GROWING UP WITHOUT GROWING APART

Finding your way
to your Child's Adulthood

A curriculum designed by parents
for parents/caregivers
who have a youth/young adult
transitioning into adulthood.

A Project produced by the Family Advisory Council of
Allies with Families
Utah Chapter of the Federation of Families for Children's Mental Health
and
Project RECONNECT
And
PASSAGES

This curriculum was generously funded by
two grants to the State of Utah
Division of Substance Abuse and Mental Health

By

The Center for Mental Health Services
Substance Abuse and Mental Health Services Agency
of the Federal Government

The Utah Chapter of the Federation of Families for Children’s Mental Health
505 East 200 South, Suite 25, Salt Lake City, Utah 84102
(801) 433-2595 or (877) 477-0764 toll free
(801) 521-0872 FAX
www.allieswithfamilies.org
allies@allieswithfamilies.org

Foreword

One of our goals as we developed this course was to help parents/caregivers have some of the tools we wished we had as we started down the road of raising a child with a serious emotional disturbance. We have experienced some things that we did not want other parents to have to go through.

Keep in mind, this is a work in progress. This is a beginning; we will be revising and learning as we teach from, and use this text. Most of the information contained within is basic. And yet when we first started, we were so overwhelmed that we needed reminders about the basics.

Hopefully, you, as parents and caregivers, can use some of the information presented. Perhaps one day you will be in a position to "give back" some of the insights, gifts, and talents you have gained as a result of working with some very special and very challenging youth.

Very special thanks to….
…the members of the Allies with Families' Family Advisory Council for Project RECONNECT, Utah's Partnership for Youth in Transition Federal Grant, and, the PASSAGES Grant Updating Committee:

Eraine Albretsen
Craig and Tena Beckstrom
Walter and Donna Brodis
Nancy Dollmeyer
Jesse Higbee
Colt and Dawna Holt
Linda Melton
Sylvia Scott
Rolf and Pamela Sorensen
Barbara Zabriskie
Patricia Baker, Staff of Allies with Families
Konne Bringhurst, Staff of Allies with Families
Lori Cerar, Staff of Allies with Families
Jane Lewis, Project Coordinator, Project RECONNECT

INTRODUCTION

Facts on Transitional Services for Youth with Mental Illnesses

Providing comprehensive support services to youth with mental illnesses transitioning into adulthood is critical to their success. Many youth age out of children's services without any transitional planning and lack skills necessary to manage their illnesses and accomplish their goals. These youth face the challenge of entering adulthood without proper services and support.

Prevalence

- More than 3 million transition age youth have been diagnosed with a mental health challenge.
- Adolescents transitioning to adulthood with mental health challenge are three times more likely to be involved in criminal activity than adolescents without an illness.
- Incarcerated youth age 18-22 are more likely to have mental health challenges than younger adolescents in the juvenile justice system.
- Transition age youth with mental health challenges have higher rates of substance abuse than any other age group with mental health challenges.
- Rates of mental health challenges are highest among young adults age 18 and rates decrease for each year thereafter.

Unmet Needs and Consequences

- **Education and Employment.** Young adults with mental health challenges face many issues when transitioning from school to adulthood. Over 60 percent of young adults with mental health challenge are unable to complete high school. These young adults are often unemployed, unable to participate in continuing education, and lack successful skills necessary for independent living.
- **Increased Risk of Suicide.** An estimated 20 percent of youth receiving treatment for emotional or behavioral problems have either contemplated suicide or attempted suicide. Less than 40 percent of youth at risk of suicide receive treatment. Suicide is the third leading cause of death among young adults age 15 to 24.

Effective Services

- **Individualized Services.** Youth in transition need services that assist them in employment, housing, and education. Research shows that these services are most effective when they are tailored to meet the goals of each young person. Services and supports also need to be developmentally appropriate in order to build on the strengths of youth in transition.

- **Personal Responsibility and Parental/Caregiver Support.** Services are most effective when youth are able to develop problem-solving skills and learn to experience consequences through their decisions. ***Parental/Caregiver involvement is key in guaranteeing that youth have a safety net of support.***

Barriers to Meeting Needs

- **Gaps in Services.** No system or agency is responsible for youth with mental health challenges transitioning into adulthood. Youth with mental health challenges may be involved with service systems such as special education, child welfare, and juvenile justice. When these youth age out of their respective youth system, they are often ignored or neglected in the transition period to adulthood.

- **Under Utilization of Services**. Many adolescents and youth in transition do not receive specialty services despite the availability of services. This is often due to the stigma associated with mental health challenges and mental health services. Furthermore, cost of services and dissatisfaction with services prevent youth from receiving treatment.

- **Lack of Support**. Many transitional youth lack the personal connections and friendships necessary for successfully managing their illness. Transitional youth are often separated from their families and do not receive adequate support.

Recommendations

Policymakers can promote improved treatment by:

- Creating a comprehensive service system for youth in transition that extends services between adolescence and adulthood.

- Encouraging the adult mental health system to develop programs and services for young adults age 18-25.

- Ensuring continued Medicaid eligibility through age 24 for youth on Supplemental Security Income (SSI) at age 18.

- Providing funding to SAMHSA in order to increase technical assistance, research, and demonstration projects to develop proven services specifically designed for transitional youth.

Vander Stoep A., Beresford S., Weiss N., McKnight B.,Cauce M., and Cohen P., (*2000*). Community-based Study of the Transition to Adulthood for Adolescents with Psychiatric Disorders. *American Journal of Epidemiology*, 152, no4, 352-362.

Teplin L., (1994). Psychiatric and Substance Abuse disorders among male urban jail detainees. *American Journal of Public Health,* 84, 290-293.

U.S. Department of Health and Human Services. Mental Health: A Report of the Surgeon General – Children and Mental Health. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of mental Health, 1999.

U.S. Department of Health and Human Services. (2001). Results from the 2001 National Survey on Drug Use and Health: Prevalence and Treatment of Mental Health Problems. U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Carson, R., Sitlington, P., and Frank, A., (1995). Young Adulthood for Individuals with Behavioral Disorders: What Does it Hold? *Behavioral Disorders*, 20, 127-135.

Hagner, D., Cheney, D., and Malloy J., (1999). Career Related Outcomes of a Model Transition Demonstration for Young Adults with emotional Disturbance, *Rehabilitation Counseling Bulletin,* March, Vol 42, 3.

U.S. Department of Health and Human Services (2002). Results from the 2002 National Survey on Drug Use and Health. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

U.S. Department of Health and Human Services (2002). The National Household Survey on Drug Abuse Report. U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

Minino AM, Arias E, Kochanek KD, Murphy SL, Smith BL. Deaths: final data for 2000. *National vital Statistics Reports,* 50(15). Hyattsville, MD: national Center for Health Statistics, 2002.

Clark, H., (2003). Transition to Independence Process Definition and Guidelines, TIP System and Development and Operations Manual, University of South Florida.

Davis M., and Vander Stoep A., (1997). The Transition to Adulthood for Youth Who Have Serious Emotional Disturbance: Developmental Transition and Young Adult Outcomes, *The Journal of Mental Health Administration,* 24:4.

CURRICULUM OUTLINE

Taking Care Of Yourself

- What Is Taking Care Of Yourself?
- How To Take Care Of Yourself
- Are You Taking Care Of Yourself?
- Managing Stress
- What Is The Real Reason We Feel "Stressed"?
- Grief
- What Is Grief?
- Why Is It Important To Grieve?
- When Is It Appropriate To Grieve?
- Stages Of Emotional Responses
- Everyone Grieves Differently

Letting Go/Dreaming New Dreams

- What Is Letting Go?
- Why Is Letting Go Necessary?
- When Is Letting Go Appropriate?
- Who Is This For?
- How To Get There…
- The Need For Prevention Planning With Transition-Aged Young People
- The Need For Support Groups
- RESOURCES

Legal Issues

- What Is This Thing Called Guardianship?
- What Is A Limited Guardianship?
- When Can An Adult Have A Guardian?
- What Power Does A Guardian Of An Adult Have?
- Why?
- When?
- Where?
- Who Is It For?
- How Do You Get It?
- RESOURCES
- Advance Directives – Self Management Plan
- What?
- Why?
- When?
- Where?
- Who Is It For?
- How To Get It
- RESOURCES
- Declaration For Mental Health Treatment - (Advance Directive)

- RESOURCES
- HIPAA - The Health Insurance Portability And Accountability Act Of 1996
- What?
- Why?
- When?
- Where?
- Who Is It For?
- How To Get It
- RESOURCES

Person Centered Planning
- What Is Person Centered Planning?
- Why?
- When?
- Where?
- Who?
- How It Works
- What If People Have Unrealistic Expectations?
- Summary Checklist
- CREATING “YOUR” WORLD!!
- RESOURCES

Foster Children Issues
- Foster Children And Education
- Obstacles To Education Success
- Lack Of Continuity In Education
- Requirements Of The Child Welfare System
- Lack Of Emphasis On Education
- Low Expectations
- An Absence Of Advocates
- The Stigma Of Being In Foster Care
- The Burdens Of Past Experience
- The Gap Between The Systems
- The Safe And Smart Program
- Adult Involvement
- ACS/Family Court Checklist On Educational Status Of Children In Foster Care
- Seven Questions To Ask At Parent/Teacher Conferences
- How To Help Your Child With Homework
- FOSTER CHILDREN & EDUCATION
- WHAT TO BRING WHEN REGISTERING A FOSTER CHILD FOR SCHOOL

What Is a Service Plan?
- Who Is Involved In Developing The Service Plan?
- What Does A Good Service Plan Look Like?

- Is Concurrent Planning Used With Teens?
- What Is “Foster Care” Or “Out-Of-Home Placement”?
- Why Would My Child Be Placed In Foster Care?
- Who Are The People Who Will Take Care Of My Child?
- What Information Do I Need To Give To The Child Welfare Agency About My Child?
- Who Advocates For The Best Interests Of My Child?
- What Is A Guardian Ad Litem?
- What Does Independent Living Mean?
- When Is A Youth Considered An Adult And Ready To Leave The Foster Care System?
- Will The Child Welfare Agency Help Prepare My Youth For Independent Living?

Developmental Milestones

- Stages Of Adolescent Development
- Early Adolescence
- Middle Adolescence
- Late Adolescence
- Tips For Working Effectively With Teens
- Transition Timeline Checklist
- Skills Assessment For Success On The Job And In The Community
- Thinking About The Future: A Transitional Planning Worksheet
- Interest Interview
- Working It Out: Learning To Negotiate With Your Teenager
- RESOURCES

Education

- What Is IDEA?
- Who Determines Eligibility?
- Members Of The IEP Team
- Section 504/Americans With Disabilities Act – *The Other Service Option*
- Who Is Eligible For Section 504?
- Section 504 Guidelines And Implementation
- Section 504 Grievance Procedure
- Utah State Office Of Education – Special Education Rules
- Keeping Records – A Journal Of Your Child’s Progress
- Evaluation Process
- Conference Planning – IEP Parent Tips
- IEP Questions To Consider
- Content Of The IEP
- Who Is The Parent?
- What Is A Surrogate Parent?
- Keeping Records – IEP Meeting
- Timelines For Transition Planning
- Acronyms

- Exiting The School System
- The IEP For Transition-Aged Students
- Parenting Post-Secondary Students With Disabilities: Becoming The Mentor, Advocate, And Guide Your Young Adult Needs
- RESOURCES
- Accommodations For Students With Disabilities In High School
- Person-Centered Planning: A Tool For Transition

SECTION 1:
INDEPENDENCE VS. INTERDEPENDENCE

Jane's story…

Jane and Sarah are sisters who are two years apart in age. Jane is currently 30 years old, married and raising Sarah's two daughters, ages 11 and 6. Sarah is currently living in another state because of outstanding warrants for her arrest. Sarah has never been married, never finished high school, has been in and out of jail, and each of her two daughters have different fathers.

Jane's story of mental health challenges began more than twenty-five years ago. It is not a story of her own mental health challenges but a story about the effects of Sarah's mental health challenges. At that time, Jane didn't know anything about mental health challenges; she just knew that her sister was always getting into trouble. In fact, at that time, Jane didn't know that eventually she was going to raise Sarah's daughters as her own and have a story to tell about the experience.

Jane was always feeling the effects of Sarah's behavior. She was always finding her own missing personal items in Sarah's drawer. She was always hearing her parents' frustrations, struggling to deal with Sarah's bad grades and disruptive behavior, always wondering if she was going to have the same problems and promising herself that she never would.

All through school, Jane never felt comfortable having her school friends come to her home to play. When she started high school, she always had the feeling she was being looked at differently. When she realized that others at school knew she was Sarah's sister, she did her best to be completely different than Sarah, but only those few who really got to know Jane, really found out who she was.

Eventually Jane's father left home, because he couldn't deal with Sarah's ongoing behaviors or the doctors who could never decide what was wrong with Sarah. The doctors offered no solutions or any help. Sarah also left home, because she couldn't deal with all the rules.

With Sarah gone, Jane finally began to blossom. Jane found out who she was; she was able, at last, to have a life without the constant pain and frustration of Sarah's behavior.

Then Sarah became pregnant with her first daughter, Ashley. If Sarah wasn't drinking, smoking, or having "scored" with some kind of drug, she was suffering through horrible depression. Ashley's birth was uneventful and Sarah finally seemed to have a fresh start to a new life as a mother; but this didn't last long. Ashley was soon being cared for more and more by Grandma and Aunt Jane than she was by her mother.

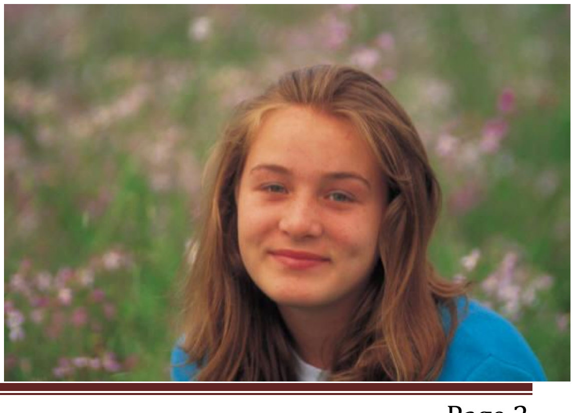
Five years later, Sarah gave birth to Brianna. During one of Sarah's periods of incarceration, she was diagnosed with Acute Personality Disorder, NOS.
Jane and her husband, Robert, were married when Ashley was about 7 years old. When Brianna was 3, she began to live permanently with Aunt Jane and Uncle Robert. Six months later, Ashley began to live with Aunt Jane and Uncle Robert as well.

After several years of frustrating negotiation, prayers, and legal expenses, Jane and Robert adopted Brianna and were granted permanent legal custody of Ashley. The "girls" seldom see their mother and almost never see their fathers, respectively.

Brianna has always been a typically developing child, but Ashley has always been a bit over the edge. Jane recognized the troubling images of Sarah's physical behaviors from the past, now being manifested in Ashley. Jane has worked to correct the behaviors which Ashley has learned from her mother.

Jane and Robert are working as a team to deal with Ashley's behaviors and struggling to find a child psychiatrist or therapist to work with Ashley. The biggest challenge was finding the correct diagnosis and a method to help Ashley without the heavy drugs usually prescribed for her mental health challenges. As Ashley's psychiatrist has said, there are not a lot of established criteria to diagnose a child of eleven years old with Acute Personality Disorder. But from Jane's past experience, she is pretty sure that this is the challenge with which Ashley suffers.

The final chapters of Jane's story of mental health challenges in her family will not be written for many years yet. Brianna's story of living with the mental health challenges of her family is just beginning. However, Brianna will have much more success writing her story, because Jane knows a great deal about what Brianna's story will be like.



Types of Relationships

- Independent – prefers a very loosely constructed connection. He or she does not want to feel either dependent on or depended upon by another person.

If you give a lot to this type of person, don't expect to get a lot in return…

- Dependent – the opposite of independent. This person wants very close connections. He or she lacks the ability to make decisions or function apart from another person and may be described as clingy.

This person draws feelings of confidence or self-worth from another.

- Codependent – an extreme caregiver. This person gives more than is healthy for a relation-ship. They want to make everything okay for everyone.

They put significant time and effort into helping others achieve their goals while feeling guilty about taking even a little time for themselves.

- Interdependent – strikes a healthy balance between giving and taking. Their sense of self-worth is not linked to others.

They can give without hurting themselves and take without feeling guilty.

Healthy Relationships

The best personal relationships are built on:
Mutual trust
Mutual respect
Effective communication
Kindness
Patience
Forgiveness
Mutual support
Shared interests
Similar values

ACTIVITY:

Defining Relationships

- Draw a circle with 5 layers.
- Put your name in the middle.
- Put the names of people most important to you in the rings closest to your name.
- List less important people in the outside rings.

Highlight the relationships that contribute most positively to your success in one color and the negative ones in another color.

Conflict in Relationships

- Conflict is a product of our being different from each other and not always seeing the world in the same way.

The goal is not to avoid conflict but to maintain a healthy relationship even in the midst of conflict.

Road to Interdependence

"In a new way all people are caught in an inescapable network, tied to a single garment of destiny. Whatever affects one affects all directly. I can never be what I ought to be until I am who I ought to be. This is the undisputed structure of reality."

Martin Luther King, Jr.
"Notes from a Birmingham Jail"

TAKING CARE OF YOURSELF

Pamela's story…

Since we became aware of NAMI six years ago, my husband and I have discovered that NAMI has been the help we needed to survive the journey of mental health challenges. The trials do not end and the pain can return. The unknown will always exist. At least we know we are not alone. This gives us strength to press forward, and more importantly, we have learned to share that hope to encourage others.

We wish we had known about Allies with Families when our children were younger. Don't we all wish we could pick our own battles and time frames! Allies with Families focuses on that period of transition from youth to adulthood. My husband and I are involved with Allies with Families on a research and development program (a model curriculum for the state) with several other parents in the hopes of helping families transition their youth through these nightmarish experiences. I am a family member, an Allies with Families researcher, a certified BRIDGES and Provider Training Instructor for NAMI, and now an Affiliate of Development of NAMI Utah. But the two most important titles I have are that of a devoted wife and the mother of 3 adult children who suffer from serious mental health challenges.

In 1995, our son, now 29 years old, was unexpectedly sent home from his church mission which was in Nebraska. He had developed some very serious mental health challenges while there. When he got off the airplane, he looked like an Auschwitz survivor from the Nazi torture camps. Our lives literally changed. We were thrown into a completely different world, a place where we had to learn what denial was and what mental health challenges were. It was a terrifying, unforgettable adjustment for our entire family. We are still adjusting. He was/is suffering from an illness not visible on the outside. As his behaviors continued to painfully surface, he was subsequently diagnosed with Schizo-Affective Disorder. "Hospital beds that are reserved for people who have mental health challenges are occupied by more people with Schizo-Affective Disorder than any other major mental health challenge." (2005)

We later learned our oldest daughter who was a runaway, and is now 30 years old, married a man who has Bipolar Disorder. Between them, they have 4 children, 3 girls and 1 boy, which we have never seen. Because of their paranoia stemming from their mental health challenges, they have completely disowned all family members on both sides.

Our youngest daughter, now 23 years old, suffers from Bipolar Disorder, ADHD and Border-line Personality Disorder with regular panic attacks associated with anxiety. Now we reflect back, realizing her illness began at age 13. Recently, she has again become tied up with the legal system. She has self mutilated because of the pain she cannot bear. One would hope and think the legal system would adjust to these severe mental health challenges. This is not so. Besides being a slap in the face, it is humiliating, costly, and one can get extremely discouraged once in the legal system.

Slowly, the legal system is implementing changes such as mental health courts. In the past, when faced with behavioral and/or mental health challenges, the legal system has usually resorted to incarceration. We build more prisons and jails, purchase assets, and create jobs based on mental health challenges. We destroy individuals and families/caregivers and pass the costs on to America. It is a self perpetuating cycle. Up front, the health care system temporarily saves money. Rather than treat those with mental health challenges with the proper medication and/or treatment, they are sent to jail because of their actions. It really boggles the mind to think this is happening. As a member of society you may ask the question, "What are the real costs of mental health challenges?"

All three of our children have challenges with substance abuse as well, which creates a dual diagnosis, the most challenging and complex. Because of these findings, my husband and I have accepted a new quest in life, one that motivates us to rise above the stigma that intensifies mental health challenges ….. pain that doesn't go away. Names and labels aren't as important as it is to listen to the voice of mental health challenges, and to learn and understand that new language.

"We would like to be known by the company that we keep." That company is our family. We are their company, hopefully forever. We both are willing to accept the challenges that come with mental health challenges. You do have a choice. You can either run or fight. When it comes to these challenges, my husband and I deal with the same things many others do. We will all choose how we deal with our "company". No one is exempt ~ it can happen to anyone.

My husband and I have faithfully taught for the past five years a 10-week BRIDGES course (an education and support program for consumers of health challenges sponsored by NAMI). Just recently a question was asked by one of our consumers in the class. He raised his hand, looked at me and asked, "Tell me, HOW DO YOU DO IT? When your daughter, whom you obviously love and care for, has an episode and becomes controlled by her illness; when she screams vulgarities, threats, and obscenities at you. How do you control yourself and take it without falling apart or losing control of yourself?"

I took a deep breath and smiled. As I looked down, I firmly patted the BRIDGES manual that was lying in front of me. Looking up, I replied to him, "Yes, it is more painful than I can de-scribe. It is the education and support I have been learning and teaching through NAMI that has been, and will forever be, my own personal strength. That is what has helped me with-stand the frightening things that take place with mental health challenges. Without constant learning by studying these challenges, I KNOW I COULD NOT DO IT ALONE. No one can do it alone … NO ONE. I have learned to mentally, physically, and spiritually remind myself to "separate the person from the problem". Those words have become a lifesaver for me. I learned them from attending my first NAMI "Family-to-Family" course.

That was the beginning for my husband and me, who did not attend willingly at first. This is when we realized how vital it is to become educated and take care of ourselves before we even attempt to help our children, something we both unknowingly thought we could do on our own. At that time, we did not know our other two children were also suffering from mental health challenges. The delay in our learning only compounded the horrible experiences we were going through. Things had been going on inside of them we knew nothing about. All three of them grew up in the scary world of mental health challenges. This was not of their choosing, or of ours, but it has miraculously led us to where we are now. We are strong advocates for "Utah's Voice on Mental Health Challenges".

……

For families living with people with disabilities, the problems that arise in getting through one day can be overwhelming. Families who have a person with a disability have all the same problems and obligations of "ordinary" families, as well as the added burden of the extra needs of that person. These families‟ lives are different than the lives of most families. Talking to others who have had to get through days much like their own provides an outlet that can't be found anywhere else.

Parents/caregivers of young adults with disabilities feel there are a lot of things they "should" be doing. There are also a lot of things they think others, including teachers, doctors, relatives, and counselors, expect of them.

What Is Taking Care Of Your Self?

Working with people can be stressful. Working with persons who are poor and who suffer from mental health challenges can be even more stressful. It is important take care yourself – physically, emotionally, and socially. You may have opportunities to attend time management and stress management workshops. At workshops, they will go into more detail about coping with the challenges of your job and your life.

How to Take Care of Your Self

Time Management

- Make a daily plan of tasks.
- Prioritize the list. Identify those tasks that have to be done today (A‟s) from those which should be done, but could be done tomorrow (B‟s), and those which are not that important (C‟s).
- Be sure to do your "A" tasks first.
- Keep lists simple and realistic.
- Carry your list with you – review it often.
- Let your list be your guide, not a ball and chain. You will find that you often have to adapt and revise.
- Be on time. Treat co-workers and family members the way you want to be treated.
- Make a "grass-catcher" list. This is an ongoing list of things to be done, without a specific deadline. When you are making your daily "to do" list, consult this "grass-catcher" list.
- Always ask "what is the best use of my time right now?"
- Don't do other people's "A" tasks at your expense.

MANAGING STRESS

What Is The Real Reason We Feel "Stressed"?

People say one of the main reasons they feel stressed is that they don't have time to think any-more. E-mail, voicemail, cell phones, pagers, faxes, and overnight mail all create a sense of urgency.

In the "good old days," we had longer work weeks (42 hours in 1952 vs. 40 today). There was downtime between tasks – to lick a stamp, walk to the mailbox, change a typewriter ribbon, flip through a dictionary, or dial a phone number.

What you can do?

1. Make a concerted effort to be the master of technology in your life.
2. Limit your use of gadgets. (A lot of people do not talk on their cell phones in their cars. They want to reclaim the private time between home and work.)

3. Limit the number of people who have access to you through technology (i.e., don't give out your access numbers to every-one).
4. Limit the amount of "information" that comes into your life (it makes no sense to listen to radio news reports and watch TV news reports).
5. Unplug technology regularly. The world doesn't need you to be on call 24 hours a day.
6. Make a special effort to connect with real things – people, animals, nature, music, art, play, laughter, and exercise.

TAKING CHARGE OF YOUR EMOTIONS

> ***"You have the capacity to choose what you think about.***
> ***If you chose to think about past hurts, you will continue to feel bad.***
> ***While it's true you can't change the effect past influences had on you once, you can change the effect they have on you now."***
>
> Gary McKay, Ph.D.,
> Author of How You Feel is Up to You:
> The Power of Emotional Choice

- Take action to deal with your burnout if you recognize it.
- Take time-outs. These can be mini time-outs, such as taking the afternoon off, or longer vacations.
- It is okay to say you are having a difficult time. We all do at times. It is not okay to ignore the stress symptoms and do nothing about them.
- Cultivate pleasurable activities and hobbies that will offer you balance and peace.
- Develop a positive, nurturing support system.
- Set limits for yourself and others. Know your own boundaries.
- Exercise regularly.

> *"Often the person who identifies himself as the curer or fixer-type healer is vulnerable to burnout."* (Rachel Naomi Remen, MD)

"Perhaps the most important thing I have learned from my work is that I can be a friend and supporter of healing; I can be a guide to people; but it is not I who does the healing. I try to heal by creating situations that seem to allow or foster healing – calmness, faith, hope, enthusiasm – and sometimes just the idea that healing is a possibility." (Martin Rossman, MD)

RECOGNIZE THE STAGES OF BURNOUT			
Stage I: Early Warning Signs	**Stage II: Initial Burnout**	**Stage III: Burnout**	**Stage IV: Burnout**
Vague anxiety Constant fatigue Feelings of depression Boredom with one's job	Lowered emotional control Increasing anxiety Sleep disturbances Headaches Diffuse back and muscle aches Loss of energy Hyperactivity Excessive fatigue Moderate withdrawal from social contact	Skin rashes Generalized physical weakness Strong feelings of depression Increased alcohol intake Increased smoking High blood pressure Ulcers Migraines Severe withdrawal Loss of appetite for food Loss of sexual appetite Excessive irritability Emotional outbursts Irrational fears (phobias) Rigid thinking	Asthma Coronary artery disease Diabetes Cancer Heart attacks Severe depression Lowered self-esteem Inability to function as a person or on the job Severe withdrawal Uncontrolled crying spells Suicidal thoughts Muscle tremors Severe fatigue Over-reaction to emotional stimuli Agitation Constant tension Accident proneness and carelessness Feelings of hostility

ACTIVITY:

1. **WRITE DOWN ALL THE PEOPLE YOU ARE.** (Possible answers: mother, father, sister, brother, aunt, uncle, teacher, coach, etc.)
2. **WRITE DOWN ALL THE PEOPLE THAT EXPECT SOMETHING FROM YOU. (**Possible answers: children, clergy, husband, wife, mother, father, etc.)
3. **WRITE DOWN YOUR EXPECTATIONS OF YOUR CHILD.** (Possible answers: have friends, finish school, go to college, etc.)

The list can get so overwhelming that finding time to attend a parent support group itself seems impossible. If parents/caregivers look at their list of things to do they may notice that some of the things listed could be done more easily (or might have already been done) by a group of parents/caregivers who share some of the same experiences.

GRIEF

What Is Grief?

Grief is a natural and normal reaction to loss. **You need to go through grief to heal** – and ultimately experience emotional growth.

Grief can bring a wide range of emotions. These can range from deep sadness to anger. Some of these feelings may be new or frightening to you. Accepting that these are normal reactions is the first step on your road to healing.

You can find ways to deal with your pain. There are many healthy ways to cope with grief. You can find ways that work for you (i.e. parent support groups, education classes, grief counselors, family therapy, individual therapy, etc.). And there's plenty of help whenever you need it.

Grief can follow many kinds of losses. The death of a loved one may cause the most intense grief. But grief can also follow other losses, such as:

- A miscarriage
- A divorce or separation
- Learning you have a disability or serious illness
- The death of a pet

These losses can bring reactions much like those that follow the death of a loved one.

Why Is It Important To Grieve?

Welcome to Holland – by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this…

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting!

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm sup-posed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around…. and you begin to notice that Holland has windmills…and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy…and they're all bragging about the wonderful time they had there. And for the rest of your life, you will say" Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away…because the loss of that dream is a very, very significant loss.

But…if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things…about Holland."

When Is It Appropriate To Grieve?

Ask the participants to suggest some feelings they have experienced. Write feelings down on the board/pad as people suggest them. Use the list below for "coaching".

> Denial; Fear; Guilt; Sorrow; Grief; Disruption of family relationships; Exhaustion of spirit and resources; Difficulty accepting the illness; Sleeplessness; Shame; Anger; Rage; Isolation; Confusion; Frustration; Depression; Apprehension about the future; etc.

What separates us from a lot of traditional thinking in the mental health field is this: **We believe these reactions are perfectly normal responses, given the catastrophes we are trying to adjust to**. (Just look at all the traumatic emotions up on the board!) We believe that we have a right to our feelings, and that we need to understand and express them. So let's spend some time learning about the predictable stages of our emotional reactions to mental health challenges.

Everyone Grieves Differently

How you grieve may depend on many factors. These include:

<u>The circumstances of the loss.</u> **Every loss is hard**. But grief may be especially intense, complex or lengthy if you have lost someone very close to you, or if the

cause of death is unknown or un-usual. For example, grief may be especially hard when the loss is:

- The death of a child, parent, spouse or life partner
- A sudden or violent death
- A death due to suicide.

Things about yourself. Personal factors can also affect your grief. These include your:

- Gender – In general, males and females have been taught different ways to handle stress and emotions. As a result, they often choose different ways to acknowledge and express their grief.
- Age and life experiences – These can affect your understanding of death and your sense of self when you experience a loss.
- Culture and faith – These may influence your beliefs about death and your responses, such as your choice of rituals for honoring someone who has died.
- Personality – Different personality traits (such as being outgo-ing, shy, expressive or thoughtful) often lead to different ways of coping with loss.

Try Keeping A Journal

This is a safe way to let out your feelings and thoughts. It can also be a way to say goodbye to your loved one. You might feel sad when you write. But you may also gain insight and a sense of relief.

Anyone can keep a journal. You don't need special skills, tools, or lots of time. You don't need to be a writer. Any notebook will do. And you can write for just a few minutes between tasks if you're busy. (You can try recording your thoughts and feelings if you'd rather not write.)

Spelling and grammar do not matter. Journal writing doesn't need to be proper or sound nice. The goal is simply to get down on paper whatever is in your heart and on your mind.

Your journal is for you only. Journal writing is a way you can express thoughts that you aren't comfortable saying aloud or that you want to keep private for any reason. You can share your journal with others if you'd like. But you don't have to.

You all recognize that mental health challenges have had an enormous impact on your lives. What you may not know is that you tend to respond to this trauma in characteristic and predictable ways. Many family members and family-member professionals have written about this "emotional response cycle" we all go through. It is such an important aspect of our course that we will go over it now in some detail.

There are some important points to emphasize here:

1. None of these stages are “wrong” or “bad”. They are normal reactions everyone experiences when struggling to cope with serious illness and trying to deal with critical disruptions in their lives.
2. This process is ongoing – for most of us it has taken years. The process is also cyclical; we will start it all over again every time our family member has a relapse, or suffers a serious setback.
3. Different family members are often at different places in the cycle, which is why we some-times have difficulty communicating with each other and agreeing on what to do.
4. This developmental account is not about expectations. This is a human process that you do your way. If you know where you are in the process you can be kinder to/or with your-self. We think it offers hope to see that we do progress through pain and grief to acceptance.
5. As you get to know each other better in this class, you will begin to recognize these stages and emotional reactions. In this way, “old timers” help “newcomers;” we inform each other, we validate our feelings.

STAGES OF EMOTIONAL RESPONSES
I. Dealing with Catastrophic Events
Feelings: Crisis; Chaos; Shock; Denial; “normalizing”; Hoping against hope
Needs: Support; Comfort; Empathy for confusion; Help finding resources; Crisis Intervention; Prognosis; Empathy for pain; Allies with Families and/or NAMI
II. Learning to Cope
Feelings: Anger; Guilt; Resentment; Recognition; Grief
Needs: Vent feelings; Keep hope; Education; Self-care; Networking; Skills training; Letting go; Cooperation from the system; Allies with Families and/or NAMI
III. Moving to Advocacy
Feelings: Understanding; Acceptance; Advocacy; Action
Needs: Activism; Restoring balance in life; Responsiveness from system; Allies with Families and/or NAMI

Do these stages look familiar to you?

It is vitally important for family members to learn about these emotional responses because where we are directs us to what we need in any given stage of the cycle. For example, look at what we need when going through the hard times of dealing with a catastrophe.

By stage 2, we are full of emotion and have a different set of needs. We need to “sound off”, learn to cope, learn all about the illness.

And by stage 3, we are getting it together. We need to restore the balance in our lives; we find purpose in advocacy and action; we help others.

RESOURCES

Allies with Families
From Hope To Recovery© classes for parents/caregivers
Operation Families Together classes for the whole family
Sibshops™ for siblings (age 7-13) of children who have mental health challenges
Call 1-877-477-0764 to find a class in your area

NAMI – Utah
Family to Family Classes
Call 1-877-230-6264 to find a class in your area

Bibliography for *Taking Care of Yourself*:

1. *NAMI – Family to Family Education Program*
2. *Allies with Families* – From Hope To Recovery© classes for parents/caregiver

SECTION 2:
PERSON-CENTERED PLANNING

Jenny's Story…

Jenny received her certificate of completion from high school. Her IEPs had always been written mostly around her academic needs, i.e., counting to 100. They did not address such things as her life dreams or even her daily goals.

Jenny has lived for the past 3 years in a small group home. In the fall after high school she enrolled in a 4-year post secondary public school. This school is specifically designed for youth with disabilities of all kinds. The first 3 or 4 meetings Jenny and her parents had with her new teaching staff were devoted to creating a "Person-Centered Plan" (Plan) for Jenny. Jenny's program coordinator from her group home attended the meetings as well. Most often, Jenny was asked what she liked to do, what she wanted to do for recreation, for a job, and what she felt like she needed help with. The Plan also considered her special needs regarding her disabilities. Her Plan zeroed in on her talents, her strengths, her goals and her dreams instead of trying to get her to do something that she was not capable of, i.e., counting to 100.

Jenny, with the guidelines of her Person-Centered Plan, has flourished this last 6 months. She takes more pride and responsibility for her chores, her volunteer job, and she can even keep her own checkbook organized and pay her own bills on time. She is beginning to feel like a part of adult society, like she is valuable and productive. Her Plan involves her school, her group home, her job and her job coach, and her parents. It has consistent goals and disciplinary actions for her to follow no matter whether she is at home, school, work, or in the community. Jenny still has a long way to go and will always need some assistance. But with her Plan she will be able to function as an adult to the best of HER abilities, just like the rest of us.

What Is Person-Centered Planning?

Person-Centered Planning provides a process or structure that assists people to plan and implement their plan. It can be the vehicle for helping people to plan for a job or career or a place to live. It can produce results that will further the inclusion of people with disabilities into activities and environments with other people in their communities.

Goals and objectives are made that help the individual achieve a life that makes sense for them, whether or not a person is in school.

A commitment is required from the individual and all the people who support him/her: parents, siblings, friends, neighbors, teachers, doctors, employers, government agencies, community service agencies, etc.
The person for whom the planning is being held is primary in this process, but he may invite family and friends, teachers, counselors, community members, and others to plan with him and think creatively about the resources and supports that might be necessary to implement his plan. There are many tools to use for planning and these tools may be combined. A few examples are Personal Futures Planning, MAPS, I Have a Dream, The Other Way, A Good Experience, and Dream Cards. Information gathered from the use of one tool may be useful in one of the other planning processes.

Personal Futures Planning is one way to do Person-Centered Planning. Think of Person Centered-Planning as the toolbox holding all the tools that are person-centered in their approach. There are many different planning tools that are person-centered, and Personal Futures Planning is just one of these tools. Person-Centered Planning is an ongoing process used to support people with serious emotional disabilities (SED) to plan for the future.

Person-Centered Planning invites us to:

- find, develop, and showcase the gifts and interests of each person
- develop a vision that expresses these gifts and interests
- build a circle of support to make this vision become a reality
- develop and implement strategies designed to achieve this unique vision

Why Do Person-Centered Planning?

"Personal Futures Planning provides strategies to increase the likelihood that people with disabilities will develop relationships, be part of community life, increase their control over their lives, acquire positive roles in community life and develop competencies to help them accomplish these goals. Futures planning helps to clarify and implement these ideals, one person at a time." Beth Mount and Kay Zwenik

Person-Centered Planning builds on a person's abilities and positive reputation, instead of trying to "fix" limitations.

When To Begin Person-Centered Planning?

Person-Centered Planning begins when a person's need or goal is identified. There are tools for all age levels and abilities—even for those who do not communicate verbally!

Where Does It Take Place?

Person-Centered Planning works best when meetings are held in informal settings. For example, people have held meetings in their homes, in restaurants, in library meeting rooms or conference rooms. There are also planning sessions held in classrooms, especially when the planning is part of a class curriculum, for example, a career class.

Who Should Be Involved In Person-Centered Planning?

Most often, the person who is the focus of the planning invites the people he wants to include. Some people have help from their family, teachers or friends to figure out whom to invite and to do the inviting. Some people send written invitations, but most use personal or phone contact.

What If The Person Can't Think Of Anyone To Invite?

It is important to meet with the person before the meeting to suggest some people to invite. Ask if they want to invite family, teachers, people with whom they live, neighbors, etc. Also ask what they do after school or after work as this may help them to think of people to invite to the meeting.

It sometimes happens that they still have no one to invite. You may want to recommend some people they do not know, but who have the same interests they do or know about resources and may be able to participate in the meeting.

Some planning can be accomplished with a group of individuals working together, or doing parts of the planning with just one or two other people. There are individuals who are facilitating or leading their own meetings. There are also individuals who are facilitating meetings for other individuals.

How it works:

Step 1: Get to know the person by learning their "Positive Reputation" and "What is Most Important (and 2nd and 3rd Most Important)" for the person to have or not have in their life. Through this we learn about their relationships with people, things, places, animals, their routines, and their lifestyle pace.

Gathering People Who are Willing to Listen and Help

- Who listens when you talk about what's important to you?
- Who keeps your needs and hopes from being ignored?
- Who treats you with respect?
- Who do you rely on and trust?
- Who stands by you through thick and thin?
- Who is willing to help you achieve your dreams?

Step 2: Use the knowledge and information learned in Step 1 to "Compare Their Current Life with Their Desired Life", and to support the person now and in the future. To do this, the team must: Identify "What Other People Need to Know to Support the Person", "What Else Do We Need to Know", and "To Whom Do We Need to Talk".

Honoring the Past and Describing the Present

Past

- What major events have shaped your life?
- What have been your major achievements?
- What have been your major challenges?

Present

- What does a typical day look like today?
- What do I like and dislike about how I spend my day (e.g. relationships, work, free time)?

Step 3: Identify the individual's and their family's "Dreams and Plans for the Future". This gives direction for planning for the person's life goals and IEP goals while they are still in school.

Identifying Interests and Strengths

- What things do you like to do?
- What are your talents and strengths?
- What aspects of your life do you enjoy the most?

Step 4: Make an "Action Plan" that is supported by the individual's IEP (if still in school) and/or Transition Plan. The Action Plan is a broad plan covering all aspects of the person’s life. The IEP and/or Transition Plan cover goals specific for school. These goals will help toward achieving the goals of the Action Plan.

Creating a Vision of the Future Based Upon Hopes and Dreams

- What new things would you like to be doing in 3-5 years?
- How would you like to spend your “free” time?
- Where would you like to live and who would you like to live with?
- What type of work is of interest to you?
- What other things would you like to accomplish in your life?

Step 5: The “Action Plan” is followed and the person has a life they want, with people who enjoy them, which leads to new interests and goals.

Developing an Action Plan

- Which parts of your future vision are most important to you?
- What do you see yourself achieving during the next year?
- What type of activities of support might you need to achieve these goals and outcomes?
- Who in your circle of support or others that might help you indicate and achieve these activities?
- When will these activities be completed and when will you and your team meet again?

Step 6: As the person learns new things, have new interests, and new goals, the process continues with Step 1.

Working the Plan

- What parts of the plan went well?
- What aspects of the plan did not work?
- What parts of the plan should be continued?
- What new steps should you add to the plan?
- What other priorities do you want to address?
- How will you address these priorities, who will help, and when will the tasks be done?
- When will you meet again and who will facilitate?

Is The Information From The Meeting Confidential?

Although people have asked this question, this has never surfaced as a major or controversial issue. People with whom the planning is being done agree to the "list of participants" and skilled facilitators recommend that any issues that may be confidential should be discussed at another time. Facilitators should

- Incorporate the plan into the Individualized Education Program (IEP) or Individualized Written Rehabilitation Plan (IWRP) with specific goals and objectives.

- Designate one person to be the "point person" with whom others can check in.

- Hold follow-up meetings.

- Suggest that people "partner" with someone else to accomplish the activity.

System Centered	*Example*	**Person-Centered**	*Example*
Focus on Labels	*A 17 year old with mental retardation*	See People First	*A person with a love of sports*
Emphasis on Deficits		Search for Gifts	
Use of "Tests"	*Assessments indicate he is a behavior problem*	Spend Time Together	*He is well connected in his community*
Focus on Changing "Negative Behavior" Behavior"		Focus on Increasing Positive Experiences	
Focus on Segregated Service Options	*He is unemployable*	Focus on Valued Roles in the Community	*He has a committed support network and interested in employment*

What If People Have Unrealistic Expectations?

Debra McLean of the Oregon Technical Assistance Corporation talks about a student with severe disabilities who wanted to be an astronaut. But it turned out what he really wanted was to wear a uniform. In other words, it is important to look for some next steps or the pieces of the dream that can be realized.

If someone wants to own and manage a coffee shop, she will first need to take at class at the community college about running a business, meet with people who do similar work, etc. People should not jump to the immediate conclusion that a person's dreams are unrealistic.

ACTIVITY:

Decorate a paper doll cut out with stickers, material, yarn, lace, etc. Think about what reflects the interests, talents and strengths of your youth.

RESOURCES

WHERE AM I GOING? How will I get there? A guide to creating your future through transition planning.
Distributed by Hawaii State Council on Developmental Disabilities and Statewide Independent Living Council of Hawaii.

Bibliography for Person-Centered Planning:

AVATAR, Incorporated, Self-Determination Training Module, Up-dated July 2002.
Missouri Parents Act (MPACT,) Transition to Empowered Lifestyles – Building a Bridge to the Future with Young Adults with Disabilities, 2001.

SECTION 3: EDUCATION

The Individuals With Disabilities Education Improvement Act (IDEA) Of 2004

IDEA is a federal law that provides for the education of eligible students with disabilities. State education agencies (the Utah State Office of Education) are charged with ensuring that local education agencies (LEAs, meaning school districts and charter schools) implement the requirements outlined under IDEA. The Utah Board of Education has adopted State Special Education Rules to provide the framework for implementation of IDEA.

The purposes of IDEA are—

a) To ensure that all children with disabilities have available to them a free, appropriate public education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living;
b) To ensure that the rights of children with disabilities and their parents are protected;
c) To assist States, localities, educational service agencies, and Federal agencies to provide for the education of all children with disabilities; and
d) To assess and ensure the effectiveness of efforts to educate children with disabilities.

Utah schools are responsible for providing special education services to eligible students, aged 3 to 22. Services are provided through a process outlined in IDEA: identification; evaluation; eligibility determination; and provision of a FAPE (as defined in the IEP), including transition services by age 16. This section outlines IDEA requirements and suggested practices for each step of the process.

Keeping Records – A Journal Of Your Child's Progress

Adapted from "For Parents of Exceptional Students" – Department of Education, Tallahassee, Florida

"The first thing I always say to other parents when they begin to have problems is, 'You have got to keep good records' – almost a daily log." I keep a little notebook in my purse to write down the problems with my son – to write the good things he does – to write down who I contacted in the system. I write their names, their phone numbers, what they tell me, when they will call back, when they don‘t – that way I have data.

Sometimes it‘s not easy – when you are under stress and duress, it isn‘t easy. But if you don‘t keep track, no one will. It is critical. Documentation may seem like another burden. But it helps keep your head straight, keeps you organized. In the end it will be less of a burden.

This record will provide valuable information to the evaluation, eligibility, and IEP teams as they determine the student‘s eligibility and special education services needed.

ACTIVITY:

File folders or 3-ring binders to bring together pertinent information to be used in organizing, preparing, and writing effective Individual Education Plans. Sections should include: General Information, Copies of Educational Plans, Timeline History, General School In-formation, Medical Records, School Evaluations/Testing, Report Cards, Phone Log/Written Correspondence, Diagnosis/Medication Fact Sheets, Agency Information, Support Group Information, and Miscellaneous Resources.

Evaluation Process For Consideration Of Initial Eligibility For Special Education Services

1. Parent(s) or school staff makes a referral for special education evaluation.
2. The school team, including the parent(s), may conduct a review of existing evaluation data, such class work, statewide test results, and other information available from the school or the parent, to determine the need for further evaluation for eligibility.
3. School provides parent(s) with Written Prior Notice of intent to conduct an evaluation and a copy of the Procedural Safeguards.
4. School requests written Consent for Evaluation from the parent(s) to conduct the evaluation for special education eligibility. The school then has 45 school days to complete the evaluation.
5. When testing is complete, the school will arrange a meeting for the team (a group of qualified individuals and the parent) to review the evaluation results and determine the student‘s eligibility for special education services.
6. If the student is found eligible for special education services, the parent is given a copy of the Evaluation Summary Report and the Written Prior Notice of Eligibility Determination.

7. An IEP must be developed by the complete IEP team within 30 days of eligibility determination and the parent(s) must give written Consent for Initial Placement in special education. A copy of the Procedural Safeguards is provided to the parent.
8. If the student is found NOT eligible for special education services, the parent is given a copy of the Evaluation Summary Report and the Written Prior Notice of Eligibility Determination, indicating that the student is NOT a student with a disability under IDEA. The parent is given a copy of the Procedural Safeguards. A parent who disagrees with the evaluation conducted may utilize the procedures outlined in the Procedural Safeguards.

Evaluation Process For Consideration Of Continued Eligibility For Special Education Services

1. The school team, including the parent(s), must conduct a review of existing evaluation data, such as class work, statewide test results, and other information available from the school or the parent(s), to determine the need for further evaluation for eligibility.
2. If, after the review of existing evaluation data the team determines the need for further evaluation or the parent(s) requests an evaluation, the school provides the parent(s) with Written Prior Notice of intent to conduct an evaluation and a copy of the Procedural Safeguards. School requests written Consent for Evaluation from the parent(s) to conduct the evaluation for special education eligibility.
3. When testing is complete or if no further evaluation is necessary, the school will arrange a meeting for the team (a group of qualified individuals and the parent(s)) to review the evaluation results and determine the student‘s eligibility for special education services.
4. If the student continues to be eligible for special education services, the parent is given a copy of the Evaluation Summary Report and the Written Prior Notice of Eligibility Determination.
5. An IEP must be developed by the complete IEP team within 30 days of eligibility determination. A copy of the Procedural Safe-guards is provided to the parent(s).
6. If the student is found NOT eligible for special education services, the parent is given a copy of the Evaluation Summary Report and the Written Prior Notice of Eligibility Determination, indicating that the student is NOT a student with a disability under IDEA. The parent is given a copy of the Procedural Safeguards; a parent who disagrees with the evaluation conducted may utilize the procedures outlined in the Procedural Safeguards.
7. A school must conduct a reevaluation: A. if the team determines that the educational or related services needs of the student warrant a

reevaluation, or B. If the student‘s teachers or parents request a reevaluation.

8. The reevaluation must occur not more than once a year unless the school and parent(s) agree otherwise and must occur at least once every three years, unless the parent(s) and the school, through the review of existing evaluation data, agree that a reevaluation is unnecessary.

The Individualized Education Program (IEP)

The IEP is the vehicle for providing needed special education and related services to eligible students with disabilities. The IEP must be developed within 30 days of the determination of the student‘s eligibility for special education and services must be provided as soon as possible.

The IEP team must include the following members:

- The parent(s) of the student;
- At least one regular education teacher;
- At least one special education teacher;
- A representative of the LEA (school or district) who;
- Is qualified to provide, or supervise the provision of, special education and related services;
- Is knowledgeable about the general education curriculum;
- Is knowledgeable about the resources of the LEA;
- The representative may delegate another LEA member of the IEP team to be the LEA representative if the above criteria are met.
- An individual who can interpret the instructional implications of evaluation results;
- At the discretion of the LEA or parent(s), other individuals who have knowledge or special expertise regarding the student, including related services personnel as appropriate; and
- Whenever appropriate, the student with a disability.

Parents are an integral part of the IEP team and must be invited to the IEP meeting. The invitation to the meeting must indicate the purpose, time, and location of the meeting and inform the parent(s) that they may bring others to the meeting who has knowledge or special expertise about the student. If the parents are unable to attend the meeting, the parents and LEA may agree to use alternative means of meeting participating, such as video conferencing and conference calls.

Who Is The Parent?

Under the Utah State Board of Education Special Education Rules (USBESER I.E.29), a parent is:

A biological or adoptive parent; a guardian, but not the State if the student is a ward of the State; a person acting in the place of a parent of a student (such as a grandparent, stepparent, or other relative) with whom the student lives; or a person who is legally responsible for the student‘s welfare; or a surrogate parent who has been appointed in accordance with these Rules.

Consistent with State law, a foster parent may act as a parent under Part B of the IDEA if the following four conditions are met:

a) The biological or adoptive parents' authority to make educational decisions on the student‘s behalf has been extinguished under State law.
b) The foster parent has an ongoing, long-term parental relationship with the student.
c) The foster parent is willing to make the educational decisions required of parents under these Rules.
d) The foster parent has no interest that would conflict with the interests of the student.

The biological or adoptive parent, when attempting to act as the parent and when more than one party is qualified to act as a parent, must be presumed to be the parent unless said parent does not have legal authority to make educational decisions for the student. If a judicial decree or order identifies a specific person or persons to act as the "parent" of a student, or to make educational decisions on behalf of a student, then such person or persons shall be determined to be the parent for purposes of these Rules.

What Is A Surrogate Parent?

A surrogate parent is a person appointed to represent a child with a disability in special education planning when:

- No parent can be identified
- No parent can be located
- A child is a ward of the State

The surrogate:

- Is not an employee of the SEA or LEA or agency involved in the education or care of the child
- Cannot have a conflict of interest
- Has knowledge and skills

The Utah Parent Center (www.utahparentcenter.org) provides training for individuals who wish to become surrogate parents.

IDEA Regulations, Sec. 300.519 surrogate parents:

a) General. Each public agency must ensure that the rights of a child are protected when—
    1. No parent (as defined in Sec.300.30) can be identified;
    2. The public agency, after reasonable efforts, cannot locate a parent;
    3. The child is a ward of the State under the laws of that State; or
    4. The child is an unaccompanied homeless youth as de-fined in section 725(6) of the McKinney-Vento Homeless Assistance Act (42 U.S.C. 11434a (6)).

b) Duties of public agency. The duties of a public agency under paragraph (a) of this section include the assignment of an individual to act as a surrogate for the parents. This must include a method--
(1) For determining whether a child needs a surrogate parent; and
(2) For assigning a surrogate parent to the child.

c) Wards of the State. In the case of a child who is a ward of the State, the surrogate parent alternatively may be appointed by the judge overseeing the child's case, provided that the surrogate meets the requirements in paragraphs (d)(2)(i) and (e) of this section.

d) Criteria for selection of surrogate parents.
    1. The public agency may select a surrogate parent in any way permitted under State law.
    2. Public agencies must ensure that a person selected as a surrogate parent—
        i. Is not an employee of the SEA, the LEA, or any other agency that is involved in the education or care of the child;
        ii. Has no personal or professional interest that conflicts with the interest of the child the surrogate parent represents; and
        iii. Has knowledge and skills that ensure adequate representation of the child.

e) Non-employee requirement; compensation. A person otherwise qualified to be a surrogate parent under paragraph (d) of this section is not an employee of the agency solely because he or she is paid by the agency to serve as a surrogate parent.

f) Unaccompanied homeless youth. In the case of a child who is an unaccompanied homeless youth, appropriate staff of emergency shelters, transitional shelters, independent living pro-grams, and street outreach programs may be appointed as temporary surrogate parents with-out regard to paragraph (d)(2)(i) of this section, until a surrogate parent can be appointed that meets all of the requirements of paragraph (d) of this section.

g) Surrogate parent responsibilities. The surrogate parent may represent the child in all matters relating to--
    1. The identification, evaluation, and educational placement of the child; and
    2. The provision of FAPE to the child.

h) SEA responsibility. The SEA must make reasonable efforts to ensure the assignment of a surrogate parent not more than 30 days after a public agency determines that the child needs a surrogate parent.

Development, Review And Revision Of The IEP

When developing the IEP, the team must consider the strengths of the student, the concerns of the parent about enhancing the student‘s education, the results of the initial or most recent evaluation of the student, and the academic, developmental, and functional needs of the student.

The IEP team must also consider special factors and, if an accommodation, device, or service is needed to provide the student a FAPE, must address the need in the IEP:

- Behavior that Impedes Learning. In the case of a child whose behavior interferes with his or her learning or that of others, consider appropriate strategies and supports, including positive behavioral interventions, to address that behavior.
- Limited English Proficiency. In the case of a child with limited English proficiency, consider the language needs of the child as those needs relate to the child‘s IEP.
- Braille Needs. In the case of a child who is blind or visually impaired, provide for instruction in Braille unless the IEP determines that it is not appropriate for the child.
- Communication Needs. Consider the communication needs of the child, and in the case of a child, who is deaf or hard of hearing, consider the child‘s language and communication needs and opportunities for communication with others, along with the full range of needs.
- Assistive Technology. Consider whether the child requires assistive technology devices and services. The team must also consider whether the student needs the device at home or in other settings in order to receive a FAPE.

The IEP must contain a statement of the student‘s present level of academic achievement and functional performance. This statement must include baseline data and a statement about how the student‘s disability impacts the student‘s access to and progress in the general education curriculum. Baseline data are required as a starting place for the team use when developing measurable annual IEP goals (the skills the student needs to learn or improve) that will be addressed during the next calendar year. When the IEP goals have been selected, the team must determine which special education and related services will be necessary to attain the goals.

The IEP team must consider any program modifications or supports for school personnel that will be provided to enable the student to access and make progress in the general curriculum. Part of this discussion will be the student‘s participation in statewide assessments and the need for accommodations during assessments and instruction.

The IEP team must review the student‘s IEP periodically, although no less than annually, and revised as appropriate. Changes may be made to the student‘s IEP after the annual IEP meeting (during the same school year) through an IEP amendment if the parent and LEA agree; this amendment may be done without a full IEP team meeting although the LEA must notify the rest of the IEP team about the changes. Parents must be provided, upon request, a copy of the amended IEP.

The IEP For Transition-Aged Students

As a parent of a student with a disability, you are probably concerned about your son or daughter as he or she makes the transition from the structured environment of school to the post-school world and all of the difficult life choices that entails. The services and supports your student needed in school may continue to be needed when he or she leaves school to pursue post secondary education, job training, work, personal and social relationships, involvement in the community, and independent living.

From the time your child begins receiving special education services; his or her Individualized Education Program (IEP) guides his or her education. During the transition years, your son or daughter‘s IEP must contain specific transition services defined by The Individuals with Disabilities Education Act Amendments of 2004 (IDEA) regulations. The transition plan will lay the path toward your child‘s young adulthood. It must reflect his or her choices, preferences, and needs in the areas of education and training, employment and independent living. IDEA requires that parents and students be involved in all aspects of transition planning and decision making. To participate effectively, and to ensure that your student receives appropriate educational services, it is important that you and your son or daughter become familiar with the transition requirements of IDEA. Parents, students, educators, and community service providers must work together to support the student in planning for and achieving his or her adult goals.

IDEA Transition Requirements

IDEA 2004 requires that, beginning not later than the first IEP to be in effect when the student turns 16 (IEP developed when the student is 15), or younger if determined appropriate by the IEP team, the IEP must include appropriate measurable post secondary goals related to post secondary education or training, employment, and independent living. These goals must be based on age-appropriate transition assessments; these assessments may be formal or in-formal and may be administered by parents or educators. Educators frequently encourage students to self-assess their skills, challenges, and preferences.

In addition to the post secondary goals, the IEP must also include a statement of transition services (see box), including courses of study, needed to assist the student in reaching the post secondary goals. The courses of study are the educational experiences, both academic and non-academic (e.g. community experiences, work experience, career counseling), that are designed to teach the student the skills he/she needs to reach the post secondary goals.

The IEP, including the transition plan, must be updated annually or more often when needed. If the student is not making expected progress toward the annual goals and in the general curriculum, the team must meet and revise the IEP. IDEA 2004 requires that schools provide periodic reports (such as quarterly reports or when other report cards are issued) to the parents on the progress the student is making toward meeting the annual goals. It is recommended that these progress reports for students with disabilities are provided at least as often as progress reports are provided for students without disabilities. Progress reports can help determine whether or not revisions to the IEP are needed.

Age Of Majority

Beginning no later than the student‘s 17th birthday, the student and parents must be in-formed on any rights under IDEA (Procedural Safeguards or parents‘ rights) that transfer to the student on reaching the age of majority. In Utah, minors become adults at age 18, unless guardianship has been awarded by the courts to another adult. Rights that transfer to the adult student include: giving consent for evaluation, eligibility, placement in special education, and implementation of the IEP; filing a complaint; and requesting an independent education evaluation.

The IEP Transition Team

Transition planning works best when students are actively involved. Family members and other adults also play important roles in this long-term planning. Teachers, administrators, and support agencies work with the student and family to reach the goals.

The IEP transition team relies on data from many sources to make decisions. Assessments, observation, testing, medical evaluation, and family history may be used to determine eligibility for adult services. Continued eligibility for services likewise relies on reevaluation and input from teachers and family.

All the professionals who work with the student must be knowledgeable about the student‘s IEP. They must understand their responsibilities and the specific accommodations, modifications, and supports that must be provided for the student in accordance with the IEP. This means that the IEP must be accessible to each of the student‘s teachers and all other service providers who implement any portion of the IEP, even if they do not attend the transition IEP meetings (for example, guidance counselors, vocational educators, social workers, psychologists). The required members of the IEP team for a transition-aged student include the parent or the adult student (a student aged 18 or older), at least one regular educator, at least one special educator, a representative of the school or district, and someone who can interpret evaluation results (this may be one of the required members of the team). The team may also include individuals invited by the parent or school/district, such as parent/student advocates, psychologists, counselors, related services providers, and, with the prior written consent of the parents or adult student, representatives of adult service agencies.

The following is a description of the roles of the key individuals involved in the transition planning process. Additional information about how these individuals may be involved in the process is addressed in the Transition Action Guide.
(www.schools.utah.gov/sars/manualsglines/pdfs/transaguide.pdf)

Students

Students, no matter what or how significant their disability may be, are the most important people involved in transition. They should be as actively engaged as possible in all aspects of their transition process. The IEP team must specifically invite the student to attend any IEP meeting in which the team will be developing a transition plan. The transition planning process should be done with, not for, the student. The student‘s IEP transition plan must be based on his or her individual needs, taking into account his or her strengths, preferences, and interests and address his or her goals for education or training, employment and independent living when high school is finished. Preparing together for IEP meetings gives students and parents the opportunity to identify and discuss the student‘s goals for the future. If the student does not attend, schools must ensure that the student‘s preferences and interests are considered when developing the IEP transition plan.

Parents

Parents know their child better than anyone else and will be the one constant factor throughout their child‘s transition from school to adulthood. Their commitment to the IEP transition team is the key to making their child‘s transition to adult living a successful one. They bring a wealth of information about their child, which has great significance when developing a plan for transition. Parents provide knowledge about their child‘s interests and medical history, as well as about their child‘s behaviors at home and in the community. Their observations, along with the expression of family‘s values, provide the transition IEP team with a greater understanding of what services may be necessary and appropriate. Parents must be invited to IEP transition meetings and in-formed prior to the meeting that the discussion will involve transition issues. After the IEP is developed, parents must be given a free copy of their child‘s IEP without having to request it. If the student has reached the age of majority (age 18), the student can invite parents to attend the meeting, but the school is not required to invite the parents or guardians.

Special Education and General Education Teachers

IDEA requires at least one special education teacher or provider of the child to be a member of the IEP transition team. The team must also include at least one general education teacher of the child if the student is or may be participating in general education. The entire IEP team determines what services the student needs, such as positive behavioral interventions, supplementary aids or program modifications, including assistive technology devices and services, and support for the teachers who serve the student.

Other School Personnel

IDEA requires a representative from the school district, usually called the LEA representative, who is knowledgeable about the availability of resources of the public agency to attend the IEP meetings. The person must be qualified to provide or supervise the provision of specially de-signed instruction to meet the unique needs of children with disabilities, be knowledgeable about the general education curriculum, and be knowledgeable about the availability of resources of the district or school. This person frequently is the school principal or his/her designee.

The team must also include an individual who can interpret the instructional implications of evaluation results. This person may be one of the other required members of the team, such as the special educator, or may be an additional member, such as a psychologist, speech-language pathologist, occupational therapist (OT), or physical therapist (PT).

Other Service Agencies

The student‘s IEP should include any needed transition services from outside agencies, such as vocational rehabilitation, county services, and post secondary programs. Adult agencies whose services link school experiences with employment, future education or training and independent living opportunities should be invited to IEP transition meetings with the prior written consent of the parents or adult student. These personnel could include representatives from residential facilities, mental health workers, county case managers, vocational rehabilitation counselors, or past or current employers. This is a critical component of transition planning. Many public and private agencies that offer adult services have eligibility criteria and waiting lists. The procedures used in each adult service system differ from school procedures. Some services from these agencies can begin before the student graduates. A smooth transition to adult services is more likely to occur if representatives from adult agencies are included in the transition IEP as early as possible.

If an outside agency fails to provide the service agreed to in the IEP, the school must call a meeting to identify alternate strategies to meet the transition objectives set forth in the IEP. IDEA does not relieve a participating adult agency of its responsibility to provide or pay for any transition services it would otherwise provide to people with disabilities who meet the agency‘s eligibility criteria. If the agency is required under Federal or State law to provide services that are also considered special education or related services, the agency must provide those services through a contract or other arrangement or through an interagency agreement. If the agency does not provide the special education or related services, the school must provide or pay for these services in a timely way and is authorized to claim reimbursement from the agency that failed to provide the services.

Other Individuals

Parents may invite anyone with knowledge or special expertise regarding the child to be on the IEP team. Such persons may be a friend or relative, an advocate, or an employer. IDEA regulations provide that the person who issues the invitation determines whether that individual has knowledge or expertise that may be helpful in the IEP meeting. Parents, the student, and the school may invite whomever they choose.

THE TEN BASIC STEPS TO TRANSITION PLANNING

1. Survey youth and/or parent-guardian transition needs and preferences
2. Develop a transition team able to help the youth achieve desired goals
3. Discuss the youth‘s post secondary goals with the transition team
4. Identify transition services needed to develop or achieve these goals
5. Assign responsibility for each transition service and set target dates
6. Establish IEP objectives for major transition service and set target dates

7. Follow up with persons assigned to provide transition services as needed
8. Reconvene the transition team if services cannot be provided as planned
9. Evaluate the statement of needed transition services (ITP) annually
10. Revise the plan and reassess youth needs and preferences, if necessary

Adopted from JoAnn Welker, Findlay City Schools and Rene Phillips, Southwester City Schools

Transition Tips for Parents

Parents and students should consider the following points when beginning the transition process and preparing for or participating in an IEP transition meeting or staffing:

- Ask your teenager what he or she would like to do with his or her life. What are his or her dreams, goals, etc.? Incorporate the responses into all aspects of transition planning. If your son or daughter is non-verbal or has difficulty communicating these thoughts, use your knowledge about him or her to make sure transition plans reflect likes, dislikes, etc.

- Know your son or daughter's needs, abilities, and skills. Be familiar with how much assistance he or she needs or does not need to accomplish tasks.

- Know what outcomes you and your teenager want. Bring suggestions to meetings on what actions you feel are needed to meet or move toward goals in the transition plan.

- Encourage your son or daughter to attend the IEP meeting. He or she will be invited. Together, prepare for the meeting.

- Encourage self-advocacy skills for your son or daughter. Have the staff direct questions to your teenager.

- Know what programs, services, accommodations, or modifications you and your teenager want. Be clear on the transition needs or issues of your son or daughter.

- Determine who will be responsible for what on the transition plan. Ask for specific timelines.

- Decide whether educational and transition programs should emphasize practical or academic goals or a combination of both.

- Become aware of community-based training opportunities your school provides. Parents and their son or daughter should decide how much the student should participate in those activities currently, as well as in the future.

- Request a copy of your son or daughter's daily schedule each quarter or semester.

- Request information on all classes available to students so your son or daughter can participate in the class selection and scheduling process.

- Determine how your son or daughter's educational and transition program could be more integrated into regular programs.

- Learn who will attend the IEP meeting. Become familiar with the roles and functions of team members.

- Arrange for a family member, friend, or advocate to accompany you and your son or daughter to planning meetings for support or note taking, if needed. In general, becoming familiar with adult service systems or agencies now will help your son or daughter in making decisions that will affect the future.

A final tip: Start thinking about your teenager‘s legal status before he or she turns 18. If your son or daughter is not able to make informed decisions about major issues (e.g., medical treatment, living accommodations, financial arrangements, etc.), your family may want to learn more about guardianship or conservatorship.

By learning as much as possible about these options, your family can ensure that your son or daughter‘s rights are protected, while allowing him or her to retain as much independence as possible.
©2001, 1995 PACER Center | ACTion Sheet: PHP-c80

Conclusion

IDEA has contained requirements for transition planning since 1991. As a parent, you can do much to help your child with a disability move through their transition years. You can become familiar with state rules and federal regulations and the procedures used in your state and school district. Appropriate transition services will enable your student to develop the skills he or she needs to achieve his or her post secondary goals and be a contributing member of the community. With knowledge of IDEA, you and your son or daughter can become stronger self-advocates, and you can help your young adult develop skills needed for the future.

Section 504/Americans With Disabilities Act—Another Service Option

The LEA may consider a Section 504 plan for students who are determined not eligible for special education services and who may need accommodations to access general education programs.

What Is Section 504?

Section 504 is often referred to as the first civil rights act for individuals with disabilities. It applies to parents, employees, and other individuals with disabilities.

It is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive Federal financial assistance from the U.S. Department of Education (ED). Section 504 provides: "No otherwise qualified individual with a disability in the United States…shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

Who Is Eligible For Section 504?

Section 504 of the Rehabilitation Act of 1973 protects students from discrimination based on their disability status. A student is eligible for accommodations under Section 504 *if the student has a mental or physical impairment that substantially limits one or more of a student's major life activities that impacts education.*

"Major life activities" include functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. When a condition does not substantially limit a major life activity that impacts education, the student does not qualify for protection under Section 504.

THERE IS NOTHING AS UNEQUAL AS

THE EQUAL TREATMENT OF

UNEQUALS.

Section 504 Guidelines And Implementation

- If the student is eligible under Section 504, the team determines accommodations and/or services that will enable the student to benefit from his/her education.

The school staff makes the necessary accommodations to allow for the student‘s disability. Parents **should** be consulted and given opportunities for input. The accommodations and/or services are then implemented.

Section 504 Grievance Procedure…

Requires a grievance procedure to deal with any discrimination is-sues. (*School district/charters may use the same procedures for re-solving disputes under both Section 504 and the IDEA or may have procedures specific to Section 504.)*

More general information about Section 504 and education is avail-able from the USOE Educational Equity Section (www.schools.utah.gov/equity/Section-504.aspx).

Exiting The School System

Graduation Options: NOTE: graduation requirements have changed as a result of the passage of HB 166 by the 2010 Utah Legislature.

High School Diploma:

- Meet all USOE and LEA course requirements.
- For the graduating class of 2010 ONLY, pass all 3 subtests of the UBSCT or;
- Document 3 attempts to pass each subtest or;
- Participate in Utah Alternate Assessment (UAA) if the IEP team has determined that the student‘s participation in statewide assessments is through the UAA.

Certificate of Completion:

- Does not meet all USOE and LEA course requirements;
- Cannot document at least 3 attempts to pass all subtests of the UBSCT;
- Has completed the senior year in high school;
- Is exiting the school system.

School district responsibility for special education services ends when:

- The student graduates with a regular high school diploma or;

- The student reaches his/her 22nd birthday -
    - Birthday between the beginning of school and December 31, exit at the beginning of the school‘s winter holiday.
    - Birthday between December 31 and the end of the school year, exit at the end of the school year.

Parenting Post-Secondary Students With Disabilities: Becoming The Mentor, Advocate, And Guide Your Young Adult Needs

The importance of involving parents in the education of elementary and secondary school students is widely encouraged. In fact, federal law—the Individuals with Disabilities Education Act (IDEA)—has created a process to involve parents in the education of their children with disabilities. Once youth with disabilities graduate from high school, however, resources and guidance to help parents with this challenging new phase of parenting become difficult to find. Yet, parents continue to be important role models and guides for their young adult sons and daughters. For students with disabilities, parents may be a key part of the support network they need to succeed in the post secondary environment.

Experts on human development consider late adolescence a very important time of life for all individuals. It is a “launching period” when parents help youth develop the skills they will need as adults. This “launching” process does not end because a student graduates from high school, reaches the legal age of adulthood (“age-of-majority”), or enrolls in a college or other training program. New and important parenting issues continue to arise as young adults grow up.

Parents As Mentors

Although parents of young adults with disabilities no longer have the same authority they once had in the lives of their children, they can provide guidance and support through a mentor or advisor role. Mentors teach, challenge, and support their protégé. A parent‘s mentoring relationship must be based on an underlying trust and respect for one‘s child as someone capable of learning how to manage his or her own life.

Whether a student has a disability or not, the greatest challenge for parents of post secondary students is learning when and how to be supportive while still encouraging self-determination and independence. It may require a giant leap of faith for parents to trust that their sons and daughters have all the resources they need to deal with the unfamiliar challenges of post secondary education. Nonetheless, post secondary schools treat students as legal adults. It is important for parents to do all they can to reinforce their faith in their child‘s ability to manage life at school.

Effective mentoring takes clear communication skills. Parents may find it helpful to learn about and practice these skills so they can use this technique consistently and well. This approach is explained in depth in the book *Don’t Tell Me What to Do—Just Send Money: The Essential Parenting Guide to the College Years* by Helen E. Johnson and Christine Schelhas-Miller.

Parents As Advocates

No matter how much parents respect and trust their children, it is difficult to let them learn from mistakes when the consequences are serious. Although parents must be careful not to “take over” the problems of their young adult sons and daughters, situations may arise when parents need to take a more active role.

Young adults often unload everyday worries on parents and then go on about their lives. Parents must distinguish between these kinds of situations and more serious circumstances—such as substance abuse, mental or physical illness, other threats to their child‘s health or safety, serious financial issues, and, for youth with disabilities, discrimination.

Once parents decide to act, their first involvement should always be directly with their son or daughter – to who parents can provide resources, information, and emotional support. Parents may also want to contact the post secondary-secondary program to ask for help assessing the situation. If the child is in college, the Disability Ser-vices Offices is a good place to start. Other offices may also be appropriate depending on the nature of the concern. These include health services, the Dean of Students, Americans with Disabilities Act (ADA) coordinators, and Section 504 coordinators. Many colleges and universities also have a parents’ program office.

Parents of students with disabilities who are concerned about their child‘s educational program or academic accommodations can draw on their experience as special education advocates. However, they will need to understand the differences between special education laws, the ADA, and Section 504 of the Rehabilitation Act. Parents may encounter some resistance to their involvement. Post secondary professionals are not used to working with parents and may see it as inappropriate or even harmful. In fact, school staff cannot legally share information with parents without a student‘s written permission.

Young adults of legal age are responsible for making their own decisions even in serious situations. Unless parents are the legal guardians of their adult child, their role is to support their son or daughter as the young adult solves his or her problems. Parents may only need to help them gather information and understand their options. Ultimately, a student‘s maturity, cultural values, and other individual characteristics will determine the kind of involvement and family support that is appropriate and helpful for each student.

So What's A Parent To Do?

The post secondary years provide students with both new freedoms and new responsibilities. Many students are living away from home for the first time or are new to making personal decisions on their own. Parents are naturally concerned about the safety, health, and social adjustment of their sons and daughters. Disability related issues can make this an even more challenging time for students and parents. However, there is help available.

Materials for parents of college students, such as the previously mentioned book by Helen E. Johnson and Christine Schelhas-Miller, can be found on the shelves of local bookstores and libraries. Several web sites have also been created for the parents of college students. Many colleges and universities, for example, provide tips for parents on their web sites. Unfortunately, these resources do not address the many unique challenges faced by students with disabilities and their families.

Information developed specifically for the parents of high school students with disabilities, on the other hand, does not cover parenting issues during the college years. These materials generally try to help parents prepare youth for the transition to post secondary education, find financial aid, and learn about ADA and Section 504. The benefits of family support may be mentioned, but what this support looks like at the post secondary level is not described. In fact, an emphasis in recent transition literature on overprotective parenting and learned helplessness has given some parents and educators the mistaken impression that parent involvement is wholly undesirable at the post secondary level.

Although not widely available, a handful of recent studies confirm the value of the supports parents provide at the post secondary level and indicate that active parent involvement can foster, rather than hinder, self-determination. Additional studies and research based guidance on these issues is needed to help parents effectively support their sons and daughters with disabilities in the post secondary years.

RESOURCES

- PACER Center, www.pacer.org
- National Center on Secondary Education and Transition, www.ncset.org/
- National Center for the Study of Post secondary Education Supports, www.rrtc.hawaii.edu/
- HEALTH Resource Center, www.health.gwu.edu
- National Information Center for Children and Youth with Disabilities, www.nichcy.org/
- **“**Understanding the Transition to College,” (George Washington University site): gwired.gwu.edu/counsel/counsel.php?id=1935
- College Parents of America, www.collegeparents.org/
- Parents Association “College Central”, www.parentsassociation.com/college/index.html
- Higher Education Center for Alcohol and Other Drug Prevention, www.edc.org/hec/parents/
- Utah State Office of Education – Special Education, www.schools/utah.gov/sars

For **individualized information, advocacy, education and referral services** contact:

- Allies with Families, 505 East 200 South, Suite 25, Salt Lake City, Utah, 84102 Phone (801) 433-2595 or toll free (877) 477-0764, Fax (801) 521-0872

  allies@allieswithfamilies.org
  www.allieswithfamilies.org

- Utah Parent Center, www.utahparentcenter.org
- Centers for Independent Living, www.virtualcil.net/cils/

(This parent brief is produced by the National Center on Secondary Education and Transition (NCSET) and PACER Center.)

SECTION 4:
LEGAL ISSUES

Bobby's story…

Bobby is a 32 year old man who has mental retardation. He is very high functioning and has a typical appearance. He has Bipolar Disorder with Schizo tendencies. Ten years ago, Bobby graduated from high school then went to a tech school. He was done with school by age 21 and continued to live with his mother. In the early 1990s, there wasn't much job placement or job coaching so he was on his own to find and hold a job. He didn't have a case manager or any mental health services to speak of. Bobby had behavioral problems and he wouldn't stay on his medication. His mother would try to help him but legally he was an adult and therefore, her hands were tied. She wasn't able to control any of his actions. Eventually Bobby ended up in a "half way type house" where other young people with behavioral problems lived. There was little to no supervision there. Bobby learned even more bad behaviors. He would steal, lie, pawn his belongings, empty his bank account to party, and was often physically violent. He would check out library books and not return them, ending up with hundreds of dollars of fines. He drank, ran around with unsavory people, and would smoke cigarettes, sometimes a pack an hour.

After about 7 years of floating around aimlessly in life not being productive and often be-ing taken advantage of by others, Bobby was put into a group home setting. Because he didn't have a guardian, the group home personnel could not stop him from doing any of the bad things that he did because according to the law, he was an adult and could make his own decisions. They had to stand by silently while he was hurting himself and others were using him for money, etc.

When Bobby was 29 years old, his mother decided that she couldn't let Bobby continue on his destructive path, so she talked to him about guardianship. He was totally against the idea, realizing that he wouldn't be able to do everything anytime that he wanted. After 3 long years of legal battles, many doctors' reports, and of Bobby doing many frightening things (which were documented), Bobby's mother was able to gain guardianship for Bobby.

Bobby has been stable for two months now. He takes his medication and has a legitimate job. He isn't allowed to leave the house without supervision and has no access to his finances. He still smokes but is only allowed one cigarette every 3 hours. He is beginning to live a productive life … finally.

What Is This Thing Called Guardianship?

Guardianship is about who can legally make decisions for someone else. It has to do with the fact that when someone turns 18 he/she becomes a legally competent adult with full adult rights and legally has the ability to make his own decisions. This fact applies equally to all and there are no distinctions that might be made because someone has a disability. People with cognitive disabilities who turn 18 may lack the functional ability to make their own decisions in some areas of their lives. People like this might benefit by having some type of assistance with decision making. Options for a person who is relatively capable in decision making might include teaching and training, and advocacy. Stronger interventions which give someone else power to make decisions in the disabled person's behalf include power of attorney or other types of advance directives, bill paying services, or guardianship. Guardianship is the most restrictive of these measures and should be used only when there is no other way to support some-one in decision making.

Five Areas Of Guardianship:

Medical
Habilitation
Educational
Residential
Financial

What Is A Limited Guardianship?

Limited Guardianship is providing care and supervision in the least restrictive form, by individualizing Guardianships so a person under the Guardianship keeps as many rights as possible. For example: Guardians are entitled to custody (where the person lives), consent to treatment (Medications and Mental Health), and receive money or property for the individual.

Under a Limited Guardianship, the guardian may not have custody, but may be allowed to consent to treatment, and receive money and property.

Utah law states "The court shall prefer a limited guardianship and only grant a full guardianship if no other alternative exists. If the court does not grant a limited guardianship, a specific finding shall be made that nothing less than a full guardianship is adequate."

When Can An Adult Have A Guardian?

A guardian may be appointed by the court for a person who the court finds meets the definition of "Incapacitated Person" – Any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, or other cause except minority to the extent of lacking sufficient understanding or capacity to make or communicate responsible decisions.

What Power Does A Guardian Of An Adult Have?

Unless the court orders otherwise, the same powers, rights and duties that a parent has for an unemancipated minor (a child under the age of 18 and not married), except that a guardian is not liable to a third person for acts of the ward (incapacitated person) solely by reason of the parental relationship.

Why Should I Consider Guardianship?

Adult children who lack functional competence may benefit by having their parents become their legal guardians. This type of guardianship allows the parents to continue to perform in the parental role by making decisions in areas where it might be difficult for their disabled adult child to do so. These areas might include medical decision making, financial management, program and educational decision making and residential placement issues, and other areas where a disabled person needs decision making support.

Guardianship is not something that should be taken lightly. It is a court process that awards some rights held by one person to someone else. It requires honesty, integrity and objectivity on the part of the guardian to support the ward in his/her wishes while at the same time acting in his/her best interests. A guardian is under jurisdiction of the court and may act in only the areas the court has defined.

Guardianship is not needed by everyone who is disabled and turns 18. Many individuals are capable of making appropriate decisions with little or no assistance. Careful consideration needs to be given to the needs of every disabled person before leaping into guardianship.

When Should I Start the Process?

Guardianship should be thought about by parents long before the youth's 18th birthday. The actual process of applying for guardianship should begin, at the earliest, between 3 to 4 months prior to the youth's 18th birthday. It can be done at any time in an adults' life.

Where Do I Start?

The legal steps to guardianship take place in the Probate Division of the District Court where the youth resides.

Who Is Guardianship For?

A guardian may be appointed by the court for a person who the court finds meets the definition of "Incapacitated Person" – Any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, chronic use of drugs, chronic intoxication, or other cause except minority to the extent of lacking sufficient understanding or capacity to make or communicate responsible decisions.

How Do I Get It?

Guardianship Associates in Salt Lake City, Utah, provides two options in pursuing guardianship – Attorney Representation and acting "*Pro Se*".

Option 1: Attorney Representation

The cost of preparing a guardianship through the Guardianship office was $805 at the time of this writing, broken down as follows:

- Attorney for you $400
- Court filing fee $155
- Contribution to Guardianship Associates $50
- Attorney for the ward $200

What documents you need to bring with you:

- A letter from your child's doctor(s) stating his/her diagnosis and that the doctor(s) believes your child would benefit by having a guardian.
- A copy of your child's psychological evaluation that shows his/her diagnosis.

Be prepared to complete a questionnaire for the attorney's office – bring your address book!

Be prepared to spend approximately 1 hour and be prepared to ask all the questions you have about guardianship.

Option 2: Acting “*Pro Se*”

If parents wish to act “PRO SE” in their guardianship proceedings (“PRO SE” means to act as your own attorney).

The cost for acting PRO SE is $405.00 broken down as follows:

- Court filing fee $155.00 **that is paid directly to the court and not to GAU**
- Contribution to Guardianship Associates $50.00
- Attorney for the ward $200.00

Guardianship Associates will provide a computer disk that has information necessary to file your own petition. This disk includes a sample guardianship petition that you can use to pre-pare your own petition. The value of acting PRO SE is that the parents or proposed guardians can avoid paying an attorney for their side of the guardianship. There is still a court filing fee and a fee for the attorney representation of the proposed ward. Guardianship Associates also asks for a $50 donation for training, information and assisting proposed guardians in obtaining representation for the proposed ward. Potential guardians should be prepared to tell the court why they want guardianship and be prepared to answer any of the judge’s questions.

RESOURCES

The Disability Law Center
At the Community Legal Center
205 North 400 West
Salt Lake City, Utah 84103
1-800-662-9080 (Voice) or 1-800-550-4182 (TTY)
801-363-1437 (Fax)

Services are statewide and free of charge to all eligible individuals in Utah.
Contact: info@disabilitylawcenter.org

Guardianship Associates

Utah Bar Association

SECTION 5:
DREAMING NEW DREAMS
LOOSENING UP

Nancy's story…

I vaguely recall some proverb that says if you give a man a meal, you have fed him for a day, but if you teach a man to fish, you have fed him for his life. I would like to use this analogy as I share an example of how to teach our seriously emotionally challenged youth, so that they can feed themselves for life.

The goal of most caregivers is to help our youth be as independent as possible, yet how we teach our children is the key to our being able to let go, and them being able to have that independence.

Recently, my child needed to ride the bus from Clearfield to Salt Lake City by herself. The location in Salt Lake City required at least one bus transfer. This was a challenging under-taking and we did some role playing on how/when to ask for directions. We also talked about not getting frustrated if she got on the bus going the wrong direction.

One of my child's caregivers had written out directions on which bus to catch and left these for my child to follow. These directions would have gotten my child to her destination, but not on the closest or most direct route. More importantly, these directions were specific to that task.

My child was still rather unsure and asked another caregiver for help knowing how to navigate this task and the reassurance that she had the directions down correctly. The second caregiver took my child, and showed her where/how to call UTA and receive directions from any destination to any destination, and how to ask the bus driver for help in identifying the correct stop.

Both sets of directions would have resulted in my child reaching her destination. But the second set of directions resulted in my child learning a life skill that she can use for future adventures. My child successfully completed the task of getting from Clearfield to Salt Lake City. She felt a sense of accomplishment as well as a sense of empowerment at having learned how to do a similar task another time.

As we teach our youth to be independent, we must keep in mind those teaching moments. With a little extra effort, we can teach a life skill that will help them reach their goals.

"Nothing will ever be attempted if all possible objections must first be overcome."

-Samuel Johnson

What Is Loosening Up?

"We don't have a clue as to what people's limits are. All the tests, stopwatches, and finish lines in the world can't measure human potential. When someone is pursuing their dream, they'll go be-yond what seems to be their limitations. The potential that exists within us is limitless and largely untapped."
- Robert J. Kriegel

Why Is Loosening Up Necessary?

Adolescence is a time of independence, a time when young adults begin to take more responsibility for meeting their own needs. Many young adults with disabilities begin to "strike out on their own" and seek less interference and involvement from their parents. **Greater independence means higher risk**. Risk taking is an essential component of adolescence and an important component of gaining independence.

When Is Loosening Up Appropriate?

When young adults with disabilities move from the school system into the community, their parents experience the same feelings that all parents do when it is time to "loosen up" and allow their kids to try things on their own. Letting sons and daughters with disabilities "try their own wings" can be more frightening because they have usually been more dependent on others.

Some parents are afraid their sons and daughters can't make it without them. Others fear transition because change involves risk and they're afraid their young adult may fail in some new task, be injured, or treated poorly.

No parent wants to expose a young person to risk, especially one who has a higher than average chance of failing. Yet most parents know that risk-taking is essential for the long-term development of social and personal competence. It is easier for parents to learn to “loosen up” when they understand what “holding on” looks like.

ACTIVITY:

(Show Garth Brooks video “Standing Outside the Fire”)

What are some examples of “holding on” to our kids too tight?

(Possible answers: always watching or calling to check on the individual, treating kids as if they were younger than their chronological age, doing things for young adults that they can do themselves, being either too controlling or too permissive.)

Who Is This For?

Parents’ fears about physical or emotional harm are real. But protecting young people from reasonable risks robs them of an opportunity to become as independent as possible as they transition to adulthood. **The passage from childhood to adulthood for all of us involves the “dignity of risk”; the right to make mistakes and learn from them.**

The negative consequences of shielding young adults from taking risks can be more damaging than the consequences of an occasional mistake or failure.

To prepare for their independence, adolescents should be given opportunities to practice prior to adolescence. A child may want to spend 2 weeks away at camp, which might terrify parents. Allowing the child to spend weekends camping with friends or spending a few nights away from home visiting a relative could gradually in-crease confidence in her or his independence.

How To Get There…

Breaking a desired goal into **smaller steps** helps build confidence and supports families as they enter this tough transition to independence.

Have any of you had success that was a result of allowing your son or daughter to “take risks”?

While young adults are preparing to transition into the community, parents' needs for support and information may be as great or greater than they were when their child's disability was first diagnosed. The support of other parents who are facing the same decisions and risks can be very valuable. It may be time to reactivate old support groups or form new ones. Together with other parents, it is easier to find out about adult services, guardianship, SSI, wills and trusts. Most of all, parents need to share their feelings with people who understand their hopes and fears.

Let's not get lost, let's help each other! Raising these kids can be tough!

What you can do is often simply a matter of what you will do.

> **"That's why," said Azaz, the Mathemagician, "There was one very important thing about your quest that we couldn't discuss until you returned."**
>
> **"I remember," said Milo eagerly. "Tell me now."**
>
> **"It was impossible!" said the king, looking at the Mathemagician.**
>
> **"Completely impossible!" said the Mathemagician, looking at the king.**
>
> **"Do you mean…." stammered Milo, who suddenly looked a bit faint.**
>
> **"Yes, indeed." they repeated together. "But if we'd told you then, you might not have gone – and, as you've discovered, so many things are possible just as long as you don't know they're impossible."**

SOMETIMES THIS IS WHAT WE NEED TO REMEMBER – TAKE COURAGE!

Although it is especially difficult for you to allow and encourage your son/daughter with disabilities to strike out on his/her own, it is easier when preparations have been made in advance. You will be less traumatized if you view "loosening up" as a process and use transition planning to provide an approach that lays adequate groundwork for successful independence. As he/she moves toward adulthood and independence, you can encourage him/her to make choices and discipline yourself not to interfere. Even if you are afraid he/she may fail at some new task or be treated poorly by others, you must recognize that risk-taking is essential for his/her personal growth, ultimate well-being, and long-term happiness.

> ***"You may be disappointed if you fail, but you are doomed if you don't try."***
>
> *- Beverly Sills*

THE NEED FOR SUPPORT GROUPS

A diagnosis of a serious emotional disturbance in a child may produce a parental sense of loss of

- a dream of a good life for the child
- the sense of the child as healthy and whole
- the sense of competence to protect the child
- the sense of control over life
- the future as dreamed

A diagnosis of a serious emotional disturbance in a child may produce **normal** feelings of

- guilt
- anger
- fear
- isolation
- frustration

These feelings may be strange and frightening for parents and families.

The stresses which the child's mental health challenge creates for the family are:

Intellectual – to master massive amounts of new and complex information;
Practical – to find solutions to the day-to-day problems of arranging personal and family life around the child's condition and treatment;
Interpersonal – to create new relationships and adapt as old ones are disrupted;
Emotional – to respond to a threat to a child's future and a family's living pattern.

Families face many challenges:

To help the child cope with the disability and its treatment while meeting the everyday pressures of growing up;

To protect and promote the emotional well-being of both individual family members and the family as a whole;
To preserve normal relations with the family members' wider community of extended family, neighborhood, friends, school, and workplace;
To build mutually trusting and cooperative relationships with the mental health care team.

These challenges also present parents with an opportunity – an opportunity to respond with solutions, assistance, and interventions which will meet the needs of their child and family, the needs of other parents/families, and the needs of the professional community serving their families. One of the most effective responses in providing support and developing coping skills has been the creation of parent support groups.

THE NEED FOR PREVENTION PLANNING WITH TRANSITION-AGED YOUNG PEOPLE

What Is Prevention Planning?

- A prevention plan is a collaboratively determined set of responses to an impending or potential high-risk situation.

Why Do Prevention Planning?

- To identify specific behaviors and clarify consequences.
- To interrupt patterns of on-going high-risk activity.
- To help people identify desired support and interventions.
- To enhance self-empowerment and coping skills.
- To provide documentation of decisions and agreements.
- To strengthen individual and team accountability.
- To increase the effectiveness and coordination of a team's response.
- To increase the likelihood that a situation will be handled in a manner most satisfactory to all.

Who Should Be Involved?

- Young person.
- Transition facilitator or service coordinator.
- Desired and/or identifiable support persons.
- Members of the transition planning team.

When To Do Prevention Planning?

- When there seems to be anxiety or concern on the part of the young person or other key players.
- When the young person is choosing to engage in high-risk activities.
- When there is an impending high-risk situation.
- When there is an ongoing pattern of high-risk behaviors.
- When a plan will enhance individual self-monitoring and self-management.

What Does A Prevention Plan Look Like?

- Many different approaches – formal and informal.
- Plans include the following basic information:

  1. State the purpose of the prevention plan.
  2. Describe the situation, including critical or target behaviors, typical precursor, and/or personal triggers.
  3. Self-management coping strategies.
  4. External supports and clear specification of roles.
  5. Interventions/action plan, including teaching of skills.
  6. Conditions for hospitalization/incarceration/crisis placement.
  7. Agreement between the young person and all key players

RESOURCES

Bibliography for Dreaming New Dreams/Loosening Up

The Need for Prevention Planning with Transition-Aged Young People - *H.B. Clark adapted (2001) from Michael Curtis and Phil Wells.*

Prevention Planning Process - *H.B. Clark adapted (2001) from Michael Curtis and Phil Wells.*

SECTION 6:
DEVELOPMENTAL MILESTONES

WHAT ARE DEVELOPMENTAL MILESTONES?

Stages of adolescent development

Adolescence can be summed up in one word: change. Only infants grow and change as rapidly and extensively as do adolescents. Understanding adolescent development—how children mature between the ages of 9 and 21, how those changes affect their families and other people around them, and how the surrounding culture and society influences that development—is critical to planning and implementing programs that can give teens the tools and skills they need to make and carry out responsible decisions.

Although adolescence is often discussed as one phase, teens actually pass through three distinct stages on their path to adulthood—early, middle, and late adolescence. Specific physical, cognitive, and social and emotional developments mark each of these stages. The changes that occur and the timing of those changes differ for boys and girls and vary greatly among individuals. However, in general, early adolescence is from the ages of 9-13, middle adolescence is from 13-16, and late adolescence is 16 and older.

EARLY ADOLESCENCE (9-13)

Physical changes and characteristics

Early adolescence is marked by significant physical changes. Girls develop breasts, grow underarm and pubic hair, and begin menstruating. Boys develop deeper voices, grow underarm and pubic hair, and begin to show other physical signs of sexual maturity.

KEYS TO EARLY ADOLESCENCE

- Significant physical/sexual maturation
- Concrete thinking
- Increasing influence of peers
- Growing independence in decision making
- Transition from elementary to middle or junior high school.

In response to these physical changes, young adolescents—girls in particular—begin to be treated in a new way by their families and by society. As their sexuality becomes more apparent, girls begin to feel differently about themselves and they engender new reactions from those around them. They may no longer be seen as just children, but as sexual beings to be protected—or targeted. Parents may become overprotective or begin to allow greater freedom. These changes are complicated by the fact that girls mature at different ages.

Boys tend to receive less information about the physical changes that accompany their transition to manhood than do girls about their maturation. For example, school classes and parents will explain menstruation, but often leave out mention of wet dreams, erections, and ejaculation when talking to boys out of fear that these topics are too sexual or controversial. Boys may start to face pressure to differentiate themselves from their mothers and from female behavior. In addition, boys often face ridicule from peers if they are slower to develop physically.

Whatever the response from the people around them, girls and boys are treated differently as they move into adolescence. Because they look grown up, society has specific social expectations for how young men and young women should behave.

These pressures can be difficult for teens to deal with, especially without guidance and support from caring, competent adults.

To further complicate this transition, recent studies have found that for some girls, adolescence is starting earlier. While the aver-age age of onset of menstruation is close to 12.5 years, a small but growing minority of girls, particularly African American girls, are actually beginning to menstruate as early as age 8 (Marano, 1997).

For these children, the shift in how they are treated by the people around them may be even more difficult to cope with. Data from the National Longitudinal Study on Adolescent Health has found that looking older than one actually is constitutes a risk factor for early inter-course, although it does not place one at higher risk of teen pregnancy (Blum and Rinehart, 1997).

Cognitive changes and characteristics

Most early adolescents still think predominantly in concrete terms. They relate information and experiences to what they currently know and have a hard time thinking about the future or about things they have never been exposed to. Their ability to think abstractly—to project into the future and to understand intangible concepts—develops as adolescence progresses.

The fact that most early adolescents cannot think abstractly has important implications for program planning and necessitates different program approaches than would be created for older adolescents. For example, pregnancy prevention programs that ask early adolescents to picture what future opportunities would be lost by becoming a teen parent will not be very effective with young people.

WHEN DO DEVELOPMENTAL CHANGES HAPPEN?

Social and emotional changes and characteristics

In the early teen years, the values that children have learned from their parents begin to be tested by peers. Peers start to exert a stronger influence, and young teens will begin to be preoccupied with how their peers dress and behave. Young adolescents will start to experiment with their identity, trying out different ways of acting and seeing how people around them react to these various strategies.

Young teens also begin to enjoy more freedom by making decisions and may receive less ongoing supervision. Because they have little experience with the consequences of their actions, early adolescence can be a time when risks are taken unknowingly. These young teens may not appreciate the potential impact of their actions.

Young adolescents may also experience a transition within the school setting from elementary school to middle and junior high school. Middle and junior high school brings with it increased responsibility and independence for which some young people are not prepared. For some young teens, a difficult transition to middle school and an unsuccessful middle school experience increases the likelihood that they will drop out of school. This is associated with a higher risk of teen pregnancy. Young people experiencing difficulty in school merit special attention.

MIDDLE ADOLESCENCE (13-16)

Physical and cognitive changes and characteristics

Middle adolescents are portrayed most frequently in the media and thought of by most adults as the “typical teenager.” In this stage, the physical changes continue. Middle adolescents begin to develop the capacity to think abstractly, but it will be several years before those habits of thought are firmly established.

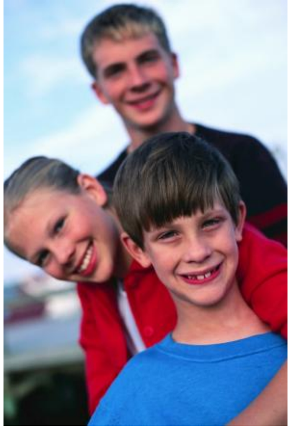
KEYS TO MIDDLE ADOLESCENCE

- **Continuing physical/sexual changes**
- **Intense focus on body image**
- **Beginning of capacity to think abstractly**
- **Enormous influence of peers/school environment**
- **Risk-taking**

One day, a middle teen is able to think long-term and project his or her thinking far into the future. The next day, he or she is back at a very concrete level, focused on the here and now, the day-to-day.

Social and emotional changes and characteristics

Teen girls, in particular, become extremely susceptible to the cultural messages they receive about appropriate body size and grooming. One observer of contemporary teen women comments: “In the twentieth century, the body has become the central personal project of American girls” (Brumberg, 1997). While a large percentage of American girls report dieting behavior as early as the 4th grade, middle adolescents sometimes develop eating disorders and other body image disturbances. Increasingly, boys in our society are also receiving pressure to look a certain way; some boys are also experiencing eating disorders and other body image problems.



HOW TO GET IT – MORE HELPFUL HINTS

Teens’ focus on physical attractiveness is heightened by the huge effect of peers on one another during this stage of development. Parents and their beliefs now may be secondary to the norms and pressures—both positive and negative—of a teenager’s peer group. Research has found that groups of friends have a greater influence than a best friend and that teens that choose positive peer groups fare much better than those who choose groups that may influence them to engage in negative behaviors.

Parents can also have an effect on how teens deal with friendships. An effective parenting style in helping to moderate peers’ influence is an “authoritative parenting style” that com-bines control and warmth (McIntosh, 1996) — that is, parents who maintain a close, warm relationship with their teen and who set and monitor reasonable limits for his or her behavior.

For many teens at this stage of development, school can become a less hospitable place. More than 80% of public school students in grades 8-11 said that they had been the recipient of unwelcome sexual comments or advances, usually from another student (Blum and Rinehart, 1997). More than 12% of students reported that they had carried a weapon to school in the past month (Blum and Rinehart, 1997).

This is particularly problematic because “school connectedness”—a student’s school attendance and perceptions that she or he gets along with, and is close to, teachers and students, and feels that other students are not prejudiced—can protect against many harmful behaviors, such as too early intercourse, emotional distress, suicidal thoughts and attempts, violence, cigarette use, alcohol use, and marijuana use (Blum and Rinehart, 1997). Young people who are being harassed or fear violence in school settings are less likely to remain connected, and feel positive about that setting, and are at risk for dropping out. This, in turn, puts young people at higher risk of early and unprotected sex.

TIPS FOR WORKING EFFECTIVELY WITH TEENS

- **Ensure that program staff are trained** in adolescent development, are comfortable with adolescents, and refrain from stereotyping teens.
- **Allow teens to develop outreach** and marketing materials for programs. This will en-sure that posters, flyers, and advertisements are in teen-friendly language and are culturally appropriate.
- **Appreciate the pressures** and issues faced by today's teens. Provide opportunities to discuss these broad struggles and not just the single issue on which a program focuses.
- **Be sure program hours are convenient** and that appropriate stipends, food, transportation money, or incentives are offered for participation.
- **Assure confidentiality to teens** and let them know up front if something cannot stay confidential. Teens are more likely to open up to adults when they trust that what they say or do will remain confidential.
- **Coordinate efforts with other youth-serving providers** to try to eliminate duplication of services, and to give young people the comprehensive information, skills, and opportunities they need to successfully negotiate adolescence.

Risk-taking is often associated with middle adolescence. Adults who work with youth must keep in mind that risk-taking behavior has positive as well as negative aspects. Adolescence is an appropriate time for trying new things and taking new risks. However, adolescents have often been portrayed as taking extreme, ill-considered risks. In fact, research shows that adolescents are about as good at assessing the actual risks of a situation or action as are their parents. This recent work suggests that helping parents to be better judges of risk will also help young people.

LATE ADOLESCENCE (16-21)

Physical, social, emotional, and cognitive changes and characteristics

Late adolescence is often thought of as early adulthood in our culture. Teens in this stage are beginning to take on adult roles and responsibilities and may be living independently from their families. The physical changes of adolescence are complete. At this stage, family influence comes into balance with messages from peers. Most late adolescents have developed a sense of identity and a sense of both their similarities and their differences from parents. Late adolescents are firmly rooted in abstract thinking. They are thinking about the future and functioning cognitively as adults.

WHY SHOULD WE KNOW ABOUT DEVELOPMENTAL MILESTONES

It takes our youth longer to achieve success, in most cases. We must start earlier and plan ahead if our youth are to face adulthood prepared.

WORKING IT OUT: LEARNING TO NEGOTIATE WITH YOUR TEENAGER

Checkpoints for Successful Negotiation

1. Communicate clearly
2. Respect the other person
3. Recognize and clearly define the problem
4. Seek solutions from a variety of sources
5. Collaborate to reach a mutual solution
6. Be reliable
7. Preserve the relationship

Negotiation is a Process

Negotiation is one of several ways to resolve conflict. It can be used when parent and teenager have taken a position on an issue. Negotiation is the process by which conflict can be re-solved so that both parent and teenager feel like they have achieved a solution.

Problem-solving negotiation is:

- Listening and understanding
- Having concern for the relationship
- Satisfying the interests of both sides
- Inventing new options
- Reaching an agreement based on fairness.

Common areas for negotiation with teenagers are:

- Money
- Grades
- Transportation
- Recreation
- Convenience
- Clothing
- Chores
- Social manners

Topics included in negotiation are chosen based on a child's skill level and maturity level. The frequency of negotiation increases as a child grows older. During late adolescence almost all rules may be negotiated, with the parent maintain a few rules that won't be negotiated. The teen is trying to break the walls to independence and may push against some of these rules.

Communication is Key

The key to effective negotiation is clear communication. Communication involves three important skills: speaking, listening and understanding. Negotiation doesn't work using just one of these skills. For example, you can't have good understanding without good listening and speaking. Negotiation is most effective when both parent and teenager are able to clearly identify and discuss their sources of disagreement and misunderstanding.

When you assume that you know what someone is going to say before he says it, you increase the chances of misunderstanding what he really does say.

Effective negotiation is a two-way process that encourages both sides to participate in making decisions. It also provides a way for parent and teenager to learn to understand each other better and to grow in their relationship. Negotiation helps create a healthy balance between giving and getting. Everyone becomes a winner through negotiation.

R-E-T-H-I-N-K the Conflict

R-E-T-H-I-N-K
is a good way to remember how to approach conflict and to begin negotiating

R **Recognize** when you're angry. Learn to help yourself relax.

Parent rethinks it:

What are my body's anger signals? Do I experience increased heart rate, muscle tension, upset stomach, and/or headache? What other feelings am I having that my anger may be hiding? Do I feel hurt, stressed embarrassed, scared?

What can I do to help myself cool down?

- Step back and take a deep breath before reacting.
- Tell yourself things like, "It's okay. Take it easy. I can handle this."
- Count to 10.
- If necessary, take a break, walk away, listen to music, chill out in your own way, and THEN deal with things.

E **Explain** the situation from the other person's point of view; empathize.

Parent rethinks it:

What is my teenager thinking? Feeling?
When I was a teenager, did I ever feel that way?
If I was in my teenager's shoes, how would I react?
What else might be going on in his/her life that may be contributing to the problem?

Teen rethinks it:

What is my parent thinking? Feeling?
If I was a parent, how would I feel?
What would I do if I was a parent in this situation?
What else is happening in Mom's or Dad's life that makes this problem difficult?

T **Think** about how you may be contributing to the problem.

Parent rethinks it:

Can I look at this situation in a different way? Can I find some humor in it?
What am I thinking about when I'm angry? Are my thoughts feeding my anger?
What else is happening in my life that might be contributing to the problem?
Is this a battle worth fighting, or should I let this one slide?

H **Hear**, really hear, what the other person is saying. Listen to the feelings as well as the words.

Parent rethinks it:

How can I be sure I understand how the other person feels and show that I do?

- Give the other person your full attention, lean forward, make eye contact, and don't interrupt.
- Test how well you understand the other person's point of view by putting his/her ideas into your own words, asking questions as necessary.
- Listen for the emotions, not just the thoughts. Say, "I can tell you feel…"

I **Include "I"** statements. Use sentences that begin with "I feel… when…" to explain how you feel.

Parent rethinks it:

How might stating my feelings help the situation?
How would a sentence that starts with "You…" make someone feel?

N **Negotiate** to try to work things out to everyone's satisfaction.

Parent rethinks it:

Have I considered how I may have helped create the problem? What might I do to help fix things?
What can I reasonably ask of the other person to help the situation?
How can I figure out a solution or compromise?

Steps of negotiation:

- Explain your position as calmly and simply as possible.
- Listen, and be sure you understand the other person's point of view.
- Don't make demands, lecture, or bring up old grudges.
- Suggest and discuss some options with which you can both live.
- If all else fails, take a break, or agree to disagree.

K Show **kindness** even when expressing anger. You can get something off your chest without trying to hurt the other person.

Parent rethinks it:

Can I say something positive about the person or the situation with my negative feelings?
Is my tone of voice calm?
Am I avoiding sarcasm and put-downs?

Can I use a sense of humor to lighten a tense moment?
Am I keeping in mind any outside issues that may be affecting how we're both feeling?
Am I focusing my comments on the problem and not the person?

RECAP: INDEPENDENCE VS. INTERDEPENDENCE

ACTIVITY:

Need: One (1) ball of yarn

Role labels for: youth, parent, educator, friend, foster parent, case worker, therapist, doctor, job coach, sibling, extended family members, etc.

Group should be in a circle. Start with the youth holding the ball of yarn.

1. Holding on to the end of the yarn, the youth passes the ball to the person who they think is most helpful to them.
2. Holding on to that section of yarn, that person then passes the ball to who they think is most important to the child,
3. And so on, and so on.

At the end you should see a web-like structure that would show the importance of interdependence in this youth's life.

RESOURCES

The Theory of Negotiation

Bibliography

Jacobson, DonnaRae, Family Science Specialist and Les-meister, Marilyn, Leadership & Volunteer, *Working it Out: Learning to Negotiate with your Teenagers,* May, 1995

SECTION 7: TRANSITION TIMELINE CELEBRATION!!!

Each member of the class should bring a food item to share.

The worksheets from previous week should be completed so the Transition Timeline Checklist can be filled out. Using this as a guide, the members of the class will have this opportunity to develop your own timeline and transition plan.

After the Activity of filling out the Transition Timeline Checklist, have a CELEBRATION, eat, read the poem, and give out certificates.

TRANSITION TIMELINE CHECKLIST

STUDENT AGE	ACTION NEEDED	BY WHOM	BY WHEN
JUNIOR HIGH			
12 – 15	Include the following areas in IEP meetings: social skills, communication, functional math, functional reading, self-help skills, self-advocacy skills		
12 – 15	Develop and use a plan to increase responsibilities and independence at home		
14+	Obtain official identification card at the Driver's License Bureau, school or bank		
14+	Initial transition meeting as part of the IEP process Begin transition-related assessment process -identify vocational interest/abilities -identify vocational support needed Include activities such as -career exploration -job sampling -introduction to vocational training		
14+	Teach student to use public transportation		
14+	Begin the process of identifying community services that provide job training and placements		
15	Prepare job placement file with references and descriptions of acquired skills		
15	Initiate application to adult services agencies with lengthy waiting lists (i.e., DSPD)		
15	Consider summer employment/volunteer experience		
SENIOR HIGH			
16 – 18*	Contact Adult Service Programs:		
	1. Education and training (postsecondary)		
	2. Social Security disability programs (includes Medicare and Medicaid		
	3. Residential Services		
	4. Vocational		
	5. Recreational/Leisure Activities		
	6. Medical		
16	Make certain transition-related assessments and goals are part of the IEP		
16+	Investigate the need for a driver's license		
16-18*	Begin job-training at community sites and/or through Vocational Education Programs		
17	Begin to consider and research guardianship		
17	Review of IEP Transition Plan		
17-18*	Take ACT and SAT tests if applicable		
17-18*	Complete applications to colleges or other Postsecondary training if applicable		

18*	Develop a resume		
18*	Update transition-related assessments and goals on IEP		
18*	Establish needed health benefits		
18*	Develop long-term financial support plan		
18*	Update postsecondary plan in cooperation with adult service agencies to determine:		
	- Vocational direction		
	- Living arrangements		
	- Transportation needs		
	- Social/recreational/leisure needs		
	- Medical/health support		

Depending on extent of disability, some students will have until their 22nd birthday to accomplish transition goals.

CERTIFICATE

allies
with families

Growing Up Without Growing Apart: Finding Your Way To Your Child's Adulthood

This is to certify that

(insert name)

has completed
*"Growing Up Without Growing Apart:
Finding your way to your child's adulthood"*
(insert date)

______________________ ______________________

Ode to the Parent of an SED Child

The developmental milestones, the struggles, and finally the letting go,
This text has just the beginning of what you'll need to know.

Heart ache, heart break, possible seizures, and even threats of suicide,
You do what you can, learn more, and stand always by their side.

You smile, and you cry, sometimes not knowing where to turn,
Some think, how to give more discipline is all you need to learn.

Anger spurts, sibling issues, insurance forms and bills,
Not to mention therapy, hospitals and so many pills.

Sometimes the pressure mounts, and for the times you yell, you will do penitence.
George Washington didn't have this much trouble, with the Country's independence.

There's IEP's, 504's, and Person Centered Planning.
No one seems to know, you'd much rather be tanning.

All day, there are meetings, groups, educating case workers and even more,
Then with that darned token economy, tonight, you'll be supervising a chore.

Along with taking care of yourself, it never is quite done,
So remember along the pathway of life, one must take some time for fun.

Then when you're almost finished, just when you think you've made it through,
You're not sure if you're still parent, or the SED person is really you!

We hope you've learned and laughed and enjoyed these classes,
'Cuz, it's to YOUR success, that we really raise our glasses.

Nancy Dollmeyer, Parent
Family Advisory Council

SECTION 8:
FOSTER CARE

What Is “Foster Care” Or “Out-Of-Home Placement”?

Foster care is 24-hour care provided by the child welfare system for children who need to move out of their own homes temporarily. If your child moves into foster care, she may live in one or more different types of placements, such as the following:

- Kinship care (placement with relatives)
- An emergency shelter
- A foster family home
- A therapeutic foster home
- A group home
- A residential treatment center, or
- An independent living arrangement for older youth

Many places use the term “foster care” when referring to any out-of-home placement.

Why Would My Child Be Placed In Foster Care?

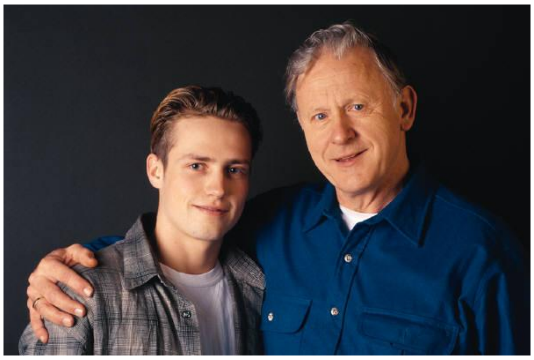
Here are several possible reasons:

- *If the court determines that your child was abused or neglected in your home* by a parent or caregiver, it may transfer custody to the child welfare agency so that your child can live somewhere else. Generally, placement in foster care is temporary and intended to give you time to make the changes necessary for your child to live safely in your own home.

- In some states, *you might decide to place your child in foster care through a short-term, voluntary agreement* with the child welfare agency. You might do this for a specific reason, for example, if you entered inpatient hospital care for a short period and had no one who could care for your child during that time.

- *If your child has a very serious emotional disturbance or disability, you might turn to the child welfare system* to provide and fund the services your child needs. This happens sometimes when parents have exhausted all possible community-based services that they can afford, and they cannot find or pay for intensive treatment services for their child. Several states have found ways to help children get intensive treatment services without involving the child welfare agency.

- *If you or someone else thinks that your child's behavior is beyond your control, the court can be petitioned to order services for your child and family.* Examples of out-of-control behavior include running away, refusing to go to school and serious sub-stance abuse problems. Utah allows placement in foster care for this reasons. The terms that are used to describe children and youth who fall into this category is ungovernable.



Who Are The People Who Will Take Care Of My Child?

- They might be a *relative (kinship care) or a close friend.* This can happen if you have suggested it, and the relative and the agency and/or court agree that it is a good plan and a safe placement for your child.

- They might be a *foster family* that you may not know. All foster parents must meet certain standards set by the state to help ensure that children will be safe and cared for. Most foster parents have been trained to understand the special needs of children who live away from their families.

- They might be *staff who work in a group or residential setting.* Group care facilities must be licensed, and staff must meet standards set by the state.

What Information Do I Need To Give To The Child Welfare Agency About My Child?

You know your child better than anyone else. When your child is being placed in foster care, it is very helpful for you to share important information about her with the child welfare agency and the people who will care for her. It is important to provide information about the following:

- Your child's daily routine and special needs (e.g., what food your child likes/dislikes)
- School placement and progress
- Your child and family's medical history
- Special care your child has received or needs
- Upcoming medical appointments
- Names of health care providers your child uses
- Allergies your child has
- Medications your child is taking

- Special treatment for developmental or behavior problems
- Information about your child’s close friends
- Names of family members and close friends who can help
- Anything else that will help meet your child’s needs and make the adjustment to a new home easier

Before you give any original documents, be sure to keep a copy. When your child returns home, all original documents that you shared with the child welfare agency should be returned to you.

Who Advocates For The Best Interests Of My Child?

Someone will be appointed to represent your child’s best interests. This could be any or all of the following:

- A guardian ad litem (GAL),
- A separate lawyer for your child, or
- In some states a court appointed special advocate (CASA).

What is a guardian ad litem?

Federal law requires states that receive federal funds for preventing child abuse and neglect to provide your child with a guardian ad litem. This is usually, but not always, a lawyer. Sometimes a trained volunteer acts as a GAL. The GAL will be a different lawyer from yours. The GAL’s job is to meet with your child and to tell the court what he believes is best for your child. The GAL may ask you questions about your child and about yourself.

What does independent living mean?

Independent living refers to a type of placement and also to a type of service for youth who become adolescents in the foster care system.

Independent Living Placement – Older youth who leave the foster care system to live on their own move into independent living situations, for example, an apartment. This includes youth who leave foster care who do not return to their own families, are not placed with relatives or guardians, and are not adopted. Some older youth, who are still in state custody, also live in independent living placements.

Independent Living Services – These services are provided by child welfare agencies for youth in foster care to help them prepare to live independently. They often focus on skill areas such as the following:

- Money management
- Locating housing

- Transportation
- Career development
- Job hunting
- Maintaining employment
- Daily living skills
- Communication skills

Other support services such as financial aid, health and mental health services, substance abuse prevention, and education or training are intended to help youth live in-dependently. Services to prepare for living independently are most helpful when they begin at an early age.

When is a youth considered an adult and ready to leave the foster care system?

Some youth in foster care move into independent living because they are too old to remain in foster care. This is called “aging out.” The age when this happens depends upon what state you live in. In some instances, youth can remain in foster care to age 21. To stay in foster care until age 21, a youth usually has to be involved in a training or an education program (such as technical school or college), have special needs, or live in a special treatment facility.

Will the child welfare agency help prepare my youth for independent living?

Yes. It is very likely that the agency will offer independent living services. A federal program, the Chafee Foster Care Independence Program, makes resources available to various states to support youth who live independently. Utah currently has a transition to adult living task force that is focusing on preparing youth for independence.

If the agency offers independent living services to my youth, does this mean it will not try to find a permanent home for him?

No. A decision to provide independent living services does not relieve the state from trying to make reasonable efforts to find a permanent home for any youth.

If my youth receives independent living services, can he still return home?

Yes. The law says that independent living services should be seen as services to help young people transition to adulthood regardless of where they live when they leave foster care.

How many youth leave foster care to live independently?

About 19,000 youth nationwide and approximately 200 in Utah leave the foster care system each year because they have reached the age of 18 and are expected to support themselves.

How can I help make improvements in the child welfare system?

Families are encouraged to express their views on how the child welfare system is working. When you feel that you are ready, you can start by asking the agency worker if there is an opportunity to fill out a satisfaction survey or to participate in a focus group. You can express your interest in becoming a member of an advisory group that meets with agency staff.

Allies with Families is a statewide family organization that you can join. As a member of Allies, you will have a group voice. Allies with Families offers support, education, training, and advocacy to families and advocates for improvement in service systems.

RESOURCES

Bibliography for Foster Parents:

A Family's Guide to the Child Welfare System: A Collaborative Effort Among the National Technical Assistance Center for Children's Mental Health at Georgetown University, Center for Child and Human Development; Technical Assistance Partnership for Child and Family Mental Health at American Institutes for Research; Federation of Families for Children's Mental Health; Child Welfare League of America, and the National Indian Child Welfare Association.