VOLUNTEER GUARDIANSHIP ONE ON ONE, INC.

117 MAIN STREET FLEMINGTON, NJ 08822

- A PROUD UNITED WAY MEMBER AGENCY -

VOLUNTEER MANUAL

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Introduction and History of VG

Volunteer Guardianship One on One, Inc. started as a response to the need for court appointed legal guardians for incapacitated adults who had no family or friends willing or able to become their guardians. The New Jersey Office of Public Guardian had generally handled these types of cases. In the mid 1990's due to budget restrictions, a moratorium was put on accepting new cases. That created a crisis on the county level because Surrogates and Judges had no one to turn to to help these very vulnerable people. Hunterdon County Surrogate Susan Hoffman and an attorney named Tony Serra developed the original concept of using volunteers in a structured way to meet this need. Traditionally, if there is no family, and the Office of Public Guardian was not available, the court would appoint an attorney to the role.

This was the case in 1997. Tony Serra, Esq. had been appointed to be the guardian ad litem for a patient in Hagedorn Geriatric Psychiatric Center in Glen Gardner. When it was determined that this patient would need a permanent legal guardian, no family or friends could be located. As had happened in the past, it was likely that Tony would be appointed. At the time, he had a secretary who had voiced a desire to find fulfilling volunteer work and to make a difference in the life of another person. When Tony and Susan Hoffman met concerning this case, it was decided that locating a volunteer would be in the best interest of the patient. Judge Bernard agreed and the program was off to its start.

Volunteer Guardianship One on One, Inc. was incorporated in 2000 and received its non-profit status at the same time. Since then, it has received funding from Hunterdon County and the State of New Jersey, Department of Health and Senior Services.

Helpful Reminders

Helpful reminders to guardians....

- Address your ward by name
- Show your genuine interest in your ward. Lead conversations into topics of interest to him/her. Be a good listener. Ask questions that require more than a "yes" or "no" answer.
- Use contact expression if both of you are comfortable with it; i.e., holding his/her hand, or touching his/her arm.
- Be optimistic. Build confidence. Foster independence...let him/her do what he/she is able to do for him/herself.
- Smile. Share laughter.
- If he/she is hard of hearing, speak clearly, elevate your voice slightly and lower the tone.
- Even if your ward is nonverbal and/or unresponsive, your presence and involvement are important.
- Respect the confidentiality of your ward.
- Be dependable. If you make a promise, keep it. In addition to other losses which your ward may have experienced, the apparent rejection of unkempt promises only increases his/her insecurity.
- Know your limitations as a volunteer. Set your own limits on how deeply involved you will become with your ward. Refrain from using your own resources to meet your ward's needs.
- Remember, it is not your responsibility to be a social worker, pastor, medical doctor, or lawyer. Refer those problems to the appropriate persons. VG board members are available to guide and assist you.
- Report any suspected incident of abuse, neglect, abandonment, or exploitation of any ward by caretakers, service providers, or others to the county Social Services and VG immediately.

Volunteer Guardian Code

As a volunteer guardian, I realize that I am subject to a code of ethics similar to that which binds professionals.

I will exercise extreme care and diligence when making decisions on behalf of my ward. I will make all decisions in a manner which protects his/her civil rights and liberties and maximizes his/her independence and self-reliance.

I will exhibit the highest degree of trust, loyalty, confidentiality, and fidelity in relation to my ward.

I will assume legal custody of my ward and ensure that he/she resides in the least restrictive environment available.

I will assume responsibility to provide informed consent on behalf of my ward for the provision of care, treatment, and services representing the least restrictive forms of intervention available.

As guardian of the estate, I shall provide competent management of the property and income of the estate. In the discharge of this duty, I will exercise intelligence, prudence, and diligence and avoid any self-interest.

I interpret "volunteer" to mean that I have agreed to work without compensation in money, but having been accepted as a worker, I expect to do my work according to standards, as the paid staff expect to do their work.

I will take an attitude of open-mindedness to my work be willing to be trained for it, and bring interest and attention to it.

I believe that my attitude toward volunteer work should be professional. I believe that I have an obligation to my work, to those who direct it, and to my ward. With this in mind, I affirm my obligation to seek termination or limitation of the guardianship whenever it is indicated.

Being eager to contribute all that I can to human betterment, I accept this code to be followed carefully and dependably.

Volunteer Guardian Job Description

Job Title: Volunteer Guardian

Purpose: To be a substitute decision-maker for the incapacitated person when no other

appropriate individual is willing or able to serve.

Accountable to: The court and the Executive Director of VG.

Responsibilities/
Duties:

While not common, court appearances may be necessary at times.

Establish a rapport with your assigned ward; and meet regularly with ward to

become familiar with his/her needs and limitations.

Make regular contacts (monthly, if possible, but at least once a quarter) with service providers involved with your ward's day-to-day care to keep abreast of

his/her general health and welfare.

Advocate for services to meet the needs of the ward.

Encourage participation by your ward in decision-making to the full extent of

his/her ability.

Comply with all statutory reporting requirements to the court/VG.

Communicate with VG staff. They can give guidance and technical assistance

should there be any changes in your ward's health or situation requiring

modifications in his/her care.

Participate in any in-service training offered.

Qualifications: The ability to communicate clearly, both verbally and in writing.

Compassion for, knowledge about and ability to work with persons who are

developmentally disabled, mentally ill, brain injured, or elderly who are

incapacitated.

Must provide own transportation.

Time

Commitment: Two to three hours per month average. May be more or less according to the

needs of the ward and your personal style.

Volunteer Guardian Job Description

Training: General orientation and training are provided by the executive director.

On-the-job training will be provided as needed by the executive director.

Technical assistance will be provided or arranged by the executive director.

Continuing Education:

In-services will be arranged periodically.

Volunteer Responsibilities

As volunteers, we accept obligations to...

- **be loyal**...to Volunteer Guardianship One on One, Inc., as well as to the wards served, maintaining confidentiality of private, personal matters.
- Be dependable...by fulfilling your obligation to the best of your ability. You have a fiduciary relationship with your ward, which carries a tremendous amount of responsibility. Inform the VG office, as well as service providers of your ward, when you will be on vacation or out of town so that your ward's needs are covered if there is an emergency when you are unavailable.
- be informed...about the services provided by VG as well as the policies established for the
 protection of volunteer guardians, their wards, and the organization. Attend orientation and
 training sessions. Read materials provided. There are reasons for all rules and regulations.
 Know them so you can be a program advocate in the community.
- be aware...of your ward's needs. Note anything unusual: abnormal confusion, disorderly surroundings, intense pain, uneaten food, etc.
- **speak up**...about matters you don't understand. Don't let doubts and frustrations drive you away.
- Be pleasant, yet assertive...in working harmoniously with service providers and others. A
 conscientious worker is as important to your volunteer position at VG as it would be to any
 position for which you would be salaried.
- Be willing to learn and keep on learning...through orientation and update/refresher training, which is essential to any job well done. Statutory and policy changes do occur, and it is our responsibility to comply with them.

Volunteer Rights

Correspondingly, every volunteer has the right to...

- be happy...and get satisfaction and a sense of fulfillment from your involvement with Volunteer One on One.
- know about the work setting...to enjoy the contact with staff, fellow volunteers, and with your ward.
- **be informed**...to be given sufficient background information on your ward; to know about VG policies and procedures; to know VG staff, and how they can assist you.
- **be trained for the job...**and to be given clear, concise instructions; to have the opportunity to ask questions if something is not understood; and have full knowledge of what VG expects from you.
- have sound guidance and directions, periodic one-on-one reviews...by someone who is experienced, well informed, patient, and thoughtful; and who is in the position to give correct answers to questions.
- be heard...and to be able to make suggestions and share an honest opinion.
- continuing education on the job...as a follow-up to initial training, and to be given information
- whatever support the program is capable of giving...through recognition and expressed appreciation for the job your are doing.

How a Guardianship is Established

A Guardianship is established in the following manner:

- A referral is received from a referral source
- Any available paperwork on the case is obtained by VG including any information on a scheduled court hearing
- Paperwork is prepared and forwarded to the Ward Acceptance Committee, if necessary
- If the Ward Acceptance Committee determines that the case is acceptable (based upon the current information), an appropriate volunteer is located
- If the Ward Acceptance Committee determines that the case is not acceptable, notify the referral source
- Contact the selected volunteer to determine if the volunteer is currently available and willing to accept the case based upon the current information
- Arrange a meeting between the ward and the volunteer
- Provide the volunteer with any available paperwork
- Contact the court appointed attorney and discuss VG's volunteer as a possible guardian.
 Provide the court appointed attorney with written information on VG and a copy of the volunteer's application
- Arrange a meeting between the court appointed attorney and the volunteer, if requested
- Prepare volunteer for court hearing
- Review the copy of the final court order to determine that the proper language has been included regarding VG's status in the guardianship
- Attend the court hearing with the volunteer

Role of the Volunteer Guardian

What is the role of the volunteer guardian?

Guardian-ward relationship is fiduciary

Guardians hold a fiduciary relationship, one of trust, with their wards. Major decisions regarding the ward's life are entrusted in faith and confidence to the guardian. The decisions volunteer guardians are asked to make are vital. Therefore, they are asked to make a long term commitment of time, effort, and emotion. Because of this relationship, it is important to know as much about the prospective ward as possible. Volunteer guardians must feel confident in developing a relationship satisfying to both, where the volunteer guardian will be advocate and friend, as well as decision-

maker.

Ward involvement in decision making Guardians will want to involve the ward in the decision-making process to the full extent of the ward's ability to participate. Although the guardian has the ultimate responsibility for making and being accountable for the decision, the ward's desires need to be considered if at all possible.

Volunteer guardians through the VG are usually guardians of the person and property and are also responsible for management of the ward's finances and property.

Depending on the type of guardianship, the guardian's responsibilities and powers will vary. See example box at right.

Guardians do not financially support

A guardian is not obligated to use his/her own money to support his/her ward. Nor is a guardian expected to provide a residence for the ward within his/her own home.

A guardian of the person has, among other duties, the responsibility to:

- Assure the ward has safe, suitable living arrangements;
- Arrange for needed support services
- Monitor the quality of support services
- Assess health needs, and arrange and authorize treatment
- Determine who will be the representative payee if the ward is on SSI or SSDI
- Take reasonable care of the ward's personal property
- Commence protective proceedings, if necessary, to protect the property of the
- Apply the ward's income to the ward's support, care, and education
- Facilitate the ward's education, social, or other activities
- Consent to marriage or adoption
- In the case of the death of the ward, arrange for final disposition of the ward's remains if the immediate family is unavailable or unwilling to assume responsibility

Role of the Volunteer Guardian

Decision-making help is available

Although guardians have the final decision, they do not have to make decisions without help. The ward probably has a support system already in place. There is likely to be a service provider, a case manager, an agency representative, and experts in the developmental disabilities, mental health, aging, medical, and legal professionals who can be contacted for consultation. VG staff are also available to assist with decision making.

Some decisions regarding wards are subject to approval of the court. These include:

- Commitment to a mental health hospital or other mental health facility
- Consent for the following treatments:
 - Electroshock therapy
 - Psychosurgery
 - o Sterilization
- Other long-term or permanent contraception
- Relinquishment of a ward's minor child for adoption
- Execution of advance medical directives including durable power of attorney for health care

Guardian of the property

Guardians of the property are responsible for:

- Setting up bank accounts
- Maintaining financial records
- Paying monthly bills

Confidentiality Issues

Guardians have a responsibility to maintain the confidentiality of personal issues regarding their wards. Information will obviously need to be shared with providers and others involved in the affairs of the ward. However, details about wards should not be shared randomly.

Guardianship termination

Termination of a guardianship is a formal procedure. Guardianship of an adult ceases when the ward dies, when the court determines that the guardianship is no longer needed, or when the court determines that the guardian is not able to continue. Judges are generally reluctant to terminate a guardianship for a ward in need until a successor guardian is nominated and approved.

Records, Reports, Forms, and other Paperwork

What paperwork is required of a Volunteer Guardian?

Information about your ward

Completing the "ward information" form in the section following this chapter will give you a handy reference of pertinent data about your ward. Ask your ward's caregiver or case manager to assist you in compiling the information if he/she does not have it ready for you.

Recording contacts

As guardian, you will be assured your ward receives the best services, and at the same time protect yourself from criticism and liability, if you review options and seek second opinions and advice from professionals. It is advisable to maintain a written record of all pertinent contacts on behalf of the ward. The record documents the effort made to make reasonable decisions. The form titled "Volunteer Guardian Contacts Regarding Ward" at the end of this chapter can be copied for this purpose or a similar form may be used.

Reports to the court

It is the volunteer guardian's responsibility to keep track of due dates of reports to the court and to submit the required reports. You will want to keep a copy of all reports in your file.

Documents you should keep in a file, including, but not limited to:

- Legal papers;
- Financial records, if any;
- Completed "Ward Information" form giving background data on the ward and family contacts, etc;
- Information and history provided when guardianship was imposed;
- Plan of care:
- Current medications;
- Copies of your reports to the court;
- List of people you have notified of your guardianship appointment.

Suggestions for Guardian Reports

The reports to the court are an important part of the duties of guardians. These reports are filed with the Surrogate's Office who monitors guardianships. Usually, forms are available at the county Surrogate's Office.

It is important that the reports are something more than an impersonal recitation of the status of the ward. The court appreciates personal details submitted in the reports and requests that the reports contain details regarding the ward's living situation, health, and well-being, frequency of visits, the opinion of the guardian regarding the quality of care that the ward is receiving, and the other details which indicate the quality of life experienced by the ward and the interest of the guardian in the ward. It is not necessary to submit copies of personal plans (or Plan of Care) to the court. Some Surrogates provide forms to complete for guarding the well being of a ward.

Thank you to everyone who works with and volunteers his/her time as a guardian. You provide a valuable service.

Records, Reports, Forms, and other Paperwork

Initial Report

The court may require an inventory soon after guardianship is granted, usually within 90 days. This inventory includes a listing of assets in the ward's name. The annual reporting usually consists of a financial accounting and a report of well being.

Annual Accounting

The forms provided by VG may be used for the report or simply used as a guide. It is due within 60 days of the anniversary of the appointment of guardianship or as noted in the court order.

Other Reports

As guardian of the person, the court may order the guardian to file other reports on the ward's condition and the guardian's performance of his/her duties. A court visitor may contact a guardian to meet with the guardian and ward; or an evaluation may be sent by the court.

Volunteer guardians who also serve as representative payees for their wards will need to make a

financial report annually to social security. The "Monthly Ledger for Ward income/Expenses," which follows this chapter, will help account for all funds. Social Security requires the accounting of all funds in the categories of 1) food and shelter and 2) other things for the beneficiary, such as clothing, education, medical and dental expenses, recreation or personal items.

The amount of money saved is also to be reported. SSI beneficiaries cannot have more than \$2000 in resources, or they will lose benefits. If the ward does have excess funds monthly, they can be put toward a burial plan.

Funds should also be reserved for prophylactic dental care. Medicaid only covers emergency dental treatment for adults. The result is usually tooth extraction.

Notifying others of guardianship

There will undoubtedly be others involved with the ward who will need to know of your involvement and authority. A list may include medical providers, service providers, bank personnel, family members, etc. As guardian, you will want to notify these people of your appointment and provide them with a copy of the letter of guardianship for inclusion in their files. This will clarify your right to be involved in decision-making. Make a list of recipients for your file so that you have a record of whom you have given a copy of the letter.

Other Record Keeping

VG asks that volunteer guardians keep track of the time spent on volunteer guardianship responsibilities. These hours and the corresponding dollar value are important to VG, a private nonprofit, to demonstrate the impact and need for volunteer guardian-ship in New Jersey. These volunteer hours are also used as match for grants which are necessary for funding VG.

Records, Reports, Forms, and other Paperwork

Involvement in care planning sessions

Service providers should notify you when planning sessions are scheduled for your ward. You have a responsibility to participate and to sign the service care plan. You should also be given a copy of the care plan. Check its accuracy and confirm follow-through.

Notes

15

In the Matter of the Guardianship) of)	ACC	OUNTING
(name of ward)) an incapacitated person)	7,00	
an incapacitateu person		
The Account dated		
balance) of, (Name of Guardian)	guardian of	(Name of ward)
is as follows:	Summary of To	tal Assets
Current Assets		Beginning Balance
Real Property (tax assessed value) \$		Ending Balance
Total Beginning Assets: \$		Total Ending Assets: \$
(Ple	Income Rec	
Total Income Received \$		
	Expenses (Please List So	<u>Paid</u> urce and amount)
Total Expenses Paid as to Assets: \$		
Beginning balance of assets as of/(Ending balance from previous accounting)	_/	
Income Received		+
Disbursements made		
Ending balance of assets as of//_		=
State of)	00	
County of)	SS	
(Guardian's name)	, beii	ng duly sworn according to law, deposes and says:
I am the guardian in the foregoing account na The account is just and true to the best of my		belief.
Sworn to and subscribed before me this		
day of		
		(Signature of guardian)
(NOTARY PUBLIC OR ATTORNEY)		

F1

In the Matter of the Guardianship) of)	ACCOUNTING	
(name of ward)) an incapacitated person)		
The Account dated	(Date of Beginnin	g balance through date of ending
balance) of		
, guardia (name of guardian)	n of	, is as follows:
(name of guardian)	(name of ward)	
SUMMAF	RY OF TOTAL ASSETS	
Current Assets	Beginning Balance	Ending Balance
(sample©		
Checking account 9bank name & acct. #)	\$	\$
Savings account (bank name & acct. #)	\$	\$
Certificate of deposit (bank name & acct. #)	\$	\$
Mutual fund (Company name & acct. #)	\$	\$
1.	\$	\$
2.	\$	\$
3.	\$	\$
4.	\$	\$

Total Ending Assets \$

Total Beginning Assets

\$

INCOME RECEIVED

(sample:

1.	Interest from bank account (bank name & acct. #)	\$
2.	health insurance refund	\$
3.	S.S.I.	\$
4.	retirement income	\$
5.	pension	\$
6.	rent	\$
7.	dividends	\$
8.	etc.	\$
9.		
1 0.		
11.		
12.		
13.		
14.		
15 .		

TOTAL INCOME RECEIVED

\$

EXPENSES PAID

This Guardian charges himself as follows:

(samp	le:	
1.	rent	\$
2.	medical expenses	\$
3.	medications	\$
4.	clothing	\$
5.	food	\$
6.	real estate taxes	\$
7.	phone	\$
8.	electric	\$
9.	personal items (toiletries)	\$
1 0.	attorney's fees	\$
11.	income tax	\$
12.	insurance expenses (life & medical insurance)	\$
13.	day care	\$
14.	in home nursing care	\$
1 5.	surrogate's fees	\$
1 6.	etc.	\$
1 7.		
18.		
19.		
20.		
21.		

Total Expenses paid as to Assets.....\$

F4

Real Property (tax assessed value)? \$			
Beginning balance of assets as of/_ (ending balance from previous accou			
Income Received		+	
Disbursements made		-	
Ending balance of assets as of/	/	=	
Comments:			
State of))		
County of)		
(guardian's name)	, being duly sw	orn acco	rding to law, deposes
and says:			
1. I am the guardian in the foregoing ac	ccount named.		
2. The account is just and true to the be	est of my knowledg	ge and b	elief.
	(signature of	guardia	n)
Sworn to and subscribed before me this, _			
(notary public or attorney)			

GUARDIAN: Questionnaire, Evaluation

Ward's name: Ward's address:	Docket No.
Guardian's name: Guardian's address:	
TELEPHONE:	
1. Guardian of: 1Person 2	Property 3Both
2. Guardian's relationship to ward:	
1spouse 2parent of w 5friend 6private atte 8other	vard 3child of ward 4other relative orney 7public guardian or agency
	Yes No If not, how many times does the average each <i>month</i> ? On average, how long is the visit (in
4. What does the guardian do for the wardManage financial affairsHousekeepingProvide TransportationFeed	f? Check all that apply:Provide necessitiesTake on outingsBatheProvide continuous care
	I's overall situation, including any significant changes in notional health and living situation that have occurred over
6. Does the guardian feel that the guardia Why?	nship should continue? 1yes 2no
7. Any changes needed in the guardianshi	p?

8. Has eligibility for been checked? Yes			ity, Medicare, Me	dicaid, SSI or Fo	od Stamps ever
9. Does the guard Please specify:	ian need assista	ance, whether fro	m the court of fro	om a community	agency?
10. Guardian's cu	rrent assessme	nt of ward's: (Che	eck a rating box fo	or each category	·)
	Excell 1	Sats 2	Fair 3	Poor 4	Don't Know
Physical health Emotional health					
Intellectual functioning					
Living situation					
11. Aside from mo	eals and person	nal care, how does	the ward spend	the day?	
12. How often doe	es the ward go a	away from the res	idence?		
13. For what purp	ose?				
14. Are the ward's Yes No					
15. Guardian: Ple	ease record any	thing you feel wou	ld be useful to th	e court below:	
Date:					

F7

LIABILITY ISSUES FOR VOLUNTEER GUARDIANS

What liability does a Volunteer Guardian have?

In today's litigious society, Volunteer Guardians need to be aware of liability issues. Any activity hat has the potential for harming or injuring another person involves some risk of liability. The area of substitute decision-making is no different.

Make prudent decisions

While lawsuits against volunteers are rare, actual liability is even less common. Liability usually results from *intentional* harm or from exercising careless judgment. Volunteer Guardians can reduce the risk of being liable for damages by fulfilling all their duties ad responsibilities in a timely manner and by making prudent decisions. Guardians will want to look at all options and the potential impact of each decision before deciding on a course of action. Seeking advice from VG staff and from experts in the field and getting second opinions, whether the decision is medical or other, will help in good decision-making. If there is doubt about a decision, solicit advice from the court.

Statute protects wards and Guardians
New Jersey statutes protect wards by allowing
any person who believes that a guardian or
conservator is not properly exercising his/her
duties to report the allegations to the clerk of
the court that established the guardianship or
conservatorship. The court may dismiss the
complaint if it feels there is no basis for it.
However, if it appears there is basis for the
complaint, the court may schedule a hearing.
The court makes the final decision as to whether
any action will be taken.

Good faith can be shown by practicing the following risk management procedures.

- read this volunteer guardianship manual
- be familiar with, and follow the National Guardianship Association's Ethics and Standards for Guardian (every volunteer is given a copy of this document);
- follow program policy and procedures and stay within the scope of your authority as defined in the New Jersey statutes;
- make informed decisions;
- approach each decision as if someone will ask you to defend it;
- keep a record of significant contacts with or regarding the ward
- keep your ward's funds separate from your personal funds;
- never loan or obligate personal funds for a ward's use or vice versa:
- keep accurate records of financial transactions;
- complete required reports accurately and in a timely fashion;
- participate in any orientation and in-service training offered by VG

The statutes grant immunity from civil liability to
Volunteer Guardians who carry out their duties of guardianship "in good faith," and without "willful or wanton misconduct or gross negligence."

LIABILITY ISSUES FOR VOLUNTEER GUARDIANS

Guardians not liable for actions of third persons

Insurance coverage for Volunteer Guardians

According to the statutes, a guardian of the person is not liable for injury to the ward resulting from the negligence or acts performed by third persons given authority by the guardian for medical or other professional care, treatment, or advice unless it was negligent of the guardian to have given his/her authority in the first place.

Insurance Coverage

Volunteer One on One, Inc. carries liability insurance for volunteer guardians. Homeowner's insurance and renter's insurance policies often include protection for volunteer activities. Because insurance policies vary greatly, volunteers should check with their own insurance agents to determine whether they are protected.

Developmental Disabilities

What are developmental disabilities?

The word disability implies that a person has a condition that prevents him/her from functioning in a way that is considered normal. When the condition is severe and appears before age 22, it is defined as a developmental disability.

Disabilities can affect many aspects of a person's life

Depending on severity, developmental disabilities can affect a person's ability to care for his/her personal needs, to learn, to communicate and make informed decisions. Developmental disabilities may affect a person's ability to be financially self-sufficient and to live independently. People with developmental disabilities do not fit easily into one description. Developmental disabilities include a broad range of disabilities and varying degrees of severity.

Four primary conditions comprise the majority of developmental disabilities:

- Mental retardation
- Cerebral palsy
- Autism
- Epilepsy

The Developmental Disabilities Act, 1990 defines developmental disability as a severe chronic disability of a person which:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the person reaches age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of life activity:
- Self care
- Receptive/expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency

More than 200 conditions included

However, more than 200 other conditions are included in the broad umbrella of developmental disabilities. Blindness, deafness, chronic mental illness, spina bifida, and other birth defects are but a few other examples. There are thousands of people in the State of New Jersey estimated to have developmental disability. Obviously, not everyone with a disability needs a substitute decision-maker. Most are able to make their own decisions and maintain their independence.

Some developmental disabilities are easier to recognize than others. Persons with mental retardation may not have any apparent physical disabilities but may be mildly to severely limited intellectually. Others may have Down Syndrome with mild to severe mental retardation and more obvious physical characteristics identifying the condition.

Cerebral palsy results in physical disabilities, but mental capability may range from profoundly retarded to extremely capable. At the other end of the scale are conditions like epilepsy which are likely to be disabling, but are not immediately recognizable except during a seizure.

Developmental Disabilities

Over the past twenty years, society has gradually come to recognize the needs and rights of people with developmental disabilities to participate to their fullest potential in all aspects of life. They can now live, work, and play in their home communities. Community based services strive to provide the necessary support through a wide variety of programs and procedures.

The Developmental Disabilities Assistance and Bill of Rights Act (1975) mandates procedures to assure individuals have the opportunity to receive services in the least restrictive and the most home and community-like setting as possible, This Act stresses the federal goals of independence, productivity, and integration. The Education for All Handicapped Children Act (1975) requires that all school-aged children, up to age 22, receive an appropriate and free education.

The Americans with Disabilities Act (ADA), 1990 prohibits discrimination against people with disabilities. It specifically addresses employment, public services, public accommodations, and telecommunications. The Individuals with Disabilities Education Act, (IDEA), 1990, is the reauthorization and amendment of the Education for All Handicapped Children Act. IDEA requires that school age children with disabilities be granted equal educational opportunities. School districts that agree to provide a "free appropriate education" to children with disabilities receive federal aid to assist them in that endeavor.

It is important for the volunteer guardian to know about the specific disability of his/her ward. Knowledge about any speech or hearing impairments will aid effective communication. Awareness of the ward's level of understanding is important to become comfortable with the ward and she/he with you before discussing important issues. It may take longer to establish a rapport and trust with a ward with developmental disabilities.

VG can assist Volunteer Guardians with the planning for the delivery of services to wards.

The Aging Process

From birth to death, the aging process involves changes in the total person. The physical, psychological and social changes all interact and influence one another. While these changes are characteristic of most older people, they may not be true for specific individuals.

Physical Changes

Aging proceeds at different rates in various parts of the body in the same person. In other words someone might have a healthy heart but poor balance. In general, the body of an older person does not function a swell as it did; but barring disease and very stressful situations, it usually continues to function adequately into old age.

Sensory Changes

Vision: Age usually means decrease in visual sharpness, slower accommodation of the eyes from close to distance, and loss of peripheral vision. The older person requires more time to adjust to different light levels and needs more light to see.

Hearing: Hearing gradually diminishes, particularly the ability to hear high pitched sounds (presbycusis). Consonants become more difficult to hear. A person with presbycusis hears speech, but has difficulty discriminating between words. For example, "fifty" and "fifteen" cents may sound the same; "dead" may sound like "red", "tooth" like "juice".

Even a slight hearing loss can limit communication and social interaction. A hearing loss can lead to depression, anxiety, and paranoia.

Aging occurs at different rates in various parts of the body in the same person.

Vision frequently declines with age

The ability to hear high pitched sounds diminishes

Taste and smell: Taste sensitivity decreases with age. The taste receptors that identify sweet and salty stop functioning first. These changes can affect appetite, causing poor nutritional intake.

Loss of ability to smell occurs with age. Because two-thirds of taste sensations depend on the ability to smell, decline in the sensory system can further depress an older person's appetite. In addition, an individual may not be able to detect warning odors—smoke, gas, and spoiled food—or body or household odors that may be offensive to others.

Sensitivity to heat and cold: Subcutaneous fat, fat beneath the skin, an important insulator, decreases with age. As fat is lost body heat escapes. As a result, older people often feel cold when others are comfortable. In winter some older people may be the victims of hypothermia, a drop in internal temperature that can be fatal if not treated promptly.

Mobility

Changes in joints and decreased bone and muscle mass can result in falls and fractures, misshapen joints, pains and stiffness. Age can also bring a decline in cardiac output, lung volume, and breathing capacity. This can cause some older people to tire easily and have limited endurance.

Digestion

Digestions slows down and becomes less efficient; reduced production of secretions that aid digestion-hydrochloric acid and bilemay account for statements such as, "I don't digest foods as well as I used to." Problems with gas and constipation may be due to increased activity of the stomach and decreased movement of the intestines, a common condition in the aged. The digestive system is also very sensitive to emotional states; the older person who is depressed or anxious may experience digestive disturbances.

Decreased taste sensitivity and ability to smell can lead to poor nutrition

Older people are more susceptible to both hypothermia and heat stroke/ exhaustion.

Older people may tire easily and have limited endurance.

Digestion may be affected by reduced secretions that aid digestion.

Elimination

Changes in the urinary system can result in more frequent urination by older people; bladder capacity may be reduced by half. Urinary incontinence can cause depression, insecurity and withdrawal from social activities.

Constipation is common among older adults. Diet, lack of exercise, and the excessive use of laxatives contribute to constipation problems.

Psychological and social changes

Older people face many changes. Retirement can provide an opportunity to pursue personal interest, but it also can mean a loss of a significant life role.

Losses increase with age; retirement can bring a fifty percent decrease in income; spouses and friends die; declining health and mobility cause changes in living arrangements. A person's identity and self-esteem are threatened by these losses.

Many older people fear dependency-whether physical, financial, emotional, or social. Throughout their lives, great value has been put on independence and "doing for oneself", so it is difficult for many to seek or accept assistance. Even when needs are overwhelming, many regard help as charity.

Cognitive changes

Intelligence, memory, and learning ability do not decline with age; limitations are more related to health than age. An individual's abilities, therefore, should not be underestimated simply because of age.

Most older persons do not have serious memory impairment, but memory does seem to alter with age. Memory of the past is usually better than of current information. For those older persons who do suffer memory loss, training can help minimize it. Frequent urination and constipation are common among older people.

The many changes older people face, as well as numerous losses, can cause psychological problems

Changes in memory and intelligence are more related to health than age.

Death and dying

Many older people need to work through grief, discuss their own deaths and express their fears. Often what is perceived as a fear of dying is actually a fear of loneliness or loss of control and independence.

Mental Health and Aging

Most older people are mentally healthy, but certain groups are at high risk for mental health problems. These include the recently bereaved, the isolated, and the physically and mentally frail, older adult.

Mental health is affected by physical conditions, poor nutrition, an overdose or interaction of medications, sensory deficiencies, and multiple social losses. Volunteers should be alert to signs of depression, hypochondriasis, and paranoia. At no time should these signs be interpreted as "normal" for older people.

While most older people are mentally healthy, numerous health problems can affect their emotional well being.

Depression

Depression is commonly triggered by loss and is a common mental health problem. Symptoms vary but the most common are: insomnia, loss of appetite and weight, decreased sex drive, constipation, lack of motivation, lack of concentration, loss of memory, feeling of hopelessness and general dissatisfaction. It has been found that ten to twenty percent of older people who appear "senile" are actually depressed.

Severe depression can be accompanied by suicidal impulses which may range from a passive wish to die to an active suicide plan. A suicide threat by older people should be taken seriously. Older adults intend to die and succeed at taking their lives.

Some indicators of a wish to die include: misuse of medication, starvation, ignoring dietary restriction, and engaging in health threatening activities. The potential suicide victim often needs the opportunity to talk or to be involved in activities that are satisfying and give the feeling of usefulness. For the person who feels that life is meaningless, reminiscing about past accomplishments often helps to give meaning to the present.

Depression, in the elderly, is generally related to the losses they are experiencing.

Be aware of indicators of a wish to die and possible remedies.

Paranoia

Paranoia is indicated when an individual attributes imaginary motivation and behavior to others. Paranoia is most common in those who have hearing and/or vision loss. These sensory changes also cause the environment to be perceived incorrectly. Organic brain damage can also result in paranoia. Paranoia in older people is often treatable and understanding the cause is essential. Treatment includes correcting sensory defects and providing a stable, familiar environment.

Paranoia is common among persons with hearing and/or visual impairments.

Mental Illness

What is mental illness?

Mental illness is a term used for a group of disorders that can cause severe and persistent disturbances in a person's thinking, feeling and relationships with others. The result is substantially diminished capacity for coping with the ordinary demands of life. Mental illness is a chronic condition that may be treated with medication. While medication can help control the symptoms of mental illness, it does not cure it. Most people who are medication compliant and have the necessary community support are able to enjoy a high quality of life.

Mental illness can cause disturbances in thinking, feeling and relationships with others.

NAMI recognizes three broad categories of mental illness

The National Alliance for the Mentally III (NAMI) groups mental illness into three broad categories: Schizophrenia, Affective Disorders, and Other. It describes schizophrenia as one of the most serious and disabling. Schizophrenia is believed to be a thought disorder. Schizophrenia may cause lack of judgment, difficulty getting along with others, or lack of feeling. Many people with schizophrenia experience feelings of being watched or harassed.

NAMI lists schizophrenia as the most serious and disabling mental illness.

Affective disorders

Affective disorders are more common. They are described as mood disturbances. An example is manic depressive illness, where a person's mood swings between high moods and low moods. This is called bi-polar. Another disorder is uni-polar where a person experiences persistent low moods or depression.

Mood disorders i.e., bi-polar and unipolar are more common.

The "other" category

In the category of "other", NAMI groups anxiety disorders, personality disorders, behavioral disorders, and abuse of alcohol and drugs when they are so persistent as to be disabling.

Disabling alcohol and drug abuse are considered mental illnesses.

Mental Illness

Delusional disorders

Kinney and Kinney, authors of <u>A Guidebook on Mental Illness</u>, include a fourth group referred to as delusional (paranoid) disorders and indicate that these are not part of another disorder such as schizophrenia.

These illnesses share certain characteristics. They are diseases of the brain. The exact causes of mental illnesses are not well understood. Experts believe that it may involve the structure and biochemistry of the brain. Heredity also may be a factor. Even stress may be a contributing factor in a vulnerable person. Although the causes may not be known, mental illness can be treated. With treatment, some patients can make substantial improvement.

With treatment some patients make substantial improvement.

Discrimination and loss of rights

Like people with developmental disabilities, people who have chronic mental illness may experience many forms of discrimination and loss of rights. The social stigma of mental illness has deterred people from seeking help. People with mental illness were often abused, exploited, or segregated without regard for their feelings or rights. Many were confined for long periods in institutions.

Community based services help many reside in home communities.

In recent years, attitudes toward the mentally ill have improved due to better understanding. Society is beginning to recognize that with treatment and care many can remain in their home communities and lead productive lives. There has been movement toward community based services and away from institutional settings.

Previously committed to institutions, many mentally ill persons can now be treated in their home communities.

Mental Illness

Support systems beyond family

A support system beyond family is frequently needed in order for a mentally ill person to remain in the community. For this purpose, counseling centers are located in regions around the state. Recently, group homes and family support groups have emerged. Public and private hospitals have opened psychiatric wards. Legal protection assures due process and incorporates the concept of treatment in the least restrictive and most therapeutic setting. The state hospital is evolving into a short-term diagnostic center and long-term treatment center for the severely ill.

Volunteer substitute decision-makers for persons with mental illness will want to learn as much as possible about their wards' illnesses. It will also be helpful for volunteers to become familiar with the support system the ward has or needs. The support system may be more fragmented than one in place for a person with a developmental disability.

See also *Mental Health and Aging* in the chapter "Understanding the Elderly".

Regional counseling centers, group homes, and support groups are some of the services now available

Volunteers will want to learn about their wards' illnesses.

TRAUMATIC BRAIN INJURY

The challenge of serving persons with traumatic brain injury

Traumatic brain injury accounts for considerable emergency hospital visits per year. Nationwide an estimated 500,000 people sustain TBI annually. TBI is caused by a blow to the head (most often occurring during a car crash) which results in a complex set of impairments affecting any one or more of the following: Memory, ability to concentrate, control of emotions and behavior, caring for oneself, balancing and walking, seeing, hearing and speaking, among others. A TBI may also cause seizures. Mild TBI can be personally devastating and more serious brain injury often results in the need for life-long medical or nursing home care.

TBIs impact victims physically, emotionally, intellectually, socially, vocationally, and financially.

Number of survivors of TBI is increasing

Individuals with TBI comprise the largest group of people with disabilities. Persons with TBI are part of a growing population of brain injury survivors that did not exist 20 years ago. Because of improvements in medical treatment, many people who would have died from their injuries in years past now have a life expectancy close to that of non-brain injured people.

Survivors of brain injury can be faced with lingering difficulties with memory, judgment, ability to adapt to changes in the world around them, the ability to solve novel problems and to interact socially. They may also have problems of muscle strength, physical coordination, vision, hearing, and/or speech. These persisting difficulties can interfere with an individual's ability to live independently, work, go to school and form relationships with others.

Unique challenge of serving persons with brain injuries:

- A large population has been injured (500,000 per year in the U.S.)
- The effects of injury do not usually disappear
- Largely a youthful population (20-30 years of age) so that the impact is long-lived
- The injury is mostly invisible-the impact is on behavior, but people "look" okay
- The consequences of injury vary greatly. Some individuals have mild injuries and are not even identified as needing help; the lives of others are devastated by the broad impact of injury
- Vocational functioning is strongly affected; many are injured early in their vocational lives or even before they have established a vocational role
- Social life is strongly affected; both family and friends
- Brain injury is highly preventable

TRAUMATIC BRAIN INJURY

Long term needs of persons with TBI have been unmet Although modern medicine is able to save more lives, the long term needs of survivors of TBI have been unmet. Since Medicaid pays for nursing home and institutional care, many survivors have been forced to live in overly restrictive and expensive settings simply because the funding for the se services is available.

Those who are discharged from inpatient settings soon discover that existing services systems do not provide specialized community based services for people with brain injury.

Funding has been for institutional care at much greater expense.

IRS Benefits for Volunteers

Expenses you can deduct for income tax purposes:

The Internal Revenue Service allows some Federal income tax deductions for volunteers. The following represent expenditures that volunteers may wish to deduct:

- Direct gifts of money (including memorials) or property to Volunteer Guardianship One on One, Inc. You may deduct the "fair market value" of property at the time of deduction.
- Automobile mileage. Starting in 1998, the income tax deduction for mileage for volunteer work is \$0.14 per mile.
 You may also deduct parking fees and tolls.
- Bus and cab transportation expenses for volunteer services.
- Meals, as well as lodging and travel expenses, may be deducted if you are away overnight.
- Telephone bills regarding your ward or VG business are tax deductible.
- Any of the above expenses which pertain to volunteer training or meetings also qualify for tax deductions.

You may not deduct:

- Expenses which have been or will be reimbursed.
- The value of your donated time.
- Dependent care (such as child care) expenses.
- Your own entertainment.

It is the volunteer's responsibility to keep track of expenses and deductions. VG will be happy to provide a signed statement verifying service to the organization.

*consult your tax accountant regarding the specific requirements for verification of the cash amount and value of non-cash donations.

Deductible items:
Cash gifts;
Service mileage;
Travel expenses;
Including meals and lodging if away overnight;
Phone bills regarding ward or VG affairs.

Keep a record of expenses.

VG will sign a statement verifying service to the organization.

Notes

Learn the language of service providers

Volunteer Guardians may encounter unfamiliar acronyms and phrases used by professionals and service providers of wards of this program. The following list, while not all-inclusive, is intended to help the lay person understand some of these terms.

Acronyms

ADD	Americans with Disabilities Act
	Aid to Families with Dependent Children
	Division on Behavioral Health in DH
	Division of Developmental Disabilities in DH
	Department of Youth and Family Services
	Department of Health
	Division of Vocational Rehabilitation
FY	Fiscal Year
GAL	Guardian-ad-litem
GPCDD	Governor's Planning Council on Developmental Disabilities
	Home and Community Based Waiver
ICAP	Inventory for Agency and Client Planning
ICF/MR	Intermediate Care Facility/Mental Retardation
IDEA	Individuals with Disabilities Education Act
	(formerly EHA, Education of the Handicapped Act)
IEP	Individual Education Plan
IHP	Individual Habilitation Plan
JTPA	Job Training and Partnership Act
	Job Training and Partnership Act
NGA	
NGAPL	National Guardianship Association
NGAPLP&APHN	Public Law (a federal law)Protection and Advocacy System, IncPublic Health Nurse
NGAPLP&APHN	Public Law (a federal law)Protection and Advocacy System, Inc.
NGAPLP&APHNSED	Public Law (a federal law)Protection and Advocacy System, IncPublic Health Nurse
NGAPLP&APHNSEDSSA	National Guardianship AssociationPublic Law (a federal law)Protection and Advocacy System, IncPublic Health NurseSeriously Emotionally Disturbed
NGAPLP&APHNSEDSSASSDI	
NGAPLP&APHNSEDSSASSDISSDISSI	
NGA	
NGA	

Administering Agency- Any governmental agency providing financial benefits that have provisions for identifying and authorizing payments to a substitute decision maker; e.g., Social Security Administration, Veterans Administration, Department of Family Services, etc.

Ancillary guardian-A guardian appointed by a court of another state for a ward who is currently a resident of this state.

Aptitude-the specific capabilities or abilities required of an individual to facilitate the learning for accomplishing tasks or job duties. A conceptual and abstract method of organizing certain groups of skills.

Architectural Barriers-Physical design and construction; i.e., curbs, door size, ramps, rest rooms, etc., which limit or impair accessibility for a person with physical disability.

Client Plan-A written program of action developed and reviewed at regular intervals. It specifies goals and objectives and identifies a continuum of services to achieve those goals and objectives.

Competitive Employment-An unstructured, regularly supervised environment where an individual must be capable of obtaining work without assistance, special modifications, or provisions and then be able to maintain that employment without extra supervision or instruction.

Comprehensive Rehabilitation Center-A center that offers medical, psychological, social, and vocational services to clients principally under one roof.

Conservator-A person appointed by the court to have the custody and control of the property of a ward.

Court-The court of competent jurisdiction; generally the District Court in the district where the potential ward resides, or did reside, when a petition for guardianship was granted.

Employability-Readiness for employment in the competitive labor market, practice of a profession, self-employment, homemaking, farm or family work (including work for which payments is in kind rather than cash), sheltered employment, homebound employment, or other gainful work.

Family Support Services-Services that strengthen the family's capability to provide care, to promote the development of family life that is as close as possible to that experienced by families without members with disabilities, and to prevent unnecessary out-of-home placements.

Fiduciary-A relationship that exists when "there is a reposing of faith, confidence, or trust, or the placing of reliance by one upon the judgment and advice of another." Fiduciary means a guardian or conservator.

Functional Education-The teaching of basic life skills with a great deal of structure in the learning situation.

Guardian-The person appointed by the court to have custody of the person of the ward.

Guardian ad litem-A person appointed by the court to represent the best interests of a proposed ward during the course of litigation.

Guardian of the estate-Conservator

Guardian of the property-Conservator

Group Home-A home for a small number of individuals with disabilities who live in the community and participate in community life.

Habilitation-The development of skills and abilities.

Incompetent-An individual who is unable, unassisted, to properly manage and take care of himself or his property as a result of infirmities of advanced age, physical disability, disease, or the use of alcohol or controlled substances.

Informed Consent-Granting permission or authority after receiving and evaluating information pertinent to making a rational decision.

Learning Disabilities-A generic term that refers to disorders manifested by significant difficulties in the acquisition and use of learning, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction. Even though a learning disability may occur with other handicapping conditions or environmental influences, it is not the direct result of conditions or influences.

Limited Conservatorship-A conservatorship in which the appointment by the court is limited in scope of duties or duration.

Limited Guardianship-A guardianship in which the appointment by the court is limited in scope of duties or duration of appointment.

Living Will-A document in which an individual expresses directions about the health care the individual wishes to receive in the event he/she has a terminal illness or is near death and is unable to make or communicate those health care decisions.

Mentally Incompetent-An individual who is unable, unassisted, to properly manage and take care of himself or his property as the result of mental illness, mental deficiency, or mental retardation.

Normalization-Placing persons with a disability in the least restrictive environment, where patterns and conditions of daily life are as similar as possible to that of mainstream society.

Physical of Mental Disability-A physical or mental condition which limits, contributes to limiting or may result in limiting an individual's functioning if not corrected.

Plenary Guardianship-A guardianship in which the appointment by the court carries the full range of duties allowable by law.

Power of Attorney-A written document in which one person (the principal) grants authority to another (the agent or attorney-in-fact) to act in the principal's behalf. There are a variety of types of power of attorney; traditional, durable, limited, medical, etc; each have differing procedures for establishment and differing authority. One common trait is that the principal must be competent at the time the power is granted.

Rehabilitation Facility-Agency of multiple, coordinated services designed to minimize the handicapping effects of a physical, mental, social and/or vocation impairment in an effort to help reach maximum potential in all areas (social, emotion, vocational, and independent living.)

Representative Payee-An individual appointed by an administering agency, such as Social Security Administration, to receive benefits on behalf of an individual to insure the funds are spent to cover basic needs such as food and shelter.

Severely Disabled-A physical or mental condition which so limits the *functional* capabilities that he/she cannot perform some key life functions and which is expected to last indefinitely. The Rehabilitation Act Amendments of 1992 define an individual with a severe disability "as an individual with a severe physical or mental impairment whose ability to function in the family or community or whose ability to obtain, maintain, or advance in employment is substantially limited and for whom the delivery of independent living services will improve the ability to function, continue functioning or move towards functioning independently in the family or community or to continue in employment, respectively."

Special Education-Education provided to exceptional children because of and geared towards their specific educational needs.

Substantial Handicap to Employment-A physical or mental disability (in light of attendant medical, psychological, vocational, educational and other related factors) which impedes an individual's occupational performance by preventing his/her obtaining, retraining or preparing for employment otherwise consistent with his/her capabilities and abilities.

Substitute Decision Maker-A person granted authority by the court, an administering agency, or client to make decisions in behalf of a ward or client.

Trust-A legally binding agreement through which one person (Grantor) transfers money or property to a trustee. The trustee is required to manage the trust property for the benefit of the grantor, or other named beneficiary, according to instructions in the trust document. There are many varieties of trusts, each having special conditions and rules.

Ward-An individual for whom a guardian or conservator has been appointed by the court or designated under New Jersey Statute.

Will-A written instrument legally executed by which a person makes disposition of his estate to take effect after his death.

Workers' Compensation-The law is intended to ensure that an employee who sustains an industrial injury, and those who depend on the employee for support, will have adequate means of support while he/she is unable to work.

Ethics and Standards for Guardians

Volunteers are asked to aspire to the highest moral and ethical standards

As substitute decision makers, Volunteer Guardians have a responsibility to meet the highest moral and ethical standards.

The national Guardianship Association's handbook, *Ethics and Standards for Guardians*, is a guide for every Volunteer Guardian associated with VG. Volunteer Guardians are urged to study the Code of Ethics and the Standards and personally adopt and follow them.