

# **MY DREAMS...MY PLAN...MY FUTURE**



**A SELF-DETERMINATION TOOLKIT FOR  
LIFE AFTER HIGH SCHOOL**

## **ACKNOWLEDGMENTS**

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## INTRODUCTION

All of us share a desire to live the most productive and fulfilling lives possible. When we apply the concept of **self-determination** to that desire, it means that we want to play an active role in shaping our lives.

Self-determination, defined as “a person’s ability to control his or her own destiny,” is a significant change from an approach in which decisions for persons with disabilities were made by professionals with little regard for the person’s own desires and hopes for the future. Self-determination encourages the development of attitudes, skills and knowledge that empower the person with the disability to control, as much as possible, his own destiny.

Although self-determination initiatives have traditionally focused on individuals with learning disabilities, they have also proven effective for young people with a much wider range of disabilities. As you and your teenager begin the process of **transition planning** (planning for life after high school) – you will participate in developing his **Individualized Education Plan** or **IEP**. You will work with teachers and other members of what will become a “transition team,” and your child will understand from the beginning that it is *his* IEP, and that *his* input about *his* future will be solicited, listened to and respected every step of the way.

The following characteristics are hallmarks of self-determination, and are qualities your child can develop as he becomes an active participant in creating his IEP:

### **Attitudes and Beliefs**

- ✍ Self-confidence
- ✍ Self-esteem
- ✍ Feeling valued by others
- ✍ Internal Locus of Control
- ✍ Determination
- ✍ Positive Outlooks

## **Skills**

- ✍ Goal setting
- ✍ Decision-making
- ✍ Self-Advocacy
- ✍ Problem-solving
- ✍ Self-regulation
- ✍ Social
- ✍ Communication
- ✍ Independent living

## **Knowledge**

- ✍ Knowledge of self
- ✍ Knowledge of resources and the system
- ✍ Knowledge of rights and responsibilities
- ✍ Perceived Options\*

We have designed this Toolkit as a resource to support self-determination in planning for life after high school. In addition to articles for parents, it contains numerous exercises that will facilitate direct participation in mapping out the future, giving him or her ownership of both the process and the outcomes. Each of these worksheets and questionnaires can be identified by the 'my worksheet' logo  in the upper right-hand corner of the page. You might want to make copies of these (and preserve the originals) so your son or daughter can repeat the exercises at yearly intervals. In some cases, we have presented the same material in more than one format in order to accommodate different learning styles and capabilities.

Not every part of the Toolkit will be applicable to every family or situation. We encourage you to adapt and adjust it to fit your needs by using just those sections that apply to you, and adding new materials and information you acquire throughout the transition process. We hope the kit will be a valuable resource for your entire family as you build self-determination into every aspect of planning, shaping, and achieving the life your son or daughter desires. (In the remainder of the Toolkit, we will use "he" and "him" to refer to the young person. This is done for the sake of simplicity and consistency, and is not meant to imply any gender bias.)

\*From "Self-Determination: A Critical Educational Outcome for Children and Youth with Disabilities" by Brian Abery, The University of Minnesota's Institute on Community Integration, 1999.



## HOW CAN SELF-DETERMINATION HELP ME?

Date \_\_\_\_\_

Name an experience you had when you were not in control; when someone else had control over something that was important to you.

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How did it feel NOT to be in control? \_\_\_\_\_

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Feelings we might have when we are not in control:

Powerless	Frustrated	Incompetent	Depressed
Angry	Belligerent	Helpless	

Name an experience you had when you were in control over something that was important to you.

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Feelings we might have when we are in control:

Powerful	Motivated	Excited	A little scared
Responsible	Alive		

**Think of self-determination as being in charge of your own life.**

Adapted from "Self-Determination: A Critical Educational Outcome for Children and Youth with Disabilities" by Brian Abery. The University of Minnesota's Institute on Community Integration, 1999.

# *Insights About Transition to Adulthood*

This is a summary of important ideas about transition to adulthood gathered from our project. Unfortunately, it doesn't really cover everything a family needs to know, but we hope that it will help put things in perspective. We've organized it into three major sections:

## **EMPOWERING FAMILIES**

Families need open, honest discussion and timely information presented in non-threatening ways.

## **DEVELOPING SUPPORT**

Real choices, changing relationships, and access to resources are the building blocks of a supported adult life.

## **BUILDING COLLABORATION**

Community networking is essential, especially when it involves adult role models.

## **EMPOWERING FAMILIES**

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**Families, including youth with developmental disabilities, need a significant amount of information about transition.**

- ✍ Visions of what is possible are limited to what is known and familiar. Information is power, whether it comes from a role model, peer mentor, book, teacher, etc.
- ✍ Families have varying levels of comfort with getting, asking for, having or not having information. In addition, families have limited and inconsistent access to needed information about:

- ✍ Special education options and methods, such as community-based instruction, appropriate placement, etc.
  - ✍ IDEA, transition planning, and IEP's
  - ✍ Civil rights, the independent living movement, and disability culture
  - ✍ Adult service systems, especially Vocational Rehabilitation
  - ✍ Supported employment
  - ✍ Assistive technology for communication and mobility
  - ✍ Housing and supported living options and
  - ✍ Techniques and creative avenues for handling bureaucratic obstacles
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- ✍ Information is especially lacking in rural communities and in Spanish and other languages.
  - ✍ In general, families from Hispanic, Native American, and other non-dominant cultures feel less informed and less confident about securing supports outside the family.

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**Families need to receive information in a personalized way, at the pace, complexity, and timing that matches their lives.**

- ✍ While each family has different needs about time of day, format, and pace of learning, many people learn best through examples and role models. Everyone needs to be able to relate new information to information they already understand or have experience with.
- ✍ Families of youth with developmental disabilities tend to have very full lives, making it hard to find time to plan ahead. A major family event such as a wedding, illness, surgery, etc., can mean that a family will have no time or energy available for transition planning for months at a time.
- ✍ Crisis points in the transition process are opportunity times when information is sought and best assimilated. Faced with an important decision, every family will want to make the best choice possible.
- ✍ In retrospect, families almost always wish they had started transition planning earlier, even if they literally had no time or resources to do so.

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**Parents and other family members need to express their concerns and fears, and have them addressed in the transition planning process.**

- ✍ Fears that are discounted or unrecognized can become exaggerated.
- ✍ Fears are based on real needs for physical and emotional safety that should be met with information, planning, skills development, mentoring, etc.

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**Support is seen differently in different cultures. Families that live in more than one culture can feel torn by these differences.**

- ✍ For example, some Native American tribes may see a disability as caused by a taboo broken by the parent during pregnancy.
- ✍ Many Hispanic/Chicano people strongly value support provided within the family, and feel that looking for support outside the family is difficult.
- ✍ Sometimes a family chooses to release or partially release deeply held cultural traditions or beliefs to pursue more supports.
- ✍ Some families prefer to maintain the values of their extended family and community even if it means accepting a more limited level of accessibility for the family member with a disability.
- ✍ It can be very difficult when a family feels caught between two cultures. In such situations, there are no right or wrong choices. Families need to be supported to make their own choices.

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**In some cultures, parents of children with disabilities may feel guilty about the disability.**

- ✍ Guilt can be like cement making it harder to let go. However, raising children, particularly children with disabilities, is hard, time-consuming work. Every parent deserves to look back at the successes of that good, hard work and be pleased.

## DEVELOPING SUPPORT

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**“Support” refers to a whole range of encouragement, equipment, activities, and systems designed to accommodate a person’s weakness or disability so that their abilities can flourish as they participate in every aspect of life.**

- ✍ Everyone needs support in their lifetime. Two examples are that everyone needs help at times with transportation, and many offices have a person whose job is to provide computer support for people who are computer-challenged.
  - ✍ Asking for help seems to be terribly difficult for most of us. It can even be culturally inappropriate to ask others for assistance.
  - ✍ If parents aren’t comfortable asking for help, their sons and daughters aren’t likely to be either.
  - ✍ Although many people in the community do want to help, offering support can be quite difficult when the help is not perceived as welcome or wanted.
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**Youth with developmental disabilities need to be asked directly and repeatedly for their opinions and preferences, and see real decisions incorporating their views.**

- ✍ Every person finds ways to communicate their likes and dislikes, joys and upsets, anger and caring. Everyone can communicate enough to have real control over decisions that affect their life.
- ✍ There are countless examples of people with developmental disabilities whose abilities have soared beyond expectations when someone persistently and thoughtfully raised those expectations. We can never fully know what another person is capable of, and we certainly won’t become aware without allowing the person to demonstrate, test, and grow in their capabilities.
- ✍ All of us spend years making mistakes and learning to make decisions on our way to adulthood. Teenagers with developmental disabilities have typically had many fewer such chances than their non-disabled peers.

- ✍ Encouraging a person through a learning process of making decisions and mistakes will over time lead to better decision-making.
  - ✍ Without those thousands of decision-making experiences, youth with developmental disabilities are likely to lack confidence, mistrust their own judgment, and expect their opinions to be disregarded.
  - ✍ Any person newly-empowered to make decisions will test to see if their choices will truly be respected.
- 

**The work of providing daily living supports is a role of parents that can be passed on to others to support the youth in becoming a self-directed adult.**

- ✍ This process is uncomfortable. It involves building a set of trusting relationships and taking real risks. Hired assistants can be unreliable. A person with a disability may not be clear about the difference between a friend and paid support staff. Close friends or family members will make different decisions than a parent might, and they can even turn out to be untrustworthy. But, these relationships can also work out beautifully.
- ✍ Long range planning is essential. Some parents think of transition planning as a way of planning for “retirement” from a part of the job of parenting. These parents will always care about and be involved in the lives of their adult children, but they can “retire” from the daily job of providing primary supports.
- ✍ Rather than feeling abandoned, most adults with disabilities who no longer rely on their parents for basic care feel relieved by this step and strongly recommend it. They want to have adult relationships with their parents that are not possible if they depend on them for daily living supports. This seems to be true regardless of the disability, as long as the support and companionships available really do meet the person’s needs.
- ✍ Starting early with this key process allows more time both for building good relationships and for building a person’s judgment about trusting others and getting help appropriately.
- ✍ Letting go can be painful. In practice, most letting go happens in the face of immediate consequences. Keeping that in mind, it is beneficial to do

advance planning whenever possible. Parents need to be forgiving of themselves. Knowing the next step does not always mean a person is ready to take it.

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**Youth with developmental disabilities need full access to communication and mobility, including community transportation.**

- ✍ Without access to communication and mobility, many youth with development disabilities will spend years of their adult lives watching television or attending day programs when they could be working in the community, living in their own homes, and building their own families.
  - ✍ Lack of access to communication or mobility is almost always a problem of empowerment. There are bureaucratic hurdles, to be sure, but assistive technology exists to accommodate virtually every disability, and legislative mandates exist for funding. If a family identifies this need early, a precedent can be established in elementary school, when the family can more easily exercise their rights. Families are likely to encounter real obstacles, but by refusing to be intimidated by culture, language, distance, pessimistic administrators, and other factors, then anyone can have access to mobility and communication.
  - ✍ Accessible public transportation is attainable using the same skills and strategies as other assistive technology, with one exception: a community must organize and advocate together for collective transportation needs to be met.
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**Persistence pays off in developing supports for employment and independent living. Many good resources are available, even if it's not always easy to find out about them.**

- ✍ Two of the largest and most important resources are the special education system and Vocational Rehabilitation, both of which are complex enough that families can easily feel intimidated trying to learn about them. Nonetheless, there are sources of clear information, including other people who have learned to work the system.

## **BUILDING COLLABORATION**

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**Families and communities both stand to gain enormously from increased dialogue between families, agencies, schools, business leaders, and other community partners.**

- ✍ If families and professionals knew about all of the existing resources, many more things would seem possible.
- ✍ Programs and service agencies generally don't realize how much they would benefit from welcoming people with disabilities and their family members as essential team members on their staffs and on decision-making boards.
- ✍ Parents rarely feel appreciated for their hard work, knowledge, and caring; instead they often feel criticized as “troublemakers” or “unconcerned.”
- ✍ Youth and adults with disabilities are not seen as capable experts and potential experts in a highly specialized field which needs to be responsive to them. They are misinterpreted, misinformed, and talked down to in meetings and planning groups because of differences in communication or decision-making style, and because of stereotypes.
- ✍ In spite of these barriers, one person can substantially improve collaboration for a person's transition planning or community when they decide to do so. Community partners often need and appreciate more information about each other, and they generally want to provide the best service they can.
- ✍ People wishing to support families need to be trustworthy and persistent.

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**Visible, credible role models are treasures for families in transition and their communities.**

- ✍ Parents benefit greatly from hearing the transition stories of adults with disabilities. A real person's story can ease a parent's fears/concerns about independence, transforming the looming unknown into specific problems to be solved. A role model can put a disability in perspective in the greater

human process of growing up, helping parents to understand their son or daughter's concerns.

- ✍ Youth benefit greatly from hearing the transition stories of adults with disabilities. A credible role model may do as much to awaken a sense of self-determination as any curriculum.
- ✍ Parents who hear transition stories from other parents can relax some of their fears and focus more on effective planning.
- ✍ Role models need to be realistic and accessible. They need to come in all genders, colors, locations, cultures, languages, vocations, with all disabilities. They need to be in person, on TV, on videos, in books, in the newspaper, in Braille, on tape, etc. Ideally, every youth with developmental disabilities would have at least one ongoing personal relationship with a believable role model who has a similar disability and whose life demonstrates something about what is possible for them.\*

\*Adapted from Desert Stars: Arizona Stories of Transition to Adulthood by Jenny Mish & Rena Bonesio, Pilot Parent Partnerships, 1998.

## IDEA AND TRANSITION

1975's Education of all Handicapped Children Act mandated a free and appropriate education for all children, regardless of disability. Fifteen years later the **Individuals with Disabilities Education Act (IDEA)** added the requirement of *transition services* to the education rights of all children, beginning at age sixteen.

This meant that every child's **Individualized Education Plan (IEP)** would include a statement of the transition services he would need to assist him in moving from school into employment and adult life in the community. The 1997 amendments to the IDEA *lowered* the starting age for transition planning from sixteen to fourteen, highlighting the importance of early planning in achieving the highest degree of success beyond the secondary school years.

Students should be encouraged to participate in educational decision-making and to sign documents and forms relating to the development of their IEP's. **However, at the age of majority, 18 years, legal rights transfer to the child.** Parental consent is no longer required. Unless you have established legal guardianship, your child will sign documents terminating educational services. It is important for you and your student to know and understand the legal implications for students who are age 18 and over.

This section covers the IEP and transition planning process, and outlines your role and your child's role in planning for his future.

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## **WHAT ARE MY RIGHTS AND RESPONSIBILITIES?**

People in the United States have many rights which are guaranteed to them by the laws of our country. One of these laws is the Individuals with Disabilities Education Act (IDEA) which gives certain rights to all students with disabilities age three through twenty-one. Under this law, you have the right to a free, appropriate education (FAPE) which includes the transition planning this Toolkit talks about.

There are other laws such as the Americans with Disabilities Act (ADA) which also apply to individuals with disabilities. As both a student and an adult, you have rights under the ADA as well as FERPA (Family Education Rights and Privacy Act), Section 504 of the Rehabilitation Act and the Vocational Rehabilitation Act.

All of us have the right to choose where we will live, what kind of work we will do, who we will see, and who we will live with. These are guaranteed by our laws and Constitution.

We also have responsibilities. We must obey the laws of our country which require us to pay taxes and obey traffic rules when driving.

At least one year before you reach the age of eighteen you must receive a written statement which tells you that the rights your parents now have will transfer to you when you reach the age of eighteen.

### **As an adult, you will have the same rights as any other person.**

Having a disability does not change or lessen your rights under the law. You have the right to a free and appropriate public education, the right to vote, the right to enter a public building, the right to use a public restroom, and the right to a minimum wage for your work.

### **Because you have rights, you also have responsibilities.**

You are responsible for speaking up for yourself in an appropriate manner, just as you expect others to speak to you. You have the right to speak up when you do not like something. You need to learn how to do so without becoming angry. You have a responsibility to learn about the choices which you can make and then try to make the best ones for you.

### **When you become an adult, you will have a right to certain information which others have about you.**

You are entitled to have copies of this information, to participate in meetings where decisions are made about your program and life, and to have your questions answered.

**You and your parents have a right to privacy and confidentiality.**

Except under very limited circumstances, schools, doctors, and other agencies cannot share information about you with others unless you or your parents have given permission by signing a consent form that explains why they will share the information and with whom.

**You and your parents have a right to due process.**

If you disagree with the educational program being offered to you, you or your parents have a right to have a due process hearing. You have a right to tell your side of the story before a hearing officer makes a decision.

**You and your parents have a right to notice.**

You must be informed of your rights and meetings must be scheduled at a time which is convenient for both you and the school.

**When you become eighteen, the law says you are a legal adult.**

If you are a male, you must register for the draft with the Selective Service, regardless of disability. You can also register to vote and are expected to represent yourself in legal matters, such as renting an apartment, getting a loan, signing a contract, or being admitted to a hospital.

When you reach eighteen, your parents are no longer legally responsible for you. You are responsible for yourself.

There may be times, however, when you need your parents to help with some legal responsibilities such as signing medical releases, handling your finances, or conducting personal business in your name. If someone else is going to represent you, they must have the legal right to do so. You may contact your state protection and advocacy agency to obtain the name of an attorney or advocate who can help you.

Adapted with permission from “Where Am I Going? How Will I Get There?” A publication of the Nevada Department of Education Educational Equity Team, Nevada Parents Encouraging Parents, and the Nevada Parent Network. 1997.

## **Helping Students Develop Their IEP's**

You know that your teenager is going to have an IEP (Individualized Education Plan), but you may be asking yourself the questions, “What do we do?” and “How do we begin?” The answers to those and many other questions are included in **Helping Students Develop Their IEP's**, a thorough, step-by-step guide to understanding and becoming actively involved in the IEP process.

**Helping Students Develop Their IEP's** is published by the National Information Center for Children and Youth With Disabilities (NICHCY) and is included in its entirety in **APPENDIX A at the end of this Toolkit.**

## **A Student's Guide to the IEP**



This companion piece, also published by NICHCY, is written specifically for the young person. In easy-to-understand language, it answers questions your son or daughter may be asking:

- ? What is an IEP?
- ? How can I help to create my IEP?
- ? Why do I need to be a part of the process?
- ? What do we do at my IEP meetings?

**A Student's Guide to the IEP** is included in its entirety in **APPENDIX B at the end of this Toolkit.**

## WHAT IS MY ROLE ON THE TEAM?

Transition planning is done as part of the Individualized Educational Program (IEP) and your participation is essential to any IEP meeting where your transition plan will be developed. Your parents or guardian will also be a part of this team. Your interests and preferences must be considered when the team makes decisions about transition services.

You play a key role on the team. This means using the information you have gathered to tell the team what you would like to have in your transition plan.

You have already begun to:

- ✍ think about what you want for your future
- ✍ take a look at yourself
- ✍ think about your goals and what you need to do to reach them
- ✍ look at the resources you may need after graduation if you are going to be independent
- ✍ gather your records and other information about yourself
- ✍ learn about programs, services and resources you may be able to use
- ✍ learn about your rights and responsibilities
- ✍ learn ways to speak up and be a self-advocate
- ✍ increase your ability to manage your own life

Adapted with permission from “Where Am I Going? How Will I Get There?” A publication of the Nevada Department of Education Educational Equity Team, Nevada Parents Encouraging Parents, and the Nevada Parent Network. 1997.



## HOW DID MY IEP MEETING GO?

DATE \_\_\_\_\_

You worked hard to get ready for the IEP meeting by learning to speak up for yourself and be a good team member. After the meeting is over, look at the following checklist to help you decide if the meeting went well.

	Yes	No
Were all the people you wanted at the meeting?	_____	_____
Did someone introduce you to everyone you did not know?	_____	_____
Did you get to ask questions?	_____	_____
Did someone answer your questions?	_____	_____
Did the other team members ask what you thought?	_____	_____
Did you talk about the things you like to do and what you want for the future?	_____	_____
Did the other team members listen to you?	_____	_____
Did you and your family, friends, and advocates help decide on the things that went into your transition plan?	_____	_____
Does your plan include goals for all the things that you think are important?	_____	_____
Does your plan say when goals should be completed?	_____	_____
Do you like your transition plan?	_____	_____

What goals will you be working on this year? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What did you like best about your IEP meeting?

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What did you wish had been different about the meeting? \_\_\_\_\_

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If you checked "YES" to many of the questions on the last page, your transition plan should be just what you wanted.

If you checked "NO" to many of the questions on the last page, then maybe the meeting did not go as well as you had hoped. Perhaps there are areas you have questions about or need more information about. You need to talk with your parents and the school team to let them know there are areas which need work.

Adapted with permission from "Where Am I Going? How Will I Get There?" A publication of the Nevada Department of Education Educational Equity Team, Nevada Parents Encouraging Parents, and the Nevada Parent Network. 1997.

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# Transition Checklist

The following is a checklist of transition activities that you and your son or daughter may wish to consider when preparing transition plans with the IEP team. Your student's skills and interests will determine which items on the checklist are relevant. Use this checklist to ask yourself whether or not these transition issues should be addressed at IEP transition meetings. The checklist can also help identify who should be part of the IEP transition team. Responsibility for carrying out the specific transition activities should be determined at the IEP transition meetings.

## Four to Five Years Before Leaving the School District

- Identify personal learning styles and the necessary accommodations to be a successful learner and worker.
- Identify career interests and skills, complete interest and career inventories, and identify additional education or training requirements.
- Explore options for post-secondary education and admission criteria.
- Identify interests and options for future living arrangements, including supports.
- Learn to communicate effectively your interests, preferences, and needs.
- Be able to explain your disability and the accommodations you need.
- Learn and practice informed decision making skills.
- Investigate assistive technology tools that can increase community involvement and employment opportunities.
- Broaden your experiences with community activities and expand your friendships.
- Pursue and use local transportation options *outside of family*.
- Investigate money management and identify necessary skills.
- Acquire identification card and the ability to communicate personal information.
- Identify and begin learning skills necessary for independent living.
- Learn and practice personal health care.

## Two to Three Years Before Leaving the School District

- Identify community support services and programs (Vocational Rehabilitation, County Services, Centers for Independent Living, etc.)
- Invite adult service providers, peers, and others to the IEP transition meeting.

- Match career interests and skills with vocational course work and community work experiences.
- Gather more information on post secondary programs and the support services offered; and make arrangements for accommodations to take college entrance exams.
- Identify health care providers and become informed about sexuality and family planning issues.
- Determine the need for financial support (Supplemental Security Income, state financial supplemental programs, medicare).
- Learn and practice appropriate interpersonal, communication, and social skills for different settings (employment, school, recreation, with peers, etc.).
- Explore legal status with regards to decision making prior to age of majority.
- Begin a resume and update it as needed.
- Practice independent living skills, e.g., budgeting, shopping, cooking, and housekeeping.
- Identify needed personal assistant services, and if appropriate, learn to direct and manage these services.

## One Year Before Leaving the School District

- Apply for financial support programs. (Supplemental Security Income, Independent Living Services, Vocational Rehabilitation, and Personal Assistant Services).
- Identify the post-secondary school you plan to attend and arrange for accommodations.
- Practice effective communication by developing interview skills, asking for help, and identifying necessary accommodations at post secondary and work environments.
- Specify desired job and obtain paid employment with supports as needed.
- Take responsibility for arriving on time to work, appointments, and social activities.
- Assume responsibility for health care needs (making appointments, filling and taking prescriptions etc.).
- Register to vote and for selective service (if a male).

## **COMMONLY ASKED QUESTIONS AND ANSWERS ABOUT TRANSITION SERVICES**

### **1. What are examples of post-school activities?**

The term *post school activities* describes what the student wants to do after high school: namely, where the student wants to live, work, recreate, and participate in his or her community.

### **2. What are the requirements regarding consideration of the student's "preferences and interests" when developing the transition services for the IEP? How are the student's preferences and interests determined?**

The student must have the opportunity to assert his or her preferences and interests during the IEP meeting when transition services are being considered. If the student doesn't attend the IEP meeting when transition services are discussed, the district must ensure that the student's interests and preferences are considered during the development of the statement of needed transition services. To accomplish this, the school district may use checklists and other relevant self-assessments, including personal interviews and situational assessments. Family members and peers can also provide information to assist in determining a student's preferences and interests.

### **3. Must each activity area be addressed at each annual review?**

Yes. Instruction, community experiences, employment and other post-high school adult living objectives, and, if appropriate, daily living skills and functional vocational evaluation must be addressed at each annual review.

### **4. What are the school district's responsibilities for inviting students to IEP meetings that address transition services?**

School districts are responsible for inviting students to their own IEP meetings. The invitation may be included in the parents' notification of the IEP meeting or it may be separate. Documentation of the student's invitation should be maintained in the student's record.

### **5. Are there any circumstances under which a student would not be invited?**

No. The rule clearly states that if a purpose of the meeting is to consider transition services for a student, the school district shall invite the student to attend the IEP meeting. The student and family may want to invite other participants of their choosing.

### **6. Which agencies should be invited to the first IEP meeting?**

School district personnel will have to rely on their best professional judgment and knowledge of adult agencies to determine which agencies to invite to the first meeting in which transition services are addressed. Copies of correspondence with invited agencies should be included in the student's records to document the invitation.

**7. What are participating agencies?**

Relevant agencies could include vocational rehabilitation centers, developmental disabilities and regional providers, employment service providers, community colleges, colleges and universities, and any other agency determined appropriate provide transition services for a student with a disability.

**8. May IEP meetings concerning transition services be conducted if parents are not in attendance?**

Yes. The IEP meeting may be conducted without the parent(s) in attendance if the school district is unable to obtain the attendance of the parents. The school district must have a record of its attempts to arrange a mutually agreed-upon time and place. If the parents cannot attend, steps shall be taken to ensure parent participation. Parent input on the IEP, including transition services, may be provided through face- to-face or telephone conferences, written correspondence, or other preplanning activities.

**9. What should the final IEP contain for a student with a disability?**

The last IEP developed before the student is expected to leave school must contain the goals and objectives that are appropriate for the one-year period of time during which the IEP is in effect. All needed interagency responsibilities or linkages should be included.

**10. Once a student is no longer the responsibility of the school, who is responsible for providing transition services?**

Designation of other participating agencies' responsibilities or linkages, or both, for providing services should be clearly stated in the IEP before the student leaves the school setting.

**11. Should needed transition services be identified when the services cannot be provided or are not available?**

Yes. Needed transition services must be identified on the IEP based on the individual student's needs, preferences, and interests. The IEP committee should identify a student's transition strengths and needs regardless of known or unknown service providers. The team should brainstorm for strategies to meet the identified needs.

**12. Do the transition requirements extend to students protected under Section 504, but not served under IDEA?**

No. Students protected under Section 504 are not required to have an IEP; however students who previously were 504 eligible may now qualify under IDEA. If they need specially designed instruction in transition services, they may qualify for IDEA and have only transition services on the IEP.

**13. How do you resolve differences between parent and student on post-school outcomes?**

Ultimately, the student's life goals are the ones being developed, and those should be given greater weight in the planning process. Attempts should be made, however, to achieve consensus through exploratory experiences and further discussions.

**14. Who decides what is actually written in the statement section on transition services? Who has the final decision?**

The student, family, school, and appropriate agencies must decide together what the content will be. A successful transition depends on all parties' working cooperatively to develop and implement the programs, services, and activities in the IEP:

Adapted from The Complete Guide to Special Education Transition Services by Roger Pierangelo and Rochelle Crane. New York: the Center for Applied Research in Education, 1997.

## Resources Related to IDEA

The most user-friendly format of the IDEA regulations can be found at the Texas Education Agency website. TEA put the regulations in a side-by-side format that includes the appropriate OSEP discussion, question or comment next to the relevant regulation. Realize that it is **300** pages.

[www.tea.state.tx.us/special.ed](http://www.tea.state.tx.us/special.ed)

NICHCY has information on the IDEA regulations as well as extensive additional information on conferences, services in different states, News Digests on related issues like assessment and inclusion.

[www.nichcy.org](http://www.nichcy.org) or call 1-800-695-0285

IDEA '97 -Office of Special Education Programs (OSEP) Information ranges from general background and Q&A to speeches, articles and the regulations.

[www.ed.gov/offices/OSERS/IDEA/](http://www.ed.gov/offices/OSERS/IDEA/)

FAPE (Families & Advocates Partnership for Education)

Varied information related to special education; juvenile justice; information in Spanish.

[www.fape.org/](http://www.fape.org/)

IDEA Practices (Council for Exceptional Children, CEC)

Calendar of events and news briefs; ideaLA W; Q & A about the regulations and effective practices; new and useful resources on subjects from adapting language arts and science materials for the inclusive classroom to Safe Schools-Safe Students to Testing Students with Disabilities.

[www.ideapractices.org/](http://www.ideapractices.org/)

To order a copy:

1. Call EDPUBS to request a printed copy at (877) 433-7827 or TTY (877) 576-7734
2. Write the Government Printing Office, Supt. of Documents, PO Box 37195-7954, Pittsburgh, PA 15250 (\$8)

It is also available in alternative formats from the Alternate Format Center, (202) 260-9895.

Arizona Department of Education

Information about the general curriculum for all students with links to district or charter school sites, information about AIMS or Arizona school report cards, etc. From the home page, click on School Support programs, then Exceptional Student Services for information related to IDEA and other special education topics.

[www.ade.state.az.us/](http://www.ade.state.az.us/)

# Resources Related to Section 504 and the Americans with Disabilities Act (ADA)

## **Comparative Analysis of IDEA, Section 504 and the ADA**

Addresses how schools are covered, eligibility, evaluation and reevaluation, special education and related services, LRE, physical accessibility, procedural safeguards, and enforcement.  
[www.at-advocacy.phillynews.com/misc/cohen2.html](http://www.at-advocacy.phillynews.com/misc/cohen2.html)

## **Section 504 and IDEA: Basic Similarities and Differences**

[www.ldonline.org/ld\\_indepth/  
legal\\_legislative/edlaw504.html](http://www.ldonline.org/ld_indepth/legal_legislative/edlaw504.html)

## **Section 504 and Education**

Information provided from the US Department of Education.  
[www.ed.gov/offices/OCR/ocr504.html](http://www.ed.gov/offices/OCR/ocr504.html)

## **504 Resources, Council of Educators for Students with Disabilities, Inc.**

Section 504 Overview, 504 Q & A -information aimed at educators  
[www.504idea.org/504resources.html](http://www.504idea.org/504resources.html)

## **Meeting the Needs of All Students Section 504**

Over 40 pages of information on Section 504 from PACER Center  
[www.pacer.org/parent/504.html](http://www.pacer.org/parent/504.html)

## **How to File a Complaint with OCR**

[www.hhs.gov/progorg/ocr/504file.html](http://www.hhs.gov/progorg/ocr/504file.html)

## **ADA National Access for Public Schools Project**

Information on nondiscrimination and effective communication, private schools, program accessibility, transportation, and miscellaneous  
[www.adaptenv.org/schools/qanda.asp](http://www.adaptenv.org/schools/qanda.asp)

## **ADA Technical Assistance Program**

Info from the regional centers funded by the Department of Education on ADA  
[www.adata.org/text-home.html](http://www.adata.org/text-home.html)

## **PACER Center -Information on 504 and ADA**

PACER has the ADA Q & A Series: The Rehabilitation Act and the ADA Connection, How can I help my son or daughter get that job?, Section 504 and postsecondary education, ADA & FMLA, Child care providers, How to file a complaint, Health care providers, **Back to School, and ADA and Transition.** On the Project Pride page, scroll down for the list of ADA Q & A topics.

[www.pacer.org/pride/pride.htm](http://www.pacer.org/pride/pride.htm)

[www.pacer.org/pride/trans.htm](http://www.pacer.org/pride/trans.htm)

## **ADA Site -AU Issues**

The sites listed above relate to school issues. This is the main ADA site.  
[www.usdoj.gov/crt/ada/adahoml.htm](http://www.usdoj.gov/crt/ada/adahoml.htm)

## **ADA Information Line**

For publications, questions and referrals  
1-800-514-0301.

## **Raising Special Kids**

Families Helping Families  
(602) 242-4366 in Arizona  
1-800-237-3007  
[www.raisingpecialkids.org](http://www.raisingpecialkids.org)

## **Additional Local Resources**

**By calling the main number for each organization listed below, you can get contact information for local branches located throughout Arizona.**

### **Division of Developmental Disabilities**

Phoenix – (866) 229-5553

### **Vocational Rehabilitation Services**

Phoenix – (602) 255-5641

### **Behavioral Health Authorities**

Maricopa County – 1-800-564-5465

### **Arizona Center for Disability Law**

(602) 274-6287

### **Independent Living Centers**

Arizona Bridge to Independent Living 1-800-280-2245

DIRECT 1-800-342-1853

New Horizons (520) 772-1266

SMILE (520) 329-6681

Assist to Independence (520) 283-2959

# GETTING TO KNOW ME

In identifying a person’s preferences, capacities and aspirations, Beth Mount challenges us to move away from a system-centered approach and toward a person-centered approach. This approach emphasizes getting to know the person and helping him build a community life where he is fully valued and can share his capacities with others:

## **System-Centered**

- Focus on labels
- Emphasize deficits and needs
- Invest in standardized tests and assessments
- Depend on professionals to make judgments
  
- Generate written reports
  
- See people in the context of human service systems
  
- Distance people by emphasizing differences

## **Person-Centered**

- See people first
- Search for capacities, gifts
- Get to know the person
- Depend on families, friends and service workers to build good descriptions
- Gather folklore from people who know the person well
- See the person in the context of his community
- Bring people together by discovering common experience\*

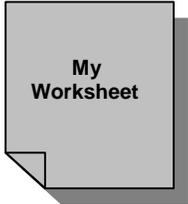
This section will help you determine your young person’s ‘total picture’ – his skills, interests, preferred environments, and the relationships he’s developed. The exercises offer different ways of finding *patterns* or *themes* among his preferences. These will provide a foundation for identifying the resources, actions, and support systems that he and his support circle will need in order to create an achievable vision for his future.

Section contents:

Who Am I? Questionnaire.....	29	
Forming My Capacity Description.....	32	
Preferences Map.....	35	
What Makes a Friend?.....	37	
Support Circle Map.....	38	
Strengthening My Support Circle.....	40	

\*From Person-Centered Planning by Dr. Beth Mount. Published by CAPACITY WORKS, PO Box 271, Amenia, NY. 12501-0271. (888) 840-8578 or in NY state (845) 373-4218.

# WHO AM I?



Date \_\_\_\_\_

The following questions are about you, who you are, and what you like. Think about the people you know and who know you, the skills and abilities you have, and the dreams you have. Take time to think about your answers. Discuss them with family, teachers, and friends. The choices are yours, but the people around you may have some important information to give you.

I am good at:

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I am not so good at:

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I like doing these things:

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I learn best when:

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These are ways I have already become independent:

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I would like people to know that:

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Before I finish high school, I would like to learn these things:

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These people are some of my friends:

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Phone \_\_\_\_\_

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Phone \_\_\_\_\_

---

Phone \_\_\_\_\_

These are some of the people who know the most about me:

\_\_\_\_\_ Phone \_\_\_\_\_

\_\_\_\_\_ Phone \_\_\_\_\_

\_\_\_\_\_ Phone \_\_\_\_\_

If I need help, I can ask these people:

\_\_\_\_\_ Phone \_\_\_\_\_

\_\_\_\_\_ Phone \_\_\_\_\_

\_\_\_\_\_ Phone \_\_\_\_\_

You will need to work with your family or someone at school to get the information you need to answer the following questions:

My disability is: \_\_\_\_\_

I need these accommodations \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

My learning style is: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

I know I can succeed when I use these strategies: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Forming a Capacity Description

Use these lists to help your young person identify his preferences. Choose items in each section that apply to your child, and fill them in the boxes on page 35.

### **Skills, Potential Skills, Interests.** Patterns to look for include:

Using hands: assembling, using tools, fixing, repairing, building  
Using one's body: being physically active, outdoor activity  
Using helpfulness: being of service, showing sensitivity to others, drawing people out  
Using artistic abilities: singing, fashioning, shaping things, dealing with colors, conveying feelings through body, face or voice  
Using analytical thinking: organizing, classifying, putting things in order, comparing evaluating, reviewing  
Using leadership: selling, promoting, persuading, leading, directing, beginning new tasks  
Using follow-through: using what others have developed, attending to details, recording, filing, classifying

### **Social Identities that are Important to the Person and Family.** Themes to look for:

Trade or work identities: being a teacher, lawyer, repairperson, restaurant worker, nurse, construction worker, beautician  
Ethnic and religious identities: African American, Asian, Hispanic, Irish, Jewish, Native American  
Interest identities: sports, music, sewing, singing, politics, bird watching, collecting, motorcycles, animals, beauty  
Appearance identities: uniforms, badges, name tags, formality or informality of dress, grooming standards

### **Environments and settings that seemed to resonate with the person.**

Noise and commotion levels: quiet places, busy places  
Ethnic places: places where people speak the same language, share similar beliefs, celebrate similar rituals  
Familiar places within walking distance, places where people know you  
Standards of efficiency and perfection: uptight, real loose, busy, laidback, repetition or variety of tasks

### **Personal characteristics that will shape community participation.** Characteristics to consider:

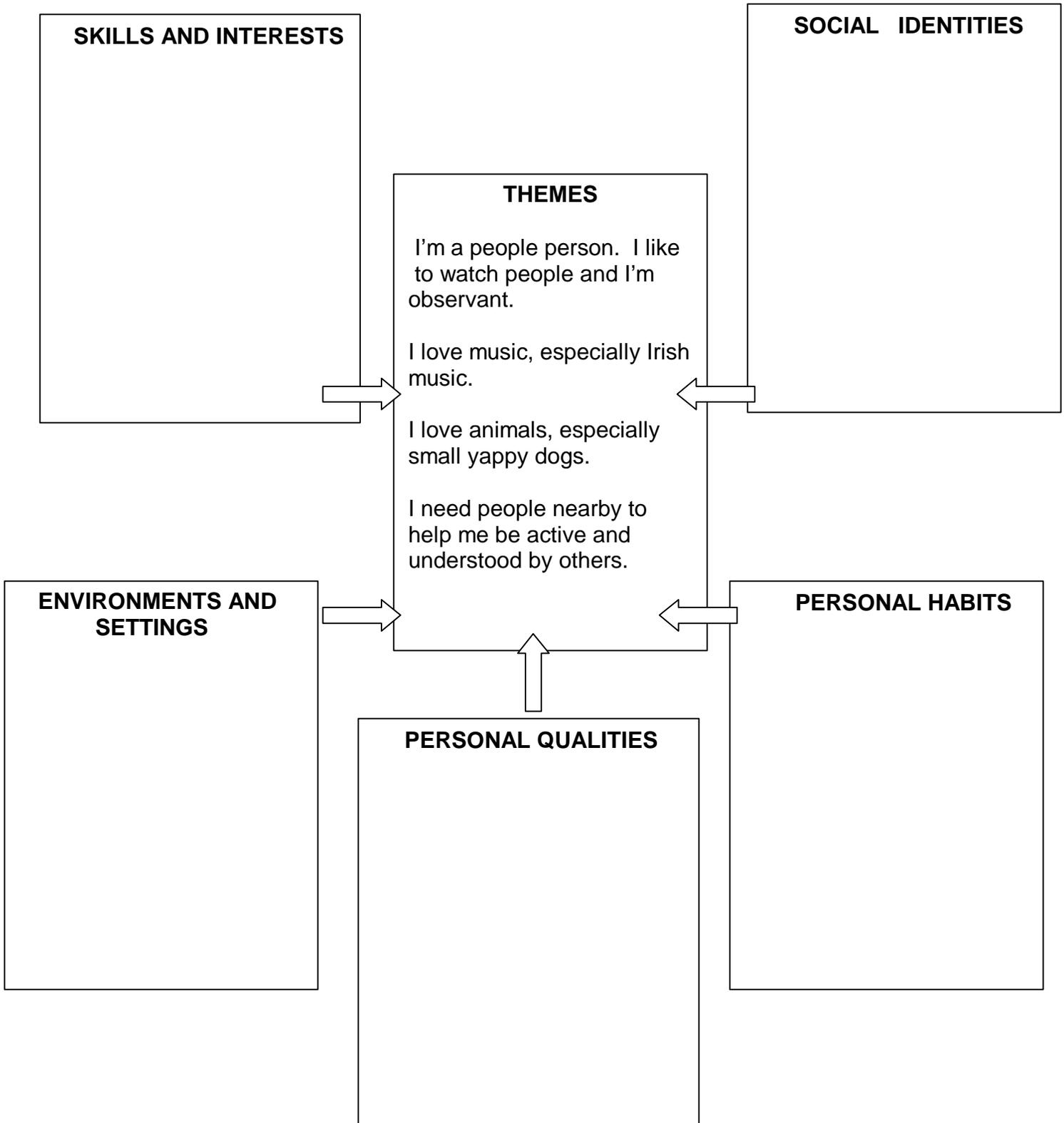
Activity levels: morning person, night person, high energy, sedentary  
Health issues: medication, stamina, side effects  
Disability issues: sensory and physical impairments and adaptations  
Structure preferences: high or low structure, fixed or flexible routines

### **Personal Qualities to appreciate and enhance.** Qualities to recognize include:

Essence: observant, calm, funny, loving, caring, energizing, kind, "brings out the best in others," gentle, provocative, smart, sensitive, effusive, tolerant.  
Ancient self: wise, spiritual, challenging, activist, seeker, rebel, warrior, peacemaker, protector, teacher, preacher

\*From Life Building: Opening Windows to Change by Dr. Beth Mount. Published by CAPACITY WORKS, PO Box 271, Amenia, NY. 12501-0271. (888) 840-8578 or in NY state (845) 373-4218

**Sample** – Look at the items in the five lists and see what “themes” emerge. This is just one way to create a “picture” or “map” of your young person’s preferences.

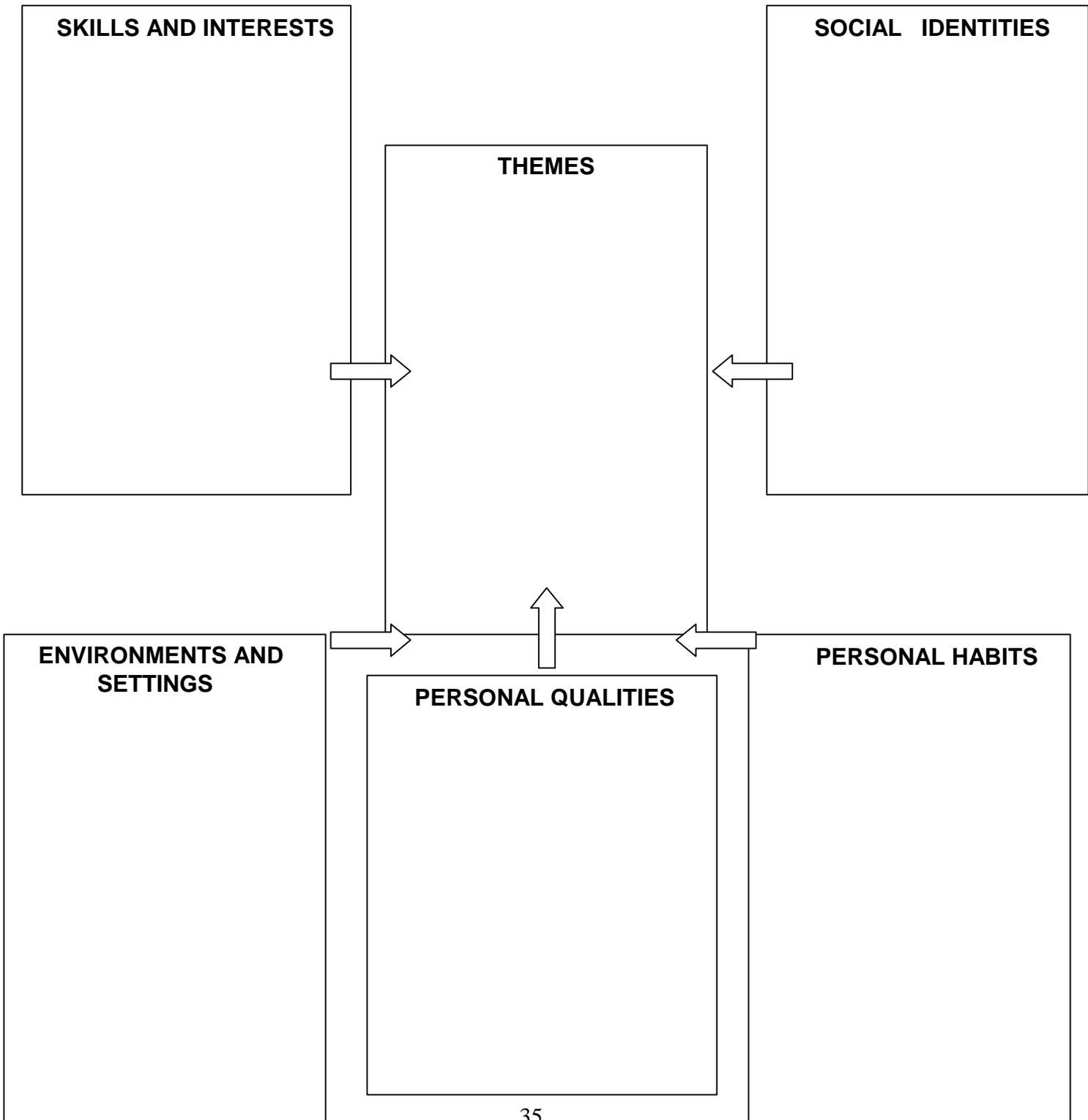


# Forming a Capacity Description



Date \_\_\_\_\_

This is one way to create a “picture” of your likes and dislikes.



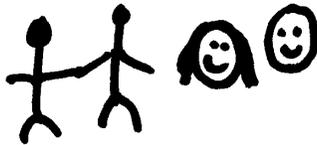


## PREFERENCES MAP - SAMPLE

**Things that work:**  
things that create interest and  
engagement



music and dancing

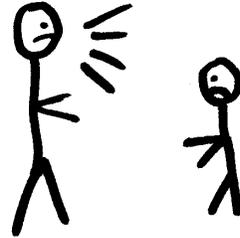


getting together with friends

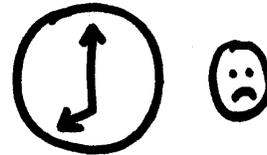


work and getting paid

**Things that don't work:**  
things that create frustration  
and upset.



being told what to do by adults



being late



when people don't listen to me

Reprinted with permission from *Self-Determination for Youth with Disabilities: A Family Education Curriculum* by Brian Abery et.al, University of Minnesota's Institute on Community Integration, 1994.



## Preferences Map

Date \_\_\_\_\_

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Draw a picture of things you enjoy

Draw pictures of things that  
make you upset or frustrated



## What Makes a Friend a Friend?

Here are some reasons that people become friends. After you read through them, have a conversation with your parents about who your friends are, and why you like them.

### **Someone you choose and who chooses you:**

“You know how sometimes you can just tell you are going to be good friends...we have a kind of understanding, we know what each other is going to say.”

### **Someone who supports you and shares with you:**

“I can talk to him anytime about anything and he will always listen and be supportive....You know he can't talk but he sure is a good listener.”

### **Someone who is good company:**

“We always like to watch TV and go to the movies together because we are friends...Friends are for having fun with.”

### **Someone who is accepting and encouraging:**

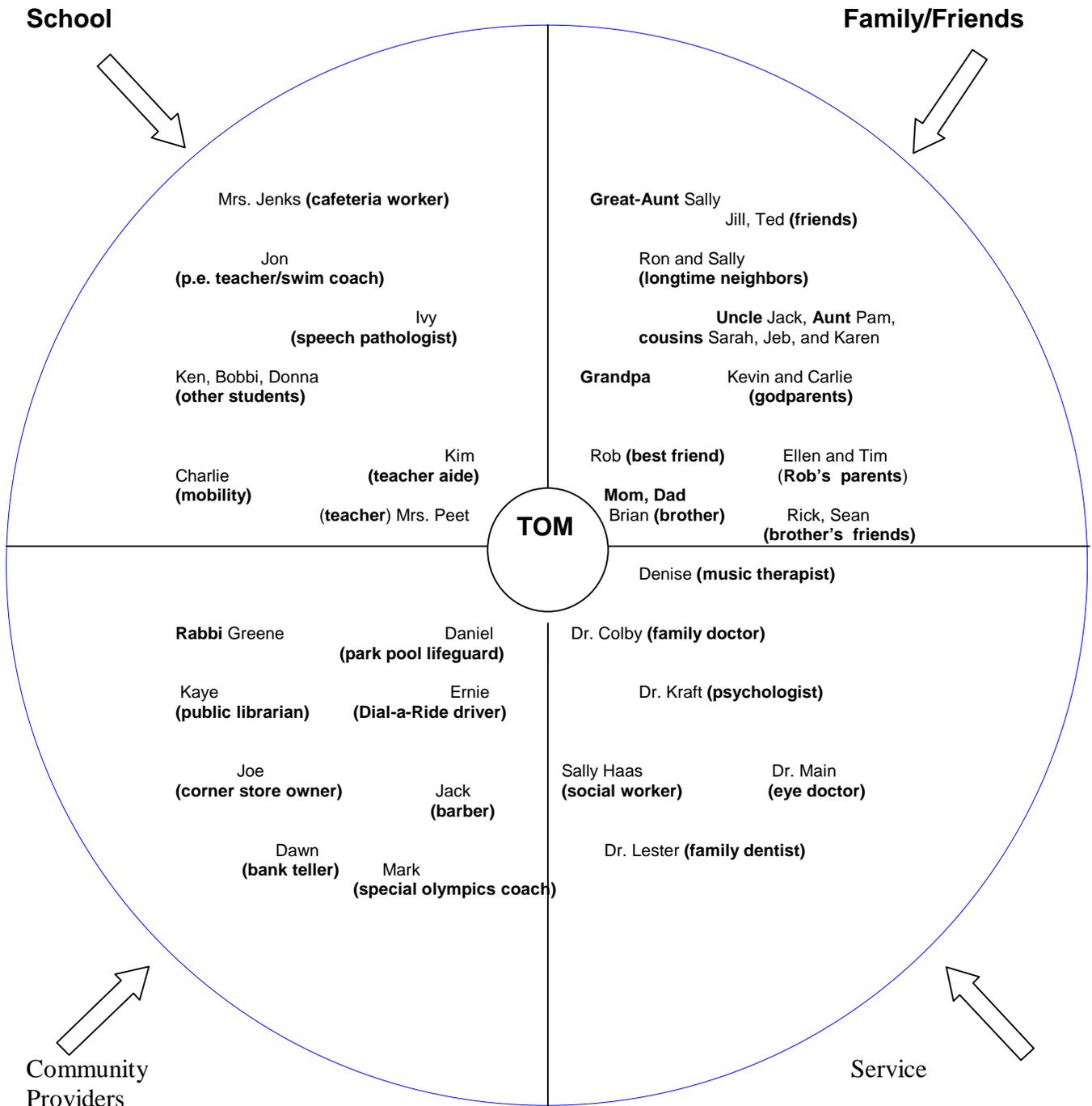
“She gives me the biggest smile even when I know I've let her down by being late...My friends were so encouraging that I was really confident when I gave my presentation in front of the class.”

### **Someone who is loyal and trustworthy:**

“My friend is so loyal, she really inspires me to be a good friend...No matter how much I change or my friends change, we'll still be friends.” \*

\*Adapted from Friends Make the Difference by Annie Rousseau. Vancouver, B.C.: British Columbia Association for Community Living.

**Circle of Support Map – Sample This is a “map” of Tom’s relationships**



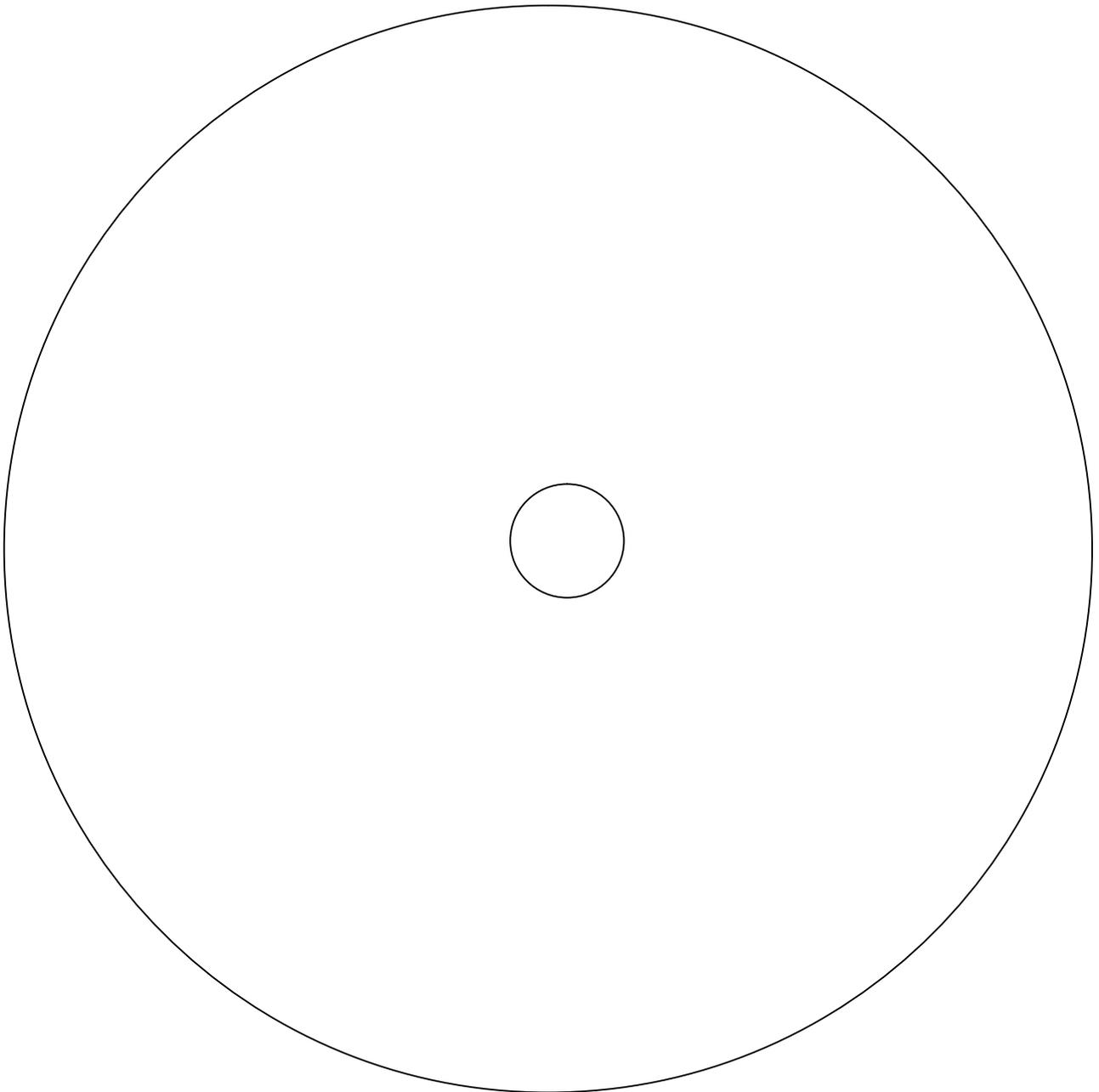
Adapted from Person-Centered Planning: Finding Directions for Change Using Personal Futures Planning by Beth Mount, Graphic Futures, Inc. New York, NY, 2000. 1-888-840-8578

## My Circle of Support Map

Date \_\_\_\_\_

My  
Worksheet

Put yourself in the center and create at least three categories.  
Put the people who are most important to you close to the center of the circle in each category.  
Some people might fit in more than one category, and that's ok.



## Strengthening My Circle of Support



Date \_\_\_\_\_

**Go back and look at the sample of Tom’s support circle. Here are some of the ways Tom said he could strengthen the relationships in his support circle:**

- ✍ I can bake cookies and take them over to Ron and Sally.
- ✍ I can invite Joe to come over and see my new dog.
- ✍ I can send birthday cards to my friends at school.
- ✍ I can call Ted and ask him to go to a movie.
- ✍ I can send a letter to my cousins and tell them about the changes in my life.

**Now look at your own Support Circle. What are some ways you could expand and strengthen your circle of support?**

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Adapted from Person-Centered Planning: Finding Directions for Change Using Personal Futures Planning by Beth Mount, Graphic Futures, Inc. New York, NY, 2000. 1-888-840-857.

## WHAT WILL I DO?

Transition planning leads to decisions about the way in which your child will spend the years after high school. As he identifies and articulates his skills, interests, preferences, and goals, he and the members of his transition team will create a plan to achieve his goals regarding post-secondary employment or additional schooling.

Section contents:

Overview: Transition Planning: A Team Effort.....	42	
Issues to Consider When Looking into Postsecondary Education.....	43	
Where Will I Work? What Will I Do? Questionnaire.....	44	
Translating Preferences into Work Opportunities.....	46	
Overview: Helping Students With Cognitive Disabilities Find and Keep a Job.....	48	
Overview: A Student's Guide to Jobs.....	48	
Job Interview Checklist.....	49	
ADA Employment Enhancers.....	51	

### **Transition Planning: A Team Effort**

As you and your teenager plan for her transition from high school to adulthood, you will build a “team” of individuals who will offer recommendations and help you make important decisions. In addition to you, your child, and other family members, your transition team will include teachers, counselors, service providers, and other professionals who can provide expertise on a variety of educational, vocational, employment, and independent living options.

**Transition Planning: A Team Effort** is a 24-page NICHCY publication which is included in its entirety in **APPENDIX C at the end of this Toolkit**.

In addition to explaining how to create an effective transition team for your young person, this guide offers helpful strategies for finding transition resources in your community.

## ISSUES TO CONSIDER WHEN LOOKING INTO POSTSECONDARY EDUCATION

What are admission requirements?

What is the grade point average? ACT? SAT?

Are there special accommodations for individuals with special needs to take entrance exams?

Are there special incentive programs?

Is there a disabled student service office on campus?

How does one contact the disabled student office? Is it open full-time or part-time?

What kind of documentation is required to verify disabilities?

Is there a disabled student organization on campus? How does one contact them?

How are the faculty informed of the necessary accommodations, if needed?

Is tutoring available? Is it individualized or group? Is there a cost involved?

Are note takers and readers available? Is there a cost involved? How are they trained?

Is it possible to arrange for tape recorder classes, computers, untimed testing, test readers?

Is it possible to relocate classes to more accessible sites?

What is the college's policy regarding course substitutes or waiver of curriculum requirements?

Are there developmental courses available? In what areas?

From Complete Guide to Special Education Transition Services by Roger Pierangelo and Rochelle Crane. Center for Applied Research in Education, 1997.

## WHERE WILL I WORK? WHAT WILL I DO?

Date \_\_\_\_\_

Deciding what kind of work you want to do is one of the most important parts of transition planning. Think about what you would like to do, where you will do it, who you will do it with, and the skills you will need to do this work.

You may not go to work right after finishing high school. You may want to go on to school or get vocational training. Whichever you choose, you will still need to think about the job or career which you would like to have as an adult. These questions and checklists should help you begin to make these plans.

I prefer to work \_\_\_\_\_alone  
\_\_\_\_\_with a few people  
\_\_\_\_\_with lots of people

I would like to work \_\_\_\_\_indoors  
\_\_\_\_\_outdoors

I like this type of work \_\_\_\_\_seated  
\_\_\_\_\_active

I would like to work during the \_\_\_\_\_day  
\_\_\_\_\_night

Do I know what kind of work I would like to do? \_\_\_\_\_yes \_\_\_\_\_no

If yes, what kind of work is that? \_\_\_\_\_

\_\_\_\_\_

Why would I like to do this?

\_\_\_\_\_

\_\_\_\_\_

**WHERE WILL I WORK? WHAT WILL I DO?**

Have I already done work of some kind?     \_\_\_ Yes     \_\_\_ No

Did I enjoy it? Why or why not? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

What kind of work would I like to try now? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

What do I need to learn in order to get this job? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

How will I get to work?   \_\_\_ walk     \_\_\_ car     \_\_\_ drive myself     \_\_\_ taxi  
\_\_\_ bike   \_\_\_ bus     \_\_\_ assisted transportation     \_\_\_ other

Will I need any of these?

\_\_\_ driver's training   \_\_\_ driver's license   \_\_\_ a car   \_\_\_ car insurance

Have I ever been tested on my work skills and interests (a vocational assessment)?

\_\_\_ Yes   \_\_\_ No

Have I ever filled out a job application?     \_\_\_ Yes   \_\_\_ No

Do I have a resume?     \_\_\_ Yes   \_\_\_ No

Have I ever been interviewed for a job?     \_\_\_ Yes   \_\_\_ No

Reprinted with permission from "Where Am I Going? How Will I Get There?" A publication of the Nevada Department of Education Educational Equity Team, Nevada Parents Encouraging Parents, and the Nevada Parent Network. 1997.

## TRANSLATING PREFERENCES INTO WORK OPPORTUNITIES

### Sample: How Curt's Preferences Translate Into Meaningful Activities

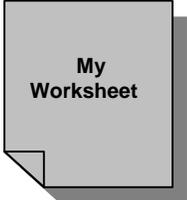
#### Preferences -- Things Curt Likes

Outdoor activities and community outings  
Loves motion (swings, rides, rocking, hand vibrator)  
Warm water, baths, private time, smells  
Smooth dry textures  
Animals  
Contact with people  
Quiet time  
Picking things up/moving things  
Eating ice cream, salty foods, finger foods  
Moderate exercises  
Repetitive Motion

#### Possible Work Activities that Incorporate Preferences

Mail delivery to post office	being outdoors, moving things, contact with people, community outings
Delivering mail on campus	pushing things, contact with people
Cleaning crew	moving things, contact with people
Local laundromat	smooth, dry textures, repetitive motion (folding), scents, warm water
Greenhouse	water, scents, community outing

Source unknown.



# Turning Preferences Into Jobs

Date \_\_\_\_\_

List some of your preferences – things you like to do, places you like to go.

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Ask some of the people in your support circle to help you think of possible jobs that would include some of your preferences.

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## **Helping Students with Cognitive Disabilities Find and Keep a Job**

Exploring employment options can be an overwhelming and sometimes frustrating experience for both parents and students. **Helping Students with Cognitive Disabilities Find and Keep a Job** offers clear and helpful strategies for finding out what opportunities exist, who could be involved in the job search process, and what kinds of support and accommodations could increase your young person's chance for success. This 20-page NICHCY guide is included in its entirety in **Appendix D at the end of this Toolkit.**

## **A Student's Guide to Jobs**



This short, but inspiring, document can be found in **Appendix E at the end of this Toolkit.** It includes photos and brief interviews with eight young people with disabilities who describe their jobs and special skills with enthusiasm, pride, and self-confidence.

## JOB INTERVIEW CHECKLIST

Date \_\_\_\_\_

Use the following checklist every time you have an interview.

In Advance:

- \_\_\_\_\_ Know exactly where the interview will be held and how to get there.
- \_\_\_\_\_ Memorize three strengths you have that relate to the job.
- \_\_\_\_\_ Have a folder ready with samples of your work, letters of recommendation, pen, pencil, paper and resume.
- \_\_\_\_\_ Have information that will be needed on an application form clearly printed in your folder.
- \_\_\_\_\_ If applying for a government job, have a copy of the completed application in your folder.
- \_\_\_\_\_ Dress appropriately for the interview. Have your clothes prepared in advance.
- \_\_\_\_\_ Complete plans for how you will get to the interview.
- \_\_\_\_\_ Complete a dry run of these plans before going to the interview.
- \_\_\_\_\_ Have clearly in mind the information you want to give and the questions you want to ask.

At the interview:

- \_\_\_\_\_ Be a few minutes early for the interview.
- \_\_\_\_\_ Tell the receptionist your name and who you have an interview with.
- \_\_\_\_\_ Be ready to answer the questions that are asked.
- \_\_\_\_\_ Have questions you want to ask about the job.
- \_\_\_\_\_ Know how you want to present your learning disability and how it relates to this job, IF you choose to.
- \_\_\_\_\_ Thank the interviewer for his time and ask for a time when they will notify you about the job.

After the interview:

- \_\_\_\_\_ Go over the interview with a friend or family member to see what you did well and what you will improve for the next interview.
- \_\_\_\_\_ Write a follow-up thank you letter.

Reprinted with permission of Interstate Research Associates, Inc., McLean, VA.

## **AMERICANS WITH DISABILITIES ACT EMPLOYMENT OPPORTUNITY ENHANCERS**

**It is important to understand your rights if you are going to have a job.**

### **TITLE I      EMPLOYMENT**

Protects applicants and employees in private sector and state and local government agencies with fifteen or more employees.

### **TITLE II      PUBLIC SERVICES**

Protects applicants and employees in small state and local government agencies employing fewer than fifteen workers. Requires that all state and local government services, programs, and activities be accessible. Targets accessibility in public transportation, such as city buses and commuter trains as well as to AMTRAK, operated by state and local government agencies.

### **TITLE III      PUBLIC ACCOMMODATIONS AND SERVICES OPERATED BY PRIVATE ENTITIES**

Targets accessibility in public transportation, such as buses and vans, operated by private entities. Prohibits private businesses and service providers, such as restaurants and banks, from discriminating against, refusing service, or excluding individuals with disabilities. Addresses accessibility in existing and newly constructed/altered public accommodations and commercial facilities. Trade associations or performing artists that lease space for a conference or a performance at a hotel, convention center, or stadium become a public accommodation that must comply.

### **TITLE IV      TELECOMMUNICATIONS**

Requires telephone companies to offer 24-hour telecommunications local and long distance relay services to customers who have hearing and speech impairments. Addresses closed captioning of public service announcements.

### **TITLE V      MISCELLANEOUS**

Prohibits retaliation against individuals who exercise their rights under ADA.

Adapted from "Job Seeking Strategies for People with Disabilities" by Melanie Astaire Witt. Peterson's Guide. 1992.

## HOW WILL I LIVE?

In addition to making decisions regarding employment and education, your child will need to create a plan for housing, transportation, community life, recreation, finances and future care needs. As an outgrowth of being an active participant in the process since the inception of his IEP planning, your young person will have developed an understanding of his rights, an awareness of his preferences and capacities, a clear idea of his goals, and the ability to advocate for the things he deserves and desires.

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## RIGHTS AND RESPONSIBILITIES CHECKLIST

Date \_\_\_\_\_

Things I might want more information about:

- Registering to vote
- Registering for the draft
- Power of Attorney
- Conservatorship
- Guardianship
- Trusts and wills
- Legal assistance
- Advocacy

As an adult, you will need to speak up for yourself. When you do this, you are being a 'self-advocate.' Good self-advocates are informed about the topic. They speak calmly and clearly. They listen while others speak and consider the importance of what they are hearing.

Am I able to act as my own advocate at this time?     Yes     No

What do I need to help me become a better self-advocate?

- Training and practice
- More opportunities to make choices
- Support group
- Other: \_\_\_\_\_

If I had a problem with a teacher, an employer, a family member, or someone I had done business with, whom would I ask for help?

\_\_\_\_\_ Phone \_\_\_\_\_

If I needed help in understanding my rights and responsibilities, who would I go to for help?

\_\_\_\_\_ Phone \_\_\_\_\_

Reprinted with permission from "Where Am I Going? How Will I Get There?" A publication of the Nevada Department of Education Educational Equity Team, Nevada Parents Encouraging Parents, and the Nevada Parent Network. 1997.

## IMPORTANT RECORDS AND PAPERS

Date \_\_\_\_\_

Some of the records you may need are:

Personal records including:

- ✍ birth certificate
- ✍ social security card
- ✍ family information
- ✍ developmental history (when you first walked, talked, rode a bike, etc.)
- ✍ residential history (where you have lived, the support and supervision you need)
- ✍ records from agencies that are providing you with services, especially those that show that you meet their eligibility requirements

Medical records including:

- ✍ names and addresses of doctors, dentists and therapists
- ✍ immunization record
- ✍ dates and results of any surgeries or medical procedures
- ✍ specialist and therapist reports

Educational records including:

- ✍ copies of IEP's
- ✍ educational assessment reports
- ✍ school progress reports and report cards

Vocational information including:

- ✍ reports from vocational assessments
- ✍ list of vocational courses taken
- ✍ work history, including dates, contact persons and telephone numbers
- ✍ resume and letters of reference

**FUTURE MAP – SAMPLE**

What are your short-term goals?

getting better grades in English class.



go to the prom



be able to stay home alone when my parents go out of town.

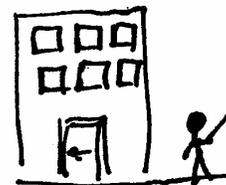


What are your long-term goals?

get my driver's license



have my own apartment.



## FUTURE MAP

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**Date**

What are some of your **short-term** goals?

What are some of your **long-term** goals?

## Planning for Living Independently

What Does This Student Need?	Actions the High School Transition Team May Recommend
ASSESSMENT that identifies strengths, needs, interests, preferences for adult and independent living, including recreation and leisure	<ul style="list-style-type: none"> <li>✓ interview youth and family regarding adult and independent living interests and preferences (use other methods to assess interests and preferences if student is nonverbal)</li> <li>✓ observe youth in independent living or recreational setting</li> <li>✓ interview youth and family regarding medical needs</li> <li>✓ interview youth and family regarding financial plans</li> <li>✓ identify transportation skills and needs</li> <li>✓ develop a list of supports student needs to be successful</li> <li>✓ identify needed natural supports, accommodations, and support services</li> </ul>
DEVELOPMENT of adult living placement options, including recreation and leisure (not needed immediately, but for planning purposes)	<ul style="list-style-type: none"> <li>✓ analyze adult living options in the local area (for example, group homes, supported living homes, roommates)</li> <li>✓ analyze locality for leisure/recreation options in the local area</li> <li>✓ coordinate with other families and youth looking for adult living options</li> <li>✓ provide training and education for families and youth regarding living and financial options for transition-aged youth</li> <li>✓ analyze community for transportation options</li> </ul>
MATCH youth to adult living placement options, including recreation and leisure	<ul style="list-style-type: none"> <li>✓ analyze the demands and expectations of the adult living and community participation options</li> <li>✓ match the student's assessment and list of supports to the demands and expectations of these options</li> </ul>
TRAINING and PREPARATION for adult living	<ul style="list-style-type: none"> <li>✓ provide instruction to prepare youth to enter identified adult living and community options</li> <li>✓ identify potential service providers for needed supports and accommodations</li> <li>✓ develop natural supports</li> <li>✓ provide opportunities to participate in the community in the identified settings</li> </ul>
PLACEMENT and FOLLOW-ALONG	<ul style="list-style-type: none"> <li>✓ monitor progress</li> <li>✓ monitor changing need for natural supports</li> <li>✓ monitor changing need for services</li> <li>✓ make adjustments, as needed</li> </ul>

## SKILLS CHECKLIST

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**Date**

**Check which of the following things you can do:**

### **Domestic skills**

- Prepare a breakfast
- Prepare a lunch
- Prepare a supper
- Prepare a snack
- Pack my own lunch
- Clean my own room
- Clean my own apartment
- Do my own laundry
- Use a washer or dryer
- Plan my own meals
- Budget my own time

### **Vocational Skills**

- Get to and from work on time
- Punch or sign in appropriately
- Perform work satisfactorily
- Work cooperatively with co-workers
- Take break/lunch appropriately
- Wear suitable clothing
- Use appropriate safety measures
- Follow directions
- Accept supervision

## Recreation/Leisure Skills

- ✍ Use my free time for pleasure
- ✍ Choose reasonable activities
- ✍ Pick a hobby
- ✍ Perform required activities
- ✍ Use community resources

## Community Skills

- ✍ Use public transportation
- ✍ Shop for groceries
- ✍ Shop for clothing
- ✍ Make necessary appointments
- ✍ Use the phone
- ✍ Use bank accounts
- ✍ Be safe in traffic
- ✍ Respond appropriately to strangers
- ✍ Know how to seek help
- ✍ Handle money

## Social/Personal Skills

- ✍ Supply appropriate personal identification when necessary
- ✍ Greet people appropriately
- ✍ Use contemporary style of dress, hair style, make-up
- ✍ Use good grooming, hygiene
- ✍ Communicate with friends and co-workers
- ✍ Be courteous and friendly

From The Complete Guide to Special Education Transition Services by Roger Pierangelo and Rochelle Crane. The Center for Applied Research in Education, 1997.

## FOUR DIRECTIONS FOR BUILDING COMMUNITY LIFE

**Questions to consider when thinking about the community in which your young person is going to live.**

### **Encourage friendships:**

- ✍ What activities bring people with similar interests together?
- ✍ What are the patterns of reciprocity?
- ✍ How do people deepen their relationships over time?
- ✍ How can people with disabilities meet new people and/or deepen their friendships with others by sharing similar interests and patterns of reciprocity?

### **Strengthen Associational Life:**

- ✍ What are the associations in the community?  
Collectors' clubs, men's and women's groups, ethnic associations, sports, health and fitness groups, personal support groups.
- ✍ What religious communities have a rich associational life?
- ✍ What artistic communities have a rich associational life?
- ✍ What are the places that are the center of voluntary networks?
- ✍ How can people with disabilities contribute and participate in the associational life of their community?

### **Make Neighborhood Connections:**

- ✍ What are the places of commerce in which a person can become a valued consumer or a regular?
- ✍ What are the commercial or civic settings that are also the center of a voluntary, informal network of people?
- ✍ What are the opportunities in local neighborhoods for daily interactions, greetings, and acts of neighborliness?
- ✍ How can people with disabilities become involved in the daily rituals of neighborhood life?

### **Build school, work, and homemaking roles:**

- ✍ What are the opportunities to be included in the life of schools: public schools, extracurricular activities, community colleges, universities, night and trade schools, study and interest groups?
- ✍ What are the job opportunities that relate to specific interests?
- ✍ What are the volunteer and leadership roles that people can assume?
- ✍ What are the choices for meaningful retirement lifestyles?
- ✍ How can people with disabilities have regular and productive roles as citizens, students, workers, volunteers and homemakers?

\*From Person-Centered Planning by Dr. Beth Mount. Published by CAPACITY WORKS, PO Box 271, Amenia, NY. 12501-0271. (888) 840-8578 or in NY state (845) 373-4218.



## THE HOUSING CHECKLIST

Date \_\_\_\_\_

### Thirty things to look at in the house where you live or want to live

The house is near other houses where people live.  Yes  No

The house is close to stores, banks, and places to eat.  Yes  No

The house is clean inside and outside.  Yes  No

There is room to move around in the house without bumping into other people.  Yes  No

There is a way to get heat into each bedroom.  Yes  No

The bedrooms have places to keep things, like a closet and a bureau.  Yes  No

The beds are nice to sleep on and are big enough for each person.  Yes  No

The house looks like a place for adults.  Yes  No

The bathrooms work well and are easy to get to.  Yes  No

There are staff around when you need help.  Yes  No

The staff knows how to help when you need it.  Yes  No

Staff can understand what you say and you can understand what they say.  Yes  No

- Staff have a van or car to take you places, like to the store or the doctor.  Yes  No
- Staff talks to you in a nice way and uses your first name.  Yes  No
- You can have friends and family come to the house and you can talk to them privately.  Yes  No
- Staff is nice to your friends and family when they visit.  Yes  No
- Everyone has a written plan of training and activities.  Yes  No
- There is training every day to help you work on your written plan.  Yes  No
- There are things to do at the house for fun and exercise.  Yes  No
- People can do things on their own like cook and wash clothes.  Yes  No
- People go to the doctor and the dentist when they need to.  Yes  No
- The food tastes good and is good for you.  Yes  No
- People get to choose things, like what clothes to wear and when to go to bed.  Yes  No
- People know their rights and staff can explain them.  Yes  No
- People do things in the community, like visit friends, go shopping or to parties.  Yes  No
- Everyone helps make up the house rules.  Yes  No
- People who live in the house want to live there.  Yes  No
- You can get your own mail and use the telephone.  Yes  No
- If you don't want to let someone in your room, you don't have to.  Yes  No
- If staff helps you with your money, they keep records of how it is spent and explain it to you.  Yes  No

Originally developed for Area IV Developmental Disabilities Board, 1983. Revised for LIFEPLAN, 1987. Revised for Read My Lips, 1988. Adapted from the Site Visit Checklist(North Bay Regional Center, 1981) by Allen, Shea & Associates, Napa, CA.



## HOW WILL I STAY HEALTHY?

Who can help me with my health needs? \_\_\_\_\_

Which non-family member would I contact in an emergency?

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

Do I carry medical information with me at all times?    \_\_\_Yes    \_\_\_No

**You should always carry a card with you that lists:**

- 1) the name, address, and phone number of your emergency contact**
- 2) a list of medications you are currently taking**
- 3) the name of your health insurance company**

Do I have health insurance?    \_\_\_Yes    \_\_\_No

How long will I be covered under this insurance? \_\_\_\_\_

Will I need to insure myself after I turn 18? \_\_\_\_\_

How will I do that? \_\_\_\_\_

Do I take any medications?    \_\_\_Yes    \_\_\_No

Do I know how to take my medications, the amount to take, and do I take them by myself without reminders?    \_\_\_Yes    \_\_\_No

Do I have an exercise plan?    \_\_\_Yes    \_\_\_No

What kinds of exercise do I like to do?    \_\_\_swimming    \_\_\_aerobics  
    \_\_\_walking    \_\_\_running    \_\_\_other

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# WORKSHEET FOR COSTING OUT EXPENSES

## Monthly Expenses:

### Housing

Rental \_\_\_\_\_  
Maintenance \_\_\_\_\_  
Utilities \_\_\_\_\_  
Cleaning items \_\_\_\_\_  
Laundry costs \_\_\_\_\_  
Other \_\_\_\_\_

### Care Assistance

Live-in \_\_\_\_\_  
Respite \_\_\_\_\_  
Custodial \_\_\_\_\_  
Other \_\_\_\_\_

### Personal Needs

Haircuts, beauty shop \_\_\_\_\_  
Telephone (basic, TT) \_\_\_\_\_  
Cigarettes \_\_\_\_\_  
Books, magazines, etc. \_\_\_\_\_  
Allowance \_\_\_\_\_  
Clothing \_\_\_\_\_  
Other \_\_\_\_\_

### Employment

Transportation \_\_\_\_\_  
Workshop fees \_\_\_\_\_  
Attendant \_\_\_\_\_  
Training \_\_\_\_\_  
Other \_\_\_\_\_

### Medical/Dental Care

Med/dental visits \_\_\_\_\_  
Therapy \_\_\_\_\_  
Nursing services \_\_\_\_\_  
Attendants' meals \_\_\_\_\_  
Medications \_\_\_\_\_  
Transportation \_\_\_\_\_  
Other \_\_\_\_\_

### Special Equipment

Environment control \_\_\_\_\_  
Elevator \_\_\_\_\_  
Equipment repair \_\_\_\_\_  
Computer \_\_\_\_\_  
Audio books \_\_\_\_\_  
Ramp \_\_\_\_\_  
Guide dog \_\_\_\_\_  
Technical instruction \_\_\_\_\_  
Hearing aids/batteries \_\_\_\_\_  
Wheelchair \_\_\_\_\_  
Other \_\_\_\_\_

### Food

Meals, snacks-home \_\_\_\_\_  
Outside of home \_\_\_\_\_  
Special foods \_\_\_\_\_  
Other \_\_\_\_\_

### Education

Transportation \_\_\_\_\_  
Fees \_\_\_\_\_  
Books, materials \_\_\_\_\_  
Other \_\_\_\_\_

**Expenses/2**

**Social /Recreational**

Sports \_\_\_\_\_  
Special Olympics \_\_\_\_\_  
Spectator sports \_\_\_\_\_  
Vacation \_\_\_\_\_  
TV/VCR or rental \_\_\_\_\_  
Camps \_\_\_\_\_  
Transportation \_\_\_\_\_  
Other \_\_\_\_\_

**Car/Van**

Payments \_\_\_\_\_  
Gas/oil/maintenance \_\_\_\_\_  
Other \_\_\_\_\_

**Insurance**

Medical/Dental \_\_\_\_\_  
Burial \_\_\_\_\_  
Car/Van \_\_\_\_\_  
Housing/rental \_\_\_\_\_  
Other \_\_\_\_\_

**Miscellaneous**

Other \_\_\_\_\_  
Other \_\_\_\_\_  
Other \_\_\_\_\_  
Other \_\_\_\_\_

**TOTAL EXPENSES: \$** \_\_\_\_\_

**Government income:** \_\_\_\_\_

**Employment income:** \_\_\_\_\_

**TOTAL INCOME: \$** \_\_\_\_\_

**Subtract total income from total expenses to determine supplementary financial needs.**

**\$** \_\_\_\_\_ **-** **\$** \_\_\_\_\_ **=** **\$** \_\_\_\_\_

**total expenses minus total income equals supplementary financial needs**

From "Estate Planning" NICHCY News Digest, Vol. 2, Number 1, 1992.

## WHAT WILL I DO WITH MY MONEY?

Date \_\_\_\_\_

Being independent takes money. Someone has to pay for your food, housing, clothing, and transportation. Just as you need to plan for your spending on a trip, you will need to plan your spending for daily living expenses. The following questions may help you make those plans. You may want to discuss them with your family or your teachers.

How much money will I need for:

Rent \_\_\_\_\_ Food \_\_\_\_\_ Clothing \_\_\_\_\_ Utilities \_\_\_\_\_  
 Recreation \_\_\_\_\_ Transportation \_\_\_\_\_ Health care \_\_\_\_\_  
 Other \_\_\_\_\_ TOTAL: \_\_\_\_\_

Where will I get the money I need?

\_\_\_ job      \_\_\_ family      \_\_\_ state or federal support  
 \_\_\_ Supplemental Security Income      \_\_\_ Supplemental Security Disability Income  
 \_\_\_ other kinds of assistance

Do I know how to do these things?

\_\_\_ make change      \_\_\_ pay bills      \_\_\_ open a bank account  
 \_\_\_ write a check      \_\_\_ balance a checkbook      \_\_\_ save money  
 \_\_\_ budget      \_\_\_ pay taxes

Will I need financial help when I leave school?      \_\_\_ Yes      \_\_\_ No

If yes, you need to ask for information about federal, state, and local support programs such as Supplemental Security Income (SSI), Plan for Achieving Self Support (PASS, which is a subsection of SSI), Medicaid, and others which may help you.

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## Trusts

Estate planning can be a complex and daunting process, which is why it is important to engage the services of professionals who are both familiar with the legal and financial aspects of estate planning *and* experienced in working with parents of persons with disabilities.

*Many parents of children with disabilities create a **special needs trust**, which keeps assets in a form that will be available to your child, but will **NOT** disqualify him for government benefits for which he is otherwise eligible.*

Because government agencies have strict regulations regarding special needs trusts, it is vital to work with an attorney, and perhaps a financial planner, who are knowledgeable about special needs trusts and current government benefit programs.

Resources that can be directed to your child's trust include:

- ✍ Standard government benefits
- ✍ Savings
- ✍ Family assistance
- ✍ Parents' estate
- ✍ Inheritances from relatives or friends
- ✍ Property
- ✍ Investments
- ✍ Military benefits
- ✍ Insurance

## Guardianship

Guardianship is the *legal* appointment of an individual who will assume the responsibility of acting in the best interest of your child in making all decisions about his personal needs and financial matters. Some individuals may only require a guardian with a more limited role, also called a conservator. Your attorney can assist you in understanding the difference between these roles, determining what your child will need, and guiding you through the process of choosing a guardian or conservator. Although parents may state in their will that they want a particular person to serve as the legal guardians or conservators for their child – *this is not legally binding. The person must go to court to obtain guardianship or conservatorship.*

From "Estate Planning" NICHCY News Digest, Vol. 2, Number 1, 1992.

## Writing the Letter of Intent

The letter of intent is something that potential caregivers can rely on for guidance in understanding your wishes of you and your child with regard to your child's future. When you prepare to write a letter of intent, ask yourself this question: "If I were no longer here to care for my child, what would someone need to know?" Although it is not a legal document, it will provide valuable information for those who are responsible for your child's future care.

How much you involve your son or daughter in writing the Letter of Intent will depend on age and severity of disability. Only you will know how much your child can understand about the process. If he is able to express his preferences, ask how he feels about the options you are considering. You may be surprised to find that discussing the future actually relieves your child. He may very well be worrying about what will happen when you are no longer there to provide whatever assistance is needed.

Involving your child in discussing and making decisions about the future may be more difficult if he has a severe cognitive disability. For these children, the Letter of Intent is especially important – it will communicate the vital information about themselves that they cannot."<sup>\*</sup>

Make sure that important people in your life know about the Letter of Intent – provide copies for legal and financial advisors, guardians, conservators, and other appropriate family members and/ friends.

Update the letter annually – incorporating new information or future plans. If something changes in your child's life – such as his caseworker or the type of medication he is taking – *update the letter immediately.*

The following pages contain a comprehensive list of items to include in a Letter of Intent. Use this outline as a guide for discussions with your child regarding his future care needs.

From "Estate Planning" NICHCY News Digest, Vol. 2, Number 1, 19

**LETTER OF INTENT**

Written by: \_\_\_\_\_ Date: \_\_\_\_\_

\_\_\_\_\_  
(Relationship to the person with Special Needs - mother, father or both)

**To Whom It May concern:**

**Information about** \_\_\_\_\_  
(Father’s name)

**General information:** List the father’s full name, Social Security number, complete address, phone numbers for home and work, county or township, date of birth, city/town/country where raised, fluent languages, religion, race, blood type, number of sisters, and number of brothers. Indicate whether he is a U.S. Citizen.

**Marital status:** Indicate the father’s marital status. If he is currently married, list the date of the marriage, place of the marriage and number of children from that marriage. Also list the dates of any previous marriages, names of other wives, and names and birth dates of children from each marriage.

**Family:** List the complete names of the father’s siblings and parents. For those still living, list their addresses and phone numbers, as well as pertinent biographical information.

**Information about** \_\_\_\_\_  
(Mother’s name)

**General Information:** (same as above for mother)

**Marital status:** (same as above for mother)

**Family:** (same as above for mother)

**Information about** \_\_\_\_\_  
(Special Needs Child)

**GENERAL INFORMATION**

**Name:** List the full name of your child. Also list any nicknames he or she likes to be called.

**Numbers:** List your child’s social security number, complete address, county or township, telephone numbers for home and work, height, weight, shoe size and clothing size.

**More details:** List your child's gender, race, fluent languages and religion. Indicate whether your child is a U.S. citizen.

**Birth:** List your child's date and time of birth, as well as any complications. List your child's birth weight and place of birth, as well as the city/town/country where he or she was raised.

**Siblings:** List the complete names, addresses, and phone numbers of all sisters and brothers. Which ones are closest to the person with Special Needs--both geographically and emotionally?

**Marital status:** List the marital status of your son or daughter. If married, list the spouse's name, his or her date of birth, the names of any children, and their dates of birth. Also list any previous marriages, as well as the names, addresses, and phone numbers for the spouses and children from each marriage.

**Other relationships:** List special friends and relatives that your child knows and likes. Describe the relationships.

**Guardians:** Indicate whether your child has been declared incompetent and whether any guardians have been appointed. List the name, address, and phone number of each guardian and indicate whether that person is a guardian of the person or guardian of the estate, plenary or limited. If successor guardians have been chosen, list their full names, addresses, and phone numbers. Even if your child has no guardian, it is often wise to state in the Letter of Intent your wishes about who you want to act as guardian if one is needed in the future. Make sure you have spoken with them.

**Advocates:** List the people, in order, who you foresee acting as advocates for your child after your death. Make sure you have spoken with them.

**Trustee:** Indicate whether you have set up a trust for your child and list the full names, addresses, and phone numbers of all the trustees.

**Representative payee:** Indicate whether your child has or needs a representative payee to manage public entitlements, such as Supplemental Security Income or Social Security.

**Power of attorney:** If anyone has power of attorney for your child, list the person's full name, address, and phone number. Indicate whether this is a durable power of attorney.

**Final arrangements:** Describe any arrangements that have been made for your child's funeral and burial. List the full names of companies or individuals, their addresses, and phone numbers. Also list all payments made and specify what is covered. Indicate your preferences for cremation or burial. Should there be a church service? If the preference is for burial, what is the best site? Should there be a monument? If cremation is the choice, what should be done with the remains?

## MEDICAL HISTORY AND CARE

**Diagnoses:** List the main diagnoses for your child's condition.

**Seizures:** Indicate the seizure history such as no seizures; no seizures in the past two years; seizures under control; or does anything "trigger" a seizure?

**Functioning:** Indicate your child's intellectual functioning level such as mild, moderate, severe, profound, undetermined, etc.

**Vision:** Indicate the status of your child's vision: normal, normal with glasses, impaired, legally blind, without functional vision, etc. List the date of the last eye exam and what was listed on any prescription for eyeglasses.

**Hearing:** Indicate the status of your child's hearing: normal, normal with a hearing aid, impaired, deaf, etc.

**Speech:** Indicate the status of your child's speech: normal, impaired yet understandable, requires sign language, requires use of communication device, non-communicative, etc. If your child is non-verbal, specify the techniques you use for communication.

**Mobility:** Indicate the level of your child's mobility: normal, impaired but self-ambulatory, requires some use of a wheelchair or other assistance, dependent on a wheelchair or other assistance, without mobility, etc.

**Blood:** List blood type and any special problems concerning blood.

**Insurance:** List the type, amount and policy number for the medical insurance coverage. What is included in this coverage? Indicate how this would change upon the death of either parent. Include Medicare and Medicaid.

**Current physicians:** List current physicians and specialists. Include their full name, type of practice, address, phone number, average number of times your child visits them each year, total charges for each doctor during the last year and amounts not covered by insurance, Medicare or Medicaid.

**Previous physicians:** List previous physicians and specialists. Include their full name, type of practice, address, phone number and the reasons they saw your child. Describe any important findings or treatment and explain why you no longer choose to consult them.

**Dentist:** List the name, address, and phone number of your child's dentist and the frequency of exams. List special treatments or recommendations the dentist has made.

**Nursing needs:** Indicate your child's need for nursing care. List the reasons, procedures, nursing skill required, etc. Is this care usually provided at home, at a clinic, or in the doctor's office?

**Mental health:** If your child has visited a psychiatrist, psychologist or mental health counselor, list the name, address and phone number of each. List the treatments, medications and the goals of the visits. What types of therapy have been successful and what types have not worked? What types of medication have been successful and what types have not worked?

**Therapy:** Does your son or daughter go to therapy (physical, speech, or occupational)? List the purpose of each type of therapy and the name, address, and phone number of each therapist. What assistive devices have been helpful? Has an occupational therapist evaluated your home to assist you in making it more accessible for your child?

**Diagnostic testing:** List information about all diagnostic testing that has been done in the past. List the name of the individual and/or organization administering the test, address, phone number, testing dates, and summary of findings. How often do you recommend that diagnostic testing be done? Where?

**Genetic testing:** List the findings of all genetic testing of your child and relatives. Also list the name of the individual and/or organization performing the tests, address, phone number, and the testing dates.

**Immunizations:** List the type and dates of all immunizations.

**Diseases:** List all childhood diseases and the date of their occurrence. List any other infectious diseases your child has now or in the past. Has your child been diagnosed as a carrier for any disease?

**Allergies:** List all allergies and current treatments. Describe past treatments and their effectiveness.

**Other problems:** Describe any special problems your child has, such as bad reactions to the sun or staph infections if he or she becomes too warm.

**Procedures:** Describe any helpful hygiene procedures such as cleaning wax out of ears periodically, trimming toenails or cleaning teeth. Are these procedures currently done at home or by a doctor or other professional? What do you recommend for the future?

**Operations:** List all operations and the dates and places of their occurrence.

**Hospitalization:** List any other periods of hospitalization your child has had. List the people you recommend to monitor your child's voluntary or involuntary hospitalizations and to act as liaison with doctors.

**Birth control:** If your son or daughter uses any kind of birth control pill or device, list the type, dates used and the doctor prescribing it.

**Devices:** Does your son or daughter need any adaptive or prosthetic devices, such as glasses, braces, shoes, hearing aids, or artificial limbs?

**Medication:** List all prescription medication currently being taken, plus the dosage and purpose of each one. Describe your feelings about the medications. List any particular medications that have proved effective for particular problems that have occurred frequently in the past and the doctor prescribing the medicine. List medications that have not worked well in the past and the reasons. Include medications that have caused allergic reactions.

**OTC:** List any over-the-counter medications that have proved helpful, such as vitamins or dandruff shampoo. Describe the conditions helped by these medications and the frequency of use.

**Monitoring:** Indicate whether your child needs someone to monitor the taking of medications or to apply ointments, etc. If so, who currently does this? What special qualifications would this person need?

**Procurement:** Does your child need someone to procure medications?

**Diet:** Does your child have a special diet? Describe the diet in detail and give reasons for the diet. If there is no special diet you might want to include food items that your child likes or dislikes.

## **HOUSING**

**Present:** Describe your child's current living situation and indicate its advantages and disadvantages.

**Past:** Describe past living situations. What worked and what didn't work?

**Future:** Describe in detail any plans that have been made for your child's future living situation. Describe your idea of the best living arrangement for your child at various ages or stages. Prioritize your desires. For each age or stage, which of the following living arrangements would you prefer?

A relative's home (which relative?).

Supported living in an apartment or house with \_\_\_ hours of supervision.

A group home with no more than \_\_\_ residents.

A state institution (which one?).

A private institution (which one?).

Foster care for a child.

Adult foster care.

Parent-owned housing with \_\_\_ hours of supervision.

Housing owned by your child with \_\_\_ hours of supervision.

**Size:** Indicate the minimum and maximum sizes of any residential option that you consider suitable.

**Adaptation:** Does the residence need to be adapted with ramps, grab bars, or other assistive devices?

**Community:** List the types of places that would need to be conveniently reached from your child's home. Include favorite restaurants, shopping areas, recreation areas, libraries, museums, banks, church, etc.

## **DAILY LIVING SKILLS**

**IPP:** Describe your child's current Individual Program Plan.

**Current activities:** Describe an average daily schedule and activities usually done on "days off".

**Monitoring:** Discuss thoroughly whether your son or daughter needs someone to monitor or help with the following items:

Self-care skills like personal hygiene or dressing.

Domestic activities like housekeeping, cooking, shopping, laundry.

Transportation for daily commuting, recreational activities or emergencies.

Reinforcement of social and interpersonal activities to develop social skills.

Other areas.

**Caregivers' attitudes:** Describe how you would like caregivers to treat matters like sanitation, social skills (including table manners, appearance and relationships with the opposite sex). What values do you want caregivers to demonstrate?

**Self-esteem:** Describe how you best reinforce your child's self-esteem, discussing how you use praise and realistic goal setting.

**Sleep habits:** How much sleep does your child require? Does he or she have any special sleep habits or methods of waking up?

**Personal finances:** Indicate whether you recommend a personal allowance for your child. If so, how much? Also list your recommendations about supervision of how the allowance is spent.

## **EDUCATION**

**Schools:** List the schools your child has attended at various ages and the level of education completed in each program. Include early intervention, day care and transition programs.

**Current program:** List the specific programs, schools and teachers your child has now. Include addresses and phone numbers.

**Academics:** Estimate the grade level of your child's academic skills in reading, writing, math, etc. List any special abilities.

**Emphasis:** Describe the type of educational emphasis (such as academic, vocational, or community-based) on which your child currently concentrates. What educational emphasis do you think would be best for the future?

**Integration:** Describe the extent that your child has been in regular classes or schools during his or her education. What are your desires for the future? What kinds of undesirable conditions would alter those desires?

## **DAY PROGRAM OR WORK**

**Present:** Describe your child's current day program and/or job.

**Past:** Describe past experiences. What worked and what didn't? Why?

**Future:** Discuss future objectives. Prioritize your desires.

**Assistance:** Indicate to what extent, if any, your child needs assistance in searching for a job, in being trained, in becoming motivated and in receiving support or supervision on the job.

## **LEISURE AND RECREATION**

**Structured recreation:** Describe your child's structured recreational activities. List favorite activities and the favorite people involved in each activity.

**Unstructured activities:** What are your child's favorite means of self-expression, interests, and skills (going to movies, listening to music, dancing, collecting baseball cards, painting, bowling, riding a bicycle, roller skating, etc.)? List the favorite people involved in each activity.

**Vacations:** Describe your child's favorite vacations. Who organizes them? How often do they occur, and when are they usually scheduled?

**Fitness:** If your son or daughter participates in a fitness program, describe the type of program as well as details about where and when it takes place and who oversees it.

## **RELIGION**

**Faith:** List the religion of your child, if any. Indicate any membership in a particular church or synagogue. List the address and the name of any contact.

**Clergy:** List any ministers, priests, or rabbis familiar with your child. List addresses and phone numbers. Indicate how often your child might like to be visited by these people.

**Participation:** Estimate how frequently your child would like to participate in services and other activities of the church or synagogue. Indicate how this might change over time. Also describe any major, valued events in the past.

## RIGHTS AND VALUES

Please list the rights and values that should be accorded your child. Here are some examples of what you might list:

- To be free from harm, physical restraint, isolation, abuse and excessive medications.
- To refuse behavior modification techniques that cause pain.
- To have age-appropriate clothing and appearance.
- To have staff, if any, demonstrate respect and caring and to refrain from using demeaning language.

## OTHER

Give an overview of your child's life and your feelings and vision about the future. Describe anything else future caregivers and friends should know about your child.

## FINANCES, BENEFITS, AND SERVICES FOR

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(Your child's name)

**Assets:** List the total assets your child has as of this date. Indicate how these assets are likely to change, if at all, in the future.

**Cash income:** List the various sources of income your child had last year. Include wages, government cash benefits, pension funds, trust income, and other income. This might include Social Security, Social Security Disability Income or Supplemental Security Income.

**Services and benefits:** List any other services or benefits your child receives. These might be services for children with physical impairments, developmental disability services, clinics sponsored by support groups, early periodic screening, diagnosis and treatment, employment assistance, food stamps, housing assistance, legal assistance, library services, maternal and child health services, Medicaid, Medicare, Project Head Start, special education, Title XX service programs, transportation assistance, or vocational rehabilitation services.

**Gaps:** Indicate whether any services or benefits are needed but are not being received by your child. Indicate whether plans exist to improve the current delivery of services or to obtain needed benefits.

**Expenses:** List all expenses paid directly by your child in various categories, such as housing, education, health care, recreation, vocational training, and personal spending. List all expenses paid directly by parents, guardians, or trustees in various categories. List estimates of all expenses paid by third parties, such as insurance companies paying doctors directly or Medicaid paying for residential services.

**Changes:** Indicate how your child's financial picture would change if one or both parents died. Be sure to list any additional cash benefits to which your child definitely would be entitled. Also list any cash benefits for which your child might be eligible.

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## Resources

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