

The background of the entire page is a close-up photograph of numerous purple flowers, likely pansies or similar varieties, with vibrant purple petals and some lighter purple or white centers. The flowers are densely packed and fill the entire frame.

Special Planning Law Workbook: Create a Personal Instruction Manual for Your Special Needs Child

**A manual to enable future caregivers and
trustees to take the best care possible of
your child.**

Pamela Parker, J.D.

Special Planning Law Workbook:
Create a Personal Instruction Manual for Your Special Needs Child

By Pamela Parker, J.D.

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Additional information and resources are available:

www.SpecialNeedsPlanningForFamilies.com

www.ParkerCounsel.com

Pamela may be contacted at:

pparker@parkercounsel.com

512-804-9934

Introduction

I was 37 years old when I lost my dad. He was not ill, he was 62 years old, and no one expected we would lose him when we did. My sister and I grieved. We cried. We tried to explain to his two year old granddaughter why he wouldn't play with her anymore. We told stories of his life and retold stories he had told us of times before we were born. We sorted through the pieces of his life and went through probate and his last bills. We filed his final tax return. And then we carried on with our lives, a little older, a little more experienced, a little sadder at times, but without any significant changes to our day to day world.

Now imagine your child with a disability when you die. No matter what the disability, if your child is dependent on you for any part of their care, their life will change drastically at your death. With you gone, their day to day life will not go on with little or no change. unless you prepare.

Every parent with a special needs child has unique daily challenges. Some of us are focused on physical care, some are busy with medical challenges, and others are trying their best to teach children to handle social interactions. Some of our lives are dominated by our children's needs, others have smaller time commitments. But the one thing that all of us share equally is a constant worry about the future our child will have when we ourselves cannot protect them.

Every parent can and should prepare three things for their child's future – people, money, and information. People to take care of things, money to cover extras, and information to guide decisions.

This workbook will help you prepare the information that future caregivers and trustees can use to provide continuity of care to your child and to continue to make decisions as closely aligned with your own philosophies as possible.

Pamela Parker

How to Use This Book

This book is a piece of a three part system of providing a safe and happy future for your child. By creating a plan that provides a community of caregivers, financing for both needs and wants, and tools to ensure continuity of care as your child transitions from your care to that of another, you can ease your own worry about the future . This book is a component of providing continuity of care for your child.

Step One: Stay calm!

This book is not a test, and you need not answer every question. Any information you provide will help future caregivers.

Step Two: Have fun.

Fill out whatever sections attract your attention. This workbook is your chance to give anyone who might care, a picture of who your child is and what makes them tick, what makes them happy. This is not a legal form, and you can say anything you want in any way that you want. Think about what you would want to know about someone who you were suddenly responsible for, and put those things down. Get a highlighter and mark things that are especially important to you. Attach pictures, tell stories, do anything that you think will help someone get to know your child well enough that they will be motivated to take good care of them.

Step Three: Spread the Word

Make sure that members of your child's family and care team know about the book. Make copies of it (or relevant sections) to give to people who work with your child now. Leave instructions to provide copies of the book to future guardians, caseworkers, trustees, and others who may work with your child or have decision-making responsibility.

Step Four: Update

As you think of additional information, or as things change, add to and modify the information in the book. This is a work in progress, just like your child, and should be added to anytime you feel like it. Staple in additional pages if you need to, or put it in a binder with medical reports or other documentation if you like. This is your book, and it should be as unique as your child.

And remember, if any section stumps you, skip it and go on to the next. Now, let's get started.

THIS BOOK IS ABOUT _____

SECTION ONE - PERSONAL AND FAMILY INFORMATION

This section provides information on your child, as well as family members and other information that may be useful to a caretaker who does not know your child well or who has not known your child very long. This will ensure that people don't drop out of your child's life simply because the caretaker did not know about them. It will also allow the caretaker to talk to your child about their past, which may bring joy or comfort to your child.

Nickname	Date of Birth	Social Security Number	Citizenship
Current address	Family or Group Home?	Name of Contact	Phone, email
School or Day Program	Address	Name of Contact	Phone, email
Language(s) spoken	Speaks	Understands	
	() Yes () No	() Yes () No	
Religion	Attends church or other religious classes	Name of pastor, priest or minister	Contact information
Cities child has lived in	Dates		
Marital status	Name of spouse		
Special friend	Relationship	Address, phone, email	
Legal Guardian	Relationship	Address, phone, email	

LIVING FAMILY MEMBERS

Name and contact information	Relationship	Visit (How frequently or not at all)	Wants to be kept informed	Inform by Phone, email, letter
	Mother			
	Father			
	Step Mother			
	Step Father			
	Maternal grandparents			
	Paternal Grandparents			
	Brother(s)			
	Sister(s)			
	Maternal Aunt(s)			
	Maternal Uncle(s)			

Additional Comments

KEY FRIENDS AND SOCIAL CONTACTS

Name, address, phone, email	Relationship	Type of interaction	Frequency	Comments

Additional Comments: _____

SECTION TWO - CURRENT MEDICAL CONDITION AS OF _____

This section describes your child's current medical diagnoses, treatments, and medications as they exist at the time you complete this workbook. This section will need to be updated periodically as conditions and medications change.

CONDITION	NEEDS ASSISTANCE AND/OR DEVICE	COMMENTS
Primary medical diagnosis		
General functioning level		
Able to feed self		
Able to bathe, brush teeth, shave self		
Able to toilet self		
Vision		
Hearing		
Speech		
Dental		
Mobility – Use a wheelchair? Walk with assistance?		
Adaptive or prosthetic device(s)		
CAUTIONS		COMMENTS
Allergies to medication		
Seasonal allergies		
Other allergies		
Seizures		
Other		

PHYSICIANS AND OTHER MEDICAL PROFESSIONALS

MEDICAL PROVIDER	NAME	ADDRESS, PHONE, EMAIL	LENGTH OF TIME AS PROVIDER	COMMENTS
Primary care physician				
Neurologist				
Other specialist				
Other specialist				
Physical Therapist				
Orthopedist				
Orthotic and prosthetic services				
Dentist				
Home care aide				
Other				
Other				
Other				

MEDICAL HISTORY

This section provides a review of your child’s medical history, to let future caretakers know about problems, diagnoses, treatments and medications that are not currently an issue but that may be useful to know at some time in the future.

CONDITION/TREATMENT/TEST	DATE	WHERE/DOCTOR	RESULTS
Genetic testing			
Other diagnostic tests:			
Surgeries (type)			
Hospitalizations and reason			
OTHER DISEASES AND/OR ILLNESSES	DATE(s)	PHYSICIAN IN CHARGE	CHRONIC OR SHORT TERM

COMMENTS

SECTION THREE - LEGAL DOCUMENTS

This section will provide information on legal and financial matters. Compiling a list of all legal and financial information in one place can keep items from being overlooked or forgotten about, and can keep things from being unnecessarily duplicated.

DOCUMENT	LOCATION OF DOCUMENTS	CONTACT
Will		
Trust		
Power of Attorney		
Medical Power of Attorney		
HIPPA Release		
Medical Insurance		
Life Insurance		
Funeral and/or burial arrangements		
Safe Deposit Box and key		
Other		

ADDITIONAL COMMENTS _____

SECTION FOUR - FINANCIAL INFORMATION

Source(s) of income	Method of payment	Frequency	Amount	Comments
Trust	Administrator	Location	Terms	Comments
Government Programs	Name of program	Eligibility	Benefit provided	Comments
Name of bank	Account Number	Type of Account	Name on account	Comments
Other assets	Source	Location	Name on account, title or deed	Comments
Debts	Type	Contact		Comments

Add any other information on financial or legal matters that a future guardian should be aware of to adequately care for your child.

SECTION FIVE - LIFESTYLE AND FUN ACTIVITIES

This section will provide the caretaker with information on how your child lives, what he or she likes to do, and what activities they are able to participate in.

How well does your child interact with peers? Does he/she enjoy spending time with others? If so, what are his/her favorite activities to do with friends?

What are your child's:

Hobbies
Skills
Physical fitness activities
Other kinds of activities

Does your child:

Have a job?
Participate in volunteer activities?

What is his/her favorite:

Place to vacation
Day trips
Other places to visit

Are there activities that work especially well?

Are there activities that have not worked well in the past?

Does your child have any condition that would restrict certain activities?

My child is/is not afraid of:

Afraid

Not Afraid

Thunder _____

Dogs _____

Cats _____

Loud noises _____

Applause _____

Other (please list):

LIKES

Foods _____

Preferred Clothing _____

Favorite toys _____

Favorite movies _____

Favorite season of the year _____

Favorite television programs _____

Favorite books _____

Favorite music _____

DOES NOT LIKE

Foods _____

Does not like to wear _____

Music _____

Other _____

SECTION SIX - PARENTING AND CARETAKING PHILOSOPHY

This section gives you the opportunity to discuss your own values, philosophy and preferences for your child. This information will help the future caretaker to provide continuity of care and to make decisions closely aligned with the way that you would likely have made them. Some of the questions are straightforward and others are designed to help you give examples of how you would deal with a new situation. You cannot provide specific answers for every situation that may arise, but this section will give your child's future caretaker guidance in carrying out your wish to have your child continue to be cared for as you have.

If changes in your child's living arrangements need to be made, how would you weigh the following factors?

Highly structured vs. more self-directed _____

Many residents vs. smaller home _____

On-site staff vs. visits and on-call staff _____

Self contained community vs. community based _____

Other: _____

What are your preferences concerning your child's religious or spiritual life?

What is your philosophy regarding medical care? On a scale of 1 – 5, (1 being strongly agree and 5 being disagree), rate each of the following statements:

- _____ Find a good doctor and follow recommendations
- _____ Always be on the lookout for new things to try
- _____ Try to get two or three opinions on any proposed treatment
- _____ Alternative medicine should always be considered as an option

Other comments: _____

What are your priorities for your child? Rate on a scale of 1 – 5 (1 being highest priority and 5 being not important):

_____ Increase independence

_____ Vocational training

_____ Skills training

_____ Activities that bring enjoyment

_____ Social interaction

_____ Living skills

Other comments: _____

NOTES

NOTES



SPECIAL PLANNING LAW WORKBOOK

Pamela Parker is an attorney with two special needs children of her own.

Her law practice is focused on helping other families with special needs children prepare for their children's adulthood and long-term future. Pamela helps parents find peace about their child's future by creating plans to provide a community of people to watch over their child, financing to take care of both their needs and wants, and continuity of care as a child transitions from a parent's care to the care of others. This workbook is an important part of providing continuity of care.

By using the charts and answering the questions in this workbook, parents will know that when they are no longer here to take care of their child, those entrusted with that responsibility will know enough about their child's unique personality and lifestyle to make informed, consistent decisions for that child. And the parents will also know that their own loving choices and the values important to them will continue to be used in making life decisions for their child.

Law Office of Pamela Parker, PO Box 80205, Austin, TX 78708

pparker@parkerconsult.com

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