Nothing Down About It: Decreasing the Fear of the Unknown for Mothers’ expecting a child with Down Syndrome

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Nothing Down About It: Decreasing the fear of the unknown for Mothers’ expecting a child with Down Syndrome

Alexandra E. Greenburg

A Capstone Project for the Bachelor of Arts in Human Development and Family Studies
Introduction

Down Syndrome is a chromosomal abnormality that is associated with an intellectual and developmental delay. This is because there is an extra full or partial copy of the 21st chromosome called Trisomy 21, which is diagnosed prenatally or at birth. Parents of children with Down syndrome felt that health professionals displayed a lack of understanding and ignorance when delivering their child’s Down syndrome diagnosis (Mengoni & Redman, 2018). This may lead to concerns on the child’s quality of life and hinder timely appropriate intervention services for a child with Down syndrome. This is why I conducted a workshop in Claremont, California providing guidance, information, and resources to expectant mothers who have just found out their child has Down syndrome providing them guidance, information, and resources.

Needs Statement

According to the Centers for Disease and Control Prevention (2017), 1 in every 700 babies are born in the United States with Down syndrome, making Down syndrome the most common chromosomal condition. When children with Down Syndrome are given adequate family support, they are more likely to live a fulfilling life. The stigma on Down Syndrome portrays that children growing up is not one of normality, but family support influences any infant’s well being as they grow up even if they have Down Syndrome (Cunningham, 1996).

Infants with Down Syndrome face physical and language challenges. According to the National Down Syndrome Society (2019), parents can give a great amount of support and encouragement when interacting with their infants. Different early intervention services help parents meet their child’s specific needs and enhance their development. Findings suggest that toddlers with Down Syndrome exhibit the greatest delays in motor milestones (Horovitz &
Matson, 2011). A study addressed how the onset of walking typically ranges from approximately 9–17 months and participants with Down Syndrome fell outside this range with about 17.45 months (Horovitz & Matson, 2011). Other common developmental areas children experience delays in consist of physical and communication development like sitting up, rolling, crawling, walking, listening, understanding, and speaking (Dragoo, 2018). Mothers can help foster their child’s developmental milestones by promoting these challenges in a way that will enhance their development.

Early intervention for infants with Down Syndrome consists of speech/language therapy, occupational therapy, and physical therapy and specific activities that are created to address children with disabilities (NDSS, 2019). These services are crucial for infants with Down syndrome. The Individuals with Disabilities Act (IDEA) is a law that mandates free programs and special education services for children with disabilities from birth through 21 years old (Dragoo, 2018). Programs such as speech and language therapy, physical therapy, and occupational therapy will enhance the development of infants with Down syndrome and minimizes their potential for developmental delay (Dragoo, 2018). In a 25-year longitudinal study by Hanson (2013), children with Down Syndrome participated in programs where they were taught to crawl, walk, follow directions, and feed themselves from birth to 3 years. Parents were involved in the implementation of all their child’s services throughout the entire study (Hanson, 2013). The children were followed up when they reached the age of 25 years old. All the participants who were in the program demonstrated these skills, rather than a group of infants with Down syndrome who did not receive early intervention services. The goal of this study was to strive for parents to support and teach their infants in daily life tasks. Once the study was
complete, the parents who participated listed receiving early intervention services as the most crucial support their child can receive (Hanson, 2013). It is important that expectant parents who receive a diagnosis of Down Syndrome know the options for enhancing their infant’s development.

Every individual has the right to education, whether or not they have a disability. After age 3, the Individuals with Disabilities Act (IDEA) mandates that all school districts provide a free, public education for children with disabilities beginning at the age of 3 (NDSS, 2019). In the 1900’s, students with intellectual and physical disabilities throughout the United States were isolated from general education classrooms in the school systems to avoid disruption towards other students (Phelps, 2003). Beginning in 1954, The Brown v. Board of Education took place, which established the “separate but equal,” which laid the foundation for disabled students, where they began to have rights throughout their education process (Phelps, 2003). Students are either evaluated or referred for special education by the parents or the primary care physician. The process begins by the parents requesting an evaluation from the local school district, then the request gets addressed by the special education coordinator or the principal (Longe, 2011). Next the school district will set up a meeting with the parents to explain the procedures and gather information about the child, which includes an evaluation to determine which classroom setting is the best option for the child (Longe, 2011). The parents and school staff will develop an Individualized Education Program (IEP) for the child. It is important that expectant parents know their children with Down syndrome have the right to education in a public school system.

Many health care professionals are not fully prepared to advise parents about the incidences of Down syndrome, advancements in diagnosis, and the correct protocols to receive
DECREASING THE FEAR OF THE UNKNOWN FOR MOTHERS’ EXPECTING A CHILD WITH DOWN SYNDROME

the right care and treatment of babies born with Down Syndrome. This leaves the parents with a lot of concerns and uncertainty of their child’s quality of life. This is why there is a high need for a workshop for mothers, that will address early intervention services, the educational process, and ways to foster their child’s physical and language developmental milestones.

The goal of this workshop is for parents to feel comforted and given a great amount of information on Down Syndrome, with hope their child will have a better upbringing. Gaining knowledge about their child can possibly reduce stress and fear that comes with raising a child with a disability. Some of the topics that will be addressed at the workshop will include early intervention services, the education process, and physical and developmental milestones.

**Theory and Development Application**

Bronfenbrenner’s Bioecological Systems theory can be applied to my project. The theory focuses on the importance of the quality and context of a child’s environment as the child grows cognitively and physically. Bronfenbrenner describes that as a child develops, their interactions in society are influenced off people which affects the child’s individual developmental outcomes (Ashiabi, & O’Neal, 2015). The developmental outcomes are based off multiple proximal processes systems: the microsystem, mesosystem, macrosystem, and exosystem. According to Bronfenbrenner’s theory, the microsystem is the immediate relationship in which the child lives. Therefore the infant’s development in this case is influenced by what their parents do at home with their children. As the mothers are helping their child do daily tasks, the infant with Down Syndrome will enhance their development. Microsystems also involve organizations and group settings the child interacts with. The infant with Down syndrome will be attending multiple early intervention programs and special school programs where they interact with others and will be
influenced off their immediate environment. In addition, according to Bronfenbrenner’s theory the exosystem level has a secondary effect on an individual’s developmental outcome because the individual is participating in a setting not actively (Ashiabi, & O’Neal, 2015). In this stage, mothers with a child with Down syndrome are their child’s biggest advocate. How much the parent is involved in their child’s life will affect the child with Down Syndrome because the types of resources and agencies the parents attend will take affect in the child’s life.

Bronfenbrenner also suggests, the individual must engage in activity to be effective, the activity must take place on a regular basis over an extended period of time, and become increasingly more complex (Ashiabi, & O’Neal, 2015). Since children with Down Syndrome experience developmental and intellectual delays, it may be particularly useful for mothers’ to be informed about resources in the community and different agencies that will allow the mothers’ to implement the resources into their child’s life, so they can reach normative developmental milestones. So far, many mothers are uneducated about Down Syndrome leading them to not be able to fully grasp what resources their child needs to reach optimal development and have a good quality of life. Therefore, I am creating a workshop to educate and better prepare mothers’ on raising their child who has down syndrome.

**Consideration of Diversity**

My project was conducted and geared toward mothers who are expecting a child who has Down syndrome. The workshop took place in Claremont, located in California. In addition, the National Survey of Children with Special Health Care Needs (2012), shows in Los Angeles County, 5.7% of individuals have an Intellectual Disability. Data also shows 27.4% of children with special needs received early intervention services and 72.6% of children with special needs
did not receive early intervention in California (NSC, 2012). The high percentage for children who did not receive early intervention services tells me that the mothers who participated in my workshop gained crucial information about services their child can get and possibly integrate them into their life once they’re born. As a result, the high percentage of children who did not receive early intervention services will decrease. The different cultural variations in Los Angeles County could play a role in why the above percentages in California vary in parents who seek early intervention services for their child with special needs.

I designed the project, knowing that I might have a culturally diverse group of participants, given the location in Los Angeles County. The ethnic composition of the mothers’ who will be attending ought to reflect Los Angeles County. The county of Los Angeles is known to be culturally diverse, with a population estimate of 10,105,518 individuals (USCB, 2018). According to the United States Census Bureau (USCB, 2018), Los Angeles county is 70.8% Caucasian, 9.0% African American, 15.4% Asian, 1.4% American Indian, 0.4% Pacific Islander, and 48.6% Hispanic or Latino. My participants reflected the diversity characteristics. Religion also plays an important role in people’s lives which could stigmatize that raising a child with Down Syndrome is frightening and an indignity society (Almeida, Arteaga, Blume, & Huiracocha, 2017). Given this stigma in some cultures, I will be working to impart positive views of Down Syndrome to mothers during my workshop.

**Learning Outcomes**

I provided one, 50-minute workshop to mothers who have just been diagnosed with a Down Syndrome Diagnosis. Children with Down Syndrome can have a good quality of life if the
mothers are provided with information about resources and different agencies throughout the community, that help their child reach full potential.

By the end of my workshop participants will be able to do the following:

1. list the early intervention resources that their child needs to ensure their quality of life
2. list information on how to begin educating their child.
3. identify ways to foster their child’s physical and language developmental milestones.

**Method**

My capstone workshop took place on November 16th at the Claremont Club, which is located in the city of Claremont, California. Below is information on the participants, procedures and materials that were used.

**Participants**

A total of 6 mothers who are expecting a child with Down Syndrome attended my workshop. Recruitment was not too difficult because my family is highly involved in the Down Syndrome community. A close family friend of mine has Down Syndrome. Therefore, the mother of the son who has Down Syndrome reached out to her friends in the Down Syndrome Association and was able to ask expectant mothers to attend. Each mother was in a different trimester period of their pregnancy. The age group of mothers ranged from 28–42 years old. The group was culturally diverse: Two participants were Caucasian, one was Asian, and three were Hispanic/Latino. All mothers who attended my workshop spoke proficient English.

**Procedures and Materials**

First, I introduced myself to the mothers and thanked them for taking the time to attend. Next, I had each mother fill out a presurvey which was accessed through my powerpoint
DECREASING THE FEAR OF THE UNKNOWN FOR MOTHERS’ EXPECTING A CHILD WITH DOWN SYNDROME

presentation. See Appendix A. The pre survey focused on the learning outcomes and asked about the mothers knowledge about Down Syndrome before the presentation. Once all the mothers completed the presurvey, I held a meet and greet activity. During this activity each mother would shake hands with another, share brief information, and lastly talk about their Down syndrome diagnosis experience. The introduction, presurvey, and meet/greet activity took a total time of 20 minutes to complete.

I then went on to present the powerpoint presentation that focused on my 3 learning outcomes. See Appendix B. I began the presentation by stating that their child will have their own strengths and leave a positive impact on their family. Next, I discussed Early Intervention services, beginning with their child’s educational process, and lastly ways parents can foster their child’s physical and language developmental milestones. I then concluded my powerpoint presentation with open questions from the mothers. The powerpoint presentation and questions took a total of 25 minutes.

Lastly, I concluded my workshop with a post assessment survey for the mothers to fill out. See Appendix D. Mothers were asked a series of questions on how they felt about the workshop and questions specifically addressing the learning outcomes. I devoted one specific question regarding each learning outcome in the post assessment survey that would determine if the goal was fully met, partially met, or not met. As the mothers were completing the post assessment survey, I handed them a few resources on helpful information about their child. See Appendix E for resources. The post assessment survey took the mothers 5 minutes to complete. The total time of my workshop was 50 minutes.
Results

Learning outcome 1 was that mothers would be able to list the early intervention resources that their child needs to ensure their quality of life (i.e., physical, occupational therapy, etc.). I believe this learning outcome was fully met. Before my powerpoint presentation I had the mothers fill out a presurvey. One of the questions I asked the mothers was to list a few early intervention services for their child and 2/6 of the mothers said “I don’t know.” The other 4 out of 6 mothers were able to list 1 to 2 early intervention services. A list of responses can be found in Table 1. In the powerpoint presentation, I focused on describing the importance and benefits of speech and language therapy, physical therapy, and occupational therapy for their child. The results of the post survey assessment proves learning outcome 1 was fully met. In the post survey assessment, I asked the mothers to list a few types of early intervention services their child can receive. This was also asked in the presurvey to compare and determine the amount of knowledge each mother had on these services. The responses indicate 6 out of 6 of the mothers were able to list the different types of early interventions that exist for their child (i.e., physical, occupational therapy, etc.) The average amount of responses listed was 2. The ratio from lowest to highest number of services listed was 1:3. Results can be found in Table 2.

Learning outcome 2 was that mothers would be able to list information on how to begin educating their child. The pre survey indicates an average score of 6/6 of the mothers knew what the IDEA Act stood for when seen. During the Powerpoint, I introduced and explained the steps to beginning the education process for their child with Down Syndrome. After the Powerpoint presentation, each mother filled out the post survey. See Appendix D. Question #4 on the post survey, specifically asks the mothers on a scale of 1-10, how prepared do they fill when it comes
to starting the education process. The lowest score was a 7 and the highest was a 10. The average score was an 8.5. See Table 5 for scores. Also in the post survey, I asked the mothers to list the steps to the education process for their child. An average of 5 out of 6 mothers listed the steps. One mother stated, “Still a little confused about the overall process, but I know now what IEP means and I am now aware that my boy has the right to education no matter what others tell me.” I feel like this is evidence that learning outcome 2 was partially met.

Learning outcome 3 was that mothers would be able to identify ways to foster their child’s physical and language developmental milestones. The pre survey indicates only 16.7% of the mothers answered “No timetable,” when asking if they knew the age their child should reach their developmental milestones. See Figure 2 for responses. The other 83.3% of mothers answered 8 months, 2 and 4 years. In the post survey, the same question was asked. Results displayed 100% for answering “No timetable.” See Figure 3. All mothers answered correctly. The last thing I did to analyze this learning outcome was ask the mothers, “Which services will help foster your child’s physical and language developmental milestones.” This was asked in the post survey. 83.3% of mothers checked, “Both 1 & 3,” which was Occupational therapy and Speech/ Language therapy. The other 16.7% of mothers answered just C. See Figure 1 for results. Both responses from the mothers were correct. I believe this learning outcome was fully met because all the mothers were able to identify ways to foster their child’s developmental milestones.

Discussion

The focus of my capstone project was to provide guidance to mothers who are expecting a child with Down Syndrome. When mothers receive the Down Syndrome diagnosis they are
often left with many stressors and fear that comes with raising a child with a disability. By giving mothers the resources and information on services their child can receive can help ensure their child will have a better upbringing. I believe this workshop was successful. The mothers were curious and engaged in the information and activities that were being done. Mothers expressed that they highly benefited from this workshop and were grateful they attended. Learning outcome 1 and 3 were fully met, while Learning outcome 2 was partially met. I still believe the workshop was an overall success because each mother felt they would learn crucial information that would help their child’s quality of life. The results were consistent with Bronfenbrenner’s Bioecological Systems theory. The infant’s development is influenced off of their mothers knowledge on what they will be doing with them at home (microsystem), the programs the child is placed in (microsystem), and special school programs (microsystem). This is why the mothers developmental characteristics worked well on the information they gained at the workshop.

In terms of diversity, I think my project was inclusive for targeting mothers who are expecting a child with Down Syndrome. I presumed that the mothers would have more knowledge about Down Syndrome and children with special needs before they arrived at the workshop. Also, in discussing Down Syndrome some cultures and individuals could have a stigma on people with disabilities.

My capstone project had a few limitations. Learning outcome 2 was only partially met. I believe I could of made this fully met, if I went slower and a little more in depth on the specifics of the educational process. Another limitation is that it was only a 1 time, 50 minute workshop. This meant that I was limited to topics to cover. I chose to focus on the ones I believed were most crucial for the mothers to know. In the future, I could strengthen my project by making it a
series of workshops covering different topics, and focusing on each one longer. Lastly, I would love to expand my capstone project for future work. If I were to do this I would advertise my workshop more and host it in different locations. I am excited to expand on this in the future. Overall, this project exceeded my expectations and expanded my knowledge on the importance of educating mothers who are expecting a child with Down Syndrome.
References


https://www.ndss.org/about-down-syndrome/down-syndrome/


U.S. Census Bureau: *Quick facts Los Angeles County, California* (2018.). Retrieved from
https://www.census.gov/quickfacts/fact/table/losangelescountycalifornia#.
Table 1

Presurvey Results Assessing Learning Outcome #1

List a few early intervention services for your child? If you do not know, simply type "I don't know"

6 responses

<table>
<thead>
<tr>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech therapy and Physical therapy</td>
</tr>
<tr>
<td>Occupational therapy and Speech language therapy</td>
</tr>
<tr>
<td>I don't know</td>
</tr>
<tr>
<td>physical therapy</td>
</tr>
<tr>
<td>Physical therapy</td>
</tr>
<tr>
<td>i don't know</td>
</tr>
</tbody>
</table>
**Table 2**

*Post Survey Results Assessing Learning Outcome #1*

List a few early intervention services for your child?

6 responses

| My child can receive therapy, do exercises, and other activities that will help enhance their motor skills and self-help skills |
| language therapy |
| physical therapy |

| going to an occupational therapist and speech therapy will help my child! I learned that I can do certain activities with my child to help grow their motor skills |
| Occupational therapy, physical therapy, and speech / language therapy |
| Ot, physical therapy, language therapy |
| physical therapy |
| occupational therapy |
| language-speech therapy |
### Table 3

**Learning Outcome #2 Postsurvey results**

<table>
<thead>
<tr>
<th>List the steps on beginning your child's education process?</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 responses</td>
</tr>
<tr>
<td>finding the best school district</td>
</tr>
<tr>
<td>creating an IEP plan for my child</td>
</tr>
</tbody>
</table>

First we need to find a school nearby that will meet my child's needs and then they will begin the evaluation process to decide if my child needs an IEP which is a plan that will help my child meet his goals throughout the school year.

1. find a school
2. communicate with teachers to see what my child needs
3. evaluation process
4. teachers will create an Individualized Education program for him if we decide we would like to attend that school

Still a little confused about the overall process, but I now know what an IEP means and I am now aware my boy has the right to education no matter what others tell me

first we have to look for the best school around locally that has special education!
After we find the best school we then will set up an evaluation process when my baby girl is ready. Once the evaluation process is over the teachers will create an IEP plan for her
Figure 1

Postsurvey results Learning Outcome #3

Which services will help foster your child’s physical and language developmental milestones. Check all that apply.

6 responses

- 1. Occupational Therapy (83.3%)
- 2. Swimming Lessons
- 3. Speech and Language therapy
- 4. Psychology therapy
- 5. Both A & C (16.7%)
Figure 2

Presurvey Percentages of Mothers identifying the age their child should reach their developmental milestones

Do you know what age your child should reach their developmental milestones?

6 responses

- 50%: no timetable
- 33.3%: 2 years
- 16.7%: 4 years
- 8 months
Figure 3

Postsurvey Results of Mothers identifying the age their child should reach their developmental milestones

What age should your child reach all their developmental milestones?
6 responses

- 100% of responses are within the range of 2 years.
Table 4

List of responses from mothers' emotions after the workshop

What are some emotions you're feeling after completing this workshop?

6 responses

<table>
<thead>
<tr>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel hopeful that my child will have a great life</td>
</tr>
<tr>
<td>I am so happy I attended Allie's workshop because I feel so much more knowledgeable on what steps and best routes to take for my child.</td>
</tr>
<tr>
<td>I am feeling more hopeful for my child, before I was lost. I am so excited for this journey</td>
</tr>
<tr>
<td>I am glad I came. I am still nervous, but I feel more excited for my child</td>
</tr>
<tr>
<td>happy and thankful I attended this because I do not feel lost anymore</td>
</tr>
<tr>
<td>grateful and relieved because this workshop gave me peace and clarity on certain subjects I was unaware about</td>
</tr>
</tbody>
</table>
Table 5

*Scale scores for each mother’s feelings on educating their child*

On a scale of 1-10, how prepared do you feel when it comes to starting your child in the education process?

6 responses
### Appendix A

#### Pre survey Questions

**Do you know someone in your life who has Down syndrome?**
- [ ] Yes
- [ ] No
- [ ] Maybe

**Do you know the different types of early intervention services that your child can receive?**
- [ ] Yes
- [ ] A little
- [ ] No clue

**List a few early intervention services for your child? If you do not know, simply type “I don’t know”**

Your answer

**Do you know what age your child should reach their developmental milestones?**
- [ ] 2 years
- [ ] 4 years
- [ ] 8 months
- [ ] no timetable

**What does IDEA stand for?**
- [ ] Individual Donor Education Act
- [ ] Individual with Disabilities Education Act
- [ ] Other

**Was your doctor helpful in providing you information about your child?**
- [ ] So helpful!
- [ ] A little
- [ ] No, I feel lost
Appendix B

Powerpoint Presentation

Nothing Down About It

Capstone workshop by Alexandra Greenburg

CONGRATULATIONS on your child!
About me

Hi Mother’s! My name is Allie Greenburg

- I’m a senior at CSUMB with a major in Human Development
- Currently a Special Ed. Aide for MPUSD
- Future Special Education Teacher

Today’s Agenda

1. Pre Survey
2. Meet & Greet Activity
3. Powerpoint presentation
4. Questions
5. Post Survey
Pre Survey

Click below for Pre Survey Link

https://docs.google.com/forms/d/e/1FAIpQLSfpbal8D_BwXNaQwR4FHWZv28SMzBLLQmlg7BzfQNOADlRxxw/viewform?usp=sf_link

Down Syndrome

- Your child will have his/her own strengths

- Down syndrome will have a positive impact on your family
Early Intervention Services

- Program that offers support and services for your child at no cost or for a “sliding-scale” fee.
  - Speech & Language therapy
  - Physical therapy
  - Occupational therapy

Continued...

- Minimizes potential for delay
- Low muscle tone
- Speech therapy is a critical component
  - Cognitive, visual, auditory, tactile, and oral motor skills
- Occupational/PT helps focus on motor development
  - Head control & body control strength
  - Helps master skills for independence
Beginning the Education Process

- IDEA Act
- Finding the best school
- Evaluation process
- Individualized Education Program (IEP)

Continued...

- Cam Brasington, a genetic counselor, says that,

  "More and more individuals with Down syndrome are finishing high school and moving onto secondary education... working real jobs for real pay."
Developmental Milestones

⭐ “You have to forget the timetable you reserve for other kids. Your child will succeed at his/her own pace”

Continued...

- Children experience delays in sitting up, rolling, crawling, walking, speaking

- As mother’s, you can promote your child’s challenges through activities because it will only enhance their development
A MOTHER’S ADVICE

What is one thing you wish to tell other mothers who have just had a child with Down syndrome?

“Don’t underestimate them. They are capable of so many things.”

What has your child taught you in life?

“Patience and to never ever take one moment for granted. Also not to take life so seriously.”

Resources

[Logos and names of organizations]
Heads up! Post survey on next slide

Thank You

Post Survey

Click on the link below

https://docs.google.com/forms/d/e/1FAIpQLSeVvWBNhb_WjfCiOVy1niMG9AzwD-CKWFGg2-PEsJlmmvl76A/viewform?usp=sf_link
Appendix C

Resources Provided
Appendix D

Post Survey Questions assessing all Learning Outcomes

On a scale of 1-10, do you feel like you benefited from this workshop?

Not at all ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ Yes, definitely!

List the steps on beginning your child’s education process?

Your answer

On a scale of 1-10, how prepared do you feel when it comes to starting your child in the education process?

Help me I’m lost ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ I got this
What are some emotions you’re feeling after completing this workshop?
Your answer

List a few early intervention services for your child?
Your answer

On a scale of 1-5, do you feel like you formed strong relationships/created a bond with other mothers who will have a child with Down syndrome?

\[
\begin{array}{cccccccccc}
1 & 2 & 3 & 4 & 5 & 6 & 7 & 8 & 9 & 10 \\
\text{Not really} & & & & & & & & & \text{Yes}
\end{array}
\]

What age should your child reach all their developmental milestones?

- 2 years
- No timetable
- 8 months
- 4 years

On a scale of 1-10, how knowledgable do you feel about discussing the Individual with Disabilities Education Act?

\[
\begin{array}{cccccccccc}
1 & 2 & 3 & 4 & 5 & 6 & 7 & 8 & 9 & 10 \\
\text{Still confused} & & & & & & & & & \text{I understand}
\end{array}
\]

Which services will help foster your child’s physical and language developmental milestones. Check all that apply.

- 1. Occupational Therapy
- 2. Swimming Lessons
- 3. Speech and Language therapy
- 4. Psychology therapy
- 5. Both A & C
NOTHING DOWN ABOUT IT: DECREASING THE FEAR OF THE UNKNOWN FOR MOTHERS EXPECTING A CHILD WITH DOWN SYNDROME

By Alexandra Greenburg
Human Development and Family Studies

Introduction

Down Syndrome is a chromosomal abnormality that is associated with an intellectual and developmental delay.

1 in every 700 babies are born with Down syndrome in the US

Parents of children with Down syndrome felt that health professionals displayed a lack of understanding and ignorance when delivering their child's Down syndrome diagnosis (Mengoni & Redman, 2018).
DECREASING THE FEAR OF THE UNKNOWN FOR MOTHERS’ EXPECTING A CHILD WITH DOWN SYNDROME

Needs Statement

Early Intervention Services

- Children with Down Syndrome experience physical and communication developmental delays like sitting up, rolling, crawling, walking, listening, understanding, and speaking (Dragoo, 2018).
- Occupational therapy
- Speech/Language therapy
- Physical therapy
Needs Statement cont’d

Education

- Beginning in 1954, the Brown v. Board of Education took place, which established the “separate but equal,” where disabled students had rights throughout their education process (Phelps, 2003).

- Individuals with Disabilities Act (IDEA) mandates that all school districts provide a free, public education for children with disabilities beginning at the age of 3.
Theory and Development

- The infant with Down syndrome will be attending early intervention services and special school programs where they interact with others and will be influenced off their immediate environment.
- Mothers are their child’s biggest advocate.

Learning outcomes

1. Mothers will be able to list the early intervention resources that their child needs to ensure their quality of life.
2. Mothers will be able to list information on how to begin educating their child.
3. Mothers will identify ways to foster their child’s physical and language developmental milestones.
DECREASING THE FEAR OF THE UNKNOWN FOR MOTHERS’ EXPECTING A CHILD WITH DOWN SYNDROME

**Method**

- 6 mothers
- Ages from 28-42
- Location in Claremont, California on November 16th
- Los Angeles county is 70.8% Caucasian, 48.6% Hispanic, 15.4% Asian
- Participants: 2 Caucasian, 1 Asian, 3 Hispanic/Latino

**Project Delivery**

- 50 minute workshop
- Presurvey
- Meet & Greet Activity
- Power Point Presentation
- Questions
- Post Survey
- Distributed resources to the mothers
Methods for Assessing Learning Outcomes

- Provided examples on different types of early intervention services their child can receive
- Emphasized the steps on how to educate their child
- Ideas on ways the mother can help promote their child’s physical & language developmental milestones

Learning Outcome #1

Mothers will be able to list the early intervention resources that their child needs to ensure their quality of life.

• Result: Fully Met

"List a few early intervention services for your child."
- Each mother was able to list 1 to 2 early intervention services
Learning Outcome #2

Mothers will be able to list information on how to begin educating their child.

• Result: Partially Met

“List the steps on beginning your child’s education process.”

  o 5/6 of the mothers were able to list the steps
  o 1 mother stated, “Still a little confused about the overall process, but I now know what IEP means and I am now aware that my boy has the right to education no matter what others tell me.”

Learning Outcome #3

Mothers will identify ways to foster their child’s physical and language developmental milestones.

• Result: Fully Met

“Which services will help foster your child’s physical and language developmental milestones. Check all that apply”

- 1. Occupational Therapy (83.3%)
- 2. Swimming Lessons (16.7%)
Discussion

**Successes** - The mothers expressed that they highly benefited from the workshop and were grateful they attended.
- LO 1 & 3 were fully met

**Limitations** - LO 2 was partially met
- 1-time workshop

**Diversity/Inclusiveness** - Special needs community

Future Direction

- Host workshop in different locations
- Create program where Doctors attend Down Syndrome Trainings to gain knowledge & skills on how to deliver a Down Syndrome Diagnosis
- Continue to break the Stigma that people have on individuals with disabilities
DECREASING THE FEAR OF THE UNKNOWN FOR MOTHERS’ EXPECTING A CHILD WITH DOWN SYNDROME

Questions?