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Creating Opportunities for Youth
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Successful Futures

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Supporting Dynamic Development of Youth with Disabilities During Transition: A Guide for Families

By Kris Peterson

Introduction

The physical and emotional changes in adolescence are comparable in complexity to the developmental phases of infancy and early childhood. The level of knowledge and skills needed by young adults in order for them to thrive in their communities is increasing.

At the same time, youth may experience decreasing structure and support in their lives as they seek to build the skills necessary for success (Simpson, 2001; Larson, Brown, & Mortimer, 2002).

Family support is key to healthy adolescence. A family enables children to experience attachment, belonging, competence, and self-esteem, and at the same time allows them to experience success and failure, adventure and retreat, independence and interdependence. For families who have teens with disabilities, adolescence can be especially challenging. This brief provides information about healthy adolescent development for youth with disabilities, focusing on the role of parents and families in supporting the successful transition to adult life.

“Independent of race, ethnicity, family structure, and poverty, adolescents who are connected to their parents, to their families, and to their school community are healthier than those who are not.”
(Blum & Mann Rinehart, 1997)

The Predicament of Parents and Families

Parents, whose roles include providing for and protecting their children, often find themselves at odds with the teen who wants to experience life, develop individual values, and achieve independence (Tempke, 1994). When a child is vulnerable, families may view control as a responsibility to ensure safety. Families may have extensive fear of how the world will treat their child, or they may hesitate to give up their primary role as protector and advocate. In spite of this, teens with disabilities want and need to experience and obtain the same things that all adolescents want and need no matter how significant their disability.

Challenges

Transition assessment and planning occur during adolescence, yet often in the search for academic and career development the vital elements of psychological,

social, emotional, and sexual development may be overlooked. Gerber and Okinow (1994) assert that the environment is crucial for these youth:

Adolescents with chronic illness or disability experience the same developmental transitions as their peers without disabilities, yet their illness or disability places them at risk for certain psycho-social problems as they move into adulthood. The risk is not solely in the medical complications of the illness or disability...rather risk is more often related to the degree of fit between the adolescent and his or her environment: family, school, peers, health care services, work, and societal attitude. The fit can lead to optimal integration and development, or it can result in isolation and low self-esteem (p.1).

LoConto and Dodder (1997) asked people with developmental disabilities, “If you could wish for anything, what would it be?” The majority response was that they wanted the same things that all people want: material goods, a home of their own, emotional and intimate connections, vacations and leisure, and a way to feel useful. So often the focus for youth and adults with disabilities is safety and physical health at the expense of a valued social role and the need for human connections.

The parent/child relationship is strongly related to adolescent well-being. Parents’ vision for the future of their children is that they will grow up, move away, and develop lives of their own (Hanley-Maxwell, 1995). Having a child with a disability, however, may seriously threaten this vision. Although families may be able to adapt, build resilience, and develop greater emotional growth and togetherness as a result of the disability, they may also experience an on-going stress as they move through the life cycles of their own development and that of their child (DeMarie & LeRoux, 2002). Some families cope with the stress by dealing with the present moment and not thinking about the future of a child with a disability. They may have experienced many disability-focused assessments and programs, resulting in little vision of independence or quality of life for their child.

Most families also experience a loss and undergo a grieving process when they have a child who is born with, or acquires, a disability (Seligman & Darling, 1997). No matter what the disability, families find themselves in “uncharted emotional territory with no guides to direct them toward ways to express their grief in a culturally acceptable format” (DeMarie & LeRoux, 2002). For some families, the chronic care needs of a child with a disability can be overwhelming and never-ending. For those who have a child with a disability, pivotal milestones such as graduation from high school can trigger stress, grief, or fears that impede a vision of normal adulthood.

In addition, the social effects of a disability also impact the parent/child relationship and family dynamics. Families may respond by becoming strong advocates or by defending and fighting for supports and services. This role can become part of their core identity and may be difficult to relinquish when the time comes to transfer advocacy responsibilities to the teen with a disability.

Meeting the Challenges: What Can Families Do?

It is important for teens with disabilities and their families to have information from physicians, teachers, social workers, and other families about adolescent development, and to receive encouragement to create a vision of adulthood (see **Table 1**). It is also vital that they experience opportunities to share their dreams and hopes, fears and frustrations, and to dialog about their visions for the future. Autonomy, independence, problem-solving, and constructive role-related changes will increase if families can build safety nets amid the fear of life-threatening decisions and risk-taking that are part of the teen experience.

The National 4-H Council has identified eight “Keys for Kids” based on the work of Konopka (1973) and Pittman (1991):

- **Security:** Youth feel physically and emotionally safe (“I feel safe.”)
- **Belonging:** Youth experience belonging and ownership (“I’m in.”)
- **Acceptance:** Youth develop self-worth (“What I say and do counts.”)
- **Independence:** Youth discover self (“I like to try new things.”)
- **Relationships:** Youth develop quality relationships with peers and adults (“I care about others.”)
- **Values:** Youth discuss conflicting values and form their own (“I believe...”)
- **Achievement:** Youth feel the pride and accountability that comes with mastery (“I can do it.”)
- **Recognition:** Youth expand their capacity to enjoy life and know that success is possible (“I feel special.”)

Adolescent development is more than high academic expectations, career development, and independence. Families play a pivotal role in supporting teens to explore their identities and make connections with peers and other adults. Understanding all aspects of adolescent development helps families of youth with disabilities and those who work with them to address these critical issues and improve adult outcomes.

Table 1. Information Parents and Families Need

Families, their teens with disabilities, and the professionals who support them will benefit from information about normal adolescent development and the parent/child relationship. Since transition planning supports a person-centered, holistic approach to life planning, it is helpful to examine the concept of “development” within the process. Highlights from extensive research and literature on adolescent development and parent/child relationships include:

Three developmental stages (Rapp, 1998)

1. Early adolescence (12-14): peer groups, emotional distance from parents, rapid growth, interest in sex;
2. Middle adolescence (14-17): self-discovery, performance orientation, vital relationships; and
3. Late adolescence (17-19): career focus, physical distance from parents, self-sustaining living.

Eight developmental tasks (Havighurst, 1972)

1. Achieving new and more mature relations with age-mates of both sexes,
2. Achieving a masculine or feminine social role,
3. Accepting one’s physique and using the body effectively,
4. Achieving emotional independence from parents and other adults,
5. Preparing for marriage and family life,
6. Preparing for an economic career,
7. Acquiring a set of values and an ethical system as a guide for behavior, and
8. Desiring and achieving socially responsible behavior.

Internal and external developmental assets (Search Institute, 2003)*Internal Assets*

Achievement motivation
 School engagement
 Homework
 Bonding to school
 Reading for pleasure
 Caring
 Equality and social justice
 Integrity
 Honesty
 Responsibility
 Restraint
 Planning and decision making
 Interpersonal competence
 Cultural competence
 Resistance skills
 Peaceful conflict resolution
 Personal power
 Self-esteem
 Sense of purpose
 Positive view of personal future

External Assets

Family support
 Positive family communication
 Other adult relationships
 Caring neighborhood
 Caring school climate
 Parent involvement in schooling
 Community that values youth
 Service to others
 Safety
 Family boundaries
 School boundaries
 Adult role models
 Positive peer influence
 High expectations
 Creative activities
 Youth programs
 Religious community
 Time at home

Core developmental tasks (Elliot & Feldman, 1990)

- Becoming emotionally and behaviorally autonomous,
- Dealing with emerging sexuality,
- Acquiring interpersonal skills for dealing with the opposite sex and mate selection,
- Acquiring education and other experiences needed for adult work, and
- Resolving issues of identity and values.

Essential requirements for healthy adolescence (Carnegie Council on Adolescent Development, 1995)

- Find a valued place in a constructive group;
- Form close, durable relationships;
- Feel a sense of personal self-worth;
- Know support systems and how to use them;
- Show constructive curiosity;
- Find ways of being useful to others;
- Acquire technical and analytical ability to participate in a global economy;
- Believe in a promising future with real opportunities;
- Master social skills and conflict resolution habits;
- Cultivate problem-solving habits;
- Achieve a reliable basis for making informed choices;
- Become an ethical person;
- Learn responsible citizenship; and
- Respect diversity.

Ages and Stages, Similarities and Differences: When Your Child has Special Needs

Children don't come with a user's manual, and more often than not, parenthood often seems like a land with no clear roadmap.... There is increasing separateness while the connection is held onto, and parents must figure out the right amount of involvement in their child's everyday life. The parent is more and more aware of the child's individuality. Interpreting the world also involves setting standards for behavior in the world outside the home.

As difficult questions come up, parents are impelled to re-examine and perhaps revise their own theories of childrearing and parenthood. Over a period of several years images of the future are formed. If there are developmental challenges, this process can be much more involved. A child with special needs will have an Individual Educational Program (IEP); may be in special classes; and may have complex medical issues, engage in numerous therapies, and need medications. Cognitive development may be slower and more difficult. The road will have more twists and turns, and the emotional terrain may be even more difficult to handle.

With the teen years, there is the onset of the Interdependent Stage, which can be extremely turbulent as teenagers challenge parents' authority. Emotional highs and lows are not far apart. Strong feelings are stirred up in parents. As their [youths'] bodies change with the dawn of their emerging sexuality, parents have to think about their authority relationship with their almost adult child. Because teenagers are by developmental necessity absorbed in themselves, they can be disrespectful, testing, worrisome, and upsetting to their parents. Parents must learn to talk less and leave the door open because their children still need them but on new terms. Limit-setting and guidance are still needed but must be based on the particular child's needs.

More than ever parents must understand the deep passions that are evoked in this stage. Particularly challenging is accepting their child as a sexual being. As the separate identity is formed, separation brings feelings of envy, fear, anger, pride, and regret. Parents of children with special needs confront the reality of how far their child may be different from the norm once again, and may have special fears about their child being taken advantage of in the world. Overall, this further redefinition of the parent-child relationship brings to all parents the image of life without children at home which now looms on the near horizon.

The Departure Stage is something parents have thought about ever since their eyes first met those of their newborn. Now parents are faced with taking stock of the whole experience of parenthood. They redefine their identity as parents with grown-up children. The parents of children with special needs face the possibility that their children can never live independently and may live with them for the rest of their lives or in a community living arrangement with supports. But for all parents, it is clearer than ever that our job is never done for we are parents the rest of our lives, but our roles with our adult children are different.

At this point, parent and child alike waving good-bye to childhood and looking out to adulthood, with wobbly knees, I might add, from my own experience with my 22-year-old son with autism. We don't know yet what the future holds for living and working. It's a scary thought when your child is young. How do we get there? This may be far from what we imagined before our child, whether typical or not, was born. Nonetheless, through acceptance and courage and endurance, the road through parenthood brings peace and love. Our special children truly light the way and help us find the inner strength and wisdom we need.¹

¹ From *Ages and stages, similarities and differences: When your child has special needs, part 2*, by R. Naseef, 2003, http://specialfamilies.alternativechoices.com/ages_and_stages_2.htm. Copyright 2003 by Robert Naseef. Adapted with permission.

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Further Reading

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Resources

Search Institute

<http://www.search-institute.org>

Keys to Quality Youth Development

<http://www.extension.umn.edu/distribution/youthdevelopment/DA6715.html>

Academy for Youth Development

The Center for Youth Development and Policy Research
<http://www.cyd.aed.org>

America's Promise

<http://www.americaspromise.org>

National Youth Development and Information Center

<http://www.nydic.org/nydic>

U.S. Department of Health and Human Services

<http://www.ncfy.com/supporti.htm>

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