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# Down Syndrome and the Importance of a Neutral Diagnosis Delivery: A Community Service Project

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# DOWN SYNDROME AND THE IMPORTANCE OF A NEUTRAL DIAGNOSIS DELIVERY: A COMMUNITY SERVICE PROJECT

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# ABSTRACT

Approximately 6,000 babies are born with Down syndrome each year in the United States – with an increasing prevalence. The literature suggests that negative societal attitudes surrounding the diagnosis of Down syndrome are often reflected in the terminology used by the medical providers delivering the diagnosis and that medical providers lack training regarding appropriate counseling.

Jack's Basket is a non-profit organization that aims to celebrate babies with Down syndrome and connect families to local resources. The researchers partnered with the organization to further explore the relationship between the diagnosis delivery method and how the recipient perceives the diagnosis.

Jack's Basket also provides educational presentations for medical providers on how to deliver unexpected news using neutral terminology to avoid implicit bias. However, their presentations lacked specific data regarding the diagnosis delivery and its effect on parental acceptance of the child. Therefore, the researchers assisted Jack's Basket in creating a survey for the organization to gain a better understanding of the Down syndrome diagnosis and receive feedback on their current programming. The researchers also secured Institutional Review Board (IRB) approval of the survey to ensure an ethical data collection process with appropriate informed consent.

This survey was sent to approximately 4,000 families in Minnesota who received a Jack's Basket between the years of 2018-2021. The survey achieved a 13.1% response rate. The survey results allowed Jack's Basket to identify areas for improvement in their programing, including communication to new members and volunteer engagement. Also, the data collected on diagnosis delivery supports further development of the organization's educational initiatives to reduce stress and anxiety among medical providers, so they can better deliver the prenatal diagnosis of Down syndrome using neutral terminology.

# ACKNOWLEDGEMENTS

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# Chapter 1: Introduction

## Introduction

In the United States, approximately 1 in every 779 babies is born with Down syndrome (Antonarakis et al., 2021). Despite Down syndrome being one of the most complex genetic abnormalities, fetal development and survival is anticipated (Antonarakis et al., 2021). Providing appropriate care for individuals with Down syndrome not only entails medical providers to remain up to date on the condition, but also to deliver the unexpected diagnosis honestly and objectively to the parents. Down syndrome is a lifelong condition, which entails a lifetime of individualized care. Although Down syndrome is accompanied by various complications, such as comorbidities and intellectual challenges, the child should be celebrated and the diagnosis should be framed with neutral terminology (Carroll et al., 2018). Therefore, the focus of this community service project is to assist in the collection of data to assess how the delivery of the diagnosis of Down syndrome affects families receiving the unexpected news. The intent is to better understand the relationship between the diagnosis delivery method and how the family perceives the diagnosis.

For this community service project, the researchers collaborated with Jack's Basket, a non-profit organization aimed at eliminating the negative social attitudes that commonly accompany the diagnosis of Down syndrome. The organization's mission is two-fold: 1) to educate medical providers on delivering the diagnosis of Down syndrome and 2) to provide resources and community support to families that are welcoming, or about to welcome, a child with Down syndrome (C. Carroll, personal communication, November 10, 2021). This organization was established in March of 2014, one year after Jack Carroll was born. Jack's Basket helps celebrate the diagnosis of Down syndrome in all 50 states and in 30 countries worldwide– celebrating over 4,500 babies with Down syndrome since its founding in 2014. A Jack's Basket includes personal letters from individuals who have a child with Down syndrome, information on organizations for families of a loved one with Down syndrome, a series of pertinent books about the journey of knowing a loved one with Down syndrome, as well as gifts such as clothes, baby books, and a blanket ("Baskets," 2021).

The researchers assisted Jack's Basket by collaborating on the creation of a survey to send to basket recipients in Minnesota, as well as completing and submitting an Institutional Review Board (IRB) approval application for the survey. The recipients will be asked to complete an anonymous survey regarding their child's Down syndrome diagnosis experience and provide feedback on the current programming of the organization. The data will be collected and analyzed by the organization in order to develop initiatives aimed at furthering medical providers' education on how best to deliver the diagnosis of Down syndrome. This chapter addresses the background, presentation, and health disparities associated with a Down syndrome diagnosis, as well as how a medical provider's training influences their delivery of the diagnosis to the parents. This chapter will also address the purpose of the community service project, the significance of the lack of formal training in delivering unexpected news, and definitions of common terms used in the community service project.

## Background

Down syndrome, also known as trisomy 21, is not only one of the most complex genetic abnormalities, but it is also the most common genetic abnormality among live births (Antonarakis et al., 2021; Ostermaier, 2020). Down syndrome is caused by an extra 21st chromosome, resulting in three copies of chromosome 21 and 47 total chromosomes. The genetic variation results in various dysmorphic features, intellectual disabilities, congenital anomalies, and other comorbidities or complications that are individual to each child with Down syndrome (Ostermaier, 2020). The incidence of Down syndrome increases as the maternal age is over 35 years old (Jain et al., 2002).

Down syndrome screening can be conducted prenatally during either the first or second trimester of pregnancy (Gupta & Kabra, 2013). The screening process is conducted through ultrasound, an assessment of biomarkers in maternal blood samples, or by measuring the pouch of fluid behind the neonate's neck while in the womb. Although screening tools can aid in the suspicion of a diagnosis of Down syndrome, they cannot be used as definitive diagnostic tools (Antonarakis et al., 2020; Agathokleous et al., 2013).

The diagnostic test for Down syndrome is karyotyping via amniocentesis and chorionic villi sampling (Asim et al., 2015; Renna, et al., 2013; Alfirevic et al., 2017). These diagnostic tests can be performed during the first or second trimester; however, the fetal risk decreases in the second trimester compared to the first (Alfirevic et al., 2017). The postnatal diagnosis of Down syndrome can be made via an examination of clinical features and a chromosomal assessment (Gupta & Kabra, 2013).

Individuals with Down syndrome experience various forms of disparities that are commonly influenced by determinants of health including access to health care, genetics, social circumstances, environmental determinants, and individual behaviors. Racial disparities are also prevalent throughout each of these determinants of health (Booth, 2011). Additionally, in the study by Nugent et al. (2018), it was found that individuals with Down syndrome are four times less likely to successfully transition from pediatric to adult care than other individuals with special healthcare needs. This study also addressed the issue that medical providers, depending on their specialty, have various perspectives on how well they are equipped to provide medical care for individuals with Down syndrome (Nugent et al., 2018). The study found that pediatricians typically felt more comfortable than primary care providers.

Currently, there is a gap in the literature about how medical providers are trained to deliver the diagnosis of Down syndrome. However, in a recent questionnaire by Gueneuc et al. (2020), medical providers reported feeling that they never received proper training on how to counsel patients with unexpected or “bad” news. Many medical providers felt that they were either never given training or that the training received was brief and inadequate. This lack of training leads to added stress for the medical provider as well as unconscious, implicit bias incorporated into the diagnosis delivery (Carroll et al., 2018). Consequently, there is a need to train medical providers to deliver the diagnosis in a way that is unbiased and tailored to the family receiving the unexpected news (Sheets et al., 2011; Carroll et al., 2018).

According to the literature, the parent’s perception of the unexpected diagnosis of Down syndrome is greatly impacted by how the medical provider delivers the news (Mugweni et al., 2021). The method of delivery does not have a formal structure and can lead to anxiety, confusion, or fear. Parents receiving this unexpected diagnosis report a preference to use “different news” instead of “bad news.” This minor adjustment makes the diagnosis neutral, allowing the parents to interpret whether the news is good, bad, or indifferent (Mugweni et al., 2021). Negative terminology, such as “bad” news, as well as focusing on the difficulties that will come with this diagnosis, have led to dissatisfaction among mothers receiving the diagnosis (Skotko, 2005).

According to Carissa Carroll, founder and executive director of Jack’s Basket, “there is a direct correlation between how the diagnosis is given and a family's ability to accept their new life” (C. Carroll, personal communication, October 8th, 2021). Through her personal experience, as well as the many mothers who have received resources from Jack's Basket, Carissa and her team help reframe the way medical providers deliver the diagnosis to improve parents' acceptance of their new baby (Carroll et al., 2018). In addition to reframing the delivery of the diagnosis, a study by Skotko found that mothers who received the prenatal diagnosis of Down syndrome suggest improving the diagnosis process by providing resources to help support the mothers and families of the child (2005). Therefore, the purpose of this community service project is to assist in the creation of a survey to collect data on how the diagnosis of Down syndrome is delivered and the efficacy of the current resources provided by Jack's Basket.

## Problem Statement

Due to the negative societal attitudes surrounding the diagnosis of Down syndrome and a lack of education regarding appropriate counseling from medical providers for the parents, it is necessary to alleviate the fears of parents and help them celebrate their child (Carroll et al., 2018). Appropriate counseling from medical providers entails a diagnosis delivery that is tailored to the parents' level of comprehension and the amount of knowledge they wish to hear at the time of diagnosis (Skotko, 2005). Additionally, the delivery must be void of bias from the medical provider and use neutral terminology, rather than framing the diagnosis as "I have bad news" (Mugweni et al., 2021). The medical provider delivering the diagnosis of Down syndrome should be trained on how to give the appropriate amount of information without overwhelming parents who are already receiving unexpected news. Therefore, expanding the education for medical providers on how to deliver the diagnosis of Down syndrome can help alleviate the negative emotions experienced by parents, such as anxiety. The data collected from the survey conducted through this community service project will help gain insight into how the diagnosis is currently being delivered and help determine how to best navigate delivering the prenatal diagnosis of Down syndrome.

## Purpose

There is limited research on how medical providers are taught to deliver unexpected news. However, the literature focuses on the lack of training and how this leads to anxiety and stress for the medical provider, as well as the parents receiving the diagnosis (Mugweni et al., 2021). Therefore, the researchers partnered with Jack’s Basket to create a survey for the purpose of collecting data on how parents felt about their child’s diagnosis delivery experience and the efficacy of the resources provided by the organization. In order to uphold ethical standards during the conduction of this survey, the researchers also applied for IRB approval on behalf of Jack's Basket. Through the data collected in the survey, the organization will be able to share the findings with medical providers in order to improve the delivery of the diagnosis of Down syndrome in hope that it will lead to better outcomes for the parents and newborn.

## Significance of the Problem

According to the Minnesota Department of Health, approximately 116 babies are born with Down syndrome annually in Minnesota (MDH, n.d.). Addressing the lack of training for medical providers on delivering unexpected news is the first step in improving the experience for parents receiving the diagnosis of Down syndrome. Furthering education for medical providers also has the potential to significantly improve the lives of the parents receiving the diagnosis (Mugweni et al., 2021). Proper support from medical providers, including resources and connections to other parents with similar experiences, has led to positive outcomes in the past. The primary goal of this community service project is to expand resources and knowledge for the organization through the ethical collection of data from an IRB-approved survey sent to previous basket recipients. Through this collection of data, the organization will be able to better educate medical providers on how to best deliver the prenatal diagnosis of Down syndrome and counsel the parents on the resources available for them and their child.

## Barriers

This community service project relies on the responses provided by a survey sent to Minnesota basket recipients. A major barrier with this survey includes individuals not receiving or responding to the survey, resulting in a small sample size. Some individuals may decide to forgo participating in the survey due to the sensitive nature of the content. Another limitation includes asking the participants to accurately recall detailed information about a highly emotional conversation. Additionally, only families in Minnesota are receiving the survey, therefore, there is a limitation in geographic representation.

## Definition of Terms

**First Trimester:** from the beginning of week one to the completion of week twelve of pregnancy (UCSF, 2021).

**Second Trimester:** from week thirteen to the completion of week 26 of pregnancy (UCSF, 2021).

**Third Trimester:** from week twenty-seven to the completion of pregnancy, often between weeks thirty-eight and forty-two (UCSF, 2021).

**Karyotype:** “the chromosomal characteristics of a cell” (Merriam-Webster, 1828, para. 1).

**Nondisjunction:** “failure of homologous chromosomes or sister chromatids to separate subsequent to metaphase in meiosis or mitosis so that one daughter cell has both and the other neither of the chromosomes” (Merriam-Webster, 1828, para. 1).

**Meiosis:** “the cellular process that results in the number of chromosomes in gamete-producing cells being reduced to one half and that involves a reduction division in which one of each pair of homologous chromosomes passes to each daughter cell and a mitotic division” (Merriam-Webster, 1828, para. 1).

**Translocation:** “transfer of part of a chromosome to a different position especially on a nonhomologous chromosome...*especially* : the exchange of parts between nonhomologous chromosomes” (Merriam-Webster, 1828, para. 1).

**Chromosome:** “any of the rod-shaped or threadlike DNA-containing structures of cellular organisms that are located in the nucleus of eukaryotes, are usually ring-shaped in prokaryotes (such as bacteria), and contain all or most of the genes of the organism” (Merriam-Webster, 1828, para. 1).

**Alpha-fetoprotein:** “a fetal blood protein present abnormally in adults with some cancers (as of the liver) and normally in the amniotic fluid of pregnant women with high or low levels tending to be associated with certain birth defects (such as spina bifida or Down syndrome)” (Merriam-Webster, 1828, para. 1).

**Disparity:** “a noticeable and usually significant difference or dissimilarity” (Merriam-Webster, 1828, para. 1).

**Chorionic villus sampling**: “biopsy of a villus of the chorion at usually 10 to 12 weeks of gestation to obtain fetal cells for the prenatal diagnosis of chromosomal abnormalities —abbreviation *CVS”* (Merriam-Webster, 1828, para. 1).

**Amniocentesis:** “the surgical insertion of a hollow needle through the abdominal wall and into the uterus to obtain amniotic fluid especially for the determination of fetal sex or chromosomal abnormality” (Merriam-Webster, 1828, para. 1).

**Aneuploidy:** “having or being a chromosome number that is not an exact multiple of the usually haploid number” (Merriam-Webster, 1828, para. 1).

**Cytogenetics:** “a branch of biology that deals with the study of heredity and variation by the methods of both cytology and genetics” (Merriam-Webster, 1828, para. 1).

**Cytology:** “the cellular aspects of a phenomenon, process, or structure” (Merriam-Webster, 1828, para. 1).

**Implicit bias:** “a bias or prejudice that is present but not consciously held or recognized” (Merriam-Webster, 1828, para. 1).

**Bias:** “a tendency to believe that some people, ideas, etc., are better than others that usually results in treating some people unfairly” (Merriam-Webster, 1828, para. 1).

**Stigma**: “a set of negative and often unfair beliefs that a society or group of people have about something” (Merriam-Webster, 1828, para. 1).

**Recall Bias: “**when participants in a study are systematically more or less likely to recall and relate information on exposure depending on their outcome status, or to recall information regarding their outcome dependent on their exposure” (Prince, 2012).

## Conclusion

There is a need for data and education regarding how to best deliver the prenatal diagnosis of Down syndrome (Carroll et al., 2018; Skotko, 2005). The goal of this community service project is to create a survey with Jack’s Basket to gather data from Minnesota basket recipients in order for the organization to develop future educational initiatives on how medical providers can best deliver unexpected news, specifically a diagnosis of Down syndrome. The following chapter reviews the current literature on Down syndrome including diagnosis, presentations, complications, and common health disparities. It also details the lack of medical provider training on delivering the diagnosis of Down syndrome and how the delivery influences the parents' perception and acceptance of the diagnosis. Down syndrome is a lifelong condition, which can entail a lifelong commitment for the parents. Making resources available for parents can allow them to celebrate their child amid this life-changing news, with the support of medical providers and a community of other parents raising children with Down syndrome (Carroll et al., 2018).

# Chapter 2: Literature Review

## Introduction

This literature review will outline the current research on the presentation, screening, diagnosis, complications, and health disparities that are associated with Down syndrome. This review will discuss how medical providers are trained to deliver a diagnosis of Down syndrome, as well as the impact this delivery has on the parents. The purpose of this literature review is to provide the reader with an understanding of what Down syndrome is and how parents are impacted by the delivery and counseling during the diagnosis of Down syndrome.

## What is Down Syndrome?

Down syndrome, also known as trisomy 21, results when an individual has an extra 21st chromosome. Typically, an individual has two copies of chromosome 21 and 46 total chromosomes, whereas an individual with Down syndrome has three copies of chromosome 21 and 47 total chromosomes (Mazurek & Wyka, 2015). The incidence of Down syndrome rises to 1 in 270 full-term births as maternal age increases over 35 years, compared to 1 in 935 for 30-year-old mothers (Jain et al., 2002; Messerlian & Palomaki, 2021).

There are three types of Down syndrome: Standard Trisomy 21, Translocation Trisomy 21, and Mosaic Trisomy 21 (Mazurek & Wyka, 2015). Standard Trisomy 21 is the most common type– comprising about 95% of cases (Gupta & Kabra, 2013). In this type, each individual body cell contains 47 chromosomes. The extra 21st chromosome is “maternal in origin and occurs due to an error in cell division known as non-disjunction during maternal meiosis 1” (Gupta & Kabra, 2013, p. 560). Translocation trisomy 21 is the second most common type– comprising between three and four percent of cases (Gupta & Kabra, 2013). In this form of trisomy 21, Robertsonian translocation causes part of chromosome 21 to translocate to another chromosome, often chromosome 14 (Gupta & Kabra, 2013). Mosaic trisomy 21 is the least common type of Down syndrome, comprising about one percent of cases (Gupta & Kabra, 2013). Unlike the previous types, mosaic trisomy 21 entails that not all individual cells have 47 chromosomes. Some have 47 chromosomes and some have the typical 46 chromosomes. Depending on the proportion of each type of cell (46 or 47 total chromosomes), this may result in a "milder phenotype" compared to standard trisomy 21 and translocation (Gupta & Kabra, 2013).

## How is Down Syndrome Diagnosed?

The diagnosis of Down syndrome can occur both prenatally and postnatally. Noninvasive prenatal screening can be followed by definite diagnostic methods for the prenatal diagnosis of Down syndrome (Vičić et al., 2017). Prenatal screening is performed solely for the purpose of risk estimation, which is the possibility the baby will be born with Down syndrome (Gupta & Kabra, 2013). Based on this estimation, the mother can make an informed decision on carrying out an invasive diagnostic test, which is associated with approximately one percent risk of miscarriage (Asim et al., 2015; Renna et al., 2013). A prenatal diagnosis allows the mother and medical providers to prepare for the birth and possible associated complications, or discuss the option of pregnancy termination (Messerlian & Palomaki, 2021).

Prenatal screening can be done in the first and second trimesters of pregnancy (Gupta & Kabra, 2013). Screening usually includes "... a combination of measuring maternal serum biochemical analytes and, more recently, the size of the fetal nuchal translucency (NT; a pouch of fluid behind the neck) in the first trimester" (Antonarakis et al., 2020, p.16). Additionally, certain physical characteristics of Down syndrome can be identified via ultrasound screening around 14 to 24 weeks of gestation which include "small or no nasal bone, large ventricles, and nuchal fold thickness" (Asim et al., 2015, p. 4). However, a definite diagnosis of Down syndrome cannot be made via ultrasound because a baby born with Down syndrome may have a normal prenatal ultrasound (Antonarakis et al., 2020).

Diagnostic tests are also used prenatally by karyotyping the fetal cells and are usually performed for women who are undergoing high-risk pregnancies, such as mothers over the age of 35 (Alfirevic et al., 2017). These diagnostic methods include amniocentesis and chorionic villus sampling (CVS) (Asim et al., 2015; Renna, et al., 2013). Early amniocentesis and CVS can be performed in the first trimester of pregnancy. However, the risk of miscarriage for amniocentesis is greater when performed in the first trimester compared to the second trimester (Alfirevic et al., 2017). Amniocentesis consists of a needle inserted into the amniotic space, where amniotic fluid will be extracted and examined for the chromosomal abnormality indicative of Down syndrome (Alfirevic et al., 2017). Chorionic villus sampling is also an invasive procedure, where either a needle is inserted into the mother's abdomen or a catheter is inserted into the mother's cervix to extract placental cells for examination (Alfirevic et al., 2017). Amniocentesis and CVS both increase risk to the fetus compared to the non-invasive screening methods for Down syndrome (Alfirevic et al., 2017). Other prenatal diagnostic methods include rapid aneuploidy testing: fluorescent in situ hybridization (FISH), quantitative fluorescence PCR (QF-PCR), and multiplex ligation-dependent probe assay (MLPA) (Asim et al., 2015).

Although a postnatal diagnosis can be made clinically, the gold standard is to confirm the diagnosis via chromosomal analysis, such as karyotyping a blood sample (Gupta & Kabra, 2013; Ostermaier, 2020). This analysis will verify the presence of an extra chromosome 21 but takes approximately two to three weeks to get results. Additionally, molecular cytogenetic methods (such as FISH) can be used for rapid diagnosis of trisomy 21. However, a karyotype is necessary to determine which type of trisomy 21 is present (Gupta & Kabra, 2013).

## Medical Presentation and Complications of Down Syndrome

At birth, individuals with Down syndrome present with distinct physical characteristics. Some specific physical characteristics include a flat nasal bridge; small mouth; protruding tongue; speckled iris; short and broad neck, hands, and fingers; and an increased space between 1 and 2 toes (also known as a sandal gap) (Gupta & Kabra, 2013). Additionally, newborns can also present with specific features that aid in the diagnosis of Down syndrome, including a flat facial profile, dysplastic ears, upward slant of palpebral fissures, abundant neck skin, a small middle phalanx of the 5th finger, hypotonia, hyper-extensibility, hyper-flexibility, and lack of Moro reflex (Gupta & Kabra, 2013).

There are various complications associated with Down syndrome. These individuals are more likely to develop "hypothyroidism, autoimmune diseases, obstructive sleep [apnea], epilepsy, hearing and vision problems, [hematological] disorders (including leukemia), recurrent infections, anxiety disorders and early-onset Alzheimer disease (AD)" (Antonarakis et al., 2020, para. 2). Additionally, 40-60% of individuals with Down syndrome will have congenital heart disease such as complete atrioventricular septal defect, tetralogy of Fallot, and other septal defects (Michael & Marder, 2021).

## Health Disparities

A major disparity for individuals with Down syndrome is access to health care (Booth, 2011; Lotstein et al., 2008; Nugent et al., 2018). Health care access is often influenced by insurance status and the availability of medical providers that are equipped to care for individuals with Down syndrome (Booth, 2011). Specifically, these individuals experience challenges with health care access as they transition from pediatric to adult care (Booth, 2011).

Due to improvements in pediatric care for Down syndrome, the current median life expectancy is into the sixth and seventh decade of life (NADS, 2018). With increased life expectancy comes the need to minimize health disparities, especially during the transition into adult care. Appropriate resources for this transition are crucial to ensure these individuals continue to receive adequate care into adulthood (Booth, 2011).

In a cross-sectional survey regarding the access to care for individuals with special health care needs, Lotstein et al. (2008) established two main concerns for the transition into adult care: health insurance and consistent care. This population not only includes individuals with Down syndrome, but also other medical conditions, especially congenital heart disease and cystic fibrosis (Lotstein et al., 2008). Overall, five difficulties were encountered by these individuals during their transition: no established source for regular care, unmet medical needs, delayed or forgone care in the past six months, underinsured, or uninsured (Lotstein et al., 2008). However, insurance status was not found to be a reliable predictor of better-established care because two-thirds of those that did not have an adequate source of established care had insurance. Therefore, access to care is not only related to insurance status, but also to having a consistent source of care or a medical provider advocating for the individual’s health (Lotstein et al., 2008).

The ultimate goals for adequate transition services include increasing life expectancy and quality of life (Nugent et al., 2018). In a study surveying children between ages 12 and 17 with special healthcare needs, it was found that 40% of adolescents with other special healthcare needs met desired goals for adequate transition in care, while only 11% of adolescents with Down syndrome met the desired goals (Nugent et al., 2018). Nugent et al. (2018) speculated that “adolescents with developmental disabilities, like Down syndrome...may be less likely than adolescents with [other special health care needs] to be encouraged to take responsibility for their care" (p. 218). Similarly, the American Academy of Pediatrics recommends that health maintenance visits begin to introduce transition and self-care at age 13 (Bull, 2011). It was found that discussing and encouraging self-care earlier in adolescence resulted in better quality of life outcomes, such as furthering education, community involvement, maintaining employment, and fewer behavioral problems (Nugent et al., 2018).

In addition to difficulties with accessing healthcare transition services, medical care is also expensive for individuals with Down syndrome (CDC, 2020). The cost of medical care for individuals with Down syndrome averaged four times higher than for individuals who did not have Down syndrome (CDC, 2020). Families of those with Down syndrome are affected financially with about 40% of families requiring a family member to stop working in order to provide needed care for their child with Down syndrome (CDC, 2020).

Other forms of disparities for individuals with Down syndrome include genetics, social circumstances, environmental determinants, and individual behaviors (Booth, 2011). Genetic components of an individual determine underlying conditions that may arise (Booth, 2011). Not only is there a higher risk for comorbidities, but these comorbidities also require special medical attention (Booth, 2011; McGrath et al., 2011). Social disparities for these individuals may include a lack of socialization or increased susceptibility for abuse (Booth, 2011). Environmental disparities include a dysfunctional system of care or differing living situations, such as living with other family members or in community homes (Booth, 2011). Individual behaviors include difficulties recognizing when medical attention is necessary (Booth, 2011).

Racial disparities are also prevalent throughout determinants of health for individuals with Down syndrome (Booth, 2011). For example, the median life expectancy for white individuals with Down syndrome increased from two to fifty years old between 1968 and 1997

(Booth, 2011). However, the median life expectancy for individuals identifying as African American only increased from one to twenty-five years, and individuals identifying as “other” increased from one to eleven years in the same time period (Booth, 2011). Additionally, maintaining a consistent source of health care is determined by many factors, such as ethnic background, intellectual disability, and lower socioeconomic status (Booth, 2011). Individuals with one of these factors are less likely to have adequate access to care and/or health insurance. However, when two or more of these factors are involved, there is a significant difficulty for that individual to receive appropriate medical care (Booth, 2011).

Health disparities for individuals with Down syndrome also include the availability of medical providers who are prepared to care for this population (Booth, 2011; Nugent et al., 2018). Medical provider perceptions of caring for patients with Down syndrome may depend on specialty or other personal factors, such as previous experience interacting with or caring for this population (Nugent et al., 2018). It was found that primary care providers often feel more uncomfortable than pediatric providers when caring for patients with Down syndrome. For instance, one survey found that “50% of internists viewed themselves as unprepared to deliver primary care for young adults with special healthcare needs, and 62% of pediatricians thought it would be difficult for these young adults with special healthcare needs to find an adult provider” (Nugent et al., 2018, p. 218). Therefore, not only is it difficult for these individuals to access and maintain adequate adult care, but medical providers also feel underprepared to care for this population. Consequently, there is a need to improve training for medical providers regarding care for adolescents and adults with Down syndrome (Nugent et al., 2018).

## Medical Provider Perspectives on Their Training in Delivering Unexpected News

Although medical providers must be knowledgeable about the health disparities and complex clinical features of Down syndrome, they must be equipped to deliver the unexpected diagnosis to the parents. Currently, research is limited on a universal standard for how medical providers are trained to deliver bad or unexpected news. However, there is some research on how medical providers perceive the training they receive.

In a questionnaire by Gueneuc et al. (2020), 193 medical providers were asked 47 questions regarding the presence or absence of prior training in delivering unexpected news and the quality of their training. When medical providers in this study commented about their education in proper counseling and delivery of a diagnosis, the majority felt that they were never given formal training on how to deliver bad news to patients. Out of all the medical providers who responded to the questionnaire, 65% reported they did not receive any formal training during their initial education, while 73% of the providers that did receive training reported that their training was “insufficient” (Gueneuc et al., 2020). A qualitative study by Mugweni et al. (2021) reported that medical providers often feel stressed and unprepared because they learned how to “deliver different news from the ‘see-one-do-one approach’” (Mugweni et at., 2021, p. 2). This approach entails watching a current medical provider complete a certain task or procedure, then completing the same task on their own in an attempt to reproduce or exemplify the actions or counseling they witnessed (Reardon, 2019).

Due to this lack of education, some medical providers may unintentionally frame the diagnosis delivery with implicit bias (Carroll et al., 2018). In many cases, medical providers have the assumption that the diagnosis of Down syndrome is bad news for the family. In reality, the emotions that accompany this diagnosis are individualized not only to each family, but also to each family member. The choice of language used during the delivery of the diagnosis can impact the way the family begins their journey of having a child with Down syndrome (Carroll et al., 2018).

A survey conducted by Skotko (2005) found that 63% of 499 medical providers “tried to be as unbiased as possible when delivering a prenatal diagnosis [of Down syndrome]” (p. 670). However, Skotko (2005) found that:

> 13% reported emphasizing negative aspects of DS so that parents would favor a termination, 10% actively ‘urge’ parents to terminate, and 10% indicated that they ‘emphasize’ the positive aspects of DS so that parents favor continuation, and 4% actively ‘urge’ parents to continue the pregnancy (pp. 670-671).

The impact of this implicit bias is shown in a study of 10 women who reported that they felt as if their decision to not terminate their pregnancy was influenced by how the medical provider presented the diagnosis and prognosis for children with Down syndrome (Skotko, 2005).

The initial diagnosis of Down syndrome ideally comes from a medical provider that is honest, compassionate, objective, and up-to-date on the diagnosis (Sheets et al., 2011). The diagnosis of Down syndrome is often done through noninvasive prenatal screening to first assess risk, before moving to a more invasive test to confirm the diagnosis (Gupta & Kabra, 2013; Asim et al., 2015; Renna et al., 2013). The medical provider will then counsel the patient on all the options they have regarding the new prenatal diagnosis of Down syndrome. The goal of prenatal genetic counseling is to “uphold patient autonomy regarding reproductive choices by providing personalized genetic information, exploring what the information means to the patient, explaining all options, and preparing the patient for the outcomes of their decision” (Sheets et al., 2011, p. 436). In addition to discussing challenges and realistic health concerns, medical providers should also provide access to support groups and other local resources available to the family (Sheets et al., 2011; Carroll et al., 2018). When the diagnosis is given, the medical provider should meet the patient where they are at by initiating a conversation in which they are able to freely discuss their own concerns, wishes, and values. From this open conversation, medical providers are given direction on how to address options for the needs of that patient and how to proceed (Sheets et al., 2011).

## How Does Medical Provider Counseling Impact Parents?

Research into how medical providers are trained in delivering unexpected news is limited, although the literature suggests that the lack of medical provider education and training impacts how families receive and perceive an unexpected diagnosis. According to feedback from parents in a study conducted by Mugweni et al. (2021), using the term "different news" is preferred over "bad news." This preference is for two reasons:

> [Firstly], the term bad news gives a negative connotation about the child and diagnosis to families and [healthcare providers]. Secondly, different news was thought to more accurately reflect the idea that news about the diagnosis is different from what parents expected about their child but not necessarily bad (Mugweni et al., 2021, p. 1).

Literature reveals that the method of delivery can lead to a wide range of negative emotions (Mugweni et al., 2021). For instance, studies show a "correlation between maternal anxiety and the focus of the initial conversation when [healthcare providers] delivered different news" (Mugweni et al., 2021, pp. 1-2).

In a study done by Skotko (2005), mothers of children who were diagnosed with Down syndrome prenatally were sent a survey to evaluate the process of receiving the diagnosis and if it could have been improved. This cross-cultural study with mothers from both Spain and the

United States was based on a previous study that had only 10 participants. The main results from the study were "...negative terminology or accentuation of difficulties was found to be quite unhelpful and resulted in long-term resentment" (Skotko, 2005, p. 671). The small study was expanded in order to get results and feedback from a larger population. The mothers from the larger study reported three suggestions that would have made the overall process of receiving the diagnosis easier. These suggestions included: "the diagnosis be conveyed in person, that up-to-date printed materials on Down syndrome (DS) be provided, and that mothers be referred to local DS support groups" (Skotko, 2005, p. 672). The study by Mugweni et al. (2021) noted that positive outcomes of delivering the prenatal diagnosis of Down syndrome come from proper support and access to information, allowing parents to "[adjust] well to the diagnosis; [show] patterns of resilience; [and have] reduced symptoms of anxiety and depression and improved quality of life" (Mugweni et al., 2021, p. 2).

On Friday, October 8th, 2021, Jack's Basket held its fifth annual gala called "You Make Me Better" where they raised over $500,000 to support the non-profit organization ("Our Annual Gala," 2021). At the gala, Leah Isakson– lawyer, wife, and mother of five children shared how she was personally impacted by receiving the diagnosis of Down syndrome. Isakson received the news that her baby was diagnosed with Down syndrome over the phone, without her husband present. The news was delivered by her medical provider with hesitation, regret, and followed by condolences. Over the course of her pregnancy, she was offered to terminate her daughter's life multiple times. Medical providers would refer to a timeline, which was the amount of time that Isakson had to terminate the pregnancy. The medical providers justified their reasoning for asking about the timeline each visit due to protocol. Due to the negativity and bias Isakson received from medical providers throughout her pregnancy, she felt "ashamed to be expecting a baby with Down syndrome, like I had done something wrong, or that I should have to apologize for her existence” (L. Isakson, personal communication, October 8, 2021).

Reflecting on the experience of her pregnancy with daughter Isabel, Isakson feels a lot of regret. At the gala for Jack’s Basket, Isakson shared her story with many medical providers in hope that they can learn from her experience and reframe the diagnosis to support the patient’s values. Isakson and Isabel’s story is only one of many stories involving families who are negatively impacted by the diagnosis and prenatal care experiences (L. Isakson, personal communication, October 8, 2021).

## Conclusion

Individuals with Down syndrome can be diagnosed prenatally or postnatally, and present with various clinical features and comorbidities that are unique to each individual (Vičić et al., 2017; Gupta & Kabra, 2013; Michael & Marder, 2021; Antonarakis et al., 2020). With increasing life expectancy, there is a need for improvement in healthcare transition services and lifelong individualized care to continue to increase life expectancy and enhance the quality of life for these individuals (Booth, 2011). Many medical providers, besides pediatricians, report feeling unprepared to adequately care for individuals with Down syndrome. Therefore, there is a limitation in access to primary care providers for adults with Down syndrome (Nugent et al., 2018).

Additionally, medical providers frequently encounter hardships while delivering unexpected news to patients (Gueneuc et al., 2021). Throughout the didactic portion of training, medical providers do not receive standardized education on how to approach the delivery of unexpected news prior to their clinical experience (Gueneuc et al., 2021). The lack of training for medical providers can lead to implicit bias due to feeling unprepared and anxious. Consequently, the parent’s perceptions and acceptance of the unexpected diagnosis can be negatively impacted (Carroll et al., 2018).

This community service project will be accomplished by collaborating with Jack’s Basket to create a survey to send to Minnesota families who previously received a basket from the organization. The researchers will also submit an Institutional Review Board approval application on behalf of the organization. The following chapter will outline the methodology, tools, population, potential barriers, and rationale of the project.

# Chapter 3: Methodology

## Introduction

This community service project was created to fill the gap in the literature regarding diagnosis delivery and parental acceptance of their child diagnosed with Down syndrome. Medical provider education and improved diagnosis delivery are necessary to alleviate the fears of parents and help them celebrate their child (Carroll et al., 2018). Jack's Basket currently needs assistance with the collection of data to enhance their current educational materials for medical providers on how to best deliver the diagnosis of Down syndrome. Through collaboration with Jack's Basket, the researchers constructed and obtained IRB approval for a survey to be sent to Minnesota basket recipients. Jack's Basket will be able to utilize the data collected from the survey to analyze the impact the diagnosis delivery has on parents, as well as the impact Jack's Basket has on the basket recipients, for the purpose of furthering medical provider education.

This chapter will address the methods used to create a survey with Jack's Basket and review the actions needed in order to apply for IRB approval. Additionally, this chapter will include the rationale, population, plan and implementation of this project. The project tools and potential barriers will also be explained.

## Rationale for Project

Currently, Jack's Basket holds virtual presentations across America to help educate medical providers on how to deliver an unbiased diagnosis of Down syndrome (C. Carroll, personal communication, November 3, 2021). These presentations lack current data related to the impact of Jack's Basket and the education of medical providers on parental acceptance of the child diagnosed with Down syndrome. This information would assist medical providers in understanding the impact the diagnosis delivery has on the recipient. Therefore, this community service project is needed to expand the organization's resources for educating current medical providers on how to deliver unexpected news. Jack's Basket will utilize the IRB-approved survey to gather parents' perspectives on their child's Down syndrome diagnosis experience in order to strengthen future educational resources for medical providers on the impact of an unbiased diagnosis, as well as a family's access to support and resources. Therefore, the data collected from this survey will help educate medical providers on reframing the diagnosis delivery using neutral terminology and raising awareness that organizations like Jack's Basket exist.

## Population

The participants for this survey will be limited to adults, above the age of 18, who have had a child diagnosed with Down syndrome and received a Jack's Basket in the state of Minnesota between 1/1/2018-12/31/2021. Jack's Basket will send the survey using the contact information collected through their "Basket Request Form," which includes approximately 4,000 individuals. All individuals must provide informed consent prior to responding. Those who do not provide consent will not be permitted to continue with the survey.

## Project Plan and Implementation

The researchers involved in this project collaborated through email and Zoom meetings with team members from Jack's Basket. The team members include Carissa Carroll, Melody Schwartzbauer, Rebecca Olson, and Erin Plummer. All individuals involved were given the opportunity to provide input on potential discussion topics via a shared Google Document, then a rough draft of potential survey questions was developed. An independent market research consultant also reviewed and provided input on the survey. After all individuals were given adequate time to review the survey questions, a final draft of questions was established.

After finalizing the survey, the researchers applied for Bethel University's Institutional Review Board (IRB) approval on behalf of Jack's Basket. Due to the sensitive nature of the survey, Bethel University Level 1 IRB approval was required (“Instructions for Review,” 2022). The process of gaining IRB approval involves multiple steps. First, each researcher involved in the study must complete the training required by the Collaborative Institutional Training Initiative (CITI) Program. For this specific project, all researchers completed the “Master’s Student Basic Course” through Bethel University. This basic course included twelve modules with required readings and quizzes.

The IRB proposal for this project was submitted on February 8th, 2022. There are multiple documents needed in order to create an application for submission to the IRB. These documents include a checklist for Bethel University’s IRB approval, a request for approval of research with human participants, and an informed consent form. Written permission for the researcher's involvement was obtained from Jack’s Basket and was submitted with the IRB approval application (see Appendix A).

The “Request for Approval of Research with Human Participants In Social and Behavioral Research” document contains all information necessary in order to submit the project for approval (“Instructions for Review,” 2022). This document included basic identifying information including the date, who is conducting the study, the title of the project, any keywords that need to be defined, the duration of this project, the research advisor, and what is being studied. The approval request also contained information on the participants, such as inclusion and exclusion criteria for those eligible to respond to the survey, and how the participants were contacted. The risks were identified prior to submission to the IRB, as well as how the researchers could minimize the risks. The invasion of participant privacy is minimal, and the voluntary nature of the survey helps to mitigate this risk, as well as the individual’s ability to withdraw their participation at any time.

The request for approval also discussed the design of this study as well as the protocol in place for survey responses. Upon opening the Google Form to complete the survey, the participants started with informed consent. This consent included information on what the survey entails, the names of the specific individuals and the organization distributing the survey, and the title of the project. The consent also addressed the survey's objective, the rationale behind the selected population of participants, the potential risks and benefits, and the sensitive nature of the survey. The participants were ensured that their privacy will be maintained due to the deidentification of the responses and that participation in this survey is voluntary. The participants were asked if they would like to continue based on the presented information. Once informed consent is obtained, Jack's Basket shared instructions on how to complete the survey. The de-identified responses will then be retrieved via Google Forms by the primary investigator, Carissa Carroll from Jack's Basket, who will be able to visualize the data for future analysis.

## Project Tools

In collaboration with Jack's Basket, the researchers created a survey to be submitted for IRB approval. Upon finalizing the survey, IRB approval (see Appendix B) was granted before the researchers released the survey to Jack's Basket for distribution. This survey included a mix of multiple choice and short answer responses asking basket recipients about their child's Down syndrome diagnosis delivery experience and their input on the resources provided by Jack's Basket. The first portion of the survey inquired about the type of medical provider who delivered the diagnosis, if there was a prior relationship established with this provider, the specific words used in the diagnosis delivery, and the overall rating of the diagnosis experience. In the second portion of the survey, the participants were asked if receiving a Jack's Basket was encouraging, if they used any of the resources provided in the basket, and which resources were most helpful.

## Ethical Implications and Potential Project Barriers

The intent of this survey is to assist Jack's Basket in their need for data on the impact of diagnosis delivery and resources on parental acceptance of the diagnosed child. A barrier to this data collection includes limited participation in the survey. Jack's Basket hopes for a 25% response rate from invitations to 4,000 participants. However, if a lower percentage of people respond to the survey, the data collected may provide a less accurate representation than a larger pool of individuals. Participants will also be restricted to Jack's basket recipients in the state of Minnesota, limiting the total number of potential participants.

In an attempt to avoid these barriers, a reminder of the participant's opportunity to engage in the survey was emailed following the initial distribution of the survey, and approximately one month was given for participants to respond. The number of survey participants may also be affected due to the sensitive nature of this project. Those who do not want to be reminded of their diagnosis experience may decide to forgo the opportunity to participate. However, this survey has obtained IRB approval, and participants are made aware of the content through informed consent. The voluntary nature and pre-approved materials allow for this project to be conducted in the most ethical and professional manner.

## Conclusion

The data collected from the survey will benefit the organization by allowing them to analyze and share the findings with medical providers in order to improve the delivery of a Down syndrome diagnosis. An additional aim of this research is to improve the diagnosis experience for parents and support the acceptance of their new child. The next chapter will discuss the project in further detail, also addressing the importance of this project as well as how the continuation of this project will provide an impact.

# Chapter 4: Discussion

## Introduction

The aim of this community service project was to assist Jack's Basket in the creation of an ethical tool to collect current data on the diagnosis delivery of Down syndrome and feedback on the organization's current programming. Therefore, the researchers applied for and received IRB approval for the survey, which included creating an informed consent form to provide to the participants of the survey. The following chapter will discuss the results of the community service project, feedback provided by Jack's Basket, limitations of the project, and recommendations for future projects to expand on the outreach to medical providers with the data collected from this community service project.

## Summary of Results

The initial diagnosis of Down syndrome inherently entails giving unexpected news that should be delivered without provider bias (Carroll et al., 2018). However, there is currently no standardized framework on how to provide appropriate counseling to patients receiving unexpected news. In an attempt to mitigate this lack of standardized framework, Jack's Basket currently offers educational presentations for medical providers on delivering unexpected news through an unbiased lens. Part of the organization's mission is educating medical providers on using neutral terminology to discuss the diagnosis of Down syndrome.

After completing the literature review and communicating with Carissa Carroll, the founder of Jack's Basket, the researchers identified a need to expand current data on how medical providers deliver a diagnosis of Down syndrome. Additionally, a needs assessment conducted with Jack's Basket explored the organization's request for current data to incorporate into their medical presentations and outreach resources. Updating the available data will benefit the organization’s ability to improve educational resources for medical providers and for individuals with Down syndrome.

This community service project aimed to expand the current data by assisting the organization in creating a survey to send to Minnesota basket recipients. The researchers also completed and submitted an IRB application on behalf of the organization to ensure the survey met ethical standards. This application also involved creating an informed consent form to provide to the participants before beginning the survey.

After completion of the community service project, Jack’s Basket received feedback from the survey participants that provided them with three identified areas of improvement for their organization: communication to new members, volunteer engagement, and data regarding diagnosis experience. In addition to improvements in these three areas, Jack’s Basket plans to publish the results of the survey with the medical providers on the organization’s board of directors. Jack’s Basket also expressed a future need for assistance with spreading their mission through connecting with healthcare providers, sharing their tools, and communicating the survey results from this community service project.

## Limitations

The goal of this community service project was to support the creation of an ethical tool in the collection of survey data by Jack’s Basket. The survey was emailed to 4,000 Jack’s Basket recipients in Minnesota, with the goal of a 25% response rate (1,000 individuals). There were 525 survey returns for a response rate of 13.1% . Several limitations of the survey have been identified for this project: response rate and biased data. These are the barriers that potentially contributed to a lower response rate: a limited scope of invitations, participants choosing to forgo the survey for various reasons, and the timing of the survey in relation to when families received the basket.

The first limitation identified was the low response rate to the survey. Invitations were only sent to basket recipients in Minnesota resulting in small sample size and thus a low response rate. Expanding into multiple geographic locations could increase responses, and in turn, collect data that is more representative of the population served by Jack's Basket. An additional cause of low response rate could be a result of the survey not being received by the intended person if they did not check their email, forgot to respond, or who had new contact information. Those who did receive the survey may have chosen to forgo the survey due to the sensitive nature of the questions involved, or due to the negative emotions and details that may resurface.

The timing of the survey may have impacted the response rate. The survey was sent to Minnesota basket recipients on March 9th, of 2022 and included those who received a basket from 1/1/2018-12/31/2021. Therefore, basket recipients were reflecting on a diagnosis experience that occurred between three months to four years ago. This time gap could have led to a lower response rate because those who received a basket four years ago may not have felt the need to reflect on their experience due to it occurring so long ago.  Additionally, the response rate could have been lower if those who received a basket within the last year felt too overwhelmed to share their diagnosis experience.

The second limitation of the survey is the potential for biased data from the participants. The individuals that responded to the survey may have recalled detailed information incorrectly. This limitation refers to recall bias in which individuals have trouble recalling information, especially from a potentially emotionally-charged experience, because our brains are always rewriting, changing, or even losing old memories (Prince, 2012). Recall bias can occur due to an emotional or traumatic event which consequently changes the event in their mind. Therefore, this could lead to incorrect or biased recollection of information while taking the survey.

The research team was excited that Jack’s Basket received responses from 525 individuals and is hopeful that this survey will help identify where medical providers are lacking in education on delivering the diagnosis of Down syndrome. By identifying this lack of education, Jack’s Basket plans to enhance educational materials for medical providers with the goal of improving how the diagnosis is delivered moving forward. A secondary outcome the research team hopes will occur, with a better diagnosis experience, is a family’s overall acceptance of the diagnosis.

## Further Projects

When a needs assessment was conducted with Jack’s Basket, Carissa Carroll addressed the opportunity to enhance the organization's current educational presentations for medical providers on the importance of an unbiased diagnosis delivery. Various avenues were available to the research team to help address the need. However, in an attempt to use time and resources most efficiently, the research team narrowed down their course of action, leaving many opportunities to further expand beyond this current community service project.

Jack’s Basket plans to implement the data collected from this project for the purpose of educating medical providers on the importance of a neutral diagnosis delivery. Future researchers can collaborate with a data analyst or statistician to assist in the analysis of the data collected from the survey created for this community service project. In addition, other projects may include implementing the data collected from this project’s survey via medical outreach initiatives. These initiatives may include creating videos and pamphlets to convey the current data that was collected. These initiatives will teach medical providers the importance of a neutral diagnosis delivery. Another future project may include creating new surveys to address additional research questions that have the potential to further enhance the current data available to Jack's Basket.

Future research projects will be decided in collaboration with the organization, Jack's Basket. The projects will be based on the organization's needs, which are subject to change. Future researchers will have the ability to build on this current community service project to positively impact the organization and its outreach in their own way.

## Conclusion

Jack's Basket is a growing organization aimed at positively impacting the lives of individuals involved on both sides of delivering an unexpected diagnosis of Down syndrome. Their outreach has greatly expanded over the years since their founding in 2014. With a growing organization comes ever-changing goals. Jack's Basket is driven with intentions to assist as many individuals as they can. Although briefly addressed in this project, many of this organization's goals remain and are evolving.

The purpose of this community service project was to create an ethical tool for Jack's Basket to collect current data on the diagnosis delivery of Down syndrome. Through this method, the researchers were able to impact not only the organization, but also families receiving the unexpected diagnosis of Down syndrome. There are still many opportunities for other researchers to impact the organization's outreach in a positive way.

A literature review revealed limited data regarding how the delivery of the diagnosis of Down syndrome impacts the family's acceptance of their child. This emphasizes the importance of future research projects to assist in expanding knowledge regarding this topic, as well as the importance of Jack's Basket and their mission. Additional research regarding the delivery of unexpected news may influence educational materials for medical providers, the individuals receiving unexpected news, and Jack's Basket.

This community service project successfully assisted Jack's Basket with collecting data that will further enhance their presentations aimed at educating medical providers on delivering an unbiased diagnosis of Down syndrome by using neutral terminology. This project also aimed to collect the data ethically and efficiently, which was ensured via IRB review and approval. The process of gaining IRB approval and the creation of the consent form taught the researchers the importance of ethical data collection. Gaining IRB approval for the survey increased awareness and educational growth by stressing that the participants of the survey were properly informed. This was accomplished by disclosing information and acknowledging the sensitive nature of the content. The researchers also gained a better understanding of the time, efforts, and impact research can have on individuals and the community.

Throughout this project, the researchers gained a deeper understanding of the impact medical providers have on their patients. Jack's Basket expressed the importance of medical providers having an unbiased approach to diagnosis delivery on how an individual will react to the unexpected news they are receiving. The researchers plan to share this knowledge with other clinicians and reflect on the learning in their future careers. They will also spread awareness of this organization and their mission to colleagues and families in order to best advocate and connect patients with the appropriate resources.

Finally, the researchers gained a better understanding and appreciation for non-profit organizations like Jack's Basket. The organization's core values of advocacy for patients and connecting them to organizations dedicated to and specialized in bettering the lives of impacted families through education, support, and resources aligns with the personal and clinical values of the researchers. This project has allowed for growth in many aspects, including the knowledge of the research team.

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# APPENDIX A:

## IRB Request for Approval

Checklist for Bethel University IRB Application

Instructions: Please ensure all steps are completed prior to submission. Failure to meet all criteria may lead to the application being sent back to you without review and will delay formal review and the start of your project.

_√___ 1. All researchers have completed the CITI training and I have attached the completion certificates to my application.

_√___ 2. I have fully completed all required areas on the IRB "Request for Approval Form" including indicating "N/A" for those areas that do not apply.

_√___ 3. I have included all research materials in an appendix to my application. This includes all materials to be used during the study (questionnaires, tests, interview questions, solicitation letters, detailed research protocol, supporting documents) as well as any ~~verbal~~ instructions I will give to participants. → survey and instructions

_√___ 4. I have included a detailed description of the sample, how the sample will be recruited, AND the recruitment materials I will use. I acknowledge that I need to submit any advertisements, emails, postings, or request documents to the IRB and have included them as an appendix with my application.

_√___ 5. If I am collecting data from members of an organization (school, business, university other than Bethel, prison, etc.), I have received prior written permission from the proper administration of that organization and have attached it as an appendix or appendices to my application.

_N/A_ 6. If I am collecting information from a protected class, such as children, I have prepared a separate informed consent for those who are legally responsible for consent.

_√___ 7. The informed consent document I have prepared includes all the necessary fields as outlined by the Bethel IRB Informed Consent Guidelines.

_√___ 8. The informed consent is free from jargon or technical terms or when those terms are used an appropriate non-technical definition is included.

_√___ 9. I have described any risks to the participants in the both the IRB application AND the informed consent document.

_√___ 10. I have described how I will attempt to mitigate the risk to participants in the IRB application materials.

_√___ 11. I have addressed how I will keep participant information both private and confidential during my project.

_√___ 12. I have explained any potential risks to privacy and confidentiality in the informed consent as well how I will work to minimize these risks.

_√___ 13. My application includes a summary of the research process and procedures that is written for a general audience. That is, any jargon or technical terms are clearly explained.

**For office use only:**

Code number ______________________________ Action:

Date reviewed ______________________________

# Request for Approval of Research with Human Participants In Social and Behavioral Research

## Institutional Review Board for Research with Humans
**Bethel University**
**P.O. Box 2322**
**3900 Bethel Drive**
**St. Paul, MN 55112**

College and Federal policies require that each project involving studies on humans be reviewed to consider 1) the rights and welfare of the individuals involved; 2) the appropriateness of the methods used to secure informed consent; and 3) the risk and potential benefits of the investigation. Bethel has a three-level review structure, such that not all research proposals need to come to the IRB committee. The levels of review and their associated criteria may be viewed on Bethel's website. **Research may not be initiated prior to formal, written approval by the appropriate committee or person.**

The information on the following pages is necessary for review. Answer each item thoroughly, and put N/A for those that do not apply. Label each piece of information by section letter (A – G), item number (1, 2, etc.), and the boldface headers for each item. **Proposals lacking information will be returned without review**. Attach your typewritten pages to this cover sheet.

Submit the completed form to the committee, either at the above address or, if this is Bethel student research, to your research advisor. You *will not* receive this proposal back, so be sure you keep a copy of the materials you submit. You will be notified by letter of the committee's decision.

A. **Identifying Information**

1) **Date** 02/06/2022

2) **Principal Investigator** –

Carissa Carroll
1170 Red Fox Road
Arden Hills, MN 55112
651-482-8076
info@jacksbasket.org

3) **Co-investigators** –

Hanna Badke, Katherine Cooley, and Christine Luce
Bethel University Physician Assistant Graduate Program
3900 Bethel Drive, St. Paul, MN, 55112
(651) 635-8000
Email addresses and phone numbers:
hanna-badke@bethel.edu // 586-419-0695
k-cooley@bethel.edu // 224-425-9090
christine-luce@bethel.edu // 608-769-8125

4) **Project Title-** Impact of Diagnosis Delivery on Parental Acceptance of Child with Down Syndrome

5) **Keywords** – Down syndrome, Diagnosis experience, Parental Acceptance

6) **Inclusive Dates of Project** – Data collection: March 4, 2022 through April 1, 2022 (approximate). Reporting the results: May 2022 (approximate)

7) **Research Advisor** –

Research Chair: Alicia Klein, PA-C
Bethel University's Physician Assistant Graduate Program
3900 Bethel Drive, St. Paul, MN, 55112
alicia-klein@bethel.edu
(651) 635-8042

8) **Funding Agency** – Not applicable.

9) **Investigational Agents** – Not applicable.

B. **Participants**

1) **Type of Participants** – The participants will be adults who had a child diagnosed with Down syndrome. These individuals have also received a basket from the organization, Jack's Basket. The baskets are care packages that include infant gifts, information about the diagnosis, and affirming messages from other parents of children with Down syndrome.

2) **Institutional Affiliation** – Bethel University Physician Assistant Master's Program

3) **Approximate Number of Participants:** Hope for 25% response rate from invitations to 4,000 participants

4) **How Participants are Chosen** – Jack's Basket will use their program records to identify email addresses provided by basket recipients to send the survey. The email addresses were voluntarily provided to Jack's Basket via the Basket Program on a Basket Request Form. These recipients are adults who have had a child diagnosed with Down syndrome who received a Jack's Basket between 1/1/2018-12/31/2021.

5) **How Participants are Contacted** – Participants are contacted via their personal email that was provided to Jack's Basket.

6) **Inducements** – Not applicable.

7) **Monetary Charges** – Not applicable.

**C. Informed Consent** – Attached.

**D. Abstract and Protocol**

1) **Research Question and Design** –

**Research question**: Does the diagnosis delivery and/or support from organizations like Jack's Basket impact the parent's acceptance of their child?

**Design**: The participants will be sent a link via email to a 23 question survey hosted on Google Forms. The survey will ask individuals who received a Jack's Basket about their Down syndrome diagnosis experience and feedback on programming and basket items.

2) **Protocol** – The organization, Jack's Basket, will invite approximately 4,000 individuals to participate. The participants will receive an email link to a Google Forms survey. The survey form will begin with an informed consent (attached) followed by instructions (below) to complete an anonymous survey regarding their Down syndrome diagnosis experience and provide feedback for the organization. The potential risks and benefits of participating will be addressed. The participants will have a brief description of what the survey will be used for in the informed consent. The participants will be informed of the sensitive nature of the survey and asked if they would like to continue based on the information presented. Once the participant completes the survey, they will submit their responses anonymously through Google Forms. The de-identified responses will then be retrieved by Jack's Basket personnel.

**Instructions** (provided after informed consent): Thank you for taking the time to complete this survey for Jack's Basket. We hope to gain a better understanding of the Down syndrome diagnosis experience and feedback on our current programming. The results will be used to improve our diagnosis advocacy and basket programs. All responses are anonymous. The survey should take approximately 5-10 minutes to complete.

**E. Risks** –

1) **Privacy** – The survey will be limited to multiple choice and a few open-ended questions. All responses are anonymous and de-identified. Therefore, no personal information will be collected with the responses. If any open box questions are used by the organization or researchers, no personal information will be linked to the response. Any self-identifiers used in the responses provided by the participants will be removed. Access to the de-identified responses will be limited to only a few approved individuals.

2) **Physical stimuli** – No known risk identified.

3) **Deprivation** – No known risk identified.

4) **Deception** – No known risk is identified.

5) **Sensitive information** –The survey contains sensitive topics that may elicit an emotional response for some participants. The survey will begin with an informed consent which will address the sensitive nature of some questions. At this time, the individual will be able to determine if they wish to proceed. The survey questions will use neutral terminology, as to not bias the participant. The questions will also use terminology that respects that the topic may give rise to recollections of past experiences that may have been distressing for some individuals.

6) **Offensive materials** – No known risk identified.

7) **Physical exertion** – No known risk is identified.

**F. Confidentiality** – The collection of data from these individuals will be supervised by Carissa Carroll, the founder and executive director of Jack's Basket. Participants will respond to the survey through the Google Forms platform. When a participant's response is submitted, the Google Form will not collect email addresses. This will allow for responses to be anonymous. Only necessary personnel will have access to the responses being collected. These individuals include Hanna Badke, Katherine Cooley, Christine Luce, Carissa Carroll, Melody Schwartzbauer, Rebecca Olson, Erin Plummer, and Steven Cooley. The data will be collected through the Google Forms platform linked to the organization's primary email (info@jacksbasket.org). This account is password protected and only Carissa Carroll (Executive Director), Melody Schwartzbauer (Operations Manager), and Kali Cox (Administrative Assistant) know the password. The individuals participating in this survey will be referred to as Jack's Basket families, to avoid any identity markers, such as gender. All questions will be multiple choice or open box questions, limiting the chance to directly identify which participants actively participate in the survey, and which do not. The de-identified response data will be analyzed, summarized, and published in the researcher's master's thesis. Jack's Basket will be listed as the organization which administered the survey. However, specific responses collected from the individuals that freely responded will be untraceable and all personal identifiers will be absent. The data will be kept electronically via google forms until the data is analyzed.

**G. Signatures** –

"I certify that the information furnished concerning the procedures to be taken for the protection of human participants is correct. I will seek and obtain prior approval for any substantive modification in the proposal and will promptly report any unexpected or otherwise significant adverse effects in the course of this study."

*Carissa Carroll*
*Melody Schwartzbauer*
*Kali Cox*
*Hanna Badke*
*Katherine Cooley*
*Christine Luce*
*Rebecca Olson*
*Erin Plummer*
*Steven Cooley*
*Alicia Klein*

**Date**: 02/06/2022

# Consent Form

You are invited to participate in a survey regarding your child's Down syndrome diagnosis experience and involvement with Jack's Basket. We hope to gain a better understanding of the diagnosis experience and feedback on our current programming.

Approximately 4,000 individuals will be asked to participate in this survey. You were selected for this study because you are a recipient of a Jack's Basket and have provided your email to the organization.

If you decide to participate, you will fill out a 23 question survey to assess your personal experiences, including mostly multiple choice and a few open-ended questions. **This survey will take approximately 5 to 10 minutes to complete.**

## Purpose:

The purpose of this study is to assess how the delivery of the diagnosis of Down syndrome affects families receiving the news. The intent is to better understand the relationship between the diagnosis delivery method and how the family perceives their diagnosis.

## Risks of Participating:

Some individuals may experience temporary discomfort associated with recalling this personal experience. We recognize that some of the questions include sensitive topics such as details and emotions involving your diagnosis experience. If at any time, you wish to discontinue your participation in the survey, you may simply exit out of the survey and no data will be collected. You may also refuse to answer certain questions.

## Benefits:

Research participants will be contributing to our knowledge base about the impact of diagnosis delivery and may feel good about helping our research efforts. Some may feel pride in adding to better diagnosis experiences for other families.

## Confidentiality:

Your participation in this research is completely anonymous. No information you share can be traced to you. The responses from this survey will be collected by Jack's Basket and analyzed by students from Bethel University's Physician Assistant Graduate Program for a master's thesis project. The de-identified survey data will only be released to the Bethel Physician Assistant students for analysis and reporting.

We may share our findings in publications or presentations. In any written reports or publications, no one will be identified or identifiable and only aggregate data will be presented.

## Summary:

Your participation is voluntary. Your decision whether or not to participate will not affect your future relationship with Jack's Basket in any way. If you decide to participate, you are free to discontinue participation at any time without affecting such relationships.

This research project has been reviewed and approved in accordance with Bethel's Levels of Review for Research with Humans. If you have any questions about the research and/or research participants' rights or wish to report a research related injury, please call:

Researchers:
Carissa Carroll, 651-456-8321
Hanna Badke, 586-419-0695
Katherine Cooley, 224-425-9090
Christine Luce, 608-769-8125
Alicia Klein, 763-486-3803

Bethel University's IRB Chair:
Peter Jankowski, 651-638-6901

Please print or save this screen of the consent form for your records.

**Agreement to Participate:**

Your participation is completely voluntary and you can withdraw at any time. By continuing, you confirm that you have read the above information and agree to participate in this research project.

To agree and take the survey, please click on the button below to start. Thank you.

## Diagnosis Survey Questions

Thank you for taking the time to complete this survey for Jack's Basket. We hope to gain a better understanding of the Down syndrome diagnosis experience and feedback on our current programming. The results will be used to improve our diagnosis advocacy and basket programs.

All responses are anonymous.

The survey should take approximately 5-10 minutes to complete.

### DIAGNOSIS EXPERIENCE

1. **How would you rate your child's Diagnosis syndrome diagnosis experience? Negative (1) Positive (5)**
    - 5
    - 4
    - 3
    - 2
    - 1

2. **What emotions did you experience after receiving your child's diagnosis? (Check all that apply)**

    Anger
    Excitement
    Fear
    Grief
    Hope
    Joy
    Peace
    Relief
    Shock
    Sadness

3. **Was the diagnosis before birth or after birth?**

    Before birth
    After birth

4. **How was your child's diagnosis of Down syndrome given?**

    In-person
    Over the phone
    Other

5. **Did you have your partner/support person present?**

    Yes
    No

6. **Who gave you the news that your child has Down syndrome?**

    Your OB
    Another OB
    Nurse
    Pediatrician
    Genetic counselor

Neonatologist
Other

7. **Do you feel like your provider was prepared for the diagnosis conversation?**
   Yes
   No

8. **What words or phrases were used by the provider when you got your child's diagnosis of Down syndrome (Check all that apply)**
   Abnormal
   Bad news
   Congratulations
   Challenges
   Chance
   Concerns
   Defect
   Difficult
   Disabled
   Disorder
   Future
   Hope
   I'm sorry
   Quality of life
   Risks
   Suffering
   Unexpected
   Other:

9. **What information were you given? (Check all that apply)**
   A connection with a parent raising a child with Down syndrome
   Medical information regarding the diagnosis
   Connection to a local Down syndrome organization
   Adoption
   Termination
   No information given
   Other (add box)

10. **What would you have liked more information on? (check all that apply)**
    A connection with a parent raising a child with Down syndrome
    Medical information regarding the diagnosis
    Connection to a local Down syndrome organization
    Adoption
    Termination
    No additional information needed
    Other (add box)

11. **When reflecting on your child's Down syndrome diagnosis experience, did the delivery of the news by the provider impact your acceptance of the diagnosis?**
    Yes
    No

12. **What was helpful in accepting your child's diagnosis of Down syndrome?**
    ____________________

13. **What would you change about the diagnosis experience?**
    ____________________

14. **Before birth diagnosis: Were you asked about pregnancy termination following the diagnosis?**
    Yes
    No

15. **Do you feel like your choice regarding termination was respected?**
    Yes
    No

**BASKET EXPERIENCE**

16. **When did you receive your Jack's Basket?**
    Before birth
    After birth

17. **Did you feel encouraged and/or supported when you received your Jack's Basket?**
    Yes
    No

18. **Did you feel that a parent connection made a positive impact on the start of your journey with your baby?**
    Yes
    No

19. **Did you connect with any of the following organizations as a result of receiving your basket? (Check all that apply)**

    Early intervention (Help Me Grow)
    Hope Story
    GiGi's Playhouse
    Julia's Way
    DSDN
    Local Down syndrome organization

20. **What were the three items that were MOST encouraging or impactful in your Jack's Basket? (Check up to three)**
    **-**Letter from parents who have children with Down syndrome
    **-**Blanket
    -Hats/booties/burp cloths
    -Onesie
    -Winkel
    -Board books
    -Bloom and/or An Uncomplicated Life
    -Signing Times video
    -Julia's Way brochure
    -DSDN brochure
    -Gigi's Playhouse brochure
    -Local DS org
    -Welcoming a Newborn / Diagnosis to Delivery book

-Bloom by Kelle Hampton
-47 Strings by Becky Carey
-Hope Story booklet

21. **What item would be most helpful to add to a Jack's Basket?**
____________________

22. **Have you gotten involved or connected with your local Down syndrome organization?**
Yes, within the first year
Yes, after the first year
No, not interested
No, too busy
No, do not have a local organization
Other

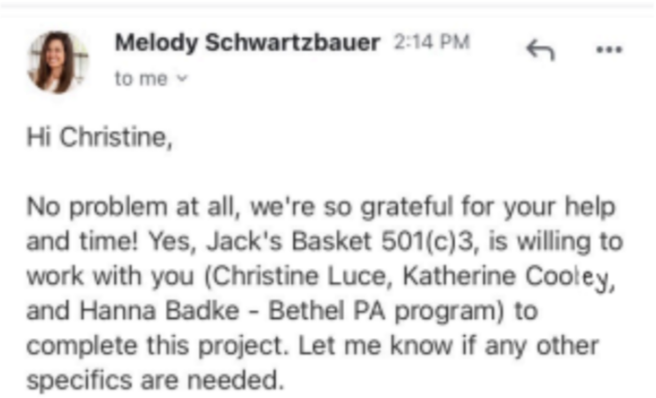
23. **Finally, please provide any additional thoughts or comments you would like to share regarding your experiences with your child's diagnosis and Jack's Basket**
____________________

Thank you. Your responses will help us improve our understanding and programming.

**Email Template to Recipients:**

> *Dear {{{Recipient.FirstName}}},*
> *You are receiving this email because your family received a basket from Jack's Basket sometime in the past four years. Would you be willing to take a five to ten-minute survey about your diagnosis experience and your experience receiving a Jack's Basket?*
> *You can complete the survey here. (link to survey)*
> *Your feedback is anonymous and helps us to better understand your experiences in order to improve our programs.*
> *Thank you!*

**Permission from Jack's Basket:**



**Melody Schwartzbauer** 2:14 PM

to me

Hi Christine,

No problem at all, we're so grateful for your help and time! Yes, Jack's Basket 501(c)3, is willing to work with you (Christine Luce, Katherine Cooley, and Hanna Badke - Bethel PA program) to complete this project. Let me know if any other specifics are needed.

# CITI Certifications:

CITI PROGRAM

Completion Date 01-Feb-2022
Expiration Date 01-Feb-2024
Record ID 46886370

This is to certify that:

**Hanna Badke**

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

**Masters students**
(Curriculum Group)
**Masters students**
(Course Learner Group)
**1 - Basic Course**
(Stage)

Under requirements set by:

**Bethel University**

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w5a5e46e4-98bc-423b-8760-11887e4da174-46886370

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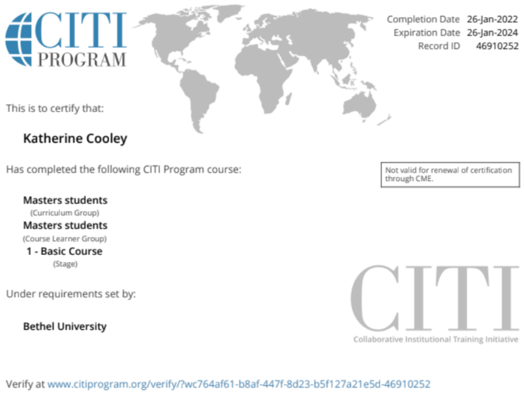

CITI PROGRAM

Completion Date 26-Jan-2022
Expiration Date 26-Jan-2024
Record ID 46910252

This is to certify that:

**Katherine Cooley**

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

**Masters students**
(Curriculum Group)
**Masters students**
(Course Learner Group)
**1 - Basic Course**
(Stage)

Under requirements set by:

**Bethel University**

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?wc764af61-b8af-447f-8d23-b5f127a21e5d-46910252

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CITI PROGRAM

Completion Date 27-Jan-2022
Expiration Date 27-Jan-2024
Record ID 46896286

This is to certify that:

**Christine Luce**

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

**Masters students**
(Curriculum Group)
**Masters students**
(Course Learner Group)
**1 - Basic Course**
(Stage)

Under requirements set by:

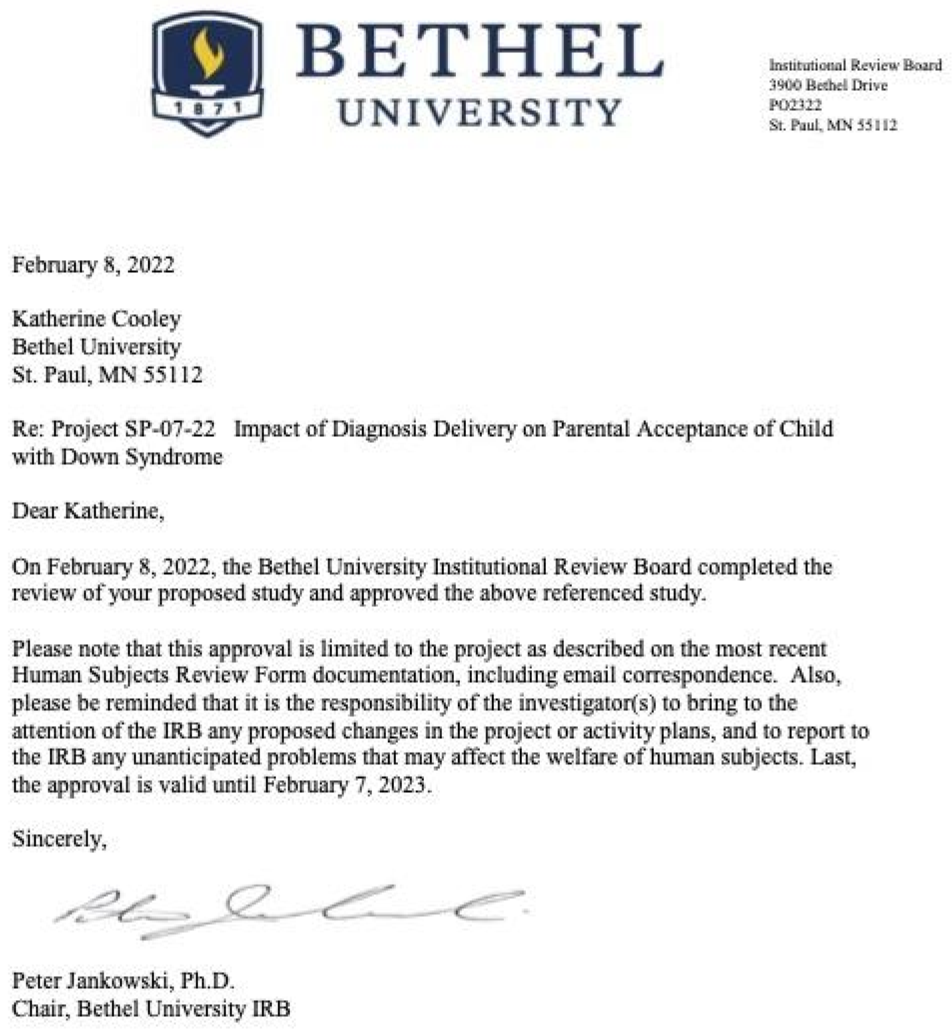
**Bethel University**

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w748147d1-5eb6-4331-bfc2-80f1f8053742-46896286

# APPENDIX B:

## IRB Granted Approval Documentation



BETHEL
UNIVERSITY

Institutional Review Board
3900 Bethel Drive
PO2322
St. Paul, MN 55112

February 8, 2022

Katherine Cooley
Bethel University
St. Paul, MN 55112

Re: Project SP-07-22 Impact of Diagnosis Delivery on Parental Acceptance of Child with Down Syndrome

Dear Katherine,

On February 8, 2022, the Bethel University Institutional Review Board completed the review of your proposed study and approved the above referenced study.

Please note that this approval is limited to the project as described on the most recent Human Subjects Review Form documentation, including email correspondence. Also, please be reminded that it is the responsibility of the investigator(s) to bring to the attention of the IRB any proposed changes in the project or activity plans, and to report to the IRB any unanticipated problems that may affect the welfare of human subjects. Last, the approval is valid until February 7, 2023.

Sincerely,

Peter Jankowski, Ph.D.
Chair, Bethel University IRB