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Childhood Disability:
Challenges and Theory-Informed Child Life
Interventions in the Healthcare Setting

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Child Life Online

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Abstract

Children with intellectual, sensory, physical, and/or speech disabilities encounter a proliferation of challenges in the healthcare environment. Such challenges are exacerbated by insufficient knowledge in doctors, nurses, child life specialists, and other healthcare providers in bias-free and specialized healthcare delivery. To remedy this, pertinent methods informed by theoretical perspectives of atypical development that ameliorate stress and augment coping in children with disabilities are warranted. Therefore, the purpose of this independent study is to provide a synthesis of the literature that chronicles this topic. Multifarious child life interventions that are premised on contemporary developmental frameworks of childhood disability will be presented. The overall objective is to enlighten healthcare personnel of the valuable and critical approaches to implement and utilize with children with disabilities in clinical practice.

Keywords: Disabilities, challenges, developmental frameworks, child life interventions

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Introduction

According to the United States Census Bureau (2018), 40.7 million of the total civilian population have a disability in the United States. This figure encompasses 2.8 million children; excluding the youth with an impaired condition that has not been diagnosed or is classed as a non-severe disability (Americans with Disabilities Act National Network, 2019). Children with disabilities often require primary and subspecialty services from multiple systems, such as public health, mental health, education, healthcare, and social services (Health Resources and Services Administration, 2019).

‘Disability’ has different specialized meanings adapted to the policy or program using the term (Francis and Silvers, 2016). For the purpose of this independent study, the legal definition listed by the Social Security Administration (n.d.) will be used, which aligns to that from the Merriam-Webster (2019) medical dictionary: ‘the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s)’. The condition or function is impaired relative to the usual standard of an individual or group and is often conceptualized as a multi-dimensional experience for the person involved (Disabled World, 2019).

The categorization of different disabilities can be complex. Loosely, four types can be distinguished: intellectual, sensory, physical, and speech (Aruma., n.d.).

Definitions

Intellectual

Intellectual disability is characterized by below-average mental ability (Bhandari, 2018). Individuals with this disability exhibit deficits in core executive function skills, which are important for adequate behavioral functioning and flexible thinking. Executive function skills

affected include managing time, diverting focus, paying attention, planning and organizing, recalling details, and initiating activities and tasks (Bhandari, 2018).

In addition, persons with intellectual disabilities may also be inept at adapting behaviors that are necessary for day-to-day living. This involves a delay in rolling over, sitting up, crawling, walking, and talking. In addition, mastery of skills such as toileting, dressing, personal hygiene, grooming, housekeeping, and feeding oneself may be impeded (Bhandari, 2018).

Sensory

Sensory disabilities can affect any of the senses, such as hearing, seeing, and touching stimuli (Abrams et al., n.d.). A person's sensory apparatus may also be severely compromised as a result of a deficit in cognitive and integrative processing of sensory information (Solomon, 2012).

Sensory processing. Persons with a sensory processing disorder (SPD) can receive information through the senses. However, problems arise when the brain registers, interprets, and processes this input atypically, which manifests as unusual behaviors in response to the physical stimulus (Sincero, 2013).

According to Miller, Nielsen, Schoen, and Brett-Green (2009), three diagnostic categories are proposed from the term SPD. Type I SPD, known as Sensory Modulation Disorder (SMD), refers to difficulty grading or regulating responses to sensory stimulation. Persons are either hyporesponsive to stimuli (respond too little or need intense stimulation to become aware of the stimulus), hyperresponsive to stimuli (respond too much, for too long, or to stimuli of weak intensity), or seek stronger stimulation (Nunez, 2018). The attributes of the stimulus (such as the frequency and intensity) are differently processed. Symptoms include fear-anxiety patterns or self-absorbed behaviors (Miller et al., 2009).

Second, Type II SPD, referred to as Sensory Based Motor Disorder (SBMD), includes symptoms of dyspraxia or related to postural control (Sincero, 2013). This encompasses difficulties in balance, core stability, motor planning, and/or sequencing movements (Miller et al., 2009).

Third, Type III SPD, named Sensory Discrimination Disorder (SDD), involves abnormal processing of auditory or visual sensory information, such as the intensity, duration, and spatial/temporal elements of sensations. SDD can present in any sensory system (e.g. proprioceptive, vestibular) and manifests as poor attention, difficulty concentrating, and disorganized behaviors (Miller et al., 2009; Sincero, 2013).

Visual impairment. A visually impaired person's eyesight cannot be corrected to a 'normal level' (Mandal, 2019). He/she either has a functional limitation of the eye, eyes, or visual system due to an injury or 'disease that can result in visual disability or a visual handicap' (Freeman et al., 2007). This leads to loss of visual acuity (inability to view objects as clearly as a healthy person), visual field (inability to see as wide an area as the average person without eye movement or head rotation), diplopia (double vision), photophobia (inability to look at light), visual distortion of images, visual perceptual difficulties, or a combination of any of these features (Mandal, 2019). Complete blindness is the most severe impairment of visual function resulting from a significant failure in the visual process (Ray et al., 2016).

Hearing loss. Hearing loss refers to the partial or complete inability to hear noises and can vary depending on the pitch (frequency) of the sounds being produced (Felman, 2018). There are four types of hearing loss: 1) Auditory processing disorder, a subtype of SDD, occurs when the brain has challenges in processing the information contained in sound; 2) Conductive hearing loss occurs when problems with the outer or middle ear interferes with the passing of sound

information to the inner ear; 3) sensorineural hearing loss occurs when the hearing organ (cochlea) and/or auditory nerve malfunction and cannot send electrical information to the brain; and 4) mixed hearing loss occurs when both sensorineural and conductive hearing loss are present (Hearnet Online, n.d.). Profound deafness is the most severe impairment of auditory function. In this condition, sound cannot be heard at all, even if amplified (Felman, 2018).

Olfactory impairment. The reduced ability to smell odors is known as hyposmia (Hawkes, 2002). Affected individuals have a higher threshold for odor and flavor perception but have a poor ability in discriminating smell or taste intensity levels (Lawless and Heymann, 1999). This condition can result from head trauma, allergies, infections, flu, or nasal polyps. At times, hyposmia is self-repairing, but much of the time remains permanent. Anosmia is the most severe deficit of olfactory function, as in this condition, no odors can be detected at all (Lawless and Heymann, 1999).

Gustatory impairment. Gustatory dysfunction is the affected perception of flavor (salty, sweet, sour, or bitter) by tongue throughout the eating process (Maheswaran et al., 2014). Ageusia is the absence of a sense of taste and hyper/hypogeusia is the enhanced/decreased sensitivity to all tastants. Dysgeusia is the unpleasant perception of a tastant and phantogeusia is the perception of taste that occurs in the absence of a tastant. Gustatory impairment is associated with decreased appetite, nausea, and dry mouth (Maheswaran et al., 2014).

Physical

Persons with a physical disability may have a locomotor impairment, defined as the inability to execute distinctive activities associated with moving personally/objects from one place to another due to afflictions of the musculoskeletal/nervous system (Goyal et al., 2000). Moreover, paralysis, amputation, deformity, or dysfunction of joints can also affect the normal

ability to move oneself or objects as a result of loss, absence, or inactivity of the whole or part of a limb (Ashok et al., 2015). Those with the condition of dwarfism, a stiff neck of permanent nature, or deformity of the body other than the arms or legs (e.g. hunched back, deformed spine) are also considered to have a physical disability (Ashok et al., 2015).

Speech

Speech and language disorders include deficits in the articulation of sounds, voice, and fluency (speech) or in the spoken, signed, or written system (language) (Prelock, Hutchins, and Glascoe, 2008). Speech and language disorders can have adverse effects on one's receptive skills (i.e. decoding, integrating, and organizing vocal input) and expressive skills (i.e. articulating sounds, exhibiting appropriate rhythm and tone, resonance during speech, and using words in meaningful contexts) required for effective communication (Prelock et al., 2008).

Speech and language impairments are distinguished from language delay, which is 'characterized by the emergence of language that is relatively late albeit typical in its pattern of development' (Prelock et al., 2008). Furthermore, unassociated with an impairment or delay, a language difference involves a systematic variation in vocabulary, grammar, or sound structures; used by a group of individuals and determined by shared regional, social, or cultural and ethnic factors (Bland-Stewart, 2005).

The Controversy Around the Use of the Term 'Special Needs'

According to disability activist Fuga (n.d.), the euphemism 'special needs' to refer to persons with disabilities reflects the best of intentions to use language that is not stigmatizing but actually overlooks the 'cultural prejudice that lies at the heart of the concept of 'special' and the isolation and marginalization that flow from that prejudice'. The fundamental needs of children with disabilities are not special but basic and human. This includes to be nurtured, educated,

communicated, work, love, and live (Fuga, n.d.). Thus, the use of this expression is condescending and patronizing, as the person with a disability may be pigeonholed in a protected and exceptionalised mental place that is segregatory and exclusive, related to a baggage of assumptions and preconceptions, and imprisoned by the way in which he/she is defined. Fuga (n.d.) and other disability activists such as Nichols (2017) assert to use the word 'disability' and not 'special needs' instead, as 'to tell it like it is' enables people with disabilities to define their own identity in which disability is an inextricable part (Fuga, n.d.). This contention is respected and abided by throughout this independent study.

Literature Review

Children with disabilities are more likely than typically developing children to experience healthcare encounters due to the prevalence of co-existing disorders such as epilepsy or attention deficit-hyperactivity disorders (Nunez, 2018). These children have more demands for primary care physician visits, non-emergent and emergent care, and specialist services. Needs for medications and hospitalization during acute episodes of illness are also increased (Edmunds and Coye, 1998).

Challenges Children with Disabilities Encounter in the Healthcare Setting

A child's coherent understanding of the medical diagnosis and procedures represents a milestone in the successful management of his/her coping and healing (Webster, 2014; Mărginean et al., 2017). Nevertheless, children with intellectual disabilities are frequently unable to represent their own health concerns due to their inability to comprehend the complexity of healthcare process (Ervin, Hennen, Merrick, and Morad, 2014). Profound problems in the conceptual domain of adaptive functioning (including knowledge and memory) may also deter the function to process hospital experiences in logical terms, leading to significant

misconceptions and misunderstandings (Marrus and Hall, 2017). For example, a child with an intellectual disability may interpret an intravenous (IV) start as punishment for misbehavior as opposed to treatment for an illness.

Cognitive challenges in recognizing, understanding, and communicating health problems can also affect adherence to medical treatment (Erin et al., 2014). Poor comprehension can inhibit the effective use of coping mechanisms, leading to heightened levels of distress and anxiety or displays of problematic behaviors (e.g. noncompliance, self-injurious tendencies) that can further complicate a child's process of preparation and capacity for resilience prior to and during stressful healthcare encounters (Nunez, 2018). In addition, deficits in basic day-to-day functions may be more troubling during hospitalization and extra assistance may be necessitated, which is not always readily available or accessible.

Moreover, effective communication is the cornerstone of care. Importantly, comprised in physician-parent-child communication is the invitation to the child and family to express their feelings, perspectives, and suggestions, which also facilitates partnership-building (Mărginean et al., 2017). However, impairment in spoken language, verbal expression, or fluency may impede effective communication and cause a strain in the patient-provider relationship. In such circumstances, the caregiver or other family members may speak on behalf of the child, being his/her 'voice' and promoting his/her rights (Glasper, 2017). With the child's true emotions only assumed through nonverbal cues such as body language and facial expressions in such situations, misinterpretations can ensue, which is anxiety-producing for him/her and the family (Nunez, 2018).

Furthermore, the five senses are the primary means active in children for meaningful learning about objects and the environment (Wortman, 1998). Nonetheless, children with SMDs

may lack the cognitive capacity to efficiently process the bombardment of unpleasant stimuli; such as the sights of fluorescent lighting, the sounds of dissonant alarms and beeps from diverse machines, and the smell of antiseptic and the artificial fragrance contained in soaps and sanitizers in the hospital (McCurdy, 2018). If a child is hyperresponsive, he/she may behave in ‘socially unacceptable’ ways, such as covering his/her ears to monitor sounds, showing aversion to the lighting, and have toileting problems due to the overpowering smell of cleaning products (Nunez, 2018; Baranek et al., 2013; National Autistic Society, 2016). On the other hand, if the child is hyposensitive, then he/she may not orient to the novel sights, sounds, or smells in the hospital environment; missing innumerable learning opportunities and socially-contingent responses foundational to social interactions and subsequent adaptive development (Baranek et al., 2013).

A child that exhibits hearing/visual/olfactory impairments may react similarly to a child that is hyposensitive to sensory information if a comorbid mental condition or SPD exists. The sense that is impaired will also hinder the input of sensory information that informs the specifics of medical procedures, such as the sight of a needle for a visually-impaired child or the sound of an inhaler puff for a child with hearing loss. Moreover, a key concern for pediatric patients who have a visual disorder is safety. Unmarked steps, uneven flooring, obstructive furniture, and other obstacles that affect spatial navigation are all safety issues (Vision Center for Excellence, 2014). In addition, hearing loss presents a threat to patient safety through inadequate communication with healthcare providers (particularly in cases with an older child or adolescent in isolation or with no family members present), risking misdiagnosis and improper or delayed medical treatment (United States Department of Justice, 2003).

A distressing tactile stimulation can be caused by pain stimuli (Andrews, 2015). In particular, children that have altered states of consciousness, severe cognitive impairments, or speech/language disorders may not be able to self-report their discomfort. Rather, they may express a subtle stress response to the pain elicited from invasive medical procedures. With the absence of a vocal cry, pain behaviors in children with intellectual disabilities may be confounded with challenging behaviors such as instinctively drawing back, decerebrate posturing, or spasticity, or baseline behaviors such as moaning and staring blankly into space (Crosta, Ward, Walker, and Peters, 2014). In both cases, if such atypical cues indicating distress are overlooked, an inaccurate pain assessment may be obtained and inappropriate pain management implemented; exacerbating the child and family's stress during challenging healthcare experiences (Andrews, 2015; Crosta et al., 2014).

Moreover, research demonstrates that children are less fearful and distressed when in a comforting position during stressful medical episodes, such as sitting upright in the caregiver's lap and maintaining a hugging hold rather than supine (Rumple and Webster, 2017). However, a child's physical disability may challenge the establishment of a suitable and reassuring hold, mitigating his/her sense of control and potentially impacting his/her compliance levels. Moreover, as opposed to cases with able children, the inability to hold a comfort position may require the presence and assistance of many staff members (Brown and Chitkara, 2014). The surrounding scene of 'white coats' may have deleterious effects on the emotional health of the child, and the idea of the child's physical impairment presenting a hindrance to the safe and effective accomplishment of medical procedures may heighten caregivers' concern and agitation (Brown and Chitkara, 2014).

Although comfort positions may be possible with children who are cognitively and not physically challenged, children with intellectual disability may exhibit reactive behaviors that are combative in nature (Gandolfo and Roell, 2017). Their sensitivities to touch, sensory processing difficulties, communication deficits, and inability to keep their bodies stationary for an extended amount of time may lead to ‘fight or flight’ responses and aggressive attempts to escape from the distressing stimuli (Kuhaneck and Chrisholm, 2012). Thus, multiple staff members may be needed for physical restraint and seclusion during invasive procedures or exams, which may lead to behavioral escalation, direction of angry outbursts at his/her caregiver or the medical providers, as well as psychological trauma (Gandolfo and Roell, 2017; Reddy, Hassuk, and Azeem, 2017).

Healthcare disparities and intersectionality. The health needs of children with disabilities are often unrecognized or unmet in comparison to children with a typical health profile (Flood, 2017). Research highlights persistent disparities in health status and disproportionately higher rates of health problems experienced by children with disabilities, such as comorbidities, chronic conditions, and preventable mortalities (Ervin et al., 2014; National Research Council, 1998).

Moreover, the intersectionality of marginalizations compound the implications of disability (Gordon, 2016). One instance is the act of correlating disability and race which is often fraught with oppressive overtones (Erevelles, n.d.). Research shows that pediatric patients of color are routinely connected to disability and face grave challenges in receiving equitable care compared to differently abled patients who are racialized as white (Gordon, 2016). For example, using an intersectional lens, Mereish (2012) found that Asian American and Pacific Islanders (AAPIs) with a learning, emotional, or physical disability reported more experiences of

discrimination in the healthcare setting, poorer physical and mental health ratings, and greater physical and psychological distress compared to AAPIs without a disability.

Moreover, there is a traditional relationship of lower socioeconomic status (SES) and difficulty accessing healthcare services in children with disabilities, which can ultimately result in an increased risk for poor health and quality of life outcomes (Raouafi, Achiche, and Raison, 2018). Barriers to obtaining healthcare result from mobility/access problems, issues with communication and/or insurance, or financial strain due to medication costs. The latter issue can also force a caregiver of low SES to reduce the medication dosage for his/her child, avoid refilling prescriptions, or not adhere to treatment regimens (American Psychological Association, n.d.). Consequently, mental health problems and risky behaviors can occur in this population, such as depression, suicidal ideation, or substance abuse (Evans, 2016).

Implications on healthcare providers. A disabled child and his/her family's access to healthcare is also affected by another major barrier: ableism. This term refers to favoring individuals that are able-bodied and assigning inferior values to those that have abnormal bodily forms/functions (Educational Resource Center on Deafness, 2013). Ableism has been a central and unquestioned part of medical history, with the notion that being 'able-bodied is best' is common sense (Reynolds, 2018). For clinicians, ableism operates in the background of their knowledge and expertise. An example of an ableist intuition is that an adolescent with a physical variation desires to walk when he may in fact be content and live a flourishing life as a wheelchair user. Consequently, 'ableism undermines clinicians' ability to engage with patients with disabilities as they in fact live their lives; it distorts communication with all patients regarding transitions into and experiences of various states of disability, whether due to age,

injury, or other factors; and it misaligns the ultimate priorities of medical care insofar as it fosters an unreflective support of normalcy' (Reynolds, 2018, p. 1183).

Furthermore, there is an alarming number of inexperienced healthcare providers across communities (Ervin et al., 2014). In relation to more complex disabilities, 'primary care physicians may not have adequate knowledge of the condition, its treatment, and the best monitoring practices' (Perrin, 2002, p. 308). Only the process of diagnosing and treating more common conditions such as motor disabilities originating from the central nervous system are more well known. Thus, children with disabilities frequently receive care from clinicians that are not appropriately trained. In addition, healthcare providers seldom have more than cursory information available pertaining to the child with a disability's health history, and thus may be unaware of related physical and medical needs (Ervin et al., 2014).

The challenges presented in treating children with disabilities may lead to exhaustion, cynicism, perceived inefficacy, and burnout in healthcare workers (Reith, 2018). A myriad of other factors can also cause burnout and affect job performance. For example, physicians frequently work overtime hours, which can result to rampant levels of fatigue, detachment from the patients and families served, poor wellbeing, and, in severe cases, increased malpractice (Plemmons, 2018). Moreover, having to complete a plethora of bureaucratic tasks to comply with misaligned and burdensome regulatory programs can impede physicians from spending critical time to patients with disabilities (Reith, 2018). Thus, burnout may explain the disconnect physicians may feel in their interactions with families, with communication less than optimal, information sharing not prioritized, and close relationships not formed; all facets integral in providing high-quality and individualized care (Sharkey et al., 2014).

Rationale

In encountering a child with a disability during child life volunteer hours in the pediatric emergency department, mastering an appropriate and sensitive approach is a struggle. Reminded that ‘parents are experts on their children’ (McKnight, 1989), a reflexive reaction is to communicate with the family member(s) about his/her role of a child life volunteer and ask their advice on how to address the child’s needs astutely. For example, in one instance with a non-verbal autistic child, a volunteer explained the reason for her visit to the caregiver and enquired about her son’s play interest. She requested ‘anything that is a vehicle, like a truck or car’; to which the volunteer granted. However, the volunteer was unsuccessful in engaging the child in play. He ushered her away using hand gestures, hurled the truck to the floor, and began to scream. Although the child’s reaction in the interaction may have been attributed to a number of plausible factors (e.g. stranger anxiety, distressing elements of the truck such as shape, color, etc.), the volunteer was irresolute in advocating for his voice, expressing empathy, and building a rapport. Perturbed, she apologized to the child’s mother for disrupting the normal ‘order of things’ and departed the room hastily.

However, the volunteer’s incertitude as a student in such circumstances comes as no surprise, as pediatric healthcare providers also lack understanding in intervening with children with disabilities (Ervin et al., 2014). Furthermore, a publication by the Child Life Council states that among providers, child life specialists (CLSs) also receive insufficient training in aptly supporting children with developmental variations (Andrews, 2015; Moore, Bennett, Dietrich, and Wells, 2015). This is discombobulating, as a CLS’s role is to use expertise in child development to devise specialized interventions to promote a hospitalized child’s coping, whether he/she is typically or atypically developing. This gap was also brought to attention in a

discussion with a child life supervisor. She voiced that ‘at times, we get it wrong when it comes to helping a child with a disability, but more often it is the disciplines we work with.’

Overall, it becomes apparent that ‘not knowing’ how to interact with children with impairments is the norm in the medical and child life profession. Therefore, one aim of this independent study is to present a number of child life interventions that educate CLSs and other healthcare providers of the apposite support strategies that are modified for children with disabilities and designed to mitigate the challenges (outlined in the literature review) this population frequently encounter in the healthcare environment.

In addition, it is paramount for CLSs to identify and apply developmental frameworks when devising plans of care for able-bodied children (Child Life Clinical Internship Task Force, 2011). Nevertheless, a theoretical lens on atypical development is also an unexplored research potential; which may justify CLSs’ deficient knowledge in intervening with children with disabilities. Thus, another goal of this independent study is to collate the perspectives from adapted frameworks of child development theories that focus on the growth of children with disabilities, as this will be indispensable in supporting and grounding the child life interventions proposed afterward.

Developmental Perspective/Background

Traditionally, schools of thought have emphasized the importance of repairing the impairments that underlie childhood disabilities in order to facilitate a healthy developmental pathway and outcome (Skelton and Rosenbaum, 2010). The logic for theorists such as Piaget, Erikson, and Vygotsky (1896-1994) was to observe the systematic changes, continuities, and milestones reached in ‘normal’ children at the same rate across ages, stages, and cultures as a result of one type of influence (e.g. biological, environmental, or parental factors). No abnormal

variations were illustrated to assess the robustness of theories in application to situations outside the norm (Koller, 2019; Skelton and Rosenbaum, 2010). However, frameworks developed after their propositions offer perspectives that conceptualize the integration of ‘disability’ and ‘development’ more effectively. This research will be explored in relation to the key tenets of the traditional notions of child development.

Piaget

The hallmark of Jean Piaget’s theory is its emphasis on children actively constructing an understanding of the world on the basis of experiences and shaping their own cognitive development (Lightfoot, Cole, and Cole, 2012). This constructivist theory reflects a gradual process with each stage laying the groundwork for the next. The first is the sensorimotor period from 0 to 2 years, where an infant seeks contact with the environment by learning or acquiring adaptations and intentionally responding to new or interesting stimuli. Next, in the preoperational period, Piaget claims that a 2 to 7-year-old is locked in egocentrism but develops knowledge derived from action and the ability to mentally manipulate symbols (Weekly, 1979). Third, in the concrete-operational period, children 4 to 11 years exchange their egocentric focus for a widening of views to include the whole environment, begin to organize information, and understand the concept of conservation (Complex Needs, 2016). Finally, in the formal operational stage which commences at 12 years, an adolescent can ‘transcend the world of the concrete’, carry out inferential thinking, and entertain numerous possibilities of a situation (Weekly, 1979, p. 10).

Adaptation is the essence of intellectual functioning in each of Piaget’s stages, consisting of two simultaneous processes: assimilation (associating new knowledge with existing patterns of thought known as ‘schemas’) or accommodation (associating new knowledge with new

schemas) (Complex Needs, 2016). A state of equilibrium is achieved once these two processes are balanced which stimulates the child to achieve higher levels of intellectual functioning in preparation for the subsequent stage (Lightfoot et al., 2012).

Although the ordering of the stages is absolute, Piaget has stressed that the age norms for each period is only an approximation, and that the complex set of characteristics that each child possesses contributes to individual differences in learning rates. Children with intellectual disabilities develop Piagetian skills and concepts in the same sequences as typically developing children but at a later chronological period, known as a developmental lag (Malik and Marwaha, 2019). In other words, the pace at which the levels are achieved and the difficulty with which new skills are acquired differ for children with intellectual variations in comparison to children that have a normal developmental trajectory.

Research shows that specialized instruction holds promise for adequate stage progression in children with intellectual disabilities (Tilstone and Layton, 2004). However, educators that inadvertently support homogeneity can cause a child with an intellectual impairment to experience chronic disequilibrium and vastly fluctuate between Piaget's stages. Thus, it is imperative for educators to individualize to the needs of the child and use suitable instructional materials in specialized learning approaches. The exploitation of senses is one method effective in helping children with intellectual disabilities assimilate and accommodate their experiences (Tilstone and Layton, 2004).

Erikson

Erik Erikson's theory of psychosocial development is an epigenetic approach to identity development which unfolds in a succession of six stages throughout childhood, adolescence, and young adulthood; resulting from the interplay between the individual psyche, the developing

biological organism, and the social, historical, and cultural context (Shevchuk, 2017). Each stage presents a new psychosocial ‘crisis’ to be resolved, which Erikson viewed as a dialectical process (Schachter, 2005).

According to Erikson, in the trust versus mistrust stage (stage one), a 0 to 18-month-old learns to trust or not trust that the world (including the primary caregiver) will supply his/her nurturance needs, leading to the virtue of hope. Next, an 18 month to 3-year-old develops the ability for muscle control and independent action in the autonomy versus shame and doubt stage (stage two), resulting in the capacity to exercise his/her will (Shevchuk, 2017). At age 3 to 5, a child acquires a sense of purpose in the initiative versus guilt stage (stage three), as he/she begins to take risks in initiating actions and exploring interpersonal skills (McLeod, 2018). Between the ages of 5 to 12, in the industry versus inferiority stage (stage four), a child develops a sense of competence in demonstrating specific skills that are valued to accomplish tasks. During adolescence, in the identity versus role confusion stage (stage five), an individual achieves fidelity by synthesizing his/her own identity and making choices of what roles he/she will occupy as an adult based on the outcome of explorations.

As the framing of the ‘crises’ of each stage reflects limitations of non-disabled assumptions and Eurocentric values (that Erikson espoused), Shevchuk (2017) offers a detailed, contemporary framework that posits different development ‘crises’ encountered by youth with disabilities presented in modern society. In stage one, the resolution of hope is problematic for caregivers of infants with a disability, as ‘medical professionals and families confuse medical procedures intended to bring an [infant] closer to society’s ‘normal’ standards with interventions needed to support [his/her] unique development from that point on’ (Shevchuk, 2017). Nurturance needs are made a secondary concern due to the preoccupation of western medicine to

‘fix’ rather than support an infant with a disability. Moreover, stage two values 'separation from others' and '[muscular] control over' nature, when a child with a physical disability may require a lifelong process of active collaboration and interdependency with others in the environment (Shevchuk, 2017).

In stage three, the measure of control is introduced by caregivers to facilitate typically developing children in their independent capabilities. However, with a disabling condition, active exploration and support of less obvious abilities as well as proactive (rather than reactive) facilitation is fundamental for the child to master a sense of purpose (Shevchuk, 2017). Further, in stage four, efforts at industry for a child with a disability seek to find alternatives to the culturally prescribed means of accomplishing goals (i.e. reading, writing, arithmetic, etc.). Any ensuing inferiority arises from the environment's lack of provision of diverse methods to foster the competence of a child with a disability and not his/her inability (Shevchuk, 2017).

In stage five, the cultural belief that disability renders one as 'defective' can have a detrimental effect on the hope of the adult roles an adolescent with a disability deems him/herself capable of fulfilling (Shevchuk, 2017). In particular, as an adolescent with a disability tends to be interdependent with the environment in order to participate in all aspects of life, social workers who are integral in providing vocational development opportunities routinely underestimate their abilities by enrolling the adolescent in 'pre-vocational services' (e.g. adjustment training, activities of daily living) rather than career development services. Thus, the crisis here is one of 'role deprivation' and not 'role diffusion', with the developmental task for the adolescent with the disability centered on proving his/her ability to fit into any kind of role; qualitatively different to freely experimenting with a range of work roles (Shevchuk, 2017).

Ainsworth

As per Mary Ainsworth's attachment theory, four attachment classifications have been defined which apply to both typically and atypically developing children. Children who exhibit a secure attachment style can rely on the primary caregiver to attend to his/her needs and successfully use the caregiver as a secure base and safe haven from which to explore and in times of distress (Cassidy, Jones, and Shaver, 2013). Whereas, children who do not develop a secure bond may display patterns of insecurity which are manifested in three different ways (Feuerman, 2019). Children with ambivalent attachments are chronically unsure of the caregiver's availability resulting to vigilance in remaining closely connected with him/her, and children with avoidant attachments are overly self-reliant and maintain an emotional distance from a rejecting caregiver. In addition, children with disorganized attachments, whose caregiver is unpredictable, cruel, or psychologically unavailable, may lack a coherent strategy for forming a clear attachment behavior with the caregiver; appearing dazed, confused, or apprehensive in his/her presence (Kerns and Brumariu, 2013; Cherry, 2019a).

Research shows a lower prevalence of secure attachment styles in children with a disability (50%) than for well children (60%) (Hearne and Pearce, 2015). Rather, children with a disability's attachment styles are more likely to be disorganized, which is thought to be partially a function of sustained stress resulting from physical and cognitive constraints impeding the ability and competence to exert control over life events and circumstances. In addition, children with a disability may experience complications early in life in social and relational behaviors characterized by smiling, approaching, and vocalizing, posing challenges for the caregiver to interpret the needs of the child. This can lead to a negative feedback loop: the less the child displays attachment-related traits, the less the caregiver responds, then the less the child

responds, and so on; intensifying the stress felt both by the child and caregiver (Hearne and Pearce, 2015).

Moreover, caring for a child with a disability inexorably presents physical and emotional burdens for caregivers, reflecting an ongoing process chronic sorrow (Batchelor and Duke, 2019). This phenomenon is referred to as the loss of the idealized or hoped-for child, which engenders feelings of chronic, dysfunctional grief interspersed with periods of calmer emotions (Teel, 1991). This response can impact the formation of a secure, intimate, and enduring bond between the caregiver and the child, as the caregiver feels burdened by the disparity between the healthy, normal child and the child with a chronic condition; potentially affecting his/her emotional ability to respond with unconditional love to the child's needs (Batchelor and Duke, 2019).

Bronfenbrenner

Urie Bronfenbrenner formulated the ecological systems theory which describes how genetic material interacts with environmental forces to determine developmental outcomes (Skelton and Rosenbaum, 2010). Children typically find themselves enmeshed in ecological systems; organized into five levels of external influence (Psychology Notes Headquarters, 2019). Each system views development as a child's 'conception of the environment, how they relate to it, and their ability to discover, sustain, and alter its properties' (Gousmett, 2006, p. 35).

The innermost level is the microsystem and consists of contexts including the child's family, peers, school, and neighborhood. Bidirectional interactions with social agents are common in this realm (e.g. between parents and teachers) (Impact of Special Needs, n.d.). Next, the mesosystem refers to connections between the settings in the microsystem, such as the relation of family to school experiences. The third level, the exosystem, suggests links between

experiences that the child does not have an active role in and his/her immediate context. Fourth, the macrosystem constitutes of the cultural domains that influence the child's values and beliefs, such as ethnicity, developing and industrialized countries, SES, and poverty (Impact of Special Needs, n.d.). Finally, the chronosystem is the patterning of events and transitions over the life course, as well as sociohistorical circumstances; such as alterations in family structure or economic cycles (Psychology Notes Headquarters, 2019).

The subsystems in the ecological model can be extended to include additional experiences encountered by families of children with disabilities. In addition to the family, assistance from healthcare members, community acceptance and support, and social, psychological, and practical aid from other caregivers may be factors in the microsystem (Gousmett, 2006). In the mesosystem, contact between the child's caregivers and neighbors, friends, and professionals can influence healthy family functioning. Actions in the exosystem, such as the media portrayal of disabilities, the quality of government services, and the accessibility of appropriate education can affect how well families cope. Finally, cultural and societal attitudes regarding disabilities and economical and political elements composing the macrosystem largely determines the professional support and programming available for children with disabilities (Gousmett, 2006).

Mitchell (1985, as cited in Gousmett, 2006) also proposed an extension of the ecological systems theory which focused on a series of challenges families of children with disabilities endure at each stage of the child's life. The list of tasks include: deciding whether to raise the child or seek adoption/institutionalization, accepting the reality of the disabling condition, establishing a secure attachment with the infant, coming to terms with the reactions of family, friends, and other people involved in the child's life, familiarizing and utilizing support services,

collaborating with other families of children with disabilities, coping with attitudes from the broader community, making decisions pertaining to special education, accepting the prolonged dependence of the child, facilitating the child's adaptation process in the community, recognizing the right of the child for maximum independence whilst addressing dependency needs, and participating in decisions relating to vocational training/placements.

Vygotsky

In addition to Piaget's belief of children constructing the environment through active exploration, Lev Vygotsky asserted that development is also shaped by cultural influences (Lightfoot et al., 2012). Children are born with basic biological constraints on their minds within cultures that provide the 'tools of intellectual adaptation'; enabling the use of basic mental abilities and higher order functions in a way that is adaptive to personalized cultural values (Cherry, 2019b). Moreover, Vygotsky placed a great emphasis on the influence of social factors preceding cognitive development, with every function in the child appearing on the social level (interpsychological) before the individual level (intrapsychological) (David, 2014). In particular, social and language skills are utilized in scaffolding learning in the zone of proximal development (ZPD), defined as the distance between a child's ability to perform a task with a 'more knowledgeable other' (e.g. adults, peers) and/or independently in sociocultural contexts (David, 2014).

Unlike other traditional theorists that harbored narrow views pertaining to only a typical developmental trajectory, Vygotsky presented a dynamic assessment of disability by distinguishing it as primary and secondary (Rodina, 2007). Primary disabilities (organic impairments such as those described in the definitions section) lead to a child's exclusion from the sociocultural, traditional, and educational environment (Rodina, 2007). This causes

secondary disability, referring to cultural distortions of socially conditioned mental functions. Thus, adapted educational milieus are warranted for children with disabilities to realize the sociocultural experience. Rodina (2007) explains that although primary deficiencies are less subject to remediation, secondary developmental complications can be eliminated by specialized medical and educational means in such experiences.

From the ZPD, enlightenment to these specialized means can be drawn (Wang, 2009). Notably, on the level in which children can solve problems under guidance or in cooperation with others of higher capability in the ZPD, Wang (2009) claims that effective teaching must offer children ‘teaching material in accordance with their learning level’ accompanied with gradual assistance and guidance prompts. This will contribute to the expansion of the cognitive development of the child. Moreover, consistent intersectional procession (through verbal or nonverbal communication) between the child and educator will help to identify the child’s learning level, ability, potential, and benefits reaped from scaffolding (Wang, 2009).

Greenspan

Stanley Greenspan developed a holistic and dynamic model encompassing six developmental capacities that conceptualize a typically or atypically developing child’s emotional and cognitive health. He propels the belief that these core components drive a child’s learning, behavior, thinking, and communication (Ross, Harrison, and Zane, 2018).

Stage one refers to an infant’s ability to feel calm, regulated, and secure while simultaneously attending to one stimulus and screening out surrounding objects (e.g. focusing on the face of a caregiver). Stage two describes a 4 to 6 month old’s ability to relate to others in a warm, trusting, and intimate manner with at least one attentive adult who woos him/her and

teaches the ‘powerful intoxication’ and ‘magnetic pull’ of human closeness and relationships (Addiction Help, 2014).

In stage three, by 18 months of age, a child develops rudimentary forms of nonverbal two-way communication with willful intention i.e. facial expressions, gestures, and body language (e.g. pointing to obtain an object or crying to seek comfort). In stage four, a 14 to 18-month-old engages in ‘circles of communication’. These are reciprocal interactive sequences of behaviors in a given communication exchange that grows in richness and complexity, enabling a child to increasingly discern patterns of behavior, problem-solve, and develop a sense of self (Addiction Help, 2014). An 18-month to 3-year-old in stage five learn to articulate a need, want, or emotion into words or symbolically substitute ideas for an action or behavior; exercising their minds, bodies, and emotions as one. Finally, from 3 to 4 years and onwards, stage six alludes to the ability to build bridges between emotions and mental images of external events, which underlies abstract, logical, and cause-and-effect thought (Addiction Help, 2014).

Higher-level cognitive, social, and motor skills including abstract, logical, and creative thought in all children (which develops in stage six) is built on the meaningful use of the ideas, with meaning imparting to ‘behavior and ideas through their connection to emotional inclination, intent, or affect’ (Greenspan and Wieder, 1999, p. 6). As children with cognitive dysfunctions may have problems in emotional processing, their ability to connect symbols and behaviors with meaning, engage in a continuous flow of problem-solving interactions and purposeful action patterns, understand social relationships, rules, sense of humor, friendship, and higher levels of shared attention may be jeopardized; affecting facets of advanced functioning and intellectual development (Greenspan and Wieder, 1999).

Child Life Interventions

The following child life-based interventions strive to embrace a strengths-based model that mitigate the challenges that children with intellectual, sensory, physical, or speech impairments encounter in the medical setting, enabling them ‘to function to the best of their ability’ (Koller, 2019; Skelton and Rosenbaum, 2010). Grounded on the progressive theoretical stances and evolving views of childhood disability, the interventions reflect a revolutionary shift beyond therapies that try to ‘fix’ the disabling condition toward approaches that adequately address present day clinical needs and promote the voice, control, mastery, agency, activity, and participation of the child in his/her healthcare experience (Koller, 2019).

Pre-hospitalization Tour and Teaching

Early communication with families, in person or by phone, is helpful in establishing the hospital’s commitment to meeting the complex needs of pediatric patients with disabilities (Sehnert, 2015). Prior to the child’s admission, CLSs can share information with the family regarding the location of designated parking spaces, automatic doors, disability access patient rooms, ramps, elevators, and bathrooms. The availability of wheelchairs, Braille systems, guide and service dogs, and hearing-impaired devices (such as closed-caption television decoders, interpreters, and personal amplifiers) can also be organized if necessitated (Saint Mary’s Health Care System, n.d.). With the arrangements of such security measures, families of children with visual, hearing, and/or mobility disorders will be reassured of a safe hospital experience.

Adaptive Care Plans

It is highly recommended that adaptive care plans (ACPs) are included in the preliminary preparation process to meet the unique needs of children with disabilities (Liddle, Burkett, Bonjour, and Risma, 2018). ACPs, created by child life personnel, augment a family-centered

care approach by partnering with families in the medical decision-making process. From a structured interview conducted with the caregiver, CLSs obtain and include ‘information about a child’s past health care experiences, stressors and reactive behaviors, how the child adapts to changes, how the child prefers to communicate and receive communication, sensory sensitivities, successful coping strategies, pain responses, and interests (motivations and reinforcement)’ (Liddle et al., 2018, p. 3). Adapted protocols, personalized preparation, and specialized support strategies appropriate for the child are also embedded in the ACP. Anecdotal evidence shows that healthcare staff have come to rely on ACPs to aid effective collaboration with families, guide clinical interventions, and provide routine and preventative care according to the accommodations outlined, as opposed to spending time addressing challenging behaviors (Liddle et al., 2018).

Modified Play Techniques

For children with intellectual impairments, Sehnert (2015) found that the modality of preoperative role play and education aids the understanding of tenets of healthcare delivery, lessens psychological discomfort, and increases coping behaviors. Children can view images of the impending procedure and familiarize with medical equipment such as a doll, hair cap, identification band, and anesthesia mask through intact senses (Fincher, Shaw, and Ramelet, 2012, as cited in Sehnert, 2015).

To deepen the learning, the ‘hand over hand’ individualized prompting strategy can be used. The CLS or caregiver employs this cueing system to teach a skill by sitting behind the child, placing his/her hands over the child’s hands, and directing the child’s hands with their own (Webster, 2019). For example, the adult can guide the child’s hand to secure the elasticated

string of the anesthesia mask over the face of a puppet. This method is particularly beneficial for children that have a low muscle tone and impaired fine/gross motor functions.

Additionally, hand over hand prompting enables children to engage in symbolic play in therapeutic activities. The play materials offered may require low-tech adaptations to fine-tune the child's independent interactions. This involves developing new play items, altering a traditional toy, or altering game rules to allow for discovery, address individual needs, and promote enjoyment, personal power, and control (National Lekotek Center, 2011). For example, light-colored toys can be placed on dark clothing or vice versa to simplify backgrounds, copy enlargements of memory game pieces can be created to improve grasp and manipulation, and unnecessary elements can be removed to enrich learning of one concept at a time in shape recognition tasks (National Lekotek Center, 2011).

With such modifications, adults can be less physically directive, allowing for a more equal partnership in supporting and encouraging the child's initiations in play. In cases where the mode of play is based on the child's interests, he/she may even have the opportunity to demonstrate splinter skills: 'an ability to do a specific task that does not generalize to other tasks' (The Audiopedia, 2018). CLSs can use splinter skills as a foundation for the child to build meaningful connections to context and/or purpose. For example, a child may enjoy playing one piece on a musical toy. As he/she plays, the adult can sing and dance, teaching the child that such activities can be paired.

Overall, in proactive scaffolding within the ZPD, the CLS offers personalized approaches (hand over hand and building on splinter skills) that involve using the child's senses to reach a state of equilibrium (with reference to Piaget and Vygotsky). Mastery of purpose, industry, competence, and control can be achieved in the interaction with diverse play materials that are

adapted or differ from conventional play items offered to typically developing children. This prepares the child with a disability for success in accomplishing unique goals important for domains of his/her development.

Occupational Therapy

Pediatric occupational therapists (POT) use meaningful activities to help children with physical, cognitive, and SBMDs ‘participate in what they need/want to in order to promote physical and mental health and well-being’ (The American Occupational Therapy Association, School Mental Health Work Group, 2012). The overarching habilitation and rehabilitation goals of pediatric occupational therapy include helping children achieve developmentally appropriate functional skills, prevent maladaptive consequences, mitigate the impacts of the impaired body part, function, or structure on the child’s activities, and ensure carry-over into other settings through support, family training, and community integration strategies (Houtrow and Murphy, 2019).

The expected ‘occupations’ of childhood that are focused on by POT in collaboration with a CLS in the healthcare setting may include helping children work on fine motor skills to grasp/release objects in medical play, learn basic and instrumental tasks (e.g. dressing, toileting, and pushing a Patient-Controlled Analgesia pump), and maintain positive behavioral reactivity (i.e. channeling anger about hospitalization in therapeutic exercises, such as drawing or role-play). A POT and CLS may also assist in the fabrication and application of equipment tailor-made for patients with physical disabilities, such as splints, dressing devices, or hearing aids (Harron, 2014).

One key task that aims to enhance the resilience of children with physical disabilities during anxiety-inducing procedures is the holding of suitable comfort positions. In particular, if

the child is in stage two of Erikson's theory placing importance on 'separation from others,' the goals of the intervention may entail assisting the child's progress from depending on others to stabilize to being able to exert autonomous '[muscular] control' over the suitable comfort position (Shevchuk, 2017). Furthermore, more long-term goals of educational interventions may include self-propelled mobility through power wheelchairs for children with physical disabilities or communication through voice synthesizers for children with speech deficits, which facilitate efforts at industry and a developing sense of competence in children in stage four of Erikson's theory (Shevchuk, 2017).

Moreover, if the child with a disability is between 0 to 3 years, evidence shows that referrals made by the child life team to early intervention occupational therapy services during hospitalization (and post discharge) is advantageous (Opp, n.d.). In particular, as per Ainsworth, attachment development is critical in this age group. Therefore, the goals the caregiver may have for the child may be based on incorporating therapy into parent-child occupations; such as pressing the buttons on the remote when watching TV together in the patient room or pointing to pictures in a book during a storytelling session facilitated by child life (Opp, n.d.). Such exercises may promote a secure and caring bond between the child and caregiver as the child is provided with opportunities to display attachment-related traits that the caregiver can respond to (Hearne and Pearce, 2015). This positive consequence may also target and attenuate emerging impacts of chronic sorrow (Batchelor and Duke, 2019).

Floortime

Floortime, developed by Greenspan, is an evidence-based practice that can be conducted by a CLS with a child with an intellectual disability in an area in the hospital where open-ended play and interaction is possible. Sessions consist of a therapeutic observation of and engagement

with the child's interests and actions whether obvious or inconspicuous in content and purpose. A continual goal is to open and close circles of communication, which is any verbal or non-verbal response with communicative intent (Rudy, 2019). One example that Rudy (2019) explains is of a child repeatedly opening and shutting a door. In Floortime, a caregiver can hide behind the door and say 'boo!' when it opens, provoking laughter in the child and motivation to continue with the behavior to elicit the same response in addition to enjoying the physical sensation created (Rudy, 2019). This interaction can be extended from a few to many steps, such as the caregiver stating: 'I can't open the door, it's stuck! Get Daddy', followed by Daddy having a difficult time too and asking the child 'do I turn or pull on the knob?' (Greenspan and Greenspan, 2017).

There are two opposite polarities of Floortime: 1) following the child's lead and joining in with his/her rhythms (which is also a core child life philosophy), and 2) inviting the child into a shared world (Greenspan and Wieder, 1999; Association of Child Life Professionals, 2019). In following the child's lead, the CLS respects and harnesses the child's natural, pleasurable, and meaningful desires, which permits entry to his/her emotional life. Next, in connecting the child to a shared world, the CLS creates opportunities and systemic challenges to expand their intellectual abilities. For instance, if a child is repeatedly banging a toy on a surface in a therapeutic play session, the CLS can engage in playful back-and-forth; such as banging another toy beside him/her to evoke laughter, reaching for the toy a few times so he/she retreats, and grasping the toy to have a tug-of-war game. A strategy using a more advanced challenge is known as playful obstruction. The CLS can take and hide the toy behind the door in front of the child, motivating him/her to reach for the knob and communicate his/her needs e.g. saying 'open.' (Greenspan and Greenspan, 2017).

To engage in Floortime interactions, it is vital to tune into a child's processing differences (Greenspan and Greenspan, 2017). For example, if a child with SPD is hyporesponsive to sound and touch, the CLS must be energetic in pulling the child into a shared world. On the other hand, if a child is hyperresponsive, the CLS has to be highly soothing and compelling. For children with deficits in auditory and/or language processing, the CLS should not slow down the cadence of words or speak in monotone, but rather repeat simple phrases while maintaining a normal rhythm that is easier for the child to digest. For children with impairments in visual spatial processing, the CLS can use visual cues to aid the development of visual memory skills. For children with problems in motor planning and sequencing, the CLS should begin with simple movements before advancing to more complex action patterns (Greenspan and Greenspan, 2017).

A series of Floortime sessions will mobilize a hospitalized child with intellectual disabilities to master the fundamentals of thinking, relating, and communicating in Greenspan's critical developmental milestones (Greenspan and Greenspan, 2017). Children will learn how to relate to the CLS and medical providers with warmth, be purposeful and take initiative with actions in medical and therapeutic tasks, and gesticulate and/or verbalize his/her needs and feelings in circles of communication. In addition, children may progress in logical thinking, problem solving, and sequencing, enabling smooth interactions with healthcare providers and a deeper understanding of the medical environment (Greenspan and Greenspan, 2017).

In addition, Floortime employs the strategy of 'heighten[ing] the effect to strengthen connectivity' with others (Salman, 2016). Thus, if the CLS trains caregivers to utilize a Floortime based program beyond the healthcare setting, relational behaviors in the parent-child dyad may be represented. The inclusion of shared attention and regulation, engagement with

trust and intimacy, and affective reciprocity in gestural communication in Floortime will abolish the negative feedback loop and set the stage for a radical shift from a disorganized attachment to a secure attachment to form between the child and caregiver (with reference to Ainsworth's theory) (Hearne and Pearce 2015).

Augmentative and Alternative Communication

Augmentative and Alternative Communication (AAC) encompasses multimodal communication tools that compensate for the disability patterns of children with impairments in speech-language, reading, writing, or auditory processing (The American Speech-Language-Hearing Association, n.d.). Typically, forms of AAC are divided into two groups: aided or unaided communication modes. Unaided modes consist of nonverbal means of natural communication (such as gestures and facial expressions), manual signs, and American Sign Language (ASL) that require motor control and communication partners that can interpret the intended message. Whereas, aided modes use external support, consisting of either low-tech systems such as a communication board with visual-graphic symbols (e.g. pictures, line drawings, or printed words) or high-tech systems such as an electronic device with symbols, words, letters, or icons that 'speak' through synthetically produced or pre-recorded digitized speech (Nicklaus Children's Hospital, n.d.; The American Speech-Language-Hearing Association, n.d.; Thunberg, Buchholz, and Nilsson, 2015).

Often, the use of unaided methods as a natural way of supporting communication is initiated by families as an important first step for later spoken language development. In particular, ASL is a popular primary communication mode for children with intact physical abilities due to its multifaceted benefits (Hakim, 2016). In pairing appropriate facial expressions to verbal statements with signs in ASL, children become equipped and receptive to learning

social communication behaviors, spatial relations, focusing skills, eye contact, and turn-taking in interaction exchanges. In the hospital, due to the paucity of medical staff members knowing ASL, qualified ASL interpreters can be consulted to relay detailed messages regarding diagnosis or treatment between providers and patients (Alison, 2019). However, it is recommended that the CLS and other healthcare professionals learn ASL in order to model and reinforce the signs the child uses in a direct interaction with him/her as effective communication partners (The American Speech-Language-Hearing Association, n.d.).

Children with a limited communication repertoire and/or a physical disability that affects their dexterity or facial features may prefer to use aided forms of communication. Typically, an interdisciplinary team including the CLS, speech-language pathologists, POTs, physical therapists, and families can work together to identify the best aided AAC to implement in hospital interventions, which can then be listed in the ACP as a key reference for other medical personnel (The American Speech-Language-Hearing Association, n.d.). The selection of the aided AAC depends on the preferences of the family as well as the availability of resources in the healthcare setting. Low-tech systems are not battery-powered and are cheaper to fabricate, whereas high-tech systems are dearer and depend on mains power and rechargeable battery packs to run sophisticated software vocabularies. Nevertheless, in comparison to low-tech tools, high-tech AAC introduces a myriad of benefits, such as customizability, auditory feedback for language learning, an opportunity for the child to develop automaticity and motor patterns, different options to represent language, and less reliance on communication partners (Liberator, n.d.).

As a supplement or substitute for oral language, AAC systems are imperative for supporting the child's social and emotional development by encouraging his/her expression of

feelings and perspectives related to hospitalization, facilitating his/her rapport with medical providers, and advocating for his/her voice and participatory role in the healthcare process (Mărginean et al., 2017; Glasper 2017). In particular, upgrading educational interventions to incorporate a form of AAC apposite for the child's learning level will enforce consistent intersectional procession between the CLS and child during the scaffolding process (referring to Vygotsky's theory) and enhance his/her comprehension of the sociocultural experience in the hospital (Wang, 2009). As a result, the power to be understood and communicate messages that are received and responded to will be greatly empowering and foster the child's intentionality and 'desire to make more meaning' of the medical proceedings (Hakim, 2016).

Sensory Environments

To mitigate sensory triggers in children with SPD, the physical environment in the hospital can be modified and emerging resources can be offered by the collaborating child life and occupational therapy teams in therapeutic and effaceable sensory-based interventions (Nicholas et al., 2016).

Sensory input for children hyporesponsive to stimuli. To curtail behaviors deemed socially unacceptable in children hyperresponsive to stimuli (Nunez, 2018), a CLS and POT can offer a range of techniques that increase the arousal levels in a child with a SMD (Piller and Barimo, 2019). In turn, his/her learning through the senses will be optimized and the assimilation and accommodation process facilitated; a key component of the Piagetian approach (Baranek et al., 2013; Tilstone and Layton, 2004). Such techniques include movement/vestibular input with vertical and linear movement, such as in a simulated moving hospital bed, rocking chair at the bedside, or the child running through a hopscotch painted on the floor in an open space in the playroom. The CLS and OT can also provide proprioceptive input with weight-bearing tasks

(which can be playful, such as a weighted doctor-themed jacket in medical play) or deep-pressure tactile input such as massages or ball ‘squishes.’ The latter may also aid in relieving stress and promoting coping abilities during challenging medical procedures (Piller and Barismo, 2019). In addition, one method that is simple and cost-effective to implement in fast-paced healthcare departments (such as the pediatric emergency unit) is a mobile sensory cart. In addition to iPads loaded with colorful and noisy games and apps, the cart can carry disposable and non-disposable tactile, hearing, and visual items for patient use in sensory management (Salassi-Scotter, Scott, and Hunt, 2014).

Sensory downplaying for children hyperresponsive to stimuli. Although Baranek et al. (2013) asserts that not orienting to sights, sounds, and smells in the environment can lead to missed opportunities for learning through the senses in children with SMD, Greenspan counter-argues that tenets that threaten the sense of security and safety in the environment (in this case, sensory overload) can jeopardize their emotional well-being and thus hamper the absorption of valuable information (Ross et al., 2018). Hence, methods that reduce sensory stimulation are necessitated. This includes arranging quiet waiting room sections, providing noise-cancelling headphones, playing soothing music, removing noisy portable machinery, and limiting traffic control to a specific number of people in the room at a time for children disturbed by auditory input; dimming the lights, offering child-sized tinted glasses, or consulting with maintenance to change the pulsating fluorescent to incandescent lighting in the patient room for children with heightened visual sensitivity; and delivering loose fitted hospital clothing (gowns, socks, etc.) to children hyperresponsive to tactile stimuli (Toner, 2019; Children’s Hospital of Philadelphia, 2019; Masters in Special Education, n.d.; Bullock, 2018; Salassi-Scotter et al., 2014). Creating a ‘safe corner’ with quiet, odorless, and imaginative items and squishy seating with bean bag

chairs, blankets, and pillows for nesting is also effective in moderating uncomfortable sensations (Homecity, n.d.).

Disabilities Education

The provision of disabilities education needs to be a central part of medical training (Wen, 2014). Child life administrators can use a generous portion of funding to develop a curriculum for disabilities education involving mandatory workshops (with presentations, interactive discussions, exercises, and handouts) conducted by CLSs for physicians to attend. The CLSs can run the sessions in collaboration with POTs, special education teachers, patients with disabilities and their families, and/or medical providers that have a disability. The latter group may be most effective to evoke change, as the experiences, perspectives, and suggestions of an individual that is both a relatable physician and a non-relatable patient with a disability is particularly influential (Wen, 2014). It is recommended that the following key topics are covered in depth in order to deepen clinicians' existing medical knowledge, enrich family and patient-centered care, and increase overall health outcomes (Reynolds, 2018).

People-first language. Healthcare practitioners are advised to be cognizant of semantics and understand the power that word choices play in influencing the effectiveness of their care of patients with disabilities (Crocker and Smith, 2019). In addition to informing providers about the negative connotations of the euphemism 'special needs' (Fuga, n.d.), the adoption of people-first language can be encouraged. By referring to the person first and the disability second (e.g. 'a child with autism' rather than 'autistic child'), people-first language is a form of linguistic etiquette that acknowledges the inherent and equal value of every individual before attaching other identities that person may view as secondary or intrinsic (Foley and Graff, 2018). At its core, using people-first language in medical practice places emphasis on the patient's

individuality, equality, and dignity, and eliminates inaccurate descriptors deemed hurtful and prejudicial (Brown, 2011).

Disability humility. To develop the virtue of disability humility, clinicians have to be trained to escape from the ableist mentality. The CLS can propose methods that work to dissolve ableist intuitions that implicitly discriminate against patients with disabilities. This includes being more mindful of inaccurate and demeaning vocabulary use (i.e. using people-first language), having an increased awareness of accessibility challenges in the medical setting, learning the appropriate ways to engage with families of patients with disabilities with empathy, sensitivity, and competence, and not pitying or infantilizing a patient with a disability based on the assumption that the condition renders him/her incapable of functioning independently and living contently (Young, 2014). The latter idea can relate to the (combined) example of an adolescent in stage five of Erikson's theory flourishing as a wheelchair user (page 16) but deprived of opportunities to foster his/her career development (page 23) (Reynolds, 2018; Shevchuk, 2017). In concert, social work and child life personnel can devise a vocational rehabilitation program which entails post-secondary education, self-advocacy training, technology services, and placement in suitable employment; all of which will assist the adolescent's gradation into an adult role inside and outside the hospital (Pacer's National Parent Center in Transition, n.d.).

Next, clinicians can be taught to adopt a 'binocular' view of disability by understanding that the phenomenon has both medical (etiology, symptoms, etc.) and social components (environmental, structural, and attitudinal barriers) (Reynolds, 2018). With this binocular perspective, clinicians will be able to actively combat the tendency to undermine a patient and family's epistemic voice and authority and learn to have the reflective depth to communicate

with, care for, and treat them with dignity. Importantly, successful communication is linked to the constructive relationship between patients with disabilities and professionals (Sharkey et al., 2014). Training practitioners how to appropriately identify and respond to complex needs and ultimately build trusting partnerships through effective communication with families will contribute to optimal health experiences and outcomes.

Moreover, in prompting the practice of disability humility, the prospect of centralizing the subspecialty treatment of children with more complex disabilities can be proposed. This may involve providing informational resources based on medical models of rarer complications along with specialized treatment strategies that can be implemented in the child's care plan (Perrin, 2002). Child life must also ensure to relay details gathered in the assessment of the child's ecological system related to his/her health history and other physical or medical needs if this is unknown to healthcare providers (Ervin et al., 2014; Gousmett, 2006). The child and family's unique preferences for healthcare influenced by macrosystemic cultural or religious ideals must also be disseminated and honored.

Combating healthcare disparities. For healthcare providers to capture and understand how the interactions between disability and race and/or SES sustain marginalization, child life can provide education based on the basis and practical application of the 'intersectional ecological framework' (Levine and Breshears, 2019). Viewing intersectionality through the lens of Bronfenbrenner's ecological systems theory, practitioners will be able to consider the multiple systemic levels of identity-related issues as well as the complicated intersections experienced by patients with disabilities that engender healthcare disparities (Gousmett, 2006; Levine and Breshears, 2019). An example of this is a family of a child with a disability that are AAPIs and their macrosystem consists of a low SES which hinders their access to disability services and

support organizations. Eliminating disparities such as this requires action on a broad scale. Alongside managerial staff, the interdisciplinary team can devise and enforce multi-level, comprehensive, and regulatory strategies that condemn discriminatory practices, encourage adherence to ethical guidelines, and ensure equitable assessment and treatment delivery to all patient populations (Wintz and Cooper, 2009).

Self-care practices. Healthcare administrators can co-instruct workshops related to burnout with child life if this is a systematic problem affecting the quality of care provided to children and families. In proactive dialogue with employees, solutions that combat burnout based on efforts at both the individual and organizational level can be planned for execution (Reith, 2018). For example, incentives can be modified to include greater schedule flexibility rather than productivity-based compensation and gathering areas with food and snacks can be arranged to promote collegial solidarity and support. Moreover, a culture of self-care can be encouraged through the furnishing of mental health services, offering mindfulness and exercise programs, and arranging memberships at local gyms (as well as coverage to attend these programs) (Reith, 2018). Such self-care methods will relieve symptoms of emotional exhaustion and ultimately improve the time, attention, patience, understanding, and consideration given to families of patients with disabilities.

Conclusion

Afflicted by functional deficits, disparities, or biases, the challenges that children with intellectual, sensory, physical, and/or speech disabilities experience in the healthcare setting are manifold. If not addressed, such problems will continue to plague twenty-first century medicine to the detriment of patients with disabilities and physicians alike. This independent study delved into adapted versions of developmental theories of atypical development which is essential to

inform the array of child life interventions subsequently delineated to confront these challenges. A direction for further research is for CLSs in healthcare institutions nationwide to apply the suggested interventions into practice. This will enable the pragmatic exploration and evaluation of the efficacy of the interventions in curtailing the stressors faced by families of children with disabilities during their hospital stay.

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