



Chapter Seven: Supporting Success

Thorough planning, detailed documentation, and careful analysis of the person's progress are all factors contributing to the individual's success. However, additional components must be addressed to assure and promote success.

Supporting Success

1. Know the person.
2. Establish a system of communication.
3. Assure health and safety:
 - handling everyday emergencies
 - responding to natural disasters
 - obtaining a complete health history
 - considerations for persons with physical and health challenges
 - considerations for person with behavioral challenges
 - obtaining informed consent
 - ensuring advanced directions
 - ensuring medication is administered as prescribed
4. Understand abuse, neglect, and exploitation.
5. Consider liability issues.

In order to promote success, a good coach needs to educate herself on the individual's situation before providing supports.

Educate yourself on the individual's situation *before* providing supports.

Understanding the individual, how he learns best, conditions that may impact health or learning, and his habits, routines, relationships and preferences, will help assure successful endeavors.

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Roller Coaster Ride

"After the individual makes the transition to a home of his own, the work really begins. I like to compare supported living to riding a roller coaster.

You and the consumer buy a ticket, then you wait around. You talk and get to know each other. You bond and share lots of anticipation. You inch forward. That's the transition phase.

Finally, you and the consumer get to the front of the line. This is what you both have been working toward. Get in! Hold on tight! Here we go! No turning back now (at least not without a lot of fuss)!

As a supported living coach your job is to ride life's roller coaster with the individual. Sometimes things move slowly and sometimes they move fast. Sometimes you go up-side-down and other times you go in circles. Sometimes you even go backward. There are dips and bumps and moments when you fear you are about to free-fall. It's fun! It's scary! It's exhilarating! It can keep you young or make you ill.

That's the roller coaster! That's supported living! That's life! Are you up for the ride?"

-Dennis Shelt; Community Circles Inc., St. Petersburg, FL

The supported living coach visits the person's home on a frequent basis. When the person first moves, the supported living coach may need to visit daily. As the person adjusts, visits can be less frequent. The coach should be observant and diligent in sensing subtle changes in the person and her home, the support services staff, and the environment and act upon those changes immediately. In many instances, crisis can be averted, or stability maintained, by quick response to such changes. Equally important, the coach should also look for things that do not change, and that should have been addressed as a form of follow-up, for example, when implementation plans are not being followed, or an ongoing concern remains unaddressed.

Crisis occur when little things go unnoticed or are not acted upon!

Establishing a System of Communication

Good planning to avoid crises includes establishing an on-going system of communication to assure that all involved parties are aware of situations, issues, and potential problems. A coordinated effort among all persons supporting the individual (whether formally or informally) must be made in sharing information as part of the ongoing monitoring of the person's situation. Care must be taken to assure the person's right to privacy, while supporting him in maintaining stability and continued success. It is crucial that communications are open and effective, as intensification in areas of support may be needed at any point in the person's life.

“A good coach has to learn to anticipate...”

Ann Millan, Parent

Without effective ongoing monitoring, and communication that is open and timely among all involved parties, overnight the person could be facing a crisis.

For example, a change in apartment management may result in upheaval to the renter's routine. Residents of a complex may be required to find a local laundromat because it is decided that on-premises laundry rooms will be closed, and all appliances removed; buildings may require tenting for termite fumigation, and residents notified in writing of the need to prepare their units and vacate within 24 hours; apartments may undergo renovation, and old gas appliances replaced by newer electrical ones.

In this one area of the person's life, a domino effect is possible. New ways of maintaining the household may need to be learned (e.g. how to get to the nearest laundromat and operate different washers and dryers, how to cook on an electric vs. a gas stove), or immediate supports provided to avert a crisis (e.g. a motel room must be found, a suitcase packed, plans for meals made, and the apartment prepared prior to termite treatment and upon re-entry).

Additionally, any one potential crisis, in any one area of the person's life, can significantly impact other areas. A renter who must vacate the premises for 48 hours may suddenly be living in temporary housing far from the bus route used to get to and from work. The sudden lack of laundry facilities in the house may result in the person's wearing soiled garments to work, and being "written up" for the same. Even more damaging, a person who is unfamiliar with the need to protect living things from the fumigation process might return to her apartment to find a beloved fish or cherished plant has died. In the worst case, the person may unknowingly begin eating from utensils and dinnerware without washing them first, and ingest poisonous residue.

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When in doubt, spread it out.

The supported living coach, in partnership with the support coordinator, the individual/guardian/guardian advocate and his family, should assure that each circle of support member understands and uses the system of communication established as a means of assuring safety. Sharing responsibility for communications increases the likelihood that things are addressed in a timely manner.

“You shouldn’t take over my whole life because I need your help with part of it.”

-Courtesy of Ann Millan.

An effective system of communication is one that is responsive to the needs and desires of the individual. There may be instances when the coach has tried to make changes to the instruction or coaching methods, yet finds the individual is still not making progress. There may also be occasions when the individual changes his or her mind regarding a goal identified on the support plan. These issues should be discussed with the individual and the support coordinator via telephone or during the quarterly meeting, if timely, and the plan changed.

On-going communication with the support coordinator and the circle of support can be helpful. As the adage "two heads are better than one" implies, the more people attempting to support the individual by brainstorming ideas, the greater the potential to find the means to successfully accomplish that end.

Assuring Health and Safety

John

A few days after John moved to his first apartment, I was invited over to have dinner. He greeted me at the door in his swimming trunks with a plate of homemade tacos. He explained he had never cooked anything before and chose tacos for dinner because he could, even though it was Tuesday and at the group home “Taco Bell nights were the last Thursday of the month”. John’s coach explained that in the group home where John had lived for 14 years, they went to Taco

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Bell on a routine schedule and John was thrilled he didn't have to wait until the end of the month to enjoy a taco.

During dinner, I noticed John refused any salsa or hot sauce for his taco. Having known John for about 15 years, I asked about the salsa. He said he "never had used it" and wasn't sure why. He told me that later he and his coach were going to "check-out" the hot tub.

When I asked John and the coach about any health concerns, neither was aware of any. I remembered that I had read somewhere, years before, that John's body had an unusual reaction to intense heat. Yet, John was not aware of the possibility and the information was not available in his new home. We made a few calls back to the group home and discovered that immersion in a hot tub could have dire consequences for John's heart, and hot sauces might create similar problems. The absence of this piece of health information might have cost John his life.

Obviously, this information should have been in John's support or transition plan and provided to John and his support staff. This information could have been used to educate John about the use of the hot tub compared to the pool, and the use of sauces and salsas, and methods for making good decisions. In addition, an evaluation by a physician might also assist John and his support staff in understanding the full impact of heat (e.g., outside temperatures, etc.) on John's daily life in Florida. This might assist John and his coach in assuring the concern remains at the forefront, and the information about his heart is provided to the support coordinator for updating his support plan.

Health and safety are issues that should be addressed any time there is a concern as well as at the time of the support plan meeting for every individual in supported living. Supported living coaches and other providers contribute to the support plan in many ways throughout the year. The annual reports submitted to the support coordinator prior to the support plan meeting offer valuable information related to safety and wellness. In addition, as discussed, pertinent information shared during quarterly housing reviews and from routine interactions may also be reflected in the support plan. Questions/concerns regarding health and safety should always be raised immediately and discussed with the individual and WSC.

Sharing information, both required and through daily interactions, will help assure that training and support are provided to the person as needed. The strategies and approaches for addressing safety concerns must be found on the implementation plan.

The DS Waiver handbook's definition for supported living coaching services states: "the Implementation Plan must contain...how home, health, and

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community safety needs will be addressed and the supports needed to meet these needs.”

Prior to the development of the annual Individual Support Plan (ISP), the Functional Community Assessment and Quarterly Housing Surveys conducted by the supported living coach, and other evaluations from pertinent providers, may indicate the need for additional instruction or supports in certain areas of health and community safety.

An important responsibility of the supported living coach is to observe health and safety issues on a frequent and ongoing basis and report any concerns. The supported living coach may be observing supports provided by other providers such as in-home supports, homemakers, Non-Residential Supports and Services (NRSS), etc. The supported living coach may need to address these issues, and involve the support coordinator when appropriate. The scheduled quarterly meeting with the support coordinator is a good time to discuss general areas of concern related to health and safety. Immediate concerns should be addressed as they are identified.

As mentioned, areas required for promoting wellness and safety may be found in the Developmental Services Waiver Services Florida Medicaid Coverage and Limitations handbook and Chapter 65B-11 F.A.C. Although previously discussed, the following is a summary of items to consider and review when planning for health and safety:

Requirements for Assuring Health and Safety:

- Transition plan meeting to communicate health and safety.
- Completion of an initial **housing survey** to ensure the home is safe.
- Documentation of a **quarterly meeting with WSC to update housing survey** for assuring that the home continues to meet basic health and safety standards.
- Maintenance of current **demographic information** regarding health, medical and emergency information in the record.
- Maintenance of copies of the **current support implementation/ transition plans** in the record.
- **Development of implementation plans that include strategies** for addressing home, health, and community safety needs.
- Completion of **the Functional Community Assessment**, which addresses “medical and health concerns.”

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- Completion of an **Annual Written Report**, which might include information on nutrition, medications, medical, and health concerns, mental health challenges, first aid, safety concerns (e.g., fire evacuations, etc.), relationships, personal care, etc.

Plan for Everyday Emergencies

It is also important to think in terms of basic safety in the home. Appliances such as smoke detectors and fire extinguishers should be installed and kept in working order. First aid kits, "bee sting" kits, and other basic response kits should be kept, purged once "effective dates" pass, and restocked. Additionally, the person should be instructed in their use.

Natural Disaster Preparedness

Every individual in supported living should have a "disaster preparedness plan" for large-scale emergencies. This plan should be tailored to his or her location, situation, and needs.

Not only does the coach consider everyday safety, it is also important to plan for natural or human disasters such as hurricanes, tornadoes, terrorism, floods, riots, 911 situations, and other large-scale emergencies. When Hurricane Andrew devastated the Miami area in 1992, many people who had developmental disabilities were temporarily "lost" to their service providers. Few agencies or individuals were prepared to deal with the chaos caused by massive destruction of neighborhoods, power outages, transportation obstacles, and communication disruptions.

As a result of this experience, the Florida Developmental Disabilities Council funded the 'Disaster Preparedness Project', which has provided training around the state and developed materials for use by professionals, families, and individuals.

One publication, [Are You Ready? Disaster Preparedness For People in Supported Living](#) and its companion videotape contain practical information that can be used to help individuals prepare for emergency situations. Contact your local Developmental Disabilities Program Office or the Central Office at (850) 488-4257.

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In addition, many local newspapers throughout Florida publish "pull-out" Hurricane Preparedness Guides that detail evacuation zones, routes and shelter locations and emergency kit/home owner preparations. These are often made available to the general public, free of charge, and can be found at designated locations, such as grocery stores, drug stores, and post offices.

A blank "Disaster Plan for Persons Served in Supported or Independent Living" is included courtesy of Lynne Daw, Developmental Disabilities Program, District II, to assist in supporting persons in planning for emergencies.

**DISASTER PLAN FOR PERSONS SERVED IN
SUPPORTED OR INDEPENDENT LIVING**

Directions: This plan must be completed with each person served in a supported or independent living arrangement (ABC components 11 or 01). The disaster plan is incorporated as part of the support plan and must be kept current. A copy is to be submitted as part of the annual cost plan/support plan packet and as changes occur during the support plan year. Copies must also be furnished to the individual/guardian/guardian advocate and to all parties assigned responsibility in the plan.

Name, address & phone Number	
Brief description of living arrangement	
Name, address, & phone # of next-of-kin or other person to contact in case of emergency	
Name, phone #, cell phone # and pager # of: - Support coordinator - Supported living coach - Res. Hab provider - In-home support provider	
Is this person ambulatory or non-ambulatory?	
Identify any sensory impairments	
List relevant health issues	
List all adaptive equipment and current meds used	
Is this person registered with County Emergency Mgmt. as a person with special needs, if so, month/year registration was last updated	
In case of mandatory evacuation where will this person go? (Be specific).	
How will this person get there? (Be specific).	
<u>Name of person responsible for:</u>	
-insuring person has all recommended disaster-preparedness supplies in stock	

DISASTER PLAN FOR PERSON SERVED IN SUPPORTED OR INDEPENDENT LIVING

-insuring person has recommended first-aid items in stock	
-insuring that person has evacuation supplies prepared	
-insuring that person is trained to use disaster-preparedness and first-aid supplies	
-notifying person of potential disaster	
-notifying person of the necessity to evacuate	
-insuring that transportation is arranged in the event of evacuation	
-insuring that adaptive equipment and medications accompany person in evacuation	
-insuring that evacuation supplies ("evacuation bag") accompany person in evacuation	
-serving as a companion to person while in special needs circumstances	
-verifying person's health and safety within 2 hrs. after Emergency Mgmt. makes announcement it is safe to go out	
-assisting the person to assess damage to home and whether it is safe to return home	
-notifying Developmental Disabilities of any client injury or illness or significant damage to client property as a result of disaster	
-training person in all aspects of this plan	

This disaster plan is current as of _____ and has been reviewed with the client and all parties assigned responsibility in the plan.

 Client Signature Date

 Support Coordinator Signature Date

Updated: _____

Copy: client, central record, DD, all parties assigned responsibility in plan

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Maintaining Health History and Information

Over the period of a lifetime, many things happen to people, which involve health information. When the person moves from place to place and from physician to physician, this information may stay in the person's personal health record at the physician's office. Most physicians' offices purge and store records every three years, so if you need information from an old record, it might not be there. Missing parts of the record may contain information that would change the choice of a present course of treatment. For example, what is the date of the last tetanus booster? Is one needed now? Has the person ever been immunized against Hepatitis B? Would there be ill effects if the person has been immunized already and we immunize again?

The health history should be complete and available so members of the circle of support and persons providing services are able to access information needed. It's a good idea that historical information is available for every health appointment, especially for initial appointments with new health care professionals.

Historical information should include a summary of key events (e.g. illnesses, hospitalizations, diagnosis, treatments, etc.) recorded over time related to the person's health. The health history should remain with the individual in her home and be kept as current as possible. It's a good idea to schedule periodic updates to the information, so that it is current at all times. Should the person become hospitalized, or receive emergency treatment of any kind, this information will be critical to medical staff.

An example of a Medical Passport format containing current health information and history follows. *Courtesy of Lynne Daw, Developmental Disabilities Program, District II.*

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MEDICAL PASSPORT

Name: _____

Residence: _____ Dates: from: _____ to: _____

Health Care Coordinator: _____ Dates: from: _____ to: _____

Health Care Coordinator: _____ Dates: from: _____ to: _____

Health Care Coordinator: _____ Dates: from: _____ to: _____

Health Care Coordinator: _____ Dates: from: _____ to: _____

Current Medical Information and History

Name: _____ Medicaid/Insurance ID number _____

SS# _____ DOB _____ Legally competent to make health care decisions Yes ___ No ___

Address _____ Phone# _____

Next of kin/guardian/health care advocate _____ Phone# _____

Relationship _____ Support Coordinator _____ Phone# _____

Primary physician _____ Phone # _____

Specialists _____ Phone # _____

Psychiatrist _____ Phone # _____ Psychiatric Diagnosis _____

Developmental Disability _____ Date of last complete Physical Exam _____

Allergies _____ Medication Alert _____

Medical Diagnoses

Immunizations current ___ Yes ___ No Hepatitis vaccine ___ A ___ B ___ Immune status ___ Carrier status

Tetanus vaccine date _____ Flu vaccine date _____

Pneumonia vaccine date _____

Health maintenance procedures _____

<u>Medications</u>	<u>Purpose</u>	<u>Dose</u>

A Diefendorf RN CDDN 2/00

Current Medical Information and History

<u>Problem List of past 12 months</u>	<u>Date</u>	<u>Treatment</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Current Problem _____

New symptoms Reoccurrence

NUTRITION

Diet _____ Food Texture _____ Supplements _____

Independent eating Needs supervision Needs some physical assistance Needs total assistance

Nutrition via tube Liquids only All nutrition

Formula and schedule _____

SPECIAL NEEDS

Vision impaired Hearing impaired Ambulatory Non-ambulatory

Assistive devices used

Hearing Aid Glasses Communication device Wheelchair

Walker Dentures Positioning device Other

Toilets independently Needs assistance Needs a toileting schedule

Continent of bowel and bladder Incontinent bladder Incontinent bowels

Behaviors which could interfere with treatment

Interventions

_____	_____
_____	_____

A Diefendorf RN CDDN 2/00

Current Medical Information and History

RECENT MEDICAL HISTORY

<u>Hospitalizations past 2 years</u>	<u>Date</u>	<u>Surgery (All known)</u>	<u>Date</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

<u>Emergency Medical Care</u>	<u>Date</u>	<u>Treatment</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____

<u>Specialist seen</u>	<u>Date</u>	<u>Reason</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____

Diagnostic Tests (Lab, X-ray, EKG, EEG, etc)

<u>Test</u>	<u>Date</u>	<u>Result</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____

EMERGENCY CARE (If going to the emergency room fill in this section)

Primary Physician notified ___Yes ___No Specialist notified ___Yes ___No Time_____

Vital signs (if possible) Temperature_____ Pulse_____ Respiration_____

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Nursing Services

Just as important as the health history, the individual receiving nursing services or who may be in need of nursing supports, should have a nursing assessment completed and in his central record. In general, the nursing assessment should reflect the person's health and any influences on the person's health. Most assessments include a review of the individual's health history.

The coach will want to review the nursing assessment as a form of introduction or review to the person's needs and overall situation. This review will help clarify the types of therapeutic supports and nursing services the person needs or is receiving.

Supporting Persons with Physical and Health Care Challenges

Some individuals who receive supports and services through supported living arrangements may experience physical or health care challenges, which will need to be addressed by the coach. These challenges or conditions are often associated with the maintenance of good health and physical well being.

Some individuals may require additional support from in-home staff, as well as from nurses or therapists (e.g., physical, occupational, nutritional, speech, etc.). These services will be authorized on the support plan and should be a part of the identified provider's implementation plans.

Seizures are a common condition among persons diagnosed with a developmental disability. It will be important for the coach to be aware of the specific type of seizures the person experiences and understand their impact on the person's daily life.

Service providers who support individuals with complex challenges related to positioning, movement, eating and/or nutrition may comprise a network of supports typically referred to as "physical and nutritional management". If someone is in need of these types of supports and services, the coach might expect to see specific plans in the record (i.e., dining plan, physical management plan, therapeutic equipment plan, etc.) which address these specific needs. In addition, persons with complex health care challenges may receive supports through nursing services where a nursing care plan or health care plan might also be included in the record.

Persons with physical, nutritional, and health care supports in place may require additional support from the coach and the support coordinator to help

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assure effective communication among all members of the circle of support, as well as the oversight to assure provision of these services.

Although not responsible for the coordination of services, the supported living coach should be aware of the person's needs, consistent with the additional plans. The support coordinator provides primary coordination and oversight for the health care of the individual when there are concerns or problems with implementation. As an advocate for the individual, the coach will communicate these clearly and in a timely manner with the individual/guardian/guardian advocate, support coordinator, nurse, and/or therapist.

As discussed earlier, establishing a system of communication among all parties will be essential to assuring the safety and health of the individual. Coaches should maintain a record of communications to assure that follow-up on issues and concerns are addressed in a timely manner.

Supporting Persons with Challenging Behaviors

One of the most challenging areas for supported living coaches is the assurance that adequate supports are in place for persons considered to have serious reputations or challenging behaviors. These individuals are typically persons who have “become famous” as a result of their reactions to the services they are offered.

Information obtained from coaches around the state indicates that persons with challenging behaviors do extremely well when services and supports are adjusted to address their needs and desires. Promoting choice, while important for all people, is especially important for persons who are telling us, by their actions, they want to exercise control over their own lives. Encouragement, opportunity, and careful integration into inclusive life experiences will be invaluable. As persons gain power and skills toward their desired lifestyle, they often may need less intervention.

Individuals with challenging behaviors typically access services from a behavior analyst and may have a “behavior intervention plan” in their records. These plans are extremely important to the individual’s success, and all staff who interact with the individual should be trained to implement the identified procedures. Again, the coach will need to establish an effective system of communication with the behavior analyst and all staff implementing the plan to ensure its success.

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Consistency among providers, settings, and routines becomes important for persons experiencing behavioral challenges. The coach and, where appropriate, in-home supports will need to work in partnership to minimize these types of stressors.

The challenge for the coach is to continue to assure that planning is centered on the individual's needs and desires (e.g., housing location, type, access to the community, etc.), and that supports are adjusted to meet those needs. Ultimately, careful planning and consideration with the individual and his circle of support will help assure the person's safety. Maintaining a balance between choice and its impact on safety will be an ongoing consideration, and one which should be addressed by the entire circle of support.

A handbook written by Michael Smull and Susan Burke Harrison entitled Supporting People with Severe Reputations in the Community, is available through the National Association of State Directors, Alexandria, Virginia (703-683-4202). This may serve as a valuable resource for coaches in supporting persons with significant reputations.

Informed Consent

'Informed consent' is a term used in the field of human services to indicate whether the person can give consent to a decision once she has the facts and information needed to make that decision. This involves the capacity to fully understand what is being consented to and its possible consequences. It also involves the capacity to make a decision and to communicate or indicate the decision of consent.

Persons who have been adjudicated incapacitated by a court or who have had a guardian advocate appointed cannot legally give informed consent; neither can some persons who have never been adjudicated incompetent. Copies of adjudications and indications where the individual cannot provide informed consent should be found in the person's central record (maintained by the support coordinator).

Obtaining this information will assist the coach in understanding what types of decision-making and communication will be necessary on the person's behalf (e.g., guardians, family members, etc.).

The physician must obtain informed consent for use of psychotropic medication, surgery, and any invasive procedure, including diagnostic procedures such as x-ray or swallow studies. The ability to give informed consent should be planned for by the coach and the circle of support.

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Indication of the person's legal status regarding informed consent should be available to the support staff who may accompany the person to health care treatments or emergency services.

The support coordinator's role is to address these issues and assure that adequate supports are in place for proper health care to occur. The coach's role is to understand the person's situation, and assure proper emergency procedures are in place.

Advanced Directives

Life planning is an important part of the aging process. As we move into adulthood, most of us think about how we choose to live our lives. This process involves good planning and making some difficult decisions about how to take care of our health.

For many persons, having control over all aspects of life is extremely important. If a person does not have a guardian/guardian advocate over health care, a way of establishing control during health emergencies and long illnesses is to establish advanced directives. The supported living coach needs to be aware of the individual's advanced directives, should the need arise to inform others of the person's decision. If the person has a legal guardian or guardian advocate over health care decisions, these decisions must be made by that person.

As mentioned, understanding the person's ability to provide informed consent is the first step in determining his wishes for care, should he become incapacitated and not be able to direct the process. In instances where a guardian has legal responsibility, the guardian and the individual should make their wishes known and copies of the advanced directives should be placed in the person's central record. Staff who support the individual will need to have this information available.

Examples of the types of information that might be found in the record include the following:

Sources of Information for Advanced Directives

- Living Will
- Health Care Surrogate Designation
- Organ donor
- Guardianship

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Sources of Information for Advanced Directives, continued

- DNR (Do Not Resuscitate) orders
- Pre-paid funeral expenses
- Burial/cremation services

A Living Will describes the person's desires regarding the dying process. It identifies circumstances (e.g., terminal condition, etc.) and the intention for treatment under specific circumstances. A Health Care Surrogate designation identifies persons who may provide informed consent for medical treatment and surgical and diagnostic procedures in the event the individual is determined to be incapacitated. A sample Living Will and Health Care Surrogate form, courtesy of *Partnership for Caring, Inc.* follows:

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INSTRUCTIONS

PRINT THE DATE

PRINT YOUR NAME

PLEASE INITIAL EACH THAT APPLIES

PRINT THE NAME, HOME ADDRESS AND TELEPHONE NUMBER OF YOUR SURROGATE

© 2000 PARTNERSHIP FOR CARING, INC.

FLORIDA LIVING WILL

Declaration made this _____ day of _____, _____
(day) (month) (year)

I, _____,
willfully and voluntarily make known my desire that my dying not be artificially prolonged under the circumstances set forth below, and I do hereby declare that:

If at any time I am incapacitated and
_____ I have a terminal condition, or
_____ I have an end-stage condition, or
_____ I am in a persistent vegetative state

and if my attending or treating physician and another consulting physician have determined that there is no reasonable medical probability of my recovery from such condition, I direct that life-prolonging procedures be withheld or withdrawn when the application of such procedures would serve only to prolong artificially the process of dying, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

It is my intention that this declaration be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and to accept the consequences for such refusal.

In the event that I have been determined to be unable to provide express and informed consent regarding the withholding, withdrawal, or continuation of life-prolonging procedures, I wish to designate, as my surrogate to carry out the provisions of this declaration:

Name: _____

Address: _____

_____ Zip Code: _____

Phone: _____

FLORIDA LIVING WILL (CONTINUED)

I wish to designate the following person as my alternate surrogate, to carry out the provisions of this declaration should my surrogate be unwilling or unable to act on my behalf.

Name: _____

Address: _____

_____ Zip Code: _____

Phone: _____

Additional Instructions (optional):

I understand the full import of this declaration, and I am emotionally and mentally competent to make this declaration.

Signed: _____

Witness 1::

Signed: _____

Address: _____

Witness 2:

Signed: _____

Address: _____

**PRINT NAME,
HOME
ADDRESS AND
TELEPHONE
NUMBER OF
YOUR
ALTERNATE
SURROGATE**

**ADD
PERSONAL
INSTRUCTIONS
(IF ANY)**

**SIGN THE
DOCUMENT**

**WITNESSING
PROCEDURE**

**TWO
WITNESSES
MUST SIGN
AND PRINT
THEIR
ADDRESSES**

**© 2000
PARTNERSHIP
FOR CARING,
INC.**

Courtesy of Partnership for Caring, Inc 6/00
1620 Eye Street, NW Suite 202 Washington, DC 20006 800-989-9455

INSTRUCTIONS

FLORIDA DESIGNATION OF HEALTH CARE SURROGATE

PRINT YOUR NAME

Name: _____
(Last) (First) (Middle Initial)

In the event that I have been determined to be incapacitated to provide informed consent for medical treatment and surgical and diagnostic procedures, I wish to designate as my surrogate for health care decisions:

PRINT THE NAME, HOME ADDRESS AND TELEPHONE NUMBER OF YOUR SURROGATE

Name: _____

Address: _____

_____ Zip Code: _____

Phone: _____

If my surrogate is unwilling or unable to perform his or her duties, I wish to designate as my alternate surrogate:

PRINT THE NAME, HOME ADDRESS AND TELEPHONE NUMBER OF YOUR ALTERNATE SURROGATE

Name: _____

Address: _____

_____ Zip Code: _____

Phone: _____

I fully understand that this designation will permit my designee to make health care decisions and to provide, withhold, or withdraw consent on my behalf; to apply for public benefits to defray the cost of health care; and to authorize my admission to or transfer from a health care facility.

ADD PERSONAL INSTRUCTIONS (IF ANY)

Additional instructions (optional):

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**FLORIDA DESIGNATION OF HEALTH CARE SURROGATE
(CONTINUED)**

I further affirm that this designation is not being made as a condition of treatment or admission to a health care facility. I will notify and send a copy of this document to the following persons other than my surrogate, so they may know who my surrogate is:

Name: _____

Address: _____

Name: _____

Address: _____

Signed: _____

Date: _____

Witness 1:

Signed: _____

Address: _____

Witness 2:

Signed: _____

Address: _____

**PRINT THE
NAMES AND
ADDRESSES
OF THOSE WHO
YOU WANT TO
KEEP COPIES
OF THIS
DOCUMENT**

**SIGN AND
DATE THE
DOCUMENT**

**WITNESSING
PROCEDURE**

**TWO
WITNESSES
MUST SIGN
AND PRINT
THEIR
ADDRESSES**

Courtesy of Partnership for Caring, Inc 6/00
1620 Eye Street, NW Suite 202 Washington, DC 20006 800-989-9455

A Guide to Supported Living in Florida

Organ donor cards indicate the individual's desire to donate her organs upon her death. Florida has specific laws related to donorship. The person's wishes related to this topic should be documented and known to support staff.

Guardianship is a legal method used for protecting a person's rights and ensuring his health and safety. However, guardianship takes away the person's right to decide. There are many different types of guardians, and it will be important for the coach to understand the guardian's role and responsibilities related to the person's wishes and directives.

DNR (**Do Not Resuscitate**) orders are established with the physician, and identify the person's desire to not be resuscitated, should breathing or heart beat stop. Information about DNRs should be available, when established, in the record, and staff made aware of the person's desires.

Pre-paid funeral and cremation services may also be found in the person's central record. They indicate the person's wishes related to service providers.

Although this information may be difficult to process, it will be important for the coach to understand the person's wishes and assure that good planning is in place to support these outcomes.

Medication Administration/Treatments

Taking medication is a daily activity for many people. Persons with developmental disabilities typically are prescribed more medication than the general population. There are a number of concerns which surround the administration, use, and impact of medications, special techniques and treatments (e.g., multiple types and combinations of medications, testing blood sugar levels daily, etc.). These issues may affect other areas of the person's life (e.g., eating, sleeping, learning, etc.).

Medication/Treatments

The supported living coach:

- Monitors impacts of medicine/treatment on the person.
- Establishes and oversees system for documenting medication administration (Policy Directive #01-01).
- Partners with WSC to coordinate communication re: possible side effects.

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Medication Policy Directive

Persons who support and live with individuals with developmental disabilities find that medications add more complexity to the daily routine. As an example, a drug which controls seizures may produce fatigue to such a degree the person is unable to stay awake.

When supports are provided for medication administration, the supported living coach assures that a system for training staff and documenting the administration of medication is in place. For the coach to assure these supports are in place, it is important that she has an understanding of the purpose, and precautions associated with the medications being used. If the individual is learning to take and order his own medication, a system for monitoring this process should also be established. When a health care professional (i.e., a nurse) is involved, the coach and in-home supports should obtain direction from that professional. Policy Directive #01-01 regarding Medication Administration and Supervision of Self-Administration of Medication provides direction and specific procedures for the provision of unlicensed staff to administer medications. Copies of this policy may be available through the District/Region Developmental Disabilities Program.

Observing for possible side effects of medications is everyone's responsibility. Thus, it is important the coach and the support coordinator work in partnership to ensure providers and, when needed, informal (unpaid) supports are aware of the medications the individual uses and their potential and identified side effects.

Sample Medication Administration Records (MARs)

Three **blank** sample medication/treatment records follow, one for medications and ongoing treatments (such as special shampoo, skin treatments, etc.), one for medications used on an as-needed (PRN) basis, and one for the authorization by the individual for self-administration of medications. (Note: If the individual is independent with medications, these forms do not apply.)

COMMUNITY CIRCLES, INC.
SUPPORTED LIVING
AUTHORIZATION FOR ADMINISTRATION AND ASSISTANCE TO
SELF-ADMINISTER MEDICATIONS

Developmental Disability Program Policy Directive #01-01 allows unlicensed supported living staff who have been trained by and have had their skills validated by a Florida registered nurse to administer or supervise the self-administration of medication by individuals. Assistance to self-administer medications may include the following activities performed by the trained, supported living staff:

If medication is kept in the original container:

1. Taking medication, in its previously dispensed, properly labeled container, from where it is stored and bringing it to the individual.
2. In the presence of the individual,
 - a. reading the label and opening the container,
 - b. telling the individual what amount of medication he/she should remove from the container (or in the case of inhaled medications, the number of premeasured doses to be taken, and instructions as to where the inhaler is to be used in the mouth or the nose),
 - c. giving the container to the individual and observing the individual as he/she removes the medication from the container to ensure that he/she removes only the quantity of medication that is prescribed,
 - d. observing the individual as he/she takes the medication,
 - e. checking to make sure that the individual has actually taken the medication (i.e., that he/she has actually swallowed the medication), and
 - f. closing the container.
3. Assisting in the application of topical medications.
4. Assisting in the placement of a patch by which medication is administered.
5. Assessing whether the individual is properly self-administering oral or nasal inhaler medication.
6. Returning the medication to proper storage.
7. Keeping a record of when supervision of self-administration of medication occurs. That record should include the individual's name, date, time, dosage, name of medication, and signature of person supervising the self-administration.

If the individual uses a pill reminder container:

1. Where appropriate, observing the individual place medications in his weekly pill reminder container, and providing direction as to which pill should be placed in the weekly pill reminder container, and in what quantities.
2. Locating the weekly pill container, which should be maintained in a safe location within the home.
3. Opening the correct slot in the weekly pill reminder container, and providing verbal instructions to the individual as to which pill or pills should be taken at that time.
4. Observing the individual take the medication, and checking afterward to be sure that the medication has actually been swallowed.
5. Closing the weekly pill reminder container.

6. Returning the weekly pill reminder container to its safe location.
7. Keeping a record of when supervision of self-administration of medication occurs. That record should include the individual's name, date, time, dosage, name of medication, and signature of person supervising the self-administration.

Developmental Disability Program Policy Directive #01-01 also allows unlicensed Supported living staff who have been trained and have had their skills validated by a Florida registered nurse to administer medication to individuals with whom they have an ongoing relationship. Supported living staff may administer medications under the following circumstances:

1. Supported living staff may only administer prescription medications, which are prescribed on a "PRN" or as needed basis and which meet the criteria specified in the December 4, 2002 amendment to Policy Directive #01-01 regarding the administration of PRN medications.
2. Supported living staff may not administer prescription medications by injection.
3. Supported Living staff may administer nebulizer treatments according to the March 10, 2004 amendment to Policy Directive #01-01.

Y I have been informed of this policy and consent to have trained, unlicensed supported living coaches who have an ongoing relationship with me provide me with assistance in self-administering my medications.

Y I have been informed of this policy and consent to have trained unlicensed supported living coaches who have an ongoing relationship with me to administer my medications to me.

Y I have been informed of this policy and wish to administer my medications independently without assistance from supported living staff.

Y I have been informed of this policy and wish to have someone other than my supported living staff provide me with assistance in self-administering my medications or administering my medications to me.

Name of designated trained individual: _____

Y I do not currently take prescription medication and do not need my supported living staff to provide me with assistance in self-administering my medications or administering my medications to me at this time.

Consumer Signature

Date

Guardian Signature

Date

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Abuse, Neglect, and Exploitation

In accordance with Chapter 415.1034, F.S., all providers supporting persons with developmental disabilities and their employees must follow procedures for reporting abuse, neglect and exploitation. The law states that anyone who knows, or has reasonable cause to suspect that someone is being abused, neglected or exploited, should immediately report such information to the central abuse registry and tracking system, using the statewide toll-free telephone number (1-800-96ABUSE or 1-800-962-2873).

Requirements Related to Abuse, Neglect, and Exploitation

Supported living coach must:

- Develop and implement policy regarding rights and responsibilities of persons receiving services.
- Develop and implement policies and procedures for reporting.
- Maintain validation that abuse training has been provided to each employee.
- Maintain evidence that training regarding abuse, neglect, and exploitation has been provided to individuals receiving services and their family/guardian.
- Maintain documented incident reports in a separate file.

Supported living providers, like all Medicaid Waiver providers, must ensure, consistent with the Core Assurances outlined in the Medicaid Waiver Services Agreement, that processes are in place to protect individuals from abuse, neglect, and exploitation. Specifically, the provider must outline policies and procedures regarding the rights and responsibilities of persons receiving services, and procedures for reporting abuse as outlined in Florida Statutes.

Verification that all employees have received the specific training required to report abuse, neglect, and exploitation must be maintained in provider records for each employee. This training documentation should include the topic, length of training session, date and location of training, name and signature of trainer, and name and signature of person(s) in attendance. Additional documentation will be necessary for proof that abuse training and information has been provided to individuals receiving services and their families.

The Abuse Registry encourages individuals to report abuse via the Hotline. In some instances, the call must be followed-up with submission of a written

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report. Each District/Region maintains forms for reporting significant events or unusual incidents, including abuse, neglect, and exploitation.

Liability Concerns

Supporting people to live in their own homes is not a structured and controlled, routine business. It places the supported living provider into the real life challenges of an occasionally chaotic and "messy" world. Many providers of supports and services have questions about legal liability. What if a person in supported living is injured or comes to harm? Who is liable? Will someone be sued? Unfortunately, there are no clear-cut answers to these questions.

The issue of legal liability depends on many circumstances and can only be addressed through an examination of individual situations. However, there are ways to demonstrate that a reasonable professional standard has been followed in the provision of supports and services. The following are some suggestions made by Legal Counsel, consulted by the original Supported Living Project, for the former Department of Health and Rehabilitative Services.

Liability

- Informed consent for supported living services should be obtained and documented.
- Supported Living Coach (SLC) provider should have functional assessments that show how training and assistance (including the intensity of support) were identified.
- Supports should be provided as authorized by the Support Plan.
- SLC maintains documentation:
 - When an individual's decision appears to not be in his best interest.
 - Verifying that alternative choices have been offered.
 - Justifying any intervention that prevents him following through on his decision.

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It may, at times, seem challenging to balance liability concerns with the rights of the individual to take risks. People need to make and have informed choices. It is the responsibility of all involved (i.e., the network of supports, the support coordinator, and the supported living coach) to respect the person's right to choose, and to provide the information and counseling necessary to assure the choice is an informed one. All possible consequences and/or outcomes of a decision should be explained.

There is value in taking risks. The dignity of risk taking is a characteristic that has social value. Risks are a natural aspect of the human experience, and are integral to the world.

Risk taking can be mitigated with careful planning and a stable support network. Supported living coaches must balance the need to exert external control and provide an appropriate amount of advice for persons with challenging behaviors. Potentially harmful choices and behavior may require specific interventions, as discussed previously in this chapter.

Choice and behavior that may result in harm to the person or others should not be ignored. The coach should carefully consider the following when planning interventions, supporting informed choice, and the dignity of risk:

Informed Choice/Risk-Taking

The coach should consider:

- Do I have consent of the person with legal authority over this situation?
- History - What is the person's previous experience in making decisions, and ability to learn from experience?
- Consequences - What's the worst-case scenario?
- Control- Does the person have low self-esteem? Is the person dependent on staff or family or the system?
- Safeguard - Can the person advocate for his rights? Is it appropriate for an advocate to represent him?

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The least intrusive means of support is the best means of support. Each situation and occurrence should be handled individually. The supported living coach should seek out advice, and consult with the person's circle of support. It is critical that communication remains open and fluid. In cases of extreme emergencies, such as an individual's arrest, the supported living coach and waiver support coordinator must be immediately notified.

Every human being has the right to learn from her mistakes, and to likewise achieve success and enjoy the self-worth and dignity won from her victories.

Remember: The best way to reduce risk is through careful planning and coordination, provision of adequate supports tailored to individual needs, use of common sense and good judgment, and a person's establishment of a solid network of natural support in the community.

In essence, when quality supports and services are provided, documented, and verified, litigation and liability potentials are minimized. As in "Andy's" situation, referenced in Chapter One, when supports are adequately and appropriately provided, supported living results in profound changes in all aspects of a person's well being. In order to achieve a standard of excellence, internal monitoring and self-assessment are key.

Chapter Summary

In order to support success, consideration must be given to the person's daily health, safety and security. Open, ongoing communication, both formal and informal, among all involved is critical to assuring that potential crises are averted. The supported living coach plans for everyday emergencies and natural disasters, and is fully familiar with the person's current and past medical history.

Documents related to informed consent and advanced directives are carefully followed and made available, along with relevant medical information, in the person's record. Any unique requirements of persons with physical and health challenges, and those with challenging behaviors are monitored, along with medication administration. The supported living coach is also informed regarding applicable laws related to abuse, neglect and exploitation. Finally, the coach balances his personal liability concerns with the person's right to make informed decisions and take risks.

With success assured, the coach continually stays focused on enhancing the quality of service. Chapter Eight focuses on the requirements and methods surrounding quality enhancement.