

A Systems Approach to Pediatric Illness and Disability: Why Family and Environment are Integral Parts of Effective Treatment.

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Abstract

Physicians caring for a child with a chronic illness or disability should consider the child's family and environment as an integral part of treatment. Pediatric illness and disability can have adverse effects on a family, and generally there are not adequate supports in place for most families facing these circumstances. There is a relationship between poverty and disability, and the mental health status, abilities, and resources of family members and caregivers affect a child's medical outcomes. Ten principles of family system medical care are presented as a framework for supporting families of children with an illness or disability. Key elements of a successful intervention program are suggested, and the way these elements and principles may challenge current medical practice is considered. The relationship between the experience of disability and culture, along with the need to view a child as part of a larger family system when planning medical treatment, are also discussed.

Introduction

There is often little or no formal, integrated support offered to families caring for a child with a chronic illness or disability (Kazak, Rourke, Alerter, Pai, Reilly & Meadows, 2007) (Kieckhefer, Trahms, Churchill, & Simpson, 2009). Many supports that currently exist are reactive, and designed for extreme crisis or pathology instead of offering preventative or proactive services. (Kazak, et al., 2007). Existing programs are often geared to families with specific diagnosis such as cancer, though families of children with more chronic, less severe illness or disability may be in greater need of support (Shudy, Lihinie, deAlmeida, Ly, Landon, Groft, Jenkins, et al., 2006). This paper proposes that integrated, standardized, universally accessible support for all families caring for a child with a chronic illness or disability would result in significantly better outcomes for both the child and their family. It will discuss the challenges and themes of caring for these children, societal and institutional factors that impact parental and family functioning, and the need for a systems view of medical care for children with chronic illness or disability. This paper proposes 10 principles of Pediatric Medical System Care, and hypothesizes a research-based model that addresses the needs of families caring for a child with a chronic illness or disability. It will also discuss the culture change necessary for a move to a 'systems approach' in pediatric medicine, and the way society impacts families caring for children who are ill or disabled.

Pediatric Chronic Illness and Disability

Chronic illness and disability may be defined as a long-term challenge that results in limitations in daily living, and “requires special assistance or adaption in function” (Coffey, 2006). Ludder-Jackson & Vessey (1996) identified additional aspects of chronic illness that may be present: “limitation of function, disfigurement, dependency on medication, special diet and/or medical technology, special ongoing treatments at home or in school, and need for medical care above the normal need for ongoing health maintenance” (Ludder-Jackson & Vessey, 1996, p. 3). As many as one in five families in the United States care for a child with a chronic illness or disability (Reichman, Corman & Noonan 2008) (Hogan, 2012) and current research shows this population is increasing (Kieckhefer, et al., 2009). The Center for Disease Control states over 7% of children and adolescents in the U.S. have a chronic health condition, and approximately 15% of all children aged 3 through 17 years have a one or more developmental disabilities. CDC statistics also show that the prevalence of developmental disabilities in children has increased 17.1% over the past twelve years, with autism increasing 289.5%, and ADHD increasing 33%. Occurrence of Type 2 diabetes has increased 30% in children from 2001-2009 (Saint-Louis, 2014) and data indicates the number of children with special health care needs continues to rise (Kieckhefer, et al., 2009). “In the US, families of children with disabilities had out-of-pocket health care expenditures that were twice that of other families” (Parish, et al., 2008, p.71-92)

Effects on Families

Caring for a child with an illness or disability can significantly affect family functioning (Reichman, et al., 2008). Families of children with disabilities are more likely to experience poverty (Shahtahmasebi, Emerson, Berridge, & Lancaster, 2011) and the presence of a chronic illness or disability in one child can require siblings, parents and extended family members to constantly adapt to “frequent changes in family structure and function” (Clawson, 1996, p.54). Effects on parents may include increased stress, financial difficulties, job loss, social isolation, marital problems and depression (Dyson 2010) (Olsson & Hwang, 2008) (Reichman et al., 2008) (Morrod, 2004). Parents whose children are admitted to Pediatric Intensive Care Units (PICU) are at risk for developing PTSD, as well as anxiety disorders and depression (Menlyk, Alpert-Gillis, Feinstein, Crean, Johnson, Fairbanks, et al., 2004). Most parents will struggle to balance the needs of a child with a chronic illness or disability with the need to maintain a balanced family life, preserve their own physical and mental health, and ensure the well-being of the rest of their family (Hexem, Bosk & Feudtner 2011) (Panicker, 2013). The challenges of caring for a child with a disability can lead to problems with siblings (Paster, Brandwein & Walsh, 2009) as the distribution of parent’s time, energy and financial resources may be skewed to the child with a disability or illness (Reichman et al., 2008). This may affect the health and development of healthy siblings (Hogan, 2012) and change the dynamics and function of these siblings within the family system (Coffey, 2006).

Children with chronic illness or disability are themselves at risk for psychological problems and learning difficulties (Menlyk, et al., 2004) that can have a “ripple

effect” on their family (Reichman et al., 2008). Yet, despite the known adverse effects of chronic illness or disability on families, there is little research on the relationship of these effects (Boebel-Toly), (Musil & Carl, 2012) or on “programs aimed at improving the nonphysiologic well-being of patients and their families” (Menlyk, et al., 2004, p.597). The lack of data is in part due to the absence of existing formal supports for families who have children with a chronic illness or disability. Though excellent care may be provided for *medical* needs, “parents typically receive little preparation” for the work and process of caring for their child (Kazak, et al., 2007). While many organizations offer support for families of children with disabilities or illness, these programs are “fragmented and difficult to navigate” (Reichman et al., 2008). Physicians are often unaware of services that may be available to families (Morrod, 2004), and parents often do not have the time or resources to locate or participate in these programs (Boebel-Toly, et al., 2012). Finally, the lack of integration between medical and mental health services (Dyson, 2010) (Kazak, et al., 2007), and the limited understanding by physicians of the impact of caring for a child with an illness or disability (Kind, et al., 2014) (Panicker 2013) (Coffey, 2006) (Sein, 1999) mean that mental health support or outside interventions may only occur when initially minor difficulties have accumulated into a crisis (Kazak, et al., 2007) (Sein, 1999). Currently, “targeted interventions have generally been focused on reducing symptoms after they develop” (Kazak, et al., 2007, p.1099-1110) instead of offering proactive supports that could reduce or prevent problems.

Doctors' lack of awareness of the "physical, psychological and economic constraints imposed by chronic illness on parents" (Panicker, 2013, p.210-219) can affect their relationship with a family. One study showed that while physician and parent ratings of the impact of a chronic illness on their child were similar, physicians' impressions of the impact of the child's illness on the *family* did not correlate (Sein, 1999). Lack of training and time constraints mean that aspects of care outside of medical needs are often not addressed as "The limitations of a brief consultation with a chronically ill patient who will have multiple needs are obvious." (Wagner, 2000)). Residency training also neglects a systems view of illness and family centered care (Kind, Goldman, Fratantoni, Wiedermann, Agrawal, & Coddington, 2014). Lack of understanding and training in medical professionals, combined with fragmentation of resources, results in many families caring for children with chronic illness or disabilities being misunderstood, overwhelmed, and offered limited or inadequate support.

Need for Support and Intervention

Why do we need to better support these families? The majority of care for children with chronic illness or disability takes place in the home (Kieckhefer, et al., 2009). This "requires parents/caregivers to be prepared and self-confident in their ability to meet the physical, social, and psychological challenges they face in managing the child's condition" (Kieckhefer, et al., 2009, p.101-8). In addition, these children will eventually need to develop the skills to manage their own illness or disability. Asking parents and families to take on significant responsibilities without

helping them learn how to do so (and teach their children) is a recipe for struggle and crisis (Panicker, 2013). The lack of preparation and support are especially problematic, as “family functioning seems to be the key to determining the adaptability of both the child and the family faced with the child’s chronic illness” (Canam, 1993, p. 47). Literature also supports that difficulties early in life “are biologically embedded and have lifelong consequences” (Shonkoff, Boyce, & McEwen, 2009, p.2252-2259), meaning parental stress and family dysfunction resulting from the presence of a child with a chronic illness or disability can have significant repercussions on the long-term health and well-being of all family members (Hogan, 2012), including the child.

Hexem et al., (2011) noted *“dimensions of the experience of illness or disability are often referred to as “caregiving” or the “burden of care”, the phrase “work of care” (WOC) specifies the physical and mental efforts of specific tasks in which parents engage, while avoiding the conflation in the term “caregiving”and the negative and potentially biased emotive connotations of “burden” (p.5).* Work of Care may be affected by a parent’s ability to perform tasks, resources (including time), outcomes, perspectives and circumstances - all of which can be interrelated (Hexem, et al., 2011). Canam (1993) lists 8 common tasks related to caring for a child with an illness or disability: 1. Accepting the condition, 2. Managing the condition daily, 3. Managing the developmental needs of the child with a chronic illness, 4. Managing the normal developmental needs of other family members, 5. Coping with ongoing stress and crisis, 6. Assisting family members to manage feelings, 7. Educating others about the chronic condition, and 8. Establishing a support system. Only one

of these eight tasks (#2) has to do with the child's direct medical needs! Lack of support for critical tasks and WOC results in adverse effects in many families of children with chronic illnesses or disabilities (Kazak, et al., 2007). This potentially results in poorer outcomes for the child, and negative effects on the family including poverty, poor family functioning, and psychological and physical health problems (Hogan, 2012) (Reichman et al., 2008) (Shahtahmasebi, et al., 2007).

Relationship Between Poverty and Pediatric Illness/Disability

Children with disabilities are far more likely to live in poverty than children without a disability, and to live in circumstances that adversely affect their cognitive and social development, academic performance and overall health (Shahtahmasebi, et al., 2011). Their families are also affected, faring “the worst for 8 of 11 measures of material hardship as compared to families of children without disabilities” (Parish, et al., 2008, p.71-92). This may be in part due to the high cost of parenting a child with a chronic illness or disability (Parish, et al., 2008) and the indirect cost of reduced maternal employment (Shahtahmasebi, et al., 2011). In addition to increased financial burden, “an even more important concern to parents may be the non-monetary costs of providing ongoing daily management” (Kieckhefer, et al., 2009). Increased stress, social isolation, poor environment, lack of skills and inadequate support can reinforce the relationship between poverty and disability (Parish, et al., 2008). The “piling up” of stress can eventually “overwhelm family resources and lead to crisis” (Canam 1993, p.49). This may be why children with chronic illness or disabilities – despite being more insured - were “61% more likely

[than those without] to have postponed necessary medical care and were 83% more likely to have postponed needed dental care” (Parish, et al., 2008, p.71-92). These statistics show access to good medical care is not enough – other aspects of WOC that affect family income, and parental and family functioning, must be addressed to ensure proper health care for a child with a chronic illness or disability. Certain “salient family characteristics” can mitigate the relationship between poverty and pediatric illness or disability (Shahtahmasebi, et al., 2011 p.667) potentially leading to better experiences and health-related outcomes for a child and members of their family.

Universal Impact of Chronic Pediatric Illness and Disability

The increased need for intervention is true regardless of the severity of the child’s condition. In some cases, families of children with an illness or disability that is perceived as “less severe” were assessed to be in greater need of intervention and support (Shudy, et al., 2006) (Webb, Cabral & Garg 2013) (Gershoff, Aber, Raver & Lennon 2007). Children with learning disabilities had multiple effects on their family, including: “stress, parenting discrepancies, negative reactions from extended family members, difficulty in interacting with the school, and mixed effects upon siblings” (Dyson, 2010). Illnesses or disabilities with behavioral components can be stigmatizing to families and result in increased social isolation (Dyson, 2010) (Reeve, 2006) (Tannen, 1996). Clearly, a broader view of WOC and the experience of parenting a child with an illness or disability, outside of medical needs or diagnosis, must be taken.

Importance of Family Functioning

To effectively treat a pediatric patient, their family and environment must be considered, assessed, and offered necessary supports or interventions. This will result in a better outcome for the patient, and less 'collateral damage' to the family. Illness or disability in one member of a family can significantly affect the entire family system, and "the family both affects and is affected by the chronic illness of a family member" (Clawson, 1996, p.54). One strong example of this is the relationship between a mother's mental health and coping skills to the outcomes of their children (Boebel-Toly, *et.al* 2012) (Menlyk, et al., 2004). In a study measuring family function in families caring for technology dependent children, "Thirty-five percent of the variance in family functioning was explained primarily by the mothers' level of depressive symptoms" and "a mothers depressive symptoms were the only significant predictor of family functioning" (Boebel-Toly, et al., 2012, p.64). A broader perspective was taken in a study of well-siblings of children with chronic illness, showing that "Socioeconomic status also influenced the mood of the mother, that in turn influenced family cohesion." (Dauz-Williams, Williams, Graff, Hanson, Stanton, Hafeman, et al., 2002). The significant economic effects of having a child with an illness or disability (Shahtahmasebi, et al., 2011) may have more than just material impact.

The importance of family function to children's well-being extends beyond a mother's mental health. Risk for some adverse effects of caring for a child with illness or disability are mitigated by certain family characteristics. For example,

although families caring for a child with a disability are more likely to experience “persistent or recurrent” poverty, “if the family has adequate personal and social resources, the families supporting a disabled child are no more likely to escape from or descend into poverty than other families” (Shahtahmasebi, et al., 2011, p.653). Knowing the potential for additional risks and poorer outcomes for families who raise children with an illness or disability (Hogan, 2012), the importance of family functioning and availability or development of social resources cannot be overlooked when considering their child’s treatment plan. Also, knowing the importance of the mother’s well being in child and family outcomes (Boebel-Toly, et al., 2012) (Menlyk, et al., 2004) (Dauz-Williams, et al., 2002), general assessments of parental economic resources and mental health should be a standard part of a child’s care. This is not only true for the care of a child with an illness or disability, but also for the care of their siblings. “Socioeconomic status and family cohesion” (both shown to be significantly affected by the presence of a sibling with a chronic illness or disability) were associated with the adjustment and functioning of well siblings (Dauz-Williams, et al., 2002). In addition to family cohesion, social support has been found to be “one of the most important factors” in positive outcomes and family experience of pediatric chronic illness (Butera-Prinzi, Nella, Heine, Rutherford, & Lattin, 2010).

If research shows that economic resources, social support, good communication, family cohesion, mental and physical health, and life-skills all contribute to better outcomes for children with chronic illness or disabilities and their families – it is significant that *these are the very characteristics placed most at*

risk by the circumstance of caring for an ill child. It is not only a severe or life-threatening diagnosis that affects families. Children with a learning disability, “despite its benign manifestation” may induce a “largely negative impact on families and siblings similar to that caused by more physical disabilities such as physical, intellectual or pervasive developmental disabilities” (Dyson, 2010, p.53). These children’s families may experience, “guilt, parenting dissonance, strained family life, unsupportive reactions from family members, negative interactions with the school, incompetent assessment, insufficient and fragmented service delivery, labeling, social isolation and problems with family coping” (Dyson, 2010, p.43). Just as children with a chronic illness may be treated only in a medical context, assessment of children with learning disabilities may occur only in the academic sphere – neglecting important social, familial, and medical factors.

Positive Effects of Pediatric Illness/Disability on Families

It is not all bad news. A child with chronic illness or disability may be a source of strength to the family (Coffey, 2006). “Family adaptation to chronic illness can generate family growth, increase individual and family autonomy, and family mastery of adaptive tasks” (Canam, 1993, p.46-53) though these responses are more likely “once they [the family] are equipped with appropriate coping strategies to assist them through difficult situations” (Paster, et al., 2009, p.1337-1342). These positive outcomes reinforce the need to take a systems perspective of pediatric illness or disability – how can a child’s medical condition cause such constructive

responses if the family's environment and experiences were not interconnected with the child's illness or disability?

And it is not just the immediate environment that is relevant. Neighborhood safety, social cohesion, and amenities such as parks and sidewalks related to whether a child had coordinated medical care or not (Aysola, Orav, & Ayanian 2011). Clearly there is a cultural/societal relationship to pediatric health that relates to child outcomes, just as there is a familial relationship. All of these relationships are neglected when a child with an illness or disability is only considered from a medical/diagnostic perspective.

Themes of Caring for a Child with Chronic Illness/Disability

Coffey (2006) identified 10 themes of families caring for children with chronic illness or disability. 1. *"Living Worried"* addresses the presence of worry as "a part of everyday life" as opposed to the less frequent worry by parents of healthy children. 2. *"Worry About the Sibling"* addresses parents' concerns about the "impact of the chronic illness on their relationship with their well children" (p.51-59). 3. *"Worry About School"* regards the parents' relationship with - and child's experience of - school. (This theme was heightened during developmental milestones.) 4. *"Being There, Just in Case"* is the concern that the child will not receive adequate care when the parent is not present or accessible. 5. *"Sadness"* and 6. *"Anger"* may be experienced at any stage of illness. 7. *"Mother as the Primary Caregiver"* is a common theme of mothers giving up their jobs to care for a child with an illness or disability. 8. *"Survival of the Family"* notes that "the impact of chronic illness was not only felt by the parents. The chronic illness has an impact on the whole family, including

extended family relationships” (p.51-59). 9. “*The Challenge of Managing*” is the challenge of navigating and coordinating multiple institutions and systems, along with daily Work of Care. 10. “*Loss of Support*” relates to the social toll on many relationships due to circumstances and responsibilities related to caring for a child with a chronic illness or disability (Coffey 2006). Common themes about caring for a child with an illness or disability are shared across all spectrums of diagnosis and severity of illness (Dauz-Williams, 2002) (Clawson, 1996). The experience of different chronic illnesses are often similar, including feelings about receiving a child’s diagnosis, effects on family function, and the challenge of illness management (Clawson, 1996). These themes - and parallel themes and experiences across multiple diagnosis (Gannoni & Rosalyn 2010), may offer a framework for standardized interventions and supports for families caring for children with chronic illness or disabilities.

Effects of Chronic Pediatric Illness and Disability on Families

In the same way the *experience* of pediatric chronic illness or disability in a family can be similar, so can the effects. A child with a disability “can have profound effects on family functioning” (Reichman et al., 2008, p.679). Their presence requires adaptation by the entire family (Clawson, 1996) as the (often changing) needs of a child with chronic illness or disability can “divert attention from other aspects of family functioning” (Reichman et al., 2008, p.683).

In addition to greater stress and anxiety, parents may experience “loss of friendships, feelings of isolation, anger, resentment, shock, and sadness” (Paster, et

al., 2009, p.1337-1342). Families of children with a disability or chronic illness may find it difficult to find childcare. This can affect employment, education, the choice to have additional children, and use of public assistance (Reichman et al., 2008).

Parents have to balance traditional parental tasks with medical appointments, treatments, and extra physical duties, while emotionally adjusting and changing expectations for their child (Lardieri, Blacher, & Swanson, 2000).

Because of the increased work related to caring for a child with a medical illness or disability, siblings may assume parental responsibilities (Coffey, 2006), affecting their relationships with parents (Reichman et al., 2008) as well as their social development, overall health, and short and long-term academic performance (Hogan, 2012).

With the challenges pediatric illness and disability present to a family, it is disconcerting that the healthy functioning of that same family seems to be essential to a positive outcome for the child (Reichman, 2008) (Canam, 2003). While there is a growing recognition of the non-physiologic impact illness and disability have on a child and family (Menlyk, et al., 2004) treatment plans often remain limited to a medical sphere (Kieckhefer, et al., 2009). It is important to take a systems view, working to stabilize the child and family's resources, offering strength-based support, and acknowledging the secondary impact pediatric illness and disabilities have on families, or outcomes will continue to suffer. This applies to a diverse group of families, "since existing models are focused on *resolving pathology*, they do not address the needs of [higher functioning] families" (Kazak, et al., 2007, p.1099-1110).

Concerns about negative health outcomes extend beyond the child with an illness or disability. Parents and siblings can experience health problems as a result of increased isolation, anxiety, tension and stress (Panicker, 2013). For example, mothers of children with learning disabilities were shown to be at increased risk for poor health and harmful stress (Dyson 2010), and siblings of children with physical disabilities had worse health than peers with healthy siblings (Hogan, 2012).

It is also important to consider the long-term effects of (even temporary) acute stress and familial dysfunction on children. “Chronic diseases can be seen as the products of repeated encounters with both psychologically and physically stressful experiences. When exposures occur during sensitive periods of development, their effects can become permanently incorporated into regulatory physiological processes, and subsequent adult disease may be viewed as the latent outcome of critical events that occurred during early periods of special susceptibility” (Shonkloff et al., 2009, p.2253). Chronic disease can be the cause of “stressful experiences” and the result of such experiences – resulting in a potential multi-generational cycle of illness and related family stress that exacerbates and repeats itself. Offering interventions that support these families, helping them manage non-medical tasks and develop life-skills, resources and social support, could mitigate the long-term negative effects pediatric illness or disability could have on a family.

Principles of Family System Medical Care

The next section of this paper will suggest a framework for supporting families of children with chronic illness or disabilities, proposing 10 Principles of Pediatric

Medical System Care. These principles are partly inspired by the successful Wraparound model (Bruns, Suter, Force & Burchard, 2005) (Burns & Goldman, 1999) and designated principles of systems of care (Stroul, Blau, & Friedman, 2010) (Rotto, McIntyre, & Serkin, 2008) (DeCarolis, 2005).

1. Care is Proactive and Preventative – providing support before a family’s problems and challenges may lead to crisis.
2. Care is Standardized - allowing support to be delivered consistently, and outcomes and costs effectively measured.
3. Universal Access - allowing any family, regardless of income, education level or socioeconomic status, to access the support they feel is necessary.
4. Care is Integrated – respecting and utilizing the perspectives and expertise of diverse group of professionals, allowing a holistic outlook on the child and their family to be considered in treatment planning.
5. Care is Strength Based and Skill Building - identifying and utilizing the family’s strengths to help them establish and work toward goals (rather than responding to pathology).
6. Care is Collaborative and Family Driven - fully incorporating cultural, social, environmental, mental health, education, and other aspects of their experience into medical care and treatment planning, supporting the family’s desired outcome.
7. Care is Individualized – geared toward the child and their family’s specific needs and desires.
8. Incorporates Community and Environment – acknowledging that social support is essential to positive outcomes for the family and child, and that the child’s environment is relevant to their medical care.
9. Tailored to Developmental Stages, and Stages of Chronic Illness – allowing for flexibility during different phases of growth and stages of illness.
10. Provides Professional Training and Development – recognizing that

culture change will be necessary for medical institutions and professionals to become collaborative and family driven in practice.

A Closer Look at Each of the Ten Principles

1. Proactive and Preventative

While education about medication and treatment protocols may be provided, often parents receive minimal or no preparation for the non-medical aspects of their child's illness or disability (Kieckhefer, et al., 2009). Because of the multiple risk factors for families of children with chronic illness or disabilities, it is important to offer supports such as preventative mental health screening, parent education, facilitated communication, skill building, goal setting, self-care and ongoing mental health treatment. These family mental health systems should be established before parents assume responsibility for care, helping families avoid crisis "that would negatively affect family functioning and the health of the child and potentially lead to the child's readmission to the hospital" (Boebel-Toly, et al., 2012, p. 67).

2. Standardized

The experience of chronic illness can be very similar among different diagnosis (Gannoni & Rosalyn 2010) (Clawson, 1996). Feelings upon receiving a diagnosis for their child, the challenges of illness management, and other common themes (Coffey, 2006) about caring for a child with an illness or disability are shared among diagnosis and severity of illness (Dauz-Williams, 2002). Effects on relationships with their children, doubt and fear, social isolation, difficulty communicating with health professionals, and the "constant recalibration to the ill child's needs" (Sein, 1999, p.178) may be experienced by families of children with severe or terminal

illness, and also by families of children with less acute illness or learning disabilities (Dyson, 2010) (Dauz-Williams, 2002). A standardized approach to supporting families, adjustable and individualized to a family's specific needs, would be simpler to implement, and potentially effective across multiple diagnosis and circumstances (Kazak, et al., 2007). Because current psychosocial care is not standardized (Kazak, et al., 2007) clinicians and researchers are not able to adequately measure a family's (often varying) ability to manage their child's needs (Kieckhefer, et al., 2009).

3. Universal Access

Current supports for families of children with chronic illness or disability are geared toward pathology (Kazak, et al., 2007) or provide material assistance based on economic need. However, the same way experiences are shared across diagnosis, they are also shared across income levels. In fact, higher incomes can correlate with *higher* levels of stress in parents of children with chronic illness (Shudy, et al., 2006). Traditional poverty measures are not enough to measure family well-being, especially because "the likelihood of living with *material* deprivation is elevated for children with disabilities across income strata" (Parish, et al., 2008, p. 71-92). Factors other than material resources can be relevant to a family's success, including social support, children's behavior, and type of medical diagnosis. "Families of children without definitive diagnosis may need the most help negotiating the system, since it is rarely clear that their children qualify for particular programs and the burden of proof often falls upon them" (Reichman, 2008, p. 681). A more significant illness may result in greater social support and compassion, potentially reducing the need for services. For example, "Stress

increased, and mother's well-being decreased, when a child's diagnosis had a "chronic" aspect [compared to acute], yet parents of children with life threatening/terminal illnesses received more support from health care personnel" (Shudy, et al., 2006, p. 203-218). Supports should be available to every family affected by pediatric illness or disability, regardless of income, education or resources, throughout the entire duration of the illness or disability and beyond if necessary. Family stress, lack of resources, and limited parental availability can affect the cognitive and social development in children who live well above the poverty level (Gershoff, et al., 2007) and this could potentially have lifelong consequences for these children and their families. Reducing the experience of trauma, and increasing parents' feelings of control and sense of safety for *all* families – not just the ones who present with the greatest needs - would be the ideal goal of intervention (Kazak, et al., 2007).

4. Care is Integrated – Medical, Mental Health & More

"Complimentary Functions" are important aspects of care that most medical doctors "have neither the skills nor the time to do well, such as counseling on behavioral change" (Wagner 2000, p.569-572). Researchers studying the effects of pediatric chronic illness on children and families have recommended incorporating mental health professionals into the main treatment team (Kazak, et al., 2007) (Walter, 2005) (Morrod, 2004). Nurses, social workers and other professionals may "ensure that critical elements of care that doctors may not have the training or time to do well are competently performed" (Wagner, 2000, p. 569-572). In addition, professional diversity will help to ensure the multiple facets and effects of pediatric

illness or disability are considered. In one study, parents expected physicians to cover psychosocial aspects of their child's care, but these were only discussed in ¼ of the visits. (While doctors recorded "80% of the discussion on physical symptoms" only 25% "of the discussions on psychosocial aspects were recorded" (Sein, 1999, p. 180). If mental health professionals are included in the treatment team, it seems likely that psychosocial aspects of care such as financial difficulties, stress, exhaustion, behavior issues, siblings, and self-care (Morrod, 2004) would receive more attention, resulting in greater parent satisfaction (Sein, 1999) and better outcomes for the child (Shudy, et al., 2006).

5. Strength-Based, and Skill Building

Most current interventions for families affected by illness or disability are reactive and pathology based (Kazak, et al., 2007). Support *should* be strength based, and promote the development of skills that could potentially help the family avert crisis. Kazak, et al., found that "most families are able to cope except for initial or recurrent periods of extreme distress" (p.1099-1110) and noted the benefits of "strength based" supports for all families. Offering parents the opportunity to build skills that help them to manage their child's treatment and family life can increase their abilities and confidence (Panicker, 2013) and lead to improved adherence to medical treatment as well as better health outcomes (Wagner, 2000). "Effective interventions tend to emphasize the acquisition of skills rather than just knowledge" (Wagner, 2000, p.569-572) and while things like family income cannot be directly changed by mental health-related interventions, "family cohesion, sibling mood, feelings of support, and self-esteem may be alterable in directions producing

positive [health] changes” (Dauz Williams 2002, p.422). Importantly, these changes, in addition to improving overall well-being of family members, can decrease dependency on doctors and other professionals (Wagner, 2000). Recognizing families’ strengths can “build up parental confidence” and “help parents mobilize their physical and psychological resources to meet the increased health care needs of their child” (Panicker, 2013, p.210-219).

6. Collaborative/Family Driven

While parents value professionals’ knowledge, they would like their own expertise about their child to be valued (Coffey, 2006). The disconnect between parents’ expectations and the focus of physicians (Sein, 1999), and the relationship between family satisfaction and the ability of medical staff to communicate effectively (Shudy, et al., 2006) highlight the need for more effective communication and consideration of families’ varied resources, cultural reference points, and priorities. Family-centeredness is one of the main components of a medical *home* (Webb, Cabral & Garg, 2013), and this ideal should be extended to any pediatric medical intervention. As some programs have shown (Butera-Prinzi, et al., 2010) (Menlyk et al., 2004) (Sullivan-Bolyai, Grey, Deatrck, Gruppuso, Giraitis & Tamborlane, 2004) families can be empowered to successfully manage a great deal of their child’s care – provided they are offered the support, skills and resources to do so. Empowering parents to feel confident to discuss aspects of care, and to negotiate with medical professionals, results in better outcomes for their children (Panicker, 2013) (Hexem, et al., 2011). Medical intervention should be “a partnership between parents and professionals with mutual decision making using

resources, opportunities and authority to manage a child's care" (Panicker, 2013, p.210-219). Treatment planning should not be limited to the negative impact of a diagnosis, but "should draw upon the coping strengths and resources of the child and family" (Sein, 1999, p.181).

7. Individualized

"Recognizing the families' strength and diversity, and facilitating decision making" are important parts of supporting parents to meet their child's health care needs (Panicker, 2013 p.210-219). Considering the complete context of pediatric illness in a family, as well as their personal and cultural preferences, is an essential part of developing an effective treatment plan - especially since including patient's preferences will more likely result in satisfied, compliant patients (Wagner, 2000). It seems reasonable to propose that including the reality of families' financial and social resources, mental health, level of functioning, relationships, skills, and current life circumstances in treatment planning would result in a greater treatment adherence, and better outcomes, for the child and their family. The common practice of prescribing medical treatment without considering the ability of parents to implement protocols, or the family and child's priorities, circumstances, or preferences, cannot be as effective as a more individualized approach. In addition to encouraging individualized treatment planning, supports and interventions must also be individualized. "Each parent's ability to learn a new skill may be different. Some parents learn technical skills related to child's care easily whereas some may need more time and effort" (Panicker, 2013, p.210-219). Assisting families in

identifying and stabilizing their personal resources will help them provide a strong foundation for their child's continued care.

8. Incorporates Community and Environment

As unique and relevant as a family's resources and preferences are the environments and communities they live within. Social and environmental factors can modify risk factors and affect personal choices (Shahtahmasebi, et al., 2011), and environmental conditions can correlate with access to health care and health outcomes (Abeyta, Tuitt, Byers & Sauaia 2012). Perhaps more significant than their immediate environment, the strength of a family's community and social relationships can have implications on the physical health and the financial and emotional well-being of all family members, including the child with an illness or disability (Reichman, et al., 2008). "Parents of children with disabilities reported less stress and fewer depression symptoms when they had access to social support" (Paster, 2009, p.1337-1342). Relationships with grandparents, extended family members, neighbors, educators, friends and coworkers may all be affected by the presence of pediatric illness or disability in a family (Reichman, et al., 2008), and the loss of support systems can be detrimental (Coffey, 2006). Familiar resources such as babysitters may become unavailable, and "in some instances, the support system was unwilling or unable to be there for the family" (Coffey, 2006, p.51-59). Interventions that help parents identify local resources, work in partnership with schools, communicate the circumstances and effects of a child's illness or disability to others, and identify circles of support, would benefit the entire family. Especially

since social support can be “one of the most important factors” in positive outcomes and family experience (Butera-Prinzi, et al., 2010, p.31).

9. Tailored to Developmental Stages, and Stages of Chronic Illness

Caring for a child with a chronic illness or disability is an “ongoing, continually shifting process whereby the illness is sometimes in the foreground and at other times in the background. When the illness is in the foreground, the focus is on the sickness, but when it is in the background the family’s focus shifts to the health and well-being of the entire family” (Boebel-Toly, et al., 2012, p.55). Because Work of Care is ever-changing, a family’s needs may be unpredictable (Hexem, et al., 2011). Demands on parents increase as they continually alter their roles and responsibilities to support their child, while working to maintain a sense of normalcy (Panicker, 2013). Time absorbed by Work of Care, financial needs, and illness management, can limit parental availability as their children grow and develop. These changes and development can, in turn, alter or complicate the Work of Care (Hexem, et al., 2011). A long-term perspective on supporting families of children with chronic illness or disability should be taken, especially since the potential effects extend beyond the immediate medical concern. For example, a child’s cancer diagnosis was shown to have long-term trauma effects, including PTSD, on families even when the child recovered completely (Kazak, et al., 2007), and symptoms of distress and depression in mothers have been shown to be greater than controls’ 6 years after a child’s initial diagnosis (Gerhardt et al., 2003).

There are several “critical times” present for parents of a child with a chronic illness (Coffey, 2006). The first is at diagnosis and initial discharge from the hospital.

The second occurs during moments of “major milestones” for the child and their peers. “Milestones not met are sources of frustration and a reminder of the child's chronic illness. Each transition was unique in its success and challenges” (Coffey, 2006, p.51-59). Effects of chronic illness, disability, and medical intervention on children, such as fear, anxiety, stigmatization and isolation, can vary with age and development (Sein, 1999) and the stage of the child's illness can be a deciding factor in parental readiness to care” (Panicker, 2013, p.210-219). All of these changes can mean “disequilibrium in the family, especially for those who are providing direct care for the child” (Coffey, 2006 p.51-59). The U.S. Social Security Advisory Board noted this problem in our current “patchwork” system of supports for children with disabilities and their families, and recommended a “coordinated and purposeful approach, with case managers and “life progression plans” to remedy the lack of support through developmental stages and the related stages of illness or disability (Social Security Advisory Board, 2006).

10. Provides Professional Training and Development

The idea of collaborative, family driven medical intervention confronts the hierarchical culture often seen in Western medical practice. One challenge is the current disconnect between families and medical practitioners. A study showed parents valued the ability of medical professionals to show compassion and respect more than their “technical competencies,” while health care providers made few references to their interactions or relationships with these parents (Panicker, 2013). Another study showed that “the behavior of hospital staff and their ability to

communicate (or not) were strong determinates of parental stress” (Shudy, et al., 2006, p.203-218). Pediatric residents who were trained in providing a ‘medical home’ admitted they “needed to better understand families’ financial, emotional, and social needs and increase families’ involvement in care planning” (Kind, et al., 2014, p.658-665). In addition to the parent/professional relationship, specialists from different areas such as medicine, mental health, nursing, and education and could be trained to communicate and work effectively together. Wagner (2000) suggests a more collaborative model, where “medical specialists in consultative and educational roles outside conventional referrals” could result in better outcomes (p.569-572). However, he adds, “the presence of a trained [patient care] team may be of little help if doctors cannot share care effectively, or if a practice’s lack of organization limits the availability of staff to work in these complimentary roles.” (p.569-572). Training that provides behavioral and clinical skills to medical professionals, and guides culture change in the medical field away from hierarchical mindsets to a more collaborative, family centered model, would help integrate mental and physical health, and support the inclusion of families as well as professionals in treatment (Walter, 2005).

Examples of Family System Medical Care in Practice

Elements of these 10 Principles of Family System Medical Care are present in several proposed standardized supports for families of children with illness or disability that have been formally studied. The Pediatric Psychosocial Preventative Health Model (PPPHM), Medical Traumatic Stress Model (MTSM) (Kazak, et al.,

2007), and Creating Opportunities for Parent Empowerment (COPE) (Menlyk et al., 2004) are hospital-based, professional interventions that support families of children with acute illness. Outpatient programs involving peer support include a peer-mentoring program for caregivers of children with Type 1 Diabetes (Sullivan-Bolyai, et al., 2004), and the 'Link-Up' program (Butera-Prinzi, et al., 2010) which offers professionally facilitated peer support for families of individuals with Traumatic Brain Injury (TBI). Both the professional-led and peer support programs produced positive results.

The Pediatric Psychosocial Preventative Health Model (PPPHM), and the Medical Traumatic Stress Model (MTSM), are offered as a "blueprint" (Kazak, et al., 2007) for clinical care of families affected by childhood cancer (and potentially for other illnesses). The initial phase of the program is an assessment to see how parents are coping with their child's illness. The PPPHM model is for families who are assessed to be competent and without significant risk for psychopathology, but who would still benefit from support. This assessment is important, since most current interventions are designed to resolve crisis or pathology – yet less than 10% of families assessed in this study were found to be in the "Clinical-Targeted" risk category (Kazak, et al., 2007). In fact, most families fell into the "Universal Risk" category, with "understandable" distress and difficulty related to their child's illness that could be alleviated by the PPPHM program. The MTSM is designed to support the 10% of families who are assessed to be at significant psychosocial risk. This program identifies several stages of trauma, and recognizes that stressors can result in severe trauma symptoms in some families. Both the PPPHM and MTSM

interventions can be tailored to the different needs of each family, and the emphasis on proper assessment assures that correct interventions are offered in a timely and proactive manner. In addition, the assumption is formal support should be offered across the entire spectrum of family response to illness, as preventative support is superior to, and more cost effective than, reactive interventions (Kazak, et al., 2007). The PPPHM and the MTSM include strategies for increasing family competence and identifying children/families in distress. Both offer individualized supports, and serve as models for treatments that are “preventative, innovative and targeted to the true needs of the child, family and health care system” (Kazak, et al., 2007, p.1099-1110).

The COPE program (Menlyk et al., 2004) is a hospital-based program consisting of three phases: 1. Increasing parental knowledge of their child’s behaviors and emotions. 2. Facilitating “direct parent participation in their children’s emotional and physical care” (Menlyk et al., 2004, p.599), and, 3. A follow up call 2-3 days after hospital discharge. The COPE program resulted in less negative parental mood vs. a control group, less depression, fewer PTSD symptoms in parents after 6 months and 12 months, and reduced parental stress (Menlyk et al., 2004). In addition, COPE mothers participated more in their child’s in-hospital care, and felt more skilled at anticipating their child’s care needs after discharge. COPE children’s behaviors were significantly better than controls, and even without any long-term COPE support post-discharge, COPE children “exhibited significantly fewer withdrawal symptoms 6 months after discharge, as well as fewer negative behavioral symptoms and externalizing behaviors at 12 months” (Menlyk et al., 2004, p.597). They were also

reported to have reduced hyperactivity and more adaptability, and far less behavioral and externalizing symptoms, than control children one year after discharge from the hospital.

Effective family support does not have to be hospital-based. One intervention program involved parent mentors who successfully raised children with Type 1 Diabetes. These mentors were trained and matched to mothers with recently diagnosed Type 1 children. This study (Sullivan-Bolyai, et al., 2004) included a 6-month trial of peer home visits and phone support vs. a control group who received no support. Baselines were recorded for overall functioning, depression, impact on family, and access to resources. Both groups were assessed at 1 and 6 months after beginning the program, and mothers who were mentored had “fewer concerns, more confidence, identified more resources and perceived diabetes as having less of a negative impact on their families” v. the control group (Sullivan-Bolyai, et al., 2004, p.476). Peer mentors were trained to offer consistent support, offer parents the opportunity to share their personal stories, and address areas of personal experience that parents felt were ignored by “medically oriented professionals” (Sullivan-Bolyai, et al., 2004). One mother noted that while “the diabetes medical team related to my child’s medical condition”, the mentor “validates my feelings” (p.482). The authors concluded, “many of the day-to-day management activities and responsibilities that concern mothers are often intangible issues that the visiting nurse [or other medical professionals] cannot address” (Sullivan-Bolyai, et al., 2004, p.477).

Another peer support program studied was the Family 'Link-Up' program, offering support to families of individuals with traumatic brain injuries (TBI). This program included facilitated "Link Ups" (peer support sessions screened to be culturally sensitive) with families sharing similar experiences, followed by a debriefing session. Along with peers, the program also used professionally trained facilitators, providing "a level of safety and support" (Butera-Prinzi, et al., 2010) for the families, while also guiding the peer-to-peer conversations. Just as in the previous peer-support study, families appreciated the "sharing and validating of common experiences" (p. 41) and also had an increased sense of empowerment and access to resources. Many caregivers said the 'Link-ups' resulted in greater feelings of compassion for themselves, and for the family member they cared for. In addition, they felt a stronger sense of community. The program also benefited the mentors (Butera-Prinzi, et al., 2010). The use of personal and familial narrative "elevated the family's knowledge to that of a professional" (p. 45) resulting in the peer mentors believing they have used their experience to contribute in a positive way.

All of these diverse interventions had positive results, showing many families affected by pediatric illness or disability would benefit from support of their psychosocial needs. None of these studies showed negative or neutral outcomes of interventions supporting the non-medical aspects of caring for a child with chronic illness or disability – in fact the results were distinctly positive. The variety of interventions studied reveals there is no single way of offering support. Collectively the studies suggest necessary elements of successful intervention programs, including: assessment, skill-based education, and an emphasis on self-care.

Assessment, Skill-based Education, and Self-care

Assessment

The COPE program (Menlyk et al., 2004) highlighted the importance of parental assessments. That the “number of stressful events in the year before hospitalization correlated significantly with PTSD symptoms [in parents] after hospitalization” (Menlyk et al., 2004, p. 601) reveals aspects of a family’s life *unrelated* to a pediatric illness may affect outcomes. Assessments can identify these circumstances, and also reveal that traditional measures of income, educational attainment, or assumptions about the severity of a child’s diagnosis are not adequate identifiers of who might be at risk for problems managing their child’s care (Gershoff, et al., 2007). For example, families that are high functioning but experience multiple challenges in a year may be in need of significant support, just as families with low incomes but strong social support may not need much intervention (Gershoff, et. al, 2007). A proper assessment would identify a family’s life-skills, social support and resources – all of which affect the family’s ability to effectively care for a child with an illness or disability while managing the necessities of daily life. Assessment would also allow for proper study and measurement of the immediate and long-terms effects of pediatric illness or disability on families. For example, mothers of children with Juvenile Rheumatoid Arthritis had “greater symptoms of distress and depression” 6 years past their child’s initial diagnosis – across a wide range of income and socioeconomic status (Gerhardt, et al., 2003). Including parental assessment as a component of pediatric medical care would provide physicians detailed information

about caregivers' resources, strengths, ability to cope, circumstances, home environment, and overall functioning. This information would guide effective interventions and medical treatment for the child, while increasing researchers' and physicians' understanding of the overall effects of pediatric illness and disability on children and families

Skill-based Education

Skill based education can offer parents tools that enable them to better care for a child with a chronic illness or disability (Menlyk et al., 2004) as well as manage multiple aspects of family life (Hexem, et al., 2011). Skill based interventions can be relatively simple. In one study (Lion, Mangione-Smith & Britto 2014, p. 11-25) a "Written Health Plan" was developed by families, along with a care coordinator and the support of their primary care physician. "Compared to controls, intervention families reported greater satisfaction with some aspects of care and less unmet need for information" (Lion, et al., p. 11-25). Follow up revealed improvements in the child's health, less strain on caregivers, and greater overall satisfaction. Another study reported that parents who created a basic, proactive "plan of action" for responding to their child's behaviors were able to cope with difficult situations more effectively (Paster, 2009). Offering organizational tools, facilitating care and safety strategies, and helping families access useful resources would make the experience of pediatric illness and disability more manageable, and less traumatic and isolating, for the child and the family (Boebel-Toly, et al., 2012). In addition, helping parents learn the skills necessary for effective Work of Care can result in their feeling more empowered and confident in their ability to care for their child

and family (Hexem, et al., 2011) and result in better medical outcomes for the child (Lion, 2014).

Emphasis on Self-care

Because the well-being of a mother or caregiver can have significant impact on the effect of pediatric illness or disability on a family (Boebel-Toly, 2012) and on a child's outcomes (Paster, et al., 2009) (Menlyk, et al., 2004) interventions that support self-care and target symptoms of depression and anxiety are recommended (Boebel-Toly, 2012). Constant worry, depression and suicidal ideation are all themes of parenting a child with chronic illness (Coffey, 2006), and parents have to manage medical care, daily routines, and coordinate services while working to maintain normalcy in their own lives, and in their family's. It is important that intervention and supports include attention to exercise and diet, relaxation exercises, and spiritual practices along with maintaining communication and social connections (Hexem, et al., 2011). Addressing the physical symptoms of stress in parents of children with chronic illness or disability, such as reduced sleep, irritability, and headaches (Shudy, et al., 2006) by incorporating caregiver interventions into a child's treatment plans can reduce adverse effects, and improve parent availability (Gershoff, et.al, 2007), adherence to medical protocols (Wagner, 2000) (Menlyk, et.al, 2004), and overall outcomes for the parent, child and family (Shonkoff, et.al, 2009). In addition, if parents are prepared and confident in their ability to meet challenges, their children will likely develop the skills, mindset and temperament to eventually manage their own illness or disability successfully (Kieckhefer, et al., 2009) into adulthood.

Another important aspect of self-care is maintaining social connections, as social support can be critical to positive outcomes and family experience (Butera-Prinzi, et al., 2010). Much of the impact of pediatric illness or disability is caused by the distress and anxiety related to a family's relationships and interactions within a community – including job pressures, financial difficulties, loss of friendships, isolation, difficulties at school and feelings of failure (Dyson, 2010) (Shahtahmasebi, 2011). Families of children with a chronic illness or disability have difficulty developing support networks and participating in community activities (Canam, 1993) resulting in social isolation. “The human brain cannot be understood outside of the context as the brain of a member of a highly social species,” (Perry, 2007 p.77) and we must consider the impact of Work of Care (and related stigma and isolation) on a family's relationships and sense of belonging.

Including parental assessments, skill-based education, and parental self-care in pediatric medical treatment planning requires considering the familial, social, economic and cultural systems a patient exists in, instead of only seeing a child in diagnostic and medical spheres. Granted, this is a large undertaking, but both the child and family would significantly benefit from a systems view (Hexem, et al., 2011).

The Need for a 'Systems View' in Pediatric Medical Care

While encouraging, the recent movement toward the integration of mental health and medicine has more to do with the individual patient, and is less about seeing the patient, their family, and their community, as a *system*. Inattention to physical,

economic, and psychological constraints on families affected by pediatric illness or disability (Panicker 2013), social and emotional impact (Dyson, 2010), and the effects of community and environment on health (Abeyta, 2012) (Shahtahmasebi, et al., 2011) creates unseen limitations on medical treatment. Improving “epidemiologic and sociological understanding of the WOC system” (Hexem, et al., 2011) would allow a child with an illness or disability to be viewed as part of a greater organism. Considering a pediatric patient and their family as part of an environmental, social, personal, cultural and economic system could offer broader options for effective medical treatment that would also potentially reduce the multiple adverse effects of pediatric illness and disability on families, and on society.

Culture Change

A systems view not easily practiced in the current model of health-care delivery in the U.S. It is important to acknowledge that the principles of ‘systems care’ (De Carolis, 2005) are a challenge to the traditional, hierarchical culture of our medical institutions. They are also a challenge to families accustomed to a culture that expects medical ‘experts’ to ‘fix’ problems, instead of being empowered to help address their own complex needs.

The need for integrated care, collaboration between mental health and other professionals, and inclusion of family’s circumstances and expertise in treatment planning is a challenge to how many of today’s doctors practice medicine (Kind, et al., 2014) (Walter, 2005) (Wagner 2000), not to mention that physicians often work within a managed care system that does not support these principles. Integrated,

holistic and universal interventions for families of children with illness or disability will require a significant shift in the culture of our health-care system and institutions. First, medical providers need to become “family centered” in their perspective on managing a child’s care (Kieckhefer, et.al, 2009) and better understand the emotional, financial and social needs of families (Kind, 2014). Children’s schools should be more prepared to support them during an illness, and liaisons to medical and educational systems should be offered to parents (Gannoni & Rosalyn, 2010). Parents need to be empowered to communicate their needs or perspectives on care without fear of damaging their relationships with physicians or other professionals, and have their own expertise and knowledge of their child valued (Coffey, 2006). The relationship between parents and medical providers will need to be modified, as parents value health care providers’ ability be compassionate and respectful (MacKean, Thurston and Scott, 2005) when many health care providers do not place equal importance on their interactions with families (Panicker, 2013), or on developing collaborative relationships with parents (Coffey, 2006).

And it is not only collaborating with families that will require a shift in culture. Diverse groups of providers, including physicians, mental health professionals community providers, nurses, receptionists and educators must learn the skills to act as a team (Kind, 2014) as their effectiveness will depend greatly on their ability to work together (Wagner 2000).

Economic Benefits of a System Approach

In addition to reducing the impact of pediatric illness and disability on families, and improving medical outcomes, a system approach to pediatric health care could also have economic benefits (Panicker, 2013) (Shonkloff et al., 2009) (Kazak, et al., 2007) (Wagner, 2000). Preventative care can be cost effective (Kazak, et al., 2007) and effective utilization of medical services, along with families feeling empowered to offer capable care at home, can lower health care costs (Panicker, 2013) (Webb 2013). Alongside direct medical costs are indirect costs and other expenses associated with caring for a child with a chronic illness or disability. In the U.S., families bear the main cost of a child's disability at a time when most mothers reduce the number of hours they work (Parish, et al., 2008). Families of children with disabilities are far more likely to live in poverty (Shahtahmasebi, et al., 2011) (Parish, et al., 2008) and lowered socioeconomic status can affect family cohesion and functioning (Dauz-Williams, et al., 2002), adversely affecting family and child outcomes (Boebel Tolv, et al., 2012). Lowered incomes can affect parenting style and parental availability (Gershoff, et.al, 2007), and cultivate environments that increase the risk of poor development, social isolation, cognitive impairment and poor health (Shahtahmasebi, et al., 2011). In addition to lowering immediate health-care costs, reducing stressors on families affected by pediatric illness or disability, and improving their overall circumstances, can increase both parents' and children's well-being - improving "societal health and longevity" (Shonkoff et al., 2009, p. 2252-2259), and lowering the occurrence of disease over an individual's lifespan, offering a long-term economic benefit to society (Shahtahmasebi, et al., 2011).

Barriers to a System Approach

Despite the potential of a system view of pediatric illness and disability to improve the experience of families and children, foster better outcomes, and reduce the medical and secondary cost of pediatric illness and disability, there are many barriers to implementing the principles of systems care. Currently, there are not enough experienced professionals knowledgeable about impact of pediatric illness or disability on families, or trained to empower parents and caregivers (Panicker, 2013). Lack of coordination (and limited availability of health records and histories to different providers) challenges professionals' ability to provide integrated care (Jaudes, Kleinberger, Harden, Masterson & Bilaver, 2012). The multiple constraints on parents caring for children with chronic illness or disabilities (Panicker, 2013) may create stress levels that impede overall functioning in families facing these challenging circumstances, including their mental flexibility, anxiety levels, and memory (Shonkoff, 2009). This adversely affects their ability to collaborate with health care providers, and to care for their children. Financial and employment difficulties that are a theme of caring for a child with an illness or disability (Shahtahmasebi, et al., 2011) (Aiesh, et al., 2008) (Coffey, 2006) can further exacerbate these stressors and effects, nourishing the exponential relationship between poverty, pediatric illness, and disability - leaving those with the fewest resources more likely to face these challenges. (According to the CDC, children living below the federal income level had higher prevalence of disabilities, and children insured by Medicaid had double the rate of children with private insurance.) The mere presence of chronic illness or disability in a child can influence an entire family

(Clawson, 1996) and affect the functioning of that family system (Hogan, 2012) (Hexem, et al., 2011) (Reeve, 2006) in ways that may not contribute to collaboration, empowerment, or family centeredness - or to the best care for the child. The health care system itself presents a barrier to efficient system care as it presents a “bureaucratic maze” (Canam 1993 p.47) that many parents find difficult to negotiate, resulting in the inclination for parents or caregivers to surrender personal responsibility to medical personnel and institutions instead of advocating for additional support or necessary resources for their child and family.

The models for intervention offered by researchers seem to assure us that formal support for families affected by pediatric illness or disability is both needed and welcomed. If barriers can be overcome, inclusive, individualized and family-centered programs can empower families to offer better care for their children, and develop the resources they need, while simultaneously taking some of the burden off of health-care providers and medical institutions.

The Importance of Community

The stress and unpredictability of chronic or acute illness calls for interventions and support in multiple aspects of a child’s life: environment, medical home, family home, school and neighborhood - as each of these can influence their experience of illness and disability (Reeve, 2006). One aspect of this support that must not be ignored is Community. Until we foster a culture that genuinely accepts and embraces those who are struggling, the experience of caring for a child with a chronic illness or disability will remain difficult. This is not because of the

characteristics of the child or their family, but instead, “the interaction between health conditions or impairments and prevailing social norms, attitudes, expectations and accommodations which lead to the social exclusion of people” (Shahtahmasebi, et al., 2011 p. 667). The spurning of families who do not meet society’s criteria for ‘success’ or ‘normality’ is a large part of what contributes to the difficulties these parents and their children face. The already present challenges of family life, additional Work of Care (Crowe, & Florez, 2006), social isolation, and financial impacts of caring for a child with a chronic illness or disability make it hard for many families to ‘keep up’ - as they may be working significantly harder, and expending far more energy, to maintain the same routines and sense of normalcy as a family not affected by pediatric illness or disability. Sein (1999) noted, “Family's coping and adaptation mechanisms should be acknowledged and seen in the light of the family's attempt to achieve an equilibrium, rather than comparing them rather negatively against ‘normal’ families” (p. 181). This struggle for balance - one that would allow parents and all their children not simply to manage their daily lives, but instead *thrive* as they care for children with chronic illness or disabilities - truly deserves respect and formal support.

Conclusion

With this support, medical outcomes for children will be improved, and families may be more likely to find the ‘silver lining’ present in their experience. While mothers of children with chronic illness and disability have more depression and anxiety (Hexem, et al., 2011) they also report experiencing strong feelings of love

and appreciation. Paster, et al., (2009) noted children with disabilities have been the source of “strengthened family ties, strengthened religious faith, and an expanded social networks” along with “greater pride and sense of accomplishment, greater knowledge about disabilities, less likelihood to take things for granted, and greater tolerance, sensitivity, and patience” (p. 1337-1342). Children with an illness or disability may change their family’s lives for the better, including adjusting the pace of their lifestyle, increasing their sense of confidence and control, and growing their capacity for patience and compassion (Paster et al., 2009) (Blacher, Baker & MacLean, 2007). These positive responses to adversity make the argument, along with negative ones, that there is a *family system* affected by pediatric illness and disability. Positive outcomes for a child with an illness or disability and their family are far more likely to be present if this system is considered in the child’s medical treatment planning, and if their family and caregivers have access to programs that help them develop and maintain skills and resources necessary to effectively manage their child’s care, while also being able to thrive as individuals, and as a family.

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