footwear with a semirigid heel counter can resist the patient's tendencies towards end-range positioning," she said.

"Physical therapy can promote midrange strengthening and postural awareness to reduce the endpoint stress patients can put on their joints," she added. "Low-impact exercise such as cycling, Pilates, and swimming are often a good fit for patients with hypermobility."

Crawling-type movements engage the entire body and provide

a challenging exercise when patients cannot load their feet, which can be an issue for children with joint hypermobility, said Kalika.

"Children with joint hypermobility have loading issues because they are usually hyperpronated and hyperextended in their knees; therefore, during gait the timing on knee flexion, hip flexion and foot pronation never couples into a shock-absorbing mechanism that is shared throughout all of these joints," he said.

Flatfoot

Kamran Hamid, MD, a foot and ankle surgeon with Midwest Orthopaedics at Rush University Medical Center in Chicago, said in a majority of children, flatfeet are a completely normal finding and should not limit their physical activity.

"I encourage parents to purchase supportive shoes and encourage their children to participate in sports and activities with their peers," he said. "Orthotics are not necessary in children with flatfeet unless their feet are painful. Children with painful flatfeet should see an orthopedic doctor specializing in pediatric orthopedics or foot and ankle orthopedics for evaluation and potential treatment with orthotics, physical therapy, or other modalities."

Caleb Backe, ACSM-CEP, a certified personal trainer with Maple Holistics in Farmingdale, New Jersey, said a good technique for youth with flatfeet is to roll a tactile ball along the arch of the foot to activate the muscles; it should be done as a relaxing warm-up before more strenuous activities.

He also recommends using a large therapy ball for children with more severe presentations. "Have the child stand on the ball while you hold their hands and encourage them to jump up and down," Backe said. "This engages their feet and ankles fully, as well as working the rest of the body."

Obesity

Obesity and associated physical ailments are on the rise in the US, and numerous studies[3,4] have identified childhood as the beginning of many lifestyle factors that result in poor adult health.

"The updated federal activity guidelines reflect the need to ingrain salubrious activity choices in our children to prevent downstream health consequences such as obesity," Sara Rubinstein said.

In some instances, children have already reached body mass index criteria for obesity prior to an intervention and are often embarrassed to participate in activities with their peers due to self-consciousness or potential bullying.

"Increased activity is sometimes not enough in these cases," Hamid said. "There are adolescent/pediatric weight loss programs associated with health systems that may be available for nutrition counseling and exercise coaching for these kids."

Additionally, patients with diseases such as muscular dystrophy or Charcot-Marie-Tooth disease will often report an increase in falls or more difficulty staying on their feet when they experience significant weight gain.

"It is part of our duty as healthcare professionals to educate our patients on the additional health concerns related to weight gain and support them to be as active as possible as this can directly affect their mobility down the road," Rubinstein said. "Utilizing pediatric physiatry in multidisciplinary clinics is another great way to promote overall wellness with pediatric patients."

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References are available at lerpediatrics.com.

Youth and young adults who wear devices face additional layers of complexity during transition. (Image courtesy of Fillauer.)

Transitions: Helping kids make the leap to adult care

In healthcare, transition refers to planning for and making the move from child to adult services. When the process isn't managed well, young adults can fall into gaps in care and declining function, health, and quality of life. Transition takes provider time and energy, but reimbursement is available.

By Emily Delzell

More than 18 million US adolescents aged 18 to 21 years need to transition each year from pediatric to adult-centered healthcare, according to the US Census Bureau.[1] When youths, families, and providers work together on transition planning, researchers have noted significant improvements in patient satisfaction and in continuity of care and adherence to care.[2]

Improved adherence to care was the most commonly reported positive quality of care outcome found in a 2017 systematic review, followed by better perceived health status, quality of life, and self-care skills.[2] The review identified increased adult visit attendance and less time between the last pediatric visit and the initial adult visit as the most common positive service-use outcomes.[2]

For Susan Labhard, MSN, RN, a transitions nurse specialist at Shriners Hospitals for Children—Portland, Oregon, optimal transition planning begins with a focus on person-centered care.

"This means looking at the individual first, not the disability; that is, they are person affected by cerebral palsy, not a cerebral palsy patient," she said. "In pediatrics, person-centered transition care means starting at age twelve or even earlier—the earlier, the better—to have ongoing conversations about the future and quality-of-life issues. Saying, for example, 'One day you will need to handle getting and taking care of your device by yourself.' And then explaining some of what that might mean, such as the need to get a good job so you can get good insurance so you can afford the device you need."

Yet, the vast majority of children do not receive any transition preparation, according to the 2016 National Survey of Children's Health, a nationally representative survey of parents.[3]

Pediatric providers can help by starting conversations about transition early and by being open to conversations with their former patients' new adult providers.

"When healthcare clinicians working in pediatric and adult care settings communicate with each other during the transfer of care and share records with each other and with youth and young adults,

> "You can start the conversation about transition from pediatric care by talking about transitions they might experience within pediatric care." —Todd DeWees, CPO

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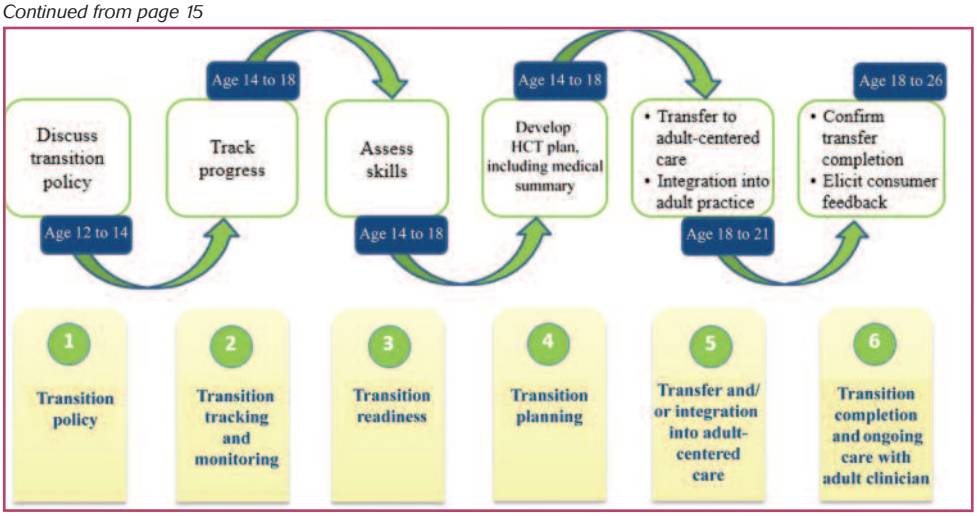

Practice or provider	#1 Transition and/or care policy	#2 Tracking and monitoring	#3 Transition readiness and/or orientation to adult practice	#4 Transition planning and/or integration into adult approach to care or practice	#5 Transfer of care and/or initial visit	#6 Transition completion or ongoing care
Pediatric[a]	Create and discuss with youth and/or family	Track progress of youth and/or family transition preparation and transfer	Conduct transition readiness assessments	Develop transition plan, including needed readiness assessment skills and medical summary, prepare youth for adult approach to care, and communicate with new clinician	Transfer of care with information and communication including residual pediatric clinician's responsibility	Obtain feedback on the transition process and confirm young adult has been seen by the new clincian
Adult[a]	Create and discuss with young adult and guardian, if needed	Track progress of young adult's integration into adult care	Share and discuss welcome and FAQs with young adult and guardian, if needed	Communicate with previous clinician, ensure receipt of transfer package	Review transfer package, address young adult's needs and concerns at initial visit, update self-care assessment and medical summary	Confirm transfer completion with previous clinician, provide ongoing care with self-care skill building and link to needed specialists

Left, top figure: Timeline for introducing the Six Core Elements into pediatric practices. Bottom figure: Summary of Six Core Elements approach for pediatric and adult practices. (Source: White PH, Cooley WC; Transitions Clinical Report Authoring Group. Pediatrics 2018;142 (5):e20182587.)

it assists the receiving clinician to offer better continuity of care," said M. Carol Greenlee, MD, chair of the American College of Physicians Council of Subspecialty Societies. She is coauthor of a 2018 clinical report[4] on healthcare transition by the Transitions Clinical Report Authoring Group, written by members of the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP).

The 2018 report describes and recommends the use of an evidence-informed structured healthcare transition process called the Six Core Elements of Health Care Transition, developed by Got Transition, a federal initiative aimed at improving the move from pediatric to adult care. One of the key steps in Element 5, Transfer of Care, involves preparing a "transfer package" for the patient's new adult providers with a readiness assessment,

plan of care with transition goals and pending actions, a medical summary and emergency care plan, and, if needed, legal documents, a condition fact sheet, and additional provider records.

The Got Transition website (gottransition.org) offers a number of tools to help clinicians develop transition services. Its many resources include downloadable PDF packages with tools such as examples of transition policies practices can adopt, transition flow sheets, readiness assessments, and sample letters to new adult providers.

"Having the adult care clinician know something about [the new patient] and their medical issues at that initial encounter helps the young adult feel more comfortable with their new clinician," Greenlee said.

Labhard agreed strongly, noting, "Children with certain conditions are now living longer than ever before and are moving into adult care, where providers may not be as familiar with their diagnoses or with dealing with a patient who is intellectually or developmentally challenged. I believe it's up to the peds side to help those adult providers help the patients."

Barriers to positive outcomes

Estimates of transition preparation among kids aged 12 through 17 years with and without special healthcare needs show that 83% of youth with special needs, including lower extremity conditions, and 86% of youth without special needs don't meet the national performance measure for transition.[4] This composite measure, developed by the AAP, examines the extent to which (1) youth had time alone to speak with the doctor or other healthcare clinician during his or her last preventive visit; (2) the doctor or other healthcare

Young patients and their families should start early in their search for adult providers who fit their needs and understand their diagnoses. (Image courtesy of Surestep.)

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clinician worked with youth to gain self-care skills or understand the changes in healthcare that happen when youth transition from pediatric to adult care; and (3) the doctor or other health care clinician talked with their pediatric patient about eventually seeing doctors and other providers who treat adults.

This lack of structured transition planning results in a number of poor outcomes, particularly for youth and young adults with special needs or chronic conditions, according to the 2018 AAP/AAFP/ACP healthcare transitions report.[4] The long list of adverse issues linked to poor or no transition planning includes medical complications, limitations in health and well-being, problems with treatment and medication adherence, discontinuity of care, patient dissatisfaction, higher emergency department and hospital use, and higher costs of care.[4]

Transition can also be emotionally tough for kids with lower extremity conditions, said Todd DeWees, CPO, a prosthetist-orthotist at Shriners Hospitals for Children—Portland.

"When patients transfer from pediatric to adult care they're moving away from someone they've known and trusted for a long time, sometimes their entire lives," he said. "Some young adults are transferring into practices that don't see a lot of pediatric patients. Those providers may, for example, be more used to dealing with elderly patients with very different activity levels and expectations, so younger patients may not get the results they were used to in pediatric care."

Kids with chronic conditions and disabilities may have additional barriers to successful transition: unstable living conditions, lack of a high school diploma or health insurance, geographical distance from appropriate adult providers, low income, and poor psychosocial functioning.[4]

Devices can present an additional layer of difficulty for patients during transition, Susan Labhard said. "A lot of patients and families don't realize somebody has to write a prescription for the prosthetic or the orthotic, and that takes time, and that often it can no longer be the person who did it when they were in pediatric care," she said.

TRANSITION RESOURCES

- **Got Transition at gottransition.org. The primary guide for transitioning from pediatric to adult care.**
- **American Board for Certification in Orthotics, Prosthetics, & Pedorthics at abcop.org. Lists certified O&P clinics by zip code or city and state.**
- **Amputee Coalition at amputee-coalition.org. Find information about financial assistance for prosthetic services, durable medical equipment, and other assistive devices.**
- **The Barr/United Amputee Assistance Fund at hispanicaccess.org/service-provider-directory/barrunited-amputee-assistance-fund-barr-foundation. Provides resources for the purchase prosthetic limbs for amputees who cannot otherwise afford them.**
- **Hanger Clinic: Financial Aid Resources for Patients with Amputations-Prostheses and Assistive Devices at hangerclinic.com/new-patient/ampower/Documents/Financial_Aid_Resources_for_Patients_with_Amputations.pdf.**

Transition planning involves significant work and time for practitioners, and many don't know they can be reimbursed for their services. (Image courtesy of Cascade Dafo.)

When youths wait until they have crisis with their device, they may have to settle for care that isn't the best fit for them, said DeWees.

"I tell kids and their families that they should start interviewing providers like me before they age out of pediatric care so they can find someone who they like and trust—and who understands their diagnosis and their device," he said. "Because, if you wait until you're nineteen and your device is destroyed and you just have to have something, you basically get what you get—and that's not always going to provide the best outcome. You may not connect with that person, their expertise may be in a different area than what your diagnosis is, or they may be a little rusty with your particular device."

How pediatric practitioners can help

DeWees stressed the need for providers to start talking early about transition with patients and families. The AAP and others suggest beginning these conversations no later than age 12, but DeWees starts introducing the concept even earlier.

"It's never too early to start talking about it," he said. "I'd rather start talking when my patient is six rather than twelve, for example," he said. "If you're preparing for that transition all the way through treatment, it doesn't come as a surprise. You can start parsing the concept in terms of how the device you're doing might look different next year or in five years, explaining how the body is going to get bigger and what that might mean for device options, or how activity is going to change over time. You can start the conversation about transition from pediatric care by talking about transitions they might experience within pediatric care."

As his patients reach their midteens, DeWees ramps up messaging about the need to prepare for the change in care. For kids with lower extremity conditions, this often means identifying not just a single provider, but an entire care team.

"I try to have conversations with both patients and their parents, because I see teenagers all day long and I know they don't listen to me," he said. "I say, 'Hey, it's time to think about finding a physician who is comfortable with your diagnosis and supervising your care, and you also need to find somebody like me, who's capable of providing you with the device you need, and you need to find a physical therapist who understands your needs, and so on. That kind of nuanced care goes so much better when you have time to research and to look for the right providers."

Then, he repeats some version of that conversation at every opportunity. "When people start to hear it over and over they often start to get the message that, hey, we really need to do this," he said.

Labhard encourages her young patients to get a new device prescription at their last encounter with their pediatric provider. "That gives patients a couple of years to get established with someone else," she said. But, like DeWees, she hopes that young patients and their families will start the search for providers who fit their needs and understand their diagnosis long before they must leave pediatric care.

"For children who need orthotic and prosthetic services, for example, I go to the American Board for Certification in Orthotics, Prosthetics, and Pedorthics website to find several certified providers geographically close to the patient so they will have some choice," she said.

The patient's location can limit options, and sometimes, she said, pediatric providers need to reach out personally to their network of colleagues to find a practitioner who will be good fit for their transitioning patient.

Insurance is also a major issue, and Labhard advises pediatric providers to have conversations about potential changes in coverage with patients and families as early as possible. "Sometimes it's easier to find the practice and provider you like and then get the insurance they take, especially in remote areas," she said.

Reimbursement

Transition planning involves significant work and time for practitioners. Many don't know they can be reimbursed for their services, said Labhard.

The American Medical Association's Current Procedural Terminology (CPT) and the Centers for Medicare and Medicaid Services have addressed the importance of care management and coordination services through code development for vulnerable care scenarios such as chronic care coordination and behavioral health.[4] Although there is not yet a code specifically defined as pediatric-to-adult transition, newly developed care management services offer an opportunity to report fee-for-service for many elements of transitional care.[4]

Several coding options are available to support transition services in both pediatric and adult care settings. In addition to evaluation and management codes for face-to-face visits, CPT includes services that address prolonged services with or without direct patient contact, medical team conferences, care plan oversight, preventive medicine counseling and behavior change interventions, interprofessional online and/or telephone consultations, and chronic and complex chronic care management.[4]

Labhard also noted the transition process typically requires a large outlay of emotional energy from providers.

"Take care of yourself first," she cautioned. "We can't burn out, we have to help those patients and families. I have to constantly renew myself. I can't be blinking on that last bar and expect to be enthusiastic and positive with patients and families. You can only do that by taking care of yourself: by eating well, getting sleep, and surrounding yourself with things that make you positive and happy—then you can give." ler

References are available at lerpediatrics.com.