



FACILITATOR'S GUIDE: PLANNING FOR A GOOD LIFE

MOVING FROM UNPREPARED TO PEACE OF MIND



full circle
CAPACITY BUILDING INITIATIVE

Connecting to
Create a Good Life



table of contents

2 Introduction

What is a Good Life	2
Background	3
Glossary of Terms	4
Framework	4
Methodology	4
Limitations and Assumptions	5

7 How to use this tool

Goal of the Tool	7
When to Use This Tool	7
Meeting Planning	7
1: Welcome and Introductions	8
2: Familiarize Families with the Guide	8
3: Collecting and Accessing	8
4: Focus	8
5: Post-Meeting Support	9
Sample Meeting Invitation	9

10 Understanding the Stages of Future Planning

Descriptions of Stages	10
Stages	11
1: Loving Friends and Family	11
2: Ability to Contribute Unique Gifts	15
3: Participating in Decision-Making	18
4: A Place to Call Home	22
5: Financial Stability	26



introduction

WHAT IS A GOOD LIFE?

What is a good life? This question is at the core of the work of the Full Circle, Capacity Building Initiative and the organizations who are part of Full Circle. Organizations involved in Full Circle include FIRST, Planned Lifetime Advocacy Network (PLAN), and the Asset Based Community Development (ABCD) Institute, with funding from the North Carolina Council on Developmental Disabilities (NCCDD). It's a unifying question for parents, caregivers, and facilitators. It opens their hearts, minds and imaginations regardless of circumstance, age, beliefs, or life experience. Asking what makes a good life gets to the root of every family's hopes and fears for their relative with a disability.

Every family's answer is unique and important.

As a Facilitator, you work with families to help them define what a good life looks like, think beyond reliance on professional services, and to get the support they need to achieve a good life. These are lofty goals, but persons with disabilities have the same goals as persons without disabilities. Our goal is to give you and the team your support the resources to set up and achieve a good life.

People with disabilities are also aging. Better medical care and good lives in the community mean that they have a longer life expectancy than they once did. As a result, they are likely to outlive their parents.

The confluence of these two trends, an aging population and longer life expectancies of people with disabilities offers new challenges and opportunities for families. Full Circle's goal is to support families have the difficult conversations and plan for their loved ones with disabilities when their parents pass away or are unable to care for them. FIRST and PLAN believe that personal support networks can fill this gap.

To Full Circle, Capacity Building Initiative, the concept of a good life means that every person:

- knows the loving support of nearby family and friends
- contributes to, and participates in, a caring and inclusive community
- is respected and empowered to make choices
- lives in a place they call home
- enjoys a meaningful and financially secure life
- has a well-planned future, enabling their family to have peace of mind



BACKGROUND

Full Circle is a capacity-building initiative designed to mobilize personal networks for people with disabilities. Full Circle helps people to expand their circles of connection and natural support in their communities, giving them more opportunities for meaningful and supportive relationships; more experiences; an overall sense of belonging; and a good, happy life. FIRST created Full Circle as part of an initiative of the North Carolina Council on Developmental Disabilities (NCCDD) and has also partnered with the ABCD Institute of DePaul University and Plan Institute, a Canadian organization supporting the work of Planned Lifetime Advocacy Network.

The Full Circle Program is an opportunity for people with disabilities, and their families and caregivers to learn more about the values, principles, practices and tools that they will use to build and nurture Personal Support Networks. Personal Support Networks are groups of people who are in relationship with an individual and are committed to help them attain their dreams and life goals. Personal Support Networks can serve as a bridge between the individual and active inclusion in the community.

They can serve in many roles based on what the individual wants and needs, such as:

- building lasting and valued friendships
- cultivating unique gifts and contributions
- being involved in the life of the community
- having supportive friends to depend on for help
- empowering personal choice and decision making
- dreaming and planning together
- securing and monitoring supports and services
- assisting with finding jobs and place to call home
- peace of mind for family members

FIRST is a resource center for persons with disabilities and their families that has been serving families in Western North Carolina since 2002 about special education issues, how their child's disability can impact their life, access to community resources, and best practice strategies. Started by a group of parents and professionals with a goal to inform and support families of children with disabilities; today it is still a family led non-profit. With our mission, FIRST provides persons with disabilities and their families with programs and advocacy to support and foster healthy, inclusive and self-determined lives, we work to support persons with disabilities and those at risk and their families. We do this with a variety of services including early intervention, parent and caregiver coaching, and support services in the home and community.

Check out of website for current projects at www.firstwnc.org.



PLAN is a family-led, non-profit organization dedicated to building inclusive communities for all citizens. Since 1989, PLAN families have been working toward the vision of inclusive communities for all citizens by building personal support networks and planning for the good lives of persons with disabilities. As a family-led organization, we support families: a person with a disability and those who love and care about them.

PLAN's cornerstone program is called Lifetime Membership: we maintain personal support networks for the lifetime of the person with a disability, even after the parents have passed away.

This tool, together with the guidance of a Facilitator, will help to organize and format all these factors so that there is a solid, long-term plan in place. By clearly defining the role of the personal support network, parents will have peace of mind for the future knowing that their son or daughter will continue to have a good life, even after they have passed away.

GLOSSARY OF TERMS

Focus person

The person at the center of the planning work.

Personal support network

A group of caring family and friends who are actively involved in the life of a person who may otherwise experience social isolation.

Guide

This document that provides information for Facilitators about how to help families and personal support networks progress with future planning.

Elements

The five priorities that make up a good life. This includes: loving friends and family, the ability to contribute unique gifts, participating in decision-making, having a place to call home, and being financially stable.

Tool

The instrument in this document that consists of a series of scales used to determine progress through the stages of future planning. In this guide, the tool has for each good life element: the desired outcome, prompting questions for consideration, and a scale of progress towards that desired outcome.

Stage

The markers along a scale that graduate towards the desired outcome. In this guide, the



desired outcome is peace of mind. In this tool each scale has six stages: Peace of Mind, Reviewing, Working, Learning, Becoming Aware and Unprepared.

Scale

The graduated range of stages that measure the progress in future planning. In this guide the scale goes between Peace of Mind and Unprepared.

Outcome

The intended results of successful future planning.

FRAMEWORK

For the purposes of future planning, the scale supports progression towards a good life. Each element of a good life: loving friends and family, a place to call home, financial security, participating in decision-making, and the ability to contribute their unique gifts is reviewed separately. The scale informs Facilitators on where to direct the families and the Personal Support Network's ongoing future planning work.

METHODOLOGY

Full Circle's methodological approach to assessing future planning is by using this tool which is rooted in the principles of the PLAN's Lifetime Membership program, which includes family leadership, developmental learning, a strength-based approach, and ensuring reliability and validity.

Family Leadership

People with disabilities and their families have a distinct talent for innovation because they are continuously inventing and creating their way out of adversity. As such, they are a primary source of social innovation and leadership. Full Circle and our partners recognize the power of family innovation and have a core value of family leadership. Family leadership is a principle woven through FIRST and PLAN in a number of ways including program involvement and organizational accountability.

Developmental Learning

Planning a good life with focus persons, families, and personal support networks is complex and emerging from situations that are dynamic and continually changing. In many cases, there are multiple people involved, high levels of innovation, fast paced decision-making, and areas of uncertainty requiring flexibility. Because of this, we used the principle of developmental learning, meaning that as needs emerge we respond appropriately and then learn from it. We use this new learning to continue to develop our programs (including its tools) and services.



Strength-Based Approach

A strength-based approach of inquiry will be appreciative and so focuses on the existing assets in our work and the progress that families have already made in establishing good lives for their sons and daughters with disabilities. Any development of ideas, recommendations, and other areas will build on what is strong in the people and program.

Validity and Reliability

Validity and reliability are important to ensure that the scoring of the indicators is free of bias and the information we collect is sound. Reliability ensures the tool is consistent. Validity ensures the tool is measuring what it is supposed to measure. The tool has been tested for both validity and reliability.

LIMITATIONS AND ASSUMPTIONS

- this tool is a person-to-person tool only, it is not a self-assessment tool
- facilitators require training and skills to administer the tool
- the focus person's and family's context and external factors of personal well-being, mental health, economic status may impact how they are able to confidently move towards planning for the future
- this tool is being used in the context of the relationship with a mentor, coach, or facilitator
- the person providing the answers has the proper accommodations for them to answer accurately

how to use this tool

This tool is a resource to help people with disabilities, families, and personal support networks work together to reach the goal of a good life for focus persons and peace of mind of parents and caregivers. This tool is not designed to be used by families in isolation without the support of a Facilitator. As a trained Facilitator, it is your role to guide the meetings by using this tool and by providing follow-up support. Be sure to familiarize yourself with the Meeting Planning section so that you have a sense of the general flow of these meetings.

Facilitators must have skills and training in the development of personal support networks. PLAN Institute's "Personal Support Network Facilitation" course is recommended.



GOAL OF THE TOOL

This tool is meant to be used by Facilitators to guide families and personal support networks during future planning meetings. Its goal is to bring peace of mind for parents by helping to create a clear plan which, with the involvement of the personal support network will ensure a good life for the focus person. The tool uses within each element of a good life scales with stages of progress to guide planning towards ensuring a good life for the focus person.

WHEN TO USE THIS TOOL

This tool will help to guide meetings held at least annually with families, focus persons and personal support networks to facilitate the creation of work plans and help get all the pieces of future planning in place.

The annual planning meetings are a chance for parents, caregivers, representatives, trustees and all others who play an important and specific role in the life of the focus person to talk, review, reflect, and provide input about planning for now and in the future in the areas of relationships, contribution, financial stability, choice-making, and having a place to call home.

MEETING PLANNING

This is a sample meeting plan for Facilitators to use in their annual planning meetings with families.

Objective

To help families identify areas to focus their planning work

Materials

Facilitator's Guide and related tools

Time

90 minutes

Preparation

Facilitators will:

- invite attendees
- review notes from any previous meetings
- develop a meeting plan
- become familiar with the indicators in the Facilitator's Guide



1: WELCOME AND INTRODUCTIONS

The welcome and introductions are often hurried, but it's well worth spending time to make families feel comfortable and oriented to the work they are about to do. The following are suggestions on how to welcome and introduce the family to the meeting:

- welcome families and other participants to the meeting
- ensure the names of all participants are known
- make the meeting as comfortable and natural as possible
- circle check-in: why is it important that you are here?
- ensure the meeting is a conversation rather than an inquiry (e.g., ask open-ended questions, build on ideas of participants, ask participants to say more about their ideas)
- re-cap the results of the last meeting (if available)

2: FAMILIARIZE FAMILIES WITH THE GUIDE

In this part of the meeting, you will introduce the guide to the families. In particular, outline what the tool is and how it can help. Ensure families understand it is only a supporting guide, not an examination of their planning process.

- you can orient families by introducing or re-introducing the five good life elements. We recommend that the Facilitator focus on one element at a time
- introduce the description of stages and the objective of attaining the goal of peace of mind for each future planning element
- introduce the prompting questions, which are used to generate discussion

3: COLLECTING AND ACCESSING

The harvest is the time to collect information from the family and personal support network for each indicator. To ensure this part of the meeting is well done, we recommend that you:

- provide an update or overview of one element
- review outcomes
- ask prompting questions one by one
- allow for a chance to respond
- take detailed notes
- reflect back what has been heard from the focus person and other participants

4: FOCUS

The focus is where you distill the information you've collected from the family and personal support network into S.M.A.R.T goals related to next steps in the planning process.



- clarify where the family might be in the planning progress
- ask family for validation and clarification
- thank families and explain next steps

5: POST-MEETING SUPPORT

In between meetings, you continue to provide support and guidance to the family and personal support network. You can provide post-meeting support by:

- discussing next steps with families and personal support network (if needed)
- helping families and the personal support network to identify priorities over the year
- providing resources as needed

Use your facilitation skills to ensure all voices are being heard and that you are using accommodating language so that everyone can participate.

SAMPLE MEETING INVITATION

This is a sample meeting invitation for Facilitators to use in their annual planning meetings.

Dear **NAME**,

*I'm writing to see if you're able to join **FOCUS PERSON, FAMILY NAMES** and me (**NAME**), to work on **FOCUS PERSON's** future planning so they can be safe and secure for the future.*

*This process will look at the five elements of **FOCUS PERSON's** good life: their loving friends and family, their ability to contribute unique gifts, their participation in decision-making, their place to call home, their financial stability, and the preparations that must take place to complete all the planning and preparation.*

Your role as a member of the personal support network would be to learn and contribute to this planning process.

*We would like to host this meeting on **DATE**, from **TIME**, and then an hour (**TIME**) to have some lunch/dinner and talk, if you wish.*

*We will meet at **PLACE, INSTRUCTIONS TO GET IN.***

*Please confirm that you would like to be a part of this process by emailing me back by **DATE** at **EMAIL.***

*With much gratitude,
HOST NAME*



understanding the stages of future planning

The planning for each good life element goes through several stages before you achieve the ultimate goal: Peace of Mind. Life is dynamic, and peace of mind is not a permanent state, which means that reviewing the stages of planning is an ongoing process.

This tool provides a way for families, focus persons, and their personal support networks to review the future plans on a regular basis and identify at which stage of planning they are in. When a life event occurs that affects future plans, then this tool can be used to guide planning so it leads back towards Peace of Mind. For example, your future planning may include the preparation of a document that is relevant to your current life situation. When this document is complete and reviewed with your personal support network, you will likely have an increased sense of Peace of Mind. Then, if that situation changes and you need to re-write the document, you may move back to Working as you prepare documents and consult supports (e.g., legal or financial advice). Once it has been re-written and reviewed, you will again be able to have Peace of Mind. Each stage of the future planning process is described in the table below.

DESCRIPTIONS OF STAGES

Peace of Mind

All planning and preparation is complete; there are no outstanding actions at this time.

Reviewing

Plans are regularly reviewed. All relevant people connected to the focus person, including family, personal support networks, trustees, representatives, authorities, etc., are familiar with the plan and know that it is up-to-date and complete.

Working

Planning is in progress. The family is establishing priorities, creating strong and comprehensive plans, preparing written documents, accessing available formalized supports, meeting and discussing plans with members of the personal support network.

Learning

Plans are developing. The family is actively accessing resources and information while developing the relationships needed to plan and prepare.

Becoming Aware

Plans are starting. The family is becoming aware of specific tasks associated with planning and preparation, including the individuals and groups to be involved.

Unprepared

No planning or preparation has begun.



stages

1: LOVING FRIENDS AND FAMILY

A network of caring relationships is the foundation for a good life. The best guarantee of a safe and secure future for a loved one with a disability is to ensure they have a caring network of family and friends who are actively involved in their life. This network of relationships is called a personal support network. Being connected to others gives life meaning, joy, and fulfillment. It creates a place for sharing life passions, challenges, and triumphs. Connections are what foster love and belonging, and they also keep us safe and secure in the community.

OUTCOME

When a focus person's good life includes loving friends and family, these will be the outcomes:

- there is an active personal support network in place
- the members of the personal support network are involved and engaged
- there is a defined plan or specified goals in place to guide the personal network's support
- the personal support network provides practical support
- the personal support network provides support to navigate the healthcare system towards good mental and physical health

✓ CHECK-IN LOVING FRIENDS AND FAMILY

1.1: Is there an active personal support network in place?

Peace of Mind

All involved feel confident that there is a strong personal support network of caring relationships actively involved and fully supportive of the focus person.

Reviewing

An active personal support network is in place, providing informal care and support as needed by the focus person.

Working

Collaborating with a Facilitator to formalize the personal support network through planning meetings and social gatherings.

Learning

Identifying and communicating with current and potential relationships about the personal support network.



Becoming Aware

Beginning to learn about personal support networks and how to build them.

Unprepared

No network of friends or meaningful relationships exists for the focus person.

1.2: How involved and engaged are the members of the personal support network?

Peace of Mind

All members of the personal support network have roles and are actively involved and engaged. There are no other needs or ideas for roles that others could play.

Reviewing

Members of the personal support network are actively involved and engaging in their assumed roles. There are regular review and planning conversations to mitigate challenges and plan for transition.

Working

Friends and relationships see themselves as part of a personal support network and work to figure out how they can best engage in the role they would like to have.

Learning

Friends and relationships that can be a part of the personal support network are invited to engage in planning conversations and learn about the specific roles they could play.

Becoming Aware

Considering existing relationships and roles that might benefit the focus person's life. Thinking about possibilities of people who can fill each of the roles.

Unprepared

Friends and relationships do not exist, or if they do, they do not have any defined or specific roles.

1.3: Is there a defined plan or specified goals in place to guide the personal network's support?

Peace of Mind

A work plan is being followed and the progress is monitored.

Reviewing

A work plan is being monitored and reviewed annually for progress.



Working

Developing a work plan for the personal support network.

Learning

Learning what constitutes a work plan and how to develop one.

Becoming Aware

Understanding what a work plan is and how it contributes to planning and preparing.

Unprepared

No work plan is in place for future planning of the focus person.

1.4: How does the personal support network provide practical support?

Peace of Mind

Practical supports are in place and working well.

Reviewing

Practical supports are in place and being fine-tuned for an optimal experience. Any available funding is being accessed.

Working

Working to engage the best support for the focus person for specific roles. All funding possibilities for supports have been explored.

Learning

Learning what is needed in terms of support for the focus person and identifying possible sources to engage and fund supports.

Becoming Aware

Understanding what is needed in terms of support for the focus person.

Unprepared

Caregivers (e.g. parents) are doing all the work to support the focus person.



1.5: How has the personal support network provided support to navigate the healthcare system towards good mental and physical health?

○ Peace of Mind

Members of the personal support network monitor changes to mental and physical health and support and manage the stability of the focus person.

○ Reviewing

Members of the personal support network are able to identify changes to mental and physical health, and engage necessary medical services to resolve or manage issues.

○ Working

Members of the personal support network can identify changes and specific challenges to mental and physical health, and can identify necessary medical services to resolve or manage issues.

○ Learning

Members of the personal support network are learning to work with appropriate medical services to resolve or manage mental and physical health issues.

○ Becoming Aware

Members of the personal support network are beginning to understand the focus person's mental and physical health status.

○ Unprepared

No one knows or understands the mental and physical health status of the focus person.



2: ABILITY TO CONTRIBUTE UNIQUE GIFTS

Every person has important contributions to make. These contributions are heightened when they are recognized. From the comfort of supportive friends, family, and members of the personal support network, people with disabilities can find opportunities to work, volunteer, create, inspire, and contribute. One of the greatest barriers our loved ones face is getting recognition for their contributions. Both the isolation that many people with disabilities face and society's narrow view of what counts as contribution are part of this problem.

There are two key ways to contribute:

- 1 contributions of **Doing** are the action-oriented contributions we are most familiar with, such as volunteering, working, playing music, performing in a dance group, looking after children, cooking dinner, and so on.
- 2 contributions of **Being** are contributions made by a person's presence. Many people with significant disabilities offer grace, caring, attentiveness, wonder, acceptance, silence, receptivity, compassion, inspiration, pleasure, gratitude, loyalty, and friendship.

Identifying a person's many gifts and contributions leads to meaningful relationships, which is the foundation of a good life.

OUTCOME

When a focus person's good life includes the ability to contribute their unique gifts, these will be the outcomes:

- the focus person experiences recognition of their contributions
- the focus person spends time in community places
- the personal support network supports the focus person's contribution
- meaningful connections are created with groups and associations in the community
- the focus person has an opportunity to share their own dreams for their life

✓ CHECK-IN ABILITY TO CONTRIBUTE UNIQUE GIFTS

2.1: How does the focus person experience recognition of their contributions?

Peace of Mind

Contributions of the focus person are recognized and actively amplified.

Reviewing

Personal support network regularly recognizes opportunities and helps to amplify the contributions of the focus person.



Working

Personal support network works on creating opportunities that recognize and help to amplify the contributions of the focus person.

Learning

Personal support network and the focus person are actively learning about the contributions of the focus person.

Becoming Aware

Personal support network and the focus person are beginning to understand the idea of contribution.

Unprepared

The focus person is not recognized for their contributions.

2.2: How does the focus person spend time in community places?

Peace of Mind

Focus person regularly spends time in community places.

Reviewing

Focus person is spending time in community places and new options are regularly explored.

Working

Focus person is being encouraged and supported to spend time in community places.

Learning

Focus person is starting to spend time in community places and learning where they enjoy spending time.

Becoming Aware

Focus person is identifying community places where they would like to spend time.

Unprepared

Focus person is not spending time in community places.

2.3: How does the personal support network support the focus person's contribution?

Peace of Mind

Personal support network supports the contributions of the focus person.



Reviewing

Personal support network reviews how to support the contributions of the focus person.

Working

Working with a Facilitator, the personal support network finds ways to support the contributions of the focus person.

Learning

Personal support network is learning about the contributions the focus person has to give.

Becoming Aware

Personal support network is beginning to understand the contributions of persons with disabilities.

Unprepared

No one is informed of the contribution possibilities of the focus person.

2.4: Are meaningful connections being created with groups and associations in the community?

Peace of Mind

Connections are made and invitations are accepted by the focus person.

Reviewing

Focus person makes connections and invitations are accepted by the focus person. Personal support network and family review the existing and potential connections for positive results.

Working

Focus person has opportunities to build connections, to offer and accept invitations.

Learning

Personal support network and the focus person are learning to find opportunities to make connections and offer invitations.

Becoming Aware

Personal support network and the focus person are beginning to understand how to find and make connections and offer invitations.

Unprepared

No opportunities for connection are available.



3: ABILITY TO PARTICIPATE IN DECISION-MAKING

A good life includes honoring the choices of people. This means recognizing their tastes, preferences, and values; it also means acknowledging their ability to discriminate, to select, and to choose. While some people assume people with disabilities are incapable of opinions or making decisions that is not our view. We believe that people are fully capable of making their intentions known, but they may need support from others.

Full Circle, Capacity Building Initiative believes in nurturing inherent decision-making abilities rather than giving someone else the power to make decisions.

OUTCOME

When a focus person's good life includes participating in decision-making, these will be the outcomes:

- there is a formal decision-making structure in place
- the focus person has experience making decisions and had their choices respected
- decision making has been part of the focus person's daily activities
- guardianship and/or Alternative to Guardianship plans has been reviewed

✓ CHECK-IN ABILITY TO PARTICIPATE IN DECISION-MAKING

3.1: Is there a formal decision-making structure in place?

Peace of Mind

Formalized legal decision documentation is in place and there are no current changes.

Reviewing

Formalized legal decision documentation is in place, reviewed by the personal support network, and the documents are current.

Working

Facilitator and personal support network are working to get formalized legal decision-making documentation in place.

Learning

Personal support network is actively identifying decision-making opportunities and learning what documentation needs to be in place.



Becoming Aware

Personal support network is beginning to understand legal decision-making and the required documentation.

Unprepared

No legal decision-making documentation is in place.

3.2: How has the focus person experienced decision-making and had their choices respected?

Peace of Mind

Focus person's decision-making ability is recognized; their choices are respected, understood, and supported by the personal support network and family.

Reviewing

Focus person's decision-making ability is recognized; their choices are respected, understood, and encouraged. Decisions are reviewed by the personal support network and family.

Working

Members of the personal support network know and understand their role in supporting decision-making.

Learning

Members of the personal support network are learning how parents have been exercising decision-making with the focus person.

Becoming Aware

Members of the personal support network are beginning to recognize the focus person's decision-making ability, the need for respect, and support in decision-making.

Unprepared

The focus person's decision-making ability is not recognized; the focus person's decisions are not respected or supported.

3.3: How has decision-making been part of the focus person's daily activities?

Peace of Mind

Decision-making is part of the focus person's daily activities, is supported and encouraged by the personal support network.



Reviewing

Decision-making is part of the focus person's daily activities. The personal support network reviews and presents opportunities for decision-making to the focus person.

Working

Personal support network is working to build decision-making into part of the focus person's daily activities.

Learning

Personal support network is learning to include decision-making in the daily activities of the focus person.

Becoming Aware

Personal support network is beginning to recognize the focus person's decision-making ability in daily activities.

Unprepared

Decision-making is not part of the focus person's daily activities.

3.4: When were the guardianship or Alternative to Guardianship plans last reviewed?

Peace of Mind

A plan is in place and maintained and there are no current changes.

Reviewing

A plan is in place and reviewed as part of the annual meetings with facilitators. The personal support network is informed.

Working

A plan focusing the person is being explored and developed.

Learning

Personal support network and family are learning about guardianship, alternative, and the roles needed; and thinking about who could take on this role.

Becoming Aware

Personal support network and family understand the need for a guardian or another plan and the characteristics of the best idea to fill the role.

Unprepared

No plan is in place and no potential plan have been identified.



3.5: When was power of attorney (an alternative to guardianship) last reviewed?

Peace of Mind

Powers of attorney for health and finances are in place, and there are no current changes

Reviewing

Powers of attorney for health and finances are in place and reviewed as part of the annual meeting with facilitators. The personal support network is informed.

Working

Powers of attorney for health and finances are in the process of being identified.

Learning

Personal support network and family are learning about the roles of powers of attorney for health and finances and thinking about who could fill these roles.

Becoming Aware

Personal support network and family understand the need for powers of attorney for health and finances, and they are thinking about the characteristics of the best person to fill the powers of attorney roles.

Unprepared

No power of attorney for health or for finances is in place. No potential Powers of Attorney have been identified.



4: A PLACE TO CALL HOME

A true home is where one chooses to be. Full Circle defines home as a place that provides continuity, privacy, and security. Creating a home is to have control over the home environment, to make sure it reflects your family member's personality, and to ensure your family member chooses who they live with. There are various options for homes, including private ownership, renting, Alternative Family Living (AFL), and even group homes. Supported Living services can support your family member in their own home. Where ever your loved one lives, they should have privacy and security.

OUTCOME

When a focus person's good life includes having a place to call home, these will be the outcomes:

- the home arrangement reflects the needs and interests of the focus person
- housing options have been explored
- thought and planning has gone towards an anticipated transition
- long-term plans have been discussed with personal support networks related to how trusts and inheritance of assets may affect what is available for the living situation
- the focus person has the required support to live happily and safely at home

✓ CHECK-IN A PLACE TO CALL HOME

4.1: Does the home arrangement reflect the needs and interests of the focus person?

Peace of Mind

Focus person is living in a home they selected, and there are no current changes.

Reviewing

Personal support network and family are reviewing the home the focus person has selected to ensure it continues to reflect their needs and interests.

Working

Personal support network and family are working to ensure the housing arrangement reflects the needs and interests of the focus person, and working to put new housing in place (if desired).

Learning

Personal support network and family are learning about the housing needs and interests of the focus person, and learning what is needed to formalize housing arrangements.



Becoming Aware

Personal support network and family are actively identifying housing options of most interest to the focus person.

Unprepared

Housing arrangements do not reflect the interests of the focus person.

4.2: What housing options are being explored?

Peace of Mind

Housing options have been explored, and there are no current changes.

Reviewing

All housing options have been explored, and the personal support network and family are reviewing to ensure that there is no additional work to be done.

Working

Personal support network and family are working to find housing options.

Learning

Personal support network and family are learning about available housing options that suit the specific housing needs and desired amenities of the focus person.

Becoming Aware

Personal support network and family are thinking about housing options and learning about the needs and desired amenities of the focus person.

Unprepared

Personal support network and family have no knowledge of housing options.

4.3: What thought or planning has gone towards anticipated transitions?

Peace of Mind

There is a plan in place for any anticipated transitions.

Reviewing

Personal support network and family are reviewing an anticipated transition for the focus person.

Working

Personal support network and family are working on a plan for an anticipated transition.



Learning

Personal support network and family are learning about the anticipated transition and what planning needs to take place.

Becoming Aware

Personal support network and family are thinking about an anticipated transition and what planning needs to take place.

Unprepared

No thought or planning has gone towards an anticipated transition.

4.4: Have long-term plans been discussed with personal support networks related to how trusts and inheritance assets may affect what is available for the living situation?

Peace of Mind

Long-term plans related to trusts and inheritances and their effect on the living situation have been discussed, and there are no anticipated changes.

Reviewing

Long-term plans related to trusts and inheritances and their effect on the living situation have been discussed, and plans are in place to mitigate risks. Plans have been reviewed by the personal support network.

Working

Families are working on a long-term plan and finding ways to mitigate negative effects of trusts and inheritances on the living situation.

Learning

Families are learning how trusts and inheritances can impact living situations and learning about possible mitigations.

Becoming Aware

Families are thinking about trusts and inheritances. They are thinking about future living situations.

Unprepared

No long-term plans related to trusts and inheritances and their effect on the living situation have been discussed.



4.5: Does the focus person have the required support to live happily and safely at home?

Peace of Mind

Required supports to live happily and safely at home are in place, and there are no anticipated changes.

Reviewing

Required supports to live happily and safely at home have been discussed, and plans are being reviewed with the personal support network.

Working

Families are working on establishing the required supports to live happily and safely at home. Families are working on finding the right supports and engaging them. The personal support network is contributing to supports.

Learning

Families are learning what supports are required to live happily and safely at home and where they can access these supports.

Becoming Aware

Families are thinking about what supports are required to live happily and safely at home. Families are thinking about where supports can be found.

Unprepared

No supports are available to help the focus person live happily and safely at home.



5: FINANCIAL STABILITY

Financial stability is integral to social well-being. Being financially secure is a priority for every family, especially when thinking about the future. It's important to be sure we have enough money for emergencies and unforeseen events, but we also want to have enough to live comfortably.

Many people with disabilities live on low incomes. Many people only have incomes from Social Security such as SSI or SSDI. We believe in using a mix of financial options to help secure the future for our loved ones and friends. We encourage families to consult with a professional to help put together the right plan for their needs. Financial stability includes will and estate planning, special needs trusts, and ABLE accounts.

OUTCOME

These are the desired outcomes that should be in place for people with disabilities so that they can have financial stability as part of the good life we want for them.

- the will has been reviewed in the past year
- a Special Needs Trust (SNT) and/or an ABLE account has been established for the person with disabilities
- a contribution has been made to an ABLE account or SNT
- the trusteeship (or guardianship) has been reviewed within the past year
- the financial plan has been reviewed within the past year
- if a payee is needed for Social Security benefits, arrangements for a new payee have been made, in the event that the current payee is no longer available

✓ CHECK-IN FINANCIAL STABILITY

5.1: When was the will last reviewed?

Peace of Mind

Family has a will that includes powers of attorney, income protection, tax reduction, trusts, and distribution of major assets. Executors are in place and the personal support network is informed.

Reviewing

Family has written a will that is current and recently reviewed. The will identifies the Powers of Attorney, protects income, reduces taxes, and arranges for trusts and the distribution of major assets. Executors are updated and in place. The personal support network is informed.



Working

Family has written a will that identifies the Powers of attorney, protects income, reduces taxes, arranges for trusts and the distribution of major assets. Executors are being formalized and informed.

Learning

Family has met with a lawyer to begin drafting a will and arranging trusts and the estate. Executors have been identified.

Becoming Aware

Family is learning about wills, trusts and estates, and thinking about executors.

Unprepared

No will in place and no executors identified.

5.2: When was the last contribution made to the ABLE account?

Peace of Mind

Ongoing contributions to ABLE account are being made when possible.

Reviewing

Contributions to ABLE account are made when possible.

Working

An ABLE account has been opened, and contributions are being made when possible. Others have been authorized to contribute.

Learning

An ABLE account is in the process of being established.

Becoming Aware

Family is learning about ABLE account and Special Need Trusts.

Unprepared

There is no ABLE account or Special Needs Trust in place.

5.3: Does the focus person have Social Security benefits in place?

Peace of Mind

Focus person has SS benefits; they have been reviewed so benefits are maximized.



Reviewing

Focus person is receiving SS benefits, but they need to be reviewed to make sure all benefits are in place.

Working

An application for SS benefits is being filed on the focus person's behalf.

Learning

Family is learning about options what is needed to apply for SS benefits.

Becoming Aware

Family is finding resources to learn more about the different SS benefits.

Unprepared

Focus person does not have SS benefits, and an application has not been filed.

5.4: When was the financial plan reviewed?

Peace of Mind

The financial plan is in place and up to date. The personal support network is aware and feels confident to implement the plan.

Reviewing

Family has finalized a financial plan that includes emergency, immediate, and long-term contingencies. The personal support network is informed of the plans.

Working

Family is writing a financial plan that includes emergency, immediate, and long-term contingencies.

Learning

Family is drafting a financial plan that includes emergency, immediate, and long-term contingencies.

Becoming Aware

Family is learning about financial planning.

Unprepared

No financial plan is in place.



related resources and key documents

Below you will find a list of the related resources and key documents for each Good Life Indicator. Check out www.firstwnc.org/fullcircle for these resources and other resources.

1: LOVING FRIENDS AND FAMILY

- learn about developing a work plan
- learn about personal support networks
- learn about Social Belonging
- read Safe and Secure pages (p. 41-54)
- complete Safe and Secure Worksheet 4
- read Future Planning Tool - Personal Support Networks (p.76 - 82)
- update members of the personal support network contact and information list
- create phone tree or emergency communication plan
- complete medical information contact and information list
- create service provider contact and information list

2: ABILITY TO CONTRIBUTE UNIQUE GIFTS

- learn about Asset-Based Community Development
- learn how to offer invitations
- complete Safe and Secure Worksheet 5
- read Future Planning Tool - Contribution (p.83 - 87)
- create a neighborhood asset map

3: PARTICIPATING IN DECISION-MAKING

- learn about legal decision-making options
- complete End-of-Life Planning (if applicable)
- read Future Planning Tool - Legal Decision-Making (p. 56 - 64)
- learn about Alternatives to Guardianship
- learn about Supported Decision Making
- create the plan for decision making for your family member



4: A PLACE TO CALL HOME

- complete Safe and Secure Worksheet 7 and 8
- read Future Planning Tool - Housing (p. 65 - 75)
- learn about housing options for your family member, remember that there are multiple options and some are only available with certain funding.

5: FINANCIAL STABILITY

- know the rules on money and eligibility for Medicaid
- learn about Will, Trust and Estate Planning and ABLE Accounts
- create Inventory of Assets and Liabilities
- Check out these resources

read more

<https://www.forbes.com/sites/nextavenue/2017/07/12/ways-to-provide-for-your-disabled-adult-childs-future/#1b77390e2bbe>

<https://www.kiplinger.com/article/retirement/T021-C000-S004-create-a-plan-for-an-adult-child-with-disabilities.html>

<https://www.ablenrc.org/frequently-asked-questions/>

<http://www.ablenrc.org/resources/webinars/>

Experts recommend working with professionals who specialize in special needs planning. Here are some organizations that can help you find the professional help that you need.

- National Academy of Elder Law Attorneys (www.naela.org)
- Academy of Special Needs Planners (www.specialneedsanswers.com)
- Special Needs Alliance (www.specialneedsalliance.org)
- The Arc (www.thearc.org)

PLANNING FOR A GOOD LIFE: MOVING FROM UNPREPARED TO PEACE OF MIND

is a tool for Facilitators to guide Future Planning meetings.

This new planning framework will help to guide meetings held at least annually with families to facilitate the creation of work plans that help get all the pieces of future planning in place. The annual planning meetings are a chance for parents, caregivers, representatives, trustees and all others who play an important and specific role in the life of the focus person to talk, review, reflect, and provide input about planning in the areas of relationships, contribution, financial stability, choice-making, and having a place to call home.

The goal is to bring peace of mind for parents by helping to create a clear plan which, with the involvement of the personal support network will ensure a good life for their loved one both now and in the future.

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For more information and resources, please go to:

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