At a societal level, the selective abortion of children with disabilities exposes the persistence of a eugenic drive for perfection that ignores and even subverts the dignity of children who are all made in the image of God.

Early information about a baby’s medical condition can lead to better treatment options. But, it is often easier to diagnose than to treat a genetic illness. For thousands of parents each year, prenatal genetic testing yields a tragic diagnosis for their unborn child, which may limit life to weeks or even days after birth.

Although precise numbers are difficult to come by, many, if not most, of these children are aborted each year. Parents who choose to carry these children to term often face a difficult journey. Thankfully, a movement is growing to provide support, encouragement and practical care for both parents and infants who have received a terminal prenatal genetic diagnosis. This was the subject of a briefing hosted by the Center this past spring on Capitol Hill for congressional staff that featured a panel of three speakers.

Several thorny issues are raised by prenatal genetic diagnosis. Although the technology is constantly improving, the tests are not 100% accurate. Getting beyond information about “elevated risk” requires more invasive techniques such as amniocentesis and chorionic villus sampling, which pose additional risks for the fetus. At a societal level, the selective abortion of children with disabilities exposes the persistence of a eugenic drive for perfection that ignores and even subverts the dignity of children who are all made in the image of God. And medical technology is constantly improving the outlook for many genetic conditions. Between 1983 and 1997, the average lifespan of Down’s syndrome patients doubled from 25 to 49 years.1

For conditions where medical technology is currently unable to extend life beyond a few months after birth, medical professionals and genetic counselors must implement policies and institutional procedures that affirm the human dignity of these little ones. Over the past several years, the young field of palliative care has rapidly expanded, as our society has increasingly recognized the need to provide the elderly or the terminally ill with appropriate care and comfort in the final months of their lives. In a few pioneering regions of the country, medical professionals, social workers and parents are working together to apply the dignity-affirming principles of palliative care to the neonatal context.

Several courageous parents who have walked this difficult journey have started organizations that provide support and information for other parents facing such a difficult road. At the Congressional briefing, one of these mothers told us her tragic, yet heartwarming, story. In 1994, after being pregnant for only 18 weeks, Nancy Mayer-Whittington learned that her unborn little girl had Trisomy 18, a rare genetic condition which is fatal, often early in a child’s life. She chose to carry her baby to term and was only able to hold Angela for ten minutes before she died. Regarding her decision to carry Angela to term she said, “I was so happy I did what I did . . . You get to see your child’s birth and death all collapsed in one time frame. What most people want for their kids is for them to go to heaven. You get to complete that journey with them . . . . Life is about relationship to God. You know that when you literally pass them from your hands to His.” Along with another mother, she cofounded the group Isaiah’s Promise as a resource for parents facing similarly difficult decisions.

Amy Kukelbeck, a former reporter and editor for The Associated Press, started http://www.perinatalhospice.org as a clearinghouse of information about perinatal hospice and palliative care for young infants. Her book Waiting with Gabriel: A Story of Cherishing a Baby’s Brief Life (Loyola Press, 2003) has been an encouragement to many families facing a terminal prenatal diagnosis. In 1994, Nancy Mayer-Whittington was the first patient her doctor had known to choose to carry her baby to term in the face of a Trisomy 18 diagnosis. And despite the efforts of these and other parents, the field of perinatal hospice is still quite small. A small study in 2007 reported that knowledge of perinatal hospice and palliative care increased to 40% the number of parents choosing to carry their terminally ill children to term.2 With adequate support, parents facing difficult prenatal diagnoses can walk through their tragedy knowing that they have parented well and given their children the dignity they deserve.

Prenatal diagnostic screening is now a routine part of obstetric care. Advances in medical technology—including genetic testing—have dramatically expanded the number of conditions that can be identified in a developing fetus. In some cases, early information about a baby’s medical condition can lead to better treatment options. But, it is often easier to diagnose than to treat a genetic illness. For thousands of parents each year, prenatal genetic testing yields a tragic diagnosis for their unborn child, which may limit life to weeks or even days after birth.

Although precise numbers are difficult to come by, many, if not most, of these children are aborted each year. Parents who choose to carry these children to term often face a difficult journey. Thankfully, a movement is growing to provide support, encouragement and practical care for both parents and infants who have received a terminal prenatal genetic diagnosis. This was the subject of a briefing hosted by the Center this past spring on Capitol Hill for congressional staff that featured a panel of three speakers.

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