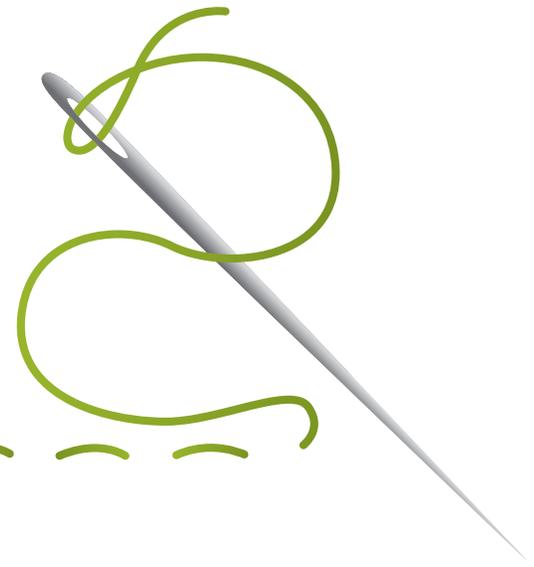


# Chapter 7

## THIS IS MY LIFE: CREATING A LIVING DESCRIPTION



# Creating a Living Description

Throughout your child's lifetime, he will come into contact with many physicians, healthcare professionals, teachers, support coordinators, employment specialists, therapists, community members, and employers. Each of them will have a special body of knowledge according to their profession. They will have expertise in their field but will never know your child as well as you. Creating a written, living description with and about your child is one way you can share the unique information that describes your child with others.

## A LIVING DESCRIPTION IS:

- An ever-changing document that has information about your child with disabilities or special health care needs
- Done **with** your child, not for them
- Unique to your son or daughter
- Created as a result of listening to your child & others who know & love them
- Easy to do & does not need a professional to facilitate the process of gathering information

## A LIVING DESCRIPTION MAY BE USED:

- To help your child get a better life, according to how he defines it
- To recognize what gifts & capacities your child brings to the community
- To put intentional focus on what is **important to** your child
- To help healthcare professionals, teachers, job coaches, employers & others better support your child
- As the foundation on which to build friendships, relationships & belonging in the community
- To guide the development of life & educational goals, therefore becoming the basis on which a formal or informal plan may be made

There are numerous resources and templates that can help you create a living description with your child along with ways to use the information to develop an action plan. Although each approach has unique features, they are all rooted in the principles of self-determination. Self-determination means giving people with disabilities and special health care needs the opportunity to steer their own boat — to be captains of their own ship. A good resource on self-determination is [www.centerforself-determination.com](http://www.centerforself-determination.com).

*Your Child will Grow & Change in Many Ways.*

With your child, revisit their living description periodically to see what needs to be added and what needs to be taken off.

# The Principles of Self-Determination

## CHOICE

People have the right to choose how they will live their lives, where and with whom. When people need help, it is friends and family closest to them who assist them in broadening their experiences and exercising their right to choose. It is essential that each person have a circle of support chosen by them.

## RELATIONSHIPS

The relationships a person has with others are like precious gems. A relationship must be treasured, nurtured, and protected.

## CONTRIBUTION & COMMUNITY

Everyone has the ability to contribute to his or her community in a meaningful way. Giving of self helps people establish a sense of belonging and identity.

## RESPONSIBILITIES

Individuals, as they take greater control and authority over their lives and resources, assume greater responsibility for their decisions and actions. Professionals and staff work for the individual, rather than for the system. Families, friends and staff assist people in creating more meaningful relationships, link them with needed supports, remove barriers, develop safety networks, and help make dreams come true while never forgetting who is in charge.

## CONTROL

People have the power to make decisions and truly control their lives. This includes gaining authority over financial resources and the power to determine what supports are necessary, how they will be implemented, and by whom. People also have control of hiring those who will provide support.

## DREAMING

All people have hopes and dreams which guide the actions they take and are the most meaningful to them. A commitment to helping people determine their dreams, respecting those dreams, and helping make dreams come true is crucial.

## DIGNITY & RESPECT

All people have the right to be treated with dignity and to be respected as a whole person. Some of life's greatest lessons are learned by making choices that are later realized to have been mistakes. All people have the right to the dignity of risk.

## FISCAL CONSERVATISM

Making things happen does not always require money. It is important that alternatives to paid support be found. Communities offer many informal resources — faith-based youth groups, boys and girls clubs, YMCA programs — with which your child can be connected.

## WHATEVER IT TAKES

The attitude, "nothing is impossible, as long as it is legal and causes no harm," is required. "No we can't," as an answer is replaced by, "How can we make this happen?"

# More on Creating a Living Description

Among the most widely used approaches to creating living descriptions and plans are Making Action Plans (MAPs), Planning Alternative Tomorrows with Hope (PATH), Personal Futures Planning, and Essential Lifestyle Planning (ELP). MAPS is about listening to a person's dreams, acknowledging their nightmares, then building a rich portrait of their gifts and talents so the person and their support team can focus on simple daily actions. PATH is a creative planning tool which starts in the future and works backwards to beginning steps which are possible and positive to meet that goal in the future. Personal Futures Planning promotes the positive futures and images of people with disabilities and shows that all of us count and all of us fit somewhere. ELP is a snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow.

As a family member, you can create a basic living description with and about your child that will be a resource for you in a variety of settings. The document is called a living description because it will need to be updated as your child grows and changes. This is not a one-time activity, but one that is on-going as more information is gathered and as changes in your child's life occur. If your child does not use words to communicate, you can make the best guess based on your close relationship with your child, on what to put into the description. At the end of this chapter, you will find an example of Brooke's one page living description developed from the forms you will find at the end of chapter 10. Additional examples of living description can be found at The Learning Community for Person-Centered Practices — visit [http://www.learningcommunity.us/sample\\_plans.htm](http://www.learningcommunity.us/sample_plans.htm) and at <http://www.inclusive-solutions.com/pcplanning.asp>.

Information for a living description comes from your child, yourself as a parent/guardian and others who know and love your child. Information is gathered through conversations with your child and with those who are important in your child's life. Conversations may take place in person, on the phone, through email or in a group. Some people hold an information-gathering party, inviting people their child wants and making it a celebration. Once information is gathered, your child has the final say over what is included in his description.

# What is in a Living Description?

Every living description includes your child's **hopes and wishes** for the future. The future may mean next week, next year or years from now. It may also include your hopes and wishes for your child. Hopes and wishes may be small or large. They may be as varied as wanting to be a veterinarian, a desire to go to Disney, saying a first word, or a child making eye contact. Just like any one of us, hopes and wishes change over time and the changes will need to be reflected in the description.

Thinking about hopes and wishes may be difficult for some parents especially when healthcare needs feel overwhelming or when your child is newly diagnosed. And sometimes your child will want something they may never achieve. If you think about your own life, ask yourself, "Have I achieved every dream of mine? Did I learn from the journey toward reaching for a particular goal?" The additional components of a living description that are described below come from The Learning Community for Person-Centered Practices.

Sometimes a child with healthcare needs or a disability becomes identified by the label they have, and at times they are seen by others according to what they can't do. One part of a living description can capture all the capabilities and gifts your child possesses. Ask your child what he does well. Think about what you love about your child. Talk to family, friends, teachers and others who know your child and ask what they **like and admire about your child**. Ask them what they see as your child's gifts and strengths. Then review the list and ask your child which descriptions he wants to include in their description.

A **relationship chart map** documents the people in your child's life and how close they are emotionally to your child. Besides providing a snapshot of your child's current relationships, this component of the living description helps determine where more relationships need to be developed. Often, we find that people with disabilities and significant healthcare needs have a lot of people who are paid to be in their life and not as many unpaid friends. When filling in a relationship chart map, put your child's name in the center circle and have your child consider the map and who he would include in each section and begin each category with the name of the person to whom he feels closest. The closer the person is to your child on an emotional level, the closer to the center they will be on relationship map. Sometimes it helps if you recreate the relationship map on bigger paper and use pictures of each person, having your child place them where they belong on the map.

Professionals in service systems are very good at providing what is important for your child. "Important for" are those things that keep people healthy and safe. Too often what is **important to** your child gets overlooked. A living description can provide this information. "Important to" includes things that make your child happy and content. It includes, among other things, people, pets, routines and rituals, products and things, interests, hobbies, what he likes to do and places he likes to go. All humans need things in their lives that are important to them. Having just a little of what makes us happy, helps to deal with life's inconveniences and stressors. The challenge often comes from finding the balance between what is important to and what is important for.

Another part of a living description can be **instructions for support**. This can be very detailed or more general depending on your child's needs. In some instances, the instructions will mean the difference between health and a health crisis. In others, instructions for supporters will mean the difference between a good day and a bad day for your child. Instructions for supports could address what others need to know or do to keep your child healthy and safe. One way to start thinking about this information is what Smull, Allen, and Bourne describe in their training, Families Planning Together (2001) as the is called a Two Minute Drill. Imagine you have an emergency and suddenly have to leave. The person who will 'fill in' has arrived and you have two minutes to give advice, suggestions, or tips about supporting your child. What would you say? Instructions for support can also include instructions for others on how to best support your child that doesn't have to do with health and safety. One way to start thinking about this is considering what is called Good Day/Bad Day. Make a list of things that would contribute to a good day for your child and make a list of what a bad day looks like for your child. There may be things on these lists that can be added to your child's "important to" list or "instructions for supporters."

A living description can include any information that you think would be helpful to others to know and support your child better. Other types of information that could be included are:

- A list of your child's doctors with contact information, the medications prescribed, what the medication is for;
- Characteristics of people who would support your child best;
- A chart that describes how your child communicates, especially if they do not use words to communicate; and
- Fears/worries, things your child doesn't like.

## Me

My name is Brooke  
I live in Virginia with my mom and dad  
I go to Varina High School  
I want to own a doggie day care  
when I graduate high school

## My Strengths & Talents

I can occupy myself for long periods of time  
I pay attention  
I am physically strong

## Words That Describe Me Best

Always cheerful  
Inquisitive  
Funny  
Cute

## What You Can Do to Help Me

Pour drinks in my cup  
Put food on a fork for me  
Help me to the bathroom, get dressed  
Help me at school "talk" to classmates  
Help me understand and do activities  
Push my wheelchair  
Give me clear and simple directions  
Hold things close to me so I can see them



## My Favorite Things

My favorite foods are chicken nuggets, potatoes  
and peanut butter crackers — and sweet ice tea  
I like riding in the car with the  
window open blowing my hair  
I love the sound of a shaking bottle of water  
I like listening to music (pop, rock and rap)  
I love going to Florida to visit my grandparents

## An Ideal Day

A big breakfast with OJ  
Going to school  
Quiet time throughout the day  
Eating every couple of hours  
Lots to drink  
Sitting with friends in class or lunch  
Chillin' in my room  
Playing or shopping with my mom and dad

## My Fears & Worries/ Things I Don't Like

Sudden noises  
When I don't know what's going to happen next  
Angry, loud voices  
Being ignored  
Bright sun or lights in my eyes  
Not having my dog (she died)

## My Worst Possible Day

Sitting at home all day with nothing to do  
Not getting enough to eat or drink  
Being ignored — especially  
when I use my body to "talk"  
Having surgery

