Future Planning

A Roadmap of our Futures Wishes

THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON
Sonoran Center for
Excellence in Disabilities

Arizona
Developmental
Disabilities
Planning Council℠

Voices From Our Community

This Roadmap reflects the efforts and contributions from individuals with disabilities, family members, direct support professionals, and other professionals in the disability field. We hope that it becomes one of many useful tools that are available to help you during your personal and unique journey of planning for your futures. Our goal is to integrate the research about future planning and apply it to something useful. Most importantly, this Roadmap reflects the experiences that you have shared with us.

Special thanks to the individuals who participated in the online surveys and interviews. Your experiences and knowledge greatly informed the development of this future planning roadmap. Your personal stories enhanced our understanding about real lives.

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Overview

Future planning is an important yet difficult process that involves gathering information, looking at options, making decisions that may change, creating back-up plans, asking for help, and a lot of self-reflection. All of this is done with the individual who has a disability as the central person who has his or her own hopes and dreams. It is a balancing act that can be made easier through open and honest conversations.

The Future Planning - A Roadmap of Our Futures, Our Wishes is divided into four chapters.

Chapter One - Future Planning: What Is It All About?

This chapter includes topics and questions that come up frequently in discussions about future planning. It is about exploring goals, triggers, options, and the personal and family journey during the planning process.

Chapter Two - Worksheets to Guide Communication and Planning

This chapter includes worksheets that can help to: get to know the individual and what is important to him or her, what is needed to support daily activities, how to enhance quality of life, and face transition and change.

Chapter Three - Important Considerations

This chapter includes topics that often come up when a person approaches adulthood. It explores financial and legal decisions while emphasizing the importance of supported decision making when appropriate.

Chapter Four – Relationships and the Human Connection

This chapter shares experiences from individuals with disabilities and their families who support them. Topics include family relationships, changing roles, professional support, value of friendships, and culture and tradition. It ends with profiles of individuals and their personal journeys.

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Profiles of Individuals and Their Personal Journeys

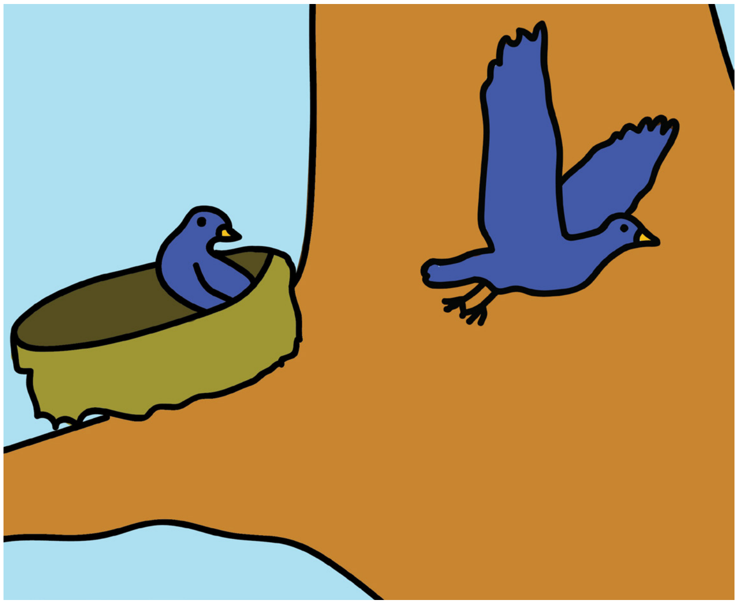
Introduction

Future Planning: A Roadmap of Our Futures, Our Wishes

Future Planning: A Roadmap of Our Futures, Our Wishes is a workbook about how to facilitate future planning. This involves gathering information, exploring choices, sharing dreams, documenting wishes, reaching goals, and creating a written plan. It includes plans for the person with a disability and for caregivers as their roles change over time. Future planning is about how families and networks of support come together to support self-determination, inclusion, integration, empowerment, and self-advocacy. This roadmap is designed as a tool to be used by individuals with intellectual and developmental disabilities, family members, direct support professionals, and advocacy groups to guide the planning process.

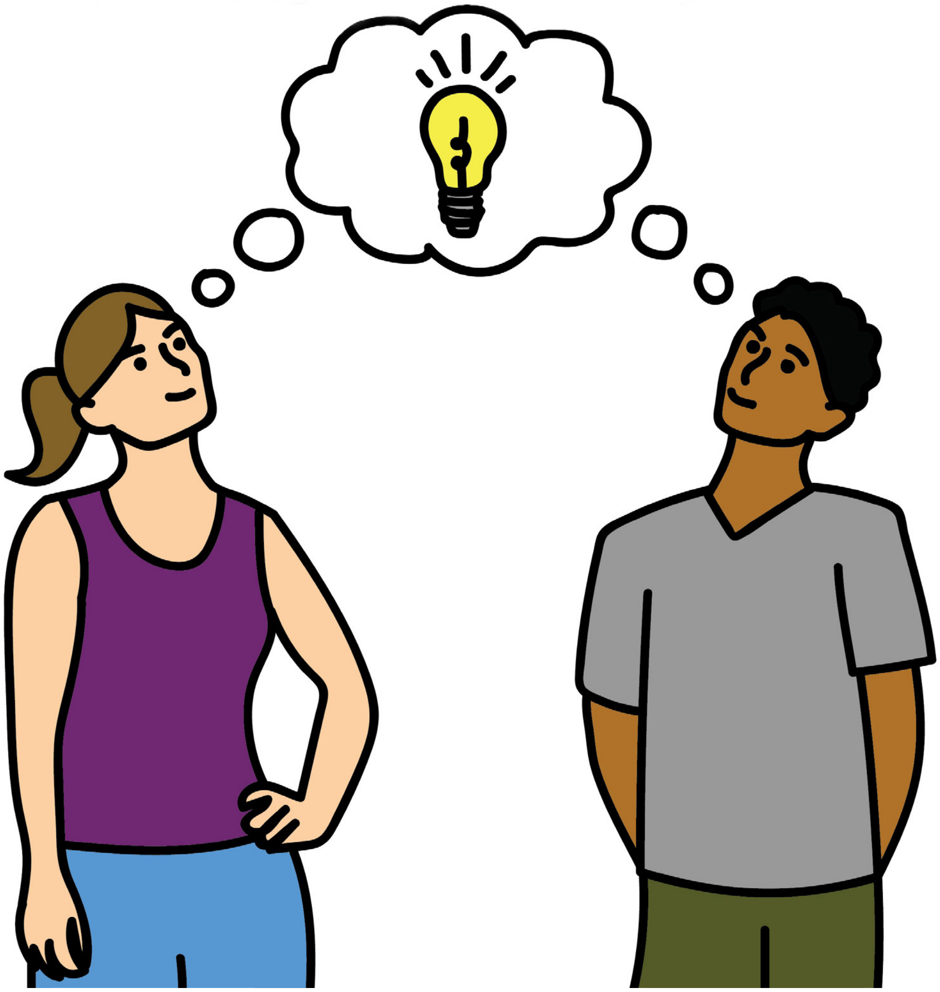
Planning is a personal journey that involves decisions, choices, and risk-taking. Some decisions will be easier than others and some will take more time to complete. It involves thinking about what has worked, what needs to change, and what experiences may influence your choices. It is a journey that is emotional, joyful, and sometimes overwhelming. There are many tasks and decisions that need to be explored and completed. Most importantly, it is person-centered and family-centered.

The creation of this Roadmap has had a journey of its own. It began in 2007 when families in Arizona shared their thoughts about future planning through interviews and focus groups. In 2016, more than 60 people with disabilities and family members participated in another future planning study. This workbook is an outcome of that study and has been made possible with funding by the Arizona Developmental Disabilities Planning Council, and reflects the contributions from individuals with disabilities, family members, direct support providers and professionals in the disability network.



Chapter One

Future Planning: What is it all about?



Think Future, Start Now

Future Planning Goals

Individuals and families often ask, “When should I or we start planning?” There is no correct answer, but many families start to think about future plans when major life transitions occur. Life transitions can be events such as moving to a new neighborhood, changing schools, graduating from high school, getting a job, changes in health, and the aging of parents and/or primary caregivers. ***The Future Planning: A Roadmap of Our Futures, Our Wishes*** was developed to help you move forward with the planning process. It was designed to meet the following goals:

- Motivate everyone to start this discussion early
- View planning as a process that keeps moving forward
- Encourage the sharing of ideas, emotions, and plans
- Integrate Person-Centered Thinking and Planning
- Dream about possibilities
- Support self-determination and self-advocacy
- Formalize planning by writing things down

Many individuals and families talk about their future wishes and plans, but struggle with taking it one step further. Begin by writing things down and expect them to change. During the planning process you and others will learn more about hopes, expectations, and what is necessary to accomplish your plan.

What are your goals?

My Journey, Your Journey, Our Journey

Key Principles to Planning

Future planning takes time so it's never too early to start! Here are key principles and values that individuals and families have taught us.

- Explore the wishes, desires, and goals that people with disabilities and their families have. They may be similar, different, or overlap each other.
- Talk openly about things and topics that can be difficult when thinking about the future. Talking through things can help you find solutions.
- There are people who want to help but don't know how. It's okay to ask for help.
- Involve people in the community who can provide different types of support and help now and in the future. Build your current and future networks and friendships.
- Think broadly about what it means to be involved, integrated, and included in the community. These concepts can mean different things to individuals. Define and clarify them.
- Learn about options and resources that may help. Resources are always changing and evolving.
- Get involved with community groups and organizations who can help you find the appropriate resources.
- Allow the individual with a disability and his or her family time and permission to share their emotions. This journey is not always easy.
- Accept that some things will work and some will not, but you have to keep trying.
- Take one step at a time, even if it feels like you are standing still.
- Keep a hopeful and positive "can do" attitude despite the challenges. The meaning of "hope" and "success" can evolve along the way.

"Hang in there despite the challenges because good things will happen."

Planning is a Process

Based on our research, individuals with disabilities and families are in different stages of their planning process. Many are “stuck” or have stopped planning for various reasons. There will be times when your plan changes, and that is “okay.” You will need different options and scenarios to think through.

There are different transition points in a person’s life, but each point can bring new opportunities to communicate with each other about goals, wishes, and concerns. At some point in the planning process, families have shared:

“I don’t know **where** to start”

“I don’t know **how** to start”

“I’ve talked about it”

“I have been thinking about it”

“I know I have to do it”

“My children will take over”

“I don’t know what will happen”

The Planning Process

Look through the Table of Contents to see the different topics. Some areas may not apply to you or your family right now but they may in the future. You do not have to complete every page or worksheet. Each worksheet was designed for a specific purpose and developed to encourage you to write things down. Writing is one way to communicate with others. The worksheets are also a way to clarify expectations and to identify **YOUR NEXT STEPS**.

Getting Ready:

- Ask what area the person with a disability wants to explore first. This will engage everyone in the discussion.
- Think about what area or topic may be the easiest or most comfortable to complete. Decide what you want to do first.
- Think about what decisions need your attention now or soon. Prioritize your tasks.

Getting Started:

- Find out what is important to other family members who will be involved in providing care and support now and in the future.
- Share the roadmap with someone who can review it with you. It can be one or more individuals who can provide ideas and support.
- Make a timeline for yourself. This timeline begins now and ends when you have a written plan. You must update your plan regularly.

Keep the Momentum Going:

- Ask for help and support along the way.
- Share your plan. Remember that it will change and evolve.
- Revisit each decision or part of your plan regularly.
- Schedule the same time each year to review your plan.

"Congratulate yourself on taking the first steps to future planning – it's a necessary thing to do."

Importance of Planning

What are Your Triggers?

Future planning takes time and some things take practice. Give yourself and the person with a disability permission to make changes and adapt the plan. It can feel overwhelming at times, but the clearer the plan, the less can go wrong.

The families we spoke to identified the following triggers, events, or changes that motivated them to start planning:

- Aging of family members or primary caregivers
- Health concerns, exhaustion, less energy
- Life transitions such as:
    - Graduation from school
    - College or continued skill development
    - Employment
    - Retirement
    - Military discharge/retirement
    - Moving to another community
- Changes in the family unit
- Person with the disability communicates verbally or through behaviors his or her desire to have more independence and autonomy
- Another person or friend made his or her own plan
- Siblings offered to get more involved or shared their concerns

What events made you decide that it was time to plan?

Why Planning Is Important To You

We all need to plan for our future. Think about the positive outcomes early planning can have:

- Gives the person with a disability time to identify what is important to him/her
- Gives you/family time to identify how my/his/her wishes and goals can be implemented
- Allows the person with a disability to maintain a big role in decision making
- Reduces confusion and chaos among other family members
- Clarifies expectations and plans
- Allows everyone to try new things and experience different opportunities
- Gives everyone time to develop new skills
- Allows people time to grieve and adapt to new realities

Why is planning important to you?

What are your benefits to planning early or starting now?

What is holding you back?

Starting Your Plans

Key Principles to Planning

There are many different ways and strategies to develop a future plan. Here are some key points to consider that may help you get you started.

There are many parts to a plan and many overlap each other. There are other tools available for many of these areas so we will focus on the process of planning, sharing of information, and how to be person-centered and family-centered. Family is defined in many ways. It can include immediate family members, other relatives, friends, and people or programs that provide support. It will be very important to define “family” with the person with a disability. He or she may have a different or special meaning of family.

Choices you make regarding one’s future can include areas about: decision-making roles, education, employment, finances, health and wellness, home life, and quality of life.

Get going by:

Redirecting your fears into concrete planning

- If you are stuck, focus on the positive things in a person’s life
- If the future is unclear, consider various scenarios and options
- Don’t assume things will happen; the unknown may be worse
- Think about it, talk about it, write about it
- Use available resources, services, and supports
- Understand what is holding you back from making plans

Things You Can Do:

- Start a journal; write down your thoughts and feelings
- Use one of the worksheets in this Roadmap and start to write down your ideas
- Identify the supports that are needed, including emotional, environmental, and physical

Explore Different Scenarios and Options

Write them down

Option 1:

Option 2:

Option 3:

Let’s start planning

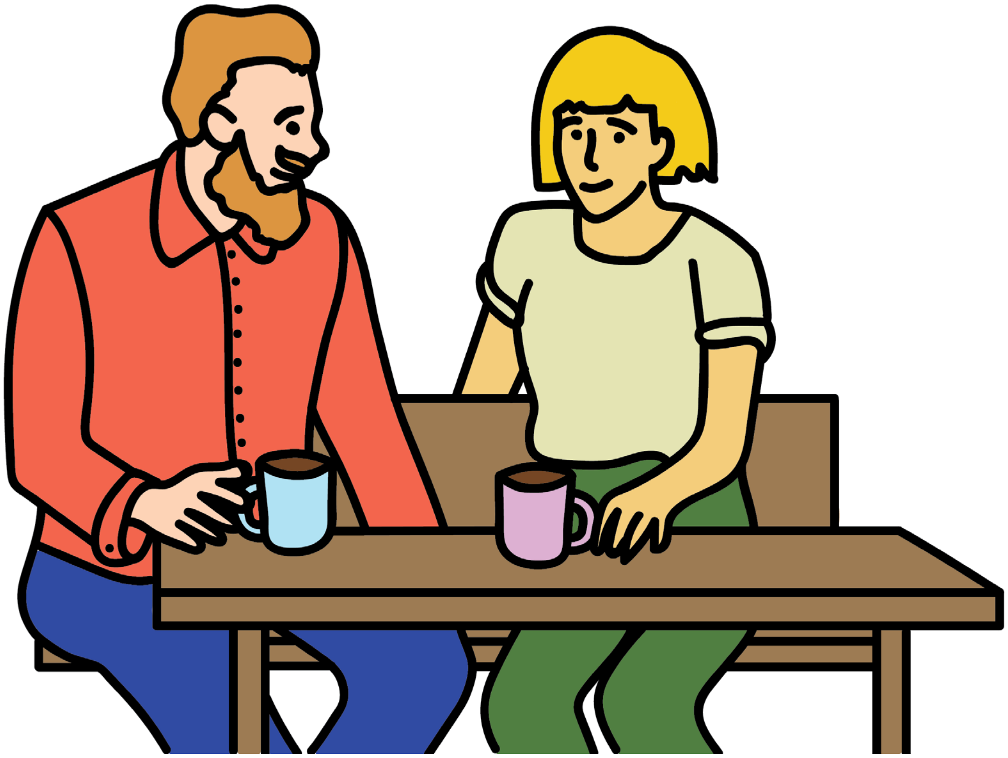
- Build your team. Find people who know you and support you
- Let go and transfer some tasks and responsibilities to others

Things You Can Do:

- Have a meeting with friends and family. Include the person with a disability as much as possible
- Start the discussion by sharing your ideas, concerns, and needs
- Give everyone time to talk
- Teach others what you know and what you hope they will learn more about
- Ask for help and be as specific as you can
- Receive help even if it’s a little uncomfortable
- End the meeting on a positive note. Some suggestions include: talk about the good things that are happening in each person’s life; share what you are grateful for; share something you like about the person with a disability and be sure to let him or her know!

Chapter Two

Worksheets to Guide Communication and Planning



Communication and Planning

Chapter Two is about engaging the person with a disability with important people in his or her life during the planning process. It is about being person-centered and family-centered. It involves taking one step at a time and moving forward. It encourages people who provide support now and in the future to do their best to:

Redirect fears into concrete planning

- Learn about and get to know the person with a disability, understand his or her dreams, and respect that person's choices, desires, and goals.
- Identify and get the information that is needed to ensure a "quality of life" that is defined by the person with a disability.
- Talk about the necessary and sometimes difficult topics.
- Use tools and strategies that will increase communication, clarify expectations, and facilitate planning.

The worksheets in this chapter were created to serve as tools that can be reviewed and completed by the individual with a disability, family members, and people or programs that provide support. Even if the person with a disability and his or her family have talked about or made plans for the future, the worksheets can provide additional information when changes are needed. Each plan should be reviewed at least yearly or on a regular schedule. For example, some families review their plans on a specific holiday like a birthday. This becomes a shared responsibility.

Each Worksheet has a Focus and Purpose

This is Me and My Life (page 23)

This worksheet provides the person with a disability a way to share important things about him or herself. It offers a chance to get to know the person and invites others to join in on the conversation. It reflects the importance of understanding what makes each of us special.

This is Me and Our Lives (page 24)

Families want their loved ones with a disability to have a good quality of life. This worksheet provides the individual and his or her family a chance to share their views of what makes life meaningful. It provides future caregivers information that increases their understanding about the choices and experiences that are important to everyone.

Things or Activities That Bring Me Joy and Make Me Feel Good (page 25)

This worksheet expands on the previous one. It provides more detail about parts of a plan and each aspect of a person's life. It shows that a "good life" is a rich life. There are topics that are easier to talk about. This worksheet provides a chance to explore and share areas that may need more attention and planning.

Pieces of Our Plan (page 27)

Individuals and families know that future planning can be overwhelming because it involves multiple decisions and tasks. This worksheet can help to break down the task of planning into smaller sections or parts. It can also serve as a checklist so that people involved in planning can see the progress being made.

Checklist of Daily Activities (page 30)

Caregiving roles can change over time. Sometimes the individual with a disability is described as being more independent in one setting over another. Family members or friends may underestimate what a person can and wants to do for him or herself. New family members who may get involved in helping with the day-to-day behaviors or new staff will need to learn about a person's abilities. This worksheet should be completed by or with the individual with a disability as well as those who provide support. It should be shared and discussed together after each person completes their own worksheet. The goal is to support independence and identify strengths.

Circle of Support: Self-Assessment Checklist (page 38)

Family members and friends who want to help may not know how. This worksheet was created to serve as a self-assessment or strategy to identify the types of support that can be provided. It can also help to minimize conflict and to clarify expectations. It was designed to open up communication and increase collaboration among family members and other important people in a person's support network. The goals are to identify strengths, individual comfort levels with different tasks, and the skills and knowledge needed to participate in caregiving.

Person-Centered Planning (page 43)

Person-centered thinking and planning is an important concept that supports self-determination. It is a guided and systematic process that identifies the steps that make dreams a reality. It involves listening to verbal expressions and observing the behaviors of persons with disabilities in order to understand what is "important to" and "important for" them. It is a balance and compromise between the two. This worksheet explains the person-centered concept and provides examples. It lists questions that need to be explored so that those involved with planning can understand and respect the decisions and choices of the person with a disability.

Employment: Finding the Right Job That Fits You (Me) (page 48)

Employment is an important activity that enhances individual lives. It involves exploring the possibilities, identifying what defines a dream job, and asking questions about the work environment. This worksheet was designed to help the person with a disability and their supports to find a job that enhances their skills and abilities and makes work enjoyable.

Training and Education: Before, During, and After High School (page 53)

Good relationships at work and at school improve team work. This worksheet is an extension of the Employment worksheet and provides strategies to create a positive learning environment at school and at work. It encourages life-long learning.

Job Coaching and Mentoring (page 56)

Job coaches play an important role. Coaches serve as mentors who guide an individual in all aspects of his or her employment. They are sometimes difficult to find so it is important to work with a coach that you like. Good communication with a coach or mentor is important. This worksheet explores how an individual with a disability can work together with his or her job coach.

Roommates: Making It Work (page 58)

A person may move out of the family home and find a roommate to share their living environment and expenses. Finding a compatible roommate requires getting to know a person's habits and routines, communicating expectations and preferences, working through conflicts, reaching compromises, and respecting different emotions. This worksheet will walk you through different topics and things to explore with roommates or potential roommates. It can serve as a way to clarify expectations and to prevent potential disagreements.

Emergency Network and Information (page 62)

When things suddenly change or when there is an emergency, it is necessary for other people to easily access information. This worksheet serves as a place to write down important information about health care providers, medications, and additional people to contact. Emergencies are stressful so understanding how a person communicates with others can often ease some of the anxiety during a difficult time. Use this worksheet as a guide to facilitate communication.

Assistive Technology (page 67)

Technology is useful, but not everyone knows what is available or how to operate assistive technology. This worksheet is a resource that provides examples and resources. It provides an opportunity to explain what is being used and what can be explored in the future.

Facing Transition and Change (page 69)

Planning for the future is not easy. There is a lot of information to share with others who will be involved in the life of the person with a disability. Future Planning involves taking risks, exploring new experiences, and facing difficult decisions about each person's future. Change can be scary.

There are many benefits to planning early. Remember to be flexible because plans will change. Caregivers also need to plan for their own personal futures. This worksheet is designed to encourage family members to be proactive by accepting help from others, reflecting on the successes of the past, focusing on the positive aspects in one's life, and taking care of their mental health. Change is inevitable and defining the meaning of hope can be helpful. There is an opportunity to define hope, identify one's creative energy, and acknowledge each person's resilience. This worksheet is an opportunity for reflection.

This is Me and My Life

My name is:

____

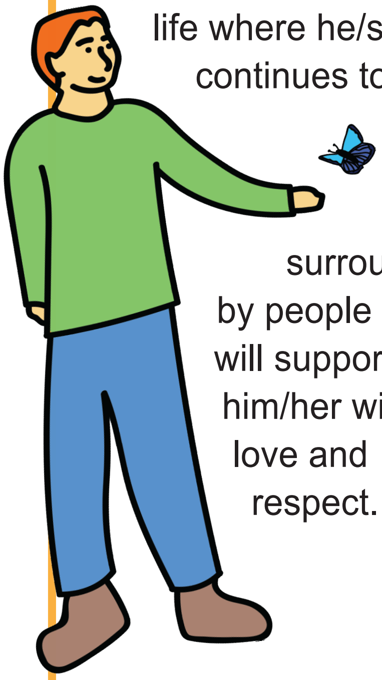
On this page, I will tell you about ME. It shows things I like, words that I use, body movements that show what I feel, what I like to do, and what makes me special. I want to tell you what is "important to me, my family, and my friends." You can write something on it too!

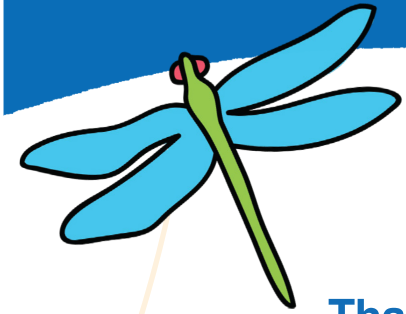
This is Me and Our Lives

I am the ___________

of _________________

Here are some examples of our life together so you can understand what is important to us. Use this information to help ____________ continue to have a good and meaningful life where he/she continues to be surrounded by people who will support him/her with love and respect.





Things or Activities

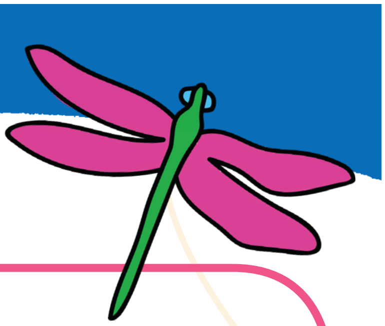
That Bring Me Joy and Make Me Feel Good

There are different parts of a person's life. In the following boxes, write down things, activities, or behaviors that make your life a "good life." Fill in as many boxes as you can. Talk about what you wrote down with people who know you now and people who want to know more about you.

Where I Live

Where I Work or Spend a Lot of Time

My Health



My Wellbeing: Fun and Good for Me

My Friends, Close Relationships

Money and Resources

Other

Pieces of Our Plan

Let’s start planning by looking at the choices I/We have.

Take a look at the things listed. You may not have to do or think about everything on the list. Pick one section or area at a time and look at your choices. Check the ones that apply to you, your family, and your support circle/network.

Places to Live

With Whom

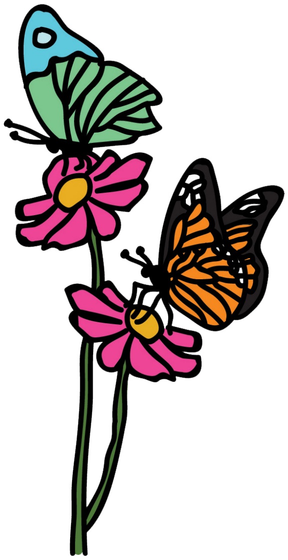
☐ **Family**
☐ **Relative**
☐ **Friend**
☐ **Paid Staff**
☐ **Partner**
☐ **Spouse**
☐ **Other:** ____________________

Where

☐ **Family Home**
☐ **Apartment or own home**
☐ **Foster Home**
☐ **Group Home**
☐ **Shared Living**
☐ **IDLA**
☐ **Other:** ____________________

Shared Decision Making

☐ **Myself**
☐ **POA: General**
☐ **POA: Health Care**
☐ **Representative Payee**
☐ **Conservator**
☐ **Guardian**
☐ **Shared**
☐ **Other:** ____________________



Place to Work

☐ **Part-time**
☐ **Full-time**
☐ **Retirement**
☐ **Other:** ____________________

Pieces of Our Plan, continued...

Check the ones that apply to you, your family, and your support circle/network.

Education

☐ Part-time
☐ Full-time
☐ Community College
☐ College
☐ Trade School
☐ Other: ___________________

Social Activities

☐ Dance
☐ Singing
☐ Sports
☐ Art
☐ Music
☐ Other: ___________________

Health and Wellness

☐ Nutrition
☐ Exercise
☐ Preventive Care
☐ Therapies
☐ Medication Management
☐ Oral Care
☐ Other: ___________________

Money and Resources

☐ ABLE Account
☐ Bill Paying
☐ Special Needs Trust
☐ Saving
☐ Budgeting
☐ Other: ___________________

Pieces of Our Plan, continued...

Check the ones that apply to you, your family, and your support circle/network.

Relationships

☐ Boy/girlfriend

☐ Dating

☐ Family Planning

☐ Marriage

☐ Other: ____________________

Transportation

☐ Bicycle

☐ Bus

☐ Van Service

☐ Car

☐ Other: ____________________

Daily Activities

☐ Grooming

☐ Bathing

☐ Cooking

☐ Eating

☐ Housework

☐ Grocery Shopping

☐ Other Shopping

☐ Other: ____________________

Checklist of Daily Activities

This checklist has many of our daily activities. It includes both simple and more difficult behaviors. Not all the activities may apply to you and where you live. This checklist is useful when you talk about what "You" (individual) can do and how much support is needed to live more independently. You can work on it separately at first. It is best to share and talk about it with family, friends, and people who provide help and support.

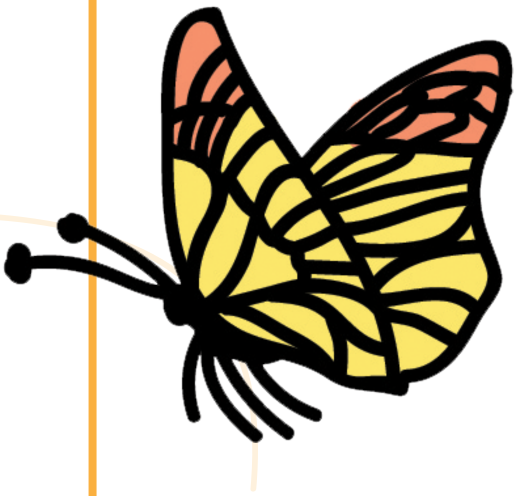
Here is a description of what the words mean.

- **Can Do It Alone:** "I" (Individual) can do it without any cues or direction. If I live alone, I do not need any assistance. I may not complete the task like others would, but I can do it safely alone.
- **Need Some Help:** "I" (Individual) need cues, reminders, or guidance. Guidance means that I may need help getting started but can complete more than half or 50% of the behavior by myself.
- **Need a Lot of Help:** "I" (Individual) need another person with me to complete the task or behavior. If alone, he/she is not able to start and finish. It is not safe for the person to try it themselves.

TIP

How to Complete:

Place a "mark" in the box that best describes the person's abilities. You can make copies and share it with your family and others to see if they agree.



Behavior or Task	Can do Alone	Need Some Help	Need a lot of Help
PERSONAL HYGIENE			
Find and use the right soap	☐	☐	☐
Wash his/her face	☐	☐	☐
Blow one's nose with tissue	☐	☐	☐
Put toothpaste on toothbrush	☐	☐	☐
Use floss for teeth	☐	☐	☐
Brush his/her teeth	☐	☐	☐
Comb his/her hair	☐	☐	☐
Rinse his/her mouth	☐	☐	☐
Fill a tub with warm water	☐	☐	☐
Take a shower	☐	☐	☐
Use shave cream and razor	☐	☐	☐
Shave face or body hair	☐	☐	☐
Find the bathroom	☐	☐	☐
Urinate	☐	☐	☐
Have a bowel movement	☐	☐	☐
Clean body after using bathroom	☐	☐	☐

Other Activities/Behaviors:

The support or assistance that would be helpful:

Behavior or Task	Can do Alone	Need Some Help	Need a lot of Help
FOOD PREPARATION & EATING			
Get the plates and utensils	☐	☐	☐
Eat with a spoon or fork	☐	☐	☐
Cut food with a knife	☐	☐	☐
Pour a drink into a cup	☐	☐	☐
Make a simple meal without the stove (like sandwich)	☐	☐	☐
Heat food in a microwave	☐	☐	☐
Turn stove on and off	☐	☐	☐
Make scrambled eggs or similar meal	☐	☐	☐
Clean the table or eating area	☐	☐	☐
Put dishes in sink or dishwasher	☐	☐	☐
Wash dishes	☐	☐	☐

Other Activities/Behaviors:

The support or assistance that would be helpful:

Behavior or Task	Can do Alone	Need Some Help	Need a lot of Help
CLEANING SKILLS			
Put trash in wastebasket	☐	☐	☐
Take out the trash	☐	☐	☐
Wipe off the table and countertops	☐	☐	☐
Make the bed	☐	☐	☐
Put dirty clothes into hamper	☐	☐	☐
Use washer and dryer to clean clothes	☐	☐	☐
Hang clothes outside to dry	☐	☐	☐
Vacuum the rug or floor	☐	☐	☐
Sweep the floor	☐	☐	☐
Clean the toilet	☐	☐	☐
Scrub the tub	☐	☐	☐

Other Activities/Behaviors:

The support or assistance that would be helpful:

Behavior or Task	Can do Alone	Need Some Help	Need a lot of Help
SHOPPING AND FINANCES			
Know how to pay with money	☐	☐	☐
Know how to count money	☐	☐	☐
Can count change	☐	☐	☐
Make a shopping list	☐	☐	☐
Know about food groups	☐	☐	☐
Choose foods that are healthy	☐	☐	☐
Push a grocery cart	☐	☐	☐
Know the size of clothes	☐	☐	☐
Know when to ask for help	☐	☐	☐
Can make a budget	☐	☐	☐
Can pay bills on time	☐	☐	☐

Other Activities/Behaviors:

The support or assistance that would be helpful:

Behavior or Task	Can do Alone	Need Some Help	Need a lot of Help
COMMUNICATION			
Use technology to communicate	☐	☐	☐
Talk using short sentences	☐	☐	☐
Use sign language	☐	☐	☐
Use email	☐	☐	☐
Use the phone	☐	☐	☐
Write a letter or note	☐	☐	☐
Take part in an online community (social media like Facebook)	☐	☐	☐
Call friends to do something together	☐	☐	☐
Request help by dialing “911”	☐	☐	☐

Other Activities/Behaviors:

The support or assistance that would be helpful:

Behavior or Task	Can do Alone	Need Some Help	Need a lot of Help
SOCIAL ACTIVITIES			
Go to restaurants	☐	☐	☐
Go to movies, plays, concerts	☐	☐	☐
Go to church, mosque, synagogue, or temple	☐	☐	☐
Play sports	☐	☐	☐
Do volunteer work	☐	☐	☐
Work at a paying job	☐	☐	☐
Walk around the block	☐	☐	☐
Go to exercise class	☐	☐	☐
Do exercise at home	☐	☐	☐
Go to dances	☐	☐	☐
Go swimming	☐	☐	☐

Other Activities/Behaviors:

The support or assistance that would be helpful:

Behavior or Task	Can do Alone	Need Some Help	Need a lot of Help
TRANSPORTATION			
Walk independently	☐	☐	☐
Use a manual wheelchair	☐	☐	☐
Use a motorized wheelchair	☐	☐	☐
Ride in a car	☐	☐	☐
Ride in a van	☐	☐	☐
Ride the public bus system	☐	☐	☐
Read the bus schedule	☐	☐	☐
Call for a ride	☐	☐	☐
Fly in an airplane	☐	☐	☐

Other Activities/Behaviors:

The support or assistance that would be helpful:

Circle of Support

Self-Assessment Checklist

This checklist is for siblings, relatives, friends, and other people who give direct care and support to the person with a disability. There are a lot of different ways to provide support and each way is valuable.

This checklist was designed to open up communication and increase collaboration among family members and individuals in the network of support. The goals are to identify strengths, individual comfort levels with different tasks, and the skills and knowledge needed to participate in caregiving. Fill out the form by yourself and then **share it with each other or those in the "circle of support."**

TIP

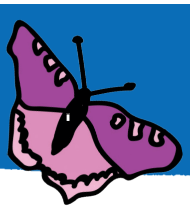
For each behavior/task, think about what you need to do or have before you can help out and write it down in the space provided.

For example:

1. Do you need to learn something about the person?
2. Do you have all the information you need to help?
3. Do you have to change something in your life before you can help (move, retire, or something else)?

I can provide this much help and support with the following:

Behavior or Task	None	Some	A Lot	To do this, I need to:
Advocacy: Support Self Advocacy for the individual	☐	☐	☐	
Advocacy: Help with Systems and Benefits	☐	☐	☐	
Companionship: Provide Respite or a Break	☐	☐	☐	
Emotional Support: Be there to listen, provide input, provide comfort	☐	☐	☐	
Find Services and Resources	☐	☐	☐	
Friendship: Be available	☐	☐	☐	
Friendship: To give and to receive	☐	☐	☐	
Friendship: Do things together	☐	☐	☐	



I can provide this much help and support with the following:

Behavior or Task	None	Some	A Lot	To do this, I need to:
Hands on Assistance • Bathing	☐	☐	☐	
• Feeding	☐	☐	☐	
• Dressing	☐	☐	☐	
• Transfer	☐	☐	☐	
• Grooming & Hygiene	☐	☐	☐	
Housework	☐	☐	☐	
Cooking: Meal Preparation	☐	☐	☐	
Coordination • Medical Care	☐	☐	☐	
• Therapies	☐	☐	☐	
• Social Activities	☐	☐	☐	
• Transportation	☐	☐	☐	
• Other:	☐	☐	☐	

I can provide this much help and support with the following:

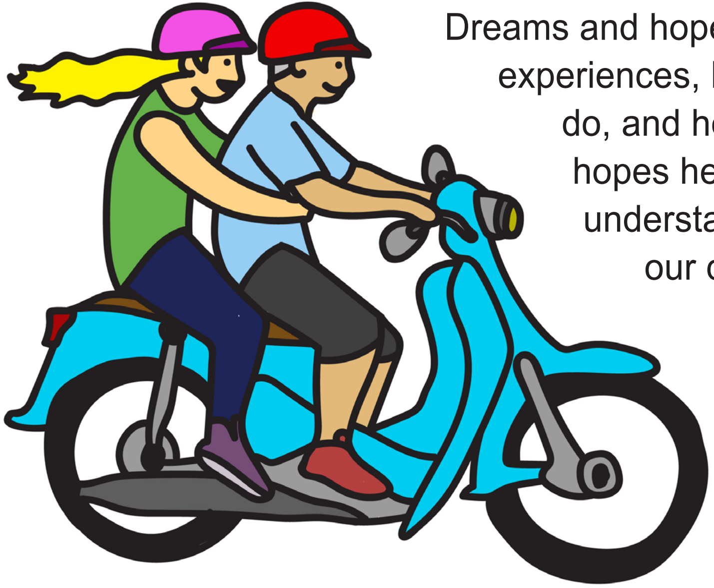
Behavior or Task	None	Some	A Lot	To do this, I need to:
Medication Management	☐	☐	☐	
Career/Employment	☐	☐	☐	
Exploration	☐	☐	☐	
Financial • Provide money	☐	☐	☐	
• Budget money	☐	☐	☐	
Relationships • Develop Relationships	☐	☐	☐	
• Teach Intimacy Skills	☐	☐	☐	
• Talk about Sexuality	☐	☐	☐	

I can provide this much help and support with the following:

Behavior or Task	None	Some	A Lot	To do this, I need to:
Legal Role • Healthcare POA	☐	☐	☐	
• General POA	☐	☐	☐	
• Payee	☐	☐	☐	
• Conservator	☐	☐	☐	
• Supportive Decision Maker	☐	☐	☐	
• Guardian	☐	☐	☐	
• Other:	☐	☐	☐	

Person-Centered Planning

Important to and Important for



Everyone has dreams and hopes throughout their life. Dreams and hopes may change depending on our age, life experiences, how we spend our time, what we see others do, and how we interact with others. Dreams and hopes help us reach our potential. They can help us understand our goals and how we get there. Sharing our dreams and hopes helps us plan for our futures.

Person-centered planning is a guided, systematic process that helps people identify the steps to make their dreams a reality. A full range of options for successful adult living is explored in partnership with important people in a person's life. Topics may include creating a vision for the future, employment, education, relationships, recreation, health and wellness.

One important piece of this planning process is to understand what is "**important to**" the person with a disability. There are also things that are "**important for**" the person. We must find a balance between the two.

The following worksheets (pages 45 and 46) are one way to help you explore and talk about the difference between what is **important to** the person and what is **important for** the person. Things that are important to the person include his or her hopes and dreams, likes and dislikes, places that are important, and special interests. At the same time, you will also identify what is important for the person, such as what is needed to ensure her/his health and safety and what will help him or her be a valued member in the community.

Important To:

Includes only what the individual is “saying” with words and behaviors. We can listen to the behavior when words and behaviors are in conflict.

Example: Sally loves motorcycles because her dad and uncle have one. Plans are made so Sally can go on periodic rides.

Example: Mohammed likes using his computer and wants to work at a store that sells computers. Mohammed and his family talk about how he will develop the skills necessary for this job.

Important For:

Includes only things that other people keep in mind when thinking about how to make sure that someone is safe and healthy.

Includes what others see as important to help the person be a valued member of their community.

Example: Manuel has a job interview with a new company. You take him shopping and he chooses a pair of shorts and a t-shirt with his favorite musical band on the front. He likes this t-shirt because it is comfortable and colorful. You share with Manuel that he can choose a dress shirt and long pants that he can wear to the job interview and to church. This way he can wear the top and bottom on more than one occasion. You tell him that it fits nicely and other people may like it too.

Example: Nicky is looking for an apartment and found one that is close to her favorite restaurant. The streets by the apartment do not have good lighting and there is no close bus stop. You talk about looking for another place in a safer neighborhood that is close to a bus stop. It may not be near her favorite restaurant but it is close to another restaurant that is similar to the one she likes.

Contributions for **Person-Centered Thinking** from **Sonoran UCEDD** staff: Jacy Farkas, MS, and Melissa Kushner, MSW.

Important To and Important For

Important To:	Important For:
What hopes, dreams, likes, dislikes, places, and special interests are important?	What is needed to ensure health and safety and become a valued member of the community?

Important To and Important For

Next Steps

Sometimes what is important to the person does not always match what is important for them. Here are some questions to think about and share with each other. Involve other people that play important and supportive roles.

How do we know what is important to the person?

How does ____________ express him or herself through words or behaviors?

Finding a balance between "Important To" and "Important For" requires tradeoffs. What are we willing to give up?

What information do we need to make informed choices?

What experiences do we need to explore or try in order to identify what may be a risk?

Resources

Person Centered Planning

Person-Centered Planning: Pathways to Your Future – A toolkit for anyone interested in Person-Centered Planning (English and Spanish).

https://sonorancenter.arizona.edu/person-centered-planning-pathways-your-future-toolkit-anyone-interested-person-centered-planning

My Interests, Hopes, and Dreams: An Exploration Tool and Guide to My Personal Preferences (English and Spanish).

https://sonorancenter.arizona.edu/my-interests-hopes-and-dreams-exploration-tool-and-guide-my-personal-preferences-available-spanish

The Learning Community for Person Centered Practices

http://www.learningcommunity.us/intro.htm

Helen Sanderson Associates: Person-Centred Practices, Sorting Important To/For

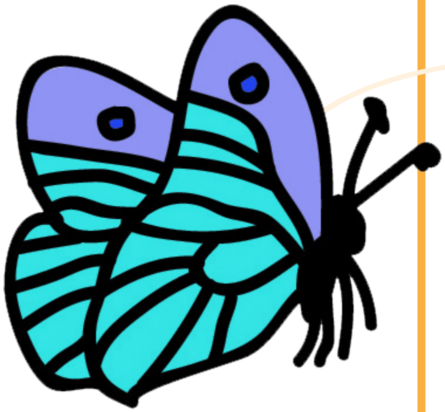
https://helensandersonassociates.com/sorting-important-to-for/

Employment

Finding the Right Job That Fits You (Me)

TIP

Finding a job involves many steps. Here are things to do as you and your family prepare to find a job that "fits" well with your abilities and your interests.



Exploring the Possibilities

A discussion about the following topics may be helpful in knowing where to look, how to prepare for the job, and what steps can be taken to make a plan of action. Talk about these things with the individual with a disability, family, friends, and other important people in one's life.

- What is a job?
- Why do people work?
- Why do you want to work?
- What are some jobs you know about?
- What kind of work do people do on these jobs?
- What jobs do your family and friends have?
  - What do they like about their jobs?
  - How did they prepare for their jobs?
- What hobbies do you have that can help you get a job?

It is hard to know what a job is really like until you see others do it or do it yourself. Look for opportunities to:

a) Volunteer at the job site or a similar place

b) Try it for a short period of time like a summer job

c) Shadow or follow someone at the work site

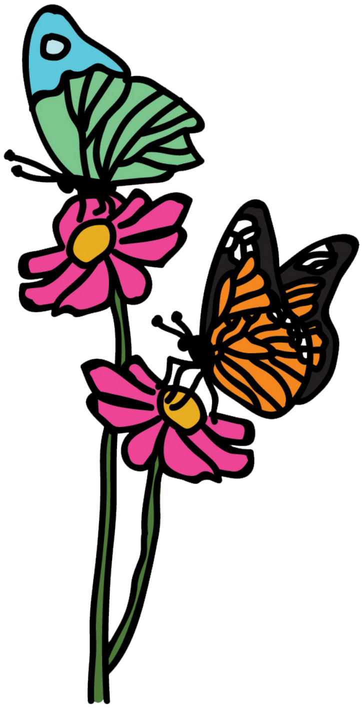
d) Visit several times with a mentor or coach who can explain how things work

Your Dream Job

What kind of job do you want? What do you dream about doing?

What type of work setting does the individual or "I" want to try? (check the boxes)

A place where:



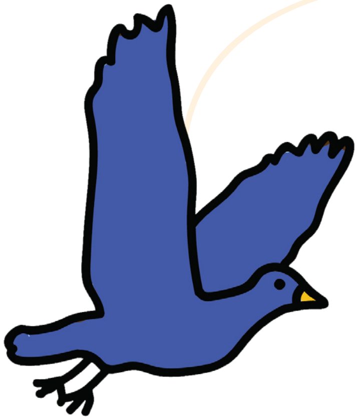
- ☐ Few or not too many people work (small business or employer)
- ☐ A lot of people work (big business or employer)
- ☐ Everyone moves fast or works fast
- ☐ Everyone moves slower and works carefully
- ☐ People work alone
- ☐ People work in a team
- ☐ People stay indoors
- ☐ People stay outdoors
- ☐ People work with their hands or with tools
- ☐ People use computers or machines
- ☐ People use their minds to solve problems
- ☐ People stay both indoors and outdoors
- ☐ People hang out together during lunch or after work
- ☐ There is a lot of contact with other workers or people
- ☐ There is not too much contact with other workers or people
- ☐ There is a lot of noise or different sounds (speakers, music, machines, etc.)
- ☐ It is quiet and peaceful (not many sounds or talking)
- ☐ Food is provided
- ☐ Parking is there for my bike, motorcycle, or car

Things to Think About

How many hours a week do you (I) want to work? Think about the time and energy you have to do the other things you enjoy. Here are some questions to ask yourself.

Questions

1. Can you work and still participate in exercise, sports, visiting friends and do hobbies?
2. Is your job close to where you live so it won't take too much time to get there?
3. Is there easy and accessible transportation?
4. Is transportation reliable and on time?
5. How much energy do I have after I work?



Write down your thoughts

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Getting Started

Now is the time to look at the person's (My) abilities and skills. There may be other skills that are needed before I get my dream job. Complete the following sentences.

Other people tell me I would be good at doing:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________

I feel I am good at doing:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________

I feel happiest when I can:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________

I need more practice doing:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________

Write down other thoughts

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Finding The Right Fit

How do I know if this job is the right fit? When you first start a new job, it may not be as much fun as you would like. Give it a good effort and see what happens.

You Can Ask

1. Do you like to go to work?
2. Do you like seeing the people there?
3. Are your supervisors (boss) nice to you?
4. Are you learning new things?
5. Do you feel like they enjoy seeing you?
6. Do you get the supports needed to do your job well?

Write down your thoughts

Training and Education

Before, During, and After High School

In school and at work, relationships are important. Everyone must work on getting along so that you can work together as a team. Some jobs need people to work alone and some jobs need people to work with others. Look at the following examples and think about how relationships can be improved in school and at work.

In school, did you get along well with your classmates?

____

What needs to happen so everyone gets along better?

____

____

What can be changed or done differently to make any experience, school, or work place better?

____

____

What can you do to make it better?

____

____

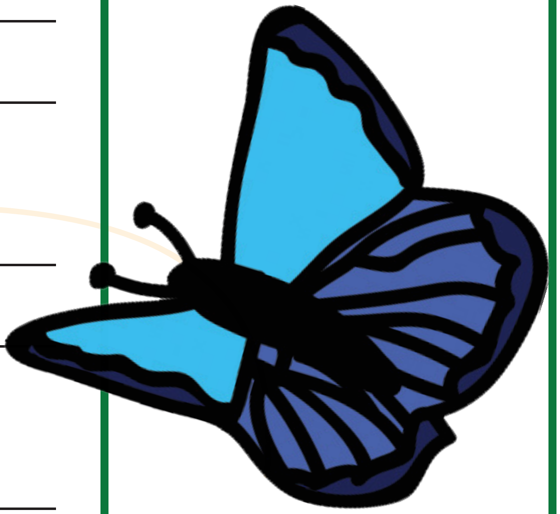
What can others do to make it better?

____

____

What skills can (or did) the person (you) develop in school?

- Middle school
- High school
- College
- Technical school
- Other educational programs



Useful Strategies

Continue to Learn New Things

Think about what other courses or classes you need to reach your career goals. There may be skills you need to have before you get into those courses too. Some courses provide information while some provide hands on experience.

Make a list of what you want to learn and how you will learn them.

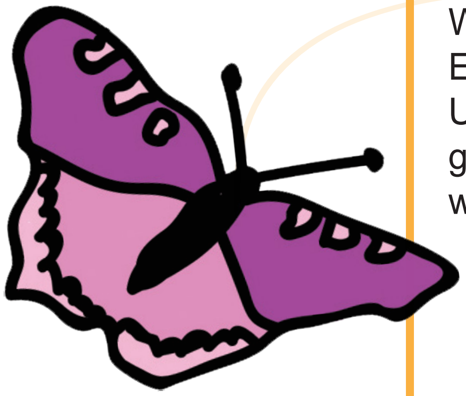
Make your plan.

Work skills can also be learned at a Career and Technology Education Center, two-year college, and four-year University. Talk with a school counselor, people who graduated from that program or school, or the place you want to work.

1. Ask what it will take to get a job and what courses will provide that information and skills.
2. Ask the educational program if they provide or help with job placement and support.
3. Ask if there is an apprenticeship program.

TIP

Talk with a school counselor, people who graduated from that program or school, or the place you want to work. Ask what it will take to get a job and what courses will provide that information and skills.



You Have a Job!

It's a great feeling to have a job. Be patient because it takes time to feel very comfortable in a new job. Think about what you need to be successful. Your job should also be fun and exciting.

We all learn differently.

Tell your coworkers and your boss how you learn.

Some people need to:

- Repeat the task over and over
- See and follow pictures
- Write down the steps
- Hear a recording of what they need to do
- Watch others do it first

All of these ways are useful strategies. You may also think of other ways that help the individual (You, Me) learn.

____

____

____

____

TIP

Be patient because it takes time to feel comfortable in a new job.

Job Coaching and Mentoring

TIP

In some cases Coaching and Mentoring may be paid for

OR

you may need to find a volunteer or friend.

Look for a Job Coach or Mentor

Talk with your support coordinator or Vocational Rehabilitation program staff about finding a job coach. Some of this is paid for or you may need to find a volunteer or friend. Also talk and work with advocacy groups, independent living centers, The Arc, and other organizations to find out what is available. The employee is the person who just got a job. The employer is the person who hired the person for the job. Communicate clearly what is expected from the job coach and when they are no longer needed.

Contributions for **Employment, Training and Education, Job Coaching and Mentoring** from **Sonoran UCEDD** staff:
Susan Voirol, MSW, Laura Schweers, BS, Melissa Kushner, MSW.

Questions To Ask Your Job Coach

Ask if he or she can help with all or some of the following:

☐ Help find natural supports at the job site to assist the employee

☐ Help clarify and understand job responsibilities and employer expectations

☐ Identify how the environment can change or adapt to support the employee

☐ Develop a sense of belonging among other employees and the job site

☐ Find ways to integrate and include the employee in job related social activities. Develop social connections

☐ Look for ways to increase safety on the job site

☐ Translate or explain in simpler language the culture of the organization or job site

☐ Ensure that appropriate job training is provided

☐ Serve as a resource finder

☐ Provide encouragement and emotional support

☐ Check in with the employee to see how things are going and what is needed to move forward

☐ Encourage employee to get feedback from boss or supervisor

☐ Practice positive ways to communicate with others

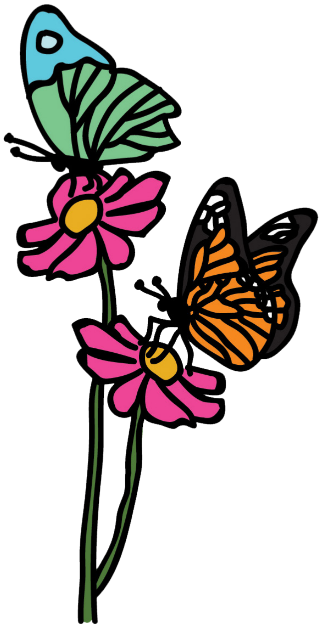
☐ Help look for assisted technology that may help make the job easier or more comfortable

☐ Provide prompting or cues at the job site until they are not needed anymore

☐ Work with the employee so that the job coach or mentor slowly does less and less

TIP

Communicate clearly what is expected from the job coach and when they are no longer needed.



Roommates

Making it Work

Having a roommate can make life happier or it can make it very frustrating. This worksheet lists things you can think about as you look for a roommate or roommates to help assure that you will find a compatible match.

You will hear many say that "communication is key." Look at ways to make communication easier and clearer. This means finding ways to make the other person feel like they can speak openly about what is on their mind. Open communication and sharing ideas will help roommates get along better. Find ways to allow your roommate to relax and be thoughtful about what you can do to help. If you don't know just ask.

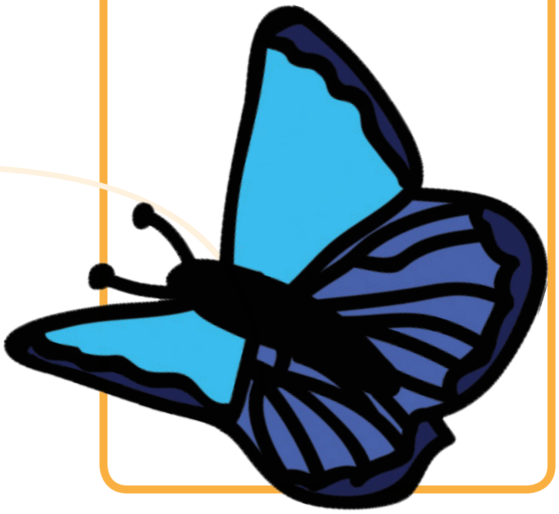
Are there habits that annoy you or annoy your roommate? Talk about things that bother you right away and don't wait until you get more upset because it happens over and over again. Good communication goes a long way when living with someone and making it work well.

On the following pages are some suggestions of things to think about that can help roommates interact with each other in a more positive and successful way. By considering these questions you will learn a lot about yourself and your roommate. This is important for the success of living together in harmony.

TIP

Good communication with your roommate will help to promote a more comfortable living arrangement.

- Be willing and open to hear suggestions and accept criticism
- Communicate openly from the very beginning
- Be willing to talk about things that might be uncomfortable
- Remain calm when having a difficult conversation



Things to Think About

Use of Space

- Be reasonable when space is limited
- How much of your belongings or things will fit in the space you will have?
- Give your roommates enough space so that you don't get in the way of their daily routine
- Be as neat as you can
- How will cleaning chores be shared?
- How would you like to decorate your space?

Daily Routine and Lifestyle

- How much social activity do you enjoy?
- Do you like to have people over? If so how often and for how long?
- How much time do you spend at home?
- What type of activities do you enjoy doing at home and how often?
- How much quiet time do you need?
- How do you like to use your quiet time?

Write down your thoughts

Things to Think About

Sleep Patterns

- Do you go to sleep early and get up early?
- Do you go to bed late and wake up late?
- Are you a light sleeper who wakes up easily or needs earplugs to sleep?
- Are you a heavy sleeper?
- What kind of alarm do you use to get up in the morning? Do you need more than one alarm?

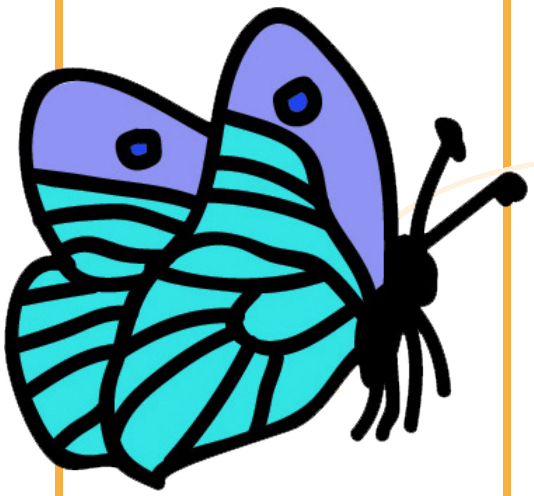
Eating Habits

- Do you prefer to eat alone or with someone?
- Who cleans up after eating?
- Do you eat three meals a day?
- What kinds of snacks do you enjoy?
- Is food shared or bought and eaten separately? If shared:
  - How will the cost be shared?
  - Who will do the shopping?
  - Who will decide what to buy?

Write down your thoughts

TIP

After you have thought about your own habits, patterns and lifestyle, consider writing down important topics to you that you would like to talk about to current or potential roommate(s).



Other Considerations

- Some people like roommate agreements as a way to talk about boundaries and expectations
- Who needs to be involved in the discussion about choosing roommates, responsibilities, and how space will be shared?
- How often will agreements be reviewed for changes
- What does compromise mean
- Don’t expect your roommate to change every part of their lifestyle or daily routine

Being Understanding of Emotions

Everyone has stress in his or her life at one time or another. When people are stressed or feeling anxious or have something on their mind that is bothering them they may act in a different way. It can be very helpful when roommates can notice and understand when their roommate is upset or having a bad day.

When people are having a bad day or don’t feel good they can also withdraw or want to stay by themselves. They can do this by getting quiet, by moving to a different corner of their space, or not talking or interacting with others. When this happens it is helpful to know what they want you to do or not do. Knowing these things about your roommate in advance will help everyone to get through what might be a hard time for someone.

Adapted from Melinda Delkic’s “Learn from my mistakes and avoid these common roommate problems” in The New York Times, August 2, 2017. Enhanced with ideas from individuals with disabilities and their families.

Emergency Network and Information

This list contains names, phone numbers, and information that are helpful in a new situation or an emergency.

In an emergency or sudden change, the following information can minimize stress or clarify the next steps.

Name of Person Who Needs Support:

____

Nickname or Preferred Name: ______________________________

First Person to Call in an Emergency:

____

Primary Care Provider

Physician ______________________________

Phone ______________________________

Nurse ______________________________

Phone ______________________________

Other (name) ______________________________

Phone ______________________________

Pharmacy

Name ______________________________

Address ______________________________

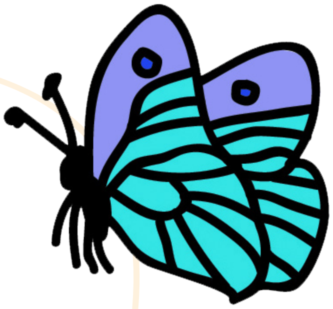
Phone ______________________________

Allergies ______________________________

____

TIP

Complete this form and leave it in a plastic bag in a location that is easily seen or accessible. Options include taping it to the refrigerator or putting it in the freezer in a plastic bag.



Medications: Name, Dosage, Frequency (with or without food)

____

____

____

____

____

____

Supplements: Name, Dosage, Frequency

____

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Other health care providers who are involved: (list their contact number)

Counselor or Therapist ______________________________

Support Coordinator ______________________________

Case Manager______________________________

Social Worker ______________________________

Occupational Therapist ______________________________

Physical Therapist______________________________

Speech Therapist ______________________________

Rehabilitation Professional ______________________________

Other Individuals To Call

Name	Contact Information	Relationship and Information or Support They Can Provide

Additional Useful Information:

Helpful Communication Strategies

New situations or sudden changes can be stressful for everyone. Write down and share what you and your loved one with a disability can teach others in hopes of clear communication and support during a stressful event.

What would you like others to know when your loved one with a disability:

Faces a sudden change: ____

____

Meets someone new: ____

____

Finds him or herself in a new situation: ____

____

Does a particular task: ____

____

Wants to share an idea: ____

____

Wants to express an emotion: ____

____

In other situations? ____

____

____

Describe and explain what some common behaviors or gestures can mean and how to communicate and respond in a supportive way.

What others should know about helpful communication strategies:

1. Behavioral Communication: behaviors, gestures, or physical movements that are used to communicate wishes, wants, and emotions:

____

____

Ways to Respond: ____

____

____

2. Verbal Communication: words, sounds, use of voice, use of body with language:

____

____

Ways to Respond: ____

____

____

3.Manual signs: writing, drawing:

____

____

Ways to respond: ____

____

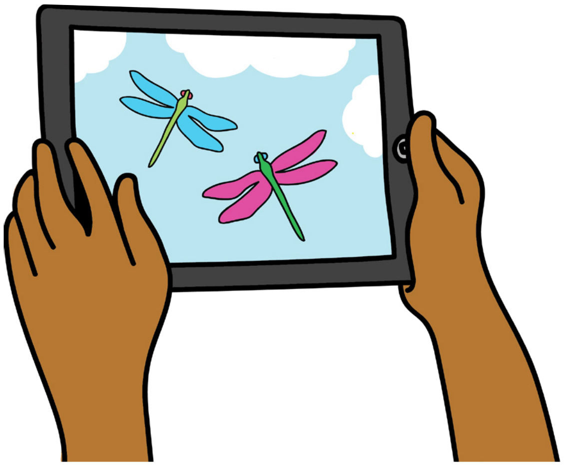
____

Assistive Technology

Assistive technology (AT) is any item, type of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. [Reference: ATiA at https://www.atia.org/at-resources/what-is-at/ (accessed 5/21/24)]

Examples of assistive technology (AT) are:

- Low-tech: communication boards
- High tech: special-purpose computers
- Hardware: prosthetics, positioning devices
- Software: screen readers and communication programs
- Inclusive or specialized learning materials and curriculum aids
- Mobility aids: wheelchair, walker, braces, power lifts



Finding the right AT is a team effort. The following organizations can provide additional information.

- AOTA, American Occupational Therapy Association
- ASHA, American Speech-Language-Hearing Association
- CEC, Council for Exceptional Children
- LDA, Learning Disability Association of America
- RESNA, Rehabilitation Engineering & Assistive Technology Society of North America

List all the assistive technology (AT) being used

Technology Used	Describe How it is Used

Identify what AT can be explored in the future.

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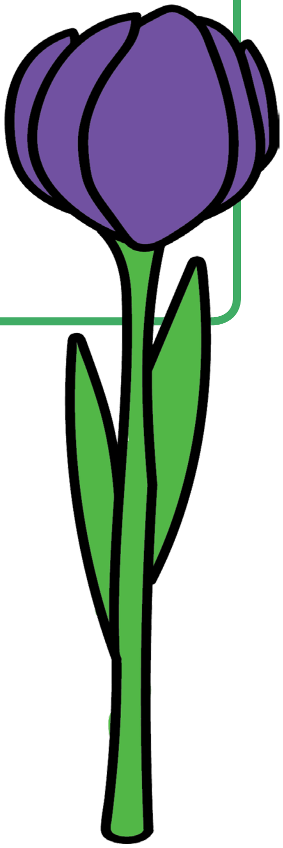


Facing Transition and Change

Change is part of life

Change happens whether we like it or not. Sometimes change and transition can be more difficult for family members when it's about planning for their futures. This section is designed to help us look at how we adjusted to past transitions in hopes of preparing us for the next one.

During life's many transitions we are faced with options and choices. Some decisions are clear and some are not. Future planning can be a daunting and difficult conversation. We can choose to "not plan" or to design a plan based on thoughtful conversations and decisions. Caregivers expressed that there are many unknowns that made them and their family member feel vulnerable. This section provides some tips on how to face change and transition and to learn from past experiences.

Possible ways to deal with change and look toward the future.

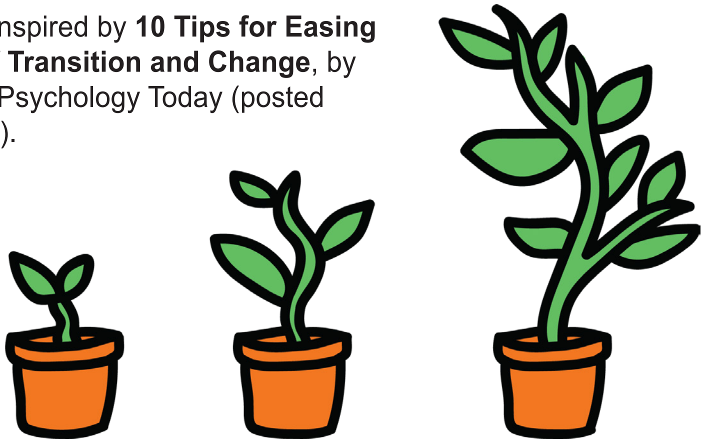
1. Recognize that some parts of future planning decisions may be more difficult than others. Feeling anxious, sad, eager, along with having feelings of joy and relief are okay.
2. Place more emphasis on the positive emotions. Don't focus on just one emotion or feeling.
3. Identify how you have managed change before and focus on what made you successful.
4. Focus on the things that you have control over and what can have a positive impact on everyone. Don't focus too much on the "what ifs." There are too many of them. Open communication will be an important part of this process.
5. Find new opportunities and be proactive. This includes trying new things, exploring other talents and interests, and expanding your network of support. Also remember to expand the network of support for the individual with a disability. The goal is to engage a variety of supports and people in the future. The more eyes and ears, the better.
6. Take time to replenish your body, your mind, and your spirit. Use respite services that are offered by friends, family, and programs. Say "yes" more often than "no."
7. Ask for help when you need it. People may not know how to help so you need to tell them exactly what they can do or provide. Be concrete and give clear instructions.

8. Try new ways to lessen your anxiety and fears. Explore complementary medical modalities, meditation, prayer, or other creative expressions.
9. Be open to hearing suggestions and ask others to be honest and open with you.
10. Remain hopeful. Hope comes in many forms.
11. Be nice to yourself. Remember that you are doing the best that you can.

Resources:

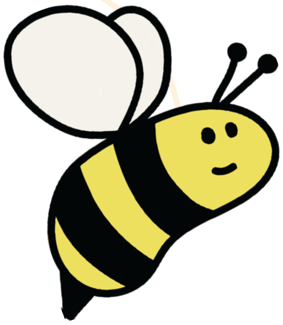
1. NAMI: National Alliance on Mental Illness. Phone: 800-950-6264. **https://www.nami.org/#**
2. Substance Abuse and Mental Health Services Administration (SAMHSA). 1-800-662-HELP (4357). **https://findtreatment.gov**
3. National Suicide Prevention Lifeline: Call 988 **https://988lifeline.org**
4. National Association of Area Agencies on Aging: **https://www.n4a.org**

This list was inspired by **10 Tips for Easing the Stress of Transition and Change**, by Ann Smith in Psychology Today (posted May 19, 2015).



TIP

Most important, if you feel stuck, alone, or sad, and are not able to move forward - find a friend, confidant, or a professional who can help.



The Meaning of Hope

We all need “hope” in our lives. Our definition of hope can change when we face new experiences, challenges, and transitions. It is important to understand that hope can be defined in many different ways. Having hope is a good thing. Answer the following question for you and for your loved one with the disability.

I define hope as: ______________________________________

____

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I hope for: ____

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Together, we hope for:__________________________________

____

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____

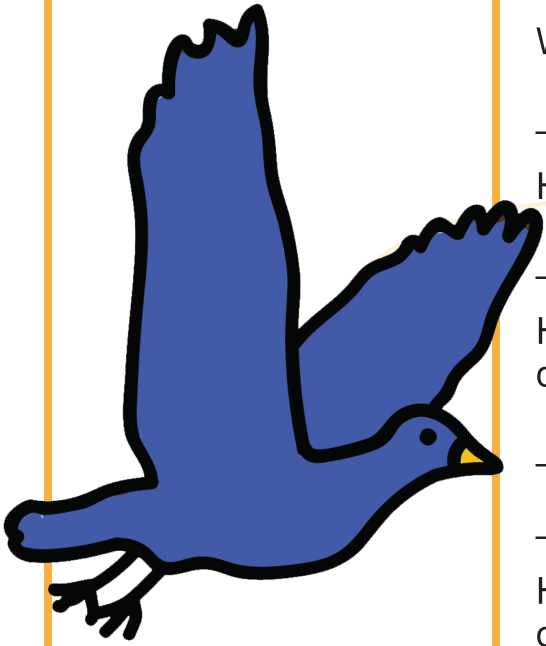
____

TIP

Our definition of hope can change when we face new experiences, challenges, and transitions. If you feel stuck, alone, or sad, and are not able to move forward - find a friend, confidant, or a professional who can help.

How I Face Transition and Change

Now is the time to look at how you are dealing with change and transition. You have faced other situations that were challenging and emotional in the past so let's look at the positive ways to move forward.



Identify past changes or transitions you have faced.

What would you do different? ____________________

____

____

What worked? ____________________

____

____

How might your experience with past changes/transitions apply to future planning? ____________________

____

____

What emotions did you feel? ____________________

____

How did you remain positive? ____________________

____

How did you keep yourself motivated if you found yourself discouraged or roadblocked? ____________________

____

____

How were you successful in the past? What did you focus on? ____________________

____

Thinking about current changes or transitions.

What would you like to try this time? ____________________

____

____

____

How can we make this experience successful? __________

____

____

My steps to take:

1. ____
2. ____
3. ____
4. ____

What kinds of help would be useful?

☐ Physical
☐ Emotional
☐ Spiritual
☐ Legal
☐ Financial
☐ Other ____________________

Suggestions other people have shared with me: __________

____

____

Additional information I need:

☐ Community Integration
☐ Employment
☐ Financial Planning
☐ Living Arrangements
☐ Quality of Life
☐ Legal Options
☐ Support Networks

My Creative Side

How I express and share my creative energy:

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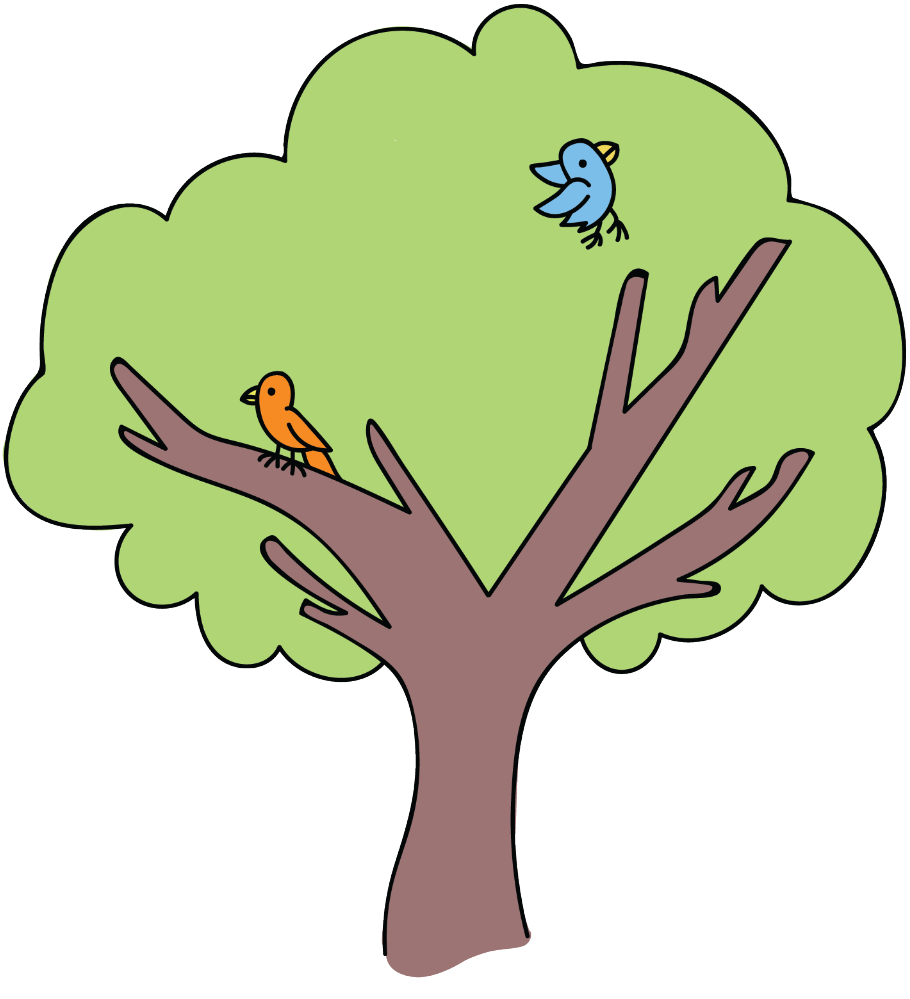
Chapter Three

Important Considerations

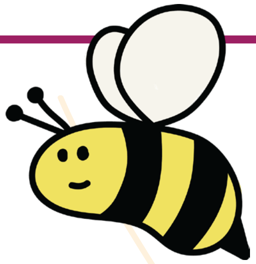


ABLE Accounts

Information about Setting Up Your Account

An **Achieving a Better Life Experience (ABLE)** account can be created as a result of the passage of the Stephen Beck Jr. Achieving a Better Life Experience Act of 2014 (ABLE Act). It is a type of tax-advantaged savings account that a person with a disability, also known as the beneficiary and account owner, can use to pay for disability-related expenses. Each person can create one ABLE account. To be eligible, the person with the disability must meet the following criteria:

- Onset of disability or blindness began before age 26
- Person is eligible for SSI, Medicaid, and other public benefits
- If person is not receiving SSI and or SSDI, but still meets the age of onset disability requirement, he/she could still be eligible. The individual must meet the Social Security's definition and criteria regarding significant functional limitations. Person must also obtain a letter of certification regarding functional limitations from a licensed physician.



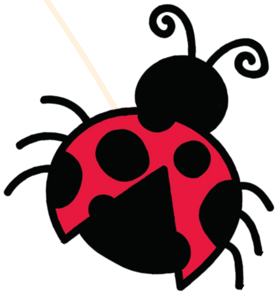
An ABLE program can be established by a State (or State agency or instrumentality of a State). An eligible individual can open an ABLE account through the ABLE program in any State, if the State permits it.

Anyone can make contributions to the account (like family and friends) and contributions must be made with post-taxed dollars. Check your state regarding tax deductible contributions. The total annual contribution for a single year as of 2024 is $18,000. This amount may be adjusted for inflation. The total limit in the ABLE account is determined by the individual state and the current government benefits the individual is receiving. For example, a beneficiary's SSI cash benefit would be suspended if their ABLE account exceeds $100,000. See https://www.ablenrc.org/what-is-able/what-are-able-acounts/ for more details.

Additional information on the following topics is available from the Social Security Program Operations Manual System (POMS) at: https://secure.ssa.gov/poms.nsf/lnx/0501130740 (accessed May 2024).

- When to exclude ABLE account contributions, balances, earnings, and distributions
- When to count ABLE account balances and distributions
- How to verify, document, and record ABLE account balances
- How to verify, document, and record ABLE account distributions
- Handling and recording ABLE prepaid debit card information

Some States formed partnerships to improve access for eligible individuals to enroll in ABLE programs. You may see different types of arrangements between States administering ABLE programs.



Additional Resources:

The Arc for people with intellectual and developmental disabilities

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. ARC encompass all ages and more than 100 different diagnoses including autism, Down syndrome, Fragile X syndrome, and various other developmental disabilities.

https://www.thearc.org/

The Arc Arizona Chapters

In Arizona, there are Arc chapters in Chandler/Gilbert (Chandler), Douglas (Douglas), Gila County (Globe), Mohave County (Kingman), Northeastern Pinal County (Kearny), Santa Cruz County (Nogales), Tempe, Tucson, YES (Cottonwood), and Yuma County.

https://www.thearc.org/find-a-chapter/arizona

ACL: Administration for Community Living

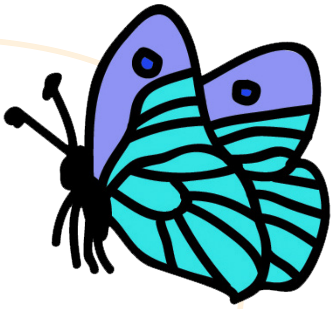
Protection & Advocacy Systems (P&As) work at the state level to protect individuals with disabilities by empowering them and advocating on their behalf. There are 57 P&As in the United States and its territories, and each is independent of service-providing agencies in their states.

https://www.acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems

Disability Rights Arizona

Protection & Advocacy System for Arizona

https://disabilityrightsaz.org



My ABLE Account Information

Name of Beneficiary and Owner of ABLE Account:

____

Contributors to the ABLE account

Name, relationship to beneficiary, and contact information

Name ______________________________
Relationship ______________________________
Contact Info ______________________________

Name ______________________________
Relationship ______________________________
Contact Info ______________________________

Name ______________________________
Relationship ______________________________
Contact Info ______________________________

Name ______________________________
Relationship ______________________________
Contact Info ______________________________

Name ______________________________
Relationship ______________________________
Contact Info ______________________________

Name ______________________________
Relationship ______________________________
Contact Info ______________________________

State where ABLE Account is located:

____

Administrative body or person to contact about the ABLE Account:

____

Person completing this page:

____

Date ______________

Supported Decision Making

Supported decision making puts the person with the disability first. He or she is the most important person and is in charge of decisions being made. It involves the belief that each person has a right to make decisions and to learn from them. That person is at the center of the team. The individual with a disability decides who is on the team with input from family and people who know and respect the person. The team can include family, close friends, direct support professionals, personal assistants, and health care professionals. In the medical field you will hear about the concept of shared decision making which is similar to supported decision making. The emphasis is on health care decisions and end of life planning.

Supported decision making is also about close relationships and the belief that each person has something valuable to give. Therefore, it is a partnership where decisions are made together. It is about providing information and different perspectives that can help the person with a disability make decisions that are important to him or her.

Here are some ideas on how to facilitate and help with supported decision making:

Communicate clearly by doing the following:

- Pay close attention to the choice of words, gestures, behaviors, and other forms of expression
- Be honest and give the facts – stay neutral as much as possible
- Allow the person with a disability to ask questions
- Allow others on the team to ask questions
- Understand and learn about appropriate technologies that are available to assist with communication
- Provide information in multiple formats that use simple and clear language
- Use scenarios or examples to understand options and choices
- Write things down so you can see and follow a person’s thoughts and choices

Identify and clarify the following:

- Person's goals
- Team's goals
- Facilitators and barriers to reach each goal
- Person's concerns regarding a decision
- Pros and cons of each decision
- Options and choices that are available
- Costs of each decision and choice

As the person with a disability ages, there are additional things to think about and discuss.

Ask the person with a disability and members on his or her team the following questions:

- What additional supports are needed?
- What becomes more important to him or her over time?
- What can influence a person's decisions as he or she ages?
- What may affect the person's health and well-being?
- How does the person define quality of life at different life stages?
- What additional resources are available as one ages?
- How do others know when the person is providing "informed consent?"
- Will members on his or her team recognize health and cognitive changes?
- How does the person with a disability typically make important and tough decisions?
- What has worked well in the past?
- What has not worked well in the past and why?

On each person's team, there may be one or two individuals who play a key role in ensuring that the person's decisions are communicated and implemented. This takes time and a commitment from these individuals. Their lives and circumstances may also change over time.

Here are other considerations:

- Who will play key roles on the individual's team?
- Who is available to help implement the decisions?
- How long will this person be available?
- Who is available if the primary contact person or persons cannot be reached?

During life's many transitions, circumstances and health conditions will change and unexpected events can occur. Shared decision making cannot be implemented for every person with a disability. It is just a part of a continuum of decision making and ability to make informed decisions.

The Continuum of Legal Options

This section is not designed to provide legal advice or recommendations. It is about how to communicate needs and wishes when involved in a legal process. When legal issues are unclear or you don't know where to start or what to ask, it is best to consult a lawyer with expertise in that area. There are also organizations in your city and state that work closely on the behalf of persons with disabilities such as Protection and Advocacy Systems, Planning Councils, and private nonprofit organizations. When reviewing printed or online materials, remember that federal and state laws do change.

There are several legal options for individuals age 18 and older who need help with decision making. The options are not covered here but a good resource is the Legal Options Manual. This manual is regularly updated so make sure that you have access to the most recent edition. You can find it through the Arizona Developmental Disabilities Planning Council or the Disability Rights Arizona links below.

Disability Rights Arizona

https://disabilityrightsaz.org

Arizona Developmental Disabilities Planning Council

https://addpc.az.gov/

Our partners include the Native American Disability Law Center in New Mexico

https://www.nativedisabilitylaw.org/

Guardianship

A Thoughtful Decision

Supported decision making and person-centered planning are important concepts and processes that protect a person's rights, self-determination, and independence. Both concepts require thoughtful and honest discussions about what the person wants, his or her ability to make informed decisions, and the availability of natural supports like family and close friends to be there when needed and during a crisis.

Guardianships are complicated and consulting a private attorney is helpful. This option should be considered as the last resort. For some individuals and families it is an appropriate option. For individuals and their families, this can be a complicated and emotional process so it is important to remember that caregivers/family members also need support and respect. Some families may seek guardianship before the person's 18th birthday so there is a smooth transition and some states allow this. Other families may wait until there is an urgent need or change. If guardianship is the best option, individuals and families may want to consider starting the process before a crisis. You don't want to place added stress on the individual and family. Check with your state laws about the filing process and requirements.

Full legal guardians have total control over decisions unless the court appoints a limited guardian. A limited guardian has decision making authority over specific areas and the individual can keep some of his or her decision making rights (for example - right to vote and privilege to drive).

The primary issue is whether the person with a disability lacks "capacity." In other words, does the individual have the ability to gather, use, and understand information that will allow him or her to make informed decisions. These areas include: health care, housing and living arrangements, friendships and intimate relationships, budgets and finances, voting, driving, entering into contracts, and other day-to-day decisions we all make. It also involves the ability to learn new skills that will assist the individual to know when he or she may be vulnerable and open to abuse (different types), neglect, and exploitation.

In Arizona, the probate judge makes the final decision about guardianship with input from a medical professional, court-appointed attorney for the individual, petitioner or their attorney, and a court-appointed investigator. If the petitioner is represented by his or her own attorney, that person also provides valuable information. The investigator's role is to serve as a neutral fact-finder who meets with the individual and person or persons requesting guardianship. The investigator may also speak with other people closely involved in the individual's life. The process can feel uncomfortable and intrusive.

The investigator's assessment will address the following sets of questions:

1. **Is a full guardianship necessary?**
    a. What decisions can the individual make independently or with some support?
    b. To what degree can the person participate in decisions?
    c. What kind of support does the individual need with his or her activities of daily living?
2. **Who is the appropriate person or persons to serve as guardian?**
    a. Are there other individuals who want to be the guardian?
    b. Is there a desire or need to have co-guardians?
    c. If co-guardians are being recommended, do they work well together?
    d. If co-guardians want to share responsibility, do they both want the authority to make decisions independent of one another?

The individual and family play an important teaching role in the guardianship process. You can provide the attorneys and the investigator a more complete picture of the life you share together.

Here are some things you can do:

- Provide a schedule or information about a typical day for the person with a disability to show how everyone interacts with each other.
- Explain how the individual participates in "activities of daily living" (bathing, eating, toileting, grooming, etc.) to show one's abilities.
- Explain and give examples of how the person communicates through words, sounds, gestures, and behaviors to show the most comfortable and effective ways to communicate.
- Provide names and contact information of people who play a close and important role in the life of the individual with a disability. This provides the opportunity to gather different perspectives.

Lastly, share your ideas for the future and how your plan will ensure a good quality of life.

Chapter Four

Relationships and the Human Connection

Voices of Individuals and the Family Members who Support Them

In this chapter, we hear the voices of individuals with a disability and from family members who support them. Their messages teach us that friendships, close relationships, and being loved are necessary to live a full and happy life. Nurturing existing relationships, forming new connections, and spending time with each other are what we all need in our daily lives.

Healthy Relationships

> *"Look at relationships and how to be in relationships in a healthy way. So you know, how to be friends, and what does that look like? What is it like to have a significant other, are you interested in that? Loving your body, knowing your body, you know accepting all those pieces and knowing how to navigate. And also being in a safe relationship or safe relationship with anybody."*

Families Need Other Families

> *"Be involved with a couple other parents that are dealing with the same issues because it's nice to have that support to bounce things off of. Myself, I think the biggest issue is the paperwork, all this—anything regarding paperwork—living trusts, guardianship, burial plans, and all that stuff is—to me, I get overwhelmed with that kind of thing where just discussing or trying to come up with ideas—I don't have a problem with that….I think, when you have a support around you. For instance, I have a friend who told me, she's got a daughter, and she's helped other people with the guardianship paperwork. She's going to help me through it. I think the support, like I said, is with other families that have already dealt with certain things."*

Changing Roles

> *"We're doing less and less for him. It's been a slow process. He's still doing—not doing some things that a typical individual his age would, so in that sense, that's—that hasn't really changed, but I think we have just probably fallen more into the role of just supervising now, rather than doing things for him. That has changed quite a bit."*

Culture, Tradition and Extended Family

“You have to also understand that as Hopi’s, we’re a communal-type people. We don’t like to send our kids off just because there are resources available to them, and they will be taken care of by somebody else. That’s not how we think. Our responsibility is to our children, and we need to keep them here in the community. We have extended families that help with that also…. He has first cousins. He’s got extended families. He’s got relatives and people that will support him however they can when the time of need comes. That’s really what we were—the whole village—I don’t know if you’ve heard that concept before, but the village raises the child…. Some people call him even from New Mexico to check on him to see how he’s doing. He’s got a lot of other people that know him. I think it makes him feel good when people are really happy to see him, too. The same way in the community he doesn’t isolate himself. He goes and visits relatives and friends. He makes friends with an effort to do that. I think he’s got a lot of social support.”

Reach Out to Me

“If there wasn’t so much crying or troubles in the world, and if I had more money to do things, it would make things a lot easier, and if people weren’t so afraid of helping people with disabilities or talking down on them, and getting more of an opportunity for employment. I think that would make things better…. They don’t want to start a friendship or a conversation, unless it’s for a disability related event, people don’t usually want to start a friendship or a conversation, because they’re not sure how that person with the disability is going to react, especially when you can see the disability.”

Technology and the Social Connection

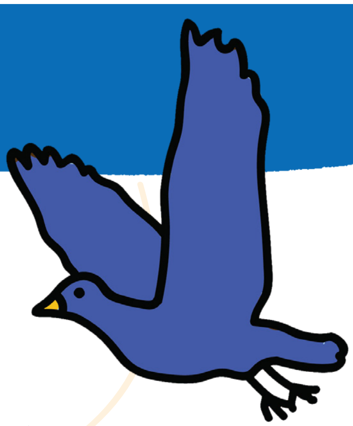
“Oh my gosh, everybody needs to have one of those - Alexa. He talks to it constantly. I can hear him in the morning say - Good morning Alexa, how are you? She will start to tell him what’s going on in the world, what the headlines are, what the weather is like. At night, the same thing. He will ask, what’s going on in Washington? What’s the weather going to be like tomorrow and she will talk to him. It’s a wonderful way to gather information but also to interact. It forces you to have speech with someone, it’s just a good tool.”

Respite is For Everybody

“I’m a father and single parent for my son. For me, taking advantage of respite was a learning curve…. Respite, it’s hard to get a family member to take advantage of it…. It’s important for the other person to have a break from you. My son needs a break from me to be around somebody else as well for a weekend and overnight….One thing all of us know that when the first time you leave your child at daycare—whether they’re two or three or whatever, if you have a child—it’s a heart-wrenching thing for you as a parent. The kid starts crying, sure. But if you were to go back and look through—if you were to somehow have a two-way glass, your child’s in there having fun. Then the reunion at the end of the day, that’s an important part of everything….Respite is a two-way street.”

Being Alone is Not Fun

“Living in an apartment was not making Tanya happy…. I could also tell she was unhappy because she would spend no time at home. When I’d call her in the evenings to check up on her, she wouldn’t be there. It was a problem waiting to happen…. Her provider came up with the Ranch setting which has just been perfect…. My feeling was Tanya needed to have other people in her home life, so she felt like it was a home rather than just an empty room to come home to at the end of the day. That was probably the biggest, most significant change in her life that has led her—what I think is really a good time in her life where she really seems happy.”



Friends Looking Out for Each Other

"He works there twice a morning helping with the farming duties. He takes care of animals, he has a roommate. For the first time ever, he has friends…. Not friends in the way that we have friends, but friends in the way that his roommate—he knows when his roommate isn't there, and they tell me that he seems sad when his roommate is not there. When his roommate comes back, he's happy. His roommate is non-verbal, but they have created a communication between the two of them, where they wait for each other when it's time to go to an activity."

Sibling As Adult Peer

"It's great. It's not something to fear or dread as being too much of a burden or too much work. It does require effort, but it's not hard. In fact, it's fun having this kind of a relationship with her. As I said earlier, if I had to live with her, that would not be fun, but being able to be an adult peer with her, and she came over to our house for lunch for Easter Sunday and had a great time. When she was ready to go home, she went home, and she'd had enough of us, and we'd had enough of her, and it was great. I would be the first to say that I don't think that our situation is what a lot of families are dealing with. I know a lot of families are still back in that phase where they are all under one roof. They're all getting on each other's nerves. I guess what I would say to those folks is this too shall pass because we were there."

Getting Reacquainted as Siblings

"Well, yeah, I'm learning a lot. I'm learning a lot from her. It's mostly for the good that's she's here, so we can work through these little hiccups or whatever you want to call frustrations. I think we can have a good thing going here. We absolutely love her. My daughter, my husband loves her. I think it's going to be a good, positive thing for us. It's just going take some time, I think, for us all to get to know each other really well. I'm ten years older than her, so when she was born, I had more to do with her when she was younger in her toddler times, and then as soon as I graduated high school, I was gone."

Impact of Professionals

“That they can make a difference. They really can and it must be very challenging….. Because you really couldn’t see the effect you’re having, but you are having an effect and it’s really important to know that…. I think that’s important to know that your helping hands and it’s so hard to find the right one or to find people, who are interested. I think these jobs are pretty hard to do and maybe not always as rewarding. I would want them to know that they really make such a huge difference. I remember the names of practically every PT, OT, and speech therapist that we’ve had. They’ve made such a huge difference and certainly every psychologist; they’ve made a huge difference. We were just talking about some of them the other day. So these are people, who we are not in touch with anymore, but they’ve made our lives manageable and also they gave me hope…. Kyle was difficult, it’s hard to see now, but he was really difficult. Especially, the teenager, he was extremely challenging. He was really mad that he wasn’t like other kids so it was a real challenging time.”

Love and the Human Connection

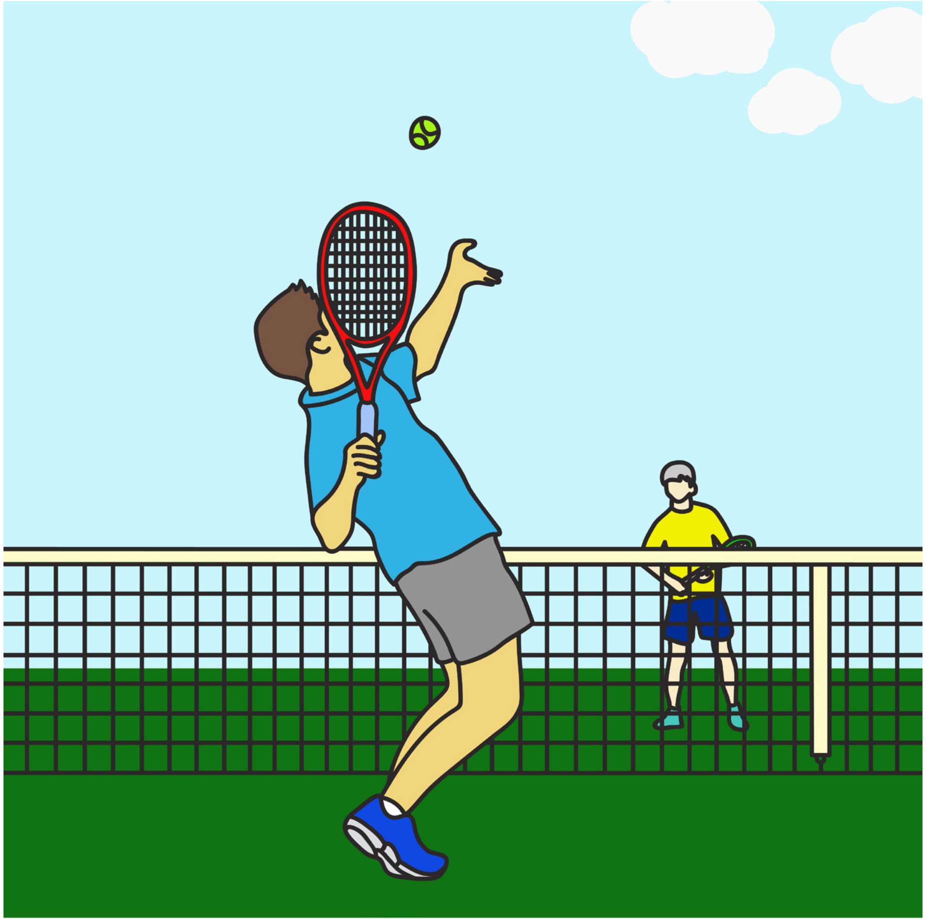
“I’ve gotten really sick of having to guess what people are thinking or feeling or whether or not they mean what they say or not, or just trying to keep me at arm’s length. If you spend five minutes with me you will find that I’m – everything is functioning but my voice is just a little bit slower than you’re normally used to hearing. I’m very bright, I’m very intellectual. And I mean what I say.”

Hope For the Future

“I want to think about maybe getting married, but I’m not too sure about that, and then I want to have children and eventually be living out on my own or even with some friends that are roommates of mine. I would like to find something that I am doing that would contribute money, but that’s really hard because there’s not much employment for people out there with physical disabilities.”

Partners in Life

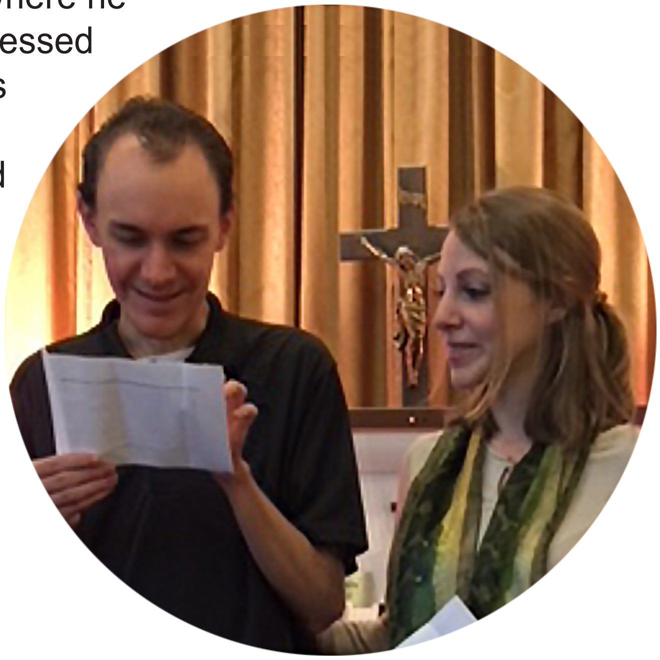
> *"I would say sometimes I worry about it more than other people do. I'm particularly anxious of my finding a partner to spend my life with…. And still to this day I'm concerned about my job possibility, but I'm much more concerned about finding a partner to spend my life with than I am about a job. But it is very much real, because we're not – we were not placed here to just work, pay bills…. We are a social culture, we are a social species. Love is a birth right from the creator. If we cannot have that we downward spiral easily."*



Christopher and Cassandra

Christopher is in his 30s and is the youngest of three siblings. His sister Cassandra lives in Tucson and the oldest sister recently moved back to Southern California where Christopher lives with his parents. Despite living in another state, Cassandra and Christopher talk frequently on the phone.

Christopher is on the autism spectrum and has an intellectual disability. From a very young age he could spell everything he wanted to say and was very good with numbers. He is a happy person and handles things with grace even when other people make assumptions about him. He is a social person, very kind, and doesn't allow his disability to get in the way of his happiness. Christopher has a passion for helping others. He participates in a day program, takes classes, volunteers at a senior home, and works at a thrift store where he enjoys organizing things. Cassandra has witnessed Christopher's evolution as a man where "he is always growing and always evolving, …he teaches his own peers, has good intuition and a good sense of what is right and wrong."



Future Planning

Cassandra and her sister have talked about sharing responsibility but they are unsure what that means or looks like for now, although they know that Christopher wants to live with family. The family started talking about future plans when their grandfather died recently. This triggered conversations about end of life, final arrangements, and what the future may look like. Loss and grief are moments that bring the family together and they use these opportunities to have those difficult conversations. Christopher said after his grandfather's death, "grandpa died and I feeling so sad but I don't cry at work because it's not appropriate." It is important to the family to talk openly, to share life's experiences, and to look at planning as something that evolves. They are flexible yet they share a commitment to talk and plan together.

Dirk and Tracy

Dirk loves to remind his sister Tracy that on September 17, 2018 he will be 55 years old. He gets more excited about planning his birthday than any other holiday. He wants burritos and pizza. Dirk also made arrangements with the owner of his Jazzercise site to dance on stage next to the instructor for a few songs. Dirk is a good dancer and the instructor mirrors his movements – he loves country western but enjoys music from all genres. Dirk was looking for an exercise option for health reasons and started Jazzercise in 2008. When Tracy comes home, he is always ready in his ercise clothes so Tracy just can't refuse.

Dirk is doing well but he has faced many transitions in his life. He and his parents moved in 2004 to be closer to Tracy and her husband Paul. They all lived in the same co-housing community. Dirk's mother died in 2010 and he became his father's caregiver until his death in 2016. He finds comfort in talking to people who knew his dad and is very much grieving like anybody would.

Dirk is currently living with Tracy, Paul, and their 16-year old granddaughter Lucy who now has her driving permit. She and Dirk often go to get ice cream. In this family, Dirk plans the social calendar for everyone.

At the co-housing community, everybody knows Dirk. His job is recycling for the community. This involves getting the garden cart and taking the paper mailings and craft room scraps to the recycling area. He also loves working with the chickens that live on the property. Everyone is very appreciative of Dirk's efforts and the best part is that Dirk has an opportunity to help other people.

Over the years, Tracy has noticed that Dirk's short term memory has been declining, but he can still do crossword puzzles. He does better with consistency and order so the family has found creative solutions that help Dirk maintain his independence. For example, Dirk can fold his laundry but has trouble organizing his drawers of clothes. His family created a new clothing system by getting a metal frame with shelves and bins. Dirk can now see the big picture and all his clothes. If he wants his Jurassic Park t-shirt, he can find it easily. The family also marked his shampoo bottle as #1 and the conditioner as #2. This makes it easier to remember which one to use first.

Future Planning

Dirk's co-guardians were his father and Tracy. Now Paul is the financial representative and Tracy will be co-guardians with her youngest daughter who lives nearby. If Tracy and Paul are not available, Dirk will live with Tracy's youngest daughter because Dirk does not want to be home alone.

Dirk's future plans involved decisions about where to live and with whom, and who is available to provide support with decision making and problem solving. Tracy also realized that social connections are a very important part of Dirk's quality of life. Dirk was dealing with the loss of his parents and also a good friend named Roy.

This friend was his support coordinator (SC) through DDD. The SC would check in with Dirk and always ask about the dances at Armory Park. They talked about the woman that Dirk sees and dances with. One day a different SC showed up and Dirk found out that Roy moved on to another job. He never received a letter or phone call from his SC. Dirk decided that he doesn't want to go to the dances anymore. Tracy realized the important role his male SC played in Dirk's life. He was a friend and a confidant. Dirk did not have a chance to say goodbye. Tracy is hoping to find someone else that Dirk can talk to about his female friend and dancing.

May 2024 update: Tracy remained Dirk's primary caregiver through his stages of dementia. She utilized resources from DDD, ALTCS and eventually Hospice to help navigate the rewards of living with people with disabilities and the challenges of supporting Dirk as he became more dependent. Dirk continued to decline due to his advancing Alzheimer's and the isolation from his social life during COVID-19. He passed away at home in July 2022. His family misses him and keeps his memory alive retelling favorite "Dirkisms." Tracy was invited to be a part of the Board of Directors for the Southern Arizona Network for Down Syndrome (SANDS) and is grateful to still be a part of the Down syndrome community.

Katie

Katie has been involved with Ability360 since 2006 and she now has a part-time position teaching people with disabilities about self-advocacy. She is passionate about her work and states that, “I love to show people how much they can do in the world and how much they can speak for themselves and do things. How much they can overcome.” Her job involves going to day programs to teach people about how they should be treated and want to be treated.

Katie has grown a lot in her confidence and skills. In her high school special education classes, she did not get a lot of support or encouragement from her teachers because of her physical and learning disabilities. She was shy and later learned that she had to feel self-confident and learn from other people. She told herself that “she had to get involved.” Being involved with Ability360 has provided opportunities for her to learn from other people. Katie is now a role-model for others.

Ever since Katie was little, she wanted to be in a pageant and she always watched them on TV. She was friends with the coordinator who started a chapter for the Arizona Miss Wheelchair pageant. Katie won first place! As the 2016 winner, she traveled to Michigan to compete in the Miss Wheelchair America contest. Katie said the highlight of the competition was, “It wasn’t a beauty pageant, it was more like what people cared about – things that meant something to them.” Katie’s message was promoting leadership for youth and young adults. This experience gave Katie more confidence. She continues to be active in sports and community service. Every month she tries to do a community service event and recently participated in a fashion show for little kids with disabilities. She got a medal for the Desert Challenge National AZ Disabled Sports Program. She practiced with a coach from January until June and competed against people from different countries like Mexico.

Future Planning

Katie lives with her mother and younger brother. She states that, “When I think about my future, sometimes it’s scary for me….I hope to be able to learn some things – I need help with managing money and budgeting.” Her dreams include marriage and having kids. She’s met a lot of people at her groups but has not met that special person yet. Eventually, she hopes to live on her own with some roommates. She would prefer to have a roommate that is organized, who has a sense of humor, is fun and likes to do things.

For now, Katie likes being with her mother and is not ready to move out. She is in her 30s; her brother is eight years younger. She has a close relationship with her mother and they talk about the future often. Katie knows that her mother is worried and wonders if Katie will be alright. Katie feels it will be okay and knows that her brother will be there to help her. Katie continues to do things for herself and others. She is an inspiration.

In Closing

Future planning is about possibilities, taking small risks, dreaming big, and creating meaningful relationships. It is about communication that is honest, gentle, and straightforward.

Here are some friendly reminders for your personal journey

- Be person-centered
- Start planning early
- Explore options
- Remain flexible
- Include siblings and family
- Ask for help
- Remain on task
- Build networks
- Stay hopeful
- Work through emotions

Arizona Developmental Disabilities Planning Council℠

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