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Promoting the Full Participation of People with Intellectual/ Developmental Disabilities (IDD) in the Life of the Catholic Church

Prenatal Poor and Difficult Diagnoses A Call for Support Ministry

By Tracy Winston, St. Mark Catholic Church, Huntersville, NC

I became aware of the issue of poor and difficult prenatal diagnoses while working with Elizabeth Ministry, which among other things relating to issues for new mothers, provides prenatal bereavement support. In particular, working with moms of children with Down syndrome, I learned that the term "atypical" is used when a physician advises that the child in being is not worthy of the effort to bring him or her to birth. This term shifts attention from the baby to the pregnancy and abortion. The physician thus moves on from this baby with anencephaly, hideous defect, heart defect, cleft palate, Down syndrome, dwarfism, etc. to the next baby. Tim Shriver in an article in Commonweal called what is happening, "silent eugenics."

Parents often do not learn enough to give informed consent. Information about outcomes is non-existent. The information given is often inaccurate, biased and given under pressure for an abortion. In Charlotte, this information is usually available at the 21 week mark and there is often less than a week for parents to absorb and research the information before the decision for abortion. There is no information given about available support or adoption. A surgical procedure: "prevents suffering and makes a loving choice." Parents may not even realize that an abortion is being proposed. One woman was advised after ultrasound to have an immediate "induction." The woman asked, "Will this help my baby?"

In the case of a "lethal diagnosis" where the child is expected to die at or shortly after birth, there is no recognition that parents will grieve whether the child is aborted or goes to term. In fact, among those who choose abortion, there are higher rates of depression and marriage issues. The Carolina Perinatal Support Network, a perinatal hospice and medical service, provides families with meaningful support and information to preserve their dignity while making plans to honor the life of their baby.

There are some excellent online resources available for parents receiving poor prenatal diagnoses. The best is *BeNotAfraid.net*, which lists parent stories by diagnosis. *Brightertomorrows.org* provides information about Down syndrome. *Perinatalhospice.org* gives information about locating support after a lethal diagnosis. A book that I highly recommend is Madeline Pecora Nugent's "*My Child, My Gift: A Positive Response to Serious Prenatal Diagnosis*" (New City Press, 2008). In the Diocese of Charlotte, each parish has received a copy.

Ministry to parents with poor prenatal diagnosis may seem overwhelming. But I believe that it is not necessary to create a new, big service. Rather, I feel quite sure that existing ministries can provide an overlay service through training. For example, a labor support person can be trained in bereavement support. Peer ministers can be present at birth. Elizabeth Ministry, Gabriel Project and Stephen Ministry are good prospects. Disability ministries could have a prenatal component and create support groups for "designer genes." Catholic hospital communities should be providing such services.

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