



## SAINT CATHERINE CENTER FOR *Special Needs*

### **Parents' Experiences – A Brief Statement of Needs**

Stress combined with inadequate coping mechanisms is an accepted contributor to poor marriage relationships and divorce. In the particular case of parents of children with developmental disabilities, it is typically a combination of multiple stressful events and issues which make ongoing demands that can undermine a marriage if there are not enough or appropriate coping mechanisms, strategies or resources.

Many that may occur are listed below. Some families may experience only one or two, none, or many of them. Please also note the pastoral implications on the next page.

- The initial experience that something is “wrong,” which if not a diagnosis, can have destabilizing effects if there are different perceptions by the wife and husband. And differing ways/ideas of men, women, and family histories/individual differences
- The diagnosis can bring relief that there is a name or it can bring grief at confirmation of the “typical” child not born and the associated expectations, even unspoken.
- The wear and tear on the spirit of each parent from going through the extra daily tasks associated with the needs of a child with developmental disabilities. Perception of different levels of involvement can cause anger, resentment.
- Physical exhaustion is often a regular part of life from sleep deprivation and/or the extent of physical involvement in care, for example, having a 6 year-old who is not toilet trained, and likes to decorate with his or her feces.
- Often there are financial issues (beyond those that normally occur in life) to provide services and supports that are needed but not “covered.” These can particularly impact the husband’s self-esteem by feeling he is not able to “take care” of his family.
- The wide assortment of needs, services, supports, extra activities, extra jobs, require a strategy of “divide and conquer” even more than typically occurs in family life that can isolate husband and wife from each other. This may be magnified by cultural expectations of independence and not asking for help.

- Families often feel isolated from “typical” families and may not have connections with families who share their struggles that could give support.
- Disagreements over appropriate courses of action can be magnified when there is different level of involvement in doctor visits and treatment appointments. Both feel the same right to decision based on parenthood, but if one parent is more involved he or she may not validate the other’s opinion/desire. Can create baggage that transcends issues.
- There can be jealousy from reduced attention/time for the spouse because of the extra time and attention needed for the child with developmental disability.
- The above also get compounded or exasperated from the needs of “typical” sons and daughters, ups and downs of life cycles, careers, illness, etc... These are an ongoing part of life.

### **Some Pastoral Implications**

- The list above focuses on the challenges and struggles. Even in families where they exist, know that there are also moments of great love, joy, happiness, etc. This also should be noted, affirmed and celebrated.
- While affirming parents in the love they have and the care they provide for their sons and daughters with special needs, be careful not to set them on a pedestal. Though well-intentioned, such comments often make it difficult for the parents to then voice the frustrations and fears they have.
- Need to educate the “person in the pew” about the struggles, and the joys, these families are living with and their need for a supportive faith community.
- This is not only a nice thing to do, but is called for by our identity as a Eucharistic people.
- Importance of preparing catechists so children can be welcomed in catechetical programs within appropriate environment-as inclusive as possible to the extent that the parent and child would like it.
- Provide respite care for parents: family fun nights, during Mass for younger children (could be beginning of religious education)
- Develop strategies to reduce sense of isolation, create connections w/ others in parishes

- Support groups for mothers and fathers, grounded in faith.
- Recognize that parents may be angry with God and/or the Church and may need someone to walk with him/her in faith.
- Meet each family where they are and determine needs; develop strategies to address needs.