

ABSTRACT

A SUPPORT GROUP FOR FAMILIES AND CAREGIVERS OF CHILDREN,
YOUTH, AND ADULTS WITH DEVELOPMENTAL DISABILITIES:

A GRANT PROPOSAL

By

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The purpose of this proposed program was to link with a local host agency, discover a potential funding source and write a grant in order to obtain funding for a support group for families of individuals with developmental disabilities (DD). Moreover, the purpose of the project was to provide funding for a family support group by partnering with South Central Los Angeles Regional Center (SCLARC). The program will be implemented at SCLARC, located in Los Angeles, California. The support group was designed to provide families with interventions, resources, and the skills needed to continue caring for family members with DDs in the best way possible without reaching burnout. A literature review was conducted to thoroughly study the impact DDs have on the affected individuals and their family members. Research demonstrates that there are numerous families in need of emotional, social, and educational support as it also suggests the need of interventions for families.

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YOUTH, AND ADULTS WITH DEVELOPMENTAL DISABILITIES:

A GRANT PROPOSAL

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TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS.....	iii
CHAPTER	
1. INTRODUCTION.....	1
Problem Statement	1
Purpose Statement	2
Multiculturalism	3
Social Work Relevance	3
Definition of Terms	4
2. LITERATURE REVIEW	5
Impact of Developmental Disabilities on Children	5
Impact of Developmental Disabilities on Families	7
Impact of Developmental Disabilities on Mothers.....	8
Impact of Developmental Disabilities on Fathers	11
Impact of Developmental Disabilities on Siblings.....	12
Impact of Developmental Disabilities on Grandparents	14
The Need for Family Support.....	17
The Value of Support Groups	20
Conclusion.....	22
3. METHODOLOGY	23
Strategies for Identifying and Selecting Potential Funding Sources	23
Criteria for Selection of the Grant	25
Description of Selected Funding Source	25
Target Population and Geographic Area	26
Description of Host Agency	27
Needs Assessment	28

CHAPTER	Page
4. GRANT PROPOSAL.....	30
Purpose of Proposed Program	30
Project Description	30
Program Goals and Objectives.....	32
Goal 1	32
Objectives.....	32
Goal 2	33
Objectives.....	33
Goal 3	33
Objectives.....	33
Program Schedule.....	33
Budget Narrative	37
Personnel Cost.....	38
Direct Program Cost.....	39
In-Kind Contributions	40
Indirect Costs.....	40
Program Evaluation	41
5. LESSONS LEARNED	42
Program Design.....	42
Identifying a Partner Agency	43
Identifying Potential Funding Sources	43
Budgeting	44
Grant Writing	45
Implications of Social Work Practice and Policy.....	45
Conclusion.....	46
APPENDIX: PROPOSED PROGRAM LINE ITEM COSTS	47
REFERENCES	49

CHAPTER 1

INTRODUCTION

Problem Statement

There are a number of children with different developmental disabilities (DD) in the United States. Developmental disabilities include autism spectrum disorder (ASD), cerebral palsy (CP), Down syndrome, epilepsy, fetal alcohol syndrome (FAS), fragile X syndrome (FXS), intellectual disability, attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), and seizure disorder; many of which are found in the majority of schools. Researchers from the Centers for Disease Control and Prevention (CDC; 2011) and the Health Resources and Services Administration (HRSA) found that 1 out of 6 children in the United States had a DD between 2006-2008. The CDC also found that the prevalence of children with developmental disabilities has increased over the last 12 years by 1.8 million. More than 3.5 million Americans live with an ASD (Ostrow, 2010). Autism Speaks (2014) found that 1 in every 68 children is being diagnosed with ASD and the prevalence is increasing.

Children with DD require special care to fit their unique needs: these needs may include medication, therapy, and particular skills that caregivers must have in order for these children to be successful to the best of their abilities. As a result, there are many families affected by the special attention their children and loved ones require. Parents as well as caregivers of children with DD are also in need of social support. The need of

support among families and caregivers of children with DD is not a new subject. Past research indicates that parents and caregivers of children with DD have a greater level of stress related to their children than parents of children without disabilities, therefore are in greater need of support (Dyson, 1997).

Past research further reinforces that support groups for parents and caregivers of children with special needs can improve family welfare by focusing on cognitive, emotional, and behavioral adjustment to their loved one's special condition (Barnett, Clements, Fialka , & Kaplan, 2003). When parents learn how to cope with their child's disability, outcomes of both family well-being and attachment security of the child can be greatly increased (Barnett et al., 2003). Similar results have been found by several researchers that indicate the continual need of support for families of individuals diagnosed with a DD (Wei et al., 2012; Yildirim, Hacıhasanoğlu Asilar, & Karakurt, 2013). Families of individuals with DD are in need of increased support and it is likely that they will continue to be in need of support and resources; therefore, they must be provided with the tools needed in order to cope with their loved one's life long disability.

Purpose Statement

The purpose of this project was to write a grant that will allow South Central Los Angeles Regional Center (SCLARC) to create a support group for families of children, adolescents, and adults with special needs. The proposed program will include the development of four groups. Each group will meet for 8 weeks and is designed to serve the families of the SCLARC consumers. This proposed support group is set to take place at SCLARC and will be facilitated by two bilingual (Spanish and English) social workers with a Master of Social Work degree (MSW). By bringing together families and

professionals, this support group will allow families to connect by sharing experiences as well as stories about their day to day living. Furthermore, education, practical tips, and skills about DD will be provided to participants, granting them encouragement and support. The program aims to help families to manage their stress and to support the positive development of their children with developmental disabilities.

Multiculturalism

DDs are reported to occur in all racial, ethnic, and socioeconomic groups (CDC, 2011). The CDC (2011) found that 1 in 63 White children were identified with ASD, 1 in 81 Black children were identified with ASD, 1 in 93 Hispanic children were identified with ASD, and 1 in 81 Asian or Pacific Islander children were identified with ASD. The proposed support group is designed to be conducted in English and Spanish given that consumers and families served by SCLARC reside in cities with a significant amount of Latino individuals (U.S. Census Bureau, 2013). According to SCLARC (2014), they served a total of 8,934 Hispanic families in the year of 2013; thus both English and Spanish resources will be offered as well as bilingual handouts. The bilingual resources will be distributed to the support group participants by a bilingual, bicultural social worker. In addition, the program is open to families of children with all types of DDs taking a multicultural approach considering the assets and needs of each family.

Social Work Relevance

As stated in the National Association of Social Workers (NASW; 2014) Code of Ethics, the primary mission of social workers is to magnify the well-being of all individuals especially the vulnerable, oppressed, and poor, through empowerment. Social workers must be educated about the existing DDs within diverse communities. The

number of children with DDs is alarming; therefore, social workers must understand the different DDs, as well as the needs of each, in order to provide services to this population. Social workers work in settings that involve families, thus they will likely encounter children within the DD population. This project aims to educate social workers about the needs and assets among the DD population and encourages them to work with this population.

Definition of Terms

The following are definitions of terms that will be frequently used throughout this project:

Caregiver: A person or family member that provides unpaid care for a loved one with chronic conditions and disabilities (Collins & Swartz, 2011).

Disability: A physical or mental impairment that limits a person's life activities (Matson, Mahan, & LoVullo, 2009).

CHAPTER 2

LITERATURE REVIEW

When a child is diagnosed with DD, family members are impacted in many ways. This literature review will cover the impact of DDs on affected children as well as their mothers, fathers, siblings, and grandparents. Furthermore, the need for family support and value of support groups for families are also discussed.

Impact of Developmental Disabilities on Children

A DD is defined as any mental disability or physical disability that establishes itself early in life and limits essential daily activities that include speaking, seeing, walking, breathing, or learning (Williams et al., 2010). Examples of DDs include ASD, CP, Down syndrome, epilepsy, FAS, FXS, intellectual disability, ADD, and ADHD, and seizure disorder. According to Matson et al. (2009), DDs impact many areas of individuals by impairing their well-being resulting in difficulties with their social skills, memory, and behavior. Other deficits include impaired motor skills as well as an inability to perform administrative activities such as brushing teeth or bathing (Matson et al., 2009). Individuals with DDs are unique because unlike the rest of the population, they have daily cognitive and emotional challenges. According to the U.S. Census Bureau, children with DDs constitute a significant fraction of all children (Reichman, Corman, & Noonan, 2008). For instance, 6% to 18% of all children in the United States have some type of DD (Reichman et al., 2008). Among the population of people with

DDs, males represent a larger portion of the total than females (Seligman & Darling, 2009).

With the enactment of the Americans with Disabilities Act of 1990, the Individuals with Disabilities Education Act of 1990, assistive technology, and de-institutionalization, individuals who are disabled or chronically ill now have the opportunity to live at home while being cared for (Reichman et al., 2008). They also have the opportunity to attend school with special allowances to meet their needs. For the enactment of these laws, many children with DDs require educational programs customized to their unique needs by developing a specific curriculum to meet their needs or altering an existing curriculum (Gargiulo, 2011). School districts differ in terms of quality of services they offer to children and adolescents with DDs (Reichman et al., 2008).

When entering adulthood, individuals with DDs have twice the mortality rate than the general population due to the impact of their DDs (Howlin & Moss, 2012). Considering all of the various factors that impact the lives of individuals with DD, another factor to consider is the effects on families because these effects have implications for the health and well-being of children with DDs as well (Reichman et al., 2008). According to Reichman et al. (2008) psychology studies demonstrate that a sizeable fraction of specific child health conditions, including DDs are closely connected with poor mental health outcomes of parents and siblings. This can mean that parents' poor mental health affects their children's prognosis.

Impact of Developmental Disabilities on Families

Many families report that having a child diagnosed with DD is a one of a kind experience that increases family members' inner strength, improves the family unit, and develops connections to religious institutions as well as community groups (Reichman et al., 2008). Along with the positive impact, a DD diagnosis can also adversely impact the lives, emotions and behaviors of mothers, fathers, siblings, and extended family members (Yildirim et al., 2013). Unfortunately, when many families learn about their child's diagnosis they have incredible difficulties sustaining family cohesion due to the presence of stressors developing as they are raising a child with special needs (Lee & Gardner, 2010). These difficult experiences result in negative effects on family members as well as family performance (Lee & Gardner, 2010).

For parents, having a child with DD increases stress and takes a toll on their mental and physical health (Reichman et al., 2008). Reichman et al. (2008) state that caring for a child with a DD affects parents' work decision-making as well as their education because of the special attention their child requires from them. In addition, parents' decision to have additional children is also impacted by the fact that they have a child with DD to care for (Reichman et al., 2008). Lindley and Mark (2010) state that some families of lower socioeconomic status experience financial burden due to a reduction of work hours or unemployment in order to care for a child with DD. For other families, financial resources decrease as they may result in them acquiring loans, utilizing their savings, selling assets, and even seeking additional employment in order to cover the necessary cost of having a child with special needs (Lindley & Mark, 2010). Parents also worry about stigma due to public experiences where others display intolerance,

carelessness, and criticism toward their child's DD (O'Connell, O'Halloran, & Doddy, 2013). Reichman et al. (2008) state that parents of children with DD have lower rates of social participation when compared with parents of children without DD. Parents of children with CP have reported to frequently feel a lack of support from the services they access (Wei et al., 2012). Seymour, Wood, Giallo, and Jellett (2013) found that parents of children with ASD reported feeling constant fatigue, anxiety, stress, and depression. Furthermore, this study revealed that children's behavior problems greatly increase parents' fatigue that leads to high levels of stress (Seymour et al., 2013). In a study conducted by Ergun and Ertem (2012), parents of disabled children reported feeling sad, angry, lonely, and guilty over their children's disabilities. Interestingly, parents of children with ASD experience greater stress levels than parents of children with other DDs (Dabrowska & Pisula, 2010).

Impact of Developmental Disabilities on Mothers

Mothers of children with DD report that their child's diagnosis does not imply in all a negative connotation as their child's diagnosis have positive outcomes such as feeling blessed and bringing their family together (Levine, 2009). However, Phetrasuwan and Miles (2009) studied the psychological well-being of 108 mothers of children with ASD and found that mothers also report parenting stress that connects them to depressive symptoms. They also found their depressive symptoms lead them to low levels of well-being. Phetrasuwan and Miles further identified that the highest sources of parenting stress in mothers emerge from managing their child's demanding behaviors as well as properly disciplining them. Other day-to-day stressors include when mothers experience difficulties making the time to take care of their own needs, balancing the needs of other

family members, and dealing with differences of opinions in regards to the care of their child with their spouses (Phetrasuwan & Miles, 2009).

Nevertheless, feelings of guilt rise in mothers for having a child with a DD when they blame themselves for their child's conditions and find themselves searching within their lifestyle for answers of what they might have done wrong during their pregnancy (O'Connell et al., 2013). In addition, mothers report being blamed by their in-laws for their child's disabilities (Ergun & Ertem, 2012). Unfortunately, some mothers of children with DDs are disabled themselves as reported by Ellen Scott (2010) who conducted open-ended, in-depth interviews with a total of 40 families of children with diverse DDs and discovered that some mothers have severe medical conditions that make it extremely difficult for them to care for their children's special needs. In addition, mothers of young children with developmental delays have poorer existing and later psychological health than mothers of children with typical development (Eisenhower, Baker, & Blacher, 2009)

It is vital to understand that when women mother children with DD, many areas of their lives change. Many mothers of individuals with DDs struggle to handle the demands of family and employment (E. Lee & Oh, 2009; Scott, 2010). The majority of mothers of individuals with DDs find it extremely difficult to manage the high demands of care work and wage work, often resulting in reduction of labor hours and even employment termination. This creates a great distress in their motherly role because they feel obligated to change their labor lives to the extent that they feel they are the ones who are disabled (E. Lee & Oh, 2009; Scott, 2010). Mothers also make sacrifices by giving up their life goals and dreams in order to care for their children with DD (Scott, 2010).

According to Scott (2010) mothers with a higher education experience a greater distress in changes in their labor force trajectories than mothers who have lower education levels. Scott further notes that mothers of children with DD experience several feelings of loss such as the loss of themselves as responsible, capable, as well as efficient workers.

Mothers of individuals with DDs often become advocates for the future well-being of their children by becoming more involved with their service providers (Peters & Jackson, 2009). Lloyd and Hastings (2009) analyzed 138 mothers and 58 fathers of children with intellectual disabilities via questionnaires in order to measure their hope toward their disabled children's life goals and found that mothers have higher levels of depression, anxiety, and stress, when compared to fathers as well as lower levels of hope. This finding may be due to the fact that the majority of mothers are the child's primary caregivers suggesting they spend more time with the child therefore, they may experience the child's challenging behavior more often. Another study conducted to examine stress in mothers and fathers of children with DDs, particularly focusing on ASD and Down syndrome, found that mothers of children diagnosed with ASD had higher levels of parental stress than fathers (Dabrowska & Pisula, 2010).

Additional challenges present themselves in the lives of single mothers who have children with DD. Kathryn Levine (2009) conducted a study by interviewing 15 single mothers of children diagnosed with a DD as a means to thoroughly explore women experiences as single-parents of children with disabilities. Levine discovered that single mothers find themselves in the position of being the sole responsible parent of their child. Levine further explains that single mothers of children with DD report not only feeling stigmatized for having a child with DD but stigmatized for being single mothers in

society. Furthermore, within their narrative reporting, single mothers emphasize how society tends to have negative perspectives of single mothers by stereotyping them to be educationally as well as financially disadvantaged and welfare-dependent (Levine, 2009). According to Scott (2010) when comparing single mothers with married mothers, single mothers encounter more barriers in the labor work force as they report extensive periods in which they struggled to sustain employment while caring for their children with DD. Single mothers are the only financial providers for their families, as they do not have the financial support from a partner (Scott, 2010). It is important to note that there is a lack of attention given to single mothers of children with DDs and there is little support for single mothers within existing interventions that are offered and available for parents of children with DDs (Levine, 2009).

Impact of Developmental Disabilities on Fathers

In addition to single mothers, according to MacDonald and Hastings (2010), fathers of individuals with DD are a group that is neglected in terms of DD and family research. MacDonald and Hastings conducted a study of 105 fathers of children with DD aiming to measure parental involvement. They discovered that working fathers are less involved in their child's daily caregiving and child-related parenting tasks; however, they are most likely involved in roles connected to child socialization as well as child-related parenting tasks (MacDonald & Hastings, 2010). Dabrowska and Pisula (2010) found that paternal stress of having a child with DD is related to their child's group status particularly on stigmatization and social attitudes toward their child with DD. MacDonald and Hastings support Dabrowska and Pisula by adding that fathers worry about stigma and are less likely to report these feelings when compared to mothers.

MacDonald and Hastings further noted that when fathers have a child diagnosed with a DD, their stage of fatherhood is impacted as unexpected feelings, experiences, and relationships emerge. As father involvement is vital for children's development, there is a high demand for interventions in order to enhance father involvement with their children (MacDonald & Hastings, 2010). As MacDonald and Hasting state that there is limited information on fathers of children with DD, social science research is necessary in order for professionals to fully understand the feelings and needs of fathers of children with DDs.

Impact of Developmental Disabilities on Siblings

Besides parents, siblings of individuals with DDs are affected as well. Siblings of individuals with DDs are a population whose lives are greatly impacted by the challenges that DD encompasses. Different study findings state various direct effects of typical developing siblings living at home with brothers or sisters with DDs (Bowie, 2012; Williams et al., 2010). Moreover, these studies have also reported close sibling relationships that exist within the dynamics of families with children with DDs. For instance, Bowie (2012) is a teenage sibling of an adolescent with a number of DDs, who wrote his perspective of having a brother with disabilities. Bowie expresses the joy of having a sibling who is different from the rest of the population as well as how proud he feels for assisting his brother with his special needs. Bowie's sibling perspective is common in many siblings as Gallagher, Kresak, and Rhodes (2010) support Bowie's perspective by providing testimonies of 20 grandmothers, in a study conducted to explore the perceptions of grandmothers regarding their needs and supports when providing care for their disabled grandchildren. When asked about their typically developed

grandchildren, grandmothers shared that siblings of children with DDs often love to overly assist their siblings to the extent that they do tasks for them. Williams et al. (2010) conducted a study on 151 parents of typically developed siblings of children and adults with DDs. In their study, Williams et al. analyzed parent responses to open-ended questions about the effects of having a child DD diagnosis. Many positive effects were found for siblings of children with DD. Positive effects include family closeness, personal maturation, and high sensitivity to the ill child (Williams et al., 2010).

On the other hand, having a sibling with a DD can be stressful, unleashing negative effects in typical developing siblings. Williams et al. (2010) found negative impacts on the emotional, mental, and physical well-being of typical developing children who have a sibling with special needs. In many cases, a great responsibility was given to these siblings as parents transformed them in to caregivers (Williams et al., 2010). Williams et al. further stated that typical developing siblings of children with DD display negative manifestations that include anger, misbehaviors, depression, jealousy, embarrassment, fear, low self-esteem, guilt, unsympathetic, and competitive behaviors. Reasons for such behavior include feeling neglected by their parents, and frustration as well as feeling overwhelmed with their sibling's diagnosis because they do not understand the scope of their sibling's disability. For example, parents report that their typical developing children seek attention inappropriately by whining, crying, and misbehaving. The negative impact continues when typical developing children begin to notice the reaction of their peers towards their siblings' DD and soon after siblings begin to worry about stigma (Bowie, 2012; Williams et al., 2010).

In addition, the impact of DD on typical developing siblings has been found to be associated with parent report of sibling deviant behavior, parental distress, and an overall impact of the child's DD on the family (Kao, Plante, & Lobato, 2009). When examining the impact of a child's DD in families, Kao et al. (2009) found the impact of the child's DD was related to behavior problems in healthy siblings. For example, typical developing siblings of children with ASD display social isolation due to feeling sad over their siblings' special conditions. This isolation results in difficulties for typical developing siblings to build peer relationships (Howlin & Moss, 2012). Furthermore, typical developing siblings sometimes fight and bully their sibling with DD (Gallagher et al., 2010). According to Reichman et al. (2008) a recent meta-analysis signifies that cognitive development and peer activities achievements are lower for siblings of children with long life disabilities. Thus, there is a need for resources that reduce negative impacts and build positive attributes for typical developing siblings of individuals with DD (Kao et al., 2009).

Impact of Developmental Disabilities on Grandparents

Grandparents are a fairly new and emerging population who are called upon to care for grandchildren with chronic developmental and emotional disabilities when their parents are unable to care for them (McCallion & Janicki, 2014). Grandparents are a source of support for families of children with special needs. Like parents, when grandparents learn about their grandchildren's diagnosis, their reactions include emotional shock, anger, and grief (M. Lee & Garner, 2010). The literature indicates that many children with DD are being cared full time by their grandparents because of family violence, abandonment, death or incarceration of a parent, and parents' inability to care

for their children due to having their own physical or cognitive impairments (Gallagher et al., 2010). Grandparents are gradually becoming more involved in the lives of children with DD and playing a role that influences the entire family (M. Lee & Garner, 2010). A study conducted with five grandfathers and 17 grandmothers currently providing care for grandchildren with special needs, found that grandparents describe their experience of having a grandchild with a DD, as an emotional roller coaster however, prideful about their family's resiliency (Miller, Buys, & Woodbridge, 2012). In this same study, grandparents expressed that they find it challenging to raise children that are unable to take care of their needs.

Gallagher et al. (2010) state that grandparents worry about their grandchildren's behaviors, tasks, and education; therefore, many grandparents have now become advocates for their grandchildren as they are involved in their education by participating in their Individualized Education Plans (IEP). Grandparent's concerns about their grandchildren are present when they think about their futures; therefore, they request to be informed of the things they have to do in order to best assist their grandchildren to prepare for their future (Gallagher et al., 2010). The concerns about their grandchildren raises a mixture of feelings such as anger, happiness, and disbelief however, grandparents choose to purposely hide their feelings in order to provide their grandchildren and families with strength (Miller et al., 2012). The experience of caring for a grandchild with DD also results in physical exhaustion for grandparents (Gallagher et al., 2010).

The personal lives of grandparents are also impacted by their self-sacrifice. Studies show (Gallagher et al., 2010; Miller et al., 2012) that grandparents of children with DD often delay life goals while other grandparents either postponed retirement

plans, postponed vacations, retire early, relocate, or put personal dreams on hold. Grandparents' lives also become impacted when they begin to have marital problems as well as family conflict due to the amount of time and effort given to their grandchildren with DD. For example, a study conducted to examine the impact of disabilities on families from grandparents' perspectives (Miller et al., 2012) revealed that tensions are developed within their spouses due to disagreements about the extent to which they should place their own life aspirations and dreams on hold in order to provide support for their families. Also, a trigger for family conflict takes place when other family members feel neglected by the amount of time grandparents spend with the child with DD and their immediate family. Miller et al. (2012) also state that grandparents express that tension builds in families when other grandchildren become angry, possessive, and jealous on how much attention as well as time is being spent with the child with DD. In addition, adult children feel jealous as well which have grandparents feeling as if they are being pressured to choose between their own families (Miller et al., 2012).

On a more positive theme, grandparents express feeling great assisting their grandchildren with their needs, especially when they are provided with social support and professional knowledge on how to best assist their needs. Witnessing improvements in their grandchildren once they have implemented knowledge attain, provides grandparents with happiness and strength (Gallagher et al., 2010). Grandparents also stated that other family members are supportive and helpful toward caring for the child with DD (Gallagher et al., 2010). Miller et al. (2012) state that grandparents play a central role in families lives by supporting their adult children with caring for their grandchildren with DDs. The literature indicates that grandparents' involvement and support to their

families of children with special needs is highly likely to increase the family resiliency and cohesion (M. Lee & Garner, 2010). Based on the available research, it is necessary to acquire a clear understanding of grandparents' involvement in the lives of children with DD as well as further understand how their roles impact the lives of families of children with DD (M. Lee & Garner, 2010).

The Need for Family Support

Greeff and Nolting (2013) suggest that there is a need for greater attention as well as support to be offered to families of children who have been diagnosed with a DD. Furthermore, Greeff and Nolting indicate that families of children with DD must develop good communication patterns, a commitment towards the family unit, and an optimistic approach toward the upcoming challenges that will be present as their child with DD physically and emotionally develops throughout life. The mental health of parents of disabled children is a current problem requiring psychological and emotional support. Additionally, parents must be provided with education as well as guidance in order for them to overcome their negative feelings and the problems that rise following their feelings (Ergun & Ertem, 2012).

In addition to their mental state due to day-to-day challenges, many parents worry about their child's future very much as they fear the years to come when their children become adults with disabilities. Adding to this stress, are the thoughts of their own absence when they will not be present to advocate and provide care for their disabled children, leaving them behind alone in a world where they would not know what support will be available for them (O'Connell et al., 2013). These findings urge government and service providers to support parents as well as other caregivers by assisting them in

proactively planning for the future of their disabled love ones in their absence (McConkey, Truesdale-Kennedy, Taggart, & Ryan, 2012). Families can be provided with support on how to adapt with their child's diagnosis by being assisted on establishing future goals that meet their family objectives (Greeff & Nolting, 2013).

The needs of children with DD are many and are viewed from the medical stand point as a personal tragedy while on the other hand; the social model views it as a social problem and proposes social change as a solution (Seligman & Darling, 2009). This social change demands offering families of individuals with DDs services that will encourage, support, and provide them with training to enhance their participation in their children's education as well as to positively affect their children's growth and development (Yildirim et al., 2013). Because young adults with DD are more likely to live in poverty, be unemployed, remain at home instead of attending social functions, and are three times more likely to be abuse or neglected in relation to children without DDs (Seligman & Darling, 2009), parents should be educated on such factual information. Experts suggest that parents and caregivers of children with a disability should be provided with psycho-education about coping with stress and fatigue as well as the impact on their wellbeing (Seymour et al., 2013). A similar study states that these families would benefit from interventions to advise them on how to cope with the various demands of raising a child with DD (Kao et al., 2009). In addition to psycho-education, Lloyd and Hastings (2009) suggest that hope, a feature of positive psychology, is a potential variable that can be integrated in interventions to help intensify the well-being of families with children with intellectual disabilities. Lloyd and Hastings state that

positive thinking is key for psychological well-being for parents raising children with special needs.

In addition to implementing positive thinking in to family interventions, families should also be provided with quality education on their family member's diagnosis. Families that are capable of making meaning of as well as accepting their challenging situation of having a child with a DD, adapt to the diagnosis in a healthier and better way than those families who are not able to do so (Greeff & Nolting, 2013). Because reacting empathically to the needs of children with DD requires emotion regulation, close attention, and cognitive adjustability on the families' part, services that concentrate on these specific abilities can serve a vital function. Over a two-year period, Prinz, Sanders, Shapiro, Whitaker, & Lutzker (2009) conducted a study on families of children with DDs, from 18 counties who participated in a Positive Parenting Program (Triple P) intervention. Prinz et al. (2009) found that this intervention demonstrated preventive impact on child maltreatment because parents were taught skills on how to ensure a safe and engaging environment for their children, promote a positive learning environment, use of assertive discipline, maintain reasonable expectations, and parental self care. Banach, Conway, Ludice, and Couse (2010) measured the effects of a six-session support group for 11 families of newly diagnosed children with ASD. Banach et al.'s (2010) study focused on advocacy skills and self-efficiency of parents coping with their child's diagnosis and found significant increases in family empowerment.

When focusing on grandparents, studies demonstrate (Gallagher et al., 2010; Miller et al., 2012) that grandparents express support needs from social service agencies, community services, and schools in order to understand their grandchildren's DDs. Like

parents, grandparents raising grandchildren with disabilities also have needs such as respite needs, informational needs on how to handle certain behaviors, and language difficulties that may be associated with the disability (Gallagher et al., 2010). As for single mothers of children with DD, it has been learned that single mothers receive little attention because the primary focus of social science research is on two-parent families (Levine, 2009). According to Levine (2009), family resilience increases when professionals work toward providing adequate resources within the existing system to facilitate development for single mother families. Nevertheless, siblings are another population that is in need of attention. There is a great demand to include siblings when assessing families with a child with DD as there are only a few measures that focus on sibling's psychological adjustment to DD (Kao et al., 2009).

The Value of Support Groups

Experts suggest that parents and caregivers of children with a disability should be provided with psycho-education about coping with stress and fatigue as well as the impact on their wellbeing (Seymour et al., 2013). Kao et al. (2009) stated that these families would benefit from interventions to advise them on how to cope with the various demands of raising a child with DD. Wei et al. (2012) conducted a study to examine the efficiency of support groups for families caring for family members with intellectual disabilities. Wei et al. reported improvement on physical-psychological health and social support in 12 participants, after participating in an intervention. Wei et al. found an improvement of somatic, anxiety, and depressive symptoms after a four-week follow-up observation. This study demonstrates that providing families of children with DDs with social support will overall improve their quality of life.

Greeff and Nolting (2013) found families who openly communicate about their situation with service providers and other people, adjust more positively than those families that do not communicate their situations to others. As a result, support group interventions are effective for improving the physical-psychological health status and social support of parents and caregivers of people with DDs (Wei et al., 2012). In a study conducted in Australia where 64 families of toddlers with DD were sampled, the researchers found that family experience with professional support is a strong predictor of family quality of life (Davis, & Gavidia-Payne, 2009). Future planning and goal setting for a child with special needs can be achieved by educating families about their child's DD and through discussions with professionals as well as other families experiencing similar situations (Greeff & Nolting, 2013).

Literature demonstrates (Hwang & Kearney, 2014) that the integration of mindfulness training in to support groups may be beneficial for parental and professional caregivers of children with DD because the practice of mindfulness has confirmed positive changes on the providers and the recipients of care. Such demonstration is based on a study conducted by Hwang and Kearney (2014) who examined three mothers of children with different DDs that participated in a 12 session mindfulness- Based Stress Reduction (MBSR) program for caregivers of children with chronic illnesses. This study aimed to observe if parenting influenced by mindfulness practice decreases disobedience, violence, and self-harming behavior of children. Upon completion of the training participating mothers were advised to apply the gained knowledge for over 52 weeks within their interactions with their children. A 70-88% decrease of disobedience, violence, and self-injury of their children was found (Hwang & Kearney, 2014). Based

on the positive evidence that mindfulness training provides, it can be assumed that training families of children with DDs mindfulness, may build them with knowledge such as stress management and skills that can be applied when caring for a child with DD.

In addition to mindfulness trainings, empowering families of children with DDs with hope may also be beneficial for caregivers and recipients. Lloyd and Hastings (2009) examined hope within parents of children diagnosed with intellectual disabilities and found that parents who have feelings of hope have increased well-being and decreased their psychological distress. Hope implementation in a support group of families of individuals with DD may as well decrease the psychological distress of the caregivers and increase their well-being as Lloyd and Hastings (2009) discovered positive outcomes for parents of children with intellectual disabilities.

Conclusion

A DD diagnoses is a life changing experience for the affected children and their families as it impacts the lives of every family member. The challenges that DD comprises are many and affect each member of the family in a unique way. Individuals with DD need patience as well as special attention in order to develop in a healthy manner and reach their full potential in order to perform tasks to the best of their abilities. Success for a person with DD cannot be reached in isolation; therefore, individuals with DDs need the assistance of their families and professionals. As DD encompasses many challenging factors, families must be supported to care for their loved one with DD in different ways including emotionally, physically, and psychologically. Thus, families need the assistance from professionals through support groups in order to meet the needs of their family member with DD and learn how to cope with a DD diagnoses.

CHAPTER 3

METHODOLOGY

Strategies for Identifying and Selecting Potential Funding Sources

The process of pursuing grant writing was initiated by setting up a meeting with Maura McGinnis Gibney, MSW, Family Resource Center Program Manager at SCLARC. Criteria for the project was identified during this initial meeting in order to further learn about SCLARC. This information was used to begin identifying and appropriate funding source. Ms. Gibney also suggested The John Gogian Family Foundation (JGFF), which met the program criteria; however, the funding available was limited.

The funding sources taken into consideration for this project were explored through several websites including Google, Google Scholar, and www.grants.gov. The search involved keywords such as *developmental disabilities grants*, *caregiver funding*, and *family support group grants*. Google and Google Scholar resulted in different websites with over 1,400,000 results. After exploring a variety of websites related to the topic, the majority were not applicable to the project because the grants did not cover the program's estimated amount funding needed (\$150,000). The majority of the available grants that were found only offered the amounts of \$2,500 to \$75,000. For example, the Health Corporation of America Foundation (HCA) was found and met the target population's needs yet it did not meet the estimated project amount needed. It was also

difficult to find grants that funded the target location for the program. Therefore, results found in Google and Google Scholar were eliminated as possible sources.

The next Internet source searched was www.grants.gov, a database for agencies to post different funding opportunities and for those who are searching for grants to locate funding sources. Keyword terms utilized for searches included *developmental disabilities*, *parent support groups*, and *grants for developmental disabilities*. In this online source there were over 200 grants found and many met the proposed grant amount of \$150,000. A diversity of agencies that fund programs serving the DD population was accessed; however, their funding requirements did not comply with the host agency's policies. For instance, Centers of Disease Control and Prevention (CDC) was a potential candidate because it provides grants for agencies that serve individuals with disabilities. However, the program's partner agency did not meet CDC's criteria because the CDC only targets agencies that are willing to participate in surveillance monitoring for developmental disabilities. This meant that the program's partner agency would need to allow the CDC access to their consumer's medical and educational centers. The partner agency was not interested in providing consumer information to external agencies at this time.

After searching different databases that lead to grants such as CDC and HCA Foundations, the Department of Education's Rehabilitation Research and Training Centers (RRTC) grant was found. RRTC met the program's requirement; however, limited information was learned because there were difficulties accessing the grant application therefore, there was uncertainty about full eligibility. After carefully

thoroughly navigating www.grants.gov, the grant application was finally accessed. Once the application's full eligibility information was reviewed, the RRTC grant was chosen.

Criteria for Selection of the Grant

The Department of Education's RRTC was found to be the most appropriate for the project because it meets the target population's needs. RRTC also meets the project's criteria and proposed grant amount. The purpose of RRTCs is to assist individuals with different disabilities as well as to assist their families in achieving their goals and improve the effectiveness of services available for them. RRTCs develop activities based on well-designed research, for the disabled population, policy makers, and other research stakeholders. RRTC funds agencies that provide services to the target population. Furthermore, RRCT provides the grant amount of \$150,000 that is needed to develop the proposed program. The grant's mission serves the proposed program's development of supporting the disabled population as well as their families via support groups. In addition, it funds agencies that are non-profit organizations such as the proposed program's partner agency, SCLARC.

Description of Selected Funding Source

Funded by the National Institute on Disability and Rehabilitation Center (NIDRR) in the year of 2004, RRTC serves under the Rehabilitation Act of 1973 in order to carry out coordinated advance programs of rehabilitation research, provide training as well as technical assistance to individuals with disabilities, their representatives, providers, and other interested parties. NIDRR intends RRTC's work to inform the design, application, and enhancement of Federal as well as State policies and programs related to helping families in support, assistance, and nurturing family members of individuals with

disabilities. Furthermore, RRTC plans and conducts research trainings, demonstration projects to develop methods as well as procedures, and rehabilitation technology. This is done to maximize the full integration and inclusion into society, independent living, employment, family support, and economic as well as social self-sufficiency of individuals with disabilities. RRTC is staffed with an experienced team of collaborators that represent a variety of disciplines such as special education, survey research, epidemiology, vocational rehabilitation counseling (VR), and economics (Disability Statistics and Demographics Rehabilitation and Training Center, 2014).

Once a year, RRTC invites applications from grant seekers who serve the population with disabilities. They provide one award in the amount of \$875,000 for a single budget period of one year for the RRCT family support. The application can be accessed via the Internet and can also be requested from the U.S. Department of Education. The application package requests that grant seekers provide narrative information such as the overview of the project, including its goals and objectives, as well as a list of proposed project staff. The application may be submitted online, by mail, or hand delivery. Once the application is submitted, an automated response will be sent in order to acknowledge its receipt.

Target Population and Geographic Area

The target population for this proposed program is 120 families who are being serviced by SCLARC and who are currently performing the role of a caregiver to a loved one with DD. These individuals must reside in Los Angeles County. According to the U.S. Census Bureau (2013), there are a total of 10,017,068 diverse individuals residing in Los Angeles County. The general population for the County of Los Angeles consists of

71.6% Caucasian/White, 48.2% Hispanic/Latino, 14.5% Asian, 9.3% African American/Black, and 9.3% American Indian and Alaskan Indian (U.S. Census Bureau, 2013). In 2013, SCLARC served approximately 11,700 individuals with DD (SCLARC, 2014). The specific cities where the target population resides according to SCLARC (2014) are Huntington Park, Maywood, Bell, Bell Gardens, Downey, Paramount, Compton, Carson, and South Gate as well as the Los Angeles communities of Watts, the Crenshaw District, Hyde Park, Leimert Park, View Park, and Baldwin Hills.

Description of Host Agency

The host agency for this project is the South Central Los Angeles Regional Center (SCLARC, 2014). The Lanterman Developmental Services Act of 1966 established the Regional Center System in order to apply its policies concerning citizens diagnosed with DDs. SCLARC is a private non-profit, community based organization that contracts with the State Department of Developmental Services to coordinate services for individuals with DD of all ages and their families. Throughout California, there are 21 regional centers serving individuals with DD by assisting them at no cost with services such as intakes, assessments, diagnosis, counseling, advocacy, early intervention services, purchase of necessary services, family support, out-of-home care, training and community education. Each Regional Center serves its own geographic area with five Los Angeles County Districts that includes Compton, San Antonio, Southeast, and Southwest. According to SCLARC (2014) cities they serve include Huntington Park, Maywood, Bell, Bell Gardens, Downey, Paramount, Compton, Carson, and South Gate as well as the Los Angeles communities of Watts, the Crenshaw District, Hyde Park, Leimert Park, View Park, and Baldwin Hills. SCLARC believes that individuals with

special needs deserve to live the highest quality life achievable in their communities (SCLARC, 2014). The DDs that SCLARC services include intellectual disability, cerebral palsy, autism, and other similar disabilities. Lastly, SCLARC is committed to provide cultural sensitive services that enhance the strengths within the families as well as to enable consumers to live independent and productive lives (SCLARC, 2014).

Needs Assessment

The need for family support services was based on personal connection to the partner agency as well as literature that indicates the importance of providing social support for families of children with DDs. Close communication was maintained with the SCLARC Family Resource Center manager, Maura McGinnis Gibney, MSW, to ensure that the program met the needs of the target population at SCLARC. Google Scholar and the California State University, Long Beach Library was also utilized as the main sources to obtain recent publicized literature on assets in the DD population. Words such as *developmental disabilities*, *support group*, *special needs*, and *families with disabilities*, were utilized in the search engines. Through this process, it was learned that families caring for a children with DDs experience enjoyment, however, they also face significant challenges that may affect the well-being of the affected child as well as the well-being of entire family (Resch, Mireles, Benz, Grenwelge, & Peterson, 2010). Different studies (Dabrowska & Pisula, 2010; Ergun & Ertem, 2012; Yildirim et al., 2013) demonstrate that these challenges create high levels of stress in families that negatively impact each family member's emotions and behaviors. For this reason, families are in great need of social support, education on DDs, and information about

available resources. The information was gathered for the development and implementation of the proposed program.

CHAPTER 4

GRANT PROPOSAL

Purpose of Proposed Program

The purpose of this proposed program is to educate and support families of individuals with DD. Moreover, the purpose of the project is to provide funding for a family support group by partnering with SCLARC. The program will be implemented at SCLARC, located in Los Angeles, CA. The support group will be designed to provide families with interventions, resources, and the skills needed to continue caring for family members with DDs in the best way possible without reaching burnout. Research demonstrates that there are numerous families in need of emotional, social, and educational support as it also suggest the need of interventions for families (Ergun & Ertem, 2012; Greeff & Nolting, 2013; Kao et al., 2009).

Project Description

The proposed program is designed to provide a weekly support group that will meet once a week for eight weeks, available for the families of the SCLARC consumers. The support group will repeat four times throughout one year. The program will take place at SCLARC located in Los Angeles, CA. According to SCLARC (2014), their agency is currently serving over 12,500 people who have been diagnosed with a DD. The high number of SCLARC consumers, demonstrate a significant number of families that can potentially participate in the support group.

Potential participants for the program will be recruited through the SCLARC roster, outreaching families of all socio-economic, racial, and ethnic backgrounds. The program coordinator will contact families via telephone as well as mail flyers with the program's overview. The program's overview information will also be posted on SCLARC website as part of the recruitment process.

This program consists of a closed group in order to provide all participants with the same information as well as to avoid group disruption that may change group dynamics. For this reason, new members may not join the group after the first session however; interested families can join the next group session. A total of eight sessions will be offered in English and Spanish, and provided four times throughout a one-year period to families who are currently providing care for a SCLARC consumer. A maximum of two family members per SCLARC consumer will be allowed to enroll in the group. A total of 30 members will be enrolled per session. Sessions will take place once a week, lasting a total of two hours per session. Sessions will take place from 7:00pm to 9:00pm in order to provide working parents with an equal opportunity to attend the group. Transportation will be facilitated for families that need assistance transporting to SCLARC. Bus vouchers or gas gift cards will be provided to each participating family. In addition, food and refreshments will be provided during each session. Two full-time bilingual, social workers (MSW), will facilitate the support group. Each facilitator must have an in-depth understanding of DDs as well as a working knowledge of family dynamics and the essential needs of families caring for individuals with DDs. In addition, the MSWs will have the training and skills to create emotional as well as practical support in order to reduce stress and help the participants to develop

constructive coping strategies. Sessions will include different topics to address the needs of families of individuals diagnosed with DDs. Topics include education, skills, resources, and interventions needed. The program will also have a part-time bilingual caregiver that will provide care for the participant's family member with DD during session if needed. The caregiver must have a thorough understanding on DDs and a two-year experience working with the DD population. Lastly, the program will also have a volunteer that will assist the social workers with the groups for the one-year period. The volunteer must be a family member of an individual with DD who is currently a SCLARC consumer.

Each session will be divided into two parts: the first hour of the session the group facilitator will teach the participants skills, interventions, and provide a variety of resources for them and their family member with DD and the second hour will be an open forum in order for families to make connections to the topic covered and discuss experienced challenges and successes.

Program Goals and Objectives

The following program goals and objectives have been established to ensure the effectiveness of the program:

Goal 1

Increase families' knowledge about individuals with developmental disabilities.

Objectives

Provide participants with detailed information on DDs and what to expect over the course of the program.

Educate participants in the proposed program about the impact of DDs on different family members.

Inform participants about general mental health concerns.

Goal 2

Increase awareness of resources available for individuals with DDs and their families.

Objectives

Provide detailed information on local resources available for individuals with DDs and their families.

Educate families about advocate skills for themselves and their family member with DD.

Provide families with a resource guide on diverse services available for their families.

Goal 3

Increase the social network among families of children with DD.

Objectives

Create a safe space for families in the program to interact with one another.

Teach skills on how to explore the internet in order to search for resources.

Inform families about self care and teach relaxation techniques.

Program Schedule

Participants will be provided with an outline detailing group topics. Listed below are the different session topics included in the program.

Session 1: The focus on the first session will be on participants introducing themselves and sharing their story with the intention to build group cohesiveness. Participants will be given with the opportunity to share challenges as well as successes among each other.

Session 2: Participants will learn about DDs and their impact on individuals. The social worker will guide discussion by providing detail information on DDs and what to expect from DDs at different ages. Time will be provided for participants to ask questions.

Session 3: Social worker will provide detail information about the impact of DDs in different family members. Participants will have the opportunity to share their family experience such as challenges and successes due to the diagnosis. In addition, time will be provided for participants to ask questions.

Session 4: The social worker will provide participants with an overview of common mental health diagnosis on family members caring for a family member with DD. The social worker will teach interventions needed to cope with caring for a family member with DD to avoid burn out. Participants will have the opportunity to discuss their own mental health in relation to caring for their family member with DD.

Session 5: Participants will have an open forum to explore types of support needed. Participants will brain storm topics as the social worker makes note of them in order to create a resource guide that will be given to all participants at the very last session.

Session 6: The social worker will inform participants of resources available for individuals with DDs and their families. Information on school's Individualized

Education Plans will be provided. The social worker will be responsible to create a resource booklet that will be given to all participants at the very last session.

Session 7: The social worker will teach participants skills on how to network. Furthermore, the Social Worker will demonstrate how to search the web for resources and will provide key terms for search engines. Participants will learn how to find resources themselves.

Session 8: The social worker will encourage participants to share their experience on attending the group. In addition, self care and relaxation techniques will be taught. A potluck will take place and prizes will be raffled. Participants will receive a certificate of completion and a gift.

It will take approximately 12 months to complete the program.

Months 1-2:

Hire two full-time bilingual Licensed Social Workers.

Purchase supplies and equipment needed to conduct program.

Topics will be developed, planned, and scheduled.

Create flyers with an overview of the support group along with dates and times.

Recruit volunteer that will assist social worker with groups.

Create pre and post surveys to monitor group progress

Month 3:

Recruit participants for support group 1.

Develop group guidelines and policies

Develop group ground rules

Conduct reminder calls for group 1 participants

Month 4:

Support group 1 begins

Groups will meet weekly for 8 weeks

Administer pre survey and measures

Month 5:

Prepare for termination

Administer post survey and measures

Evaluate outcomes

Brainstorm session to improve for support group 2

Month 6:

Recruit participants for support group 2

Prepare for implementation of support group 2

Contact group 2 participants to remind them of about first session

Support group 2 begins

Administer pre survey and measures

Month 7:

Prepare for termination

Administer post survey and measures

Evaluate outcomes

Month 8:

Recruit participants for support group 3

Prepare for implementation of support group 3

Contact participants to remind them about first session

Support group 3 begins

Administer pre survey and measures

Month 9:

Prepare for termination

Administer post survey measures

Evaluate outcomes

Month 10:

Recruit participants for support group 4

Prepare for implementation of support group 4

Contact participants to remind them about first session

Support group 4 begins

Administer pre survey and measures

Month 11:

Prepare for termination

Administer post survey measures

Month 12:

Evaluate outcomes from all 4 support groups

Follow up with families

Budget Narrative

The total projected budget for this project is \$149,652 which will be needed in order to efficiently implement the program for one year. The family support group will deliver two facilitators, one caregiver, one volunteer, various resources, transportation assistance, food and beverages, and applicable material to meet the needs of families

caring for a family member with DD. A detailed line-item budget may be found in the appendix section.

Personnel Cost

Two full-time bilingual social workers (MSW) will be hired for the program. They will report to SCLARC's Program Director. The MSW's primary responsibility will be to facilitate the family support groups. One MSW will facilitate the family support group in Spanish and the other MSW will facilitate the family support group in English. Their position will be responsible for the programs development, activities, and decisions. Both MSW's will collaborate to recruit families, perform outreach, brainstorm specific activities per session, evaluate the program, and conduct necessary research. Furthermore, they will call families on a weekly basis to remind them of upcoming sessions. They will also make themselves available for office hours in order to meet with families on one-to-one consults, when families have further questions, comments, or suggestions in regards to covered topics. In addition, they will help SCLARC Family Resource Center Program when needed and available. Each MSW will be compensated with \$45,000 plus \$9,000 for benefits at 20%. The annual cost for two MSW's is \$108,000.

One part-time caregiver will be hired for the program at 40 hours per month. The caregiver's responsibility will be to care for individuals with DDs while their families are attending the support group. In addition, their responsibility is to plan and develop activities for the individuals with DD. This includes researching, brainstorming, and preparing appropriate workshops. The caregiver position will be compensated at an hourly rate of \$15/hour. The annual cost for one caregiver is \$7,200.

One bilingual volunteer will be recruited from SCLARC parent volunteers. The volunteer position will receive a \$1000 annual stipend in appreciation and support to the program. Volunteers will report to the MSW's. This position will be responsible for assisting the MSW's during sessions with tasks such as distributing documents to group participants and ensuring that each session has all the printing and supplies necessary. Total personnel cost is \$116,200.

Direct Program Cost

Program Supplies: An average of \$300 per month will be utilized to provide paper, pens, visual aids, arts and craft materials, poster boards, white boards, paint, and markers to assist in the educational piece of the program. Total amount for program supplies for the entire year is \$3,600.

Office Supplies: An average of \$200 per month will be utilized to provide essential office equipment to assist program's personnel. Supplies include pens, highlighters, markers, planners, folders, tape, and staplers. Total amount for the office supplies for the entire year is \$2,400.

Printing and Postage: An average of \$300 per month will be utilized for printing and postage. This includes printing and mailing flyers to families for the recruiting process. The total amount of printing and postage for the entire year is \$3,600.

Phone Bill: An average of \$50 per month will be utilized for the telephone bill. This includes recruitment and session reminder calls to families. This also includes other interactive communication between families and facilitators. The total amount of the telephone bill for the entire year is \$600.00.

Food and Refreshments: A light snack will be provided at each group. This includes snacks and drinks for the participants to enjoy during sessions. The total amount of food and refreshments allocated for groups for one year is \$2,000.

Program Evaluation: An average of \$5000 will be utilized to contract an external evaluator. An external evaluator will serve to enhance the validity of the program.

In-Kind Contributions

Transportation: The agency will provide transportation to existing clients participating in this program who do not have any means of transportation (Estimated value: \$6,720).

Computers: There will be a total of four computers that will be used. (Estimated value: \$2,200).

Office Phones: A total of four phones will be used. (Estimated value: \$200).

Television and Projector: These will be provided by the agency. (Estimated value: \$2,000).

Office Space (rent and utilities): Two office spaces and use of the multipurpose and conference rooms for groups will be provided by the host agency. (Estimated value: \$18,000).

Total in-kind donations is \$29,120.

Indirect Costs

Administrative Overhead: Ten percent or \$16,252 of total budget will be allocated for administrative overhead to manage the grant.

Program Evaluation

The program will be evaluated in order to obtain participants' mental health symptoms, progress, effect, and satisfaction. On session number one and session number 8, families will be required to complete a Patient Health Questionnaire (PHQ-9) as well as a Generalized Anxiety Disorder 7-item (GAD7). The purpose of the PHQ-9 and the GAD7 is to assess families' mental health symptoms gearing to target depression and anxiety (Kroenke, Spitzer, & Williams, 2001; Spitzer, Kroenke, Williams, & Lowe, 2006). Changes in symptoms are not expected to occur however, symptoms in participants can possibly change because participants were given an outlet. In addition, participants will also complete pre and post questionnaires that will be performed by an external evaluator. The pre and post questionnaires will measure participants' knowledge, coping ability, and group satisfaction. The results of the pre and post questionnaires will assist in resuming and altering services in order to meet family needs.

CHAPTER 5
LESSONS LEARNED

Program Design

Interest in designing this program was inspired by personal experience. Basic information about the importance of the topic was known prior to the development of the project. The program designed was structured based on a thorough research on the topic. An intensive review of literature was conducted. Through intensive research (Dabrowska & Pisula, 2010; Lee & Gardner, 2010; Reichman et al., 2008; Seymour et al., 2013), it was found that parents of individuals with DDs experience high levels of stress as they are raise their children with DDs. There are numerous affected families in need of resources who could benefit from support groups that provide them with emotional support and psycho-education (Kao et al., 2009; Seymour et al., 2013; Yildirim et al., 2013). A support group for families of individuals with diverse DDs will enable these families to interact with other families who understand what they are going through and are willing to share the kind of everyday insights that only come from firsthand experience. The support that families will attain from their peers is a unique emotional identification that will add to the professional support. With information attained from the literature review for this thesis, the process of developing the program goals was initiated. The goals are (1) To provide support to the families of individuals with DD by introducing interventions as well as skills needed for themselves, other family members, and their family member with DD, (2) To increase awareness of resources available for

individuals with DDs and their families, and (3) To increase families' social network. The objectives for the program goals were then identified and activities to meet the program goals were easier to create.

Identifying a Partner Agency

Identifying the program partner agency was a simple task due to familiarity with the agency and their services. SCLARC is a private non-profit, community based organization that services individuals with DD of all ages and their families. SCLARC services individuals with DD by assisting them at no cost with services such as intakes, assessments, diagnosis, counseling, advocacy, early intervention services, purchase of necessary services, family support, out-of-home care, training and community education. It was identified that SCLARC provides services that perfectly meets the needs of the program. In order to obtain an approval to utilize SCLARC, close communication was kept with Maura McGinnis Gibney, MSW who is the Family Resource Center Program Manager at SCLARC. A meeting with Mrs. Gibney was scheduled. During this meeting, there was an open discussion about the services SCLARC provides as well as the development of the proposed program. After a detailed discussion, Mrs. Gibney gave the authorization to utilize SCLARC as a host agency for the project.

Identifying Potential Funding Sources

The funding sources taken into consideration for this project were explored through several websites including Google, Google Scholar, and www.grants.gov. The search involved keywords such as *developmental disabilities grants*, *caregiver funding*, and *family support group grants*. Google and Google Scholar resulted in different websites with hundreds of results. After exploring a variety of websites related to the

topic, it was challenging to locate funding agencies that provided grants that met the program projected budget of \$150,000. Therefore, Google and Google scholar were eliminated as search engines for locating a grant. The funding search was then focused on www.grants.gov. After carefully reviewing different potential funding agencies the Department of Education's RRTC grant was found. RRTC's criteria met the needs of the program and the host agency met their funding requirements. RRTC was chosen as it was identified to be a perfect match for the project.

Budgeting

There was a lot of brainstorming involved in order to identify every expense of the program with the best intentions to meet the needs of individuals with DDs as well as the needs of their families. Once it was decided that the budget would be \$150,000, the larger expenses such as salaries for MSWs were analyzed. Having qualified MSWs facilitate groups for families of individuals with special needs was considered vital because they will hold important roles as group facilitators. For this reason, the bigger expenses of the budget were allocated for salaries.

Following the salaries, other necessary expenses followed such as equipment, supplies, and food for the group participants. Once salaries, materials, and equipment were budget, other miscellaneous things such as office supplies, were included in the budget. Through the process of researching staff salaries, service fees, and item prices, it was learned that initiating a program as well as maintaining it, is highly expensive. It was also learned that high costs make interventions difficult to develop, negatively impacting the target population.

Grant Writing

Due to the lack of knowledge and experience with grant writing, close communication was kept with the thesis advisor Kristina Lopez, for education on the grant writing process. Through this education, the process of identifying needs for a grant was understood as well as the importance of learning explicit key terms for research. In addition, reviewing previous theses for examples, provided via California State University, Long Beach Beachboard site, was performed for the grant writing process. During the search for funding sources, it was difficult to minimize search results due to the magnitude of sources found. It took a lot of time to narrow down information and rule out probable funding sources relevant to the proposed grant. After carefully reviewing potential funding sources, the Department of Education's RRTC was chosen due to meeting the target population's needs, the project's criteria, and proposed grant amount. Once this funding agency was chosen, the application was accessed.

Implications of Social Work Practice and Policy

Through the writing process of this grant thesis, the importance of the role of social workers in the special needs population was learned. As stated in the NASW Code of Ethics (2014), the primary mission of social workers is to magnify the well-being of all individuals specially the vulnerable, oppressed, and poor, through empowerment by servicing with integrity and competence (NASW, 2014). A program developed by social workers in order to provide a support group for families of individuals with DDs is greatly beneficial as literature demonstrates that social workers are capable to empower people to gain control over their own feelings, enabling them to cope with their disadvantages (Littlechild, 2012). By providing families with interventions, resources,

and skills from professionals, they can better manage their caregiver role as well as benefit their family member with DD (Kao et al., 2009; Wei et al., 2012). The need of qualified professionals in the lives of families of individuals with DDs is evident. Social workers have the skills to improve the quality of life among families of children with DDs through support, education, advocacy, and sympathy.

Conclusion

There were many lessons learned throughout the development of this project. Writing a grant to design a program that will provide educational, emotional, and social support for families of individuals with DD was a long process however, enjoyable. It took a lot of thorough research and dedication to identify the target population's needs in order to design a competent support group for families of individuals with DDs. Much research was conducted to locate potential grant funding sources appropriate for the program. Locating grant funding was a difficult task. Budgeting the program was time consuming due to the importance of carefully calculating its needed expenses. The process of the grant thesis writing was made a less difficult task due to the guidance and assistance of Kristina Lopez.

APPENDIX
PROPOSED PROGRAM LINE ITEM COSTS

Expenses for 1 Year of Proposed Program

Salaries

2 Full-time MSW	\$90,000.00
2 MSW Benefits @ 20%	\$18,000.00
1 Part-time Caregiver 40hr/month @\$15/hr	\$7,200.00
Volunteer	\$1,000.00
TOTAL PERSONNEL COST	\$116,200.00

Direct Program Cost

Program Supplies	\$3,600.00
Office Supplies (paper, pens, staples, etc.)	\$2,400.00
Printing and Postage	\$3,600.00
Phone Bill	\$600.00
Food and Refreshments	\$2,000.00
Evaluation	\$5,000.00
TOTAL DIRECT PROGRAM COST	\$17,200.00

In-Kind Contributions

Transportation	\$6,720.00
Computers	\$2,200.00
Office Phones	\$200.00
Television and Projector	\$2,000.00
Office Space	\$18,000.00
TOTAL IN-KIND PROGRAM COST	\$29,120.00

TOTAL PERSONNEL COST	\$116,200.00
TOTAL DIRECT PROGRAM COST	\$17,200.00
TOTAL IN-KIND PROGRAM COST	\$29,120.00
ADMINISTRATIVE OVERHEAD @ 10%	\$16,252.00
TOTAL PROGRAM COST	\$178,772.00

TOTAL REQUESTED FROM THE FUNDER	\$149,652.00
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