The Advocacy Alliance has a proud history of service. Founded as a Mental Health Association in 1955, we have grown tremendously over the years, expanding our reach to 39 counties in Pennsylvania. Our mission is to promote mental well-being, and support Recovery for adults who have a mental illness; Resiliency for children and adolescents who have emotional/behavioral disorders; Everyday Lives for individuals who have developmental disabilities; and Independence for older adults and individuals with physical disabilities, by providing advocacy and services.

VALUES

RESPECT for those we serve and for one another.

DEDICATION to the persons we serve and the work we do.

COLLABORATION AND SHARING for the benefit of those we serve.

TRUST in one another.

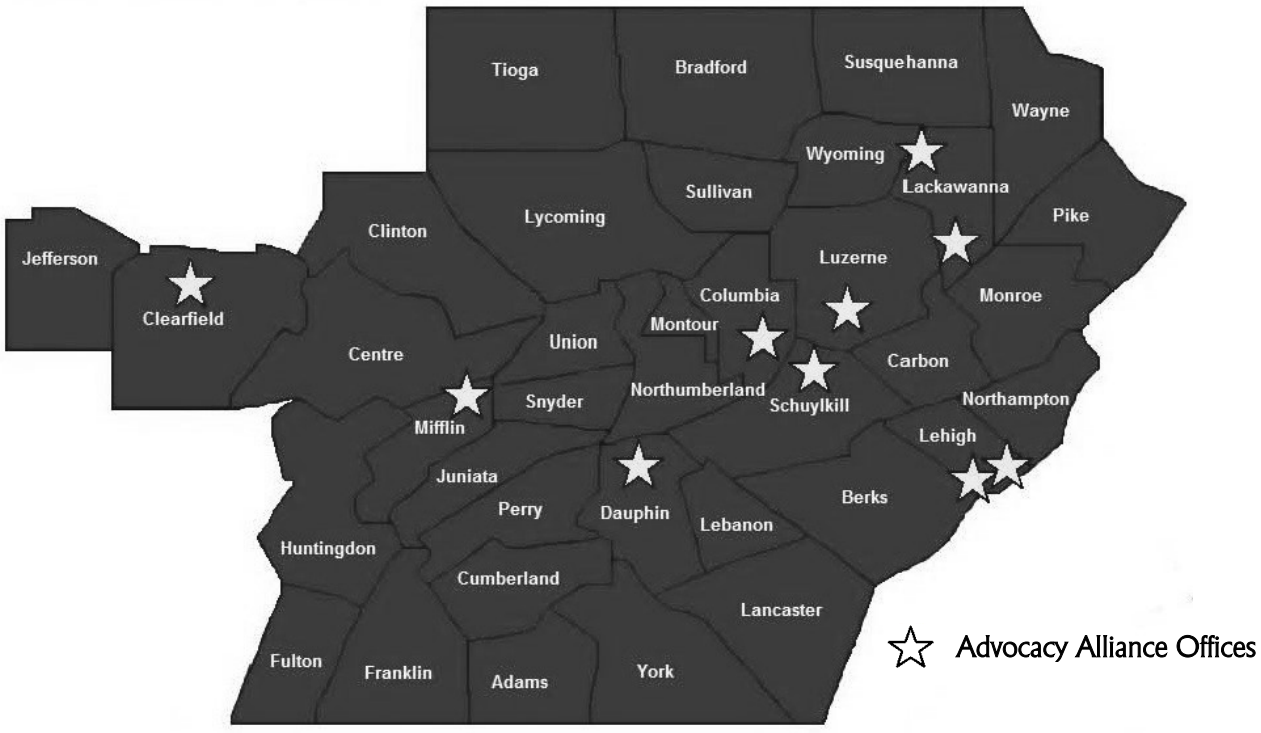
CONFIDENCE in the rightness of our mission.

KNOWLEDGE and the sharing of knowledge.

LOYALTY to our mission, to those we serve, and to one another.

LEADERSHIP in service to persons who have a mental illness and persons who have developmental disabilities.

SERVICE AREA



MAPPING THE FUTURE

A WORKBOOK TO PREPARE FOR THE FUTURE OF YOUR LOVED ONE WITH SPECIAL NEEDS

ACKNOWLEDGMENTS

Family members of persons with developmental disabilities contributed to the content of this workbook, with William Sukus as the driving force behind the entire project and without whose leadership and passion, this project would have never come to fruition. The following are acknowledged for sacrificing time with their families to review draft versions and to come together to discuss content: Scott and Debbie Crispell; Ruth and Sharon Tucker and others. Their input resulted in this workbook. Further acknowledgement is extended to Scott Crispell, who graciously provided his editorial skills.

ADDITIONAL RESOURCES

The Advocacy Alliance recognizes the continued efforts of persons with developmental disabilities, their families, and the community members who strive to make the idea of an Everyday Life – a typical life like anyone else's – a reality.

Please visit the Advocacy Alliance's website for more resources and information helpful in planning for your loved one: www.theadvocacyalliance.org.

The Advocacy Alliance has a presence in Northeastern and Central Pennsylvania, the Poconos and the Lehigh Valley, and can be in contact with a person who has special needs on a regular basis. The Advocacy Alliance can assess and monitor needs on an ongoing basis and serve in an advisory capacity on a variety of issues, including physical and behavioral health, and government and private service options.

For additional copies of this guidebook, please contact the Advocacy Alliance toll-free at 1-877-315-6855 or info@theadvocacyalliance.org.

AN IMPORTANT MESSAGE
FOR PARENTS AND GUARDIANS

May 2007

Dear Parent/Guardian,

As a parent/guardian of a person with special needs, you know the difficulty in preparing for the eventuality of no longer being able to ensure that your loved one maintains his/her current quality of life. The Advocacy Alliance recognizes this difficulty and has compiled this workbook in an effort to provide parents/ guardians with a tool to make planning for your loved one a less daunting task.

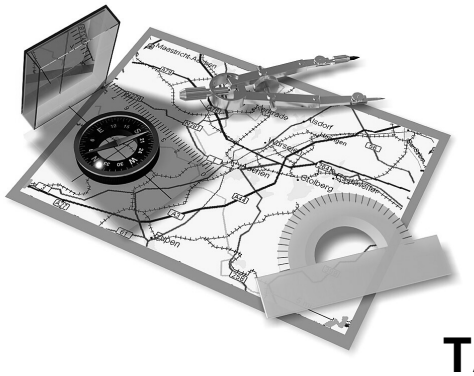
This workbook can be your "Letter of Intent" and the information you include in this workbook will be used to make it easier for the quality of your loved one's life to continue after you can no longer care for him/her. This workbook is intended to be used, either in whole or in part, as you feel it applies to your loved one's life, with the information changing over time. As an ever-changing picture of your loved one's life, it is recommended that you update the information in this workbook annually, the time of the Individual Support Planning (ISP) process may be a good time to do this.

As a parent, I know that writing my "Letter of Intent" was a very difficult thing to do. However, I believe it is one of the most important things I have ever done for my loved one and am confident that you will feel the same.

If you need assistance with this workbook, please call the Advocacy Alliance toll free at 1-877-315-6855 or e-mail them at info@theadvocacyalliance.org.

Sincerely,

William P. Sukus
Parent and Member of the Board of Directors of the Advocacy Alliance



MAPPING THE FUTURE
A WORKBOOK

TABLE OF CONTENTS

NOTES

INTRODUCTION

What is a Letter of Intent?

- A detailed but easy to understand description of your loved one's current life – it's more of a history than a *letter.*
- Your wishes (instructions) for your loved one's future after you can no longer provide care for him/her.

Who should write a Letter of Intent?

- A parent or guardian of a person with special needs – like Developmental Disabilities, Autism, or Down Syndrome.

When should you write a Letter of Intent?

- As soon as possible and it should be copied and kept with your important documents, like your will or insurances.
- Give copies of your Letter of Intent to all of the people in your life who will help carry out your wishes for your loved one.
- Examine the Letter of Intent at least once a year so that you can update or change information.

Why create a Letter of Intent?

- You know your loved one better than anyone else and a Letter of Intent will share your knowledge and experience with others when you are unable to do so.
- A Letter of Intent is useful in emergency situations should something happen to you and someone else needs to provide care for your loved one.
- A Letter of Intent will provide you with a peace of mind knowing your loved one will continue to live a healthy, happy, and fulfilling life after you are unable to care for him/her.

Is a Letter of Intent a Legal Document?

- A Letter of Intent is **not** a legal document, but is used to:
    - Help in planning your estate – this should be used as the "Cover Letter" when writing your will and establishing a Trust.
    - Let others know how to care for your loved one – like how your loved one communicates and good ways to address behaviors.
    - Let others know what your loved one needs, like medications, doctor appointments, or dentist appointments.

How do I get additional workbook sheets?

- For additional workbook sheets, please visit our website at www.theadvocacyalliance.org or call toll free 1-877-315-6855.

I. BASIC INFORMATION

Name (First, Middle, Last):_____

What does your loved one like to be called (like a nickname)? _____

_____

What is your loved one's functioning level (if known)?_____

_____

Home Address

Street Address:_____

_____

City:_____ State:_____ Zip: _____

Home Telephone Number: _____
(Area Code)

Social Security Number: _____/_____/_____

Date of Birth: _____/_____/_____
(MM/DD/YYYY)

Place of Birth

Hospital Name:_____

City:_____State:_____

II. EMERGENCY INFORMATION

Emergency Contact Person(s) – who should be called in case of an emergency? Please list contact persons in order of contact.

1. Name: _____

Relationship: _____

Home Phone Number: _____
(area code)

Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

2. Name: _____

Relationship: _____

Home Phone Number: _____
(area code)

Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

3. Name: _____

Relationship: _____

Home Phone Number: _____
(area code)

Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

III. PROVIDERS

Primary Care Physician, General Practitioner

Name: _____

Office Phone Number: _____
(area code)

Cell Phone/Pager Number: _____
(area code)

Office Address: _____

_____

Dentist

Name: _____

Office Phone Number: _____
(area code)

Cell Phone/Pager Number: _____
(area code)

Office Address: _____

_____

Supports Coordinator (also called a MH/MR Caseworker or Social Worker)

Name: _____

Office Phone Number: _____
(area code)

Cell Phone/Pager Number: _____
(area code)

Office Address: _____

_____

Psychiatrist

Name: _____

Office Phone Number: _____
(area code)

Cell Phone/Pager Number: _____
(area code)

Office Address: _____

_____

Psychologist

Name: _____

Office Phone Number: _____
(area code)

Cell Phone/Pager Number: _____
(area code)

Office Address: _____

_____

III. Providers (Continued)

Specialist or Therapist (any health care professional your loved one needs to visit and what that specialist or therapist does)

Name: ______________________________

Office Phone Number: ______________________________
(area code)

Cell Phone/Pager Number: ______________________________
(area code)

Program Name: ______________________________

Program Director's Name: ______________________________

Office Address: ______________________________

____

Specialist or Therapist (any health care professional your loved one needs to visit and what that specialist or therapist does)

Name: ______________________________

Office Phone Number: ______________________________
(area code)

Cell Phone/Pager Number: ______________________________
(area code)

Program Name: ______________________________

Program Director's Name: ______________________________

Office Address: ______________________________

____

Specialist or Therapist (any health care professional your loved one needs to visit and what that specialist or therapist does)

Name: ______________________________

Office Phone Number: ______________________________
(area code)

Cell Phone/Pager Number: ______________________________
(area code)

Program Name: ______________________________

Program Director's Name: ______________________________

Office Address: ______________________________

____

IV. MEDICAL INFORMATION

Physical Health

Most people either have Medical Assistance, like Access or Access Plus, or private insurance, like Blue Cross or First Priority. This is how your loved one's medical care is paid for.

Medical Assistance Card (Access, Access Plus, Medicare, etc.)

Medical Assistance (MA) Caseworker:_____

Recipient (Rscp.) Number (ten numbers):_____

Social Security Number:_____/_____/_____

Private Insurance (like Blue Cross, Blue Shield, First Priority, Geisinger, Aetna, etc.):

Name of Company:_____

ID Number:_____

Help with Medical Assistance

For help with issues regarding your loved one's Medical Assistance, call the Family Care Manager toll free at 1-800-543-7633 (if under age 21) or toll free at 1 -800-692-7462 (if 21 years of age or older).

Medical History

Should you become unable to care for your loved one, what kind of information about your loved one's medical history and general health should someone else know? A Medical History can help a new caregiver get a complete picture of your loved one and be able to help him/her better if your loved one is sick. If you don't have a Medical History or other information, you can list where that history can be found (like with your loved one's Primary Care Physician or Supports Coordinator).

Remember: You may want to check with your loved one's Primary Care Physician to make sure that he/she is automatically receiving medical information from your loved one's Specialists. You can request that any Specialists your loved one uses send all information to the Primary Care Physician.

What is/are your loved one's main diagnosis(es) (e.g. Autism, Down Syndrome, and Developmental Disabilities, etc.)? _____

_____

_____

Does your loved one have a Medical History with his/her family doctor?

☐ Yes ☐ No

Does your loved one have a completed Health Risk Profile (HRP)?

☐ Yes ☐ No

If you answered Yes, you can attach a copy of the HRP to this document.

IV. MEDICAL INFORMATION (CONTINUED)

Does your loved one have seizures or has had seizures in the past?
☐ YES ☐ NO

If you answered **YES**, describe the seizure activity:

☐ Under control
☐ Currently happening
☐ Not currently happening
☐ Have **not** happened in the past two years
☐ Have happened, but not in the past year

Describe what you do during a seizure:_____

_____

Describe what prompts seizures:_____

_____

Does your loved one have an ongoing health problem(s)? ☐ YES ☐ NO

If you answered YES, describe the health problem(s):_____

_____

Medications (prescribed by the doctor and/or bought at the drug store, like vitamins or pain killers)

_____ _____ _____
_____ _____ _____
_____ _____ _____

Allergies (e.g., to medicines, bee stings, or foods)

_____ _____ _____
_____ _____ _____
_____ _____ _____

List any medications used/tried in the past that did not work for your loved one:

_____ _____ _____
_____ _____ _____

Devices (e.g., glasses, hearing aids, special shoes, or artificial limbs)

_____ _____ _____
_____ _____ _____

IV. MEDICAL INFORMATION (CONTINUED)

Behavioral Health

Does your loved one have an Individual Behavioral Health Plan (IBP)?
(This is usually to address behavioral problems or unusual behaviors)

☐ YES ☐ NO

If you answered YES, you can attach a copy of the IBP to this document.

What is the best way to address any problem behaviors or outbursts with your loved one? Please describe below:

Use this area to note anything else about your loved one's medical information you feel others should know. Remember – to be used to help give care to your loved one when you are unable.

V. EDUCATION

Does your loved one currently attend school or pre-school? ☐ YES ☐ NO

If YES, where?_____

Teacher's Name:_____

Intermediate Unit (IU) Supervisor:_____

Speech Therapist:_____

Physical Therapist:_____

Occupational Therapist:_____

Do you/your loved one have an Individual Family Service Plan (IFSP) if age 3 or younger? ☐ YES ☐ NO

If you answered YES, you can attach a copy of the IFSP to this document.

Does your loved one have an Individual Education Plan (IEP)? ☐ YES ☐ NO

If you answered YES, you can attach a copy of the IEP to this document.

List those individuals involved in your loved one's IFSP/IEP Planning Meeting (usually held in May or June).

_____ _____

_____ _____

_____ _____

_____ _____

Post Graduation

Where did your loved one go to school?_____

Did your loved one complete/graduate from high school?_____

Did/is your loved one taking classes after graduating from high school? ☐ YES ☐ NO

If **YES**, where?_____

If **NO**, would your loved one like to take classes? ☐ YES ☐ NO

If YES, what kind of classes (e.g., reading, art, crafts, cooking, writing, or computers)? List the classes:

_____ _____

_____ _____

_____ _____

_____ _____

VI. WORK, DAY OR DAY PROGRAM

Does your loved one have an Individual Support Plan (ISP)? ☐ YES ☐ NO

If you answered YES, you can attach a copy of the ISP to this document.

Does your loved one attend a day program? ☐ YES ☐ NO

Name of Program:_____

Contact Person:_____

Phone Number: _____
(area code)

Address:_____

Is your loved one working at a job in the community (e.g., supermarket or restaurant)? ☐ YES ☐ NO

Name of Program:_____

Contact Person:_____

Phone Number: _____
(area code)

Address:_____

Is your loved one working in a workshop? ☐ YES ☐ NO

Name of Program:_____

Contact Person:_____

Phone Number_____
(area code)

Address:_____

What does your loved one like about his/her **work, day, or day program**?

_____

_____

What ***do you like*** about your loved one's **work, day, or day program**?

_____

_____

VI. WORK, DAY, OR DAY PROGRAM (CONTINUED)

What type of **work, day, or day program** has worked best for your loved one?

What kind of **work, day, or day program** would ***you like*** for your loved one in the future?

VII. EVERY DAY LIFE

This information is to help someone who does not know your loved one and would like to get an idea of what your loved one does on an average day, including what kind of food your loved one likes, what his/her hobbies are, what his/her daily chores are, what kinds of help they need with daily tasks like brushing his/her teeth. The more information you can provide, the better picture people can get of an average day for your loved one.

Communication skills (what best describes the ways your loved one communicates):

☐	☐	☐	☐	☐	☐	☐
Does not communicate (talk)	Talks using words	Communicates with a delayed response	Uses gestures (hand signals)	Uses regular sign language	Uses own kind of sign language	Uses a device to talk (like a picture board or computer)

Describe any special ways your loved one lets you know what they want, like, or need:

VII. EVERY DAY LIFE (CONTINUED)

Other Skills

Can your loved one:

Shower, brush teeth, dress? ☐ With Help ☐ Alone

Notes:_____

_____

_____

Cook? ☐ With Help ☐ Alone

Notes:_____

_____

_____

Do Household Chores (e.g., cleaning, vacuuming, or dusting)?

☐ With Help ☐ Alone

Notes:_____

_____

_____

Shop (e.g., for clothes or groceries)? ☐ With Help ☐ Alone

Notes:_____

_____

_____

Manage Finances (e.g., pay bills and balance a check book)?

☐ With Help ☐ Alone

Notes:_____

_____

_____

VII. EVERY DAY LIFE (CONTINUED)

Do Outside Chores (e.g., mowing the lawn or raking leaves)?

☐ With Help ☐ Alone

Notes:_____

_____

_____

What else should a caregiver know about your loved one's daily life and tasks (e.g., sleep habits, special chores, transportation needs, or spending money)?

_____

_____

_____

Does your loved one have any special needs with his/her food (e.g., vegetarian, diabetic, spiritual, or religious) that must be met?

_____

_____

_____

_____

What are your loved one's favorite foods?

_____

_____

_____

_____

_____

VIII. RELIGION AND SPIRITUALITY

Does your loved one have a religion or spiritual preference? ☐ YES ☐ NO

If YES, what is your loved one's religion?_____

If your loved one attends a place of worship, where does he/she attend?

Name:_____

Street Address:_____

City:_____State:_____Zip Code:_____

Phone Number: _____
(area code)

If your loved one attends a place of worship, how often and when do they attend?

_____

Does your loved one have a friendship with any clergy person?
☐ YES ☐ NO

Name:_____

Home Phone Number: _____
(area code)

Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

Does your loved one attend any special events held by his/her place of worship (e.g., picnics or holiday programs)? ☐ YES ☐ NO

Do you see your loved one becoming more or less involved in his/her place of worship in the future? ☐ YES ☐ NO

How or why?_____

Please note any other activities associated with your loved one's religion or spirituality:

_____

IX. Family and Personal Activities

Does your loved one go on vacations? ☐ YES ☐ NO

If **YES**, who organizes the vacations?_____

If **YES**, how often does your loved one take a vacation?_____

If **YES**, when does your loved one take a vacation (e.g., summer, during a holiday, or winter)?_____

If **YES**, does your loved one have a regular vacation spot (e.g., Disney, Wildwood Beach, the Outer Banks, or a family cabin)?_____

Does your loved one have a regular social activity (e.g., going to the movies, going out on dates, or going out for dinner)? ☐ YES ☐ NO

If **YES**, with whom does your loved one go on these activities?

Name:_____

Relationship:_____

Home Phone Number: _____
(area code)

Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

Name:_____

Relationship:_____

Home Phone Number: _____
(area code)

Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

IX. Family and Personal Activities (Continued)

Use this area to express values that you feel are important in your loved one's life.

X. Planning

In this section are questions about where you see your loved one after you are no longer able to be involved in his/her life. The questions and your answers will help the people who will provide care for your loved one know where you see your loved one in the future, what your hopes and dreams are for your loved one, and what you think will best help your loved one continue to grow and live a happy and healthy life. The answers to some of these questions will change as your loved one gets older. Some questions may not apply to your loved one at this time, but may in the future.

When completing this section, it may help to look at what is important in your loved one's life now and what may change when you are no longer able to care for your loved one and as your loved one ages. For example, if your loved one will need to move to another state, county, or town/city, he/she may not be able to continue his/her current job, keep his/her current Supports Coordinator, or be involved in the same church. If your loved one will be moving, it is important to learn about the area where he/she will go and ask questions to help guide you in completing your Letter of Intent. Some questions may include:

- What kind of services are available for my loved one in this state, county, and town/city?
- Are people with special needs encouraged to live an Everyday Life in this new area?
- Is the new neighborhood accepting of people with Special Needs?
- Will the new living situation help my loved one continue to have a good quality of life?

X. PLANNING (CONTINUED)

What are the most important things in your loved one's life right now?

☐ Family ☐ Other: _____

☐ Work ☐ Other: _____

☐ Finance (money) ☐ Other: _____

☐ Friends ☐ Other: _____

Where do you see your loved one living after you can no longer provide care for him/her? Remember that when you change where a person lives, everything in that person's life will change.

Consider that some services or supports that your loved one receives now may not be available in all states, counties, and towns/cities.

State: _____

County: _____

Town/City: _____

With whom do you see your loved one living after you are unable to provide care for him/her? Please number the following options in the order you wish each to be considered.

_____ Alone

_____ Parent Name: _____

_____ Relative Name: _____

_____ Guardian Name: _____

_____ Other: Name: _____

In which type of living arrangement do you see your loved one after you are unable provide care for him/her?

_____

How many people do you see your loved one living with (including caregivers)?

☐ Alone ☐ 1-2 ☐ 2-4 ☐ 4-6 ☐ 6-8 ☐ 8 or more

X. PLANNING (CONTINUED)

Do you have a person or an agency chosen to see that your desires for your loved one to maintain a heightened level of services will be carried out?

☐ YES ☐ NO

If **YES,** note the person/agency below:

Name (Person or agency):_____

Contact person's name if agency:_____

Home/Agency Phone Number:_____
(area code)

Street Address:_____

City/State/Zip Code:_____

Work Phone Number:_____
(area code)

Cell Phone Number: _____
(area code)

Do you think your loved one would be helped by:

☐ Having his/her own bedroom, no matter where he/she lives (consider your loved one's need for privacy)

☐ Having a roommate who shares the same bedroom

☐ Having an apartment/house with another person, but separate bedrooms

☐ Living in the same neighborhood where he/she lives now

☐ Moving to live closer to his/her work/day program

☐ Living in a rural (county) environment

☐ Living in a suburb (a quiet neighborhood outside of a city)

☐ Living in a city ☐ Living near a bus stop ☐ Living close to loved ones

☐ Living within walking distance of a grocery store ☐ Having a pet (e.g., cat or dog)

☐ Other: _____

☐ Other: _____

X. PLANNING (CONTINUED)

What would you want reviewed (checked) on a regular basis and how often?

☐ Residence How frequently? _____

☐ Recreation options How frequently? _____

☐ Therapy appointments How frequently? _____

☐ Doctor appointments How frequently? _____

☐ Dental appointments How frequently? _____

☐ Day program/workshop How frequently? _____

☐ Other How frequently? _____

What kind of supports do you think your loved one will need in his/her home?

☐ 24 hour supervision

☐ Supported Living (someone to come daily and help with cooking, cleaning, or laundry)

☐ Minimal Supports (someone to come 2 to 3 times a week to help with household chores)

☐ Other Describe: _____

_____

Should you have questions about the benefits your loved one receives, please contact the Social Security Office toll free at 1-800-772-1213 or online at www.ssa.gov.

If your loved one will need to move after you can no longer care for him/her, who will help them find a place to live?

Family Member/Loved one:

Name: _____

Relationship: _____

Home/Agency Phone Number: _____
(area code)

Direct Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

X. PLANNING (CONTINUED)

Friend:

Name: _____

Relationship: _____

Home/Agency Phone Number: _____
(area code)

Direct Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

Supports Coordinator/Casemanager:

Name: _____

Relationship: _____

Home/Agency Phone Number: _____
(area code)

Direct Work Phone Number: _____
(area code)

Cell Phone Number: _____
(area code)

Additional Notes:

_____

_____

_____

_____

_____

_____

_____

_____

_____

XI. Special Needs Trusts—A Fact Sheet

What Is a Special Needs Trust?

A Special Needs Trust is a legal instrument that appoints a Trustee, a person or entity, as nominal owner of assets to be held or used for the benefit of a person with special needs. A Special Needs Trust can protect the assets from being counted as a resource by the Social Security Administration and the Pennsylvania Department of Public Welfare, thereby protecting need based government benefits such as Supplemental Security Income (SSI) and Medical Assistance (MA).

Why Have a Special Needs Trust?

- To shield a person with special needs from designing individuals who may otherwise take advantage;
- To provide a means for others to gift the person with special needs without placing government benefits at risk; and
- To provide a shelter for any financial windfall that might occur, e.g, proceeds from a lawsuit or back payment from a benefit source.

What are Allowable Expenditures?

The Trustee decides when, how much, and for what purpose the assets of the trust are used. The assets of the trust may only be used for the benefit of the person with special needs. Allowable expenditures are made for supplemental needs, rather than basic life-sustaining needs. Some examples of allowable expenditures are: medical equipment; independent evaluations; vacations; school or camp tuitions; and personal assistance.

How Can The Advocacy Alliance Help?

The language of a Special Needs Trust may empower the Trustee to employ an agent, such as the Advocacy Alliance, to assist in the performance of its duties. The Advocacy Alliance knows that the purpose of a Special Needs Trust is to enhance the quality of life of persons with special needs. The Advocacy Alliance has a demonstrated expertise in recognizing the needs of persons with special needs, specifically persons who have developmental disabilities. The Advocacy Alliance has a presence in Northeastern Pennsylvania, the Poconos and the Lehigh Valley, and can be in contact with a person with special needs on a regular basis. The Advocacy Alliance can assess and monitor needs on an ongoing basis and serve in an advisory capacity to the Trustee on a variety of issues, including physical and behavioral health, and government and private service options.

How Can I Contact The Advocacy Alliance?

Email: info@theadvocacyalliance.org

Toll Free at 1-877-315-6855

XI. SPECIAL NEEDS TRUSTS—A FACT SHEET (CONTINUED)

A partial listing of non-profit corporations in Pennsylvania that provide Special Needs Trust Services

Advocacy Alliance
846 Jefferson Avenue
P.O. Box 1368
Scranton, PA 18501
1-877-315-6855
www.theadvocacyalliance.org

ACHIEVA
711 Bingham Street
Pittsburgh, PA 15203
1-888-272-7229
www.achieva.info

ARC Community Trust of Pennsylvania
1010 West Ninth Street
King of Prussia, PA 19406-1214
(610)265-4700, Ext. 228
www.arccommunitytrustpa.org

Arlington Heritage Group, Inc.
301 Horsham Road, Suite L
Horsham, PA 19044
(215)672-1184

KenCrest Services
502 West Germantown Pike, Suite 200
Plymouth Meeting, PA 19462-1307
(610) 825-9360
www.kencrest.org

Life Enrichment Trust
100 Passavant Way
Pittsburgh, PA 15238
1-888-764-6467
www.lifeenrichmenttrust.org

PLAN of PA
230 Sugartown Road,
Suite 205
Wayne, PA 19087
Phone: 610-687-4036
www.planofpa.org

Secured Futures
4747 E. Elliot Rd. Ste 29-217
Phoenix AZ 85044
Phone: 602-635-6674
www.SecuredFutures.org

NOTES

The Advocacy Alliance Services

Adult Mental Health Advocacy

The Advocacy Alliance's advocates ensure that persons in the community who experience mental illness are heard, serve as their own spokespersons, and that the focus of their treatment, housing and employment is based on their individual needs for Recovery. Our advocates, including Certified Peer Specialists, also work at Clarks Summit State Hospital, with former patients of Allentown State Hospital and in community adult psychiatric in-patient units, helping to see that persons understand their rights, their rights are respected, and their services are helpful.

Child and Family Mental Health Advocacy

The Advocacy Alliance's Children's Mental Health Advocate works with families of children who have emotional/behavioral disorders to help them understand and ensure the protection of their rights in the children's mental health and other child-serving systems of care, as well as at the Youth Development Center at Hickory Run. Our advocate ensures that families' voices are heard and included in the dialogues on the regional, state, and federal levels, the results of which are policies and programs which affect children and their families.

Community Support Program

As Northeast Pennsylvania Region Coordinator for Community Support Program (CSP), the Advocacy Alliance's goal is to educate and to assist local communities in improving opportunities and services for persons who are involved with mental health and/or substance abuse issues. The CSP is a coalition of mental health consumers of services, family members, advocates and professionals who work together to ensure quality of life issues for persons who have a mental illness.

Early Intervention Evaluation Teams

The Advocacy Alliance facilitates teams which include two of the following disciplines: occupational therapy; physical therapy; speech therapy; nursing; and special needs instructors. The teams evaluate children, from birth to 2 years and 9 month of age, to determine if they are eligible for early intervention services. The reasons for children are referred for an evaluation include: speech delay; motor delay; cerebral palsy; torticollis; down syndrome; sensory, behavior, hearing and vision concerns; dwarfism; and failure to thrive.

Guardianship/Trust Services

When adults are adjudicated incapable, a Guardian of Estate is needed to manage the individuals' assets to assure that their needs are met and to protect them from designing persons. The Guardian of Person is needed to assist individuals to live in the least restrictive settings with the necessary support services that can enhance or maintain their care and safety. A Power of Attorney (POA) is a written legal document that allows an individual to appoint someone to be their agent in order to give the person authority to act on the individual's behalf. The Advocacy Alliance staff provides these services in accordance with the national standards provided by the National Guardianship Association and by the mandates of the court under 20 Pa. Cons. Statue Section 5510 et seq.

The Advocacy Alliance administers Special Needs and other Trusts, including Payback Trusts and Common Law Special Needs Trusts, which are created for individuals who have disabilities who are often in need of preserving their governmental benefits. A trust can provide for supplemental needs to add to the beneficiary's quality of life and ensure the governmental benefits remain in force to provide basic support such as shelter, medical care, and maintenance.

Education Funded Special Needs Trusts are funded by a school district through litigation for educational needs and compensation. These trusts are defined by the trust agreement and if the monies are not spent, they return to the school district.

The Advocacy Alliance facilitates Recovery and Resiliency focused teams whose expressed purpose is to assess adults' and children's/adolescents' levels of satisfaction with the mental health and/or drug and alcohol services they receive, to inquire as to their wants and needs, and to learn what they think would help in the delivery of services. Survey teams are comprised of individuals and families of individuals who use mental health and/or substance abuse services.

Currently the Advocacy Alliance is establishing a "Pooled Trust" or "OBRA Trust" for the benefit of individuals who have a disability. These trusts can be joined by the individual, a parent, grandparent, or ordered by the court and can be joined with small amounts of money but pooled to maximize earning potential through investments.

Health Care Quality Units

The Advocacy Alliance facilitates Health Care Quality Units (HCQUs) which work to support and improve the developmental disabilities community service systems by building capacity and competency to meet the physical and behavioral health care needs of persons who have developmental disabilities. The primary activities of the HCQUs include: assessing the person's health and systems of care; providing clinical health care expertise to residential and day program providers; providing health related training; and integrating community health care resources with state and regional quality improvement structures and processes. The primary goal of the HCQUs is to assure that the persons served by developmental disabilities programs are as healthy as they can be, so that each person can fully participate in community life.

INCIDENT MANAGEMENT SERVICES

Incident Management is a subset of a larger risk management process that ensures that the health, safety, and rights of persons receiving developmental disabilities and persons receiving mental health supports and services are respected.

Incident Management is a statewide process for reporting, categorizing and investigating incidents entered in the HCSIS (Home and Community Services Information System) Database System. All reports are reviewed in order to determine that appropriate actions have taken place to protect the individual receiving developmental disabilities and/or mental health supports and services.

INDEPENDENT MONITORING FOR QUALITY TEAMS

The Advocacy Alliance facilitates teams of consumers of developmental disabilities services, family members, and community volunteers who are dedicated to the continuous improvement of the quality of services and supports for persons who have developmental disabilities. The teams conduct surveys of consumers of develop-mental disabilities services, facilitate self-advocacy groups, speak with consumers of developmental disabilities services and family members to determine their levels of satisfaction with services, and educate the community.

RECOVERY CENTER

The Recovery Center is person-driven center located in Scranton where persons receiving mental health services come together in an atmosphere of mutual support for the process of supporting their individual Recovery. The Center offers members an environment where they can enhance and expand activities of self advocacy such as Peer Specialists Programs, Mental Health Advanced Directives, and Community Support Programs, as well as develop and implement educational programs on issues relating to mental wellness and Recovery.

REPRESENTATIVE PAYEE PROGRAM

The Advocacy Alliance's Representative Payee Program is a system of financial and budgetary management for persons who have a mental illness, persons who have developmental disabilities, and older adults who are unable to manage their monthly Social Security benefits, other benefits and financial affairs.

VENDOR/FISCAL AGENT SERVICES

The Advocacy Alliance's Vendor/Fiscal Agent Services provide employer related services for persons who have a physical disability, persons who have developmental disabilities or their representatives, and older adults or their representatives. We partner with the person or their representative in the use of self-directed attendant care services by assuring compliance with federal, state and local employer requirements, thereby reducing their burden as employer without diminishing their right of self direction.

WARM LINES

The WARM LINES are a confidential, one-on-one telephone support service for persons who have a mental illness and are experiencing sadness or loneliness or just want to share good news. It is staffed by trained persons who are in Recovery from a mental illness and who understand the needs of their peers.