Parent Workshop:

Supporting Your Typically Developing Sibling

by

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AN APPLIED PROJECT

Submitted in partial fulfilment of the requirements for the degree of

MASTER OF EDUCATION IN SPECIAL EDUCATION

VANCOUVER ISLAND UNIVERSITY

We accept the Applied Project as conforming to the required standard.

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Abstract

Sibling relationships play an important role in a family system which can be influenced by the attitudes and behaviours of parents. Having a child with a disability in the family presents a distinctive set of challenges for the entire family. Research has shown that some typically developing siblings have negative experiences whereas others have had a positive experience. This project is a workshop that is designed to educate parents and caregivers about the lived experiences of children who have a sibling with disabilities. Once the parents and caregivers gain a better understanding of the impact a child with a disability has on the interrelationships of individuals in their family, they will be more cognizant of their own stressors their typically developing child experiences, as well as have the tools to strengthen their familial relationships. Parental initiative to understand their children and their family dynamics could strengthen the relationship between the parent, caregiver, the typically developing sibling and the child with a disability.

Keywords: parents, workshop, typically developing siblings, special needs, children with disabilities
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Chapter One: Introduction

I live and work in Barbados. Over the years, I have worked with four families who have children with dependent special needs such as Autism, Angel Man Syndrome and Down Syndrome. As I worked with families, I have witnessed the imbalance of attention paid to typically developing siblings and the lack of outside support available to these parents have. I have witnessed the frustrations of typically developing (TD) children, and I am very motivated to try to help them in a way that will allow them to reach their potential.

I witnessed a striking example of this imbalance last year in a nuclear family consisting of two children—a young sister, and an older brother. The younger sister, age three, has Down Syndrome while her older brother, age six, is a typically developing boy. While I was working at a camp that was run by the children’s mother, I observed an altercation which convinced me of the dire need for training or support for parents to differently negotiate situations between differently abled and TD siblings. During the altercation, the younger sister had taken away a toy from her brother because she tended to want what he had in that moment. She took the toy away and her brother’s reaction was to hit her and take the toy back, which made her cry. Their mother reacted by grabbing her son, scolding him for hitting his sister, and consoling the little girl. While the mother was consoling the little girl, the brother repeatedly asked me why his sister didn’t get in trouble and why his parents always give her special treatment. I attempted to explain to him, the best I could, that it was because she was younger and different than him. During our conversation, I realized that he had no idea that his sister had a disability, which was causing resentment towards her. In reflection, I wonder if the outcome of this situation might have been different if the family had had training or support in handling situations between differently abled and TD siblings.
As it relates to special needs, Barbados has not progressed as far as Canada. There is not much support for parents, let alone support for siblings. I began to wonder if having a workshop, that would provide families with the skills parents need to create a more nurturing environment for themselves and their children, could make a difference in the lives of these families. This project is important to me because I hope it will create an awareness in Barbados of how having a child with disabilities can affect the entire family and the family dynamics. I also hope this information will remove the misconception that having a child with a disability in the family is a burden, and more problematic than it truly is. Having a child with a disability is difficult, but with the right knowledge, support, and resources, it is manageable.

Background

The structure of the family, the familial relationships, and the characteristics of each individual child, all impact the relationship between siblings. The relationship between parent and child has the greatest influence on both sibling relationships, and the individuality among the siblings. Temperament, sex, health, or hereditary traits are some of the characteristics that contribute to their individuality, which affect sibling relationships (Hartwell-Walker, 2016).

The best examples children have, to assist them in learning how to form long lasting relationships outside of their family, are through family relationships. Siblings are an important part of childhood and growth; their relationships influence the personality, social and cognitive skills, self-concept, and values of a child. They also influence the role children play in peer groups, how they choose their friends, and their role in society. While parents teach children the social niceties of more formal settings, siblings teach each other how to interact, react, and overall behave in everyday experiences (Ciciora, 2010; Kuehn, 2013; Nauert, 2010; Super, 2016). In a newspaper article by Dolan (2010), Laurie Kramer—an expert in family studies—stated that siblings “are closer to the social environments that
children find themselves in during the majority of their day, which is why it’s important not to overlook the contributions that they make on who we end up being” (para. 7).

Although siblings have an impact on social behaviour, they can also shape each other's personalities, and birth order can be key in their development. Several articles (Dinkmeyer, Dinkmeyer, & McKay, 1978; Sailor, 2014; Voo, 2017) proposed different personality traits that go with each birth order. For example, firstborns are described as reliable, cautious, controlling and have an innate need to be the best at everything they do. They tend to act as surrogate parents and enjoy the power they are sometimes given over their younger siblings. In contrast, middle children are considered people-pleasers, somewhat rebellious, and thrive on friendships. They tend to use older siblings as models for behaviour and, as a result, meet milestones earlier. Last-born children are considered fun-loving, outgoing, and self-centred. Because a last-born is the baby of the family, parents tend to be a more relaxed with their parenting style the final time around. They occasionally view themselves as inferior to an elder sibling (or siblings) and can become competitive.

Given the importance of a sibling’s role in the development of a child’s social behaviour, personality development, and communication skills (Pancare, 2017), it is valuable to investigate the relationship between a TD child and their sibling who has a disability. Having a child with a disability can have a profound effect on the family. This can be especially hard on children who must learn how to be a brother or sister to someone who has a disability. They become aware of the large amount of family time, money, attention, and support that goes towards their less abled sibling, and this can be a hard reality to adjust to. However, it is very important that a TD sibling adjusts to their differently abled sibling because their response to their sibling can affect the overall adjustment and development of self-esteem in both children (National Dissemination Center for Children with Disabilities, 1988).
Understanding this background has led me to believe in the importance of creating a resource to help parents. My intention is to create a workshop that will provide parents with information to help them tend to the needs of their typically developing children. The goal of this workshop is to help parents deepen their connection to their children and foster self-love, responsibility, resiliency, and self-esteem. As a resource, workshops can provide ways to create an intensive educational experience in a short amount of time; introduce new concepts; and incite participants to investigate it further on their own. Workshops can also help create a sense of community or common purpose among its participants (Community Tool Box, 2018).

**Purpose Statement**

Every family has different dynamics, rules and systems. There are various family structures such as single parents, households with multiple different generations, and households with other significant stressors including more than one member with a disability. Families also have their own beliefs, values, and needs. Regardless of familial circumstances, the purpose of a parent workshop is to provide supportive strategies to families. The primary reason for this project is to help parents of differently abled children find ways of giving attention, information, and support to the other children in their families. Parents will gain insight into TD siblings’ needs and experiences. This will involve exploring practical ideas for paying attention to TD siblings, strategies to explain the concept of disability, and recognizing, managing, and supporting the complex emotions and feelings of TD siblings. It will also aim to provide parents with the skills to get more cooperation from their children, as well as to communicate better. Parents will explore how to encourage their children to try new things and to persevere in their academic and social lives, without placing undue pressure on the children. They will also learn how to balance the needs of everyone in the family, as well provide tools to improve family functioning.
One of the most important things parents can do is support their children. This workshop will encourage parents to support and acknowledge their TD child's feelings about their differently abled brother or sister, or about family life and school. Attending the workshop may not be able to change what is happening at home, but it will help parents respond to how their child feels about things in a way that makes them feel like their parents really care and understand. The workshop will also enable parents to gain better communication skills with other professionals who work with their children, especially teachers. This is important because educators who understand “the family dynamic for a student with disabilities is critical for differentiation. Being aware that there is a typically developing child in the family, as well as potentially even in the same school, could be a great asset for in-home instruction and assistance outside of the classroom” (Charalambous, 2016, para. 2).

The following question will guide this project: *How can a workshop make a significant difference in the way parents of children with disabilities, manage the development and the well-being of their typically developing children?*

**Rationale**

Parents spend a substantial amount of their time and energy on making sure that their differently abled child’s needs are met, but often that intensity and focus isn’t spent on their typically developing child. In other countries, there is a lot of research exploring the differently abled and typically developing sibling relationship and how it affects the typically developing child. However, there is little research found in the Caribbean region. In the Caribbean, specifically Barbados, special education isn’t as well developed and funded as it is in Canada. By extension there is not a lot of discussion about how having a child with special needs can affect a typically developing sibling, thus there are no means of support for these families apart from private counselling. Doing a workshop in Barbados is the best way
to enable parents to aide both their differently abled and typically developing child’s
development and self. It will also be a cheaper and possibly a more informative option for
some families, as well as creating comradeship among those who may have shared
experiences.

Living with a child who has a disability can be very daunting for families with all the
difficulties and challenges that it entails. Many parents tend to feel very isolated and that the
pressures of dealing with their child on a day-to-day basis is not understood by others.
Workshops can be a tremendous source of help to families who have a child with disabilities
by enabling parents to share resources with one another. The workshop setting also allows
parents to share their experiences of living with a child with a disability and a typically
developing child, and receive and share advice on how to work with different professionals
they encounter. Workshops also allow parents to express their frustrations, and have their
feelings validated and understood. Through the groups, parents gain knowledge about school
services, and events. Other benefits include the opportunity to forge long-lasting friendships
with other families that understand their experiences. Parents can seek other outlets of
support, for example, the internet. Although the internet is a great resource to use, joining a
local workshop where there is face-to-face contact can help to build a more solid sense of
community. Finally, joining a workshop can motivate parents to use their voice to influence
the services provided by local government or health service providers, and thereby create a
better future for families with a child with a disability.

**Brief Overview of Project**

To better understand the challenges faced by children with a differently abled sibling,
it is necessary to review research and studies regarding family stressors associated with living
with and raising a child with disabilities. It is essential to understand the sibling relationship
before examining the impact of living with a child with a disability on the sibling
relationship. Research indicates that having a child with a disability affects all the members of the family, therefore it is important to look at the real-life experiences of TD children and their effects on them. In addition, it is important to examine parents’ or guardians’ perceptions of the relationship between their child with special needs and typically developing child, the effect a child with disabilities has on parents or guardians themselves, and the families’ quality of life. Research engaging those topics will be covered in the next section, Chapter Two. Chapter Three explores the importance of the project form, and a detailed layout of the workshop. The final chapter includes reflections and conclusions of this entire paper.
Chapter Two: Literature Review

This chapter reviews research on lived experiences of family members who have a child with special needs. The literature review addresses: (a) the lived experiences of typically developing siblings who have a brother or sister with a disability while also showing the similarities and differences of these reports worldwide; (b) research into how parents themselves perceive the relationship between their child with special needs and typically developing child(ren); (c) how having a child with disabilities influence parents themselves; and (d) how it has affected the families’ quality of life. The purpose of this literature is to identify the experiences of siblings and parents of a child with a disability, which provides the foundation for the workshop described in Chapter Three.

Sibling Experiences

Over the last two decades, a growing body of research has focused on siblings of children with disabilities. These siblings have often been described as forgotten children and are identified as the family members most neglected during their sibling’s serious childhood illnesses (Nielsen et al., 2012). However, the literature on the experiences of children with siblings with disabilities reflect mixed research. The results from some studies offer positive findings, others present negative findings, and there are some studies that suggest mixed responses.

Positive experiences. Supporting TD children can create a ripple effect in the lives of those involved. By supporting their TD children, parents can help strengthen relationships within the entire family. This familial dynamic can result in a comfortable and open environment where communication between family members is more effective, resulting in parents being more aware of, and in tune with their all their children’s needs. This awareness results in the well-being of the children in the long term and enhances the likelihood of them
becoming well-adjusted adults who can contribute to the community in which they live in useful ways. It is also important to realize that “not all siblings will experience concerns and, with an increased understanding of the issues for siblings, it is fairly easy to support children, so their adjustment can become more positive” (Siblings Australia Inc., n.d.-b, para. 2). It is not possible to remove all the stresses, but parents can help children manage them.

Few studies in this literature show the positives of living with a child with a disability. However, Ali and Sarullah (2010) found that through strong attachment, positive acceptance can occur between typically developing children and their siblings with special needs—as well as their positive relationships with parents and peers. Martirosyan (2013) suggested similar findings among Norwegian children with a sibling with Down syndrome. Her study concluded that the relationship between TD children and parents showed no differences; each relationship was found to be one of caring and closeness. These studies reflect the kind of acceptance that has been shown by typical family members towards the presence of siblings with special needs in their families.

In relation to family dynamics, typically developing siblings expressed that the relationship with their parents is filled with open communication and trust (Pit-Ten, Cate & Loots, 2000). Ali and Sarullah (2010) found that when parents share information with their TD children, it enabled the children to understand and support their siblings with a disability, in addition to strengthening their parent-child relationship. However, some studies (Ali & Sarullah, 2010; Pit-Ten, Cate & Loots, 2000;) acknowledged that their parents’ attempt to treat all their children equally.

Negative experiences. When there is a child with a disability or chronic illness in the family, the developmental benefits resulting from the sibling relationship can be altered. A common example is the limited opportunities to interact with other children outside the
family, and therefore, there is applied pressure on the social interaction between siblings (National Dissemination Center for Children with Disabilities, 1988). Reports have shown that children who have siblings with special needs have a broad range of feelings towards them (Eames, 2013; Strohm, 2002). Children who have siblings with disabilities often feel guilty of not having a disability themselves and of their accomplishments while their brother or sister struggles. They also tend to feel embarrassed by the questions or attention they receive from strangers, or when their siblings act out and display societally unacceptable behaviour in public.

Hartwell-Walker’s (2016) work specifically explored the experience of typically developing siblings. According to the author, typically developing siblings are aware of the strain their parents go through with their differently abled brother or sister, and they often place unimaginable pressure on themselves to be perfect for their parents. Being the more capable child results in typically developing siblings adopting the role of caretaker for their brother or sister. They are also expected to understand that their brother or sister’s needs, especially medical complications, takes priority over theirs. Additionally, the author reported that, from a young age, typically developing children are expected to help care for their sibling with special needs, even if that sibling is older than they are. With this type of responsibility, typically developing siblings may appear to be very independent, however Hartwell-Walker warned that this might be a premature conclusion because having a huge amount responsibility at such a young age can result in emotional distress later in life.

King, Alexander, and Seabi (2016) reported that within an African context, TD siblings experience differential parental treatment and discipline in comparison to their sibling with Attention Deficit Hyperactivity Disorder (ADHD). Martirosyan (2013) also found differential treatment as well as the imbalance of attention TD children get, in a Norwegian family. However, TD siblings also acknowledged their parents’ attempt to treat
all their children equally (Pit-Ten Cate & Loots, 2000). Typically developing siblings also experience rejection from their sibling with a disability (King, Alexander, & Seabi, 2016) as well as social exclusion from their peers (Martirosyan, 2013; Pit-Ten Cate & Loots, 2000).

Research has also suggested that TD siblings experience the burden of caring for their sibling with a disability (King et al., 2016) and additionally, worry about the future and the health of their sibling with a disability (Pit-Ten Cate & Loots, 2000). Fullerton, Totsika, Hain, and Hastings (2016) found that siblings of children with life-limiting conditions (LLCs) experience higher levels of emotional and behavioural difficulties when compared to the population norms. They also reported that in comparison to the population norm, siblings of children with LLC were described having lower quality of life. Fullerton et al. accumulated this information to explore the psychological adjustment, quality of life and sibling relationships between TD children and children with life-limiting conditions, whereas previous studies only focused on sibling relationships.

An issue that is often overlooked by parents is that children who have siblings with disabilities often do not have a deep understanding of the disabilities. As a result, they have no understanding about why a sibling with a disability is acting the way they are (Strohm, 2002). When a typically developing sibling has questions or concerns about their sibling’s disability, it should be encouraged and respected by the parents, not be a topic that is ignored or avoided. Being aware of the features or behaviours of a disability can greatly help children navigate through family life and sibling relationships, especially when negative occurrences happen because they can then learn not to blame themselves when their parents react in certain ways to circumstances that are beyond their control (Strohm, 2002). A lack of information can result in siblings finding themselves in a quandary because they don’t know who to talk to, what they feel, or how they feel about family situations. This, in turn, can complicate sibling relationships. Furthermore, even when a TD sibling understands
information about their sibling’s disability, there is a dire need for the typically developing siblings to express their feelings. “Parents and professionals need to be aware that there may be a gap between the non-disabled sibling's knowledge and actions. A non-disabled sibling may be able to rationally explain a brother’s or sister's disability to inquiring friends or neighbours but may still exhibit temper tantrums over the same sibling's actions in the home” (National Information Center For Children and Youth With Disabilities, 1994, para. 19).

Typically developing siblings have reportedly expressed conflicting emotions and responses towards their siblings with a disability. Research shows that siblings expressed their feelings of love, pride, support, embarrassment, and concerns for their sibling with a disability’s social acceptance and safety (Ali & Sarullah, 2010; Angell, Meadan, & Stoner, 2012; Pit-Ten Cate & Loots, 2000; Woodgate, Edwards, Ripat, Rempel, & Johnson, 2016). They often feel both love and resentment for their brother or sister. Understanding that the disability is not their siblings fault, does not prevent them from feeling embarrassed or impatient by their condition. The attention their siblings get from their parents can also trigger jealous and resentful feelings.

**Parental Perception of Sibling Relationships**

**Perceptions of both parents.** According to research in this area, raising children with different types of disabilities can cause different kinds of parental stress and sibling relationships in families. Research has found that parents often report that TD siblings experience problems with emotional and behavioural adjustments, issues with pro-social behaviour and peer relationships (Chan & Lai, 2016; Goudie, Havercamp, Sahr, & Jamieson, 2010; Griffith, Hastings, & Petalas, 2014;). Conversely, Nielsen et al. (2012), and Chan and Lai (2016), found that TD siblings are not significantly impacted by their siblings with a
disability. Parents in the Nielsen et al. (2016) study stated that the relationship between siblings was empathetic, kind, involved and rarely avoidant.

**Mother’s perceptions.** Mothers are considered to be major caregivers, and more accessible than their partners, and as a result they are usually the main target as research participants for many researchers who choose to explore familial matters. The following studies support this statement.

Toly, Blanchette, Sikorski, Musil, & Al-Hamed (2017) explored the experiences of typically developing siblings growing up in a household with a technology-dependent child, from the perspective of the mother of the household. Due to technological advances, the survival rate of children dependent on medical technology has increased significantly over the past 25 years, which resulted in a life-long impact on their families. To accurately represent the experiences of typically developing siblings who are living in a family with a technology-dependent child, Toly et al. (2017) used a qualitative, and descriptive research design. 82 mothers participated in this study. The mothers answered a demographic questionnaire and took part in interviews about experiences of their well children. The findings reflected the effects and experiences of their typically developed child. The first theme, well-sibling adjustment, found describes the impactful change that families go through when they fit the technology-dependent child’s care and treatment into everyday family life, which has become the family’s “new normal”. A positive aspect that was revealed was the well-siblings of a technology-dependent child resulted in the development of altruistic and prosocial behaviours. The downside suggested there were negative experiences and behaviours typically-developing siblings endured while living with a technology-dependent child.
However, in a study conducted by Choi and Van Riper (2014) most mothers described problems in the sibling relationship despite indicating that their typically developing children were not experiencing psychological or behavioural problems, despite living with a sibling with a disability. It was found that family factors were strong predictors of sibling psychological, behavioural and relational adaptation, whereas demographic characteristics of the family significantly influence sibling adaptation. These results bare similarities to the Goudie et al study previously mentioned.

While studies like Choi and Van Riper (2014) and Toly et al. (2017) focused on the psychological adjustment of parents of children with disabilities, Huang, Ososkie, and Hsu (2011) focused on the influence of having a child with a disability on marital relationships. Huang et al examined and described whether having a child with mental retardation can have an impact on marital and sibling relationships within Taiwanese families. The outcomes indicated that the marital relationships of the parents improved after they had a child with a disability. Through this study, it was reflected that interaction patterns between siblings with and without disabilities were influenced by the relative age of children without disabilities. Overall, the information generated from this study reflects the positive change in attitudes Taiwanese people have toward people with disabilities.

Parental Experiences

There is a range of factors influencing the relationship between parents and between each parent and a child with a disability. The processes by which they operate and the possible impact of those relationships on family members’ wellbeing are also aspects that should be observed by researchers. Research that compiles findings on family functioning among families with typically developing children provides a useful model upon which to build understanding of families living with a child with a disability.
**Coping strategies.** Raising a child with a disability can be exhausting, and can have an impact on parental health and wellbeing, which is why parents develop coping strategies to survive. According to Alexander and Walendzik (2016), parents of children with Down Syndrome who use regenerative coping strategies tend to experience less anxiety and somatisation symptoms. Whereas other parents who use dysfunctional coping strategies like self-blaming and denial, suffer from depression and physical symptoms. In addition to this, parents of children with autism who experience parental fatigue, unfortunately use ineffective maladaptive coping strategies such as self-blame, and disengagement adversely create more stress for themselves (Seymour, Wood, Giallo, & Jellett, 2013). In Ghana, Oti-Boadi (2017) suggested that mothers of children with Intellectual Disabilities (ID) used the following strategies to cope with their child’s diagnosis and the changes in their life. Some of the mothers used their spiritual beliefs. They stated that believing God gave them a child with ID for a reason helped them cope with their circumstance. Holding onto hope was another strategy they used. Being hopeful that there will be better days to come relieved the stressors the mothers felt. Lastly, the support mothers get from their family members, friends, church, and healthcare professionals was essential to sustaining their sanity.

**Quality of life.** According to Whiting (2014), parents experience stress in the following three areas: lack of time, taking on multiple roles, and being known as the “disabled” family. However, while both parents are sharing this experience, McStay, Trembath, and Dissanayake (2014) discovered that mothers experience higher levels of stress and lower quality of life (QOL) than fathers of children with Autism Spectrum Disorder (ASD) while also stating that a family’s sense of coherence is important for the positive experiences for parents. On the other hand, Mugno, Ruta, D’Arrigo, and Mazzone (2007) found that in comparison to parents of children with developmental disorders, parents who have children with Pervasive Development Disorder (PDD) experience significantly lower
QOL, but parents who have children with High Function Autism (HFA) experience higher levels of stress. Oliveria and Limongi’s (2011) findings contradict the findings of the previous studies. They found that parents of children with Down syndrome have reported good QOL. This indicates that “parents’ quality of life depends on their children’s disabilities” (Kotzampopoulou, 2015, p. ii).

**Conclusion**

The focus of this chapter was to review the literature regarding the lived experiences of families with a child with a disability. The findings for the reviewed studies reveal that experiences of this nature, depends a lot on the type of disabilities and its severity. Some experiences can be generalized whereas others are specific to the culture. Research findings on sibling experience, the parent’s perception of their relationship and parent’s own experience help to substantiate this project. The following section, Chapter Three, gives a detailed description of the workshop. The results from the findings in each theme provides the foundation for the topic of each session in the workshop. The theme “Sibling Experiences” is addressed in sessions two and three. The “Parental Perception of Sibling Relationships” theme is discussed throughout the workshop, because it targets the parents of children who have siblings with disabilities and relies on their perception of the sibling relationships in their family. The final theme is the “Parental Experiences”, which addresses the personal experience of parents and indicates their needs.
Chapter Three: Considerations for Implementation of the Project

Introduction

The literature reviewed in the previous chapter suggested inconsistent findings regarding the experiences of siblings of children with disabilities. Some studies indicate that siblings were negatively impacted, whereas other studies report that children who have siblings with disabilities were positively impacted and little to no significant problems; they were supportive, kind, and empathetic towards their sibling with a disability. It is imperative that parents and caregivers of differently abled children be aware of the stressors and challenges their typically developing (TD) children experience on a daily basis. Furthermore, research confirms that parents themselves experience stressors and challenges.

Therefore, a once a week, 2-hour workshop for seven weeks could be an effective way to educate parents and caregivers regarding the issues and stressors perceived by TD children along with adjustment behaviors they could use to cope with a child with a disability in the family.

According to Placed (n.d.)—an educational organization whose goal is to encourage young people to be able to influence, be inspired by, and learn about the work around them—workshops have many benefits. A workshop provides the participants with information that they themselves would not have the time to research. It also proves to be effective in improving the capabilities of the participants to make informed decisions about various practices, and the knowledge gained during a workshop is typically important in changing people's intentions about how they approach situations. Furthermore, workshops provide participants with safe spaces to try out new strategies they are not confident using, and allow participants to learn and perfect those strategies without immeasurable consequences. Workshops can also assist participants in better understanding concepts because they allow them to get feedback from their peers and presenter, which would direct them towards
favorable outcomes should they encounter similar issues in a real-life situation. Lastly, a workshop’s overall all benefit is the sense of community it can create among its participants, thus resulting in bonds between them (Placed, n.d.).

The following sections of this chapter will explain in detail the development of this project, its intended audience, and equipment and environment suitable for the workshop, along with a detailed outline of this workshop.

**Development of Project**

Young children tend to spend more time with their brothers and sisters than with their parents and primary caregivers, thus their relationships with their siblings become the most important and meaningful relationship they have. Regardless of the disability, children spend most of their time with their family. The responses of people around them certainly influence children’s reactions, including their families. Some parents want to seek assistance with their TD siblings and the ups and downs of their daily lives, and how to handle any difficulties that may arise. Parent education and support can be beneficial not only for the children but also for the parents.

A psychoeducational workshop for parents and caregivers of children with disabilities and their TD siblings is a suitable place for the participants to get educated as well as gain a sense of community with other participants. The overall intent of the workshop is to: (a) educate the parents and caregivers to provide support with having a sibling with a disability; (b) educate parents regarding issues their TD child faces; (c) identify the anxiety and stress indicators in sibling children; (d) create open communication between themselves and their typically developing children; and (e) create positive relationships between siblings.

The main goal is to help families create safe and secure environments for both the TD children and child with special needs.
**Intended Audience**

This psychoeducational workshop is geared to educate parents and primary caregivers who have children with cognitive disabilities as well as TD children. Participants who could benefit from this workshop are: primary caregivers, parents (single, divorced, foster and step parents), and extended family members (uncle, aunts, grandparents).

**Environment and Equipment**

The workshop will be conducted in a large room that can accommodate up to 35 people comfortably. The room should be well lit with minimum distractions and wheelchair accessibility. The presentation room will need to be equipped with a white board with expo markers, a media system, a TV or monitor that can display clearly a Power Point presentation, and video. The room will have comfortable seating, and participants will be provided with handouts of the power point presentation. The participants of this workshop will also be provided with childcare services, at no expense. They will be given the choice between childcare at the location of the workshop sessions or, money to pay a babysitter/nanny to watch their children at home.

**Workshop Overview**

The psychoeducational workshop will consist of seven (120 minute) group sessions, conducted over a seven-week period, at the same location and time each session. Session one will be an introductory session, where everyone one will familiarize themselves with each other and what the workshop will be about. Session two will focus on explaining the disability to the sibling child. Session three will address issues for siblings of children with a disability. Session four will focus on how to identify anxiety and stress in sibling children and teach them how to deal with difficult situations. Session five will target the importance of communication and teach sibling children how to express their concerns. Session six will explore how to create a positive relationship between siblings. The final session will be a
Session one: Introduction. This workshop begins with an introductory session where participants will be provided with an introduction to the objectives of the workshop and a rationale of why the workshop is an effective way to teach the skills parents and primary caregivers need to support their typically developing sibling children. The participants will be advised to bring notepaper, a pen, and a bottle of water to each subsequent session. Introductions will occur, and participants will be asked to elaborate on why they chose to join this workshop, and any other details they might want to share with the group.

Once the introductions are over, the topic of the role of the caregivers in supporting their TD child will be discussed. This discussion will be addressed with caution because it is imperative that the abilities of the caregivers do not appear to be questions. However, the role of the caregiver does need to be addressed. The aim of this discussion is to reinforce the parents’ knowledge of the rights they have when it comes to advocating for their differently abled child as well as addressing their TD child psychological development. The importance of taking care of themselves and their partner—as well as the demands of the role of being the educator, listener, social networker, and health care provider—are just some of the information that will be discussed in this session.

Towards the end of this session, two handouts will be given out to the participants. One handout will be given to the participants with the details of what is to be expected in the following workshops (see Appendix B). The other handout provides the participants with a list of books they can purchase for their sibling children; for each book, a summary is provided (see Appendix C). This session is not expected to take the full 120 minutes because it is only the introductory session.
Session two: Explaining the disability. Following the introductory session, Session Two will target how participants can explain the disability to the TD sibling child, and its importance. Talking to a TD child about his or her sibling’s disability can help improve the TD child’s understanding of why things are different with their brother or sister. It also helps to improve the relationship between siblings and maintains trust between parent and child, thus strengthening their own relationship. The session will begin with an overview of the objective of this session, which is to help participants address their child’s curiosity about their sibling’s disability. After the objectives, a discussion on the importance of talking to siblings about disability or illness and why, will follow. The expectation of this discussion is to initiate the participants’ awareness regarding how they can help their children, and why encouraging these conversations is important for their TD child’s development. This discussion will then lead into a conversation regarding the experience of participants’ discussions with TD children about their sibling’s disabilities.

After the discussion, a handout will be given out titled “How to Explain Disability to a Child” (see Appendix D) which they will browse. This handout provides the participants with the Four C’s when discussing the disabilities to their child; the five things to bear in mind when talking to people about disabilities; and suggested phrases to use when explaining a disability to a child which is organized by age (see Appendix D). Once they’ve read the handout, the participants will be given an opportunity to take part in a role-playing activity. For this activity, participants will break into small groups (evenly divided) and given scenarios which they will then have to strategize about how to handle specific situations. Each scenario will deal with situations where they would have to decide how to approach a child’s curiosity about their sibling’s disability. Once they’ve had time to discuss their approach, they will come together, and each group will present their scenario and solution and their peers will provide feedback.
After this activity, a TEDx Talk video by Kiran Kumar (2017) will be played. In the video, Kiran Kumar talks about autism: what it is, its history, and his personal experience with this disability that his sister has—meanwhile advocating for Applied Behaviour Analysis (ABA) therapy. The aim of this video is to show the impact and importance of providing sibling children with knowledge about their sibling with a disability.

The intended outcome of this session is for participants to see the need to educate their TD children so they can advocate for their siblings when their parents and primary caregivers cannot. After the video, a guest speaker, an adult with special needs who has grown up in Barbados, will join the session. The speaker will speak for approximately 20 minutes about his/her personal experiences and will also explain how impactful an open discussion about disabilities can be. The guest speaker will also provide the participants with tips and the appropriate language and terms to use when they have this discussion with their TD children. Once the guest speaker has finished, a final handout for this session will be given to the parent participants to take home. The handout is titled, “Do’s and Don’ts: How to Talk to Your Kids About Disability” (see Appendix E). It provides participants with some guidelines when talking to their children.

**Session three: Issues faced by the typically developing child.** Session three will address issues facing siblings of children with a disability. Being aware of the burdens their children endure can help participants create a healthier lifestyle for their child, as well as facilitate their emotional development. Being a TD sibling of a child with special needs comes with unique challenges. It becomes even more challenging if they feel like they are facing these challenges alone. Highlighting the signs and issues that these children face help parents and primary caregivers make TD children’s experience more memorable. The objectives of this session are to have participants understand the perspective/experiences of
their TD child as well as to reflect on their own home experiences and how the participants can improve.

After the objectives have been shared, the participants will be shown a four-minute video clip on this session’s topic (NHS Choices, 2011). In the video, two sisters, Charlotte and Chloe talk about the issues they face while having a sibling with cerebral palsy. This video was chosen because it shows two different perspectives; Charlotte’s, who is the eldest sibling, who has experienced life without a differently abled sibling, and Chloe’s, who is the youngest sibling, who has not experienced life without a differently abled sibling. At the conclusion, the participants will then be asked to reflect on conflicts they may have had with their sibling child and the underlining issue that could have caused a rift. They will also be given the opportunity to reflect on any possible signs they could have missed with which their TD child was struggling, but was overlooked because their child with special needs needed them at the same time. Following their reflection, the participants will be asked to write down a thought that came to mind that they would like to share—and how they handled it—so it can be discussed with the group.

Additionally, there is always a risk that TD siblings may experience bullying and teasing at school because their family is different. Therefore, the topic of bullying is crucial. We are often reminded of the devastating realities caused by bullying and, it is important to take bullying seriously and to act to curtail it. The participants will be presented with the warning signs of bulling and actions the participants can take to help put an end to it.

After the discussion has ended, a guest speaker, an adult TD sibling of a child with special needs who has grown up in Barbados, will join the session. The speaker will speak for approximately 20 minutes about his/her experiences of living with a child with a disability, providing insight into what it was like in his/her childhood and adolescence, the challenges he/she faced, how his/her parents or primary caregivers handled issues that ensued, as well as
advice for the participants in the session. Having a guest speaker for this session is important because it provides the participants with input from an individual who is of similar cultural background and can help them have a better idea of the experiences their TD child may encounter as they navigate through adolescence. Any queries or questions the participants may have will be answered once the guest speaker has shared his/her experience. Before this session is concluded, the participants will be given a handout (see Appendix F) that provides them with common issues their sibling children may face and ways of responding suggested by experienced parents.

The theme of this session follows session two because discussing the disability can help reduce the anger and confusion the TD child might feel, thus lessening the issues that they face. The participants can come up their own solution due to the knowledge provided by the prior session.

**Session four: Identifying stressors.** How to identify anxiety and stress in TD children—and teaching them how to deal with difficult situations—will be the focus of session four. Not all children who have siblings with disabilities experience issues or difficulties in their daily life. For those children who find things difficult and stressful, it is important that parents or primary caregivers provide help and support. The objectives of this session are to help the participants identify anxiety and stress in their TD children, and to help them come up with solutions and provide coping strategies to help their TD children.

Once the objectives have been shared, the participants will be shown an eight-minute video. In the video, pediatrician and adolescent specialist Ken Ginsburg discloses how stress looks different at different ages, and how parents or primary caregivers can teach, as well as model their child’s coping strategies that will help them to feel safe and secure (Ginsburg, 2016). Following the video, a handout, titled “What signs might indicate stress” (see
Appendix G), will be given to the participants and discussed. The handout provides participants with what to look for when or if their TD child’s behavior changes.

The question “Has your sibling child shown any of these?” with the follow up question “What did you do to help your sibling child overcome this?” will lead the discussion. The participants will then be given another handout titled “What siblings need?” (see Appendix H), which outlines simple solutions that the participants can do to help their TD children in a moment of distress. This handout will be explored, and the participants will be encouraged to voice their opinions on what is written on the handout and provide their own tips. Before this session concludes, the participants will be given another handout that will provide them with tips about how to reduce their child’s stress and anxiety (see Appendix I).

This session is a continuation of session three. It provides solutions that will lessen the anxiety, tension, and negativity in the family’s household.

**Session five: Importance of communication.** Session five will target the importance of communication and teaching TD children how to express their concerns. Acknowledging the TD child's feelings about their brother or sister with a disability, or about family life and school, is one of the most important things that can help TD children. Changing the home environment for the sibling child may be difficult; however, the way they are responded to can make them feel you they are cared and understood (Sibs, 2018). Taking time to listen carefully to listen to a child’s problems can result in creating a positive difference to the relationship between a guardian and their TD child. The aims of this session are to create an open and safe environment for their TD children to express their emotions, as well as create a more secure and strong relationship between themselves and their TD children.

This session starts with the announcement of the objectives, followed by an analysis of ways the participants can acknowledge their TD child’s feelings. Listening to TD siblings’
complaints and upsets; what to avoid with feelings—such as blaming, making excuses for the child with disabilities, and solving; how to acknowledge feelings; helping your TD child deal with worry; and helping your TD child deal with embarrassment (Sibs, 2018) are some of the ways that will be discussed. After this analysis is concluded, the participants will then prepare to watch a 21 minute TEDx Talk video by Alicia Arenas (2010); where she expresses what it means to be a sibling of a child with special needs. In this video Arenas recalls her personal experience of living with two siblings with special needs, having lost one brother to the world of autism and another to a terminal illness. In the overall message of her speech, Arenas tells parents of children with special needs to stop overlooking their TD children.

To continue the message of the video, a guest speaker will be introduced, who will speak for thirty to forty-five minutes. The guest speaker will be a local Child Psychologist who will provide the participants with tips and strategies about how to create a secure environment in which their TD child can feel safe and comfortable to speak freely to their guardians. After the presentation of the guest speaker, the participants will be given ample time to ask questions. The book *How To Talk So Kids Will Listen & Listen So Kids Will Talk* written by Adele Faber and Elaine Mazlish (1980), will be recommended at the end of this session. This book supplies the reader with the know-how they need to be more effective with their children and more supportive of themselves. Faber and Mazlish’s methods of communication offer innovative ways to solve common problems. This session is essentially a continuation of session four.

**Session six: Developing a positive relationship between siblings.** Creating a positive relationship between siblings is the focus of Sessions Six. The objective of this session will help the participants create a positive relationship between siblings, as indicated in the title. Once the objective has been stated, sibling rivalry will be discussed. Sibling rivalry is a normal part of having a sibling. Having to share the attention and affection of
parents is enough to drive a wedge between siblings. “Through expressions of sibling rivalry, children are reacting to the denial or felt denial of their needs for dependence and the affection of their parents. To punish children for these acts of jealousy tends to confirm their feelings of loss and resentment” (Sailor, 2014, para. 16). Rivalry over power, attention, and companionship will be discussed as well as the approach parents take to reduce it.

This will then be followed the question: “What can you do to create a strong bond between siblings?” A few participants will be asked to share their ideas about how they can achieve this. Then, a discussion about how to deal with the fairness issue and teaching siblings how to interact with each other, as well as the ways to create strong bonds between siblings will take place. For example, some strategies might include: giving appropriate attention to each child; being cognizant of the amount of attention given to each child and always include the TD sibling in family discussions and decisions; fostering positive communication and sibling interactions; supporting and encouraging your children as they learn to communicate with each other; as well as creating opportunities for your children to do activities in which both can participate. Lastly, redefining independence for their child and teaching the concept of interdependence are other ways to enable siblings to form a positive relationship (Enriquez, n.d.).

The participants will then be given an opportunity to take part in a role-playing activity. For this activity, participants will break into small groups (evenly divided) and given scenarios, which they will then have to strategize about how to handle specific situations; each scenario will deal with situations where they would have to decide how to soften a tense altercation between siblings making sure that it will not ruin the relationship they have with one another. Once they’ve had time to discuss their approach, they will come together, and each group will present their scenario and solution and their peers will provide feedback. After the role-playing activity, a guest speaker will be introduced, who will speak for thirty to
forty-five minutes. The guest speaker will be a local child psychologist or a family therapist, who will provide the participants with tips and strategies about how to assist their TD child and sibling with a disability with their communication and relationship as well as activities they can share with them. After the guest speaker has finished presenting, the participants will be given ample time to ask questions. Before the end of this session, the participants will be directed towards a website called “Games all Children Can Play” (Scope About Disability, 2017), which provides them with games that they can introduce to their children.

**Session seven: Review and final session.** The final session, session seven, will be a review and conclusion pertaining to the previous sessions. In this session, any questions or additional information will be addressed, and provide the participants with closure. The participants will be given ample time to socialize amongst themselves, with refreshments. This session will not be expected to last over an hour, it is also optional to occur.

**Conclusion**

The focus of this chapter was to provide a detailed description of each session in the workshop in addition to the linkage between each session. Chapter four, the final chapter, will provide a discussion of the overall project including the limitations found as well as what was learnt from the research gathered in creating this workshop.
Chapter Four: Reflection

Summary

The purpose of this project was to create a workshop to educate parents, caregivers, as well as family members about the impact having a child with a disability can have on the typically developing (TD) siblings in the family. Research has shown that having a child with disabilities affects all the members in the family. It is important to first look at the stressors the TD child experiences to understand their emotions which strain the relations within the family as a unit. Caregivers will learn to understand the importance of explaining the disability to the TD child, and how it affects their overall perception of their differently abled sibling. They will also learn about the issues TD siblings face, and how their experience differs from that of their caregivers. Parents will learn how to identify anxiety and stress in TD sibling children and teach them about how to deal with difficult situations. Lastly, they will learn about the importance of communication, and the need to teach TD sibling children how to express their concerns. Once educated, parents and caregivers will be able to effectively support their children and improve their daily lives.

Discussion

The purpose of creating this workshop is to support parents and caregivers and educate the adult family members about the effects a disability has on the entire family. Disabilities affect every member of the family in varying degrees—depending on the nature of the disability and its severity. Parents, grandparents, caregivers, and extended family members need to be made aware that living with a child with disabilities affects the child’s siblings as much as it affects them. This workshop is designed to inform the caregivers of the impact the child with disabilities has on the typically developing siblings, the issues they experience and the ways in which caregivers can help them cope in these situations. As much
as they love their brother or sister with a disability, they often do not understand why their sibling with a disability does not adhere to the familial and social rules as they do. As mentioned in previous chapters of this research, TD siblings may possibly internalize this, experience guilt, form resentment, self-blame or an array of other negative feelings.

Caregivers of children with disabilities need to recognize the increased levels of stress of their children experience while they meet the demands of their family. Caregivers, especially mothers, find it very difficult to cope, when they have a child with a disability in their care; they are confused and often consumed by the demands of their role that they occasionally (and inadvertently) neglect the care of their typically developing child. Some parent participant studies show that these TD siblings have internalized those problems, and some studies show that they are very well adjusted; the reason for this contradiction could be that parents spend so much time attending to the needs of the child with a disability that they are unable to accurately tell what the typically developing child is going through. A workshop would be a supportive way to inform parents and family members of the challenges and feelings typically developing siblings face in their daily family life situation. It’s important to note that the workshop is structured to educate and inform the adult family members – the parents, and caregivers—about the effects of disabilities on the family. Also, the workshop is organized concisely and can be easily followed and understood by anyone who attends. As the purpose of the workshop is to educate and inform, I have not included any interventions.

Reflection

I have been working with children with disabilities for the past six years and during this time I have had valuable opportunities to observe and learn from each member of the family. I have observed how they adjust and cope with the demanding needs of their child with a disability, as well as strive to achieve a balanced life for every family member.
Through these years of experience working with these families, I have come to strongly believe that there is a strong connection between sibling relationships and overall quality of family life. Taking care of children with disabilities and typically developing children is a challenge for parents; their job is never done. Working with families I saw first-hand the confusion and struggles that go on at home; the roles each member of the family plays with the child with a disability; and the results of the child with a disability being the centre of focus.

In the Caribbean, Special Needs is a topic that is almost never discussed. Doing research—and raising awareness about special needs issues—in the Caribbean can help broaden public information, interest, and awareness. It important to rectify the limited information and the lack of resources that are in place. It is also necessary to properly support and educate families living with children with disabilities. Currently in Barbados, there is a foundation for families with autistic children that provides funding. Although that is a wonderful short-term support for those select families, my concern is that this foundation only provides funding for one selected family for only one year. Then, the resources the family had access to are taken away, and they must continue to struggle to find a way to provide for their autistic child. The financial struggle alone will alter the dynamics of the family—and if they have a TD child as well—that severely limits their personal needs and resources. In general, funding must be broader. But importantly, support and education can come in different forms, other than money. My solution suggests both education—and lasting support through the relationships that will (hopefully) be formed among the participants.

Throughout the process of forming this workshop, I’ve learnt that providing typically developing children with the knowledge of the disability their sibling has can greatly impact their home life. There is significant proof that once the typically developing sibling has been
provide with knowledge about their sibling’s disabilities that there is an increase in emotional and behavioural issues. It begs to question why this step isn’t the first thing they do once their typically developing child is at the appropriate age. It can be possible that they might not want to acknowledge their child’s disability or may not have anticipated their typically developing child’s curiosity.

The hope for this workshop is that once it has concluded is that it turns into a support group for the families involved, as well as to encourage participation from other families. There is a lack of support for families in Barbados, thus the importance of converting this workshop into a support group. The participants can then pass on the knowledge they have acquired from the workshop. The focus of the support group can begin as support for the parents; then a support group for the siblings can be added. The workshop does discuss the need for support for siblings; this can encourage the caregivers and the workshop director to spearhead support groups for the local children. There is a variety of information for how to get this started.

I have also discovered that there are not a lot of positive findings—in the research—about how to create a positive relationship between a typically developing child and a child with a disability. There is ample research directed solely towards typically developing sibling relationships. There is ample information on the dynamics and effects of sibling relationships, however there is no information on how to better the relationships between them. These types of information would be useful for families who experience problematic sibling relationships; it can create a better life for all family members and it is imperative to consider. Providing guardians with this knowledge can save them the pain of having to endure or observe the demise of the relationship between their children.
The fear that guardians experience in terms of seeking help is another revelation I have had while doing research. The stigma that is forced onto these families is terrifying and unjust. They need to be assisted and overcome feelings of ostracization by a situation that they did not bring onto themselves or ask for. An example of this poignant issue is an article that I read by McGill-Smith (2010) where she discusses what parents go through once they became aware of their child’s diagnosis. This is a shared dilemma that parents in Barbados experience.

When I was working with a family, the mother shared a painful story which explained why she took so long to seek help for her daughter with Down Syndrome. She told me that shortly after her daughter was born, a family member told her husband that they will never experience genuine happiness because of their “problem”. That same family member also told her that as a mother it is her responsibility to stay home and teach her child because no one will want to deal with a child like her, and that if they did that the child would never be accepted by children her age and even be bullied. She also stated that strangers come up to her and express their pity and tell her unkind things about her daughter in a good-natured tone. Thus, the need for this workshop—to create a strong sense of community so families are aware that they are not alone in their experiences.

Limitations

This project targets families in Barbados, however the literature reviewed in this paper represent the experiences of families who are not from Barbados or even in the Caribbean. This could be seen as a limitation because it brings into question whether the findings from the literature review can be applicable to Barbadians; there are significant cultural differences and beliefs, which often play a huge role in the perceptions of the participants. The reliability of this workshop is another possible issue. Workshops are an effective way to educate individuals, however the information provided in this study may not
be as beneficial as foreseen by the researcher. An interesting finding is that the parent perception of sibling relationships has not been well studied, because most family research is biased with data from mothers. This may be because mothers are more motivated than fathers to seek out, participate, and complete in most family research studies. There is also a gap in research about other cognitive disabilities, apart from Autism. There is significant research done on the lived experiences of family members with children with Autism, but nearly not as much research on families with children with other common cognitive disabilities. The imbalance of information creates a deficit in the information offered to those who have children with disabilities other than Autism.

**Conclusion**

Overall, this project will contribute to the research around special needs, specifically their effect on their family. The aim for this entire project is to encourage other researchers to consider how they can support dynamics and structures of families with children with disabilities, as well as focus less on deficit focused family problems and solutions.
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Appendix A – **Parent Workshop: Supporting Your Typically Developing Sibling**

**Workshop Outline**

**Rationale**

A workshop is an effective way to provide a group of people with information that they may not have attained on their own. The intent of this workshop is to provide guardians with information to help them tend to the needs of their typically developing children. The literature reviewed in this document in part, provides a foundation for this workshop as well as shows the need for a workshop. By exposing the experiences of the TD child, both from the children themselves and their parents, it reveals that these children do need extra help and support like their sibling that has a disability. While not all siblings have negative experiences, those that do will need the extra support and parents will benefit from this workshop. This workshop will cater to the emotional needs of the typically developing child as well as strengthen relationships within the family.

**Target Participants**

Guardians

- Child with a cognitive disability
- Typically Developing sibling

**Objectives**

1. Participants will learn how to build confidence, self-esteem, and security in their typically developing child.

2. Participants will understand how they can support their child at home.

3. Participants will learn how to help develop/nurture a healthy relationship between their typically developing child and their sibling with a disability.

4. Participants will learn how to create and nurture a safe and comfortable environment for themselves and children.

5. Participants leave the workshop feeling empowered to support their children.

**Sessions**

7 sessions (Once a week)
1. Introductory Session
2. Explaining the disability to the sibling.
3. Issues siblings of children with a disability may experience.
4. How to identify anxiety and stress in siblings.
5. Creating open communication between themselves and their Typically Developing children.
6. Creating a positive relationship between siblings.
7. Review.

**Time**

2 hours (120 minutes)

**Set Up**

- Tables and chairs in a central meeting space (auditorium)
- Refreshments in the back of the room.
- Workshop will be open 30 minutes prior to allow mingling and refreshments.

**Materials**

**Presentation Format**

- Computer, projector, and speakers (for the purpose of playing videos)
- Handouts/flyers
- Miscellaneous items (pens, paper, boards, etc)

**Services**

- Childcare at home or at the location of the meetings.
Session #1

“Introductory Session”

Objective:

- Introduce the objectives of the workshop.
- Provide a clear understanding of the role caregivers play

Handout:

#1.1 - Detailed outline of what it going to happen in the following sessions
#1.2 – Book list

Activity:

* Introduce myself and give a detail description of my educational background
  my motivation for starting this workshop
* Explain the objectives of the workshop and why I thought that there was a need
  for it
* Participants introduce themselves and share other information about themselves
  (their choice)
* Discuss their role in their family
* Give Handout #1.1 and #1.2.
* *END SESSION*
Session #2
“Explaining the disability to the sibling”

Objective:
- Help participants address their sibling’s curiosity

Video:
Understanding my Sister | Kiran Kumar | TEDxYouth@AnnArbor
https://www.youtube.com/watch?v=YwqfIoK3e84

Handout:
#2.1 - How to Explain Disability to a Child
#2.2 - Do’s and Don’t’s

Activity:
* Describe the aims of the session.
* Discuss: the reasons whether it is important to talk to siblings about disability or illness and why
* Ask parents if any of them have had the talk with their child about their sibling’s disability. If “yes” is an answer, follow it with the question “How did it go?”; “Do you think discussing the disability with your child help them in anyway?”
* Give out handout #2.1
* Role play; Create scenarios and have them form a group (evenly divided) and figure out how they will handle the situation; come together and each group present their scenario and solution and then their peers provide their input.
* Play video; this video will show why you should discuss your child’s disability with their sibling. They can advocate for their sibling.
* Guest Speaker: Adult with a disability talks about experiences (allow questions) 20 minutes
* Give out handouts #2.2; discuss if necessary
* *END SESSION*
Session #3
“Issues siblings of children with a disability may experience”

Objective:
- Have participants understand the perspective/experiences of their child
- Engage the participants in a deep reflection about their own child’s experiences

Video:
Sisters Charlotte (19) and Chloe (9) talk issues they face while having a sibling with a disability:

Handout:
#3.1 - List of common issues faced by siblings and ways parents can appropriately respond.

Activity:
* Explain the aim for this session (Enforce that this is a judgment free zone)
* Show the video (Charlotte and Chloe) *end video at 4:36*
* Ask parents to write down any possible issues that they think affect their typically developing siblings
* Discuss their notes between themselves; have them voice ways in which they can handle each issue and share their perspective on their peers’ issues (depending on whether their peer is accepting of this)
* Discuss the topic of bullying in school; “Is your sibling child being bullied?”
* Discuss the topic of bullying in school; “Is your sibling child getting hurt?”
* Guest Speaker: Adult Sibling talks about experiences (allow questions) 20 minutes
* Give handout #3.1; Look over handout and ask any questions, if any.
* *END SESSION*
Session #4
“How to identify stressors in siblings”

Objective:
- Help participants identify anxiety and stress in their sibling child
- Help participants come up with solutions and provide coping strategies to help their sibling child.

Video:

Handout:
#4.1 - What signs might indicate stress
#4.2 – What siblings need
#4.3 - 12 tips Reduce Your Child's Stress and Anxiety

Activity:
* Explain the aim for this session
* Play video; Recognizing & Managing Stress in Children by K Ginsburg
* Discuss handout #1; and answer the two following questions: 1. Have you seen any of these signs in your sibling child? 2. What did you do to help your sibling child overcome their dilemma.
* Give handout; Look over hand out and ask any questions, if any.
* *END SESSION*
Session #5

“Creating open communication between themselves and their typically developing children”

Objective:
- Create an open and safe environment for their sibling children to express their emotions
- Create a more secure and strong relationship between the participants and their sibling children

Video/Book:
How To Talk So Kids Will Listen & Listen So Kids Will Talk by Adele Faber and Elaine Mazlish
TEDXSanAntinio; Alicia Arenas – Recognising Glass Children
https://www.youtube.com/watch?v=MSwqo-g2Tbk

Handout:

Activity:
- Explain the aim for this session
- Play video; Alicia Arenas – Recognising Glass Children
- Review; Ways to Support your sibling child with their feelings
- Guest Speaker; Child Psychologist: - will provide the participants with tips and strategies about how to create a secure environment in which their sibling child can feel safe and comfortable to speak freely to their guardians
- *END SESSION*
Session #6
“Creating a positive relationship between siblings”

Objective:
- Help participants create a positive relationship between siblings.

Video/Book:

Handout:

Activity:
- State the objectives
- Discuss sibling rivalries
- Think and discuss: “
- Role play; Create scenarios and have them form a group (evenly divided) and figure out how they will handle the situation; come together and each group present their scenario and solution and then their peers provide their input.
- Guest Speaker; Child Psychologist- will provide the participants with about how to assist their TD child and sibling with a disability with their commination and relationship as well as activities they can share with them.
- Introduce the participants to the website “Games all children can play”
- *END SESSION*
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Great Books
if you have a Brother or Sister with Special Needs
Oh Brother! Growing Up with a Special Needs Sibling

**About the book:** Living with a sibling who has special needs can be difficult for a child to deal with, day after day. This book provides anecdotal examples, self-help guidelines and practical coping techniques to promote positive, realistic attitudes as well as the benefits of having a special needs sibling.

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs

**About the Book:** In Views From Our Shoes, 45 siblings share their experiences as the brother or sister of someone with a disability. The children whose essays are featured here range from four to eighteen and are the siblings of youngsters with a variety of special needs, including autism, cerebral palsy, developmental delays, ADD, hydrocephalus, visual and hearing impairments, Down and Tourette syndromes. Their personal tales introduce young siblings to others like them, perhaps for the first time, and allow them to compare experiences. A glossary of disabilities provides easy-to-understand definitions of many of the conditions mentioned.

Living with a Brother or Sister with Special Needs

**About the book:** Living with a Brother or Sister with Special Needs focuses on the intensity of emotions that brothers and sisters experience when they have a sibling with special needs, and the hard questions they ask: What caused my sibling’s disability? Could my own child have a disability as well? What will happen to my brother or sister if my parents die? Written for young readers, the book discusses specific disabilities in easy to understand terms. It talks about the good and not-so-good parts of having a brother or sister who has special needs, and offers suggestions for how to make life easier for everyone in the family.

Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs

**About the book:** Being the Other One is based on the author’s own experience (as a sibling of a sister with cerebral palsy) and on extensive interviews she conducted with siblings of all ages. In clear and compassionate terms, Strohm explores the often secret feelings of siblings and offers valuable strategies for coping with the challenges they face.

The Sibling Slam Book: What It’s Really Like To Have A Brother Or Sister With Special Needs

**About the book:** The Sibling Slam Book doesn’t slam in the traditional sense of the word. The tone and point-of-view of the answers are all over the map. Some answers are assuredly positive, a few are strikingly negative, but most reflect the complex and conflicted
mix of emotions that come with the territory. Whether they read it cover to cover or sample it at random, teenagers will surely find common ground among these pages and reassurance that they are not alone. It is a book that parents, friends, and counsellors can feel confident recommending to any teenager with a brother or sister with a disability.

**Special Siblings: Growing Up with Someone with a Disability, Revised Edition**

**About the book:** In this absorbing and candid book, Mary McHugh reveals what she experienced as the sister of a man with cerebral palsy and mental retardation—and shares what others have learned about being and having a special sibling. Weaving a lifetime of memories and reflections with relevant research and interviews with more than 100 other siblings and experts, McHugh explores a spectrum of feelings—from anger and guilt to love and pride—and helps readers understand the issues siblings may encounter in:

- **childhood**—such as dealing with their own needs for attention and information, identifying with their parent’s grief, understanding their sibling’s disability, and coping with their own feelings
- **adolescence**—such as participating in family discussions, fitting in with peers, searching for their own identity, and talking to a counsellor or therapist
- **adulthood**—such as building a support system, navigating adult relationships, deciding whether to have children, and planning for their sibling’s future care

Emotional and enlightening, this book is a must-read for teen and adult siblings—and all professionals who support people with disabilities and their families.

**Special Brothers and Sisters: Stories and Tips for Siblings of Children with Special Needs, Disability or Serious Illness**

**About the book:** *Special Brothers and Sisters* is a collection of real-life accounts from the brothers and sisters of children with special needs, disability or serious illness, ranging in age from 3 to 18 years. They explain, in their own words, what it’s like to live with their siblings. There is a lot of advice available for parents of a child with a disability or illness, but very little about the important issue of educating their siblings about how they feel, and why they may behave differently from other children. These stories— from 40 different families—come with related tips to help siblings deal with some of the things that happen in their family lives. The book also provides a helpful glossary to explain, in child-friendly language, the disabilities and medical conditions mentioned, including: * ADHD * autism * cerebral palsy * cystic fibrosis * Down syndrome. Special Brothers and Sisters is an engaging and educational collection that will enable young people and adults to share in the extraordinary experience of being a sibling of a child with special needs, a disability or serious illness.
**The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults With Disabilities**

**About the book:** If you’re a teenaged or adult brother or sister of someone with a disability, then this book is expressly for you. It offers a sense that you’re not alone, tips on how to talk to your parents about plans for your sibling, and a crash course in guardianship, medical & legal issues, and government benefits if you’re already caring for your sib.

Edited by experts in the field of disabilities and sibling relationships, The Sibling Survival Guide focuses on the topmost concerns identified in a survey of hundreds of siblings.

**Just Because**

**About the book:** Amusing and often touching, this story encompasses the issue of disability in a charming celebration of sibling friendship to which all children can relate. My big sister Clemmie is my best friend. She can’t walk, talk, move around much, cook macaroni, pilot a plane, juggle or do algebra. I don’t know why she doesn’t do these things. Just because.

A younger brother describes all the fun he has with the big sister he loves so much—just because, in this heart-warming picture book about being perfectly loved, no matter what. He is enthusiastic about just how loving and special she is, and delights in telling us about all the fun things they do together. Only as his tale unfolds does the reader begin to realize that his sister has special needs—and by then the reader just accepts, as he does, all the wonderful things about her. Teachers and librarians will appreciate this book for its sincere and convincing treatment of children with special needs, while parents will use this book to encourage sibling friendship and to read with children who are beginning to ask why a child they know is “different.”

[All summaries were taken from amazon.com]
Appendix D

Handout #2.1

How to Explain Disability to a Child

Be mindful of the Four C’s:

Compassion: Show a child you fully understand what a hurtful thing a disability can be.

Communication: Explain as much as you possibly can about the disability so a child does not become frightened by the unknown.

Comprehension: Make sure a child understands that the disability is never the child’s fault.

Competence: Convey the sense that even though a disability is very hard to deal with, a child with a disability will make progress and learn to do new things.

Here are five things to keep in mind when you talk to your child about people with disabilities:

1. Kids with special needs are different, and that’s not a bad thing.
2. Kids with disabilities are also the same as other kids.
   Talk about the things your child and the child with special needs have in common
3. People with special needs or disabilities are not necessarily sick.
   The disability itself, though, is not a sickness or something bad. Nor is it something other kids can “catch”—an important distinction to make when explaining disabilities to children.
4. Words matter.
   It’s OK to teach children the right words to talk about our differences: disability, special needs, even the names of specific disabilities. In addition to words like “sick” and “wrong,” try to replace the word “normal” with “typical”
5. It’s OK to ask questions.
   Kids are naturally curious, and that is wonderful! Don’t feel like you have to shush your child when they ask about disabilities. If you don’t know the answer, that’s OK too! As a professional that works with your family.
Suggested phrases to use when explaining a disability to a child:

<table>
<thead>
<tr>
<th>Age of the Child</th>
<th>When speaking to a child with a disability</th>
<th>When speaking to a child without a disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2 to 4</strong></td>
<td>We don’t know why, but sometimes children are born without everything their bodies need, and that’s what happened to you. That means you’re going to have to work harder and we’re going to work hard to help you.</td>
<td>Most children like you are born with everything they need, but sometimes children are born without everything they need. Sometimes they need crutches or wheelchairs or braces to help them do what you do naturally.”</td>
</tr>
<tr>
<td><strong>5 to 8</strong></td>
<td>“It’s really tough when your body can’t do everything you want it to do. It’s not fair that you have to work so hard to make your body do what you want. But everyone has some activities that are easy for them, and some that require more effort. You have this problem, but you’re lucky to have lots of talents, too.”</td>
<td>“Kids are all different, and they have different strengths as well as things that are harder for them. Some things that are easy for you to do are very difficult for other children to do. It takes a lot of courage for kids with physical disabilities to keep trying and working at it.”</td>
</tr>
<tr>
<td><strong>9 to 12</strong></td>
<td>It’s a bad break for you to be born with a disability that makes things harder. But remember your abilities, too and work to strengthen them. It’s natural sometimes to feel angry but try not to give up.</td>
<td>Whenever you see someone with a disability, remember that even though they are having a hard time, they’re still kids who need friends and understanding.</td>
</tr>
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[ Handout adapted from: mychildwithoutlimits.org and scarymommy.com ]
Appendix E

Handout #2.2

Do’s and Don’ts:

How to Talk to Your Kids About Disability

**Do:** Talk to your children about disability (if they ask).

Children are naturally inquisitive, and if they see a person with a disability they are going to be curious; that’s a good thing. If they ask a question, take the time to answer as openly and as honestly as possible. You don’t need to explain why a person might look different, you just need to acknowledge that they do. For example, if your child asks, “Why is that person in a wheelchair?” or “Why does that person only have one arm?” – it’s OK to say you don’t know. In fact, making assumptions is usually worse.

**Don’t:** Make a big deal about it.

Children undoubtedly notice disability, but typically don’t see the disability as a defining feature of a person in the way many adults do. Sometimes sitting your child down to discuss disability can in fact make disability seem even more scary. If you feel that you need to talk to your child about disability before they approach you, try to make it part of everyday conversation.

**Do:** Encourage your children to ask if someone needs help.

As a mother, I hope to raise empathetic and compassionate children, but there is a distinct difference between encouraging our children to be helpful, and encouraging them to force that help onto someone who might appear to need it more simply because they have a disability. We want to empower our children to be respectful of others; the best way is to encourage them to always ask if someone needs help — and most importantly, to respect the answer. We don’t want children to feel obligated to help others simply because they have a disability. Again, this sends a message that people with a disability are in some way
less able than they are, and that is simply not true. We don’t want to establish a sense of power, because help is something we all need from time to time, regardless of whether we have a disability or not.

**Do:** Talk about aids such as wheelchairs and artificial limbs.

When a child first sees a wheelchair or any other object that assists a differently abled person in their day-to-day life, it might seem unusual and even scary. Simply explain to your child that the device helps the person to walk, see, hear etc.

**Do:** Focus on what a person can do rather than what they can’t.

Often when we see a person with a disability we assume their life is difficult, and we think of all the things they can’t do or might struggle with. Instead, let’s focus on what people can do. A great way to do this is through watching athletes with a disability play various sports. Sports such as swimming, athletics, wheelchair tennis and wheelchair basketball. There are also some incredible artists and scientists with a disability. Make a conscious effort to learn more about their work.

[ Handout adapted from themighty.com ]
## Appendix F

### Handout #3.1

<table>
<thead>
<tr>
<th>Common issues</th>
<th>Ways of responding suggested by experienced parents</th>
</tr>
</thead>
</table>
| **Limited time and attention from parents** | • Protect certain times to spend with siblings, for example bedtime, cinema once a month  
• Organise short-term care for important events such as sports days  
• Sometimes put the needs of siblings first and let them choose what to do. |
| **Why them and not me?** | • Emphasise that no-one is to blame for their brother or sister’s difficulties  
• Come to terms yourself with your child’s disability  
• Encourage siblings to see their brother or sister as a person with similarities and differences from themselves  
• Meet other families who have a child with a similar condition, perhaps through a support organisation. |
| **Worry about bringing friends home** | • Talk over how to explain a brother or sister’s difficulties to friends  
• Invite friends round when the differently abled child is away  
• Don’t expect siblings to always include the differently abled child in their play or activities. |
| **Teasing or bullying about a brother or sister** | • Recognise that this is a possibility and notice signs of distress  
• Ask your child’s school to encourage positive attitudes to disability  
• Rehearse how to handle unpleasant remarks |
| **Stressful situations at home** | • Encourage siblings to develop their own social life  
• A lock on a bedroom door can ensure privacy and avoid possessions being damaged  
• Get professional advice about caring tasks and handling difficult behaviour in which siblings can be included  
• Try to keep the family’s sense of humour. |
### Restrictions on family activities
- Try to find family activities that everyone can enjoy, for example swimming, picnics, etc.
- See if there are holiday schemes the sibling or differently abled child can take part in.
- Use help from family or friends with the differently abled child or siblings.

### Guilt about being angry with a differently abled brother or sister
- Make it clear that it’s all right to be angry sometimes – strong feelings are part of any close relationship.
- Share some of your own mixed feelings at times.
- Siblings may want to talk to someone outside the family.

### Embarrassment about a brother or sister in public
- Realise that the behaviour of typically developing family members can cause embarrassment sometimes.
- Find social situations where the differently abled child is accepted.
- If old enough, split up for a while when out.
- Together.

### Protectiveness about a very dependent or ill brother or sister
- Explain clearly about the diagnosis and expected prognosis – not knowing can be more worrying.
- Make sure arrangements for the other children can be made in an emergency.
- Allow siblings to express their anxiety and ask questions.

### Concerns about the future
- Talk over plans for the care of the differently abled child with siblings and see what they think.
- Find out about opportunities for genetic advice if.
- This is relevant and what siblings want.
- Encourage them to leave home when they are ready.

[ adapted from contact.org.uk ]
Without the maturity to understand and express the range of feelings they might experience, children may act out the feelings through their behaviour. Of course, all children may show these signs of stress from time to time. Even if a sibling does, it may not be related to being a sibling of a child with disability. But the following signs might indicate that a sibling needs some extra support:

**Withdrawal**

Children might withdraw to protect themselves physically and/or emotionally. Sometimes that can be a very useful strategy but if continued over time it may not be the most helpful way to manage. Younger children might regress, e.g., need to wear nappies again or be more ‘clingy’.

**‘Acting up’ behaviour**

Children might adopt disruptive or aggressive behaviours in an effort to cope with their feelings. This might also indicate a need for attention.

**Being the ‘good child’, a people pleaser**

Siblings may feel that they want to help make things better for parents who they see as being stressed, and so try to be the ‘good child’. Also, whilst siblings can gain much from helping to care for a brother or sister with disability or illness, some children throw themselves into caregiving, denying or ignoring their own needs. They can become used to always putting the needs of another before their own. This can be particularly unhealthy if the child has also adopted the role of ‘people pleaser’.

**Perfectionism, overachieving**

Siblings can feel a pressure to be perfect, in order to make up for the limitations of their brother or sister. They can develop an exaggerated fear of failure, of letting down their
parents. Their self worth can become totally dependent on their successes, which can increase the risk of depression in future years when they don't feel good enough.

**Anxiety, depression, low self-worth**

Some children will develop longer-term anxiety in response to the various stresses, fear or embarrassment. Siblings may learn very early that things can go wrong in life. They might see a brother or sister suffer and not feel hopeful things will improve. In terms of family activities they may feel powerless to change what happens. Young siblings might say things like, “my parents never come to see me play basketball”, “all they care about is my sister”, “I can’t do anything”. Some are at risk of developing a general feeling of hopelessness.

**Stomach aches, headaches, sleep problems**

Anxiety and depression can sometimes show up in physical complaints. Of course not all physical complaints are the result of stress, but they are signs to consider when thinking about the needs of siblings. Some siblings have developed eating disorders in adolescence.

**School, social difficulties**

If children start to struggle with school or friendships it might mean that they are experiencing isolation, teasing or a sense that ‘no-one understands’.

[taken from http://siblingsaustralia.org.au]
What Siblings Need

For siblings to grow up feeling strong and secure they need the following:

Information

Children need to know about the disability or illness and how it will affect their brother or sister and the whole family. This will prevent siblings developing unnecessary fears and worries about the disability or illness. It will also help them explain the disability to others. The level of detail can increase as children age. If the information is unclear or difficult to explain, professionals can help families with this.

Being involved

Children can be involved in discussions about family routines, the changes that might occur because of the disability, and the role each family member plays in creating a strong, caring family. This can add to their sense of value as contributing members of the family. Of course, not all children will want to be involved but they need to be allowed the opportunity.

Opportunities to express feelings

Being open about feelings – the good and not so good – helps children to cope. They can learn that it is ok to have a mix of feelings, that all brothers and sisters have mixed feelings from time to time. They can learn that it is okay to feel angry, sad, fearful, embarrassed, and that such feelings do not mean they do not love and care for their brother or sister. However, they need to know that not all behaviours are okay. They need help to cope with feelings in ways that do not harm themselves or others.
Skills to deal with difficult situations

Children cope better if they have the skills to deal with situations that arise. Sibling groups can help children feel stronger and more able to influence what happens around them. Other resources, like books and the internet, can also help.

A sense of being special too

Most children will understand the extra attention given to a child with disability if they are helped to feel important too. Parents, professionals or extended family/friends can all show interest in a sibling and help them to feel special.

Feeling valued

Assisting in the care of a child with disability and being appreciated can add to a sibling’s sense of competence and self-worth. They can feel especially important if they contribute in meaningful ways, e.g., teaching skills, helping to play; rather than just caregiving. However, it needs to be kept in balance.

Independence

Siblings need to develop some independence and social connection through spending time with peers doing a range of activities. At home, they need their own space and privacy.

Contact with other siblings

Siblings can share experiences with other siblings and learn they are not alone. Just as parents gain support from other parents, siblings also gain from this type of interaction.

A wide social network

A strong social network, including adults and children, gives siblings a sense of value. It also provides people to whom they can turn for support.

[taken from http://siblingsaustralia.org.au]
11 Tips to Reduce Your Child's Stress and Anxiety

1. *Encourage your child to face his/her fears, not run away from them.*

When we are afraid of situations we avoid them. However, avoidance of anxiety-provoking situations maintains the anxiety. Instead, if a child faces his or her fears, the child will learn that the anxiety reduces naturally on its own over time. The body cannot remain anxious for a very long period of time so there is a system in the body that calms the body down. Usually your anxiety will reduce within 20-45 minutes if you stay in the anxiety-provoking situation.

2. *Tell your child that it is okay to be imperfect.*

Often, we feel that it is necessary for our children to succeed in sports, school, and performance situations. But sometimes we forget that kids need to be kids. School becomes driven by grades, not by enjoyment of learning if an 85 is good, but not good enough. This is not to say that striving is not important. It is important to encourage your child to work hard but equally important to accept and embrace your child’s mistakes and imperfections.
3. **Focus on the positives.**

Many times, anxious and stressed children can get lost in negative thoughts and self-criticism. They may focus on how the glass is half empty instead of half-full and worry about future events. The more that you can focus on your child's positive attributes and the good aspects of a situation, the more that it will remind your child to focus on the positives.

4. **Schedule relaxing activities.**

Children need time to relax and be kids. Unfortunately, sometimes even fun activities, like sports, can become more about success than they are about fun. Instead, it is important to ensure that your child engages in play purely for the sake of fun. This may include scheduling time each day for your child to play with toys, play a game, play a sport (without it being competitive), doing yoga, paint, have a tea party, put on a play, or just be silly.

5. **Model approach behaviour, self-care, and positive thinking.**

Your child will do what you do. So, if you avoid anxiety-provoking situations, so will your child. If you face your fears, so will your child. If you take care of yourself and schedule time for your own needs, your child will learn that self-care is an important part of life. If you look for the positive in situations, so will your child. Children learn behaviours from watching their parents. So, when you think about your child’s psychological well-being think about your own as well.

6. **Reward your child's brave behaviours.**
If your child faces his or her fears, reward this with praise, a hug, or even something tangible like a sticker or a small treat. This is not bribery if you establish this as a motivator prior to your child being in the situation. If you reward behaviours your child will engage in them more often.

7. **Encourage good sleep hygiene.**

Set a bed time for your child and stick to that bed time even on weekends. Also have a 30-45 minute bed time routine that is done every night. This helps your child to transition from the activities of the day to the relaxed state necessary to fall asleep.

8. **Encourage your child to express his/her anxiety.**

If your child says that he or she is worried or scared, don’t say "No you’re not!" or "You’re fine." That doesn’t help your child. Instead, it is likely to make your child believe that you do not listen or do not understand him/her. Instead, validate your child’s experience by saying things like "Yes, you seem scared. What are you worried about?" Then discuss your child’s emotions and fears.

9. **Help your child to problem solve.**

Once you have validated your child’s emotions and demonstrated that you understand your child’s experience and are listening to what your child has to say, help your child to problem solve. This does not mean solving the problem for your child. It means helping your child to identify possible solutions. If your child can generate solutions, that is great. If not, generate
some potential solutions for your child and ask your child to pick the solution that he or she thinks would work best.

10. *Stay calm.*

Children look to their parents to determine how to react in situations. We’ve all seen a young child trip and fall and then look to their parent to see how to react. If the parent seems concerned, the child cries. This is because the child is looking to their parent for a signal of how to react to the situation. Children of all ages notice their parent’s emotions and resonate with them. If you are anxious, your child will notice that anxiety and experience an increase in his/her own anxiety. So, when you want to reduce your child’s anxiety, you must manage your own anxiety. This may mean deliberately slowing down your own speech, taking a few deep breaths to relax, and working to ensure that your facial expression conveys that you are calm.

11. *Practice relaxation exercises with your child.*

Sometimes basic relaxation exercises are necessary to help your child to reduce their stress and anxiety. This might mean telling your child to take a few slow, deep breaths (and you taking a few slow breaths with your child, so your child can match your pace). Or it might mean asking your child to image him or herself somewhere relaxing, like the beach or relaxing in a backyard hammock. Ask your child to close his/her eyes and imagine the sounds, smells, and sensations associated with the image.

[Handout adapted from https://www.psychologytoday.com]