Life with Down Syndrome:

Influences on the Development

Of Social Skills

An Honors Thesis (HONRS 499)

by

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Abstract

Down Syndrome is a genetic disorder that has been studied for nearly 150 years. During that time, people living with Down Syndrome have faced many adversities from multiple sources. Because they were originally seen as outcasts, most people living with Down Syndrome were originally institutionalized. This created negative notions about them as it kept them from being able to interact with their family and community. Over time, most of these notions were resolved as opportunities became available for people with Down's such as health and technology advancements, education (both about the disorder and schooling for students with Down's), and programs such as Special Olympics. Throughout my thesis, I analyze the affect that these new opportunities have had on people with Down Syndrome, mainly their social interaction. What I hope to accomplish with my thesis is to determine if a person born with Down Syndrome has a predetermined capacity/limitation toward social interaction or if that social interaction can be affected by the environment in which he or she is raised.

Acknowledgements

First and foremost I would like to thank Ryan. His life-lessons have helped me become the person I am today. He was the inspiration for my thesis and will continue to be a role-model in my life.

I would also like to genuinely thank Dave Bahlmann for his constant help and support throughout the development of my thesis. He opened me up to a sea of knowledge on a topic that I thought I already thoroughly knew. Through meeting him, I have learned not only more about Down Syndrome, but also myself.
December 10, 1981. He was born Ryan Steven Novak, the first child of my parents and in time my older brother. One would think this is a time for celebration in a couple’s life. It should be a time to be glad that God blessed you with the ability to bring someone into this world. Yet this birth wasn’t what either of the parents expected. My brother was not only born without a right arm, but he was also born with Down Syndrome. The news didn’t come until the day after the birth, when the doctor told Linda Novak that her son was actually a “mongoloid.” Yet the doctor informed them that they had the option to give him up and have him placed in an institution, so they “could lead more of a normal life.”

Brian was an orphaned child with Down Syndrome. Just prior to his second birthday in March of 1979, he was scheduled to be placed in a state institution since no one was willing to adopt him. Dave Bahlmann caught wind of this the Friday before the Monday he was to be placed. He decided that he and his wife would intervene and adopt Brian.

Danny Lynch was born just less than two years ago. It was the second child of Coach Joey Lynch and his wife. When Coach Lynch went to see his newborn son shortly after birth, the nurse approached him in tears. Worried that something was wrong, he asked the nurse what the problem was. After she composed herself, she told Coach Lynch that his child was also born with Down Syndrome.

According to the National Down Syndrome Society (NDSS), slightly more than 400,000 people in the United States live with Down Syndrome. Roughly 6,000 babies are born with Down Syndrome every year. Babies born with this chromosomal defect are at an increased risk for certain medical conditions. These include but are not limited to thyroid conditions, congenital heart defects, Alzheimer’s disease (later in life), respiratory and hearing problems, and childhood leukemia. Due to the advancements in modern medicines, the majority of these conditions can be attended to and cured allowing the child to live a much longer life. Less than 30 years ago in 1983, the life expectancy for a child with Down’s was only 25 years-old. Today it is now 60 allowing them to lead much longer, filled lives (National Down Syndrome Society).
Although it is a positive that people with Down Syndrome are living longer, it comes with a downside. Two conditions, dementia and Alzheimer’s disease, affect people with Down Syndrome more than any other condition during old age. Dementia and Alzheimer’s both cause memory loss but Alzheimer’s also affects the person’s ability to perform basic daily activities.

**Down Syndrome and Alzheimer’s**

<table>
<thead>
<tr>
<th>Age</th>
<th>Patients with DS affected</th>
</tr>
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<tbody>
<tr>
<td>30-40</td>
<td>0-10%</td>
</tr>
<tr>
<td>40-49</td>
<td>10-25%</td>
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<tr>
<td>50-59</td>
<td>20-50%</td>
</tr>
<tr>
<td>60+</td>
<td>60-75%</td>
</tr>
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</table>

*Source – Alzheimer’s Disease*

Another complication with the increase in life expectancy is the possibility that the person with Down Syndrome will outlive his or her parents. The parents then question, who is going to take care of my child? There is the option that the child can live with other siblings but when that brother or sister has a family of their own with a number of kids, taking care of someone with Down Syndrome and possibly Alzheimer’s can be a tough task. Because of this, life planning is essential for people living with Down Syndrome. Knowing where they will go in case their caregivers pass away needs to be determined in advance.

As I begin, I want to explain my roadmap for this paper. What I hope to accomplish with my thesis is to determine if a person born with Down Syndrome has a predetermined capacity/limitation toward social interaction or if that social interaction can be affected by the environment in which he or she is raised. What I mean by this is, are children with Down Syndrome born with certain skills or attributes that make them act a certain way or are those skills and attributes developed through activities and situations they become involved with during their life. I have personally met with three
people that are living with Down Syndrome and spoke with someone who recently just had a baby with Down Syndrome. By seeing what these people have been or will be getting involved with, I will see how this affects their growth, mainly in developing life skills (skills that will allow them to be contributing members of society). I will then compare certain events that they have been involved in and compare them to the events that a person without Down’s Syndrome has been involved in and see what impact the interaction in the activity has on the individuals.

Not only am I going to take personal interactions into account while developing this thesis, but also I am going to do research through other types of mediums. I would like to see if society’s past views of Down Syndrome had an impact on the social development of a child with Down’s Syndrome. For example, before the 1980’s children born with Down Syndrome were often institutionalized as the parents did not want to keep the child nor was it adopted (did this affect the child?). Now in 2011, many parents want to adopt a child with Down Syndrome with there even being waitlists to receive a child with this condition. Yet before we get into the social development of a child with Down Syndrome, let’s first talk about the condition that is Down Syndrome.

The condition now known as Down Syndrome was discovered by Doctor John Langdon Down in 1866. He noticed that a lot of the patients he was treating at his institution for mental retardation shared similar features (Brill 24-25). Because there was no name for the condition at the time, Dr. Down referred to these patients as “Mongoloids.” He used this term as the slanted eyes of the patients reminded him of the people from Mongolia (Brill 26). It wasn’t until the 1960’s when Asian doctors felt the term was racist, that scientists decided to call the condition Down Syndrome.

Down Syndrome is a genetic condition in which there is an extra copy of the 21st chromosome (Trisomy 21). Because of this, the individual has 47 total chromosomes instead of the usual 46. This causes delays in the development of a person’s physical and intellectual characteristics. Down
Syndrome occurs in about every 700 births, making it the most common chromosomal disorder. It affects all races, nationalities, and ethnicities (National Association for Down Syndrome).

From the time that Dr. Down discovered “Down Syndrome” until 1959, researchers were trying to figure out what exactly caused the genetic condition. When Dr. Down first discovered the condition, one notion was that women who received an education caused them to have retarded children, but he rejected that idea. He actually believed the cause of Down Syndrome was that one of the parents had tuberculosis. Another belief came from physician G.E. Shuttleworth in 1886 and it was that Down Syndrome was a result of an undeveloped fetus. Research continued until the 1950’s when more powerful microscopes became available. Because of this, in 1959, French doctor Jerome Lejeune discovered that Down Syndrome resulted in an extra copy of chromosome 21. This showed for the first time that Down Syndrome was a result of genetic makeup and had nothing to do with the parents (Brill 27-28).

The diagnosis of Down Syndrome is simple once the child is already born. This is because the physical characteristics are usually so distinct that it can be detected without a chromosome test. The common physical characteristics include smaller extremities (mainly nose and ears), upward slanted eyes, low muscle tone, a single crease across the palm, and a flattened face.

To confirm the visual diagnosis, a karyotype is administered which displays all of an individual’s chromosomes and this usually shows the extra 21st. The cause for Down syndrome is called nondisjunction, which occurs when cell division does not go as planned. This occurs at conception and has nothing to do with anything the mother does during pregnancy (National Association for Down Syndrome).

Many mothers are concerned about having a child with Down Syndrome and are unsure what precautions they can take to protect their child. There is currently nothing a mother can do to keep
their baby from having Down Syndrome. The only power a mother has with the chance of having a child with Down Syndrome is with what age she has the child. It is a fact that the likelihood of a woman to give birth to a baby with Down's increases with age. A common notion is that older parents give birth to the majority of children with Down Syndrome. This is both true and false. It is true that the older a woman is, the more likely she can give birth to a baby with Down Syndrome. Yet, because the majority of women over time have given birth at an early age, most Down Syndrome births come from women younger than 35 (Myths and Truths).

According to the National Down Syndrome Society, the likelihood increases only slightly in the early years. For example, at the maternal age of 21, there is a 1 in 1700 chance, or a .0006% chance. At the age of 22 there is a 1 in 1500 chance, or .0007%. Yet jump ahead to 29 where it seems more women are having children due to careers and other life events and now the likelihood is 1 in 950, or .0011%. It is when a mother gets older than 35 when it significantly increases (age 40 – 1 in 100, age 49 – 1 in 10).

<table>
<thead>
<tr>
<th>Maternal Age</th>
<th>Incidence of Down Syndrome</th>
<th>Maternal Age</th>
<th>Incidence of Down Syndrome</th>
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<tbody>
<tr>
<td>20</td>
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<td>36</td>
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<td>1 in 15</td>
</tr>
<tr>
<td>34</td>
<td>1 in 450</td>
<td>49</td>
<td>1 in 10</td>
</tr>
</tbody>
</table>

-NDSS.org
Incidence and Maternal Age

Between 1970 and 2004, the average age of a woman giving birth for the first time rose from 21.4 to 25.2 in the US. Not only did it rise, but in 2005 one in every 12 births was to a mother aged 35 or
older. In fact, the number of women between the ages of 35 and 39 to have their first child in the past 30 years has multiplied by 10 (Gregory 2-3). With a current trend of women putting off childbirth (most likely for career goals), many expectant mothers are taking measures to see if their child has Down Syndrome. Screening and diagnostic tests are available to determine the baby’s health prior to birth. The screening tests estimate the risk while the diagnostic tests give the concrete answer if the baby has Down Syndrome. Although the number is on the rise for women having children at an older age, the National Down Syndrome Society states that due to higher fertility rates in younger women, 80% of children born with Down Syndrome are being born to women aged 35 or younger.

Because women are waiting to have children at a later age and Down Syndrome occurs more in older women, wouldn’t that mean there would be an increase in Down Syndrome pregnancies? One British newspaper claimed that in 1989/90 there were 1,075 diagnoses of Down Syndrome in England and Wales. By the year 2007/08, that number had risen to 1,843, or a 71% increase (Boseley). Yet the paper does not go into detail with things such as if the diagnoses were accurate or even more important, if they took into account an increase in population growth. However, to date no definitive studies have been completed that would either confirm or deny this conclusion.

“The Triple Screen” and sonograms are the two forms of screening tests. The Triple Screen combines three blood tests to measure substances in the blood. A sonogram shows some physical traits that would indicate the baby having Down’s.

There are three diagnostic tests that can be performed today:
- Amniocentesis (test done between 12-20 weeks)
- Chorionic Villus Sampling (8-12 weeks)
- Percutaneous Umbilical Blood Sampling (after 20 weeks)

*Source – National Association for Down Syndrome*

These tests are used to alert parents if they are going to have a child with Down Syndrome and then to possibly prepare for life with the child. Before these tests were available, the child having Down Syndrome would be a surprise to the parents. Before these tests were available and Down Syndrome
being thoroughly researched, there were many ill-conceived notions. Prior to the condition being discovered and studied, many people with Down Syndrome were put into institutions as there was no community support for them as they were seen as outcasts. The benefit of being in an institution was that the person would receive a lifetime of care but it came at a cost of them rarely leaving the institution or ever seeing their families again. The majority of people with Down Syndrome did not receive an education as doctors believed they were incapable of learning (Brill 24-25).

Starting in the late 1800s, some educators noticed that patients with Down Syndrome could make progress. A 19th century physician, Samuel Gridley Howe, came up with the idea of having organized education for children with disabilities (Brill 25). He created a school and it was originally named Institution of The Massachusetts School for the Idiotic and Feeble-Minded Youth (Howe). Both Dr. Down and Howe believed that life in an institution prevented a person with Down Syndrome from leading a productive life. Being able to be active in the community was a way that would allow the person with Down Syndrome to grow socially and develop the life skills not possible in an institution (Brill 27). The important part is giving that child the opportunity that he or she needs and that starts with the parents knowing that life with a child with Down Syndrome can be promising.

"Physicians often paint a limited picture of today’s opportunities for people with Down Syndrome, and new parents, with no introductions to Down Syndrome, have nothing else to believe,“ explained Brian Skotko, author of Common Threads: Celebrating Life with Down Syndrome. “It is not until they meet other families and receive accurate information that they realize their physicians’ words are (sometimes) limiting.” (Doctors Too Negative).

In 2005, Skotko sent an 11-page survey to five different Down Syndrome parent organizations. Of the 3,000 surveys he sent, he obtained 1,250 responses. Many of the mothers reported that a majority of the physicians and nurses were “overwhelmingly” negative when their diagnosis of the fetus/newborn involved Down Syndrome. Yet as time has gone on, more recent mothers have seen the
physicians becoming more compassionate when administering a Down Syndrome diagnosis (Doctors Too Negative).

 Sitting down with my mother, Linda Novak, I asked her what her views were on Down Syndrome before having Ryan. “Prior to having Ryan we (she and my dad) knew very little about Down Syndrome. I had a neighbor once when I was younger that had a sibling with Down Syndrome and they never let her out of the house. I only saw her one time when I went into their house and I was absolutely shocked because for one, I rarely saw a child with Down Syndrome and secondly I had no idea that she had another sister. My neighbor’s family thought it would be better for everybody (i.e. the child, family and community) to keep the child hidden in the house and not to have society judge her.”

 “When Ryan was born, we just didn’t know what to do. It was our first child and we wanted to love him so much but he was...different. At that time, they were called Mongoloids. The nurse called him a Mongoloid. It sounded so ugly and he was my child. I cried. I cried for months about this because I just couldn’t accept him. We couldn’t accept him. I had to take him wherever I went because your Dad was gone (on business) but when I took him out I made sure to keep him covered up and not because it was cold out,” my mother explained.

 I then asked my mother at what point she decided that she was going to have to take care of Ryan, to start loving him and truly accepting him. “It took me six months and it took your Dad about a year. It was tough being out on our own in California (my Dad was transferred from Indiana to California one year before for work) with no family to lean on. But one day I just thought to myself, ‘God gave me this child for a reason and I need to accept it.’ From there on out I changed my attitude. I defended him and I started showing him off more. People were going to know that we had a child and we didn’t need to be ashamed about it. How we approached the situation at first was not right, but it WAS NOT easy.
We had no idea what to do and we were young. But we learned and we love him so much and wouldn’t change him for anything. He has done for us just as much if not more than what we have done for him,” (Linda Novak Interview).

When talking with Coach Lynch, I mentioned to him how society’s views on Down Syndrome have evolved over the years. “I knew the basics about Down Syndrome but having Danny was the first time we have been so closely involved with it (Down Syndrome). The doctors gave us some information about what to expect. Through talking to many people involved with Down Syndrome, we realized that Danny was going to be in a society where he would have many opportunities,” explained Coach Lynch. I then asked him how he wanted to present Danny to the public. “Well the biggest thing is we are NOT going to hide Danny. He is our child and he is a special part of our family. When we meet people, we aren’t going to go up to them and say ‘hey, this is our Down Syndrome child Danny. We are going to say this is our child, Danny.’ It’s true that not everyone will accept him. We have already faced that now but you know what, not everybody likes me and you. We will just keep introducing Danny to as many people as we can and we know his personality can take it from there,” (Lynch Interview).

Keeping a child with Down Syndrome from interacting with others would most likely have a negative affect on the child. Just as sitting in your house all of your life never talking to anybody would make you a different person, such is similar with a person with Down Syndrome not interacting in society. Coach Lynch is not only being proud of his son, but he is benefiting Danny by getting him involved. He will be able to learn many life skills by interacting with both peers and others in his community. Those life skills can be learned through everyday situations and also in programs that are available when the child is young.

Early childhood is an important time in regards to the development of a child. The child learns all the basic skills they need to survive – physical, cognitive, language, social and self-help. Growth milestones for each child can be estimated, but for children with Down’s this is a little more difficult.
These children often face delays in all aspects of growth processes. Because of this, a program called “Early Intervention” (EI) was created to try and get Down Syndrome children to the milestones they need to achieve quicker (Early Intervention – NDSS).

According to the National Association for Down Syndrome, EI is a program of therapy mandated by the federal law known as the Individuals with Disabilities Education Act (IDEA). The law simply states that all young individuals that qualify must be given the opportunity by the state to receive these services. The program is a combination of therapy and activities that are targeted towards the developmental delays that children with Down Syndrome face. The most common types of EI services are physical therapy, speech and language therapy, and occupational therapy (EI – NDSS).

A young child’s mind is like a sponge thrown into a large bowl of water – it has the ability to absorb everything. Because of this, it is important to get the child involved in EI soon after birth. The program usually lasts until the child turns three. If the child is still in need of EI services beyond that time, some groups provide services until the child enters kindergarten (EI – NDSS).

The early milestones in a child’s life are always important to the parents. The first words, crawling, standing, walking, and even the first sentence are things you typically hear parents rejoice over. Children continue to develop from the moment they are conceived on throughout their childhood and into adulthood. With children, specific milestones are achieved in four areas of development.

These areas include gross and fine motor, language skills, social development, and self-help skills. For children without disabilities, they generally achieve these milestones through their early years. For example:
<table>
<thead>
<tr>
<th>Time Frame (approximate)</th>
<th>Acquired Skill</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 months</td>
<td>Sits without support</td>
</tr>
<tr>
<td>9 months</td>
<td>Stands while holding something</td>
</tr>
<tr>
<td>11 months</td>
<td>Says “mama,” “dada” purposefully</td>
</tr>
<tr>
<td>14 months</td>
<td>Eats with fingers</td>
</tr>
<tr>
<td>19 months</td>
<td>Uses spoon and fork</td>
</tr>
<tr>
<td>14-20 months</td>
<td>Walks without support</td>
</tr>
<tr>
<td>27 months</td>
<td>Jumps with both feet</td>
</tr>
<tr>
<td>33 months</td>
<td>Holds simple conversation</td>
</tr>
</tbody>
</table>

Children with Down Syndrome will achieve the same milestones, but it will be on a much more case per case basis. For these children, it is more important to look at the fact that the child achieves the milestone and in the order that they do, as opposed to the age when it is achieved.

It is important to know that many children can develop on their own but with much more difficulty. EI is put in place to keep the child from reaching a certain point in development and then getting stuck there. Because of this, “the goal of early intervention programs is to enhance and accelerate development by building on a child’s strengths and by strengthening those that are weaker, in all areas of development,” (EI – NDSS).

Physical therapy for patients with Down Syndrome, just like in regular physical therapy, focuses on the main movements of the body. These are the motor skills that the children with Down Syndrome are generally lacking. When an infant is first growing, he/she learns to gain control of the head and to be able to sit in an upright position. Because children with Down Syndrome have low muscle tone, this is hard for the child to maintain. The physical therapy helps improve muscle tone and enables children with Down Syndrome to gain the tools necessary to achieve the milestones.

Another skill that is worked on during physical therapy is fine motor development. This involves all the activities for a child to get an understanding of its environment. Exploring a room, grabbing items, following movements with their eyes, rolling over and crawling are all important when it comes to the development of fine motor. Development of these skills is vital because children learn by
interacting with their surroundings. Being able to roam about freely within the child’s surroundings is important (EI – NDSS).

Speech and language therapy is another important aspect of EI. Although children without Down Syndrome typically say their first words around 10-12 months, children with Down’s often do not say their first words until the ages of two to three. Because of this, speech and language therapists are needed to guide the children and help them develop pre-speaking skills. Some of the techniques they use include imitating/echoing sounds (works on mouth movement), turn taking skills (in playing games), auditory skills (listening to sounds for an extended period of time), tactile skills (touch by hand and mouth), oral motor skills (tongue usage), cognitive skills (cause and effect) and visual skills (EI – NDSS).

One interesting way speech and language skills can be improved is through breastfeeding. The reason being, both breastfeeding and speech use the same physical structures in performance. By being breastfed, a child can strengthen both the jaw and facial muscles used in communication. Mothers with a child that has Down’s are strongly encouraged to breastfeed (EI – NDSS).

Because it takes such a long time for children with Down Syndrome to speak, it is common for them to learn sign language. It can be frustrating for a child to want to say or express a thought but be incapable of forming the words. By using sign language, the child with Down Syndrome can express what he or she is thinking as they have the skills with their hands but just can’t form the thought through words. The children go from using sign language as their primary way of communicating, to then mixing speaking and sign language, to finally simply speaking.

“Brian learned a lot of sign language and was able to express what he was feeling to us even though he couldn’t talk quite yet. He can still recite his ABC’s to this day and it has been 30 years since he has needed to use those skills,” Mr. Bahlmann explained.

Occupational therapy works with the skills a child needs to be independent. Examples of some of these skills include opening and closing doors, grabbing, releasing and stacking certain objects.
Everyday skills such as getting dressed, feeding one’s self, and interacting with others is taught during occupational therapy (EI –NDSS).

Early intervention teaches children with Down Syndrome the basic tools they need to interact in their environment. The use of those tools will help determine how socially interactive the child will be able to become. Just because one has the best pencil and paper known to civilization doesn’t mean one will write a piece that will be the next Pulitzer Prize in journalism. A combination of tools, skills and knowledge is needed to achieve the goal. Such is the case in social interaction. A child with Down Syndrome may be able to form words and sentences, but if he or she can’t conduct a conversation then building relationships will be much more difficult.

According to down-syndrome.org, social development includes social interactive skills with children and adults, social understanding and empathy, friendships, play and leisure skills, personal and social independence and appropriate behavior. Being socially interactive, that is creating friendships and interacting with peers, is largely influenced by the skills learned during EI. These include social independence, speech and language abilities, and any amount of cognitive delay. The majority of individuals with Down Syndrome are able to act in a way that is appropriate for their age. The ones that are unable to are the individuals that have developed behaviors that limit their social interaction. The development of social skills is important to all individuals as those activities influence almost all the activities in your day-to-day life. Developing friendships, the ability to socialize, and simply taking care of yourself is all a result of your social development (DSE).

Because expanding on your social skills typically requires interaction with others, it is important to be able to understand the feelings of the person with whom you are interacting. Being able to carry on a conversation with someone is one of the building blocks of social development. It has been said that most individuals with Down Syndrome, starting when they are young children, have a keen sense of
other’s emotions. As was stated before, it typically takes a child with Down Syndrome longer to be able to start speaking and forming sentences than another child without Down’s. Yet because so much of communication is non-verbal, often times a child is able to understand how an able-speaking person is feeling without understanding the words that are formed. Many authors and researchers have concluded that individuals with Down Syndrome have relatively good social skills. By possessing these social skills, children with Down’s tend to be better socially equipped than other children with “similar levels of cognitive and communication delay,” (DSE).

Even though the majority of children with Down Syndrome can decipher the non-verbal skills, it would be a mistake to think that this is a feature all of the children possess. Just as every child is different when it comes to achieving milestones in development, every child is different socially. How the child interacts is influenced by a variety of factors. These factors include “temperament, experiences in the family, school and community and the way they are treated by others.” Social interaction is also affected if the child has another condition such as autism. It is important in this situation to remember that the degree of social skills could be affected by Down Syndrome or autism (DSE).

The development of a child socially is a process that begins the day the child is born. Because the people that see the infant the most are the parents and care takers, they have a powerful influence on this development. Because every child and parent is different, the types of relationships are endless. “Development is a dynamic and interactive process in which the (behaviors) of children and parents influence each other, and the children’s ongoing experiences influence their development in addition to their biological makeup.” Buckley, Bird and Sacks believe that the social development of a child with Down’s is influenced by four specific agents – temperament and personality, language and cognitive abilities, family environments, and expectations and management (DSE).
Dictionary.com defines temperament as “the combination of mental, physical, and emotional traits of a person; natural predisposition.” Personality is similar to temperament but it focuses more on the visible aspects of one’s character (dictionary.com). As previously stated, all people with Down Syndrome are their own unique person. There is no specific gene that makes them happy or upbeat constantly. Certain people are extremely active and anxious while others are calm and even-keeled. Children with Down Syndrome have about the same range of temperamental and personality characteristics as children without Down’s (DSE).

Temperament is not something that can be definitively defined by a researcher. It is more of a generalization made by observing certain actions of a child. Certain traits that can be observed include “activity level, regularity in biological functions such as hunger, sleep and bowel movements, readiness to accept new people and new situations, adaptability to changes in routine, sensitivity to noise, bright lights and other distractibility and degree of persistence.” After analyzing these varying characteristics, researchers have been able to come up with four degrees of temperament – easy, difficult, slow to warm (cold at first but then opens up), and intermediate. In studies done classifying children with and without Down Syndrome aged 12-36 months, it was shown that there were significant variances between the two (DSE).

<table>
<thead>
<tr>
<th>Temperament Study (ages 12-36 months)</th>
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<tbody>
<tr>
<td>Degree</td>
</tr>
<tr>
<td>Easy</td>
</tr>
<tr>
<td>Difficult</td>
</tr>
<tr>
<td>Slow to warm</td>
</tr>
<tr>
<td>Intermediate</td>
</tr>
</tbody>
</table>

Source – Down Syndrome Education

One can see that children with Down Syndrome have a greater distribution than children without Down Syndrome. The children without Down Syndrome mainly find themselves in the categories of easy and intermediate whereas children with Down Syndrome are mostly in Easy and then scattered throughout the other three categories. The biggest differences are seen in the slow to warm and intermediate
categories. Children with Down Syndrome in the slow to warm category more than doubled children without Down Syndrome and in the intermediate category there were 50% more children without Down Syndrome than with Down Syndrome. This study shows two things: (1) all children have different levels of temperament and (2) some children with Down Syndrome, like children without Down Syndrome, will be more challenging to manage and raise.

Having the proper language and cognitive abilities will have a large impact on social development. If a child is unable to speak/speak properly or struggles to understand his or her environment then the child will not be very successful in interacting with others. By not understanding the world around them properly, children with Down Syndrome will take a much longer time to understand proper behaviors in certain situations. If a parent is unable to communicate to a child that what he or she did is improper, they may continue to perform that activity. It is possible that children with Down Syndrome are at a higher risk of developing social and behavioral problems throughout their childhood and into the teen years due to the communication gap between parent and child. While this may be true to a limited extent, the majority of children with Down Syndrome show improvements in behavior and social competence as age increases (DSE).

Family environment also has a strong influence on the development of a child. The relationships that the child has with each of the members of the household will help shape the person that child will become. By having a supportive group at home, the child will feel loved and accepted by the people around him or her. All families are different and, because of this, certain households may provide more of a supportive emotional climate for their child with Down Syndrome than others. For the households that find it more difficult to provide a proper, nurturing climate, the child may be more inclined to develop social and behavioral difficulties. The problems that could cause a less than favorable environment at home are endless but some possible examples are: single parent having a difficulty
raising the child and maintaining a job, parents being unemployed, poor housing, reluctant acceptance of the child’s disability (DSE).

*Expectations and Management* also influence the social development of a child with Down Syndrome (DSE). The social feedback the parents give to the child is going to influence how they perceive their actions. If a parent is upset with the behavior of a child and he or she is reprimanded, then the child will most likely not repeat this behavior. Children with disabilities typically get treated a bit more leniently than children without disabilities. Should the parent set his or her expectations based on the child’s age or cognitive abilities?

When speaking with Coach Lynch, I asked him this same question based on their interaction with his son Danny.

“We are going to treat him the same way that we treat JJ (Coach Lynch’s other son and Danny’s older brother). If he (Danny) does something that is wrong, then we are going to let him know. We are not going to create an environment in the household that makes JJ feel that Danny is at an advantage and can get away with things that we object JJ on,” (Lynch interview).

It is important in raising a child with Down Syndrome to continually set the achievement and expectation “bar” high. Having low expectations for the child with Down Syndrome will allow for underachievement and stagnant growth. Setting expectation levels at a high, but attainable, level will allow the child to continue growing and not regress in their progress.

One way to help in raising the child is to have them develop routines and give them clear behavior expectations. By giving the child structure, it will allow the parents to be more consistent in the negative behaviors that they allow. Although a child with Down Syndrome is different than a child without, they still have the ability to behave in “socially age-appropriate ways (DSE).”

This is shown perfectly as Brian and his sister, Abby, and Ryan have schedules that they HAVE to maintain. How they maintain them are slightly different but it is precise to them. Simply by going over
for dinner one night to the Bahlmann's house gave me an insight into Brian and Abby's world where I saw that they have routines that are important. One such example is: Brian eats a snack every night at 8. Mr. Bahlmann said that at 8 pm every night, Brian will be at the kitchen table eating his ice cream sandwich. While I was in Brian's room with him and Abby looking at some Elvis memorabilia, she kept reminding him that he was missing his 8:15 shower. He needed to get in there so she could get her shower/bath in right afterwards.

Their schedules revolve around time and routines whereas Ryan's schedule revolves around activities. Ryan is on his "own-time" and there is no way around it. My family likes to say that he is in "his own world and we just live in it." When my mom tells him to get up out of bed, it may be an hour or two before he leaves his room because he doesn't need anyone telling him what to do. When we are heading out to some place, he will get in the car when HE WANTS to get in the car, again because he is the boss of his own life. Another example is the fact that he always has three meals a day and a snack at night. He may not come downstairs until 1 pm but he will eat breakfast and often follow it up with lunch without even getting up from the table.

Having Ryan be on his "own-time" can add stress to the family. My mom is trying to get everyone together and get us on our way and he sometimes keeps us from leaving when we want to. By allowing him to constantly leave when he wants would show him that there is no punishment for moving at his own pace. Ryan, like other children with Down Syndrome, need to be held accountable for their actions and know that if they do not do what is expected of them that it may result in a negative consequence (i.e. not going on the trip with the family, loss of TV privileges, etc.).

The routines seem to give them structure. It is not to say that they don't add variety by doing different things during the day. I feel that this feature simply shows their dedication to tasks. Just like in the alphabet you don't have B without A, same goes with Brian, Abby and Ryan. Those three like to go through their checklists before moving on to another task. Unfortunately these routines sometimes get
so ingrained into their habits that they become resistant to change on occasion. At times persons with Down Syndrome do not handle change (work/time/food change) well to the point where they can be disruptive. Some examples are: unwilling to take on a new task at work, taking a shower at a different time, or eating what everyone else is for dinner. Because change is a key part of life, people with Down Syndrome must be challenged and held accountable in order to evolve in their lives.

Education is also used in providing children with Down Syndrome the life skills they need. The goal for almost any child is to possess the resources to become an independent person. This is true with children with Down Syndrome, but unfortunately they have fewer overall opportunities that would help them gain this independence. By being involved in school and other activities outside of the home, the children with Down Syndrome are exposed to situations and people they may not normally see. These children are involved in activities and are sometimes in the same classrooms as children without Down Syndrome. Schools refer to this program as mainstreaming, inclusion, or integrated classrooms (Brill 41-42).

Deciding what type of classroom to place a child with Down Syndrome in is determined by the individualized education plan (IEP). Once it is decided at what level the child can learn, the classroom type is selected. Some of the options include:

- A class with nondisabled students
- A class with nondisabled students and a teacher assistant to assist the child with Down Syndrome
- Part of the day with nondisabled & the other part with children with disabilities
- A class with children with disabilities learning the same material but at a slower pace
- A class with children with disabilities but activities such as gym, art and music with nondisabled students (Brill 44)

Many children with Down Syndrome only stay in classrooms with other children with disabilities. This is known as Special Education isolation. Those children are only in those rooms so they can learn at their own pace and also so they will not slow down the pace at which children without disabilities can learn. By having them only interact with other children with disabilities, children with Down Syndrome
are not exposed to the full range of personalities. By limiting their interaction, this could possibly limit their development. Brian, Abby and Ryan all graduated from high school. To show briefly some differences between the individuals and classes, Abby attended many classes with nondisabled students as she was able to comprehend the material. Ryan on the other hand, was in a classroom with other students with disabilities but did activities such as gym and art with students without disabilities. Because of the different classes they were involved in, Abby is much more social (involved in community activities, has a boyfriend, etc.) than Ryan.

Not only does inclusive education help students with Down Syndrome, but it helps students without Down Syndrome as well. Many times students without disabilities do not encounter a child with a disability until he or she is placed in the same classroom as the student. It could be argued that education has changed the social aspect of Down Syndrome more than anything else in the history of this chromosomal defect. Before children without Down Syndrome were able to interact with children with Down Syndrome, many negative notions existed. Since the students have been allowed to interact, they both have been able to learn about each other and a lot of the negative stigmas have been erased.

Another avenue that can be utilized in helping a child with Down Syndrome develop life and social skills is through Special Olympics. The program was founded in the 1960’s by Eunice Kennedy Shriver, sister of President John F. Kennedy. Many say she was inspired by her sister Rosemary Kennedy, who had an intellectual disability. She started by having summer camps at her home in Maryland for both children and adults with intellectual disabilities. At the camps the participants were involved in sports and other physical activities to explore their capabilities. In 1968, the first International Special Olympics Summer Games were held at Soldier Field in Chicago. From there it continued to spread throughout the United States and eventually the rest of the world (Special Olympics History). It is probable that a significant amount of people know who JFK is and do not know Eunice Kennedy Shriver.
Yet it can be argued that Eunice has had more of an impact on the world than JFK could have ever achieved.

Special Olympics is open to "Anyone... (that has) an intellectual disability, cognitive delay, or a development disability, that is, functional limitations in both general learning and adaptive skills." Regarding age, potential athletes must be 8 to participate in the main program. They can participate as long as they want with there being no maximum age limit. For those that want to get involved before they are 8, there is a program for children ages 2 to 7 called Young Athletes (Athlete Resources).

_The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community._

*Source – Special Olympics Mission*

In an effort to objectively measure the success the programs have on athletes, Special Olympics has been documenting the effects that take place since 2001. They have done this with certain research studies conducted with prestigious universities and survey organizations.

44,000 events are conducted each year by Special Olympics. That number translates to at least 121 events every day of the year. There are 3.5 million athletes in more than 170 countries participating in Special Olympics around the world. Researchers have looked into why families and athletes participate in Special Olympics. It is said that the answers are fairly similar no matter what country the question is asked. "Family members around the world view Special Olympics primarily as an opportunity for social interaction and enhanced self-esteem, with health and sports skill improvement as other high priorities," (Demographics).
In all five countries represented in the figure, the improvement of self-esteem/self-confidence and social skills represents at least 50% of the goals for a family’s goals for athlete participation (in the US it is nearly 75%). Many families over the 40 years of Special Olympics have provided anecdotes claiming the positive impact the involvement in the program has had on their child, mainly with building self-confidence. “...The positive effects of participation in Special Olympics are universal and... parallel the positive effects experienced by people without intellectual disabilities who are active in sports (Impact of Spec. Olymp.).” In one of the studies, slightly more than 90% of all athletes benefited with an increase in self-esteem and self-confidence after their time in Special Olympics. It was also noted that, “Special Olympics significantly increases social activity among people with intellectual disabilities and between individuals with and without intellectual disabilities,” (Impact of Spec. Olymp).

Because of improvement in social skills and self-esteem in the older athletes, why not form a program that would prepare younger children for life’s challenges? This was achieved by Special Olympics Young Athletes program. It is a “motor and social skill development program that prepares children ages 2-7 for participation in Special Olympics training and competitions, and provides them with important life skills,” (Young Athletes). One of the main initiatives is to enhance early skill
development and enforce the skills learned during EI. The program was started in 2005 in only 11 countries but has expanded to a total of 23 countries with 9,000 current participants.

Not only do the athletes improve their physical skills, but their social skills are also improved. This is a result of the children being in an environment that is conducive to interacting with other children who face similar intellectual and physical disabilities. The children seem to show a boost in confidence after spending time with Young Athletes. This can then carry over when they attend school and have to interact in many new environments such as the classroom, lunchroom, or playground. A study by the University of Massachusetts, commissioned by Special Olympics, was done to see what benefits, if any, came from participation in Young Athletes. Initial results from the studies show that “participation in Young Athletes may lead to improvements in motor development, social and emotional development and communication development,” (Young Athletes).

Teachers were surveyed in the majority of countries where the Young Athletes program is in effect. They were asked about several types of skills that the young student possessed and if they have improved during the time in the program. Here are some of the results:

<table>
<thead>
<tr>
<th>Type of Skill</th>
<th>% of total teachers noting improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social</td>
<td>84%</td>
</tr>
<tr>
<td>Motor</td>
<td>82%</td>
</tr>
<tr>
<td>Communication</td>
<td>78%</td>
</tr>
<tr>
<td>Cognitive Ability</td>
<td>75%</td>
</tr>
<tr>
<td>Adaptive Behavior</td>
<td>72%</td>
</tr>
</tbody>
</table>

Source – Special Olympics Resources

Not only are these skills improving at the Young Athlete’s competitions and in the classrooms, but in the home as well. Parents are reporting they have also seen improvement in the five skills that were attested above. This is a positive sign as it shows what the children are learning is transferring to other settings. If it can transfer from the program to the classroom to the home, then it can eventually
transfer into the community where the child will need to be able to interact on his or her own (Young Athletes).

I compare my brother joining Special Olympics to me joining a junior golf program when I was young. It is the summer before 1st grade and I was nervous because I didn’t have many friends entering my new school and was rather shy and introverted. My dad knew that I liked golf and decided to have me join the junior golf program at the golf course where there would be many other kids there in my age range. By interacting in the sport over the summer, I was able to develop some friendships I wouldn’t have had if I stayed at home all summer. On top of that, a lot of the kids in the program were attending my school and knew of my shyness which became almost non-existent by the first day of class.

I was extremely nervous heading into my first years of school but by interacting in sports and other activities, I was able to develop my social skills and develop relationships that helped me become the person I am today. My brother may not have been as nervous as I was, but he went through similar situations. He didn’t know many people when he was younger but met many friends at school, got involved in Special Olympics, and was the equipment manager for the local high school football team. By being involved in these activities, he was able to be shaped into the out-going person that he is today.

The growing amounts of opportunities today are allowing people with Down Syndrome to become more involved, whether it be at home or in the community. One way Brian participates in the community is by voting and working at a local non-profit organization called Hillcroft Services (Abby also works there). Ryan is involved by working at the outlet mall where he has been an employee at Eddie Bauer for almost 10 years. These activities allow them to get involved and let them be a part of something that everyone else is involved in: the community. Being involved in these activities allow Brian, Abby and Ryan to build the life skills that shape them into who they are and who they will
become. These opportunities, plus many more (hopefully) will be available for young Danny as he continues to grow.

I believe, through how I have been raised and after the extensive research that I have done for this paper, that every person is special and a product of one’s environment. What I mean by this is that where somebody comes from will help shape them and give them perspective for the rest of their life. Picture someone’s personality/temperament/social skills as a ball of Play-Doh. The “Doh” comes out of the can soft and ready to be molded, just like a child is when he or she is born. The ball doesn’t come into the world as a block of cement that is set and unable to be shaped. The situations that a person goes through (i.e. the people he/she meets, activities involved in, environment raised in) will have a hand in shaping that ball.

Through technology and health advancements, Early Intervention and educational inclusion, people with Down Syndrome are being able to live longer, more fulfilling lives. The amount of opportunities for them are continually growing and allowing them to become more involved in their communities. Just as a person with Down Syndrome learns to adapt to change, society will continue to adapt to people with Down Syndrome.

As one parent of a Young Athlete put it, “Every child needs to be cheered on... every child has potential.”
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