

family

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Abstract

This short, family-affirming paper lists the values and principles which should be behind family focused services. It supports the uniqueness of families and that they should be the ultimate decision makers with respect to themselves and their child or adult with a disability. **Keyword: Professionals**

VALUES AND PRINCIPLES BEHIND FAMILY-FOCUSED SERVICES

1. FAMILIES OF CHILDREN OR ADULTS WITH DISABILITIES ARE NOT DISABLED FAMILIES

Children with disabilities do not "cause" families to be dysfunctional; indeed, these families may fall along the whole range from extremely successful (that is, all members of the family are reasonably satisfied with their family life) to extremely unsuccessful. Thus, a family entering services is presumed healthy until proven otherwise.

Implications of this principle are:

- All families have resources to meet their own and their child's needs; these should be identified and used in a meaningful way in program plans.
- Because families are not "patients", they occupy a position of full respect and partnership with professionals, ranging from policy/planning to the individual service level.

2. EVERY FAMILY IS UNIQUE

Families differ in size, structure, resources, attitudes, and cultural background. In fact, families vary so widely and on so many dimensions that we must conclude that every family is unique and that no "formula" approaches to families will work.

Implications of this principle are:

- Everyone, even those with no living blood relatives, has a "family".
- Informal, non-standardised approaches to identifying family strengths and needs are best.
- Family support should be individualised.
- A variety of services and information, in a variety of formats, should be available.
- Materials, services, and staff should be culturally sensitive and relevant.

3. THE FAMILY IS THE ULTIMATE DECISION MAKER WITH RESPECT TO THEMSELVES AND THEIR CHILD OR ADULT WITH A DISABILITY

Families should be in control of all decisions, including decisions about how much control and involvement they wish to have. Even in cases of minimal involvement, parents should be recognised as the primary decision makers and as the experts on their child, and, for families of adults, should be recognised as major advocates on behalf of the person with a disability.

Implications of this principle are:

- A need is not a need unless it is recognised by the family.
- As experts on the person, families should be actively involved in assessments.
- Families should receive timely, full, honest, complete, and understandable information to allow them to make informed decisions.
- Families should be equipped with skills to allow them to work effectively with professionals.
- Families should be helped to learn how to transfer decision-making from themselves to their child with a disability as the young person grows toward adulthood.
- Programs should serve as advocates with and for families to get services from other programs and professionals and to facilitate inter-agency co-ordination of those services.

4. PROGRAMS SHOULD BE SENSITIVE TO FAMILIES' EMOTIONAL NEEDS

Professionals should recognise that families look to them for support as they face the emotional stresses associated with having a family member with a disability. Also, it is important to recognise that dealing with professionals is in itself stressful; therefore, staff should be sensitive and considerate of these needs.

Implications of this principle are:

- All interactions should be scheduled at times and locations most comfortable for families.
- Language used by professionals should be sensitive to possible misinterpretations by families.

- Identification of family strengths/needs should be non-intrusive, respectful of family privacy, and tied directly to the needs of the person with a disability.
- Staff should be non-judgmental, unhurried, and considerate of families.
- Trust and rapport should be earned by program staff rather than expected, and take time to build.
- Programs should provide families with options for mutual support from other families who have children with similar needs.

5. ALL FAMILY MEMBERS AND ALL FAMILY NEEDS ARE EQUALLY IMPORTANT

The family should not be expected to sacrifice itself to the needs of the person with a disability - the whole family has needs that deserve to be met. Also, both person and family have a variety of needs that may take precedence over educational needs from time to time.

Implications of this principle are:

- The whole family should be involved whenever possible in decision-making about the program.
- A variety of options for services for all family members (e.g., fathers, siblings, grandparents) should be available.
- Parents should be encouraged to "pace" themselves and to balance their child's needs with their own and other family members.
- Families should be encouraged to look at the whole person and not just at the deficits of the person with a disability.

6. FAMILIES ARE CONSTANTLY CHANGING

Families are in a constant state of change. Also, families need to recognise the implications of today's decisions for tomorrow; they need to learn to prepare themselves and their family members for the future.

- Family service plans should be flexible and responsive to changing events in the family.
- Goals for both the person and the family should be oriented toward preparing for the future.