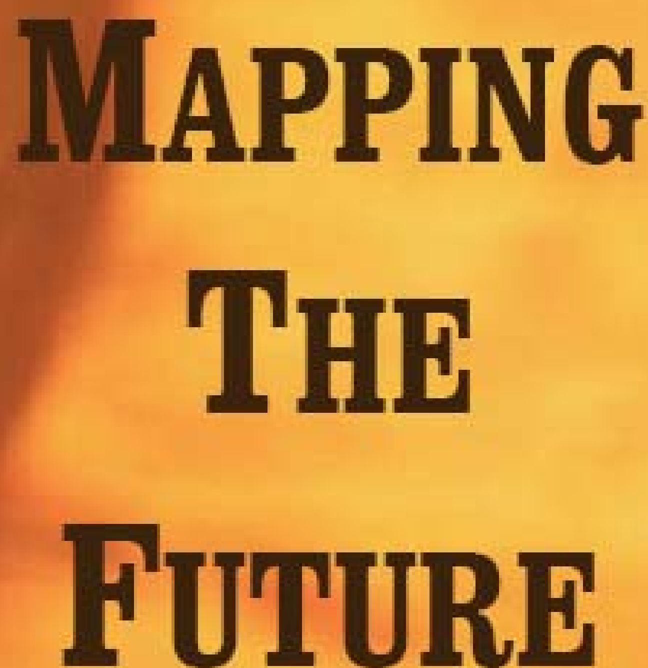


Mapping The Future

A Workbook to Prepare for the Future of Your Loved One with Special Needs

The only way to predict the future is to have power to shape the future.
– Eric Hoffer

the Advocacy Alliance

...promote mental well-being, support Recovery for adults who have a mental illness, Resiliency in children and adolescents who have emotional disorders and Everyday Lives for persons who have mental retardation and other developmental disabilities and provide to them advocacy and culturally competent 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.

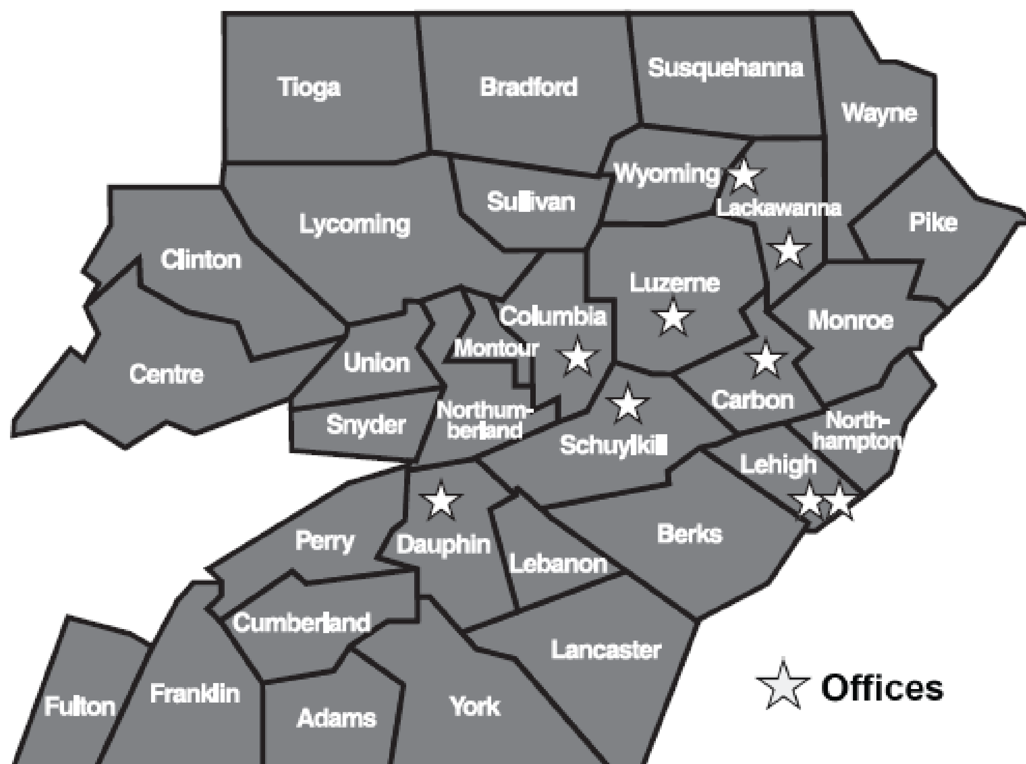
CONFIDENCE in the rightness of our mission.

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 mental retardation and other 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 mental retardation and other 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 mental retardation and other 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.

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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.

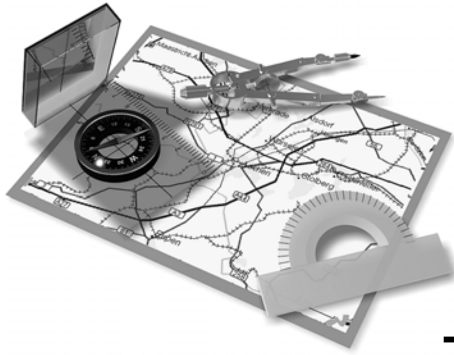
This workbook can be your "Letter of Intent" and the information you include in this workbook will be used to make it easier for the quality of your loved one's life to continue after you can no longer care for him/her. This workbook is intended to be used, either in whole or in part, as you feel it 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

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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 Mental Retardation, 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 Mental Retardation, 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.

____

____

____

____

____

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____

____

____

____

____

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 on-line 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 mental retardation and other 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

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

The Arc of Berks County
Kenhorst Professional Center
1829 New Holland Road, Suite 9
Reading, PA 19607
(610)603-0227
www.berksiu.org/arc

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The Advocacy Alliance Services

Adult Mental Health Advocacy

Our 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 also work at Clarks Summit and Allentown State Hospitals and in community adult psychiatric in-patient units, helping to see that persons understand their rights, their rights are respected, and their stay is helpful.

Children/Family Mental Health Advocacy

Our advocates work with children who have emotional/behavioral disorders and their families to help them understand and ensure the protection of their rights in the children's mental health and other child-serving systems of care. Our advocates ensure 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.

Recovery Centers

The Recovery Centers are person-driven centers located in Scranton and Pottsville where persons receiving mental health services come together in an atmosphere of mutual support for the process of supporting their individual Recovery. The Centers offer 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.

Consumer Financial Management

Our representative payee program is a system of financial and budgetary management for persons who have a mental illness, persons who have mental retardation, and older adults who are unable to manage their monthly Social Security benefits, other benefits, and financial affairs.

Our vendor/fiscal agent program provides employer related services for persons who have a physical disability, persons who have mental retardation or their representatives, and older adults or their representatives. Our program partners 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.

We also provide other fiduciary services including guardianship of person/estate, asset management/liquidation, and power of attorney.

Social Club

We offer a safe, supportive environment in Lackawanna County (Friendship "7" Social Club founded in 1962) for persons in the community who have a mental illness or emotional problem to come together, socialize, and enjoy programs.

Health Care Quality Units

We facilitate Health Care Quality Units (HCQUs), the responsible entities to the County Mental Health/Mental Retardation Programs for monitoring the overall health status of persons with mental retardation receiving services. The HCQUs work to support and improve the mental retardation community service systems by building capacity and competency to meet the physical and behavioral health care needs of persons who have mental retardation. 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 mental retardation programs are as healthy as they can be, so that each person can fully participate in community life.

Community Education

We promote public awareness of mental health and mental retardation issues, problems, services, and treatment. We educate the general public and solicit support for or opposition of legislation and public policy related to mental health and mental retardation. We also provide educational opportunities, most often partnering with persons who have a mental illness and/or persons who have mental retardation and families, not only for those we serve but for the general public as well.

Consumer/Family Satisfaction Teams

We facilitate Recovery and Resiliency focused teams that include persons who have a mental illness and families, whose expressed purpose is to assess adults' and children's/adolescents' levels of satisfaction with the mental health services they receive, to inquire as to their wants and needs, and to learn what they think would help in the delivery of services.

Independent Monitoring Teams

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