

## **Case Preparatory Work: Genetic Counseling Mary, a Prenatal Client with Intellectual Disabilities**

Thanks to Carrie Prochniak, Master's candidate in Genetic Counseling at the University of Cincinnati, Cincinnati, Ohio, for her work as a contributing author for this case.

Commentary by Brenda Finucane, MS, CGC, Executive Director, Elwyn Genetics, Elwyn, PA

### **Learning Objectives**

1. Discuss how reproductive options, decision making or genetic testing may be influenced by the presence of mild intellectual disability in a genetic counseling client.
2. Determine the relative importance of steps in the genetic counseling process when working with an adult with mild intellectual disability.
3. Identify online and community resources that contribute to case preparatory work when providing genetic counseling to adults with mild intellectual disability.

*Tracey is a genetic counselor working in a Children's Hospital that provides comprehensive genetic services. At the end of the week, Tracey received a phone call from a community social worker about her client, Mary, who receives services from local agencies supporting individuals with intellectual disability. Mary is 19 years old and she has an appointment for genetic counseling early next week. The social worker stated that the reason for referral is that Mary is pregnant and Mary's mother is concerned that the baby will be born with developmental disabilities. The social worker explains that Mary is "mildly mentally retarded." Mary will be accompanied to the genetic counseling appointment by her mother.*

### **Personal Reflections**

What are your first instincts about this case?

Have you ever handled a genetic counseling session like this?

### **Perspectives**

As the genetic counselor, what thoughts and emotions might Tracey be thinking and feeling about this situation?

What thoughts and emotions might the social worker be thinking and feeling about this scenario?

What thoughts and emotions might Mary's mother be thinking and feeling about this situation?

What thoughts and emotions might Mary be thinking and feeling?

How do the perspectives of the individuals involved in this case overlap? What aspects of their perspectives are unique?

How do you think the potentially varied perspectives should impact Tracey's preparation for the genetic counseling session?

How do you think these perspectives might impact the effectiveness of the genetic counseling session?

### **Health Disparities**

A comprehensive government document addresses health disparities specific to the population of individuals with intellectual disabilities: "Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation" (U.S., 2001). This document can be found at: <http://www.surgeongeneral.gov/topics/mentalretardation/retardation.pdf>. Many forms of health disparities affect the population of individuals with intellectual disabilities, including a lower life expectancy,

increased morbidity rates (i.e. epilepsy, behavioral disorders), an increase in negative determinants of health (i.e. high levels of obesity, low employment), difficulty accessing services, and a lack of quality services. "Closing the Gap" and Kerr (2004) suggest that health disparities for individuals with intellectual disabilities are due to four major factors: a lack of understanding of their special health care needs by health care providers, problems with getting health care services, difficulties growing up and living with disabilities, and healthy lifestyle issues.

Persons with intellectual disabilities often have concerns about the attitudes of their health care professionals and the quality of their health services (Kerr, 2004). Physicians and providers may be unwilling to accept the individual with intellectual disabilities as a patient. They may prefer to interact directly with a family member and only indirectly with the patient. Because there are numerous gaps in the scientific knowledge base regarding health care needs of this population, the quality of health services is compromised. This lack of knowledge of the population translates into a lack of knowledge usable by caregivers, physicians, and other health care providers. For example, providers may not be aware of a patient's special health needs, leading to inaccurate diagnoses or overmedication. "Closing the Gap" recommends developing practice guidelines and methods to measure quality care in all medical institutions for patients with intellectual disabilities (U.S., 2001).

Physicians who specialize in caring for patients with intellectual disabilities may not be widely available, leading to the next health disparity: getting health care services. Not only are physicians who specialize in intellectual disabilities difficult to identify, patients may also have difficulties making travel arrangements for appointments - whether it be to the next city or across the country. Patients' decreased mobility, along with sensory impairment and communication difficulties, may create more barriers (Kerr, 2004). In addition to accessing medical care, individuals with intellectual disabilities often have trouble paying for the care they need. While Medicaid offers extensive coverage for children, after becoming an adult, the coverage dwindles drastically (U.S., 2001).

When an individual with intellectual disabilities becomes an adult, the family may have to assume more responsibilities for the patient's health and well-being. These responsibilities may have been previously managed by health care providers and the government. Families must coordinate multiple services to care for the individual and offer financial support to the person due to the losses in Medicaid coverage (U.S., 2001). As persons with intellectual disabilities grow older, they face expected age-associated conditions as well as conditions specific to their population, such as premature dementia. Problems with medication needs or mobility may be incorrectly perceived as an issue associated with the intellectual disability rather than the simple factor of age.

The last major disparity involves the roles of health providers, individuals with intellectual disabilities and their caregivers in preventing illness, secondary disabilities and maintaining good health. The disparities are even more overwhelming when the individuals with intellectual disabilities are from minority communities. These persons come from different cultures, may speak different languages, and often have a low socioeconomic status (U.S., 2001).

The U.S. Public Health Service recommends several changes to help reduce health disparities for persons with intellectual disabilities. They advise giving priority attention to research for individuals with intellectual disabilities. They also urge collaboration between various types of health care providers to expand knowledge of specialized care. Addressing the health care needs of individuals in this population may be more suitable for settings that provide *interdisciplinary* health care services. Bigham, Thompson, and Scannell (2007) reported that persons with intellectual disabilities, as well as their caretakers, supported the creation of a national directory listing healthcare providers specialized in their population. This Provider Directory was created by the American Academy of Family Physicians and can be found at <http://www.aafp.org/online/en/home/clinical/publichealth/specialolympics.html>. Establishing standards of clinical practice and evaluation of services for persons with intellectual disabilities are also recommended. Further, "Closing the Gap" suggests the need to change the financing of health care for this group, and to address the public's misconceptions (U.S., 2001).

## The Genetic Counseling Session

What would be the most appropriate next step for Tracey to take when preparing for this genetic counseling session?

- a) Work up a differential diagnosis for Mary to determine recurrence risk
- b) Talk to the social worker about Mary's living situation and the relationship between Mary and her mother
- c) Alert Child Protective Services so Mary's child will be properly cared for
- d) Research ways to talk to Mary about sexual abuse and the sexual abuse laws in the state

b) is the most appropriate response. Tracey should talk to the social worker to get a better idea about Mary's home situation. Tracey will want to know how much support, if any, Mary has from her mother and others for her physical and emotional needs and decision making in pregnancy, and the possibility of future parenting. It is important not to focus on Mary's disability but to identify resources and modifications that may be needed to provide appropriate health care and support (Smeltzer, 2007).

It is natural for genetics professionals to try to get to the bottom of the underlying cause for intellectual disability. However, the genetic counselor must determine if providing Mary with a recurrence risk will be helpful to her decision-making, or if exploring the relevant psychosocial issues is more likely to provide the most beneficial information for both the counselor and the client.

Although up to 80% of individuals with mild developmental disabilities may experience sexual abuse (Lumley & Scotti, 2001), consensual sexual relationships exist among adults with intellectual disability. It is inappropriate to assume Mary was the victim of abuse. Sexuality is a healthy part of any individual's life, including adults with developmental disabilities. Additionally, reproduction allows adults with intellectual disability to participate in social roles often denied to them. Mary's situation is not uncommon: although 60-90% of people with mild developmental disabilities want to be married and raise children, 75% of their parents are opposed (Aunos & Feldman, 2002). Thus, for women who have been denied control over their own choices, they may see the ability to reproduce as a powerful statement of independence.

Many parents with mild intellectual disability will ultimately have their parental rights terminated by protective services. This is due to many factors, including lack of support to parents as well as increased scrutiny of protective services. Additionally, parents with mild developmental disabilities are often presumed to be incompetent. Problems are often attributed to the parent's developmental disabilities, instead of exploring whether there are other complicating factors or circumstances. Although one must balance parental rights with concerns for child welfare, parents with mild developmental disabilities can become successful parents with proper support. It is important not to assume that disabled women are unable to parent; many women with disabilities have been very successful mothers (Smeltzer 2007). Parenting skills can be taught to adults with mild intellectual disability by facilitating their enrollment in relevant classes and connecting them with appropriate social services.

## Components of the Genetic Counseling Session

Consider the relative importance of discussing these points with Mary during her genetic counseling session. Note yes or no as appropriate if you would include these components in the session. Which component is most important to include? Which component is least important to include?

- \_\_\_ Set goals and perform contracting at the outset of the appointment
- \_\_\_ Review Mary's medical history and her pregnancy history
- \_\_\_ Determine who the father of the baby is (for genetic or other reasons)

- \_\_\_ Take a complete pedigree
- \_\_\_ Review genetic causes for developmental disabilities
- \_\_\_ Talk about recurrence risks
- \_\_\_ Talk about Mary's reproductive options in terms of screening and diagnosis
- \_\_\_ Talk about Mary's psychosocial situation including her feelings about her pregnancy
- \_\_\_ Explore Mary's past decision-making processes
- \_\_\_ Connect Mary with community resources

Although a genetic counselor's instinct may be to conduct a comprehensive genetic counseling session with Mary, there are several barriers to taking this approach. Mary may be an unreliable historian, so generating a complete pedigree may be too difficult to accomplish during the session. The family history could be done, with Mary's consent, by talking with a support person before the session. Discussing risks and inheritance patterns may be too abstract for Mary to understand, so your time with Mary may be better spent discussing psychosocial concerns. Because she may have had little or no past experience making her own decisions, it may be more useful to focus on Mary's current beliefs and helping her formulate future plans. Empowering care and effective communication will focus on a woman's abilities rather than on her disabilities (Smeltzer, 2007).

### **Who Should Be Present During the Genetic Counseling Session?**

If Tracey had the opportunity to decide, who should she ask to attend the genetic counseling session?

It is helpful to involve all people in Mary's support network in the counseling process. By talking to the social worker, Mary and Mary's mother, the genetic counselor should determine who has been a source of support for Mary in the past and at present. The genetic counselor should explore whether Mary's sphere of available support is adequate and broad enough to assist her in the challenges that lie ahead. Family members may have negative reactions and questions about the prospect of a woman with disabilities managing care of her baby (Smeltzer, 2007). Therefore, the genetic counselor may also want to spend some time with Mary alone. This client-centered approach may help the genetic counselor get a better idea of Mary's needs and give her an opportunity to share her concerns directly, without interested others speaking for her. The genetic counselor might ask Mary the following questions, either by herself, or in the presence of support persons, depending on what seemed most appropriate.

- What do you think about having a baby?
- What do you think you'll have to do to take care of the baby?
- Who will help you take care of the baby?
- Tell me about your friends. What do you do with your friends?
- Who do you talk to when you are happy?
- Who do you talk to when you are sad?
- Who do you talk to when you don't know what to do?

### **Legal and Reproductive Rights**

Many potential barriers stand between individuals with intellectual disabilities and health care providers. Examples of these barriers include negative biases, unfamiliarity with the intellectually disabled, and difficulty communicating effectively with each other (Grabois, 2001). Appropriate reproductive health

services for intellectually disabled women are also inadequate. Fundamentally, women with intellectual disabilities often lack knowledge about sexuality. They are often excluded from discussions about sex and reproduction during their school years (Smeltzer et al., in press). In addition, many health care providers fail to discuss the matter due to the assumption that the women are asexual (Grabois, 2001). A lack of reproductive knowledge can lead to unplanned pregnancy. It is important that all women, regardless of intellectual status, have access to reproductive services. Indeed, all women are guaranteed this right under the Americans with Disabilities Act (ADA).

In 1990, the ADA legislated equal rights for individuals with disabilities with respect to employment, public service, and health care services (Gooding, 1995). The ADA establishes the fundamental expectation that should ensure patient autonomy, proper health care treatment, and reproductive services for all people (Judge, n.d.) Under the ADA, health care providers are legally obliged to provide equal treatment to disabled individuals and if it is not currently available, to make the necessary accommodations in order to provide equal treatment.

Autonomy, “which focuses on self-governance, has been a guiding value in health care since the late 1960s and early 1970s. Today, in nearly every state in the United States, a Patients’ Bill of Rights legally establishes clients’ rights to accept or refuse any medical treatment” (Veach, LeRoy, & Bartels, 2003). Autonomy means that a patient understands and has control of medical decisions that affect him/her. The National Society of Genetic Counselors Code of Ethics states that counselors should “enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences (NSGC). For a patient to give informed consent for medical treatment, he/she must understand in broad terms what the treatment will involve (Gooding, 1996). The minimal amount of information that should be provided to the patient about treatment is: (1) the risks and benefits; (2) any side effects or complications; (3) likelihood of improvement with and without and; (4) any alternative methods (Levy et al., 1996).

Individuals have the right of informed consent as long as they are competent decision-makers (Parry & Phillips, 2002). As a general rule, individuals with intellectual disabilities capable of decision making can be expected to have the right to informed consent. Of course, there is great variation from person to person in the capacity to make decisions, which may also vary from decision to decision (Levy, 1996). It can be difficult to test for competent decision making capabilities and a definite measure is not available. Incompetency under one civil standard may have little relevance to incompetency under another civil mental health standard, and legal decisions may vary depending on the issues at hand and/or by jurisdiction (Parry, 2002). Unless determined otherwise, every adult is presumed to be competent and to have the right to informed consent (Levy, 1996). The right to informed consent includes the right to be free of influence from others by means of coercion, fraud, duress, force, or deceit (Parry, 2002). In addition, the HIPAA regulations define many aspects of patient’s privacy; individuals with disabilities are subject to the same regulations as the general population for all health care (HIPAA Privacy Rules).

If an individual cannot make autonomous decisions, his/her decisions are typically made by a guardian. There are different levels of guardianship for persons with intellectual disabilities. Guardianship can be temporary to permanent, with an extensive scope that includes all decision-making rights, or one that is limited to specific rights such as protecting the individual’s finances (Parry, 2002). Guardianship laws vary from state to state. For example, some states have established advocacy groups to enhance individual decision making when necessary. New York State has a Surrogate Decision-Making Committee for individuals living in state-run facilities who cannot make their own decisions (Levy, 1996). Individuals also have the right to appoint a person of their choice as their health care proxy. Documentation is required to appoint the specified person who will act as a proxy if healthcare decisions are needed (Jetty, 2005). A health care proxy is not a permanent assignment. Proxy status can be revoked by the protected individual or by a third party if the proxy is unable to fulfill the appropriate obligations (Jetty, 2005). The opportunity to appoint a health care proxy is intended to provide a trustworthy advocate for the individual with disabilities. However, one study showed a tendency for proxies to overestimate the level of impairment and to underestimate health-quality of life for people with disabilities (Andreson, 2001). The study indicated that proxies tend to misjudge the severity of the

disability and the well-being of the person they make decisions for. When a client is not in control of his/her own decisions, medical diagnosis and treatment regimes become more complex. It is important for the health care proxy to remain impartial in terms of personal perspectives, and committed to ensuring outcomes that are in the best interest of the client.

Women of minority groups have been targeted by racist sterilization groups (Socialistworker, 2004). Women with disabilities have reported being offered immediate termination of pregnancy based on the assumption that they do not want to be pregnant or should not be having children (Carty, 1998). It is important to avoid suggesting directly or indirectly that a woman with a disability is unfit and irresponsible for considering childbearing (Smeltzer, 2007). Legally, all women have the right to decide what happens to their body. In 1973, a Supreme Court ruling gave women the right to terminate pregnancy (USA, 2006). In addition, the ADA prohibits physicians working in private offices and publicly-funded clinics from engaging in actions that may prevent women with disabilities from obtaining equal reproductive health care services (Grabois, 2001). Therefore, women with disabilities are subject to the same rights to abortion as all women.

Women with intellectual disabilities who want to be parents may have difficulty maintaining custody of their children or they may encounter other threats to their parental rights (Judge, n.d.). According to the ADA, legally disabled parents have a right to the same services, programs, and activities as the general public. Parents with intellectual disabilities may require modified services to assist them in regaining custody or preventing termination of parental rights. They should be able to assert an ADA claim if the state fails to make needed and reasonable modifications in their services (Judge, n.d.). Other laws pertaining to the issue include the Rehabilitation Act Section 504 and the Federal Adoption and Safe Families Act (ASFA), which require that reasonable modifications be provided to ensure individuals with disabilities have equal opportunity to participate in and benefit from programs and activities that receive public funding (Judge, n.d.).

### **Summary: Case Preparatory Work**

Current genetic counseling job tasks were determined by the American Board of Genetic Counseling as the outcome of a Genetic Counseling Practice Analysis (Hampel et al., 2009). The following lists the **Case Preparatory Work** tasks:

1. Evaluate referral information to determine
  - a. appropriateness
  - b. urgency
  - c. need for consultation with other experts (e.g., cardiologist, dermatologist, etc.)
  - d. need to obtain additional information
  - e. need to include relevant family members in the evaluation
  - f. need to include interpreters
2. Review medical records
3. Review of literature and other resources
4. Develop preliminary risk assessment and/or differential diagnosis
5. Confirm eligibility and availability of genetic testing and/or research studies
6. Arrange preliminary diagnostic tests

Genetic counseling referrals come from a variety of sources, often from health care providers and self-referrals, and less commonly from community service providers such as social workers. The stated reason for referral is that Mary's mother is concerned about the baby being born with developmental disabilities. We don't know about other factors that may have precipitated this referral.

- Does the mother believe Mary's intellectual disabilities are genetic?

- Does the social worker have concerns that the mother would pressure Mary into having an abortion?
- Is the mother concerned that Mary is incapable of parenting?
- Have there been fetal exposures?
- Are there worries about Mary being the victim of incest or sexual abuse?
- Are there other family members with intellectual disabilities?

We can only consider that these or other thoughts and questions might have motivated the social worker to refer Mary. We also wonder if the social worker discussed the process of genetic counseling with Mary and her mother so they would know what to expect from the appointment. Given the challenges faced by individuals with intellectual disabilities in accessing appropriate health care, the genetic counselor may or may not have the opportunity to review medical records with useful information about Mary's intellectual disabilities, whether she has had any genetic testing, etc.

The genetic counselor will automatically be prepared to be on the lookout for any red flags that could provide insight into the cause of Mary's intellectual disabilities, such as dysmorphic features, birth defects, chronic health problems, etc. However, the risk assessment and differential diagnostic approaches do not appear to be a top priority in this case. Tracey will also need to explore issues of informed consent and patient autonomy, especially when the discussion moves into the risks and benefits of prenatal testing. From a legal standpoint, we don't know how much autonomy Mary has to make her own health care decisions.

Because we know so little about Mary, one of the most important approaches to case preparatory work in this case is for Tracey to initiate a conversation with the social worker prior to the appointment. At this time, Tracey should gain a better understanding of Mary's past medical and psychosocial history, the relationship between Mary and her mother, other family members and support persons, living arrangements, communication patterns. The culturally competent genetic counselor will not stop there, however. Tracey should also give the client a chance to speak for herself and express her interests and desires. Mary's mild intellectual disabilities are not contraindications for holding these discussions. Lastly, it is important to allow Mary's mother to weigh in about her perspectives on these issues. It is appropriate for Tracey to consider the words and images she will use when counseling the client. She will want to keep the messages short and to the point and focused on addressing Mary's questions and aligned with her expressed agenda. Tracey will want to use a variety of learning strategies, and ask Mary and her mother for their feedback.

### **Cultural Immersion Activities**

<http://www.thearc.org>

*The Arc is an organization that promotes and improves supports and services for all people with intellectual disabilities and their families. They provide access to the information and resources individuals need regarding intellectual disabilities. Their website offers links to local Arc chapters in your community. At your local chapter, you can become a member and participate in events with intellectually disabled persons. The Arc also holds a National Convention each year that is open to the public.*

<http://www.ndss.org>

*The National Down Syndrome Society's website includes a section titled "Get Involved." Here you can find out about national events and walks in your area as well as how to volunteer.*

<http://www.specialolympics.org>

*Special Olympics has offices in over 120 countries around the world. Each office has opportunities to become involved by volunteering your time, coaching a team, donating money, or even simply being a fan at the games.*

## Resources

Take some time to identify resources in your community for parents with mild intellectual disabilities.

Related internet resources:

- ▶ [www.thearc.org](http://www.thearc.org)
- ▶ [www.Disability-abuse.com](http://www.Disability-abuse.com)
- ▶ [www.diverse-city.com](http://www.diverse-city.com)
- ▶ [www.nichcy.org](http://www.nichcy.org)
- ▶ [www.austin-safeplace.org](http://www.austin-safeplace.org)
- ▶ [www.ndss.org](http://www.ndss.org)

## Cultural Competence

- Use the preferred term “intellectual disabilities” and explain its meaning with your clients, without labeling or stigmatizing the client. Assess and incorporate the client’s unique abilities, rather than her limitations.
- Seek guidance from colleagues in genetics and other specialties with more experience working with clients with intellectual disabilities.
- Be aware of your biases and limitations. If you are not confident in your ability to work with individuals with intellectual disabilities in a respectful and meaningful manner, refer the patient to a colleague who is. Keep learning.
- Ask about the client’s competence to provide informed consent before the session. Involve caregivers, guardians, and the family as appropriate.
- Obtain as much information as possible about the client’s history before the session.
- Decide what information is essential to communicate. Use simple terminology accentuated by visual aids. Check for acceptance of your educational strategies and modify your communications as needed.
- Focus the counseling session on the client’s concerns and abilities.
- Consider changes that can be made at your workplace (including location and financial issues) to provide equal access and delivery of genetic services for individuals with intellectual disabilities.

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## Assessment and Evaluation Questions

### Case Preparatory Work: Genetic Counseling Mary, a Prenatal Client with Intellectual Disabilities

1. True/False

Although many people with developmental disabilities or intellectual disability want to be parents, the large majority of their parents are opposed.

2. True/False

It is reasonable to assume that when an individual with developmental or intellectual disability becomes pregnant that the pregnancy is a result of sexual abuse.

3. True/False

Parenting skills cannot be taught to people with developmental or intellectual disabilities.

4. True/False

It may be more beneficial to discuss psychosocial concerns rather than medical facts with individuals with intellectual disability or developmental disability when facilitating medical decision making.

5. True/False

If family or medical history is essential to the counseling session, talking with family members or a social worker beforehand with the client's consent may be more beneficial than relying on a client with intellectual disability or developmental disabilities.

**For questions 6-10, please read Finucane, B. (1998). [Acculturation in women with mental retardation and its impact on genetic counseling](#). *Journal of Genetic Counseling*, 7 (1), 31-47.**

6. True/False

Acculturation is a term that describes when individuals of a stigmatized minority group adopt the behavior, values or viewpoints of the dominant culture to which they wish to belong.

7. True/False

Having an intellectual disability is one of the most stigmatizing of all conditions; thus individuals with intellectual disabilities often try to "pass" for normal in their eyes and the eyes of others.

8. True/False

Genetic counselors often think of mildly intellectually disabled individuals when they think of mental retardation, and thus are well equipped to recognize individuals with mild intellectual disabilities.

9. True/False

Individuals with mild intellectual disabilities may view the possibility of having a child with an intellectual disability as "not as bad" as having a child with a physical disability, and thus may be more concerned about physical disabilities than intellectual disabilities.

10. True/False

Women with mild intellectual disabilities may be highly motivated to achieve and maintain pregnancy in order to belong to the dominant culture.

**The following questions are for CEU learners only:**

1. I feel I have achieved the following objective as a result of this learning activity:

Discuss how reproductive options, decision making or genetic testing may be influenced by the presence of mild intellectual disability in a genetic counseling client.

**4= Great extent      3= Moderate extent      2= Slight extent      1= Not at all**

2. I feel I have achieved the following objective as a result of this learning activity:

Determine the relative importance of steps in the genetic counseling process when working with an adult with mild intellectual disability.

**4= Great extent      3= Moderate extent      2= Slight extent      1= Not at all**

3. I feel I have achieved the following objective as a result of this learning activity:

Identify online and community resources that contribute to case preparation work when providing genetic counseling for adults with mild intellectual disability.

**4= Great extent      3= Moderate extent      2= Slight extent      1= Not at all**

4. Please rate the overall effectiveness of this case in promoting learning.

**4= Great extent      3= Moderate extent      2= Slight extent      1= Not at all**

5. Please rate the overall quality of this case.

**4= Great extent      3= Moderate extent      2= Slight extent      1= Not at all**

6. The content of this case was presented without bias of any commercial drug or product.

**4= Great extent      3= Moderate extent      2= Slight extent      1= Not at all**

7. The technology used was appropriate and effective.

**4= Great extent      3= Moderate extent      2= Slight extent      1= Not at all**

**Disclaimer**

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