



History of Roadmap Project

- Funding: 2016 and 2017- 2018
- Focus: Applied Research
- Outcome: Create variety of planning tools in different formats
- Products:
 - *Future Planning A Roadmap of Our Futures, Our Wishes*
 - Infographics: Employment and Planning
 - Audio Stories: 2 families



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Project Objectives

- Collect data through surveys and interviews
- Apply findings into trainings for
 - Direct support professionals (DSPs)
 - Families and caregivers
- Create a workbook on future planning
 - For persons with disabilities, families, DSPs
- Design tools that reflect the lives of individuals with disabilities and their families



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Outcomes

Cycle One: 2016

Data Collection:

- Survey: N=99
- Interviews:
 - 44 family members
 - 19 individuals with disabilities

Cycle Two: 2017-2018

- Trainings
 - Family members
 - DSP, Professionals
- Create Products/Tools



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What We Know & Learned

- **Future Planning is Difficult**
- Opportunities become limited as one ages
- Wishes, goals & expectations must be clear
- Person-centered planning is central
- Family members' roles will evolve/change
- Social relationships are important
- Individuals with disabilities and families need emotional support & guidance



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Trainings: 2017

Date	Site/Partner	Attendance	Providers	Family CGs
April 28	Tucson DDD	19	17	2
July 14	Phoenix DDD	14	11	3
July 29	Tucson CPES	12	6	6
Sept 8	Phoenix Arc	3	0	3
Sept 27	Tucson	18	5	13
Oct 27	Sierra Vista	7	5	2
Dec 4	Tucson	3	1	2
TOTAL		76	45	31



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Training Topics

- When and how to start planning
- Topics to explore and discuss
- How to facilitate conversations among individuals and families
- Principles of person-centered planning
- Introduction of tools and worksheets that facilitate communication and planning



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A Roadmap of Our Futures Our Wishes

Chapters:

1. Future Planning: What Is It All About?
2. Worksheets to Guide Communication and Planning
3. Important Considerations
4. Relationships and the Human Connection



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Chapter One Future Planning: What is it all about?



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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?

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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 how to start"

"I don't know where to start"

"I've talked about it"

"I know I have to do it"

"I have been thinking about it"

"My children will take over"

"I don't know what will happen"

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Explore Different Scenarios and Options

Write them down

Option 1:

Option 2:

Option 3:

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Chapter 2 Worksheet Topics

- This is Me, My Life, Our Lives (2)
- Activities That Bring Me Joy
- Pieces of Our Plan
- Checklist of Daily Activities
- Circle of Support: Self Assessment
- Person-Centered Planning
- Employment: Right Fit, Training, Job Coaching (3)
- Roommates
- Emergency Network
- Assistive Technology
- Facing Transition and Change (2)
- Meaning of Hope

Chapter Two
Worksheets to Guide
Communication and Planning

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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)?

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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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Advocacy: Help with Systems and Benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Companionship: Provide Respite or a Break	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Emotional Support: Be there to listen, provide input, provide comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Find Services and Resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Friendship: Be available	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Friendship: To give and to receive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Friendship: Do things together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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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

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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


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Chapter Three
Important Considerations



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Chapter Four
Relationships and the Human Connection



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- **ABLE Accounts**
- **Voices of Individuals and Families**
- **Supported Decision Making**
- **Profiles and Personal Journeys**
- **Guardianships**

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Voices of Individuals and Families

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."

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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 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."

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Dirk's Life and Plan



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 burrito and pizza. Dirk also makes arrangements with the center of his Jazzercise class to dance on stage next to the instructor for a few songs. Dirk is a good dancer and the instructor reminds 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 exercise 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 cohousing 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 know his dad and is very much grieving his anybody would.

Dirk is currently living with Tracy, Paul, and their 16-year-old granddaughter Lucy who no longer 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 cohousing 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 children 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 so she and the family have 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 shirt, he can find it easily. The family also marked his shampoo bottles 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 is very 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 Jimmy Park. They talked about the woman that Dirk sees and dances with. One day 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 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. It is important to provide information and closure in all relationships because attachments are formed like everyone else.

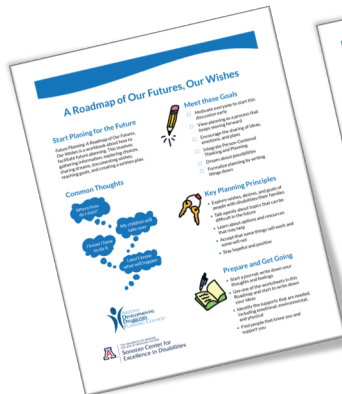
Tracy feels blessed to live with Dirk. She describes him as "one of the funniest people I know. He is interesting and because of co-housing, he can have a nice co-existence with family, neighbors and friends."





Accessible Products

- Fillable
- English and Spanish



Additional Tools



- Audio Stories:
 - Becky
 - Heath
- Infographics:
 - Planning & Employment
- Training Videos:
 - How to use Roadmap
 - Worksheets



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