

PHILOSOPHY & VALUES

LIFE CYCLE

Introduction

There are some experiences, thoughts, feelings, and needs at various points in the human life cycle that most everyone experiences. Some stem from surprises, transitions, or new opportunities. Each person is unique and responds differently. However, knowing "typical" patterns will help you listen, and allow you to choose responses that are both empathic and helpful to someone experiencing a new or different phase of life.

The Life Cycle

Typically, human beings are born and reared through childhood. Most people experience adolescence, and test their wings in early adulthood, often pairing up and forming a new family. In the middle years, working and rearing children are common demands for many. At some point (typically ages 55-70), adults step away from their main pursuit (job, career), and do other things in retirement.

While this brief overview of the typical life cycle is without surprises, discovering that a child has a significant disability can dramatically change the pattern of life for a family. In response, one parent may decide to stay at home with the new baby for a longer period of time than was previously planned. Or, a parent who intended to stay at home may have to return to work for medical insurance reasons. Decisions about having other children may be reconsidered, for a variety of emotional or financial reasons. The family may move to be closer to a medical center or a community that they've heard provides good disability services. A child with a disability may remain with their family well into their adult years.

Childhood and Adolescence

Loss, grief, confusion, and acceptance

Children with visible disabilities (e.g., Down syndrome, cerebral palsy, and spina bifida) are usually identified at birth, and with advancing medical technology, many are identified prior to birth. Others, who have disabilities that are not visible, such as those with behavioral or emotional concerns, or language delays or speech disorders, may not be diagnosed until later (sometimes much later).

Shock is a typical initial reaction of parents who have learned of their child's disability when it is unexpected. However, some parents realize as their child grows that something does not seem quite "right" or they intuitively "feel" that something is different. These parents often report spending many hours taking their child to someone they hope can give them an answer, confirm their concerns, or provide a diagnosis. Whether they learn about their child's disability at birth or later in childhood, parents may experience denial, anger, or disappointment.

After the initial feelings subside, many parents begin their search for information. They may read a lot, surf the web, or spend time with doctors and other professionals, trying to sort things out. Many parents report that talking with another parent who has experienced a similar situation is particularly helpful.

Guilt shame and blame (including self-blame) are not uncommon feelings. It is well to remember that even in situations like Fetal Alcohol Syndrome, harming the fetus is rarely intentional. Once more prevalent than today, feelings of shame often stem from beliefs of the early 1900's, when mental retardation was considered the basis of social problems like criminality, promiscuity and poverty.

Once the shock wears off, there may be a rather long period of uncertainty or emptiness as Mom and Dad deal with the day-to-day realities of coping with their child's disability, and struggle to reconcile the new realities with earlier views of how life would be. It takes time to figure out what impact the disability will have over the long pull, and how the parents ultimately want to proceed. IF feelings have been aired, and if parents have an opportunity to talk (and be with) other parents in similar circumstances, and if professionals are thoughtful and supportive, reconciliation and acceptance will generally occur. Acceptance is about restructuring one's thoughts (e.g., cognitive coping), building strength, moving ahead in ways that are respectful of everyone's needs and desires. As a support coordinator (formally known as service coordinator), here are several things you can do to help:

- Express genuine and positive interest in the child with a disability
- Be open and friendly with all family members (including dads and siblings)
- Listen with interest and understanding
- Avoid being drawn in to support certain points of view (e.g., blame, anger), unless the point is how wonderful this child and this family is
- Talk about possibilities and opportunities
- Support loving every child
- Be resourceful (e.g. information on support groups, if asked)
- Through time, help the family develop expectations that are reasonable (neither too high, nor too low) and challenging for the child with a disability

Parenting

Parenting is a challenge, whether the child has a disability or not. Many questions and issues are common; others relate to the disability or are affected by the fact of disability. Early on, many parents will have many appointments with doctors, therapists and the like. This can be exhausting. Many parents will want to do or try everything, so they won't look back later and feel they didn't do enough. Some of what they will want may not, in the opinion of some professionals, be a wise use of resources. But every child is unique, and parents will be thinking that an intervention either will help or won't help.

Some parenting matters are affected by the disability. Some parents, for example, will appear to be overprotective and not allow their children to learn from the “rough and tumble” of life. Other parents will deal with the child with a disability much as they would their other children. If both parents work, many issues will be typical of any family: affordable child care, health insurance, finding babysitters, and so forth. Depending on how open parents are to expressing their real feelings, and how creative they are (e.g. in finding time for themselves), certain marital and related issues may emerge. Support groups of various kinds (for parents, moms, dads, siblings) are an excellent resource for these and other reasons.

As time goes on, many parents become somewhat isolated, especially if their only child has a disability and it is substantial or complicated. It often helps if the parents can connect with other parents “who understand” and who deal with disability related issues themselves. These relationships can be extremely helpful, especially where parents have a need for specialized information (e.g. a dentist that works with children with behavior difficulties, etc.). But, the downside is that parents may feel somewhat alienated from other parents who are not facing disabilities or major illnesses.

Many parents have issues with schooling and related services. They may want a friend or Support coordinator to assist them in confronting school-related issues such as: inclusion, aides, access to courses, work experience, etc. (www.dese.mo.gov/divspeced/)

Adolescence may be especially trying for the parents of a child with a disability, just as it is for many families of children without disabilities. Such issues as allowance, having friends over, getting oneself up in the morning, dressing like other children, and going through puberty are common. Because the child with a disability may need extra support, the child may end up foregoing many typical teenage experiences.

Finally, there is the matter of “life beyond high school,” and the child may need extra support to pursue his/her dreams. (www.dese.mo.gov/divspeced/parentresources.html)

Siblings and extended family

Having a brother or sister with a disability poses some unique challenges. How will siblings, with or without disabilities, relate to one another? What about friendships? Is everyone comfortable about airing feelings? Many siblings report that when properly directed, sibling support groups can be very valuable. They can get a feeling they are not alone. It is okay to express some feelings that would be a risk in talking with Mom and Dad, such as guilt and jealousy or anger, etc. We know that unexpressed feelings can have injurious repercussions. Better to know and understand, and then to move on to ways of including disability within the normal course of family life. (www.dese.mo.gov/divspeced/parentresources.html)

Grandparents often feel very deeply for both their grandchildren and their own offspring. They will need time (and support) in finding ways to include disability within their usual pattern of

life. It is extraordinarily helpful when all the adults can talk with one another, support one another, and find ways of helping each other.

Sexuality

Sexuality is a positive and fulfilling aspect of life that, if not addressed through education and support, can result in negative or abusive outcomes. It is sometimes difficult to address with individuals and families. Deeply embedded in most cultures are beliefs that can stand in the way of dealing with sexual issues objectively. A parent may believe that the child is or will be asexual, and provide too little information and counsel too late. They may keep their child out of sex education at school. Parents may dread pregnancy so much that they interfere with typical dating patterns. They may enclose, and overprotect the child. Sexuality resources exist to address sexuality, adapted to the learning needs and styles of people with intellectual impairments, and you may need to track these down. (www.moddrc.org)

Transitions

With a greater need for support, and limited options available, transitions can be more time consuming for parents than for others without disabilities. Then, too, anxiety may be heightened because of the vulnerability of the child, and his/her inability to fend well for him or herself. In childhood, the individual and family typically face several important transitions: 1) birth center to home, 2) home to Early Start services, 3) Early Start to pre-school, 4) pre-school to elementary school, 5) elementary to middle school, and 6) middle school to high school. (www.dese.mo.gov/divspeced) Regarding transitions, here are some ways you can help:

- Provide information about options or put the family in touch with those who can.
- Develop a plan and assist in its implementation.
- Urge the child and family to talk extensively about their desired futures.
- Accompany families to meetings, and advocate for collaborative services in line with how the child and family envision a desired future.
- Speak up and, as appropriate, suggest a review date and time for team members to get back together to assess whether their plan is working.
- Be sure someone is willing and able to serve as “quarterback” for any team effort that involves multiple steps by many individuals.

The Adult Years

Life beyond school

In the adult years, the idea is for the person with a disability to experience a rich and rewarding life. Realistically, this usually means lives can be similar to those without disabilities who have limited resources with *inclusion, independence, productivity, interdependence, and empowerment* given expression in various ways consistent with each person’s personality and values.

Work, training, day activity

How will an adult with a developmental disability, of working age (18-64) and no longer attending school, spend the work day? The answer depends on several factors:

- What the person wants to do?
- What skills, interests, and attitudes does the person possess?
- What family and cultural expectations (and protective strategies) are in place?
- What resources are available to assist in making the desired outcome a reality?
- What supports/services are needed?

Transition Services

Transition services are provided through special education in local schools. They are mandated by federal special education legislation, beginning at least by age 16 and preferably at 14.

Transition services include:

- Training programs, resource materials, and handbooks that describe transition services.
- Identification of the role and responsibilities of special education in the transition process.
- Implementation of systematic vocational education curriculum.
- Materials, resource manuals and training programs to support active participation of families in the planning and implementation of transition related goals and activities.
- Identification of resources and training that will support the implementation of individualized transition planning.
- Coordination with other specialized programs that serve students who face barriers to successful transition.

A coordination transition-planning meeting (conducted along with the IEP) should include representatives of agencies who would serve the individual after graduation. Transition is a purposeful, organized and outcome-oriented process designated to help students with developmental disabilities move from school to employment and a quality of adult life.

Expected student outcomes of a successful transition include meaningful employment, further education, and participation in the community (for example: living arrangements, social activities, recreational activities, on-going educational opportunities, etc.).

Regarding options, most communities offer a variety of education and training opportunities, in the form of community college programs, adult school, employment training programs, and private schooling. Most communities offer Supported Employment Services, funded through the Department Elementary and Secondary Education (DESE) Division of Vocational Rehabilitation. (<http://dese.mo.gov/vr/vocrehab.htm>)

Supported Employment typically involves working 20 or more hours a week at or above minimum wage, in a job in the community, with assistance from a job coach. Individual placements, work crews, and enclaves represent typical options.

The Division of Vocational Rehabilitation may support such programs financially (funding for job coaching, job skill training, and sheltered employment and assessments). Regional

Offices/SB40 Boards may fund a variety of types of options for day services.

<http://dese.mo.gov/vr/vocrehab.htm>

As a support coordinator, you can help individuals (and families) set and achieve their goals in several ways.

- Listen carefully to hopes and dreams.
- Encourage regular lives (competitive employment/supported employment).
- Suggest that individuals (and families) visit agencies providing day program services.
- Counsel individuals about differences in service availability (one may not be able to be placed in a competitive job for some time, whereas availability of a traditional day program could be immediate).
- Help the person figure out how to productively spend his or her time while waiting for the preferred services (volunteering at the local food bank).

Where to live (alone or with others)

Many young adults, with or without disabilities, live with their families (mom, dad, and siblings) in the years just beyond high school. Indeed, some continue living with families longer. If not living with family, the options generally include:

Host Homes:

- Personal assistants are included
- An *independent living arrangement* with some training and support, fading too little or no paid support after a planned period of time.
- A *supported living arrangement*, with one or two others, with as much support as needed to live successfully in one's own home.
- And Supportive living arrangement to include individualized supportive living which can offer minimal to 24 hour support, health care oversight, and personal assistant

Congregate living such as:

- A *group home* or other small congregate setting with 24 hour care, support, personal assistant, and health care oversight.
- A *Skilled Nursing Facility* (SNF) provides 24 hour care supervised by a licensed nurse and provides treatment prescribed by a physician.
- A *Residential Care Facility* (RCF), RCF I provides shelter, board, some protective oversight, and basic health care.

Intermediate Care Facility (ICF-MR) 24 hour care

- Personal assistants are included
- A certified *foster home* or *family home* for one or two children or adults living in the same home with individuals or families who provide support.

Fundamentally important is how the person wants to live. In addition, support groups (or transition classes) can help. To grow up and leave school can be traumatic for everyone, but leaving the parental home to live elsewhere, can be even more emotional, including fears as to whether the son or daughter will be safe, well cared for, and still eager to be with family and friends. Parents who have devoted time and attention to child-rearing may, in addition, be at “loose ends” regarding what they want to do once that stage of their life has been completed.

Relationships and leisure

None of us is “all work and no play.” In adulthood, some individuals with developmental disabilities will form intimate (often lasting) relationships. Some will marry, others will live together, and still others will live apart, but still see each other often. If a person is moving from one setting to another, maintaining old relationships, as well as forming new ones, can be vital for the person’s well-being. Friendship information and maintenance can be assisted by the right kind of services and supports.

Leisure-time pursuits and recreation are important at all ages. The kinds of pursuits are usually like those of the general population: church, sports, fitness activities, hobbies, visual and performing arts, public service, clubs, and simply getting out to see and do things (farmer markets, craft fairs). In this area, the support coordinator can help by:

- Acknowledging the importance of relationships and leisure-time pursuits for mental and physical health.
- Promoting services which help support and maintain relationships and leisure time activities.

Planning for the Future

Planning for the future typically refers to steps that families take to provide support for their child with a disability for that time when parents are incapacitated or deceased. The concept often begins with discussions and informal plans within the family; the writing down of basic knowledge possessed by family members and the articulation of family hopes for the future. Eventually this moves to decisions to seek (or not seek) limited or full guardianship, the writing of wills, estate planning and use of special needs trust instruments. Sometimes funeral arrangements are made in advance for the person with the disability.

Interest (and concern) in these areas can surface at any time. A young couple, for example, may be taking a vacation and worry about what will happen to their children if they were to die in an airplane crash. Discussions within the family are likely to be ongoing and reflect what is happening to siblings as they grow to maturity. Location, marital and family status, presence or absence of siblings or other extended family. These and other factors play a part in the thinking of most parents.

Support coordinators can help by:

- Bringing appropriate learning opportunities to the attention of families (workshops on Financial Planning or Special Needs Trusts).
- Urging parents to have properly executed wills that acknowledge all of their children.

- Explaining how *Supplemental Security Income (SSI)* and other benefits may be affected by inheritances that are not carefully considered.
- Maintaining a list of lawyers (and parent organizations) that specialize in disability-related Financial Planning issues, or can refer to those who do.

Retirement

Retirement is very much an individual issue. Some elders, whether they have a developmental disability or not, want to retire in order to pursue other interests (further education, spiritual renewal, travel). Some, however, want to continue with life, pretty much as is. A lot depends on aspirations, financial resources, health status, and the kinds of services and supports that are available. Residential Care Facilities for the elderly and nursing homes offer some retirement-related services. Elders who continue to live in their family homes, beyond the lives of parents, often want to continue in their own homes, and may benefit from *Personal Assistance* or similar services. Elders who reside in regular care homes may, unfortunately, be expected to subordinate their personal desires to those of the care provider or other residents. All too often, an elderly individual is forced to continue working or attending a day program, because of a need for supervision and the financial pressure that staying home may put on the residential service provider.

Issues that Cut Across the Life Cycle

Independence

How independent does a person want to be? How independent can a person be? Being able to take care of personal needs, and being able to perform most activities of daily living such as shopping, cooking, banking, and the like, is wholly positive, not only because of the freedom (and choice) such capabilities support, but fewer paid services are needed. *Independence* is only one of many positive values and can conflict with interdependence, inclusion, and the like. If an adult is independent, for example, and lives alone with few friendships and feels lonely or isolated, then some rebalancing is needed. It is important to observe, to inquire, and to listen carefully and not jump to conclusion as to how a person should live. With advancing years, especially in the face of any health and safety needs, a person may ask for less independence by, for example, trading independent living for assisted living of some kind.

Inclusion and community

How much (and how likely) one is to be included in family, neighborhood, and community life can be an issue at any age. In childhood, it may mean going to the neighborhood school, playing with neighborhood children, and the like. As an adult, it may mean spending time off the job with co-workers or being included with community groups of one kind or another (a model train club, health and fitness group, church). As a senior citizen, it may be participating in activities for elders.

Empowerment

Being *empowered* means knowing what a person wants, being motivated to seek it out, and having the resources (knowledge, experience, dollars) to get it. In other words, empowerment is

about: 1) preferences and drive, 2) knowledge of options, and 3) the capacity to get what we want. As with independence and inclusion, empowerment is an issue cutting across the lifecycle.

Health and health care

A person with a disability, especially a physical one, may need a lot of health services early in life (multiple operations) and late in life. In the intervening years, from early childhood to old age, both health and health care needs may or may not be very different from that of a person without a disability.

Yet, over the years, a variety of questions (or issues) can arise, including:

- Paying for health care (staying on a parent's insurance, getting Medicaid).
- Eating right and staying physically fit.
- Being comfortable when examined by a nurse or doctor.
- Working effectively within a managed care environment.
- Getting needed preventive care.
- Managing chronic conditions (seizures, asthma, diabetes, high blood pressure).
- Getting needed health care advocacy.
- Having access to health care professionals who are caring and competent.

Clearly, some of these matters vary by age and other factors. Also, stereotypes sometimes get in the way of proper practice. Many women with developmental disabilities, for example, are not sexually active. Some people assume that female reproductive health issues are, therefore, of no great importance. Of course, this is not the case.