

## **Case 10.**

Sharon Duchesneau and Candace McCullough are both deaf, and are the parents of a deaf child, Jehanne. To increase the chances of having a second deaf child, they selected a sperm donor with a family history of several generations of deafness. Their son, Gauvin, was born with a complete hearing loss in one ear and a serious hearing loss in the other. Although a hearing aid would allow Gauvin some level of hearing in the one ear, his parents refuse any treatment that allows even residual hearing, saying they will allow him to choose hearing or deafness when he is older.

The use of reproductive technologies to select for desired traits has long raised ethical concerns about using technologies to give children a disproportionate advantage. The decisions of Gauvin's parents to ensure he would be born deaf, and remain deaf, have raised the issue of defining "handicap" and "enhancement". While many believe deafness to be a disability – it is listed as such in the Individuals With Disabilities Education Act, and many sperm banks will not accept sperm from donors who have congenital deafness – others, such as Gauvin's parents, believe deafness to be a benefit.

Critics of genetic selection for deafness or failure to remediate hearing loss consider deafness to be a disability that limits a child's potential. They believe deafness limits pleasure and safety, creates difficulty in acquiring language, impedes communication, and may cause a child to be ostracized. Children's rights advocates strongly oppose selecting for deafness, as inability to hear limits language development and career options, and eliminates the ability to hear the sounds of music, nature, or human speech. Children who grow up with hearing playmates often find these friendships diminish as talking in adolescence becomes as important as the physical play of childhood. Others fear that selecting deafness for a child may lead to more restrictive use of reproductive technologies for parents at risk of conceiving a child with genetic maladies such as Cystic Fibrosis or Tay Sachs. If parents are allowed to select for deafness, some ask if parents may also select for blindness.

Proponents argue that the deaf community experiences a degree of emotional intimacy not achieved in the hearing world, and these bonds of community outweigh the benefits of hearing. Deaf people often have a heightened sense of smell, touch and vision. In an interview in the Washington Post, Candace McCullough called deafness a cultural identity, not a handicap. Supporters say that McCullough and Duchesneau did not create a handicapped child: they allowed a handicapped child to be born. Jim Roots, of the Canadian Association for the Deaf, sees no difference in deaf parents who wish to have a deaf child like themselves, and hearing parents who fit a child with hearing aids, use cochlear implants, or resort to surgery to allow their children to hear. Clients of sperm banks are able to choose characteristics they want in a donor, such as height, hair color, race, and other traits, and are able to choose a donor without evidence of disease or disability who matches themselves as closely as possible. Why should deaf parents not be allowed to select traits that reflect themselves in their children?