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Child life specialists as facilitators of child participation : a thematic literature review

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**CHILD LIFE SPECIALISTS AS FACILITATORS OF CHILD PARTICIPATION:
A THEMATIC LITERATURE REVIEW**

by

Caron Mills, BA, Ryerson University, 2006

A Major Research Paper
presented to Ryerson University

In partial fulfillment of the requirements for the degree of

Master of Arts
in the Program of
Early Childhood Studies

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Master of Arts
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ABSTRACT

The child's right to participate is a fundamental right outlined in the *UN Convention on the Rights of the Child*. Canada signed and ratified this convention in 1991. Through secondary literature and the author's personal experience this paper explores the child's right to participate in the context of Canadian pediatric medicine. In particular, this paper examines if and how a child is encouraged to participate in their health care, and which members of the health care team facilitate this participation. The paper also outlines a number of factors that limit or enhance child participation. Recommendations and next steps are included in the paper with the purpose of enhancing the quality and amount of participation that is offered to pediatric patients within hospital settings. One recommendation that is developed and discussed is the increased role of the child life profession as a tool for enabling child participation.

Key words: Child participation, pediatric health care settings, child life specialists

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Table of Contents

The Evolution of Children's Rights	2
The United Nations Convention on the Rights of the Child	3
The Three P's: Provision, Protection, Participation	4
Child Participation	6
The Child's Right to Participation in a Health Care Setting	8
<i>Right to Expression</i>	8
<i>The Right to Information</i>	12
<i>Right to Decision Making</i>	16
Factors That Impact Participation	21
<i>Style of Patient Care</i>	21
<i>Child's Competence Levels</i>	23
<i>Information Delivery</i>	26
<i>Time Pressures</i>	27
<i>Parental Control</i>	28
<i>The Right to Protection vs. The Right to Participation</i>	31
<i>Child Life Programs</i>	32
Conclusion and Further Recommendations	38
<i>Recommendation for Policy-Makers</i>	40
<i>Recommendations for Health Care Professionals</i>	41
<i>Recommendations for Parents</i>	43

Disease or illness has the potential of affecting all children during their childhood. The *UN Convention on the Rights of the Child* articulates under the child's right to provisions that every child must receive high quality health care. Children also have the right to participate in all aspects of their lives (Convention on the Rights of the Child, 1989). Therefore, a medically fragile child who is experiencing hospitalization is entitled to receive not only the best care possible, it is also essential that he or she becomes a participatory member in making the decisions surrounding his or her treatments and medical care.

In this paper, I will review the scholarly literature on child participation within the health care setting in order to explore the extent to which the child's right to participate, one of the fundamental principles of the *UN Convention on the Rights of the Child*, is honoured within the pediatric hospital setting. I will be focusing on North America and briefly on China and Sweden I will first discuss whether or not and how a hospital setting is fulfilling the child's right to participate. In particular, I will present findings regarding how children are being encouraged to participate in hospital care and which members of the medical community are facilitating participation. I then will discuss the prevalent factors that limit or enhance a hospitalized child's ability to participate in their care. In addition to the scholarly literature, I will also draw upon my own experience as a child life specialist in a children's hospital. I will conclude this paper by providing recommendations and next steps for enhancing the quality and amount of participation that is offered to pediatric patients within the hospital setting in Canada.

The Evolution of Children's Rights

It is important to understand the evolution of children's rights to recognize why such value should be placed on the child's right to participate. In Canada, as in most developed countries, the rights of the child have undergone a substantial process of evolution. The changing roles and rights of children have had a significant impact on the way Canadians view children as well as on the public policies and laws that effect children and their families. Howe (2001) describes this evolution over three time periods. First, during the colonial times parents held all the fundamental rights and as a result children were seen as possessions of their fathers. Society expected parents to look after and educate their children but there were no laws that protected children against abuse and neglect. Children began to be seen as a separate class of immature adults around the mid-twentieth century. During this second stage, parents continued to have possession over their children but Canadians began to recognize that it was the state's responsibility to intervene when parents were abusive, neglectful or mistreated their children. Finally after World War II, children were no longer viewed as objects, but seen as a group who had their own fundamental rights.

This shift in how children were viewed influenced the development of the *United Nations Convention on the Rights of the Child*. Neither the *Universal Declaration of Human Rights* nor the *International Covenants on Human Rights* consider the specific rights of the child, so the *Convention on the Rights of the Child* was drafted. The UN decided to create a specific document for children because they believed the world's children are a particularly vulnerable group that is entitled to special care and protection (Convention on the Rights of the Child, 1989).

The United Nations Convention on the Rights of the Child

The United Nations was created in 1945 by 51 countries with the purpose of preserving peace throughout the world (UN in Brief, Chapter One, n.d.). Sixty three years later the UN has taken on a broader humanitarian role, as shown by the multiple conventions that the organization has adopted. As mentioned above the *Convention on the Rights of the Child* is a document that was created by the United Nations that is dedicated to the protection of children as it outlines and promotes their rights. This document is not an international law; it is a set of principles outlined by the UN that countries can use as a guide for making domestic laws, best practices and policies for the children of their country (Stasiulis, 2002).

A child is defined by the UN as “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier” (Convention on the Rights of the Child, 1989 pp. 2). The *UN Convention on the Rights of the Child* is the first and only comprehensive document in the world that recognizes the unique developmental needs of children and clearly acknowledges children as independent rights-bearing individuals (Canadian Coalition on the Rights of the Child, 2002). There have been 191 countries that have signed and ratified the convention; this is the largest support by nations that a human rights treaty has ever received (Canadian Coalition on the Rights of the Child, 2002).

Canada signed and ratified the *UN Convention on the Rights of the Child* in 1991. This signified that Canada has committed to the agreement and follows through domestically by bringing laws, policies, and practices in line with the standards of the Convention. The ratification demonstrated that Canada recognizes that children have

rights and that they should be protected as individual persons (Howe, 2001). The convention once again prompted changed in perspectives on the relationship between adults and children. Adults who interact with children are expected to evolve from being providers and protectors to becoming individuals who help create opportunities and ensure that the fundamental rights of Canadian children are being honoured (Pais, 2000).

The Three P's: Provision, Protection, Participation

The primary focus of the *UN Convention on the Rights of the Child* is “the best interests of the child” (Hammarberg, 1990). To ensure that this is achieved, the rights of the child are outlined in the 41 articles contained in Part One of the Convention on the Rights of the Child. These rights can be easily understood by grouping the articles into three sections, most commonly referred to as the three P's: Provision, Protection and Participation (Hammarberg, 1990).

“Provision” refers to the child’s right to have their basic needs fulfilled. Children must be provided with basic necessities such as food, shelter, education and health care. They also need to be provided with the opportunity to experience recreation and play, as well as have a name, nationality, and to be cared for by their parents (Howe, 2001).

The right to “protection” ensures that children are shielded from harmful acts or practices (Hammarberg, 1990). Children have the right to be protected from abuse and neglect, they must not be discriminated against and it is essential that they are sheltered from sexual and economic exploitation (Howe, 2001).

“Participation” refers to the child’s right to play a primary role in matters and decisions that affect them. This is achieved by providing children with the opportunity to

be heard and express themselves as well as sharing relevant information with them so they can be actively involved in decisions (Canadian Coalition on the Rights of the Child 2002). The convention does not suggest that children make all the decisions independently; however, it imposes an obligation on adults to respect each child's right to participate. This means listening to the views being expressed by the child and considering these opinions when decisions affecting the child are made (Landsdown, 2000). The Convention outlines that parents and adults are responsible for providing guidance and developmentally appropriate opportunities for children to be included as active and valuable participants in decision making processes that involve themselves (Canadian Coalition on the Rights of the Child, 2002).

In general, Canadians and those in other developed countries are much more aware of the concept of the child's rights to provision and protection than they are of the concept of the child's right to participation in decision making processes. Due to this lack of awareness the right to participate is often neglected in the developed world. For example, in Canada the right to protection is guarded by the Criminal Code which is a federal statute that protects Canadians from harmful criminal offenses. Section 265 states that all Canadians – including children – are protected from assault, when an individual intentionally applies force to another person either directly or indirectly (Canadian Legal Information Institute, 1985). And, in Ontario the provision that all children are entitled to the right to a quality education is governed by the Ontario Education Act. Section 32 of that act states that all Ontarians have the right to a free public education (Canadian Legal Information Institute, 1990). But the laws governing a child's right to participate fall in a grey area, at best.

The principle of participation is most often overlooked. Before the *Convention on the Rights of the Child* the right to participation did not exist in a single previous international human rights document (Howe, 2001). Adults don't know how to help children participate, nor are they aware that children should be participating, therefore, this section of the convention is poorly supported and under emphasized in most countries' domestic legislation. Another mitigating factor is that the child's right to participate may be viewed by many adults as not always being consistent with a child's best interests (Howe, 2001). The thinking that parents and other adults always know best restricts meaningful opportunities in which children should be encouraged to participate.

Child Participation

For the purpose of this paper, the focus will be on the child's right to participate, one of the fundamental values of the *UN Convention on the Rights of the Child*. Articles 12 and 13 of the Convention recognize the child as someone who is able to share his or her thoughts and perspectives and enrich the decision making process. It values children as important contributors and essential agents of change (Pais, 2000).

Article 12 articulates that all children who are able to form their own views have the right to express those views to others (Convention on the Rights of the Child, 1989). Respecting the views of a child means that the child's views should not be ignored nor should they be the only view point that is taken into consideration (Pais, 2000). Adults are responsible for listening to children's ideas and suggestions and genuinely considering them when making a decision (Pais, 2000). Article 12 of the Convention also stipulates that children have the right to express their views in all contexts of their

lives; among their family, school, community and particularly in any judicial or administrative events that involve the child (Convention on the Rights of the Child, 1989). For example, it is essential for children to be involved in everything from deciding their household chores, designing programs and recreational facilities in their community, as well as making the decision as to who they will live with in the case of parental separation.

Article 13 stresses the importance of children having the "...freedom to seek, receive and impart information and ideas of all kinds" (Convention on the Rights of the Child, 1989 pp. 4). Sharing information is a prerequisite for individuals to be able to have a meaningful level of participation (Pais, 2000). It is essential because once the child has all the facts, they are more capable of weighing options and consequences which help them make an appropriate, thoughtful decision. Alderson's (1993) research found that children at a very young age want to know about and are capable of handling information that can be complex and difficult even for adults. That is not to say that all information is suitable for child consumption, it is important for the information shared to be age-appropriate and communicated in a way that is developmentally appropriate. For example, using sensitivity and an appropriate pace when providing painful information to young children is vital to enhancing their understanding without undermining their innocence and corrupting their child like state (Alderson, 1993).

Section 13 outlines that information can be communicated through many different media: verbally, in writing, print, art, television or film (Convention on the Rights of the Child, 1989). The form of communication is the child's choice and it is important for adults to offer methods that enable the child to convey the information in an

age appropriate way. Having the right to receive information and express their views is necessary for enabling children to participate in the decision making process that has an impact on their lives.

It is important to mention that the *UN Convention on the Rights of the Child* does not believe that children should make all decisions affecting themselves independently. The Convention applies for all children from birth to 18 years, therefore, throughout childhood, children need to be provided with meaningful and age appropriate opportunities to participate in their lives (Canadian Coalition on the Rights of the Child, 2002). The adults involved in children's lives are expected to provide support and opportunities where children can be actively engaged in participating and making decisions that affect their everyday lives. Age appropriate opportunities to participate are important in helping children develop their decision making skills. As children develop and mature, their capacity for making decisions increases, and as a result adults are expected to provide less scaffolding. This enables children to make decisions and participate in their lives with more independence as they grow capable (Canadian Coalition on the Rights of the Child, 2002).

The Child's Right to Participation in a Health Care Setting

Right to Expression

A child who is in a hospital setting must be given the opportunity to express his or her thoughts, emotions, fears and uncertainties, and it is important that his or her views are genuinely taken into account in all matters that affect the child (Canadian Coalition on the Rights of the Child, 2002). Health care professionals, which include nurses,

doctors and members of the professional services: child life specialist and physiotherapists as well as parents are obligated to respect and listen to the views expressed by children when decisions affecting them are being made (Lansdown, 2000). It is also important to keep in mind that the *UN Convention on the Rights of the Child* does not intend that respecting children's rights means that their views always prevail, but they should be genuinely taken into account (Lansdown, 2000).

Some of the literature explores the negative effects that can occur when children do not have the chance to express themselves while staying in the hospital. For example Chen et al. (2004) explore the effects of cultural expectations on children in China, where an individual's behaviour is viewed as a reflection on the family. Chinese children learn at an early age to self regulate and hold in their thoughts and feelings that are believed to be disruptive or inappropriate "...expressions of physical and emotional distress must be controlled to avoid bringing shame or embarrassment to the family" (Chen et al., 2004, pp. 35).. This can affect an individual's well being, especially for a hospitalized child. Fielding et al. (1985) as cited in Chen et al (2004), found that because hospitalized Chinese children were discouraged from expressing themselves they showed behaviours such as crying, avoiding of eye contact, rocking, self-comforting aggressive behaviour, resistance and wetting and soiling.

The front line nurses have the most consistent interaction with patients in a hospital setting and work directly with hospitalized children and their families. This close relationship enables the front line nurse to be an advocate in ensuring that the views and beliefs of the child he or she is caring for are being heard and considered (Hallstrom & Elander, 2004). In a study conducted by Bricher (2000), six experienced pediatric nurses

were interviewed to investigate how nurses can help improve hospitalized children's feelings of powerlessness. A major theme that emerged from the interviews was the importance of nurses developing trusting relationships with the children they were working with (Bricher, 2000). Trust is seen as a cornerstone in helping children open up and share their thoughts and feelings (Bricher, 2000).

Hospitalized children want to get to know their nurse as a person because it makes it easier to approach them (Coyne, 2006). Some nurses felt that a trusting relationship is a valuable tool because it encourages patients to express their perceptions of their hospital experience with their nurses (Bricher, 2000). This could help the nurses provide a better service and level of care to their patients. However, other nurses did not treat the relationship genuinely, especially when a child did not want to co-operate with the medical procedure that the nurse had to deliver. During these instances nurses did not listen to why the patients didn't want the procedure, nor did they work with them to make it easier. Instead, they used their authority to get the job done and ignored the child's expression of fear or uncertainty (Bricher, 2000).

Coyne (2006) explores different perspectives that children, parents and nurses have about child participation. A valuable point mentioned in this article was expressed by the children themselves; children reported that there was a lack of consultation over simple issues such as where the bed was placed in the room, what clothes they wore in the hospital and what food they had at mealtimes. This made the children feel that they had no choices once they were hospitalized – they had to conform completely to the hospital routine. The children studied also felt that their medical concerns were not listened to by nurses and doctors. The children felt that their views were not actively

consulted, and on the occasion that they were expressed, the children felt like they were ignored or received no weight. The nurses mentioned that they did not encourage children to voice their views and opinions unless it was obvious that the parents were happy to have the child consulted and involved (Coyne, 2006). Parents were seen as the child's sole representative in the hospital. Therefore it could be concluded that the patients' parents were the reason why children were not expected to express themselves. Although, this does not dismiss health care professionals from being the leaders in promoting and ensuring that the child's right to express themselves is honoured while in the hospital.

A study that focused on children with Scoliosis and their involvement in decision making showed that views expressed by these children were taken into consideration by health care professionals. The children and families in the study were asked to decide if the child should or should not have surgery to correct the curves in their back. The children were encouraged to express their fears and ask questions surrounding the surgery which allowed the doctors to provide information to help ease their uncertainties (Angst & Deatrick, 1996). The children were also expected to vocalize when they wanted to have the surgery and this was respected during scheduling (Angst & Deatrick, 1996). In this study it seemed as if the children involved were not only asked to express their thoughts and views but that these views were genuinely taken into account by the health care professionals involved. It is important to mention that the patients in this study were aware that they were in need of surgery over a period of many years. Therefore, there was no sense of urgency for the procedure to happen which provided time for the children to express themselves and for the doctors to respond.

In my experience, I have found that being hospitalized is a very frightening experience for a child. It is important to recognize that sick children benefit from expressing more than just their thoughts and feeling about a procedure that they are going to have. They also need to have an opportunity to express their thoughts and feelings surrounding being away from home, sleeping in a strange place, missing school and friends - all the changes that occur when a child is hospitalized.

The Right to Information

For a hospitalized child to make an informed decision and to be legitimately involved in their health care it is important for them to have the correct information. Not only does this keep them involved and knowledgeable, but it also helps reduce the anxiety that is prevalent among hospitalized children because their fears and uncertainties can be explained through age appropriate language and information. For example, I have found that it is common for a young child who is receiving a feeding tube to fear that the tube is going to go up into their brain because of the way that it is inserted. But through using pictures and explanation this fear can be alleviated because children learn that it goes down to their stomach through their nose. Adult patients are provided with information about their illnesses and treatments, hospitalized children should also be provided this service. Not only is it a right under the *UN Convention on the Rights of the Child*, it is also a valuable service that helps put children at ease during a very scary and stressful period of time.

Research shows that children are interested in receiving information about things that affect them (Pantell et. al, 1982 ; Lansdown, 2000). Not only are they interested they

are also capable of dealing with distressing and difficult information (Lansdown, 2000). Pantell et al. (1982) states that children are able to "...retain some information better than adults" (Pantell et al., 1982). Children, even from a young age are able to understand more about medical issues than what is assumed (Tates & Meeuwesen, 2000). Not only are children interested and capable of knowing the information, it also helps reduce the anxiety that they feel while in the hospital. School age children use the information seeking techniques as a coping strategy to help manage stress that is caused by hospitalization (Thompson, 1994; Coyne, 2006). It is mentioned in Coyne's (2006) article that children need information so that they can understand their illness, be involved in their care and be able to prepare themselves for procedures. Once children were provided with information they felt happier and reassured, which allowed them to be more prepared and less anxious about undergoing a procedure.

The most predominant strategy that children use to seek information was to ask health care professionals such as doctors and nurses. They also found it beneficial to talk to other children in the hospital who had a similar condition or who were experiencing similar procedures (Coyne, 2006). If children believe that it is valuable and beneficial to seek information from their doctors and nurses it is important to explore if doctors and nurses are enthused about providing children with information.

Coyne (2006) suggested that some nurses do not want to provide children with information about their illness and treatment. They feel that offering this information can sometimes empower a child and this can result in children challenging their nurse's decisions and care. When a patient is non-compliant it is difficult for a nurse, and nurses do not like to lose their power to a child. It appears that the nurses used for this research

do not respect the child's right to participate. They find it an annoyance having to deal with children who question their care and make their job difficult and more time consuming (Coyne, 2006).

Pantell et al's (1982) article is a study that examines how physicians communicate with children and their families when discussing illnesses and treatment plans. The study found that doctors have two main tasks when they meet with children and their families; they are interested in gathering information and giving information (Pantell et al., 1982). The results from the study found that the doctors interact with the children when they were trying to gather information about the child and their medical history. When physicians were providing information about the child's illness or treatment, however the doctors interacted directly with the parents of the child, paying little attention to the child (Pantell et al., 1982). Although this study was conducted a number of years ago, a more recent study discussed in Tate and Meeuwesen's (2000) article had similar findings. The general practitioners in their study discussed medical history with the child and all information that was shared about the child's illness and the treatment was directed towards the parent (Tate & Meeuwesen, 2000). It is interesting to note that in the timeframe between when these two articles the *UN Convention on the Rights of the Child* was created and signed, yet there appears to be no improvements regarding the child's right to receive relevant information about their sickness or treatment plan.

Child life programs, which have become a standard in most large pediatric institutions, have a significant role in helping children receive and understand information about their medical condition and treatments. Child life specialists are professionals that have been added to health care teams whose responsibility is to provide

hospitalized children and their families with the support they need. Child life specialists use play to help present information to children in an age appropriate way (Child Life Council, 2006). Play is a child life specialist's most valuable tool because it encourages children to actively engage with their surroundings. This allows children the opportunity to explore and manipulate, helping them develop an understanding of their environment.

Medical play is a child-directed play method that child life specialists use to help kids manipulate and actively engage with the medical equipment that is used in their procedures (Child Life Council, 2006). Through these experiences children can ask questions to enhance their understanding, which enables them to approach their medical procedures with confidence and familiarity (Anderson et al., 1985). Gaynard (1990) states that medical play allows children to understand what is happening to them, and allows them to become familiar with procedures that they will be involved with. A study used to examine the effect of therapeutic play on children admitted to day surgery discovered that children who received medical play before their surgery showed much lower anxiety levels than children who did not receive the intervention (William, Lopez & Lee, 2007). The children participated in hospital tours, observed a doll demonstration, and they were encouraged to touch and manipulate all the materials in the operating room. This intervention helped the children gain relevant information about their surgery which in return eliminated many of their uncertainties enabling them to be better prepared.

Right to Decision Making

In the past, children were rarely involved in their health care visits and they played no role in making decisions that affected them (Butz et al., 2007). The shift from delivering health care using a patient-centered technique instead of the focus being on doctor-centred care, as well as the development of the *UN Convention on the Rights of the Child* has encouraged health care professionals to include children in decision making.

The ideal of shared decision making between adult patients and doctors is supported by most health care professionals (Rylance, 1996; Butz et al., 2007). Decision making in a health care setting is defined as "...the contribution of individuals towards decisions related to their health or illness" (Angst & Deatrck, 1996, pp. 175). And, shared decision making is defined as "...an active mutual partnership between the physician or other health care providers and the patient" (Butz et al, 2007, pp. 111). Thus, in an adult patient and doctor relationship the interaction is a two way process between the patient and the health care professional.

However, when a pediatric patient is the focus, the interaction becomes triadic where three parties are involved: the child, parent and the health care professional (Hallstrom & Elander, 2005). Based on a pediatric patient's age and maturity, the decision making process can become a dual interaction where just the patient and the health care professionals are involved. This decision making style rarely exists among pediatric patients because parents and health care professionals feel that children are not competent to make their own decisions (Runeson et al., 2002).

Yet as I argue in this paper, it is important for a hospitalized child to be involved in making decisions about the care that they receive. Not only is it emphasized in the *UN Convention on the Rights of the Child* as a pillar of the child's right to participate, it also benefits the child. Becoming a meaningful decision maker is a skill that needs to be developed over time. As children grow they develop decision making skills. It is important to acknowledge that children with chronic or terminal illnesses may have insight and maturity that is beyond their years (Harrison et al., 1997). By involving children in making decisions, children are gaining cognitively. To help develop these skills, it is important for health care professionals and parents to include children in different ways when making decisions. Both by including them in shared decision making and by encouraging them to make decisions independently when it is appropriate for their developmental capacity (King & Cross, 1989). The doctor or parent must be able to assess the child's ability to make decisions and then provide the child with decisions that match or challenge their ability.

There are many different strategies that can be used to help develop decision making skills. Children can be included in decision making by being provided with options that they can choose, such as choosing which nurse performs the procedure, participating in bandage removal, deciding how they want to position themselves, choosing if they want to watch or not and deciding who is in the room when a procedure is being conducted (Runeson et al., 2001). King and Cross (1989) provide strategies in their article for including children of different capacities in decision making. A toddler can be provided with the choice of where they would like to be examined; on the table, floor or in their parent's lap. A preschooler can be included by obtaining the historical

information from the child rather than the parent. For a school aged patient, the health care professional should discuss the treatment plan with them and ask for their thoughts and input. A portion of a pre-teen or teenage child's medical visit should be alone with the doctor; this maintains privacy, creates a relationship between child and physician and encourages the child to make decisions independently from their parents.

On top of the cognitive benefits there are many other reasons why it is important to include children in the decision making process. There are studies that show that the child's involvement in decision making positively enhances their compliance with the care and treatment plan they have been asked to follow (Butz et al., 2007; Hallstorm & Elander, 2005). This not only benefits pediatric patients it is also beneficial for healthcare professionals because they can accomplish their treatments and procedures in less time because the child is cooperating. When children are involved and are asked their opinions, they have a sense of control. This results in them being able to positively adjust to the treatment that has become a part of their daily lives (Hallstorm & Elander, 2005). There are also many psychological benefits that children gain by being involved in the decision making process. Participating in making decisions can simplify the situation for a child. This helps them understand and become prepared for the procedure, and how it will be completed. This reduces the fear and anxiety that a child might experience when undergoing a procedure (Runeson et al., 2001).

The *UN Convention on the Rights of the Child* outlines that it is important for parents and other adults to respect children as active and valued participants in making all decisions that affect them (Canadian Coalition on the Rights of the Child, 2002). In a pediatric medicine setting this means that children should be involved in all decisions that

impact their treatment and care plans. It is important to establish if parents and members of the health care team are genuinely including pediatric patients in these types of decisions.

Hallstrom and Elander (2004) conducted a study that explored what kinds of decisions were made by pediatric patients during their hospitalization. The study examined 218 medical and nursing decisions concerning a group of 24 hospitalized children. It found that very few of these decisions were made independently by children and their families, only three decisions were made by children on their own, and two of those decisions were made by the same child (Hallstrom & Elander, 2004). Although all the decisions made by the pediatric patients were respected by the health care professionals, none of them were related to issues surrounding their medical condition or treatment plan. Two of the decisions that were made by a child focused on whether the nurse stayed in his or her room or not, in both cases the nurse was not in the room for a medical reason, but for entertainment or social reasons (Hallstrom & Elander, 2004). And, the final situation where a decision was made by a patient was about whether or not the patient wanted to watch television (Hallstrom & Elander, 2004). Out of all the decision making opportunities that were observed there were no situations that included children making decisions about their medical care. Not only is this disappointing, it shows that medical practitioners grossly undervalue the child's right to make decisions about their care.

An interesting finding from Hallstrom and Elander's (2004) study was that parents and children protested about one-third of the 218 decisions that were made, and very few were reconsidered. There were 12 decisions that were reconsidered; all were

protested by the child. Therefore it seemed that health care professionals paid more attention to protests from children than their parents. The authors from the study draw the inference that this is the case because the children protested physically. Therefore medical professionals would do whatever they needed to in order to get the child to co-operate (Hallstrom & Elander, 2004).

Angst and Deatruck (1996) completed a study that focused on examining the involvement of school-aged children with cystic fibrosis (CF) and with scoliosis in making decisions about their own health care. The decisions that affected CF patients were issues surrounding the everyday management of their treatment. It was found that the children with cystic fibrosis felt uninvolved and did not feel like their health care providers or parents encouraged their involvement. The children diagnosed with scoliosis made decisions based on a surgery that they could have. These children felt like they were included and were also encouraged by adults to be involved in making decisions.

The study found that the type of decision and the illness influenced the type of participation that the children experienced when making decisions about their care. For the children with CF, the study found that they were not encouraged by their parents to make decisions about their care. The main reason why parents did not encourage their children to be involved was because to the severity of their illness. The consequences of making the wrong decision were very high (Angst & Deatruck, 1996). Some of the decisions that CF patients would need to make are related to their antibiotic therapy and a wrong decision could result in a compressed lung. It is important to mention that there are other decisions that incur less risk. The children could be involved with decisions regarding enzyme intake and diet choices. Although in the study these decisions were

also not encouraged (Angst & Deatrick, 1996). The children with scoliosis were involved with making a decision about a surgery that they could have to fix the curves in their back. The patients knew for many years that they could have this surgery. The decision could be made over a number of years and there was no pressure or sense of urgency (Angst & Deatrick, 1996). Therefore parents felt more comfortable assisting and encouraging their child to make the decision about when and if to have surgery independently.

Factors That Impact Participation

There are many factors that are indicated throughout the literature that limit or enhance the amount and quality of child participation that occurs in pediatric medical settings. These factors include: the style of patient care; deciding if children are cognitively capable of participating; the way that information is provided to children; the amount of time health care professionals have to encourage child participation; and the role that parents play in enabling their child to participate. One of the pivotal reasons why children do not participate in their health care is because of the perceived conflict between the child's right to protection and the child's right to participate. Many adults in today's society believe that by not including children in their medical care is looking out for their child's best interests, but, this is not necessarily the case.

Style of Patient Care

There are many different ways that physicians engage their pediatric patients in their medical care. Three of the most predominant ways are; physician-centred care,

patient-centred care, and family-centred care. The way that doctors approach care giving can have implications on the level of participation that the child is involved in.

Traditional medicine has always supported a physician-centered approach, but over time, the role of physicians and health care professionals has evolved to support a patient-centered approach when providing health care (Davidoff & Laine, 1996). A patient-centered care method involves the doctor valuing patients' perspectives, sharing important information with them as well as supporting and encouraging the patient to be involved in joint decision making (Davidoff & Laine, 1996; Wassmer et al., 2004). All these characteristics of patient-centered care are consistent with the child's right to participate as outlined in the *UN Convention on the Rights of the Child*. Although physicians have supported the ideal of patient centered care among the adults under their care, the participation of children has not gained the same support and needs to be encouraged by health care professionals as part of a patient-centred approach.

In the late 1990's, the concept of family-centred care began to emerge as an approach that included the entire family when caring for a hospitalized family member. The Institute for Family Centred Care defines family centred care as "...an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families" (Cross et al., 2004, pp. 495). This method of providing health care is now common, as health care professionals try to create a culture where parents, caregivers, family members and the health care team collaborate when caring for a pediatric patient.

Although this is a positive method to use when caring for children, it does not fully support the child's right to participation as articulated under the *UN Convention on*

the Rights of the Child. The main focus of family-centred care is on the parents and family members of the hospitalized child. It encourages parents to have a better understanding of their child's condition to, identify the individuals who are responsible for their child's care and increase their level of knowledge of their child's condition, but it neglects their child's ability to participate. Family-centred care helps parents make more informed decisions as well as empowers them to participate in their child's care giving.

Child's Competence Levels

A major reason why many health care professionals are anxious about including children in discussions and decisions affecting their health care is because they are uncertain about the child's competence level. "A child's competence is a function of age, cognitive abilities and personal experience" (Hallstrom & Elander, 2005). Traditionally, Piaget's developmental stages have been a dominating source behind research that focuses on the ideas that children have surrounding their health and illness. Jean Piaget is a cognitive theorist who, through research, has identified four stages of cognitive development that children actively engage in throughout their growth through childhood. The four stages are; sensorimotor (birth-2 years), preoperational (2-7 years), concrete operational (7-11 years) and formal operational (11 years and older).

The sensorimotor stage is defined by Piaget as the stage where infants and toddlers manipulate and explore their world with their senses. During this period infants and toddlers are constantly faced with new experiences and by manipulating what's around them they begin to gain knowledge and build schemes. Many health care

professionals believe that children in this stage have no capacity to make significant decision about their health care and that the parents or caregivers are responsible for making these decisions on the child's behalf (Harrison et al., 1997). However, this does not mean that infants and young children should be excluded entirely from participating in their medical experiences.

The preoperational stage is Piaget's second stage of cognitive development. Throughout this stage children begin to develop and use symbols to represent their world and the knowledge that they developed in the previous stage (Berk, 2003). In this stage children learn to use language and they also begin to engage and learn through sociodramatic play however logical thoughts have not yet been mastered (Berk, 2003). Therefore, children in this stage do not have the ability to make decisions independently, but they should not be eliminated from the decision making process completely. Children should participate in their care by being provided with appropriate information about their illness and treatment, expressing themselves and having their thoughts and opinions heard by parents and health care professionals. For example children should be encouraged to play with medical equipment to help them understand and make rudimentary decisions about the procedure they are going to go through. They also should be provided with developmentally appropriate outlets to help them express themselves such as drawing, painting, dramatic play or puppet story telling.

School-aged children (7-11) are in the concrete operational stage, this is an important milestone for children because they begin to develop a thought process that closely resembles that of adults. Children begin to think in an organized and logical manner about concrete things and tangible events (Berk, 2003). The final stage is the

formal operational stage (11+). At this stage individuals have the capacity to engage in logical, abstract and scientific thinking at a level that is comparable to adults (Berk, 2003). Many researchers believe that children who are in these two stages have the ability to make decisions about their health care at the same capacity as an adult (Weithorn & Campbell, 1982; Harrison et al., 1997).

A study conducted by Weithorn and Campbell (1982) found that children who were nine years old were able to understand the basics about their illness and rate the disadvantages and advantages of the treatment options that they were provided with by their health care professionals. Having this skill set enhances these children's abilities in making decisions about their medical care and treatment. The 14-year-olds who were studied exhibited the same abilities as adults in making educated decisions about withdrawing from or having a particular medical treatment (Weithorn & Campbell, 1982).

It is important to recognize that Piaget's stages of cognitive development are not the only perspective that should be used when establishing a child's competence level. There are a variety of different factors that can advance or deter a child's capacity for making decisions. When deciding on a child's decision making capacity it is important for health care professionals to take into account the child's previous experiences, parental expectations, as well as the religion, values and beliefs that are followed by their family. For example, a child, who from a young age has been encouraged by his or her parents to take part in discussions at home and whose views have been respected might be years ahead of their developmental age, when it come to participating in discussions with others (Dixon-Woods et al., 1999). These previous experiences have likely

equipped them to voice their opinions and to contribute to the decisions that are being made about their health care. Children who have experienced previous hospitalizations or who have lived with a terminal illness usually have a matured level of competence compared to children who are having the experience for the first time (Dixon-Woods et al., 1999).

Information Delivery

As mentioned earlier in the paper, it is important for children to be provided with accurate information about the medical condition and the treatment plan that has been developed for them. A child's ability to participate will be better because they were able to gain and understand important information. Dixon-Woods et al. (1999) point out in their article that the way information is provided to children can lack meaning and inhibit their understanding. Most of the materials and methods of communicating information in pediatric hospitals is geared for parents, they are not child focused nor do they apply to children of different ages and abilities (Dixon-Woods et al., 1999). For example information pamphlets are available, but these are text based and are neither interesting nor appropriate for children. It is believed that one of the main reasons why informative materials haven't been developed specifically for working with children is because of the lack of research and evidence suggesting why these materials are important and how these materials should be created for children (Dixon-Woods et al., 1999).

In today's society where hospitals exist in large multicultural centres, there are many children and families whose first language is not English. These language barriers make it difficult for children to attain information during their pediatric medical

experience. “Language barriers decrease patients understanding of their disease processes and subsequently, impact their compliance with treatment and follow-up” (Hampers et al., 1999, pp. 4). By not providing translators or alternative methods to offer non English speaking children information about their illness and procedures we are denying them their right to participate in their care. Therefore it is important for pediatric medical settings to create methods that help such children understand important information. This can be done by providing interpreters as well as using non verbal methods to share information, for example through pictures, play experiences or in age appropriate text written in the child’s first language.

Time Pressures

A major barrier that affects the level of participation that health care professionals engage pediatric patients in is time. The work situation for nurses and doctors is very stressful; they are usually pressured for time. Staff feel that the lack of time they have lead them to violate childrens’ right to participate because they have to rush medical examinations and treatment (Runeson et al., 2001). However the benefits of finding time to engage patients is evident as shown in Runeson et al’s. (2001).article in which a nurse describes an experience where she spends time familiarizing the patient with the medical equipment that will be used for his treatment. She introduces the child to the ventilation mask that will be used in his procedure by playing peek-a-boo, and then there is time for the patient to manipulate and play with it on his own and ask any questions. All these interactions allowed the child to become more comfortable with the mask which resulted in the patient having a successful procedure (Runeson et al., 2001).

Parental Control

Parents play a prevalent role in their child's level of participation during a pediatric medical experience. The familial experiences, religious affiliation, attitudes, values and beliefs can all help determine the level of involvement that their child experiences surrounding the information they receive, their self expression as well as their role in the decision making process (McCabe, 1996).

There are many parents who believe that it is very important for their children to be considered participatory members during their hospital stay. When children are encouraged by their parents to be involved in decisions and discussions within the home, parents tend to believe that it is important for this to be maintained while they are experiencing hospitalization. According to Coyne (2006) some parents who want their children to be independent, fear that their children will lose their sense of independence if active involvement is withdrawn when they are ill in the hospital (Coyne, 2006). Other parents of chronically ill children thought that their children should participate in their care. The children, through their own experience gained considerable knowledge about their illness like the best way to do a particular procedure. Therefore these parents felt that this knowledge should be respected and taken into consideration during their child's care.

Not all parents feel that their children should be involved and encouraged to participate during their hospitalization or health care visits. Some parents can be debilitating towards their child's right to participate. Some parents are overbearing during interactions between health care professionals and their children. Tates and Meeuwesen (2000) found in their study that parents significantly dominated the conversation during

health care consults about their child, for example, when the physician asked a direct question to the child the parent answered Wassmer et al. (2004) results were similar in that they found that parents contributed to 25% of the conversation, the doctor contributed 61% and the child only contributed to 4.1% of the conversation. The parental control that existed in these two examples caused the child to be excluded because a majority of the interaction was between the parent and the doctor. The child would sit silently waiting for the appointment to be over (Tates & Meeuwesen, 2000; Wassmer et al., 2004). It was also noted that physicians often strive for the child to be an active participant during health care visits, but parents end up wanting to lead the visits, blocking their children from having an opportunity to participate (Tates & Meeuwesen, 2000).

There are a variety of motives that cause parents to take over and reduce their child's level of participation. It is believed by many parents and health care professionals that allowing a child to participate during a medical session will prolong the length of the visit (Butz et al., 2007) Therefore, a major reason why parents take control during their child's medical consultations is because they feel that their time is limited, therefore they do all the questioning and answering because they are worried that they won't have enough time to discuss all their child's health care needs (Wassmer et al., 2004). For this instance it is important for health care professionals to make it a priority to talk and interact with the children during their visits. By asking children the necessary questions, for example, where it hurts and how strong the pain is during medical examinations, children are participating in the consultation. Parents should not need to be completely ignored, because the parents' knowledge is important (Tates & Meeuwesen, 2000).

However it is important for the parents' knowledge to supplement the information that is gained through interactions with the child.

The culture, values and beliefs of parents may be another contributing factor to why a child's participation level is limited. Parents who value an authoritarian approach to child rearing usually follow a paternalistic model during their child's health care consultations (Wassmer et al., 2004). Such parents often ensure that their child's needs are met but they do not take their child's rights into account when providing these needs. This does not honour the child's right to participate because the "...the parents speak on behalf of their child and treat the child as a passive bystander" (Wassmer et al., 2004, pp. 1505). In addition to various parenting styles, children have different personalities. Some may be shy and some have been socialized to be passive and timid, and this may result in them not wanting to participate in their health care. Therefore, children with these characteristics may feel uncomfortable being involved and want their parents to speak on their behalf.

Having an ill child is very scary and worrisome for a parent. Some parents may have reservations about including their child because they are concerned. For example, parents may fear that their child might not be cognitively mature enough to understand the information that they may be given. They may also not want to provide their child with information about their illness or treatment plan because they fear it might frighten their child (Coyne, 2006). Many parents feel uncomfortable including children in making decisions about their health care. It was reported in Coyne's (2006) article that some parents worry that their child would make the wrong decision about their treatment options. This is worrisome for parents because they fear that there is no room for a wrong

decision to be made. It can be surmised that underlying these parental impulses is that the parents want to protect their child. However, by blocking their children from participating the parent may in fact be hampering their child's ultimate progress and needs.

The Right to Protection vs. The Right to Participation

As mentioned earlier in the paper, the child's right to protection is one of the three pillars of fundamental rights in the *UN Convention on the Rights of the Child*. The child's right to protection refers to the child being protected from harmful acts or practices. Sometimes a parent's concern about protecting their child can override or take precedence over the child's right to participation. Although it is every parent's desire to protect their child from events that are scary, uncomfortable, painful, or unknown, which are all experiences that may occur during hospitalization, parents should not deny their child their right to participation. Lansdown (1994) as cited in Bricher (2000) claims that there is a dilemma inherent in parents who want to act in their child's best interest because "...it has the potential to be used as a tool by adults to override the wishes and feelings of children" (Bricher, 2000, pp. 3). It is natural for some parents to keep their child from participating especially if the parent feels that it is not in their child's best interests.

However, child participation in the hospital setting is not mutually exclusive to their protection or best interests. Parents need to be educated on the benefits surrounding child participation, and how to fulfill these rights in an environment that is safe, encouraging and protects the child's best interest. It is important for adults and parents to

acknowledge that according to the *UN Convention on the Rights of the Child*, children have rights, and that they are obligated to respect them. To the extent that the right to participation appears to conflict with a child's best interest or protection, creative thinking and special child focused programs within hospitals can help ensure that both rights are engaged and even synergized.

Child Life Programs

Having child life specialists available to children and families who come in contact with the pediatric health care system positively influences the child's right to participate. As mentioned earlier child life specialists are professionals that have been added to health care teams whose responsibility is to provide hospitalized children and their families with the support they need. Child life programs have existed since the early 1920's "but the child life movement gained its greatest momentum in the 1950's and 1960's" (Thompson & Stanford, 1981). Since the 1960's the number of child life programs has doubled resulting in more than 400 child life programs being offered in pediatric hospitals across North America (Child Life Services 2006). Although the child life profession has experienced substantial growth over the past 50 years, child life specialists and their programs are still a relatively new phenomenon.

The article written by Anderson et al. (1985) suggests that the use of child life programs in American hospitals is essential in ensuring that the care hospitalized children receives is of the highest calibre. "One of the most progressive, useful, and humane programs to be initiated in recent years is the child life concept" (Anderson et al., 1985, pp. 467). Child Life Services (2006) also believes that child life programs are effective

because they provide pediatric patients with developmentally appropriate play opportunities, age appropriate preparation before procedures and develop coping strategies with the children. These are all attributes that make a child's hospital stay a more comfortable and positive experience.

A child life specialist is traditionally found in in-patient pediatric health care settings as well as ambulatory clinics, emergency departments, rehabilitation and hospice programs and sometimes in dental and doctor's offices. They have a minimum of an undergraduate degree in child development or a related field. Child life programs have become prevalent among large pediatric settings (Child Life Council, 2006). A survey that was completed by the National Association of Children's Hospitals and Related Institutions found that 95% of the 118 American hospitals that responded to the survey employed child life specialists.

Professionals in pediatric medical settings realize that the psychosocial support provided by child life specialists to sick children and their families is an important and beneficial service. Not only does it improve their hospital experience, it also encourages children to achieve their right to participate. Child life specialists help patients achieve their right to participate because they offer information and teaching opportunities to prepare children for procedures, they help children plan and practice coping strategies that they can use during procedures, and they encourage children to express their thoughts, fears and emotions by providing appropriate expressive therapy activities.

Play is a child life specialists' most valuable tool and it has a variety of purposes in a child life program. One fundamental purpose of play is that it is fun and familiar to all children (Child Life Council, 2006). Play helps create a sense of normalcy in an

environment where everything is new and unknown. Through play children are able to do things that they like to do, take a break from their hectic hospital schedule and continue with activities that they may engage in when at home. Play helps create a positive experience for a child in the hospital.

Play can also be used to help children participate in their health care in a developmentally appropriate way. Medical play is a form of play conducted by child life specialists that help hospitalized children gain information about their illness and the treatment plan or procedures they will encounter. Medical play is a child-directed activity that allows children to actively engage and explore medical equipment that they will experience (Child Life Council, 2006). A common form of medical play that is facilitated by child life specialists is through using medical play dolls to act out a medical procedure that a child is going to have. This is a child-directed activity where patients are able to use real medical equipment on a plush doll; it is commonly used to help patients with IV starts. Children are able to use the medical equipment to start an IV on their doll themselves. This can be done a number of times during their stay and it is sometimes used as a coping strategy to help the children prepare, right before a procedure. Through this experience children become more familiar and comfortable with the equipment, they act out and talk about coping techniques that they would like to use during their procedure and the activity also empowers patients to ask questions or discuss concerns that they may have about the procedure. All these benefits encourage child participation because the medical play helps children gain information in a safe and fun way that is at their own pace, and uses language that they understand.

There are many therapeutic values to play. Children can express their thoughts and feeling non-verbally through their play experiences. Wikstrom (2005) examined a play therapy unit in a Swedish hospital. Play therapy in Sweden is a widely accepted program that is offered to all hospitalized children. Children in Sweden can visit the play therapy unit whenever they wish and if they are unable to do so due to illness the play therapist comes to visit them. Wikstrom (2005) believes that play therapy is a valuable tool to help children cope with their illness and allows children an opportunity to express themselves in an age appropriate way. The study explains how using expressive materials, such as modeling clay, paint or listening to music in a play room helps children understand and communicate their thoughts and feelings about being hospitalized. The results demonstrated that children describe themselves and their hospital experiences through their art projects. Some themes that were expressed through their art were powerlessness, fear and loneliness. Wikstrom (2005) notes that the expressive materials are a flexible intervention that play therapists can manipulate and tailor to meet the variety of needs and challenges that face children in hospitals.

Dramatic or dress-up play is another valuable outlet for children to relieve emotional stress that they may be experiencing while being sick in the hospital (Jessee et al., 2000). Dramatic play allows children to use their imagination to act out themselves or pretend to be a different person or thing. It is important for dramatic play to be open-ended and child directed, but it is valuable for the child life specialist to provide props and materials that the child would see and experience during their hospital stay. In the hospital setting, child life specialists help children engage in dramatic play where the patient pretends that they are the baby's doctor or nurse. The child life specialist provides

a patient with a baby doll, and medical equipment but allows the patient to care for the baby however they choose.

In my experience as a child life specialist I have engaged a patient in this form of dramatic play. This experience for the child was very valuable because it provided an outlet for the patient to express uncomfortable feelings that she had around getting her blood pressure taken. During the make believe play, the patient pretended to be the nurse and was checking the baby's vitals signs, just like the patient experiences. During this play session, the patient expressed through her dialog that it is uncomfortable for the baby to have their blood pressure taken. After asking the patient questions as to why it was uncomfortable, we discussed coping strategies that would make it more comfortable. We practiced these coping strategies by having the baby doll do them and then the patient tried them as well. From this experience, the patient did not only feel safe enough to express her concern, she also gained a coping technique that was used when her nurse took her blood pressure. Jessee et al., (2000) state in their article that dramatic play helps hospitalized children express their thoughts and feelings, assimilate their reality, master their environment, as well as learn how to cope effectively with the treatments and procedures they are involved with. All these characteristics support the hospitalized child's right to participate.

Ensuring that a hospitalized child is being guaranteed his or her right to participate is one of the most important roles for a child life professional. This can be achieved through child life specialists advocating for children, and educating parents and allied health care professionals of children's rights and how to fulfill them.

Child life specialists are capable of developing trusting relationships with the children with whom they work within the hospital. Because of this relationship, children feel comfortable expressing their fears and needs to their child life specialist. Child life professionals can help the children they are working with express their concerns by providing them with developmentally appropriate outlets, which can be used by the children to inform their parents and health care professionals. For example, in my practice as a child life specialist I have helped teenagers make “please knock signs” to help communicate to health care professionals that they want their personal space to be respected. I have also represented patients by communicating with their health care professionals, letting them know that their patient would like to alter their medication time so that they can have recreational time in the hospital lounge.

It is important for child life specialists to educate the health care team about what the child’s right to participate means and how they can use child life specialists to help fulfill these rights. Child life specialists need to educate allied health care professionals about their role and the services and benefits they provide to patients. Indeed, Anderson et al. (1985) assert that one of the roles of child life specialists is to provide frequent seminars providing information about the services offered by child life specialists. The article also stresses the importance of educating residents in hopes that they will learn about child life early on in their careers, which will result in them valuing and promoting the role of the child life specialist. If the health care team is unaware of a child life professional’s role they will not utilize them properly. “To be effective members of the health care team, it may be important for health care team members to have a shared understanding of one another’s roles” (Cole et al., 2001, pp. 2).

As mentioned earlier in the paper, while some parents are supportive of their child's participation, many parents have reservations about including their child as a participatory member. Thus, it is also valuable for child life specialists to educate parents and family members about their role, the benefits of including children in their hospital care and how they can assist in this inclusion. Child life specialists can help ease parents' fears by providing them with a variety of different age appropriate techniques that they can use to help include their child. They can also use parents as partners and draw upon the parent's knowledge to learn more about the child.

Conclusion and Further Recommendations

As I have discussed in this paper there are three prevalent groups that are responsible for ensuring that children are guaranteed the right to participate. These three groups are the policymakers, health care professionals and parents or adult family members. In order to ensure that children are given the opportunity to participate in their own care some vital changes must be made.

Although Canada made a commitment 18 years ago to provide Canadian children with the fundamental rights as outlined in the *UN Convention on the Rights of the Child*, the Federal Government and the Provincial Governments have neglected to ensure that every child receives his or her right to participate, particularly in pediatric health care settings. As this review has demonstrated there is very little evidence that shows that Canada has embedded child participation into policies that have been developed for pediatric health care.

Further, as discussed the child life profession plays a major role in encouraging children to be active participants in their health care. It is important and necessary for children to be valuable contributors to the decision that involve them. Child life specialists enable children to express themselves and help them receive the necessary information about their illness and treatment program. However, child life programs remain a low priority.

The way a program is funded is an indicator of the value a society puts on it. Child life programs in Ontario do not receive consistent funding, they draw their funds from a patch work of sources from many different hospital departments and community fundraising initiatives. My position for example as a child life specialist at Sick Kids is funded through two different sources through the hospital. Two days a week I am paid for by my unit, and the other day I am paid for through a research budget. And, each of my colleagues has their own different medley that funds their salary. This unpredictable funding strategy makes the child life position vulnerable because there is not one specific source dedicated specifically to funding child life specialists.

Also almost all of the supplies that child life specialists use when working with the children in the hospital are paid for and provided through outside temporary fundraising initiatives, the only source of funding to purchase much needed supplies. Outside funding sources can be unreliable and inconsistent they mean that less value is placed on the child life program than if they had permanently funding.

Inconsistent funding structures create limited opportunities for trained and certified child life specialists. The Child Life Council states that the ratio should be one child life specialist to 15 to 20 inpatients. This ratio is rarely met. In my experience the

ratio is usually one child life specialist to 30 pediatric patients leaving the child life specialists stretched thin and fueling the high turnover rate in this profession because specialists get tired and burnt out.

Recommendation for Policy-Makers

Child life programs must be a stable resource that is available to all pediatric patients in Canadian hospitals. Provincial policies need to be developed to make this a reality in four main areas.

Universality. Child life programs need to become a stable fixture among hospitals that interact with a pediatric population. All children who need medical attention should have access to child life services.

Stable funding. All hospitals would be allocates a certain portion of their budget to the child life programs they offered.

Quality of care standards. A ration no greater than one child life specialist to 15 patients would be required, and all the necessary equipment and materials will be supplied.

Education standards. All licensed child life specialists should be required to attain at least an undergraduate degree as well and child life certification.

Policy progress towards these four areas is the bare minimum for ensuring that governments especially in Canada fulfill their commitments to the *UN Convention on the Rights of the Child*.

Recommendations for Health Care Professionals

Health care professionals work directly with children during their health care experiences, therefore it is important for them to be leaders in encouraging children to participate in their care. Currently this does not exist. As mentioned earlier in the paper members of the general public are unaware of the child's right to participate – this is also the case for professionals who work with children in the healthcare field. Both those responsible for the education of health care professionals and those who are responsible for the day-to-day work of health care professionals must take important steps in improving the following areas.

Education. The literature shows that many health care professionals do not think that children are cognitively competent enough to participate in making decisions about their health care. It is important for doctors, nurses and other health care providers who work with children to be educated in child development during their schooling. This knowledge base will help them understand the different levels of cognitive development, which will help them know the different ways that children can be engaged based on the child's previous life experience, culture as well as the developmental stage they are in.

Awareness. It is important for every health care professional to become aware of the child's right to participate. There are a variety of different facets that can be used to build health care professionals' awareness. During staff orientation child participation should be discussed, reading material on the subject should be provided through journal articles, hospital wide web based media or work place continuing education sessions. These information materials would provide new techniques that health care professionals can

use in their practice to ensure that they are improving their ability to provide children with opportunities to participate.

Every health care professional that begins their career at the hospital has an initial introduction and training session. It is important that during this in-service training they are exposed to child life specialists. The child life specialists in pediatric hospitals must make it a priority to present their role, explaining what they do and why it is valuable. It is also important that to enhance participation among children that they explain what child participation is, the benefits of including the child and how they promote child participation. Not only will this initial education represent that child life specialists are valuable members of the health care team it will also ensure that new health care professionals know when and how to use child life specialists so that they ensure child participation exists.

An example of how to heighten awareness for health care professionals and the general public would be to celebrate National Child Day in the hospital. National Child Day is held every year on November 20th in Canada (Canadian Children's Rights Council, 2007). One of the main purposes of this day is to support the rights of Canadian children. It is an initiative to educate and heighten the awareness of Canadians' understanding of the *UN Convention on the Rights of the Child* and the fundamental rights that are outlined. It would be valuable to celebrate National Child Day within pediatric hospitals across the country. Not only would this remind health care professionals as to children's rights and their duty to uphold them, it would also make parents and community members more aware as well.

Child life specialists also need to reflect on how they can improve their practice and how they facilitate participation among the children that they work with. Many pediatric hospitals have a children council, this is a board that is comprised of children who have experienced a stay in the hospital or who are presently in the hospital. Child life specialists need to consult with the children they work with, whether it is on an individual basis or through the council. This is valuable because it will allow children to express if they feel like they are being included in their health care and what changes can be made to better facilitate their participation.

Recommendations for Parents

As I have discussed in this paper it is clear that some parents may play a role in hindering their child's opportunities to participate during their health care. There is a misconception among many parents that by providing information, encouraging self expression and by including their child in decisions this could result in negative consequences. There was a variety of literature that dismissed this notion by outlining the many positive benefits that encouraging a child to participate had. The lack of understanding that many parents have is a major contributing factor to their discouragement to child participation. Parents often feel that too much information will scare their child, they also tend think that their child does not have the cognitive capabilities to make decisions, and many worry that their child is too young to know or express how they feel.

Parents must be provided with a hand-out when they first arrive with their child to the hospital. This hand-out should inform parents of all their child's rights during their

stay at the hospital. In particular it should include information about child participation and how the hospital will help parents guarantee that they fulfill their child's rights. It is important to remember that parents of a sick child are overwhelmed when they first come to the hospital and they are bombarded with papers to sign and literature to read therefore they may need more than just a pamphlet. This is why it is important for child life specialists to make it a priority to introduce and explain their role to each new patient and family that is admitted to the hospital. They should provide an easy way for them to be contacted by the family and continue to check in and help meet their needs. By creating this relationship right from the beginning, parents and children will begin to rely on their child life specialist as a support and have them help ensure that their child is included as a participant. And parents may also have ideas about how a child may want to participate.

Canada has signed and ratified the *UN Convention on the Rights of the Child* and to date little has been done to fulfill its obligations towards ensuring a child's right to participate, especially in regards to the child's rights in a pediatric medical setting. Canada must make significant progress towards ensuring children are encouraged and expected to be participatory members in all aspects of their lives. This will make Canada a leader in the international community, fulfilling its commitment to the *United Nations Convention on the Rights of the Child* and most importantly improving and benefiting the lives of all Canadian children.

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④ BL-75^D-42