

## Tip Sheets

### Living with a Disability: The Family Perspective

Families of young children with special needs face unique challenges when looking for childcare. By learning the family perspective, early childhood educators can demonstrate an increased level of empathy and sensitivity about the impact of a child's disability on parents/family members.

#### More Alike than Different

Inclusion is a practice and a philosophy of care. As educators, we must emphasize the need for acceptance and respect of diversity for family structures, values, and members.

Parents of children with disabilities have child care needs and concerns similar to families with children who are typically developing. Although each family is unique, when we consider how families are more alike than different in the ways they cope/function, we can better serve all children and their families.

#### Shifting Your Perspective

- Support parents' hopes/dreams for their child.
- Suspend judgment of families/their behavior.
- Be patient. People need time to find their own personal way through unexpected events, such as after the diagnosis- or birth of a child with a disability.
- View this as an opportunity to strengthen trust.
- Maintain supportive partnerships, and recognize the importance of your relationships.

#### How Families Function

To understand the unusual circumstances of families with children who have special needs, we must begin with what is important to all families.

#### What is the purpose of family?

Simply stated, it is to meet the basic needs of individual members and the family unit as a whole.

In discussing the family systems from a global perspective, Turnbull et al. (2010) describes the eight functions performed by family members as:

1. **Economic:** Generating income and making family financial decisions
2. **Daily care:** Providing health care and fulfilling home tasks, such as maintenance and food
3. **Recreation:** Providing individual and family recreation and the enjoyment of hobbies
4. **Self-esteem:** Establishing self-identity, self-image, and a sense of belonging
5. **Affection:** Nurturing and loving; expressing emotion and intimacy
6. **Spirituality:** Solving problems, giving feedback and advice, and shaping values and beliefs
7. **Education:** Encouraging schoolwork, continuation education, and cultural appreciation
8. **Socialization:** Choosing a career, developing a work ethic, and supporting interests

Regardless of a disability, different make ups of families yield different family functions, stresses, strengths and responsibilities. For example, lack of child care may affect a family's ability to accomplish some family tasks.

What works for one family may not work for another. Therefore, it is important that educators are sensitive to the needs of all.

Because families have different levels of flexibility and adaptation, how they cope with stressful life events (as a unit and as individuals), will be unique.

For example, a family unable to meet basic needs will most likely have difficulty in mobilizing the support, resources, time, or energy required to meet the extra demands of a child with a disability.

### How the Disability Affects Families

A family's survival and well-being depend on their ability to meet such basic needs as housing, food, transportation, and health care. When a child is born with a chronic illness or disability, the entire family system is under significant stress.

The degree to which a disability affects a family, however, is unique to each child and depends on many variables within the family system, such as:

- The nature of the disability.
- The make-up of the family's members.
- Whether family supports are in place.
- Economic supports.
- Beliefs about disability, parenting, and values including cultural views on disability.

### Additional Stress and Trauma

Additional circumstances that may impact how a disability affects a family include:

- The additional stresses faced by families that have emigrated to this country (e.g. adjusting to a new culture or language barriers).
- The coping abilities of individual family members and the family unit.
- Economic strain, health problems, needs of siblings, or job-instability.

### Relationship-Building with Parents

Relationships are critical for the success of any child. As you work to maintain supportive

partnerships with a family of a child with a disability, it is helpful to:

- Embody the belief that the child is a child first.
- Voice your enthusiasm for providing special needs care.
- When first meeting a child and their family, ask open-ended questions like, "Tell me about a typical day for Miko" or "In what ways do you consider Tom to have special- care needs?"
- Share your observations, concerns, or feelings routinely and honestly. Ask for assistance from parents in solving specific problems.
- Note and share the positive things about the child's day and the contributions a child makes. Share even the smallest gains.
- Understand that a parent may feel additional guilt or sadness when a child is left in care.
- Have information available on family supports and local resources in your community.
- Be sensitive to sibling issues and include them in your conversations.
- Recognize that when parents seem quiet, sad, angry, or irritable, their feelings probably have nothing to do with you.

### Additional Resources

Disability Hub MN

<https://disabilityhubmn.org/for-families>

For more information, visit [www.inclusivechildcare.org](http://www.inclusivechildcare.org).

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