Working to Understand the Social and Genetic Aspects of Down Syndrome
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Introduction
Down Syndrome is a common human genetic disorder known to cause intellectual disabilities and other health problems. This project focuses on the programs available to people in West Michigan and examines the way this disorder affects individual families. I worked with the Down Syndrome Association of West Michigan (DSAWM) to create a new-parent pamphlet that gives expecting families an idea of what it is like to raise a child with Down Syndrome and a list of resources available to them. I interviewed parents of children with Down Syndrome to learn what resources the DSAWM had provided to them and to find out the most important things for new parents to know. The current etiology of the disorder was examined through literary research.

Why Study Down Syndrome?
• There are many children with Down Syndrome in the West Michigan area and 38% of people in the United States know someone with Down Syndrome.
• The Down Syndrome Association of West Michigan is a well-established resource willing to assist me in my research.
• While Down Syndrome is known to be caused by a trisomy of chromosome 21, the exact etiology and genetic mechanisms of the disorder are not well understood.

Methods
Contacting the DSAWM
• I met with a resource development assistant who put me in contact with parents of children with DS in the West Michigan area.

Interviewing Parents
• I created 10 interview questions for parents to answer via email, personal interview, or phone interview.
• Six parents with children of varying ages responded.
• Three main questions were used for the pamphlet (right) and certain responses from each parent were chosen.

Parent Interview Questions
1. How many children do you have and what are their ages? How many of your children have Down syndrome (DS)?
2. Did you find out that your child/children had DS before or after they were born?
3. Did you have any interaction with a genetic counselor before or after giving birth? If so, how do you believe that did or did not benefit you?
4. Do you have any involvement with the Down Syndrome Association of West Michigan (DSAWM)? If so, what resources have they provided you with and which of those resources would you consider the most beneficial?
5. What do you think are the biggest (or most relevant) differences between raising a child with DS and a child without?
6. What are your concerns for your child/children as they age? Do you think they will be able to have some level of independence in adulthood?
7. How do you think having a child with DS has affected the other members of your family, either in a positive or negative way?
8. What are your concerns for you child/children as they age? Do you think they will be able to have some level of independence in adulthood?
9. What, in your opinion, is the most important thing for expecting parents of a child with DS to know?
10. Please feel free to tell me any more information/comments/concerns that you think I should know about in this section.

Creating the Pamphlet
• The pamphlet was produced using Adobe InDesign™ software with the help of writing/advertising student, Jessica Swarts.
• Information and resources for the pamphlet were gathered from materials provided by the DSAWM and from literature research.

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