The Continuum of Care for Individuals With Lifelong Disabilities: Role of the Physical Therapist

Margo N. Orlin, Nancy A. Cicirello, Anne E. O’Donnell, Antonette K. Doty

Many individuals with lifelong disabilities (LLDs) of childhood onset are living longer, participating in adult roles, and seeking comprehensive health care services, including physical therapy, with greater frequency than in the past. Individuals with LLDs have the same goals of health and wellness as those without disabilities. Aging with a chronic LLD is not yet well understood; however, impairments such as pain, fatigue, and osteoporosis often present earlier than in adults who are aging typically. People with LLDs, especially those living with developmental disabilities such as cerebral palsy, myelomeningocele, Down syndrome, and intellectual disabilities, frequently have complex and multiple body system impairments and functional limitations that can: (1) be the cause of numerous and varied secondary conditions, (2) limit overall earning power, (3) diminish insurance coverage, and (4) create unique challenges for accessing health care. Collaboration between adult and pediatric practitioners is encouraged to facilitate smooth transitions to health practitioners, including physical therapists. A collaborative client-centered emphasis to support the transition to adult-oriented facilities and promote strategies to increase accessibility should become standard parts of examination, goal setting, and intervention. This perspective article identifies barriers individuals with selected LLDs experience in accessing health care, including physical therapy. Strategies are suggested, including establishment of niche practices, physical accessibility improvement, and inclusion of more specific curriculum content in professional (entry-level) doctorate physical therapy schools.
Individuals with lifelong disabilities (LLDs) of childhood onset are living longer lives, necessitating transitions from pediatric health care to appropriate, ongoing community-based adult health care. Health care for individuals with disabilities has received attention in Healthy People 2020 with several related objectives: (1) reduce barriers and increase access to primary and preventive care; (2) increase the number of youth with disabilities who have discussed the transition from pediatric to adult care with their health care provider; and (3) reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs. The more current public health view of disability from a social construct/model perspective rather than solely a medical construct aids in framing transition as a societal responsibility. It also parallels how the World Health Organization (WHO) defines its terms of impairment and disability in a participatory context of health and wellness in the International Classification of Functioning, Health and Disability (ICF) model. Using this context, transition planning to move from pediatric physical therapist practices to adult-centered practices must address not only individual needs in the major domains of the ICF of body function and structure, activity, and participation but also environmental elements in physical and attitudinal contexts.

Childhood onset conditions are numerous, with each possessing unique features demanding distinctive attention. We acknowledge and recognize that we cannot adequately discuss all of the disabilities of childhood onset. The focus of this perspective article, therefore, will be LLDs that are primarily developmental and complex with multiple body systems involvement. These LLDs include cerebral palsy (CP), myelomeningocele, Down syndrome, and intellectual disabilities. The habilitative services for people with these childhood onset conditions are well established as a collaborative effort across multiple disciplines due to the complexity of medical issues and the need for support in everyday life roles. However, as youth with LLD transition into adulthood, they and their families often experience difficulty accessing adult health care services, including physical therapy intervention. This transition difficulty, identified by the entire medical community, is challenging because formalized pathways facilitating pediatric to adult health care systems have been difficult to implement with any significant reform, resulting in a patchwork approach.

Adult health care service transitions are frequently difficult to navigate, particularly for the complex needs common in people with LLDs of a developmental origin. The American Academy of Pediatrics has recognized the need for an earlier and more coordinated approach to transition for youth with special health care needs from pediatric to adult health care settings. Fifty-three percent of physicians identified limited understanding and comfort with conditions experienced by adults with LLDs. Similarly, physical therapists in adult settings often have less experience and content-specific continuing education regarding age-related issues secondary to childhood onset conditions that add complexity to the treatment of adults with LLDs. Consequently, adults with LLDs can experience limited access to a knowledgeable and experienced physical therapist. Improving transitions from pediatric to adult-oriented health care requires that adult-oriented practitioners understand the activity limitations and ongoing impairments that often evolve in these individuals, leading to barriers to satisfactory life participation. Clients seek services, not for their medical diagnoses, but rather for improving their ability to participate in meaningful community and life activities.

Pediatric practitioners need to support such transitions and collaborations with physical therapist colleagues in adult-oriented practices to better serve the needs of adults with LLDs. In 2005, the American Physical Therapy Association (APTA) House of Delegates identified this need of improving transition from pediatric to adult health care in physical therapy by passing RC34 – 05. This document dedicated resources to form the Continuum of Care for Lifelong Disability (COCLLD) task force to develop educational materials and a plan to ensure that all physical therapists are adequately trained in providing care to individuals with LLDs across the life span. The goals set forth by RC34 – 05 included: (1) explore the magnitude of the issues, (2) improve the content of entry-level education within the context of a doctoring profession, (3) educate members to create an environment of autonomous practice for physical therapists working with people who have LLDs, and (4) explore and promote the role of physical therapists in a variety of practice settings to the membership and the public. Since its inception, the COCLLD task force has developed continuing education courses and technical assistance documents. This work continues today with ongoing document development, disseminated through APTA’s clinician website, PTNow.org.

It is critical that physical therapists understand this patient population’s unique demographics and the impact of aging with concomitant body structure changes. Multiple complex elements can either prevent or enhance a smooth transition from pediatric to adult health care to afford consumers with LLDs needed...
Table 1.
Descriptive Statistics of the Demographics of Individuals With Developmental Lifelong Disabilities

<table>
<thead>
<tr>
<th>Number</th>
<th>Age Range</th>
<th>Data Description</th>
<th>Source and Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>764,000</td>
<td>Adults and children</td>
<td>Have cerebral palsy in the United States</td>
<td>United Cerebral Palsy Association^8</td>
</tr>
<tr>
<td>400,000</td>
<td>Adults and children</td>
<td>Have Down syndrome in the United States</td>
<td>National Down Syndrome Society^10</td>
</tr>
<tr>
<td>1/691</td>
<td>Infants</td>
<td>Will be born with Down syndrome each year</td>
<td>National Down Syndrome Society^10</td>
</tr>
<tr>
<td>1,500</td>
<td>Newborn infants</td>
<td>Will be born with spina bifida each year</td>
<td>Parker et al^11</td>
</tr>
<tr>
<td>3,886,158</td>
<td>All ages</td>
<td>Have intellectual disabilities or developmental disabilities</td>
<td>Larson et al^12</td>
</tr>
<tr>
<td>339,429</td>
<td>18–21 y</td>
<td>Number of older adolescents enrolled in US schools in 2008–2009 ready to transition out of school</td>
<td>Data First: US Department of Education’s Office of Special Education Programs^13</td>
</tr>
</tbody>
</table>

physical therapist services. This article describes the group of youth and adults with LLDs that is developmental in nature, includes examples of unique challenges they face as adults, presents specific issues that affect the health care transition and service delivery, and concludes with potential physical therapist practice solutions that will both improve transition and assist in developing strategies for long-term management.

Consumer Demographics

Numerous sources and different means of capturing statistics regarding children, youth, and adults with LLDs, especially those who are in transition to adulthood, make it difficult to have a clear idea of the scope of this population. The incidence and prevalence data are important to know to plan effectively for the needs of the individuals with these disorders. Table 1 is a summary of the important demographic statistics that describe these groups. The data represent a cohort of potential patients quite likely unfamiliar to the majority of adult providers in the US health care system. Contributing to these numbers are increased survivability of childhood onset conditions, health care advances leading to longer life span, and improved educational and therapeutic services during childhood and adolescence, including supportive technology such as power mobility, augmentative communication, and nutritional supplementation. Despite gains in survival rates and improved technologies, individuals with complex LLDs and their families continue to confront significant medical, physical, emotional, and financial challenges as they age into adulthood, including a lack of medical and rehabilitation care specifically related to their unique needs. For example, increased morbidity in adults with myelomeningocele has been correlated with a lack of coordinated multidisciplinary care equipped for the complex needs of these individuals.1,15 Furthermore, the lack of appropriately coordinated medical care is reported to be one of the biggest challenges faced by adults with myelomeningocele.1,15

Individuals with LLDs are entering adult health care systems, living communities, and workplaces often ill prepared or unprepared for appropriate and meaningful participation.16 Best practice to meet their needs is not clearly known because the effect of aging with chronic conditions is only partially understood.17,18 For example, pain and fatigue are 2 commonly reported problems in adults with CP.19–21 The etiology of these 2 problems is often unclear, making it difficult to understand the true impact of problems such as pain and fatigue on other aspects of health and participation in important everyday life activities.22 Physical therapists are uniquely positioned to provide age-appropriate anticipatory guidance, examinations, and interventions for adults with LLDs by promoting health and wellness throughout aging and by preventing and providing intervention for body system impairments and secondary medical conditions. Use of supportive technology and environmental adaptations for postsecondary education, vocational training, and the workplace, and independent/supported living are equally appropriate to consider.

Individuals Aging With LLDs

Disability does not cause ill health.23 Maintaining health and wellness is as important to people with LLDs as to those without them. Research, although limited, informs us that the aging process of some individuals with LLDs is different from that of the general population.24,25 For many individuals with LLDs, the common age-related changes seen in older adults without CP occur earlier in people with LLDs. Therefore, these changes need to be known and considered so that during transition...
to adult-oriented practice, appropriate examination, program planning, and anticipatory guidance can occur. Individuals with LLDs and their caregivers may not have accurate knowledge and expectations of their aging bodies or how activity affects them, especially if their health care practitioners have not shared the information with them.

Some of these age-related body structure and function impairments that begin earlier in life in people with LLDs fall within the scope of physical therapist practice and thus are important to summarize here. Many orthopedic problems that begin during childhood continue into adulthood.26 For example, cervical spine impairments have been reported in adults with CP,27,28 and adults with Down syndrome have an increased risk of early-onset musculoskeletal disorders such as osteoporosis,29 mid-cervical arthritis, and foot and hip malalignments.24 Osteoporosis from inactivity in this population also has been documented.30 Secondary conditions involving the musculoskeletal and cardiopulmonary systems that affect fitness, mobility, psychosocial wellness, and life participation have been reported.51,52 Osteoarthritis in individuals with CP may occur due to restricted joint range of motion and altered muscle performance,53 which are common in this group. Several authors have reported the activity restriction of early walking cessation for some ambulatory individuals with CP51,54 for a number of reasons, including pain, fatigue, and decreased gait function.28 Many individuals with LLDs report having ongoing musculoskeletal, pain, and mobility issues in adulthood19,51,52,54,55 and may benefit from physical therapy. Andersson and Mattsson54 reported that 19% of survey respondents indicated that improved walking was partly due to regular physical training. These findings suggest the importance of regular and appropriate physical exercise for particular activity-related goals.

Such impairments and activity restrictions can affect participation opportunities,56 which may benefit from intervention from appropriate adult health care providers, including physical therapists. If not addressed, decreased activity and participation may result, with potentially significant consequences to health and well-being. A model of the causes and consequences of health decline in adults with CP, based on current evidence, that illustrates this concept was proposed by Peterson et al.56 Utilizing the ICF framework, these authors suggested that this is a cyclical process including early key deficits of reduced muscle volume, spasticity, and orthopedic malalignment that lead to earlier secondary declines, including muscle weakness, fatigue, and lack of activity. These factors place adults with CP at a higher risk for further decline of muscle function, cardiometabolic disorders, motor deterioration, and decreased opportunities for participation in life roles and activities. This framework provides a foundation for discussing the importance of regular physical activity, in particular for adults with CP, as an ongoing part of a management plan throughout the life span. Such discussions are important to physical therapist practice.

Physical therapists most familiar with youth with LLDs frequently have pediatric practices and do not follow these individuals into adulthood; however, those who primarily treat adults should also understand the different challenges of these consumers who seek physical therapy. It is critical for physical therapists to have a clear understanding of the unique life-span needs of these clients. Numerous factors affect their receipt of health care and how such services should be delivered.

Access to Community Health Care Services
Transition to and access to appropriate adult-directed health care are challenging for individuals with and without LLDs. Seeking and receiving health care is dependent upon need, access, and availability of services and financial or other related resources such as government-sponsored health care programs. Aging process differences associated with the LLD health conditions and medical diagnoses will challenge developing patient and provider relationships. Challenges may include provider lack of comfort and knowledge and limited physical access to clinic and office environments. Needs for caregiver assistance and assistive technology for communication, as well as access to appropriate adult health care screenings, can also be barriers. Addressing these challenges is a part of a unique client-provider partnership that will require creativity and problem solving, potentially leading to client satisfaction.

Financial Resources and Health Care Coverage
Pediatric physical therapy is provided in a variety of settings: hospitals, public and private schools, medical centers, and private clinics. In the public schools, physical therapy, under the federally mandated Individuals With Disabilities Education Act (IDEA),57 is administered at no charge to children who qualify. Services via IDEA are generally not provided by medical insurance and terminate during the year of the student’s 21st birthday or upon high school graduation. As individuals transition to the adult health care system, they become responsible for service payments either through insurance or private payment. Physical therapists working with adults with LLDs need some understanding of the unique health care insurance and financial resource issues. This
Understanding is important to be able to deliver appropriate physical therapist services while being adequately reimbursed, which also may mean providing clients with information that can assist them in finding financial and insurance resources. The type and extent of health care coverage often depend on a person’s or family’s work situation, income level, age, or health status. Many people with chronic disabilities are either unemployed or underemployed, making private or employer-sponsored health insurance or health-related services unavailable or unaffordable. Low income is a common problem for people with disabilities. Some individuals with disabilities who work have employer-sponsored health insurance, but many more do not, particularly those who work part-time. People working full-time are more likely to have employer-contributed insurance plans compared with those working part-time in addition to having sufficient income to purchase coverage if necessary.

People with LLDs who are unemployed or underemployed are either uninsured or receive insurance through a government program, either Medicaid or Medicare. For those who qualify, Supplemental Security Income (SSI) can assist with cash benefits and Medicaid. Adults over 18 years of age with LLD who work and have a qualifying disability under federal guidelines can receive Social Security Disability Income (SSDI) and thus are eligible for Medicare. Some adults with LLD receive health care services from both programs, but difficulty coordinating both programs can be a barrier to receiving appropriate health care services, including physical therapy. The Affordable Care Act (ACA) has specific provisions for assistance to coordinate care between the 2 programs, designed to make this transition easier between childhood and adult care.

Medicaid is state administered, unlike the federally administered Medicare program, and coverage for physical therapy differs from state to state. In certain states, there is no Medicaid coverage for physical therapy, making services difficult for some people to access. Individuals who are forced to rely solely on government-administered insurance plans have greater challenges finding and paying for appropriate health care that could meet aspects of the complex needs associated with specific conditions. Even with private insurance, interventions and specialized equipment are often not covered expenses. Consequently, as adults with LLDs transition to adult care, they may struggle to find and afford needed interventions and equipment, which they may have had access to as children and youth. The ACA has provisions designed to improve health care and access to services for individuals with disabilities such as eliminating coverage discrimination based on pre-existing conditions. These provisions may make transition to adult services, including physical therapy, easier. Many individuals with LLDs will continue to be covered under Medicaid, Medicare, or both, and even with these federal provisions, states will have some Medicaid plan flexibility. The Arc has published a thorough analysis of the ACA for people with disabilities, which can assist physical therapists to understand how to guide their clients through the reimbursement system for physical therapy services.

### Access to Primary Health Care and Preventive Services

The lack of health care providers who understand the special needs of youth and adults aging with LLDs is evident, as more adult medicine practitioners are enrolling individuals aging with disabilities in their practices. When the health care environment is not accessible and health care providers are not skilled in providing care to people with disabilities, both physical and emotional harm to the individual may result. Unfortunately, however, it can be difficult to find health care professionals who are experienced in providing coordinated and continuing care to adults with LLDs.

Specific complaints include inadequate physical accessibility to providers’ offices and treatment rooms, difficulty using equipment, and poor visual aids. Findings from a 2002 survey of California physicians showed that 20% were not familiar with the Americans With Disabilities Act (ADA), and 45% were not aware of the ADA architectural requirements. Therefore, it is not surprising that examination room accessibility (15.4%) and examination table accessibility (49.1%) were the most commonly cited problems for individuals with physical disabilities.

Each provider office needs to assess equipment issues of accessibility such as examination tables, space for wheelchairs to allow independent transfers, and testing equipment that can be adjusted for the unique performance abilities of individuals with motor challenges. Treatment areas, particularly when a private space is required, need to be large enough to accommodate a patient seated in a wheelchair, particularly power wheelchairs. Individuals with LLDs and physical disabilities need appropriately skilled and sensitive office staff to ensure safe transfers to and from wheelchairs or scooters to examination tables and to be positioned comfortably once transfers are completed. Another, safer option would be to have electronic examination tables to facilitate transfer ease.

Behavior and communication difficulties for individuals with intellec-
tual disabilities require that practitioners take more time for interaction and care, which may present a barrier to appropriate health care access but is an important feature of competent, patient-centered care for individuals with disabilities of all types. Additional appointment time is likely required to perform transfers safely and protect patient privacy and dignity. Adults with LLDs who use augmentative communication devices should be supported in using their devices for independent communication with the health care provider, ensuring patient-to-provider communication rather than caregiver-to-provider communication.

Physical therapists who do not typically serve adults with LLDs need to consider and address these accessibility issues so these clients can make a successful transition to their adult practices. In adult-oriented practice settings, physical therapists should orient and inform clinic or department staff regarding germane issues specific to these clients, especially physical environment needs. Physical therapists have a unique perspective to act as a resource to other medical professionals who provide annual or periodic/episodic routine care, such as medical or dental care. Additionally, physical therapists can help clients and their families to advocate for access needs as they transition to all-adult health care environments. A survey of 501 primary care physicians indicated that only 22.8% had some medical school training related to physical disability issues, and only 34.1% had such training in their residency program, although more than 72% of those surveyed agreed that this type of training is needed. Clearly, pediatric- and adult-oriented physical therapists collectively have a responsibility in facilitating clients’ transition path from pediatric to adult health care systems.

### Caregiver Assistance

Many adults with LLDs rely on a family member or caregiver for daily needs. Assistance may be needed with any or all parts of a provider visit, including identifying the need for the visit, seeking a referral from the primary care provider for services, scheduling the appointment, arranging transportation, and navigating in and out of the office. Once in the provider’s office, issues of communication may only be achieved with caregiver contribution. Follow-through with any home program such as an exercise program may be impossible without assistance. Therefore, providers must be inclusive and responsive to the clients’ caregivers by providing specific explanations and instructions to establish greater certainty of home program adherence. Providers also must be sure that caregivers are clearly informed about follow-up visits, referrals, and medication use, if necessary.

### Psychosocial Issues

Psychosocial influences are those that affect mental health and often appear in individuals as difficulty with functioning in social situations and trouble communicating with others. Such problems can lead to depression, anxiety, stress, and poor self-esteem. As a result, individuals with LLDs often exhibit poor social interaction and a lack of coping skills, making transition from pediatric skilled therapy services to adult services troublesome. Some individuals may continue to need skilled rehabilitation services and opportunities for recreation in the community, whereas others may only need participation in community-based social and recreational activity programs. There may be many opportunities to take part in community programs that offer social and physical activities; however, people with LLDs face challenges in these environments secondary to lack of experience and social isolation. Compared with same-age peers, people with LLDs are more frequently challenged during transitions within health care and in the community because of these differences.

Research regarding individuals with physical disabilities indicates that physical activity and social interaction with peers can have a positive effect on psychosocial function. For individuals with cognitive impairments, the issues are often magnified due to limited ability to understand and communicate effectively. Research concerning youth and adults participating in organized adapted sports suggests that self-efficacy and quality of life are significantly related outcomes. Further investigation is needed, but current literature proposes that physical activity may have a positive effect on psychosocial functioning in youth and adults with LLDs.

### Community Fitness Opportunities

Adults with LLDs repeatedly report interest in health, wellness, and fitness activities. Lack of inclusive and accessible fitness centers, however, is a barrier to physical activity. Limitations of access are related to the physical environment, actual fitness equipment, information, policies, and professional staff knowledge and attitudes. Facilities attempt to be welcoming through accessibility and programming but are often constrained by physical space and demand for classes that are rigorous rather than inclusive. Community fitness center equipment is generally not designed for individuals with disabilities or wheelchair users and may be a major deterrent to participation in community programs and facilities run by national fitness corporations. Personal training is commonly available in most fitness centers; however, there is no research regarding appro-
appropriate frequency, intensity, or duration of physical activity to improve physical fitness in people with LLD working with personal trainers. The prevalence of overuse injury in people with CP must be considered as a possibility in aging individuals who exercise, but exercise instructors and athletic trainers have little or no knowledge of fitness adaptation for individuals with LLDs. Fitness center members with an LLD and neuromusculoskeletal impairments may need monitoring and guidance by a physical therapist.

Exercise, fitness programs, and strength training have been shown to improve health, fitness levels, and motor abilities in adults with LLDs. Fitness can be achieved through individual home programs. However, the social aspect of going to a gym, receiving support, and engaging in camaraderie with gym members and fitness staff is beneficial to the social well-being of adults with CP and can increase community participation and commitment to exercise and inclusion. Physical therapists can be practitioners of choice to assist adults with LLDs by designing and monitoring physical activity programs that include appropriate, safe, and individually meaningful outcomes. With community commitment and physical therapy consultation, these adults may be able to take place in socially appropriate and stimulating community environments.

Implications for Physical Therapist Practice
Physical therapists working in adult practice settings should be willing and prepared to provide services to people with LLDs. Several authors have suggested various roles and interventions for physical therapists working with adolescents and adults with LLDs. However, physical therapists providing services to adults report the following barriers:

(1) extra time required to work with patients with complex conditions, (2) lack of insurance coverage, and (3) lack of experience with LLDs. The physical therapist’s role in providing these services can be unique because of the chronic and multisystem nature of the conditions and can extend beyond direct therapeutic or manual interventions. Broad-based interventions can range from management of pain to providing assistive technology for mobility and communication independence, as well as home, work, and recreational independence and disability rights advocacy. The adult emphasis on participation in life roles and corresponding activities requires ecologically based assessments in inclusive settings specific to individual consumer’s goals. This approach suggests consideration of utilizing the ICF model with its more holistic paradigm of a biopsychosocial model of care. The Figure is an illustration of how the ICF model can be used to plan for a health need for a client with an LLD transitioning to adult health care. In addition to impairment-level therapy interventions, participation in meaningful lifetime activities to adults with LLDs must be considered. Physical therapists can be present with young adults in the appropriate environments to evaluate skills, implement intervention strategies, and collaborate with their support networks. The following are examples of potential physical therapist roles with these clients:

- Promote community, leisure, and health-related fitness activities.
- Help prevent secondary conditions and promotion of wellness by providing anticipatory guidance beginning at the time of transition and continuing as needed.
- Provide input and intervention for mobility, biomechanics (positioning), materials access, public transportation, assistive technology, and movement dysfunction.
- Practice problem-solving skills with clients such as asking for help and instructing others to correctly and safely assist in performance of activities.
- Assist with job development, job coaching, and job placement options through intervention assistance to improve personal management, job supports, or use of assistive technology to negate effects of any physical impairment on job performance.
- Consider the need for assessment and consultation regarding how to live and work within the community rather than within a segregated setting.
- Collaborate with other professionals (vocational, educational, adult living, medical, and other community-based agencies) to address barriers to functioning and ensure success.
- Offer assessments and consultations at community centers.
- Help prevent secondary conditions while promoting wellness.
- Consult and collaborate with medical and nonmedical professionals to facilitate and support the transition of individuals with LLDs from pediatric to adult-oriented practitioners.

Direct service opportunities may occur during the times of the day that the individual is at home, work, postsecondary education, fitness centers, and medical appointments. Physical therapists should be involved in educating clients, support staff, coworkers, caregivers, medical providers, and transportation workers. Table 2 outlines examination and intervention roles for physical therapists working with adults with LLDs across life domains.

Solutions
The ADA sets standards for accessibility of public accommodations, commercial facilities, and private...
entities; however, barriers still exist that prevent full access to fitness and recreation facilities for individuals with disabilities. Physical therapists have the knowledge and skills to help fitness facilities achieve accessibility by making access and egress areas larger, improving changing rooms and workout areas for wheelchair users and individuals with other mobility challenges, and adapting equipment for greater universal usage. Physical therapy consultation should be available in fitness centers for adults with LLDs to assist in developing safe and effective exercise programs with regard to consumer activity limitations and related impairments. Fitness activities can be easily adapted for adults with LLDs, including changes in the way a fitness activity is performed or the amount of assistance needed, to be beneficial. Physical therapists are ideal professionals to provide information and consultation regarding accessibility issues in other health care environments such as medical and dental offices where some examinations necessitate transfers out of a wheelchair.

Embedding case studies and content related to adults with LLDs in entry-level physical therapist education program courses across body systems is strongly encouraged. This approach should prepare students to better understand the lifelong nature of the strengths, limitations, and impairments in people with LLDs. Students should leave their physical therapy education programs prepared to provide age-appropriate services in adult-oriented practice settings for all potential clients. Examination and diagnosis by physical therapists based on identification of activity limitations and body structure impairments should be focused within various contextual environments and appropriate body systems. Medical diagnoses such as CP, Down syndrome, or myelomeningocele may be taught in a specific pediatric course; however, such conditions should not be linked with a specific age group. Age, as a framework, may help guide an approach to examination and intervention at points along the life span but should not limit scope of practice within a setting. The ability and skill of the physical therapist to address issues such as low back pain, knee instability, limited neck range of motion, gait asymmetry, and sit-to-stand transfers are key regardless of a patient’s age or underlying health conditions.

**Conclusion**

Two of the largest transition barriers are the inability of child-centered health care professionals to “let go”
Table 2.
Examples of Physical Therapist Examination and Intervention for Adults With Lifelong Disability Across Life Domains

<table>
<thead>
<tr>
<th>Setting for Examination and Intervention</th>
<th>With Whom?</th>
<th>Examples of Physical Therapist Examination and Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adult Living and Community Participation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health/wellness facility</td>
<td>Client, Families/caregivers, Support staff, Fitness staff</td>
<td>Examination: ecological assessment or published tools documenting needed skills in the fitness facility, measures of fitness, and interview of clients' needs/preferences to determine the ability to perform tasks and barriers, safety, and supports/interventions needed for client success. Client-related instruction: appropriate fitness activities for specific disability, transfers, mobility within a facility. Coordination/communication/documentation: collaborate with fitness center staff about facility accessibility; records for fitness program. Procedural interventions: provide strength and flexibility exercise.</td>
</tr>
<tr>
<td>Health care system</td>
<td>Client, Families/caregivers, Support staff, Preventive/routine care and specialty providers</td>
<td>Examination: ecological assessment or published tools documenting skills needed to communicate with and physically access the adult health system to determine the barriers, safety, ability to perform task, and supports/interventions needed for client success. Client-related instruction: identify local adult medical professionals with client/families, practice role playing with client for communication related to medical care, teaching self-determination/advocacy skills. Coordination/communication/documentation: assist client/family with health care transition plan; therapist may need to collaborate with adult medical providers about disability and facility barriers. Procedural interventions: strategies for access to medical facilities, instruction in self-advocacy techniques, travel training.</td>
</tr>
<tr>
<td>Transportation systems</td>
<td>Client, Families/caregivers, Support staff, Transportation agencies, Community planners, and drivers</td>
<td>Examination: ecological assessment or published tools documenting needed skills for public or self-owned transportation to determine the barriers, safety, ability to perform task, and supports/interventions needed for client success. Client-related instruction: educate transportation personnel and fit client needs within available resources; teach client how to access transport system. Coordination/communication/documentation: coordinate schedules for transport and available services. Procedural interventions: travel training, strategies for safety and overcoming potential barriers.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Setting for Examination and Intervention</th>
<th>With Whom?</th>
<th>Examples of Physical Therapist Examination and Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment and Postsecondary Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competitive or supported employment Postsecondary education (university or community college)</td>
<td>Client/families and caregivers, Employer, Coworkers, Job coach, University/college disability services, Personal care attendants</td>
<td>Examination: ecological assessment or published tools documenting needed skills in the specific setting (work or educational campus) to determine the supports and interventions needed for client success. Client-related instruction: practice problem-solving skills with clients such as asking for help and instructing others to correctly and safely assist in performance of activities, hiring and firing personal care attendants. Coordination/communication/documentation: collaborate with adult service agencies such as vocational rehabilitation and developmental disabilities agencies, university staff, and health clinics; complete paperwork to obtain powered mobility; document the supports needed for work and educational environments. Procedural interventions: - Provide adaptations to task or recommend assistive technology - Task-specific training (eg, using the computer, operating power wheelchair) - Relaxation activities across environments.</td>
</tr>
</tbody>
</table>
of their relationships with children they have served for years and a distrust of adult-centered health care services. Increasingly, adults with LLDs are challenging adult health care providers to examine their own practices and previously held expectations of people aging with LLDs. The need for more data is clear. Current work has begun to clearly describe the issues faced by adolescents and adults with LLDs, including health disparities, psychosocial issues, financial and caregiver resources, and health provider knowledge and preparation. This article has presented the literature and a perspective on how physical therapists can provide services to individuals with LLDs as they transition to and become part of the adult health care system. Physical therapists providing care in adult practices should recognize that, although the client with LLDs may have received his or her medical diagnosis in childhood, the services being requested are for adult-related health care needs and concerns. The childhood diagnosis identifies the history of the condition and provides a framework for secondary conditions experienced in adulthood. Preventing secondary impairments; determining and providing appropriate supports, adaptations, and accommodations; and advocating for routine health care screenings and tests are all within the responsibilities of the physical therapist. Physical therapists must partner with clients with LLDs to identify the issues and craft solutions to improve overall successful transition to adulthood that is person-centered and specific to each client’s unique needs.

All authors provided concept/idea/project design and writing.


References


