Low-Income Autistic Children in the Pediatric Hospital: Best Care Practices to Enhance Capabilities

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Abstract

The current research study utilizes a novel approach to disability rights, the Capabilities Approach to Disability, to formulate a moral argument for implementation of best care practices catered toward low-income children with Autism Spectrum Disorder. I argue that best practice implementation is the best way for pediatric health care providers to fulfill their moral responsibility to protect against the central capability deprivation of this uniquely disadvantaged group.

Keywords: Autism Spectrum Disorder, Low-income, Pediatric Health Care Providers, Capabilities Approach to Disability

Introduction:

The hospitalization of a child is an emotionally charged experience for the patient and family. Patients are thrust into an unfamiliar and over-stimulating environment filled with strange people, beeping machinery, and cramped spaces. For a child with a neurological disorder such as Autism, the emotional and cognitive demands of such an intense and foreign atmosphere can quickly grow unbearable. This is particularly true of low-income Autistic patients, who may not receive home-based intervention services that aid the child in coping with an emotional experience. Therefore, health care providers (HCPs) in the general pediatric hospital have a special responsibility to ensure low-income Autistic children receive an adequate threshold of therapeutic care. Throughout this paper I will utilize the capabilities approach to disability to outline how current practices in pediatric care uniquely disadvantage low-income Autistic patients, and research from the fields of healthcare and developmental psychology to outline best care practice strategies to promote patient capabilities.

The American Psychiatric Association (2016) defines Autism Spectrum Disorder (ASD) as a neurological disorder characterized by literal thinking, difficulty processing emotion, sensitivity to sensory stimuli, communicative limitations, and repetitive behaviors. The Center for Disease Control (2014) reports that ASD affects approximately 1 in 68 live births, of which approximately 1 in 42 are male and 1 in 189 are female.

Despite its frequency, physicians and other HCPs commonly lack a concrete understanding of ASD, which leads to only 18% of families receiving additional information from their physicians about ASD after diagnosis (Rhoades, Scarpa, & Salley, 2007).

Additionally, physician knowledge does not seem to grow with experience as first and fourth year medical students perform similarly on questionnaires regarding the causation, prognosis, IQ

profiles, and treatment options for ASD (Shah, 2016). Children with Autism and similar intellectual disabilities are hospitalized frequently due to disease comorbidities, accidental injury, harmful behavioral expression, and other factors. A study of an Australian pediatric sample found that 64.9% of intellectually delayed children are hospitalized within the first five years of life, in comparison to 48.2% of neurotypical children (Williams et. al, 2005). This is particularly true of low-income families, who rely heavily on emergency services for primary care.

According to a poll of over one thousand patients conducted in FAIR Health (2015), 32% of families with an annual income below \$35,000 depend on the emergency room for access to care, in comparison to 21% of families in the \$35,000-49,9000 range, and 15% of families in the \$50,000-74,900 range. Therefore, it is the responsibility of all pediatric HCPs to implement best care practices catered to the needs of low-income ASD patients.

According to Amartya Sen's capabilities approach, states and governments have a moral obligation to promote another's right to a dignified life through the advancement of the other's capability, or choice, to fulfill necessary "beings and doings" known as functionings (Ingrid, 2016). Martha Nussbaum's capabilities approach modifies Amartya Sen's theory, by setting a standard for basic social justice which consists of individuals having an adequate threshold level of ten central capabilities. Recently, the capabilities approach has been applied by thinkers to disability by distinguishing disability as a capability deprivation (Mitra, 2006).

The capabilities approach to disability states that deprivations from the ten central capabilities result in increased disability through further socio-emotional, cognitive, and physical delay (Burchardt, 2004). Before the disabilities rights movement of the 1960's, the medical model of disability determined disability as resulting from an individual's condition and not from social determinants such as lack of accommodations (Michigan Disability Rights Coalition,

2017). More recently, the social model has sought to define disability as exclusion driven by structural barriers which restrict disabled individuals from participating in society (Michigan Disability Rights Coalition, 2017). According to the social model, lack of accommodations, such as wheel-chair accessible buildings, exaggerate disability beyond the limitations of the individual's pre-existing condition.

The capabilities approach to disability expands upon the social model by defining disability in terms of capability deprivation (Mitra 2006). Low-income families are particularly at risk for the capability deprivation of their ASD child, since they encounter barriers to receiving adequate health services. Therefore, the capabilities approach advocates that HCPs have a moral responsibility to enhance best care practices toward children with ASD from low-income backgrounds. In the following pages, I will introduce three specific barriers that contribute to the unique disadvantage of low-income ASD patients, and strategies to revise best care practices to remediate these barriers and promote patient capabilities.

Current Practice and Capability Deprivation:

Low-income ASD children face barriers to effective care which limit their central capabilities. In this essay, I will outline how pediatric HCPs have a moral obligation to serve this uniquely disadvantaged group by outlining three key barriers, and relating each directly to contributing to a central capability deprivation. First, barriers to diagnosis negatively impact the child's central capability of bodily health by placing the child at risk for increased developmental delay and harm due to neglected comorbid illness. Second, low-income ASD patients face barriers to the central capability of affiliation, as HCPs commonly lack the skills required to work with a patient with limited verbal ability. Third, low-income ASD patients face barriers to

the central capability of senses, as standard HCP practice may inflict undue harm upon an ASD patient whose sensory processing may be over-burdened in a traditional hospital setting.

Diagnosis and Bodily Health

Early detection of ASD enables a child to receive the intervention services necessary to promote their optimal cognitive, physical, and socio-emotional development, and therefore the central capability of Bodily Health (Kleist, 2017), attainable. Additionally, correct diagnosis of future comorbidities, or co-existing conditions, is central to maintaining optimal health.

To achieve central capability of Bodily Health families must receive a timely diagnosis of first ASD and then possible disease comorbidities. For this to be achieved, doctors must have adequate knowledge of ASD and effectively communicate their knowledge with families through conversation and referral to Early Intervention (EI) services. It is key that physicians communicate the availability of services to promote the child's developmental growth beyond the hospitalization experience.

EI services are guaranteed to families under Part C of the Individuals with Disabilities Education Act (IDEA) (Center for Parent Information and Resources, 2016), but if a family is not referred to services due to delayed diagnosis or lack of physician knowledge, they may lose the opportunity to participate. Currently, the average age of diagnosis is a little over 3.5 years (Fountain, 2010), but recent results from the Infant Brain Imaging Study indicate that the early developmental stages of ASD can be detected as early as 6 months (Autism Speaks, 2012). The American Academy of Pediatrics recommends that all infants are screened for ASD during routine wellness visits at 18 and 24 months (AAP, 2016). Nonetheless, 32% of low-income families do not have access to a primary care physician, and instead seek ER services for medical

treatment (FAIR Health, 2015). Diagnosis before age three enables a child access to EI services, which delivers specialists from the fields of education, nursing, occupational and physical therapy directly to the child's home to enhance the child's cognitive, socio-emotional, and physical development in the family's daily routine (Center for Parent Information and Resources, 2016). As detection technologies grow more sophisticated, HCPs in the general pediatric hospital must prioritize achieving early detection and early referral to intervention services.

Unfortunately, low-income ASD children struggle to obtain an early diagnosis, since age of diagnosis is highly determined by socio-economic status. In a longitudinal study of all Californian children diagnosed with Autism across ten birth cohorts from 1992 to 2001, Fountain, King, and Bearman (2010) found socio-economic status (SES) to be the strongest predictor of age of diagnosis. The study found factors such as parental race, education, and immigration status to predict age of diagnosis over factors such as severity of symptom expression, and geographical proximity of a child psychiatrist. The study revealed that children of high SES receive a diagnosis on average six months earlier, at 3.4 years, in comparison to low SES children, who typically receive a diagnosis at 3.9 years (Fountain, 2010).

Beyond diagnosis, low-income families struggle to receive care that is sensitive to their health needs during a hospitalization experience. HCPs are commonly blind to comorbid disease factors contributing to an ASD child's behavior, since they are overly focused on the child's "core diagnosis" of ASD (Siegal, 2015). In Siegal (2015), which examined physician practices toward ASD individuals on a pediatric psychiatric ward, it was revealed that children with intellectual disorders, such as ASD, compromise 10-20% of the patient population, but that physician practices lead to mistakes in identifying comorbid illnesses. The study outlined that children with ASD are commonly sent to the psychiatric ward due to the externalization of

problem behaviors such as aggression, self-harm, or decline in functioning. The study found that doctors over-emphasized the pre-existing condition of ASD, and failed to look effectively at medical or environmental factors that might have triggered the problem behaviors (Siegal, 2015).

According to Scarpinato, Bradley, Kurbjun, Bateman, Holtzer, and Ely (2010), seizures, gastro-intestinal disorders, sleep disorders, and psychiatric disorders are more common among children with ASD than the general pediatric population. Screening for these common comorbidities, as well as common conditions for the general pediatric population, such as dental problems and urinary tract infection, can ensure that the child's change in behavior is not misattributed to the core diagnosis of ASD. Due to the communicative limitations that ASD children face, it is particularly important that HCPs screen thoroughly for possible co-occurring conditions, since patients may not be able to adequately describe the source of their discomfort.

Common psychiatric comorbidities or children with ASD include anxiety, ADHD, and depression (Scarpinato et. al, 2010). When screening for these conditions, HCPs must note how a child's behavior differs from what is commonly seen in a child with ASD (Siegal, 2015). When designing a treatment plan, HCPs look to families to provide information about how to create a calm and therapeutic environment for their child (Johnson, 2013). Nonetheless, lack of access to EI services may decrease a family's ability to provide intervention strategies learned at home. Therefore, HCPs must be supplied with their own knowledge to implement strategies independently of family contributions.

Correct diagnosis promotes not only the central capability of bodily health, but the central capabilities of life and bodily integrity as well, which are defined as the ability to live a long and meaningful life, and to have control over one's body (Kleist, 2017). Proper and early diagnosis ensures a child lives longer, is physically well enough to participate in their environment, and

has the control over one's body to move freely between spaces. Without proper diagnosis, proper treatment is impossible. Nonetheless, for treatment to be successful, a physician's ability to communicate with the patient and family must be effective as well.

Effective Communication and Affiliation

Nussbaum defines the central capability of affiliation as the right to "be treated with dignity and equal worth" and participate in "relationships of mutual recognition" (Kleist, 2017). For the capability of affiliation to be realized, the physician, child, and family must all effectively communicate. Children with ASD are commonly delayed in their acquirement of speech, and many never acquire spoken language (APA, 2016). Others may obtain a limited vocabulary, or rely on repetitive speech patterns to convey their thoughts (APA, 2016). In determining a diagnosis and implementing care, it is critical to account for the communicative barriers children with ASD face. In addition, it is critical to include families in this discussion to promote strategies that can translate beyond the hospitalization experience.

Many non-verbal ASD children master alternative versions of communication, through use of a communication device or adaptive sign language. In an emergency, a child may be separated from their communication device, but questions about communication methods are not standard practice during a patient's entrance screening (Siegal, 2015). In addition, it is uncommon for HCPs to be trained in adaptive sign, which may leave a child incapable of advocating independently for their needs. This is particularly true of a low-income child, whose parents may be unable to take time off work to translate a child's thoughts.

Children with ASD may struggle to read posted information, and follow verbalized instruction. Nonetheless, alternative methods of displaying information and conveying

instructions, such as graphics and scales, are not always provided (Siegal, 2015). Finally, ASD children may have trouble processing verbal cues, but staff members are not always trained to slow, exaggerate, and simplify their speech to increase patient comprehension (Siegal, 2015). According to Johnson and Rodriquez (2013) family-centered practices are at the core of treatment with an ASD child, and HCPs rely on parents to contribute strategies to enhance communication. This reliance on parents may turn problematic if parents are incapable of making time in their schedule to attend the child's bedside, or if the home-based care practices are insufficient due to lack of access to EI services. If a child is incapable of verbalizing the source of their pain or discomfort, it may cause a HCP to miss a medical diagnosis, or the failure of a treatment method, and may result in serious emotional and physical harm to the child (Siegal, 2015).

Failing to establish effective communication deprives the child of the capability of affiliation, as the child is deprived of the dignity and recognition required by the capabilities approach (Kleist, 2017). Therefore, HCPs have a moral obligation to establish best practices to increase effective communication for children with ASD, particularly those from a low-income background. Therefore, questions regarding methods of communication should be incorporated as standard practice during all entrance screenings (Siegal, 2015). In addition, alternative methods of conveying information should be incorporated. For example, accompanying verbal speech with visual supports, such as pictures outlining scheduling or procedures, can ensure that the child's processing of information is made accessible (Bultas, Johnson, Burkett, and Reinhold, 2016). Enabling a child to process information increases their ability to anticipate future events, which in turn decreases their anxiety (Bultas et. al, 2016). Decreasing an ASD child's anxiety reduces the likelihood that will express problematic behavior, such as self-harm through

slapping, kicking, of self-induced vomiting, to self-regulate emotion and calm the stress response (Johnson & Rodriquez, 2013).

A Social Story, which outlines expected behaviors and responses, can aid the child in formulating expectations about a non-routine situation, such as a medical procedure (Bultas et. al, 2016). An additional cue for behavior, such as a Social Story can provide a script on how to behave and respond during a given situation, since ASD children struggle to interpret emotion. This cue can serve to augment a child's processing of the informational and emotional content of a HCP's procedure plan. Therefore, adaptation of simple discourse strategies increases the child's capability of affiliation by respecting the child's need to form realistic expectations about how a procedure will affect them physically and emotionally.

In addition to prioritizing effective communication with patients, HCPs have an obligation to prioritize critical conversations with parents of the ASD child, particularly those from low-income backgrounds. According to Johnson and Rodriquez (2013), families from low-income backgrounds cite "distrust", "lack of health care access", and "knowledge deficit of ASD" when interviewed about the greatest challenges they faced in seeking treatment for their ASD child. Rhoades, Scarpa, and Salley (2007), interviewed families of ASD children about who and what contributed to their knowledge of ASD. Of the families surveyed, only 21% of families cited physicians as a contributing factor, while 73% cited the internet (Rhoades, Scarpa, & Salley, 2007). Indeed, 18% of families reported that they received no additional information about ASD from their physician after diagnosis, and only 41% reported their physician took time to talk about ASD (Rhoades, Scarpa, & Salley, 2007). In addition, only 45% of physicians offered information about additional resources, such as referral to EI services which are offered to infants ages 0-3 at risk for developmental delay (Rhoades, Scarpa, & Salley, 2007). Failure to

effectively communicate options and expectations to families deprives patients from receiving information about available intervention services, which leaves the family in further isolation in seeking help for their child beyond the hospitalization experience.

Even if the family has been notified of the option of EI services, low-income families face additional structural barriers to accessing EI services. Carr and Lord (2016) outline lack of transportation, inflexible work schedules, and language barriers as contributing factors that restrict low-income families from successfully completing intervention programs. Without knowledge or access to these services, a child is deprived of the capability to achieve the highest level of developmental possible, and therefore experiences increased disability under the capabilities approach to disability model (Mitra, 2006). Therefore, physicians must implement communication strategies that enhance both the patient and their family's comprehension of options and potential outcomes. These practices can then be complemented by the implementation of developmentally appropriate accommodations for the ASD child's environment and procedural protocol.

Accommodations and Senses (Add insurance piece- parents may not have leverage to ask for better accommodations)

According to Nussbaum's capabilities approach, the central capability of senses requires that individuals can "have pleasurable experiences and avoid unnecessary pain" (Kleist, 2017). Failure to distribute proper accommodations to ASD patients may contribute to a child experiencing undue emotional and physical pain. Children with ASD are sensitive to sensory stimuli and have difficulty processing various demands from the external environment (APA, 2016). Loud machinery, bright lights, painful procedures, and unfamiliar people can quickly overload an ASD child's sensory coping capacities and antecede engagement in self-harming

behavioral expression (Bultas et. al, 2016). Therefore, HCPs should seek to enhance the child's capability of senses by implementing small accommodations in the child's physical space and treatment protocol.

Commonly, children with ASD cope with overwhelming stimuli through engagement in self-stimulating behavior, known as "stimming". Common stimming behaviors include hand-flapping and repetitive vocalization patterns (APA, 2016). Since stimming behavior aids in anxiety reduction, HCPs should aim to reduce disturbance of these behaviors. Therefore, use of medical materials that may inhibit the child's ability to move freely should be minimized (Johnson and Rodriquez, 2013).

Enhancement of the child's physical space can aid the child in engaging in self-regulatory behaviors (Siegal, 2015). Standard hospital rooms lack privacy, and are frequented by staff members. Frequent disturbances interfere with an ASD child's ability to filter through external stimuli. These increased cognitive demands can exhaust a child's coping resources and deplete their ability to harness control over their emotions. Therefore, HCPs should seek to offer ASD patients opportunities to regain a sense of control through the presentation of options regarding treatment plans. Small alterations to the child's environment can help achieve this goal. For example, the child can be provided with the option to enter a quiet room when they feel they need a break from treatment (Siegal, 2015). In addition, the child can be offered decisions about which actions, such as blood pressure or heart-rate measurement, are performed first (Johnson & Rodriquez, 2013). To further the child's sense of control, doors to hallways can be kept closed, rooms can be cleared of clutter, and noise minimized (Johnson & Rodriquez, 2013).

Furthermore, unit programming can be altered to accommodate the child's needs. Due to cognitive and communicative limitations, children with ASD may not benefit from traditional talk-therapy (Siegal, 2015). Therefore, alternative therapies that are developmentally appropriate, such as life-skill training and art therapy, can be provided (Siegal, 2015). These interventions can improve the ASD child's functional behaviors, and allow the child opportunity for emotional expression.

Children with ASD commonly do not respond to traditional forms of discipline or reinforcement. Applied Behavioral Analysis (ABA) therapy is a data-driven educational strategy commonly used in interventions for children with ASD. HCPs can be informed of the basic tenants of ABA, such as emphasis on positive reinforcement of goal behaviors, to help guide a patient and their family in promoting behaviors that will ease the child's hospitalization experience. For example, if a child is known to panic during an injection, the child can be instructed in a simple breathing exercise before the injection is made. Then, the child can be asked to engage in the breathing exercise during the injection. If the child successfully performs the technique, the physician can celebrate the child's accomplishment, and therefore reinforce the child's likelihood to engage in that behavior independently during the next injection procedure.

Increasing the child's sense of control promotes the central capability of senses by minimizing undue stress, as well as the other central capabilities of bodily integrity and control over one's environment. Bodily integrity is defined as the ability to "have sovereignty over one's body" (Kleist, 2017). Giving the child options in areas wherever possible enables an ASD child to maintain a level of power over what occurs with their body. Additionally, the capability of control over one's environment, which is defined in both political and material terms (Kleist,

2017), is supported by offering the child an opportunity to have their voice heard, and make choices regarding care outcomes.

Conclusion

The capabilities approach to disability defines disability in terms of capability deprivation (Mitra, 2006). Current pediatric practices contribute to capability deprivation for low-income children with ASD. Specifically, lack of HCP knowledge of ASD contributes to poor diagnosis, effective communication, and accommodations for ASD children. Low-income families are particularly impacted by lack of physician knowledge, since barriers to EI services reduce their own understanding of ASD and effective intervention strategies.

Lack of proper diagnosis, effective communication, and adequate accommodations deprive ASD children from the central capabilities of bodily health, affiliation, and senses, imagination, and though. These capability deprivations are compounded for low-income ASD children, as low-income parents may not have the flexibility, information, o transportation necessary to seek additional forms of care and intervention.

Deprivation from central capabilities is morally impermissible under the capabilities approach to disability. Therefore, HCPs have a moral responsibility to refine standard practices to increase the therapeutic benefit of ASD children. Particularly, HCPs must seek to implement best care practices which detect ASD and co-morbid conditions quickly, enable the patient and family to fully comprehend all informational and effective information, and properly accommodate the child's socio-emotional needs.

The best care practices outlined in this essay represent strategies that can be adopted by a HCP in their conduct toward an ASD patient and their family to enhance their therapeutic

experience. I believe implementation of these practices will be particularly impactful for low-ASD patients, who are uniquely disadvantaged in their access to diagnosis, EI services, and medical care. A therapeutic environment enhances a child's ability to grow their cognitive, emotional, and physical resources. Therefore, implementation of best care practices catered to a child's disability and work to enhance the patient's capability to pursue a meaningful life. Implementation of these practices enhance a child's ability to comply with the emotional demands set forth by a hospitalization experience, and therefore ease the child's treatment process for the patient, family, and hospital staff.

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