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The Importance of Counseling and Education for Parents of Children with Chromosome Abnormalities

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The Importance of Counseling and Education for Parents of Children with Chromosome Abnormalities

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Abstract:

Educational counseling provides information about resources and treatments available, as well as coping strategies that may be beneficial to families with a child suffering from a disability. The purpose of this study is to determine if a specific parent educational counseling program may improve outcomes for the child's development and family quality of life. Fifty parents (ages 25-50) with children (ages 3-18) who have a chromosome abnormality and at least one comorbid condition will be recruited from pediatric offices in Massachusetts through flyers and nominations. Participants will be separated into two groups and will undergo the five-year longitudinal study. A control group will receive no educational counseling program (n=25), but will receive the same questionnaires and compensation as group two. The second group (n=25) will be enrolled in the counseling program and will attend focus group discussions once a month. Both groups will complete seven questionnaires: at baseline and then in increments of 12 months. Reported family quality of life and child outcomes will be measured to determine the effectiveness of a program to help parents raise a child with a chromosome abnormality. Physicians can refer parents to the program as part of diagnosing and treating the child.

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Introduction:

According to the March of Dimes Foundation, 1 out of every 150 babies is born with a chromosome abnormality (March of Dimes, 2013). There are many chromosome abnormalities that affect children, some of which include Down syndrome, Tetrasomy 18p, Turner syndrome, Klinefelter syndrome, and Williams syndrome. In these disorders, an unusual number or structure of the chromosome has occurred. Structural abnormalities range from deletions, duplications, and translocations, to inversions and rings (National Human Genome Research Institute, 2014).

Children with these changes to their genetic makeup may also suffer from comorbid conditions as a result of the chromosome alterations. For example, Tetrasomy 18p affects multiple body functions and structures including the gastrointestinal system, intellectual development, and muscle tone (Genetics Home Reference, 2014). Children with Down syndrome may have a variety of birth defects in addition to cognitive delays, behavioral problems, and intellectual disabilities (Genetics Home Reference, 2014). Klinefelter syndrome is associated with physical and cognitive development (Genetics Home Reference, 2014).

While the previously mentioned conditions are only some of the possible disorders that could result from changes in the chromosomes of a child, there are many more that cause similar problems physically, cognitively, and developmentally. According to the Centers for Disease Control and Prevention (2013), out of every thirty-three births, one baby will be born with a birth defect. Down syndrome is the most common chromosome abnormality with a prevalence of 1 in 691 newborns; there is an estimated 6,037 cases each year (CDC, 2013). Other chromosomal abnormalities are not as common, but still occur with enough frequency to require attention. For

example, Trisomy 13 affects 1 in every 7,906 births and Trisomy 18 affects 1 in every 3,762 births (CDC, 2013).

With such a multitude of potential challenges that arise when caring for a child with a chromosome disorder, it is important that caregivers be provided with counseling and education on the condition their child has and services available to help both the child and the family. The knowledge of treatment options available helps the caregivers improve outcomes of special needs children born with chromosome abnormalities and opens new doors for treatment that may have not been available before. Additionally, parent counseling could lead to significant increases in the family's quality of life.

The challenges that come with raising a child with disabilities can lead to increased stress and decreased quality of life in caregivers who are not properly equipped to handle such challenges. According to a study conducted by Minnes *et al.* (2014), the methods parents used to cope with distress and child characteristics most strongly predicted whether or not positive gains for the children and lower parental stress occurred. The coping mechanisms of the parents were the strongest predictors of distress and positive gains. The coping mechanism that turned out to be a strong predictor of feelings of positive gains by the parents was reframing (Minnes *et al.*, 2014). Reframing is a mechanism by which someone shifts the way they look at a situation from potentially negative to a more positive experience that can be learned from. Families that care for these individuals may also suffer emotionally and economically. Necessary treatment may be turned down because of the financial burden that would result. Treatments that help the child improve also have positive impacts on the family.

There are many services and treatment options available to these children. These services focus on helping the children achieve the highest abilities possible based on individualized plans.

Physical therapy is used to help combat problems with muscle tone and the performance of physical activities such as learning to crawl, walk, and achieve balance and coordination (KidsHealth, 2014). Speech therapy is used to help with difficulties producing sounds, saying words, producing speech that flows, voice disorders, and even problems with swallowing or eating (KidsHealth, 2011). Occupational therapy can help with everyday activities that the child performs. Occupational therapists may also make recommendations for equipment that can help the child with tasks in the household and train the children and parents on its use (The American Occupational Therapy Association, 2014) Some caregivers find it helpful to hire extra help for in the home. This may be in the form of a nanny, a mother's helper, or a home-care nurse depending on the financial situation of the family. This extra help can lighten the burden of caregivers who feel that they benefit when they have, for example, multiple children to care for, full-time jobs, or a household to maintain. The one-on-one assistance for the child eases the pressure of the family and provides support for the home environment (Axelsson, 2014).

Counseling and education provides information about resources available, ways to improve coping strategies, and treatment options. This creates better outcomes for the family as a whole: parents, other siblings, and the child with the chromosome abnormality. The current research indicates that a chromosome abnormality may cause many deficits in the physical, mental, and emotional characteristics of the affected child. There is also agreement among numerous researchers that counseling and education are beneficial to families with a child that suffers from a disability. However, this research has not been completed for families of those whose child has a chromosome abnormality. As more research is conducted on chromosome changes and how they affect development, new treatments and care plans become available. Presently, there is no specific educational counseling program that is most ideal for families

affected by a chromosome abnormality that could improve outcomes for the development of the child and increase family quality of life.

Literature Review:

The following review of the literature will present recent studies of how families of children with chromosome abnormalities may experience increased life stressors and explore what these predictors of distress are. Studies regarding the stress and well being of parents of children with disabilities will be presented in conjunction with studies that describe promoting an environment that helps determine the child's quality of life. Studies that explore methods of counseling, programs that provide help to parents, and other options available to parents of children with disabilities will be discussed.

Stress and Quality of Life of Parents of Children with Chromosome Abnormalities

A study by Minnes et al. (2014) aimed to find the predictors of distress and well-being of parents with developmentally disabled children during the child's transition into school years. Participants included 155 mothers- ages 22 to 66 years- of 42 girls and 113 boys, whose mean age was 4.9 years. The children's diagnoses included Autism Spectrum Disorder, unspecified intellectual disability or developmental delay, Down Syndrome, and other genetic conditions. The study involved an online survey using the following measures: Scales of Independent Behavior- Revised, Family Empowerment Scale, Positive Gain Scale, and Parenting Stress Index Short Form. It was found that parent coping strategies most strongly predicted positive gain and level of parental distress. Reframing, as a strategy, predicted positive gains. Additionally, parent empowerment predicted greater positive gain and decreased parental distress. Parent empowerment can be related to feelings of self-efficacy, where parents feel that they have the strength and ability necessary to achieve goals and overcome obstacles. Limitations of this study

were that the results were based off of self-report by the parent, a lack of participation by fathers, and a vague definition of what qualifies as formal social support. Additionally, inclusion criteria of adaptive behavior scores below 85 excluded lower functioning children whose parents may have provided valuable information to this study and changed the results.

Kalay et al. (2009) studied the type of environment that has the best impacts on the well-being of children who are intellectually disabled. Health professionals, teachers, and parents of children with intellectual disabilities completed a questionnaire, followed by use of a Delphi survey. By using the Delphi survey, there was more than one round of information collection from the questionnaires that occurred. Feedback gained from the previous questionnaire is presented in the subsequent round of data gathering in an attempt to reach a consensus. Seventy-one participants took the first round of the questionnaire and fifty-nine in the second round. The items that were ranked among the most important by all three groups of participants were attitudes of family members, health practitioners, and teachers, support from family members and faculty at school, government policies, programs in the community, and social services. Limitations of this study included differences in responses between health professionals and parents and ranking by these groups. The aspect of the child's life most focused on by these groups may have been different. For example, parents may have focused more on the emotions of the child while teachers focused on physical assistive devices. Responses ranked according to 75% of participants were used in reporting results. An additional limitation of this study was the dropout rate during the multiple rounds of questionnaires.

Both of these studies described predictors of stress in family life and effects on the quality of life of the family and child. These studies discussed important factors that parents consider to have greatest impacts on how they cope with problems that they may face, the

environment that is best for their family as a whole, and how the most positive gains can be met. With greater feelings of self-efficacy and positive reframing, parents may become better caregivers for their children and experience a higher quality of family life. Important aspects of a child's environment were chosen that were thought to have the best impact on a child with disabilities.

Methods of Counseling Parents

Axelsson (2014) conducted a study in which the role of a personal care assistant for both the child and the child's family was investigated. This study utilized a mixed method design, where a qualitative interview was completed based on information gained from a previously performed quantitative cross-sectional study. The cross-sectional study involved 60 families with disabled children ages 5-20 years old. These families completed a questionnaire that included questions about 56 family activities that gave information about the family dynamics and the level of assistance each child needed to perform these activities. Based on this questionnaire, 11 parents and 9 of their personal assistants were asked to complete an individual semi-structured interview. The study found that the assistant played roles in helping both the child and the parents. For the child, the assistant was found to have the following roles: helped with basic functions and activities of daily life, provided care the child needed, helped the child become more engaged, provided a positive attitude, and served as a friend. For the family of the child, the assistant served a balancing role by reducing burdens and chores of the parents and allowing the caregivers time to rest. A limitation of this study included attrition because the number of participants who completed the second part of the study decreased from that of the first part, which potentially affected the validity of the study. Additionally, a panel chose the responses that carried on into the next round, which may have introduced biases and affected validity as well.

A study by Haugstvedt et al. (2012) aimed to explore how parents handle situations after attending a group-based counseling program that was largely based on Gestalt education, emphasizing a holistic approach to learning, along with personal construct theories. The study consisted of 67 parents, of which, 29 were fathers and 38 were mothers. Focus group discussions were held after the completion of the counseling program. Based on these discussions, categories of parents' experiences were developed. The category of most importance was improved handling of the situation by enhanced self-understanding. Self-understanding was achieved through experiencing themselves in a new way, having a set of peers with similar experiences, and counselors that allowed the exploration of thoughts, emotions, and reactions. The discussion contributed to parents finding new possibilities and priorities in handling situations. They were able to learn better ways to use their resources and find satisfaction by gaining a sense of self-understanding and seeing what held importance in their lives. A limitation of this study was the recruitment method used, where parents who responded may have been those seeking help with life situations. Other limitations were that the use of a focus group could have limited the responses by participants and facilitators may have impacted the outcomes of the group discussions.

Danino et al. (2012) conducted a study that focuses on parents of children with learning disabilities as they are often under stress, feel helpless, or feel depressed. Participants included 169 parents, of which 70% were mothers. The 169 participants were divided as follows: 93 to group counseling, 45 to individual coaching, and 31 parents on a waiting list (control group). These parents had children with learning disabilities ranging from ages 6 through 18. Parental stress in parent-child interactions, parental coping, social support, and the therapeutic value of therapy were measured using various indices. Outcome, process, and therapeutic factor

questionnaires were administered to measure the success of the counseling sessions. Among the treatment groups, those who attended group counseling reported lower parental stress than those who attended individual coaching. Increased stress was reported for the control condition. There were no differences in parental coping between the treatment groups found, but both reported gains. Limitations of the study included external validity because the participants only represented middle-class families and an uneven distribution according to gender occurred as 70% of the participants were mothers, and 70% of the children were boys.

All three of these studies show the benefits that counseling and education can provide to parents of children with chromosome abnormalities. The gains received from counseling-whether social support, coping mechanisms, or opportunities available- could create a better quality of life for parents and their families. Additionally, more positive coping responses and reduced stress could lead to more positive interactions and better outcomes for the child.

The above studies supported the idea that counseling and education for parents of children with chromosome abnormalities would be beneficial. However, there is a lack of application of a specific program to parents of these children. The Minnes et al. and Danino et al. studies were made up of either all mothers, or a majority of mothers participating, resulting in a lack of validity if application to fathers occurred. The Minnes et al. and Kaley et al. studies described predictors of distress and positive gains in the parents' lives and discussed the factors in the child's environment that parents felt best impacted the quality of life of the child. However, no further steps in creating a program that will provide these positive gains and best quality of life for families with children who have these disabilities. The studies by Axelsson, Haugstvedt et al., and Danino et al. described methods of counseling, programs, and options available to parents could be used to develop a program that would best suit the needs of parents

with children with chromosome abnormalities. While the current research has found predictors of distress, beneficial child-rearing environments, and helpful methods of counseling, the results are broad and have not been used to create a cohesive program for a specific population. Based on the above findings, the proposed study will investigate the impact of an educational counseling program for parents with children who have chromosome abnormalities on the developmental outcomes of the child and family quality of life.

The purpose of this study is to determine if a specific educational counseling program for parents may improve outcomes for the development of the children with chromosome abnormalities, increase family quality of life, and allow for the utilization of the many treatment options that are available to the children.

Objectives:

1. To compare reported quality of family life between two groups over a five-year time period.
 - Hypothesis: A reported increase in family quality of life will occur if enrolled in the five-year parent-counseling program for those with a child who has a chromosome abnormality.
2. To determine if the parent counseling program will lead to improved outcomes for the child's development.
 - Hypothesis: A reported increase in the number of improved outcomes will occur in those children whose parents participated in the 5-year parent-counseling program.

Methods:

Design

This study will involve a longitudinal study utilizing an educational counseling program that will occur over a five-year time period. This study will provide correlational data, measuring the association between undergoing the program and perceived quality of family life as well as the improvement of outcomes for the child. From this data, conclusions may be drawn regarding how effective this program was in improving perceived quality of life and childhood outcomes. Subjects will be divided into two groups, with twenty-five participants in each group (50 total participants). The two groups are those that will receive the educational counseling program and those that will not receive the program upon enrollment in the study. The group that will not receive the program will serve as a comparison group upon which results of the program may be measured. Participants in both groups will complete questionnaires that will assess the demographic information of the family, the child's clinical diagnoses, and perceived family quality of life. Participants will complete these questionnaires at zero (baseline), and in increments of every twelve months following the start of the program. A final questionnaire will be given twelve months following program completion. For the duration of the program, weekly educational programming events will occur in which professionals (i.e. therapists, physicians, etc.) will come to the meeting and provide an hour-long informational session. Topics that will be discussed include sources of parent empowerment to overcome challenges, therapies available to help children with disabilities, and positive coping mechanisms. Additionally, focus groups will be held once a month in which a trained facilitator will lead discussions on resources currently available for the child (i.e. behavioral therapy), methods of coping with challenges, sources of support, participants' feelings toward the program, and changes that have occurred

since beginning the program. Numbers will be assigned to each participant to maintain anonymity of both the questionnaire and focus group responses. The study will be submitted to the IRB for approval prior to beginning the study's sampling and recruitment process. Participants who remain enrolled in the program will receive compensation of three free weeklong summer camp sessions provided for children with disabilities at a nearby youth center. Both groups will receive this same compensation.

Participants

For this study, the target population is both mothers and fathers of a child with a chromosome abnormality between the ages of 3 and 18 years, living in the United States. The participants must be between the ages of 25 and 50 years. The accessible population is mothers and fathers living in the state of Massachusetts. Snowball sampling, a type of nonprobability sampling, will be used to recruit participants for this study. The recruitment of participants will be based on specific criteria: raising a child with a chromosome abnormality. The initial subjects will be recruited through flyers posted in pediatric offices across three counties in central Massachusetts. The initial subjects will then be asked to nominate additional subjects they know that fit the study's criteria and provide us with contact information for them. A total of fifty participants will be recruited so that each group will contain twenty-five participants. Inclusion criteria include raising a child diagnosed with a chromosome abnormality and at least one comorbid condition (i.e. Autism, physical disability, etc.). An additional inclusion criterion is that the parents must be enrolled in health insurance policies at the start of and expected to be for the duration of the program. Exclusion criteria include parents below the age of twenty-five or above the age of fifty. There is no exclusion criteria based on ethnicity, socioeconomic status,

specific type of chromosome abnormality, or number of other children in the household. Subjects must sign an informed consent form prior to enrollment in the study's program.

Instruments

Participants in both groups will complete seven questionnaires throughout the duration of the program. Focus groups guided by two trained facilitators will also be held once a month for the duration of the program to discuss subjective experiences of the program and outcomes. The first written questionnaire will include demographic information (i.e. socioeconomic status, highest level of education, gender), child's diagnoses, number of family members and their ages (Appendix A). Also included in the first questionnaire is The Family Quality of Life Scale (FQOL Scale) developed by the Beach Center on Disability (2012, Appendix B). The FQOL Scale contains five subscales and 25 items to assess family satisfaction and quality of life for families of children who have disabilities. Items are ranked using a 5-point scale to rate satisfaction. This FQOL Scale will also be used in the seven subsequent questionnaires. The other survey used on all seven questionnaires will be the Family Outcomes Survey designed by The Early Childhood Technical Assistance Center (2006, Appendix C). The Part B (619) Version of this survey will be used. However, questions 16-18 under the section titled "Feelings About Your Child's Preschool Program" will not be included. This survey includes five family outcomes that assess the extent to which families rate in achievement of these outcomes, using a 5-point rating scale. Family outcomes include: Understanding Your Child's Strengths, Abilities, And Special Needs, Knowing Your Rights and Advocating For Your Child, Helping Your Child Develop and Learn, Having Support Systems, Accessing Your Community, and Feelings About Your Child's Preschool Program. Mean scores are calculated for each indicator and a mean score for a section equal to or above 4.0 indicates that the family meets that indicator. This can be used

to calculate the percentage of families participating in the program who meet each indicator as well. Scores for each section will not affect participation in the program, even if one or more indicators are met.

Procedure

Once participants have been recruited and signed the consent forms, each participant will be assigned to one of two groups and will be given an identification number to be used for anonymity purposes. This will occur at the introductory meeting. The introductory meeting will also summarize the study, provide a calendar of events, and introduce focus group facilitators. Participants in this study will be tested at various points throughout the study. Questionnaires will be filled out a total of seven times: at the start of the study, twelve months after start, twenty-four months after start, thirty-six months after start, forty-eight months after start, sixty months after start, and then once more at the point twelve months after the program has been completed. The questionnaire completed at the start of the study will serve as the baseline for this research. This questionnaire will be made up of three surveys that include demographics and basic information, The FQOL Scale, and the Family Outcomes Survey. Both groups in this study will complete this questionnaire at the same time points and in the same location in the research facility. The difference between the two groups is that Group 1 will receive educational counseling programs and focus group discussions. Focus group discussions will occur on the last Monday of every month throughout the program duration. Weekly educational programs will occur in our research facility and will be available online as a webinar for participants living further from the study location. Focus group and data collection sessions are mandatory to attend at the facility. Participants who fail to attend or make up these sessions will forfeit their participation and compensation in the study. Those who complete the study each year will

receive compensation in May of every year for the duration of the study. This will be in the form of three free weeklong summer camp sessions provided for children with disabilities at a nearby youth center. Both groups will receive this same compensation via email or mail every May for the duration of the program. A detailed timetable of this procedure can be found in Appendix D.

Data Analysis

Descriptive statistics will be used first in the analysis of the data from this study to match the objectives. Due to the nature of this study employing multiple points of data collection, analysis will occur for each set of questionnaires. The Statistical Package for the Social Sciences (SPSS) software will be used for analysis of the data. The p-value for a statistically significant difference between the groups will be set to <0.05 . This study seeks to determine whether a parent educational counseling program (independent variable) will lead to increased reported family quality of life (first dependent variable) and improved child outcomes (second dependent variable). Therefore, the MANOVA test will be used to determine whether or not there is a difference in measurement between the two groups in this study. Analysis using this test will compare changes in reported family quality of life between two groups (objective one) and changes in outcomes for the child between two groups (objective two). Both The FQOL Scale and the Family Outcomes Survey have a numerical score that can be compared between the two groups to determine the significance of the null hypotheses (that there will be no differences between the scores on either measure for the two groups). Graphs of changes in numerical values will show be able to show if differences between the two groups occur. The analysis of this data will show how effective the parent-counseling program is in improving reported family quality of life and outcomes for the child with a chromosome abnormality. This will show how the

program for this population could be valuable to parents raising a child with a chromosome abnormality.

Predictions:

Based on previous studies, it is predicted that after a five-year parent educational counseling program, there will be an increase in reported quality of family life for those raising a child with a chromosome abnormality. Subjects who participate in the program will report increases in the quality of life that their family experiences. These increases will not be seen as significantly in subjects who do not attend the program's educational or counseling sessions. Additionally, it is expected that there will be an increase in the number of improved outcomes for the development of the child with the chromosome abnormality. The increases in family quality of life and improved outcomes are predicted to continue as long as the participants remain enrolled in the program.

Discussion:

The major strength of this study is that it is a novel program created for a population that previously did not have access to a program of this type. A second strength of this study includes having a control group that will serve as a comparison when exploring the results of the study. This enables the effectiveness of the educational counseling program to be examined. Another strength is that because this study is longitudinal, there is data from time points over a five-year period. The effects of this program can be examined by comparing data at various times throughout the study to the baseline measurements taken prior to beginning the program. Changes in the subjects over time can be observed in order to see how these changes developed. Adequate data collection can also be achieved. A fourth strength is that the sample size for this study is relatively large for the population of families raising children with a chromosome

abnormality. This allows for applicability to these families that were not involved in the study as high external validity is expected. The inclusion and exclusion criteria along with random assignment to control versus experimental group allowed for some control over confounding variables. The instruments used are also a strength as they give valuable information regarding family quality of life and the outcomes of the child.

Limitations of this study include the presence of other possible confounding variables that were not controlled for. While the longitudinal design is considered a strength, it can also be a limitation as there is a risk of attrition of participants. The length of the program could lead to some parents dropping out of the study, decreasing the sample size and amount of data collected. Additional confounding variables may develop during the length of the program as well. This program is specific to a particular population so generalizability of this study beyond this population is limited.

Conclusion:

The purpose of this study is to determine if a specific educational counseling program for parents may improve outcomes for the development of the children with chromosome abnormalities, increase family quality of life, and allow for the utilization of the many treatment options that are available to the children. Based on previous studies, it is expected that this five-year program will increase the quality of life reported by the family and lead to an increased number of improved developmental outcomes for the child with the chromosome abnormality. This program has a clinical application. Physicians can refer parents to the program when initially diagnosing a child and to patients that have already been diagnosed with a chromosome abnormality. Pamphlets explaining the program can be distributed upon referral as well. Further studies could explore the effectiveness of this program with respect to specific ages of the child.

Groups could be separated according to the ages of the children, such as toddlerhood, early elementary, late elementary, etc. This could make sure that other variables such as attending school, entering puberty, and other life stages can be controlled for. Future studies could also use participants who have children with chromosome abnormalities that do not have the same diagnoses as the children whose parents were included in the study.

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Appendix:

Appendix A: Background and Demographic Information

Questionnaire Number 1

Part 1: Background and Demographic Information

Program Identification Number: _____

Child's age:

Child's gender:

Child's diagnoses:

Does your child attend school? If yes, please list type of school (i.e. special needs classroom, private school, public school, etc.)

Do you currently have in-home care assistance (i.e. nanny, home health nurse, etc.)? If yes, please list below.

Number of family members living in household [please put age and relationship to child in parenthesis e.g. 5 members- mother (34 years old), sister (7 years old)]:

Please list the highest level of education for each primary caregiver:

Approximate combined household income:

Part 2: The Family Quality of Life Scale (FQOL Scale)

Part 3: Family Outcomes Survey

Appendix B: The Family Quality of Life Scale (FQOL)

FAMILY QUALITY OF LIFE (cont.)

How satisfied am I that...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. My family enjoys spending time together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My family members help the children learn to be independent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My family has the support we need to relieve stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My family members have friends or others who provide support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My family members help the children with schoolwork and activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My family members have transportation to get to the places they need to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My family members talk openly with each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My family members teach the children how to get along with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My family members have some time to pursue our own interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Our family solves problems together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My family members support each other to accomplish goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My family members show that they love and care for each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My family has outside help available to us to take care of special needs of all family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Adults in our family teach the children to make good decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

FAMILY QUALITY OF LIFE (cont.)

How <u>satisfied</u> am I that...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
15. My family gets medical care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My family has a way to take care of our expenses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My family is able to handle life's ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Adults in my family have time to take care of the individual needs of every child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. My family gets dental care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. My family feels safe at home, work, school, and in our neighborhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. My family member with a disability has support to accomplish goals at school or at workplace.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. My family member with a disability has support to accomplish goals at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. My family member with a disability has support to make friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix C: Family Outcomes Survey – Part B (619) Version

Family Outcomes Survey

Part B (619) Version

The Family Outcomes Survey is designed to provide a way for you to describe your family and the ways you support your child's needs.

Instructions:

- This survey should be filled out by the person in your family who has the most interaction with preschool special education services.
- All of the responses include the word "we" or "our." This refers to your family. Usually this means parents and others who support and care for your child. But every family is different, so think of what "family" means to you when answering.
- On every page, you will be asked to answer questions like the example below:

How much does your family know about dinosaurs?

1	2	3	4	5	6	7
We know a little about dinosaurs		We know some about dinosaurs		We know a good amount about dinosaurs		We know a great deal about dinosaurs

- Read each question and circle the number that best describes your family right now.
- If a statement almost describes your family, but not quite, circle the number just to the left or the right. For example if you feel that the statement 5 "We know a **good amount** about dinosaurs" almost describes your family, but not quite—circle the 4.
If you do not know how to answer a question, or if you are not comfortable answering the question, skip it and go to the next question.

© 2006. Version: 11-10-06 (rev. 2-22-07). This survey was developed by Don Bailey, Kathy Hebbeler, and Mary Beth Bruder as part of the Early Childhood Outcomes (ECO) Center. Permission is granted to reproduce this survey for state and local program use. When reproducing, please identify as "Developed by the Early Childhood Outcomes Center with support from the Office of Special Education Programs, U.S. Department of Education." Please contact staff@the-ECO-center.org if you wish to use or adapt the survey.

Family Outcomes Survey

UNDERSTANDING YOUR CHILD'S STRENGTHS, ABILITIES, AND SPECIAL NEEDS

1. *Your child is growing and learning. How much does your family understand about your child's development?*

1	2	3	4	5	6	7
We are just beginning to understand our child's development		We understand some about our child's development		We understand a good amount about our child's development		We understand a great deal about our child's development

2. *Some children have special health needs, a disability, or are delayed in their development. These are often referred to as "special needs." How familiar is your family with your child's special needs?*

1	2	3	4	5	6	7
We are just beginning to understand our child's special needs		We understand some about our child's special needs		We understand a good amount about our child's special needs		We understand a great deal about our child's special needs

3. *Professionals who work with you and your child want to know if the things they do are working. How often is your family able to tell if your child is making progress?*

1	2	3	4	5	6	7
We seldom can tell if our child is making progress		We sometimes can tell if our child is making progress		We usually can tell if our child is making progress		We almost always can tell if our child is making progress

KNOWING YOUR RIGHTS AND ADVOCATING FOR YOUR CHILD

4. *A variety of programs and services may be available to help your child and family. How much does your family know about the programs and services that are available?*

1	2	3	4	5	6	7
We are just beginning to learn about the programs and services that are available		We know some about the programs and services that are available		We know a good amount about the programs and services that are available		We know a great deal about the programs and services that are available

5. *Families often meet with professionals to plan services or activities. How comfortable is your family participating in these meetings?*

1	2	3	4	5	6	7
We are just beginning to feel comfortable participating in meetings		We are somewhat comfortable participating in meetings		We are generally comfortable participating in meetings		We are very comfortable participating in meetings

6. *Families of children with special needs have rights, including what to do if you are not satisfied. How familiar is your family with your rights?*

1	2	3	4	5	6	7
We are just beginning to understand our rights		We understand some about our rights		We understand a good amount about our rights		We understand a great deal about our rights

HELPING YOUR CHILD DEVELOP AND LEARN

7. *Families help their children develop and learn. How much does your family know about how to help your child develop and learn?*

1	2	3	4	5	6	7
We are just beginning to know how to help our child develop and learn		We know some about how to help our child develop and learn		We know a good amount about how to help our child develop and learn		We know a great deal about how to help our child develop and learn

8. *Families try to help their children learn to behave the way they would like. How much does your family know about how to help your child learn to behave the way your family would like?*

1	2	3	4	5	6	7
We are just beginning to know how to help our child behave the way we want		We know some about how to help our child behave the way we want		We know a good amount about how to help our child behave the way we want		We know a great deal about how to help our child behave the way we want

9. *Families work with professionals to help their children learn and practice new skills at home or in their communities. How often does your family help your child learn and practice these new skills?*

1	2	3	4	5	6	7
We are just beginning to help our child learn and practice these skills		We sometimes help our child learn and practice these skills		We usually help our child learn and practice these skills		We routinely help our child learn and practice these skills

HAVING SUPPORT SYSTEMS

10. Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it?

1	2	3	4	5	6	7
We seldom have someone to talk with about things when we need it		We sometimes have someone to talk with about things when we need it		We usually have someone to talk with about things when we need it		We almost always have someone to talk with about things when we need it

11. Families sometimes must rely on other people for help when they need it, for example to provide a ride, run an errand, or watch their child for a short period of time. How often does your family have someone you can rely on for help when your family needs it?

1	2	3	4	5	6	7
We seldom have someone we can rely on for help when we need it		We sometimes have someone we can rely on for help when we need it		We usually have someone we can rely on for help when we need it		We almost always have someone we can rely on for help when we need it

12. Most families have things they enjoy doing. How often is your family able to do the things your family enjoys?

1	2	3	4	5	6	7
We seldom are able to do the things we enjoy		We sometimes are able to do the things we enjoy		We usually are able to do the things we enjoy		We almost always are able to do the things we enjoy

ACCESSING YOUR COMMUNITY

13. All children need medical care. How well does your family's medical care meet your child's special needs?

1	2	3	4	5	6	7
Our medical care meets few of our child's needs		Our medical care meets some of our child's needs		Our medical care meets many of our child's needs		Our medical care meets almost all of our child's needs

14. Many families have a need for quality childcare. By this, we do not mean occasional babysitting, but regular childcare, either part-day or full-day. How well does your family's childcare meet your child's needs?

- CHECK HERE IF YOUR FAMILY HAS NOT WANTED CHILDCARE, AND GO TO QUESTION 15.
- CHECK HERE IF YOUR FAMILY HAS WANTED CHILDCARE BUT IT IS NOT CURRENTLY AVAILABLE, AND GO TO QUESTION 15.

1	2	3	4	5	6	7
Our childcare meets few of our child's needs		Our childcare meets some of our child's needs		Our childcare meets many of our child's needs		Our childcare meets almost all of our child's needs

15. Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now?

- CHECK HERE IF YOUR FAMILY HAS NOT WANTED YOUR CHILD TO PARTICIPATE IN SUCH ACTIVITIES AND GO TO QUESTION 16.

1	2	3	4	5	6	7
Our child seldom participates in the activities we want		Our child sometimes participates in the activities we want		Our child usually participates the activities we want		Our child almost always participates in the activities we want

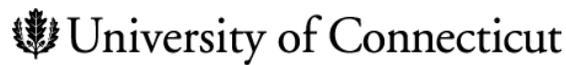
Appendix D: Timetable of Study

November 1, 2014	IRB approval
December 1, 2014	Snowball Sampling Method
January 1, 2015	Begin training Focus Group Facilitators
January 1, 2015	Begin recruiting subjects and Educational program professionals for weekly meetings

July 20, 2015	Have 50 participants; Complete consent forms
July 30, 2015	Complete Training Focus Group Facilitators
August 1, 2015	Informal meeting to introduce Focus Group Facilitators, provide summary of the program details and calendar provided in folder; Assign groups; Complete Baseline questionnaire
August 3, 2015	First weekly educational programming meeting
August 31, 2015	First monthly Focus Group session held
Aug 1, 2015- Aug 1, 2016	Weekly meetings and monthly sessions continue (first Monday of the month= weekly program; last Monday of the month= focus group)
August 1, 2016	Second Questionnaire completed
Aug 1, 2016- Aug 1, 2017	Weekly meetings and monthly sessions continue
August 1, 2017	Third Questionnaire completed
Aug 1, 2017- Aug 1, 2018	Weekly meetings and monthly sessions continue
August 1, 2018	Fourth Questionnaire completed
Aug 1, 2018- Aug 1, 2019	Weekly meetings and monthly sessions continue
August 1, 2019	Fifth Questionnaire completed
Aug 1, 2019- Aug 1, 2020	Weekly meetings and monthly sessions continue
August 1, 2020	Sixth Questionnaire completed; Program Counseling and Education Sessions Complete.
August 1, 2021	Seventh (12-month follow up) Questionnaire completed
May 25 th of each year in program	Distribute compensation (vouchers for free camp sessions)
August 15, 2021	Data Analysis + Results
February 2022	Publish Findings

Appendix E: Consent Form

Consent Form for Participation in a Research Study



Student Researcher: Brooke Fortner

Study Title: The Importance of Counseling and Education for Parents of Children with Chromosome Abnormalities

Introduction

You are invited to participate in this research study to assess the effectiveness of a five-year counseling and education program for parents of children with chromosome abnormalities. You are being asked to participate because you are an adult raising a child with a chromosome abnormality in Massachusetts.

Why is this study being done?

The purpose of this research study is to determine if a specific educational counseling program for parents may improve outcomes for the development of children with chromosome abnormalities, increase family quality of life, and allow for the utilization of the many treatment options that are available to the children.

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will be asked to provide a copy of your child's medical chart in which the physician's diagnoses are clearly noted. This is to ensure that your child meets criteria required for you to participate. After this has been completed, a questionnaire will be distributed that includes questions about demographic information of the family, the child's clinical diagnoses, perceived family quality of life, and information regarding your child's development. This study will be conducted over a five-year period and will take place in our research facility. You will be asked to complete this questionnaire again in increments of every twelve months following the start of the program. A final questionnaire will be given twelve months following program completion. For the duration of the program, weekly educational programming events will occur in which professionals (i.e. therapists, physicians, etc.) will come to the meeting and provide an hour-long informational session. Focus groups will be held once a month in which a trained facilitator will lead discussions on resources currently available for the child, methods of coping with challenges, sources of support, your feelings toward the program, and changes that have occurred since beginning the program.

What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the study.

What are the benefits of the study?

We hope that your participation in this study increases your reported quality of life and improves outcomes for your child.

Will I receive payment for participation? Are there costs to participate?

There are no costs to participate, aside from money you use in transportation to the facility. There will be compensation for participants who remain enrolled in the program will receive three free weeklong summer camp sessions provided for children with disabilities at a nearby youth center. These vouchers will be given at the end of each year of program completion for the duration of the program.

How will my personal information be protected?

The following procedures will be used to protect the confidentiality of your data. The researchers will keep all study records (including any codes to your data) in a securely locked location. Participants will be assigned a random identification number so that questionnaire responses and participation remains anonymous. Responses will not be kept in the same location as the master key that links participants with their identification numbers. This master key will be kept for up to five years following program completion. Only the researchers will have access to the locked files where all records are kept. At the conclusion of this study, the researchers may publish the findings. Information will be presented in summary format and participants will not be identified in any publications.

We will do our best to protect the confidentiality of the information we gather from you but we cannot guarantee 100% confidentiality.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. You will be notified of all significant new findings during the course of the study that may affect your willingness to continue.

For all focus group discussions and surveys, you do not have to answer any question that you do not want to answer.

Whom do I contact if I have questions about the study?

“Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this study or if you have a research-related problem, you may contact the student researcher Brooke Fortner at 727-207-3408. If you have any questions concerning your rights as a research participant, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

Documentation of Consent:

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible risks and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I have received a copy of this consent form.

Participant Signature:

Print Name:

Date:

Relationship (only if not participant): _____

Signature of Person
Obtaining Consent

Print Name:

Date: