Adopting the Genetically Imperfect Child

A genetic counselors approach to helping a mother adopt out a fetus with a genetic disorder

Tag Words: Adoption, Genetic Disorder, Prenatal Genetic Testing, Genetic Counseling, Inherited Diseases.

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Summary: Fetuses that test positive for diseases lead to difficult decisions that the female carrying the fetus must confront. The genetic counselor can play an important role in providing options. Here we discuss one of those options; the adoptability of a newborn special needs child.

Minimizing Genetic Disorders in Society
Genetic information is increasingly being utilized as a tool for the treatment of medical conditions. However, genetic disorders are the result of permanent lifelong chromosomal defects that cannot be cured at the present time. The only solution for minimizing genetic disorders in society is to carry out a prenatal diagnosis on a developing fetus and to abort it if that fetus tests positive. It is not possible to cure a genetically inherited disorder because that disorder is encoded into the DNA of every cell in that individual’s body. That’s trillions of cells that would be required to be genetically reconstituted. Chronic Villus Sampling is just one example of a prenatal test that a hospital can perform on a fetus that is at least 10 weeks into gestation. Such prenatal tests can detect a handful of genetically inherited disorders, but just because a fetus test positive for a certain disorder does not mean that it does not have options fitting into society. With proper guidance from a genetic counselor, that fetus could be adopted out within days of being born.

Genetic Disorders Determined by Prenatal Testing
Below is a list of only a few common genetic disorders that can be identified by prenatal procedures.

- **Down Syndrome**- also known as Trisomy 21, is characterized by the individual having three copies of chromosome 21 that causes permanent mental retardation (1).
- **Turner Syndrome**- is a sex chromosome abnormality characterized by female individuals having only a single copy of chromosome X (1).
- **Klinefelter Syndrome**- is another sex chromosome abnormality characterized by male individuals having two X chromosomes instead of just one (1).
- **Cystic Fibrosis**- is disorder of the “cells that produce mucus, sweat and digestive juices. These secreted fluids are normally thin and slippery, but end up becoming thick and sticky. Instead of acting as a lubricant, the secretions plug up tubes, ducts and passageways, especially in the lungs and pancreas making the individual life difficult”(2).
- **Spina Bifida**- is a neural tube defect that has not yet been proven/disproven of being a genetic disorder. “In unborn babies with spina bifida, the neural tube fails to develop or close properly causing defects in the spinal cord” (2).
• **Sickle Cell Anemia** - is an inherited blood hemoglobin anemia in which the red blood cells are not flexible and round, but instead are more sticky and shaped like sickles and crescent moons. “These irregularly shaped cells can get stuck in small blood vessels, which can slow or block blood flow and oxygen to parts of the body” (2).

There may not be cures for genetic disorders but there are temporary treatment options that make life easier for individuals that have certain disorders. For example, an individual with Cystic Fibrosis can live a long healthy life as long as they consistently combat their mucus problems on a daily basis with the help of modern medicine and technology. Options such as this can improve the quality of life of individuals with genetic disorders. People around them may not even realize that they have a genetic disorder.

**Prenatal Testing for Genetic Disorders**

There are many different approaches to obtain a prenatal diagnosis with amniocentesis, and chronic villus sampling being the most commonly used and preferred methods.

Amniocentesis is “a medical procedure that determines the genetic makeup of a fetus in utero in which a long needle punctures the uterus, with the guided help of ultrasound, to extract amniotic fluid” (3). Before this procedure is allowed to be carried out, a risk assessment must be done by the genetic counselor that informs the patients that the results may take up to three weeks to complete with the possibility of a repeat sample being necessary. The procedure is generally regarded as being safe, but if the medical professional is new to the procedure, then that inexperience is calculated as a risk as well. Once all the paper-work is cleared and the parents to be approve of the procedure, the hospital uses ultrasound to check exactly what stage of the pregnancy the developing embryo is in, and to see physically how it is arranged inside the uterus. The embryo must be at least 15 weeks into gestation for a satisfactory sample to be obtained safely (1). Next, with the help of the ultrasound, the approved doctor directs a needle, puncturing the mothers’ uterus, and extracts a certain amount of amniotic fluid surrounding the embryo. The extract is a combination of fluid and cells which are separated and tested separately. The fluid immediately undergoes certain biochemical studies, whereas the cells need to be cultured for up to three weeks in order for there to be enough samples for complete genetic analysis. Once everything has been tested and determined, the results are reviewed by the genetic counselor whose job it is to compile all the results into a case and present it to the family.

Chorion biopsy, also known as chorionic villus sampling (CVS), is a medical procedure in which a small piece of placental tissue is extracted from the mother’s uterus for genetic analysis of the unborn child (3). Just like in amniocentesis, a risk assessment must be carried out by the genetic counselor before the procedure is allowed to take place. After all of the paperwork is completed, the procedure starts with basic ultrasound to determine the best way to extract a sample from the placenta. Depending on the physical arrangement of the fetus, the doctor can extract a sample of the placenta by either guiding a thin tube into the mothers’ cervix, or inserting a needle into her uterus (2). Both approaches successfully obtain placenta samples. The sample can be fully analyzed within days depending on the complexity of the lab analysis. Once everything has been tested and determined, the results are reviewed by the genetic counselor whose job it is to compile all the results into a case and present it to the family.
The Role of a Genetic Counselor
Human genetics is the science of chemical identification of individuals with the goal of uncovering imperfections along chromosomal loci. A genetic counselor’s job is to look over such information and acts as a medical messenger for all the risks, realities and perceptions associated with the identified conditions. By definition, genetic counseling “is the process by which patients or relatives at risk of a disorder that may be hereditary are advised of the consequences of the disorder, the probability of developing or transmitting it and of the ways in which this may be prevented, avoided or ameliorated” (1). Genetic counseling is an incredibly complicated job because the geneticist has to present potentially dreadful information to their patient in a manner that is downright, comprehensible, and respectful. This information has to have been compiled into a case by the counselor, in which the patient’s family medical history, treatment options, risk assessment, laboratory paperwork, and possible support/advocacy groups all relevant to the disorder are all at hand to formulate a plan (4).

Adopting out the Genetically Disabled Child
News that a female carrying a fetus that just tested positive for a disorder, especially if the pregnancy was a planned one, can be devastating. The most important thing to do is not to panic. The clients need a few days to come to grips with the news and you need to give them that space. The mother should take a few days off to consider her options which in turn can help dictate a better future for that fetus. Before that female makes a decision, her genetic counselor briefs her about the typical lifespan and medical cost of a child with that disorder. The female then decides whether or not to continue with the pregnancy and accept responsibility of the baby. This way when the baby is born, it will receive all the care and support it needs to live the longest life possible. If taking responsibility of the child is not something the pregnant female wants to do, then the genetic counselor helps the female reach out to social workers in adoption agencies that agree to offer the baby to their clients. That newborn will be labeled a special needs child by the adoption agencies due to the fact that it has a genetic disorder. According to The Adoption and Safe Families Act of 1997, every state must produce an annual report on how many adoptions took place and how many children are in foster care (5, Pg. 379). According to the child welfare summary sent to congress, the State of New Jersey had a total of 1,564 adoptions during 2010 (5, Pg. 227). However, they have not stated how many of those adoptions included children with special needs due to the fact that such information is not required to be reported to the government. The only way to obtain such information is to individually reach out to each adoption agency and personally ask them how many of their adoptions included children with special needs. Those families that adopt children with genetic disorders have big hearts and their contribution to society makes them heroes. It is easy to see that genetic counselors offer tremendous support helping put up newborn children up for adoption, but not every child will be adopted as a newborn. Those children that do not get adopted out are forced to live in a foster home until they are placed with a family or grown up.

The Special Needs Child
When filling out adoption forms, most agencies will ask the potential adopting parents if they would be interested in adopting a special needs child. According to Bethany Christian Services, a local New Jersey Adoption Agency, a special needs child is defined as being “a child older than the age of five, children part of a sibling group that require being adopted together, precious ones with a history of trauma, and children with identified physical, developmental, or emotional
delays/disabilities”(6). This special needs children label is used by adoption agencies to make it clear to the adopting parents that the child in question might be more difficult to raise. Although this label may decrease the chances of the child being adopted out, it ensures that the child receives only the most dedicated of adoptive parents. Unfortunately, due to the fact that the special needs label is inclusive of many different types of children, only a small percentage of those with genetic abnormalities are included in the pool of “special needs children”.

**Community Action: Examining The Prospects of Adopting a Newborn Special Needs Child**

In an effort to encourage families to adopt a genetically imperfect child, every certified adoption agency in the State of New Jersey has been reached out to by phone and email. The goal was to obtain information specifically about the adoptability of special needs children compared to normal children because adoption agencies are not required to release information about special needs adoptions to the government. New Jersey has a total of twenty-two certified adoption agencies that help guide interested parents through the long and complex legal processes associated with adoptions (7). Out of all those twenty-two agencies, only ten were generous enough to at least partially answer the questionnaire posted below. The rest have proven to consistently filter out the need to answer the questions by transferring the call to a voicemail system, or by offering an email address to send the questionnaire to. Only one agency responded to the twenty-two emails sent out, and none of the agencies responded to the voicemail messages left to them. Three Jewish adoption agencies, out of four, all made it clear in a nice professional manner, that they are not allowed to answer such questionnaires. Those families seeking adoption in a Jewish agency need to contact them individually. This outreach project is purposely confined to just the State of New Jersey, as different states have different adoption laws and regulations.

**Questionnaire**

Adoption agencies were called and asked the following questions:

1) How many adoptions did your agency have in 2012? _________

2) How many of those adoptions were
   a. newborn children less than 2 years of age _________
   b. children over 2 years of age _________
   c. special needs children _________

3) Do you require the adopting couple to have a certain income? _____. What income do you look for? ______

4) Is the adopting couple counseled on the financial, medical and emotional/behavioral needs of the child prior to finalizing an adoption? _______.
   Explain____________________________________________________________________

5) State and federal programs may exist that would provide financial assistance for the special needs child. Is the adopting couple made aware of the various financial aid programs that might impact their decision to adopt a special needs child? _______.
   Explain____________________________________________________________________
6) Are children with certain disorders less “desirable” and more difficult to adopt out? _____
Which ________________________________.

7) Do some adopting couples seek to specifically adopt a special needs child? ____________
Reasons given_______________________________________________________________

8) With what level of certainty would your agency be able to place a newborn special needs child in a loving home? _______________________________________________________________

If the person answering the phone was unable to answer these questions, it was requested that someone associated with and knowledgeable about the agency fill out our questionnaire by email. Unfortunately, the answers to questions 7 and 8 will not be discussed because not enough responses were collected.

Understanding the Questionnaire Results
Based on the information gathered from the questionnaire, last year (2012) there were a total of 291 confirmed adoptions in the State of New Jersey of which only 20 consisted of special needs children. That means that less than 7% of all 2012 adoptions in NJ were special needs children. Almost all of those 291 adoptions consisted of children under the age of two which classifies them as desirable newborns. When asked about a minimum required income for adoption, the highest demanded number was 35,000 dollars annually, and the lowest demanded income was 26,000 dollars annually, but most of the agencies explained that it depends on the individuals involved. When asked about demanding that the couple be counseled on financial, medical, and emotional/behavioral needs of the adopted child prior to finalizing the adoption, every adoption agency unanimously made it clear that they will demand everything necessary until they are comfortable knowing the adopting family has only good intentions for the child. The question about making the adopting family aware of state and/or federal financial assistance programs in order to convince the parents to adopt a special needs child had an expectable answer. In a general sense, the agencies explained that if the family is undecided about what kind of child to adopt, then in some cases that can happen, but it’s all up to what the parents want. The question about certain disorders being more difficult to adopt out, went unanswered with every agency questioned probably due to the fact that special need adoptions are not popular enough for there to be such competition. All of these results are important, but surprisingly shocking. Since the special needs children label includes more than just children with genetic disorders, the actual percent is significantly less than that whole seven percent. The problem is that there is no way to know which children have genetic defects because it is not recorded.
Outreach Data

![New Jersey Adoptions 2012](image)

Figure 1. This double bar graph includes only the adoption agencies that responded to the questionnaire during the outreach project. The blue data shows the total number of adoptions that each agency had in 2012. The red data shows the total number of special needs children that have been adopted in 2012.

Concluding Statements

There are no reliable sources available to the public about how many special needs children are adopted annually. Adoption agencies are not required to answer such information because not every agency offers special needs children. In order to truly find out the adoptability of special needs children, The Adoption and Safe Families Act of 1997 needs to be amended to require such information to be recorded and made available to the public.

Contact Information for Adoption Agencies in New Jersey

The list below is an alphabetical directory of all the New Jersey adoption agencies (that were operating in 2013) that a couple can refer to. Those agencies marked with an * did not provide information for this outreach project.

<table>
<thead>
<tr>
<th>Name of Adoption Agency</th>
<th>Phone #</th>
<th>Website</th>
<th>Email Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Loving Choice Adoption Associates</td>
<td>(732) 224-0924</td>
<td><a href="http://www.alovingchoice.com">www.alovingchoice.com</a></td>
<td><a href="mailto:info@alovingchoice.org">info@alovingchoice.org</a></td>
</tr>
<tr>
<td>Adoptions from the Heart</td>
<td>(856) 665-5655</td>
<td><a href="http://www.adoptionsfromtheheart.org">www.adoptionsfromtheheart.org</a></td>
<td><a href="mailto:adoption@afth.org">adoption@afth.org</a></td>
</tr>
<tr>
<td>Bethany Christian Services</td>
<td>(201) 703-4371</td>
<td><a href="http://www.bethany.org">www.bethany.org</a></td>
<td>Email Built into Website</td>
</tr>
<tr>
<td>Organization</td>
<td>Phone Number</td>
<td>Website</td>
<td>Email</td>
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<tr>
<td>Better Living Adoption Services, Inc.</td>
<td>(908) 654-0277</td>
<td><a href="http://www.betterlivingadoption.com">www.betterlivingadoption.com</a></td>
<td><a href="mailto:betterlivingadoptionservices@comcast.net">betterlivingadoptionservices@comcast.net</a></td>
</tr>
<tr>
<td>Catholic Charities of the Archdiocese of Newark</td>
<td>(201) 246-7378</td>
<td><a href="http://www.ccannj.com">www.ccannj.com</a></td>
<td><a href="mailto:Catholic-Charities@ccannj.org">Catholic-Charities@ccannj.org</a></td>
</tr>
<tr>
<td>Catholic Charities, Diocese of Trenton*</td>
<td>(609) 386-6221</td>
<td><a href="http://www.catholiccharities.trenton.org">www.catholiccharities.trenton.org</a></td>
<td><a href="mailto:info@cctrenton.org">info@cctrenton.org</a></td>
</tr>
<tr>
<td>Catholic Charities, Diocese of Camden, Inc.*</td>
<td>(856) 691-1841</td>
<td><a href="http://www.catholiccharities.camden.org">www.catholiccharities.camden.org</a></td>
<td>Email Built into Website</td>
</tr>
<tr>
<td>Children’s Aid &amp; Family Services, Inc.*</td>
<td>(201) 226-0300</td>
<td><a href="http://www.cafsnj.org">www.cafsnj.org</a></td>
<td><a href="mailto:info@cafsnj.org">info@cafsnj.org</a></td>
</tr>
<tr>
<td>Children’s Home Society of New Jersey</td>
<td>(609) 695-6274</td>
<td><a href="http://www.chsofnj.org">www.chsofnj.org</a></td>
<td><a href="mailto:mbraun@chsofnj.org">mbraun@chsofnj.org</a></td>
</tr>
<tr>
<td>Division of Youth and Family Services*</td>
<td>(609) 292-4441</td>
<td><a href="http://www.njadopt.org">www.njadopt.org</a></td>
<td>Email Built into Website</td>
</tr>
<tr>
<td>Family and Children’s Services*</td>
<td>(908) 352-7474</td>
<td><a href="http://www.facsnj.org">www.facsnj.org</a></td>
<td><a href="mailto:info@facsnj.org">info@facsnj.org</a></td>
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<tr>
<td>Family Options*</td>
<td>(732) 936-0770</td>
<td><a href="http://www.famopt.org">www.famopt.org</a></td>
<td><a href="mailto:info@famopt.org">info@famopt.org</a></td>
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<tr>
<td>Golden Cradle Adoption Services, Inc.</td>
<td>(800) 327-2229</td>
<td><a href="http://www.goldencradle.org">www.goldencradle.org</a></td>
<td>Email Built into Website</td>
</tr>
<tr>
<td>Harvest of Hope, Family Services Network*</td>
<td>(732) 247-1270</td>
<td><a href="http://www.harvestofhopefamily.com">www.harvestofhopefamily.com</a></td>
<td><a href="mailto:HOH@harvestofhopefamily.com">HOH@harvestofhopefamily.com</a></td>
</tr>
<tr>
<td>Homestudies and Adoption Placement Services*</td>
<td>(201) 836-5554</td>
<td><a href="http://www.haps.org">www.haps.org</a></td>
<td><a href="mailto:info@haps.org">info@haps.org</a></td>
</tr>
<tr>
<td>Jewish Family Services of Central New Jersey*</td>
<td>(908) 352-8375</td>
<td><a href="http://www.jfscentralnj.org">www.jfscentralnj.org</a></td>
<td><a href="mailto:info@JFSCentralNJ.org">info@JFSCentralNJ.org</a></td>
</tr>
<tr>
<td>Jewish Family Service of MetroWest*</td>
<td>(973) 765-9050</td>
<td><a href="http://www.jfsmw.org">www.jfsmw.org</a></td>
<td>Email Built into Website</td>
</tr>
<tr>
<td>Jewish Family &amp; Children's Services of Greater Monmouth County</td>
<td>(732) 774-6886</td>
<td><a href="http://www.jfcsmonmouth.org">www.jfcsmonmouth.org</a></td>
<td><a href="mailto:info@jfcsmonmouth.org">info@jfcsmonmouth.org</a></td>
</tr>
<tr>
<td>Jewish Family and Vocational Services of Middlesex County*</td>
<td>(732) 777-1940</td>
<td><a href="http://www.jfvs.org">www.jfvs.org</a></td>
<td><a href="mailto:office@jfvs.org">office@jfvs.org</a></td>
</tr>
<tr>
<td>Lutheran Social Ministries</td>
<td>(609) 386-7171</td>
<td><a href="http://www.lsmnjadoption.org">www.lsmnjadoption.org</a></td>
<td><a href="mailto:adoption@lsmnj.org">adoption@lsmnj.org</a></td>
</tr>
<tr>
<td>United Family and Children’s Society*</td>
<td>(908) 755-4848</td>
<td><a href="http://www.unitedfamily.org">www.unitedfamily.org</a></td>
<td><a href="mailto:info@unitedfamily.org">info@unitedfamily.org</a></td>
</tr>
<tr>
<td>Youth Consultation Service</td>
<td>(973) 854-3611</td>
<td><a href="http://www.ycs.org">www.ycs.org</a></td>
<td>Email Built into Website</td>
</tr>
</tbody>
</table>
Dear Senator Bob Smith,

My name is Mariusz Roszkowski, and I am rising junior at Rutgers University studying genetics with aspirations of going to graduate school to study genetic counseling. I am currently doing a research project about a genetic counselors approach to helping adopt out a newborn child that has a genetic disorder. Adoption agencies classify these children as special needs when offering them to their clients. Unfortunately, special needs adoptions are not required to be reported to the government which means that it is impossible to know how many special needs children are annually adopted out.

The reason why I am writing to you today is to make you aware of this problem and to offer a solution that federal and state government should consider. The Adoption and Safe Families Act of 1997 is a public law that requires each state to record the total number of adoptions annually. I believe this portion of the law should be amended to also include the total number of special needs children’s adoptions in each state annually or at least in the state of New Jersey. This will legally force for such information to be recorded and made available to the general public.

Thank you,

Mariusz Roszkowski

References

Other References used but not directly referred to:


Adoption and Safe Families Act of 1997
(Public Law 105-89)
SEC. 203. Performance of States in Protecting Children.

(a) ANNUAL REPORT ON STATE PERFORMANCE.—Part E of title IV of the Social Security Act (42 U.S.C. 670 et seq.) is amended by addition at the end of the following: SEC. 479A. Annual Report.
The Secretary, in consultation with Governors, State legislatures, State and local public officials responsible for administering child welfare programs, and child welfare advocates, shall:
(1) develop a set of outcome measures (including length of stay in foster care, number of foster care placements, and number of adoptions) that can be used to assess the performance of States in operating child protection and child welfare programs pursuant to parts B and E to ensure the safety of children;
(2) to the maximum extent possible, the outcome measures should be developed from data available from the Adoption and Foster Care Analysis and Reporting System;
(3) develop a system for rating the performance of States with respect to the outcome measures and provide to the States an explanation of the rating system and how scores are determined under the rating system;
(4) prescribe such regulations as may be necessary to ensure that States provide to the Secretary the data necessary to determine State performance with respect to each outcome measure, as a condition of the State receiving funds under this part; and
(5) on May 1, 1999, and annually thereafter, prepare and submit to the Congress a report on the performance of each State on each outcome measure, which shall examine the reasons for high performance and low performance and, where possible, make recommendations as to how State performance could be improved.